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Web-Based Cognitive Testing of Older Adults in Person Versus at Home: Within-Subjects Comparison Study

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Abstract

Background: Web-based research allows cognitive psychologists to collect high-quality data from a diverse pool of participants with fewer resources. However, web-based testing presents unique challenges for researchers and clinicians working with aging populations. Older adults may be less familiar with computer usage than their younger peers, leading to differences in performance when completing web-based tasks in their home versus in the laboratory under the supervision of an experimenter.

Objective: This study aimed to use a within-subjects design to compare the performance of healthy older adults on computerized cognitive tasks completed at home and in the laboratory. Familiarity and attitudes surrounding computer use were also examined.

Methods: In total, 32 community-dwelling healthy adults aged above 65 years completed computerized versions of the word-color Stroop task, paired associates learning, and verbal and matrix reasoning in 2 testing environments: at home (unsupervised) and in the laboratory (supervised). The paper-and-pencil neuropsychological versions of these tasks were also administered, along with questionnaires examining computer attitudes and familiarity. The order of testing environments was counterbalanced across participants.

Results: Analyses of variance conducted on scores from the computerized cognitive tasks revealed no significant effect of the testing environment and no correlation with computer familiarity or attitudes. These null effects were confirmed with follow-up Bayesian analyses. Moreover, performance on the computerized tasks correlated positively with performance on their paper-and-pencil equivalents.

Conclusions: Our findings show comparable performance on computerized cognitive tasks in at-home and laboratory testing environments. These findings have implications for researchers and clinicians wishing to harness web-based testing to collect meaningful data from older adult populations.

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KEYWORDS
web-based testing; aging; cognition; neuropsychology; mobile phone

Introduction

Background
The internet is an increasingly popular medium for running behavioral experiments in psychology [1-4]. In 2017, approximately a quarter of research papers in 4 top cognitive psychology journals featured at least one web-based study, up by 5% from the past 5 years [5]. This is an exciting paradigm shift for researchers given that web-based methods allow for the cost-effective collection of larger data sets from broader geographical regions and more diverse participants [6-10]. A growing number of studies have validated the use of web-based
behavioral research by reproducing benchmark findings in cognitive psychology among web-based samples (eg, attentional blink, Flanker, Simon) [7] or finding equivalent performance between web-based and laboratory-tested samples on memory, perception, and attention tasks [8,11-15].

Cognitive aging research especially stands to reap the benefits of web-based testing: Participation among older adults may be hindered by restricted mobility and access to testing sites. As a result, many studies rely on convenience sampling where participants are self-selected due to the ease of recruitment and willingness to participate [16]. This is problematic as convenience samples of cognitively normal older adults tend to be younger and better educated than those recruited via population-based sampling [16-19] and more likely to have a family history of Alzheimer disease [17], all factors that can skew research findings. A similar issue exists in research on neurodegenerative diseases, where the research samples are overwhelmingly White, well-educated, and have a high socioeconomic status, limiting the generalizability of clinical research to the population at large [20].

An obstacle to web-based aging research is that adults aged above 65 years have lower rates of technology adoption than their younger peers [21] and unfamiliarity with computers may affect performance on computerized tasks. Moreover, Mechanical Turk by Amazon, the most popular crowdsourcing platform for psychology researchers, has a population of workers that tends to be younger than the overall population [22]. Nonetheless, some studies have examined cognitive abilities in large web-based samples with ages ranging from 10 to 70 years [23,24] and 10 to 85 years [25]. Web-based data collection has also been used to investigate age-related changes in prospective memory [26] as well as working memory and visuospatial processing [27]. More commonly, however, web-based research among older cohorts is often used to test the validity and reliability of web-based neuropsychological batteries for clinical purposes of cognitive screening [28] or tele-neuropsychology [29]. A small body of work in tele-neuropsychology has explored the use of web-based cognitive screens for self-monitoring of cognitive impairment [30-32]. There are promising avenues for better detection and monitoring of cognitive impairment using well-established cognitive tasks [33-35]. Nevertheless, most clinicians (ie, neurologists, neuropsychologists) continue to rely on paper-and-pencil testing conducted during in-office visits, using technology only sparingly in their assessments [36,37].

Given the ongoing effects of COVID-19 on health care delivery and behavioral research, there is a pressing need to establish and validate protocols for remote cognitive testing among older adults. A chief concern, however, is whether performance within a standard testing situation is comparable with testing done in an unsupervised web-based format [38]. Using a within-subjects design, Assman et al [39] found that a self-administered web-based cognitive battery (NutriCog) provided similar information to a version supervised by a neuropsychologist. However, they found learning effects such that performance was better on the second completion of the battery, independent of the mode of administration. A recent study by Backx et al [40] also used a within-subjects design to examine the effects of testing environment (supervised in the laboratory vs unsupervised at home) on performance on the Cambridge Neuropsychological Test Automated Battery. They found comparable performance across contexts, although reaction times (RTs) were slower in the web-based version. Although the results of these studies are encouraging, they did not examine older adults specifically. An advantage of supervised testing is that the neuropsychologist or experimenter can clarify instructions, provide encouragement, and ensure that the setting is free of distractions for participants—this may be especially important with older participants who are likely to be less fluent with technology. However, older adults may also be more stressed in such situations: novel testing locations have been shown to disproportionately stress older adults relative to younger adults, leading to greater age differences in memory [41].

Objectives
The aim of this study is to investigate using a within-subjects design whether performance on computerized cognitive tasks differs as a function of the testing environment in a group of community-dwelling older adults aged above 65 years. We selected cognitive tasks that are well established in both experimental research and neuropsychology, have low susceptibility to practice effects, and are known to be sensitive to age-related changes. The word-color Stroop task [42] (response inhibition and processing speed) is a widely used test in both experimental psychology and clinical neuropsychology, with a large body of work demonstrating declines in Stroop performance due to normative aging [43] and age-related neurodegenerative disease [44]. Similarly, paired associates learning (PAL) has long been used as a measure of the associative nature of episodic memory, which is well-known to be affected during normative aging [45] and is strongly implicated in Alzheimer disease [46-48]. Participants completed computerized versions of these tasks in 2 testing sessions spaced 24 hours apart: unsupervised in their own home using their personal computer as well as supervised by an experimenter in the laboratory. If the testing environment does indeed affect performance on these web-based measures, we would predict a significant difference between scores across the 2 conditions: given the paucity of previous findings using these particular measures, we did not have any strong a priori hypothesis with respect to the directionality of effects of testing environment on performance (ie, performance would be better or worse in person vs on the web). In addition, we explored the extent to which scores on computerized cognitive tests correlated with their gold standard neuropsychological test equivalents and the extent to which performance on computerized tests is associated with technology use and familiarity.

Methods
Participant Recruitment
This study was powered to detect moderate effect sizes (Cohen $d=0.50$) at a power $>0.80$ (two-tailed $\alpha$ at .05). To date, no studies have compared these experimental measures across testing conditions among older adults; however, a handful of studies have compared performance on web-based
neuropsychological tests as a function of testing location [28,39,40] and found moderate effects of testing location. A power analysis using G*Power 3 [49] determined that a sample size of 34 would be required to detect moderate effects (Cohen \( d = 0.50 \)) with a power > 0.80 (two-tailed distribution with an \( \alpha = .5 \)). A total of 38 adults age above 65 years were recruited via the York Research Participant Pool and agreed to participate in the study. The data of 6 participants were excluded: 3 due to computer-related issues and 3 due to participant error. The analyses included 32 participants (20 females). Participants were screened to ensure that they were diagnosed with any medical, neurological, or psychiatric condition known to impact cognition.

Measures

**Web-Based Cognitive Tasks**

In total, 3 experimental tasks were completed on a computer. For the in-person testing session, the tasks were presented on a 23.8” Dell monitor and responses were provided on a QWERTY keyboard. The specifications of the computer used in the web-based testing session are unknown as participants used their personal devices. However, participants were told before being enrolled into the study that a QWERTY keyboard was required.

1. **Word-color Stroop task**: 36 congruent (eg, blue in blue ink) and 36 incongruent (eg, blue in yellow ink) stimuli were randomly presented to participants using PsyToolKit [31,32]. Participants were instructed to press the r, y, g, and b keys on the keyboard in response to words presented in red, yellow, green, and blue, respectively. If they did not respond within 4500 milliseconds, the following stimulus was presented. Participants first completed a practice trial with 6 trials before beginning the main task. Key outcome measures were raw RTs to respond to the congruent and incongruent trials, and errors (eg, pressing on the key corresponding to red when the ink was blue).

2. **PAL task**: 32 unrelated word pairs (eg, baker-wagon) were selected from the study by Connor et al [50] and divided into 2 sets of 16 pairs (set A and set B). There were no differences in word frequency or concreteness between sets. \( F_{1,30} < 1 \). Stimuli were presented using Qualtrics. In total, 16 unrelated word pairs (eg, tool-coast) were randomly presented, one at a time, for 4 seconds followed by a 1-second interstimulus interval (study 1). Immediately after, participants completed a self-paced cued recall (eg, tool-?) for the word pairs they had just studied (immediate recall 1) using the keyboard to type their responses. The same study-test cycle was then repeated (study 2 followed by immediate recall 2). After a 15-min delay, they completed the delayed recall portion of the PAL task (eg, tool-?) at their own pace. Key outcome measures were a PAL learning score calculated by adding the number of correctly recalled words during immediate recall 1 and 2 as well as a PAL delayed memory score defined as the number of words recalled during the delayed cued recall.

3. **International Cognitive Ability Resource (ICAR)**: The ICAR is a public-domain cognitive assessment tool [51] that includes 4 item types measuring reasoning: three-dimensional rotation presents cube renderings and asks participants to identify which of the response choices is a rotation of the target stimulus. The letter and number items show participants a short digit or letter sequence and ask them to identify the next position in the sequence from among 6 choices. The matrix reasoning items present 3x3 arrays of geometric shapes with one of the 9 shapes missing, and participants are instructed to identify which of the 6 geometric shapes best complete the stimulus. Finally, the verbal reasoning items include logic questions. We created 2 sets of problems each with 4 items from each item type for a total of 16 questions per set (set A and set B). Stimuli were presented using Qualtrics. Participants were given 7.5 min to complete 4 verbal reasoning and 4 letter and number problems, followed by 7.5 min to complete 4 matrix reasoning and 4 three-dimensional rotation problems from the ICAR. All questions were in a multiple-choice format, and participants used the mouse to select their answer. The key outcome was total accuracy across verbal and matrix questions (score from 0 to 16).

**Standardized Neuropsychological Tasks**

The following neuropsychological tasks were administered in person by a research assistant. All testing was performed under the supervision of a licensed neuropsychologist (KR). The verbal Paired Associates subtest of the Weschler Memory Scale -IV (WMS-IV) and Color Word Interference test of the Delis-Kaplan Executive Function System (D-KEFS) were included so that we could compare performance with their computerized analogs (PAL and Stroop task, respectively). The Montreal Cognitive Assessment (MoCA), Patient Health Questionnaire-9 (PHQ-9), and Shipley Verbal subtest were included for the purposes of describing our sample and ensuring that participants did not exceed clinical cut-offs for cognitive impairment or depression.

1. **Verbal Paired Associates subtest (WMS-IV)** [52]: this test assesses the ability of an individual to learn unrelated word pairs. Participants were given the task according to standard instructions. Specifically, they were presented with 14 pairs of unrelated words at a rate of 1 pair every 3 seconds. They were then given the first word of each pair and asked to recall the second word. This was repeated for 4 trials using the same list of word pairs. After a delay of 15-min, participants were again given the first word of each pair and asked to recall the second word. Key outcomes include the total number of correctly recalled word pairs across the immediate recall trials (learning score) and the total number of words recalled after the delay (delayed score). These raw scores were then converted to age-corrected scaled scores.

2. **Color Word Interference test (D-KEFS)** [53]: participants were administered the color naming and interference conditions of this task according to standardized instructions. In the color naming condition, participants were shown a page of colored patches and had to name them one by one as fast as possible, without making mistakes. In the interference subtest, participants were shown a page with names of colors printed in various colors...
and were instructed for each word to name the color the word was printed in, rather than read the word itself. Participants were told to complete the task as quickly as possible without making mistakes. Key outcomes for both subtests were the time to completion (in seconds). These raw scores were then converted to age-corrected scaled scores.

3. MoCA [54]: this is a brief administered screening tool used to detect cognitive impairment. It assesses cognitive domains including short-term memory, visuospatial processing, executive functioning, attention, and orientation in time and space. The key outcome was the total score out of 30 (for geriatric samples, scores >26 are considered normal, whereas scores 18-25 indicate mild cognitive impairment, 10-17 indicate moderate cognitive impairment, and less than 10 indicate severe cognitive impairment).

4. PHQ-9 [55]: this is a self-administered 9-item measure of depression severity. The key outcome was the total score out of 27, with higher scores indicating greater depression severity.

5. The Shipley Verbal subtest (from the Shipley Institute of Living Scale) [56] was included as a brief measure of verbal abilities (scores range from 0-40, with higher scores reflecting greater ability). This test requires participants to identify synonyms for stimulus words presented in a multiple-choice format.

Computer Questionnaires
The 20-item Computer Anxiety Scale [57] and the 19-item Computer Anxiety Rating Scale [58] are questionnaires asking individuals to indicate their level of agreement (1: strongly disagree to 5: strongly agree) with statements pertaining to attitudes toward computer use (eg, I feel apprehensive about using computers). The Computer Aversion, Attitudes, and Familiarity Index [59] is a 40-item questionnaire that prompts participants to indicate the extent to which statements about computer use and feelings surrounding computers apply to them (−3: absolutely false to +3: absolutely true; eg, I enjoy using computers).

Procedure
All participants completed both an in-person testing session at the laboratory and a web-based testing session at their home, 24 hours apart. Whether participants completed the first testing session on the web (home first) or in-person (laboratory first) was counterbalanced across participants (Figure 1). The assignment of participants to order of testing (home first vs laboratory first) and order of test administration in the laboratory setting (web-based tests first vs paper-and-pencil tests first) was determined using a Latin square design. Upon recruitment, a participant was assigned to the next row in the Latin square, which determined their testing orders.

Figure 1. Flowchart of counterbalancing participant assignment to conditions in the experiment. ICAR: International Cognitive Ability Resource; PAL: paired associates learning.

Web-Based Testing Session
Participants were sent a link to the study on the Qualtrics platform via email. After providing consent, they first completed the PAL task using stimuli from set A or B (set used was counterbalanced across participants). Finally, participants were redirected to the PsycToolkit site [60,61] to complete the word-color Stroop task. Participants were prompted to enter a 3-digit identifier before each task.

In-Person Testing Session
Participants completed 2 blocks of testing during the in-person session: an experimental testing block and a neuropsychological testing block. The order of the testing blocks was
counterbalanced across participants. The experimental testing block was identical to the web-based testing session, with the exception that the PAL stimuli and the ICAR problems were different. For example, if a participant studied set A during the web-based testing session’s PAL task, they studied set B during the in-person testing session. Importantly, both the web-based testing and the in-person testing were completed on the PsyToolkit website, ensuring that the only difference between conditions was the testing location. In the neuropsychological testing block, participants completed the immediate and delayed recall conditions from the WMS-IV VPA (Verbal Paired Associates) test: the color naming condition and the interference condition from the D-KEFS Color Word Interference Test, MoCA, and the Shipley vocabulary test. In the 15-min interval between the VPA learning trials and the delayed cued recall, the following questionnaires were administered: PHQ-9, Computer Attitude Scale, Computer Anxiety Rating Scale, and Computer Familiarity Scale.

**Statistical Analyses**

All analyses were conducted in Jamovi (version 1.2.27) using R statistical language, and an alpha level of .05 was used throughout.

To avoid the undue influence of extreme outliers on the Stroop task, trials where the participants responded under 200 milliseconds or over 4000 milliseconds were excluded. This led to 1.5% of total trials being excluded in the laboratory condition and 2% being excluded in the home condition. The Stroop data of 1 participant were removed in the home condition due to the fact that they missed all trials (RTs >4500 milliseconds).

Mixed analyses of variance were conducted to examine how performance on the outcome measures of our computerized experimental tasks (Stroop, PAL, and ICAR) varied as a function of testing environment (home vs laboratory) and testing order (home first vs laboratory first). In addition, Bayesian inferential testing was performed to provide a more comprehensive perspective on the equivalence of the test data across testing environments. This approach allows us to assign a probability of the null hypothesis or alternative hypothesis being true, given our obtained data [62]. Specifically, we conducted paired $t$ tests and calculated corresponding Bayes factors for each $t$ test using the BayesFactor R package [63] implemented in Jamovi to investigate the PAL total scores in both conditions (learning and delayed recall), mean RTs for Stroop (congruent, incongruent, and inhibition), and total scores on the ICAR reasoning task using testing environments as the paired conditions. The null hypothesis was defined as no meaningful difference in performance on these measures across testing environments, whereas the alternative hypothesis would be defined as a significant (nondirectional) difference in test scores between tasks done in the laboratory and on the web. As there are no prior studies on paired associate learning and Stroop task performance across in-laboratory and web-based settings, we did not have a strong a priori hypothesis regarding the presence or directionality of any effects of testing environment, other than a general alternative hypothesis of nonequivalence across testing conditions. In addition, given the lack of previous studies, we had no scientific knowledge to inform the most appropriate prior distribution. Thus, we used a Cauchy distribution centered around 0 (ie, the null) and specified a width parameter of 0.707. Results are presented in terms of a Bayes factor (BF01), which denotes the probability of the observed data, given the null hypothesis. Bayes factors were interpreted using the guidelines by Lee and Wagenmakers [64], which are as follows: Bayes factors below 1 are seen as evidence for the alternative hypothesis (0.33-1: anecdotal evidence, 0.1-0.33: moderate evidence; and <0.1 strong evidence), and Bayes factors above 1 are seen as evidence for the null hypothesis (1-3: anecdotal evidence, 3-10: moderate evidence; and >10 strong evidence).

To explore the validity of these experimental measures, Pearson correlations were conducted to explore the association between performance on the computerized experimental tasks and their pencil-and-paper analogs currently used in clinical practice. Specifically, we examined the relationship between performance on the computerized Stroop and the D-KEFS Color Word Interference Test as well as performance on the PAL task and the WMS-IV Verbal Paired Associates test. In addition, Pearson correlations were conducted to investigate the association between scores on the questionnaires querying computer attitudes, familiarity, and outcome measures on the computerized experimental tasks and the neuropsychological tests.

**Results**

**Participant Characteristics**

Demographic variables and neuropsychological scores as a function of testing session order are shown in Table 1.
The years of education of the 2 participants could not be confirmed. There were no significant differences in age (t30=15; P=.88) or years of education (t30=0.01; P=.99) as a function of session order. Participants assigned to the home-first testing order had marginally higher scores on the (PHQ-9) than those assigned to the laboratory-first testing order (t30=2.02; P=.05); however, none of the participants exceeded the clinical cut-off for major depressive disorder on the PHQ-9 (total score ≥10). There were no group differences in the MoCA (t30=0.57; P=.58) nor the Shipley vocabulary test (t30=1.02; P=.32).

**Performance on Experimental Tasks Across Testing Environments: Frequentist Analyses**

**Stroop Task**

We first conducted a 2 (Stroop condition: congruent vs incongruent)x2 (testing environment: home vs laboratory) repeated measures ANOVA with raw RTs as the dependent variable. RTs were significantly faster in congruent trials than incongruent trials (F1,30=54.54; P<.001; η²p=0.65), and there were no group differences in RTs across testing environments (F1,30=1.15; P=.29; η²p=0.04). The Stroop condition×testing environment interaction was not significant (F1,30<1; P=0.77; η²p<0.01). Next, we wanted to examine whether first being administered the Stroop test at home or in the laboratory would affect Stroop performance. A 2 (Stroop condition: congruent vs incongruent)x2 (order of testing environment: home first vs laboratory first) mixed ANOVA with reaction time on the Stroop test completed at home revealed a significant effect of condition (F1,30=81.33; P<.001; η²p=0.73) and no order effect (F1,30=1.46; P=.24; η²p=0.05). The interaction was insignificant (F1,30<1; P=.43; η²p=0.02). The same analysis as above was conducted but with RT on the Stroop test completed in the laboratory. Participants were faster on congruent trials than incongruent trials (F1,30=30.40; P<.001; η²p=0.51), and there was no order effect (F1,30<1; P=.52; η²p=0.01). The interaction was insignificant (F1,30<1; P=.59; η²p=0.01).

We repeated the set of analyses above to examine Stroop errors as a function of testing environments and testing order. A 2 (Stroop condition: congruent vs incongruent)x2 (testing environment: home vs laboratory) repeated measures ANOVA with errors on the Stroop test completed in the laboratory. Participants made more errors on the incongruent compared with congruent trials (F1,30=11.33; P=.002; η²p=0.27). There was no significant main effect of the testing environment (F1,30<1; P=.55; η²p=0.01), and the Stroop condition×testing environment interaction was insignificant (F1,30=2.41; P=.13; η²p=0.07). A 2 (Stroop condition: congruent vs incongruent) x2 (order of testing environment: home first vs laboratory first) mixed ANOVA with errors on the Stroop test completed at home revealed a significant effect of condition (F1,30=90.94; P<.001; η²p=0.94) and no order effect (F1,30=1.29; P=.27; η²p=0.04). The interaction was insignificant (F1,30=1.99; P=.17; η²p=0.06). The same analysis as above was conducted but with errors committed on the Stroop test completed in the laboratory. Errors were equivalent across conditions (F1,30=1.45; P=.24; η²p=0.05) and the order of testing environment main effect was
insignificant ($F_{1,30}=2.28; P=.14; \eta^2_p=0.07$). The interaction was insignificant ($F_{1,30}<1; P=.87; \eta^2_p<0.01$).

Finally, Stroop effects were calculated for each participant by subtracting the RT for congruent trials from the RT for incongruent trials. We then conducted a 2 (testing environment: home vs laboratory)$\times$2 (order of testing environment: home first vs laboratory first) mixed ANOVA with these Stroop effect scores as the dependent variable. The results showed no significant main effect of the testing environment ($F_{1,29}<1; P=.78; \eta^2_p<0.01$) or order of testing environment ($F_{1,29}<1; P=.45; \eta^2_p=0.02$). The testing environment$\times$order of testing environment interaction was insignificant ($F_{1,29}<1; P=.89; \eta^2_p<0.01$).

**PAL**

We conducted a 2 (testing environment: home vs laboratory)$\times$2 (order of testing environment: home first vs laboratory first) mixed ANOVA with PAL learning scores as the dependent variable (Table 2).

<table>
<thead>
<tr>
<th>Table 2. Mean performance on experimental tasks as a function of testing environment and order of testing environment (SDs in parentheses).</th>
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<tbody>
<tr>
<td>Variables</td>
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<tr>
<td></td>
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<tr>
<td>Word-color Stroop</td>
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<tr>
<td>Congruent—RT&lt;sup&gt;d&lt;/sup&gt; (ms)</td>
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<tr>
<td>Incongruent—RT (ms)</td>
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<td>Interference scores (ms)</td>
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<td>Paired associates learning</td>
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<tr>
<td>Learning scores</td>
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<td>Delayed cued recall</td>
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<td>ICAR&lt;sup&gt;e&lt;/sup&gt; scores</td>
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<sup>a</sup>Laboratory testing session on day 2.
<sup>b</sup>Home testing session on day 1 and laboratory testing session on day 2.
<sup>c</sup>Laboratory testing session on day 1 and home testing session on day 2.
<sup>d</sup>RT: reaction time.
<sup>e</sup>ICAR: International Cognitive Ability Resource.

Results showed no significant difference in cued recall learning scores across testing environments ($F_{1,30}=3.57; P=.07; \eta^2_p=0.106$) or as a function of the order of testing environment ($F_{1,30}<1; P=.79; \eta^2_p<0.01$). The testing environment$\times$order of testing environment interaction was insignificant ($F_{1,30}<1; P=.94; \eta^2_p<0.01$).

Next, we conducted the same analysis as above, with delayed cued recall scores as the dependent variable. There was no effect of testing environment ($F_{1,30}=1.66; P=.21; \eta^2_p=0.05$) or order of testing environment ($F_{1,30}<1; P=.64; \eta^2_p<0.01$). The interaction was insignificant ($F_{1,30}<1; P=.99; \eta^2_p<0.01$).

**ICAR**

We ran a 2 (testing environment: home vs laboratory)$\times$2 (order of testing environment: home first vs laboratory first) mixed ANOVA with ICAR scores as the dependent variable (Table 2). This showed insignificant main effects of testing environment ($F_{1,30}=1.55; P=.22; \eta^2_p=0.05$) and order of testing environment ($F_{1,30}=2.28; P=.14; \eta^2_p=0.07$). The interaction was insignificant ($F_{1,30}<1; P=.78; \eta^2_p<0.01$) or order of testing environment ($F_{1,29}<1; P=.45; \eta^2_p=0.02$). The testing environment$\times$order of testing environment interaction was insignificant ($F_{1,29}<1; P=.89; \eta^2_p<0.01$).

The Bayesian paired samples $t$ test of PAL learning scores yielded a Bayes factor of 1.04, indicating that the data could be consistent with either the null hypothesis or the alternative hypothesis. However, on PAL delayed recall, there was a Bayes factor of 2.44, providing anecdotal evidence that data were 2.44 times more likely under the null hypothesis (ie, the groups of test scores were equivalent across testing environments). In terms of Stroop RT performance, results from the paired $t$ test for the congruent condition indicated that the data were 3.4 times more likely under the null hypothesis than the alternative hypothesis (BF01=3.40). Similarly, RTs from the incongruent condition and the Stroop effects (incongruent RT-congruent RT) also provided moderate evidence that the null hypothesis was more likely than the alternative hypothesis (BF01=3.12 and 4.34, respectively). Finally, the Bayesian paired $t$ test on the ICAR reasoning total scores yielded a Bayes factor of 2.63, providing anecdotal evidence that the data were more likely consistent with either the null hypothesis or the alternative hypothesis.
under the null hypothesis than the alternative hypothesis. Collectively, these results bolster the notion that there was no meaningful difference in performance on computerized PAL, Stroop, and ICAR reasoning tasks when done in a laboratory or on the web. Prior and posterior distribution plots and Bayes factor robustness checks are provided in Multimedia Appendix 1.

Correlations Between Computerized Tasks and Standard Neuropsychological Tests

Regarding Stroop performance, we found no significant correlation between mean RT for the congruent condition and color naming on the D-KEFS Color Word Interference Test ($r=0.13$; $P=.47$; 95% CI $-0.23$ to $0.46$). However, we did find a significant positive association between mean RT in the incongruent condition and the inhibition subtest ($r=0.69$; $P<.001$; 95% CI $0.46$ to $0.84$). We found a similar significant positive association between PAL total learning scores across 2 trials and the total learning score on the WMS-IV Verbal Paired Associates test ($r=0.67$; $P<.001$; 95% CI $0.42$ to $0.83$). In terms of delayed recall, there was also a significant positive association ($r=0.67$; $P<.001$; 95% CI $0.41$ to $0.82$). Collectively, these findings suggest a robust association between performance on web-based computerized tests and standard neuropsychological tests completed in person.

Table 3. Pearson correlations among questionnaires.

<table>
<thead>
<tr>
<th>Questionnaires</th>
<th>Mean (SD)</th>
<th>1</th>
<th>2</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Correlation coefficient</td>
<td>$P$ value</td>
</tr>
<tr>
<td>1. CAAFIA&lt;sup&gt;b&lt;/sup&gt;</td>
<td>$-11.20$ (13.30)</td>
<td>__&lt;sup&gt;c&lt;/sup&gt;</td>
<td>—</td>
</tr>
<tr>
<td>2. CARS&lt;sup&gt;d&lt;/sup&gt;e</td>
<td>$40.30$ (14.00)</td>
<td>$-0.649$</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>3. CAS&lt;sup&gt;e&lt;/sup&gt;</td>
<td>$70.10$ (10.10)</td>
<td>$0.487$</td>
<td>.005</td>
</tr>
</tbody>
</table>

<sup>a</sup>CAAF: Computer Aversion, Attitudes, and Familiarity Index.
<sup>b</sup>Higher scores on the CAAF reflect greater familiarity and more positive attitudes toward computers.
<sup>c</sup>Correlation scores not applicable.
<sup>d</sup>CARS: Computer Anxiety Rating Scale.
<sup>e</sup>Higher scores on CARS and the Computer Anxiety Scale (CAS) reflect lesser and greater computer-related anxiety, respectively.

Questionnaire scores did not differ as a function of the order of the testing environment for the CAS ($F_{1,30}=3.31$; $P=.08$), CARS ($F_{1,30}=1.80$; $P=.20$), or ICAR ($F_{1,30}<1$; $P=.77$). There were significant correlations between CAS and CARS scores and ICAR scores completed at home ($r=0.50$, $P=.004$ and $r=0.45$, $P=.01$, respectively). However, there were no significant correlations between these measures when completed in the laboratory nor were there any other significant correlations between scores on any of the questionnaires and performance on the computerized tasks (Multimedia Appendix 1).

Discussion

Principal Findings

The primary aim of this study is to examine whether performance on computerized versions of well-known cognitive tasks (ie, word-color Stroop, PAL, and matrix and verbal reasoning) would vary as a function of the testing environment (supervised in the laboratory vs unsupervised at home) among healthy older adults. Our results align with other studies that found comparable results across testing environments using a within-subjects design [39,40] and extend them to older adults. Our findings are encouraging for researchers and clinicians looking to harness web-based testing among older adult populations. We found no significant differences in performance on any of the computerized tasks across testing environments, a pattern of results supported by complementary Bayesian analyses. Crucially, there were no order effects, that is, whether participants completed the at-home or in-person testing session first had no influence on performance. There was no consistent correlation between the measures of computer familiarity or attitudes and performance on any of the computerized tasks. This is congruent with past research finding that computer familiarity did not mediate benefits derived from web-based memory training [65]. There is some evidence, however, that the total learning score on PAL may not be equivalent across

Test-Retest Reliability of Web-Based Cognitive Measures

We also conducted intraclass correlations between PAL and Stroop scores obtained at home and in the laboratory to obtain an estimate of the reliability of these measures over time. Regarding the Stroop test, there were adequate ICC (intraclass correlations) values between scores obtained in the laboratory and on the web for the congruent ($r=0.72$; $P<.001$; 95% CI $0.49$ to $0.85$) and incongruent ($r=0.75$; $P<.001$; 95% CI $0.53$ to $0.87$) conditions. The ICC for the interference condition was modest ($r=0.61$; 95% CI $0.34$ to $0.79$). For PAL, there were adequate ICC values between scores obtained in the laboratory and on the web for the total learning score ($r=0.70$; $P<.001$; 95% CI $0.46$ to $0.84$) and delayed recall score ($r=0.73$; $P<.001$; 95% CI $0.51$ to $0.86$) conditions.

Correlations Between Computerized Tasks and Computer Questionnaires

Scores on the 3 questionnaires (ie, Computer Anxiety Scale [CAS], Computer Anxiety Rating Scale [CARS], and Computer Aversion, Attitudes, and Familiarity Index [CAAF]) were scored for each participant. The mean scores and correlations among the questionnaires are shown in Table 3.
contexts, given the $P$ value approached significance and the Bayesian analysis indicated that the data were not more consistent with either the null hypothesis or alternative hypothesis. Further studies are required to replicate this finding and establish a more precise estimate of any putative differences due to the testing location. It is interesting to note that the scores obtained during web-based testing (ie, in the participant’s home) were higher on average than those obtained in the laboratory, which is counterintuitive to the idea that performance should suffer in an uncontrolled environment with more potential distractors. Nevertheless, the results indicate that older adults can produce equivalent results on tests tapping into various cognitive domains, regardless of whether they are done at home or in the laboratory.

Our findings are reassuring for experimental researchers seeking to extend their web-based research program to older adult populations. Our findings support the viability of testing older adults in their homes, which is likely a lower stress environment than a laboratory or office [41]. Past studies have found that older adults report preferring computerized over traditional assessments [66] and that they value being able to choose the timing [67] and circumstances [68] of at-home assessments. Our findings also have relevance for clinical neuropsychology, a field that has been slow to integrate technology into practice [36]. Although our study was among cognitively healthy adults, the fact that we found equivalent task performance on several cognitive tests across testing environments supports the further investigation and validation of computerized measures in geriatric patients, which can open new avenues for the diagnosis and monitoring of cognitive functioning. Adapting experimental paradigms into clinical assessment protocols may prove useful for increasing precision in measuring underlying cognitive constructs (ie, validity) and in drawing brain-behavior associations [69]. Important next steps would be to validate web-based testing as an appropriate means to measure cognition to support diagnosis and also as an appropriate assay of everyday functioning in key cognitive domains such as memory [70], given that age differences in memory tend to be minimized in the real world relative to laboratory settings [71].

The need for further research into the utility of remote testing has been brought to the forefront by the ongoing COVID-19 pandemic. Much of the extant work has focused on administering existing cognitive screens and neuropsychological tests via tele-conferencing [29,39,66,72,73] rather than exploring updated options, such as using well-validated experimental tasks in a clinical context. Looking into the future, incorporating data collected from wearables, smartphone apps, and/or other sensors may also provide a rich source of data for better detection and monitoring of cognitive [37,74] and mood symptoms in neurodegenerative diseases [75]. For example, if some cognitive domains can be reliably measured using web-based cognitive tasks with acceptable psychometric properties [28,76-78], clinical practice can shift toward more remote monitoring of cognitive changes in memory or executive functioning, given that these domains are key factors in the loss of functional independence in neurodegenerative diseases [79].

An additional, encouraging finding regarding the validity of these computerized measures is that participants’ performance on web-based computerized cognitive tasks was significantly associated with performance on analogous standard neuropsychological tests, with correlations in the order of 0.6, and CIs showing a lower-bound correlation of approximately 0.4. These findings suggest that across a sample of healthy older adults, the rank order of their performance on standard neuropsychological tests is generally preserved when examining web-based test scores. However, unlike the Stroop and the PAL tasks, we did not include a paper-and-pencil analog for our computerized ICAR task, so we could not estimate its validity with current clinical tools. Although subsequent research is needed with more robust samples, these preliminary results are consistent with a recent study [75] showing that normative data from web-based measures can be used for individual differences research and eventually to guide decision making about individual patients.

**Strengths and Limitations**

Our study examined cognitive task performance across at-home and in-laboratory settings within the same group of older adults. A limitation of our study is that participants were recruited via a university participant pool. As discussed above, it is likely that participants recruited via population-based sampling would be lower in education and higher in age, which would likely yield lower familiarity with computer usage. However, it is important to note that over time, older cohorts will be increasingly technology savvy, so this will not be an enduring issue: 67% of adults aged above 65 years report going on the internet, up from 13% in the early 2000s, and the figure increases to 82% when we look at the youngest-old between the ages of 65 and 69 years [21]. Our study also had participants performing the web-based tasks on different devices as the at-home computer was their own. Although this was not an issue for our purposes, future research should consider using the same devices, especially for screening and diagnosis. Finally, it should be noted that 3 participants (9% of our sample) had to be excluded due to user problems. Our study required individuals to navigate to 2 different platforms to complete the tasks, which may have added confusion. Improving the design of computerized tasks continues to be an important goal for bringing cognitive testing on the web.

**Conclusions**

In summary, we provide evidence that healthy older adults who conduct computerized cognitive tests on a web-based platform can produce results comparable with those obtained in a laboratory environment. Moreover, performance on these web-based measures was correlated with standard neuropsychological test performance but was not correlated with technology familiarity. The results serve as a starting point for future studies on the validity of web-based platforms for measuring cognition in healthy and unhealthy aging populations.
Conflicts of Interest

None declared.

Multimedia Appendix 1
Supplementary correlational matrix and output of Bayesian analyses.

References


Abbreviations

CAAFI: Computer Aversion, Attitudes, and Familiarity Index
CARS: Computer Anxiety Rating Scale
CAS: Computer Anxiety Scale
D-KEFS: Delis-Kaplan Executive Function System
ICAR: International Cognitive Ability Resource
ICC: intraclass correlations
MoCA: Montreal Cognitive Assessment
PAL: paired associates learning
PHQ-9: Patient Hospital Questionnaire 9
RT: reaction time
VPA: Verbal Paired Associates
WMS-IV: Weschler Memory Scale -IV

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Implementations of Evidence-Based eHealth Interventions for Caregivers of People With Dementia in Municipality Contexts (Myinlife and Partner in Balance): Evaluation Study

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Abstract

Background: Very few evidence-based eHealth interventions for caregivers of people with dementia are implemented into practice. Municipalities are one promising context in which to implement these interventions due to their available policy and innovation incentives regarding (dementia) caregiving and prevention. In this study, two evidence-based eHealth interventions for caregivers of people with dementia (Partner in Balance and Myinlife) were implemented in 8 municipalities in the Euregion Meuse-Rhine. Partner in Balance is a blended care, 8-week, self-management intervention intervention designed to aid caregivers of people with dementia in adapting to their new roles that is delivered through coaches in participating health care organizations who are trained to use it to offer online support to their clients. Myinlife is an eHealth/mHealth intervention integrated into the Dutch Alzheimer’s Association website and available from the App Store or Google Play, designed to help caregivers of people with dementia use their social network to better organize care and share positive (caregiving) experiences.

Objective: This study’s objectives were to evaluate the success of the implementation of Myinlife and Partner in Balance and investigate determinants of their successful implementation in the municipality context.

Methods: This study collected eHealth use data, Partner in Balance coach evaluation questionnaires, and information on implementation determinants. This was done by conducting interviews with the municipality officials based on the measurement instrument for determinants of implementation (MIDI). These data from multiple sources and perspectives were integrated and analyzed to form a total picture of the determinants (barriers and facilitators to implementation in the municipality context).

Results: The municipality implementation of Partner in Balance and Myinlife showed varying levels of success. In the end, 3 municipalities planned to continue the implementation of Partner in Balance, while none planned to continue the implementation of Myinlife. The 2 Partner in Balance municipalities that did not consider the implementation to be successful viewed the implementation as an external project. For Myinlife, it was clear that more face-to-face contact was needed to engage the implementing municipality and target groups. Successful implementations were linked to implementer self-efficacy and sense of ownership, which seemed to be absent in unsuccessful implementations.

Conclusions: The experiences of implementing these interventions suggested that this implementation context was feasible regarding the required budget and infrastructure. The need to foster sense of ownership and self-efficacy in implementers will be integrated into future implementation protocols as part of standard implementation materials for municipalities and organizations implementing Myinlife and Partner in Balance.

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KEYWORDS
eHealth; mHealth; implementation science; dementia; caregiving; municipality

Introduction

Dementia is a progressive, neurodegenerative disease accompanied by cognitive decline in multiple domains, as well as mood and behavior changes. Informal caregivers play an indispensable role in providing high-quality care for people with dementia [1]. Supporting informal carers of people with dementia is essential, as informal caregiving can potentially allow people with dementia to delay institutionalization and result in positive effects on the person with dementia’s physical and mental health [2]. Given the fact that there are currently 50 million people with dementia worldwide and this number is set to triple by 2050 [3], the rising cost of dementia care and its reliance on informal care is a significant concern for many modern health care systems [4]. Informal caregiving can have both positive [5] and negative [6] effects on the informal caregivers’ physical and mental well-being, and the negative consequences of caregiving can include social isolation, depressive symptoms, stress and anxiety, financial issues, and sleep problems [7,8].

eHealth interventions have been suggested as a means to meet both the demand for more cost-effective dementia health care [9,10] and the need for effective informal caregiver support [11]. Here, eHealth interventions are “treatments, typically behaviorally based, that are operationalized and transformed for delivery via the internet” [12]. Many recent systematic reviews have shown evidence of the effectiveness of eHealth interventions for caregivers of people with dementia, with intervention studies reporting improvements in a variety of caregiver outcomes including increased positive experiences with the caregiving process, self-efficacy, and confidence, in addition to the reduction of stress, experienced burden, and depressive symptoms and anxiety [13-16].

Unfortunately, previous research has shown that very few of these eHealth interventions for caregivers of people with dementia are implemented into practice [17]. Here, implementation refers to “the process of putting to use or integrating evidence-based interventions within a setting” [18]. More generally, only 3% of evidence-based psychosocial interventions for dementia are translated into practice [19]. Lack of proven effects on health care outcomes, doubts from implementing health care staff, meager implementation coordination and management, lack of information on the implementation context, and the fact that users are seldom involved in the eHealth development have been cited as important barriers to the implementation of evidence-based interventions [20-23].

This study was designed to address the lack of information on the implementation context. One potentially important and well-suited implementation context for eHealth interventions for caregivers of people with dementia in Northern Europe is the local municipality. Municipalities are districts or towns with local governments. A municipality’s governing functions can vary from country to country. In general, the municipality is responsible for local services, such as health care, education, recreation, and sport. The municipality context was chosen because municipalities often have policy incentives and funds to address both dementia and caregiving challenges, as well as innovation budgets that are suitable to finance online solutions [24,25]. In this study, two evidence-based eHealth interventions for caregivers of people with dementia (Partner in Balance and Myinlife) were implemented in 8 municipalities in the Euregion Meuse-Rhine (EMR) by municipality officials and by personnel in the local, participating health care organizations. The main research question addressed barriers and facilitators to implementing evidence-based eHealth interventions for caregivers of people with dementia in a municipality context. This study’s specific objectives were to evaluate the success of the implementation of Myinlife and Partner in Balance and investigate determinants of successful implementation of the interventions in the municipality context.

Methods

Study Background

This implementation study took place in the context of the euPrevent Senior Friendly Communities (SFC) project [26], which is based on the World Health Organization’s Active Ageing framework [27]. This project took place between September 2016 and December 2019, and data collection continued until March 2020 (see Figure 1 for a timeline of the project). In this project, 32 municipalities signed up on a first-come, first-serve basis, with the aim to become more senior-friendly. After a kickoff conference with the participating municipalities and other stakeholders, the project assessed what the municipalities were already doing for their aging population and how they could improve. Informed by this assessment, municipalities selected activities from a so-called activity buffet, which consisted of 15 preexisting activities. These activities were aimed at improving the mental health of the municipality’s aging population by focusing on various aspects of dementia and age-related depression. The activities included a theater production, consultations with experts on various topics, a photo exhibition, courses on relevant topics and psychoeducation, creation and organization of local groups of elderly people, outreach activities, and eHealth interventions to support caregivers of people with dementia. These activities were to be implemented before a final conference with municipalities and stakeholders. Implementation and use of the chosen interventions were included in the participation in the SFC project, meaning that all activities were free of costs for both municipality and users. Data collection took place parallel to the described activities and in 3 phases: preparatory, implementation, and evaluation.
The activity buffet included two eHealth interventions to support caregivers of people with dementia: Partner in Balance and Myinlife. These interventions were included in the activity buffet by the SFC project team due to their promising research results and local origin (they were developed with the EMR). There also was a desire to offer remote support options such as eHealth within the project, and these interventions met this need. Neither had been widely implemented previously, so there were no expectations about which intervention would be easier to implement. Six municipalities opted to implement Partner in Balance (4 in the Netherlands, 1 in Belgium, and 1 in Germany), and 3 opted for Myinlife (2 in Belgium and 1 in Germany). Table 1 depicts relevant characteristics of the SFC municipalities that chose to implement eHealth in their communities. A more detailed description of the municipalities' eHealth choice process is provided elsewhere [25].

Table 1. Characteristics of the participating municipalities.a.

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Value, n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of municipalities that chose Partner in Balance</td>
<td>6</td>
</tr>
<tr>
<td>Number of municipalities that chose Myinlife</td>
<td>3</td>
</tr>
<tr>
<td>Municipality average general population</td>
<td>36,376</td>
</tr>
<tr>
<td>Municipality average population age &gt;65 years</td>
<td>7349</td>
</tr>
<tr>
<td>Municipality average estimated dementia population</td>
<td>1434</td>
</tr>
</tbody>
</table>

*aPopulation statistics sourced from the euPrevent Senior Friendly Communities project [25,26,28].

**eHealth Interventions**

**Partner in Balance**

Partner in Balance is an evidence-based eHealth intervention designed to aid caregivers of people with dementia in adapting to their new roles that is delivered through coaches in participating health care organizations who are trained to use it to offer online support to their clients. It is a blended care, 8-week, self-management intervention consisting of (1) an in-person intake session with the coach to acquaint the caregiver with Partner in Balance, select online modules, and set goals; (2) tailored online thematic modules including psychoeducation, behavioral modeling, videos of carers discussing their experiences with the chosen themes, change plans, and email feedback from the coach over 8 weeks; and (3) an in-person evaluation of the program with the coach to assess previously set goals. The in-person meetings between caregiver and coach usually take place at the coach’s place of work (eg, a dementia case management organization) although some coaches choose to visit the caregiver at home. The at-home use of the chosen modules by the caregivers is asynchronous and the responsibility of the caregiver, although the coach provides encouragement and feedback via email. Partner in Balance coaches are required to have experience in health care and dementia care. All coaches take part in a 2-hour Partner in Balance training course with presentation of the intervention and exercises in coaching and self-management techniques. Detailed information about the program components and development is presented elsewhere [29]. Partner in Balance was shown to cause improvements in caregiver outcomes such as mastery, self-efficacy, and quality of life [29,30].

**Myinlife**

Myinlife is an eHealth intervention designed to help caregivers of people with dementia use their social network to better organize care and share positive (caregiving) experiences. Myinlife has been integrated into the Dutch Alzheimer’s Association website [31] and can also be downloaded from the App Store or Google Play free of charge. In previous research, Myinlife has shown potential to make caregiving easier and help caregivers gain more control over their schedules [32,33]. Myinlife has the following functionalities: Profile, Circles, Timeline, Calendar, Helping, Personal Messages, Care Book, and Compass. Caregivers use these functionalities independently (with no help from a coach) to facilitate the organization of care for the person with dementia. Although Myinlife does not make use of a coach, it still requires local health care organizations to facilitate the dissemination and implementation of the intervention by promoting its use among the local population.

**Use Data**

Implementation use data was collected for the following measures: number of municipalities choosing one of the interventions, number of research team implementation hours (both face-to-face and remote), number of information
technology support hours, and number of accounts (caregivers and coaches). No data were collected on the effect of the intervention or the caregivers’ experiences with the program, as this was assessed in previous research [30].

**Partner in Balance Coach Evaluation Questionnaire**

Because Partner in Balance (but not Myinlife) makes use of a coach as part of its blended approach, evaluation questionnaires were sent to all Partner in Balance coaches who took part in the coach training as part of the SFC project. An English translation of the coach evaluation questionnaire can be found in Multimedia Appendix 1. The questionnaire asked the participants of the training to rate the usability and relevance of Partner in Balance for caregivers and coaches. It consisted of 11 multiple-choice items rated on a 5-point scale (1=completely disagree to 5=completely agree) and 5 open-ended items. A version of this questionnaire had previously been used in the Partner in Balance process evaluation [34].

**Determinants of Implementation**

The measurement instrument for determinants of innovation (MIDI) is designed to assess which determinants may affect implementation, and it can be applied before or after the introduction of an innovation [35]. The MIDI groups determinants into 4 categories: determinants associated with the innovation, adopting person (user), organization, and sociopolitical context. The MIDI was developed to be used in a research context to explore the experiences of intermediary users (“professionals whose actions determine the degree of exposure of end users to the innovation”) of the innovation [36]. To construct the MIDI, determinants were extracted from the results of 8 empirical studies on the implementation of evidence-based innovations and discussed with 22 implementation experts [36]. The instrument consists of 29 questions, each designed to explore a particular determinant. Responses consist of a number on a 1- to 5-point Likert scale and an explanation of the reasoning behind the given score. However, in this study, due to the small sample size, no quantitative MIDI scores were collected, and the MIDI was used instead as a semistructured interview guide to ensure that various domains of implementation were discussed in the evaluation. Multimedia Appendix 2 contains an English version of the MIDI as it was used in these interviews.

**Data Collection**

**Use Data**

After each interaction with the municipality, implementation data were anonymously logged in a customized data collection platform with separate entries for each municipality. The interactions included emails, telephone calls, and meetings. The dates and time required for these interactions were logged, including preparations and travel time. Data were logged for all municipalities by author HLC from the start of the implementation in January 2018 until the end of implementation in December 2019.

**Partner in Balance Coach Evaluation**

Coaches were sent the evaluation questionnaire via email at the end of the SFC project in December 2019 and asked to reply via email. Reminders were sent after 6 and 12 weeks. Email responses were stored on the described data collection platform.

**Determinants of Implementation**

Interviews with the municipality representatives responsible for the intervention implementation were conducted to explore determinants of implementation. However, at the end of the project, not all municipalities had achieved the level of implementation necessary to appropriately evaluate implementation determinants using the MIDI questionnaire. The level of eHealth implementation was considered adequate to evaluate determinants if municipalities had completed the implementation activities planned in the initial interviews. These differed per municipality [25] and included a minimum implementation threshold to be considered for determinant assessment. For Myinlife, municipalities must at least have organized caregiver meetings around the intervention. For Partner in Balance, municipalities must have completed a coach training and appointed an organizational Partner in Balance administrator who oversaw the municipalities’ coaches. Implementation levels were assessed prior to the interview by phone by author HLC; 5 municipalities were assessed as having completed the minimum level implementation necessary to conduct an evaluation interview using the MIDI questionnaire as a semistructured interview guide. Interviews were an average of 31 minutes long. For the remaining 3 municipalities, information was collected on the current level of implementation and what steps still needed to be taken via email for one municipality (due to municipality time restraints), via face-to-face meeting for a second, and via telephone meeting for the third.

Interviews occurred between August 2019 and March 2020 and were conducted by author HLC in Dutch, French, or English according to municipality preferences. The MIDI interviews and face-to-face and telephone meetings were recorded and later transcribed verbatim. The written email evaluation was also stored on the data collection platform.

**Informed Consent and Ethical Approval**

All participants (municipality interviewees, Partner in Balance coaches, and experts) had received an information letter explaining the aims of the study, which also guaranteed the anonymous processing of their data and responses, in addition to the option of discontinuing study participation at any point. All participants signed an informed consent form. Ethical approval for the study was granted by Maastricht University’s Medical Ethical Oversight Commission (approval number 2018-0489).

**Data Analysis**

**Use Data**

After activities were logged in the online data collection platform by author HLC, total implementation and support hours were automatically calculated across entries and subsequently exported.

**Partner in Balance Coach Evaluations**

Responses were logged in the online data collection platform. Quantitative scores were calculated, and qualitative responses
were analyzed inductively by author HLC using analysis software Atlas.ti 8.3 for Macintosh (Atlas.ti Scientific Software Development GmbH). Inductive analysis was used because there were no expectations as to what the open question replies would be. For this analysis, individual codes were independently grouped into themes and categorized by authors HLC and LMMB. Subsequently, HLC and LMMB compared these themes and categories in a consensus meeting with author MEdV to resolve any differences and confirm the final thematic analysis.

**Determinants of Implementation**

Authors HLC and LMMB independently coded the semistructured interviews using deductive thematic analysis in Atlas.ti. In contrast to the open questions in the coach evaluations, it was expected that the interviews would reflect the thematic groups of the consolidated framework for implementation research (CFIR) and not new inductive groups. This is why deductive thematic analysis was used for the interviews. The deductive codes used were CFIR constructs (Table 2). CFIR is an established framework for mapping implementation of evidence-based interventions and can also be used for eHealth interventions [38]. CFIR comprises 5 domains (intervention characteristics, outer setting, inner setting, characteristics of individuals, and process) with 39 implementation constructs. For the analysis, authors LMMB and HLC applied the CFIR codes in Table 2 to interview transcriptions and compared interview segments with the same deductive codes across interviews. Again, HLC and LMMB compared the independently applied codes in a consensus meeting with author MEdV to resolve any differences of opinion. The focus of this analysis was to shed light on the breadth of implementation determinants (barriers and facilitators) in the municipality context.
<table>
<thead>
<tr>
<th>CFIR\textsuperscript{b} domains</th>
<th>Deductive CFIR construct codes</th>
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<tr>
<td>Intervention characteristics</td>
<td>Intervention source</td>
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<td>Evidence strength and quality</td>
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<td>Relative advantage</td>
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<td>Complexity</td>
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<td></td>
<td>Design quality and packaging</td>
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<td></td>
<td>Cost</td>
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<tr>
<td>Outer setting</td>
<td>Patient needs and resources</td>
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<td></td>
<td>Cosmopolitanism</td>
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<td></td>
<td>Peer pressure</td>
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<td></td>
<td>External policy and incentives</td>
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<tr>
<td>Inner setting</td>
<td>Structural characteristics</td>
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<td></td>
<td>Culture</td>
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<td>• Tension for change</td>
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<td>• Compatibility</td>
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<td>• Relative priority</td>
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<td>• Incentives and rewards</td>
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<td>• Goals and feedback</td>
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<td>• Learning climate</td>
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<td>• Leadership engagement</td>
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<td>• Available resources</td>
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<td></td>
<td>• Access to knowledge and information</td>
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<tr>
<td>Characteristics of individuals</td>
<td>Knowledge and beliefs about the intervention</td>
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<td>Self-efficacy</td>
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<td>Individual stage of change</td>
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<td>Individual identification with organization</td>
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<td>Other personal attributes</td>
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<td>Process</td>
<td>Planning</td>
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<td>Engaging:</td>
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<td></td>
<td>• Opinion leaders</td>
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<td>• Formally appointed internal implementation leaders</td>
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<td>• Champions</td>
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<td>• External change agents</td>
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<td>Executing</td>
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<td>Reflecting and evaluating</td>
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\textsuperscript{a}Adapted from Damschoder et al [39].

\textsuperscript{b}CFIR: consolidated framework for implementation research.
Results

Use Data (Quantitative)

Table 3 shows the use data for Partner in Balance and Myinlife (January 2018 to December 2019). The data show that Myinlife was not chosen a single time in the Netherlands and that Partner in Balance was a more popular choice, especially in the Netherlands. One of the 6 municipalities that initially selected Partner in Balance chose to discontinue the implementation after the first meeting due to a lack of information on future financing and pricing after the project end; this is discussed in depth elsewhere [25]. This municipality is therefore not represented in the table, and averages are calculated over the 5 municipalities that sustained the Partner in Balance implementation. A total of 145 hours were spent on the implementation of Partner in Balance (average 29 hours per municipality), while 54 hours were spent on the implementation of Myinlife (average of 18 hours per municipality).

Table 3. Use data by intervention.

<table>
<thead>
<tr>
<th>Measurement</th>
<th>Partner in Balance</th>
<th>Myinlife</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of times implemented by municipalities</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>Number of times implemented by municipalities</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Number of times implemented by municipalities</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Total number of implementation hours (average)</td>
<td>21 (4)</td>
<td>3 (1)</td>
</tr>
<tr>
<td>Total remote research team hours</td>
<td>124 (25)</td>
<td>51 (17)</td>
</tr>
<tr>
<td>Information and communication technology support hours</td>
<td>48</td>
<td>5</td>
</tr>
<tr>
<td>Number of accounts created</td>
<td>22</td>
<td>29</td>
</tr>
<tr>
<td>Number of accounts created</td>
<td>22</td>
<td>__a</td>
</tr>
</tbody>
</table>

*aNot applicable.*

Partner in Balance Coach Evaluations (Quantitative and Qualitative)

Of the 26 coaches who took part in the coach training, only 22 coaches created Partner in Balance coach accounts. An average of 5 coaches were trained per Partner in Balance municipality. Across municipalities, coaches recruited by the municipalities were dementia case managers (7/26), volunteers (3/26), nursing home personnel (6/26), municipality personnel responsible for caregiving (4/26), and dementia outreach nursing staff (6/26). Of the coaches who were sent the coach evaluation questionnaire via email, 64% (14/22) responded, with 57% (8/14) of those (6 Dutch and 2 Belgian coaches) stating they had not been able to use Partner in Balance in their work and thus did not complete the questionnaire. When asked to provide reasons they were not able to begin coaching, 75% (6/8) of those responded: lack of interest from the caregivers in their caseload (n=1), lack of digital skills in caregivers in their caseload (n=1), lack of time to implement the intervention (n=3), and lack of dementia caregivers in their current caseload (n=1), with 2 spontaneously mentioning they found Partner in Balance a very useful and worthwhile tool, despite the barriers. The remaining 43% (6/14) replied with completed questionnaires: 2 from Dutch municipalities, 2 from the German municipality, and 2 from the Belgian municipality.

The results from the completed questionnaires showed that coaches found Partner in Balance to be moderately useful (mean 3.7 [SD 0.8]) and moderately easy to integrate into their jobs (mean 3.3 [SD 0.8]). It was also perceived as a clear added value to the caregiver (mean 4.5 [SD 0.5]) and to the coach, but to a lesser degree (mean 3.5 [SD 0.8]). In general, coaches found it moderately difficult to recruit suitable caregivers (mean 3.5 [SD 1.6]), although this question was not completed by the 2 German coaches. Regarding its advantages for common practice, coaches reported an enriched contact with the caregiver (mean 4.1 [SD 1.0]). They expected the intervention to be time-efficient (mean 4.1 [SD 1.0]) but not cost-efficient (mean 2.8 [SD 1.0]) in the long run. Coaches would recommend Partner in Balance to other care professionals (mean 4.0 [SD 0.9]). Qualitative analysis of the open-ended questions resulted in 2 main findings: lack of digital literacy in the target population and lack of necessary time for the trained coaches to recruit caregivers were perceived as significant barriers.

Determinants of Implementation (Qualitative)

Characteristics of the Intervention

Complexity

In general, respondents described Myinlife as easy to use. However, one municipality official thought Myinlife was too complicated, as it focused on both online care coordination and positive engagement. This respondent recommended simplifying Myinlife to just the agenda function. Similarly, Partner in Balance was perceived as clear and easy to use. Municipalities found the intervention and coach training easy to understand. However, they would have preferred a more practical, hands-on training in smaller groups, as the training was too theory-focused, and more implementation tips would have been after the first meeting due to a lack of information on future financing and pricing after the project end; this is discussed in depth elsewhere [25]. This municipality is therefore not represented in the table, and averages are calculated over the 5 municipalities that sustained the Partner in Balance implementation. A total of 145 hours were spent on the implementation of Partner in Balance (average 29 hours per municipality), while 54 hours were spent on the implementation of Myinlife (average of 18 hours per municipality).
welcome. Also, while Partner in Balance was easy to understand, there were a lot of tasks and organizing involved in making it work (finding coaches, advertising, coordinating, etc), which made it somewhat complex.

Design Quality and Packaging
For both interventions, it was reported that more face-to-face meetings and trainings and more advertising and promotional materials were needed. In general, it was suggested that the packaging of the interventions needed to be expanded. For instance, several respondents mentioned that they would like an implementation guidebook. In the current form, coaches receive a guidebook during the training, but the suggested implementation guidebook would help management facilitate the adoption, implementation, and maintenance of the intervention. This would contain a general implementation package, consisting of an implementation protocol and premade templates for social media posts, posters, and flyers.

I think it would really help if you had some kind of general promotion campaign or something, where you have flyers and messages and stuff that you can use. Because now, you really only have the information that is on the flyer on the website, which is actually very similar. And from there you have to figure out everything yourself, and think of messages... While, if you really have posters and flyers and advertising pieces for the local newspapers and such, I think you really already can reach the target group much better. [Municipality R3 (Partner in Balance)]

Cost
For Partner in Balance, municipalities confirmed that they thought the suggested price model of payment per client was reasonable in theory. The suggested financiers were municipalities and advertisers/sponsors. Regarding Myinlife, municipalities liked the idea of clients downloading from the App Store or Google Play, as this seemed to contain less liability for the municipality. In these cases, they suggested price points of €5 ($5.61) and €10 ($11.21). Some respondents also suggested the interventions be free.

Relative Advantage
At the end of the implementation, some respondents still preferred face-to-face contact for discussing dementia case management issues. They said that typing sensitive issues on the Partner in Balance platform could be hard for caregivers and coaches, as meanings could be more easily misconstrued than in face-to-face conversations. Myinlife was considered to be expensive in terms of necessary implementation time compared with having a speaker give a lecture on the topic of dementia caregiving, especially as it is currently impossible for the municipality to see if people are actually using the Myinlife platform. They also wondered if Myinlife really posed an added value compared with other online solutions such as WhatsApp and Facebook. Nevertheless, 28% (9/32) of municipalities in the SFC project chose to implement these eHealth interventions in their communities (although only 8 continued this implementation), indicating that they perceived these interventions as having a relative advantage over the other activities on offer in this project.

Characteristics of Individuals

Self-Efficacy
Self-efficacy was a recurring topic in the interviews, especially for Partner in Balance, where more guidance of the caregivers and coaches was needed. Both coaches and organization coordinators were uncertain about whether they could fulfill their role and scared to make mistakes. These fears eased once they started the coaching and reported more confidence with increased experience. Municipality officials reported that successful coaches had confidence in the intervention and their own ability to use it to help their clients.

I think that first step was really a big step. But it’s not about saying, “I’m not going to do this.” More, “How do I go about it,” “What is in here?” And from the moment it develops. That’s why I also printed it, had read it, and done all of that while learning, only then did I feel like, okay, now I dare to approach someone with this. [Municipality 4 (Partner in Balance)]

Knowledge and Beliefs About the Intervention
Municipality officials believed that the interventions would be effective at improving outcomes for caregivers, as this had been proven in previous research which they were familiar with. However, some officials wondered whether these effects would also be obtained outside the research context. For both interventions, there were significant privacy and liability concerns.

I think you should have it in the App Store anyway. And I think that an IT professional from a municipality is really not going to get involved in this, there is also the security issue. If we offer it, and data is lost because you no longer maintain it properly than we are responsible, because we offer it, so I will never get myself into that legal mess. [Municipality 2 (Myinlife)]

There were also more general concerns regarding the timeliness and fit of the eHealth interventions in the current dementia health care setting. In particular, they wondered if there was sufficient digital literacy in caregivers, coaches, and in the municipality itself.

Inner Setting

Structural Characteristics and Networks and Communication
Municipality officials said that much more structural integration was needed. The implementation of the eHealth interventions was usually the sole responsibility of one person within the municipality. Municipality officials stressed that this was not enough, and that there should be a team to tackle the implementation together. As they recommended including this in the product itself, this is discussed in more detail under Characteristics of the Intervention. Municipalities added that it
was easy to set up the necessary meetings with the Partner in Balance team.

Look what we can still do is try to launch it in concrete care situations, to see if people use it. But yes, if the guidance is not there, I do not know if they will manage. [Municipality 2 (Myinlife)]

Implementation Climate
For both interventions, there was not enough goal setting and feedback, interventions had low relative priority, and there were no incentives or rewards to encourage the implementation into clinical practice. As management is primarily interested in concrete output, it is important to keep track of the output and use of the interventions. This is currently possible to track digitally for Partner in Balance but not for Myinlife.

Readiness for Implementation
Respondents indicated that there were few resources (especially in terms of available time) to spend on the implementation, as well as a lack of leadership engagement.

Outer Setting
Cosmopolitanism
Regarding how the implementing organizations are linked to other organizations, respondents stated that the interventions needed to be offered through an external party (not through the municipality) and cooperation with care providers would always be necessary, as they would have to agree to execute the interventions. Some municipalities reported that the SFC project had been a good chance to connect and strengthen their local dementia care networks.

Patient Needs and Resources
Myinlife and Partner in Balance were both perceived as fitting caregiver needs. However, for Myinlife, there was little enthusiasm from the local target population, as evidenced by the lack of attendance to the planned Myinlife caregiver meetings.

I think we’ve determined that this should work in principle... But maybe, indeed, it just doesn’t fit what people here want, what they need, what they feel comfortable with. Or maybe we just didn’t reach them despite all the effort... That is also possible. [Municipality 3 (Partner in Balance)]

External Policy and Incentives
Partner in Balance was described as fitting well into initiatives around generalized services, current internal caregiver and prevention policies, and municipality innovation budgets. These budgets are facilitated by the outer setting, but their use is determined by the inner setting (municipality). The municipalities that had these innovation budgets mentioned that these budgets could potentially be used in the future to purchase licenses for the further implementation of Partner in Balance, if the experiences were positive.

Yes, I think it fits within the policy yes. It fits within the informal care policy, is increasingly in line with the policy of health insurers, who say if we support... [Municipality 1 (Partner in Balance)]

process
Engaging
Municipalities implementing Myinlife indicated that a more hands-on demonstration and sales-pitch–like approach were needed to convince health care partners to cooperate in the dissemination of the intervention and less of an academic presentation. There was not enough engagement of the target populations (both of Partner in Balance coaches and dementia caregivers), although 2 municipalities did involve local dementia groups in their activity choice and subsequent eHealth implementation. More opinion leaders and internal implementation leaders were needed.

I introduced this. My supervisor, yes, but I work in my department alone.... We have not really discussed it with anyone else. So, my supervisor is not actively pushing this now either. [Municipality 4 (Partner in Balance)]

Planning
These new plans include involving more local health care groups (for Partner in Balance), more advertising and communications, which are more direct (for both Myinlife and Partner in Balance), and more structural goal setting and feedback (for Partner in Balance, this pertains to coaching; for Myinlife, this is tracking how many people use the intervention). Reflecting and evaluating was not a big part of this implementation but was seen as important for the future implementation of both interventions.

Evaluation
Integrating the use data, coach questionnaires, and municipality interviews, it appears that the implementation of Partner in Balance and Myinlife showed varying levels of success in different municipalities. In the end, 3 municipalities planned to continue with their implementation of Partner in Balance beyond the study period, while no municipalities planned to continue with their implementation of Myinlife. What these 3 Partner in Balance municipalities had in common was that they considered the implementation of the intervention to be a success. These municipalities appeared to have a sense of internal responsibility to facilitate the implementation of Partner in Balance and devise creative solutions. The 2 Partner in Balance municipalities that did not consider the implementation to be successful seemed to see the implementation as more of an external project, where the municipality’s role was more to facilitate than execute. For Myinlife, it was clear from the municipality interviews and use data that more time was needed to successfully embed the
intervention into the local health care landscape. Despite Myinlife not necessitating the recruitment of coaches, it was clear that more face-to-face contact was needed to engage the implementing municipality and target group.

Discussion

Principal Findings

This study integrated use data, coach questionnaires, and interviews to evaluate the implementations of Partner in Balance and Myinlife. These two eHealth interventions for caregivers of people with dementia were implemented in 8 municipalities in the EMR. This study’s objectives were to evaluate the success of the implementation of Myinlife and Partner in Balance and investigate determinants of the successful implementation of Myinlife and Partner in Balance in the municipality context. The analysis of the implementation determinants showed that there were unsuccessful aspects of the implementation, including the lack of goal setting and incentives, low priority, few resources, and lack of leadership. In order to successfully bring evidence-based eHealth interventions for caregivers of people with dementia into practice, a number of important improvements must be made in the implementation of these interventions.

Improvements for Partner in Balance Coaches

A main finding from the interviews with municipality officials regarding the Partner in Balance implementation was the need to increase the self-efficacy of the Partner in Balance coaches. Coaches reported that uncertainties about whether they were ready to coach and insecurities about whether they could do a good job were significant barriers to starting to coach caregivers. Hence, an important lesson from this study is that Partner in Balance cannot increase caregivers’ self-efficacy without first ensuring that coaches have a minimum level of self-efficacy to start the coaching. This is supported by previous research, which has described care professional self-efficacy as a major facilitator of successful intervention implementation in a variety of contexts [40-42]. Bandura et al [43] described 4 ways to increase self-efficacy: mastery experiences, vicarious experiences, verbal persuasion, and monitoring physiological states. Subsequent research built on this by examining how self-efficacy can be enhanced through training in professional caregivers of people with dementia, which can potentially increase intervention adherence [44]. Discussing common barriers to implementation among the training participants, addressing barriers through role-playing, and providing constructive feedback on the role-play have been shown to increase dementia care professional self-efficacy [45]. In the future, Partner in Balance will incorporate these methods into coach trainings to help coaches develop the self-efficacy necessary to start coaching with Partner in Balance.

In their responses to the request to complete the Partner in Balance coach evaluation questionnaire, several coaches mentioned that they were not able to offer Partner in Balance to any caregivers, as their clients were not familiar with the use of online interventions. These clients were often older, and previous research has indicated that advanced age is a barrier to adopting eHealth due to related declines in motor, cognitive, and perceptive abilities and the difficulties accompanying the rapidly changing technological market [46-48]. In general, studies regarding older adults’ attitudes toward eHealth interventions have produced mixed results [49-51]. It is also important to consider health care professionals’ attitudes toward eHealth for dementia and their role as gatekeepers in deciding whether to offer eHealth interventions such as Partner in Balance to caregivers. In line with this research, a recent systematic literature review on the attitudes of health care professionals toward eHealth described workload concerns, lack of incentives, perceived threats to autonomy, liability concerns, and lack of organizational support and cooperation as important implementation barriers [52]. Here too, a possible remedy for these eHealth challenges experienced by health care professionals is the embedding of improved eHealth education in their standard training [53,54].

Improvements for Municipalities

For both Myinlife and Partner in Balance, municipality officials reported that their municipality implementation teams were often understaffed. Previous research on municipal eHealth for home care [55] and dementia care [56] has underscored the importance of municipality-specific protocols when implementing eHealth in these contexts. Based on this study, these protocols should specify how to form municipality implementation teams, including suggestions to involve at least 2 people in the team and schedule regular progress meetings within this team. These meetings should discuss new promotion ideas and opportunities using templates for the promotion and advertising of the interventions. Additionally, these meetings should monitor the success of the intervention implementation, as municipality officials reported that their management is most interested in demonstrable output. For Partner in Balance, it is possible for organizations to monitor the number of coaches and participating caregivers. However, there is currently no way to determine whether Myinlife is successfully being used in the community. Previous research on organizational learning as a method for eHealth benefit realization in a municipal health care context emphasized the importance of reviewing and evaluating results and establishing potential for further benefits [57]. This makes it possible for the implementation teams to set and achieve goals around use in the community. In this study, not doing so was counterproductive for both team motivation and acceptability of the time spent on implementation to management. For both Partner in Balance and Myinlife, future implementation packages should include protocols on setting use goals in the regularly scheduled team meetings, and the interventions should include functionalities to easily track these statistics.

Improvements for Project Management

In order to recruit external health care organizations, the municipality is required to recruit coaches (for Partner in Balance) and integrate interventions into larger health care structures that can offer it as part of their services (for Partner in Balance and Myinlife). This requires regular meetings to follow up on coaches’ experiences, where coaches can learn from each other, share tips and tricks, and discuss their progress. The involvement of the management of these external health
care organizations is crucial, as they can offer incentives for successful coaching and adapt structures to facilitate the integration of Partner in Balance into the coaches’ tasks. For example, it is important that management ensures that time spent coaching can be declared to the health insurer as provided care. Previous research has reported this as a significant determinant of successful eHealth implementation for healthcare professionals [58]. Thus, future implementation packages should include protocols for these organizations on how to organize the suggested meetings, internal monitoring, and incentives, including the declaration of coached hours to health insurers. To facilitate this, future implementation packages should also suggest appointing an eHealth ambassador within the organization whose function is to ensure that these meetings take place, and provide a reliable and continuous level of enthusiasm for the intervention. Previous research has advocated the use of ambassadors in implementing eHealth [32,59-61].

**Sustainability Measures**

Despite the relative ease of setting up the infrastructural aspects of this project, implementation was only successful in just over half of the municipalities. It is clear that successful implementation depends on more than merely setting the necessary structures in place. This study’s interview findings indicated that successful implementation was tied to a sense of ownership and responsibility from the municipality officials. This is in line with previous research, which has pointed to a lack of eHealth ownership at both local and national levels as a considerable implementation barrier [62,63]. Therefore, future implementation packages for Myinlife and Partner in Balance will include suggestions on how to achieve sustainability by increasing sense of ownership and end user adherence in general. An important element of this is the reflection and feedback exercises that will also be part of new measures to monitor the interventions (described above), as they have been shown to improve eHealth ownership and adoption [64]. In addition to scheduling the described reflection and role-playing exercises, previous research on increasing the adherence of end users to eHealth interventions recommends persuasive system design, which is used to aid the development of information systems to shape attitudes and behaviors [65]. This approach recommends that interventions incorporate on-the-spot reminders and feedback to increase end user adherence. Hence, future implementations will incorporate more intervention monitoring and reflection moments for implementers and end users. This new approach to training coaches is expected to reduce the uncertainties reported by coaches concerning their abilities to coach.

Finally, it is also important to consider why Partner in Balance was more often successfully implemented in this municipality context than Myinlife. Previous research has indeed shown that blended eHealth interventions for caregivers of people with dementia are more effective at improving outcomes for caregivers of people with dementia than nonblended interventions [13]. One potential explanation for the increased success of Partner in Balance in this particular context is that its blended aspect (the human contact between caregiver and coach) not only increases effectiveness through improved caregiver outcomes but also through a possible effect of increasing engagement among implementers. Here, Partner in Balance required more hours to implement in the municipality context than Myinlife. It is possible that these additional face-to-face hours required to implement Partner in Balance (but not Myinlife) increased implementers’ sense of ownership of the successful implementation of the intervention. Therefore, future implementers of nonblended eHealth interventions in this context could consider incorporating this human interaction by way of face-to-face meetings about the intervention or caregiver support groups discussing the intervention to facilitate implementation by increasing the implementation hours and thus potentially the sense of ownership. Of course, this study also shows that this blended aspect is more resource intensive. Future research could investigate the comparative cost-effectiveness of these interventions in order to weigh costs and benefits.

**Strengths and Limitations**

This study had several important strengths. First, this study is one of few to examine the further implementation of eHealth interventions for caregivers of people with dementia after the trial phase. This study uses various measures from multiple perspectives to construct a thorough evaluation of the implementation of these interventions in a municipality context. As a result, this study is able to shed novel light on the currently underexplored organizational and contextual implementation determinants. Second, by focusing on the municipality context specifically and by taking the time to explore this context in depth, this study has successfully identified the municipality as a potential distributor with the financial means to further disseminate evidence-based eHealth interventions for caregivers of people with dementia.

This study also has several limitations. First, this study did not explore the experiences of caregivers using the Partner in Balance and Myinlife interventions. As a result, we have no information on actual eHealth use and do not know how the caregiver target group used and evaluated the interventions in this context. This is because both Partner in Balance and Myinlife were previously assessed for usability and effectiveness by caregivers in a series of trials [29,30,33,66] informed by the Medical Research Council framework [67]. The aim of this study was to gain information on their broader implementation contexts. Second, there was a moderate response rate to the request to complete the Partner in Balance coach evaluation questionnaire (64%), with only 6 coaches submitting completed questionnaires (and 8 providing details on why they had not yet started coaching). As a result, there is no information on how the nonresponders experienced Partner in Balance, causing a potentially biased sample of responses from coaches who might be more positively disposed toward the intervention. Next, this study was unable to take into account the views of the municipalities that chose not to implement Myinlife or Partner in Balance. While it was not this study’s aim to generalize these qualitative findings to all municipalities, it is possible that this study represents a sample of municipalities that have more positive attitudes toward eHealth for dementia and its implementation than other municipalities. Nevertheless, it is still useful to document and learn from these (potentially more engaged) municipalities, as they can provide valuable insight.
into the feasibility of eHealth for dementia in this context and into municipality needs. Third, the focus of this study was to shed light on the breadth of implementation determinants encountered in bringing evidence-based eHealth interventions for caregivers of people with dementia from research into practice. The aim was to provide a complete overview of the encountered barriers and facilitators using data from a variety of sources. As a result, it must be acknowledged that this study lacks a more elaborate in-depth analysis of the process characteristics of the 8 municipality implementations. Future research will address this topic extensively. Finally, it must be acknowledged that all authors (with the exception of HJT) were involved in the development of Myinlife and Partner in Balance and are therefore potentially not unbiased. However, the authors were also interested in differences between the interventions and were in this sense unbiased. Moreover, it is the authors’ belief that this type of implementation research is essential for evidence-based interventions, and researchers should more often conduct longer term implementation research on their own interventions.

Conclusions
This study provided a thorough exploration of the feasibility of the implementation of eHealth interventions to support caregivers of people with dementia in a municipality context. Future implementations can make use of protocols that provide municipalities and organizations with suggestions on how to tackle implementation challenges and realize improvements for the (Partner in Balance) coaches, implementation team, and external implementing organizations. In general, it is important to foster a sense of ownership of the success of the eHealth intervention in the municipality and dementia health care context, as this was seen as a main determinant of success in this implementation project. For Partner in Balance, an important finding was that the self-efficacy of coaches must be increased before they can be expected to help caregivers elevate their levels of self-efficacy regarding dementia caregiving. For Myinlife, it was necessary to involve more face-to-face contacts and integrate the intervention more into other local health services, despite it not being designed as a blended intervention. These insights will be integrated into future implementation protocols that will become a standard part of the Myinlife and Partner in Balance implementation packages for municipalities and organizations.

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Conflicts of Interest
HLC, LMMB, MEV, and FRJV were involved in the previous development of Myinlife and Partner in Balance. All other authors have no conflicts to declare.

Multimedia Appendix 1
Partner in Balance coach evaluation questionnaire.
[DOCX File, 24 KB - aging_v41e21629_app1.docx ]

Multimedia Appendix 2
Measurement instrument: description and operationalization of determinants.
[DOCX File, 21 KB - aging_v41e21629_app2.docx ]

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Abbreviations

CFIR: consolidated framework for implementation research
EMIR: Euregion Meuse-Rhine
MIDI: measurement instrument for determinants of innovation
SFC: Senior Friendly Communities

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Family Caregiver Needs and Preferences for Virtual Training to Manage Behavioral and Psychological Symptoms of Dementia: Interview Study

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Abstract

Background: Behavioral and psychological symptoms of dementia (BPSD) are associated with increased stress, burden, and depression among family caregivers of people with dementia. STAR-Caregivers Virtual Training and Follow-up (STAR-VTF) is adapted from an evidence-based, in-person program that trains family caregivers to manage BPSD. We used a human-centered design approach to obtain feedback from family caregivers about STAR-VTF. The program will be evaluated using a pragmatic randomized trial.

Objective: The objective of the study was to understand the needs of family caregivers for improving BPSD management and the extent to which caregivers perceived that STAR-VTF could address those needs.

Methods: Between July and September 2019, we conducted 15 semistructured interviews with family caregivers of people with dementia who receive care at Kaiser Permanente Washington in the Seattle metropolitan area. We identified participants from electronic health records, primarily based on a prescription for antipsychotic medication for the person with dementia (a proxy for caregivers dealing with BPSD). We showed caregivers low-fidelity prototypes of STAR-VTF online self-directed materials and verbally described potential design elements. We obtained caregiver feedback on these elements, focusing on their needs and preferences and perceived barriers to using STAR-VTF. We used a hybrid approach of inductive and deductive coding and aggregated codes to develop themes.

Results: The idea of a virtual training program for learning to manage BPSD appealed to caregivers. They said health care providers did not provide adequate education in the early disease stages about the personality and behavior symptoms that can affect people with dementia. Caregivers found it unexpected and frustrating when the person with dementia began experiencing BPSD, symptoms they felt unprepared to manage. Accordingly, caregivers expressed a strong desire for the health care organization to offer programs such as STAR-VTF much sooner. Caregivers had already put considerable effort into problem solving challenging behaviors. They anticipated deriving less value from STAR-VTF at that point. Nonetheless, many were interested in the virtual aspect of the training due to the convenience of receiving help from home and the perception that help from a virtual program would be timelier than traditional service modalities (eg, face to face). Given caregivers’ limited time, they suggested dividing the STAR-VTF content into chunks to review as time permitted. Caregivers were interested in having a STAR-VTF provider for additional support in managing challenging behaviors. Caregivers reported a preference for having the same coach for the program duration.
Conclusions: Caregivers we interviewed would likely accept a virtual training program such as STAR-VTF to obtain information about BPSD and receive help managing it. Family caregivers anticipated deriving more value if STAR-VTF was offered earlier in the disease course.

(Keywords: dementia; Alzheimer disease; behavioral symptoms; caregivers; internet-based intervention; education; behavior; symptom; psychology; qualitative; caregiver; intervention; training; virtual care; digital health)

Introduction

Alzheimer disease and related dementias (ADRD) are irreversible, progressive brain disorders that eventually affect a person’s ability to perform basic activities, including bathing, feeding, and dressing. ADRD is the fifth leading cause of death among people 65 years and older in the United States [1]. The US prevalence of ADRD is projected to nearly triple from 5 million in 2014 to 13.9 million in 2060 [2]. People with dementia require high levels of care, most of which is provided by informal caregivers such as spouses and adult children. Up to 90% of people with dementia will experience behavioral and psychological symptoms of dementia (BPSD) over the course of their illness [3]. BPSD that can be particularly challenging to family caregivers include agitation, anxiety, irritability, depression, delusions, hallucinations, and sleep changes. BPSD are associated with increased stress, burden, and depression among family caregivers of people with dementia [4,5].

STAR-Caregivers (STAR-C) is a nonpharmacological intervention endorsed by the US Department of Health and Human Services Administration on Aging in which a coach trains family caregivers over multiple face-to-face sessions on how to manage BPSD. STAR-C is demonstrated to reduce caregiver burden, caregiver depression, and the frequency and severity of BPSD [6]. The STAR-C training is 6 sessions, covering topics such as expectations about ADRD, communication with a person with ADRD, strategies for dealing with BPSD, and coping with caregiving, including pleasant activities for caregivers and patients. In its original form, coaches conduct in-person weekly sessions with caregivers in their homes with follow-up telephone calls. Despite evidence to support its efficacy, STAR-C has not been widely disseminated across health care and community settings, in part due to the cost of providing in-person training and using printed materials [7-9].

To address these implementation barriers, a Kaiser Permanente Washington Health Research Institute pragmatic trial is testing the feasibility of STAR-C Virtual Training and Follow-up (STAR-VTF) (ClinicalTrials.gov NCT04271046) [10], which will deliver the training to family caregivers virtually. Caregivers will complete online training modules asynchronously, have 30-minute weekly telephone check-ins with a coach (social worker or mental health counselor) at Kaiser Permanente Washington (KPWA), and have ongoing support from the coach via secure email messages within the KPWA member portal. Caregivers will access the online training modules via a website hosted on the Kaiser Permanente School of Allied Health Sciences extended learning management system. Caregivers will log in to the website from their preferred web browser using their email address and a user-generated password. While caregivers will not enter personal health information or other identifiable information, the website will automatically collect their IP addresses. The KPWA technology risk review team declared caregivers’ use of the website as minimal risk. Only caregivers living in Washington State that meet eligibility for the pragmatic trial will have access to the website.

While considerable evidence supports the efficacy of STAR-C, and implementation challenges from a health care system perspective could be addressed by changing the modality of program delivery from in person to virtual, family caregivers’ views on participating in a virtual training program are needed. A framework for using human-centered design to improve the implementation of evidence-based interventions recommends that early phases of the design process focus on gathering information to understand the viewpoints of all stakeholders [11]. This information is then used to iteratively design, build, and test solutions that directly address the needs and preferences of all stakeholders, particularly end users such as family caregivers in STAR-VTF. Human-centered design is widely considered the key to designing tools that end users will find useful and easy to use, factors that are associated with acceptance and actual use of tools [12].

Early in STAR-VTF development, when the original in-person training was being adapted for virtual delivery, our research team used a human-centered design approach to obtain feedback from family caregivers on the idea of a virtual training program. The objective was to understand the needs of family caregivers for improving BPSD management and the extent to which they perceived that a program such as STAR-VTF could address their needs. To achieve this, we conducted and analyzed 15 semistructured interviews with family caregivers of people with ADRD who receive care at KPWA in the Seattle metropolitan area. The COVID-19 pandemic has shed light on the urgent need to design and evaluate digital health strategies that offer support virtually [13], especially for families caring for vulnerable older adults. Effective digital health strategies to support family caregivers are critically needed during the pandemic and will remain important in the post–COVID-19 era.

Methods

We conducted semistructured interviews with family caregivers of people with ADRD. The institutional review boards at Kaiser Permanente Washington Health Research Institute and the...
University of Washington approved the study. Study participants provided written informed consent.

**Recruitment**

To identify potential study participants, we extracted data from the KPWA electronic health record (EHR) and administrative claims system to identify patients aged 65 years or older with an ADRD diagnosis and a new prescription for an antipsychotic medication within the past 2 years. A prescription for an antipsychotic medication was a proxy for identifying caregivers who may have struggled with managing BPSD. We excluded patients with an International Classification of Diseases Ninth Revision—Clinical Modification (ICD-9-CM) or ICD-10-CM diagnosis of bipolar disorder or schizophreniform disorder and those in assisted living or skilled nursing facilities. For patients meeting our criteria, we mailed a packet to their caregiver with a cover letter describing the goals of the study and a consent form. One week after the mailing, a study staff member phoned caregivers to invite study participation. The staff member attempted up to three calls with up to two voicemail messages. Caregivers interested in participating were screened for eligibility during the phone call. Caregivers were eligible if they were 21 years or older; were an adult child, spouse or partner, or close friend of the patient; lived with the patient (or within 5 miles); provided at least 8 hours of care per week; and lived in King, Snohomish, or Pierce counties, Washington. We excluded caregivers with a diagnosis of ADRD. For eligible, interested caregivers, the staff member scheduled a date, time, and location to conduct the interview.

**Data Collection**

We conducted all interviews in person between July and September 2019. Interviews took place at a convenient location for caregivers, such as homes or KPWA facilities. Using a semistructured interview guide, we asked caregivers what challenging BPSD the patient experienced, how caregivers typically responded to BPSD, and how BPSD affected caregivers. Next, we used 2 storyboards to illustrate the potential experience of a caregiver using STAR-VTF to learn how to improve management of BPSD (Multimedia Appendix 1). The first storyboard depicted a caregiver struggling with behavioral symptoms in the person with dementia and learning about STAR-VTF through a health care provider. The second storyboard depicted a caregiver choosing which behavioral symptom to focus on, using STAR-VTF to learn strategies for responding to the symptom, and speaking on the phone with a coach for additional support. We asked caregivers questions to gauge their initial reactions to the idea of STAR-VTF and their interest in using the virtual program. Finally, we showed caregivers low-fidelity prototypes of the STAR-VTF online self-directed materials and verbally described potential design elements, including information content, visual and auditory presentation of information, and user interaction (Multimedia Appendix 2). We asked caregivers questions to obtain feedback on these design elements, elicit needs and preferences, and understand perceived barriers to using STAR-VTF.

We surveyed caregivers for sociodemographic and caregiving characteristics. Caregivers received US $100 for participating. All interviews were audiorecorded and transcribed verbatim by a professional transcription company. The transcripts were proofread by the interviewer. Interviews were 40 to 60 minutes.

**Data Analysis**

We used Dedoose version 8.1.8 (University of California, Los Angeles) to manage the coding process. The first author (MR) read all interview transcripts and developed an initial codebook containing deductive codes about the extent to which caregivers perceived STAR-VTF to align with their informational, educational, psychosocial, and accessibility needs. Two members of the research team independently coded interview transcripts using the deductive codes in the initial codebook. They applied additional inductive codes based on the content of responses that were not covered by the original deductive codes. For all 15 transcripts, after coding each transcript, we reviewed the coding as a group. During these meetings, we reconciled coding disagreements through group discussion and transcript review. We revised and expanded the initial codebook throughout the coding process. After completing coding, members of the research team met regularly to discuss the coded excerpts; identify themes representing caregivers’ informational, educational, psychosocial, and accessibility needs; and identify exemplary quotes to represent each theme.

**Results**

**Characteristics of Study Participants**

From the EHR and claims data, we identified 54 potential study participants (ie, caregivers of patients who met the patient eligibility criteria) and mailed packets to them. Among these, 12 caregivers could not be reached by telephone, 17 were ineligible, and 8 declined participation. We scheduled interviews with the remaining 17 who were eligible and interested in participating. We were unable to conduct 1 interview because the patient with ADRD died before the scheduled interview. We were unable to conduct 1 second interview because the caregiver was not aware that the patient had an ADRD diagnosis, and the research team determined it would be difficult to have a meaningful conversation about the caregiver’s experience caring for a person with ADRD. Therefore, we completed interviews with 15 caregivers (Table 1).

In the following sections, we present the informational, educational, psychosocial, and accessibility needs that family caregivers perceived would prompt their use of a program such as STAR-VTF. In addition, we present characteristics of STAR-VTF that caregivers perceived would address their needs (Table 2).
### Table 1. Characteristics of family caregivers and description of the caregiving situation (N=15).

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Family caregivers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (years), mean (SD)</td>
<td>72 (10)</td>
</tr>
<tr>
<td>Female, n (%)</td>
<td>10 (67)</td>
</tr>
<tr>
<td><strong>Race, n (%)</strong></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>13 (87)</td>
</tr>
<tr>
<td>American Indian or Alaska Native</td>
<td>1 (7)</td>
</tr>
<tr>
<td>Asian</td>
<td>1 (7)</td>
</tr>
<tr>
<td>Hispanic or Latino ethnicity, n (%)</td>
<td>0 (0)</td>
</tr>
<tr>
<td><strong>Education, n (%)</strong></td>
<td></td>
</tr>
<tr>
<td>Post–high school training other than college (vocational or technical)</td>
<td>2 (13)</td>
</tr>
<tr>
<td>Some college</td>
<td>4 (27)</td>
</tr>
<tr>
<td>College graduate</td>
<td>8 (53)</td>
</tr>
<tr>
<td>Postgraduate</td>
<td>1 (7)</td>
</tr>
<tr>
<td><strong>Occupational status, n (%)</strong></td>
<td></td>
</tr>
<tr>
<td>Employed</td>
<td>3 (20)</td>
</tr>
<tr>
<td>Unemployed</td>
<td>1 (7)</td>
</tr>
<tr>
<td>Student</td>
<td>1 (7)</td>
</tr>
<tr>
<td>Retired</td>
<td>10 (67)</td>
</tr>
<tr>
<td><strong>Income (US $), n (%)</strong></td>
<td></td>
</tr>
<tr>
<td>$20,000 to $34,999</td>
<td>1 (7)</td>
</tr>
<tr>
<td>$35,000 to $49,999</td>
<td>1 (7)</td>
</tr>
<tr>
<td>$50,000 to $74,999</td>
<td>4 (27)</td>
</tr>
<tr>
<td>$75,000 to $99,999</td>
<td>5 (30)</td>
</tr>
<tr>
<td>$100,000 to $199,999</td>
<td>1 (7)</td>
</tr>
<tr>
<td>$200,000 or more</td>
<td>1 (7)</td>
</tr>
<tr>
<td>Prefer not to answer</td>
<td>2 (13)</td>
</tr>
<tr>
<td><strong>Member of Kaiser Permanente Washington, n (%)</strong></td>
<td>9 (60)</td>
</tr>
<tr>
<td><strong>Relationship to person with dementia, n (%)</strong></td>
<td></td>
</tr>
<tr>
<td>Spouse or partner</td>
<td>10 (67)</td>
</tr>
<tr>
<td>Child</td>
<td>2 (13)</td>
</tr>
<tr>
<td>Other family member</td>
<td>2 (13)</td>
</tr>
<tr>
<td>Friend</td>
<td>1 (7)</td>
</tr>
<tr>
<td>Lives with person with dementia, n (%)</td>
<td>15 (100)</td>
</tr>
<tr>
<td><strong>Duration in caregiving role (years), mean (SD)</strong></td>
<td>5 (5)</td>
</tr>
<tr>
<td><strong>Caregiving hours per week, n (%)</strong></td>
<td></td>
</tr>
<tr>
<td>15 to 20</td>
<td>2 (13)</td>
</tr>
<tr>
<td>21 to 24</td>
<td>1 (7)</td>
</tr>
<tr>
<td>35 or more</td>
<td>12 (80)</td>
</tr>
</tbody>
</table>
Table 2. Summary of caregivers’ perceptions about needs and STAR-VTF characteristics that would address them.

<table>
<thead>
<tr>
<th>Family caregiver perceived needs</th>
<th>STAR-VTF&lt;sup&gt;a&lt;/sup&gt; characteristics to address needs</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Information and education</strong></td>
<td></td>
</tr>
<tr>
<td>What BPSD&lt;sup&gt;b&lt;/sup&gt; to expect</td>
<td>Providing education earlier in disease stage (prior to symptoms) about what BPSD a person with dementia could experience</td>
</tr>
<tr>
<td>Tailored help on how to manage BPSD</td>
<td>Offering examples of problem-solving strategies that could work for the particular BPSD caregiver is dealing with</td>
</tr>
<tr>
<td><strong>Psychosocial support</strong></td>
<td></td>
</tr>
<tr>
<td>Encouragement</td>
<td>Incorporating words of encouragement throughout training as caregiver learns to manage BPSD</td>
</tr>
<tr>
<td>Coping with BPSD</td>
<td>Teaching caregivers strategies for managing their own frustrations with BPSD</td>
</tr>
<tr>
<td>Supportive services</td>
<td>Connecting caregivers with vetted respite care and other supportive services, including caregiver support groups</td>
</tr>
<tr>
<td><strong>Accessibility</strong></td>
<td></td>
</tr>
<tr>
<td>Timing of program</td>
<td>Offering STAR-VTF to caregivers earlier in their roles as caregivers</td>
</tr>
<tr>
<td>Modality of program delivery</td>
<td>Making STAR-VTF virtually accessible to provide convenient and timely help</td>
</tr>
<tr>
<td>Time required to participate</td>
<td>Breaking up content into small chunks that caregivers could review as time and space permits</td>
</tr>
<tr>
<td>Access to a designated provider</td>
<td>Having the same coach assigned to caregivers throughout duration of program</td>
</tr>
</tbody>
</table>

<sup>a</sup>STAR-VTF: STAR-Caregivers Virtual Training and Follow-up.
<sup>b</sup>BPSD: Behavioral and psychological symptoms of dementia.

Information and Education Needs

The idea of the health care organization offering a virtual training program for caregivers to learn to manage BPSD was largely appealing to caregivers. They discussed the importance of learning early what BPSD they could expect in the person with dementia as the disease progressed and receiving tailored help on how to manage BPSD.

Learning Early What BPSD to Expect

When the person with dementia was diagnosed, caregivers were only vaguely aware of BPSD that some people with dementia experience. One caregiver expressed this scenario as “going in blind.” As the disease progressed, caregivers were startled to observe symptoms they did not anticipate, such as the person with dementia crying excessively. According to caregivers, health care providers did not provide sufficient warning of the personality and behavioral changes they might observe in the person with dementia. These changes became a source of deep frustration for caregivers, as they neither expected nor felt prepared to manage them. In response to the idea of STAR-VTF, one caregiver explained why it would be valuable to incorporate education earlier in the disease stage (prior to symptoms) about what BPSD a person with dementia could experience:

I can see where caregivers will just fall apart with some of these behaviors if you don’t know what’s coming. And it’s not that I have anything against the doctors. They don’t have time. Maybe they don’t even know, but they don’t have time to really prepare you for what you’re taking on. But that’s what caregivers need to be told from the beginning. Are you going to be caring for your husband or, you know, your parent? Here’s a program to help you, to help you strategize through these difficult behaviors that might lie ahead for you. I think that really appeals to me and needs to be said in the very beginning, not when you’re extremely desperate.

Caregivers also explained that knowing BPSD could occur and worsen as the disease progressed would help them to plan medical procedures (eg, elective surgery) before it became too challenging for the person with dementia to comply. In addition, it would help caregivers plan home modifications to ensure a safe environment for the person with dementia.

Receiving Tailored Help on How to Manage BPSD

After viewing prototypes of STAR-VTF, caregivers recognized the usefulness of learning problem-solving strategies that they could then apply to any challenging symptom. However, caregivers stressed their need to also receive tailored advice for problem-solving specific BPSD. For example, one caregiver suggested adding a search feature to STAR-VTF to find targeted advice on how to solve particular symptoms:

Right now, it’s very general, okay? So, this is how you—you—this is what process you go through to solve issues. And the better you get at that process, the better you are at solving the issues, right? That come up in your day-to-day lives. But if you have a specific issue that is kind of quirky or way off in right field…Is there a backup situation where you can look something up? So that could be added on to this program. Once they [caregivers] go through the basic training.

A factor driving the suggestion to include tailored advice within STAR-VTF was caregivers’ desire to quickly address a challenging symptom. Some caregivers described feeling
“desperate” when the person with dementia was experiencing BPSD. While caregivers recognized the value of going through the trial-and-error, problem-solving process that STAR-VTF teaches, they also perceived the amount of time required to go through this process as a limitation:

It's not something that, okay, we can spend the next week and a half going over this and trying...It's something—you need something, like, within an hour type of deal...that's what I found more often when we had serious concerns or questions, you know; I would go online and search other people having the same exact circumstances and how did they handle it and what worked and what didn't work.

In those difficult moments, caregivers desired to know specific strategies to try immediately to improve the situation. Thus, according to caregivers, STAR-VTF could be improved by incorporating a combination of teaching general problem solving and offering examples of strategies that could work for particular BPSD as they arise.

Psychosocial Support Needs
Caregivers discussed their psychosocial needs and how they envisioned STAR-VTF to support them. In particular, caregivers described a need to receive encouragement, learn how to cope with BPSD, and connect with supportive services.

Encouragement When Learning to Manage BPSD

Through educational materials, family members and friends, other family caregivers of people with dementia, and their own experience, some caregivers had identified successful strategies for managing particular BPSD. For example, at the suggestion of her daughter, one caregiver used a whiteboard to write answers to questions the person with dementia asked repeatedly so that the caregiver could point to the whiteboard instead of having to constantly repeat herself. Nonetheless, the process of identifying successful strategies was hard. They were discouraged when strategies that worked for other caregivers in managing a particular symptom did not work for them. They were also discouraged when strategies that had worked for them in the past were no longer effective. Consequently, caregivers underscored the importance of STAR-VTF offering encouragement during the process of learning to manage challenging symptoms:

Caregivers carry around a lot of guilt because they want to be perfect. We love our mates. We love whoever we’re caring for. We want to do it right. What worked last week doesn’t necessarily work this week. So, if a solution that worked last week doesn’t work, then persevere. I would say that. Persevere for another solution...Caregivers need to be assured that no one solution is going to be perfect for everyone. But to persevere, because there is something out there that will work.

Assuring caregivers that what worked for one isn’t necessarily going to work for another. Because as a caregiver, you so often have people say to you, “oh, yeah, well, so-and-so did this and had no problem”...So, I guess caregivers need to be assured that if something doesn’t work, it doesn’t mean that they are a failure; it just means try—here are some other things to do.

Caregivers expressed differences in opinion on how this type of encouragement could be embedded within STAR-VTF. Some suggested the STAR-VTF self-guided modules could display words of encouragement throughout the training and tailor these messages based on caregivers’ responses to interactive exercises. Others felt that only a human could express this empathy. One caregiver stated:

It’s that personal relationship of somebody understanding where you are and, you know, patting you on the shoulder and saying that must be really tough. And I don’t know how you convey that the same way on a website.

Copies With BPSD

Symptoms of people with dementia that caregivers described as particularly challenging were insomnia, asking repetitive questions, and having trouble getting to the toilet. Caregivers described their frustration with not understanding why the BPSD were happening and how they could handle them. When asked how they envisioned STAR-VTF would provide support, a theme that resonated with many caregivers was teaching strategies for managing their own frustrations with BPSD. One caregiver suggested that STAR-VTF put more emphasis on reducing the caregiver’s frustration rather than reducing the challenging symptom in the person with dementia:

So, you said something about helping reduce the challenging behaviors? If you phrase it like that, it makes it sound like that’s something that can be fixed. And maybe then what happens if it doesn’t change? I just, you know, maybe the emphasis could be on how you deal with the challenges in a way that’s less frustrating for both you and the patient as opposed to reducing the challenging behavior.

According to caregivers, health care providers treating the person with dementia did not offer support to help caregivers cope with the frustration of BPSD. Caregivers wanted health care providers to acknowledge their challenging situation and direct them to supportive services. One caregiver said that for 4 months, a neurologist was trying different medications to treat a brother who took care of his wife with Alzheimer’s. Of this time, she stated:

Those are four months where I needed someone, and I didn't have anybody to talk to. And I think if caregivers, for instance, were told by their doctors—and we are part of Kaiser—it would be wonderful to have them say there’s help for you. I needed someone to tell me this is a very challenging job. And it’s not that I wasn’t aware. Because I have a brother who took care of his wife with Alzheimer’s, and, you know, I knew all that, but I needed a doctor to tell me this is really difficult. There’s help for you. And there’s this program [STAR-VTF]

What motivated caregivers to improve their own mental health and well-being was a perception that if they felt better
emotionally, they would be better able to provide care to the person with dementia. As one caregiver put it:

My goal is to keep her here at home as best I can. And if I break down, then you’ve got two to take care of.

**Supportive Services**

Throughout the different stages of dementia, caregivers reported taking it upon themselves to seek education and supportive services. In the early stages, caregivers described a desire to gain a better understanding of dementia and its progression. One caregiver described how invaluable it had been for her to read books and academic articles on the topic. After viewing prototypes of STAR-VTF, the caregiver suggested adding more content that explained what dementia is and providing additional reading materials:

I thought that there ought to be definitions and some sort of information on what dementia is and Alzheimer’s is, the differences. Not a great deal of difference, but just a—that sort of thing for me would be important. Books to read, you know.

In the middle and later stages of the disease, caregivers described a need to learn what respite services were available to provide short-term breaks from caregiving. Caregivers expressed an interest in both in-home services and adult day care programs. However, according to caregivers, finding trustworthy service providers was difficult. Some caregivers talked about negative experiences with service providers they had identified online. Caregivers strongly desired for the health care organization to vet respite care programs and guide caregivers on how to choose a program that was right for their unique situation. One caregiver suggested that the role of the STAR-VTF coach include connecting caregivers with respite care and other supportive services:

I know one of my things coming up is that I’m going to need to have in-home assistance, and it’s for short term—maybe it’s just a daycare that I need to take him to but where are they, who they are, if we could have resources that we could look at. Thinking this will meet this need, this will meet that need, and at least give you someone [in STAR-VTF] to access and say, “Hi, I’m so-and-so and this is my situation. Can you help me?”

Throughout their caregiving journey, caregivers described a desire to learn about and join a caregiver support group. Caregivers who had joined a support group stated that it was helpful to share their stories with other caregivers and get advice on various aspects of caregiving. They were interested in the health care organization helping caregivers to connect with support groups for family caregivers of people with dementia. For example, one caregiver described an online support group she participated in regularly and suggested that STAR-VTF inform caregivers about it:

I’ve been in touch with an online group...that is designed for people who are dealing with caregiving of those with Alzheimer’s. And they allow you to post any kind of question you have, any kind of circumstance you found yourself in, and see what kind of feedback others can give you. And it’s really an excellent resource...Sharing information of what they have experienced and how they dealt with it to give you ideas...And so, with your program [STAR-VTF], I don’t know if you have a place where you’re going to link to other possible resources. This [online caregiver support group] would be a strong resource to link to.

The internet was a major source of information for most caregivers. However, they often found the amount of information online to be overwhelming. Furthermore, despite the vast amount of information online from different types of sources, caregivers desired a single source (“one-stop shop”) of comprehensive and high-quality information. To that end, caregivers envisioned that STAR-VTF would consolidate educational materials and information on the availability of supportive services. Caregivers could then rely on and turn regularly to STAR-VTF as a major source of information, knowing that it came from the health care organization, which caregivers unanimously perceived as trustworthy.

**Accessibility Needs**

Caregivers discussed needs related to the accessibility of STAR-VTF, including the timing of offering the program to caregivers, modality of program delivery, time required to participate, and inclusion of a designated provider.

**Timing of Program**

When asked whether they could envision using STAR-VTF, caregivers answered affirmatively but expressed a desire for the program to be offered earlier in their role as caregivers for multiple reasons. As described above, caregivers suggested providing information about BPSD before the person with dementia begins experiencing symptoms and before caregivers begin trying their own strategies for challenging symptoms. These caregivers perceived that STAR-VTF would have been more useful to them when symptoms first began appearing:

This [STAR-VTF] would be key to get into people’s hands at the earliest possible time. Because beyond that, then somebody—I mean, like we’ve already—we learned by trial and error how to do exactly what you’re saying to do in this program.

Having this [STAR-VTF] as something to help you adjust early on and not have to learn on your own is definitely a plus...because we have already kind of figured out some plans and realized certain things. And our own private research got us to where we are, you know. And, of course, I mean, obviously, we talked to docs a few times, but we were already on a pathway of controlling behaviors, in other words. When she got into stage 3, we had a pretty good handle on things by then—but this [STAR-VTF] would have definitely helped when we first got her five years ago.

Another reason why caregivers suggested that STAR-VTF be offered earlier is so the STAR-VTF coach could be with them from the start. According to caregivers, the ideal scenario would
be for the coach to get to know each caregiver and their caregiving situation over time. Caregivers could then trust the coach’s advice, knowing that it was informed by an in-depth understanding of their unique situation. One caregiver indicated that she would be reluctant to trust a coach whom she had met only in the later stages of her husband’s disease:

If I’m really going to put my trust in this program, I would probably have to start at the beginning. I don’t think if I jumped in in the middle or towards the end, I would feel like, well, they [the coach] didn’t know about this earlier on, and so maybe the information they’re giving me now isn’t considering what happened. But I think if you probably started right from the start, like he was diagnosed today and so you said go onto this online program and we could help you, I think you could grow with the program and I think develop a pretty good trust.

Thus, while the reasons that drove preferences for the timing of the program differed among caregivers, the consensus was that STAR-VTF would be a valuable support if it were offered early in their caregiving experience.

Modality of Program Delivery
The virtual aspect of STAR-VTF was appealing to the majority of caregivers, including those who did not consider themselves to be technologically savvy. The latter group underscored their need for a user-friendly design, particularly so they could easily locate and navigate the STAR-VTF website, recover from errors, adjust the text size, and receive technical assistance. Caregivers perceived that participating in a virtual program from home would be more convenient than a program requiring in-person attendance at a health care facility. According to caregivers, the latter would necessitate finding someone to care for the person with dementia or having the person with dementia accompany them to the in-person visit. For some caregivers, neither of these options would be practical. Hiring professional care would be costly and taking the person with dementia to a health care facility would be challenging. For one caregiver, virtual participation was the most attractive aspect of STAR-VTF, given the difficulty of getting her mother to accompany her on an in-person visit:

That’s one of the problems we have is it’s almost impossible to get her out of the house, you know, she gets so upset, you know, going to the doctor…So, I can see—that’s where I would see the most important part about it [STAR-VTF] being online is you can get that help at home.

There was also a perception among caregivers that a virtual program would result in more timely help compared with the program requiring in-person attendance. As one caregiver described, as long as a device was available to access the STAR-VTF website, caregivers would have help at their fingertips. She went on to say:

You wouldn’t have to call a doctor to get answers…It’s there when you’re having those feelings and they’re very frustrating feelings and you don’t know what to do…If you’re at the end of your rope and you don’t have an answer, you can immediately sit down at your computer or your tablet or with your phone and get in there and it’s like, I’m frustrated. Let’s see why. Yeah, that’s the behavior that he’s doing. It affects me this way. Let’s figure out what we can do about it. It’s having this—it’s right there. It’s here at the house. It’s not, you know, something that I have to make—I spend so much time on the phone waiting…over 35 minutes on the phone waiting to speak to the neurologist’s nurse the other day.

Caregivers hoped that STAR-VTF would enable them to access help the moment they experienced a need instead of having to wait to speak to a member of the health care team on the phone or in person. (Some caregivers reported a 2- to 3-month wait for a clinic visit with a specialist.) All caregivers owned at least one device (e.g., smartphone, tablet, laptop, desktop computer) they could use to participate in a virtual training program.

Time Required to Participate
Even with a virtual program, caregivers were concerned about the limited amount of time and space they had to devote to STAR-VTF. The vast majority of study participants provided care to the person with dementia for 35 hours or more per week (Table 1). Caregivers said the person with dementia would likely make it difficult for them to concentrate for long stretches of time on the STAR-VTF training materials. When asked to elaborate, caregivers used expressions such as “needy,” “constantly interrupts me about things,” and “requires a lot of attention” to describe the person with dementia. One caregiver explained what she would need to be able to fully engage with the STAR-VTF online content:

I would need privacy and to be away. I couldn’t be in the same room with my husband [with dementia] who was giving me grief or being demanding or unpleasant or whatever. So, I think for me to use the program, I would have to be in a place where I could presume I have some privacy and some time, and it requires the concentration to be able to focus on it and not being distracted by other things, I think.

To facilitate their use of STAR-VTF under these circumstances, caregivers suggested that the online content be broken up into small chunks that they could review as time and space permitted. Caregivers also suggested having the ability to pause a module, if needed, and then be able to pick up where they left off when they returned to it later.

Having Access to a Designated Provider
Of the aspects of STAR-VTF that we described using prototypes, of notable interest to caregivers was the availability of a coach to provide support beyond the self-directed online materials. Caregivers described an unmet need to have access to a designated health care professional they could turn to for help when they were experiencing difficulties with BP S D. According to caregivers, people with dementia receive care from multiple health care providers within the same practice area, depending on appointment availability. For example, one
caregiver described how his wife with dementia had recently visited 3 different primary care providers, all at different health care facilities. While these providers were, “real nice, really good, and really helpful,” the caregiver desired a single provider who had direct knowledge of their clinical and caregiving situation instead of a provider who “doesn’t have any idea except what they see in the medical record.” Thus, if caregivers were to participate in STAR-VTF, it mattered considerably that the same coach be assigned to them throughout the duration of the program. Caregivers described being in extremely stressful situations that sometimes resulted in them losing their temper, becoming angry, and yelling at the person with dementia. These would be the types of situations caregivers would want to share with the STAR-VTF coach, simply to vent but also to receive help.

However, caregivers need to trust the coach to feel comfortable sharing openly and honestly about the caregiving situation. Caregivers explained that trust would develop only with time and repeated interactions with the same person. In response to a question about whether caregivers would be willing to share with the coach their responses to interactive exercises within the self-directed online materials, one answered yes but only if it were consistently the same coach with whom they had a trusting relationship:

Yes. Here we’re talking about a coach that I’ve been working with on and on and on because I’m working on the program, right? So, I have developed trust with the coach. So, yes, I would talk to her about that. But, I would be a little hesitant if the coach was brand new, I didn’t know her, I didn’t have any experience with her, and then maybe one week this one comes, but next week she can’t come so a substitute comes and, I mean, I know they’re both qualified, but you don’t know the second person and you don’t know whether the trust is there as much as with the first person.

In addition to having access to a designated STAR-VTF coach, caregivers discussed a desire for this person to have extensive practice experience working with people with dementia and their family caregivers. This qualification would help caregivers trust the information provided by the coach.

Discussion

Principal Findings

We found that family caregivers of people with dementia were interested in the idea of a virtual training program for learning to manage BPSD. Caregivers in our study reported that health care providers did not provide adequate education in the early stages of the disease about the types of personality and behavioral symptoms that can affect people with dementia. When the person with dementia began experiencing BPSD, it was unexpected and frustrating for caregivers, since they felt unprepared to manage the symptoms. For this reason, caregivers expressed a strong desire for the health care organization to offer programs such as STAR-VTF much sooner. When we interviewed them, many caregivers were reflecting on their extensive experience with BPSD, leading them to recommend STAR-VTF for those with less experience.

Furthermore, the virtual aspect of the training program appealed to nearly all caregivers in our study. Caregivers were interested in virtual training because of the convenience of receiving help from home and a perception that a virtual program would result in more timely help compared with traditional service modalities (eg, face-to-face visits, calling consulting nurse service). Given caregivers’ limited time and privacy for reviewing the STAR-VTF training materials, they suggested breaking up the content into small chunks that they could review at time and space permitted. Finally, caregivers desired continuity by having the same STAR-VTF coach assigned to them throughout the program duration. Collectively, our findings provide a better understanding of the type of support that caregivers need to manage BPSD. Our results indicate that caregivers perceived that features of STAR-VTF could address their needs.

Based on our findings, which were collected during the intervention design process, we improved STAR-VTF for testing in our pragmatic randomized trial [10]. We incorporated a feature in the STAR-VTF modules that enables caregivers to pause the training and continue later from that point. Multiple members of the research team iteratively reviewed the modules in a testing environment and identified usability issues to address prior to trial recruitment. During the trial, we will collect and monitor structured responses from caregivers after their completion of each module to assess perceived usability and usefulness. Furthermore, we gave each STAR-VTF coach a designated panel of caregivers to promote continuity of support. STAR-VTF coaches were trained on the importance of expressing empathy and offering encouragement during difficult times, helping caregivers to problem solve specific behavioral symptoms, referring caregivers to KPWA community resource specialists to help them find supportive services (eg, respite care), and helping caregivers learn how to use their electronic devices to access the STAR-VTF training materials. We were unable to address caregivers’ preference to offer STAR-VTF earlier. Since caregiver outcomes are not tracked within the EHR, we currently have no pragmatic alternatives to using a prescription for an antipsychotic medication as a signal for when a caregiver needs help managing behavioral symptoms and could benefit from participating in STAR-VTF. New research is needed on earlier identification of caregivers who are experiencing problem behaviors in people with ADRD.

Comparison With Previous Work

While family caregivers may not provide much assistance to people with dementia in the early stages of disease, Whitchall and Orsulic-Jeras [14] argue that this is a critical time for family caregivers to obtain information and education about the disease, symptoms, and progression. In our study, caregivers believed they would have benefited from education about BPSD much earlier. This finding is consistent with research by Boots et al [15], which reported that retrospectively, family caregivers of patients with late-stage disease did not believe they had sufficient knowledge in the early stages about the manifestations of dementia. Furthermore, while health care providers are an important and trusted source of information for family caregivers
of people with dementia [16], our participants reported that they did not provide sufficient information about the personality and behavior changes that people with dementia can experience. Complementary to our findings, Peterson et al [17] reported that the perception among caregivers was that health care providers offer little to no useful information about dementia and caregiving. In surveys, caregivers also report that their need for information on what to expect as dementia progresses is not met by health care providers [18,19].

STAR-VTF could be offered earlier, before the person with dementia begins experiencing changes in their behavior, as caregivers in our study suggested. For example, caregivers could learn about the activators-behaviors-sequences problem-solving strategy in advance before they need to apply it. Wald et al [20] observed that family caregivers of people with dementia requested that information about a variety of topics (including BPSD and its management) be provided at the time of diagnosis rather than when the need arose. However, in a study examining the acceptability of structured discussions about future care during the early stages of dementia, Orsulic-Jeras et al [21] found that dyads of a family caregiver and person with dementia perceived one of the major drawbacks of the program was discussing topics that did not apply to their current situation. For example, study participants stated that they did not currently have “those conditions” and were not currently experiencing problems. Thus, a compromise for STAR-VTF timing could be to first offer caregivers program components that are most relevant in the early stages of the disease (eg, realistic expectations about dementia and possible BPSD) and reserve components that are narrowly focused on problem solving for later stages when the person with dementia begins experiencing BPSD. How health care organizations can identify the optimal point at which caregiver needs for BPSD management begin to arise and thus offer the problem-solving components of STAR-VTF is a critical topic requiring future research. An important consideration is not offering the program too early, when caregivers deem the training irrelevant, but not waiting until the situation has escalated to the point of requiring antipsychotic medications.

The COVID-19 pandemic has substantially increased interest in virtual health services. We conducted interviews in the summer and fall of 2019, prior to the pandemic and the rapid shift to virtual services. At that time, most caregivers in our study perceived the virtual aspect of STAR-VTF as an attractive feature. After viewing low-fidelity prototypes of STAR-VTF, caregivers noted the potential convenience of accessing support virtually and receiving timely help. We note that our study sample was predominantly White and highly educated, representing US groups with the highest internet usage. Of White adults, 92% use the internet (compared to 85% and 86% of Black and Latino adults, respectively), and 98% of college-educated adults use the internet (compared to 71% of adults with less than a high school education) [22]. All caregivers in our study had internet access at home and owned devices (eg, laptop, desktop) that would be required for participation in a virtual training program. A systematic review of internet-based interventions to support family caregivers of people with dementia reports that, among family caregivers with high digital literacy and internet access, such interventions produce beneficial impacts on caregiver depression, anxiety, and burden [23].

Limitations

Our study has limitations worth noting. First, we used a dispensed prescription for an antipsychotic medication as a proxy for identifying family caregivers dealing with BPSD in the person with dementia. This inclusion criterion likely biased our study sample toward caregivers caring for a person in the later stages of dementia when BPSD are most prevalent. Their needs for help in managing BPSD and their perception of the potential usefulness of STAR-VTF could differ from caregivers who are caring for a person in the earlier stages of dementia. However, the experiences of family caregivers in our study made them especially knowledgeable about family caregiver needs regarding BPSD management throughout the disease trajectory. Second, our sample was of KPWA members living in 3 western Washington counties that included the Seattle metropolitan area. As a qualitative study, we did not aim for generalizability [24]; however, we note that our findings represent the perspectives of a limited group. KPWA members are predominantly White and highly educated, so 13 of 15 (87%) participants were White and none were Latino. Our experience suggests that Latino KPWA members may be less likely than non-Latino White members to be prescribed antipsychotic medications. Future research needs to explore this hypothesis.

Conclusions

Our findings contribute new knowledge about family caregivers’ views on participating in a virtual training program for the management of BPSD. Family caregivers needed information about BPSD and help in managing it, and they stated that STAR-VTF had the potential to directly address these needs. Furthermore, caregivers were attracted to the convenience of accessing the training virtually. They felt that a virtual training program would be more beneficial if it were offered early in their caregiving experience. Accordingly, our findings shed light on the need for future research to identify the optimal point at which to offer STAR-VTF. Offering the program too early risks providing training that is irrelevant to caregivers’ current situation, while offering it too late risks providing training after caregivers have already spent significant effort problem solving challenging behaviors on their own. Overall, our findings provide evidence that family caregivers would likely accept a program such as STAR-VTF focused on BPSD management that is offered entirely virtually.

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Conflicts of Interest
None declared.

Multimedia Appendix 1
Storyboards used during interviews with caregivers.
[PDF File (Adobe PDF File), 416 KB - aging_v4i1e24965_app1.pdf ]

Multimedia Appendix 2
An example of a low-fidelity prototype used during interviews with caregivers.
[PPTX File , 4155 KB - aging_v4i1e24965_app2.pptx ]

References

Abbreviations

ADRD: Alzheimer disease and related dementias
BPSD: behavioral and psychological symptoms of dementia
EHR: electronic health record
ICD-9-CM: International Classification of Diseases Ninth Revision—Clinical Modification
KPWA: Kaiser Permanente Washington
STAR-C: STAR-Caregivers
STAR-VTF: STAR-Caregivers Virtual Training and Follow-up

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Attitudes Toward Technology and Use of Fall Alert Wearables in Caregiving: Survey Study

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Abstract

Background: Wearable technology for fall alerts among older adult care recipients is one of the more frequently studied areas of technology, given the concerning consequences of falls among this population. Falls are quite prevalent in later life. While there is a growing amount of literature on older adults’ acceptance of technology, less is known about how caregivers’ attitudes toward technology can impact care recipients’ use of such technology.

Objective: The objective of our study was to examine associations between caregivers’ attitudes toward technology for caregiving and care recipients’ use of fall alert wearables.

Methods: This study examined data collected with an online survey from 626 caregivers for adults 50 years and older. Adapted from the technology acceptance model, a structural equation model tested the following prespecified hypotheses: (1) higher perceived usefulness of technologies for caregiving would predict higher perceived value of and greater interest in technologies for caregiving; (2) higher perceived value of technologies for caregiving would predict greater interest in technologies for caregiving; and (3) greater interest in technologies for caregiving would predict greater use of fall alert wearables among care recipients. Additionally, we included demographic factors (eg, caregivers’ and care recipients’ ages) and caregiving context (eg, caregiver type and caregiving situation) as important predictors of care recipients’ use of fall alert wearables.

Results: Of 626 total respondents, 548 (87.5%) with all valid responses were included in this study. Among care recipients, 28% used fall alert wearables. The final model had a good to fair model fit: a confirmatory factor index of 0.93, a standardized root mean square residual of 0.049, and root mean square error of approximation of 0.066. Caregivers’ perceived usefulness of technology was positively associated with their attitudes toward using technology in caregiving (b=.70, P<.001) and interest in using technology for caregiving (b=.22, P=.003). Greater perceived value of using technology in caregiving predicted greater interest in using technology for caregiving (b=.65, P<.001). Greater interest in using technology for caregiving was associated with greater likelihood of care recipients using fall alert wearables (b=.27, P<.001). The caregiver type had the strongest inverse relationship with care recipients’ use of fall alert wearables (unpaid vs paid caregiver) (b=–.33, P<.001).

Conclusions: This study underscores the importance of caregivers’ attitudes in care recipients’ technology use for falls management. Raising awareness and improving perception about technologies for caregiving may help caregivers and care recipients adopt and better utilize technologies that can promote independence and enhance safety.

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KEYWORDS
wearables; falls alert technology; falls; caregivers; care recipients
Introduction

By 2035, adults 65 years and older in the United States are projected to outnumber children (under 18 years), mostly due to the continued aging of the Baby Boomer generation [1]. The proportion of older adults aged 65 years and older will increase from approximately 1 in 7 today to approximately 1 in 5 in 2030, when nearly all Baby Boomers will be of typical retirement age [2]. The majority of older adults will need long-term services and support during their lifetime [3]. The rapid growth of the oldest population (ie, those 85 years and older), individuals who tend to have more health conditions and disabilities, will compound the need for care with most requiring some level of care by either paid or unpaid caregivers [4].

According to the American Association of Retired Persons 2020 Report: Caregiving in America [4], caregivers report that the adults who receive care (care recipients) have more comorbid conditions that require care for medical and support than was reported by caregivers in 2015. Increasingly, unpaid caregivers are turning to assistive intelligent technology and wearables for assistance and support in caregiving [4]. Wearable technology is a category of electronic devices that are worn as accessories, embedded in clothing, implanted in the user's body, or even tattooed on the skin. Wearables can be powered by microprocessors to send and receive data via cellular networks and the internet [5-7]. Our review of recent literature on technology and caregiving offered multiple examples of digital technology adoption by caregivers and care recipients in the realms of education, care recipient data collection, sensors and monitoring, clinical care delivery, and social support [4,6,8-12]. While these studies [4,6,8-12] document the broad array of categories of digital and technology development, limited information is available about factors influencing care recipients’ technology adoption.

Wearable technology for fall alerts among older adult care recipients is one of the more frequently studied areas of technology, given the concerning consequences of falls among this population. Falls are quite prevalent in later life; approximately 1 in 4 community-dwelling older adults fall each year, and 20% of falls result in injury [13]. The consequences of falls can trigger a downward trajectory of dependence among older adults and can result in increased health care emergency room visits and hospitalization, staggering health care costs, and premature death [13-15]. Research suggests that caregivers are increasingly interested in purchasing and using wearable and other monitoring technology to help reduce caregiver burdens and allow older adults to remain independent in their own homes [9]. A recent literature review by Stavropoulos et al [10] included reviews of systematic reviews and case studies, including studies in which the aims were to assess if the caregiver was more comfortable due to the care recipient use of the wearable and if the care recipient felt more independent [10-12,16,17].

In recent years, falls have become viewed as preventable with evidence-based programs helping older adults prevent and better manage risk factors associated with falling [18]. Concurrently, technology tools are being developed to help older adults and their caregivers predict and prevent falls [18]. Of particular interest is the growing market for fall alert systems, which are intended to help older adults reduce fear of falling and stay independent by ensuring that help will be available in the event of a fall. There is now a plethora of medical alert systems with fall detection, and while there are market comparisons and a growing amount of literature on older adults’ acceptance of technology, less is known about how caregivers’ attitudes toward technology can impact care recipients’ use of such technology [6,8-12,16,17,19,20].

The objective of this paper is to better understand associations between caregivers’ attitudes toward technology for caregiving and care recipients’ use of fall alert wearables.

Based on an adapted framework of the Technology Acceptance Model (TAM) [21,22], we constructed a structural equation model to test the following hypotheses: (1) higher perceived usefulness of technologies for caregiving would predict higher perceived value of and greater interest in technologies for caregiving; (2) higher perceived value of technologies for caregiving would predict greater interest in technologies for caregiving; and (3) greater interest in technologies for caregiving would predict greater use of fall alert wearables among care recipients.

We further based our analyses on specific demographic factors and caregiving contexts available from the data in our survey. In addition, our analyses were based on the following subhypotheses, supported in the literature: (1) younger age among caregivers would predict greater perceived usefulness, perceived value, and interest in using technology; (2) more demanding caregiving situations such as longer caregiving hours and dementia among care recipients would increase caregivers’ interest in technology; (3) older age among care recipients would predict greater health care needs and fall risks, hence more need for and use of fall alert–related technology [22,23]; and (4) use of or preference for using family (ie, unpaid) caregivers is most likely associated with economic status (ie, the ability to pay for caregivers) and the availability of unpaid caregivers as well as care recipients’ health conditions [23,24]. Correlates that predict the use of paid versus unpaid caregivers may also influence the use of fall alert technologies. Thus, we also examined whether care recipients’ use of fall alert wearables would be associated with caregiver type (paid or unpaid).

Methods

Model Construction

For this study, we adapted a validated model of technology acceptance by users in organizations, based on the TAM and an updated version (TAM2) [21,22], to guide the development of the survey instrument and data analyses to identify factors influencing caregivers’ and care recipients’ use and perceptions of technologies associated with caregiving. A meta-analysis of 88 studies in different fields [25] indicated that TAM is “a powerful and robust predictive model” to understand technology acceptance of users in various contexts. Davis [26] originally empirically validated TAM to explain users’ willingness to use new technologies in organizations. In 2015, Marangunic and
Granić [27] stated that TAM “has evolved to become the key model in understanding the predictors of human behavior toward potential acceptance or rejection of the technology.”

In this study, we adapted TAM and TAM2 to build and test a framework (Figure 1) that includes factors regarding caregivers’ perceptions about how useful and valuable technologies might be in their caregiving activities. The key constructs of TAM and TAM2, perceived usefulness, attitudes toward using technology, intention to use, and usage behaviors were adapted to caregivers’ perceived usefulness, perceived value of technology, interests in using technology, and care recipients’ use of technology, respectively. Attitudes toward a behavior consists of personal evaluation of the specified behavior [27]. In the adapted model, attitudes toward using technology was adapted to perceived value of using technology in caregiving. Figure 1 illustrates our adaptation of the TAM2 model with its 3 key constructs (caregiver’s perceived usefulness, perceived value, and interest in using the technology) and other factors that potentially may directly or indirectly influence care recipients’ use of fall alert wearables.

Figure 1. Initially hypothesized model predicting care recipient’s use of fall alert wearables. CG: caregiver; CR: care recipient.

Data Source and Study Participants

This study used a cross-sectional online survey collected from 626 paid and unpaid caregivers for adults 50 years and older. The caregivers were recruited through an internet panel (Qualtrics XM) in November 2019. Survey respondents were eligible to be included in this study if they were aged 18 years or older, were either paid or unpaid, and provided at least 8 hours of care per week for at least one person who was over 50 years of age and who lived in a home environment. The recruited sample was targeted to resemble the population distribution across 4 US regions (eg, northwest: 17.2%; midwest: 20.9%; west: 23.8%; south: 38.1%) based on 2018 census data [28]. In addition to quotas by regions, quota sampling was predetermined for gender (approximately 75% female and 25% male), age (at least 50% of the sample 50 years and older), and race (maximum 60% White) to account for the known demographic characteristics of caregivers for middle-aged and older adults in the United States [4]. The survey design and study implementation were submitted to the Texas A&M University institutional review board and received approval for exemption (IRB2019-1128M).

Variables

Caregiver’s perceived usefulness of technologies in caregiving was measured using 6 items on the extent technology helps with (1) reducing the caregiving burden in the future; (2) enabling the care recipient to live more independently; (3) enabling caregiver to have a better quality of life; (4) improving the caregiver’s relationship with their care recipient; (5) improving communication with the care recipient’s family and friends; and (6) improving communications with the care recipient’s health care team. Each item was measured on a 0-to-100-point slider, with higher scores indicating greater perceived usefulness. For the 6 items, Cronbach $\alpha=92$. The Kaiser-Meyer-Olkin measure was 0.89, and the Bartlett test of sphericity ($\chi^2_{15}=2458.77, P<.001$) suggested that the data were appropriate for factor analysis. Exploratory factor analysis showed that the 6 items adequately loaded onto one construct (eg, scree plot and eigenvalues). Average variance extracted was 0.67 indicating that the construct sufficiently explains the item variances.

Caregiver’s attitudes toward various safety-related technology for caregiving was assessed by asking perceived value of (1) watches and wearables that enable emergency calls and provide easy to use communications with family members; (2) cameras...
and alerts to make the house safe; (3) wearable technology to track care recipient health conditions (eg, breathing, pulse, and blood pressure); (4) watches and wearable sensors to monitor and send emergency alerts about falls; (5) watches and sensors that provide care recipient’s location; and (6) wearables and sensors that alert if care recipients are at risk for falls. The survey respondents rated perceived value of each technology on a 0-to-100-point slider, with higher scores indicating greater perceived value of the technology in caregiving. For the 6 items, Cronbach \( \alpha \) was .91. The Kaiser-Meyer-Olkin was 0.90, and Bartlett test of sphericity was statistically significant \( \chi^2 = 2130.27, P<.001 \). Exploratory factor analysis showed that the 6 items adequately loaded onto one construct. The level of variance captured by the construct was considered acceptable with average variance extracted of 0.64.

Two items were used to measure caregiver’s interest in using technology for tracking their care recipient’s location and providing alerts if their care recipient is at risk for a fall. The valid response range for the 2 items was 0 to 100 points, using a slider with higher scores indicating greater interests in using the technology. The Spearman-Brown reliability estimate for the 2 items was 0.75.

The online survey collected sociodemographic characteristics of caregivers and caregiving context, as well as the caregiver’s oldest care recipient’s age, dementia diagnosis status, and use of fall alert wearables (eg, pendant or other wearable to alert others that a fall has occurred). Sociodemographic characteristics of caregivers included age in years, gender, race/ethnicity, place of residence (rural vs urban), education (associate degree or less education vs bachelor degree or higher education), employment status (employed for wages or self-employed vs other), previous year’s household income (<US $50,000 vs ≥$50,000), and financial stress (ie, “In general, how do your finances usually work out at the end of the month? Do you find that you usually: end up with some money left over/have just enough money to make ends meet/not have enough money to make ends meet?”). Self-reported zip codes were approximated to the census tract–based rural-urban commuting area codes [29]. Caregiving-related information included caregiving type (informal or unpaid vs formal or paid) for the oldest care recipient and the number of weekly hours of caregiving for the oldest care recipient.

**Statistical Analyses**

Characteristics of the study’s caregivers, their care recipients, and caregiving contexts, as well as caregivers’ attitudes toward using technology in caregiving, were described using mean and standard deviation or frequency and percentage. Independent group comparison (eg, 2-tailed independent t test or chi-square test) was used to compare each described characteristic by care recipient’s use of fall alert wearables. Next, a structural equation model was performed to test the hypothesized model (Figure 1). Goodness of fit was determined using confirmatory factor index (CFI), root mean square error of approximation (RMSEA), and standardized root mean square residual (SRMR)—good to fair was defined as CFI>0.90, RMSEA<0.08, and SRMR<0.08. Modification indices were also reviewed to explore potential model improvements. Figure 2 shows the final model used in this study. All statistical analyses were performed using SAS (version 9.4, SAS Institute) and with only included the caregivers who had valid data on all variables used in the structural equation model (548/626, 87.5%). Given potential differences between paid and unpaid caregivers, the independent group comparison was conducted to compare each described characteristic by caregivers’ paid status (Multimedia Appendix 1), and the hypothesized model (after excluding caregiver payment status) was tested separately among the paid (116/548, 21.2%) and unpaid (432/548, 78.8%) caregivers (Multimedia Appendix 2 and Multimedia Appendix 3).
Results

Study Population

Table 1 describes the characteristics of the caregivers and care recipients and the caregiving context. The mean age of the caregivers was 58.1 (SD 14.1) years, and the majority were females (417/547, 76.2%), non-Hispanic White (354/545, 65.0%), from an urban area (500/547, 91.4%) and had some college or higher educational attainment (420/548, 76.6%). Over 43% (237/548) were employed for wages or self-employed, and slightly more than half (279/548) had a total household income less than $50,000 in 2018. Approximately 55% (296/542) of caregivers reported some level of financial stress (ie, having just enough money to make ends meet or not having enough money to make ends meet). The mean age of care recipients was 74.5 (SD 11.93) years, and 23.4% (128/542) of caregivers reported their care recipient was diagnosed with dementia. The majority of the caregivers lived with the care recipient (311/548, 56.8%), were unpaid for the care or assistance they provided to their care recipients (432/548, 78.8%), and a reported weekly average of 37.5 (SD 28.98) hours providing care.

Fewer than 28% (153/548) of the study’s care recipients used a fall alert wearable. In a bivariate analyses comparing caregivers for those who do not use fall alert wearables to those who do use fall alert wearables found that the caregivers of those who used fall alert wearables were significantly younger ($P<.001$), less likely to be non-Hispanic White ($P=0.005$), and under financial stress ($P=0.003$). They were also more likely to be employed for wages or self-employed ($P<0.001$). Furthermore, the care recipients who used fall alert wearables were significantly older ($P<0.001$) and more likely to have dementia ($P=0.01$) than those not using fall alert wearables. Caregivers of those who used fall alert wearables reported fewer weekly hours of caregiving ($P=0.002$) and were also significantly less likely to be an unpaid caregiver ($P<0.001$) or to live with the care recipient ($P<0.001$). Caregivers of care recipients using fall alert wearables had significantly greater perceived usefulness ($P<0.001$), perceived value ($P<0.001$), and interest ($P<0.001$) in using technology in caregiving than caregivers of those not using fall alert wearables.
Table 1. Characteristics of the study respondents and caregiving context and caregivers’ attitudes toward using technology in caregiving.

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>All (N=548)</th>
<th>Care recipients using fall alert wearables (n=153)</th>
<th>Care recipients not using fall alert wearables (n=395)</th>
<th>P value&lt;sup&gt;a&lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (years), mean (SD)</td>
<td>58.1 (14.07)</td>
<td>53.2 (16.58)</td>
<td>59.8 (12.90)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Gender, n (%)</td>
<td></td>
<td></td>
<td></td>
<td>.71</td>
</tr>
<tr>
<td>Female</td>
<td>417 (76.2)</td>
<td>115 (75.2)</td>
<td>302 (76.6)</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>131 (23.8)</td>
<td>38 (24.8)</td>
<td>93 (23.4)</td>
<td></td>
</tr>
<tr>
<td>Race/ethnicity, n (%)</td>
<td></td>
<td></td>
<td></td>
<td>.005</td>
</tr>
<tr>
<td>Non-Hispanic White</td>
<td>354 (65.0)</td>
<td>82 (53.6)</td>
<td>272 (69.4)</td>
<td></td>
</tr>
<tr>
<td>Non-Hispanic Black</td>
<td>93 (17.1)</td>
<td>38 (24.8)</td>
<td>55 (14.0)</td>
<td></td>
</tr>
<tr>
<td>Non-Hispanic Asian</td>
<td>35 (6.4)</td>
<td>10 (6.5)</td>
<td>25 (6.4)</td>
<td></td>
</tr>
<tr>
<td>Non-Hispanic other races</td>
<td>9 (1.7)</td>
<td>2 (1.3)</td>
<td>7 (1.8)</td>
<td></td>
</tr>
<tr>
<td>Hispanic</td>
<td>54 (9.9)</td>
<td>21 (13.7)</td>
<td>33 (8.4)</td>
<td></td>
</tr>
<tr>
<td>Education level, n (%)</td>
<td></td>
<td></td>
<td></td>
<td>.87</td>
</tr>
<tr>
<td>High school or lower</td>
<td>128 (23.4)</td>
<td>35 (22.9)</td>
<td>93 (23.5)</td>
<td></td>
</tr>
<tr>
<td>Some college or higher</td>
<td>420 (76.6)</td>
<td>118 (77.1)</td>
<td>302 (76.5)</td>
<td></td>
</tr>
<tr>
<td>Employment status, n (%)</td>
<td></td>
<td></td>
<td></td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Employed for wages or self-employed</td>
<td>237 (43.2)</td>
<td>96 (62.7)</td>
<td>141 (35.7)</td>
<td></td>
</tr>
<tr>
<td>Not employed for wages, not self-employed</td>
<td>311 (56.8)</td>
<td>57 (37.3)</td>
<td>254 (64.3)</td>
<td></td>
</tr>
<tr>
<td>Household income, n (%)</td>
<td></td>
<td></td>
<td></td>
<td>.72</td>
</tr>
<tr>
<td>Less than US $50,000</td>
<td>279 (50.9)</td>
<td>76 (49.7)</td>
<td>203 (51.4)</td>
<td></td>
</tr>
<tr>
<td>More than US $50,000</td>
<td>269 (49.1)</td>
<td>77 (50.3)</td>
<td>192 (48.6)</td>
<td></td>
</tr>
<tr>
<td>Financial stress, n (%)</td>
<td></td>
<td></td>
<td></td>
<td>.003</td>
</tr>
<tr>
<td>End up with some money left over</td>
<td>246 (45.4)</td>
<td>79 (52.3)</td>
<td>167 (42.7)</td>
<td></td>
</tr>
<tr>
<td>Have just enough money to make ends meet</td>
<td>212 (39.1)</td>
<td>61 (40.4)</td>
<td>151 (38.6)</td>
<td></td>
</tr>
<tr>
<td>Not have enough money to make ends meet</td>
<td>84 (15.5)</td>
<td>11 (7.3)</td>
<td>73 (18.7)</td>
<td></td>
</tr>
<tr>
<td>Residence, n (%)</td>
<td></td>
<td></td>
<td></td>
<td>.29</td>
</tr>
<tr>
<td>Rural</td>
<td>47 (8.6)</td>
<td>10 (6.5)</td>
<td>37 (9.4)</td>
<td></td>
</tr>
<tr>
<td>Urban</td>
<td>500 (91.4)</td>
<td>143 (93.5)</td>
<td>357 (90.6)</td>
<td></td>
</tr>
<tr>
<td>Care recipient</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age (years), mean (SD)</td>
<td>74.5 (11.93)</td>
<td>77.2 (12.21)</td>
<td>73.5 (11.95)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Having dementia, n (%)</td>
<td></td>
<td></td>
<td></td>
<td>.01</td>
</tr>
<tr>
<td>Yes</td>
<td>128 (23.4)</td>
<td>47 (30.7)</td>
<td>81 (20.5)</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>420 (76.6)</td>
<td>106 (69.3)</td>
<td>314 (79.5)</td>
<td></td>
</tr>
<tr>
<td>Caregiving context</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Paid for caregiving</td>
<td></td>
<td></td>
<td></td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Paid caregiver</td>
<td>116 (21.2)</td>
<td>68 (44.4)</td>
<td>48 (12.2)</td>
<td></td>
</tr>
<tr>
<td>Unpaid caregiver</td>
<td>432 (78.8)</td>
<td>85 (55.6)</td>
<td>347 (87.8)</td>
<td></td>
</tr>
<tr>
<td>Weekly hours of caregiving&lt;sup&gt;b&lt;/sup&gt;, mean (SD)</td>
<td>37.5 (28.98)</td>
<td>31.3 (23.83)</td>
<td>39.3 (30.00)</td>
<td>.002</td>
</tr>
<tr>
<td>Living with the care recipient, n (%)</td>
<td></td>
<td></td>
<td></td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Yes</td>
<td>311 (56.8)</td>
<td>53 (34.6)</td>
<td>258 (65.3)</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>237 (43.2)</td>
<td>100 (65.4)</td>
<td>137 (34.7)</td>
<td></td>
</tr>
<tr>
<td>Caregivers’ attitudes&lt;sup&gt;c&lt;/sup&gt;, mean (SD)</td>
<td>58.3 (25.57)</td>
<td>68.2 (21.94)</td>
<td>54.5 (25.86)</td>
<td>&lt;.001</td>
</tr>
</tbody>
</table>
Model Fit and Refinement

Goodness of fit, of the model shown in Figure 1, indicated good-to-fair model fit (CFI 0.93, SRMR 0.049, RMSEA 0.067). All hypothesized paths were statistically significant, except for the paths from age to perceived value (P=0.73) and interests (P=0.15) in technology in caregiving. Removing these 2 statistically insignificant paths did not change the direction or statistical significance of other paths in the model, and only minimal changes in the parameter estimates were observed, although the second model, shown in Figure 2, goodness-of-fit remained good-to-fair (CFI 0.93, SRMR 0.049, RMSEA 0.066).

Path Coefficients

Figure 2 presents the standardized path coefficients of the final structural equation model. Caregivers’ perceived usefulness of technology was positively associated with their attitudes toward using technology in caregiving (b=0.70, P<0.001) and interests in using technology for caregiving (b=0.22, P=0.003). Greater perceived value of using technology in caregiving predicted greater interests in using technology for caregiving (b=0.65, P<0.001). Greater interests in using technology for caregiving was associated with greater likelihood of care recipients using fall alert wearables (b=0.27, P<0.001). Younger age of caregivers predicted greater perceived usefulness (b=–0.14, P<0.001). Care recipients of unpaid caregivers were less likely to use fall alert wearables (b=–0.33, P<0.001) than care recipients of paid caregivers. Fewer caregiving hours (b=–0.07, P=0.03) and presence of dementia among care recipients (b=0.12, P<0.001) predicted greater interests in using technology for caregiving. Care recipients’ age was positively associated with the use of fall alert wearables (b=0.11, P=0.004).

Table 2 presents direct and indirect effects of caregivers’ age and attitudes and caregiving context on care recipients’ use of fall alert wearables. In terms of total effects, caregivers’ interests in using technology for caregiving had the strongest positive effects on care recipients’ use of fall alert wearables (b=0.27, P<0.001), followed by caregivers’ perceived usefulness of technology in caregiving (b=0.18, P<0.001), and caregiver’s attitudes toward using technology in caregiving (b=0.17, P<0.001). The strongest inverse relationship was with caregiver type (unpaid vs paid caregiver) (b=–0.33, P<0.001). While the observed total effects were statistically significant, the magnitudes of the relationship tended to be weaker for hours of caregiving (b=–0.02, P=0.46), caregiver’s age (b=–0.03, P=0.003), and care recipient having dementia (b=0.03, P<0.001).

Paid and Unpaid Caregivers

As shown in Table 1, nearly 79% (432/548) of the caregivers were unpaid. Multimedia Appendix 1 shows the comparison of caregiver and care recipient’s characteristics based on caregivers’ paid status. Compared to unpaid caregivers, paid caregivers were younger (48.0 years vs 60.8 years, P<0.001); less likely to be non-Hispanic White (P<0.001), having some college or higher educational attainment (P<0.001), and living with the care recipients (P<0.001); and more likely to be employed (P<0.001). The oldest care recipients of paid caregivers were more likely to have dementia than the oldest care recipients.
of unpaid caregivers \( (P<0.001) \). There were statistically significant differences in the self-reported financial stress among paid and unpaid caregivers \( (P=0.034) \). While there were 38.3% \((44/115)\) and 49.6% \((57/115)\) of paid caregivers having some money left over and having just enough money to make ends meet, respectively; there were 47.3% \((202/427)\) and 36.3% \((155/427)\) of unpaid caregivers having some money left over and having just enough money to make ends meet, respectively. Paid caregivers reported significantly greater perceived usefulness \( (P=0.002) \) and interests \( (P=0.004) \) in using technology in caregiving than caregivers of those not using fall alert wearables.

The model fit among paid caregiver was fair \( (CFI 0.93, SRMR 0.076, \text{and RMSEA 0.062}) \) and was comparable to the comprehensive model \( (CFI 0.93, SRMR 0.049, \text{and RMSEA 0.066}) \). The 3 prespecified hypotheses remained statistically significant, and corresponding path coefficients were comparable to the comprehensive model \( (\text{Multimedia Appendix 2 shows the model among paid caregivers and Figure 2 shows the comprehensive model}) \). Paid caregivers’ perceived usefulness of technology in caregiving was positively associated with perceived value of \( (b=0.67, P<0.001) \) and interest in \( (b=0.36, P=0.02) \) technology for caregiving. Higher perceived value of technology for caregiving was predicted greater interest in technologies for caregiving \( (b=0.65, P<0.001) \); and greater interest in technologies for caregiving predicted greater use of fall alert wearables among care recipients \( (b=0.21, P=0.02) \). None of the 4 subhypotheses remained statistically significant among paid caregivers.

The model fit among unpaid caregivers was good to fair \( (CFI 0.93, SRMR 0.051, \text{and RMSEA 0.069}) \) and was comparable to that of the comprehensive model \( (CFI 0.93, SRMR 0.049, \text{and RMSEA 0.066}) \). All path coefficients remained statistically significant, and path coefficients were comparable to the comprehensive model \( (\text{Multimedia Appendix 3 shows the model among unpaid caregivers and Figure 2 shows the comprehensive model}) \). Unpaid caregivers’ perceived usefulness of technology was positively associated with their attitudes toward using technology in caregiving \( (b=0.71, P<0.001) \) and interests in using technology for caregiving \( (b=0.17, P=0.03) \). Greater perceived value of using technology in caregiving predicted greater interests in using technology for caregiving \( (b=0.67, P<0.001) \). Greater interests in using technology for caregiving was associated with greater likelihood of care recipients using fall alert wearables \( (b=0.31, P<0.001) \). Younger age of unpaid caregivers predicted greater perceived usefulness \( (b=-0.13, P=0.005) \). Fewer caregiving hours \( (b=-0.09, P=0.02) \) and presence of dementia among care recipients \( (b=0.13, P<0.001) \) predicted greater interests in using technology for caregiving. Care recipients’ age was positively associated with the use of fall alert wearables \( (b=0.11, P=0.02) \). For both paid and unpaid caregivers, caregiver’s interest in using technology for caregiving had the strongest positive effects on care recipient’s use of fall alert wearables \( (b=0.21, P=0.023 \text{ in paid caregivers; and } b=0.31, P=0.028 \text{ in unpaid caregivers}) \), followed by other attitudinal variables. Estimated total effects of caregiver’s perceived usefulness of technology in caregiving was \( b=0.16 (P=0.032) \) in paid caregivers and \( b=0.20 (P<0.001) \) in unpaid caregivers; and estimated total effects of caregiver’s attitudes toward using technology in caregiving was \( b=0.13 (P=0.036) \) in paid caregivers and \( b=0.21 (P<0.001) \) among unpaid caregivers.

**Discussion**

**Principal Findings**

From our analyses, we have demonstrated that the adapted TAM2 concepts of caregivers provide support for our hypotheses about care recipients’ use of fall alert wearables, which is reflective of previous literature \([12,20-25,30]\). Our model demonstrated that both high perceived usefulness and value of technology for caregiving was associated with greater interest in technologies for caregiving and that greater interest in technology for caregiving was predictive of greater use of fall alert wearables among care recipients, although only 28% \((153/548)\) of our study’s care recipients used fall alerts. While statistically significant, our results suggested that younger age among caregivers was among the less powerful predictors of perceived use, attention and interest in technology for caregiving.

Our results demonstrated that the strongest predictor of care recipients’ use of fall alert wearable was the type of caregiver and that care recipients with paid caregivers were more likely to use this type of technology than care recipients with unpaid caregivers. While not expected, this may reflect the scenario where the path of caregiving for older adults typically begins with a family member or unpaid caregiver who lives in close proximity to the care recipient and provides human monitoring. Concerns for falls often results in investment in fall alert wearables for older adults living independently \([9]\).

Our subhypothesis that more demanding caregiving situations, including longer hours of caregiving and instances of dementia among care recipients, was partially supported in this study. As hypothesized, dementia among care recipients positively predicts their use of fall alert wearables. However, contrary to our hypothesis, fewer caregiving hours was associated with care recipient’s use of fall alert wearables. A potential interpretation may be that caregivers providing fewer hours of care could be more inclined to use wearables to compensate for longer durations of non-supervised time. According to the subgroup analyses based on caregiver’s payment status, the statistical significance of the subhypotheses are likely to be largely driven by unpaid care recipients, who constituted almost 79% \((432/548)\) of the total analytic sample. While caregiver’s attitude toward technology in caregiving were significantly associated with care recipient’s use of fall alert wearables in both paid and unpaid caregivers, caregivers’ and care recipients’ age, and caregiving situations were significantly associated with care recipients’ use of fall alert wearables only among unpaid caregiver participants. The smaller sample size of paid caregivers may have limited the statistical power of the model. Another potential explanation is the differential involvement of paid and unpaid caregivers in caregiving decisions \([29]\).

There is relatively little research that examines how caregivers and their care recipients (either paid or unpaid) actually use fall alert technology in their everyday lives or how such experiences
may affect their safety and well-being. The little research that exists is limited in scale, often focused on care recipients with dementia and on cross-sectional interview methodologies focused on the adoption of the wearable fall alert technology [12,31-38]. Limited attention is typically given to how caregivers and their care recipients use wearable fall alert technology as their care and support needs change over time. In contrast, a study by van Heek et al [39] provided an empirical examination of caregivers’ acceptance of assistive technologies. However, van Heek et al [39] focused on design perspectives including gathering of data, data access, and storage duration, as well as perceived benefits and barriers, in order to integrate caregivers’ perspectives into design of technologies. Our results align with those of other recent studies [38-46] showing that there is a greater likelihood for adoption and use of fall alert wearables among care recipients with dementia, which is assumedly negotiated by the caregiver as a result of care recipient incapacity.

Limitations

There were some limitations to our study. First, our caregiver population in the panel-based survey may not be representative of the caregiver population across the United States, despite our best efforts. While we have used quota sampling to match the distribution of key characteristics (eg, geographical region, age, gender, and race), this online sample excludes caregivers without access to internet and related technology (eg, computer, smartphone, or tablets). We assume that respondents who are more willing to sign up to participate because they are comfortable with technology. Thus, caregivers who do have online access but are not as comfortable with technology may have elected not to participate. We also excluded caregivers who might have had online access but who had limited English proficiency. While we asked participants to self-identify as either paid or unpaid, there was no way to tell if there were subsets of unpaid caregivers who received some sort of stipend or benefit. With our cross-sectional design, it was not possible to draw conclusions about the causality between attitudes, caregiving contexts, and use of fall alert wearables. Additionally, the proposed model is limited by lack of potential factors, such as perceived ease of use for specific technology, fall history, and interpersonal relationships between caregivers and care recipients. In addition, the care recipients’ use of fall alert wearables were proxy-reported by caregivers, a further study using direct observation or self-reported measure by care recipients could supplement the proxy-reported evidence. More information on the types of technology and how the specific technologies are used would help establish circumstantial data to set out recommendations for practice and policy. Future research using in-depth interviews with caregivers to explore the nuances of technology adoption would be instructive for understanding more about the context driving our quantitative research findings. Despite these limitations, we believe our data and analyses provide important new information on how caregivers’ attitudes and values about technology influence adoption about the use of fall alert wearables for the protection and safety of their care recipients.

Conclusion

With this study, we have taken a small step in addressing the knowledge gap about how caregiver attitudes affect adoption of assistive intelligent technology such as wearable fall alert technologies in caregiving, but much remains to be learned. With the growth of the aging population over the forthcoming years, and the anticipated rise of the occurrence of falls and related injuries based on the increasing numbers of older Americans, the caregiving workforce will benefit from advanced and effective technologies used in caregiving. It will continue to be crucial for public health researchers to keep pace with the advances of technology and maintain an advocacy role for both caretakers and care recipients in the adoption and use of technology to support their health and wellbeing.

Acknowledgments

We thank all of the caregivers who participated in our online survey which formed the basis of this research. The caregiver survey was funded by contributions from DVD Associates LLC, Clairvoyant Networks Inc, and The Texas A&M Center for Population Health and Aging.

Conflicts of Interest

DVD was employed by DVD Associates LLC and is an editor for JMIR Cancer. SP is employed by Clairvoyant Networks Inc. The remaining authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Multimedia Appendix 1
Characteristics of the study respondents based on caregivers’ paid status.
[DOCX File .21 KB - aging_v4i1e23381_app1.docx ]

Multimedia Appendix 2
Revised model predicting paid care recipient’s use of fall alert wearables.
[DOCX File .138 KB - aging_v4i1e23381_app2.docx ]

Multimedia Appendix 3

http://aging.jmir.org/2021/1/e23381/
Revised model predicting unpaid care recipient’s use of fall alert wearables.

References


**Abbreviations**

- **CFI**: confirmatory factor index
- **RMSEA**: root mean square error of approximation
- **SRMR**: standardized root mean square residual
- **TAM**: Technology Acceptance Model

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Providing Medical Information to Older Adults in a Web-Based Environment: Systematic Review

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Abstract

Background: Cancer is a disease that predominantly affects older adults, and several organizations recommend the completion of a geriatric assessment to help with cancer treatment decision-making. Owing to a shortage of geriatric teams and the vast number of older adults diagnosed with cancer each year, a web-based geriatric assessment may improve access to geriatric assessment for older adults. We systematically reviewed the literature to obtain the latest evidence for the design of our web-based geriatric assessment tool Comprehensive Health Assessment for My Plan.

Objective: This review aimed to probe the following questions: what is the impact of providing health test results to older adults in a web-based environment without the presence of a health care provider for patient-centered outcomes, including satisfaction, perceived harm, empowerment, quality of life, and health care use (eg, hospitalization, physician visits, emergency room visits, and costs), and what recommendations do older adults and developers have for designing future apps or websites for older adults?

Methods: This systematic review was guided by the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-analysis) statement. Studies were limited to publications in English that examined a web-based tool that provided test results to older adults (aged ≥65 years) without the presence of a health care provider. A health sciences librarian performed the search on November 29, 2019, on the following electronic databases: MEDLINE, Embase, CINAHL, PsycINFO, and the Cochrane Library. The quality of the included studies was assessed using the Mixed Methods Appraisal Tool Version 2018. The findings are summarized narratively and in tabular format.

Results: A total of 26,898 titles and abstracts were screened by 2 independent reviewers, of which 94 studies were selected for a full-text review, and 9 studies were included in this review. There were only 2 randomized controlled trials of high quality that explored the effects of receiving health care results on the web via eHealth tools for older adults or provided evidence-based recommendations for designing such tools. Older adults were generally satisfied with receiving screening results via eHealth tools, and several studies suggested that receiving health screening results electronically improved participants’ quality of life. However, user interfaces that were not designed with older adults in mind and older adults’ lack of confidence in navigating eHealth tools proved challenging to eHealth uptake and use. All 9 studies included in this systematic review made recommendations on how to design eHealth tools that are intuitive and useful for older adults.
Conclusions: eHealth tools should incorporate specific elements to ensure usability for older adults. However, more research is required to fully elucidate the impact of receiving screening and results via eHealth tools without the presence of a health care provider for patient-centered outcomes in this target population.

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KEYWORDS
eHealth; systematic review; geriatric assessment; geriatric oncology

Introduction

Background

For older adults with cancer, several organizations recommend the completion of a geriatric assessment to help with cancer treatment decision-making [1,2]. A geriatric assessment consists of several questionnaires and tests that assess the medical, social, and psychological functioning of older adults to determine what interventions could be implemented to optimize their health and well-being [3]. However, owing to the shortage of geriatric teams and the large number of older adults diagnosed with cancer each year, access to a geriatric assessment remains to be limited. A web-based geriatric assessment may improve access for older adults. Although a few web-based geriatric assessment tools have been developed [4-6], these tools do not provide older adults with their test results without a health care provider being present. In addition, these tools would not increase access to a geriatric assessment because they still require the input of health care professionals, who are currently in low supply and high demand. Our overarching aim is to review the literature to develop a web-based geriatric assessment, the Comprehensive Health Assessment for My Plan (CHAMP), which will provide test results directly to older adults and help triage patients who are in greater need of geriatric consultation. To best design the CHAMP tool, we were interested in understanding the impact of receiving health test results in a web-based environment without the presence of a health care provider on older adults. We were also interested in consolidating the recommendations made by older adults and website developers for designing web-based tools for older adults. Therefore, we systematically reviewed the literature to obtain the latest evidence to inform the future design of our CHAMP tool.

As older adults with multiple comorbidities make up an increasing proportion of the population, there is a growing focus on equipping these patients with the tools needed to manage their own health. The aim is to provide patients with a sense of control over their medical conditions and decrease health care utilization [7]. Older patients particularly value the ability to manage their health independently at home, and minimizing reliance on health care resources, such as emergency rooms and inpatient units, is therefore an important outcome measure [8-10]. One strategy to meet these needs is the development of web-based health management tools that can be linked to patients’ eHealth records and accessed from personal devices (such as smartphones, tablets, and laptops). A wide variety of eHealth tools have been developed [5-7,11]. For example, some enable patients to view results of laboratory and imaging tests [11], whereas others provide customized health care advice or allow patients to communicate directly with members of their health care team [12]. Web-based tools have also been developed for the management of specific medical conditions such as cardiovascular disease [13] and diabetes [14]. The adoption of these resources was found to improve patient outcomes in these studies. In a small study of 169 computer users aged 50 years and older, Zettel-Wattson and Tsukerman [15] discovered that 90% of participants found patient portals helpful for managing their health and 80% felt that portals gave them control over their health. A systematic review by Ferreira et al [16] showed that providing patients access to their electronic medical records improved patient understanding of their disease and helped break down barriers in the physician-patient relationship.

Despite the number of eHealth tools and their potential to enhance patient care, barriers exist to widespread adoption, especially among patients older than 65 years. Previous studies have cited concerns about privacy and security, lack of access to technology, low computer literacy, high computer anxiety, complex user interfaces, and concerns about losing face time with health care providers as key factors that prevent older adults from routinely using eHealth management systems [7,17-20]. Disparities in uptake have also been found based on age group, ethnicity, education level, and physical and cognitive abilities [7,18,21]. Studies have varied in their conclusions about optimal eHealth tool design, and few have offered specific recommendations to address these barriers. Some authors suggest that complete medical records, medication lists, test results, and condition-specific health advice are consistently appreciated by patients accessing web-based portals [15,17,22]. Khan et al [23] studied perceptions of a medication management system and found that participants enjoy visual representations of data but would also like accompanying text descriptions to fully understand their meaning. Furthermore, some patients desire the ability to receive appointment reminders, refill medications, or communicate with health care professionals through secure messaging. However, the impact of various designs on patient-centered outcomes remains to be fully explored [24].

Objectives

To best design the CHAMP tool to deliver geriatric assessment results to older adults with cancer, our review questions were as follows:

1. What is the impact of websites and apps providing health test results to older adults in a web-based environment without the presence of a health care provider for patient-centered outcomes such as satisfaction, empowerment, quality of life, and health care use (eg,
hospitalization, physician visits, emergency room visits, and costs)?

2. What recommendations do older adults and developers have for designing future apps or websites for older adults?

We were most interested in understanding the impact of receiving health care screening and test results in the electronic environment on patient-centered outcomes such as satisfaction, empowerment, and quality of life compared with cancer-specific outcomes such as progression-free survival because we expect that the results of this literature review will be applicable to the care of older adults in many other fields of medicine, not just oncology. Furthermore, in geriatric oncology, factors other than progression-free survival and other cancer-specific outcomes are of substantial importance. Quality of life, overall functioning, and health care use have become increasingly important from the patient’s viewpoint. Hence, it is both of service to the patients that we care for, and to other providers of care for older adults to understand the impact of receiving health results in a web-based environment from the patient perspective [25,26].

Methods

Review Methodology

We used systematic review methodology according to the Cochrane Handbook [27] and guided by the Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) statement [28].

Search Methods

Database searches were conducted by a health sciences librarian (MG) in Ovid MEDLINE, Ovid Embase, EBSCO CINAHL Plus with Full Text, Ovid PsycINFO, and the Cochrane Library using the Wiley interface. A combination of database-specific subject headings and text word searches was used to search for concepts included in our population intervention comparator outcomes search with publication date limits applied to identify articles published in the last 10 years. Keywords included “telehealth,” “eHealth” or “mHealth” or “mobile health” or “digital health” or “telecommunications” or “electronic mail” or “cell phone” or “smartphone” or “Internet” or “Mobile Applications,” “older adults,” and “aged.” Although a geriatric assessment is not the same as a patient portal (the former is a health assessment, whereas the latter is a web-based shared medical record), we expanded the search to include portals to identify any studies that looked at the impact of providing test results web-based on older adults’ health outcomes. The results of this search were imported with other search results. Published filters were applied to limit the publication type to randomized controlled trials (RCTs) [29-32]. See Multimedia Appendix 1 for the MEDLINE search. The searches were run on November 29, 2019, and the search period was from January 1, 2009, to November 29, 2019. The search period was limited to 2009 onward to ensure that any apps and website or design recommendations would still be relevant as eHealth is a rapidly developing field. Publications in English were eligible for inclusion. Reference lists of included studies were reviewed to identify any additional relevant studies.

Papers were included if the following criteria were met:

- Included a population of older adults (aged above 65 years or the mean or median age in the study population was above 65 years, or if younger, subgroup analysis of those above 65 years was reported)
- Included an intervention in which older adults received results of health screening or tests completed in a web-based environment or eHealth (not including live chats with nurses, therapists, or doctors to go over test results)
- Compared the intervention to receiving the results of tests or screening in person from a health care provider or had no control group
- Focused on the following intervention outcomes: (1) patient-centered outcomes such as satisfaction, perceived harm, anxiety, depression, distress, empowerment, and quality of life; (2) health care use (eg, hospitalization, physician visits, emergency room visits, and costs); and (3) patient understanding of instructions of the tool used or provided recommendations on how to design eHealth tools for older adults

Study Selection

We included studies through a two-step process (see Figure 1 for our PRISMA flowchart). First, abstracts and titles were screened by two independent reviewers. Then, all potentially relevant full-text articles were reviewed for study inclusion by two independent reviewers. We used the Covidence software [33] to facilitate the study selection process. In case of disagreements, a third reviewer reviewed the abstract or full text, and a consensus decision was made whether to include or exclude the study.
Data Abstraction

We used standardized data collection forms developed by the research team using Excel. Data were abstracted by two reviewers independently and compared. The information that was abstracted included characteristics of the study population, study design details, details of the intervention (app or website), the methodology used to develop the app or website, details on the app or website, the impact of receiving web-based results for patients (on the aforementioned patient-centered outcomes), and details on the analyses used. For papers referring to a published study protocol, we obtained the study protocol paper to obtain the full methodological details of the study. After data abstraction, we had the missing information from all 9 studies. We contacted the authors of all the studies via email to inquire about missing information, and authors of 4 studies responded. As the studies were heterogeneous in design, intervention delivered, and outcome measures used, we summarized the abstracted data qualitatively because a meta-analysis was not possible.

Quality Assessment

We assessed the quality of the included studies using the Mixed Methods Appraisal Tool (MMAT) version 2018 [34-36]. MMAT is a quality assessment instrument that is useful for assessing qualitative, quantitative, and mixed methods studies. We noticed that several studies included a qualitative component (eg, multimethods and mixed methods studies); therefore, we chose to use MMAT over Cochrane Risk of Bias tool, which is not able to review these qualitative components. We used MMAT to review study quality, but we did not exclude any study based on the score as our aim was to understand all the evidence that was available and use that for our development of a web-based geriatric assessment.

Data Analysis

We summarized the results using a narrative descriptive synthesizing approach. A pooled analysis was not conducted because of heterogeneity in study inclusion criteria, interventions, and outcomes.

Results

Description of Included Studies

Of the 9 studies included in this review, 4 were qualitative studies [37-40], 2 were RCTs [41,42], 2 were mixed methods studies [43,44], and 1 was a quasi-experimental controlled study [45]. Overall, 8 studies were conducted in the United States [37-42,44,45], whereas 1 was a multinational study conducted in Western Europe [43]. All 9 studies included in this systematic review were published between 2015 and 2019. The sample size of the studies ranged considerably, with qualitative studies ranging from 24 to 44 participants [37-40] and the RCTs ranging from 50 to 272 participants [41-43]. The mixed methods study
ranged from 88 (47 for the focus group and 41 for the pilot trial) [43] to 123 participants (23 for the focus group and 100 for the phone survey) [44], whereas the quasi-experimental study had 200 participants [45]. In addition, 4 studies evaluated the attitudes and experiences of older adults with patient portals [38,39,44,45], 2 studies tested web-based apps developed to deliver condition-specific (e.g., cancer, cardiovascular disease) interventions [37,43], 1 study tested a user interface for a home health website [40], 1 tested a web-based decision aid [42], and 1 tested a theory-based patient portal training program [41]. A summary of the characteristics of each study included in this systematic review is shown in Table 1.

Table 1. Description of the included studies.

<table>
<thead>
<tr>
<th>Study (reference)</th>
<th>Study design</th>
<th>Location</th>
<th>Sample size; population</th>
<th>Average age (years)</th>
<th>Female (%)</th>
<th>Sampling</th>
<th>Intervention app or tool</th>
<th>Analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alpert et al (2016) [39]</td>
<td>Qualitative</td>
<td>United States</td>
<td>31 patient interviews; 2 focus groups of 13 health care professionals</td>
<td>Not reported (range 18-79)</td>
<td>58</td>
<td>Convenience</td>
<td>My preventative care patient portal</td>
<td>Critical incident technique</td>
</tr>
<tr>
<td>Baier et al (2015) [40]</td>
<td>Qualitative</td>
<td>United States</td>
<td>13 home health consumers; 28 case managers</td>
<td>71% ≥65 years; mean not reported</td>
<td>85</td>
<td>Convenience</td>
<td>Home health web-based app user interface</td>
<td>Content analysis</td>
</tr>
<tr>
<td>Irizarry et al (2017) [44]</td>
<td>Mixed methods</td>
<td>United States</td>
<td>100 older adults in phone survey, 23 in focus group</td>
<td>Focus group: 73; phone survey: 77</td>
<td>Focus group: 52.2%; phone survey: 46.2%</td>
<td>Convenience</td>
<td>Patient portal</td>
<td>Thematic analysis, Kruskal Wallis rank test, chi-square test</td>
</tr>
<tr>
<td>Jongstra et al (2017) [43]</td>
<td>Pilot RCTa</td>
<td>Western Europe</td>
<td>41 older adults with elevated CVDb risk</td>
<td>69</td>
<td>56</td>
<td>Random</td>
<td>Web-based app (HATICE) for older adults with CVD risk</td>
<td>Descriptive statistical analysis</td>
</tr>
<tr>
<td>Loh et al (2018) [37]</td>
<td>Qualitative</td>
<td>United States</td>
<td>18 older adults with malignancy; 13 caregivers</td>
<td>Patient: 77; caregiver: 70</td>
<td>Patient: 17; caregiver: 92</td>
<td>Convenience</td>
<td>TouchStream app to deliver geriatric oncology interventions</td>
<td>Conventional content analysis</td>
</tr>
<tr>
<td>Nahm et al (2019) [41]</td>
<td>RCT</td>
<td>United States</td>
<td>272 older adults with chronic disease</td>
<td>70</td>
<td>70.2</td>
<td>Convenience</td>
<td>Theory-based patient portal e-learning program</td>
<td>Linear mixed model, t test, chi-square test</td>
</tr>
<tr>
<td>Portz et al (2019) [38]</td>
<td>Qualitative</td>
<td>United States</td>
<td>24 older adults with chronic disease</td>
<td>78</td>
<td>71</td>
<td>Stratified</td>
<td>Kaiser permanente colorado’s patient portal—my health manager</td>
<td>Theoretical analysis based on the technology acceptance model</td>
</tr>
<tr>
<td>Smallwood et al (2017) [42]</td>
<td>Pilot RCT</td>
<td>United States</td>
<td>50 older women with BMDc indicating osteopenia or osteoporosis</td>
<td>Median 79 years; mean not reported</td>
<td>100</td>
<td>Stratified</td>
<td>Decision aid within patient portal for osteoporosis</td>
<td>ANOVA, t test, chi-square test</td>
</tr>
<tr>
<td>Toscos et al (2016) [45]</td>
<td>Quasi-experimental controlled</td>
<td>United States</td>
<td>200 patients with significant CADd</td>
<td>Average age not reported; 58% older than 66 years</td>
<td>Not reported</td>
<td>Personal health record</td>
<td>Linear regression, t test, Cochran-Mantel-Haenszel test</td>
<td></td>
</tr>
</tbody>
</table>

aRCT: randomized controlled trial.
bCVD: cardiovascular disease.
cBMD: bone mineral density.
dCAD: coronary artery disease.

Quality of Studies Included

The application of MMAT to each study included in this review is shown in Multimedia Appendix 2. Overall, there were no studies of high quality that looked at the effect of web-based screening without the presence of a health care provider on older adults or evidence-based eHealth design. Most studies that were included had small sample sizes [42-44] and used convenience sampling [37,39-41,44], thereby increasing the risk of selection bias. We were unable to determine if the outcome assessors were blinded in all RCTs [41,42], and we were unsure how randomization was performed in one of the RCTs [42]. In half
of the qualitative studies included in this systematic review, we were unable to determine if there was coherence between the qualitative data source, analysis, and interpretation [37,40].

The results of our systematic review are stated in the order of our aims. First, we review our findings on how receiving health screening in a web-based environment affects satisfaction, perceived harm, quality of life, and health care utilization by older adults. Second, we consolidate evidence-based recommendations on how to design eHealth tools that are useful and engaging for older adults.

Objective 1: Effects of Health Screening in a Web-Based Environment

A total of 7 studies in this review evaluated the effects of receiving health screening tests or results in a web-based environment without the presence of a health care provider on older adult participants’ satisfaction (n=6), perceived harm (n=5), and quality of life (n=5) [37-39,41,42,44,45]. No studies included in this review reported on the effect of eHealth tools on health care use by older adults. The main findings of these studies are shown in Table 2. Screening results from eHealth tools were generally well received by older adults, but several studies suggested that older adults felt anxious about using new technology [37,38,41,44]. In total, 63% of patients in the study by Loh et al [37] found the TouchStream health app, used to deliver geriatric interventions to older adults with cancer, enjoyable to use. A total of 20 participants (87%) in the study by Irizarry et al [44] felt that patient portals were generally useful. Five physicians (56%) in the study by Alpert et al [39] suggested that the investigated patient portal improved patient empowerment. Participants in the study by Portz et al [38] indicated that the Kaiser Permanente patient portal improved patient-provider communication and saved patients time and money. Older women with osteoporosis felt more prepared to make treatment decisions after using the web-based decision-making tool designed and studied by Smallwood et al [42]. Most participants in the same study [42] were able to complete the web-based decision aid, although 5 participants (17%) entered the information incorrectly.
Table 2. Effects of receiving health information in web-based environment for older adults.

<table>
<thead>
<tr>
<th>Study</th>
<th>Satisfaction</th>
<th>Perceived harm</th>
<th>Quality of life</th>
<th>Health care use</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alpert et al (2016) [39]</td>
<td>Patients found the portal useful for instantly accessing medical information. This feature accounted for more than half of the positive incidents recorded. Patients appreciated receiving laboratory test results.</td>
<td>A total of 11% of negative incidents were because of patients having difficulty interpreting laboratory test results. Patients were concerned when information was incorrect or not updated. There were more negative incidents (n=82, 72.6%) than positive incidents (n=31, 27.4%)</td>
<td>Physicians (n=5, 56%) suggested that the portal made patients feel empowered</td>
<td>NS a</td>
</tr>
<tr>
<td>Irizarry et al (2017) [44]</td>
<td>A total of 87% (n=20) of participants generally felt that the patient portal was useful. Participants with both low and high health literacy expressed interest in portal training. Participants who had experienced chronic illness praised the convenience of web-based laboratory results.</td>
<td>57% of participants (n=13) had anxiety and frustrations about using technology because of their perceived lack of technological skills. This caused them to rely on family members to use the patient portal</td>
<td>NS</td>
<td>NS</td>
</tr>
<tr>
<td>Loh et al (2018) [37]</td>
<td>Most patients (n=10, 63%) and caregivers (n=8, 73%) enjoyed using the eHealth app to connect with their care providers and manage their health. Most patients or caregivers found the health app easy to use</td>
<td>One patient (6%) suggested that the app may be difficult for someone with less experience using technology</td>
<td>25% (4/16) of patients commented that the app would be most useful for patients living alone</td>
<td>NS</td>
</tr>
<tr>
<td>Nahm et al (2019) [41]</td>
<td>NS</td>
<td>NS</td>
<td>Patient portal training improved user health decision-making, patient-provider communication, and eHealth literacy. At 4 months after patient portal training, changes in self-efficacy (P=.02) and patient portal usage (P=.03) were significant</td>
<td>NS</td>
</tr>
<tr>
<td>Portz et al (2019) [38]</td>
<td>Users suggested the patient portal was useful for accessing health information and communicating with their health care providers</td>
<td>Users were anxious that program updates would cause the portal to become unfamiliar or too difficult to use</td>
<td>Users believed the patient portal saved them time and money</td>
<td>NS</td>
</tr>
<tr>
<td>Smallwood et al (2017) [42]</td>
<td>Participants were able to complete the web-based decision aid with minimal assistance. Subjects who used the decision aid compared with those who did not use it felt more prepared to make decisions about their treatment (P&lt;.001)</td>
<td>Some patients (n=5, 17.2%) incorrectly entered information into the decision tool</td>
<td>NS</td>
<td>NS</td>
</tr>
<tr>
<td>Toscos et al (2016) [45]</td>
<td>The mean activation of participants was of the highest possible level (level 4) throughout the study</td>
<td>NS</td>
<td>Patient activation was higher in portal users, but not statistically significant. Portal users showed health improvements at 12 months in HbA1c, LDL, SBP, and DBP, but only HbA1c (-0.19; P=.005) was statistically significant. BMI was unchanged throughout the study</td>
<td>NS</td>
</tr>
</tbody>
</table>

aNS: not studied.
bHbA1c: glycated hemoglobin A1c.
cLDL: low-density lipoprotein.
dSBP: spontaneous bacterial peritonitis.
eDBP: diastolic blood pressure.

Although participants were generally positive about the use of eHealth to receive screening or test results, several studies noted that older adults reported feeling anxious about using eHealth technology [38,39,44]. Participants—especially those with low health literacy—felt afraid to make mistakes because of their lack of technological experience. Many of these patients commented that computer use was not common in their working environment, which accounted for their lack of experience.
These participants often avoided technology use altogether and preferred a family member accessing their patient portal on their behalf [44]. Participants in the study by Portz et al [38] noted specific anxiety about program updates to eHealth tools that made eHealth tools difficult to use after patients had learned and were comfortable with the tools. Difficulty in interpreting and applying laboratory results was also a concern among older eHealth users [39]. However, several studies noted that patients still enjoyed being able to view their laboratory results on the web [38,39].

Despite computer anxiety being common among this population, many older adults, including those with low health literacy, were still interested in learning how to use a patient portal [44]. Patient portal training may be an important solution to low confidence that prevents many older adults from utilizing patient portals. Nahm et al [41] conducted an RCT and found that a theory-based patient portal e-learning program resulted in statistically significant improvements in patient portal self-efficacy, health decision-making, patient-provider communication, and eHealth literacy 3 weeks after portal training. Patient portal self-efficacy remained significantly higher in the intervention group at 4 months [41]. Participants from several studies recommended providing an instructional video or detailed written instructions to aid platform navigation [40,43]. Participants with both high and low health literacy felt that task-based training programs were a valuable but underutilized tool to increase confidence and knowledge on how to navigate eHealth tools [44].

Objective 2: Designing eHealth Tools for Older Adults

All 9 studies included in this review provided recommendations on how to develop eHealth tools that are intuitive, useful, and engaging for older adults. The specific recommendations can be divided into 3 basic categories: (1) user interface (how the participant interacts with the eHealth tool), (2) functionality (what the participant wants the eHealth tool to do), and (3) information included (what the participant wants the eHealth tool to say). A summary of the recommendations can be found in Table 3.
### Table 3. Older adult and investigator recommendations for eHealth tools.

<table>
<thead>
<tr>
<th>Theme and study</th>
<th>Older adult recommendation</th>
<th>Investigator recommendation</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>User interface</strong></td>
<td><img src="image.png" alt="Image" /></td>
<td><img src="image.png" alt="Image" /></td>
</tr>
</tbody>
</table>
| Alpert et al (2016) [39] | - Write information as bulleted lists  
- Dictionary to look up challenging terminology | - Create an interactive user interface  
- Use images that represent the information being presented  
- Use motivational voice, not passive voice |
| Baier et al (2015) [40] | - If the page requires scrolling to view all the content, add a pop-up to remind the user to scroll down  
- Allow users the option to increase font size  
- Results and health information should be easily printed  
- The web-based apps should be optimized for mobile devices | - Avoid writing in all caps  
- Use serif fonts  
- Use contrasting colors to enhance readability  
- Provide prompts for functions  
- Write at a sixth-grade reading level, limit technical language  
- Include definitions for medical terms  
- Directly label graphs  
- Limit comparisons with 3-4 points |
| Jongstra et al (2017) [43] | - Use large font size  
- Use simple and consistent layout with large buttons  
- Use images and distinct colors to facilitate page navigation  
- Include audio option | - Ensure reliable internet access  
- Provide stylus for touchscreen devices  
- Provide a list of voice options if audio included  
- Optimize the app for mobile phones and tablets  
- Ensure screen brightness, font and color are easily readable |
| Loh et al (2018) [37] N/A | - Use larger font and contrasting colors | N/A |
| Portz et al (2019) [38] | N/A | - Automatic entry of patient’s lab scores to decrease incorrect information |
| Smallwood et al (2017) [42] | N/A | - Ability for physician to confirm if their patient viewed or understood the information provided to them |
| **Functionality** | ![Image](image.png) | ![Image](image.png) |
| Alpert et al (2016) [39] | - Ability to communicate with the physician regarding information received on the portal  
- Seamless and intuitive password retrieval | N/A |
| Baier et al (2015) [40] | - Add detailed instructions at the beginning of the eHealth tool to help users learn how to navigate the tool | N/A |
| Irizarry et al (2017) [44] | - Include task-based training to help users understand how to navigate the different features of the patient portal | - Integrate the patient portal with in-person clinical encounters  
- Allow personnel to edit missing or inaccurate information in the patient portal |
| Jongstra et al (2017) [43] | - Provide a way for patients to ask questions about navigating the online platform  
- Include an instructional video to aid in platform navigation | - Include games, goal setting, automated messages among other interactive features to motivate eHealth use |
| Loh et al (2018) [37] | - Participants found functions including appointments, medications, nutrition, and exercise reminders helpful | - If symptom reporting is included, ensure that feedback is provided on reported symptoms  
- Provide digital activity tracker when exercise intervention is recommended  
- Incorporate nonmedical functions such as social activities, jokes, games, etc |
| Nahm et al (2018) [41] N/A | - Implement patient portal training for older adults | |
Information included

A total of 7 studies identified functions that participants found most useful to include in an eHealth tool [37-41,43,44]. A common suggestion among older adults was to include detailed instructions within the eHealth tool [20,40,43,44]. Several suggestions were given as to how instructions should be included. Participants in the study by Baier et al [40] recommended detailed written instructions accessible within the eHealth tool. Participants in the study by Irizarry et al [44] suggested that task-based training was most helpful for learning how to navigate the tool. Alternatively, instructional videos and communication methods that allowed participants to ask questions about navigating the platform were recommended by participants in the study by Jongstra et al [43].

Both authors and participants of 3 studies commented that the eHealth tool should be integrated with the in-person clinical environment [38,39,44]. Participants commonly cited the ability to communicate with their physician through the eHealth tool as an enjoyable and useful feature [38,39]. Physicians generally felt that the patient portal empowered patients, but they wanted the ability to confirm if their patient viewed and understood the information provided to them via the eHealth tool [39]. Portz et al [38] suggested using face to face or phone time to encourage portal use in patients.

Finally, 2 studies recommended including fun, interactive features such as games, jokes, social activities, or automated motivational messages to promote tool use and make the tool more enjoyable for older adults [37,43].

### Functionality

A total of 7 studies identified functions that participants found most useful to include in an eHealth tool [37-41,43,44]. A common suggestion among older adults was to include detailed instructions within the eHealth tool [20,40,43,44]. Several suggestions were given as to how instructions should be included. Participants in the study by Baier et al [40] recommended detailed written instructions accessible within the eHealth tool. Participants in the study by Irizarry et al [44] suggested that task-based training was most helpful for learning how to navigate the tool. Alternatively, instructional videos and communication methods that allowed participants to ask questions about navigating the platform were recommended by participants in the study by Jongstra et al [43].

Both authors and participants of 3 studies commented that the eHealth tool should be integrated with the in-person clinical environment [38,39,44]. Participants commonly cited the ability to communicate with their physician through the eHealth tool as an enjoyable and useful feature [38,39]. Physicians generally felt that the patient portal empowered patients, but they wanted the ability to confirm if their patient viewed and understood the information provided to them via the eHealth tool [39]. Portz et al [38] suggested using face to face or phone time to encourage portal use in patients.

Finally, 2 studies recommended including fun, interactive features such as games, jokes, social activities, or automated motivational messages to promote tool use and make the tool more enjoyable for older adults [37,43].

<table>
<thead>
<tr>
<th>Theme and study</th>
<th>Older adult recommendation</th>
<th>Investigator recommendation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Portz et al (2019) [38]</td>
<td>Participants were interested in using e-visits and chat functions with providers</td>
<td>Portal designers should consider including functions that integrate eHealth with physical clinic visits</td>
</tr>
<tr>
<td>Information included</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alpert et al (2016) [39]</td>
<td>Include personalized, not generic health information</td>
<td>N/A</td>
</tr>
<tr>
<td></td>
<td>Patients appreciated receiving laboratory results but sometimes had difficulty interpreting them</td>
<td>N/A</td>
</tr>
<tr>
<td>Jongstra et al (2017) [43]</td>
<td>Provide practical and reliable health information</td>
<td>N/A</td>
</tr>
<tr>
<td>Loh et al (2018) [37]</td>
<td>N/A</td>
<td>Tailor interventions and activities to the individual</td>
</tr>
<tr>
<td>Toscos et al (2016) [45]</td>
<td>N/A</td>
<td>Apply a user-centered design approach to tailor the portal to the specific population that it is designed for</td>
</tr>
</tbody>
</table>

aN/A: not applicable.

### Discussion

#### Principal Findings

The aims of this systematic review were two-fold. First, we were interested in understanding how receiving health screening in a web-based environment without the presence of a health care provider affects satisfaction, perceived harm, quality of life, and health care use by older adults. Second, we were interested in consolidating evidence-based recommendations on how to design eHealth tools that are useful and engaging for older adults. We found that older adults generally had positive experiences with receiving test results via eHealth tools, and numerous features have been suggested to enhance patients’ web-based experiences. Although much literature is available on the impact of eHealth tools for younger patients, older adults represent a unique subgroup of patients whose needs differ greatly [46-48]. To the best of our knowledge, there are currently no systematic reviews on the effects of receiving health screening or results via eHealth tools either on older adults’ health care satisfaction, perceived harms, quality of life, or health care use or on the optimal design for eHealth tools for older adults. It is important to understand the unique experiences provided to them via the eHealth tool [39].}

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(page number not for citation purposes)
of older adults because they are often less proficient with technology than younger patients are and may require different supports [49]. As a rapidly growing population of health care consumers, older adults are positioned to benefit greatly from the use of eHealth tools if these tools are designed in ways that are attractive to older adults.

From the 9 studies included in our review, several key themes emerged. Multiple studies noted that while older adults were generally optimistic about eHealth tools, lack of technology experience and fear of failure were barriers to use [37,38,44]. Both older adults and researchers recommended detailed instructions and comprehensive training to improve older adults’ confidence in using eHealth tools [40,41,43,44]. Although it is encouraging that most older adults found receiving screening tests and results via eHealth to be useful, there is currently not enough research available to draw conclusions on the impact of receiving test results in a web-based environment without the presence of health care providers on older adult satisfaction, perceived harm, and quality of life. The possible harms of providing older adults with screening results via eHealth tools are anxiety caused by technology use, confusion among older adults who may be unable to interpret their results, and disparity caused by those who are less likely to benefit from eHealth tools because of low technology or health literacy. We were unable to find any information on the effect of eHealth screening tools on older adult health care utilization and hence cannot recognize any trends or draw any conclusion on health care use.

There were substantial recommendations from the studies included in this systematic review on how to design eHealth tools for older adults. A user interface that is accessible and intuitive to older adults is imperative for promoting tool uptake and use and was the most commonly made recommendation provided by older adults. Further recommendations included ensuring that the layout and text used in the tool is accessible to users with vision or hearing impairments and is logical to those with less technological experience. Furthermore, eHealth tools should be enjoyable for older adults to use. Designing a tool that includes interactive features, uses a positive tone, and ensures a seamless technological experience creates an environment that promotes eHealth tool uptake.

To promote eHealth use among older adults, the tools must provide functions and content that are useful for older adults. Participants emphasized the importance of integrating the eHealth tools with the physical clinic environment by facilitating communication with their physicians. Older adults suggested that personalized information, interventions, and activities were more useful and engaging than generic recommendations.

**How Does This Compare With the Literature?**

Although there are several systematic reviews that investigate the effect of eHealth tools on healthy aging outcomes such as physical activity, diet, and psychological well-being [50-52], we were unable to find a systematic review that investigated the effects of receiving screening results without the presence of health care providers in older adults. Furthermore, we were unable to find a systematic review that consolidated evidence-based recommendations for designing eHealth tools for older adults. Kampmeijer et al [53] completed a systematic review on the use of eHealth tools in health promotion and primary prevention for older adults. Similar to our findings, Kampmeijer et al [53] found that usability and accessibility were important facilitating factors in older adults’ use of eHealth tools [53]. Buyl et al [52] completed a systematic review on the effect of eHealth interventions on healthy aging outcomes such as physical activity, psychological well-being, and overall health. Similar to our study, Buyl et al [52] were unable to draw conclusions on most health-related outcomes as they also found the quality of studies to vary considerably and the certainty of evidence to be low. However, Buyl et al [52] found that eHealth tool use improved older adults’ physical activity. Strengthening digital competency was a critical component of encouraging eHealth tool use among older adults, which is similar to our finding that older adults desire training programs to feel confident in using eHealth tools. However, our study differs from those by Buyl et al [52] and Kampmeijer et al [53] because both studies investigated eHealth tools that encouraged physical activity, psychological well-being, and primary prevention strategies for older adults, whereas we investigated tools that provided screening results to older adults without health care providers present. Furthermore, Narasimha et al [54] completed a systematic review of the optimal design of telemedicine for older adults. Encouragingly, the authors found that older adults were generally positive about their experience with telehealth, although a lack of confidence with technology and physical impairments (for example, hearing difficulty) proved to be a challenge. These results are similar to our findings that although older adults are optimistic and willing to use eHealth tools, designing tools that accommodate common physical impairments and include training are important for user confidence and uptake. Our systematic review is different from Narasimha et al [54] because we investigated evidence-based recommendations for developing eHealth tools, not telemedicine.

**Limitations**

After removing duplicate and irrelevant papers, a small number of studies were used for our final analysis, which limits the generalizability of our findings. Although many titles and abstracts were found, we applied the RCT filter as we were interested in studies that examined the intervention ideally to a comparator group. However, few studies used an RCT design, and 4 studies used a qualitative design. By applying the RCT filter, it is possible that we may have missed additional qualitative studies. However, the gold standard for evaluating interventions is the RCT design, and these studies, including quasi-experimental studies, would have been identified in our search. Furthermore, most of the studies used convenience sampling to recruit participants, which introduces significant selection bias. In addition, the studies often had small sample sizes of less than 100 patients. These limitations further constrain the applicability of the results to larger and more diverse populations. Finally, many studies did not look at the sustainability of portal use, or the duration of follow-up was not reported. Therefore, it is unclear if any benefits that were identified are sustained over a significant period.

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Implications

Our findings suggest that although older adults are generally satisfied with receiving screening tests and results via eHealth tools, improper design, and lack of confidence with technology are common barriers to use in this population. Patients and caregivers should initially receive basic training on how to use eHealth tools to mitigate patient concerns (eg, about complex user interfaces) and minimize the impact of low computer literacy. To optimize the usability of eHealth tools, they should include customizable features (such as alerts, medication reminders, and appointment scheduling) as well as easy-to-read displays (eg, with large fonts and contrasting colors). In addition, eHealth tools should be integrated with physical clinic visits to facilitate communication between patients and their health care providers. By incorporating these features routinely into the design of patient portals, older adults will be more likely to embrace technology that can potentially improve their health. However, our review demonstrates that the literature on this topic remains sparse, and there is a need to further study the effects of eHealth tools on important patient-centered outcomes such as satisfaction, perceived harm, quality of life, and health care use. Older patients highly value the ability to remain at home, and avoiding emergency room visits and hospitalizations, making this an important outcome to consider in research involving older adults [8-10].

The findings from this systematic review will aid in the design of our CHAMP tool for older adults with cancer. Notably, one aim of this systematic review was to understand the impact of receiving test results in a web-based environment without the presence of health care providers on older adults. Although older adults generally appreciated receiving their results on the web, several studies noted that older adults desired the option to review their results with a health care professional. This supports our proposed CHAMP tool in which patients will use the tool to receive health care recommendations specific to their needs. Patients who are in high need of geriatric interventions will be identified and triaged to see a geriatrician. Those who are determined to have a low need for geriatric support will receive evidence-based recommendations determined by their unique health care needs and goals. These patients may also use the findings and recommendations of the CHAMP tool in discussions with their primary practitioner or oncologist. Hence, both low- and high-risk patients have the option to review and discuss the findings from the CHAMP eHealth tool with a health care professional.

The abundance of design recommendations made by older adults in the studies included in this systematic review will aid us in designing the CHAMP tool in a way that is most intuitive for older adults. Several design recommendations such as goal setting, live chat functions, and interactive games are more suited toward eHealth tools that are meant to be used longitudinally, whereas the CHAMP tool will be a one-time eHealth screening tool. However, these recommendations are still useful for researchers designing longitudinal eHealth tools for older adults.

Recommendations for Future Research

The development and use of eHealth tools among older adults are an understudied area with an opportunity for more learning, particularly given the growing uptake of eHealth tools by older adults [55]. Currently, there is not enough research available to draw conclusions about the impact of receiving test results on the web on outcomes such as satisfaction, perceived harms, quality of life, and health care use for older adults. Future studies should investigate these outcomes in controlled trials that examine the impact of receiving test results on the web without a health care provider present. Future studies should also use random sampling methods that allow for greater generalization of the results. Finally, we were unable to find any research on the long-term implications of eHealth tools on the health and well-being of older adults or on health care use. Future studies should incorporate long-term follow-up and include health care use as an outcome to understand the extent of the benefits of eHealth tools.

Acknowledgments

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Conflicts of Interest

None declared.

Multimedia Appendix 1
MEDLINE search.
[DOCX File, 16 KB - aging_v4i1e24092_app1.docx]

Multimedia Appendix 2
Quality assessment of included studies assessed with the Mixed Methods Appraisal Tool.
[DOCX File, 15 KB - aging_v4i1e24092_app2.docx]

References


Abbreviations

- **CHAMP**: Comprehensive Health Assessment for My Plan
- **mHealth**: mobile health
- **MMAT**: Mixed Methods Appraisal Tool
- **PRISMA**: Preferred Reporting Items for Systematic Reviews and Meta-analyses
- **RCT**: randomized controlled trial

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Technology-Assisted Home Care for People With Dementia and Their Relatives: Scoping Review

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Abstract

Background: Assistive technologies for people with dementia and their relatives have the potential to ensure, improve, and facilitate home care and thereby enhance the health of the people caring or being cared for. The number and diversity of technologies and research have continuously increased over the past few decades. As a result, the research field has become complex.

Objective: The goal of this scoping review was to provide an overview of the research on technology-assisted home care for people with dementia and their relatives in order to guide further research and technology development.

Methods: A scoping review was conducted following a published framework and by searching 4 databases (MEDLINE, CINAHL, PsycInfo, and CENTRAL) for studies published between 2013 and 2018. We included qualitative and quantitative studies in English or German focusing on technologies that support people with dementia or their informal carers in the home care setting. Studies that targeted exclusively people with mild cognitive impairment, delirium, or health professionals were excluded as well as studies that solely consisted of assessments without implication for the people with dementia or their relatives and prototype developments. We mapped the research field regarding study design, study aim, setting, sample size, technology type, and technology aim, and we report relative and absolute frequencies.

Results: From an initial 5328 records, we included 175 studies. We identified a variety of technology types including computers, telephones, smartphones, televisions, gaming consoles, monitoring devices, ambient assisted living, and robots. Assistive technologies were most commonly used by people with dementia (77/175, 44.0%), followed by relatives (68/175, 38.9%), and both target groups (30/175, 17.1%). Their most frequent goals were to enable or improve care, provide therapy, or positively influence symptoms of people with dementia (eg, disorientation). The greatest proportions of studies were case studies and case series (72/175, 41.1%) and randomized controlled trials (44/175, 25.1%). The majority of studies reported small sample sizes of between 1 and 50 participants (122/175, 69.7%). Furthermore, most of the studies analyzed the effectiveness (85/233, 36.5%) of the technology, while others targeted feasibility or usability or were explorative.

Conclusions: This review demonstrated the variety of technologies that support people with dementia and their relatives in the home care setting. Whereas this diversity provides the opportunity for needs-oriented technical solutions that fit individual care
arrangements, it complicates the choice of the right technology. Therefore, research on the users’ informational needs is required. Moreover, there is a need for larger studies on the technologies’ effectiveness that could contribute to a higher acceptance and thus to a transition of technologies from research into the daily lives of people with dementia and their relatives.

**KEYWORDS**

dementia; home care; assistive technologies; scoping review

**Introduction**

About 50 million people worldwide suffer from dementia, and there are almost 10 million new cases every year [1]. Dementia is an umbrella term that describes a syndrome, usually of a chronic nature, in which there is a disorder of several higher cortical functions: memory, thinking, orientation, language, judgment, and learning [2]. Due to the disease, people with dementia are restricted in their activities of daily life. Furthermore, the prevalence of challenging behaviors such as anxiety, hallucinations, delusions, or disinhibition is high [3-5]. Over the course of the disease, different needs for support occur. These needs range from assistance with activities of daily living (eg, personal hygiene), psychosocial support (eg, coping with the disease), and help with disorientation [6]. Nevertheless, people with dementia want to live at home as long as possible [7,8], and moving to a new environment (eg, long-term care) increases confusion, disorientation, and behavioral symptoms [9,10]. Home care is mostly provided by relatives, which can result in conflicts between the support needs and requirements of those affected and the available resources of the informal caregivers. Relatives often feel obliged [11] and have a high burden of care [12,13]. This causes tension in the family system and a feeling of being overwhelmed. As a result, the quality of care cannot be maintained, and even a move to a long-term care setting is necessary [14].

Assistive technologies can potentially maintain and support home care arrangements and consequently avoid or postpone residential care [15,16]. They have various aims, such as supporting communication [17-19], providing timely education or therapy for people with dementia and their relatives [20,21], offering assistance with daily activities (eg, cooking) [22], or reducing disease-related risks (eg, getting lost) [23]. Thereby, they encourage independence and social inclusion [15,16,24]. On the other hand, a recent study did not demonstrate a significant reduction in caregiver burden, anxiety, and depression in a large study population [25]. The evidence therefore does not seem to be clear. Barriers to the use of assistive technologies included perceptions of the high cost of formal assistive technologies; dilemmas regarding the timing and stage of technology use; and a lack of information and support from formal health and social care services about access, sources, timing, and options for use [26].

With regard to the different support domains, there is a wide diversity of assistive technologies, ranging from simple applications to complex multicomponent technologies. Assistive technologies can be defined as technological devices aimed “(…) to maintain or improve an individual’s functioning and independence to facilitate participation and to enhance overall well-being” [27]. Research and development in this field has increased significantly in recent years due to technological progress, increasing demand and research funding [28]. However, the research area is very confusing due to the large number of different technologies with varying degrees of development for different target groups as well as various objectives of these technologies. We therefore conducted a scoping review to provide an overview of existing research on assistive technologies for people with dementia and their families in the home setting, guided by the research question: What types of assistive technologies are described in the current scientific literature for people with dementia and family carers to support care in the home setting?

**Methods**

We conducted a scoping review following the steps described by Arksey and O’Malley [29] with an extension by Levac et al [30]. The steps include (1) formulating the research question; (2) identifying relevant studies; (3) selecting relevant studies; (4) charting the data; (5) collating, summarizing, and reporting results; and (6) consultation. We did not publish a protocol for this review and used PRISMA-ScR (Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews) for reporting of this review [31].

**Eligibility Criteria**

We included publications with qualitative or quantitative study designs focusing on technologies supporting people with dementia or their informal caregivers in the home care setting published between January 2013 and October 2018 in the German or English language. The time restriction of 5 years prior to the search date was chosen due to the rapid and significant changes that are made in the digital sector. We included studies conducted in day care centers and nursing homes because some of the technologies tested in these settings are also described as suitable for use in the home setting.

We excluded studies targeting people with mild cognitive impairment or delirium only as well as studies on electronic aids (eg, electric wheelchair) or technologies for the sole purpose of dementia assessment or diagnostics without any implication for the home care of people with dementia. Additionally, we excluded studies on technologies that are exclusively used by health professionals. We also excluded studies that only reported on technical aspects or parts of a technology (eg, interfaces or prototypes) as well as systematic reviews and study protocols.

**Search Process**

We searched the databases MEDLINE, CINAHL, PsycInfo, and CENTRAL up to October 2018. To develop the search
strategy, the review team brainstormed potentially important search terms, scoped relevant studies for controlled vocabulary, and searched the MeSH browser for relevant MeSH terms mapped to uncontrolled vocabulary. The search strategy was reviewed internally via the Peer Review of Electronic Search Strategies (PRESS) guideline [32]. Two review authors (AS, SP) independently screened titles, abstracts, and full texts for inclusion. In cases of uncertainty, a third author (SN) was consulted.

Data Extraction and Critical Appraisal

Two study authors (AS, SP) extracted the following study characteristics using a standardized data extraction sheet and resolving differences by discussion: authors, year of publication, study design, study aim, country, setting, sample size, name of technology, type of technology, and aim of technology.

We did not perform a standardized critical appraisal of the included studies with, for example, the Cochrane Risk of Bias tool, since our goals were to give an overview and map out topics.

Synthesis

We report the results in a structured and narrative synthesis, graphically, and in tabular form. Therefore, we grouped the studies' technologies thematically and mapped out the study designs, technology groups, and goals of the studies.

Additionally, we compared the settings, target groups, and sample sizes. The trends in publication numbers as well as the inclusion of the target groups were analyzed. We report the results with descriptive statistics in absolute and relative frequencies. A brief report on the nonformalized consultation process by means of expert discussions at 2 conferences is incorporated in the discussion.

Results

The database search identified 5328 titles. After abstract and full-text screening, 158 publications describing 175 studies with a total of 10,167 participants were included. See the PRISMA flowchart [33] for the illustration of the search process (Figure 1) and the multimedia appendices for the studies’ references (Multimedia Appendix 1) and study details (Multimedia Appendices 2-4). The divergent number of studies and articles can be explained by the fact that several different case studies on different technologies are combined in 1 article. These studies do not meet the criteria of case series or multiple case studies. In addition, different studies, which varied in design, were described in 1 article.

In order to answer the question of existing assistive technologies to support people with dementia and their relatives, a diagram was created clustering the different types of technologies under investigation (Figure 2).

Figure 1. PRISMA flowchart.
Figure 2. Relative frequencies of the types of technologies in the included studies (n=175).

About half of the studies (86/175, 49.1%) addressed different applications on computers, laptops, or tablets. Furthermore, robots (25/175, 14.3%) and telephone interventions (22/175, 12.6%) were frequently studied. Among robotic systems, PARO (PARO Robots US Inc, Itasca, IL) was the most commonly covered technology (10/175, 5.7%). Other technologies such as gaming consoles (1/175, 0.6%), apps on smartphones (4/175, 2.3%), ambient assisted living (8/175, 4.6%), and monitoring systems (12/175, 6.9%) were covered less frequently.

The studies can be classified according to different study characteristics. Focusing on the target group, technologies were primarily used by people with dementia (77/175, 44.0%), their relatives (68/175, 38.9%), or both target groups (30/175, 17.1%). With regard to the technology groups presented, most of the studies in which robots were tested were conducted with people with dementia (23/25, 92%). Computer programs (16/20, 80%) and apps on tablets (9/11, 82%) were also tested most commonly with people with dementia. Telephone-based interventions (22/22, 100%), internet courses (9/9, 100%), special websites (9/9, 100%), and online social networking or support groups (8/10, 80%) were almost exclusively related to family carers. When both target groups were addressed, monitoring (7/30, 23%) and ambient assisted living systems (5/30, 17%) were examined more frequently.

With respect to the setting, 60.0% (105/175) of the studies were conducted at home, 20.0% (35/175) in nursing homes, 11.4% (20/175) in day care centers, and 5.1% (9/175) in more than one setting. Concerning the technology groups, more than two-thirds of the studies with robots were conducted in nursing homes (17/25, 68%). Telephone interventions (22/22, 100%), apps on computers (6/6, 100%), and monitoring systems (9/12, 75%) were tested exclusively or predominantly in the home setting. Computer programs were tested more frequently in day care centers (8/18, 44%) and nursing homes (5/18, 28%) than at home (3/18, 17%). Furthermore, almost all studies that focused on the relatives took place in the home environment (66/68, 97%), and studies focusing on both target groups were more likely to take place at home (19/30, 63%) than in nursing homes (8/30, 27%). People with dementia were most often studied in nursing homes (27/77, 35%). However, a similar proportion of this target group was assessed at home (20/77, 26%) and in day care centers (19/77, 25%).

Overall, the number of included publications per year was relatively stable over time, with a mean of 26 publications per year. The number varies between a minimum of 21 publications in 2016 and a maximum of 34 publications in 2017. Table 1 shows the number of publications per year and target group of the technical intervention.

<table>
<thead>
<tr>
<th>Target group</th>
<th>Publication year</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>2013</td>
</tr>
<tr>
<td>People with dementia</td>
<td>10</td>
</tr>
<tr>
<td>Caregivers</td>
<td>7</td>
</tr>
<tr>
<td>Both people with dementia and caregivers</td>
<td>7</td>
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</tbody>
</table>
There is a noticeable increase in the number of publications focusing on people with dementia between 2016 (n=5) and 2017 (n=17). Additionally, it becomes clear that the number of publications with the target group of relatives increases significantly from 2013 to 2015, and they represent the largest target group from 2014 to 2016. From 2017 onwards, this trend changed, and most interventions investigated assistive technologies for people with dementia. In 2018, the number of publications of these target groups is approximately the same (caregiver n=10; people with dementia n=11). Few of the studies focused on both target groups as users of technologies.

The assistive technologies were also investigated according to their study designs. Case studies represented 33.1% (58/175), 25.1% (44/175) were randomized controlled trials (RCTs), and 10.3% (18/175) were post-studies. Only a small proportion of the studies used case series (14/175, 8.0%), an exclusively qualitative design (14/175, 8.0%), a controlled trial (7/175, 4.0%), or a cross-sectional design (7/175, 4.0%). The remaining studies were classified as having “other” designs (13/175, 7.4%).

Grouping study designs by target groups, the largest percentage of studies focusing on patients with dementia used case studies (37/77, 48%). Subsequently, case series and RCTs represented the second largest proportion for this target group (11/77 each, 14%). Regarding the relatives, most studies used RCTs (30/68, 44%) and pre-post designs (14/68, 20.5%). When both target groups were investigated, case studies were mostly utilized (14/30, 47%). Case studies in general mainly consisted of people with dementia (37/58, 64%) or both target groups (14/58, 24%). In the qualitative studies, all target groups were examined with similar frequency (people with dementia and both groups: 5/14, 36%; relatives: 4/14, 29%).

When stratified by setting, in day care centers, mainly case studies and series were conducted (18/20, 90%). Case studies also accounted for half of the research in nursing homes (18/35, 51%). In contrast, the number of RCTs was highest in the home setting (35/105, 33.3%), followed by case studies and case series (29/105, 27.6%) as well as pre-post studies (15/105, 14.3%). In addition, most qualitative studies were conducted at home (10/14, 71%). Regarding the number of participants and study designs, 25% (11/44) of RCTs incorporated 1-10 people, and 30% (13/44) of RCTs incorporated each of 51-100 and ≥201 persons. With respect to the technology group, most of the RCTs and controlled trials were performed with testing telephone interventions (18/51, 35%), robots (8/51, 16%), and internet courses (7/51, 14%). In the case studies and case series, applications on computers, tablets, and laptops (38/72, 53%) as well as robots (10/72, 14%) were examined most frequently.

Regarding the number of participants, the majority of studies included 1 to 50 persons (1-10: 59/175, 33.7%; 11-50: 63/175, 36.0%). Table 2 shows the number of publications by the technologies’ target group and sample size. In smaller studies with a maximum of 10 participants, the proportion of publications about people with dementia (38/59, 64%) was particularly high. In studies with 51 or more participants, the majority of studies focused on caregivers (51-100: 12/19, 63%; 101-200: 11/14, 79%; ≥201: 9/16, 56%).

<table>
<thead>
<tr>
<th>Target group</th>
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<tr>
<td></td>
<td>1-10</td>
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<tr>
<td>People with dementia</td>
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<tr>
<td>Caregivers</td>
<td>10</td>
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<td>Both people with dementia and caregivers</td>
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</tbody>
</table>

The nature of assistive technologies is particularly determined by its purpose. For better comparability, 8 categories of technology aims were formed. As some technologies had multiple functions, they were assigned to more than 1 category in order not to simplify their complexity.

The largest proportion of technologies aimed to enable or support therapeutic or caring interventions (85/308, 27.6%). Therapeutic technology–supported interventions included online therapy for people with dementia or their caregivers or art therapeutic interventions via a technical device (n=31) [37,38]. Care interventions sought to increase the safety of people with dementia, for example by detecting the danger of falling at an early stage (n=54). A specific example was the study by Bayen et al [39], which analyzed how continuous video monitoring and review of falls of individuals with dementia can support better quality of care. Abbate et al [40] used a wireless accelerometer and electroencephalograph logger integrated in a minimally invasive monitoring sensor system with the aim of detecting possible falls and their causes. Care interventions also included online training programs for relatives with the goal of improving caring by trying to facilitate everyday life (eg, dealing with people with dementia). The European project STAR offers caregivers of people with dementia (both formal and informal) online training in order to better understand the disease and provide higher quality care [41]. Furthermore, 25.3% (78/308) of the technologies aimed to positively influence the symptoms of people with dementia such as disorientation or fear. Other technologies have been used to increase the knowledge of people with dementia or their relatives, such as through special websites (34/308, 11.0%), to enable or improve communication (29/308, 9.4%; eg, by providing an easy-to-use interface that allows people with dementia to contact their relatives) [42], or to enhance the skills of people with dementia in particular (20/308, 6.5%). Skill improvement included abilities such as remembering, orientation, and movement. This involved games that increased cognitive performance [43] or interventions to improve mobility [44]. An equal share of technologies (12/308 each, 3.9%) wanted to support activities of daily life (eg, by...
guiding people with dementia in their activities [22,45] or improve engagement (eg through entertaining games [46]). “Other aims” were described for 12.3% (38/308) of the technologies. Overall, the objectives of the technologies were very broad. Due to the high complexity of technologies and the poor reporting, categorization of technology aims can only be based on the information provided by the studies. Therefore, the categories cannot be clearly distinguished from each other. In this context, caring tends to be a superficial main category, as many authors merely state an improvement in care provision as an aim, without describing in detail what the intervention specifically addressed in terms of needs.

A large percentage of the studies aimed to investigate the effects of the technology, either in terms of demonstrating effectiveness (85/233, 36.5%) or, more generally, by evaluating the assistive technologies (23/233, 9.9%). With regard to factors influencing intervention effects, few of the studies had the goal of measuring acceptance (16/233, 6.9%) or usability (23/233, 9.9%). In order to gain a first or deeper insight into the possible modes of action of the technologies, the minority were labelled as exploratory (22/233, 9.4%) or feasibility studies (31/233, 13.3%).

The objective of analyzing effects was similarly high in all studies regardless of the target group (people with dementia: 42/100, 42.0%; relatives: 33/84, 39%). The effectiveness was tested especially in studies in day care centers (17/26, 65%). Furthermore, many of the case studies pursued this aim (27/80, 34%). Case studies often examined the feasibility (13/80, 16%) or usability (11/80, 14%), or they were used for exploration (8/80, 10%). Feasibility, in turn, was given as the aim of the study in both target groups equally frequently (people with dementia: 13/100, 13%; relatives: 11/84, 13%). Many of these feasibility studies investigated technical interventions on computers, tablets, or laptops (21/31, 68%).

**Discussion**

Overall, this scoping review gives a comprehensive overview of the current literature and shows the diversity of assistive technologies for people with dementia and their family caregivers. There is a comparable amount of studies focusing on people with dementia as well as their caregivers. On the one hand, this demonstrates the increased availability of assistive technologies for informal caregivers; on the other hand, this demonstrates recognition of family members and people with dementia as consumers.

Many of the studies had the aim of demonstrating the effectiveness of the technology, although most of them were case studies with small sample sizes. This indicates that many of the technologies were rather rudimentarily tested, and only a very limited number of findings about effects or feasibility has been established, resulting in low confidence in the results. However, this seems odd, as usually a lot of financial and personal resources have to be invested in the development of a technology. Consequently, it would be reasonable to test them adequately. However, we acknowledge that it is difficult, especially for profit-oriented companies, to scientifically test the effectiveness of their developed technologies due to potential conflicts of interest. Evidence for the effectiveness of interventions through RCTs and controlled trials is more prevalent, although still limited, for telephones, robots, and internet courses. In total, a large proportion of studies was aimed at the technical evaluation, exploration, usability, or feasibility of an assistive technology. This indicates that many technologies for people with dementia and their informal carers are still in an early development stage. There is a need for larger studies of technologies’ effectiveness. A broad evidence base about the benefits and risks of technologies for users is crucial to promote their acceptance and therefore achieve a transition of technologies from research into the daily lives of people with dementia and their relatives [47]. Successful technology arrangements were often characterized by pragmatic adaptation and combination of new with old equipment by the people with dementia or their caregivers [48,49].

We found heterogeneous technologies in our review. Telephone interventions have been frequently analyzed. A major advantage of telephone interventions is that there is no need to purchase expensive technologies because existing resources can be used. Furthermore, the technology is already known, used, and therefore accepted by the users. This could have the advantage, especially for people with dementia, that they could still use this technology in a later phase of the illness without being challenged with learning something new. Hence, use in everyday life seems more easily compared to other technologies. Internet courses are low-threshold interventions that can provide timely education for caregivers and reduce stress [50]. Additionally, they are relatively low-cost developments compared to, for example, a robotic system. Robots, by contrast, are complex technologies that can provide support in many ways (eg, socioemotional support, taking over household tasks, guiding actions, or recognizing and intervening in changing or dangerous situations). As we stated before, one robotic system, called PARO, has been of great interest for researchers. Studies using PARO were mostly placed in nursing homes or day care centers and evaluated its effectiveness. Reviews, which specifically analyzed robots for older people with and without dementia, found positive but not always significant effects on behavioral and emotional aspects, quality of life, and communication [51-53].

In a large number of interventions, both target groups were involved (eg, in order to individualize the interaction between the technology and people with dementia, their family chose photos, music, or videos [38]). Few of the technologies were designed to involve both target groups with the aim of supporting their interaction or communication [54]. This again shows the variety of application areas regarding assistive technologies for people with dementia and their family caregivers. To ensure that results are generalizable, we suggest that future reviews analyzing the effectiveness of assistive technologies focus on a group of technologies that are similar regarding their technical components, aims, and target groups. Corresponding to the last step of the scoping review process model, the results of the scoping review were presented and discussed at 2 conferences in the form of a poster presentation and a lecture by experts in the field of health care research and practical care of people with dementia [55,56]. The main questions asked referred to the acceptance and adoption of the
technologies in the household. The topic of acceptance of the technologies is hardly represented in the studies. Studies referring to the fact that the users have accepted the technologies and integrated them into their households usually provided a detailed description of how this process took place and whether there were any facilitation efforts (eg, external support by the project team) or how the acceptance was determined. Studies that explicitly investigated acceptance measured the use of the technology, user attitude, user mood (eg, relaxed or joyful), or user satisfaction [37,57,58]. Cristancho-Lacroix et al [59] reported a lack of acceptance, which was measured using qualitative data. It remains unclear which specific aspects have a negative impact on acceptance. Few of the studies explicitly reported on challenges in using the technology or barriers to use [37]. Especially with the large number of case studies, we would have expected more detailed information regarding this issue. In addition, this information could be of importance in determining whether interventions can be recommended by health care professionals or so that people with dementia and their families can decide whether to use a technology. Based on the experts’ comments, we conclude that more and in-depth evidence is needed about the user acceptance of such technologies. Studies should be based on relevant theories such as the unified theory of acceptance and use of technology (UTAUT) [60], in order to gain meaningful and valid results with regard to the implementation. Specific concepts like the non-adoption, abandonment, scale-up, spread, sustainability (NASSS) framework can be helpful to evaluate factors influencing the adoption of technologies in order to plan an effective implementation [61]. It also requires industry and service providers to take a user-centric approach to design and deployment [62]. People with dementia and their caregivers identified clear information pathways for assistive technologies as essential for both service providers and service commissioners [63].

Due to the exploratory nature of the scoping review, it has to be considered that studies may have been overlooked despite the broad search because of the restrictions in databases, languages, and period of time. Because of the broad research question and heterogeneous study situation, a more in-depth analysis of specific technologies was not suitable. Furthermore, studies whose results did not demonstrate acceptance or positive outcomes may not have been published (publication bias). A particular difficulty arose in extracting data from studies and classifying technologies due to the poor reporting of the studies. This was especially prevalent for the methodological approach of the studies, description of the users, and use of the assistive technologies. In contrast, these studies focused more on technical aspects of the technologies, such as the design of an interface or data streams of systems. We still included studies with a focus on technical aspects when they reported how the technology was tested, because that was of particular interest in our review. In these cases, it was also more difficult to determine the purpose of the technology. Therefore, these were categorized based on the authors’ explanations. A standardized description of the technologies using the CONSORT EHEALTH [64] or the TIDieR [65] checklist could contribute to a better understanding. In addition, the user group of people with dementia was insufficiently described in some cases. This refers to the existence of a concrete diagnosis of dementia and its testing, form of dementia, and symptoms of the disease, especially with regard to communication skills. Some participants were described as having dementia, but in the testing of cognitive abilities, they only showed limitations in the area of mild cognitive impairment. This makes it difficult to identify relevant studies and assess the transferability of study results.

Overall, there is great diversity in assistive technologies for people with dementia and their family caregivers. This becomes particularly clear when analyzing the different types of technologies and their purposes. One advantage of this diversity is that different technologies can address different problems and needs. Thus, the repertoire for the solution of these different problems is extended by technical interventions. This gives people with dementia, their relatives, and health care professionals more options for tailoring care arrangements to their needs. On the other hand, the diversity of technologies makes it more difficult for end users in particular to gain an overview of existing possibilities. This is especially true when technologies are developed for a broad group of users (eg, elderly people or people with cognitive disabilities). Here, it is even more complicated to decide on the appropriateness of the application of a specific assistive technology in a specific case. This results in the necessity of a user-oriented database to inform potential users about the available technologies. We recommend that the database includes various information of the technology, such as specific target group, aims, effectiveness, and user experiences. Therefore, an analysis of the users’ informational needs would be beneficial. Furthermore, there is a major need for well-developed and tested interventions. This includes the measurement of not only (health) care outcomes but also feasibility and acceptability. Participatory design and development processes have to be implemented to fulfill the needs as well as acceptability, usability, and ethical issues of future users [23,66,67]. It is possible that case studies have remained at this level of research with no apparent follow-up projects because only low acceptance or effects have been identified. At the same time, there is a broad need for (1) technologies to assist people with dementia in several areas, (2) identification of the characteristics these technologies should have based on the users’ needs, and (3) information on these technologies that is required by the users [68]. We believe that this scoping review can contribute to further guide research on assistive technologies for people with dementia and their family caregivers.

Acknowledgments

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Authors' Contributions
CD and SP conceptualized the study. SN developed the search strategy and conducted the search. AS and SP conducted the screening, data extraction, and data analysis. SN was the third rater during the screening. CD and SP interpreted the data. SP wrote the first manuscript draft. AS, CD, CK, ET, GE, SK, SN, SP, and TG revised the manuscript.

Conflicts of Interest
None declared.

Multimedia Appendix 1
Search strategy for MEDLINE.
[DOCX File, 12 KB - aging_v4i1e25307_app1.docx]

Multimedia Appendix 2
Study details—people with dementia.
[DOCX File, 64 KB - aging_v4i1e25307_app2.docx]

Multimedia Appendix 3
Study details—informal carers.
[DOCX File, 61 KB - aging_v4i1e25307_app3.docx]

Multimedia Appendix 4
Study details—both target groups.
[DOCX File, 39 KB - aging_v4i1e25307_app4.docx]

References


Abbreviations

- NASSS: non-adoption, abandonment, scale-up, spread, sustainability
- PRESS: Peer Review of Electronic Search Strategies
- PRISMA-ScR: Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews
- RCT: randomized controlled trial
- UTAUT: Unified theory of acceptance and use of technology
Understanding Technology Preferences and Requirements for Health Information Technologies Designed to Improve and Maintain the Mental Health and Well-Being of Older Adults: Participatory Design Study

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Abstract

Background: Worldwide, the population is aging rapidly; therefore, there is a growing interest in strategies to support and maintain health and well-being in later life. Although familiarity with technology and digital literacy are increasing among this group, some older adults still lack confidence in their ability to use web-based technologies. In addition, age-related changes in cognition, vision, hearing, and perception may be barriers to adoption and highlight the need for digital tools developed specifically to meet the unique needs of older adults.

Objective: The aim of this study is to understand the use of technology by older adults in general and identify the potential barriers to and facilitators of the adoption of health information technologies (HITs) to support the health and well-being of older adults to facilitate implementation and promote user uptake. In addition, this study aims to co-design and configure the InnoWell Platform, a digital tool designed to facilitate better outcomes for people seeking mental health services, to meet the needs of adults 50 years and older and their supportive others (eg, family members, caregivers) to ensure the accessibility, engagement, and appropriateness of the technology.

Methods: Participants were adults 50 years and older and those who self-identified as a supportive other (eg, family member, caregiver). Participants were invited to participate in a 3-hour participatory design workshop using a variety of methods, including prompted discussion, creation of descriptive artifacts, and group-based development of user journeys.

Results: Four participatory design workshops were conducted, including a total of 21 participants, each attending a single workshop. Technology use was prevalent, with a preference indicated for smartphones and computers. Factors facilitating the adoption of HITs included personalization of content and functionality to meet and be responsive to a consumer's needs, access to up-to-date information from reputable sources, and integration with standard care practices to support the relationship with health professionals. Concerns regarding data privacy and security were the primary barriers to the use of technology to support mental health and well-being.

Conclusions: Although HITs have the potential to improve access to cost-effective and low-intensity interventions at scale for improving and maintaining mental health and well-being, several strategies may improve the uptake and efficacy of technologies by the older adult community, including the use of co-design methodologies to ensure usability, acceptability, and appropriateness of the technology; support in using and understanding the clinical applications of the technology by a digital navigator; and ready availability of education and training materials.

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https://aging.jmir.org/2021/1/e21461
KEYWORDS
aging; mental health; technology; mobile phone; community-based participatory research; health care reform; stakeholder participation

Introduction

Strategies for Healthy Aging
The global population is aging rapidly. Within the next 40 years in Australia, for example, one-third of the population will be aged 50-65 years and a further quarter will be 65 years and older [1]. The economy will require a level of productivity from these people not previously seen. As such, there is a growing interest in strategies for supporting and maintaining health and well-being in later life to improve the social and economic participation of older adults to meet the demands of an aging society [2]. Efforts aimed at optimizing mental health and well-being are important contributors to achieving this mission.

Internet Use Among Older Adults
The international literature indicates that approximately two-thirds of adults aged 65 years and older report internet use [3,4], and these older adults also represent the fastest-growing group of internet users [5]. Thus, using health information technologies (HITs) for mental health screening, intervention delivery, and routine outcome monitoring will be an increasingly viable option for older adults globally. The increase in internet use among this population has spurred a growing interest in the development and implementation of HITs for improved health and well-being for older adults [6-8].

HITs
HITs are being developed rapidly for improving the delivery of mental health care for both consumers and health professionals and for facilitating improved self-management of care [9]. To that end, HITs have been shown to be effective for the management and treatment of symptoms in a range of mental health and medical conditions, including depression [10-12], diabetes [13], weight loss [14], problematic alcohol use [15], sleep [16], exercise [17], and social connectedness [18]. Barring some exceptions, including a diet diary app for older adults with age-related macular degeneration [19], few HITs have been designed specifically with older adults in mind. As such, this represents a largely untapped market for potential web-based tools to improve the health and well-being of older adults.

Importantly, in a study of older adults (N=221) presenting to a specialized memory clinic for concerns regarding new-onset cognitive decline and/or mood symptoms, most participants (198/209, 94.6%) reported that they would find it useful to be able to access a website designed to support healthy aging, including physical health and cognition, self-management of existing conditions, and routine tracking of changes in health outcomes over time. Similarly, most respondents also reported interest in a website designed to specifically measure mood-related concerns and changes (172/206, 83.5%) [20]. Despite having interest in and motivation to use HITs to improve their health and well-being [20,21], some older adults still lack confidence in their ability to use web-based technologies [22,23]. It has been demonstrated that older adults will only adopt new technologies when their apparent usefulness and usability outweigh concerns related to technological complexity and decreased social connection [24]. In light of these factors and age-related changes in cognition, vision, hearing, and perception, it is critical that HITs be tailored to the older adult community, taking into consideration their unique needs as users.

Participatory Design
Using strategies to enhance community and consumer acceptability, usability and engagement with HITs is a priority in the health, medical, and research sectors internationally [25,26]. To this end, co-design methodologies, including participatory design and user testing, are widely recognized as key to ensuring the quality, usability, and acceptability of HITs for specific user groups—in this case, older adults. Research has shown that the active participation of all stakeholders throughout the design of technical systems and services helps ensure that the end product meets the needs of its intended user base, improves usability, and increases engagement of all individuals [27-29]. Importantly, there is an emerging evidence base reflecting the benefits of co-design with older adults, including those with dementia, and their family and caregivers, to enable strengths-based, person-centered care [30,31]. Our research team’s established co-design methodologies explicitly position users as empowered participants in all stages from design and development through to implementation and impact evaluation [28,29,32,33].

The InnoWell Platform
In 2017, the Australian Government Department of Health and InnoWell Pty Ltd (a joint venture between the University of Sydney and PwC, Australia) entered into a 3-year funding agreement to deliver Project Synergy (2017-2020), a series of collaborative research trials with the specific purpose of co-designing and implementing innovative HIT solutions, including the InnoWell Platform, to enable improved mental health service delivery in Australia, facilitating better outcomes for people with lived experience, supportive others, health professionals, and service providers [9]. As described in detail by Davenport et al [34], the co-designed InnoWell Platform was developed through Project Synergy (by InnoWell) to collect information from multiple sources to formulate a comprehensive understanding of a consumer’s needs and to monitor their progress over time. These sources comprise web-based, self-reported questionnaires assessing a range of health domains (ie, psychological distress, suicidal thoughts and/or behaviors, daily functioning, depressed mood, cognition, sleep-wake cycle, social connectedness) from both consumers and their health professionals and objective behavioral data collected via third-party integrations (eg, Fitbit trackers). The multifaceted and multidimensional assessment results are designed to be understandable directly by consumers and to be reviewed in collaboration with their health professional to promote shared decision making and collaborative care and to facilitate routine
outcome monitoring, clinical review, and coordinated care to ensure that all consumers receive the right care first time.

Objectives

We now aim to customize and configure the InnoWell Platform to meet the needs of an older age group (50 years and older) and their supportive others (eg, family members, caregivers) to ensure the accessibility, engagement, and appropriateness of the technology. We defined older adults as those aged 50 years and older as this aligns with our previous work investigating technology use and preferences among this group [20]. Furthermore, the age of 50 years relates to the onset of disorders in later life [35] and the identified age range during which it is recommended to address risk factors (ie, cardiovascular disease, obesity, diabetes) known to undermine healthy aging [36]. Furthermore, we seek to understand the potential barriers and facilitators of HIT use for older adults to better identify and understand ways to promote adoption and facilitate successful implementation.

Methods

Participants

This study aimed to recruit up to 50 participants, including a combination of older adults and their supportive others. The inclusion criteria for participation in the study required participants to be aged 50 years and older or self-identify as a supportive other (eg, family member, caregiver), to be proficient in English, and to have completed the required informed consent process.

Recruitment Strategies

This study was advertised through the University of Sydney’s Brain and Mind Centre, including through active research clinics working with older adults and via nongovernmental (ie, Dementia Australia) and private organizations (ie, InnoWell) associated with the Brain and Mind Centre. The recruitment strategy included the use of postcards and A3/A4 posters in both paper-based and digital forms, depending on the preference of the advertising site (eg, poster displays, postcards at reception, posting the digital advertisements on the research sites and social media pages).

To avoid any perceived coercion, recruitment was passive such that a potential participant needed to contact the senior research health professional (HL) who, only on a potential participant’s request, then forwarded the study Participant Information Sheet and Consent Form. All participants were provided with detailed information about the study both before attending a participatory design workshop and again on arrival at the workshop. At the beginning of each workshop, the facilitators provided the participants with an opportunity to ask questions and clarify details of the research before providing written informed consent. Potential participants were reminded that participation was entirely voluntary and that if they agreed to participate, they could withdraw their consent at any time without being required to provide any reasons and with no impact on their relationship with the University of Sydney, the Brain and Mind Centre, InnoWell, or the participating clinics through which they were recruited.

Participatory Design Workshops

A series of 4 group-based workshops of approximately 3-hour duration, each with up to 10 participants, were conducted with older adult stakeholders to discover, evaluate, and prototype acceptable design solutions for the InnoWell Platform. These sessions involved an iterative knowledge translation process so that initially generated ideas can be further developed (and fed back on) by participants in subsequent workshops (Multimedia Appendix 1 presents a sample agenda). All workshops were coordinated by 2 facilitators (one of whom was a health professional) and a scribe was present to take detailed notes. Two facilitators were considered important; the first facilitator guided the research questions and session plan, and the second facilitator ensured that all participants’ voices were heard within the workshop.

As in our previous co-design research [29], the facilitators used a variety of methods within the workshops, including prompted discussion, prototyping, creation of descriptive artifacts, and group-based development of user journeys (a series of steps illustrating how an individual might interact with the prototype). It is important to note that the InnoWell Platform is being designed and developed iteratively; therefore, although a version of the InnoWell Platform has been built, the participants were not exposed to the technology as part of the workshops to avoid bias in their thinking. As such, a blue sky approach (ie, brainstorming without limitations or practical constraints) was used for prototyping to ensure that the necessary features and functionality that may be unique to the older adult community were captured. On the basis of previous studies exploring the use of technology for health-related purposes by older adults [4,24,37,38], a number of critical areas were explored, including (1) preferred devices, (2) common uses of technology, (3) use of technology to support health and well-being, (4) features or functionality that promote user engagement, (5) interest in and preferences for digital health services, and (6) concerns related to data privacy and confidentiality.

Data Analysis

Interpretation of the qualitative data from the workshops, including scribe notes and artifacts, followed established thematic techniques [39]. All raw data were reviewed and checked across all participants by a senior research health professional (HL), and a coding framework outlining all key concepts was developed. Data were coded in NVivo 12 software (QSR International) using this framework. The coding followed an established iterative process of reading, coding, and exploring the pattern and content of coded data, followed by reflection and discussion. Similarities and differences in opinion were examined, and differences were dealt with through discussion to reach consensus. Coding was conducted initially by the senior research health professional (HL) and a randomly selected subsample of 10% was checked for inter-rater reliability by a research officer (AR); agreement was substantial (κ=0.631) [40]. In alignment with the topics explored in the participatory design workshops, themes were then organized as follows: (1) preferred device; (2) well-being as a concept; (3) barriers to and facilitators of technology use generally; and (4) barriers to and facilitators of technology use to support mental health and...
well-being, including a prototype of the InnoWell Platform configured for older adults. All themes were checked against each other and back to the original data to ensure that all relevant references had been collated. This process resulted in a thematic framework that was internally coherent and consistent.

Ethics
This research study was approved by the University of Sydney’s Human Research Ethics Committee (Project No. 2019/172).

Results

Demographics
A total of 4 participatory design workshops (all 3 hours in duration) were held between September and November 2019. The aim of each workshop was to actively engage the older adult community in discussions about how technology may be used to promote mental health and maintain well-being. A total of 21 adults (43% female) aged 50 years and older attended the workshops, 2 of whom also identified as supportive others. All participants attended only one workshop. Although the sample size was smaller than planned, the richness of the data and the consistency of the themes indicated that we had reached saturation. To ensure participant confidentiality, further demographic details were not collected as part of this study. No participants expressed concern about or experienced any distress in any of the workshops.

Technology Preferences
When asked What is your favorite piece of technology, participants reported a range of preferences, including computers, tablets, eBook readers, basic mobile phones, wearables, and televisions. However, the smartphone was the most frequently referenced device (Textbox 1) for several reported reasons:

- my phone is always on...used for a lot of functional things—news, transport, a lot of informational things. [Workshop 1]
- I read the paper on my phone. [Workshop 2]
- ...to stay connected. [Workshop 4]
- I use notes a lot for writing poetry. [Workshop 4]

Computers were also referenced frequently as a preferred device because of the diversity of available functionality, such as “creative work...music...Photoshop,” “YouTube extreme sports...puts you in places you’ve never been...online shopping,” “use it for music composition and practice,” and “love using YouTube...added value for my work” (all from Workshop 1).

Tablets were largely referenced in relation to games and ease of access to information (ie, news, politics, sports). However, there was an indication that smartphones, tablets, and computers were used interchangeably for the purpose of accessing the internet, with 1 participant noting:

- It’s all the same to me...if I’m out it’s the phone, at home it’s the tablet or phone. [Workshop 4]

Participants also referenced the use of apps and e-tools both in relation to entertainment, for example, Spotify for “access to music...listen to podcasts” (Workshop 1) and to support health and well-being, including “Headspace app for meditation...keeping in contact with kids through various apps” (Workshop 3); “Lumosity...I had to wean myself off it...I was becoming competitive with it and couldn’t get to sleep” (Workshop 3); and “family history and that’s a real brain teaser to follow different leads...it’s very complex and good for the brain” (Workshop 3).

Textbox 1. Codes related to technology preferences theme (63 references).

<table>
<thead>
<tr>
<th>Preferred devices used by older adults include:</th>
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<tbody>
<tr>
<td>• Smartphone (18 references)</td>
</tr>
<tr>
<td>• Computer (15 references)</td>
</tr>
<tr>
<td>• Apps and e-tools (10 references)</td>
</tr>
<tr>
<td>• Tablet (9 references)</td>
</tr>
<tr>
<td>• Basic mobile phone (3 references)</td>
</tr>
<tr>
<td>• eBook readers (3 references)</td>
</tr>
<tr>
<td>• Wearables (3 references)</td>
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<tr>
<td>• Television (2 references)</td>
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</table>

Well-Being
As shown in Textbox 2, two primary themes emerged from the discussions about well-being, with concepts being referenced more frequently than strategies. In relation to the former, references to health and functional capacity were the most common. Participants consistently characterized well-being as a holistic combination of mental and physical health, with one stating:

- It’s not just the absence of sickness but capacity to do what you want with your body, such as reach maximum heart rate...the presence of strength...feeling good. [Workshop 3]

There were also several references to self-awareness and acceptance, noting that well-being relates to “relationship to yourself or with others” (Workshop 1) and “my own state of mind” (Workshop 2); well-being was conceptualized as being “personal to you...for example, someone immobile for life could still have well-being” (Workshop 3).
Although referenced less frequently, participants indicated that well-being also relates to safety (ie, “feeling good and feeling safe” [Workshop 3]), social connectedness (ie, “connection to people” [Workshop 1]), and resilience or the ability to “move through” (Workshop 3) challenging events. Although there was consensus as to the conceptualization of well-being, some participants indicated that the term had become a buzz word (Workshop 2) used for marketing purposes. In addition, it was noted that well-being can be negatively impacted by stigma, as 1 participant stated:

Those who struggle most with stigma are those with mental health issues...frustrated by telling their story over and over. [Workshop 3]

Several strategies to promote or maintain well-being were referenced with similar frequency, including leisure activities, such as a break from work (Workshop 2) and a massage (Workshop 3) and diet and exercise (Workshop 2). Although some participants referenced the importance of social connectedness (Workshop 2), others indicated a need for self-reliance, noting:

I’d manage it myself, wouldn’t want to burden other people. [Workshop 2]

Finally, there were mixed responses regarding the value of information and tips, with 1 participant noting:

A friend who worked in arthritis research used to send me information and I trusted it. [Workshop 2]

Another stated:

I wouldn’t be interested in daily tips. [Workshop 2]

Textbox 2. Codes related to well-being theme (48 references).

<table>
<thead>
<tr>
<th>Concepts (37 references)</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Health and functional capacity (15 references)</td>
</tr>
<tr>
<td>• Self-awareness and acceptance (10 references)</td>
</tr>
<tr>
<td>• Marketing purposes (3 references)</td>
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<tr>
<td>• Social connectedness (3 references)</td>
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<td>• Resilience (2 references)</td>
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<td>• Safety (2 references)</td>
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<tr>
<th>Strategies (11 references)</th>
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<tr>
<td>• Leisure activities (3 references)</td>
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<td>• Diet and exercise (2 references)</td>
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<tr>
<td>• Information and tips (2 references)</td>
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<tr>
<td>• Self-reliance (2 references)</td>
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<tr>
<td>• Social connectedness (2 references)</td>
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Barriers to and Facilitators of Technology Use

When discussing the use and impact of technology in daily life, two primary themes emerged—barriers and facilitators (Textbox 3), with the latter being referenced with greater frequency. In particular, social connectedness was one of the primary ways in which participants were making use of technology, with participants commenting:

Technology is my communication...email and text are important for me to keep in touch. [Workshop 2]

It’s a huge difference to me with three children who live in the US. [Workshop 3]

Skype/FaceTime with family makes you feel connected. [Workshop 3]

It creates easier, less formal contact with friends. [Workshop 3]

Interestingly, the potential for technology to drive social disconnection and miscommunication was noted as a potential barrier as a participant stated:

It worries me that young people don’t know a life without a screen...they don’t know how to connect without an app. [Workshop 3]

One participant questioned:

Why don’t you just call...there can be miscommunication with texting. [Workshop 1]

Furthermore, it was also agreed that connecting via technology is not equivalent to in-person. One participant commented:

I know I can do it on the computer, but I enjoy the contact...it’s having a human element. [Workshop 3]

Another stated:

If I can do it as a video, then I can see my grandchildren...but I can’t have a hug. [Workshop 3]

Games, such as “Word with Friends...Candy Crush...Bridge” (Workshop 4) and “Spider Solitaire” (Workshop 4) and information and new learning were also frequent uses of technology, including references to websites related to news and travel and “YouTube…gives you video tutorials” (Workshop 3).

It’s a huge difference to me with three children who live in the US. [Workshop 3]

Skype/FaceTime with family makes you feel connected. [Workshop 3]

It creates easier, less formal contact with friends. [Workshop 3]
Although participants indicated that the ease of access to information was a facilitator to technology use, noting, “You can’t beat Wikipedia for instant information about anything” (Workshop 1), it was also highlighted that this changes the way we think. For example, in relation to the consumption of media, one participant stated:

The way I read and get information now is much more snapshot rather than long form journalism. [Workshop 1]

Another participant noted:

Problem-solving is lacking as you can just tap on a screen and get information...they don’t question whether it’s the right information. [Workshop 3]

In relation to the latter, participants indicated that the credibility of the source was important when using the internet or web-based tools. Information produced by the government, reputable health organizations, universities and academics, and individuals with higher degrees or qualifications were more likely to be perceived as trustworthy and reliable. At the same time, however, the potential for misinformation and limited detail was referenced, with some skepticism expressed about news sources, including:

We’re in the age of misinformation, they don’t want us to know the truth. [Workshop 1]

If you can get someone to click on a headline, that’s more valuable than relating it to the article. [Workshop 1]

In addition, 1 participant referenced security concerns in relation to web-based data sharing, stating:

Anything on the Internet I just don’t really trust, I don’t want to put my information of any kind out there. [Workshop 2]

The potential anxiety-provoking nature of technology was referenced, albeit infrequently, with a participant commenting:

My older friends get anxious if something goes wrong and they don’t know how to fix it...they aren’t feeling confident. [Workshop 3]

Digital literacy was characterized as a skill:

You have to learn it, like anything else. [Workshop 3]

Finally, work requirements were noted as a driver of technology use, whereas lack of interest was a barrier.

Textbox 3. Codes related to barriers and facilitators to technology use theme (63 references).

<table>
<thead>
<tr>
<th>Barriers (28 references)</th>
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<tbody>
<tr>
<td>• Changes the way we think (9 references)</td>
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<tr>
<td>• Misinformation and limited detail (8 references)</td>
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<tr>
<td>• Social disconnection and miscommunication (4 references)</td>
</tr>
<tr>
<td>• Not equivalent to in-person (3 references)</td>
</tr>
<tr>
<td>• Anxiety (2 references)</td>
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<tr>
<td>• Lack of interest (1 reference)</td>
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<td>• Security concerns (1 reference)</td>
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<table>
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<tr>
<th>Facilitators (35 references)</th>
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<tbody>
<tr>
<td>• Social connectedness (13 references)</td>
</tr>
<tr>
<td>• Games (6 references)</td>
</tr>
<tr>
<td>• Information and new learning (6 references)</td>
</tr>
<tr>
<td>• Credibility of the source (4 references)</td>
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<tr>
<td>• Ease of access (4 references)</td>
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<tr>
<td>• Work requirements (2 references)</td>
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HIT Use

As shown in Textbox 4, barriers and facilitators again emerged as the primary themes when discussing the use of technology specifically for health-related purposes and co-designing a prototype of the InnoWell Platform for older adults. Access to information was the primary facilitator referenced, in relation to being able either to read up on a problem and present that to doctors (Workshop 1) or to go back to the internet to take the time to review and be critical of information discussed in an appointment with a health professional (Workshop 1). Although HITs are not equivalent to in-person care, that is, “Need face-to-face to establish trust for subsequent phone or emails...you feel you know the person” (Workshop 1), it was noted that they provide improved access to care. For example, the convenience, that is, “face-to-face is best, but over the phone is convenient” (Workshop 1) and anonymity afforded by technology may “be a good thing for people suffering mental health...if it was face-to-face or someone they knew they would be less likely to do it at all” (Workshop 3). Whether the technology was endorsed by a health professional or endorsed by a family member or friend were noted facilitators of HIT adoption and engagement, with participants indicating they...
would use it if “recommended...by my doctor” (Workshop 2) or “a certain friend or family member” (Workshop 2).

It was recognized that the ability for technologies to be integrated with health care increases the transparency in care:

...the doctor used to just have it, now you have it on your computer...you have all your health information at your fingertips. [Workshop 4]

In addition, it affords the opportunity for coordinated care, allowing shared information between treating health professionals. One participant stated:

I see it as a total package, it’s just part of your wellbeing. My different medical people should know if I have a heart issue or if I’m seeing a psychologist. [Workshop 2]

As a caveat, ownership and personal choice with data provides consumers with the option “to decide who can see what and which doctors have access” (Workshop 4). Security concerns were referenced as the primary barrier to HIT use, with concerns noted to include “once your email is connected, essentially hackers could get a lot” (Workshop 4), “not getting jobs...not getting insurance” (Workshop 3), and “people will target you with products based on information gathered” (Workshop 3).

From a technical perspective, user experience and customization were referenced as facilitators of use. Data tracking was also an attractive feature, including the ability to track physical activity and weight loss using apps such as MyFitnessPal and via wearables (ie, Fitbit). In addition, competition is a potential driver for technology use. For example, 1 participant commented:

...subscribed to Lumosity for about a year...it was lots of fun...tried to improve my score to be in the top percentile for my age group. [Workshop 2]

However, the potential for misuse was also identified as “over-notifications could feel like bullying” (Workshop 1) or result in an “obsession with the data” by users (Workshop 1). Data entry and tracking requirements were also viewed as a potential barrier to use, as it “might be another stressor for some people” (Workshop 3), particularly “once they are unwell” (Workshop 3).

Although not raised as a personal concern by any of the participants, limitations in digital literacy was referenced as a potential barrier as it was noted that:

...technology is not usable by a lot people in my generation...at the moment there is a generational cut-off. [Workshop 4]

In addition, lack of interest in HITs, including how they work, may also reduce uptake.
**Textbox 4.** Codes related to technology use to support health and well-being theme (308 references).

### Barriers (57 references)
- Security concerns (18 references)
- Lacks credibility of health professional (10 references)
- Not equivalent to in-person care (10 references)
- Potential for data misuse (9 references)
- Data entry and tracking requirements (8 references)
- Lack of interest (7 references)
- Digital literacy (1 reference)

### Facilitators (59 references)
- Information (13 references)
- Data tracking (10 references)
- Access to care (8 references)
- Endorsed by health professionals (7 references)
- Coordinated care (5 references)
- Integrated with health care (5 references)
- User experience and customization (3 references)
- Ownership and personal choice with data (3 references)
- Competition (3 references)
- Endorsed by a family member or a friend (2 references)

### Prototype features and functions for a digital platform customized for older adults (192 references)
- Barriers (34 references)
  - Impersonal and social disconnection (5 references)
  - Lacks credibility of health professional (5 references)
  - Privacy and security risks (5 references)
  - Competition (4 references)
  - Limitations and potential errors (4 references)
  - Anxiety about seeking help (2 references)
  - Digital literacy (2 references)
  - Generic information (2 references)
  - Misinterpretation of information (2 references)
  - Requirements for use (2 references)
- Facilitators (158 references)
  - Personalization (32 references)
  - Information and resources (15 references)
  - Interoperability and data tracking (13 references)
  - Credible source or endorsed by health professional (12 references)
  - Interaction with health system (12 references)
  - Prevention and risk reduction (11 references)
  - Access (10 references)
  - Recommendations and interventions (10 references)
  - Anonymity (8 references)
  - Goal setting (6 references)
Prototyping the InnoWell Platform for Older Adults

Building on the foundation of their experiences with health care systems and technology generally and HITs specifically, participants co-designed a prototype of the InnoWell Platform for older adults, identifying features and functionality that would be barriers to and facilitators of adoption and implementation. Importantly, facilitators were referenced far more frequently than barriers, potentially reflecting the interest in and increasing use of technologies to support health and well-being. The primary driver for use was personalization (ie, a tool that is designed to meet a consumer’s requirements and that responds to the data entered by a consumer to meet a consumer’s needs) as participants noted:

-I can see a clear use...someone wakes up and feels bad or experiences a new symptom...they go on this software and it give them some triage to start with. [Workshop 1]

...questions about you and your situation...sends you off to areas of the site that could be useful. [Workshop 3]

It could be like a referral service to send you in the right direction. [Workshop 3]

Interoperability (ie, the ability of the digital tool to exchange information with other technologies such as apps and wearables) and data tracking were identified as factors that may facilitate personalization. For example, one participant stated they would:

-be able to input data about my arthritis, pain levels, tracking what’s happening with my fingers...I assume it would give me lots of information, things to do...take some ownership of my tracking. [Workshop 2]

Interestingly, the need for personalization was coupled with a desire for anonymity. It was suggested that the user “could create a username” (Workshop 1), with participants agreeing that “the information going in is so sensitive that I would only do it anonymously” (Workshop 1). Furthermore, the ability to store health information in a personal data record, that is, “it knows all my background” (Workshop 3) was valued by participants. However, it is important to note that privacy and security risks were frequently referenced barriers as cybersecurity was characterized as “an arms race...people employed in security are constantly trying to stay in front of the hackers” (Workshop 1).

The ability to find up to date information and resources was also referenced as a facilitator of use—a place to ask “those silly questions you just can’t ask in an intimidating environment” (Workshop 2) and gain better understanding of “what to tell your [general practitioner] GP...teaching you the things you need to tell your specialist” (Workshop 2). However, there was some concern that the misinterpretation of information might be a barrier, recognizing a “risk of creating a device that leads people to self-diagnosing” (Workshop 2) and that generic information may not have much benefit if it is “not personalised” (Workshop 3) and “only answers a silly little thing” (Workshop 3).

Participants wanted there to be an interaction with health care, potentially as a “referral to a specialist” (Workshop 1), a way to “fast track the system...direct you to service” (Workshop 1), or a tool to enhance the care provided by a health professional, that is, “If I brought it in and showed it to her, she’d probably work collaboratively with me.” (Workshop 2). Recommendations and interventions were also a desired feature, with ideas including “interventions to do balance exercises” (Workshop 1), “video training about how to do a guided [meditation] session” (Workshop 3), and “virtual group sessions” (Workshop 3). However, the potential for error was cited as it was recognized that there is an inherent “risk with assuming that feeding information in means the outcomes will be right” (Workshop 1). Figure 1 reflects one participant’s conceptualization of how he or she might use this type of tool. By inputting information about current symptoms and desired services or activities, the digital tool would then provide tailored recommendations.

Participants indicated that they would be more likely to use this type of tool if it came from a credible source or was endorsed by health professionals, highlighting the need for the content to be “developed by an organisation that is already trusted” (Workshop 2). Similarly, a digital tool was viewed to lack the credibility of a health professional, thereby potentially preventing use as participants were not interested in “replacing GPs or specialists” (Workshop 2). The potential for a digital tool to be impersonal was also referenced as a barrier, particularly for older adults who “could be more isolated...need someone that cares...the connection is still important” (Workshop 1). Figure 2 presents a hypothesized user journey created by participants, highlighting the way in which they would use the prototype of the digital tool, including the information that they would input to personalize the results, the manner in which a health professional could make use of that information to coordinate care, and the support provided via the digital tool.

<table>
<thead>
<tr>
<th>Concept</th>
<th>References</th>
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<tbody>
<tr>
<td>Personal data record</td>
<td>6 references</td>
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<tr>
<td>Education and training</td>
<td>5 references</td>
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<tr>
<td>Empowering</td>
<td>5 references</td>
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<tr>
<td>Social connection and support</td>
<td>5 references</td>
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<tr>
<td>Diagnosis</td>
<td>2 references</td>
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<tr>
<td>Supportive other functionality</td>
<td>2 references</td>
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<tr>
<td>User experience and design</td>
<td>2 references</td>
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Although there was minimal reference to the need for the tool to be able to provide a user with a *diagnosis*, participants reported an interest in *prevention and risk reduction* or “something that would keep me away from the doctor...preventative but also health generative...keeps you healthy and active” (*Workshop 1*). **Goal setting** was a potential motivator of use, with participants noting that users “would establish goals after going through a level of entering information” (*Workshop 1*) and recognizing that “goals could change as you go through” (*Workshop 1*). On the other hand, **competition** was referenced as “demotivating...don’t want people to fail and say I won’t look at that again” (*Workshop 1*) and “a huge problem...a goal isn’t a goal unless there’s a success or failure measured” (*Workshop 1*).

It was widely recognized that a digital tool has the potential to improve **access** to health care, particularly for individuals in remote areas where “distance becomes a disability” (*Workshop 1*). Empowering users was also referenced as an important component, with a need for a strength-based approach because “older people are told you can’t do that anymore...celebrate what they are doing” (*Workshop 1*). Although referenced infrequently, participants indicated *that they were more likely to use a digital tool that had a good user experience and design.* Furthermore, it was recommended that users would benefit from education and training resources, “information on how to use it – a tutorial or mind map...give people an idea of what kind of help they could get” (*Workshop 3*). This may be particularly relevant for older adults with poor digital literacy as “people will always be left out if it is on a computer” (*Workshop 1*) or for those who experience anxiety related to help seeking, where the technology should not be “too daunting” (*Workshop 1*). However, neither of these barriers were reported to be personal concerns for the participants.

**Figure 1.** App prototype of a digital tool to support health and well-being.
Discussion

Technology Use by Older Adults

Our results align with previous findings that older adults routinely engage with a range of technologies, including computers, mobile phones, eBook readers, and tablets. Importantly, the preference for smartphones highlights a change in device use among older adults. Although previous studies have found that the use of home computers was nearly universal in a sample of older adults (93%), the use of smartphones was far less frequent (52%) [20]. The present results emphasize the rapid growth in smartphone ownership among older adults in recent years and the effect of aging [41], with younger people with greater digital literacy and experience with technology moving into the older age group. For example, among Americans aged 65 years and older, ownership of smartphones increased from 23% in 2013 to 42% in 2016 [4]. It is important to recognize that device adoption varies considerably with age, education, and household income. The proportion of older adults who own a smartphone or tablet is markedly higher for those aged 65 to 69 years (59% and 41%, respectively) relative to those aged 75 to 79 years (31% and 28%, respectively) [4]. Similarly, individuals with higher levels of education (a bachelor’s degree or beyond) are significantly more likely to have a computer and/or smartphone [20]. As such, consideration of the digital divide is crucial when considering technology use among older adults, as there may be barriers to access (eg, internet, smartphone) that preclude their engagement with web-based tools, including for, but not limited to, information and entertainment purposes and for the purposes of improving and maintaining health and well-being.

Components of and Strategies to Support Well-Being

Participants generally conceptualized well-being as an absence of illness (ie, feeling healthy) and the capacity to fulfill one’s goals and carry out activities of one’s choice. However, there was also recognition that illness or disability and well-being are not mutually exclusive; rather, there is a need for personal awareness and acceptance of self. The fulfillment of basic life needs, namely, safety in one’s surroundings, connection to others, and resilience (ie, the ability to bounce back in the face of stressful events) were also referenced. Importantly, participants noted that stigma can detract from well-being as it may be a barrier to seeking and accessing help for mental health problems. The factors of well-being identified by participants align with the 6 components of the Ryff model of psychological well-being [42], which includes self-acceptance, mastery of the environment, autonomy, positive relationships, personal growth, and life purpose. Our results highlight the consistency of views on psychological well-being among older adults over more than 30 years and, importantly, suggest these are key targets for health-related interventions.

Several strategies to promote and maintain well-being were referenced equally, including maintaining a healthy diet and exercising regularly, engaging in leisure activities, and making use of health-related information and tips. Consistent with the recognition that social connectedness is a key determinant of health [43,44], participants agreed that social connectedness is an important component of well-being. However, this was balanced with a need to be self-reliant in maintaining one’s well-being so as not to burden others. HITs have the potential to provide low-cost intervention and prevention tools that are designed specifically to target components of well-being [42] and symptoms of mental illness, such as anxiety, depression, and problematic health behaviors (eg, alcohol, gambling, and smoking). In fact, a meta-analysis found that apps were superior...
to control conditions in improving stress levels and quality of life and depressive and generalized anxiety symptoms, with no marked difference relative to active interventions, including in-person treatment [45].

**Benefits and Pitfalls of Technology Use**

Although there is no doubt that technology has the potential to facilitate social connection via phone calls, videoconferencing, text messaging, group chats, and even games, participants agreed that in-person connection remains a vital part of personal relationships and interactions with health professionals. In a recent study, it was shown that when allowed to rely on a smartphone for information, participants were less likely to speak to other people and felt less socially connected than those who were not allowed to use phones [46]. As evidenced by our participants, older adults will engage with social media to stay connected to family and friends; however, previous qualitative work in this area revealed that older adults prefer deep, thoughtful, one-on-one communications as opposed to the light-touch, group-based interactions promoted through social media [47]. These findings suggest that it is important to ensure that HITs are well integrated with the health care system, enabling the therapeutic relationship between a consumer and health professional as opposed to rendering it unnecessary. This may be a particularly important consideration for older adults who tend to experience greater degrees of social isolation and loneliness, which are known risk factors for health problems, including cognitive decline and depression [48].

In addition to social connection, several participants also reported engaging with technology to play games, such as *Candy Crush* and *Words with Friends*. Interestingly, older adults aged 65 years and older are the fastest-growing segment of new digital game players in Australia [49]. Although utility as a leisure activity is important, gaming may also present an opportunity for incidental cognitive assessment, where changes in game behavior or performance may be indicative of decline at its earliest stage, thereby facilitating early intervention strategies to mitigate known modifiable risk factors such as depression, midlife hypertension, midlife obesity, and low physical activity [50]. Importantly, a systematic review of gamified cognitive assessment and training paradigms found evidence suggestive of associated improvements in engagement, intrinsic motivation, and training outcomes (when relevant) [51,52]. In addition to promoting repeated engagement, gamifying cognitive tasks can improve usability, decrease test anxiety, and increase ecological validity [51]. Further research is now required to validate the application of game design principles to cognitive assessment to improve sensitivity to the earliest signs of decline and to cognitive training to promote engagement, real-world transfer, and sustainability of outcomes.

**The Potential Impact of Health Information Technologies**

The disruption caused by the COVID-19 global pandemic has resulted in a greater need for and reliance on digital health care for screening, treatment, and ongoing maintenance of health. To this end, HITs offer a viable alternative for those who prefer or are required to use digital health care due to health concerns (eg, during the COVID-19 pandemic) and geographic, transport, or mobility constraints. One of the marked discrepancies between our study and others that have investigated technology use for health-related purposes by older adults relates to familiarity with and confidence in using technology. Although this was not a personal concern among our participants, a lack of familiarity with technologies has frequently been cited as a potential barrier to adoption for older adults [53], specifically in relation to web-based health care information seeking [54]. As referenced previously, consideration of the **digital divide** is crucial to ensure that those who may not have easy access to technology, or the skills required to use it, are not excluded from receiving mental health care delivered via HITs. Recommendations to bridge the digital divide include (1) technology subsidies for low-income consumers, (2) user-friendly technologies appropriate for consumers with physical disabilities and cognitive impairment; and (3) demonstrations and training opportunities for consumers who might not otherwise have the opportunity to learn how to use available technologies [55].

Furthermore, health services are also encouraged to consider the addition of a digital navigator to their care team to improve the uptake and implementation of HITs within care [56]. The role of a digital navigator is 3-fold: (1) evaluate HITs, such as apps, and make appropriate recommendations to health professionals; (2) set up technology and troubleshoot with the consumer, thereby allowing the health professional to focus on the clinical interaction with the consumer; and (3) interpret and report salient data collected by the HIT to both the consumer and the health professional in a user-friendly way to inform care and self-management. Although the current use of HITs among older adults is relatively low, this does not appear to be due to lack of interest [20] but rather due to the need for education and training in relation to the potential benefits of HITs and the practicalities of engagement with these technologies [57]. As such, a digital navigator has the potential to be particularly impactful for the older adult community, including both for consumers and their families and for health professionals.

**Prototyping the InnoWell Platform for Older Adults**

Importantly, many of the features and functions suggested by participants for the digital tool align with the core principles underpinning the design and development of the InnoWell Platform, which include increasing access to standardized, broad-based assessment; identifying and tracking consumer needs; matching those needs with personalized care options; and enhancing the quality of care provided to consumers [34]. Although the assessment was not discussed per se, participants recognized that the more information that was input into the digital tool, including via interoperable devices, increased the likelihood of personalized feedback and recommendations. Furthermore, the ability to track and store data over time was valued by participants as a means to better understand what information, resources, and intervention strategies were associated with positive health outcomes based on personal goals relative to those that were not effective for the consumer. It was also recognized that a personal data record, only shared with health professionals with the consumer’s permission, had the potential to facilitate coordinated care across health professionals and services and to prevent the need to retell one’s
story repeatedly to new providers. Although it was noted that HITs have the potential to improve access to services, particularly for consumers in regional or remote areas, there was consensus that HITs cannot and should not replace health professionals. Even when developed and delivered by a credible source, it was believed that HITs are not comparable with in-person care and that the connection with a health professional remains a valued part of seeking and receiving care. That said, participants consistently stated that they would make use of an HIT if asked to do so by a health professional.

Despite the willingness to engage with HITs, data privacy and security concerns were frequently referenced as barriers to use, which aligns with previous user-centered work in this area [58]. This is perhaps not surprising, given the frequency of data breaches globally. For example, the United States Department of Health and Human Services’ Office for Civil Rights breach portal listed 510 health care data breaches of 500 or more records in 2019, reflecting a 196% increase from 2018 [59]. Needless to say, adherence to relevant privacy policies is paramount in the development and implementation of HITs to protect consumers’ health information from being disclosed for marketing purposes or, perhaps more importantly, identity theft and fraud.

Importantly, the results of this study have translated to a configuration of the InnoWell Platform specifically tailored to older adults. The broad-based assessment, for example, has been modified to reflect areas of health that are particularly relevant to older adults, including cognition and pain, and to incorporate assessment tools specifically designed for the older adult community (as opposed to tools used in configurations of the InnoWell Platform designed for young people or veterans). All informational materials provided within the InnoWell Platform are appropriate for older adults. For example, fact sheets are provided regarding the benefits of physical activity or the health impacts of excessive alcohol use for older adults. Furthermore, the care options embedded within the InnoWell Platform have been revised to reflect the needs of older adults, such as recommendations for apps for cognitive training, medication management, and cardiovascular health. The design and development of additional features and functionality of the InnoWell Platform based on the information gathered in this study are currently under consideration for inclusion in the next iteration of this innovative HIT.

Limitations

This study has some limitations that are important to note. All participants in this study were regular users of technology with high levels of digital literacy. As such, the accessibility, engagement, and appropriateness of technology for novice users or those who do not have easy access to technology could not be explored. In addition, only 2 supportive others were included in the participant sample, thereby limiting any conclusions that can be drawn about the features or functions of HITs that may be appropriate specifically for this user group. Finally, to promote patient privacy, no demographic information was collected from participants; therefore, we were unable to comment on factors such as age range, highest level of education, or occupational status (eg, retired). This also precludes the ability to investigate differences in technology preferences based on age (eg, 50-64 years vs 65-80 years).

Conclusions

Older adults readily engage with a range of technologies in day-to-day life, with current participants endorsing a preference for smartphones and computers relative to other devices. HITs have the potential to improve access to cost-effective and low-intensity interventions at scale to improve and maintain mental health and well-being. Participants referenced personalization and the ability to access up-to-date, credible information and resources as primary facilitators of HIT adoption, with a strong desire for integration with standard care practices to preserve personal connections with health professionals. Data privacy and security risks were a primary barrier to HIT use, although this may be mitigated if the source of the digital tool is reputable. Variability in digital literacy among older adults also has the potential to limit the adoption of such tools. However, several strategies may improve uptake and efficacy, including active co-design of HITs specifically with the older adult community to ensure usability, acceptability, and appropriateness; support for HIT selection and use of clinical applications via a digital navigator; and education and training materials embedded within the HIT.

Future Directions

The configuration of the InnoWell Platform specific for older adults is now being trialed in a naturalistic 90-day user testing study. Participants aged 50 years and older are invited to engage with the InnoWell Platform for a period of 90 days and asked to complete short web-based surveys at 5 time points (baseline [or day 1], day 15, day 30, day 60, and day 90), regarding the quality, usability, and acceptability of the functionality of the prototyped InnoWell Platform. Eighteen participants have enrolled in this study to date, and results are expected to be submitted for publication in early 2021. The findings will inform the iterative redesign and development of the InnoWell Platform before the implementation within an older adult health service setting. Furthermore, participant feedback will also be used in the design and development of other HITs for the older adult community, such as gamified cognitive tests to assess and monitor cognitive functioning over time and multifaceted, interactive web-based interventions to support and maintain mental health and well-being.

Acknowledgments

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Authors’ Contributions
The authors IH and TD were integral in securing funding to support this study. The study was designed by HL and TD, with subsequent contributions by AR. All data analyses were conducted by HL and AR. All authors contributed to and approved the final manuscript.

Conflicts of Interest
IH was an inaugural commissioner on Australia’s National Mental Health Commission (2012-2018). He is the Co-Director, Health and Policy at the Brain and Mind Centre (BMC), University of Sydney. The BMC operates early-intervention youth services at Camperdown under contract to headspace. He is the Chief Scientific Adviser to, and an equity shareholder in, InnoWell. InnoWell was formed by the University of Sydney (45% equity) and PwC (45% equity) to deliver the Aus $30 million Australian Government–funded Project Synergy (2017-2020), a 3-year program for the transformation of mental health services and to lead transformation of mental health services internationally through the use of innovative technologies. The other authors have no conflicts of interest to disclose. The source of funding does not entail any potential conflict of interest for the other members of the Project Synergy Research and Development Team.

Multimedia Appendix 1
Older adult participatory design agenda.

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