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Original Paper

# Attrition in an Online Loneliness Intervention for Adults Aged 50 Years and Older: Survival Analysis

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## Abstract

**Background:** Online interventions can be as effective as in-person interventions. However, attrition in online intervention is high and potentially biases the results. More importantly, high attrition rates might reduce the effectiveness of online interventions. Therefore, it is important to discover the extent to which factors affect adherence to online interventions. The setting for this study is the online Friendship Enrichment Program, a loneliness intervention for adults aged 50 years and older.

**Objective:** This study examined the contribution of severity of loneliness, coping preference, activating content, and engagement in attrition within an online intervention.

**Methods:** Data were collected from 352 participants in an online loneliness intervention for Dutch people aged 50 years and older. Attrition was defined as not completing all 10 intervention lessons. The number of completed lessons was assessed through the management system of the intervention. We tested 4 hypotheses on attrition by applying survival analysis (Cox regression).

**Results:** Of the 352 participants who subscribed to the intervention, 46 never started the introduction. The remaining 306 participants were divided into 2 categories: 73 participants who did not start the lessons of the intervention and 233 who started the lessons of the intervention. Results of the survival analysis (n=233) showed that active coping preference (hazard ratio [HR]=0.73), activating content (HR=0.71), and 2 indicators of engagement (HR=0.94 and HR=0.79) lowered attrition. Severity of loneliness was not related to attrition.

**Conclusions:** To reduce attrition, developers of online (loneliness) interventions may focus on stimulating active behavior within the intervention.

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**KEYWORDS**

online intervention; loneliness; attrition; coping; engagement; older adults

## Introduction

During recent years, the number of online interventions has increased rapidly. Online interventions offer possibilities for reaching more participants [1], are more cost-effective, and are less prone to stigma than in-person interventions [2]. Another advantage is that participation in online interventions can be undertaken as per participants' preferred pace, as opposed to the fixed structure of in-person group interventions.

Furthermore, online interventions can be as beneficial as in-person interventions [3,4]. They are often self-guided, that is, there is no contact between the participant and a coach or therapist [5]. Eysenbach [6] points out that online interventions are characterized by high attrition, which is also stressed in later studies [7]. During intervention trials, participants drop out quite easily, without further consequences. The understanding of factors associated with attrition is limited. In this study, we examined factors that may be associated with attrition in an

online self-guided loneliness intervention for older adults. Loneliness is nowadays considered as 1 of the main social problems in society [8]. Fighting loneliness contributes to the improvement of individual well-being and lowers the risk of poor health and early mortality.

It is important to gain more insight into online intervention attrition for 2 reasons. First, dropout attrition, which refers to participants dropping out of the study but not leaving the intervention, affects the study's effectiveness [6]. If dropout attrition is selective, study results are biased. Moreover, dropout attrition affects the statistical power of the study. Second, participants who discontinue the intervention during the course of the intervention (nonusage attrition [6]) do not benefit from the intervention optimally. Although Eysenbach's paper [6] was published several years ago, his ideas regarding attrition are still topical today [7,9]. One way to improve the effectiveness of the intervention is to reduce nonusage attrition. This study aimed to provide more insight into factors affecting nonusage attrition in online self-guided interventions.

We examined several factors that might be related to nonusage attrition. Although research on attrition in online interventions is still limited, we have expectations with respect to nonusage attrition. First, participants who are severely lonely may be most likely to complete the intervention. The review of studies on the severity of the target problem as a factor in intervention dropout by Melville et al [10] reveals that participants with less severe problems are more likely to drop out, as they may be less motivated to invest time and effort into working on the problem. We, therefore, hypothesized that lonelier participants are more likely to complete the intervention (hypothesis 1).

Coping preference may be another factor affecting attrition. We distinguish between active and regulative coping [11]. People who have a preference for active coping want to tackle the loneliness problem by changing the undesirable situation, for example, by engaging in social activities. This suggests that people who tend to use active coping more often keep trying and persevere in completing the intervention (hypothesis 2a). In contrast, people with a preference for regulative coping do not attempt to deal with the problem itself. Instead, they try to minimize the emotional consequences of the problem by, for example, distracting oneself from the undesired situation. We, therefore, expect that participants with a preference for regulative coping are more likely to drop out (hypothesis 2b).

The intervention content itself can stimulate more active responses to address the problem at hand [12]. Assignments involving activity directed at a desired goal, when completed successfully, may offer rewards (such as satisfaction) that encourage participants to stay in the intervention longer. Stimulating active coping through the intervention's content increases the likelihood of completing the intervention (hypothesis 3).

In online interventions, there is often little or no supervision on usage, and it is not always clear to which extent participants use the intervention as intended [6]. In addition, the intervention used in this study has no supervision. In other types of interventions, for example, drug trials, participants are supervised closely because quitting can have (health)

consequences related to the medication that is being tested. Attrition is likely a consequence of lack of user engagement [7,13,14]. An early sign of this lack of engagement is that a participant hesitates to follow through after signing up or is slow in fulfilling tasks in the intervention [6]. A sign of sufficient engagement would be the enthusiasm with which participants start the intervention, for example, in terms of compliance with the intervention. We, thus, expect that participants showing high engagement at the start of the intervention are more likely to complete the intervention than participants with low initial engagement (hypothesis 4).

Other user-related characteristics that are associated with attrition in online interventions have been identified. Melville et al [10] suggest that having a partner reduces the likelihood of attrition, which may indicate that support, for example, provided by the partner, reduces the dropout rate [15]. However, an association between having a partner and dropout was not found in a meta-analysis [5]. Self-efficacy may also be related to attrition in online interventions, but the effects are ambiguous. A study by Glasgow et al [14] demonstrates that participants with (topic-specific) high self-efficacy are less likely to be engaged with the intervention on an ongoing basis and have a higher likelihood of not participating in the follow-up observation. In contrast, Wangberg et al [16] show that higher self-efficacy is related to more intense usage of the intervention. These contradictory findings necessitate further study of the effect of self-efficacy on attrition. Proficiency with information and communication technologies (ICTs) may also be related to attrition. Mathew et al show that participants with good internet skills are more likely to use an online physical activity intervention [17]. Finally, some studies show lower dropout rate among females, participants in older age categories, and participants with a high educational level [5,16].

The setting for this study is the online Friendship Enrichment Program (oFEP), a loneliness intervention for adults aged 50 years and older [18]. To the best of our knowledge, no other studies specifically examined attrition in online loneliness interventions. Therefore, this study aimed to discover the extent to which the abovementioned factors affect adherence to an online loneliness intervention.

## Methods

### Design of the Intervention and Study

The oFEP is an intervention for people aged 50 years and older. It is a Web-based adaptation of a successful in-person intervention [19]. The oFEP is an 11-week intervention consisting of an introductory lesson followed by 2 blocks of 5 lessons. The intervention was designed with the intention that participants complete 1 lesson each week. Participants could delay the start of a lesson if that was more convenient for them (eg, because of a vacation or hospitalization). One of the assumptions behind the intervention was that, to fully benefit from the intervention, it is best to complete all the lessons. The website of the intervention is in Dutch and designed in such a way that the website and the lessons can function on various types of devices. A previous study on the oFEP [18] showed that the program alleviates the loneliness of its participants to

some extent. The study by Bouwman et al gives a more detailed description of the program [18].

We collected data at 4 time points: before the start of the intervention ( $T_1$ ), after the first block of the intervention ( $T_2$ ), at the end of the intervention ( $T_3$ ), and 1 year after the intervention ( $T_4$ ). The questionnaires at  $T_1$  and  $T_4$  were identical, and the questionnaires at  $T_2$  and  $T_3$  were shortened versions of the same questionnaire. Besides loneliness, other concepts, such as social self-efficacy, self-esteem, and participation, were measured. Participation in the intervention automatically meant participation in the study, which was communicated to the participants before signing up for the intervention. Starting to answer a questionnaire was a requirement to gain access to the next lesson. However, item nonresponse did not have consequences for participation. For this study, we used the baseline questionnaire and activity logs of intervention usage obtained through the management system of the intervention.

We identified 3 phases during which participants could drop out of the intervention. The first was directly after signing up for the intervention and before providing any information. Participants who dropped out in this phase never started the intervention and did not fill out any questionnaire ( $n=46$ ). The second phase was before one participates in lessons. These participants filled out the baseline questionnaire and completed the intervention's introduction ( $n=73$ ). The third phase was during the actual participation in the intervention ( $n=151$ ). This category included all participants who completed between 1 and 10 lessons of the intervention.

## Participants

Recruitment was done online through a banner on a website for adults aged 50 years or older to enable meeting and shared activities and through articles in 8 (regional) newspapers. Older age (being 50 years or older) was the only inclusion criterion for participation. The intervention was not advertised as a loneliness intervention but as an intervention to *benefit more from friendship*. Participation in the intervention was free of charge, and no reward was offered for participation in the study. All communication with the participants was automated, and only if a problem occurred, participants could contact the researcher.

## Measurements

### Attrition

We assessed the number of lessons participants completed through the management system of the intervention. Completion of the intervention is operationalized as completing the introductory lesson and all 10 substantive lessons. We considered a participant to have dropped out when the number of lessons followed was lower than 10.

### Loneliness

Loneliness was measured with the De Jong Gierveld Loneliness scale [20]. The 11-item scale consists of a 6-item scale for emotional loneliness and a 5-item scale for social loneliness. The scale includes statements such as "There is always someone I can talk to about my day-to-day problems" for social loneliness

and "I miss having a really close friend" for emotional loneliness. Answer categories were "Yes!," "Yes," "More or less," "No," and "No!" Loevinger coefficient for scale homogeneity was  $H=0.53$ , and  $\rho=0.91$  for reliability.

## Ways of Coping

Ways of coping was measured following the method used by Schoenmakers et al [21]. Participants responded to statements related to active and regulative coping with loneliness. Participants were asked whether or not they thought the stated action was suitable for someone who experienced loneliness. Moreover, 3 statements represented active coping ("Attend a course to learn to make and keep friends," "Go to places or club meetings in order to meet people," and "Become a volunteer"), and 3 statements represented regulative coping ("Keep in mind that other people are lonely as well, or even more lonely," "He/she should appreciate the existing contacts with relatives and friends more," and "Family and friends should point out that he/she must not complain and be realistic").

## Intervention Content—Inclusion of Active Elements

The intervention consisted of 2 blocks of 5 lessons of which content differed in activating the participant, but not in topic. The introductory lesson was the same for all participants and introduced some key concepts of the intervention (such as friendship) and let participants reflect on the current state of their network. Subsequently, there was an active and a reflective block. The active block was designed to stimulate participants' behavior. Participants were given information on the topics and stimulated to actually work on different aspects of friendship mainly through assignments. Participants were invited to renew contact with old friends and initiate small talk with people in the neighborhood. The lessons aimed to educate participants on several aspects regarding social relationships, in order to equip participants with skills to use in different situations. The reflective intervention part consisted of more passive content, which included different stories about friendship. The reflective block stimulated reflection on the 5 topics through existing texts and videos on friendship, for example, a newspaper item on having a holiday by yourself and a comedian talking about cross-sex friendship. Participants were randomized in 2 groups: 1 group started with the active intervention block, followed by the reflective intervention block; the other group followed the blocks of the intervention in a reversed sequence.

## Engagement—Tempo

The first variable for engagement was the tempo at the start of the intervention, which was the time elapsed between the introductory lesson and the first lesson. Information was obtained through the management system of the intervention.

## Engagement—Number of Diaries

The second variable used to measure engagement was the number of diaries the participants filled out. Each day, regardless of whether or not participants used the intervention that day, participants received an invitation to fill out a daily diary. The number of diaries participants filled out between the introductory lesson and the first lesson ranged from 0 to 14.

## Other Factors

### *Self-Efficacy*

Self-efficacy was measured with a topic-specific measure of self-efficacy. The Social Self-Efficacy Scale refers to the individual's belief in his or her ability to engage in social contacts [22]. An example of 1 of the 4 items used is as follows: "It is difficult for me to make new friends." Scores range from 4 to 20; reliability  $\alpha=.70$ .

### *Information and Communication Technology Proficiency*

ICT proficiency was assessed with 2 items, with 1 item asking: "Do you have to ask for help from others when using your computer or mobile phone?" Answer categories were "No," "Yes, fewer than a couple of times a year," "Yes, a couple of times a year," "Yes, a couple of times a month," "Yes, a couple of times per week," and "Yes, daily." A higher score (range 1-6) indicated that more frequent help was needed. In the second item, we asked participants how many types of devices they owned. Categories were desktop, laptop, tablet, smartphone, and smart TV.

### **Procedure**

We described the differences between 3 categories of participants at baseline: participants who signed up for the intervention and started the lessons, participants who signed up but only completed the baseline questionnaire and the intervention's introductory lesson but no further lessons, and a third category of participants who signed up, completed the baseline questionnaire, but never started any of the intervention elements. We tested the hypotheses on nonusage attrition by applying survival analysis (Cox regression in IBM SPSS Statistics 25 for Windows) among participants who started the lessons (N=233). The total number of lessons (1-10) was used as time variable. The hazard ratio (HR) and the 95% CI are presented. Tolerance of predictors ranged between .76 and .95.

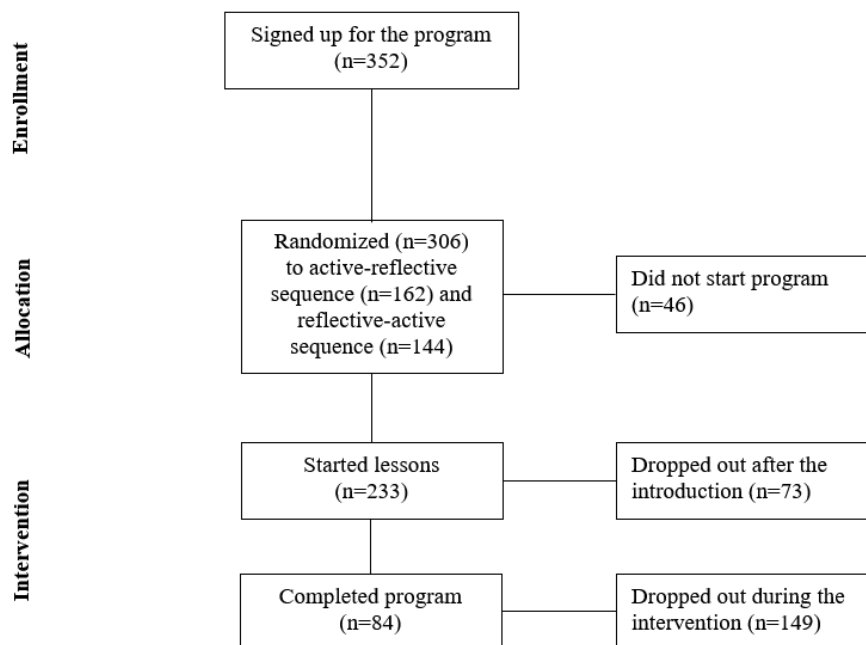
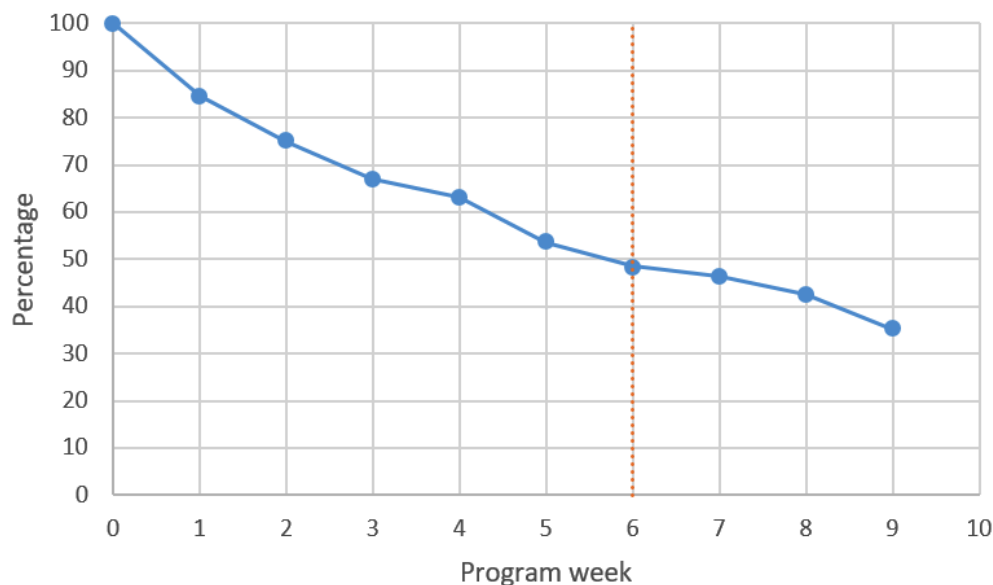
Hypothesis 1 was tested by adding loneliness at baseline to the survival model. We added variables for the active (hypothesis 2a) and regulative (hypothesis 2b) coping preference to the multivariate model. Confirmatory 2-factor analysis was performed in Mplus [23] for the *ways of coping* measure, using the robust weighted least square estimator [24]. Hypothesis 3

was tested by adding the variable representing the activation by intervention content to the model (active-reflective sequence and reflective-active sequence). Finally, hypothesis 4 was tested by adding the 2 engagement variables to the model: tempo and number of diaries. Due to the relatively small sample size, all hypotheses were tested in bivariate models first, followed by 1 multivariate model. To better understand the meaning of the actual size of the estimated coefficients, we calculated the median survival time in weeks for the 10th and the 90th percentile scores of relevant independent variables. Calculations were made in a multivariate model with the survival procedure in IBM SPSS Statistics 25 for Windows. Continuous variables were categorized according to the percentile scores.

## **Results**

Between April and July 2013, a total of 383 persons signed up for the intervention, of which 6 never provided any data. The baseline questionnaire was filled out by 352 participants, and 313 participants were randomized into 1 of the 2 sequences (Figure 1 provides a flowchart of participation). Most of the participants were female (77.6%; 273/352). Less than half of the participants (42.1%; 148/352) had a partner. The median educational level was 7 on a scale ranging from 1 (primary education) to 9 (university).

Of the 352 participants who filled out the baseline questionnaire, 46 participants only provided information at baseline but did not start the intervention, and 306 started the intervention, of which 162 were in the active-reflective and 144 in the reversed sequence. Among the 306 participants who started the intervention, 73 participants did not take part in any of the substantive lessons, but only completed the introductory lesson, leaving 233 participants who followed the substantive lessons. The 233 participants followed on average 6.2 lessons (SD 3.6). Figure 2 shows the percentage of dropouts per program week. The vertical dotted line in Figure 2 indicates the average program weeks the participants completed before dropping out. All 10 lessons were completed by 82 participants (35%; 82/233); 11 of those 82 were study dropouts because they did not fill out the follow-up questionnaire at the end of the intervention. They did, however, remain in the analysis because baseline data and data on time in the intervention were used. The remaining 151 participants (64.8%; 151/233) were nonusage dropouts.

**Figure 1.** Flowchart of participation in the intervention.**Figure 2.** Attrition per program week (n=233). The dotted line represents the median survival time in program weeks.

The 2-factor structure of the 6-item questionnaire developed by Schoenmakers et al [21] was confirmed for our data by means of a confirmatory factor analysis (root mean square error of approximation=.00, comparative fit index=1.00, Tucker-Lewis index=1.01;  $\chi^2_8=7.7$ ,  $P=.47$ ). The mean social self-efficacy score at baseline was 11.4 (SD 3.0). The mean number of diaries participants filled out between the introductory lesson and the first lesson was 3.67 (SD 2.41). For tempo, a score of 0 indicated that the participant was on track and took 7 days between the 2 lessons. A negative score indicated that the participant took longer than scheduled. The score was calculated by dividing the number of days between the 2 lessons by 7 (indicating 1 week) and was reverse coded (mean  $-0.90$  [SD 2.53]; range

$-19.43$  to  $0$ ;  $n=233$ ). Positive scores were not possible because the first lesson became available 7 days after completion of the introductory lesson. With regard to ICT help, a higher score represented more frequent help was needed (mean 2.37 [SD 1.09]). On average, participants owned 2.1 types of devices (SD 1.1).

We compared participants in the 3 phases of nonusage dropout, that is, 46 nonstarters, 73 starters who took the introductory lesson only, and 233 starters with substantive lessons followed (Table 1). The first 2 categories had no follow-up time and thus had no value for tempo. No difference was observed in baseline characteristics for the 3 categories of participation.

**Table 1.** Descriptive statistics for 3 types of participants at baseline.

Variables	Participants who only provided baseline information (n=46)	Participants who only took the introduction (n=73)	Participants who started substantive lessons (n=233)	F test (df)	Chi-square (df)	P value
Baseline loneliness (0-11), mean (SD)	7.9 (3.5)	7.5 (3.6)	8.1 (3.0)	1.1 (2, 349)	— <sup>a</sup>	.33
Active coping (0-3), mean (SD)	2.7 (0.6)	2.7 (0.6)	2.7 (0.6)	0.1 (2, 326)	—	.92
Regulative coping (0-3), mean (SD)	1.8 (1.0)	1.6 (0.8)	1.7 (0.9)	0.5 (2, 326)	—	.59
Active-reflective sequence (vs reversed), n (%)	—	33 (45)	129 (55)	—	—	—
Tempo in the first intervention week (−19.4 to 0), mean (SD)	—	—	−0.9 (2.5)	—	—	—
Number of diaries in the first intervention week (0-14), mean (SD)	—	—	3.7 (2.4)	—	—	—
Age (50-88 years), mean (SD)	61.7 (6.0)	63.0 (8.1)	61.7 (7.1)	1.0 (2, 349)	—	.38
Female (vs male), n (%)	31 (67)	59 (81)	183 (79)	—	3.3 (2 <sup>b</sup> )	.19
Educational level (1-9), mean (SD)	6.7 (1.8)	6.3 (2.1)	6.5 (2.1)	0.4 (2, 349)	—	.70
Partner (vs no partner), n (%)	20 (43)	37 (51)	91 (39)	—	3.1 (2 <sup>b</sup> )	.21
Social self-efficacy (4-20), mean (SD)	11.8 (3.4)	11.8 (2.7)	11.2 (3.0)	1.7 (2, 349)	—	.19
ICT <sup>c</sup> proficiency: help needed (1-6), mean (SD)	2.4 (1.1)	2.5 (1.0)	2.3 (1.1)	0.9 (2, 349)	—	.40
Number of types of ICT devices (1-5), mean (SD)	1.9 (1.0)	2.2 (1.2)	2.0 (1.1)	1.4 (2, 349)	—	.24

<sup>a</sup>Not applicable.

<sup>b</sup>n=352.

<sup>c</sup>ICT: information and communication technology.

Results from survival analysis among 233 participants who started the lessons are presented in Table 2. In contrast to hypothesis 1, both the bivariate and the multivariate models showed that the baseline level of loneliness did not affect the probability of dropping out.

With respect to hypothesis 2, neither a preference for active nor for regulative coping had an effect on dropout probability in the bivariate analysis. In the multivariate model, however, hypothesis 2a was supported: active coping led to a lower probability of dropping out of the intervention (HR=.73). For participants with high preference for active coping (90th percentile) the median survival time, that is, time that they stay in the intervention, was 8.0 weeks. Participants with low preference for active coping (10<sup>th</sup> percentile) stayed in the intervention for 5.6 weeks.

Hypothesis 3 on active intervention content was supported in the multivariate model but not in the bivariate model. Participants starting with the active intervention content had a lower probability of dropping out (HR=.71; multivariate model) than other participants. For participants who started with the active intervention content, the median survival time was 7.8

weeks, and participants who started with the reflective content had a median survival time of 5.9 weeks.

To test hypothesis 4 on engagement, we included *tempo* and the number of diaries filled out in the first week of the intervention. The correlation coefficient was .36 ( $P<.001$ ). The hypothesis was supported. Thus, the probability of dropping out was lower when tempo was higher when the participant sticks to the intended pace of the intervention. Participants with high tempo had a median survival time of 9.0 weeks, whereas participants with low tempo had a median survival time of 2.6 weeks. The probability of dropping out was also lower when 1 or more diaries were filled out. Participants who filled out 6 or more diaries (90th percentile) had a median survival time of 9.0 program weeks, and participants who did not fill out diaries (10th percentile) had a median survival time of 2.0 weeks.

Of the other factors, only the number of types of ICT devices affected nonusage attrition in the bivariate analyses. This effect did not show up in the multivariate model. Participants owning more types of ICT devices had a higher probability of dropping out. In the multivariate model, more highly educated participants had a lower probability of dropping out. Participants with a high educational level had a median survival time of 6.1 weeks, and those with a low level had a median survival time of 6.8 weeks.



**Table 2.** Cox regression of nonusage attrition (n=233).

Variables	Bivariate		Multivariate	
	HR <sup>a</sup> (95% CI)	P value	HR (95% CI)	P value
Baseline loneliness (0-11)	1.00 (0.95-1.06)	.97	1.00 (0.94-1.07)	.91
Active coping (0-3)	0.81 (0.64-1.03)	.09	0.73 (0.57-0.93)	.01
Regulative coping (0-3)	1.04 (0.84-1.24)	.70	1.01 (0.83-1.22)	.94
Active-reflective sequence (vs reversed)	0.81 (0.59-1.11)	.19	0.71 (0.50-1.00)	.049
Tempo in first intervention week (-19.4 to 0)	0.89 (0.85-0.93)	<.001	0.94 (0.89-1.00)	.049
Number of diaries in first intervention week (0-14)	0.79 (0.73-0.85)	<.001	0.79 (0.72-0.86)	<.001
Age (50-86 years)	0.99 (0.96-1.01)	.26	0.99 (0.97-1.02)	.43
Female (vs male)	0.80 (0.55-1.15)	.23	1.14 (0.75-1.72)	.55
Education (1-9)	0.96 (0.89-1.04)	.32	0.92 (0.84-0.96)	.04
Partner (vs no partner)	1.19 (0.86-1.65)	.29	0.95 (0.66-1.36)	.77
Social self-efficacy (4-20)	1.01 (0.96-1.06)	.77	0.99 (0.93-1.06)	.84
ICT <sup>b</sup> proficiency: help needed (1-6)	0.93 (0.80-1.07)	.29	0.96 (0.82-1.12)	.59
Number of types of ICT devices (1-5)	1.16 (1.00-1.34)	.048	1.14 (0.97-1.35)	.12

<sup>a</sup>HR: hazard ratio.

<sup>b</sup>ICT: information and communication technology.

## Discussion

This study aimed to gain insight into the factors affecting attrition in an online loneliness intervention. The participants in the oFEP suffered from loneliness varying in intensity so that they form an appropriate sample to study the extent to which severity of the problem affects attrition. There was no support for hypothesis 1 that participants with more severe loneliness remain in the intervention longer than mildly lonely participants. Coping style affected attrition. People with a preference for active coping, who thus are more motivated to tackle the loneliness problem, stayed in the intervention longer (hypothesis 2a; and hypothesis 2b did not find support). Receiving content focused on active coping first (as opposed to reflective content; hypothesis 3) also increased adherence. The effect of engagement with the intervention (hypothesis 4) turned out to be the most important of the factors studied. Participants who were more engaged with the intervention, meaning they participated in the lessons at the intended pace and filled out diaries, were less likely to drop out of the intervention. Finally, we also explored the association between several other, mainly personal, characteristics and attrition. More educated participants tended to stay in the intervention longer. This could be understood from the format of the lessons. Higher education may enable participants to read and comprehend written text better, and hence these participants adhere more to the intervention.

These findings imply that, when trying to increase adherence to an online intervention, it is not necessary to select participants based on the severity of their problem. It seems to be beneficial to pay attention to coping preference and stimulate more active coping. For future interventions, it may be useful to try to persuade people to engage in more active coping, even when

this is not their preferred coping style. This approach complies with the notion that it takes a lot of effort to tackle problems such as loneliness and with the finding that loneliness interventions are often not successful [25]. Moreover, the success of efforts to combat loneliness is not always immediately apparent [26]. Future interventions may attempt to stimulate participants even more to engage in active coping, for example, with testimonials that focus on the benefits of engaging in active coping, or by pointing out that the extra effort that active coping requires may pay off. Lucas et al [27] suggested that it is possible to break through regulative coping preferences and passive social behavior. Priming lonely individuals to engage in more positive behavior can reduce their focus on cautious social behavior. Our finding that engagement affects attrition provides especially valuable insight for future interventions. It allows intervention developers to intervene with additional resources as soon as participants seem to lower their engagement. For example, in the oFEP, we can send an extra message as a reminder to participants who do not participate in the second lesson within 10 days. Furthermore, the importance of following the lessons of the intervention at the intended pace of 1 per week can be stressed throughout the intervention. A word of caution here is that there might be between-person differences in which principles work best to increase engagement [28]. What works for or is preferred by 1 participant, might not be preferred by another. It seems that some level of personalization of the intervention is required, but further research on this topic is needed. Instead of increasing engagement of participants, an intervention developer can also use participants' engagement as a selection criterion, for example, to direct the limited resources to only those participants who are most likely to complete the intervention. Selection can, in that case, be done by means of a brief preintervention.

There are 2 design issues in this study that need discussion. The questionnaires were included in the intervention and not presented as separate study. Completion of certain parts of the program triggered the release of the questionnaires, and only after completion of the questionnaire, the participants could continue with the intervention. By making these design choices, we lost the possibility to distinguish nonusage attrition from dropout attrition. Including the questionnaires in the intervention may have increased participants burden and could thus potentially affect the results. A limitation is that we were not able to assess how the loneliness of participants who dropped out from the intervention developed over time. It can be that they had already benefited from the lessons and were able to reduce their loneliness, similar to participants who completed the intervention. If this is the case, the intervention was successful and participant's nonusage attrition is a conceivable choice. However, continued participation might contribute to a further strengthening of the person and his situation. Furthermore, this study only looked at baseline characteristics as factors influencing attrition. Unfortunately, not all factors of interest were observed at least weekly, preventing the inclusion of time-varying characteristics into the analysis. The severity

of the problem and the engagement with the intervention may change in the course of the intervention. With respect to the measurement of the variable *tempo*, we limited it to the first week and did not extend it to the whole intervention. The latter is problematic for participants who dropped out of the intervention before completion of the intervention. Furthermore, we reasoned that tempo in the first week of the intervention indicated the initial commitment of the participant to the intervention. Finally, by conducting and reviewing only 1 intervention, we did not test the importance of design characteristics. The review of Murray et al [9] shows that a sound theoretical foundation [29], tailoring [16], and the use of prompts [30] result in an intervention design with improved participants' adherence to the intervention.

In conclusion, we observed that active coping prevents attrition. Eysenbach [6] argues that high attrition is a weakness of all self-guided online interventions. However, our study suggests that improvement is possible. Future online loneliness interventions might try to lower attrition by stimulating active behavior, for example, by offering a variety of exercises and an active approach toward participants with a slow pace in conducting intervention activities.

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## Authors' Contributions

TB, TT, and MA designed the study. TB was responsible for collecting the data. TB, TT, and MA participated in analyzing the data. TB drafted the manuscript. All authors critically revised the manuscript for important and intellectual content.

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## Conflicts of Interest

None declared.

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## Abbreviations

**HR:** hazard ratio

**ICT:** information and communication technology

**oFEP:** online Friendship Enrichment Program

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Original Paper

# Perceptions of the Diabetes Online Community's Credibility, Social Capital, and Help and Harm: Cross-Sectional Comparison Between Baby Boomers and Younger Adults

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## Abstract

**Background:** The use of online health communities such as the diabetes online community (DOC) is growing. Individuals who engage in the DOC are able to interact with peers who have the same medical condition. It is not known if older adults are perceiving the DOC differently compared with younger adults.

**Objective:** The purpose of this study was to explore and understand how the DOC is perceived in terms of social capital, source credibility, and help and harm. The findings from this study will shed light on how users of different age groups (baby boomers and younger adult counterparts) perceive DOC use.

**Methods:** This study represents a subset of participants from a larger study of DOC users. Baby boomers and younger adults with diabetes were recruited from the DOC to participate in a cross-sectional survey. Demographics, electronic health use (reasons to join the DOC, DOC intensity, DOC engagement, internet social capital, and help or harm from the DOC), source credibility, health-related quality of life, and diabetes self-care data were collected. We examined the differences between baby boomer and younger adult responses.

**Results:** The participants included baby boomers (N=76) and younger adult counterparts (N=102). Participants scored their diabetes health care team (mean 33.5 [SD 8]) significantly higher than the DOC (mean 32 [SD 6.4]) with regard to competence ( $P<.05$ ) and trustworthiness (diabetes health care team mean 36.3 [SD 7.1]; DOC mean 33.6 [SD 6.2];  $P<.001$ ). High bonding and bridging social capital correlated with high DOC intensity ( $r=.629$ ;  $P<.001$  and  $r=.676$ ;  $P<.001$ , respectively) and high DOC engagement ( $r=.474$ ;  $P<.01$  and  $r=.507$ ;  $P\leq.01$ , respectively). The greater majority (69.8%) reported the DOC as being helpful, and 1.8% reported that the DOC had caused minor harm. Baby boomers perceived DOC credibility, social capital, help, and harm similarly to their younger adult counterparts.

**Conclusions:** Baby boomers are using and perceiving the DOC similarly to younger adults. DOC users find the DOC to be credible; however, they scored their health care team higher with regard to competence and trustworthiness. The DOC is beneficial with low risk and may augment current diabetes care.

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**KEYWORDS**

diabetes mellitus; online social networking; social capital; trust; social media; older adult

## Introduction

### Background

Diabetes is a complex chronic condition that requires ongoing attention to day-to-day activities to achieve adequate glucose management. Individuals with diabetes are expected to spend more than 2 hours per day carrying out recommended self-care [1]. The time and intensity required for self-care, the complexities of diabetes, and the often unavoidable health fluctuations associated with their condition can be physically and emotionally taxing. Therefore, adequate informational and emotional support is imperative for patients to effectively manage their diabetes [2-4].

There has been a paradigm shift in which the patient's role has elevated from a passive recipient to an active consumer of health care [5]. As active consumers, patients are seeking more information to assist them in making decisions about their health. This is particularly true for individuals with chronic conditions who need information that will allow them to be successful in long-term disease management. Access to the internet has provided consumers with a myriad of easily accessible health information resources to support health care decisions, including social networks such as diabetes online communities (DOCs).

DOCs are grassroots digital locations in which individuals affected by diabetes interact, educate, and offer support to peers [6,7]. DOC use is associated with self-care, quality of life, and better glycosylated hemoglobin (HbA<sub>1c</sub>) [7]. Older adults, specifically, have found DOCs to be useful in improving knowledge about self-care and receiving emotional support [6,8].

The prevalence of, and proportion of, older adults with diabetes is simultaneously increasing. Baby boomers (born from 1946 to 1964), responsible for the vast growth of older adults, have a higher incidence of chronic conditions such as diabetes [9,10]. With the oldest baby boomer turning 65 years of age in 2011, the number of older adults with diabetes is rapidly increasing. Online health information seeking, such as DOC use, has been viewed as helpful in providing secondary prevention [11]. Baby boomers are the first generation to age using the internet and social media. Importantly, the adoption of online health communities is on the rise for older adults [12,13]. Therefore, it is important to determine if baby boomers perceive the credibility of online communities differently than their younger counterparts as this may inform online community use as they age.

One way that individuals establish credibility of online health information is through the guidance of peers as suggested in the Apomediation theory. The Apomediation theory proposes that individuals can bypass the traditional hierarchical medical system and, through a filtering process, collaborate with experienced peers who guide them toward credible and relevant information [14]. As it relates to diabetes, individuals may be more reliant on their health care providers upon initial diagnosis. However, over time, autonomy, knowledge, and self-efficacy are gained, allowing for interaction with experienced peers.

Source credibility is one of the domains identified in the Apomediation theory [14,15] and will be measured in this study.

### Source Credibility

Health information is not credible without trust in the message and source. Source credibility, defined as a characteristic that helps readers determine if information is believable, is associated with perceptions of competence, trustworthiness, and goodwill/caring [16]. Research suggests that online health community users are more likely to perceive community information as credible if it is based on firsthand knowledge of living with a health issue [17]. Furthermore, source credibility has been associated with emotional support in online health communities [18]. Although source credibility in peers may develop through the exchange of personal information and shared experiences, source credibility may be more difficult to ascertain in online environments because of reliance on text without the support of nonverbal cues and facial expressions [18,19].

### Social Capital

Participating in online health communities improves social capital [20]. Social capital, a term coined by Putnam [21], comprises the social connections, networks, and trust that allow individuals to work together as a community. There are 2 types of social capital. Bonding social capital includes close family and friends and is exclusive. Bonding social capital promotes group cohesion and social support. Bridging social capital is inclusive and is made up of heterogeneous networks of connections with weak ties. Bridging social capital allows for diffusion of information and diverse perspectives [22]. A number of studies have found an association between social capital, health and mortality [23-27]. Among those with chronic conditions, including diabetes, having a large network of social connections is associated with better self-management, physical and mental well-being, and coping [28]. Lack of social capital has been identified as a barrier in diabetes self-management [3]. Little is known about source credibility or social capital as it relates to peer health in the online context.

### The Diabetes Online Community Providing Help or Harm

It is unclear if individuals perceive DOC use as being helpful or harmful. The Pew Internet and Life Project found that 30% of US adults report that they or someone they know had been helped by following the advice or health information found online and only 3% reported being harmed [29]. In contrast, there is a potential for harm, such as inaccurate health information being reported and followed, public displays of unhealthy behaviors, and psychological impact from accessing offensive or biased content [30]. Therefore, it is important to evaluate how DOC users perceive information shared on the DOC as it relates to being helpful or harmful.

Despite the growing reach of the DOC, there is limited research focused on social capital, source credibility, and whether or not the DOC is helpful or harmful. The overarching objective of this study was to explore how the DOC is perceived as it relates to social capital, source credibility, and harm by way of age groups. Specifically, we aimed to understand the differences

between younger adults (born between 1965 and 1996) and baby boomers (born between 1946 and 1964). The findings from this study will illuminate the possible benefits and disadvantages to DOC use.

## Methods

### Sample and Setting

The study sample was from a larger study of DOC users (N=183). Participants were eligible for the parent study if they were aged 18 years or older, had a diagnosis of diabetes (type 1, type 2, or latent autoimmune diabetes of adulthood), and could read English. Anyone identifying as a minor, caregiver for someone with diabetes, or having gestational diabetes was not included. Participants were recruited by posting information about the study with a link to the survey. Key opinion leaders shared the survey to support snowball sampling. The full sample included 183 adult DOC users. The participants completed a 129-item online survey using Research Electronic Data Capture (REDCap) software (Nashville, TN). A subsection of baby boomers completed an interview. The study procedures were approved by the University of Utah Institutional Review Board and the respective DOC administrators (TuDiabetes and Diabetic Connect). Previous research from the parent study has been published elsewhere [6,7].

This study focused on 176 DOC users categorized as baby boomers or younger adult counterparts. Participants born in 1945 or earlier were not included in this study (N=5).

### Measures

This paper will examine online survey results from the parent study survey including demographics specific to baby boomers compared with younger adult counterparts, electronic health use (reasons to join the DOC, DOC intensity, DOC engagement, internet social capital, and perceived help or harm from the DOC), source credibility, HRQOL (health related quality of life), and diabetes self-care. Details for each measure are noted below.

### Demographics

Social and demographic data included 11 items focused on gender, marital status, education level, employment, annual household income, age, ethnicity, race, country and state, living setting, and insurance status.

### Health History

Self-reported health history data included 8 items focused on diabetes type, length of diabetes duration in years, current diabetes treatments, most recent HbA<sub>1c</sub> level, type of medical practice and provider used for diabetes care, frequency of diabetes provider visits, and diabetes-related complications.

### Electronic Health Use

Twenty-two items were collected on how participants navigate the DOC and if the participants' health care provider supported their DOC use.

### Reasons to Join the Diabetes Online Community

Participants were asked to identify reasons why someone with diabetes should join the DOC. Thirteen items were developed based on an anecdotal dLife (Diabetes Life) article [31].

### Diabetes Online Community Intensity

The DOC Intensity Scale is an 8-item tool adapted from the Facebook Intensity Scale [32] to measure how often and for how long individuals engaged in the DOC and to determine emotional connectedness and integration into daily activities. Scores range from 0 to 5 with higher scores indicating more DOC intensity. The Cronbach coefficient for DOC intensity was .85.

### Diabetes Online Community Engagement

The DOC Engagement Scale is a 5-item tool developed by the authors and informed by qualitative analysis [33] to measure engagement or interaction with other DOC users. Specifically, this tool was used to measure whether or not participants shared clinical information, requested or provided clinical guidance or feedback, or received or provided emotional support. Scores range from 0 to 5 with higher scores indicating more DOC engagement. The Cronbach coefficient for DOC engagement was .73.

### Internet Social Capital Scale

The Internet Social Capital Scale is designed to measure bonding (10 items) and bridging (10 items) social capital in both online and offline populations using a 5-point Likert scale [34] such as DOC use. The Likert response scale ranges from strongly agree to strongly disagree. The terms *offline* and *online*, which can be used interchangeably based on the study population, were replaced with *DOC* in this study. There were 3 questions from the Internet Social Capital Scale bonding subscale that did not pertain to the study population. The question "If I needed an emergency loan of \$500, I know someone online that I can turn to" was changed to "If I needed an emergency loan of diabetes supplies, I know someone on the DOC I can turn to." The questions "The people I interact with on the DOC would put their reputation on the line for me" and "The people I interact with on the DOC would be good job references for me" were omitted from the survey. Permission was obtained from Williams [34] to use and adapt the Internet Social Capital Scale for this study. The adapted 7-item bonding social capital scale and 10-item bridging social capital scale each have possible scores of 0 to 5; higher scores indicate higher levels of social capital. In this study, the Internet Social Capital Scale will measure DOC bonding and bridging social capital.

### Help and Harm

Overall, 2 questions were asked related to perceived help and harm, asking participants if they, or anyone they knew, had been helped or harmed by following advice or health information found on the DOC. Responses included major help, moderate help, minor help, no help, or do not know. Responses were then dichotomized into yes and no responses with regard to any help or harm, or no help or harm.

### **Health-Related Quality of Life**

The SF12-v2 (short form 12-item version 2) is a 12-item tool used to measure physical and mental health status. A 4-week recall was used in this study. Norm-based scoring (mean 50 [SD 10]) was used for this analysis [35]. The Cronbach coefficient for the SF-12v2 was .88 (physical=.77 and mental=.86).

### **Diabetes Self-Care**

The Self-Care Inventory Revised (SCI-R) is a 15-item tool to measure diabetes self-care behaviors and can accommodate natural variation in treatment plans for patients with type 1 and type 2 diabetes. The scores range from 0 to 100 [36]. The Cronbach coefficient for the SCI-R was .68.

### **Source Credibility**

The revised source credibility scale [16] was used to measure how participants viewed the credibility of the diabetes health care team and the DOC. The scale includes 18 items measuring 3 factors—competence, trustworthiness, and goodwill/caring—using a 7-point semantic differential scale. The Cronbach alpha scores range from .85 to .92 when looking at the dimensions separately and .94 when scored as a single measure. This scale was used twice in this study; first, to measure how participants rated the source credibility of their diabetes health care team. The diabetes health care team included anyone who cared for the patient's diabetes. Second, it was also used to measure how participants rated the source credibility of the DOC. Possible scores ranged from 0 to 42.

### **Analysis**

A participant code was assigned to all survey responses, and all data were maintained in REDCap [37]. Data were screened, and multiple entries were cleaned accordingly. Missing data were imputed with the appropriately scaled item means in the calculation of total scores for the validated scales in accordance with standard scoring methods. All other missing data were excluded pairwise. There were less than 10% of missing data for each analysis.

Statistical analysis was performed using SPSS 21 (New York City, New York) [38]. Analyses were conducted to determine the relationships between and interactions among demographic variables, source credibility, social capital, help, and harm. These analyses included correlations, independent and 1-sample *t* tests, and analyses of variance (followed by LSD (least significant difference)-adjusted post hoc tests, where appropriate). For inference, the alpha was set at .05.

## **Results**

### **Participant Characteristics**

A total of 178 participants met the criteria for this study: 43% were baby boomers and 57% were younger adults. Overall, the participants were more likely to be female, white, living in the United States, educated with a college degree, and insured and have type 1 diabetes. Baby boomers were more likely to be living in the United States and more likely to have type 2 diabetes or latent autoimmune diabetes of adulthood (LADA) compared with younger adult counterparts. There were no significant differences between baby boomers and younger adult counterparts regarding gender, education level, income, or presence of insurance (see Table 1).

### **Diabetes Online Community Source Credibility**

The mean DOC competence score was 31.9 (SD 6.5), the mean DOC caring/goodwill score was 31.9 (SD 7.2), and the mean DOC trustworthiness score was 33.6 (SD 6.3). Each factor score had a possible range of 0 to 42. The Cronbach coefficients for the DOC source credibility scale were DOC competency, alpha=.89; DOC caring/goodwill, alpha=.89; and DOC trustworthiness, alpha=.91.

DOC source credibility (competency, caring/goodwill, and trustworthiness) positively correlated with diabetes self-care, DOC intensity, DOC engagement, and bonding and bridging social capital as detailed in Table 2. DOC competence scores were higher ( $P<.05$ ) for individuals who had told their health care providers about their DOC use and felt supported to continue doing so (mean 34.3 [SD 6.1]) than those who were not sure if their health care providers supported their DOC use because they had not told their health care providers about it (mean 31 [SD 6.6]). Similarly, all participants reported higher DOC caring/goodwill scores if they had told their health care providers about their DOC use and their health care providers supported it (mean 34.7 [SD 5.4];  $P<.01$ ) or were not sure if their providers supported their DOC use even after they had reported it (mean 34.2 [SD 7.4];  $P<.05$ ) when compared with those who had not told their health care providers about their DOC use at all (mean 30.8 [SD 7.4]). DOC source credibility factor scores were not related to age, gender, diabetes type, diabetes duration, diabetes treatment, diabetes-related complications, HbA<sub>1c</sub>, or health-related quality of life. There were no significant differences for DOC source credibility factors (competence, caring/goodwill, or trustworthiness) between baby boomers and younger adult counterparts.



**Table 1.** Demographics of study participants, N=178.

Variable	Baby boomers <sup>a</sup>	Younger adult counterparts <sup>b</sup>	Total	P value
Age (years), mean (SD); range	— <sup>c</sup>	—	43.8 (13.2); 18-67	—
<b>Gender, n (%)</b>				<b>.18<sup>d</sup></b>
Female	51 (67.1)	77 (75.4)	128 (71.9)	—
Male	24 (31.6)	23 (22.5)	47 (26.4)	—
<b>Race, n (%)</b>				<b>.65<sup>d</sup></b>
American Indian or Alaskan Native	0 (0)	2 (2.0)	2 (1.1)	—
Asian	1 (1.3)	2 (2.0)	3 (1.7)	—
African American	1 (1.3)	1 (1.0)	2 (1.1)	—
White	73 (97.3)	96 (93.1)	169 (94.9)	—
<b>Country, n (%)</b>				<b>.025<sup>d</sup></b>
United States	69 (90.7)	78 (76.5)	147 (82.6)	—
Not United States	7 (9.2)	23 (22.5)	30 (16.9)	—
<b>Education, n (%)</b>				<b>.69<sup>d</sup></b>
Some high school	0 (0)	2 (2.0)	2 (1.1)	—
High school graduate	5 (6.6)	5 (4.9)	10 (5.6)	—
Some college	14 (18.4)	13 (12.7)	27 (15.2)	—
Associate's degree	9 (11.8)	11 (10.8)	20 (11.2)	—
Bachelor's degree	25 (32.9)	39 (38.2)	64 (36)	—
Graduate or professional degree	23 (30.3)	31 (30.4)	54 (30.3)	—
<b>Insurance, n (%)</b>				<b>.062<sup>e</sup></b>
Insured	73 (96.1)	84 (82.4)	157 (82.6)	—
Uninsured	2 (2.6)	9 (8.8)	11 (16.9)	—
<b>Diabetes type, n (%)</b>				<b>.007<sup>d</sup></b>
Type 1	45 (59.2)	82 (80.4)	127 (71.3)	—
Type 2	18 (23.7)	13 (12.7)	31 (17.4)	—
Latent autoimmune diabetes of adulthood	13 (17.1)	7 (6.9)	20 (11.2)	—

<sup>a</sup>n=76 (42.7%).<sup>b</sup>n=102 (57.3%).<sup>c</sup>Not applicable.<sup>d</sup>Chi-square test.<sup>e</sup>Fisher exact test.

**Table 2.** Correlations for diabetes online community source credibility, N=178.

Variable	Diabetes online community (DOC)		
	Competence	Caring/goodwill	Trustworthiness
Diabetes self-care	.144	.158 <sup>a</sup>	.169 <sup>a</sup>
DOC intensity	.364 <sup>c</sup>	.465 <sup>c</sup>	.322 <sup>c</sup>
DOC engagement	.196 <sup>b</sup>	.285 <sup>c</sup>	.215 <sup>b</sup>
Bonding social capital	.368 <sup>c</sup>	.504 <sup>c</sup>	.412 <sup>c</sup>
Bridging social capital	.369 <sup>c</sup>	.484 <sup>c</sup>	.380 <sup>c</sup>
Physical HRQOL <sup>d</sup>	-.002	.040	.060
Mental HRQOL	-.021	.014	.034

<sup>a</sup> $P < .05$ .<sup>b</sup> $P < .01$ .<sup>c</sup> $P < .001$ .<sup>d</sup>HRQOL=health related quality of life.

### Diabetes Health Care Team Source Credibility

The 3 factors of source credibility were also measured to determine the credibility of information coming from the participants' diabetes health care provider team. The mean score for diabetes health care provider team competence was 29.8 (SD 5.5), caring/goodwill was 32.8 (SD 9.1), and trustworthiness was 36.1 (SD 7.4). The Cronbach alpha values for the diabetes health care team were as follows: competence,  $\alpha = .90$ ; caring/goodwill,  $\alpha = .95$ ; and trustworthiness,  $\alpha = .93$ .

The relationships were identified between DOC and diabetes health care team source credibility scores (see Table 3). DOC competence and trustworthiness positively correlated with diabetes health care team trustworthiness. There were no relationships between DOC caring/goodwill and diabetes health care team competence or caring/goodwill.

Baby boomers (mean 34.61 [SD 9.0];  $P < .05$ ) found their diabetes health care provider team as having more caring/goodwill than younger adult counterparts (mean 31.46 [SD 9.0]). There were otherwise no significant differences between groups with regard to diabetes health care provider competence or trustworthiness factors.

There were differences in how all participants scored source credibility when comparing the DOC and their health care provider team. Participants scored their diabetes health care team (mean 33.5 [SD 8]) significantly higher than the DOC (mean 32 [SD 6.4]) with regard to competence ( $P < .05$ ) and trustworthiness (diabetes health care team mean 36.3 [SD 7.1]; DOC mean 33.6 [SD 6.2];  $P < .001$ ). There was no statistically significant difference in how participants scored DOC and diabetes health care team caring/goodwill.

There were similarities and differences in how DOC and diabetes health care team source credibility were associated with diabetes self-care, DOC intensity, DOC engagement, bonding and bridging social capital, and health-related quality of life (see Table 4). DOC and diabetes health care team source credibility were similar in that all source credibility factors correlated with diabetes self-care. Conversely, although DOC source credibility was associated with DOC intensity, DOC engagement, and bonding and bridging social capital, diabetes health care team source credibility correlated with health-related quality of life.

**Table 3.** Pearson product correlations between diabetes online community and diabetes health care team source credibility, N=178.

Variable	Diabetes online community		
	Competence	Caring/goodwill	Trustworthiness
Diabetes health care team competence	.098	.115	.148
Diabetes health care team caring/goodwill	.152 <sup>a</sup>	.119	.140
Diabetes health care team trustworthiness	.257 <sup>b</sup>	.137	.270 <sup>c</sup>

<sup>a</sup> $P < .05$ .<sup>b</sup> $P < .01$ .<sup>c</sup> $P < .001$ .

**Table 4.** Pearson product correlations for diabetes health care team source credibility, N=178.

Variable	Diabetes health care team		
	Competence	Caring/goodwill	Trustworthiness
Diabetes self-care	.188 <sup>a</sup>	.176 <sup>a</sup>	.195 <sup>a</sup>
Diabetes online community (DOC) intensity	.038	.008	.054
DOC engagement	.117	.128	.148
Bonding social capital	.000	-.012	.002
Bridging social capital	.124	.114	.129
Physical HRQOL <sup>b</sup>	.214 <sup>c</sup>	.234 <sup>c</sup>	.195 <sup>a</sup>
Mental HRQOL	.268 <sup>d</sup>	.340 <sup>d</sup>	.247 <sup>d</sup>

<sup>a</sup> $P < .05$ .<sup>b</sup>HRQOL=health related quality of life.<sup>c</sup> $P < .01$ .<sup>d</sup> $P < .001$ .

### Social Capital

The Internet Social Capital Scale bonding mean score was 3.08 (SD 0.64) and bridging mean score was 3.68 (SD 0.68). The Cronbach coefficient for the Internet Social Capital Scale was .89 (bonding=.69 and bridging=.92). High bonding and bridging social capital correlated with high DOC intensity ( $r=.629$ ;  $P<.001$  and  $r=.676$ ;  $P<.001$ , respectively) and high DOC engagement ( $r=.474$ ;  $P<.01$  and  $r=.507$ ;  $P<.01$ , respectively; see Table 5). Furthermore, high bonding ( $P<.001$ ) and bridging ( $P<.001$ ) social capital was identified in those who reported yes

to all 13 reasons to join a DOC (see Table 6). Bonding ( $P<.001$ ) and bridging ( $P<.001$ ) social capital scores were higher in those who had told their health care provider about their DOC use and felt supported (bonding mean 3.5 [SD 0.63]; bridging mean 4.2 [SD 0.51]) or were not sure (bonding mean 3.26 [SD 0.57]; bridging mean 3.93 [SD 0.48]) than those who had never told their health care providers about their DOC use at all (bonding mean 2.94 [SD 0.59]; bridging mean 3.48 [SD 0.68]). There was a negative correlation between bonding social capital and age ( $r=-.200$ ;  $P<.01$ ).

**Table 5.** Correlation matrix for health indicators, N=178.

Indicator	1	2	3	4	5	6	7
Diabetes online community (DOC) intensity	1.00	— <sup>a</sup>	—	—	—	—	—
DOC engagement	.572 <sup>b</sup>	1.00	—	—	—	—	—
Physical HRQOL <sup>c</sup>	-.043	.102	1.00	—	—	—	—
Mental HRQOL	-.076	.074	.651 <sup>b</sup>	1.00	—	—	—
Bonding social capital	.629 <sup>b</sup>	.474 <sup>b</sup>	.022	.028	1.00	—	—
Bridging social capital	.676 <sup>b</sup>	.507 <sup>b</sup>	-.010	-.014	.679 <sup>b</sup>	1.00	—
Diabetes self-care	.236 <sup>d</sup>	.170 <sup>e</sup>	.097	.301 <sup>d</sup>	.127	.234 <sup>d</sup>	1.00

<sup>a</sup>Not applicable.<sup>b</sup>Significance at the  $<.001$  level.<sup>c</sup>HRQOL=health related quality of life.<sup>d</sup>Significance at the  $<.01$  level.<sup>e</sup>Significance at the  $<.05$  level.

**Table 6.** Diabetes online community users who reported diabetes online community benefits and its relationship to bonding and bridging social capital, N=169–176.

Diabetes online community (DOC) benefit	Bonding social capital		Bridging social capital	
	Mean (SD)	P value	Mean (SD)	P value
<b>Feel understood</b>				
Yes	3.2 (0.61)	<.001	3.9 (0.53)	<.001
No	2.6 (0.53)	<.001	2.9 (0.64)	<.001
<b>Feel less alone</b>				
Yes	3.2 (0.62)	<.001	3.9 (0.55)	<.001
No	2.7 (0.48)	<.001	3.1 (0.71)	<.001
<b>Feel more empowered</b>				
Yes	3.3 (0.62)	<.001	3.9 (0.53)	<.001
No	2.6 (0.50)	<.001	3.0 (0.62)	<.001
<b>Feel support through rough times</b>				
Yes	3.3 (0.58)	<.001	4.0 (0.45)	<.001
No	2.7 (0.58)	<.001	3.3 (0.71)	<.001
<b>Learn new diabetes management strategies</b>				
Yes	3.2 (0.63)	.001	3.8 (0.58)	<.001
No	2.7 (0.63)	.001	3.1 (0.77)	<.001
<b>Learn research and treatment alternatives</b>				
Yes	3.2 (0.63)	<.001	3.8 (0.60)	<.001
No	2.7 (0.56)	<.001	3.0 (0.76)	<.001
<b>Get answers to diabetes questions</b>				
Yes	3.2 (0.63)	<.001	3.8 (0.56)	<.001
No	2.7 (0.53)	<.001	3.1 (0.73)	<.001
<b>Learn about potential side effects of drugs or devices</b>				
Yes	3.2 (0.62)	<.001	3.9 (0.59)	<.001
No	2.8 (0.63)	<.001	3.4 (0.75)	<.001
<b>Learn things that my health care provider did not know</b>				
Yes	3.2 (0.63)	<.001	3.9 (0.60)	<.001
No	2.9 (0.61)	<.001	3.4 (0.72)	<.001
<b>Learn strategies to improve insurance coverage for diabetes related medications, supplies, or tools</b>				
Yes	3.8 (0.63)	<.001	3.9 (0.62)	<.001
No	2.8 (0.55)	<.001	3.5 (0.67)	<.001
<b>Discussed a topic learned from DOC with my health care provider</b>				
Yes	3.3 (0.63)	<.001	3.9 (0.57)	<.001
No	2.9 (0.58)	<.001	3.5 (0.68)	<.001
<b>Help others</b>				
Yes	3.2 (0.61)	<.001	3.8 (0.54)	<.001
No	2.6 (0.57)	<.001	3.0 (0.87)	<.001

## Help

The greater majority of DOC participants (69.8%) reported that they or someone they knew were helped by following advice or health information on the DOC; although, 27.3% were not

sure. Those with type 1 diabetes (count 88, expected count 84.4) or LADA (count 16, expected count 14) were more likely to report help from the DOC when compared with those with type 2 diabetes (count 16, expected count 21.6;  $P<.05$ ). There were differences in DOC source credibility scores for caring/goodwill

and levels of help from the DOC:  $F_{2,166}=5.29$ ;  $P<.01$ . Those who reported that the DOC provided any level of help (mean 33.1 [SD 6.2]) had higher DOC caring/goodwill scores than those who reported “don’t know” (mean 29.3 [SD 8.8]). There were no significant differences in the perception of the DOC being helpful among baby boomers or younger adult counterparts.

### Harm

There was a very small percentage (1.8%) of participants who reported that they or someone they knew had been harmed, with the degree being minor, by following the advice or health information found on the DOC. Nearly half (45%) of the DOC participants reported that they did not know if harm had taken place. Participants had higher DOC competence scores if they reported no harm (mean 33.1 [SD 6.2]) than those who reported “don’t know” (mean 30.7 [SD 6.7];  $F_{2,166}=3.53$ ;  $P<.05$ ) and had higher DOC caring/goodwill scores if they reported no harm (mean 33.3 [SD 6]) than those who reported “don’t know” (mean 30.7 [SD 8.2];  $F_{2,165}=3.67$ ;  $P<.05$ ). Furthermore, participants had higher DOC trustworthiness scores if they reported no harm (mean 35 [SD 5.8]) than those who reported “don’t know” (mean 32.4 [SD 6.6];  $F_{2,161}=4.3$ ;  $P<.05$ ). There were no significant differences in the report of being harmed by gender or diabetes type. In addition, there were no significant differences in perception of the DOC being harmful among baby boomers or younger adult counterparts.

## Discussion

### Principal Findings

This is the first study known by the authors to examine differences in how baby boomer and younger adult counterparts perceive the DOC in terms of social capital, source credibility, and help and harm. Below, we discuss the significant findings and the implications for clinical practice.

Despite considerable differences generationally, in this study, baby boomers and younger adult DOC users perceived the credibility of DOC information similarly. Baby boomers are the first generation to transition into older adulthood with internet skills. Positioned as digital natives, baby boomers had to learn computer, internet, and social media skills later in life, opposed to digital natives or younger adults, who grew up with these technologies. Studies have shown that baby boomers are more trusting of online health information compared with older adults [39], which may explain why there was no difference between age groups. Baby boomers will seek out the internet first with health-related questions [40], which may be one way for baby boomers to be able to find DOCs.

Although there have been documented benefits to DOC use [7,41,42], baby boomers, in particular, may experience other benefits not yet explored. Research indicates isolation and loneliness is an increasing concern in older adult populations [43,44]. One solution to mitigate feelings of seclusion in older adults with diabetes is DOC use. In a semantic analysis of 1 DOC, TuDiabetes, Lewis et al found that older adults with type 2 diabetes used DOCs for companionship and support [45]. A

content analysis of DOC users on Twitter found that participants anticipated that they would continue using the DOC into old age, maintaining lifelong connections with peers they interact with now [46]. Finally, a qualitative study of older adult DOC users suggests that the DOC provides a consistent source of support even when someone’s physical location may change [41]. As older adult social networks get smaller because of death and relocation, the DOC may be one for maintaining social connections and avoiding isolation while supporting health.

DOC users find the information found on the DOC to be credible, overall. However, we found that DOC users found information from their health care providers to be more competent and trustworthy than the information found on the DOC. In contrast, research specific to 1 type of DOC focused on patient-driven diabetes innovation, with membership of mostly individuals with type 1 diabetes, found that peers were reported to be more trustworthy than health care providers [47]. Perhaps, this can be explained by the difference between a general DOC and a specialty DOC or the presence of various types of diabetes that we studied compared with type 1 only.

DOC source credibility was associated with high diabetes self-care and high social capital. DOC users were able to validate their experiences through homogenous DOC users, while gaining diverse information from heterogeneous DOC users to improve self-care. Obtaining these different perspectives on diabetes care provides DOC users with more depth of knowledge when making their own health care decisions [41] and supports patient activation [48]. Although we did not seek out information specific to the presence of misinformation, which can impact a DOC user’s perception of source credibility, other research has found that misinformation in the DOC is uncommon and corrected by peers in the DOC or benign when it does occur [33,49-51].

Interestingly, DOC users who felt supported by their health care provider to use the DOC found the information on the DOC to be more credible and helpful. This suggests that health care providers play a role in how DOC users perceive DOC source credibility and should engage in the DOC, as recommended by Brady et al [52], to understand the resources available to people with diabetes. A 2017 American Association of Diabetes Educator National Practice survey found that 34.7% of diabetes educators are recommending DOC sources to their patients and nearly three-quarters (73.4%) are using the DOC themselves in some way [53]. Although there is evidence that diabetes educators seem to be embracing DOCs, it is unknown if other health care providers, including those who routinely care for individuals with diabetes, are actively or passively participating in DOCs.

DOC users have high bonding and bridging social capital scores. Those who felt more connected to the DOC reported greater benefits with regard to knowledge attainment, social support, and empowerment. Those with high bridging social capital also had high diabetes self-care scores. Perhaps, this can be explained by the information gained from individuals who may have different diabetes experiences and treatment regimens that provide sources of education. One study found that 76% of DOC users learned new diabetes management strategies from

their peers [7]. In another study, when compared with non-DOC users, DOC users engaged in more self-care activities related to healthy diet, exercise, checking glucose, and taking insulin [54]. This study also indicates that individuals are able to learn things that their health care providers did not know through social capital.

Social capital provides a sense of social connectedness. Putnam [22] found that social connectedness strongly predicts altruism. Altruism has been identified in other online communities [6,28,55,56]. Individuals who engage in the DOC may be providing emotional, informational, instrumental, or companionship support to other DOC users for several reasons. DOC users may want to prevent others from experiencing any hardships they may have encountered, as such, they provide information to support learning. Conceivably, altruism comes full circle in that the support an individual DOC user provides the community is reciprocated in ways that benefit the individual DOC user in some way. For example, a baby boomer DOC user transitioning into retirement may find meaning and purpose in supporting other DOC users, which has been associated with improved physical function [57].

Overall, the DOC was seen as helpful and study participants reported minor harm only in a few instances. The findings were similar to those of a national survey of the general population [29] and another specialty DOC study [47]. There were marked differences in participants who were not sure if they were helped or harmed by the DOC, which warrants further study. Although additional information about harm was not asked in this study, our findings, and findings of others [47] who explored help and harm in a similar way, suggest that DOC use is beneficial with low risk. It is important to note that online peer health may not be helpful for all individuals with diabetes [58]. A secondary factor that unites peers, such as gender, culture, age, or shared experience [59], which is available within the DOC, may be necessary for optimal outcomes.

In summary, individuals seek online health information to fill a gap in their health care needs. The DOC appears to fill a void

in the current health care system with regard to day-to-day support [6,7,54,60] and is perceived as credible and helpful. Health care providers need to understand that although they are key sources for health information, they are among a large network of potential health information sources [61,62], which may include family, friends, and online peers with a similar condition. Access to social support, which has been identified within the DOC, can mediate better health outcomes [63] for baby boomers and younger adults.

### Limitations

The sample was overwhelmingly white and living in the United States, which may not be representative of the entire DOCs studied. Furthermore, this study examined only those who could read English. Individuals engaged in non-English speaking DOC sites (ie, EstaTuDiabetes) may elicit different results. The DOC source credibility measured a collection of information from the participant's interaction with DOC users as a whole when in fact a DOC user may rely on information from select individuals and avoid information from others. For those individuals who reported harm, it is unknown if that harm caused physical or mental harm or another form of harm. Finally, because of self-selection, generalizations should not be made.

### Conclusions

This is the first study to identify how DOC users view source credibility specifically to the DOC and their diabetes health care providers, social capital, and help and harm from the DOC. Baby boomers and younger adults perceived the credibility of DOC information similarly and found DOC use to be beneficial with low risk. DOC users found their health care providers to be more competent and trustworthy compared with the DOC, suggesting that DOC users find their health care provider valuable, despite their DOC use. Furthermore, a randomized clinical trial with DOC-naïve participants is warranted to understand the impact of DOCs on health outcomes, including variations of help and harm.

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### Conflicts of Interest

None declared.

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## Abbreviations

- HbA<sub>1c</sub>**: glycosylated hemoglobin  
**DOC**: diabetes online community  
**LADA**: latent autoimmune diabetes of adulthood  
**REDCap**: Research Electronic Data Capture  
**SCI-R**: Self-Care Inventory Revised

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Review

# Innovative Assisted Living Tools, Remote Monitoring Technologies, Artificial Intelligence-Driven Solutions, and Robotic Systems for Aging Societies: Systematic Review

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## Abstract

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**Background:** The increase in life expectancy and recent advancements in technology and medical science have changed the way we deliver health services to the aging societies. Evidence suggests that home telemonitoring can significantly decrease the number of readmissions, and continuous monitoring of older adults' daily activities and health-related issues might prevent medical emergencies.

**Objective:** The primary objective of this review was to identify advances in assistive technology devices for seniors and aging-in-place technology and to determine the level of evidence for research on remote patient monitoring, smart homes, telecare, and artificially intelligent monitoring systems.

**Methods:** A literature review was conducted using Cumulative Index to Nursing and Allied Health Literature Plus, MEDLINE, EMBASE, Institute of Electrical and Electronics Engineers Xplore, ProQuest Central, Scopus, and Science Direct. Publications related to older people's care, independent living, and novel assistive technologies were included in the study.

**Results:** A total of 91 publications met the inclusion criteria. In total, four themes emerged from the data: technology acceptance and readiness, novel patient monitoring and smart home technologies, intelligent algorithm and software engineering, and robotics technologies. The results revealed that most studies had poor reference standards without an explicit critical appraisal.

**Conclusions:** The use of ubiquitous in-home monitoring and smart technologies for aged people's care will increase their independence and the health care services available to them as well as improve frail elderly people's health care outcomes. This review identified four different themes that require different conceptual approaches to solution development. Although the engineering teams were focused on prototype and algorithm development, the medical science teams were concentrated on outcome research. We also identified the need to develop custom technology solutions for different aging societies. The convergence of medicine and informatics could lead to the development of new interdisciplinary research models and new assistive products for the care of older adults.

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**KEYWORDS**

innovative assisted living tools for aging society; artificially intelligent home monitoring; older adults; robotic technologies; smart home

## Introduction

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Life expectancy has increased worldwide, and countries have been experiencing the same challenges regardless of the

geographical location. According to the US Census Bureau, the population aged  $\geq 65$  years is expected to double over the next three decades and reach 83.7 million [1]. One of the most significant challenges of the aging population is that the incidence of chronic conditions such as dementia, Alzheimer

disease, congestive heart failure, and cancer and the need for medical attention have increased. However, rapid advances in technology have revolutionized medicine along with health care for the elderly.

Using a personal computer, remote patient monitoring device, smartphones, and mobile apps to improve the quality of the older persons' lives was not an option in the past. Each new technology enabled researchers and clinicians to develop new disease management protocols, especially for frail elderly people with chronic diseases and dementia. Recent randomized controlled trials and systematic reviews have documented that remote monitoring reduces specific 30-day hospital readmission and mortality rates [2,3]. Aging in place is defined as "remaining living in the community, with some level of independence, rather than in residential care" [4]. Although technology usage is limited among seniors aged  $\geq 75$  years, several prototype and experimental systems were developed, and various studies were conducted to support the elderly by clinicians, computer scientists, data scientists, and engineers; however, few studies explored the current trends in senior care technology research [5]. Therefore, the aim of this study was to explore the current research trends and level of evidence for remote patient monitoring, smart home, and artificially intelligent monitoring systems.

**Table 1.** Keywords and synonyms.

Keyword	Synonyms
Elderly	Aging (MeSH) <sup>a</sup> or Aged (MeSH) or Elderly People
Home care	Nursing Home (MeSH) or Home Health Care or Independent Living (MeSH)
Assistive technology	Ambient Assistive Living or Smart Home Technology or Telemedicine (MeSH) or Assistive Technology or Self-Help Devices (MeSH) or Artificial Intelligence (MeSH) in Eldercare

<sup>a</sup>MeSH: Medical Subject Headings.

## Inclusion and Exclusion Criteria

Quantitative, qualitative, and mixed method peer-reviewed publications and published conference papers were included. Research articles and case reports related to assistive technology

## Methods

### Study Design

The literature search was conducted in February 2019. Remote monitoring and intelligent health care technologies research conducted in both health care and technology disciplines as well as the following literature repositories were chosen for the search: Cumulative Index to Nursing and Allied Health Literature Plus, MEDLINE, EMBASE, Institute of Electrical and Electronics Engineers Xplore, ProQuest Central, Scopus, and Science Direct.

A variety of synonymous terms were combined using Boolean logic, and a combination of three groups of keywords—(1) elderly, (2) home care, and (3) assistive technology—was selected as the keywords. To include all relevant publications, their thesaurus equivalent words and associated Medical Subject Headings terms—aging, aged, telemedicine, elderly people, nursing home, home health care, independent living, ambient assistive living, smart home technology, self-help devices, and artificial intelligence (AI) in older people's care—were also included in the search (Table 1). We analyzed each article by the level of evidence and study type, objectives, and highlights. A combination of quantitative and qualitative approaches was used in the data analysis.

assessment for elderly care, set in homes, smart homes, experimental settings, nursing homes, and rehabilitation settings were selected.

The inclusion and exclusion criteria are listed in [Textboxes 1 and 2](#), respectively.

#### Textbox 1. Inclusion criteria.

- Published after January 2000 in English language
- Peer-reviewed journal articles and published conference papers
- Studies that focused on the latest technological, artificial intelligence, and complex software algorithms solutions for elderly care and novel assistive technologies and independent living
- Studies set in homes, smart homes, experimental laboratory settings, nursing homes, or rehabilitation settings
- Publications related to older people's care, independent living, and novel assistive technologies

#### Textbox 2. Exclusion criteria.

- Published before January 2000 in languages other than English
- Literature reviews and systematic reviews
- Book chapters, dissertations, theses, magazine articles, reports, wire feeds, position papers, editorials, white papers, and working papers

## Study Selection

A total of 1721 publications were found at the end of the initial search of the selected databases. Search strings and return values for each database are listed in [Textbox 3](#) and [Table 2](#), respectively. The list was filtered by removing duplicates, the

remaining abstracts were assessed, and the publications that did not meet the inclusion and exclusion criteria were excluded. At the end of this process, 91 eligible publications for inclusion were identified. [Figure 1](#) displays the search diagram and the number of articles assessed at each stage of the review.

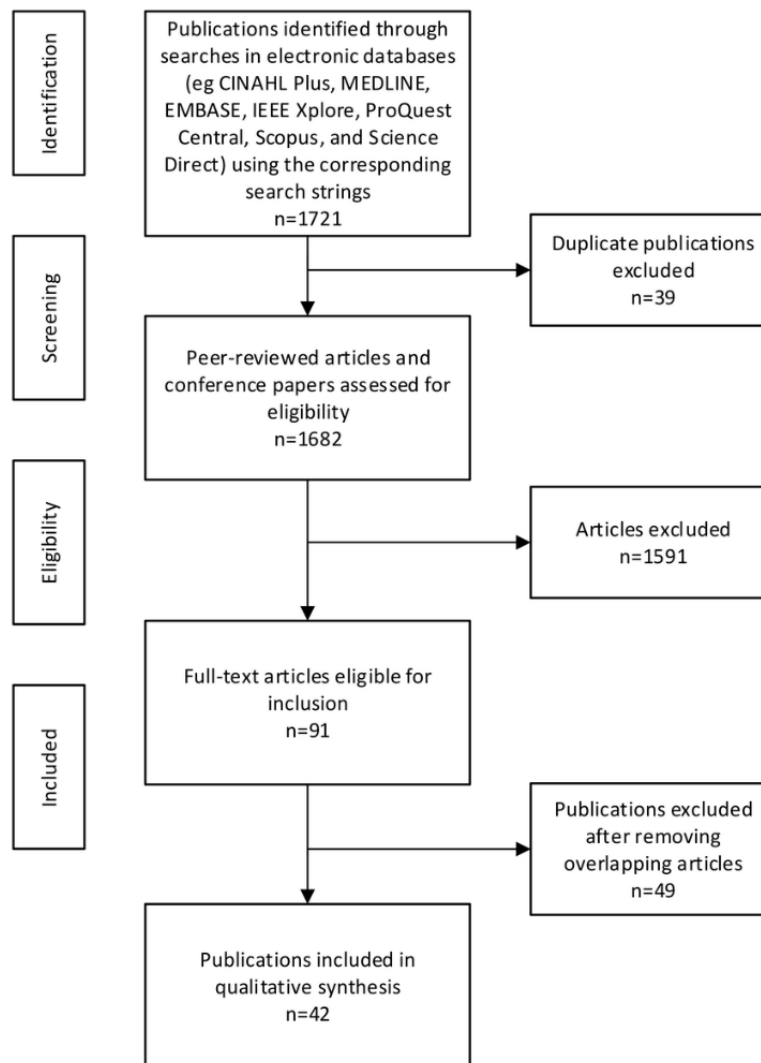
### Textbox 3. Search string.

("Aging" OR "Aged" OR "Elderly People") AND ("Nursing Home" OR "Independent Living") AND ("Self-Help Devices" OR "Telemedicine" OR "Ambient Assistive Living" or "Service Robot")

**Table 2.** Search queries and return values.

Database name	Return value (n)
Cumulative Index to Nursing and Allied Health Literature Plus	93
MEDLINE	159
EMBASE	279
Institute of Electrical and Electronics Engineers Xplore	31
ProQuest Central	747
Scopus	352
Science Direct	60

**Figure 1.** Search methodology. CINAHL: Cumulative Index to Nursing and Allied Health Literature; IEEE: Institute of Electrical and Electronics Engineers.



## Results

Analysis of the 91 full articles revealed innovative technologies that were developed to monitor older people's activities using various sensors, telemedicine, assistive robots, and remote monitoring devices. [Multimedia Appendix 1](#) lists the characteristics and highlights of the included studies [6-86].

Our review determined that the studies either focused on technology acceptance or examined the development of new patient monitoring and smart home technologies, real-time transmission of raw data, and AI algorithms. In the publications reviewed, most articles were qualitative, and only five studies were randomized controlled trials. First, we categorized the articles by types of study design. Most studies were quasi-experiment (n=43) and case reports (n=39). The others were case-control studies (n=3), cohort studies (n=1), and randomized controlled trials (n=5). The number and percentage of these articles are listed in [Table 3](#).

Second, we evaluated the levels of evidence of each article. The Oxford Centre for Evidence-Based Medicine levels rates evidence based on the study design, rigor, and validity and judges the strength of evidence in a technically accurate and

easily understandable manner. Therefore, this well-established and accepted standard was selected to determine the level of evidence [87]. The majority of the articles were listed as Level IV evidence that represents poor or nonindependent reference standards (49/91, 49%). Only 6% (6/91) of articles were listed as Level I evidence, which represents the studies with good reference standards. The classification of publications by levels of evidence is shown in [Table 4](#).

Third, to determine the current status and future challenges of disruptive technologies to support independent living, the selected articles were analyzed with regard to study objectives. [Figure 2](#) summarizes the focus of the articles evaluated. Of 91 articles, the majority were focused on older adults' acceptance and adoption of monitoring technology (n=17), smart home and telemedicine apps (n=16), robotic technologies (n=14), and usability evaluation (n=11). Many researchers evaluated novel remote monitoring technologies (n=10) and artificially intelligent assistive technologies (n=9). The remainder of the publications were about pattern recognition (n=6), wearable and mobile technologies (n=5), context-aware framework (n=2), and privacy considerations (n=1).

Fourth, as there is no widely accepted classification system to evaluate elderly care research that focuses on technology solutions, we conducted a thematic analysis, removed overlapping articles, identified 42 publications, and analyzed each device and app. Braun and Clarke [88] thematic analysis method was used to determine the patterns.

Finally, the studies that represent evolving topics were identified, and four themes emerged: technology acceptance and readiness, novel patient monitoring and smart home technologies, intelligent algorithm and software engineering, and robotics technologies (Multimedia Appendix 2) [6-29,56,57,65,73,103].

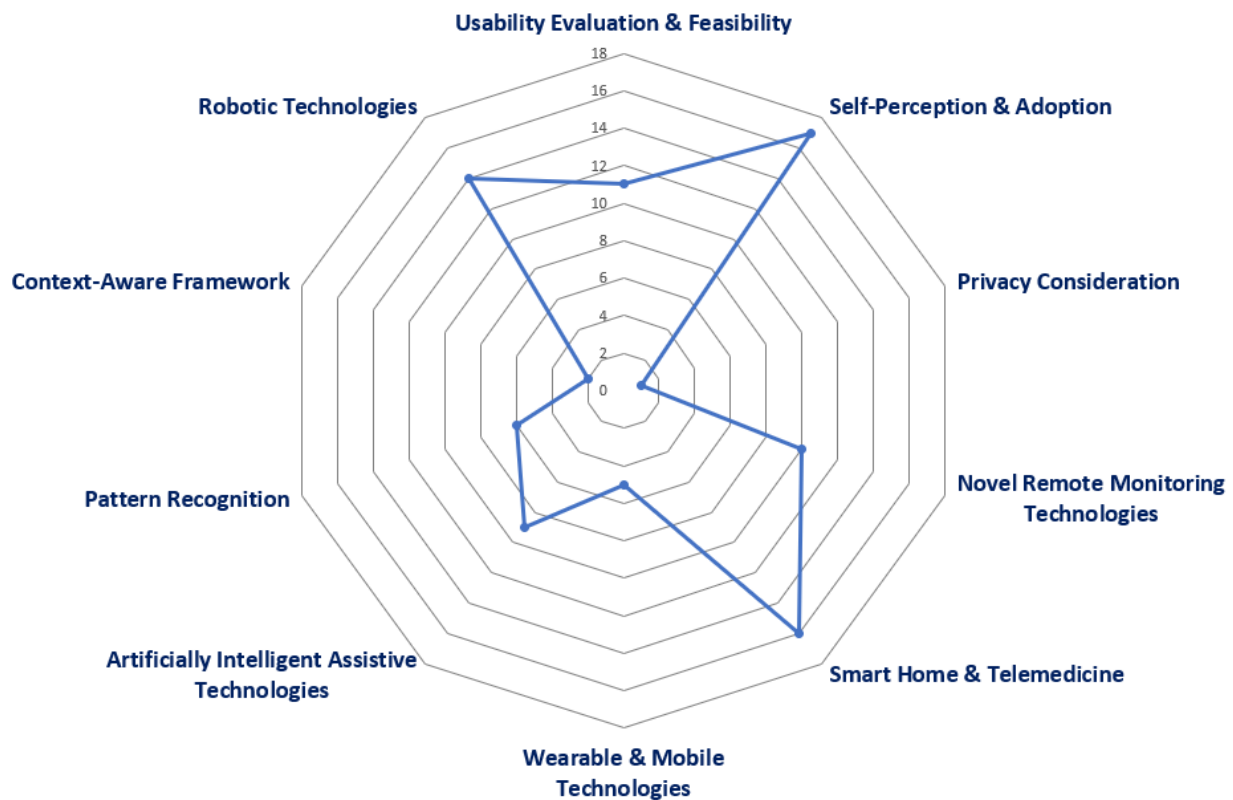
**Table 3.** Study types (N=91).

Category	Articles, n (%)
Case report	39 (42)
Case-control study	3 (3)
Cohort study	1 (1)
Quasi-experiment	43 (47)
Randomized controlled trial	5 (5)

**Table 4.** Levels of evidence (N=91).

Category	Articles, n (%)
I	5 (5)
II	6 (6)
IV	45 (49)
V	35 (38)

**Figure 2.** Study by research focus.



## Technology Acceptance and Readiness

### Overview

This theme encompasses studies related to technology adoption. Researchers investigated older adults’ willingness to accept contactless monitoring technologies, specific electronic health system, and smart home–based technologies such as bed, motion, kitchen safety, and fall detection sensors [6-8].

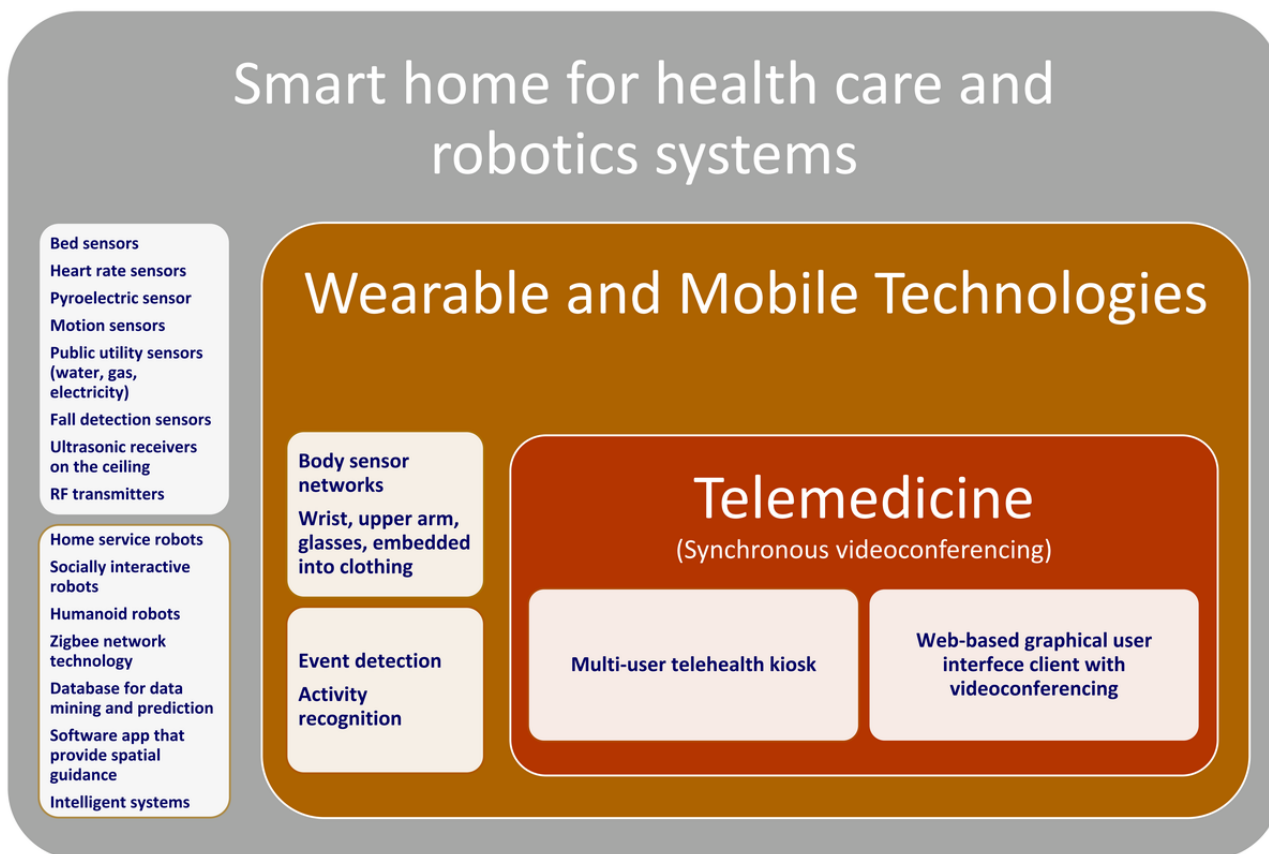
In addition to technology adoption, some studies explored perceived usefulness of telehealth kiosk—telehealth care systems that measure bed and chair occupation and detect falls, privacy concerns of in-home monitoring systems, older people’s attitudes toward assistive telemonitoring systems, acceptability of home monitoring technologies, and video-based monitoring technologies that capture data about daily activities [9-89]. Caregivers’ acceptance of home telecare technologies was also investigated along with wearable and ambient technologies [14,15].

## Novel Patient Monitoring and Smart Home Technologies

This theme comprises sophisticated systems that consist of home service robot; home and body sensor network; mobile device; cloud servers and remote caregivers; supervised machine learning approach and context-based reasoning to perform a clinical assessment of dementia; proof-of-concept platforms that consists of a Zigbee network, sensors, a home client, and remote server; and novel protocols over SMS to monitor elderly and alert caregivers when a fall occurs [90-92].

Common denominators for smart home for health care, robotics, wearable and mobile systems, and telemedicine apps were determined by analyzing each device and app. Our study revealed that researchers who focused on smart homes preferred novel sensor systems and ultrasonic receivers and transmitters for their study, and those who focused on remote monitoring preferred custom wearable devices and telemedicine equipment (Figure 3).

Figure 3. Technologies used for aging societies. RF: radio frequency.



In Europe, an international experimental Ambient Assisted Living project called Enhanced Complete Ambient Assisted Living Experiment successfully tested fall detection, activity classification, and energy expenditure algorithms to monitor patients’ activity and reduce morbidity and mortality [17]. Another novel technology explored by researchers was virtual reality (VR), and new technologies about the display quality, presence, user input, fidelity, and usability of virtual experiences demonstrated effectiveness to assess functional behavior and emphasized the potential of VR technology to empower dementia patients [18].

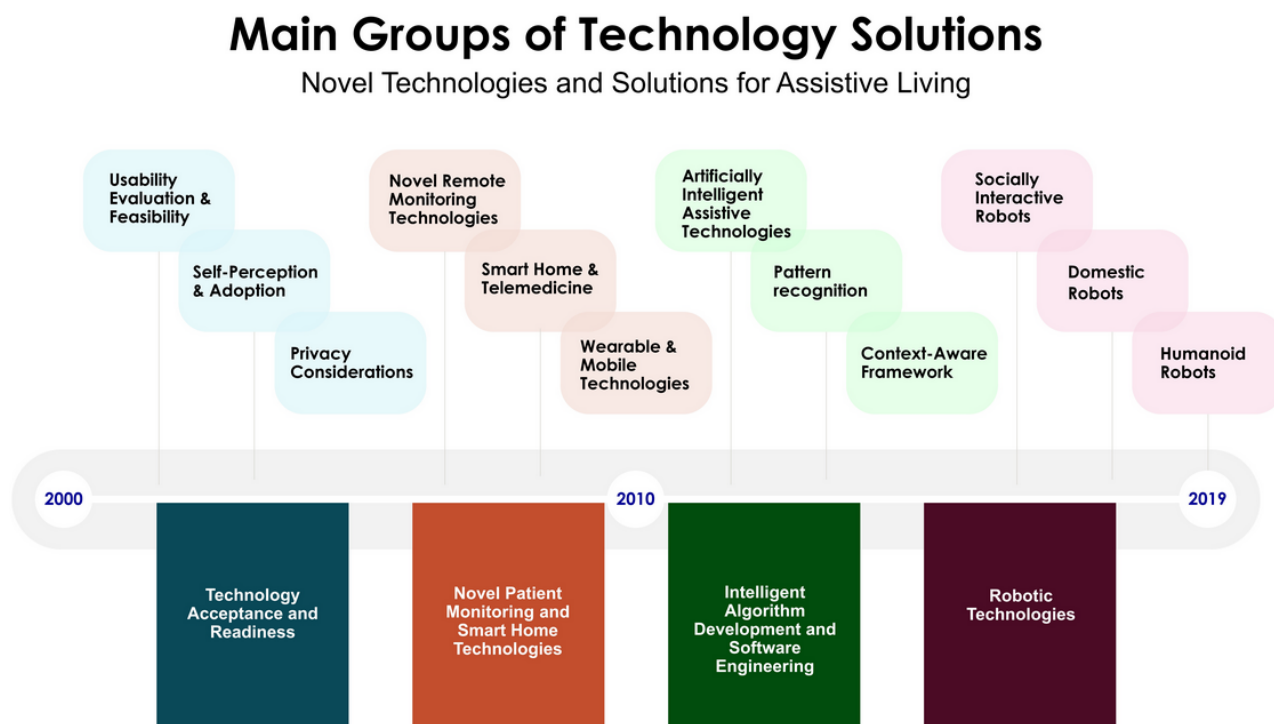
Several experimental prototype devices were also developed to monitor elderly patients’ progress and treatment. With regard to innovative low-cost Bluetooth-enabled technologies, some researchers developed a tediagnosis system for early detection of Alzheimer disease and captured the movement patterns [93]. A Web-based home monitoring system using wearable sensors was developed for patients with Parkinson disease [94].

A randomized controlled trial was designed to evaluate the Integrated Telehealth Education and Activation of Mood project’s clinical outcomes and demonstrated that the integration

of telemonitoring intervention improved geriatric home care patients' problem-solving skills and self-efficacy in managing their chronic illness [19]. In a different study, a sensor network system that comprised ultrasonic receivers, signal generators, radio frequency transmitters, ultrasonic 3D tags, and a computer successfully detected the accident-prone events in advance [95].

The increasing availability of the broadband internet, cellular communication technologies, internet of things apps that connect multiple devices and the decreasing cost of sensors have transformed various industries and markets. Our study demonstrates the potential of novel platforms that can improve assisted living and elderly care (Figure 4).

**Figure 4.** Technology solutions for elderly care.



### Intelligent Algorithm Development and Software Engineering

This theme comprises data mining algorithms that collect data about the environment and intelligently predict possible problems to make health care decisions, context-aware middleware to sense and respond to the user's environment, pyroelectric sensors, and infrared optoelectronic components designed to detect electromagnetic radiation and analyze the reasoning process in order to detect elderly people's activity [21-96].

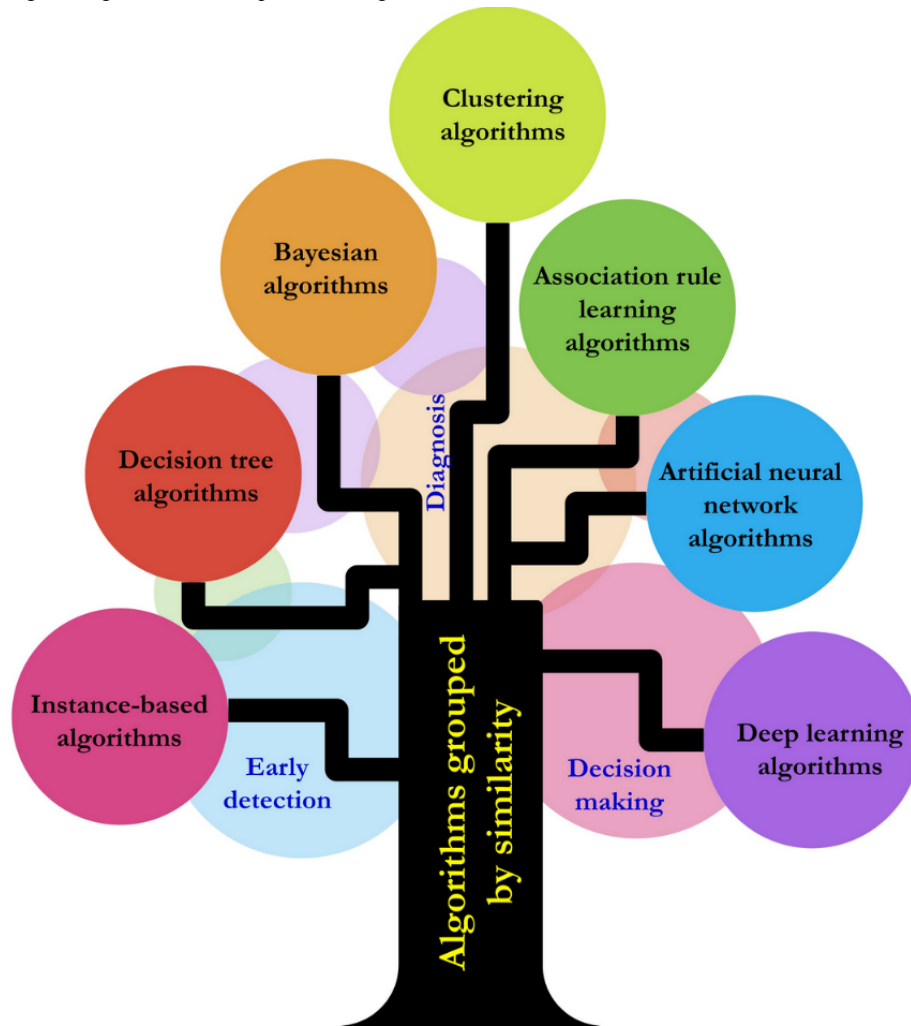
Some researchers developed predictive models and reported the optimal classifier of assistive technology adoption for people with dementia [22]. Another proof-of-concept navigation system based on augmented reality successfully generated a route to a

specific destination based on the user context including well-known places, social relationships, and point of interest (Figure 4) [23]. In information science, the term *ontology* encompasses entities, relations, functions, axioms, and instances. Ontology-based models combine data from multiple sources [97]. Researchers designed and successfully tested an ontology-based prototype knowledge system that can collect data from an RGB camera, 3D depth camera, and microphones [98].

Figure 5 summarizes the AI algorithms used for independent living apps. Most AI studies focused on instance-based algorithms, decision tree, Bayesian algorithm, clustering, association rule learning, artificial neural network, and deep learning algorithms.



Figure 5. Artificial intelligence algorithms for independent living.



## Robotics Technologies

This theme encompasses various robotic technologies that affect elderly care. Although some studies investigated a range of advanced AI technologies [24,99], others examined simple versions to evaluate robot-assisted activities. The increasing number of individuals that require rehabilitation and assistance has driven innovators to develop new robotics systems that can be integrated with elderly care solutions. Telepresence, companion, home automation and service, rehabilitation and health monitoring, and reminder robots can assist individual living.

The researchers who assessed AI technology for domestic assistive services developed eight different scenarios to understand the usefulness of the domestic robot in everyday situations and partially validated their results with experiments involving 100 participants [100]. Other researchers who evaluated robotic technologies used commercially available robots with tactile, light, and posture sensors and focused on studies about socially interactive robots. Similarly, a team of researchers in Japan developed a partner robot to relieve the solidarity feeling of elderly through conversation, quizzes, tongue twisters, and arithmetic calculations, and the experimental results were found to be promising [25].

Telepresence robots are remote-controlled devices that a user can drive from a different location and communicate with a remote site using the integrated videoconferencing systems.

A team of researchers used a sensor network infrastructure that comprised pressure monitor, glucose, weight, and oxygen sensors integrated with a telepresence robot. The project received support from the European Commission and deployed in real homes across Europe [26]. Another multidisciplinary effort to develop a mobile robotic assistant was the Pearl project. Researchers from the University of Michigan, University of Pittsburgh, and Carnegie Mellon University developed an autonomous robot to provide cognitive orthotic functions and tested it in a residential retirement community successfully [27].

Interestingly, some studies did not find any difference between a therapeutic robot and plush cats, and others emphasized technical challenges of intelligent modular service mobile robots that comprised tactile, infrared, and ultrasound sensors; Kinect and voice generation; and recognition systems [24,101]. Robots may also not be the best solution for certain care-related activities. A remote-controlled Spykee robot was used to make home hazard assessments for fall preventions, and it did not find an agreement between the robot and in-person video assessment [28]. A recent study conducted in Europe evaluated a software framework's efficiency using a humanoid robot and

validated each solution's efficiency using simulation and real case experiments [99].

This study revealed the multidisciplinary aspect of robotic technology and the development of autonomous mobile robots that can interact with elderly people and provide therapeutic benefits. The implementation of autonomous robots in elderly care requires collaboration among academic institutions, clinicians, and industry players and a focus on continuously improving the health care experience.

## Discussion

### Principal Findings

The purpose of this literature review was to determine the best available evidence about the development and implementation of technological solutions for elderly care, and in this paper, we report that the evolving technology trends can transform the aging population and ways that AI and pattern recognition might impact older individuals' care.

Specifically, we examined publications about intelligent remote monitoring, smart home health care, and robotic technologies to respond to the following research questions: (1) *what are the current trends in aging-in-place technology research?* and (2) *what is the level of evidence for remote patient monitoring, smart home, and artificially intelligent monitoring systems?*

To answer the first question, we determined the wide range of studies that focused on technology acceptance, novel patient monitoring and smart home technologies, intelligent algorithm development and software engineering, and robotics technologies. To answer the second question, the breakdown of the articles identified that most studies (85%) had poor reference standards without an explicit critical appraisal (Table 3), and the majority of the publications were qualitative.

This literature review demonstrated that most studies between 2000 and 2010 were designed to examine older adults' perceptions of technology. Intelligent assistive technologies have changed with an unpredictable pace, and consequently, there has been an increasing interest in exploring patient monitoring and home care technologies. The studies about technology acceptance led to more sophisticated studies that used wireless monitoring devices, sensors, intelligent algorithms, and experimental or quasi-experimental research methods. Thus, these studies can be considered as the first era of technology research for the aging society (Figure 4).

After 2010, we noticed an increase in the number of studies that explored prototype system development, implementation of new smart home technologies using sensors, development of assistive robots, and design of new AI and machine learning systems to support elderly care. The advancements in technology gave the researchers the ability to develop sophisticated AI algorithms, integrate advanced context acquisition methods, and analyze and automate high-level and complex tasks. This period can be considered as the second era of technology research for aging society, as many studies documented the potential use of robotic technologies, reported encouraging adoption rates, and recommended further experimental studies.

Our analysis demonstrated that many of the studies used unique technological solutions for different elderly groups. For example, studies that support independent lifestyle were designed for older people living alone in their home, whereas studies about new technologies for dementia and patients with Alzheimer disease were designed for older people living in nursing homes.

Data generated from medical devices have been growing so fast that using manual techniques to analyze data is not an option anymore to monitor home care patients. A recently published study assessed the use of patient-generated data in clinical practice and emphasized its impact on health outcomes [102]. Over the last decade, there has been a significant increase in the number of studies that focused on AI and machine learning. Some studies investigated user perceptions, barriers, and novel system development using sensors and smart home devices, whereas others focused on the development of context-aware and adaptive technology development. This technology can be integrated into different environments; can collect specific information such as temperatures, geographic locations, and user preference; and can deliver the relevant data depending on a set of variables unique to the user. Our review also revealed that the focus of AI apps for elderly care and sophisticated algorithms could improve the accuracy and the progress of analytical techniques. Therefore, it is likely that when combined with AI apps, remote monitoring systems will work faster and make more accurate predictions.

Moreover, this study identified several studies about novel innovative systems to monitor older people's health. Many of these studies were proof-of-concept systems to demonstrate the feasibility of the proposed equipment or app. It is quite challenging to determine the benefits and long-term impact of each technology or prototype systems because some technologies might become widely adopted in time, whereas others cannot find enough support for implementation. Furthermore, designing studies to validate health care institutions', nursing homes', and individual patients' technology adoption rates for elderly care might be challenging. Thus, we recommend nationwide studies to monitor technology adoption trends. Although this is an ambitious objective for individual researchers, governments and academic research institutions can collaborate and conduct these studies.

### Limitations

This study has some limitations. First, most study findings were not comparable because of the various research settings and types of technology used. Second, the majority of the studies were uncontrolled and had small user groups, and their level of evidence was between IV (45/91, 50%) and V (35/91, 39%). Owing to small sample sizes and methodological weaknesses in the studies, it was difficult to generalize their outcomes.

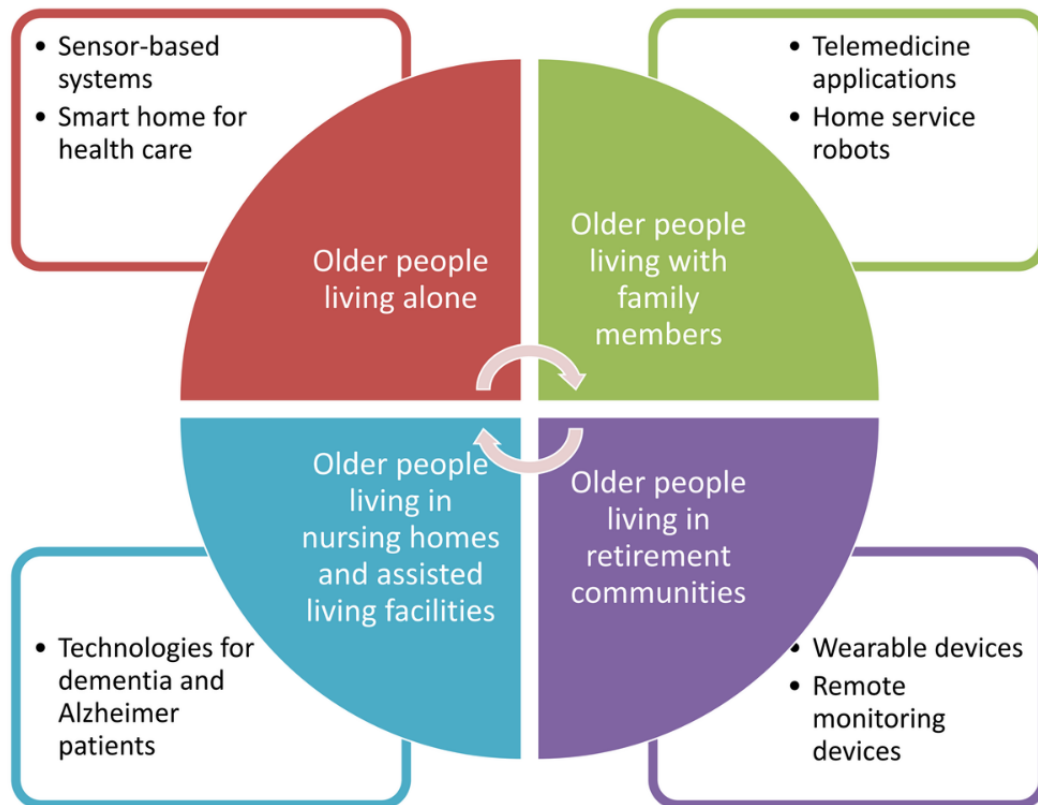
### Conclusions

Medical and engineering sciences have different principles and use different approaches for assisted living, home care, and telecare innovations. It is probable that older people's care will rely more on technology-driven patient solutions and AI algorithms to determine early warning predictions and initiate the interventions at earlier stages. Hence, we also propose the

development of custom technology solutions for different aging societies: (1) novel smart home apps and sensor-based systems for older people living alone, (2) home service robots and telemedicine apps for older people living with family members, (3) wearable and remote monitoring devices for older people living in retirement communities, and (4) technologies to assist older people with dementia living in nursing homes and assisted

living facilities (Figure 6). Machine learning and AI might be embedded into any hardware device, and further study is needed to identify aging society's custom technological needs and determine AI research priorities. Taking into consideration different aging societies' custom needs will improve older people's independent living skills and elderly patients' health care outcomes.

**Figure 6.** Technology solutions for different aging societies.



## Conflicts of Interest

None declared.

## Multimedia Appendix 1

Characteristics of included studies.

[DOCX File, 35 KB - [aging\\_v2i2e15429\\_app1.docx](#)]

## Multimedia Appendix 2

Emerging technology solutions.

[DOCX File, 18 KB - [aging\\_v2i2e15429\\_app2.docx](#)]

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## Abbreviations

**AI:** artificial intelligence

**VR:** virtual reality

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Original Paper

# Exploring Older Adults' Beliefs About the Use of Intelligent Assistants for Consumer Health Information Management: A Participatory Design Study

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## Abstract

**Background:** Intelligent assistants (IAs), also known as intelligent agents, use artificial intelligence to help users achieve a goal or complete a task. IAs represent a potential solution for providing older adults with individualized assistance at home, for example, to reduce social isolation, serve as memory aids, or help with disease management. However, to design IAs for health that are beneficial and accepted by older adults, it is important to understand their beliefs about IAs, how they would like to interact with IAs for consumer health, and how they desire to integrate IAs into their homes.

**Objective:** We explore older adults' mental models and beliefs about IAs, the tasks they want IAs to support, and how they would like to interact with IAs for consumer health. For the purpose of this study, we focus on IAs in the context of consumer health information management and search.

**Methods:** We present findings from an exploratory, qualitative study that investigated older adults' perspectives of IAs that aid with consumer health information search and management tasks. Eighteen older adults participated in a multiphase, participatory design workshop in which we engaged them in discussion, brainstorming, and design activities that helped us identify their current challenges managing and finding health information at home. We also explored their beliefs and ideas for an IA to assist them with consumer health tasks. We used participatory design activities to identify areas in which they felt IAs might be useful, but also to uncover the reasoning behind the ideas they presented. Discussions were audio-recorded and later transcribed. We compiled design artifacts collected during the study to supplement researcher transcripts and notes. Thematic analysis was used to analyze data.

**Results:** We found that participants saw IAs as potentially useful for providing recommendations, facilitating collaboration between themselves and other caregivers, and for alerts of serious illness. However, they also desired familiar and natural interactions with IAs (eg, using voice) that could, if need be, provide fluid and unconstrained interactions, reason about their symptoms, and provide information or advice. Other participants discussed the need for flexible IAs that could be used by those with low technical resources or skills.

**Conclusions:** From our findings, we present a discussion of three key components of participants' mental models, including the people, behaviors, and interactions they described that were important for IAs for consumer health information management and seeking. We then discuss the role of access, transparency, caregivers, and autonomy in design for addressing participants' concerns about privacy and trust as well as its role in assisting others that may interact with an IA on the older adults' behalf.

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**KEYWORDS**

intelligent assistants; artificial intelligence; chatbots; conversational agents; digital health; elderly; aging in place; participatory design; co-design; health information seeking

## *Introduction*

### **Background**

Advances in the field of artificial intelligence have led to growth in the number of consumer technologies that use intelligent assistants or intelligent agents (IAs) to help individuals with everyday tasks. The ubiquity of these technologies has led to a re-emerging interest in the use of IAs for aging and consumer health. IAs have the potential to provide older adults with new ways of managing their personal health and wellness decisions at home. Among the tasks that aging health care consumers often self-manage is the process of finding and making sense of health information to inform and provide self-awareness of their health and to support consumer health decisions.

Currently, many consumers rely on online health information to support health decisions and manage their health at home. A 2013 report of online health information seekers found that approximately 59% of respondents had searched online for health information for themselves or others [1]. In addition, access to online health information has been linked to improved health outcomes, especially among older adult populations [2]. Therefore, online health information is perceived as an essential resource to assist older adults with health care management and decisions [3]. Despite the potential benefits, many consumers still face challenges when searching for health information online [4-8]. Prior work has found that older adults face usability and accessibility challenges when searching for health information online and may find online health information overwhelming and have trouble understanding it [9-11].

### **Older Adults and Online Health Information Search**

The use of online health information by older adults to aid in health decisions has been largely beneficial. A large part of consumer decision making is the ability of an individual to use information they have gathered (prior knowledge) to inform their current decisions [12]. Older adults use online health information for a variety of reasons, including to support health decisions, search for information provided during doctor's visits, and to manage disease [3,6,13]. A review of research regarding older adults' online health information-seeking practices found that access to online health information was effective for improving several health outcomes (eg, adherence and overall quality of life) [2,14]. However, despite the many benefits, many older adults find it difficult to search for health information online.

Cline and Haynes [5] found that, in general, consumers face a myriad of challenges when searching for health information on the internet. Among these challenges are being presented with too much information, the use of technical language, and usability [4-8]. Because the information presented is often broad and difficult to navigate, users can also become confused or anxious [5,8]. Similarly, in the past, many online health websites

were plagued with usability and accessibility challenges that made them difficult for older adults to navigate [9,10]. In addition to technical challenges, older adults have also been found to face other more general challenges related to understanding health information (ie, lower health literacy levels) and negative attitudes toward technology that can make it difficult for them to effectively make use of online health information resources [11]. Therefore, gaps in knowledge still exist on how to best support older adults' consumer health information search practices and ways to help them find and understand the information they need to make informed consumer decisions about their health.

### **Supporting Consumer Health Information Search**

The emergence of new approaches for personalizing information and experiences has led to an increase in the number of intelligent interfaces that can assist with health tasks. The use of tailoring has been widely used in the area of health communication to reduce task complexity and simplify decision making among different groups of users [15]. However, researchers are beginning to explore how personalization, a form of digital tailoring, can be used to help improve online health search and communication tasks [16-23].

Several researchers have studied personalized approaches to support consumer search and understanding of health information [20,22-24]. For example, Fink and colleagues [24] explored the use of a guided search for assisting older adults with Web searches. They found that participants who used the guided search felt their search process would improve in the future. Several researchers have also looked at frameworks and models to support adaptive health interfaces [20,22,23] and further work on adaptive interfaces in health [16,21]. These interfaces automatically or semiautomatically change content or information based on knowledge of the user [25].

Shakshuki et al [20] proposed a multiagent learning technique for supporting adaptive health interfaces. Suggs and McIntyre [21] found that the availability of online tailored health communication for patients is increasing; however, it is not well-known what aspects of tailored communication contribute most to decision making. Similarly, Eslami and colleagues [16] found that although users were open to adaptation, it was important to identify the needs and preferences of users in context. Therefore, computer-based tailoring strategies are one way to support positive health outcomes [6,21,22], while also supporting the specific needs of users in the context of the health task [16].

Computer-based intelligent approaches, such as the use of IAs, represent an opportunity to personalize information, content, or processes to assist older adults with managing and finding relevant consumer health information at home. However, despite growing interest in IAs for aging and consumer health, and the importance of user perception on acceptance and adoption of

emerging technologies, there are still significant gaps in literature regarding how older adults perceive IAs for consumer health, their perceptions of how IAs should behave and assist them, and how they would like to integrate IAs in their health care regimen at home. Gaining a better understanding of older adults' beliefs and mental models of IAs for consumer health information management and search could lead to the design of tools that better align with their needs and better adoption and long-term use of these tools with potentially better health outcomes. The goal of this study is to explore older adults' perceptions, challenges, and needs for assistance to identify design opportunities for intelligent interfaces to support them in this task.

## Methods

### Overview

To understand older adults' perspectives regarding IAs for health information management and search, we conducted a design workshop with 18 older adult participants to identify their mental models. In this workshop, our goal was to better understand how older adults perceive an IA that would assist them with health tasks in their homes, including the physical form of the product (eg, how it looks), the function, and their beliefs and concerns about how it could be integrated and used within their home environment [26]. Two researchers assisted with the workshop. The workshop occurred over one day in July 2017 in a local senior center in Indianapolis, IN, and included several phases that involved different activities. We scheduled breaks between each phase to allow participants time to regroup and researchers time to prepare and transition to the next phase.

### Recruitment

We obtained institutional review board approval from Indiana University in Indianapolis, IN, before conducting the study. We recruited 18 participants from a local senior center. The only inclusion criteria were that participants be 60 years of age or older and have an interest in the purpose of the study. The senior center coordinator assisted with recruitment by sending our recruitment documents to their participant base, collecting names and contact information of interested participants, and helping to coordinate the workshop on-site. Written informed consent was collected on the day of the workshop. On arrival, each participant was provided with an informed consent document describing the purpose of the study, the study procedures, their right to leave the study at any point during the workshop, and contact information for the study principal investigator. In the session, participants were provided with time to read the informed consent or the option for the researcher to read the document to them. Participants were asked to sign the informed consent document if they were interested in proceeding. The workshop proceeded once all participants signed and returned their informed consent documents.

### Participants

Participants' ages ranged from 61 to 93 years (mean 76, SD 8). Fifteen participants identified as female, and the remaining

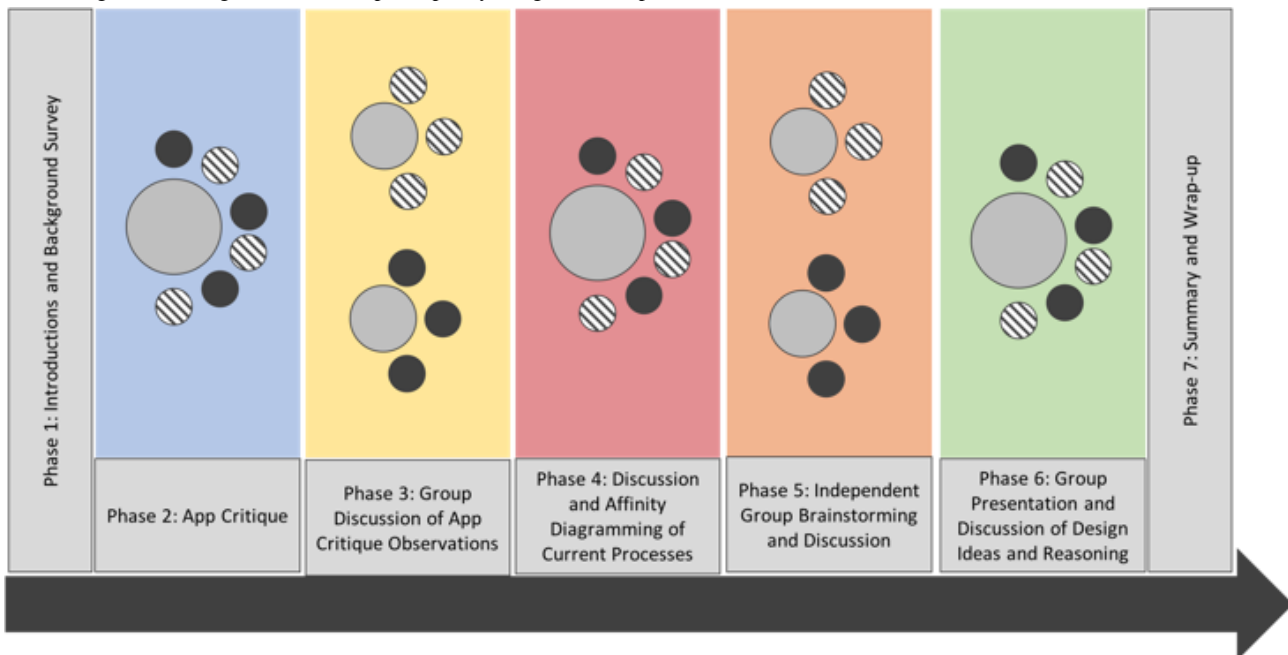
identified as male. Most participants (n=9) reported earning a high school diploma or equivalent (ie, GED), four participants earned an associate's degree or equivalent, and five participants reported that they earned less than a high school education. All but one participant (n=17) was retired.

Most (n=8) participants self-rated their current health status as relatively healthy. Six participants rated their current health status as somewhere between healthy and not so healthy, and three participants rated their health status as not so healthy. One participant did not rate their current health status. Reasons participants listed for their rating of relatively healthy included participation in regular exercise and healthy eating, not having any ailments (ongoing chronic illnesses or health issues), minor ailments such as slightly elevated blood pressure due to stress and acid reflux, not taking much medicine for their age, and being a three-time cancer survivor (ie, being diagnosed with cancer three times and surviving each time). Reasons participants listed for a rating between healthy and not so healthy included trying to eat healthier, borderline diabetes, slightly elevated or chronically high blood pressure and cholesterol, arthritis, joint and back pain, and minor complaints. Participants that rated themselves as not so healthy noted their reasons as having a disease such as congestive heart failure, multiple chronic conditions (chronic obstructive pulmonary disease and diabetes), and having a myocardial infarction.

In addition to demographic questions, we asked participants questions about their technology use. Most participants (17/18, 94%) did not use technology regularly (defined as more than 5 days per week); however, 11 (61%) participants reported browsing the internet periodically (1-2 days per week) using a mobile phone, tablet, or computer. Two participants browsed the internet on a regular basis (more than 3 days per week). Most participants (14/18, 11%) used a basic cell phone (ie, without smartphone capabilities) regularly or more than 5 days per week. Two (11%) participants used a smartphone and two (11%) participants used a laptop regularly. Three (17%) participants used a desktop; three (17%) participants used a touch-based tablet such as an iPad regularly. Of those that tracked their health information, most used paper and pen, but two participants reported using a mobile app to track their health indicators and one participant each used a wearable fitness tracker (Fitbit), diabetic meter, and desktop software. Fewer participants used technology to manage or organize health information. Only two participants reported using a website or other technology to manage health information.

### Participatory Design Workshop

The workshop was conducted in several phases with break periods interspersed between design activities to allow periods of rest for the participants and time for the researchers to organize data and prepare for subsequent phases (see Figure 1). On arrival, participants were greeted and provided with additional information about the study and a consent form. Once we obtained consent, we also asked participants to complete a demographic and computer use survey (phase 1).

**Figure 1.** Diagram outlining the flow of the participatory design workshop.

Participants were then asked to critique WebMD on a mobile or Web-based interface (phase 2). We first introduced the app to the larger group, and participants were later asked to divide into groups to complete the critique activity. The purpose of the critique session was two-fold. First, the critique acted as an icebreaker for groups of participants to get to know one another. Second, we wanted to introduce the participants to the idea of considering the benefits and tradeoffs of a design to prepare for later design activities. Groups were given time to try the interface and discuss the benefits and challenges with their teammates. Participants were provided with a printed copy of a list of questions to consider, including their initial impressions of the interface, what they liked and disliked about the interface, and how they may or may not use it. One person in each group was also asked to take notes as their team reviewed the interface. At the end of the critique, each team presented their thoughts to the larger group of participants (phase 3).

Researchers then engaged participants in an affinity diagramming session (phase 4) to identify how they manage and search for health information, the challenges they face, and their use of technology to assist in the process. Affinity diagramming is a process in which individuals iteratively cluster opinions, experiences, or insights to keep design teams grounded in data [27]. One researcher facilitated the discussion while the second researcher took notes. Participants were asked questions about how they keep track of health information at home. Participants wrote responses on sticky notes and placed them in a common area. Afterward, one researcher led the group in a discussion of the responses as the other researcher continued to take notes.

After a short break, participants brainstormed ideas for an intelligent or “smart” interface that might assist them with finding and managing consumer health information (phase 5). To give some guidance on the definition of an IA, the facilitator provided a scenario that included a user interacting with a nontechnical form of assistance, such as asking a doctor to find

health information. The facilitator explained that a smart interface might perform similar tasks. The facilitator also explained that they could think of a technology that could assist them with questions they had about their health. However, because we wanted to understand participants’ ideas of how an IA for health might look and work, the facilitator emphasized that their ideas could be any tool or product that they felt could assist them with achieving this goal.

For this part of the workshop, participants were divided into five groups of at least three team members and spent approximately 30 minutes brainstorming and discussing their ideas. Each group was again provided with a set of questions to help them think through the reasons behind their designs and to help us keep track of their reasoning. The questions focused on helping them think about what type of assistance they wanted, how they would use their technology, and the reasons for their decisions. One group member was asked to take notes to later report to the group.

Both facilitators walked around to listen in on discussions and to take notes. Toward the end of the design activity, each researcher visited briefly with each group to help them refine their ideas and prepare for presentation. After the design activity, each team presented their idea to the larger group for discussion along with their reasons for their decisions (phase 6). However, it is important to note that because the goal of the workshop was to understand participants’ beliefs and not to explore novel designs, we did not participate in the idea generation as to not bias our results. Finally, participants were asked for any additional feedback on the study, thanked, and provided with a US \$20 gift card for their time (phase 7).

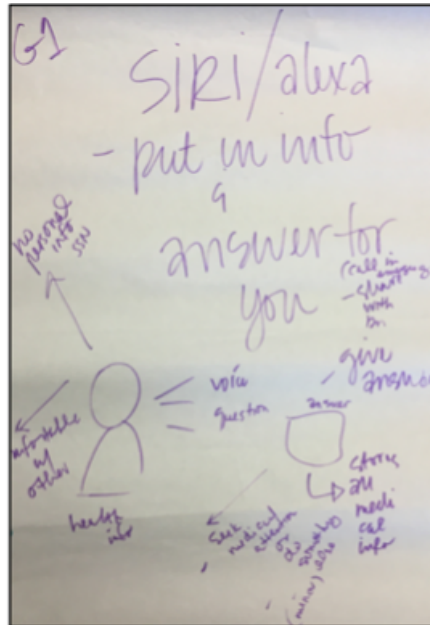
### Data Analysis

Researchers took detailed handwritten notes of participant responses and their research observations. Immediately following the workshop, the two researchers who facilitated the workshop met to debrief and compare notes. The workshop

sessions were audio-recorded and later transcribed to supplement researchers' notes about participants' responses to questions in group discussions and sketches of the participants' design concepts (see Figure 2). All artifacts collected during the workshop, including large sticky notes of design concepts sketched during the workshop, images of the affinity diagramming results, and participants' written descriptions of

their ideas, were compiled to supplement the transcripts and notes. Data analysis involved open coding of data by three researchers to identify common themes in the data to create a list of codes [28]. Codes were iteratively refined and later applied to qualitative data. High-level themes were developed using axial coding. Data collected in the demographic survey were analyzed using descriptive statistics.

**Figure 2.** Brainstorming sketch from the design workshop for group 1.



## Results

Themes emerging from the design workshop centered on older adults' perceptions of their expectations of how IAs could be designed and used for consumer health information search and management, concerns they had regarding using IAs for consumer health search activities, and concerns about potential barriers that would limit their ability to integrate IAs in their home.

### Health Information Management Strategies and Challenges

The findings from the participatory design workshop's affinity diagramming session revealed that 7 of 18 participants did not have strategies in place to manage their health information. However, during the discussions, most participants agreed that there was value in keeping track of health information themselves and, therefore, a combination of their interest in improving their health and past challenges with attempting to use technology to manage their health motivated their participation in the workshop. The advantages they discussed included scheduling, facilitating discussion with their doctor, staying informed, and being able to better monitor their health and identify a serious illness.

Of the 11 participants who did manage their health information, most used a paper-based filing system or calendar ( $n=5$ ) or relied on their doctor to provide information about their health ( $n=4$ ). Participants discussed several types of health information they tracked, including medication information, appointments,

insurance information, and alternative treatments. Of those participants who searched for health information, most ( $n=6$ ) used that information to consult with their doctor and also included at least one other person in their health care management routine. In addition to their doctor ( $n=6$ ), participants discussed that they would also include immediate family members (eg, spouse or child) on issues related to their health ( $n=13$ ).

Our participants saw value in keeping track of health information and being able to search for consumer health to support decisions and next steps. However, although most participant groups discussed that they had attempted at one point to find health information, not all participants currently actively managed their own health information or searched for health information at home.

### Participants' Design Scenarios

Of the five groups of participants, four described ideas about IAs. One group (group 2) described their preference for talking with a health care provider or another caregiver in lieu of any other type of assistance. The design ideas presented by the groups were not completely novel as different aspects of the design have been addressed in other ways by technology. However, comparing the form, features, and functionality discussed and how participants described the assistance helped us to understand their perspectives of how they believed IAs for consumer health information management and search would look, behave, and be integrated into their lives. We did provide abstract guidance on what to design (IAs for assistance with

health searches at home), and the participants also critiqued a website earlier in the workshop. However, similar to Davidson and Jensen [29], we found that the critique did not influence creativity of ideas and each group developed somewhat unique designs. We provide a brief description of each subsequently.

### ***Intelligent Voice Assistant for Health***

Participants in group 1 posed the idea of an intelligent voice assistant (eg, smart speaker) that they could ask health questions, and it would respond with appropriate answers. They discussed that their idea was inspired by commercials they had seen for Echo and Google Home, and they felt that this would be a good way to interact with health information. However, different from existing devices, the system would store their health history and provide answers that were specifically relevant to them. The system would provide options for them to easily share information with caregivers and could automatically differentiate between minor and severe medical situations to detect emergencies.

### ***Talk With a Health Professional or Caregiver***

Participants in group 2 expressed that they preferred to talk with a health care professional instead of interacting with an IA for health. They felt that talking to a health care provider would be faster for finding answers to health questions because the provider would already know their medical history. Participants had not experienced challenges with quickly communicating with their doctor in the past. They noted that their opinion might change if their providers were “very busy.”

### ***Simple Interactions and Simple Information***

Group 3 felt that the technology medium that communicated the information would not matter as long as it was easy to learn, use, and provided simple interactions. They described that the system might ask them questions (but not too many) about health conditions or symptoms and provide tailored search results. They also stressed that information communicated should above all be easy to understand and use simple language that is not overwhelming.

### ***Q&A Health Website***

Group 4 described a health website or “personal device” that could provide them with “simple” answers to the questions they asked. The inspiration for this design came from the participants’ experiences attempting to use the internet to find information, and the challenges they encountered using different websites. The website would not include any advertisements and could provide answers that were tailored to them. The assistant would also provide suggestions on other topics, such as how to manage their chronic illness or alternative medications to try.

### ***Automated Phone System***

Group 5 described an automated phone system for finding answers to health questions. The inspiration for this design came from participants’ beliefs that they felt not all older adults would have access to technology, such as an iPad, computer, or even the internet, but they felt that most would have a phone at home. They described that the automated system would store

information about a user’s health history and emergency contacts, which they would enter during account setup. The user could then call the system to receive personalized answers to their questions, connect with local providers, or find information about symptoms or medications. The system could also compare symptoms with their health history to infer about and diagnose serious illness or emergencies.

### **Types of Assistance Described**

From the scenarios, five themes emerged related to the ways participants believed an IA might benefit or improve their day-to-day consumer health tasks at home. Because of past difficulties searching for health information at home, all the ideas proposed by the four groups were ideas for IAs that could make searching for health information easier (see Table 1).

Participants described how an IA might help them find relevant information faster by using knowledge of their health to provide tailored responses or narrow search results. For example, a member of group 3 expressed frustration with trying to find information relevant to their needs online:

*[When searching for health information] Get to the point. I don’t want to have to [search through] 50 answers just get to the point. I mean I tried to get on sites [health websites] and everything...you know people say go here or something like that and you get there [to the website] and it says well you have to do this and you have to do this and this and this. Hey, you know, I just want to go there and get to the point.*

Both groups 3 and 4 discussed the complexities of searching for and understanding health information. Therefore, their groups suggested features that could narrow choices and remove irrelevant information to support a straightforward search process. Groups 1, 4, and 5 proposed interfaces that could help with the search process by using knowledge of their medical history to provide personalized versus generic information.

Two groups also described in their scenarios instances in which an IA could help them make sense of health information by simplifying medical or health jargon and descriptions of health text. Groups 3 and 4 described a desire for features to help simplify the process of making sense of health information:

*Explain things in plain language...currently it’s [health information] hard to understand [Group 3]*

Therefore, participants proposed IA features that not only helped them find relevant information faster, but that could also assist them with understanding the information once presented. Similarly, groups 1, 4, and 5 suggested that IAs could provide them with advice and recommendations about illnesses, symptoms, and medications. For example, when describing their design scenario, group 5 explained that their automated phone system would allow a user to “call in to ask a question about a symptom or illness and get an answer.” They described that the user would have a code that would allow them to store their information, and after entering the code they could “ask questions about some type of symptom they may have.”

**Table 1.** Types of assistance that groups mentioned when describing their intelligent assistant concept.

Type of assistance	Group(s) <sup>a</sup>
Finding relevant consumer health information	1, 3, 4, and 5
Making sense of consumer health information	3 and 4
Providing advice/recommendations	1, 4, and 5
Facilitating collaborative decisions	1, 3, 4, and 5
Diagnosing serious or emergency illnesses	1 and 5

<sup>a</sup>Group 1: intelligent voice assistant for health; group 3: simple interactions and simple information; group 4: Q&A health website; group 5: automated phone system.

Although each group brainstormed their design scenarios independently of other groups and the researchers, the mention of “simple search,” “simple language,” and “simple direct answers” were pervasive as each group shared their design scenarios with the larger group. The participants’ desire for simplicity was mainly due to their experiences and perception of the complexity of the online search process for health information. Therefore, most participant ideas centered on how IAs could support the search process by removing some of that burden from the user. However, groups were not fully trusting of IAs for certain search tasks as evidenced by their dialog on the importance of including functionality that allowed the system to facilitate collaborative decisions about their health with a doctor or family member. All groups mentioned features that allowed them to collaborate with doctors or family members involved in their caregiving and health care decision making:

*We were thinking [initially] a personal device [the interface idea], but maybe it could share with the doctor or family that you would want to include in decision-making processes [Group 4]*

The spokesperson for the group indicated that they originally felt that the interface should include some sort of option for storing information locally, so that the user could limit access to their medical information and preferences; however, they decided that it would be useful to share information with others that could provide input to the users’ decisions. Groups 1, 3, and 5 agreed that there would be cases in which they would prefer or feel more comfortable talking with a health care professional. They indicated that their interface idea included features that would allow them to share information and include either a health care provider or family member in their decisions if they desired.

Finally, two groups discussed scenarios in which their assistant would help with the diagnosis of serious illness (eg, congestive heart failure) by learning about their health and reasoning from their queries:

*[I would include] all my medical information, my medical history, like if I have congestive heart failure and if I am having pains or something, I could ask it something and it could tell me if I need to seek medical help or maybe it could get me something that I could use to ease it myself. [Group 1]*

## Proposed Technology Medium and Ways of Interacting

Each of the four groups that presented ideas for IAs introduced different mediums, including a voice assistant, website, and an automated telephone system; one group was apathetic about the medium but stressed that it should be simple, easy to learn, and easy to use. Most of the discussion about form centered around the need for IAs to be integrated into technology that is familiar or that provides for natural interactions that are easy to learn. Some participants also discussed the need for the technology to be easily accessible to those with and without technology resources at home. However, we also found that the groups described similar qualities when discussing their assistant and how it would work. The purpose of the workshop was to understand older adults’ mental models of IAs for health; therefore, each group (except for group 2), proposed some level of intelligent interaction. Apart from intelligence, groups seemed to describe mediums with which they were either already familiar (website, telephone) or that could be easily learned through natural interaction (voice assistant, simple medium):

*They have these books for everything. So, we put down “Health Info for Dummies”...It could be a website or whatever...Put it [the information] in simple language so that people will know what it is. Also, not 50 pages of blah blah blah...just simple, simple language, easy to use. [Group 3]*

Participants also described fluid and unconstrained interactions with their assistant noting at times that they felt the assistant should reason about their symptoms, provide recommendations or information, and seamlessly move from one health topic to the next:

*A machine like Alexa, [you] put in all the medical information that pertains to seniors like arthritis, headaches, broken hips, and all that stuff...we ask it a question and it answers it...You know, [you can say] I have a headache, I have this, I have that. Give them the symptoms just like you do on a tablet, and it will come up with the answer. [Group 1]*

At the same time, groups also described the need for the assistant to be transparent about its limitations for providing safe advice and instead be able to switch from the role of assisting with care to facilitating care:

*If it’s not serious [the situation], the system could instead provide them with a list of doctors names and*



*numbers that they could contact in their area for help*  
[Group 5]

Therefore, although participants described different mediums, they all seemed to value familiar and natural mediums that were easy to learn and use. In addition, groups seemed to value interactions that were transparent but also fluid and unconstrained.

### Concerns for Home Integration

Participants discussed two major concerns about integrating IAs for health in their homes. First, groups expressed concerns about privacy and described ways their IA might secure user information:

*If there was some way of being able to store your own information on your own device. You know like...if you have access to the internet then they have access to your answers too, so I don't like that, but if there were some way of cutting that out where you can access the Web without having to give it back all your information it would be nice to have your own personal thing. I don't know how that would work.*  
[Participant, group 4]

All four groups raised similar concerns about privacy. Another group suggested using a code to limit access to personal health data using their automated phone system: "I'm just speaking for the people that don't have access to the internet, so the phone would be ideal for them, and they could put in a code or something if they didn't want people to get to that information" (Participant, group 5).

Participants raised a different set of concerns about internet access and availability at home and potentially being limited to certain mediums. Group 1, when brainstorming ideas for a solution, eventually settled on a voice assistant but considered their past challenges of finding a stable internet connection. They considered that other older adults may not have internet access at home and that they might have to negotiate for technology resources to be able to adopt the IA for health. The following conversation occurred between two participants in group 1:

*PA: I don't think a lot of seniors have Wi-Fi.*

*PB: They don't because I come here [to the center] and then I can use it [the internet] here but I don't have it at home. But, my neighbor across the street...*

*PA: Yeah, sometimes you can pick up on.*

*PB: So, I went over there [the neighbor's house]...*

*PA: Like the folks next door?*

*PB: You have to get their Wi-Fi [password]...*

*PA: Right.*

*PB: and I did go over and ask them could I, you know, did she have Wi-Fi and she said yes, now since she told me, I can use this [the Wi-Fi] at home.*

Another participant expressed that she also wished that there was not such a reliance on internet access when using different apps:

*I just wish it [health apps] worked without the internet because I let mine [internet] go because my computer messed up and I was like oh well, I'm just not going to get another one [computer]. I [now] ask the kids something and they always Google it or do whatever they do to try and find out [for me]. They will try and find out from different people the symptoms or what they do to cure it, but that's not actually what it is.*  
[Group 5]

Participants' choice of medium and concerns for adoption also seemed to take into account whether or not they felt the system could be seamlessly adopted into their existing home environment without consequence.

## Discussion

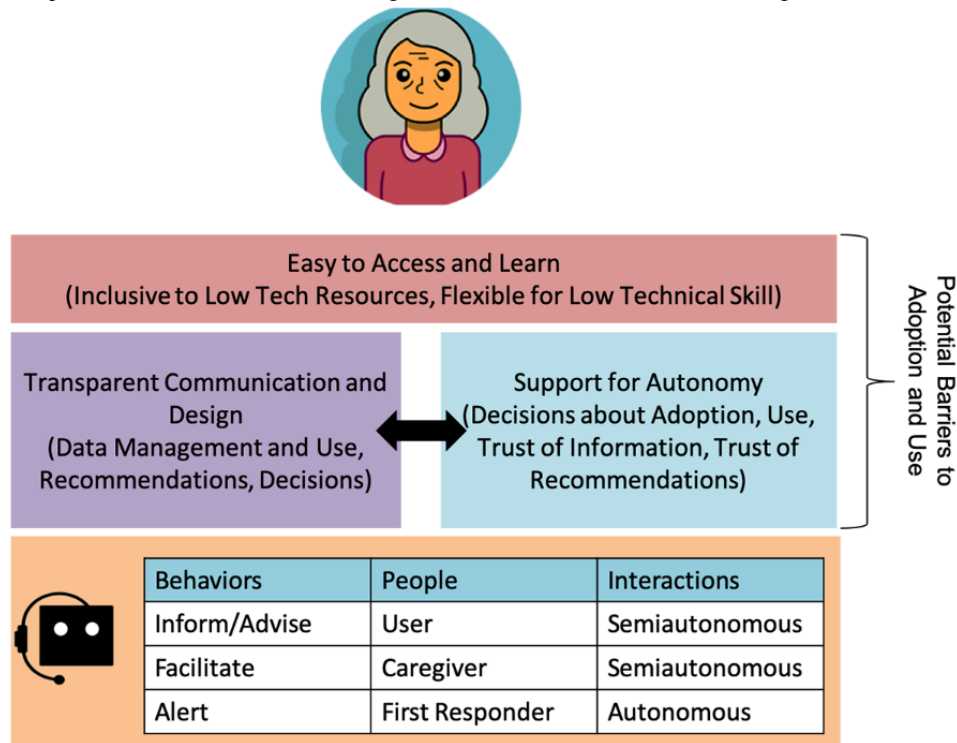
We provide a summary of our findings of participants' beliefs and mental models regarding the use of IAs for health information search and management at home.

### Modeling Interactions Between Older Adults and Intelligent Assistants for Health Information Management

Overall, our participants desired an IA that could reduce the time and effort it takes for them or others involved in their health care regimen (ie, caregivers, doctors) to find, manage, and share consumer health information relevant to their needs. Several groups discussed ideas related to the use of tailoring or personalization to improve search, navigation, or response. In general, the participants who suggested a technological solution wanted IAs that addressed some of the challenges they encountered with health information management and search that they felt were not currently being addressed or could be better addressed with an intelligent interface. From our findings, we contribute a model describing the categories of behaviors, people, and types of interactions participants expected from an IA for health as well as how participants expect these interactions to take place (see [Figure 3](#)).

In the model, the first layer relates to ease of access and learning. Before considering other factors, the ability to access the features provided by an IA for health, whether it be access to the IA in a low-tech resource environment or access by someone with low technical skill, can influence whether the IA is adopted. The discussions about the look and feel (form) of the IA centered around mediums that participants were already familiar with or natural (ie, perceived easy to learn) to emphasize the notion that interacting with an IA should not be cumbersome and should limit or eliminate their current challenges with health information management and search tools they had tried opposed to making the process more difficult.

Figure 3. Model of participants' desired interactions with intelligent assistants for health information management and search.



The second layer focuses on transparency and autonomy, which not only plays a role in the potential adoption of an IA for health but also for long-term continued use. If older adults need to understand how the IA works and the need for governing the tasks supported by IAs are not met, it may influence initial adoption or use over time. We categorize access, transparency, and autonomy as potential barriers to adoption and long-term use because our findings suggest that these factors are often considered apart from the type of support provided. An IA may provide adequate support for a health information management or search task, but if it is not easily accessed, learned, or does not provide the proper levels of transparency and autonomy, our findings suggest it may not be adopted or may ultimately be abandoned. For example, a user may want help understanding what data are shared about themselves and, ultimately, if a certain IA feature is something they would like to adopt.

The third level represents communication and interaction between the user and the IA or other individuals involved in their care. Our findings suggest that the relationships between the three categories of behaviors, people, and interactions were somewhat fluid and reciprocal in that each category in some way related to and was dependent on the others. The behaviors described as tasks for IAs were sending alerts, facilitating interactions with others involved in their care, and informing or advising personal health decisions. The people participants discussed apart from themselves as being potential users that might interact with an IA on their behalf were informal caregivers (eg, child, spouse), formal caregivers (eg, doctor, nurse), and first responders (ie, emergency medical providers). Interactions described were either autonomous (ie, completed by the IA without their involvement) or semiautonomous (ie, completed by the IA with their involvement). For example, the ideas presented regarding IAs for alerts mainly focused on first responders; in this situation, participants desired more

autonomous interactions that could initiate assistance if they were unable to do so themselves. When describing IAs that helped with the facilitation of health tasks, the discussion centered on formal and informal caregivers and the exchange of information for assisting them with awareness and decision making. In these instances, participants described more semiautonomous interactions in which they had control over what information was shared and when.

**Relationship to Prior Work**

Some of the open issues that emerged from our findings are known or have been addressed in other fields of study. For example, participants discussed their desire for tailoring and personalization. In the field of health care, the idea (and practice) of tailoring information has been used for some time to provide personalized content to health care consumers [15]. In computer science and human-computer interaction, intelligent interfaces that gather user characteristics automatically or manually have been widely leveraged to adapt and provide users with personalized experiences [20,22-24]. Therefore, it is well-known that using IAs to personalize or adapt information and content can simplify the process for users. Therefore, our work builds on this prior work citing participants' desires for personalized features in the design of consumer health information management and search tools. However, the success of any intelligent interface design and implementation project often largely depends on understanding users' goals and needs for that specific task [19,25]. Our work contributes insight and understanding regarding how older adults perceive IAs might be useful to assist them with consumer health information management and search tasks at home. These insights can begin to help designers and researchers understand where implementation of IAs might likely yield adoption in this context. However, more research is needed to completely

understand how to address these needs in a way that provides the transparency and autonomy desired, but that also considers other factors such as safety.

### **Design Considerations: What Do These Findings Mean for the Design of Intelligent Health Information Management Tools for Older Adults?**

We preface our discussion of design implications by revisiting the focus of this research, which was to explore older adults' mental models and beliefs regarding IAs for consumer health and, specifically, IAs in the context of health information management and search. Therefore, we did not discuss IA for use in hospital or formal medical settings apart from supporting interaction with formal caregivers. We also acknowledge that some of the ideas presented by the groups may not seem novel; however, our goal for the participatory design session was not to develop novel tools or critique the participants' designs, but to learn through the design sessions about participants' challenges, concerns, and to identify considerations for future design.

### **Addressing Current Challenges and Motivating Use Through Autonomy**

Human-computer researchers have emphasized the importance of understanding users' goals and expectations for automation when designing intelligent interfaces [19,25]. Our findings highlight several areas in which participants felt support from an intelligent agent might be useful to them. Many of the areas discussed stemmed from prior and current challenges they experienced managing and searching for health information in a consumer setting. Although some of these challenges have been addressed in prior work, it may be useful for designers and researchers in the future to better understand why participants have not considered adopting these solutions. More research on current approaches to addressing the highlighted areas and the benefits and tradeoffs can help researchers better understand the role of automation and whether it meets users' needs and expectations. In addition, understanding how the individual expects to govern the task can help further identify areas in which IAs might be most appropriate and also how to design these assistants in a way that supports users' goals for autonomy.

### **Leveraging Relationships With Health Care Providers and Caregivers**

Most participants described the importance of being able to engage with a doctor or another health care professional if needed. Groups that proposed these solutions were aware that there might be cases in which they would prefer or feel more comfortable talking with a health care professional. In addition, because health care providers and other caregivers often participate in collaborative decision making [3], an IA that could leverage these relationships and improve these collaborations may be beneficial, particularly to older adult users or other users that rely on these relationships to manage their health.

In parallel, it can also be useful to explore the role of intelligent interfaces for facilitating the exchange of information between formal and informal caregivers. Although we do not anticipate it to be desirable for an interface to fully replace the role of

caregivers in consumer health decisions, there are opportunities to explore how these systems can better support the relationship between stakeholders, the exchange of information, and the steps leading to the decision to better empower the consumer. Further, similar to exploring how these interfaces might impact health care providers and caregivers, it would be important to also consider the effect they may or may not have on relationships and the decision-making process.

### **Providing Intelligent Assistance Through Familiar and Accessible Mediums**

The adoption of health technologies and the use of the internet for health information is growing among older adults [1]. However, there is still significant concern about older adults' access to technology, in particular when related to access and internet skill [30]. Our participants expressed similar concerns about whether tools that include IAs would be accessible to them due to limited technical resources at home or limited technical skills. Therefore, a common theme from the designs from our older adult participants was that intelligent health tools must provide flexible access, but also be accessible to individuals that may have limited technical skill.

With the emergence of intelligent voice assistants, such as Siri or Alexa, the move to more natural interaction is already underway. However, more work will be needed to understand if these types of assistants can be useful in the context of health information management and search. Another key consideration will be how we can design IAs for health that support older adults without requiring a new device or technology. Although some participants expressed they would consider adopting a new medium, others discussed concerns about cost and infrastructural barriers that might limit their access and use of IA for health in a consumer setting. Participants' perceptions were that IAs are data-intensive and rely heavily on a stable internet connection to facilitate interactions. Therefore, the need for internet would be a barrier for adoption for some. Exploring inclusive designs that address the varying needs of older adults may lead to more widespread access to and adoption of IAs that assist with consumer health information management and search practices.

### **The Role of Transparent Design for Supporting Users**

Emphasis on designing intelligent systems that are transparent and easy to understand has increased in recent years. One key theme that emerged directly and indirectly in the workshop was the importance of being able to understand system actions. All our participants valued privacy and trust, and those that proposed technical solutions emphasized the need for privacy and trust in their discussions. Explainable interfaces are one approach re-emerging to improve transparency [31]. In addition, processes for creating transparent designs have been recently proposed [32]. However, there is still a lot we do not know about how to design interfaces that support this transparency. Figure 4 summarizes the different types of transparency mentioned by participants in the discussions as a first step to understanding what participants want to be explained [32]. In addition, we include potential questions of interests to other stakeholders who may interact with an IA on behalf or in collaboration with the participant (see Figure 4).

**Figure 4.** Example of questions to improve the transparency of system actions for older adult users and those involved in their care.

Individual	How are data managed?
	How is data used?
	Who has access to data?
	Why was a recommendation made?
	Why was this information provided compared to others?
Formal/Informal Caregiver	How does this relate to the individual?
	Why am I being notified?
	What information was provided?
	What information was not provided?
First Responder	Why was an alert issued?

Participants raised concerns about how an IA would secure and manage their data. Participants also expressed concerns about being able to trust system recommendations and the situations in which a system recommendation may need further confirmation from a health care provider. However, because the participants envision that it would be responsible and useful for caregivers and first responders to also interact with an IA on their behalf, we expect that there may also be ways to help them better interpret the information and recommendations provided to them. If the user wants to discuss something with their doctor, it may be helpful to provide the doctor with information about why the IA provided certain information or did not provide other information to assist the doctor in their discussion. Overall, with a focus on health, it will be important for IA designers to explore methods for helping users and others involved to understand how their data are used and managed as well as how recommendations are made. In addition, given the potentially diverse abilities of older adults, there may also be a need to explore how to approach the design of these interfaces in a way that supports their diverse and changing abilities.

### Limitations and Future Work

Our study represents an exploratory step in understanding older adults' perceptions of intelligent interfaces that assist them with consumer health information tasks at home. The needs and desires for health information search support at home that are described in this paper are limited to the participants that were involved in the design workshop and their unique experiences and challenges. Also, because our study only focused on consumer health information search and management tasks, the findings may or may not apply to other contexts. It is possible that there are wider ranges of needs or desires for support that were not identified. Additionally, many of the older adults in our study were limited technology users and expressed challenges with searching for health information in the past. Therefore, it is possible that older adults who use technology more regularly may have different ideas about how technology

might assist them. In the future, we will continue to explore the design of personalized tools to support older adults' health decisions. One of our future goals is to include caregivers in discussions about IAs for health information search. Although this study focused only on older adults' beliefs, we did find that most of our participants (n=13) currently included caregivers in their health information search and management process at home. In the future, it will be useful to include caregivers' perspectives as well. Further, we will build on the findings of this study to design tools and evaluate them with older adults. We are exploring one of the ideas (voice assistants) discussed by participants as an option for delivering health information to better understand the contextual factors that exist around interacting with health information using voice.

### Conclusion

In this paper, we present findings from a participatory design workshop in which older adults brainstormed and conceptualized ideas for technology to assist them with consumer health information management and search at home. Five groups of older adults (N=18) brainstormed and described scenarios of ways an intelligent interface solution could or could not assist them in finding information and searching and managing health information in a nonclinical setting (ie, at home outside the doctor's office). Four of the five groups presented solutions involving technology, whereas one group expressed their desire to forgo any type of software intervention and talk directly with their health care provider.

Our findings suggest that older adults have clear beliefs about how IAs might assist them with health information management and search. Although participants saw the benefit of IAs for health, older adults had concerns related to autonomy and transparency in design. Our research identifies a set of key factors that older adults perceive as important in the design of an IA for health. Because the perception of benefit (ie, perceived benefit) is a key factor when older adults make decisions to

adopt a technology [33], the initial step of understanding beliefs regarding IAs for health is important to designing technologies that are likely viewed to provide benefit to older adults. Therefore, this work contributes (1) a better understanding of older adults' mental models toward IA for health and (2) a set of initial considerations for designing IAs that assist older adults with health information search and management. Although our focus is older adults and some aspects (eg, the role of caregivers)

may apply differently in other contexts, we anticipate that our findings can help inform the design of IAs that support others in managing and searching for health information at home. In addition, the discussion of participants' expectations, experiences, and interface support needs can help designers, researchers, and developers of consumer health search interfaces brainstorm and identify solutions that address these challenges.

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## Conflicts of Interest

None declared.

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## Abbreviations

**IA:** intelligent assistant or intelligent agent

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Original Paper

# Exploring the Perceived Usefulness and Ease of Use of a Personalized Web-Based Resource (Care Companion) to Support Informal Caring: Qualitative Descriptive Study

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## Abstract

**Background:** Informal carers play an increasingly vital role in supporting the older population and the sustainability of health care systems. Care Companion is a theory-based and coproduced Web-based intervention to help support informal carers' resilience. It aims to provide personalized access to information and resources that are responsive to individuals' caring needs and responsibilities and thereby reduce the burdens associated with caregiving roles. Following the development of a prototype, it was necessary to undertake user acceptability testing to assess its suitability for wider implementation.

**Objective:** This study aimed to undertake user acceptance testing to investigate the perceived usefulness and ease of use of Care Companion. The key objectives were to (1) explore how potential and actual users perceived its usefulness, (2) explore the barriers and facilitators to its uptake and use and (3) gather suggestions to inform plans for an area-wide implementation.

**Methods:** We conducted user acceptance testing underpinned by principles of rapid appraisal using a qualitative descriptive approach. Focus groups, observations, and semistructured interviews were used in two phases of data collection. Participants were adult carers who were recruited through local support groups. Within the first phase, think-aloud interviews and observations were undertaken while the carers familiarized themselves with and navigated through the platform. In the second phase, focus group discussions were undertaken. Interested participants were then invited to trial Care Companion for up to 4 weeks and were followed up through semistructured telephone interviews exploring their experiences of using the platform. Thematic analysis was applied to the data, and a coding framework was developed iteratively with each phase of the study, informing subsequent phases of data collection and analysis.

**Results:** Overall, Care Companion was perceived to be a useful tool to support caregiving activities. The key themes were related to its appearance and ease of use, the profile setup and log-in process, concerns related to the safety and confidentiality of personal information, potential barriers to use and uptake and suggestions for overcoming them, and suggestions for improving Care Companion. More specifically, these related to the need for personalized resources aimed specifically at the carers (instead of care recipients), the benefits of incorporating a Web-based journal, the importance of providing transparency about security and data usage, minimizing barriers to initial registration, offering demonstrations to support uptake by people with low technological literacy, and the need to develop a culturally sensitive approach.

**Conclusions:** The findings identified ways of improving the ease of use and usefulness of Care Companion and demonstrated the importance of undertaking detailed user acceptance testing when developing an intervention for a diverse population, such as informal carers of older people. These findings have informed the further refinement of Care Companion and the strategy for its full implementation.

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**KEYWORDS**

caregivers; information technology; internet

*Introduction*

**Background: The Burden of Caring and the Potential of Digital Interventions**

Informal carers, who provide unpaid physical, practical, and emotional care, play a particularly vital role in supporting the growing older population, of whom an increasing proportion live with multimorbidity, frailty, and other complex health and social care needs [1]. In the United Kingdom, there are an estimated 7.6 million informal carers aged >16 years, with a significant number of these aged >65 years [2]. Collectively, they form an essential part of the social care system that is estimated to save the state £132 billion every year; without it the provision of care would be unacceptably limited or unaffordable [2]. Hence, supporting the sustainability and effectiveness of informal caregiving is of major importance to individuals, families, and the wider society.

The potential of digital technologies to facilitate access to services and information to support health and well-being is becoming ever more recognized [3,4], and digital technologies are increasingly being used by carers to support their caregiving activity and responsibilities [5-7]. Indeed, digital interventions may significantly enhance the carer’s ability to quickly access information and support. However, identifying reliable, current, and easily accessible resources may be time consuming and challenging, especially for those with limited information technology (IT) literacy [8]. Although an online portal that brings together guidance from carer support organizations, information about activities, and social groups is likely to be of considerable use to carers [9], to date an easy-to-navigate program for carers that provides personalized information, resources, and support to address individual needs has been lacking.

**Care Companion—a Coproduced Theory-Based Digital Resource for Unpaid Carers**

To help address the need for individually tailored resources, we developed a Web-based platform (Care Companion) to provide profile-driven support to informal carers [10]. The platform was coproduced with older carers and utilized a theory-based approach to support resilience and sustainability and is underpinned by a biopsychosocial model of carer resilience proposed by Parkinson et al [11]. The model comprises 5 independent domains (extending social assets, strengthening psychological resources, ensuring timely availability of key external resources, maintaining physical health, and safeguarding quality of life) that can be targeted to strengthen carer resilience and coping (see Figure 1 for intervention framework). It is recognized that digital interventions that target multiple domains and incorporate a personalized approach that is adaptive to ever-changing needs and issues are more likely to improve carers’ health outcomes [12].

Care Companion was developed with older carers in mind and includes a guided walk-through of the site, which can be accessed at any time (see Figure 2). It offers links to (1) condition-specific and generic information, local support groups, and other third-sector organizations (see Figure 3), (2) a personal journal for carers to record information, feelings, and thoughts that they deem important (see Figure 4), (3) an address book where carers can save important contacts (see Figure 5), and (4) other features to support self-monitoring (eg, mood of both the carer and the person in their care) [10] (see Figure 2). The resource library targets 3 key areas: carer needs, general information and advice, and sustaining the carer. Users can also access carers’ stories that are designed to promote self-efficacy beliefs through vicarious learning [13].

**Figure 1.** The Care Companion intervention framework.



Figure 2. Features of Care Companion: home screen (top) and demonstration of the guided walkthrough available on the site (bottom).

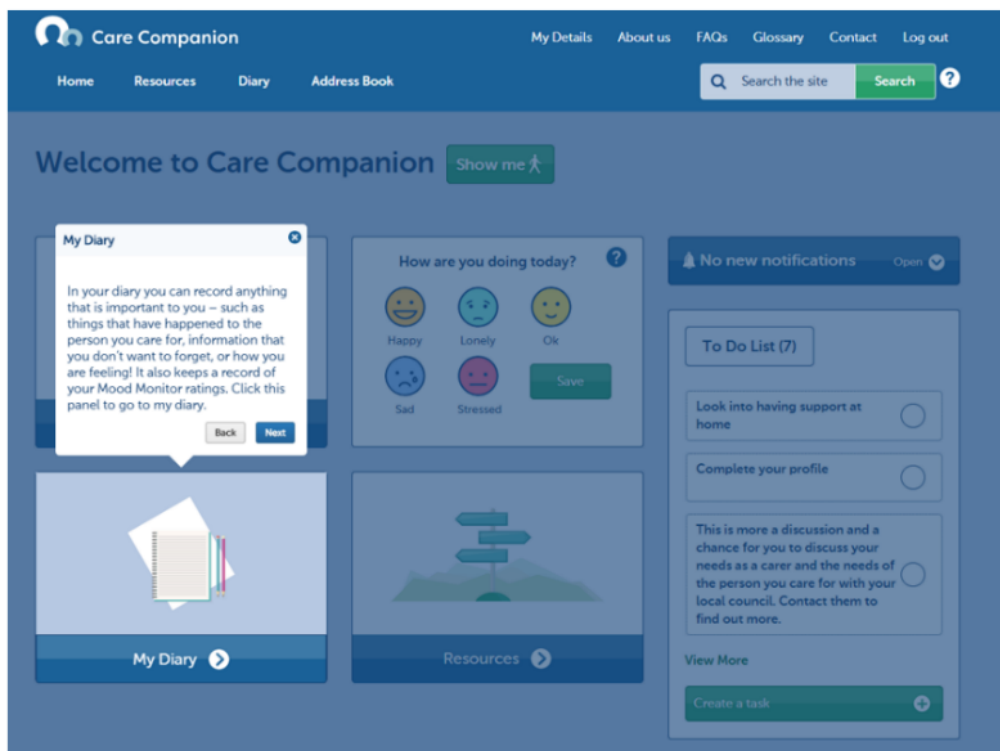
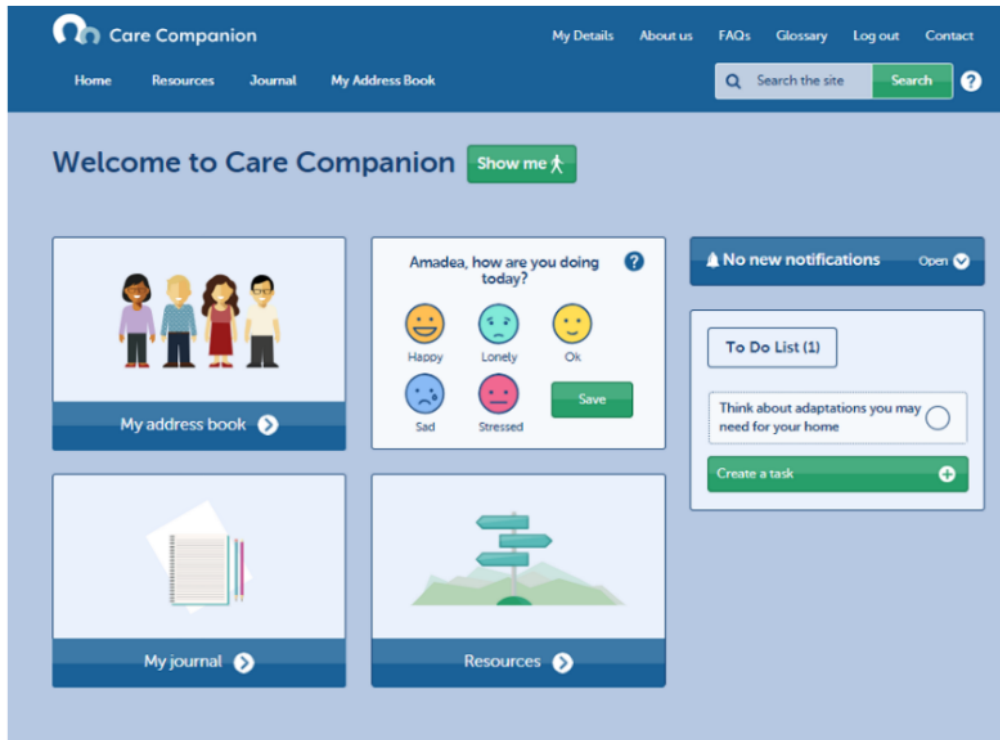


Figure 3. Features of Care Companion: resources.

The screenshot shows the 'Care Companion' website interface. At the top, there is a navigation bar with the site logo, 'Care Companion', and links for 'My Details', 'About us', 'FAQs', 'Glossary', 'Contact', and 'Log out'. Below this is a secondary navigation bar with 'Home', 'Resources' (highlighted), 'Diary', and 'Address Book'. A search bar is located on the right side of this bar. The main content area features a 'Resources' section with a 'Show me' button and a 'View My Resources' button. The primary focus is on 'Care Needs: Pancreatic Cancer', which is displayed as a grid of nine resource cards. Each card includes a representative image and a title with a count of resources. The cards are: 'Emotional Support (5)', 'Take A Break (1)', 'Local Support Groups (1)', 'Relationships (1)', 'Communicating with Healthcare Professionals (5)', 'Planning Ahead (2)', 'Financial Help and Benefits (2)', 'Carers' Stories (1)', and 'Planning Ahead > End of Life Care (1)'.

Resource Title	Count
Emotional Support	5
Take A Break	1
Local Support Groups	1
Relationships	1
Communicating with Healthcare Professionals	5
Planning Ahead	2
Financial Help and Benefits	2
Carers' Stories	1
Planning Ahead > End of Life Care	1

Figure 4. Features of Care Companion: journal.

The screenshot displays the 'Care Companion' web interface. At the top, there is a navigation bar with the logo and menu items: 'My Details', 'About us', 'FAQs', 'Glossary', 'Contact', and 'Log out'. Below this is a secondary navigation bar with buttons for 'Home', 'Resources', 'Diary', and 'Address Book', along with a search bar and a help icon. The main content area is titled 'Your Diary' and includes a 'Show me' button. A prompt asks 'Would you like to know more about your Diary?' with a 'Yes I would' button. The interface is divided into two main sections: 'Your Next Appointment' and 'Add a new appointment'. The 'Your Next Appointment' section shows a message: 'You don't have any future appointments stored on Care Companion'. The 'Add a new appointment' section contains form fields for 'Title', 'Start Time' (09:32), 'End Time', 'Location', and 'Date' (13/08/2019), with a 'Save' button. Below this is the 'Add a Diary Entry' section, which includes a tag selection area, form fields for '\* Diary Title:', '\* Date:' (13/08/2019), and '\* Time:' (09:32), a large text area for the 'Entry:', and a 'Save' button.

**Figure 5.** Features of Care Companion: address book, populated with pre-existing contacts of local support groups and with functionality to add own entries.

The 'Browse All Contacts' button takes you to a directory of local and national Contact Information that may be relevant to your situation. From here, you can save information to Address Book so that is easy to find when needed.

You can create new entries in Address Book using the form below. These can be edited by clicking 'Edit' or removed completely by clicking the X in the top right corner of the contact form.

**Create a Contact**

Organisation Name \*

(and / or) a Person's Full Name \*

Phone Number \*

Email \*

Address \*

Additional Notes (Optional)

Save

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01926888899

Stour Court, Shipston-on-Stour, CV36 4HF

## Importance of User Acceptability Testing

The number of older people accessing the internet and taking advantage of Web-based services is increasingly rapidly [9,10,13,14]. However, older individuals often have lower levels of confidence in using new technologies compared with younger people [9]. Applying user-centered approaches to understanding the context in which digital health technologies will be used is particularly important when developing interventions for older people [15]. As such, the coproduction of Care Companion was shaped by interviews, focus groups, and workshops with carers [10], underpinned by a theory-driven process of coproduction [16]. This informed its design, content, and implementation.

Having developed a full working version of Care Companion, there was now a need to test user acceptance with a more diverse range of users and stakeholders than those that had participated in the coproduction. User acceptance testing was undertaken to ensure Care Companion's compatibility with different needs [15] and explore potential barriers and facilitators to its use [17].

Barriers to using Web-based technologies include issues surrounding accessibility, such as the availability of digital devices or internet connections, lack of digital skills, and lack

of motivation or awareness of the potential benefits of engaging with technologies. In addition, a lack of trust in digital technologies, such as fear of crime and Web-based scams, concerns relating to privacy, and uncertainty about the credibility of sources of information, may also affect their uptake and use [18,19]. Such barriers may be particularly pertinent to older carers.

Other possible barriers to adoption of Care Companion may include language, culture, and ethnicity. There are estimated to be around 600,000 ethnic minority carers in England and Wales [20], and yet the scope of the initial coproduction had largely excluded consideration of the specific needs associated with culture and ethnicity. The omission of different sociocultural perspectives might inadvertently contribute to inequalities in access to health and social care [21,22]. Hence, user acceptance testing provided an opportunity to explore how different cultural values and norms may influence the uptake and usage of Care Companion.

## Aims and Objectives

The aim of this study was to undertake user acceptance testing to explore the perceived usefulness (how useful the features of the platform are in everyday life) and ease of use of Care

Companion and to identify refinements that might be needed before it becomes widely available.

The key objectives were to (1) explore the perceived usefulness and ease of use of Care Companion among the actual and potential users, (2) determine the barriers and facilitators that may affect its uptake and use, including the possible effects of culture and ethnicity, and (3) gather suggestions to inform plans for its wider implementation.

## Methods

### Theoretical Approach

The study was underpinned by the principles of rapid appraisal [23]. This is a pragmatic approach to obtaining information about a specific set of questions within a time and resource-limited real-world setting and has been successfully applied to health services research [24]. It enables rapid assessment of community perspectives of needs and supports translating these findings into action [23].

We adopted a qualitative descriptive approach [25,26] to the analysis of data. Although qualitative description is the least theoretical of qualitative approaches to research [27], it is relevant for generating information about the experience of a specific phenomenon in situations where time and resources are limited [26]. It is less interpretive than other forms of qualitative enquiry as it neither requires the researcher to move far beyond the data nor requires a conceptual or highly abstract rendering of the data [27].

The Unified Theory of Acceptance and Use of Technology (UTAUT) [28] was used to help identify outcomes of interest that are relevant to the adoption and uptake of Care Companion, particularly its technical and practical aspects, as their refinement was recognized as being essential for the platform's wider launch.

### Study Design

Qualitative methods including focus groups, observations, and semistructured interviews were used to explore key issues surrounding the use and implementation of Care Companion. The study aimed to recruit older carers through purposive sampling. The study was conducted iteratively, with two phases of data collection, each designed to explore different elements of the platform's use. We aimed to recruit a diverse mix of

carers, including individuals from South Asian ethnic backgrounds, from community groups within the local area.

In the first phase, semistructured interviews were undertaken while the carers tried using Care Companion to elucidate how they approached and navigated the site. The second phase involved focus group discussions and participants trialing Care Companion for up to 4 weeks, followed by a semistructured interview in which they shared their experiences of its use. The findings from both phases were used to shape subsequent technical development of Care Companion.

### Phase 1: Testing Accessibility

Participants were recruited through local carer groups who met regularly and agreed for a member of the research team to drop in during their meetings. Carers were provided with a tablet device and guidance on how to create their profile in Care Companion. They were then interviewed as they navigated the site to (1) understand their interaction with the platform, (2) identify elements that they struggled with, and (3) gain an overall view of their interest and enthusiasm in using it. A *think-aloud* method [30] was used wherein participants were encouraged to voice their thought processes as they navigated the platform to explain why they chose each section. The questions presented to carers while using the site focused on the ease of use, whether the layout was intuitive, whether the appearance was appealing, and ideas on how it could be improved.

Following a brief presentation, participants were asked general questions about their use of digital technology, how they search for information, their initial impressions of Care Companion, which elements they thought would be most useful, and the potential barriers to use. They were then invited to use Care Companion for up to 4 weeks, and those interested were invited to participate in a follow-up telephone interview to discuss their experiences. Further details about how participants from focus groups participated in interviews can be found in [Multimedia Appendix 1](#). The semistructured telephone interviews were planned to last 20 to 30 min and followed a topic guide (see [Multimedia Appendix 2](#) for interview questions) informed by the concepts of the UTAUT [28]. All interviewees signed consent forms.

[Table 1](#) illustrates how the study meets the criteria for rigor defined by Lincoln and Guba [29] using a framework provided by Bradshaw et al [26].

**Table 1.** Demonstrating rigor in exploring the usefulness and ease of use of Care Companion.

Criteria	Definition of criterion	Examples of how criterion is addressed
Credibility	The confidence in the truth of the research findings. Credible and plausible research findings must be drawn from the participants' original data and need to be correct interpretations of these data.	<ul style="list-style-type: none"> <li>Trusting relationships between participants and the research team may increase participants' willingness to share their experiences. A number of steps were taken to build trust: Relationships between the research team and the support groups were developed through past exchange of emails and telephone conversations; The team made use of the Medical School, National Health Service, local authority, and Age UK logos on all communications about the study and on the platform; Furthermore, leading (and trusted) members of the support groups helped arrange focus groups and thus facilitated recruitment; During the focus groups and interviews, the researcher discussed the importance of supporting informal carers, expressing compassion and empathy for those in caring roles</li> <li>Findings from the interviews and focus groups were shared and discussed with the study's panel of carers that helped verify the findings. Member checking occurred with 1 participant who was interested in being involved in the project long-term. All findings from the study were shared and discussed with its carer advisory panel</li> <li>Data were collected through a variety of methods from people with a range of caring experience. Data analysis was discussed among the members of the research team. These steps aided triangulation</li> <li>Participants were invited to remain engaged by continuing their use of the Care Companion and provided with contact details should they wish to share more feedback with the research team. Some were invited to being involved through membership of the study's carer panel</li> </ul>
Confirmability	The extent to which findings can be confirmed to be real. The extent to which it can be shown that the interpretation of the findings is clearly derived from the data.	<ul style="list-style-type: none"> <li>Interviews were audio recorded and transcribed verbatim. Transcripts were stored securely on protected computers</li> <li>Notes were taken during focus group discussions and think-aloud interviews</li> <li>An audit trail capturing participant interest, data collection, and the research path was kept</li> <li>Data analysis was conducted in NVivo</li> <li>Direct quotations are used to illustrate the findings and to show that the findings represent the gathered data and are not biased by researchers</li> </ul>
Dependability	Establishes whether the study's findings are consistent and repeatable	<ul style="list-style-type: none"> <li>An audit trail was established describing the study's procedures and progress, including changes that needed to be made during the study</li> </ul>
Transferability	The extent to which the findings can be applied to other contexts	<ul style="list-style-type: none"> <li>The study used purposeful sampling</li> <li>Notes were kept by the researchers during data collection. Researchers were reflexive about their potential impact on the data collection process and other contextual factors</li> </ul>

## Ethical Approval

The study received ethical approval from the University of Warwick Biomedical Sciences Research Ethics Committee.

## Analysis

All interviews and focus groups were transcribed verbatim, anonymized, and managed and analyzed using NVivo [31]. Thematic analysis [32] was applied to the data, and a coding framework was developed iteratively during analysis by AT, EF, and BL. This followed a 5-step process of familiarization, identifying a thematic framework, indexing, charting, and mapping and interpretation [28]. Field notes were used to support contextualizing and interpretation of the transcripts—particularly in relation to the think-aloud interviews where participants used and pointed to different aspects of the platform. Coding was conducted inductively [33]. Once coding was complete, key themes were identified, explored, and interpreted by all authors. The analysis of each phase of the study also informed the subsequent phases of data collection

and analysis. The final analysis involved synthesizing information from each phase of data collection and integrating the different themes into a broader thematic structure [34].

## Phase 2: Group Discussions, User Acceptability Testing, and Semistructured Interviews

Participants were recruited from local carer groups organized by charities including Parkinson's UK and a local South Asian carers' support group. Care group facilitators were contacted through email and asked whether a researcher could join one of their weekly meetings to conduct a focus group.

## Results

### Participant Recruitment

Participants who took part in think-aloud interviews were recruited through local carer support groups. A total of 4 carers with differing levels of IT literacy agreed to participate. They predominantly cared for individuals with neurodegenerative

diseases, such as dementia. In total, 4 focus groups were conducted involving a total of approximately 50 participants. Groups varied in size, reflecting the availability and willingness of the different carer groups' members to participate. Of the participants, 16 expressed an interest in testing Care Companion. Of these, 2 participants declined taking part in a follow-up interview (one told us that they struggled to use the site, and the other felt that the platform did not add to the support they

were already receiving). In addition, two other individuals recruited through carer groups volunteered to use Care Companion and participate in a follow-up interview. A total of 10 participants did not respond to the contact made by the research team for follow-up interviews, leaving a total of 6 interviews that were conducted with participants (see Table 2 for further details).

**Table 2.** Summary of participants in user acceptability testing.

Identifier	Recruitment strategy	Gender	Participants, n	Details about caring responsibilities
<b>Phase 1</b>				
<b>Data collection by think-aloud interview</b>				
P1-1	Rural café for supporting older people and their carers	Female	1	Lived separately from person needing care
P1-2	Rural café for supporting older people and their carers	Female	1	Lived with person needing care
P1-3	Rural café for supporting older people and their carers	Male	1	Lived with person needing care
P1-4	Rural café for supporting older people and their carers	Female	1	Lived with person needing care
<b>Phase 2</b>				
<b>Data collection by focus group</b>				
FG 1	Rural café for supporting older people and their carers	3 females	3	All 3 participants were carers for somebody they lived with (parent or spouse).
FG 2	Local Parkinson disease charity	Large group — mixture of males and females	37	The group was a mixture of people in care and their carers
FG 3	Local Parkinson disease charity	3 males and 4 females	7	The group was predominantly made up of carers, 1 participant identified as caring for himself
FG 4	South Asian carer network	1 male and 2 females	3	All lived with person needing care
<b>Data collection by interview</b>				
P2-1	Referred by carer panel member	Male	1	Living with and caring for spouse for 2 years at the time of the interview
P2-2	Rural café for supporting older people and their carers	Female	1	Caring for 4 years, providing daily care at the time of the interview
P2-3	Recruited through invitation sent to dementia support group	Male	1	Living with and caring for spouse for 4 months at the time of the interview
P2-4	Rural café for supporting older people and their carers	Female	1	Living with and caring for parent for 7 months at the time of the interview
P2-5	Local Parkinson disease charity	Female	1	Living with and caring for spouse for 6 years at the time of the interview
P2-6	Local Parkinson disease charity	Male	1	Living with a condition, care for self and support their carer to care for them

## Interview Findings

The key themes identified in the interviews related to the perceived usefulness and ease of use of Care Companion; its appearance and ease of use; the profile setup and log-in process; the safety and confidentiality of personal information; barriers to use and uptake and suggestions for overcoming them; and suggestions for improving Care Companion. Quotes that most

clearly illustrated these themes were selected. These are discussed below.

### *Usefulness and Ease of Use of Care Companion*

The breadth of available, trustworthy, and bespoke resources and contacts listed on Care Companion (see Figure 2) was rated highly by carers. Participants thought this would make the platform an extremely useful resource for aiding their



caregiving. They contrasted this with their experience of using regular search engines that can generate an overwhelming number of results that may not necessarily be relevant. Participants were positive about the fact that this was a resource aimed at carers rather than care recipients. This highlights the scarcity of such resources and that the carer is often overlooked when they are supporting someone with more immediate needs.

*I find that by going onto this Care Companion site, there's a lot of information that can be easy sort of broken down. And you sort of can get to calm down a little bit and think; probably life isn't quite as bad as you first thought it was, you know. There is help out there. And it triggers it in the right sort of way...it's got the potential of something being very good. Like I said, with Google, it tends to be a bit overwhelming. With this particular site, it's tending to hone in and cut down that overwhelmingness. [P2-3]*

*It's just the way I was thinking about things. I suppose it's the way my brain is programmed at the moment that everything is for the cared for rather than myself. So, I was thinking that I really should look at it from a totally different angle and use it for my own benefit rather than [P2-2]*

In contrast, one carer did not participate in a follow-up interview as he felt that Care Companion did not add anything to the support he was already receiving.

The journal feature was received with particular enthusiasm for its potential to log events, appointments, medications, symptoms, and other important aspects of their caring role. It was suggested that this feature would encourage the ongoing use of Care Companion:

*I think it would be something that would be very useful, and certainly for me particularly with regards to the journal because at the moment I don't keep a log of everything that happens. And I do realize now, through just sort of playing around with the package, I do realize just how important that would be to me, to be able to just keep a record [P2-2]*

*I felt that it was a very useful site; I wished I'd known about it 12 months ago. The journal I think will be useful because you could transfer that information to the GP. [P2-1]*

*I think it's the journal I would probably find most useful, being able to express my feelings, for want of a better expression really. [P2-4]*

Although Care Companion is aimed at carers, some participants felt that it could also be very useful for the care recipient—to either help themselves or help support their care provider. This was seen as a way of facilitating mutual support to maintain higher levels of independence. It further highlighted the often-blurred boundary between caregiving and self-caring roles, particularly in the early stages of a condition, and that Care Companion should be inclusive in enabling this.

### **Appearance and Ease of Use**

Participants were satisfied with the appearance of the site and found it intuitive to use. The headings and signposting within the site were considered to be clear, making its different features easy to find and access (see [Figure 2](#)). The guided walk-through was considered to be a useful feature. Some, however, noted that they struggled using it until they had familiarized themselves with the site. Some cited their relative lack of experience with technology as a barrier to easy use:

*The appearance was good. The ease of access was alright when I'd learnt how to use it, you know. I'm not a computer expert, but once I'd found my way around yes it's relatively easy. [P2-1]*

### **Profile Setup and Log-In Process**

A number of key subthemes emerged relating to profile setup and logging in. These include the difficulties of remembering passwords and email addresses and the sensitivity and relevance of profile questions.

#### **Remembering Passwords and Email Addresses**

Although participants found accessing the platform straightforward, some expressed concern with remembering their log-in details. Indeed, we observed some carers struggling to verify their email when first registering for an account on the platform, either because they were unsure about how to access their email or because they could not remember a password.

#### **Two-Factor Authentication**

Participants were cautious of Care Companion's 2-step verification log-in system, where users would input their email and password before getting an automated phone call that delivered a onetime 4-digit code that was needed to allow access. Although 2-step verification was used to help prevent unauthorized log-in to users' accounts and safeguard their data, participants' initial views were that this measure was cumbersome. It was, however, accepted that it plays an important role in protecting their information:

*I did not like that you needed an automated telephone call to provide a validation code each time you logged in. If someone doesn't have access to a telephone then they would not be able to use. [FG4, female carer]*

#### **Sensitivity and Relevance of Profile Questions**

Some participants noted that certain questions in the profile setup needed further consideration. For instance, at the time of study, the profile questions required carers to comment on their financial situation; it was suggested that this question could be considered stressful for some and that there should be an option to say *unwilling to answer* or *do not know*. Other participants felt that some of the questions were subjective and, therefore, difficult to answer. For example, when rating the independence of the person in their care, one carer noted that this could be difficult to answer. Participants did, however, recognize that the personalization of the resources depended on these questions being answered. Participants also suggested using additional questions to help enhance personalization:

*If someone is under pressure, you know, if they've got financial problems then that's just sort of dramatic overload on the issue isn't it, so yes that's relevant. [P1-1]*

*So you might...you might need another saying I don't know, can't say or don't know, or something like that. Do you know what I mean? I mean you could even have a situation where you had a carer who was looking after the person, and their finances were being dealt with by another family member somewhere at the other end of the country. [P1-3]*

### **Safety and Confidentiality**

Participants were concerned about their safety and confidentiality when using Care Companion. They were aware of Web-based scams and expressed concern as to how their information was kept secure, as well as the risks associated with uploading and downloading personal information. Participants were also keen to understand how Care Companion would comply with new general data protection regulation legislation [35] and wanted to know how their information was stored and who would have access to it:

*And people should be, it should be explained to people that if they're going to download it, are you downloading it to a secure place, you know. And give people plenty of prompts to make sure that they could say yes, I'm happy doing this. [P1-3]*

### **Barriers to Use and Uptake and Suggestions for Overcoming Them**

Participants identified a number of issues that could present barriers to the use of Care Companion and its wider implementation. There were concerns expressed about those from lower-socioeconomic backgrounds without access to digital devices being excluded from adopting Care Companion. Other participants noted that some older carers have low levels of digital literacy, which could prevent access to the platform. In addition, South Asian participants highlighted that Care Companion was only available in English, which would hinder access to caregivers with a limited ability to read English. It was also noted that carers of a South Asian background may be hesitant to adopt Care Companion for the fear of how this may impact other statutory support that they are receiving. To this end, they advised that the platform's purpose as an information and signposting tool be emphasized:

*One thing you've got to be careful of, for people on benefits or...social housing all that side of*

*things—welfare; that this [Care Companion] has got nothing to do with that. This community of people just in general will be very cagey if they thought that this was going to impact. So you need to be quite clear in the message that this [Care Companion] is for information purposes only...it wouldn't affect their care or their rights—it's just signposting. [FG4, female carer]*

Participants commented, both in interviews and group discussions, that many carers use devices other than computers to access online services, such as tablets and smartphones. It was suggested that having Care Companion optimized for the use on tablets or smartphones could help overcome some of the extrinsic hardware barriers to accessing the service. In-person training sessions were also recommended to help demonstrate Care Companion and improve the uptake of the platform.

Carers of an Indian background noted that including more visual graphics, such as video to help explain and demonstrate the platform, would bypass the need for verbose text and be helpful for people with limited ability to read English. They also stressed that, for Indian communities, it might be beneficial to adopt a community-driven approach to help spread awareness of Care Companion. This would help enhance carer trust in the platform and thus increase the likelihood of individuals taking-up the service. To this end, promotion of the platform may be advanced by working alongside prominent and well-respected persons and religious groups based in these communities:

*I think the only way that you would get other [Indian] people to use it [Care Companion] is perhaps through word-of-mouth...it's essentially about referring them to this resource...I think that would be essentially the best way to target it to other people. [FG4, female carer]*

*I think it's about trust. Because if they know you and you say, "oh I used it-it helped me, take a look" I would say well they've recommended it, they've got reasons behind it...it's like an added bonus. [FG4, female care]*

### **Suggestions for Improving Care Companion**

Care Companion was still under development at the time of data collection. As a consequence, some participants encountered technical difficulties that have since been resolved. In addition, the carers suggested several improvements to the features of the platform that are summarized in [Table 3](#).

**Table 3.** Summary of suggestions for improvement of Care Companion.

Feature	Suggested improvement
Journal	Add tagging options or subsections that allow users to categorize their entries, and thus enable easier retrieval of information; Improve the ability to search for entries by displaying a calendar; Add the ability to enter events that will occur in the future
Mood monitor	Increase the number of “moods” available, in particular a “stressed” option
Address book	Enhance the personalization of relevant contacts. (In its test format, the contacts list was not as profile-driven as the resources)
Resources	Inclusion of additional links in the resources section to websites that they knew about and thought might be valuable to others
Profile questions	Inclusion of additional profile questions to drive further personalization, such as age categories
Search functionality	In earlier stages of development, the platform’s searching function was limited and often had errors

## Discussion

### Principal Findings

This study has (1) explored the perceived usefulness and ease of use of Care Companion among older carers, (2) identified several barriers and facilitators that may affect its uptake and use, and (3) gathered suggestions for its further refinement and wider implementation. Recruiting different groups of carers to those who had participated in its coproduction [10] helped validate key themes that had been previously identified and also provided new insights. Overall, the carers who participated in our study perceived Care Companion to be a valuable and useful tool to support them in their caregiving activities.

The breadth of personalized, easily accessible, and carer-centered information on a single platform that is easy to navigate was especially celebrated by the participants. In addition to the resources section that had information relevant to supporting and informing caring roles, the journal feature within Care Companion was received with particular enthusiasm. Participants valued its ability to log events and thoughts and other important aspects of their caring role, such as medications, symptoms, and appointments. Facilitators to the uptake and the use of Care Companion were felt to include its simple and intuitive design and the breadth of personalized information. The main barriers to use included low digital literacy, access to digital technologies, the complexity of 2-factor authentication, and an inability to read English.

During the interviews and focus groups, a number of suggestions were voiced to help refine Care Companion. These included enhancing existing features (eg, the addition of tags in journal entries to enable easier retrieval of information) and ways of encouraging wider uptake and use. These included the following suggestions: running brief local training courses to support those with low technological literacy, optimizing the platform for use on devices other than computers (namely tablets and smartphones), and including more visual graphics to mitigate verbose text and the associated language barriers. Finally, suggestions emerged for a more culturally informed strategy to promote Care Companion within Indian communities by way of a community-driven approach to maximize trust in the service.

### Impact of User Acceptability Testing

Both phases of user acceptance testing were used to drive changes to the Care Companion prototype. These changes include the following: enhancements to the journal feature to enable scheduling of appointments and tagging of entries, additional profile questions relating to ethnicity, religion, and culture to drive further personalization of resources, simplification of the 2-step authentication process, and removal of technical difficulties experienced by users.

### Limitations

Carers face a number of burdens, including a lack of free time for themselves [1]. Inevitably, they are a difficult population to recruit for the purposes of research. Therefore, we adopted a highly flexible and opportunistic recruitment strategy that used a range of different interview and observation methods and settings to collect data. The focus groups were based on pre-existing groupings and thus differed widely in size. The strength of this approach was the convenience to participants. However, using pre-existing groups meant that there was little possibility for collecting sociodemographic data on participants, and this inevitably raised questions about representativeness. In addition, in a large focus group, it is not possible to ensure that everyone’s views can be fully heard, and some participants may not have felt confident to express their opinions in front of such a large group.

The study had limited funding and had to be completed within a relatively short timescale to inform the planned area-wide implementation of Care Companion. Hence, it had a relatively small sample size that limits the generalizability and transferability of the findings.

The study aimed to explore how factors, such as culture and ethnicity, may influence the uptake of Care Companion. As this was a rapid and small study, we only targeted local South Asian groups, as these represent the largest ethnic minority groups in England [21,36]. Although we attempted to explore the potential of using Care Companion with South Asian carers, we experienced significant difficulties in recruiting participants. As a result, we were only able to recruit carers of Indian heritage, therefore exploring only their experiences rather than a diversity of South Asian perspectives. This may have been because the research was undertaken during summer months which coincided with holidays and religious events. Furthermore, the researcher (BL) was a male, which may have made it difficult to recruit South Asian female carers [36].

Furthermore, caregiving is understood as an intrinsic part of family duty among many South Asian communities [21,37], meaning that members of these communities may not identify as carers because they locate their caregiving within broader religious and cultural norms [37]. South Asian caregivers may, therefore, better recognize themselves as persons who are fulfilling their duty to the family and community, rather than as *carers*. Although the problem of identifying as a *carer* is not unique to South Asian communities, it can hinder access to vital support and resources [38] and may be particularly pertinent to these communities.

Although we were not able to recruit participants from a diverse range of ethnic and cultural groups, the insights that emerged from those that did participate illustrated the need for further, more detailed exploration of the role culture and ethnicity may play in the uptake of such technologies.

Although the sample size was relatively small, it is worth acknowledging that there was a high level of coherence and conformity among the data that were collected through a variety of techniques. Data saturation was reached in discussions about the usefulness of the platform.

### Comparison With Previous Studies

Although the use of digital technologies is increasing throughout all age groups across the population, there remains greater fear and anxiety among older adults toward using them, as well as a lack of confidence in their own skills and abilities to do so [39]. Our study suggests that older carers recognize that online technologies are potentially valuable and relevant. Our findings demonstrate that members of this group are willing to learn how to navigate through a well-designed and tailored platform, such as Care Companion. This is in line with the model of technology acceptance proposed by Barnard et al [40].

Participants in our study indicated that an in-person introduction to Care Companion, such as through brief individual or group training sessions, could help increase the understanding and uptake among older carers. Studies have shown that supportive environments can have a powerful role for encouraging the use of digital technologies, whether through step-by-step guidance, offering a friendly space to use trial and error methods, or through providing an instruction manual [40]. Preferably, this should involve a user-centered model where an individual's unique characteristics and needs are taken into consideration [41].

Concerns about online security and confidentiality are reported in other studies [42,43], where older adults report fear that their personal data may be misused and manipulated [42]. Our study shows that older carers are aware of these risks and are eager to understand how their personal information is being stored and used. They were concerned that if they uploaded personal information this would compromise their safety and there might

be the possibility of other people reading and accessing their private notes. This highlights how important it is for platforms, such as Care Companion, to be unambiguous and transparent about how information is stored and that this is presented clearly in simple language. Although 2-factor authentication is in place to help protect users' information, for Care Companion, this entailed users receiving a phone call with a 4-digit pin code whenever they logged in from a different internet protocol address; this verification process was seen as cumbersome and off-putting. There is a need for authentication mechanisms to be accessible and inclusively designed for a broad range of users [44]. As a result, Care Companion's 2-factor authentication process has now been modified to include a number of changes to make it easier to hear and understand the automatic call back. The introduction of an *I'm ready* button to allow users time to find their telephone or a pen and paper on which they could write down the code, has also been added.

The journal feature of Care Companion was widely considered to be the most useful aspect of the platform and which would encourage the site's continuous use. Writing expressively about emotionally triggering events is recognized as having positive effects on physical and mental well-being [45,46]. This may help the carers to understand, regulate, and process difficult emotions and so shape affective and cognitive state, as well as serve as an aide-memoire when explaining issues to a health or social care provider [46].

### Conclusions

Exploring the acceptability and aspects of use of Care Companion has been an informative and important step between the coproduction process and the wider realization and evaluation of the platform. A number of insightful lessons emerged, illustrating the importance of careful user acceptance testing [15].

The key findings identified during the coproduction phase of Care Companion's development were reinforced by this study. These include the need for resources aimed specifically at carers (instead of care recipients); importance of personalized information; and the value of having a journal. This acceptance testing further highlighted issues that had not previously been identified during the coproduction phase, which include the importance of transparency for security and data usage; minimizing barriers to initial registration; and offering demonstrations to support a wider uptake by people with low technological literacy. In addition, this study underscores the need to develop a culturally sensitive approach to promoting Care Companion that works in partnership with and reflects the diversity of the local population.

The evidence from our study is relevant to the wider development of digital interventions for carers and is now informing the strategy for a full area-wide implementation of Care Companion.

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### Conflicts of Interest

None declared.

## Multimedia Appendix 1

Details of data collection.

[\[PDF File \(Adobe PDF File\), 72 KB - aging\\_v2i2e13875\\_app1.pdf \]](#)

## Multimedia Appendix 2

Interview schedule–think-aloud interviews.

[\[PDF File \(Adobe PDF File\), 52 KB - aging\\_v2i2e13875\\_app2.pdf \]](#)

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## Abbreviations

**IT:** information technology

**UTAUT:** Unified Theory of Acceptance and Use of Technology

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Original Paper

# Promoting Identification and Use of Aid Resources by Caregivers of Seniors: Co-Design of an Electronic Health Tool

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## Abstract

**Background:** The importance of supporting caregivers is recognized in home care for older persons, and facilitating their help-seeking process is a way to meet that need. The use of electronic health (eHealth) is a potentially promising solution to facilitate caregivers' help-seeking process.

**Objective:** The aim of this research was to develop, in partnership with community organizations, health and social service professionals and caregivers, an eHealth tool promoting the earlier identification of needs of older persons and an optimal use of available resources.

**Methods:** To design the tool, 8 co-design sessions (CoDs) were conducted and 3 advisory committees were created (in 11 regions) in Quebec between May 2017 and May 2018. A variety of methods were used, including the sorting method, the use of personas, eHealth tool analysis, brainstorming, sketching, prototyping, and pretesting.

**Results:** A total of 74 co-designers (women n=64 and men n=10) were recruited to participate in the CoDs or the advisory committees. This number allowed for the identification of needs to which the tool must respond and for the identification of its requirements (functionalities and content), as well as for the development of the information architecture. Throughout the study, adjustments were made to the planning of CoD, notably because certain steps required more sessions than expected. Among others, this was true for the identification of functionalities.

**Conclusions:** This study led to the development of an eHealth tool for caregivers of functionally dependent older persons to help them identify their needs and the resources available to meet them.

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**KEYWORDS**

caregivers; aged; help-seeking behavior; community-based participatory research; eHealth; telemedicine

## Introduction

### Background

It is recognized that aging of the population has an impact on health and social service professionals (HSSPs) who provide care and services to these individuals. This reality, added to a recognition of the benefits of keeping seniors at home [1,2], has resulted in a reorganization of services in Quebec where home care is now promoted [3]. This choice has an impact on caregivers, who are often asked to contribute to home care for older persons with decreasing independence, both physical and psychological [4-6]. Although this role can be rewarding, *l'Appui pour les proches aidants d'âinés*, a nonprofit organization in Quebec that supports caregivers, reveals that 99% (3771/3809) of participants in their study reported a negative impact of caregiving on their health [5]. They report anxiety or anguish (37% 1409/3809), fatigue (32% 1219/3809), and sleep problems (22% 838/3809) and mention needing home care (28% 1067/3809), professional help (26% 990/3809), respite (23% 876/3809), information and advice (12% 457/3809), and support (11% 419/3809) [5]. It is important to note that although nearly one in 4 participants report needing respite, 94% (3581/3809) say they never use these services [5].

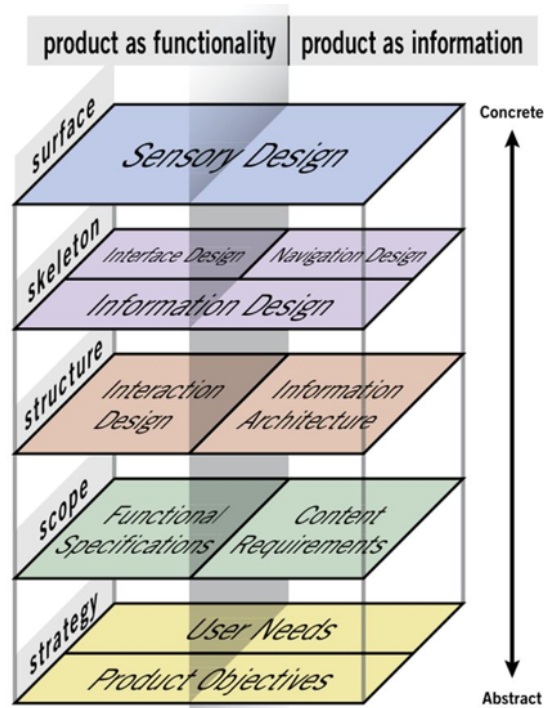
So, the importance of assisting caregivers is recognized and, in response, many support programs, resources, and services are offered by health and social service facilities and by community-based and private organizations [6]. There are a number of benefits to using these services, both for the caregiver and the person with decreasing independence [6]. However, it appears that they are still less used. Some tools exist in Quebec to facilitate caregivers' help-seeking process but most are intended for HSSPs and not specifically for caregivers. Moreover, it appears that despite the existence of these tools, the available resources are not widely known and they are seldom used by caregivers.

A pilot study conducted by Latulippe et al [7] highlights the factors influencing caregivers' help-seeking process. This study reveals that they need effective tools early in the process of the loss of independence to help them identify the appropriate resources to meet their needs and those of the older person they are helping. It is often after the first signs of exhaustion that caregivers undertake the help-seeking process, but it is difficult for them to know the most appropriate resource for their situation without the assistance of HSSPs [8,9]. The use of electronic health (eHealth) is a potentially promising solution to facilitate caregivers' help-seeking process [10]. Thus, the goal of this research was to develop, in partnership with community organizations, HSSPs, and caregivers, an eHealth tool promoting an earlier identification of the needs of functionally dependent seniors and an optimal use of available resources.

### Conceptual Framework

To develop this eHealth tool, we followed a user experience (UX) perspective. Using a UX perspective for the design of a technology involves going beyond instrumental need and acknowledging the use of this technology as a "subjective, situated, complex and dynamic encounter," considering the user's internal state, the characteristics of the product design and the context of interaction with the product [11]. We used the *Elements of User Experience* UX framework (Figure 1), which proposes 5 steps for the development of user-centered technologies: (1) identification of the strategy (product objectives and user's needs), (2) identification of the scope (functional specifications and required content), (3) development of the structure (interaction design and information architecture), (4) creation of the skeleton (interface, information, and navigation design), and (5) creation of the surface (sensory design) [12].

Figure 1. Elements of user experience (Garrett 2011).

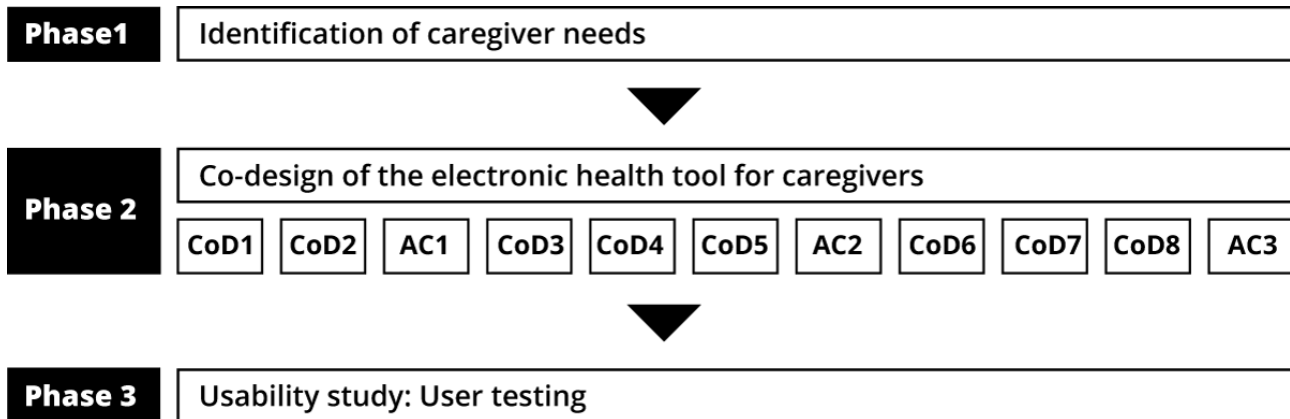


### Objectives of This Paper

The protocol of this project presenting the details of the methodology has been published in the *Journal of Medical Internet Research* protocols [13]. The results of phase 2 of this research are now presented in 3 different papers. The first focuses on identifying needs as the first step in co-design. The second concerns the development of the functionalities and

contents of the tool. The purpose of the third article, this paper, was to present the whole process of phase 2: the development of an eHealth tool for caregivers using a co-design approach. It also aims to explain the differences between what was planned and what was achieved, to present the tool developed, and to discuss the benefits and challenges of using a co-design approach. Figure 2 illustrates where this paper is situated in the entire process of the study.

Figure 2. Design phase of the entire project and steps involved in this publication (in bold). CoD: co-design session; AC: advisory committee session.



## Methods

### Study Design

A method based on a co-design participatory approach was used to achieve the objectives of this study. According to Harder et al [14], the co-design approach is different from the positivist perspective as participants are not studied objectively. From a co-design perspective, the distinctions between researcher, practitioner, and user are blurred. At the end of the level of participation spectrum, engagement of the participant is described as “full partnership” or “learning as one”[...] [14].

On the basis of a literature review of 10 years (2002-2012) of participatory design (PD) research, Halskov and Hansen present the fundamental aspects of PD [15]—(1) politics: people who are affected by a decision should have an opportunity to influence it, (2) people: people play critical roles in design as experts in their own lives, (3) context: the use situation is the fundamental starting point for the design process, (4) methods: methods are means for users to gain influence in design processes, and (5) product: the goal of participation is to design alternatives, improving the quality of life.

According to this approach, the actors directly concerned by the project objectives, here the caregivers themselves, as well as the community organizations and HSSPs providing care and services, were included at each stage of the study, not as participants but as co-designers [16]. This approach ensures that the tool meets the user needs for an eHealth tool [17].

To apply this approach, 8 co-design sessions (CoDs) and 3 advisory committee sessions (ACs) were planned (Figure 2). The CoDs, lasting 3 hours, consisted of following the steps of Garrett's model (Figure 1). The ACs were also 3 hours long, and the role of these committees was to guide the progression of the tool to ensure continuity between the CoDs and coherence between the decisions taken by the co-designers participating in different sessions [13].

To optimize the tool, we considered the factors contributing to reducing social health inequalities (engagement of future users in the co-design, the help-seeking process, access to eHealth technologies, knowledge related to the utilization of eHealth technologies, eHealth literacy and cultural competency, and learning capacity) throughout the development of the eHealth tool [18]. This aspect is the subject of the thesis of one doctoral student who is part of the research team and will, therefore, not be discussed in the context of this article. We also considered the intrinsic experience of people who participated as co-designers during the CoDs and ACs. This aspect is the subject of the thesis of another doctoral student who is also on the research team. Their publications will come later.

As mentioned earlier, a more detailed description of the method (participants and selection criteria, recruitment, content planned for each CoD, data collection, and ethical considerations) can be found in the published protocol of the study [13]. We still offer a summary for an overall assessment of the process.

## Recruitment

The sampling strategy was based on the importance of including all potential users in designing the tool. Therefore, co-designers were recruited from 3 categories of users: caregivers, service providers from community settings, and professionals from the health and social services network. The advisory committee included researchers (VP, VP, VD, and SE), caregivers, community workers, and HSSPs. The research team included a Doctor of Philosophy (PhD) student and UX expert (MT), a PhD student (KL) working on the factors reducing social health inequalities, a research professional who is an anthropologist and trained in qualitative research (MC), and the project director (DG).

This study was a multicentric project. To ensure a representative sampling of the different situations in Quebec regions, recruitment covered 11 regions of Quebec (including rural and urban areas) between May 2017 and May 2018. To recruit co-designers, the home care and elderly care management of the 11 Integrated Health and Social Service Centres (CISSS) were contacted to recruit 2 HSSPs per CISSS. In addition, these workers were asked to recruit caregivers using their services. Members of community organizations were recruited through

direct contact via phone or email. They were also asked to publicize our recruitment announcement among caregivers attending their institution and activities. Finally, recruitment announcements for caregivers were posted in 30 family medicine groups throughout the province.

The study received ethical approval from the *comité d'éthique du CIUSSS Capitale Nationale* (2016-2017-10MP), and informed consent was obtained from each participant. Participants also received a symbolic compensation amount (Can \$20) to cover potential fees for travel and parking.

## Data Collection

A variety of methods were used to promote participation of all co-designers in the process throughout the project's evolution. Sometimes the activities were carried out in a large group (project presentations, the sorting method, plenary sessions, brainstorming, and the conclusions) and sometimes in subgroups (prototyping, eHealth Tool comparative analysis, sketching, and pretesting). The subgroups were divided in a mixed way or by type of co-designers (caregivers, HSSPs, or community workers). Mixed subgroups were used when we wanted to cross perspectives, whereas division by type of co-designer was used when we wished to highlight the perception of caregivers. For each subgroup, a moderator (a member of the team for each subgroup) monitored the conduct of the activity and the role of each participant.

As illustrated in Figure 2, the CoDs were interspersed with the ACs (September 2017, December 2017, and June 2018). Members of the advisory committee did not intervene directly in the CoD. However, results collected during the CoDs were reported to the advisory committee when decisions had to be taken or when co-designers differed. These decisions were made by reaching a consensus among the committee members.

The data were obtained via the notes taken by moderators during and after the working sessions, any artifacts produced, and a synthesis of audio recordings. The role of the research team was very important in this study as they were also acting as co-designers, according to the co-design study plan [17]. Each member of the research team participated in data collection and worked in partnership with other co-designers at every step of the design process.

## Data Analysis

For data analysis, an analytical questioning method was employed [19]. This method consists of the development of an investigative framework according to the research objective, followed by careful and repeated reading of the material under study to answer the initial questions. Therefore, the researcher questions the corpus, acquires a first-level response, and converts the answers into additional and more precise questions. Finally, by answering these newly generated questions, we obtain more detailed answers or new questions if needed.

Following the analytical questioning method, the objectives of each CoD were articulated in question form as a first step. The investigative framework for each session is detailed in Table 1.

**Table 1.** Investigative framework.

Analytical questions	Co-design (CoD) and advisory committee (AC) sessions
Based on the needs identified in the pilot project, the literature and potential additions by the group, which ones should be prioritized in the design of the tool?	CoD1 and AC1
What are the general requirements (ex: I want someone to be there to answer my questions) and specific requirements to consider (ex: I want a forum)?	CoD1, AC1, CoD3, and CoD4
What does the tool need to do to meet these needs in considering the characteristics of the individuals concerned and their own experience?	CoD2
Based on the identified needs, what would this tool look like, what would it do?	AC1
What features would meet the needs and requirements of previous groups?	CoD3, CoD4, CoD5, AC2, CoD6, and CoD7
What content elements would meet the needs and requirements of previous groups?	CoD5, AC2, CoD6, and CoD7
Which architecture or structural design of the information would facilitate intuitive access to content?	CoD5, AC2, CoD6, CoD7, CoD8, and AC3
How should we interact with the site functionalities to facilitate intuitive access to content?	CoD5, AC2, CoD6, CoD7, CoD8, and AC3
What design of interface elements can facilitate interaction between the user and the functionalities, as well as movements through the architecture?	CoD7, CoD8, and AC3
How effective are the graphic processing of the elements of the interface, the visual processing of the text, the elements of the page and the navigation?	CoD8 and AC3

The research team systematically applied the analytical questioning method after every CoD and AC. Each member condensed the data (notes, artifacts, and a synthesis of audio recordings) of their subgroup and, for group activities (plenary discussions), 1 member was designated to perform the analysis. According to the investigative framework, answers to the initial questions were reported in a Microsoft Word or Excel document. Subsequently, several meetings were held to discuss the analytical results, to verify and confirm the results obtained, and to check whether the objectives were achieved or if more work was needed to reach them. This data analysis was necessary to plan the following session.

## Results

### Co-Designers' Characteristics

A total of 74 co-designers (women n=64 and men n=10) were recruited for this project (Table 2).

We initially hoped to have co-designers with a variety of characteristics, in terms of their profession (social worker, occupational therapist, physiotherapist, doctor, and nurse), their organization (administrative agency, association, organization, and other), and their sociodemographic attributes, to ensure that the tool is developed taking into account a diversity of people [13]. This appears to have been achieved, except for gender and ethnicity. Caregivers, community workers, and HSSPs are more often female [20,21]; this reflects the reality. Furthermore, our co-designers were predominantly Caucasian.

**Table 2.** Description of co-designers.

Caregivers socio-demographic characteristics	Caregivers (n=30)	Community workers (n=26)	Health professionals (n=18)
<b>Sex, n</b>			
Women	26	20	18
Men	4	6	0
Age (years), range (mean)	42-88 (77.9)	24-66 (44.8)	29-53 (39.6)
<b>Education level, n</b>			
Elementary school	1	0	0
High school	10	1	0
College	4	4	6
Vocational studies	1	0	3
University	12	21	9
None	1	0	0
N/M <sup>a</sup>	1	0	0
Age of the relative (years), range (mean)	61-96 (78.2)	— <sup>b</sup>	—
<b>Relationship to the person for whom they provide care, n</b>			
Children	8	—	—
Sibling	3	—	—
Spouse/husband	17	—	—
Friend	2	—	—

<sup>a</sup>Not mentioned.

<sup>b</sup>Not applicable.

### Co-Design Process

Throughout the progress of the study, adjustments were made to plan the CoD, notably because certain steps, among others the identification of functionalities, required more sessions than expected. A potential explanation for this is that the co-designers were not experts in Web design, and they had more difficulty identifying the functionalities needed to meet the targeted needs. In accordance with the design process and with the study by Garrett [12], existing tools in the same category should be

analyzed. The choice was made to explore 9 existing eHealth tools (selected by considering the functionalities included to expose participants to a variety) with the co-designers to help determine which seemed relevant to meet the identified needs (CoD3). The development of content items also took longer than expected. Table 3 summarizes the planned content of the CoDs and the ACs, as described in the study by Latulippe et al [13], the content covered after the adjustments, the methods used, and the results achieved.

**Table 3.** Co-design sessions' content.

Co-design session and content planned	Covered content	Activities and methods	Achievements
<b>1, 2, and 3—Strategy: user needs and product objectives</b>			
Identification of content and functional requirements that must be included to meet the user's needs	Identification of the needs; identification of tool requirements based on prioritized needs and the variables to consider; and comparison of existing tools	Sorting method; brainstorming; persona; and workshops in subgroups	Identification of 8 needs not covered by any contents or functionalities in the other tools
<b>4 and 5—Scope and structure: functional specifications, content requirement, interaction design, and information architecture</b>			
Identification of content and functional requirements that must be included to meet the user's needs (continued); design of information architecture to facilitate intuitive access to content; interaction design: development of the course of the application with the aim of facilitating the user's tasks and defining how the user interacts with the functionalities of the site	Identification of content and functional requirements to meet the 8 user's needs not covered by the other tools; choice of functionalities and design of information architecture	Group brainstorming; paper prototype; development from the material provided of the desired site architecture in 3 subgroups	Creation of 3 interactive PDF files (based on paper prototypes) representing what the tool should look like, what functionalities it should include, and how it should be organized
<b>6—Structure and skeleton: interaction design and information architecture and information design</b>			
Design of information architecture (continued); interaction design (continued); design of the interface elements to facilitate the user's interactions with the functionalities of the application: navigation, terminology, density of the text, and interface	Creation of content for different functionalities and pages and result ranking filter	Brainstorming and workshops in subgroups	Content for the caregiver profile, resource profile, needs identification questionnaire, visual analog scale, and draft of the caregiver's testimony video and first draft of the research tool
<b>7—Skeleton: interface and navigation design</b>			
Design of the interface elements (continued)	Validation of the content created in Session 6; discussion of privacy issues as opposed to the user experience; finalization of the algorithm database for the search tool; determination of the degree of detail of the search results; development of the keyword lexicon; and validation of the information architecture and interaction design of the site with a medium-fidelity prototype (clickable version)	Workshops in subgroups	Adjustment of the need identification questionnaire; and layout proposal for search results on the results page; draft of the keywords lexicon in association with the database
<b>8—Skeleton: aesthetic</b>			
Graphic treatment of interface elements, and visual treatment of the text, elements on the page and navigation.	Usability test of a high-fidelity prototype (Web); presentation of different homepage proposals; -verification of the understanding of the visual analog scale; decision on which information should appear on the results page and in which form; content creation for pop-ups, pre-checking of phrases to support the quality of service, and draft for the virtual tours video; and finalization of the list of keywords (lexicon) in association within the database	Pretest; workshops in subgroups; and open discussion	Completed list of keywords (lexicon) in association with the database; collection of co-designers' impressions about the site in general; and draft of virtual tours video

### Strategy and Scope (Functionalities and Content Identification)

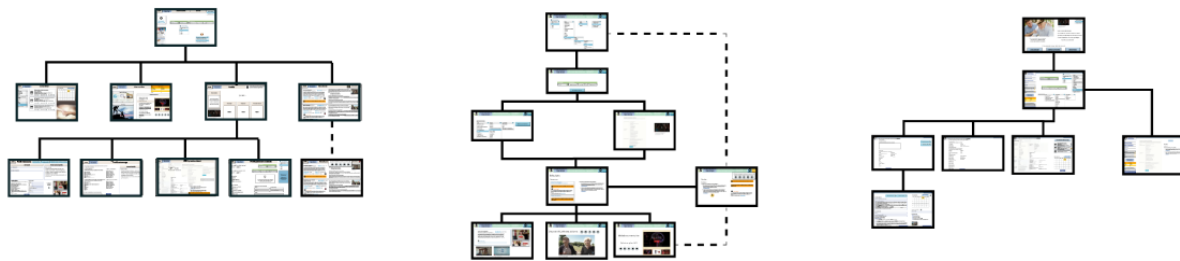
The first 2 CoDs, as well as the first AC, clarified the objectives of the eHealth tool and allowed for the prioritization of the needs to which it must respond (objective 1). This part of the study is described by Latulippe et al [22]. Following the identification

of needs, CoDs 3, 4, 5, and 6, along with the second AC, allowed for identification of the requirements (functionalities and content) that must be included to meet the needs. Tremblay et al [23] describe this part of the project. Please also note that content elements were developed throughout the 8 CoDs. These will be presented in the *Information Design* section.

## Structure and Skeleton

The structure plane includes information architecture, which is the creation of a pattern that represents how users will access content. CoD 5 allowed for the development of the information architecture. Consequently, co-designers were divided into small working groups (including at least 1 caregiver in each). We chose low-fidelity prototyping to produce paper-based Web page designs corresponding to identified requirements. Prototyping is an effective method to advance the idea under study (here the eHealth tool) while quickly getting feedback from co-designers [17]. Thus, all functionalities and content requirements were represented by images, and co-designers were asked to place them (or remove or add them) according to the optimal organization of a website (home page, results page, etc). The 3 proposals for the information architecture design are presented in Figure 3.

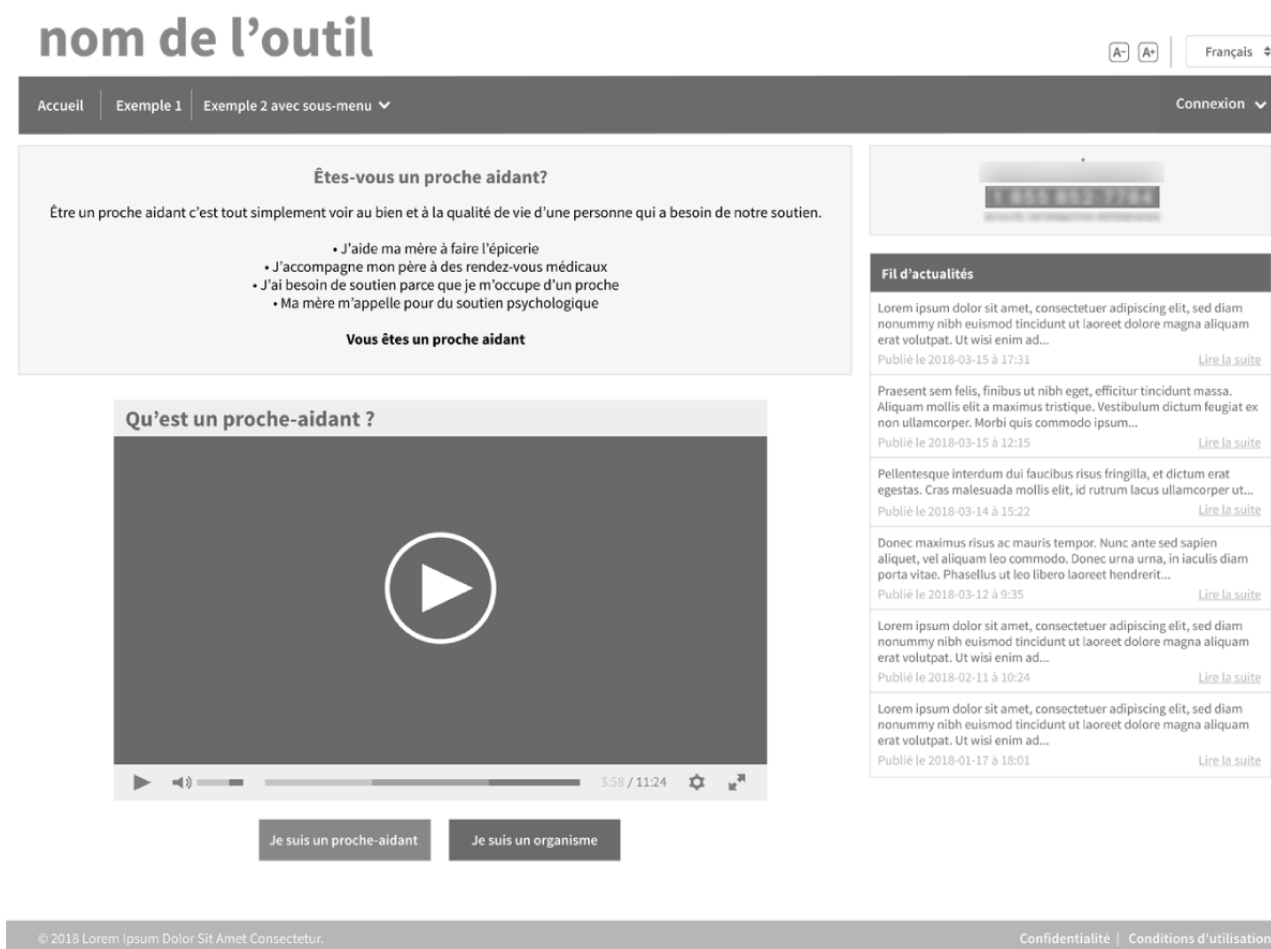
**Figure 3.** Information architecture design proposals.



Following this CoD, the research team reproduced the 3 proposed structures of the eHealth tool in an interactive PDF format. These 3 PDF proposals were then introduced to members of the advisory committee during a second meeting session.

Advisory committee members were invited to explore the proposals. They were also encouraged to discuss them to make choices for the nonconsensual elements. At this stage of the project, a Web designer was recruited to design Web mock-ups, and a programmer analyst was brought in to analyze the requirements and program a first version of the eHealth tool. We deliberately chose a black-and-white version for the mock-ups of pages because we wanted to isolate aspects of information architecture, interaction, and interface design and avoid any influence that colors might have (Figure 4) [24,25].

Figure 4. First version of the tool.



## Information Design

We completed the production of the content items of the tool in the 6 to 8 CoDs. We also intended to work on navigation and interface elements, as well as graphic design of the tool during these sessions. However, the time required to determine the functionalities and develop the content of the tool did not allow us to complete these steps as planned. Nonetheless, even if no specific activities addressed these steps of the design process, co-designers commented on the desired colors and on the visual aspect of the tool (eg, a minimalist aesthetic), which allowed the UX expert and the programmer to develop a beta version of the eHealth tool (Figure 5).

Thus, all of these CoDs aimed to develop an eHealth tool to help caregivers in (1) recognizing their role as caregivers, (2) establishing their needs and those of the elders they support, and (3) identifying resources that meet their needs. The requirements (functionalities and content) needed to meet these objectives were identified and organized according to a structure that meets the needs and characteristics of potential users (seniors' caregivers). In the beginning of the process, we did not know exactly the type of eHealth tool we were going to

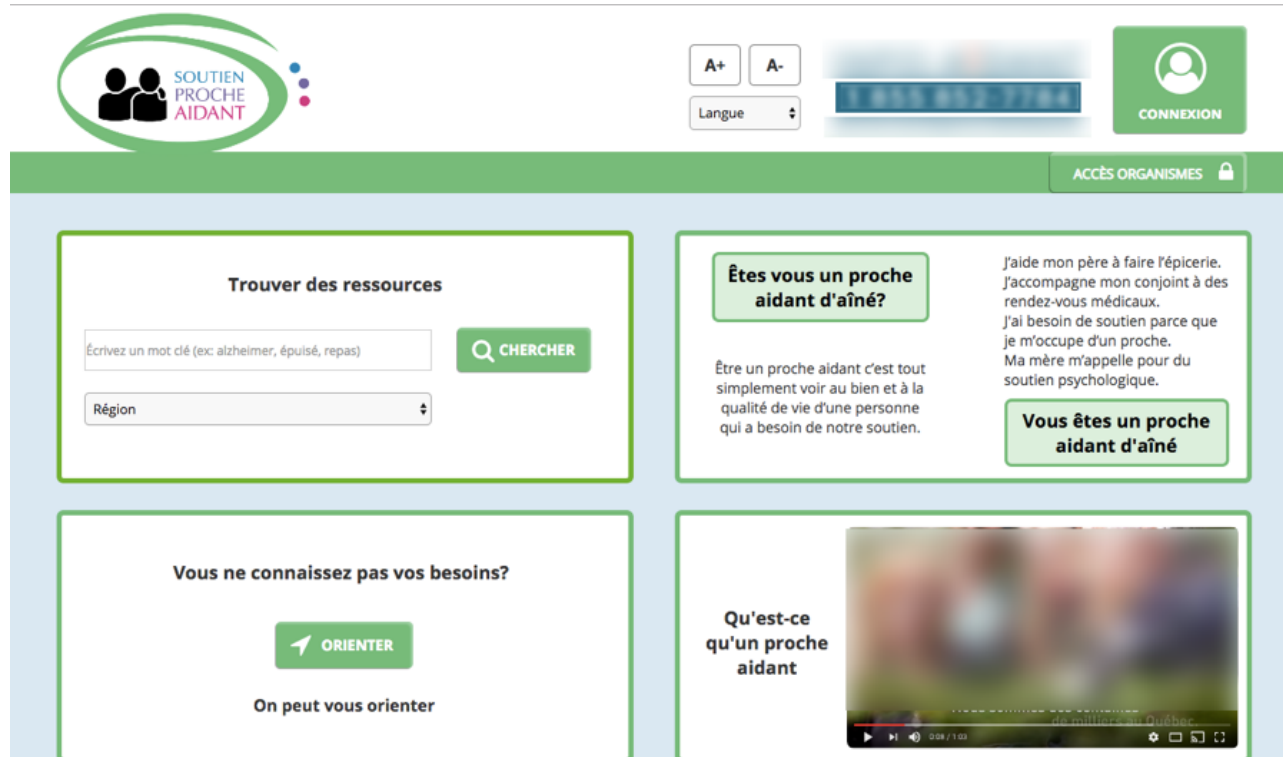
design as we let co-designers decide on the form, consistent with their needs. A website with a responsive grid that fits on a tablet was chosen because caregivers using the internet tended to use a search engine from a tablet or their computer during their help-seeking process. The website option was developed based on the actual digital literacy profile of caregivers in Quebec.

The design of the website includes the following:

1. A definition of a caregiver, including a video.
2. Reference to a resource person as needed.
3. A search tool by keywords and region or geographical area with the possibility of carrying out an advanced search.
4. A questionnaire to help caregivers identify their needs.
5. Access for organizations to register their services and activities and to submit documents and videos.
6. A Results page organizing results in 3 categories: organizations, activities, and documents.
7. The ability to add testimonials and virtual tours for each formal service to encourage caregivers and make them comfortable using the services.
8. A Profile page for caregivers where they can register their favorites and access a personal activity calendar



Figure 5. Version 2 of the tool.



## Discussion

### Principal Findings

This study led to the development of an eHealth tool (a website) that allows caregivers to identify their needs and those of the older person they support and to effectively pinpoint resources to meet those needs. To date, although it is necessary to better support caregivers to preserve their health and quality of life and to ensure the safety and well-being of functionally impaired seniors, it is recognized that caregivers still have difficulty in identifying their needs and those of the elders they support and that they make scant use of available resources [6]. As there were already tools available to help caregivers in this process, co-designers first questioned the relevance of developing an additional tool. However, it emerged that none of the existing tools completely meet the needs of the caregivers or were fully adapted to their situations.

Co-design is a promising avenue for the design of eHealth technology as it has the potential to increase the correspondence between user needs and the technology developed. When users participate as co-designers, they engage as experts in terms of their own experience with technology [15]. To our knowledge, few studies have used a co-design approach to develop an eHealth tool for caregivers in Quebec. Other studies have explored a participatory approach, such as co-design in eHealth for caregivers in other countries, emphasizing the potential of including caregivers as co-designers [26-29]. This is particularly important for caregivers of older persons as they may be elderly themselves and as current statistics in Quebec reveal a digital divide related to age (65 years and more) [30]. When elder caregivers participate in the design of technologies, we can expect them to make design decisions corresponding to their

willingness to use the technology designed. In this case, we believe it might increase the use of the website, enabling us to reach the goal of this research project: allowing caregivers to find appropriate resources by themselves.

### Engagement

The participation of the people targeted by the eHealth tool in the development of eHealth promotes their ability to be healthy, committed to improving the status of caregivers and, thus, reducing their risk of social health inequalities [18]. From a social justice perspective, the active participation of those concerned is a democratic process that reconciles freedoms, individual preferences, and collective choices [31]. The use of a co-design approach may allow this type of participation. It involves the groups that are experiencing the problem through a research process that combines the roles of creator, decision maker, and user simultaneously [32]. In this sense, it appears to be a genuine means of operationalizing democracy. The activities and methods used were intended to facilitate the ability of co-designer to engage in creation and innovation regardless of their technological skills.

The more concrete the methods (eg. prototyping from an image), the easier it seemed for co-designers to come up with ideas. Working in a subgroup with the presence of a moderator (a member of the team for each subgroup) encouraged a fair discussion, an ease in expressing themselves, and optimal participation for each individual.

### Challenges and Solutions

We encountered various challenges associated with the co-design approach. The principal challenges and solutions found by the research team were (1) the recruitment of caregivers, (2) discussion outside the scope of the research, (3)

the limited ability of some co-designers to view functionalities, (4) the short intervals between the CoDs, (5) the place of the research team, and (6) the collaboration of experts in various domains.

### ***The Recruitment of Caregivers***

As with most studies using this population, the recruitment of caregivers, considering the limited time they have available, was a challenge [33]. To reduce the burden of participation and to promote recruitment, we adjusted the methodology so that caregivers were solicited for only one 3-hour work session and not for the entire co-design process. We also worked with community organizations to provide respite and transportation solutions to caregivers attending these sessions. With these adjustments, we were able to recruit 30 caregivers and achieve our objectives.

### ***Discussion Outside the Scope of the Research***

During the sessions, caregivers felt the need to express their emotional burden due to the role that they are fulfilling. In addition, the HSSPs and community workers wanted to communicate some frustrations related to their work. This context led toward discussions not initially planned in the working sessions. This had an impact on the time available to reach our goals. It was challenging to recognize this issue in the discussion while attempting to stay focused on the goal of the meeting. However, empathetic listening has been prioritized. We planned the sessions leaving at least 20 to 30 min without activity to have enough time to accommodate such needs. This certainly contributed to the fact that we were not able to devote a session exclusively to the sensory design stage of the Garrett model, but we still managed to gather information through other activities.

### ***The Limited Ability of Some Co-Designers to View Functionalities***

The limited ability of some co-designers (caregivers and professionals) to view functionalities was another concern. Sometimes, co-designers were not all able to fully engage during CoDs because of a lack of design or technological knowledge or simply because of a failure to comprehend. Other studies also encountered this difficulty [28,34]. When we realized this, we explored increasingly concrete activities to facilitate this participation.

### ***The Short Intervals Between the Co-Design Session***

The short intervals between CoDs constituted a challenge. We planned approximately 1 CoD per month to respect our schedule. However, the time needed to analyze data and plan the following CoDs consistent with results forced us to shift some sessions. The analytical questioning method proved to be a good choice to focus on the questions to be answered for the next step. Thematic analysis, for example, would have required much more time between coding sessions.

### ***The Place of the Research Team***

The research team worked closely with participants in the cocreation process. This collaboration between the research team members and other co-designers might have influenced the results. That said, close interaction and collaboration

between co-designers and researchers remains a fundamental aspect of the co-design approach. Knowledge creation in co-design should be considered in terms of group cognition, which includes researchers [35]. If the team is considered to be part of the co-design, it means that team members share their thoughts with other co-designers. This can influence the decisions made by the group and may compromise the group's power sharing. Conversely, if the research team is not part of the co-design, it may have omitted some important considerations such as what is realistic for the programmer, ideas from the academic literature, or the clinical experience of members. To maintain our role as co-designers while respecting the decisions or ideas coming from other co-designers, the research team carefully noted the provenance of ideas to distinguish them from those of the other co-designers, in case there would be contradictory choices. In such a case, the advisory committee was called upon to take the decision.

### ***The Collaboration of Experts in Various Domains***

Another challenge stemmed from the fact that the research was conducted by experts from various domains. Therefore, a gap between the design research of insiders (those from the design domains) and that done by outsiders (researchers from other domains) emerged [36]. In fact, major difficulties in co-design are the diversity of approaches and a lack of common vocabulary to describe its characteristics, resulting in a growing bank of unrelated works and a lack of transdisciplinary understanding [14]. During the preparation sessions, we had to repeatedly clarify the vocabulary used and discuss our respective perspectives. Nevertheless, the presence of co-designers from a variety of domains has enriched the creative process and contributed to the rigor of the approach.

Thus, design is a complex cognitive activity [37], and users might encounter difficulties at certain steps of the process. Technical knowledge and technological acceptance have major impacts on design decisions. Yet, even if the investments in terms of efforts and cost might appear greatest with a multicentric and multisegment co-design user approach, it remains a promising and innovative avenue in the design of information and communication technologies in the eHealth domain. It allows for a deeper and broader understanding of human experience with technology, along with a better comprehension of nondesigners engaging in a design activity. To foster the potential efficiency of eHealth technology, we must continue to collaborate with different fields of expertise and embrace a *designerly way of thinking* when conducting co-design research. Experts from the design domain should increase collaboration with HSSPs. Design heuristics should be considered a framework for the design of eHealth technologies [38].

### **Limitations**

This project, beyond its challenges and solutions, has certain limitations. Among other things, the majority of participants are from the province of Quebec and speak French; we know that the notion of caregiving can vary according to different cultures [39]. In addition, the cultural competence of an eHealth tool is an important factor to consider in reducing social inequalities in health [40,41]. We were able to observe cultural

differences related to the different regions (eg, feeling of strong isolation in Gaspésie, importance of the first nations in Côte-Nord, and complexity of the location of organizations in Montreal), and these differences were taken into account in the tool. However, it does not yet take into account the differences related to ethnic origin. This study will have to be continued.

### Benefits of the Project

The impacts of this project are unprecedented as it was carried out in a rigorous study involving stakeholders in 11 regions in the province of Quebec to consider the contexts that may vary according to the region. The project will definitely serve to optimize the help-seeking process through the website developed. Moreover, the questionnaire created can play an important role to support the identification of needs to assist caregivers to better prepare themselves. Even before the emergence of difficulties and depending on the trajectory of the disease, the questionnaire can support the identification of needs rather than acting in response to the gradual loss of autonomy.

So, this not only allows for the maximizing of the autonomy, security, and quality of life of the functionally impaired older persons, but it also enables them to remain at home longer as the risk of caregiver exhaustion is reduced. This initiative will allow caregivers to have more control over various situations as they will be better equipped to cope. The benefits are also important for functionally impaired older persons as they can count on quality help from a better-equipped caregiver. Finally, throughout the project, the partnership with key players, such

as members of community-based organizations and HSSPs, ensures that the proposed tool complements existing tools.

### Conclusions

This study led to the development of an eHealth tool for caregivers of functionally impaired older persons to help them identify their needs and the resources available to meet them. This tool will help caregivers to optimize their process of seeking help and to prepare for the trajectory of the disease even before the onset of hardship, rather than acting in response to an increased need for care. This proactive approach has the potential to not only maximize the autonomy, safety, and quality of life of the older person assisted but to also prolong their home care as the risk of caregiver burnout will be reduced. This initiative will allow caregivers to have more control over the various situations, as they will be better equipped to deal with them. They will also be better prepared for the evolution of the disease. Another important outcome of this project is improving the support for older persons with a loss of autonomy. Indeed, the person can count on quality help from a better-equipped caregiver. Moreover, the fact of offering this tool to caregivers as soon as the diagnosis is made will ensure elders' right to self-determination is respected by optimizing their autonomy and involving them in decisions concerning them before difficulties arise. The next step will involve user testing to confirm the effectiveness of the design product, which will be the final stage of this study (phase 3), and an evaluation of its usability and will be done in the following months.

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### Conflicts of Interest

None declared.

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## Abbreviations

- AC:** advisory committee session  
**CISSS:** Integrated Health and Social Service Centre  
**CoD:** co-design session  
**eHealth:** electronic health  
**HSSP:** health and social service professional  
**PD:** participatory design  
**PhD:** Doctor of Philosophy  
**UX:** user experience

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Original Paper

# An Intergenerational Information and Communications Technology Learning Project to Improve Digital Skills: User Satisfaction Evaluation

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## Abstract

**Background:** “Digital Partners” is an intergenerational information and communications technology learning project carried out in the municipalities of Vic and Centelles (Catalonia) from April to May 2018. Within the framework of the introduction of community service as a subject in secondary education, the Centre for Health and Social Studies (University of Vic) created a training space with 38 intergenerational partners (aged 14-15 years and >65 years), with the aim of improving the senior users’ digital skills in terms of use of smartphones and tablets, thus helping reduce the digital divide in the territory.

**Objective:** The aim of this paper is to evaluate the satisfaction of both junior and senior participants toward the intervention and to explore its main drivers.

**Methods:** Participants who volunteered to participate in the study were interviewed. Quantitative and qualitative data gathered in paper-based ad hoc surveys were used to assess participants’ satisfaction.

**Results:** The experience shows a broad satisfaction of both junior and senior users. The project’s strengths include the format of working in couples; randomly pairing individuals by operating system; the ability to practice with the device itself; individuals’ free choice to decide what they wish to learn, develop, or practice; and the availability of voluntary practice material that facilitates communication and learning. With regard to aspects that could be improved, there is a need to review the timetabling flexibility of meetings to avoid hurrying the elderly and to extend the project’s duration, if necessary.

**Conclusions:** This activity can serve to create mutual learning through the use of mobile devices and generate security and motivation on the part of the seniors, thus reducing the digital divide and improving social inclusion.

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**KEYWORDS**

active aging; digital inclusion; ICT program; intergenerational relationships; civic participation; community service

## Introduction

The fourth industrial revolution is increasingly revealing its implications, potentially widening the digital divide and increasing inequality and social atomism. The evident

emergence of the use of mobile devices has resulted in some surprising statistics: 99% of young people between the ages of 16 and 24 years in Spain have used a mobile phone in the last 3 months (Figure 1) [1]. More surprisingly, and unlike other technologies, the use of mobile devices is similar between

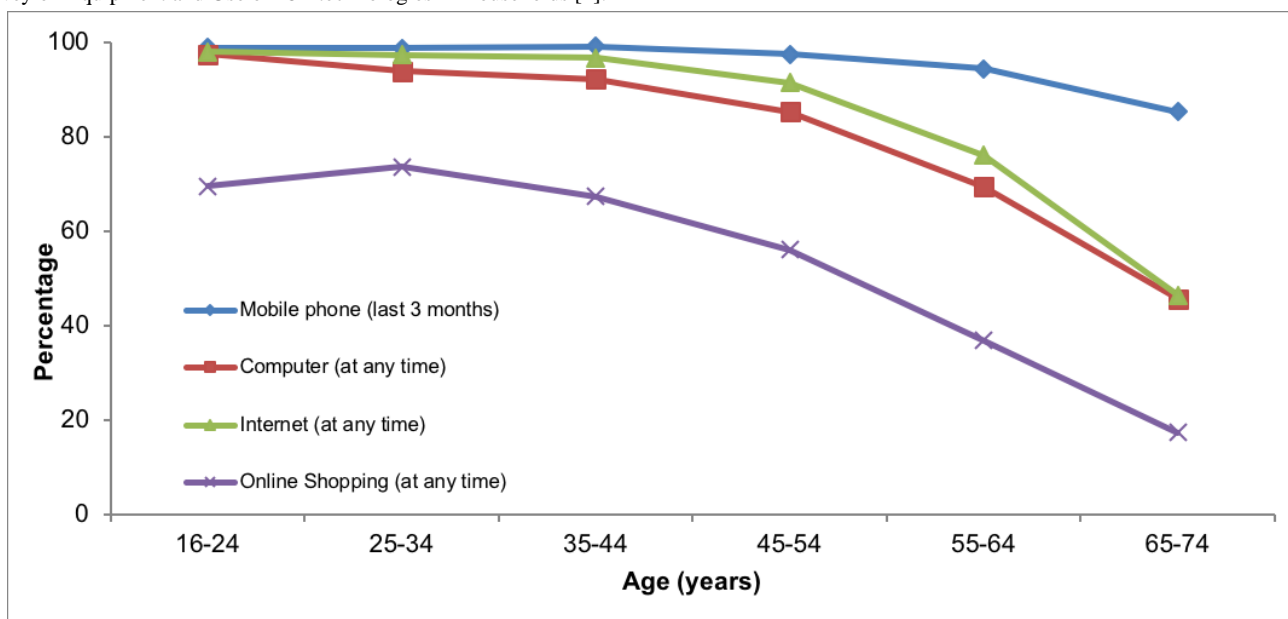
generations: The uptake of mobile devices between older and younger generations only decreases by 15%, whereas other technologies have a significantly lower acceptance rate among people of older age, suggesting that the use of mobile technology by the elderly may not differ much from that of young people, and this trend is important in relation to forecasts of demographic ageing for developed countries [2,3].

The context of this study is Osona, a region located in the northeast corner of the Central Catalan Depression. With 150,000 residents, its population structure includes medium and small areas affected by social isolation and difficulties associated with an ageing population [4,5]. In this region, the 2017-2018 school year included community service as a voluntary academic activity in the secondary education centers [6]. The Centre for

Health and Social Studies designed the project and invited two secondary education schools to participate together with the corresponding University Extension Classes (educational centers for the elderly).

Social common perceptions and assumptions about older people are mistakenly based on stereotypes [7,8]. According to the data presented, new technologies may be encouraging structural changes in the seniors' social and relational behavior. Thus, it is necessary to understand and take into account their facilitating and acceptance factors. The literature shows that the adoption of mobile devices by older people responds to motivations that are very similar to those affecting young people and adults (Textbox 1) [9,10,11].

**Figure 1.** Use of different forms of information and communications technology according to age, as a percentage of the total population. Source: Survey on Equipment and Use of ICT technologies in Households [1].



**Textbox 1.** Motivations and obstacles to the use of mobile devices by the elderly, based on the study by McGaughey [ 9].

**Motivations:**

- Enjoyment/fun
- Expressivity
- Self-awareness
- Prevention (personal)
- Security (personal)
- Ability to communicate with others
- Freedom
- Autonomy
- Usefulness
- Social influence
- Availability of the service
- Value of the service
- Characteristics of the product
- Reduced costs

**Obstacles:**

- User interface
- Program interface
- Size of the device
- Shortcomings in ease of use
- Complexity of the device
- Availability of the service
- Costs (device and service)
- Availability of infrastructure
- Loss of privacy
- Physical abilities
- Cognitive abilities
- Lack of confidence
- Lack of training/knowledge

## Methods

The junior users were 42 young people between the ages of 14 and 15 years, mostly girls (65%), who were voluntarily recruited by their teachers. The schools had contacted the promoters because they were interested in a collaborative activity. These are centers that collaborate throughout the year with other intergenerational activities. The senior users were 38 individuals aged over 65 years, mostly women (75%), who were voluntarily

recruited from the aforementioned University Extension Classes (February/April 2018). The juniors and seniors made up a total of 38 digital couples.

During the preparatory session, each junior received a document containing guidelines on content related to the use of mobile devices, divided into two blocks depending on the type of device (mobile phone or tablet) and three levels of difficulty (basic, medium, and advanced). A summary of the material is presented in [Textbox 2](#).



**Textbox 2.** Structure and content of student training.**Theoretical module 1:**

Brief explanation of what aging is, what variables influence it, stereotypes, and opportunities for technological change.

**Exercise:**

Older people are shown in everyday situations with mobiles, and young people have to say what they see and what perceptions they have. It seeks to explore the potential and difficulties in the use of technology by senior citizens and break stereotypes. It encourages discussion about what we mean by seniors, where individual differences are given, and brainstorming about their motivations.

**Theoretical module 2:**

Aspects that should be taken into account to teach senior citizens how to use mobiles are listed below:

(1) the intergenerational relationship; (2) personal aspects (attitude, acceptance, empathy, assertive communication, values, and motivation); (3) the learning process (individual differences: age, physical and cognitive status, educational level, lived experiences, personal interests, knowledge, expectations, and needs); (4) technical aspects (content, simplify, facilitate help, encourage, and respect the privacy); and (5) practical guidelines.

**Exercise:**

Different objects from different generations are presented to introduce the subject of shared languages and cultural meanings.

The material was specially prepared by the psychologist involved in the project, taking into account the following factors: the need to cover some of the most common uses of mobile devices, the degree of learning difficulty of each item, and the added value of the content in relation to the basic operation of the devices (for example, the optimization of battery usage). The material was provided as an optional ad hoc technical guide to be consulted in case the participants needed help in finding topics to work with in a particular order during the sessions. Content that might be sensitive or represent a degree of risk to the participants, such as actions requiring the use of a credit card, were excluded both from the material and the activity.

The sessions were based on the Intergenerational Mentor-Up philosophy and the Collaborative Learning methodology [12-17]. The advantages associated with this learning method at the academic, social, and psychological levels have been widely recognized, showing that greater performance in the use of mobile technologies favors social contact, reduces loneliness, and improves mental well-being [18-20]. The sessions were organized into two parts: in the first part, a psychologist conducted a training session for youngsters on active ageing, learning, and the pedagogy of digital skills among seniors. In addition, two specialists showed them case studies concerning the teaching and learning of digital competences.

The participants then conducted two or three "Digital Partners" sessions, lasting for about 1.5 hours, which were coordinated and supervised by the same psychologist. Students were asked to present themselves, ask how they could help, explore for how long the seniors had been using the device, how they had learned to use it, which functionalities they used the most, what they wanted to learn, and what their interests were in order to assess their needs and plan an answer; adjust the learning according to the person; show interest; and be friendly, empathetic, and respectful.

The pair worked with their own devices (it allows them to have hands-on experience and ask practical questions to resolve their real-life doubts) and were randomly paired on the first day.

They remained the same throughout the sessions. Once participants formed by couples, if a special need was detected, couples were relocated according to the specifics on the basis of the advice of the student's tutor (who knows the academic level, experience, and mastery of the language of young people).

During the recruitment process, users were asked which operating system (Android or IOS) they were most familiar with (in the case of juniors) or which system they used (in the case of the seniors) to ensure they possessed the necessary digital skills, so that the digital partners were the most suited according to their needs. The room in which the sessions were conducted was equipped with Wi-Fi and was set up especially for the activity, with the desks spread out as much as possible, each with two chairs, and labels announcing the type of software that was to be used. Each table was provided with support material for taking notes. In the absence of one of the seniors, the juniors were reassigned to an existing couple to provide extra help.

At the end of the last session, a voluntary, anonymous, ad hoc, nonvalidated, paper-based, 17-item questionnaire was filled out by all the participants who were able to freely devote as much time as they needed to answer the questions. This paper aims to outline the design and results of the project to understand the key determinants of success of the intervention in order to bring old and young people together in a shared learning activity. A descriptive analysis was carried out to distinguish between qualitative and quantitative data.

## Results

### Quantitative Evaluation

The variables and scores corresponding to the quantitative evaluation are shown in Table 1. The number of high scores is of particular interest (the lowest average score was 8.7/10), indicating both a possible high level of satisfaction with the intervention and a possible lack of critical consideration on behalf of the respondents, potentially because of peer influence when filling in the questionnaires.

**Table 1.** Average scores (out of 10) according to the question sets.

Set and question	Juniors	Seniors
<b>Teachers</b>		
Teachers' mastery of the subject	8.86	9.42
Clarity and coherence in the presentation of the information	9.12	9.25
Attention to personal enquiries and relationship with students	9.46	9.69
<b>Content</b>		
The contents learnt are useful	9.03	9.45
The materials used or recommended are useful for learning	9.48	9.09
Suitability of the educational methodology, exercises and case studies	9.64	8.83
<b>Organization and facilities</b>		
Information and attention received before the project	8.98	9.05
Efficiency in resolving incidents, if any	9.58	9.3
Operation of technical and audio-visual media	8.79	8.83
Suitability of classrooms or laboratories (face-to-face sessions)	9.17	9.3
<b>Format and duration of the activity</b>		
Duration of training (only applicable to the juniors)	8.71	N/A <sup>a</sup>
Timetabling of sessions	9.2	9.58
Duration of sessions	8.86	9.27
<b>Activity</b>		
Belief that what you have learnt will be of personal benefit you	9.44	9.59
The activity has met your expectations	9.38	9.46
Overall evaluation of the activity	9.48	9.55

<sup>a</sup>Not applicable.

## Qualitative Evaluation

The quantitative analysis consists of two forms of participation: in the first part, the participants are asked to identify the strengths and potential areas for improvement in the activity. These are summarized in [Table 2](#).

The answers, which represent the main results of this experience, show that the activity had a positive impact on the juniors from

the point of view of personal experience, interpersonal relations, and self-esteem; that the seniors considered the ability to use their own smartphone or tablet very useful and the involvement of only two people made it easy to deal with their questions and needs in a personalized way; and that both juniors and seniors value the fact that they always worked with the same partner. On the other hand, both groups of participants thought that the timing, duration, and scheduling of the sessions were aspects that could be improved.

**Table 2.** Summary of answers (verbatim) of the qualitative evaluation.

Open questions	Juniors	Seniors
What are the project's advantages?	<ul style="list-style-type: none"> <li>• Meeting someone different</li> <li>• Everyone benefits</li> <li>• Learning about life</li> <li>• Having the same partner</li> <li>• That a child can help an adult</li> </ul>	<ul style="list-style-type: none"> <li>• Being able to practice with your own mobile or tablet</li> <li>• Having a private teacher</li> <li>• Young people cheer you up</li> <li>• Working with a partner and punctuality</li> <li>• Having the same partner</li> <li>• Being able to clear up doubts and needs</li> <li>• Working with a partner</li> </ul>
What would you change about the project?	<ul style="list-style-type: none"> <li>• Earlier</li> <li>• Longer</li> </ul>	<ul style="list-style-type: none"> <li>• Doing a course that lasts a whole term</li> <li>• Having more sessions, since some topics are difficult</li> <li>• More days (1 hour a day)</li> <li>• Cover more in two days</li> <li>• Poor acoustics in the classroom</li> <li>• That we are given suggestions as to what to learn</li> </ul>

**Textbox 3.** Summary of answers (verbatim) to the question, “Out of everything you’ve learnt, what 3 did you like the most?”

**WhatsApp:**

- Sending WhatsApps
- Sending location
- Sending voice messages
- Taking photos
- Sending photos
- Creating groups
- Sharing YouTube videos
- Accessing archived messages

**Using a mobile phone:**

- Connecting to a Wi-Fi network Changing screen settings
- Creating widgets
- Using the camera
- Creating photo albums
- Connecting the tablet to the mobile
- Learning about the battery
- Setting alarms

**Other:**

- Sending emails
- Using YouTube
- Understanding and learning how to use Instagram
- Learning how to share content between different platforms
- Understanding notifications

In the second part of the qualitative approach, a random selection of participants were asked a question while they were participating in the sessions: The senior users (25 respondents) were asked, “Out of everything you’ve learnt, which 3 items did you like the most?” The answers are summarized in [Textbox 3](#), highlighting the learning elements related to the use of WhatsApp and using the phone, in general, as well as a general feeling of having gained confidence in using the device.

The junior participants were also individually chosen at random to answer the following question: “What have you got out of this activity?” We identified three areas of consensus: first, working on stereotypes (with comments such as “some of them don’t have children or grandchildren,” “some of them are fun,” or “some of them know a lot about using a mobile phone”); second, the sense of personal fulfilment (for example, “it makes you feel good to help,” “happiness,” “it’s nice to help,” “really good”); and finally, it shows the importance of the fact that the activity allowed them to take decisions in guiding their partner’s learning, face up to challenges, and learn new things (eg, “they’ve asked me something I don’t know, so I’ll look into it for the next session”). The majority stated that they made use of the user’s guide of suggested topics and that they referred to the contents at a basic level. Thus, on the one hand, the seniors who signed up had a very basic knowledge regarding the use

of mobile devices and, on the other hand, the uses and contents that interested them the most were those that allowed them to have better control over the device.

In keeping with the quantitative evaluation, the results generally show a very high level of satisfaction and highlight its main drivers. From the point of view of personal experience, the participants emphasized the significance of learning and collaborating with another individual. The activity’s strengths were the format of working in pairs; pairing people by operating system; the use of the participants’ own mobile phones; the freedom to decide what they wished to learn, develop, or practice; and the availability of voluntary practice material, which facilitates communication and learning. It has been shown that the activity can serve to create mutual learning through the use of mobile devices and generate security and motivation on the part of the seniors, thus reducing the digital divide and improving social inclusion [21-24].

## Discussion

### Principal Findings

The quantitative results presented can be taken into account in terms of *positively* assessing to what extent the objectives have been met, but they unfortunately do not provide useful insights

on the success drivers of the interventions. Nuances and critical aspects to be taken into account in further studies can be derived only from the qualitative evaluation, which is in line with previous literature showing that seniors can benefit from the learning process and improve their digital self-efficacy and that the intervention can be successful in building an intergenerational bridge [25-27]. Previous analysis also shows that those benefits are not systematic and depend on the meaningfulness of the activities, organization of the program, and participants' knowledge of the other generation [28]. This can explain the assessed success of our program, which emphasized the student training and material preparation.

### Limitations

We were unable to analyze variations in the effectiveness of our intervention due to resource limitation. Therefore, further studies attempting to replicate the intervention described here should analyze these variations, depending on the previous senior digital literacy and age. Moreover, constant developments in mobile devices (versions, design, capacities, etc) suggest that such training, as that described herein, should have a longer continuity to better assess the effect of the intervention over time. In addition, the questionnaire should be further adapted to capture all the critical analyses of the youngsters.

### Implications and Recommendations

The activity's success is based on its design, which takes into account the needs and abilities of the participants: location,

facilities and design of the spaces, training young people receive, and materials used in conducting the sessions, paying special attention to the seniors' learning environment so that they can take full advantage of opportunities to improve their knowledge and skills, and the learning environment of the young people so that they can carry out their tasks effectively while also enjoying learning. Similarly, attention must be paid to certain requirements that may affect development of the activity: connectivity, noise level in the classroom, dividing the participants into pairs, the duration and timetabling, and the type of training (which should be personalized and adapted to the users' needs, although they should also have material available to them as a guide if they so wish).

Many functions of so-called smartphones have been designed without taking into account the needs of senior users; nevertheless, seniors are interested in improving their knowledge and learning to use technology to take advantage of what it offers, as shown by their motivation in carrying out the activity, but also in relation to the dynamics of the session (personalization) and the learning contents (basic). This project addresses the risk of a digital divide, which can increase social inequality. It does so by empowering and transmitting skills. The intergenerational approach leads to mutual and fundamentally bidirectional learning and allows older people to resume their traditional role as transmitters of knowledge.

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### Conflicts of Interest

None declared.

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## Abbreviations

N/A: not applicable

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Original Paper

# Understanding Comorbidities and Their Contribution to Predictors of Medical Resource Utilization for an Age- and Sex-Matched Patient Population Living With HIV: Cross-Sectional Study

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## Abstract

**Background:** More than 60% of people aging with HIV are observed to have multiple comorbidities, which are attributed to a variety of factors (eg, biological and environmental), with sex differences observed. However, understanding these differences and their contribution to medical resource utilization remains challenging as studies conducted exclusively and predominantly among males do not translate well to females, resulting in inconsistent findings across study cohorts and limiting our knowledge of sex-specific comorbidities.

**Objective:** The objective of the study was to provide further insight into aging-related comorbidities, their associated sex-based differences, and their contribution to medical resource utilization, through the analysis of HIV patient data matched by sex.

**Methods:** International Classification of Disease 9/10 diagnostic codes that comprise the electronic health records of males (N=229) and females (N=229) were categorized by individual characteristics, chronic and mental health conditions, treatment, high-risk behaviors, and infections and the codes were used as predictors of medical resource utilization represented by Charlson comorbidity scores.

**Results:** Significant contributors to high Charlson scores in males were age (beta=2.37; 95% CI 1.45-3.29), longer hospital stay (beta=.046; 95% CI 0.009-0.083), malnutrition (beta=2.96; 95% CI 1.72-4.20), kidney failure (beta=2.23; 95% CI 0.934-3.52), chemotherapy (beta=3.58; 95% CI 2.16-5.002), history of tobacco use (beta=1.40; 95% CI 0.200-2.61), and hepatitis C (beta=1.49; 95% CI 0.181-2.79). Significant contributors to high Charlson scores in females were age (beta=1.37; 95% CI 0.361-2.38), longer hospital stay (beta=.042; 95% CI 0.005-0.078), heart failure (beta=2.41; 95% CI 0.833-3.98), chemotherapy (beta=3.48; 95% CI 1.626-5.33), and substance abuse (beta=1.94; 95% CI 0.180, 3.702).

**Conclusions:** Our findings identified sex-based differences in medical resource utilization. These include kidney failure for men and heart failure for women. Increased prevalence of comorbidities in people living long with HIV has the potential to overburden global health systems. The development of narrower HIV phenotypes and aging-related comorbidity phenotypes with greater clinical validity will support intervention efficacy.

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**KEYWORDS**

HIV; sex differences; Charlson scores; comorbidity; electronic health records; health resource

## Introduction

### Background

A variety of comorbidities characterize long-term survivorship with HIV, which is not merely explained by the decrease in AIDS-related mortality. An average of 3 aging-related comorbidities are observed in 60% to 90% of people living with HIV/AIDS (PLWH), aged 50 years and above [1,2]. They are attributed to antiretroviral toxicity, persistent immunodeficiency, and inflammation [2]. Biological sex-related differences also contribute to the determinants of such aging-related comorbidities in populations living with HIV [3,4]. Sex differences are observed in the pathogenesis of HIV and other infectious diseases. Differences exist between males and females for a variety of factors including biological, genetic, environmental, and sociobehavioral [3,4]. Studies have also found sex differences in HIV viral and immunological response as well as disease progression [3,5]. However, challenges exist in clinical studies to isolate biological sex differences and gain a more in-depth understanding of how HIV affects health-related outcomes. Current gaps in knowledge include the lack of understanding of the impact of sex-based differences on the presence of non-AIDS-related comorbidities [4,5]. The presence of multiple comorbidities, observed in HIV, include characteristics of aging-associated phenotypes such as disability and frailty [6]. However, phenotypes are studied far more in the aging field, which is not specific to HIV [7-9]. Poor health outcomes such as disability and frailty increase the risk of poor functional status, which complicates access to care and disrupts disease self-management, resulting in increased medical resource utilization [9]. Therefore, effective interventions require the identification of narrower phenotypes with greater clinical validity [7,10,11]. Exploratory studies should report outcomes based on sex to determine when such differences warrant more focused investigations [4]. HIV research that defines sex differences will ensure intervention efficacy in males and females and will allow for the observation of pathway differences to support effective HIV treatment and ultimately cure.

### Objectives

This study provides an understanding of sex-related differences and has identified multifactorial determinants of aging-related comorbidities and their contributions to medical resource utilization, which are represented by Charlson comorbidity scores [12-14]. This cross-sectional study looked at the presence of comorbidities and not HIV-related contributions (eg, disease stage and immune status) to the development or proliferation of comorbidities. Clinical data that comprise electronic health records (EHRs) were analyzed, and within- and between-group differences identified for a patient population of PLWH were matched by sex. An exploration of HIV clinical data is required to gain further insights into the sex-based differences that may have clinical consequences and contribute to increased medical resource utilization. In fact, higher Charlson scores indicate the increased likelihood that a predicted outcome will result in higher resource utilization or 1-year mortality [12,15,16]. As this study focused on morbidity, not mortality, Charlson scores served as an indicator of medical resource utilization. Here, we

report the following: (1) the prevalence of comorbidities by sex and (2) predictors of medical resource utilization represented by Charlson comorbidity scores that comprise the factors of individual characteristics, chronic conditions, mental health conditions, treatment, high-risk behaviors, and infections by sex. Our findings can inform the design and implementation of effective interventions to reduce the chronic disease burden, decrease medical resource utilization, and support successful aging with HIV [3,4].

## Methods

### Patient Population

We analyzed EHR data for HIV-infected males (N=229) and females (N=229) matched on sex. Records were retrieved from a New York City clinical data warehouse for adult inpatients aged 18 years and older from January 2006 to December 2014. Institutional review board approval was obtained from the Columbia University Irving Medical Center to analyze the deidentified EHRs data, which excluded all potentially identifiable patient information (eg, name, address, and date of birth). Patients were not involved in data analysis or interpretation. Patient personal contact information was not shared with investigators. After data cleaning, which included the removal of incomplete International Classification of Disease (ICD) 9/10 codes, a total of 786 HIV-infected males (N=524) and females (N=262) remained for matching, identified as HIV infected by HIV-related diagnostic codes. Mahalanobis propensity score matching was used to find the female patients comparable to male patients [17]. Female patients were matched to male patients with the closest propensity scores. After the removal of unmatched data, a sample of 229 males and 229 females remained. Propensity score matching allows for meaningful comparisons between groups and reduces confounding factors in the statistical assessment of outcomes [17]. We developed a dataset very limited in missing data, as clinical datasets are known to have a variety of missing data elements. Diagnostic codes (ICD 9/10) came from past medical histories, clinical encounters, and problem lists. Diagnostic codes were organized under the factors of individual characteristics (eg, ICD9/10: 262—malnutrition), chronic conditions (eg, ICD9/10: 401, 401.1, 401.9—hypertension), mental health conditions (eg, ICD9/10: 311—depressive disorders), treatment (eg, ICD9/10: V58.11—chemotherapy), high-risk behaviors (eg, ICD9/10: 305.1—tobacco use), and infections (eg, ICD9/10: 70.54—hepatitis B). Patients were distributed into nonmutually exclusive groups based on sex. Inclusion in a diagnostic group was the existence of the diagnostic code in the patient chart history.

### Statistical Analysis

We examined the predictors of medical resource utilization represented by Charlson comorbidity scores. We summarized our results with descriptive statistics, bivariate analyses, and linear regression models. To determine the relationship between identified predictors and Charlson scores, we calculated Pearson Product Moment Correlations. *t* tests assessed the differences in continuous variables, and chi-square test assessed the differences in categorical variables. A total of 3 independent



stepwise multiple regressions (ie, all patients, male only, and female only) were performed to identify the relative importance of significant Charlson score predictors ( $P < .05$ ). A stepwise approach was used to prevent bias in the selection of variables in the final models [18]. We report betas and CIs for regression analyses. SPSS 23.0 was used to conduct data analysis.

## Results

### Patient Characteristics

We included 458 patients in our analysis, aged 18 to 85 years, with the mean age of 50.3 (SD 14.1 years). The racial distribution of the female sample (N=229) includes 39.7% (91/229) blacks, 14.4% (33/229) whites, 0.4% (1/229) Asian, 0.4% (1/229) Native American, 0.8% (2/229) Native Hawaiian/Pacific Islanders, 11.9% (27/229) other, and 32.5% (74/229) unknown or declined. The male sample (N=229) includes 23.3% (53/229) blacks, 26.5% (61/229) whites, 0.8% (2/229) Asian, 0.4% (1/229) Native American, 0.4% (1/229) Native Hawaiian/Pacific Islanders, 13.9% (32/229) other, and 34.6% (79/229) unknown or declined. The average length of hospital stay was 9.65 (SD 11 days) for males and 9.45 (SD 13 days) for females. For males, the average HIV RNA viral load

distribution was  $\leq 500$  copies/mL: 24.1% (55/229); 500-4999 copies/mL: 41.4% (95/229); 5000-49,999 copies/mL: 20.7% (47/229); and  $\geq 50,000$  copies/mL: 13.8% (32/229). The average CD4+ lymphocyte counts (CD4) for males were  $\leq 200$  cells/ $\mu$ L: 16.5% (38/229); 201-349 cells/ $\mu$ L: 22.7% (52/229); 350-500 cells/ $\mu$ L: 24.4% (56/229); and  $\geq 501$  cells/ $\mu$ L: 36.4% (83/229), with 63.6% (146/229) prescribed antiretrovirals. For females, the average viral load distribution was  $\leq 500$  copies/mL: 31.5% (71/229); 500-4999 copies/mL: 27.8% (64/229); 5000-49,999 copies/mL: 27.8% (64/229); and  $\geq 50,000$  copies/mL: 13.1% (30/229). The average CD4 counts for females were  $\leq 200$  cells/ $\mu$ L: 15.4% (35/229); 201-349 cells/ $\mu$ L: 17.9% (41/229); 350-500 cells/ $\mu$ L: 21.4% (49/229); and  $\geq 501$  cells/ $\mu$ L: 45.3% (104/229), with 72% (165/229) prescribed antiretrovirals. The top 6 ICD9/10 codes for males were hypertension, current tobacco use, noncompliance with treatment/regimen (not following the treatment or regimen prescribed for improved health outcomes) [19], hyperlipidemia, history of tobacco use, and depression. The top 6 ICD9/10 codes for females were hypertension, current tobacco use, and history of tobacco use, uncomplicated asthma, acute kidney failure, and hyperlipidemia (Table 1). Charlson scores ranged from 0 to 20, with an average of 7.72 (SD 9.7) for males, and 0 to 18, with an average of 6.90 (SD 9.45) for females (Tables 1 and 2).

**Table 1.** Descriptive statistics for medical resource utilization (Charlson scores).

Variable	Males (n=229)	Females (n=229)	All (N=458)
<b>Individual characteristics</b>			
Age, mean (SD)	51.5 (13)	51.5 (13)	50.3 (14.1)
Length of hospital stay, mean (SD)	9.65 (11)	9.45 (13)	9.58 (12)
Malnutrition, n (%)	35 (15.2)	25 (10.9)	60 (13.1)
Noncompliance with treatment/regimen, n (%)	38 (16.5)	32 (13.9)	70 (15.2)
<b>Chronic conditions, n (%)</b>			
Diabetes mellitus II	25 (10.9)	29 (12.6)	54 (11.7)
Hyperlipidemia	37 (16.5)	35 (15.2)	72 (15.7)
Hypertension	55 (24.0)	62 (27.0)	117 (25.5)
Atherosclerosis	31 (13.5)	18 (7.8)	49 (10.6)
Atrial fibrillation	11 (4.8)	5 (2.1)	16 (3.4)
Heart failure	23 (10.0)	24 (10.4)	47 (10.2)
Uncomplicated asthma	19 (8.2)	37 (16.5)	56 (12.2)
Acute kidney failure	30 (13.1)	37 (16.5)	67 (14.6)
<b>Mental health conditions</b>			
Depressive disorder	35 (15.2)	31 (13.5)	66 (14.4)
<b>Treatment</b>			
Chemotherapy	25 (10.9)	18 (7.8)	43 (9.3)
<b>High-risk behaviors</b>			
Substance abuse	33 (14.4)	19 (8.2)	52 (11.3)
Current tobacco use	54 (23.5)	40 (17.4)	94 (20.5)
History of tobacco use	36 (15.7)	39 (17.0)	75 (16.3)
<b>Infections</b>			
Chronic hepatitis C	33 (14.4)	27 (11.7)	60 (13.1)

**Table 2.** Correlations and *P* values for medical resource utilization (Charlson scores).

Variable	Males (n=229)		Females (n=229)		All (N=458)	
	Correlation	<i>P</i> value	Correlation	<i>P</i> value	Correlation	<i>P</i> value
<b>Individual characteristics</b>						
Age	0.359	.001 <sup>a</sup>	0.118	.14	0.24	.001 <sup>a</sup>
Length of hospital stay	0.186	.001 <sup>a</sup>	0.148	.05 <sup>b</sup>	0.169	.02 <sup>b</sup>
Malnutrition	0.289	.001 <sup>a</sup>	0.085	.26	0.198	.18
Noncompliance with treatment/regimen	-0.01	.90	0.058	.38	0.024	.66
<b>Chronic conditions</b>						
Diabetes mellitus II	0.026	.64	-0.054	.51	-0.016	.74
Hyperlipidemia	0.053	.49	0.082	.20	0.068	.31
Hypertension	0.084	.22	-0.058	.53	0.011	.17
Atherosclerosis	0.242	.001 <sup>a</sup>	-0.008	.73	0.138	.001 <sup>a</sup>
Atrial fibrillation	0.101	.14	-0.005	.21	0.061	.28
Heart failure	0.153	.03 <sup>b</sup>	0.159	.04 <sup>b</sup>	0.155	.04 <sup>b</sup>
Uncomplicated asthma	-0.024	.70	0.026	.60	-0.003	.96
Acute kidney failure	0.195	.001 <sup>a</sup>	0.12	.10	0.153	.03 <sup>b</sup>
<b>Mental health conditions</b>						
Depressive disorder	-0.028	.64	-0.036	.62	-0.03	.45
<b>Treatment</b>						
Chemotherapy	0.197	.001 <sup>a</sup>	0.167	.05 <sup>b</sup>	0.185	.001 <sup>a</sup>
<b>High-risk behaviors</b>						
Substance abuse	-0.002	.94	0.151	.05 <sup>b</sup>	0.069	.42
Current tobacco use	-0.042	.49	-0.09	.25	-0.06	.31
History of tobacco use	0.183	.001 <sup>a</sup>	0.139	.04 <sup>b</sup>	0.159	.001 <sup>a</sup>
<b>Infections</b>						
Chronic hepatitis C	0.175	.001 <sup>a</sup>	0.107	.14	0.144	.001 <sup>a</sup>

<sup>a</sup>*P*<.01.<sup>b</sup>*P*<.05.

### Predictors of Medical Resource Utilization

Bivariate analyses revealed significant contributions to high Charlson scores for a variety of factors in our patient population. These include the individual characteristics of older age ( $\geq 50$  years;  $X^2_{19}=149.9$ ), longer length of hospital stay ( $t_{456}=2.96$ ), and noncompliance with treatment/regimen ( $X^2_{19}=30.8$ ). In addition to the chronic conditions of hyperlipidemia ( $X^2_{19}=31.2$ ), hypertension ( $X^2_{19}=54.5$ ), atherosclerosis ( $X^2_{19}=38.6$ ), acute kidney failure ( $X^2_{19}=32.7$ ), and heart failure ( $X^2_{19}=53.5$ ), significant differences also included the treatment of chemotherapy ( $X^2_{19}=81.8$ ), the high-risk behavior of current tobacco use ( $X^2_{19}=31.6$ ) and history of tobacco use ( $X^2_{19}=35.9$ ), and the infection of chronic hepatitis C ( $X^2_{19}=54.8$ ; [Table 3](#)).

Bivariate analyses also revealed significant contributions to high Charlson scores within sex groups for a variety of factors. For males, these include the individual characteristics of older age ( $\geq 50$  years;  $X^2_{19}=80.5$ ), longer length of hospital stay ( $t_{227}=2.60$ ), and malnutrition ( $X^2_{19}=19.7$ ), in addition to the chronic conditions of atherosclerosis ( $X^2_{19}=44.4$ ), acute kidney failure ( $X^2_{19}=32.3$ ), and heart failure ( $X^2_{19}=51.5$ ). Significant differences also included the treatment of chemotherapy ( $X^2_{19}=55.4$ ), the high-risk behavior of history of tobacco use ( $X^2_{19}=41.3$ ), and the infection of chronic hepatitis C ( $X^2_{19}=38.1$ ; [Table 3](#)). For females, these include the individual characteristic of older age ( $\geq 50$  years;  $X^2_{19}=77.8$ ) in addition to the chronic conditions of hyperlipidemia ( $X^2_{19}=31.2$ ) and hypertension ( $X^2_{19}=52.3$ ). Significant differences also included the treatment

of chemotherapy ( $X^2_{19}=32.3$ ), the high-risk behavior of substance abuse ( $X^2_{19}=36.8$ ), and the infection of chronic hepatitis C ( $X^2_{19}=30.4$ ; Table 3).

The stepwise multiple regression for all patients identified the most significant ( $P<.05$ ) contributors to high Charlson scores to be the individual characteristics of older age (beta=1.91; 95%

CI 1.22-2.60), longer length of hospital stay (beta=.039; 95% CI 0.12-0.065), and malnutrition (beta=1.88; 95% CI 0.882-2.87); chronic conditions of acute kidney failure (beta=1.29; 95% CI 0.347-2.24) and heart failure (beta=1.22; 95% CI 0.104-2.33); treatment of chemotherapy (beta=3.37; 95% CI 2.22-4.53); history of high-risk behavior of tobacco use (beta=1.03; 95% CI 0.130-1.93); and infection of chronic hepatitis C (beta=1.10; 95% CI 0.097-2.109; Table 4).

**Table 3.** Chi-square/*t* tests for outcome variable: medical resource utilization (Charlson scores).

Variable	Males (n=229)		Females (n=229)		All (N=458)	
	$X^2$ (df)	<i>P</i> value	$X^2$ (df)	<i>P</i> value	$X^2$ (df)	<i>P</i> value
<b>Individual characteristics</b>						
Age <50 years and ≥50 years	80.5 (19)	.001 <sup>a</sup>	77.8 (19)	.001 <sup>a</sup>	49.9 (19)	.001 <sup>a</sup>
Length of hospital stay <sup>b</sup>	-2.60 (227)	.001 <sup>a</sup>	-1.18 (227)	.07	-2.96 (456)	.001 <sup>a</sup>
Malnutrition	42.8 (19)	.001 <sup>a</sup>	17.3 (19)	.15	26.9 (19)	.10
Noncompliance with treatment/regimen	19.7 (19)	.26	20.5 (19)	.12	30.8 (19)	.04 <sup>c</sup>
<b>Chronic conditions</b>						
Diabetes mellitus II	23.7 (19)	.13	13.8 (19)	.16	14.3 (19)	.15
Hyperlipidemia	18.8 (19)	.15	31.2 (19)	.03 <sup>c</sup>	31.2 (19)	.03 <sup>c</sup>
Hypertension	28.2 (19)	.07	52.3 (19)	.001 <sup>a</sup>	54.5 (19)	.001 <sup>a</sup>
Atherosclerosis	44.4 (19)	.001 <sup>a</sup>	9.8 (19)	.26	38.6 (19)	.001 <sup>a</sup>
Atrial fibrillation	29.1 (19)	.06	10.4 (19)	.22	21.5 (19)	.11
Acute kidney failure	32.3 (19)	.03 <sup>c</sup>	27.1 (19)	.08	32.7 (19)	.03 <sup>c</sup>
Heart failure	51.5 (19)	.001 <sup>a</sup>	22.8 (19)	.14	53.5 (19)	.001 <sup>a</sup>
Uncomplicated asthma	16.5 (19)	.17	22.5 (19)	.13	16.3 (19)	.15
<b>Mental health conditions</b>						
Depressive disorder	30.4 (19)	.06	11.9 (19)	.15	19.0 (19)	.12
<b>Treatment</b>						
Chemotherapy	55.4 (19)	.001 <sup>a</sup>	32.3 (19)	.03 <sup>c</sup>	81.8 (19)	.001 <sup>a</sup>
<b>High-risk behaviors</b>						
Substance abuse	21.2 (19)	.14	36.8 (19)	.001 <sup>a</sup>	28.0 (19)	.07
Current tobacco use	29.1 (19)	.07	13.1 (19)	.22	31.6 (19)	.03 <sup>c</sup>
History of tobacco use	41.3 (19)	.001 <sup>a</sup>	19.2 (19)	.13	35.9 (19)	.01 <sup>c</sup>
<b>Infections</b>						
Chronic hepatitis C	38.1 (19)	.001 <sup>a</sup>	30.4 (19)	.01 <sup>c</sup>	54.8 (19)	.001 <sup>a</sup>

<sup>a</sup> $P<.01$ .

<sup>b</sup>Length of hospital stay values display *t* tests for outcome variable: medical resource utilization.

<sup>c</sup> $P<.05$ .

**Table 4.** Linear regression models of best fit for medical resource utilization (Charlson Scores).

Variables	Unstandardized coefficient beta, mean increases (95% CI for beta)	P value
<b>All patients model, N=458</b>		
<b>Individual characteristics</b>		
Age <50 years and ≥50 years	1.91 (1.218-2.595)	.001 <sup>a</sup>
Length of hospital stay	.039 (0.012-0.065)	.004 <sup>a</sup>
Malnutrition	1.88 (0.882-2.873)	.001 <sup>a</sup>
<b>Chronic conditions</b>		
Acute kidney failure	1.29 (0.347-2.241)	.008 <sup>a</sup>
Heart failure	1.22 (0.104-2.328)	.03 <sup>b</sup>
<b>Treatment</b>		
Chemotherapy	3.37 (2.218-4.529)	.001 <sup>a</sup>
<b>High-risk behaviors</b>		
History of tobacco use	1.03 (0.130-1.932)	.03 <sup>b</sup>
<b>Infections</b>		
Chronic hepatitis C	1.10 (0.097-2.109)	.03 <sup>b</sup>
<b>Male-only model, N=229</b>		
<b>Individual characteristics</b>		
Age <50 years and ≥50 years	2.37 (1.446-3.286)	.001 <sup>a</sup>
Length of hospital stay	.046 (0.009-0.083)	.02 <sup>b</sup>
Malnutrition	2.96 (1.721-4.204)	.001 <sup>a</sup>
<b>Chronic conditions</b>		
Acute kidney failure	2.23 (0.934-3.521)	.001 <sup>a</sup>
<b>Treatment</b>		
Chemotherapy	3.58 (2.164-5.002)	.001 <sup>a</sup>
<b>High-risk behaviors</b>		
History of tobacco use	1.40 (0.200-2.607)	.02 <sup>b</sup>
<b>Infections</b>		
Chronic hepatitis C	1.49 (0.181-2.791)	.03 <sup>b</sup>
<b>Female-only model, N=229</b>		
<b>Individual characteristics</b>		
Age <50 years and ≥50 years	1.37 (0.361-2.375)	.008 <sup>a</sup>
Length of hospital stay	.042 (0.005-0.078)	.03 <sup>b</sup>
<b>Chronic conditions</b>		
Heart failure	2.41 (0.833-3.984)	.003 <sup>a</sup>
<b>Treatment</b>		
Chemotherapy	3.48 (1.626-5.328)	.001 <sup>a</sup>
<b>High-risk behaviors</b>		
Substance abuse	1.94 (0.180-3.702)	.03 <sup>b</sup>

<sup>a</sup>P<.01.

<sup>b</sup> $P < .05$ .

The final stepwise multiple regression model for male patients identified the most significant ( $P < .05$ ) contributors to high Charlson scores to be the individual characteristics of older age (beta=2.37; 95% CI 1.45-3.29), longer length of hospital stay (beta=.046; 95% CI 0.009-0.083), and malnutrition (beta=2.96; 95% CI 1.72-4.20) in addition to the chronic conditions of acute kidney failure (beta=2.23; 95% CI 0.934-3.52); the treatment of chemotherapy (beta=3.58; 95% CI 2.16-5.002), the history of high-risk behavior of tobacco use (beta=1.40; 95% CI 0.200 to 2.61), and the infection of chronic hepatitis C (beta=1.49; 95% CI 0.181-2.79), as the most significant ( $P < .05$ ) contributors to high Charlson scores (Table 4).

The final stepwise multiple regression model for female patients identified the most significant ( $P < .05$ ) contributors to high Charlson scores to be the individual characteristics of older age (beta=1.37; 95% CI 0.361-2.38) and longer length of hospital stay (beta=.042; 95% CI 0.005-0.078) in addition to the chronic conditions of heart failure (beta=2.41; 95% CI 0.833-3.98); the treatment of chemotherapy (beta=3.48; 95% CI 1.626-45.33), the high-risk behavior of substance abuse (beta=1.94; 95% CI 0.180-3.402), as the most significant ( $P < .05$ ) contributors to high Charlson scores (Table 4).

## Discussion

### Principal Findings

With immune restoration and viral suppression leading to long-term survivorship with HIV, there is a need to increase our focus on the management and prevention of comorbidities. Therefore, it is essential to improve our understanding of aging-related comorbidities and sex differences in HIV clinical outcomes and survival. To further explore these differences and their contribution to medical resource utilization, we analyzed EHR data for HIV-infected patients matched by sex.

Phenotype frameworks view aging within a broader context of objectively defined phenotypic manifestations (eg, comorbidities and physical-social functioning). We observed the sex-related interplay between individual characteristics, chronic conditions, treatment, mental health conditions, high-risk behaviors, and infections and their contribution to medical resource utilization.

Our results contribute to the development of narrower HIV phenotypes with greater clinical validity. Charlson comorbidity scores are robust predictors of both medical resource utilization and 1-year mortality [15,16,20] and are essential for epidemiological investigations on age and survival [18]. However, the use of Charlson scores to understand medical resource utilization in populations of PLWH with comorbidities remains sparse [14,21]. Although no significant differences existed in mean Charlson scores for males and females, contributions to medical resource utilization differed based on sex.

The lack of significant differences in Charlson scores for our matched sample is not reflected in the published literature as studies have shown that males have significantly higher morbidity rates than females [4,22]. However, the contribution

of factors to the utilization of medical resources was different for males and females [12]. Our regression models for our patient population identified age as a significant contributor to high Charlson scores. Age was the second highest for all patients, first in the male-only model and third in the female-only model. Similar to aging in uninfected populations, males exhibited higher Charlson scores based on age [23]. Results were different for females as the treatment of chemotherapy was the most significant contributor to high Charlson scores, followed by heart failure. Chemotherapy was the second most significant contributor in males, and heart failure was not in the male-only model. Antineoplastic chemotherapy is understandably a significant contributor to medical resource utilization as such treatment is a consequence of diagnosed malignancies [24,25]. Their toxic effects can result in inadequate nutrition, making patients vulnerable to malnourished states [26]. Although malnourishment was not significant in the female-only model, it was the third significant contributor in the all patient and male-only models. Non-AIDS-defining cancers are increasing in populations of PLWH [27], which includes coinfection by oncogenic viruses such as hepatitis C virus (HCV), which is also a significant contributor in our all patient and male-only models. Heightened cancer risk includes behavioral risk factors as well, such as cigarette smoking. History of tobacco use was also a significant contributor in our all patient and male-only models. Antineoplastic agents are a significant problem in populations of PLWH, with potentially overlapping toxicities with antiretroviral therapy [24,25]. A better understanding of such interactions will be critical for cancer survival in this population.

Heart failure was the second most significant contributor in the female-only model, eighth in the all patient model and not present in the male-only model. Cardiovascular-related illness is a known risk factor in PLWH, with heart disease being a common complication [28,29]. PLWH have increased cardiovascular disease-related mortality compared with uninfected groups [5,27]. A longitudinal study revealed that risk of cardiovascular-related mortality increased steadily for PLWH from 1999 to 2013, with a decrease in risk observed in uninfected groups [30,31]. Similar to our findings, previous studies have indicated an increased risk of myocardial infarction and stroke in females compared with males [4,5]. Females have higher inpatient mortality after myocardial infarction at younger ages than males, with greater complications after invasive interventions. Cardiovascular-related outcomes for females living with HIV compared with males also include more severe strokes, longer length of hospital stay, and higher mortality [5,27]. Length of hospital stay was also a significant contributor in all 3 models and a major financial burden on the US health care system. HIV-related hospitalizations are characterized by some of the more expensive diagnostic categories [3,18]. In populations of PLWH with no comorbidities, studies have shown a 60% increase in length of stay and a 70% increase in medical resource utilization, compared with uninfected populations [32]. Our heart failure results align with the literature on HIV-infected females. However, studies have shown lower uptake of

cardiovascular disease-related interventions among females with HIV compared with males [3].

Acute kidney failure was the fourth most significant contributor in the male-only model, fifth in the all patient model, and not present in the female-only model. Although HIV nephropathy has decreased with antiretroviral therapy, compared with uninfected groups, the prevalence of kidney disease remains high for PLWH of all ages [27]. Studies have shown that kidney-related comorbidities are associated with extremely high medical costs, as indicated in our models [27]. Kidney disease is a major burden to HIV as a result of risk factors including HCV coinfection [29,33]. HCV was a significant contributor in the male-only and all patient models, aligning with our kidney disease findings and consistent with the natural history of HCV among PLWH [28,29]. The amplified effects of HCV on HIV cellular replication are known to go beyond liver-related diseases and increase the likelihood of inflammation-related illnesses such as non-AIDS cancers and cardiovascular diseases in this population as well [30,33,34]. Given the prevalence of HCV in PLWH, studies are needed to model ways in which HCV accounts for the development of comorbidities to support primary prevention [30,34].

Although research has shown higher substance use in males living with HIV compared with females, substance abuse was reported in the female-only model. Moreover, 8% of females living with HIV report substance abuse, with significantly higher reports in populations of males living with HIV, particularly men who have sex with men [18]. In our dataset, substance abuse is a combined variable comprising substance use disorders, including alcohol, cannabis, stimulants, hallucinogens, and opioids [22,31]. A substance use diagnosis puts patients at great risk for developing comorbidities, resulting in its significant contribution to high Charlson scores. Diagnoses of opioid abuse have resulted in the exacerbation of existing comorbidities and make medical and treatment adherence difficult [31]. Five times higher viral loads are seen in PLWH who report the use of stimulants [31,35], which is a consequence of poor adherence to antiretroviral use, increased utilization of emergency health care resource, and increased rates of chronic conditions [31,35].

### Limitations

The paper is a cross-sectional analysis of diagnostic codes from EHRs. We did not assess multiple comorbidities in our cross-sectional study, and trends in comorbidities over time were not evaluated. We analyzed documented diagnoses of comorbidities for people living with HIV. We do not explore HIV-related contributions (eg, disease stage and immune status) to the development or severity of comorbidities, only their

documented presence or absence. Therefore, diagnosis dates were not considered. Future longitudinal studies in similar populations should account for these additional factors, track HIV disease stage and immune status over time, and utilize different analytical approaches to explore the development of comorbidities and their contributions to medical resource utilization. Our sample was not matched on other factors such as socioeconomic status. EHR data are collected during the course of clinical care and not collected for research purposes. Understandably, sociodemographic information was incomplete for a variety of indicators including race. We did not explore the contribution of HIV-related clinical indicators (CD4, viral load, and antiretrovirals). As a cross-sectional study, the analysis of HIV-related clinical indicators one point in time would not be informative to the presence and absence of the observed comorbidities. Future longitudinal studies should analyze HIV-related clinical indicators over time to explore their potential contribution to the development of comorbidities.

Certain antiretroviral medications are linked to increased cardiovascular risk [30,31]. Therefore, antiretroviral regimens and changes in regimens over time should be included in future analytic studies as well.

### Conclusions

Our analysis provides evidence to further support insight into long-term survivorship with HIV. Similarities and differences were observed between HIV-infected males and females and factor-specific contributions to medical resource utilization. Our findings contribute to the literature on sex-based differences with HIV infection and aging-related comorbidities or phenotype development in aging populations of PLWH. Moreover, cohort studies report that females are better controllers of HIV, although the mechanisms have been unclear [9,11,36]. Sex-specific mechanisms of protection must also be explored in future studies as females generally demonstrate phenotypes of viral control [37]. Targeted interventions should also include nonclinical differences between males and females, such as health education for effective symptom management. In a study that comprises HIV-infected males and females with similar demographics and clinical characteristics, more females acknowledged asking clinicians about the symptoms of aging-related comorbidities and were provided such information without request. The study also revealed that 80% of females desired symptom-related information compared with 22% of males [36,38]. To date, little attention is given to interventions targeting HIV aging phenotypes and sex-based differences, with HIV-infected populations generally being ignored in intervention research [36-38]. Biological sex must be considered in clinical intervention development and implementation to improve HIV- and health-related outcomes for males and females.

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## Conflicts of Interest

None declared.

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## Abbreviations

- EHR:** electronic health record
  - HCV:** hepatitis C virus
  - ICD:** International Classification of Disease
  - PLWH:** people living with HIV/AIDS
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Original Paper

# Social Support Patterns of Middle-Aged and Older Adults Within a Physical Activity App: Secondary Mixed Method Analysis

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## Abstract

**Background:** Physical activity (PA) is critical for maintaining independence and delaying mobility disability in aging adults. However, 27 to 44% of older adults in the United States are meeting the recommended PA level. Activity trackers are proving to be a promising tool to promote PA adherence through activity tracking and enhanced social interaction features. Although social support has been known to be an influential behavior change technique to promote PA, how middle-aged and older adults use the social interaction feature of mobile apps to provide virtual support to promote PA engagement remains mostly underexplored.

**Objective:** This study aimed to describe the social support patterns of middle-aged and older adults using a mobile app as part of a behavioral PA intervention.

**Methods:** Data from 35 participants (mean age 61.66 [SD 6] years) in a 12-week, home-based activity intervention were used for this secondary mixed method analysis. Participants were provided with a Jawbone Up24 activity monitor and an Apple iPad Mini installed with the UP app to facilitate self-monitoring and social interaction. All participants were given an anonymous account and encouraged to interact with other participants using the app. Social support features included comments and *likes*. Thematic coding was used to identify the type of social support provided within the UP app and characterize the levels of engagement from users. Participants were categorized as superusers or contributors, and passive participants were categorized as lurkers based on the literature.

**Results:** Over the 12-week intervention, participants provided a total of 3153 likes and 1759 comments. Most participants (n=25) were contributors, with 4 categorized as superusers and 6 categorized as lurkers. Comments were coded as emotional support, informational support, instrumental support, self-talk, and other, with emotional support being the most prevalent type.

**Conclusions:** Our cohort of middle-aged and older adults was willing to use the social network feature in an activity app to communicate with anonymous peers. Most of our participants were contributors. In addition, the social support provided through the activity app followed social support constructs. In sum, PA apps are a promising tool for delivering virtual social support to enhance PA engagement and have the potential to make a widespread impact on PA promotion.

**Trial Registration:** ClinicalTrials.gov NCT01869348; <https://clinicaltrials.gov/ct2/show/NCT01869348>

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**KEYWORDS**

social support; aged; middle aged; physical activity; technology; fitness tracker

## Introduction

### Physical Activity and Social Support

Physical activity (PA) is critical during the aging process to help maintain independence and delay the development of mobility disability. Yet, in a study conducted by Keadle et al in 2016, less than 50% of healthy older adults achieved the recommended PA level [1]. In fact, research has found that adherence to PA guidelines or interventions decreased from 80% to 50% over 12 months [2]. Traditional PA interventions are labor intensive for both the research team and the participants. Recent advances in technology have produced methods (eg, wearable activity trackers) that allow for less labor-intensive PA intervention design [3]. Wearable activity trackers have been shown to be a promising tool to augment traditional PA intervention designs by replacing the need to manually record PA through passive activity tracking [3]. Activity trackers also expand on limited feedback of pedometers by providing goal-setting assistance and extensive feedback on progress and encouraging social interaction [4]. Despite a surge in the use of activity trackers within PA interventions, it is not yet clear how middle-aged and older adults use the virtual support features to promote PA engagement. Given that social support is a psychosocial factor that has been consistently identified as a critical factor for the adoption and maintenance of PA behavior [5,6], it is important for us to examine this influential psychosocial factor to provide insight for future PA intervention designs.

Social support is defined as an interpersonal exchange that increases self-esteem and offers acceptance, value, and motivation to individuals [7]. In a study, individuals who perceived low social support within their social environment were found to be 2 times more likely to be sedentary [8]. Reviews have indicated that shared experience, such as exercising in a group setting (eg, walking club) or being socially connected (eg, community facilities or virtual blogs), can help shape and foster the adoption of PA behavior [9]. Furthermore, empirical evidence has indicated that social support is an influential behavioral change technique that has the potential to encourage PA among older adults [6,10,11] and promote adherence to PA recommendations [5,12]. Using the self-determination theory (SDT) as the framework [13], Vallerand posited that social support can affect the degree of motivation (also referred to as the degree of self-determination) and, in turn, affect health behavior [14]. George et al explored the mechanistic relationship further by using the hierarchical model of intrinsic and extrinsic motivation models and found that perceived social support positively associated with the 3 components of basic psychological needs (autonomy, competence, and relatedness) as indicated by SDT [13,15]. In turn, the psychological needs were positively associated with motivation and PA intention [15]. Thus, we can posit that social support plays a critical role in meeting the basic psychological needs and, in turn, increases motivation to engage in PA.

### Social Support Constructs

Constructs of social support, through social media or conventional means, can be categorized as emotional, informational, instrumental, or appraisal support as described by Heaney and Israel [16]. Emotional support is an expression of empathy, love, trust, or care. Informational support provides advice or information. Instrumental support provides tangible aid. Appraisal support provides information that is useful for self-evaluation [16]. Support can also come from within the individual through self-talk [17,18]. Self-talk can be a discussion with oneself or a multiparty dialog [17], and it can be positive or negative among individuals [18]. With the increase in mobile phone usage and wearable activity tracker usage, individuals seeking support can do so using social networks available in mobile apps. Research shows that social networking sites (SNSs) have been used to provide informational support (eg, guidance), instrumental support (eg, connect individuals with resources), and emotional support. In addition, SNSs have also been used to facilitate behavior change interventions [16,19-22]. Specifically, de la Peña and Quintanilla found that health-related Facebook communities were able to provide informational, instrumental, and emotional support needed for members to achieve their goals [20] through features such as *likes* and *comments* [20]. The *like* feature is a form of emotional support by providing users positive and indirect feedback. The *comments feature* in itself is a form of emotional support. However, it is also used to provide appraisal support (ie, constructive feedback) or instrumental and/or informational support (ie, suggestions or connection with resources).

Nevertheless, individuals vary in how they participate in SNSs to receive and provide social support. Researchers confirmed that the 90-9-1 principle (also known as the 1% rule) developed by digital marketing researchers [23] also reflected the phenomenon observed within the digital health environment [24]. Researchers found that content came within the digital health SNSs or the internet support groups came from superusers and contributors [24-26]. Most content was provided by superusers who represent approximately 1% of the members in the SNSs. Contributors generated a minority of the content, and they represent about 9% of the members. Most members in the digital health support system are considered as lurkers (~90%). These are individuals who observe without active participation [27-29].

### Objective

Although the popularity of receiving and providing social support through SNSs is rising, the usage pattern for health and PA promotion among middle-aged and older adults remains unclear [30]. There is preliminary evidence that older adults who use virtual support provide comments that align within the constructs of social support [31], but they are cited as being apprehensive about communicating with strangers [32] although an increasing number of older adults are on social media sites [33]. Thus, the purpose of this secondary data analysis was to describe the social support patterns among middle-aged and

older adults using a mobile phone app as part of a behavioral PA intervention and evaluate them within the constructs of social support. We hypothesize that social support patterns in our cohort of middle-aged and older adults will align with the social support constructs and social network engagement pattern.

## Methods

### Study Design and Population

This study was a secondary mixed-method analysis with data retrieved from a randomized controlled study (Trial Registration: NCT01869348). Data were drawn from a 12-week, randomized controlled behavioral PA study. The primary study's recruitment and intervention methods are published elsewhere [34]. The eligibility criteria were as follows: (1) aged 55 to 79 years, (2) body mass index of 25 to 35 kg/m<sup>2</sup>, (3) able to read and understand English, (4) able to read the print off of a tablet, and (5) cleared to participate as determined by the Physical Activity Readiness Questionnaire [35]. Participants were enrolled and started the intervention between 2014 and 2016. This secondary analysis included 35 of the 40 study participants who used the UP app (Jawbone, San Francisco, CA) and who always had at least one participant (herein referred to as peers) to communicate with during the week. Due to rolling enrollment, the actual number of peers fluctuated on a weekly basis (between 0 and 10). Of the 40 participants, 5 were not included in this analysis because they either refused to participate in the intervention after the wait-list period or did not have at least one peer to communicate with during any point of the intervention.

### Procedures

Eligible participants were randomized to either the intervention group or the wait-list control group. The intervention provided a wearable activity monitor (UP24 by Jawbone, San Francisco, CA) and a mobile tablet device (iPad Mini by Apple, Cupertino, CA) and received scripted, brief weekly telephone cognitive behavioral counseling. The wait-list control group received all the intervention components after their 12-week final assessment. The UP app was preinstalled on the tablets so that the participants could view their activity and interact with other participants. All participants were given an anonymous account (eg, Monopoly icons) and were *friend*ed with the other participants and the interventionists. Interventionists used the app for surveillance of the participants only unless there was a software update. The participants were encouraged, but not required, to socialize with others. Participants were instructed to ignore friend requests from unknown users. The app posted individual entries for each person and their peers' activity progress daily in the *news feed*. Participants were able to comment and *like* the entries; these interactions were analyzed to estimate social support. Interactions were categorized as *received* and *given* support based on whether a comment or *like* was given to or received by a peer. Regardless of their social engagement, participants received notifications from the app when they received a comment or a *like* from a peer. For this reason, *given* support was used for data analysis. Additional UP app features, including leaderboards and challenges, are described in depth elsewhere [36]. The overall study protocol

was approved by the university's institutional review board, and all participants provided written informed consent.

### Data Analysis

NVivo 11 Pro (QSR International) was used for qualitative analysis, and SPSS version 20 (IBM, Armonk, NK) was used for quantitative analysis. Descriptive analyses were conducted using means and frequencies for comments given and received. Furthermore, interquartile range (IQR) for given support (comments or *likes* given to peers) was used to identify superusers and lurkers because it approximated the participants' engagement with social features. Participants above the 75th percentile in both social support categories (given *likes* and comments) were classified as superusers. Participants below the 25th percentile in both social support categories were classified as lurkers. For qualitative analysis, a combination of directed and conventional qualitative content analysis was used to analyze the app comments [37]. Codes were based on major social support constructs: emotional support, informational support, instrumental support, appraisal support, and self-talk [10,13,14]. Additional codes were developed through conventional qualitative analysis from reading through the comments. Moreover, 2 graduate-level investigators independently coded the comments, and agreement was determined using the NVivo software. Disagreement was settled through discussion and joint review of the comments among coders and the principal investigator (EL) who is a behavioral scientist. Due to protocol restrictions, no quotes from participants were abstracted from the app. Only the quantitative report and the coded qualitative themes are reported.

## Results

### Descriptive Information

Table 1 displays the baseline characteristics of the participants (n=35). On average, participants had 8 peers (range 4-13) to socialize with over 12 weeks.

Throughout the study, there were 3153 *likes* and 1759 comments. The most *likes* received by one person was 524, and the most comments were 291 with a median of 61 *likes* and 32 comments received. Of 35 participants, 3 did not receive a *like* or comment over the 12-week period. The median number of *likes* given was 2, with a range of 0 to 986 and an IQR of 40. The median number of comments given was 14, with a range of 0 to 344 and an IQR of 45. The median number of self-talk comments given was 4, with a range of 0 to 232 and an IQR of 16. Moreover, 11% participants (4/35) were above the 75th percentile in given *likes* and comments. These 4 superusers combined accounted for 72.60% (2289/3153) and 51.28% (902/1759) of the total *likes* and comments, respectively. Conversely, 17% participants (6/35) can be classified as lurkers because they were below the 25th percentile of comments given, and they did not give any *likes*. The remaining 25 participants were classified as contributors—the *likes* or comments given were within the IQR. This group accounted for 27.40% (864/3153) *likes* and 48.72% (857/1759) comments. Lurkers had fewer peers (average: 6; range: 4-9) to communicate with throughout the 12 weeks than contributors (average: 8; range: 6-13) and superusers (average: 9; range: 8-11). Complete social

support values for all participants are depicted in Table 2. The likes and comments in the table reflect given support, as this

reflects the participant's engagement with the social features.

**Table 1.** Baseline demographic characteristics by study group (N=35).

Characteristics	Intervention (n=19)	Wait-list control (n=16)	Total (N=35)
Female, n (%)	16 (84)	13 (81)	19 (83)
<b>Ethnicity, n (%)</b>			
Non-Hispanic white	11 (58)	9 (56)	20 (57)
Other	8 (42)	7 (44)	15 (43)
College graduate, n (%)	12 (63)	10 (63)	22 (63)
Age, mean (SD)	61.32 (5)	62.06 (7)	61.66 (6)
Body mass index, kg/m <sup>2</sup> , mean (SD)	29.99 (3)	30.80 (4)	30.36 (3)

## Common Themes

The comments within the app mostly followed the major social support constructs, as described in the Introduction section [10,13,14]. The only theme that was not prevalent was appraisal support. Some comments that were useful for self-evaluation were coded as a subtheme of emotional support. In addition to emotional support, other major themes included informational support, instrumental support, self-talk, and *other* theme. Each major theme had additional subthemes. Figure 1 illustrates the hierarchy of major and subthemes in the comments.

The intervention group participants gave more comments than the wait-list control group participants, but the most prevalent themes were the same between the 2 groups. Agreement between the 2 coders ranged from 53.4% to 99.4% for each theme. The lowest agreement was with self-talk (67.9%) and emotional support (53.44%). Table 3 displays the number of comments given by the participants per major theme. Several comments were coded into numerous themes. Emotional support was the most prevalent, followed by self-talk, other themes, informational support, and instrumental support.

Emotional support was further categorized as concern, gratitude, sharing, motivating, and social norms. *Concern* comments were those that expressed concern for their peer's health and well-being. *Gratitude* comments expressed thanks to fellow peers for their support. *Sharing* comments were conversation-like posts. *Motivating* comments were further categorized as congratulatory, encouragement, impressed, compliment, and verbal persuasion. *Verbal persuasion* were short, encouraging comments such as *woo-hoo* and *yay*. *Social norms* was further categorized as agreement and comparison.

Subthemes of self-talk included anecdote, feelings (positive and negative), planning, and reflection. Anecdotes were comments

that shared personal information or a personal story but were not directed to a peer. *Positive* or *negative* comments toward an individual's own activity were coded as *feelings*. There were no negative comments between peers. *Planning* comments were the result of an individual planning future PA. Comments where an individual would reflect on their past PA or other health behaviors were coded as *reflection*.

Other themes were subcategorized as correction, technical problems, greeting, health behavior, and unknown. Users cannot edit a previous comment within the app; therefore, additional comments that fixed a previous comment were coded as a *correction*. Comments that expressed technical issues with the Up24 band or the app were coded as *technical problems*. *Greeting* comments were further subcategorized as welcome and salutation. Users had the option to also monitor their sleep and diet behavior, which were the 2 subthemes for *health behavior*. Finally, any other comments that could not be coded into the aforementioned themes were coded as *unknown*.

Informational support included informative and inquiry comments. Informative comments educated peers on PA, the app, or the Up24 band, and inquiry comments posed a question to peers. Instrumental support was further categorized as competition, exercise companion, and participatory support. Comments that mentioned an *exercise companion* differed from *participatory support* because the exercise companion was exercising with the individual's friend or family member, whereas participatory support came from discussing meeting for in-person exercise with their peers in the study. Participants were not expected to exercise with one another, but comments indicated that participants contacted one another and walked together on at least 12 occasions. All participatory support was organized in the app among the participants.

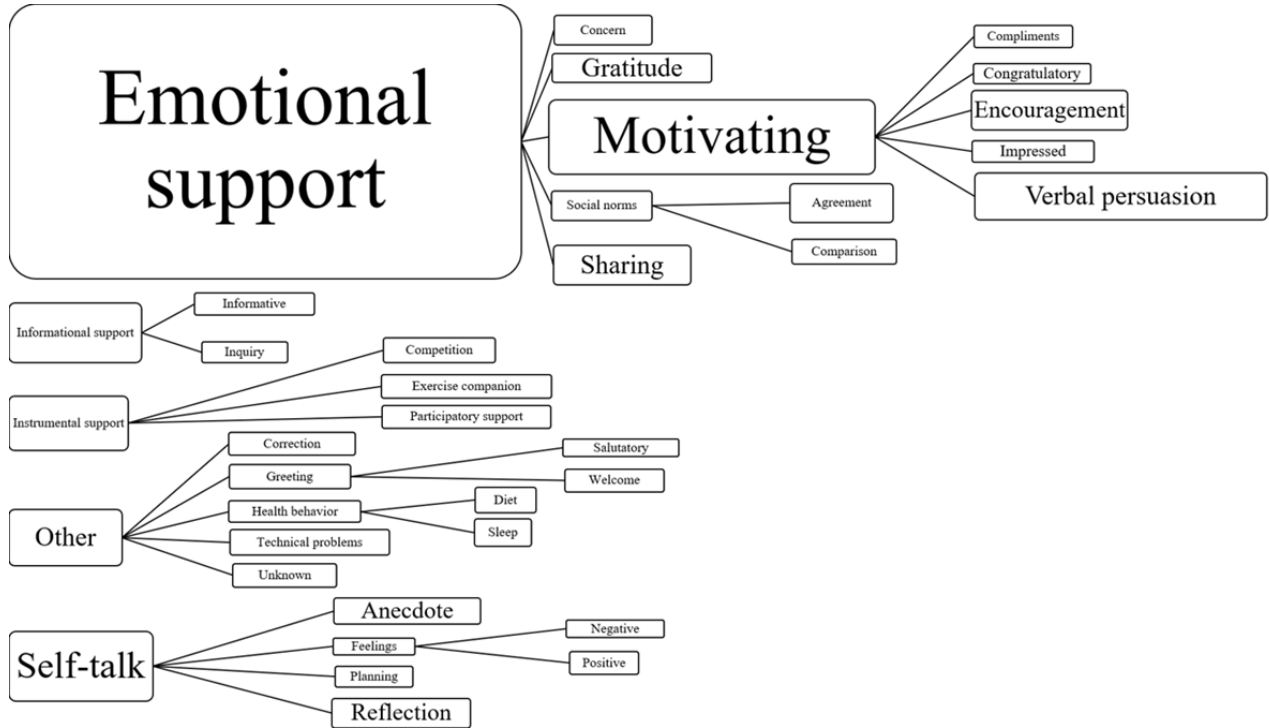
**Table 2.** Participants' characteristics and social engagement (N=35; 1-16 were wait-list control participants, and 17-35 were intervention participants).

No	Gender	Peers	Likes (N=3153), n (%)	Comments (N=1759), n (%)	Self-talk comments (N=758), n (%)
1 <sup>a</sup>	F <sup>b</sup>	10	299 (9.48)	166 (9.43)	31 (4.1)
2 <sup>a</sup>	F	9	986 (31.27)	340 (19.32)	105 (13.9)
3 <sup>a</sup>	M <sup>c</sup>	7	544 (17.25)	344 (19.55)	232 (30.6)
4 <sup>d</sup>	M	6	2 (0.06)	0 (0.00)	0 (0.0)
5 <sup>d</sup>	F	8	0 (0.00)	16 (0.90)	13 (1.7)
6 <sup>d</sup>	F	8	0 (0.00)	4 (0.22)	2 (0.3)
7 <sup>d</sup>	F	13	2 (0.06)	9 (0.51)	3 (0.4)
8 <sup>d</sup>	M	10	1 (0.03)	5 (0.28)	3 (0.4)
9 <sup>d</sup>	F	9	45 (1.42)	30 (1.70)	18 (2.4)
10 <sup>d</sup>	F	9	0 (0.00)	1 (0.05)	1 (0.1)
11 <sup>d</sup>	F	8	6 (0.19)	5 (0.28)	4 (0.5)
12 <sup>e</sup>	F	7	0 (0.00)	0 (0.00)	1 (0.1)
13 <sup>3</sup>	F	8	0 (0.00)	0 (0.00)	0 (0.0)
14 <sup>e</sup>	F	9	0 (0.00)	0 (0.00)	0 (0.0)
15 <sup>e</sup>	F	4	0 (0.00)	0 (0.00)	0 (0.0)
16 <sup>e</sup>	F	6	0 (0.00)	0 (0.00)	0 (0.0)
17 <sup>a</sup>	F	11	460 (14.58)	52 (2.95)	26 (3.4)
18 <sup>d</sup>	F	6	5 (0.15)	57 (3.24)	16 (2.1)
19 <sup>d</sup>	F	6	24 (0.76)	223 (12.67)	82 (11.2)
20 <sup>d</sup>	M	7	0 (0.00)	0 (0.00)	0 (0.0)
21 <sup>d</sup>	F	6	2 (0.06)	194 (11.0)	85 (11.2)
22 <sup>d</sup>	F	6	5 (0.15)	40 (2.27)	14 (1.8)
23 <sup>d</sup>	F	6	8 (0.25)	15 (0.85)	8 (1.1)
24 <sup>d</sup>	F	11	0 (0.00)	76 (4.32)	38 (5.0)
25 <sup>d</sup>	M	8	1 (0.03)	23 (1.30)	2 (0.3)
26 <sup>d</sup>	F	6	338 (10.7)	14 (0.79)	9 (1.2)
27 <sup>d</sup>	F	6	13 (0.41)	17 (0.96)	12 (1.6)
28 <sup>d</sup>	F	6	26 (0.82)	13 (0.73)	4 (0.5)
29 <sup>d</sup>	F	6	0 (0.00)	24 (1.36)	16 (2.1)
30 <sup>d</sup>	F	8	279 (8.84)	46 (2.61)	17 (2.2)
31 <sup>d</sup>	M	10	1 (0.03)	1 (0.05)	1 (0.1)
32 <sup>d</sup>	F	13	40 (1.26)	4 (0.22)	0 (0.0)
33 <sup>d</sup>	F	12	0 (0.00)	1 (0.05)	1 (0.1)
34 <sup>d</sup>	F	10	66 (2.09)	34 (1.93)	14 (1.8)
35 <sup>a</sup>	F	6	0 (0.00)	0 (0.00)	0 (0.0)

<sup>a</sup>Superuser.

<sup>b</sup>F: female.  
<sup>c</sup>M: male.  
<sup>d</sup>Contributor.  
<sup>e</sup>Lurker.

**Figure 1.** Social support themes. The size of each box represents the prevalence of the different comment themes (not to scale). Study themes were developed based on the work of Heaney and Israel, Cavallo et al, and Cousins et al.



**Table 3.** Number of comments by themes.

Themes	Intervention (n=19 participants)	Wait-list controls (n=16 participants)	Total participants (N=35)
<b>Emotional support<sup>a</sup>, n comments (%)</b>	<b>475 (50.6)</b>	<b>596 (67.3)</b>	<b>1071 (58.72)</b>
Concern <sup>b</sup>	29 (3)	24 (3)	53 (3)
Gratitude <sup>b</sup>	75 (8)	107 (12.1)	182 (10.0)
<b>Motivating<sup>b</sup></b>	<b>317 (33.8)</b>	<b>420 (47.4)</b>	<b>737 (40.4)</b>
Compliment <sup>c</sup>	41 (4)	54 (6)	95 (5)
Congratulatory <sup>c</sup>	53 (6)	60 (7)	113 (6.2)
Encouragement <sup>c</sup>	75 (8)	89 (10)	164 (9.0)
Impressed <sup>c</sup>	45 (5)	70 (8)	115 (6.3)
Verbal persuasion <sup>c</sup>	155 (16.5)	215 (24.3)	370 (20.3)
Sharing <sup>b</sup>	92 (10)	80 (9)	172 (9.4)
<b>Social norms<sup>b</sup></b>	<b>42 (5)</b>	<b>18 (2)</b>	<b>60 (3)</b>
Agreement <sup>c</sup>	13 (1)	5 (1)	18 (1)
Comparison <sup>c</sup>	32 (3)	13 (2)	45 (3)
<b>Informational support<sup>a</sup>, n (%)</b>	<b>64 (7)</b>	<b>18 (2)</b>	<b>82 (5)</b>
Informative <sup>b</sup>	23 (2)	2 (0)	25 (1)
Inquiry <sup>b</sup>	40 (4)	17 (2)	57 (3)
<b>Instrumental support<sup>a</sup>, n (%)</b>	<b>48 (5)</b>	<b>11 (1)</b>	<b>59 (3)</b>
Competition <sup>b</sup>	20 (2)	0 (0)	20 (1)
Exercise companion <sup>b</sup>	17 (2)	10 (1)	27 (2)
Participatory support <sup>b</sup>	12 (1)	1 (0)	13 (1)
<b>Self-talk<sup>a</sup>, n (%)</b>	<b>220 (23.4)</b>	<b>188 (21.2)</b>	<b>408 (22.4)</b>
Anecdote <sup>b</sup>	83 (9)	85 (10)	168 (9.2)
<b>Feelings<sup>b</sup></b>	<b>49 (5)</b>	<b>38 (4)</b>	<b>87 (5)</b>
Negative <sup>c</sup>	15 (2)	6 (1)	21 (1)
Positive <sup>c</sup>	34 (4)	31 (4)	65 (4)
Planning <sup>b</sup>	42 (5)	16 (2)	58 (3)
Reflection <sup>b</sup>	98 (10)	78 (9.0)	176 (9.6)
<b>Other<sup>a</sup>, n (%)</b>	<b>132 (14.1)</b>	<b>72 (8)</b>	<b>204 (11.2)</b>
Correction <sup>b</sup>	6 (1)	9 (1)	15 (1)
<b>Greeting<sup>b</sup></b>	<b>23 (2)</b>	<b>24 (3)</b>	<b>47 (3)</b>
Salutatory <sup>c</sup>	10 (1)	11 (1)	21 (1)
Welcome <sup>c</sup>	15 (2)	10 (1)	25 (1)
<b>Health behaviors<sup>b</sup></b>	<b>52 (6)</b>	<b>22 (3)</b>	<b>74 (4)</b>
Diet <sup>c</sup>	7 (1)	0 (0)	7 (0)
Sleep <sup>c</sup>	46 (5)	23 (3)	69 (4)
Technical problems <sup>b</sup>	33 (4)	16 (2)	49 (3)



Themes	Intervention (n=19 participants)	Wait-list controls (n=16 participants)	Total participants (N=35)
Unknown <sup>b</sup>	6 (1)	3 (0)	9 (1)
Total comments <sup>d</sup>	939 (51.5)	885 (48.5)	1824

<sup>a</sup>Major themes; themes were developed based on the work of Heaney and Israel, Cavallo et al, and Cousins et al.

<sup>b</sup>Submajor themes.

<sup>c</sup>Minor themes.

<sup>d</sup>Some comments were coded into several submajor or minor themes. Therefore, the total depicts the total number of comments under the major theme.

## Discussion

### Principal Findings

Our exploratory study on social support patterns of middle-aged and older adults using a mobile app found that without being mandated to socialize with other participants, the 35 participants who used the app as part of the intervention produced a total of 1759 comments and 3153 *likes* over a 12-week intervention period. Of 35 participants, 4 were classified as superusers because they were above the 75th percentile for all support categories (given *likes* and comments), whereas 6 participants were classified as lurkers for falling below the 25th percentile in given comments and did not give any *likes*. Common themes coded from the content of comments followed constructs of social support, with the most prevalent comments classified as emotional support followed by self-talk.

Our evaluation partially supports the 90-9-1 principle in that the smallest portion of participants was superusers [24]; however, our sample did not follow the same distribution. We found that 17% (n=6) of participants were lurkers, 71% (n=25) were contributors, and 11% (n=4) were superusers. Contributors were the largest group, which is contrary to the 90-9-1 principle that states lurkers are the most prevalent [24]. Despite the increase in superusers and contributors, their contribution in the app was similar to previous evaluations. Van Mierlo investigated the 90-9-1 principle in 4 digital health social networks and found that the superusers, the top 1%, accounted for 73.6% of posts, whereas contributors accounted for 24.7% of posts [24]. In our study, superusers and contributors accounted for a comparable 72.6% and 27.1% of *likes*, respectively. The larger proportion of superusers and contributors in our sample may be the result of the intimate nature and anonymity of the study. At any given time during the study, there were only 1 to 10 peers for a participant to interact with versus the possible hundreds of peers on an SNS. It is unclear whether the size of the social group may have affected support provision behavior. However, too few peers may have inhibited social interaction and is a clear limitation of this exploratory investigation.

Previous research suggests that older adults are apprehensive to communicate with strangers [32]; the anonymous nature of the team may have also contributed to increased interactions in our study, as individuals were known by their icon rather than their real name. Some participants used these icons as a conversation starter, which helped to increase social engagement. This may have also affected the type of support that was provided. The anonymity did not result in negative

comments toward peers, only in the form of self-talk. Participants may have been supportive because of their shared interests in the intervention or the surveillance of the intervention. Future research should investigate the effect of group size, anonymity, and icon personae on social interaction within apps or SNSs.

Although the number of comments varied between intervention and wait-list control participants, the most prevalent themes remained the same. The rank of themes by prevalence was emotional support, self-talk, other, informational support, and instrumental support. This trend is similar to that observed in women who used Fitbit and its Web-based social network [38]. A total of 20 women enrolled in a 6-week study were given a Fitbit Flex to monitor their activity and access to the Web-based Fitbit system. The social features of the Fitbit system included a message board for communication and a leaderboard [38]. The study found the most prevalent comments were motivational (emotional support), followed by sharing of PA ideas (informational support) and exercising with others (instrumental support). Self-talk and other types of comments were not reported. Results of the multilevel model analyses showed that social contact had a significant effect on PA, but it is unclear which type of support influenced PA the most [38].

Similar results were found in a PA intervention for individuals with Parkinson disease. Participants were given a Fitbit zip and assigned a peer mentor to help promote PA. The peer mentors were *friends* with the participants through the Fitbit system. As *friends*, the mentors were able to provide emotional support, through comments and *likes*, and instrumental support, through social comparison of activity. After an 8-week period of peer mentorship, participants increased their PA by 31% [39]. Yet, it is still unclear which type of support was driving the PA change. In traditional in-person social networks, emotional support has a considerable impact on PA compared with other types of support [40,41]. More research is needed to determine how PA is affected by each type of support (emotional support, instrumental support, informational support, and self-talk) within a virtual environment. Studies by Colon-Semenza et al and Arigo mandated social support, whereas this study did not [38,39]; researchers should also investigate the impact of mandated versus organic social engagement.

### Limitations

The informed consent document did not ask for clearance to share comments from the app, as we did not expect virtual social support to be so prevalent. Furthermore, challenges related to the recruitment strategy of pilot trial should be considered in interpreting these data, as they caused the number of

simultaneous peers to shift throughout the intervention period. Due to these limitations, this study is limited to a description and was not able to further examine the comments or their potential impacts on intervention effectiveness. The intervention was designed to impact PA behavior, which provides further limitations for this secondary data analysis. Participants' prior experience on social media use was not captured. As the inclusion of wait-list participants, change in PA as a result of social interaction could not be assessed. Therefore, our results are exploratory in nature, and no conclusions on the relationship of social support and PA could be made. Preliminary results from Arigo [38] and Colon-Semenza et al [39] suggest that more virtual social interaction results in more PA, but these studies were among young adults and Parkinson disease patients, respectively. These results are not necessarily generalizable to middle-aged and older adults. Furthermore, this study neither provides a network analysis of the relationship between lurkers, contributors, and superusers nor accounts for the fluctuating number of peers. This clear limitation of this study should be addressed in future trials by ensuring timely recruitment in small cohorts. Our thematic coding of the participants' comments was conducted independently by 2 coders following qualitative analysis guidelines, but an external researcher was not involved in the study to review the themes. This may limit the internal validity of our evaluation. Most of our participants were non-Hispanic white and female, and future research should include a more diverse sample. The strength of this study includes a thorough description of how older adults support their unknown peers using an app and evidence of the

acceptability of anonymous social support in addition to counseling calls from research staff.

## Conclusions

Use of wearable activity monitors that have a social networking feature is on the rise both commercially and in research [38,42]. Their features, similar to other SNSs, have the potential to make a widespread impact on PA promotion in the clinical and community settings. However, to our knowledge, use of the social networking features of these devices to provide social support are seldom reported or evaluated [30]. The results of our study suggest that middle-aged and older adults were willing to use social tools in a PA app to communicate with unknown, anonymous peers (total of 3153 likes and 1759 comments over 12 weeks). Social support in our study also happened organically without being required as a part of an intervention. Social support provided in the app followed constructs of social support [37]. The most prevalent type of support was emotional support. Contrary to the 90-9-1 principle, most participants were contributors (71.4%), with only 11.4% superusers and 17.1% lurkers. In combination with the other implemented behavioral change techniques [4], our findings provide further support for the potential usefulness of wearable activity monitors as a promising intervention tool to encourage behavior change. Future research is needed to investigate the potential of these social support features to change PA behavior. Practitioners should be aware that these features exist in many available PA apps and may be used by patients to provide and receive support. However, education needs to be provided regarding information security.

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## Conflicts of Interest

None declared.

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## Abbreviations

- IQR:** interquartile range
- PA:** physical activity
- SDT:** self-determination theory
- SNS:** social networking site

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