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Original Paper

# Influence of Anthropometrics on Step-Rate Thresholds for Moderate and Vigorous Physical Activity in Older Adults: Scientific Modeling Study

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## Abstract

**Background:** Adults and older adults are recommended to engage in 150 minutes of moderate (MPA) to vigorous (VPA) aerobic physical activity (MVPA) per week, with the heuristic message of 3000 steps in 30 minutes (100 steps per minute [spm]). However, this message is based on adult populations, with a paucity of research on step-rate thresholds that correspond to absolute MVPA (moderate=3 metabolic equivalents [METs], vigorous=6 METs) and relative MVPA (moderate=40% estimated MET<sub>max</sub>, vigorous=60% estimated MET<sub>max</sub>) in older persons, who have lower stride lengths and a lower exercise capacity. Also, there is a need to consider the influence of anthropometric differences when quantifying the relationship between step rate and intensity-related physical activity.

**Objective:** This study assessed absolute and relative MVPA step-rate thresholds and anthropometric factors (ie, height, leg length, and body mass index [BMI]) in older adults.

**Methods:** Nineteen older adults (7 females; age 69 years, SD 2, BMI 26 kg/m<sup>2</sup>, SD 4) completed a staged treadmill walking protocol: six minutes at 2.4, 3.2, 4.0, 5.6, and 6.4 km/h. Steps were manually counted and volume rate of oxygen consumed (VO<sub>2</sub>) was measured via indirect calorimetry. Aerobic fitness was estimated via the submaximal single-stage treadmill protocol.

**Results:** When BMI was considered, mixed effects modeling revealed absolute and relative MPA step-rate thresholds of 108 spm and 117 spm, respectively. Absolute and relative VPA corresponded to step rates of 135 spm and 132 spm, respectively. Neither height nor leg length improved the ability of the model to predict stepping cadence from METs.

**Conclusions:** In general, older adults need to walk faster than 100 spm (ie, approximately 110 spm) to reach MPA and in excess of approximately 130 spm to achieve VPA, depending on BMI status. Health care professionals and researchers should adjust cadence-based recommendations for differences in BMI in their older patients and consider using relative intensity to most appropriately tailor their physical activity recommendations.

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**KEYWORDS**

aging; walking; public health; cadence; physical activity intensity

## Introduction

Leading a physically active lifestyle is associated with numerous health benefits among older adults that include improved cardiovascular and metabolic health and a reduction in all-cause mortality [1-3]. When objectively measured, only 12% of Canadian older persons achieve the national physical activity guidelines that recommend 150 minutes of moderate-to-vigorous aerobic physical activity (MVPA) per week [4]. Older adults report walking as the most common form of physical activity [5], with research showing that MVPA is attainable in this population [6].

Initially, 3000 steps in 30 minutes (or 100 steps per minute [spm]) has been proposed as a heuristic cadence-based recommendation to achieve moderate-intensity physical activity (MPA) (3 metabolic equivalents [METs]) in adults [7]. More recent studies have validated this public message [8-10]; however, most research has been conducted in samples of young adults with few studies investigating this relationship in older adults [11,12]. Older adults experience physiological and biomechanical changes that decrease their exercise capacity and stride length [13,14]. These age-related processes limit the generalizability of cadence-based MVPA thresholds that are based on young adult samples.

Many studies have quantified MVPA in terms of absolute intensity, where MPA and vigorous-intensity physical activity (VPA) are defined as 3 METs and 6 METs, respectively. However, the Canadian Society of Exercise Physiology (CSEP) [15] and American College of Sport Medicine [16] recommend using individualized intensities for exercise prescription, where MPA is 40% of maximal aerobic fitness ( $VO_{2max}$ ) and VPA is 60% of  $VO_{2max}$ . Relative metabolic intensities may have greater applicability to older adults who, on average, are less aerobically fit and benefit from individualized exercise prescriptions [17-19].

As highlighted in a recent narrative review on the topic [20], there are only two studies that have examined MPA step-rate thresholds in older populations, and they report conflicting findings. Serrano et al [12] observed that 40%  $VO_{2reserve}$  (mean 3.3 METs, SD 0.8) was associated with approximately 115 spm and that body weight and self-selected walking cadence best predicted ( $R^2=0.34$ ) the cadence required to reach relative MPA. However, Peacock et al [11] observed that absolute MPA step-rate thresholds were lower in older adults than their previously published sample of young adults [21] when matched for height (at 170 cm: young=104 spm; older=91 spm) and that METs were best predicted ( $R^2=0.50$ ) when step rate, height, and age were predictor variables. Interestingly, both studies analyze the cadence-intensity relationship using linear methods, whereas this relationship has been shown to be curvilinear [8,9,22-24]. Despite the inconsistency in the existing literature, both studies clearly demonstrate that anthropometrics (ie, height or body weight) alter MVPA step-rate thresholds in that shorter and/or lighter individuals generally need to take more steps to reach the same intensity as their taller and/or heavier counterparts.

Given the disagreement in the current literature regarding appropriate MPA step cadences for older persons as well as the lack of consideration for VPA, there is a need to investigate step-rate recommendations for both absolute and relative MPA and VPA in an aged population. Therefore, the purpose of this study was to use mathematical modeling with anthropometric factors as predictor variables to calculate older adults' individualized step rate. Using these models, we will determine step-rate thresholds that define both absolute and relative MPA and VPA in our sample of older adults.

## Methods

### Demographics

Nineteen older adults (7 females) aged mean 68.8 (SD 2.3; 65-74) years volunteered to participate in this study. All participants were initially screened for age (over 65 years) and cleared for MVPA using the Physical Activity Readiness Questionnaire Plus (PAR-Q+) [25]. All participants completed a CSEP Physical Activity and Sedentary Behavior Questionnaire (PASB-Q), a valid and reliable measure of weekly MVPA [26]. The study was approved by the Research Ethics Board at Acadia University (REB#15-20), and all subjects provided written informed consent before participating. All participants were recruited via a community-wide email and by word of mouth in Wolfville, Nova Scotia, from May 2015 to September 2015.

### Anthropometrics

Height and weight were measured without shoes using a calibrated stadiometer and scale (Health-O-Meter, Sunbeam Products Inc) to the nearest 0.5 cm and 0.1 kg, respectively. Leg length was measured with participants in the seated position using a tape measure (cm) as the distance from the greater trochanter to the floor without footwear.

### Aerobic Fitness

Aerobic fitness was estimated using the validated Ebbeling walking treadmill protocol [27]. The Ebbeling consists of two 4-minute walking stages. The first stage is designed to reach a speed that elicits approximately 60% of the participants' estimated heart rate maximum (ie,  $220 - \text{age}$ ), and the second stage involves increasing the treadmill grade by 5%. Treadmill speed and steady-state heart rate are used to estimate  $VO_{2max}$  [28]. A submaximal test was chosen over a maximal test for safety reasons and to minimally influence the subsequent walking assessment. Furthermore, the time frame of this particular test (8 minutes) corresponds to the time restraints experienced by qualified exercise professionals to counsel, assess patients' physical fitness, and produce an optimal exercise program. Following the submaximal aerobic test, a resting period of 20 to 30 minutes was allotted to ensure participants returned to a rested state.

### Treadmill Protocol

The study design and protocol were adapted from our previous investigation in young adults [29]. Prior to testing, the metabolic cart (TrueOne 2400, Parvo Medics) was calibrated using nitrogen and 2 primary standard gas mixtures to an error of 0.01%. The pneumotachometer was calibrated using a 3-L

syringe that delivered fixed volumes at different flow rates. Volume calibration was verified to a value less than 0.1 L. Heart rate was monitored using a telemetry transmitter attached across the sternum (T31, Polar Electro). Participants were familiarized with the Borg scale and asked to estimate their rating of perceived exertion (RPE) on a scale of 6 to 20 [30]. Participants were fitted with a headpiece, a 2-way nonbreathing valve (Hans-Rudolph Inc), a noseclip, and a mouthpiece.

Participants performed up to five 6-minute walking bouts on a calibrated, level treadmill at 2.4, 3.2, 4.0, 5.6, and 6.4 km/h (1.5, 2.0, 2.5, 3.5, and 4.0 mph, respectively). Each bout was separated by a 4-minute standing rest period to ensure minimal drift of metabolism between stages. The order of treadmill bouts was progressive because of concerns that some participants would be unable to walk at the higher speeds due to limitations in fitness. Considering the relationship between step rate and metabolic activity is likely altered at jogging and running paces in comparison to walking, only walking was permitted.

Steps were manually counted by two researchers during minutes 2 to 3 and 4 to 5 of each stage in order to obtain the gold standard step counts per minute for each stage. A video camera filmed the feet of the participant in case the researchers recorded greater than 1 step difference during a stage. The steps counted during minutes 2 to 3 and 4 to 5 of each stage were averaged and multiplied by a factor of 6 to determine the number of steps for each 6-minute stage. Of relevance, the steps counted during minutes 2 to 3 and 4 to 5 were always within 2 spm. The test was terminated by completing the protocol of all 5 stages, volitional fatigue, or if the participant reached 85% of their estimated heart rate maximum or RPE was greater than 17 [28]. An appropriate cooldown was administered by the researcher while monitoring the participant's heart rate recovery.

Steady-state volume rate of oxygen consumed ( $\text{VO}_2$ ) for each 6-minute walking bout was obtained using indirect calorimetry, where steady state was defined as a heart rate change of less than 5 beats per minute, consistent with previous research [10].  $\text{VO}_2$  and heart rate data were recorded at 15-second intervals for the duration of the protocol. Steady-state  $\text{VO}_2$  for each participant was recorded as an average of the last 4 minutes of each bout to limit the variability introduced by oxygen kinetics at the onset of each protocol stage.

### Data and Statistical Analysis

Statistics were completed in R version 3.4.1 (R Foundation for Statistical Computing) and SPSS Statistics for Mac version 23.0 (IBM Corp). Descriptive statistics are presented in the text as mean and standard deviation or proportion (%). Statistical significance was accepted as  $P < .05$ .

Participants' relative estimated  $\text{VO}_{2\text{max}}$  was divided by 3.5 mL/kg/min to calculate their maximum METs. For absolute intensity, MPA and VPA were classified as 3.00 to 5.99 METs and  $>6.00$  METs, respectively. For relative intensity, MPA and VPA were classified as 40% to 59%  $\text{MET}_{\text{max}}$  and  $>60\%$   $\text{MET}_{\text{max}}$ , respectively. For each stage, METs were calculated by dividing steady-state  $\text{VO}_2$  by 3.5 mL/kg/min. Stepping rate was computed as the average between manually counted steps

during minutes 2 to 3 and 4 to 5 of each stage. Step length (meters per step) was determined by dividing treadmill speed (meters per minute) by step rate.

Multiple regression, mixed effects models, and receiver operating characteristic (ROC) curve analyses were used to differentiate step-rate cut points for both MPA and VPA. The multiple regression approach was used to develop an equation that predicts step rate using metabolic activity and a combination of body mass index (BMI), height, and/or leg length, consistent with previous research [9,24]. However, multiple data points from each individual were used in the current analysis, thus violating the assumption of data independence. Therefore, mixed effects modeling was used to overcome this limitation by incorporating random intercepts to account for the data-dependence structure. ROC curves were used to evaluate optimal step-rate cut points that resulted in the highest sensitivity (true positives) and specificity (true negatives) for intensity-related physical activity as derived via Youden's index. For ROC area under the curve (AUC) analysis, below 0.70 was considered poor, 0.70 to 0.80 considered fair, 0.80 to 0.90 considered good, and 0.90 to 1.00 considered excellent [31].

Subject-level plots of step rates as a function of METs indicated that the relationship between these variables was curvilinear. The model presented by Beets and colleagues [9], which used METs, METs<sup>2</sup>, BMI, leg length, and BMI×METs as predictors of step rate, was used as the starting model. Parameters were added or removed (eg, height, body weight, METs<sup>3</sup>) according to relative goodness of fit and model complexity and based on *a priori* knowledge regarding the relationship among the variables of interest and the objective of this study. Of the candidate models, relative Akaike information criterion (AIC) scores (a model comparison measure) were used to determine which among them were most probable to minimize the information loss (ie, which model was closer to the true model or the data-generating model). AIC comparisons were used to identify which models are best at trading off bias versus variance among the fitted model parameters [32]. As such, AIC comparisons were used to identify which models were expected to maximize predictive accuracy. Model diagnostics were run for the best mixed model for each height, body weight, BMI, and/or leg length as predictors. The inclusion of height, leg length, or body weight as predictor variables did not improve the predictive capabilities of the model, whereas BMI alone drastically increased the ability of model to predict step rates from metabolic activity. Assumptions of normality, homoscedasticity, and independence were assessed via residual plots. The relationship among predictors was assessed via scatter plots.

## Results

### Participants

On average, participants self-reported 234 (SD 157) minutes of MVPA per week. Most participants (13/19) reported at least one yes to a question on the PAR-Q+. The mean (SD; range) values of leg length, height, and BMI were 96.2 (SD 7.6; 82-108) cm, 169.8 (SD 7.3; 160-187) cm, 26.3 (SD 3.5;



20.6-31.2) kg/m<sup>2</sup>, respectively, with participants being classified as healthy BMI (18.6-24.9 kg/m<sup>2</sup>; 6/19) overweight (25.0-29.9 kg/m<sup>2</sup>; 9/19), or obese class one (30.0-34.9 kg/m<sup>2</sup>; 4/19). Median values for leg length, height, and BMI were 95.0 cm, 168 cm, and 26.2 kg/m<sup>2</sup>, respectively. The average estimated VO<sub>2max</sub> of the sample was 31.0 ml/kg/min (SD 2.9; 25.7-35.7). Participants were classified as fair (7/19), good (7/19) or very good (5/19).

As demonstrated in Table 1, all outcome variables progressively increased with faster walking speeds. Subject relative moderate

METs and relative vigorous METs were 3.5 (SD 0.3) METs (median 3.5 METs) and 5.3 (SD 0.5) METs (median 5.3 METs), respectively.

### Multiple Regression

The multiple regression model generated to predict MVPA step rates from METs and BMI is presented in Table 2. Step rates were accurately predicted when BMI was a predictor variable ( $R^2=0.774$ ;  $P<.001$ ). Predicted absolute and relative intensity-related physical activity step-rate thresholds using the median values for BMI (26.2 kg/m<sup>2</sup>) are presented in Table 3.

**Table 1.** Description of measured variables at each treadmill speed.

Stage (speed)	Value, n	Step rate (spm <sup>a</sup> ), mean (SD)	METs <sup>b</sup> , mean (SD)	VO <sub>2</sub> <sup>c</sup> (mL/kg/min), mean (SD)	Step length (meters), mean (SD)	Heart rate (bpm <sup>d</sup> ), mean (SD)	RPE <sup>e</sup> (6-20), mean (SD)
Stage 1 (2.4 km/h)	19	91 (9)	2.4 (0.2)	8.4 (0.8)	0.45 (0.05)	83 (10)	8.5 (1.0)
Stage 2 (3.2 km/h)	19	104 (8)	2.7 (0.3)	9.5 (0.9)	0.52 (0.04)	85 (11)	9.5 (1.1)
Stage 3 (4.0 km/h)	19	110 (7)	3.1 (0.2)	10.7 (0.8)	0.61 (0.04)	88 (11)	10.7 (1.5)
Stage 4 (5.6 km/h)	18	125 (6)	4.4 (0.5)	15.2 (1.9)	0.75 (0.03)	105 (12)	12.2 (1.8)
Stage 5 (6.4 km/h)	14	133 (6)	5.7 (0.6)	19.9 (2.0)	0.81 (0.04)	117 (11)	13.5 (2.4)

<sup>a</sup>spm: steps per minute.

<sup>b</sup>METs: metabolic equivalents.

<sup>c</sup>VO<sub>2</sub>: volume rate of oxygen consumed (mL/kg/min).

<sup>d</sup>bpm: beats per minute.

<sup>e</sup>RPE: rating of perceived exertion (6-20).

**Table 2.** Multiple regression and mixed effects models to predicted step rate from metabolic equivalents.

Analysis	Model	Adjusted R <sup>2</sup> (P value)
Multiple regression	$-50.768 + (71.707 \times \text{METs}^a) - (9.650 \times \text{METs}^2) + (0.543 \times \text{METs}^3) + (1.775 \times \text{BMI}^b) - (0.394 \times \text{BMI} \times \text{METs})$	0.774 (<.001)
Mixed methods <sup>c</sup>	$-84.321 + (91.209 \times \text{METs}) - (12.968 \times \text{METs}^2) + (0.772 \times \text{METs}^3) + (2.211 \times \text{BMI}) - (0.549 \times \text{BMI} \times \text{METs})$	— <sup>d</sup>

<sup>a</sup>METs: metabolic equivalents.

<sup>b</sup>BMI: body mass index (kg/m<sup>2</sup>).

<sup>c</sup>Recommended model to predict step rate.

<sup>d</sup>An R<sup>2</sup> value is presented for the multiple regression but not the mixed method model.

**Table 3.** Minimum step rates for both absolute and relative moderate and vigorous intensity walking as established using multiple regression, mixed effects model, and receiver operating characteristic curve analyses.

Analysis	Intensity-related physical activity step rates			
	Absolute MPA <sup>a</sup> (3 METs <sup>b</sup> )	Absolute VPA <sup>c</sup> (6 METs)	Relative MPA (40% MET <sub>max</sub> <sup>d</sup> )	Relative VPA (60% MET <sub>max</sub> )
Multiple regression	107.7	133.9	116.2	130.9
Mixed model	108.2	134.5	117.3	131.5
ROC <sup>e</sup> curve	104.3	140.0	118.5	127.3

<sup>a</sup>MPA: moderate-intensity physical activity.

<sup>b</sup>METs: metabolic equivalents.

<sup>c</sup>VPA: vigorous-intensity physical activity.

<sup>d</sup>MET<sub>max</sub>: estimated VO<sub>2max</sub> divided by 3.5 mL/kg/min.

<sup>e</sup>ROC: receiver operating characteristic.

**Mixed Effects Modeling**

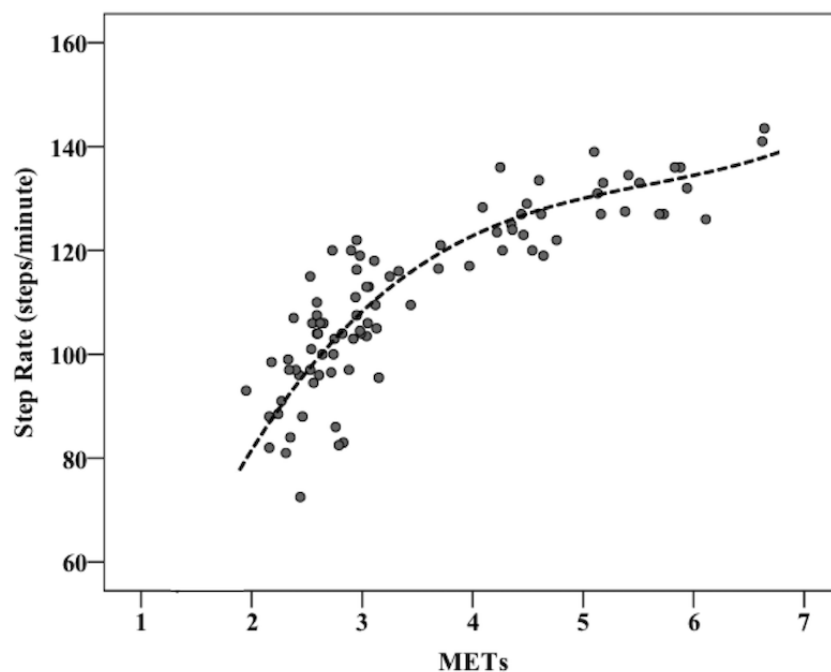
Similar to previous research [7], intercepts were allowed to vary among participants (ie, random intercept modeling was used). Regardless of intensity, the mixed effects model yielded similar step rates compared to the multiple regression model when BMI was used as a predictor (see Table 3). Figure 1 demonstrates the curvilinear relationship between step rate and metabolic activity with the mixed effects model as the reference line (median BMI 26.2 kg/m<sup>2</sup>). The influence of BMI on the relationship between step rate and metabolic activity is further presented in Table 4. Due the interaction effect between BMI and METs, a greater BMI was associated with faster step rates at 3 METs but with slower step rates at higher METs (ie, 5 METs and 6 METs). Likewise, the positive BMI coefficient (2.111×BMI) and the negative BMI\*MET interaction (-0.549×BMI×METs) cancel out at 4 METs, resulting in no

influence of BMI on step-rate thresholds at this intensity (see Table 4).

**Receiver Operating Characteristic Curves**

Data used for absolute MVPA and relative MVPA calculations were dependent upon the average MET values for the respective walking stages. The absolute MPA (3 METs) ROC curve was generated based on stages 1 to 3 (mean ranging from 2.4 to 3.1 METs). The optimal step rate was 104.3 spm, with 83.3% correctly classified as achieving MPA and 71.1% correctly classified as not achieving MPA (AUC 0.791 [95% CI 0.658-0.923], SE 0.07, P=.002). The relative MPA (3.54 METs) ROC curve was generated based on stages 2 to 4 (mean ranging from 2.7 to 4.4 METs). The optimal step rate was 118.5 spm, with 83.3% correctly classified as achieving MPA and 86.8% correctly classified as not achieving MPA (AUC 0.939 [95% CI 0.878-0.999], SE 0.03, P<.001).

**Figure 1.** Scatter plot demonstrating the relationship between metabolic equivalents (METs) and step rate. The reference line is the mixed effects model using the sample's median value for body mass index.



**Table 4.** The relationship between step rate and metabolic activity when adjusted for body mass index.

BMI <sup>a</sup> (kg/m <sup>2</sup> )	Step rate (steps per minute)			
	3 METs <sup>b</sup>	4 METs	5 METs	6 METs
20	105	123	133	141
22	106	123	132	139
24	107	123	131	137
26	108	123	130	135
28	109	123	129	132
30	110	123	128	130
32	111	123	127	128

<sup>a</sup>BMI: body mass index (kg/m<sup>2</sup>).

<sup>b</sup>METs: metabolic equivalents.

For both relative and absolute VPA (5.31 METs and 6.00 METs), the ROC curve was generated based on stages 4 and 5 (mean ranging from 4.4 to 5.7 METs). The optimal step rate for relative VPA was 127.3 spm with 75.0% correctly classified as achieving VPA and 70.0% correctly classified as not achieving VPA (AUC 0.804 [95% CI 0.655-0.953], SE 0.004,  $P=0.004$ ). The absolute VPA ROC curve corresponded to a step rate of 140.0 spm with a sensitivity of 66.7% and a specificity of 100% but did not reach statistical significance (AUC 0.793 [95% CI 0.453-1.000], SE 0.17,  $P=.10$ ).

## Discussion

### Principal Findings

The primary purpose of this study was to determine the step-rate thresholds associated with MPA and VPA in both absolute and relative terms for older adults. The most accurate model included BMI but not height or leg length as predictor variables in this diverse sample of older adults. In absolute terms, MPA (ie, 3 METs) and VPA (ie, 6 METs) corresponded to approximately 110 spm and approximately 135 spm, respectively. Unlike the previously established 100 spm required to achieve MPA in adults, the results of this study demonstrate that older adults need to walk faster to achieve the same intensity; however, this relationship is altered by BMI status. The sample's relative MPA (ie, 3.5 METs) and relative VPA (ie, 5.3 METs) equated to approximately 117 spm and approximately 132 spm, respectively.

Recent reviews [19,20] discussing the cadence required to achieve MPA and VPA demonstrate the need for more evidence regarding the recommended walking intensity in older populations. Our observed results highlight the importance of considering participants' physical characteristics when prescribing cadences in older persons. For MPA in absolute terms, older adults who have greater BMI need to take slightly more steps than those with a lower BMI (approximately 5 spm difference between 20 kg/m<sup>2</sup> and 30 kg/m<sup>2</sup>). However, this relationship is reversed and magnified at higher MET values (eg, 5 to 6 METs) with older individuals who have higher BMIs needing to take fewer steps per minute to equate to the same intensity as individuals with lower BMIs (approximately 11 spm difference between 20 kg/m<sup>2</sup> and 30 kg/m<sup>2</sup>). The observation that BMI influences MPA step-rate thresholds has been previously observed in young adults [9], in which they also observed negative interaction effects between BMI and METs (BMI\*METS\* $-0.52$ ) in their proposed model ( $R^2=0.68$ ). Contrary to their model, this study's proposed equation ( $R^2=0.77$ ) was not improved by adding leg length or height as predictor variables, suggesting that BMI impacts the metabolic requirements of walking more than leg length and height in elderly individuals.

The existing studies in older persons have demonstrated that the relationship between cadence and MPA is influenced by either height [12] or body weight [11]. Of relevance, BMI and body weight were not explored as predictor variables by Peacock et al [11]. One limitation of the previous literature is that they modeled the relationship between step cadence and metabolic

activity as linear, whereas we clearly demonstrate that it is curvilinear (see Figure 1), which would alter step rate predictions. Additionally, the model proposed by Serrano et al [12] uses body weight and self-selected walking cadence to predict MPA in relative terms; using self-selected cadence as a predictor variable decreases the practicality of their model in comparison to using height or BMI. The model proposed by Peacock et al [11] uses step rate as a predictor variable and METs as the outcome variable, requiring a back calculation of the required cadence for a given MET value. Consistent with some [9,24], but not all [11,21] previous research, we used step rate as the outcome variable because it does not require a back calculation of MET values making it is much easier to use by health care and exercise professionals in calculating their patients' MVPA step-rate thresholds. As well, both methods produce almost identical values. We do acknowledge that metabolic intensity is a function of stepping cadence but we opted for an equation that is simpler, performs just as well, and is easier to use.

A systematic review by Slaght and colleagues [19] calls for more evidence regarding the prescription of walking cadence as a means of increasing physical activity in practical settings. Whether older adults achieve MPA at higher cadences than their younger counterparts (eg, 100 spm) is controversial in the literature; however, our results demonstrate that 3 METs is reached at 105 to 110 spm in older adults, depending on BMI status. Certainly, there is merit to the heuristic public health recommendation of 3000 steps in 30 minutes (ie, 100 spm). However, individualizing step-rate thresholds would minimize the potential error associated with not considering BMI. This is of particular importance when recommending cadences that equate to higher intensity physical activity as VPA step-based thresholds are more affected by BMI status (128 to 141 spm between 20 and 30 kg/m<sup>2</sup>; see Table 4). To the authors' knowledge, this is the first study to evaluate VPA step-rate thresholds in older adults. Given the practicality of the 3000 steps in 30 minutes message for MPA, providers may consider recommending 4000 steps in 30 minutes (approximately 133 spm) as a general message to help their patients achieve VPA. However, the study's reference equation is provided so that providers can individually tailor step rates when deemed appropriate (ie, a physical activity monitor study), based on a patient's personal level of fitness and calculated moderate and vigorous MET targets. Of importance, our population is representative of a typical older Canadian adult with an average  $VO_{2max}$  of fair to good (ie, approximately 7 to 9 METs) [15,33], self-reported MVPA of approximately 30 minutes per day (or 210 minutes per week) [34], and a BMI in the overweight category (eg, average Canadian approximately 28 kg/m<sup>2</sup>) [35], which highlights the generalizability of this study's results.

### Limitations

This study may be limited by our laboratory evaluations across a defined set of walking speed in that the proposed models are limited to step rates between approximately 90 to 135 spm. Although a broad range of walking conditions were used, more stages in the vigorous zone would have improved our predictions of VPA cadences. However, to our knowledge, this is the first



study to investigate VPA step-rate thresholds in older populations. Furthermore, the findings of our study may be limited to BMI status' as the range of BMIs in this sample was 20.6 to 31.2 kg/m<sup>2</sup> and there were only 4 participants in the obese class 1 (30.0 to 34.9 kg/m<sup>2</sup>) category. However, the overall trend of lower VPA step-rate thresholds as BMI increases would likely not change if a greater proportion of obese persons were studied. Regardless, future research incorporating older adults of a broader range of BMI status' (ie, obese class 2, obese class 3) are warranted. There may be differences in applicability to free-living conditions, although walking on a treadmill is kinetically and kinematically equivalent to walking over ground in healthy subjects [36]. As well, our sample size may be considered a limitation, but it is reflective of similar studies investigating MVPA step-rate thresholds [8,9,11,22,23], and participants completed up to 5 walking stages that resulted in multiple data points per subject. We do acknowledge that a larger sample size would likely corroborate the findings of this study and anticipate that the results from the forthcoming Cadence-Adults study will further strengthen recommendations for MVPA step-rate thresholds in young and older adults [20]. Lastly, the use of a submaximal assessment of aerobic fitness may be considered a limitation; however, the single stage

treadmill protocol is a valid indicator of aerobic fitness [27] and the most practical for exercise professionals to adopt given their limited time allotted to assess patient fitness and provide an exercise program. Future research should evaluate the effectiveness of pedometer-based goals (ie, 3000 or 4000 steps in 30 minutes) in helping more of the older adult population achieve the national physical activity guidelines and reduce their risk of chronic disease.

## Conclusion

Walking is the most common form of leisure-time physical activity among older adults but the cadences required to achieve MPA and VPA in this population are understudied. This study provides evidence that older adults achieve absolute MPA and VPA at approximately 110 spm and approximately 135 spm, respectively, which is higher than the public health recommendation of 100 spm required to reach MPA previously reported. Further, anthropometric factors such as BMI significantly influence the curvilinear relationship between step rate and intensity-related physical activity. The findings of this study support that health care professionals and researchers should individualize MVPA step-rate thresholds based on their elderly patients' body sizes and, when possible, use relative MPA and VPA values.

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## Conflicts of Interest

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## Abbreviations

**AIC:** Akaike information criterion  
**AUC:** area under the curve  
**BMI:** body mass index  
**CSEP:** Canadian Society for Exercise Physiology  
**MET:** metabolic equivalent  
**METmax:** relative estimated  $VO_{2max}$  divided by 3.5 mL/kg/min  
**MPA:** moderate-intensity physical activity  
**MVPA:** moderate-to-vigorous physical activity  
**PAR-Q+:** Physical Activity Readiness Questionnaire Plus  
**PASB-Q:** Physical Activity and Sedentary Behavior Questionnaire  
**ROC:** receiver operating characteristic  
**RPE:** rating of perceived exertion  
**spm:** steps per minute  
**VO<sub>2</sub>:** volume rate of oxygen consumed  
**VO<sub>2max</sub>:** maximal aerobic fitness  
**VPA:** vigorous-intensity physical activity

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Original Paper

# When More Than Exercise Is Needed to Increase Chances of Aging in Place: Qualitative Analysis of a Telehealth Physical Activity Program to Improve Mobility in Low-Income Older Adults

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## Abstract

**Background:** A telehealth-delivered physical activity program was implemented within two low-income older adult housing properties utilizing the Otago exercise program, a physical therapy program endorsed by the Centers for Disease Control and Prevention to improve balance and strengthening in community dwelling older adults and by the National Council on Aging as the highest level of evidence for fall prevention programs. Participants were also given Fitbit activity monitors to help track their activity.

**Objective:** The goal of this project was to increase older adults' daily physical activity in hopes of decreasing chronic disease morbidity, disability, and falls, and decrease social isolation.

**Methods:** The Otago exercise program was conducted via telehealth twice weekly for 12 weeks. Participants also wore Fitbit activity trackers to encourage physical activity outside of the group classes. Postintervention qualitative interviews were conducted, recorded, transcribed, and analyzed using discourse analysis.

**Results:** Twenty-one older adult participants from two low-income properties in Charleston, SC, participated in the 12-week telehealth physical therapy program. Postintervention qualitative interviews revealed that the two sites were very different in their participation in the program and their main concerns surrounding aging in place. One site had a community-oriented outlook and enjoyed participating in physical activity together; whereas, the other site had very few participants and referenced depression and social isolation as main concerns.

**Conclusions:** A telehealth physical therapy-led intervention to increase physical activity in low-income older adults aging in place was successfully implemented and attended; however, it became clear in postintervention qualitative interviews that social isolation and depression were prevalent and mental health needs to be addressed along with physical health to encourage successful aging in place.

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**KEYWORDS**

older adults; low income; physical activity; aging in place; social isolation; qualitative research

## Introduction

Physical inactivity increases the risk of adverse health conditions in older adults, including coronary heart disease, type 2 diabetes,

and breast and colon cancers [1]. Globally, 67% of adults older than 60 years are sedentary for more than 8.5 hours per day [2]. The World Health Organization calls for a 10% increase in physical activity (PA) and encourages community-based collaborations to formulate evidence-based, cost-effective means



to achieve this goal [3]. PA can decrease the chance of falls [4], cardiovascular disease [5], and arthritis pain [6-8]. In addition, PA can increase memory performance [9] and improve functioning with arthritis [6-8]. Older adults spending less time in sedentary behavior have a greater chance to age successfully and to age in place [10], with improved health-related quality of life [9].

Incidence of chronic diseases, such as diabetes, cancer, heart disease, stroke, and Alzheimer disease, increase as people age. Three out of four adults in the United States have more than one chronic disease [11]. Chronic disease can greatly affect an individual's ability to age in place by decreasing the ability to perform activities of daily living such as bathing, dressing, cooking, and taking medications. The inability to perform these activities can also restrict a person's desire to interact with others, creating or increasing social isolation [12]. In turn, social isolation can lead to depression [13-15], which can also decrease seniors' ability to care for themselves [16,17] and affects their ability to age in place. Social isolation in the older adult has also been linked to increased falls [18]. In this paper, we report on the first year of our project to increase low-income older adults' daily PA in hopes of decreasing chronic disease morbidities, disability, and falls.

To address issues of aging in place in their low-income older adult residents, the Humanities Foundation, a nonprofit affordable housing provider in South Carolina, Georgia, Virginia, and Louisiana, partnered with the College of Nursing at the Medical University of South Carolina (MUSC). To better understand residents' views on aging in place in their current living situation at Humanities Foundation properties, researchers from the MUSC had previously conducted a survey of interest in health care with 165 residents of Garden Vistas and five other low-income residential sites sponsored by the Humanities Foundation. In addition, nursing students conducted 14 individual interviews with residents at Garden Vistas, on their perceptions of aging in place. Predominant themes in those initial responses were fear and worry about personal safety, their ability to retain some degree of mobility, and social isolation [19].

Given current research on the intersections between low income, isolation, and depression, as well as other mental health issues, those initial responses and the 2017 interview replies are not surprising. For example, an earlier research review by Golant [20] noted that "an emerging literature casts doubt on whether staying put can be a one-size-fits-all solution." Shin et al [21] noted the prevalence of depression for residents of public housing; Xiang et al [22] identified this depression as stemming from unmet needs. A National Council on Aging survey [23] highlighted the vulnerability of low-income adults; Brown et al [24] reported that nearly 40% of homeless adults had depression. A report by the Kenan Institute [25] identified renters as one of the three vulnerable groups who would need a great deal of help if they were to age in place.

Fitbit wearable fitness trackers meet high reliability and validity requirements for parameters such as step counts. Telehealth and remote videoconferencing have been effectively used to deliver rehabilitation after total knee replacement, strokes, and physical

therapy to Veterans. Our project used wearable fitness trackers, combined with integrated feedback software and televideo to bring physical therapy (PT) student providers "into the room" with the older adult, hoping to provide motivation for the participants to become more physically active, and ultimately improving health, reducing falls and enhancing aging in place.

PA interventions incorporating technology have garnered research support for nursing and rehabilitation with older adults. Weinstock et al [4] utilized videoconferencing between diabetes educators and older adults to enhance pedometer effectiveness and found that participants in the telemedicine group had fewer declines in PA and physical impairment compared to those not using telemedicine. Silveira et al [5] and Wu et al [6] delivered PA interventions to older adults and found that community-based PA and videoconferencing produced higher retention, greater reduction in falls, and improvement in balance and health measures [5,6]. Compennolle et al [7] integrated pedometers and an internet-based PA program for adults at risk for chronic medical problems and found step counts and a computer-based intervention led to more accurate PA reports [7].

Activity trackers can increase PA when used in the appropriate context and are particularly effective with support infrastructure. Activity trackers providing real-time feedback are even more effective [26]. Fitbit wearable fitness trackers meet high reliability and validity requirements for parameters such as step counts [27]. Telehealth and remote videoconferencing have been effectively used to deliver rehabilitation after total knee replacement [28], stroke [29], and PT to Veterans [30].

Based on the information collected from residents of the Humanities Foundation, a telehealth-delivered PA program was implemented within two of the Humanities properties. It used the Otago exercise program, a PT program endorsed by the Centers for Disease Control and Prevention to improve balance and strengthening in community dwelling older adults [8] and by the National Council on Aging as the highest level of evidence for fall prevention programs [31]. Participants were also given wearable activity monitors (Fitbits) to help them track their own activity. The goal of the project was to increase older adults' daily PA in hopes of decreasing chronic disease morbidities, disability, and falls. Combining the PA program with the activity tracker was intended to accustom both nursing and rehabilitation professionals to the combination of telehealth delivery and wearable technology as a means of reaching low-income seniors with varying mental health and typically sedentary lifestyle.

## Methods

### Sample Recruitment

The first sites chosen in collaboration with the Humanities Foundation were (1) Garden Vistas, two residences for seniors built since 2010, with 72 and 59 apartments respectively, located on the same road in a newly developing suburban area, and (2) Garden North, a 36-apartment cluster in the middle of the city. Each site offered one- and two-bedroom residences. After study approval was obtained from the MUSC institutional review



board, flyers were sent to individual apartment mailboxes and posted in elevators and on bulletin boards. They advertised the free exercise class to be offered by MUSC and the opportunity to wear Fitbit fitness trackers. An on-site recruiting meeting was publicized and held. Inclusion criteria for the study were (1) older adults aged 55 years and older living in a Humanities Foundation apartment complex, (2) able to stand for 15 minutes, (3) able to walk 150 feet with or without an assistive device, (4) able to follow simple instructions for exercise, and (5) able to wear, operate, and charge the Fitbit HR fitness tracker. The following were exclusion criteria: (1) inability or unwillingness of participant to give informed consent and (2) physical, cognitive, sensory, or psychiatric disability that would limit participants from partaking in a PA program or wearing a fitness tracker.

### Physical Activity Program

Participants who met the inclusion criteria were entered into the study. Prior to the start of the 12-week program, participants wore the Fitbit HR fitness trackers for one week to record preintervention step counts. Participants were trained on the use of the fitness trackers and instructed to wear them daily. Data from the trackers was downloaded and shared with each participant on a weekly basis. Preintervention data were also collected on each participant using the Self-Efficacy for Exercise Scale [32], a demographic questionnaire, a 30-second sit-to-stand test [33], the Mini Balance Evaluation Systems Test, the Berg Balance Scale [34], and a two-minute walk test. This information was also collected postintervention. Participants then took part in a group telehealth PA using the Otago exercise program. The program was delivered to each site twice weekly

via televideo by a PT student who was overseen by PT faculty from MUSC.

### Qualitative Interviews

Participants who had agreed to be in the program were told by the study coordinator that they would be telephoned by the second author, a professor of linguistics with more than 30 years' experience in conducting and interpreting oral interviews. She introduced herself and reminded participants she was part of the team because of her research on language and aging and previewed the major questions she would ask (*italicized in Textbox 1*).

Calls were made to their residence using Skype; audio-recorded using Call Recorder; reformatted as wav files using Audacity; transcribed by VerbalInk, a HIPAA-compliant medical transcription company; and retained by the authors. All participants were called up to five times or until they answered; four never answered. Approximately 80% were reached and recorded. Seven (33%) were recorded twice; none refused the calls. Questions used were designed by the authors and reviewed by all team members (see *Textbox 1*). Interviews averaged 8 minutes. Follow-up interviews with Garden North participants averaging 5 minutes were collected a year later using the same interviewer, technique, equipment, and approach. In addition to asking if participants still exercised in any way, retained or used their Fitbits, and would be willing to join another exercise group, these interviews also included the Patient Health Questionnaire-2. There were 10 of 14 (71%) reached and recorded; one had moved away and the other three never answered.

**Textbox 1.** Preintervention and postintervention interview questions. Questions in italics are original interview questions. Nonitalicized questions are additional questions asked by interviewer. PT: physical therapy.

#### Preintervention Interview Questions

1. *Tell me about your usual exercise/physical activity.* Do you usually exercise on your own? Do you ever volunteer with other programs or to help others? Tell me about that.
2. *Why do you think being physically active is important?*
3. *How do you feel about participating in group exercises?*
4. *How do you feel about participating in an exercise program over the TV?*
5. *Tell me what you know about Fitbits [tracker].* Have you ever worn one or any other type of activity bracelet? Would you be open to wearing one? What makes you think that you would be comfortable wearing one? What makes you think it would help increase your physical activity?

#### Postintervention Interview Questions

1. *Tell me about your current usual exercise/physical activity.* Do you usually exercise on your own? Do you ever volunteer with other programs or to help others? Tell me about that.
2. *Why do you think being physically active is important?*
3. *How do you feel about participating in group exercise?*
4. *What did you think about the physical activity program that was done over the TV?* What specific aspect did you like? Was there something specific that you disliked? What would you like to see done differently?
5. How did the nursing students do when they collected your vital signs, helped you with the Fitbit [tracker], and helped with the exercises? What do you think they could have done differently?
6. *How did the PT students do in giving the exercise program? What do you think they have done differently?*
7. *What did you think of the Fitbit?* Was it easy to use? How did it increase your physical activity—or did it? Why do you think many people like to wear it all of the time?

A single coder (the second author) coded all transcripts for the identification and interpretation of key themes, using hierarchical coding achieved through multiple readings and successive codings, supported by keyword analysis (a kind of content analysis) using WMatrix for computer-assisted qualitative discourse analysis [35]. The first author, who had been on site and had personally interacted with participants, reviewed the interpretation for both coherence and representativity; disagreements were resolved, and full consensus was reached.

## Results

### Sample

A total of 21 participants were recruited for the study. Participant demographics are shown in Table 1.

With two exceptions—both of whom said they did some limited walking daily—respondents at all sites admitted in the preintervention interview to doing very little exercise, but said they were concerned about balance and maintaining their health. All thought that group exercises sounded good, agreed to try out telehealth-delivered exercise instructions, and were willing to try a Fitbit tracker although only one or two had seen advertisements for it. In the postintervention interviews, respondents announced they would welcome a second program, liked the group activity, and the telehealth delivery, had little to say about the nursing students, and thought the Fitbit was definitely worth the trouble it took to remember to charge it. Five persons from Garden North were called again after the postintervention call because of their enthusiasm for the program and asked if they would be “ambassadors” to explain the program to other foundation-supported low-income residences; all agreed.

**Table 1.** Participant demographics at Garden Vistas and Garden North (N=21).

Variable	Garden Vistas sample (n=6)	Garden North sample (n=15)
<b>Gender, n (%)</b>		
Female	5 (83)	14 (93)
Male	1 (17)	1 (7)
Age (years), mean (SD)	72.8 (9.7)	72.3 (7.9)
Age (years), range	58-83	57-85
<b>Race, n (%)</b>		
White	3 (50)	0 (0)
Black	3 (50)	15 (100)
Ethnicity (not Hispanic or Latino), n (%)	6 (100)	15 (100)
<b>Marital status, n (%)</b>		
Never married	0 (0)	2 (13)
Married	1 (17)	3 (20)
Divorced	2 (33)	5 (33)
Widowed	1 (17)	5 (33)

**Table 2.** Garden Vistas: exercise experience and socialization.

Sample themes and quotations	Code exemplar	Categories
<b>We can tell you about our exercise but not about ourselves</b>		
We're doing balancing exercises that are helping us a lot, my balance seems to be getting better.	Balance exercise	Exercise types
The property that we live at we have a class on Monday, Wednesday and Friday where we do core strengthening exercises.	Core exercises for some	“The property that we live at”—not called a home
We compare our steps: mall walk and garage walk.	Some talk about counting steps	Some conversation
<b>Lack of socialization contributes to depression</b>		
There's not much socializing, we should repeat the program.	Missing socialization	Lack of socialization
Maybe the building as a whole can socialize.	Possible solution to no socialization	Lack of socialization
I fight depression by getting dressed and going anyplace.	Have to fight depression	Depression
You're gonna laugh, I make my bed. Then you don't get back in it.	Make self get up	Depression
I think it's just getting together as a group and you know socializing and doing these exercises and having fun doing it together.	What I'd like to see: having fun together	Need more socialization

Garden North differed from Garden Vistas in a number of ways, primarily keyed to residents' needs and the quality of the community. Although Garden Vistas had more than three times the number of potential participants, only a few agreed to join the project. The major issue seemed to have been their own perceptions of a need for better mental health. As shown in Table 2, Garden Vistas participants had very little to say about the program other than to report on the exercises they had been shown; instead, they wanted to talk about how they tried to combat depression and isolation.

Garden North residents, on the other hand, had a great deal to say—and much of it was about how Garden North was a real community, which accounted, the respondents felt, for their not feeling socially isolated or consistently depressed. Individuals at Garden North had problems—some were former alcoholics or addicts, many had chronic diseases and comorbidities—but they helped one another through the bad times. This is especially noteworthy because the majority of the residents at Garden North, sited in an inner-city urban neighborhood, were of one of the most vulnerable groups in the low-income population, African American [25]. Table 3 displays Garden North's categories and themes.

**Table 3.** Garden North: exercise experience, recruiting, socialization, and neighborhood.

Sample themes and quotations	Code exemplar	Categories
<b>Exercise is fun and beneficial</b>		
It was fun. It was something I've been wanting to do it and after that, I had an opportunity to do it in here. I just went on and then joined in and started doing it and the work got real good.	This is something desired before it started	A person could join in and have fun
Yeah, I lose a lot. Yeah, it makes me lose a lotta weight. I don't eat as much as I used to eat so, yeah, everything is fine.	Weight loss is important	Exercise is beneficial
<b>Recruit older persons individually for success</b>		
Everybody start coming by. She started with six people but we ended up with a good group, we have two sections.	Others were curious about the group	Groups expanded quickly
We're senior residents up here. And she approached me. I don't know who she approached here, but she stated what she wanted, and we all complied with that.	Older persons solicited individually to join group	Personalized approach seems to have worked with older people
<b>We are a community like one of family members</b>		
Well, it's more like a family, a family thing and everybody care about one another over here and everybody come here and they love to be here and they wish they could live in this place. It's just nice. Everybody gets along real well and we look out for one another, help one another out and all of that and then we go on trips and stuff. It's just a lotta fun.	We act like a large family, taking care of one another and going out together	We like to do things with one another
We're all old. We're all struggling to make tomorrow or the day-after-tomorrow. Why strong? I guess we're survivors. We just wanna survive. Some of us are ex-alcoholic, ex-drug-addiction. Well, I guess it just gives you incentive to strive for something better in life.	We're old, want to help one another survive	Survival means helping one another
<b>We don't buy into stereotypes of age</b>		
Now, what is old? To me what is old? Old is how you feel. It's a state of mind. My mother's 84. She acts like she's in her 40s or something. I wish I could move as fast as her. She's just always on the go. She dances. She goes on long drives. She goes out to the beach.	Chronological age doesn't mean being old	Age is a state of mind
Is it because we all been here together for so long and we know each other. We know the good, the bad, and the ugly. We always try to help one another out when we're ill...	We are long-term residents and we know a lot about one another	We know one another very well
<b>We actively practice socialization</b>		
Once we all moved into this building we got to know one another. We used to always have dinners or we'd have breakfast every Saturday morning. We had gotten that started. Then we all joined in together where we had president, vice president, you know, and we put things in paper so we could all see what we wanted to do. Then we'd start decorating the building for Christmas and stuff and Easter.	We started by eating together, then organized, and moved to decorating "our home"	This is a community, not a "property"
<b>We're right in the middle of everything here</b>		
Yeah, the neighborhood is nice. You've got the store. You've got the eating place. You've got the Chinese, the school, the library, the arcade next door and [crosstalk]—And the park and all of that. It's just nice. It's a nice neighborhood to be in.	Itemizes what's available in the immediate neighborhood	Neighborhood has everything a person could want

A year later, when follow-up interviews were conducted with 10 of the 13 remaining Garden North participants, all 10 reported they were continuing to do some exercise if not all the specific exercises that they had learned in the class. Most no longer used or could not find their Fitbits—one complained that she kept forgetting to take it off before washing dishes, another explained that hers “blew up,” but one still wears her watch. All have kept up with some of the walking and the step climbing, all said they would like to take class with one another and liked telehealth. Only one reported that she had become depressed but that visiting a doctor at MUSC and talking about depression with her sister was allowing her to see improvement.

## Discussion

Comments by participants in the two groups index the differences in their attitudinal approaches to the program. Garden Vistas participants noted the lack of socialization in their building and while doing the program. They had little conversation with one another and their interviews typically focused on how to combat depression while living in “the property”: note that nobody called it a residence or a home or even an apartment. It was seen as a property that belongs to somebody or something else, not to them.

Although the program was new at each of the sites, it was easier to administer and to encourage at Garden North because many of the residents felt they lived in a community, with stores, a park, a library, and other places for outside interaction being seen as an easier walk. Interestingly, distance from outside locations was similar at each site. However, automobile and truck traffic patterns at Garden Vistas made walking outside more difficult, with longer isolated stretches between traffic

lights and crosswalks and fewer low-income, mom-and-pop stores. In addition, Garden Vistas had little community “feel”; indeed, many residents seemed to be dazed and fearful, seeking isolation while wishing for activities that could involve friendship. Mental health loomed as a much more prevalent issue at Garden Vistas: people at Garden North were aware of one another’s mental health needs, from addiction to depression, in ways that residents at Garden Vistas were not. At the conclusion of the study, interested participants who had been to the majority of the PA sessions were asked if they would be comfortable to continue to lead the sessions twice weekly. Several participants from each site were trained to continue on with the PA groups.

The study had several limitations including a small sample size. The sample was taken from two low-income retirement communities managed by the same property management company, which may limit generalizability to the population; however, the two properties were vastly different in their demographic data. Use of the PA trackers may be limited in this older adult, low-income demographic, although some participants really enjoyed wearing the trackers.

It is clear that PA and socialization is critical to older adults who are aging in place. More importantly, mental health—not just physical health—has to be considered when attempting to engage older adults in group activities. Mental health plays a role in physical health as well as socialization and is a key component to healthy aging in place. Future studies need to be aware of older adults’ mental health needs and these needs should be addressed to encourage socialization and PA. Integrating mindfulness, depression screening, and other mental health screening and education into future aging-in-place interventions is a necessity.

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## Conflicts of Interest

None declared.

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## Abbreviations

**MUSC:** Medical University of South Carolina

**PA:** physical activity

**PT:** physical therapy

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Original Paper

# Understanding Care Navigation by Older Adults With Multimorbidity: Mixed-Methods Study Using Social Network and Framework Analyses

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## Abstract

**Background:** Health and social care systems were designed to be used primarily by people with single and acute diseases. However, a growing number of older adults are diagnosed with multiple long-term conditions (LTCs). The process of navigating the intricacies of health and social care systems to receive appropriate care presents significant challenges for older people living with multiple LTCs, which in turn can negatively influence their well-being and quality of life.

**Objective:** The long-term goal of this work is to design technology to assist people with LTCs in navigating health and social care systems. To do so, we must first understand how older people living with LTCs currently engage with and navigate their care networks. No published research describes and analyses the structure of formal and informal care networks of older adults with multiple LTCs, the frequency of interactions with each type of care service, and the problems that typically arise in these interactions.

**Methods:** We conducted a mixed-methods study and recruited 62 participants aged  $\geq 55$  years who were living in England, had  $\geq 2$  LTCs, and had completed a social network analysis questionnaire. Semistructured interviews were conducted with roughly a 10% subsample of the questionnaire sample: 4 women and 3 men. On average, interviewees aged 70 years and had 4 LTCs.

**Results:** Personal care networks were complex and adapted to each individual. The task of building and subsequently navigating one's personal care network rested mainly on patients' shoulders. It was frequently the patients' task to bridge and connect the different parts of the system. The major factor leading to a satisfying navigation experience was found to be patients' assertive, determined, and proactive approaches. Furthermore, smooth communication and interaction between different parts of the care system led to more satisfying navigation experiences.

**Conclusions:** Technology to support care navigation for older adults with multiple LTCs needs to support patients in managing complex health and social care systems by effectively integrating the management of multiple conditions and facilitating communication among multiple stakeholders, while also offering flexibility to adapt to individual situations. Quality of care seems to be dependent on the determination and ability of patients. Those with less determination and fewer organization skills experience worse care. Thus, technology must aim to fulfill these coordination functions to ensure care is equitable across those who need it.

**KEYWORDS**

care navigation; long-term conditions; multimorbidity; older adults; social network analysis

## Introduction

### Background

While people now live longer than previous generations, they do not necessarily live well for longer [1]. With the increase in life expectancy, there is also an increase in long-term conditions (LTCs), such as arthritis, diabetes, and heart disease. In addition, a growing number of older adults are diagnosed with  $\geq 2$  LTCs, also referred to as multimorbidity [2,3]. Health and social care systems were primarily designed for the management of people with single diseases and acute conditions rather than those with multiple LTCs, resulting in difficulties in care provision and navigation (ie, finding the right type of care, in the right place, and at the right time) for those with multimorbidity [4]. Care systems are, for example, often not connected in the way patients expect [5,6]. This can lead to expectations remaining unmet, as well as over, under, and inappropriate use of the care system [5,7,8]. Furthermore, the incurable nature of LTCs, combined with the burden they can place on people's lives, increases the importance of maintaining and improving the quality of life [4]. Patients with multimorbidity especially value clear communication and accessibility of providers. Particularly for older individuals with multimorbidity, there is an urgent need for support in appropriately navigating the care system to maximize health and well-being.

### Prior Work

One approach to addressing this need is the provision of designated "care navigators"—professionals who support patients in their "pathway" or "journey" through the care system. In their task of guiding patients through the system, care navigators focus on the needs of individuals. Studies in the cancer care setting have shown the benefits of care navigators [9-11]. However, despite having a positive effect on patients' satisfaction, quality of life, and functionality [7,12], the high cost of care navigators remains a barrier to their wider employment [13]. Furthermore, their involvement in the patients' journey tends to be limited to short amounts of time [14] and focus on single LTCs (eg, cancer) instead of multiple LTCs [6].

A potentially more cost-effective, accessible, and equitable solution lies in the use of technology to aid care navigation [8,15]. Indeed, it could be argued that care navigation is an information management and communication problem; these are exactly the types of problems that information and communications technology is well suited to solving. Some work is beginning to emerge on this topic. For example, Yao et al [15] proposed the design of a navigation support system for patients modeled on decision-support tools more commonly designed for clinicians. By providing patients with a unified and integrated view of their specific care continuum, Yao et al [15] aimed to help patients understand and manage their health care. Their prototype design did not directly involve patient

data or consultancy but focused on pathways derived from medical guidelines. Yao et al [15] commented that navigation programs need to truly focus on patients to help them to manage this task, suggesting that a better understanding of patients' needs concerning care navigation and multimorbidity is required to design effective support systems. Zulman et al [14] addressed this issue by outlining patients' need. The following 3 themes emerged from their study: (1) *patients with multimorbidity manage a high volume of information, visits, and self-care tasks*; (2) *they need to coordinate, synthesise and reconcile information from multiple providers and about different conditions*; and (3) *their unique position at the hub of multiple health issues requires self-advocacy and expertise* [14].

However, Zulman et al [14] did not provide a detailed understanding of stakeholders involved in the care network. To date, no previous study has investigated the structure of the care network of older people with multiple LTCs. There is very limited knowledge available to researchers on how older people with multimorbidity interact and engage with their care network. These gaps in knowledge make it difficult for anyone to design appropriate care navigation support for these patients.

### Goal of This Study

For technology to support older adults in care navigation, an understanding of both the care system and people's experiences of that system is needed. This study is the first step in the experience-centered design [16] of tools to support care navigation. The goal of this paper is to describe and analyze the challenges inherent to care navigation, and in doing so, outline design opportunities for technology to support older adults with multimorbidity when navigating the care system. As such, we contribute to the current knowledge by providing a systematic exploration of older people's existing experiences, needs, and goals in care navigation, while relating these to their personal care network (PCN; people providing them with care). Using a mixed-methods approach, this study aimed to identify the type and number of caregivers (formal and informal) involved in the care of older people with multimorbidity. Through quantitative [social network analysis (SNA)] and qualitative (framework analysis) methods, we examine and explore older people's experiences and needs in relation to navigating their care. This analysis considers the breadth and depth of participants' experiences but still allows actionable reflections on challenges and opportunities for the human-computer interaction community when designing for multiple conditions.

## Methods

### Study Design

We performed a pragmatic mixed-methods study to understand care navigation from the perspective of older adults with multiple LTCs (refer [10,17] for a detailed discussion of mixed-method study designs). The intention was 2-fold as follows:

1. Understanding PCNs surrounding older people with multimorbidity. *This included identifying which caregivers were involved, why and how were they involved.*
2. Understanding the experiences of older people with multimorbidity in relation to care navigation. *This encompassed examining how the PCN currently functioned and how it should be functioning for older people with multimorbidity.*

Quantitative (questionnaire) data were needed to help answer the question of “who” was involved in the PCN of a wide range of participants, and to some extent, “why” they were involved. Qualitative (semistructured interview) data were used to give in-depth information about the latter, as well as details of “how” those people were involved, and in “what” way the network functioned. A tranche of quantitative data was initially collected and analyzed. This initial analysis was used to guide the design of the qualitative interviews. Specifically, interviews focused on topics that were recognized as important in the initial analysis. Interviews were then started, with the remainder of the quantitative data being collected and analyzed concurrently with the interview strand. Ethical approval for the research was obtained through the “University of Lincoln’s” ethics board and the Ethical Committee of the “national health care body.”

### Sample and Recruitment

Eligible participants had to be aged  $\geq 55$  years, living in England, and diagnosed with at least 2 LTCs. We aimed for a minimum of 50 questionnaire respondents and a 10% subsample for the interviews. The study was advertised through a number of methods. First, emails and social media messages were posted by both a university and an age-related nongovernmental organization. Second, flyers were created and placed, with agreement, in churches, community halls, and charity shops. Third, posters and information sheets were placed in 101 general practices. Fourth, people engaging with a pilot care navigation project run by a nongovernmental organization were contacted directly. Once the questionnaire was completed, eligible respondents (ie, those living locally to the lead researcher) were offered the option to participate further through a semistructured interview. Those who decided to do so, were contacted to further discuss the study, check their consent, and clarify any further questions. In agreement with the participants, a place for the interview was decided (usually the participants’ home).

### Data Collection

To understand the range of experiences encountered by people with multimorbidity in navigating the health and social care system, it was necessary to capture information about participants’ communications, interactions, and relationships with a range of different people, services, and institutions involved in their care. Two distinct instruments were designed to collect the data in this mixed-methods study.

### Social Network Questionnaire

Social network questionnaires have been found to be useful for the assessment of connections and relationships between people or social actors [18]. The “egocentric” SNA is a subtype of SNA that aims to specifically understand the relationships surrounding one focal unit or actor in a network [18]. The egocentric SNA

provided a method for us to assess the patients’ perspective of their own care network. Very few examples of validated and nonvalidated questionnaires for social network data were found at the start of this study [19,20], and none existed specifically to gather data about a participants’ PCN. Therefore, a new questionnaire was developed. Our questionnaire was designed primarily on “name generator” questions. These questions asked participants which formal and informal caregivers they were in contact with, the frequency of contact, and the reason for contact (eg, treatment, support; Figure 1). The majority of questions were close-ended, allowing direct comparison of the data across participants (Figure 1).

An initial draft of the questionnaire was reviewed by 6 members of a Patient and Public Involvement group. Based on their feedback, an adjusted version was sent out for pilot-testing among 3 members of the public (who met the inclusion criteria for the study), 2 members of a “Later Life” forum, and 2 academics independent from and unfamiliar with the research. This group of people completed the questionnaire and provided feedback that led to final adjustments of the questionnaire (Multimedia Appendix 1).

### Semistructured Interviews

The questionnaire was not intended to provide nuanced data on, for example, the “strength” of connections that patients had with care providers; to address this, semistructured interviews were planned (Multimedia Appendix 2). The final topic guide included questions on patients’ needs regarding (digital) care navigation support and their current experiences and barriers to using such technology.

### Data Analysis

This study gathered both quantitative and qualitative data, thus requiring a number of different types of analyses, plus a strategy for integrating data across those methods.

### Quantitative Analysis: Social Network Analysis and Descriptive Analysis

This study used the SNA to interpret questionnaire responses. In care settings, SNA has, for example, been used to describe and understand the social aspects of communication patterns [21], investigate the impact of social capital on health and well-being [22], and look at the influence of social networks on frail older people’s life satisfaction [23]. The SNA includes 2 main components—“actors” and “relationships.” Actors in the SNA are represented by points and referred to as nodes. Nodes are the individual units that are connected by the relations (ties). The ties (relationships) or “edges” in the SNA are represented by lines (Figure 2) and can display any possible connection between the nodes of interest such as friendships, collaborations, and information flows.

To visually support the analyses of these structures, the SNA uses graphs, also called sociograms [24], an example of which is shown in the simplified example in Figure 2. We used SPSS Statistics V22 (IBM Corp) for *descriptive analysis* of the data and Gephi 0.9.1 [25] as *visualization and exploration* software assisting the SNA and providing sociograms of the PCNs.

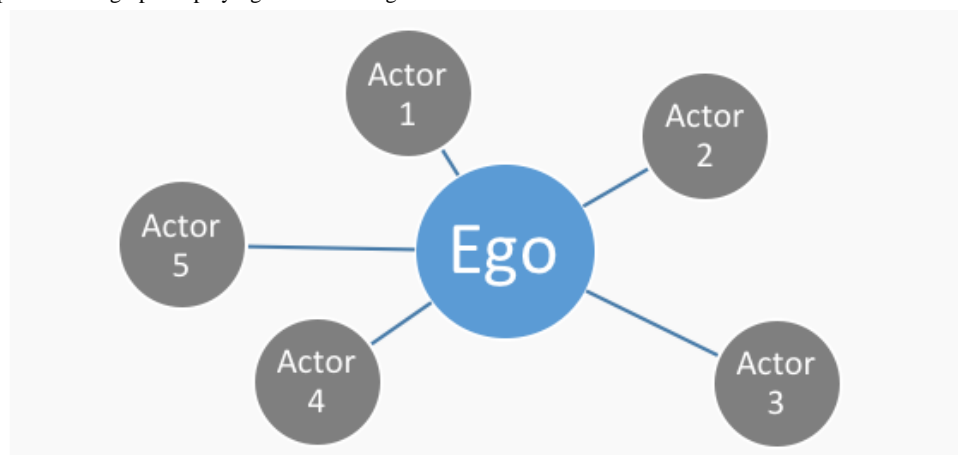
Figure 1. An example question of the social network questionnaire for the study.

**i) General practitioner (GP)**

I don't have any contact with this professional → Go to question 6.j)

<p><b>Frequency of contact</b></p> <p><input type="checkbox"/> Every day</p> <p><input type="checkbox"/> Once or more a week, but not every day</p> <p><input type="checkbox"/> More than once a month, but not every week</p> <p><input type="checkbox"/> Once a month</p> <p><input type="checkbox"/> Every 1 or 2 months</p> <p><input type="checkbox"/> Every 3 or 4 months</p> <p><input type="checkbox"/> Every 5 or 6 months</p> <p><input type="checkbox"/> Every 7 to 12 months</p> <p><input type="checkbox"/> I don't know</p>	<p><b>Main type of support provided</b></p> <p><input type="checkbox"/> Information and advice</p> <p><input type="checkbox"/> Emotional support</p> <p><input type="checkbox"/> Practical support</p> <p><input type="checkbox"/> Care (eg, assessment, treatment, prescription)</p>
<p><b>Main way of contact</b></p> <p><input type="checkbox"/> Electronically (eg, email)</p> <p><input type="checkbox"/> By telephone</p> <p><input type="checkbox"/> In person (face to face)</p>	<p><b>Other types of support provided</b></p> <p><input type="checkbox"/> Information and advice</p> <p><input type="checkbox"/> Emotional support</p> <p><input type="checkbox"/> Practical support</p> <p><input type="checkbox"/> Care (eg, assessment, treatment, prescription)</p>
<p><b>Reason for contact</b></p> <p><input type="checkbox"/> Short term problem not related to my chronic condition(s)</p> <p><input type="checkbox"/> Short term problem related to my chronic condition(s)</p> <p><input type="checkbox"/> Chronic condition</p>	<p><b>Level of satisfaction with support</b></p> <p><input type="checkbox"/> Very unsatisfied</p> <p><input type="checkbox"/> Unsatisfied</p> <p><input type="checkbox"/> Satisfied</p> <p><input type="checkbox"/> Very satisfied</p>
<p><b>Roughly how many different GP's have you seen in the last 6 months?</b></p> <div style="border: 1px solid black; height: 30px; width: 100%;"></div>	

Figure 2. The example network graph displaying nodes and edges.



**Qualitative Analysis: Framework Analysis**

Framework analysis [26] was selected as the most suitable method to analyze the semistructured interviews. Framework analysis is a specific type of thematic analysis, usually with greater emphasis on the transparency of the analytical process [26] and linkage between the stages of analysis [27]. This analysis was an inductive, iterative, and continuous process in this study. It allowed for concepts to emerge as we progressed

through the analysis process. However, at the same time, we had a clear understanding of the purpose of the research and the question that needed answering [28].

The qualitative analysis involved 3 separate stages, although these were not necessarily linear in progression and moving between different stages was not uncommon. In the first instance, the transcripts were line-by-line coded. This process was assisted by the NVivo 10 software package and resulted in several open codes (eg, difficulties finding the “right” person



to contact and perception of limited communication between providers) that were later grouped as categories (eg, barriers in care navigation) and supported the themes from the framework. Second, both within and between transcripts, a search was conducted for remarkable and noticeable differences and similarities between participants (eg, patients with family living nearby vs those with family further away). Third, reoccurring codes, differences, and similarities were grouped and brought together as subcategories within the following 7 themes: (1) meaning of the PCN; (2) structure of the PCN; (3) roles and responsibilities in the PCN; (4) first point of contact; (5) service organization or operation; (6) PCN interaction and communication; and (7) technology.

## Results

### Sample Characteristics

We recruited 62 participants, all aged  $\geq 55$  years, living in England, and diagnosed with  $\geq 2$  LTCs. While 37 participants accessed the questionnaire via a Web-based link, 25 completed a paper version. Of all, 28 participants reported as male, 14 as female, and the remaining 20 preferred not to say or left the question blank. On average, questionnaire participants were 72 years old (range, 55-94 years). Participants indicated they had been diagnosed with a variety of LTCs, the five most common being musculoskeletal conditions, cardiovascular disease, bowel diseases, respiratory conditions, and diabetes. We excluded participants with conditions affecting cognitive and memory abilities from the study. No significant relationship was found between age and the number of LTCs ( $r = -.112$ ,  $P = .51$ ), and no significant difference was observed in the sample for the number of LTCs between men and women ( $F_{2,4} = 2.327$ ,  $t_{2,4} = -1.239$ ,  $P = .23$ ). All participants reported they had been diagnosed with their first LTC  $> 2$  years ago. The majority of participants who answered the question relating to the time of diagnosis ( $n = 36$ ) had their first diagnosis  $\geq 10$  years ago (52.8%, 19/36), and 47.2% (17/36) had the diagnosis  $< 10$  years ago.

Semistructured interviews were conducted with a rough 10% subsample of the questionnaire sample (4 women and 3 men). On average, interviewees aged 70 years (range, 57-83 years) and had 4 LTCs (range, 2-8).

### Understanding the Personal Care Network: Caregivers

To understand our participants' PCNs, we identified, for each participant, which caregivers were involved, as well as their reason for involvement. Across the questionnaires, a total of 39 different actors were reported by participants (Figure 3). Actors closer to patients and conveying stronger ties (ie, thicker lines) were more frequently indicated by participants. Consequently, actors further away from and connected with patients through thinner ties were overall less indicated by the sample. The closeness or distance of these actors to patients is also represented by the size of the nodes. Bigger and smaller nodes, respectively, reflected actors more or less frequently mentioned

to be involved in the PCN of participants. On an individual level, the number of *important* actors varied across participants, from as little as 1 to as many as 20. Regarding participants' *contact* with actors, similar results were observed. On average, the PCN of patients contained 7 actors.

Those (2/7) who lived further away from their immediate family or did not have certain people within that group (eg, partner), tended to elaborate in greater detail the structure of those living around them. Interviewees who did not have their family nearby showed higher reliance on neighbors, friends, and even people in the wider community.

### Understanding the Personal Care Network: Domains of Care

We identified 4 domains of care as follows: health care actors in the community (HCC); health care actors at the hospital (HCH); social care actors in the community (SOCC); and informal care (IC) actors. Figure 3 displays the structure of the PCN according to these domains of care. The different domains of care were allocated different colors to provide a domain-sensitive graph. The average amount of actors indicated as important per domain was slightly higher for HCC ( $n = 4$ ) than the other domains (SOCC, 1; HCH, 3; and IC, 2). The domain-specific averages relating to contact did not show much internal variation; generally, participants indicated 3 HCC, HCH, and IC actors they were in contact with and 1 in the domain of SOCC.

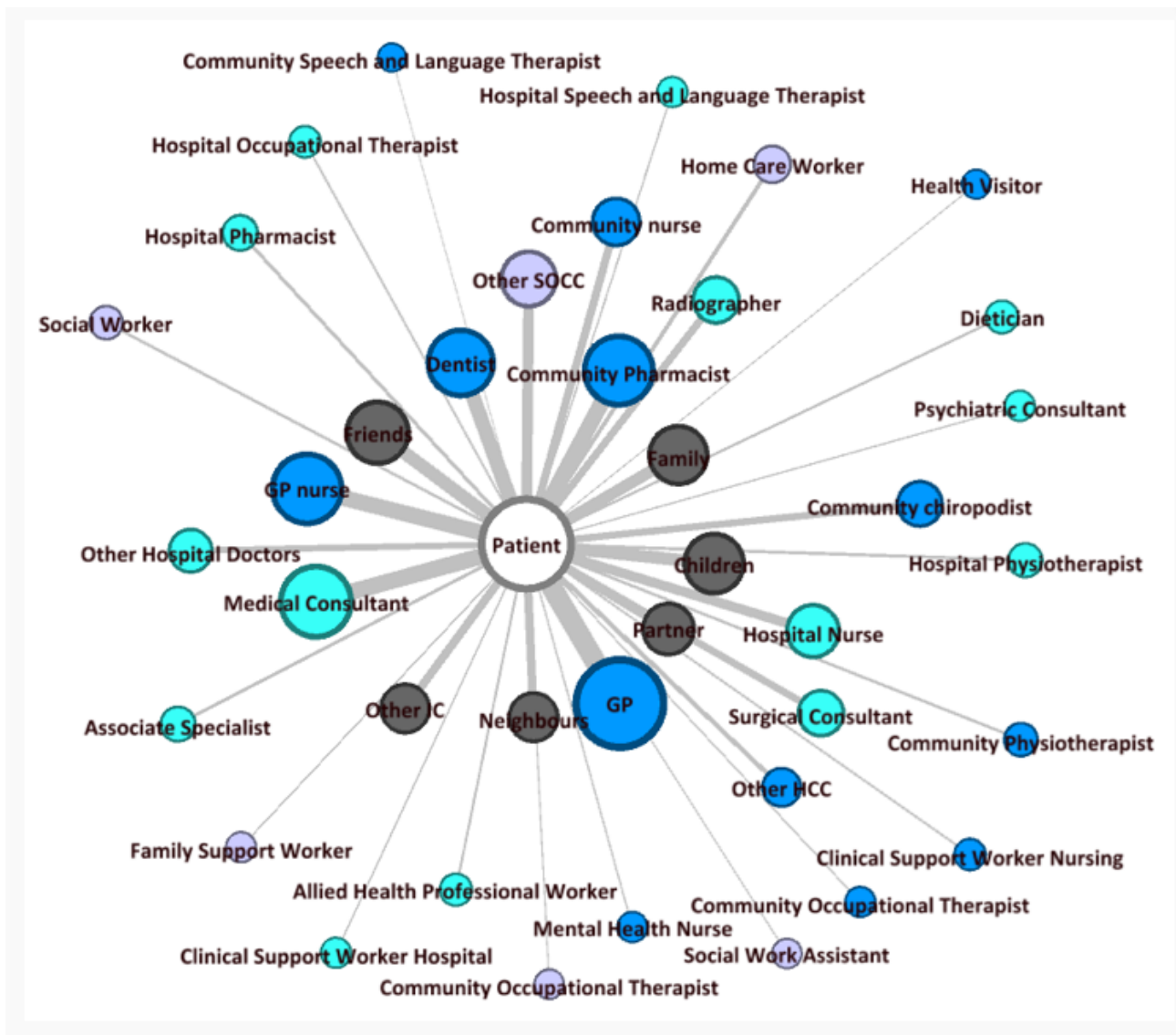
Both the interview and questionnaire data suggested a smaller involvement of formal social care than any other type of care (ie, hospital care, primary care, and informal and third sector care). Less than a third (30.6%, 19/62) of the participants indicated  $\geq 1$  SOCC actors to be involved in their PCN. Over double this number (67.7%, 42/62) was reported for HCC actors, and 51.3% (32/62) indicated the involvement of HCH and IC actors.

### Understanding the Personal Care Network: Levels of Care

Unlike the questionnaire, the interviews did not predefine domains (ie, SOCC, HCC, HCH, and IC) for inquiry. As such, the groups of care that emerged from the interview data were based on patients' perceptions of the type or levels of support they provided. In other words, this added detail on why certain actors were involved in patients' care. When describing the PCN during the interviews, participants tended to distinguish 3 levels of support as follows: support provided on a *day-to-day* basis, frequently used services or providers for *monitoring and follow-up*, and "*exceptional*" care delivered by professionals.

*[...] there are local charities, there's the stoma nurses, there's the local Ileostomy association. I go to see a consultant once a year at the hospital so to me that is the...my care network, as well as friends and family. [pp7]*

**Figure 3.** Actors involved in participants' personal care networks. Colors represent separate domains of care: blue, health care actors in the community (HCC); cyan, health care actors at the hospital (HCH); purple, social care actors in the community (SOCC); gray, informal care (IC). GP: general practitioners.



The interviews revealed that daily continuous support was mainly provided by informal caregivers, whereas follow-up activities and expert care were situated, respectively, on the level of primary and secondary care.

*[...] So you've a group of more exceptional people to access than you have informal care givers who are there on a day to day basis. And then you've those that you basically access on a frequent basis to keep in check with the conditions that you have. [pp5]*

Integration of the data further led to the identification of 5 main categories of actors in the PCN (Figure 4)—the patient himself or herself (1), the general practitioner (GP) practice (2), the informal network (3), the experts involved depending on the type of LTCs patients were diagnosed with (4), and additional services used as required (5). The first 3 (1-3) were found to be the “core” of the PCN, remaining relatively stable across patients' time living with LTCs. The presence and number of experts (4) and additional services (5), however, were more subject to change.

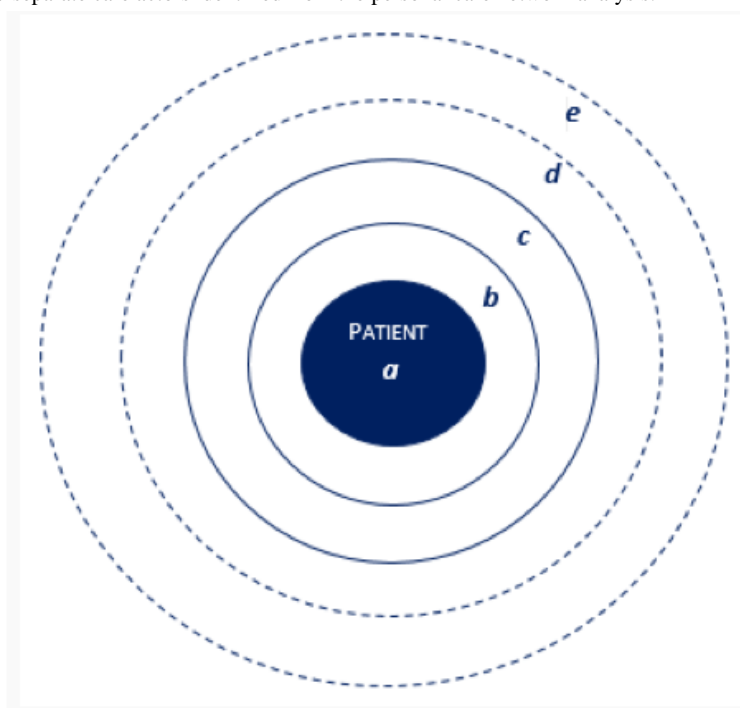
### Patients' Personal Care Network Experience

To help us understand patients' experience in terms of care navigation, we examined the functioning of these 5 main categories of actors in the PCN. We investigated the functioning of patients (1); GP practice (2); informal network (3); experts (4); and additional services (5) in terms of their roles and responsibilities.

#### *Patient: Self-Care, Disease Management and Assertive Communicator*

The interviews showed a strong sense of awareness among participants in terms of their own responsibility as a patient. Interviewees (n=7) pointed out how their own actions contributed to their health (physically) and well-being (mentally). From the interviews, 2 distinct types of behavior emerged—actions undertaken to remain as healthy as possible (self-care) and measures taken to control and manage one's LTCs (disease self-management).

**Figure 4.** Representation of the 5 separate care actors identified from the personal care network analysis.



Another element that emerged (3/7) was the need to find activities that were possible or adjustable to the interviewees' LTCs. One participant, in particular, found this a struggle.

*[...] go to the gym at least three times a week. And do euhm, we do aqua aerobics as that is all I can do, I can only do things in the pool. Because, because anything else is not good for arthritis. So yes, that's mainly what we do to stay healthy and try to eat healthy. [pp2]*

Two patients disclosed a mental health issue (ie, depression). However, all interviewees spontaneously stated the importance of self-care in terms of mental health (well-being), sometimes (n=2/7) even if that meant potentially going over their physical limit.

*[...] my responsibility is obviously to keep as healthy as possible, mentally and physically. [pp6]*

Self-care behavior also included seeking help from the actors in the PCN to, for example, prevent worsening of the situation.

In relation to disease self-management, interviewees emphasized their responsibility in terms of medication adherence, attendance of appointments, and daily monitoring of their conditions. Depending on LTCs participants were diagnosed with, disease self-management and self-care sometimes overlapped and at other times challenged one another.

Based on the experience, participants developed their own personal ways to practically manage their LTCs and the people involved in their PCN. The use of diaries to keep track of appointments was present in all interviewees (n=7). In addition, some (2/7) kept a log of the reason and outcome of appointments as well as their medication.

*Diary and yeah I've various things on my computer, like I have a medication list knowing what the*

*medication is for [...] I have, every time I go to the GP or go to the doctor or go to the to the hospital, I've a list of every time I've been. Because often when you go they'll say to you 'and when did you last do this?' and I was thinking I'll never going to remember so I actually got a log, I started it in 2008, every appointment I've ever been to. [pp2]*

Occasionally, 2 of the 7 patients mentioned that they felt as if they were not given the tools to keep track of their health and/or care.

*You know all this business with that they said they gonna let, you can access your medical record? But you can't! [pp4].*

The third main activity that arose across interviews was the patients' need to be assertive, determined, and proactive. Patients felt that the way the care system was set up required them to persevere in their navigation and deal with a number of complex barriers in accessing services, which could add frustration. The process involved in dealing with switchboards or finding the "right" person to talk to was found challenging.

*But if I hadn't sort of kept phoning them I probably would have been just struggling on my own. [pp7]*

*PP: It's like a minefield.*

*I: Mhm, how do you do that (navigation)?*

*PP: With difficulty, with difficulty... you know, you spend hours on the phone, press button A, press button B, number one for this, number nine for that, five for this... and all the while everything is a recorded, recorded answer, it's a program, everything is robotic, you don't speak to a person. It's a minefield, it's a battlefield trying to get through, you speak to one, "oh I can't deal with that I'll put you through to my colleague" and you explain everything*

*over again and then “oh no you need to speak to such and such” [...] and then I get frustrated because they’ve given me the wrong number. And so if they’re doing their job properly, again like I say there’s a right way and a wrong way. [pp4]*

Sometimes patients were left at a “loose end”; not having anything or anyone in place to follow-up on the situation. At other times, patients felt they were sent “backward and forward” across the system.

*[...] the other thing I expected from hospital and I kept asking for it. Is you know, some sort of physiotherapy type of thing [...] I was hoping that somebody somewhere would you know suggest physiotherapy or something. But there was absolutely nothing, you feel and this is why I had the mental health problem to start off with [...] And nobody was giving you any advice. [pp7]*

*[...] You then get a phone call from somebody on the switchboard, who then passes it on to somebody else, euhm, to a manager, to see you then, to see that you... you speak to the telephone person who then puts you on to somebody for, I I thought they were from the team, the safeguarding team but no they were only a receptionist that takes the minor details, who then passes you on to somebody else who you speak to then for an hour on the phone, who then says I will pass your details on to a line manager to see if you were a, a visit from a social worker so you tell the story to five people... and then you might have forgotten something which happened in the first place or... you could have added a bit on, do you know what I mean? [pp4]*

### **General Practitioner Practice: Gatekeeper and General Monitor**

GP practices were reported by participants, both in the interviews and questionnaires, to hold a central position in their PCNs. The interviews revealed that this central position was the result of and strengthened by 2 main roles—the GP’s “gatekeeper” role and their function as a general monitor of patients’ health.

All interviewees discussed the process of referral through GP practices, and the GP in particular. Access to different (health and social care) services in primary, secondary, and sometimes even third sectors care was gained through the GP. Exceptions to this were patients (partly) choosing to take the route of private care (2/7), but even then, the GP was often asked for information on services that could be approached.

*Yes, everything has to go through the GP, well not the dentist, but everything else goes through the GP surgery. [pp2]*

*I got in from our local general practitioner, a list of companies offering private auxiliary care help. [pp6]*

Apart from being the figure in charge of referral, providing access to other parts in the care system, the GP practice was also seen as the place to monitor patients’ general health. General check-ups were often scheduled ahead (eg, every 6

months) to keep an eye on patients’ LTCs such as diabetes. The disease-specific follow-up (if needed) did, however, not fall under the responsibility of the GP practice (see section on experts) according to the study participants.

### **Informal Network: Day-to-Day Support**

Drawing on the interview analysis, the informal network was reported to be the main source for patients’ day-to-day support. Depending on its structure (ie, solely family and friends or also including the wider community), roles and responsibilities of informal actors were shared differently and divided among those involved.

*[...] We are lucky at our bowls club because we have a restaurant and we have a bar, you know so it is very convenient. And this to me is that sort of care in the community is where people look out for each other you know? [pp1]*

Day-to-day support mainly involved practical and emotional support. Practical support, such as transportation, was often mentioned (n=5/7) when discussing the importance of family and friends.

*Sometimes use a friend of church for attending the doctor at surgery when I haven’t been able to drive myself [...] I have an address book and I try not to bother the people with surnames starting with ‘A’ too frequently (laughs). Which today we will stick the pin in the ‘W’s’ or the ‘S’s’ or the ‘C’s’ or...you know. [pp6]*

Second, friends (and sometimes the wider informal network) were a source of information. Information and advice were in particular sought in relation to “connections” friends might have access to and the patient (currently) did not.

It was noted that for advice on medical issues, participants were more inclined to rely on professionals than on informal actors.

*I don’t wanna bother them with things they can’t necessarily answer. I mean if effectively it’s a medical problem you need to see a doctor, don’t you? You don’t ask them...well apart from my friend whose daughter is a doctor so that sort of helps. [pp2]*

Third, family and friends played an important role in emotionally supporting patients by, for example, being an outlet to talk through acute episodes of LTCs or take their mind of the situation.

*Okay they haven’t got a title as such, but yeah without yeah, without partner and children yeah I don’t know if I would have actually got through the mental rather than the physical sort of thing. [pp7]*

Finally, immediate family and partners were frequently mentioned to provide informal (social) care. Informal actors often were the ones mentioned under the category “other” SOCC.

*Euhm, feeds me, I think the other aspect is that euh general hygiene of euh washing, ironing clothes and things like that...and euh, I mean general, generally*



*helps me and I imagine she helps me more than I help her. [pp6]*

### **Experts: Condition-Specific Needs**

The type(s) of experts involved in a PCN was dictated by the type of LTCs patients were diagnosed with. The role patients perceived experts to have, however, largely remained the same regardless of their specialism. According to the interviewees, specialists at the hospital were a source of disease-specific testing or monitoring and information.

*I have to go and have my heart check and see that I'm alright. And I spent a lot of time in the hospital I know my way around there as well. You know (laughs) because I have to go to the heart clinic, the chest clinic, the blood place and then anything else. I mean I am forever...X-Ray, I mean you know so yes I know the hospital quite well. [pp1]*

### **Third Sector, Private Care, and Organizations**

The fifth and final group that arose from the data was care provided by organizations, patient groups, etc. Third sector and charity organizations generally comprised services that were used as “substitutes” to health service care or ways to support needs that were not addressed elsewhere. As such, this group reflected a personalized addition to the PCN of patients with multimorbidity in accordance to their needs. Services included gardening and companies specialized in transportation for disabled patients.

Apart from substituting health service care, private care was also sought by patients that wanted timely advice or care.

*And sometimes I, the person that I've seen, there's a private physio, he's, if I want it done quickly. [pp2]*

## **Discussion**

### **Principal Findings**

Our results draw a picture of a spread out and at times fragmented care system particularly challenging individuals with multimorbidity because of the need to facilitate information exchange among multiple stakeholders. Communication with, and between, providers constitutes a central challenge in care navigation. Most importantly, our results show that patients rely on a broad network spanning informal and formal care providers and also on public and private stakeholders, introducing barriers that extend beyond information sharing.

The major factor leading to a satisfying navigation experience that resided within the control of patients was an assertive, determined, and proactive approach. The system, for example, did not always allow patients to see the same provider. The way the care system was set up required participants to persevere in their navigation and deal with a number of complex barriers to accessing services, which could add frustration. Many times, patients felt they were sent “backward and forward” across the system. The finding that the quality of care was essentially dependent on the determination and ability of individual patients may lead to inequitable care. Those with less determination and poorer organizational skills appear to receive worse care. Thus,

technology solutions must aim to fulfill these coordination functions, to ensure care is equitable for those who need it, not just those who ask loudest. Likewise, despite the significant role that informal caregivers play in the lives of patients with multimorbidity (eg, to facilitate attendance of appointments and support day-to-day care), many patients were aware of the burden they placed on these individuals involved in their care and were thus hesitant to place repeated demands on single individuals. While technology cannot solve some of the practical challenges of managing multiple LTCs, it can support patients in the management of their IC network, and possibly contribute to the reduction of informal caregiver burden by exploring how to effectively involve the wider community in care.

According to patients, the different parts of the care system formed separate entities. Smooth communication and interaction among different parts of the care system led to more satisfying navigation experiences. However, for many interviewees, it remained unclear whether this actually took place. Participants relied on their assumptions, as well as their experience, to judge this. On the level of provider-provider communication between colleagues, referral was mentioned as an indication that providers were interacting (eg, receiving copies of letters sent between providers) and was highly valued by patients. However, referrals do not include the extensive transfer of information; therefore, with an apparently limited crossover of information among professionals, it was frequently the patients' task to bridge and connect the different parts of the system. Interestingly, existing technology largely focuses on the management of single diseases; for older adults with multiple LTCs to benefit from technology that supports care navigation (eg, mobile apps or Web-based logging solutions), an integrated approach that considers the complexity of the situation of an individual, how they manage their conditions, and seek to involve other stakeholders is required.

### **Limitations and Future Work**

There are some limitations and opportunities for future work that arise from this study. Most importantly, the outcomes of our mixed-methods approach to requirements analysis needs to be further validated by putting our findings into action: designing and implementing a care navigation tool to support older adults with multimorbidity. Furthermore, future work needs to consider the nature of our findings; questionnaire data were obtained from participants residing in England, and follow-up interviews were carried out with geographical restrictions, suggesting that findings need to be interpreted in this light and need to be reproduced on a national or international level to account for differences between care systems.

### **Conclusions**

This study stands at the intersection of care and technology, understanding the experience of care navigation for older adults with multimorbidity, as a step toward building technology to facilitate this process. We demonstrate that a mixed-methods approach can deliver insights across the breadth and depth of the care navigation process and outline complexities that need to be considered by both researchers and designers. Moving beyond care navigation, the detailed level of insight provided by the SNA and framework analysis highlights one of the core



challenges for the human-computer interaction research in health care settings; while people see potential in the application of technology to care, they first and foremost want *better* care.

## Conflicts of Interest

None declared.

Multimedia Appendix 1  
Questionnaire.

[PDF File (Adobe PDF File), 1MB - [aging\\_v1i2e11054\\_app1.pdf](#)]

Multimedia Appendix 2

Interview schedule.

[PDF File (Adobe PDF File), 55KB - [aging\\_v1i2e11054\\_app2.pdf](#)]

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## Abbreviations

**GP:** general practitioner  
**HCC:** health care actors in the community  
**HCH:** health care actors at the hospital  
**IC:** informal care  
**LTC:** long-term condition  
**PCN:** personal care network  
**SNA:** social network analysis  
**SOCC:** social care actors in the community

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Original Paper

# Association Between Advanced Care Management and Progression of Care Needs Level in Long-Term Care Recipients: Retrospective Cohort Study

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## Abstract

**Background:** Long-term care insurance systems in Japan started a special senior care program overseen by qualified care managers (also known as advanced care managers). However, the relationship between advanced care management and outcomes in long-term care recipients remains unknown.

**Objective:** We aimed to compare the outcome of long-term care recipients using facilities with advanced care management and conventional care management, in terms of care needs level progression.

**Methods:** We conducted a retrospective cohort study using the Survey of Long-Term Care Benefit Expenditures in Japan. We identified those aged  $\geq 65$  years who were newly designated a care need level of 3, and received long-term care services between April 2009 and March 2014 in Tokyo. We compared survival without progression of care needs level between the groups, with and without advanced care management, using the Kaplan-Meier method. Factors affecting the outcomes were determined using a multivariable logistic regression model fitted with a generalized estimating equation.

**Results:** Of 45,330 eligible persons, 12,903 (28.46%) received long-term care based on advanced care management. The average duration of progression-free survival was 17.4 (SD 10.2) months. The proportions of five-year cumulative progression-free survival were 41.2% and 32.8% in those with and without advanced care management, respectively. The group with advanced care management had significantly lower care needs levels (odds ratio 0.77, 95% CI, 0.72-0.82,  $P < .001$ ).

**Conclusions:** Advanced care management was significantly associated with improved care needs levels.

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**KEYWORDS**

community health services, health services for the aged, integrated care, long-term care, patient care planning

## Introduction

In 2000, the Japanese government introduced Long-Term Care Insurance (LTCI) for the elderly, which provides welfare and health care services with comprehensive care management [1-3]. Eligible persons can receive a variety of services, such as nurses' visit, rehabilitation at home, bathing service at home, meal services at home, and rental service for welfare equipment [4-6]. Long-term care support specialists called "care managers" oversee the services provided by nurses, physical therapists, and professional caregivers [7-9]. The main tasks of care managers are: (1) assessing care needs and health problems of the elderly and their families; (2) coordinating care providers and designing long-term care service plans and care programs; and (3) monitoring and evaluating the long-term care service plans and care programs [10-11].

In 2006, the government introduced the higher-level position of "advanced care manager," who must have at least five years of experience as a care manager and are expected to design higher quality long-term care service plans and care programs [4,12]. In April 2009, the government began additional payments (also known as "care management premiums") for long-term care agencies with advanced care managers [13]. However, little is known about the effectiveness of this governmental policy and whether it has improved long-term care in Japan. Specifically, it remains unclear whether care coordination by advanced care managers is associated with improved outcomes of elderly persons. In the present study, we compared the progression of care needs levels of long-term care recipients with advanced care management and conventional care management, using a national long-term care database in Japan.

## Methods

### Study Design and Data Source

The study design was a retrospective cohort study. We used data from Japan's Ministry of Health, Labour and Welfare that was collected as part of the Survey of Long-Term Care Benefit Expenditures [14]. This national data set contained baseline characteristics and information on living arrangement, dementia, care needs levels (ranging from 1 to 5), type of long-term care services, type of long-term care agencies, and care managers in charge of care plans.

The targeted population was elderly persons, who were eligible for the LTCI services in Tokyo between April 2009 and March 2014. The study subjects were selected based on the following criteria: (1) persons of  $\geq 65$  years; (2) those who were newly designated a care needs level of 3; and (3) using long-term care service plans and care programs that were designed by care managers. Care needs level 3 indicates a moderate level of assistance required for everyday activities, such as standing, excretion, and bathing. We excluded individuals who were: (1) using in-home services for less than six months; and (2) not using in-home services for more than one month.

## Measurements

### The Outcome

The outcome of the present study was progression in care needs level. This was measured according to the criteria of "independence degree of daily living for the elderly," which was created by the government to assign elderly persons a score from 1 (less dependent) to 5 (more dependent) [1,4,6,15]. Care needs levels were normally reassessed every 12 months.

### Advanced Care Management

The advanced care manager system was introduced to improve quality of care management for long-term care recipients [4,12,16]. Advanced care managers must have more than five years of experience as a care manager [17,18]. The government started care management premiums for long-term care agencies with at least one advanced care manager under the LTCI in 2009 [13].

### Data Analysis

#### Progression-Free Survival Analysis

We used the Kaplan-Meier method and log-rank tests to compare survival without progression of care needs levels (ie, transition from care level 3 to 4 or 5) between the groups with and without advanced care management. The progression-free period was counted from the month participants received their care needs level 3 designation to the month care levels started to change, indicating a decline in health. Censoring criteria were: (1) no events, (2) hospital admission or nursing home admission, and (3) death during the study period.

#### Risk Factors

To examine risk factors associated with progression in care needs level, we used a logistic regression model fitted with a generalized estimating equation to account for the differences in follow-up period lengths. The dependent variable was the progression of care needs levels. The predictor variables included: (1) demographic variables (age, gender, and living alone); (2) dementia (level of independent living  $\geq 3$ ); and (3) type of agency with and without advanced care management. These variables were based on a previous study and existing knowledge of risk factors for the progression of care need levels [19]. The threshold for statistical analyses was set at  $P < .05$  in a two-tailed test. Statistical analyses were performed using Stata (version 14, Stata Corp, Texas, USA).

#### Ethical Considerations

Ethical considerations were examined in accordance with the Japanese epidemiological guidelines for secondary data analysis [20]. This study was approved by the Institutional Review Board at The University of Tokyo, Japan. The requirement for informed consent was waived because of the anonymized nature of the data in the database.

## Results

We identified 45,330 eligible people during the study period. The baseline information is shown in Table 1. The number of elderly people with and without advanced care management

were 12,903 (28.46%) and 32,427 (71.53%), respectively. The progression-free period lasted on average for 17.4 (SD 10.2) months. A total of 10,327 patients had an increased care needs level.

Figure 1 shows the progression-free survival curves in the groups with and without advanced care management. The proportions of five-year cumulative progression-free survival in the groups with and without advanced care management were 41.2% and 32.8%, respectively ( $P < .001$ ). The hazard ratios of

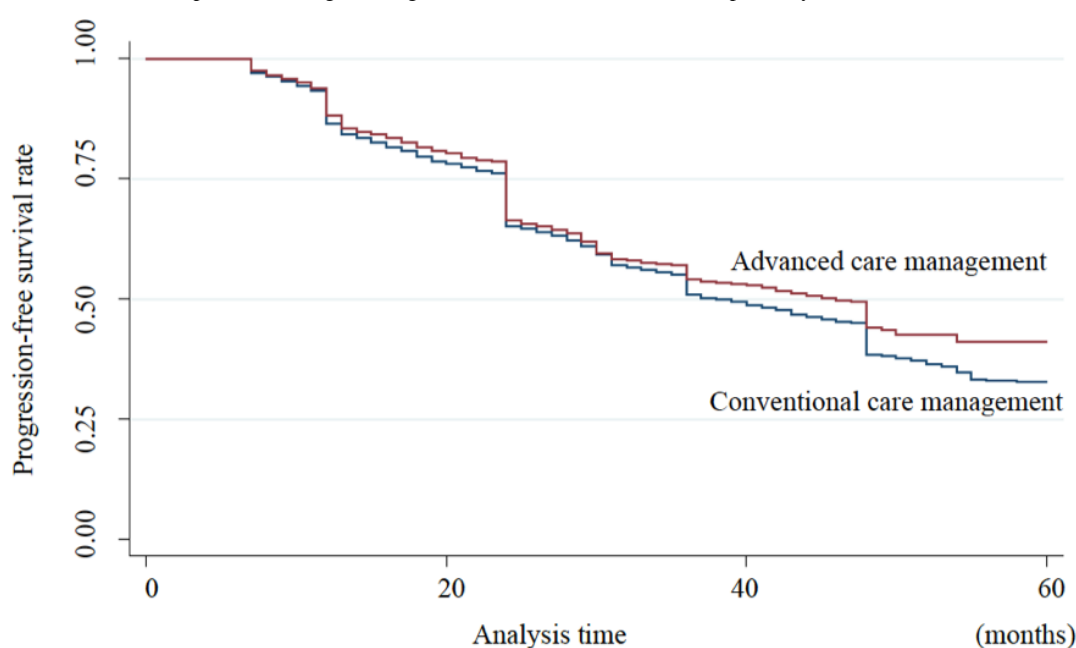
the groups were not constant over the study period, having changed at the regular reassessment months (eg, 6, 12, 24, 36, and 48 months).

Table 2 summarizes the risk factor analysis indicating that those with advanced care management were significantly less likely to experience increasing levels of care (odds ratio [OR] 0.77, 95% CI 0.72-0.82,  $P < .001$ ). Age was significantly associated with progression of care needs level (OR 1.01, 95% CI 1.01-1.02,  $P < .001$ ).

**Table 1.** Study population treated in long-term care agency in 2009-2014. A total of 29,815,241 receipt data were analyzed in 45,330 patients during the analysis for 5 years.

Variable	Value
<b>Elder person characteristics</b>	
Age (years), mean (SD)	82.7 (7.83)
<b>Gender, n (%)</b>	
Male	17,113 (37.75)
Female	28,217 (62.25)
<b>Living alone, n (%)</b>	
Yes	6465 (14.26)
No	38,865 (85.74)
<b>Dementia, n (%)</b>	
Level of independent living $\geq 3$	11,262 (24.84)
Other	34,068 (75.16)
<b>Agency characteristics, n (%)</b>	
<b>Types of management</b>	
Advanced care management	12,903 (28.46)
Conventional care management	32,427 (71.54)

**Figure 1.** The Kaplan-Meier method for care level progression. Analyzing care level change in 45,330 patients showed that the 5-year cumulative progression-free survival rate of the special and the general agencies were 41.2% and 32.8%, respectively.





**Table 2.** Risk factor analysis for care level progression using a generalized estimating equations model. The generalized estimating equations model showed that age and dementia were risk factors associated with care level progression. Advanced care management and living alone reduced the risk for deterioration of care levels.

Variable <sup>a</sup>	Odds ratio (95% CI)	P value
Age (years)	1.01 (1.01-1.02)	<.001
Gender (female)	1.04 (0.99-1.08)	.13
Living alone (yes)	0.81 (0.76-0.87)	<.001
Dementia (yes)	1.40 (1.33-1.47)	<.001
Type of management (advanced care management)	0.77 (0.72-0.82)	<.001

<sup>a</sup>All variables were entered into the statistical analysis (forced entry).

## Discussion

### Primary Findings

We found that elderly persons with advanced care management were significantly less likely to experience care needs level progression than those without it. Previous small studies suggested that advanced care managers could appropriately assess and care for elderly persons based on their extensive experiences [21,22]. They could combine a variety of care services efficiently and design them suitably due to their extensive knowledge of the subject. They were also more likely to coordinate care teams effectively with their vast experience in long-term care. Therefore, the advanced care managers can improve care service plans and programs, which may have a meaningful impact on the outcomes of older persons.

Furthermore, agencies with advanced care managers can provide better educational environments than those without, since one of their basic duties of these professionals is training and supporting other care managers [21,23]. We believe such an educational environment may have an impact on the outcomes discussed in this paper. Further studies are needed to assess this.

In our risk factor analysis, age and dementia were risk factors for the progression of care needs levels. These results were consistent with those in previous studies [24-26]. Studies conducted in other countries also identified age and dementia as major risk factors for the deterioration of functional levels amongst the elderly [27-29]. Regarding the hazard ratio in the progression-free survival analysis, we noted ratio changes in both groups at the regular reassessment months. It is possible that some older adults did not apply for the reassessments when their functional and psychosocial statuses deteriorated seriously. Additional research focusing on the reassessments is needed.

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### Conflicts of Interest

None declared.

### Policy Implications

The care management premiums for advanced care management was introduced to enhance health care service quality and improve outcomes [13]. Without any evidence for the efficacy of this policy, there has been on-going discussions about additional preferential treatment for long-term care agencies with advanced care managers [30]. Although our study did not analyze the direct effect of this policy, we believe additional preferential treatment for advanced care management may be useful for improving health care among the elderly.

### Study Limitations

Our study has several limitations. First, because the present study was based on an observational design, there may have been unmeasured confounding factors that could have affected the progression of care needs levels. The national survey did not capture diagnosis, medications, family history, educational status, living status, or living areas in Tokyo. To investigate the effects of these factors, it would be important to reassess the data of individual recipients in the future. As for demographic characteristics, a previous report showed similar demographic characteristics across agencies [31]. Second, our findings may not be generalized to other countries.

### Conclusion

The present study used a national long-term care database to show that elderly persons utilizing advanced care management had a lower probability of deteriorating health (eg, progression of care needs levels). Our findings suggest that advanced care management may be effective for improving the outcome of long-term care recipients.

## Multimedia Appendix 1

Flow diagram (45,330 eligible people identified during the study period).

[PDF File (Adobe PDF File), 166KB - [aging\\_v1i2e11117\\_app1.pdf](#)]

## Multimedia Appendix 2

Study population treated in long-term care agency in 2009-2014 by type of care management.

[PDF File (Adobe PDF File), 63KB - [aging\\_v1i2e11117\\_app2.pdf](#)]

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## Abbreviations

**LTCI:** Long-Term Care Insurance

**OR:** odds ratio

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Original Paper

# Usability and Acceptability of a Home Blood Pressure Telemonitoring Device Among Community-Dwelling Senior Citizens With Hypertension: Qualitative Study

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## Abstract

**Background:** Hypertension is a major cause of cardiovascular disease in older individuals. To ensure that blood pressure (BP) levels are within the optimal range, accurate BP monitoring is required. Contemporary hypertension clinical practice guidelines strongly endorse the use of home BP measurement as a preferred method of BP monitoring for individuals with hypertension. The benefits of home BP monitoring may be optimized when measurements are telemonitored to care providers; however, this may be challenging for older individuals with less technological capabilities.

**Objective:** The objective of this qualitative study was to examine the usability and acceptability of a home BP telemonitoring device among senior citizens.

**Methods:** We conducted a qualitative descriptive study. Following a 1-week period of device use, individual, semistructured interviews were conducted. Interview audio recordings were anonymized, de-identified, and transcribed verbatim. We performed thematic analysis on interview transcripts.

**Results:** Seven senior citizens participated in the usability testing of the home BP telemonitoring device. Participants comprised females (n=4) and males (n=3) with a mean age of 86 years (range, 70-95 years). Overall, eight main themes were identified from the interviews: (1) positive features of the device; (2) difficulties or problems with the device; (3) device was simple to use; (4) comments about wireless capability and components; (5) would recommend device to someone else; (6) would use device in future; (7) suggestions for improving the device; and (8) assistance to use device. Additional subthemes were also identified.

**Conclusions:** Overall, the home BP telemonitoring device had very good usability and acceptability among community-dwelling senior citizens with hypertension. To enhance its long-term use, few improvements were noted that may mitigate some of the relatively minor challenges encountered by the target population.

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**KEYWORDS**

blood pressure; telemonitoring; community-dwelling; qualitative

## Introduction

Population aging is occurring in countries across the world at a rate that by 2050, nearly 25% of the global population is expected to be over the age of 60 years [1]. Advanced age is often complicated by cardiovascular morbidity, which frequently leads to disability and death [2]. Hypertension is a major cause of cardiovascular disease in older individuals [3,4], but senior citizens also derive greater benefits from treatment of elevated blood pressure (BP) than younger patients [5,6]. The management of hypertension in senior citizens can be challenging and must balance the risk of treatment-related serious complications (including hypotension, postural dizziness, syncope, falls, and metabolic side effects) [3,7-9] against the well-established cardiovascular benefits associated with BP lowering.

To ensure that BP levels are within the optimal range, accurate BP monitoring is required. Contemporary hypertension clinical practice guidelines strongly endorse the use of home BP measurement as a preferred method of BP monitoring for individuals with hypertension [10]. The benefits of home BP monitoring may be optimized when measurements are telemonitored to care providers [11,12]. BP telemonitoring involves the electronic and secure transmission of BP readings in real time to a central electronic health care portal, with summarized BP data presented to patients and providers. Through process automation and protocolization, BP telemonitoring can ensure that home BP monitoring is performed in a guideline-concordant manner, ensuring the proper frequency and timing of BP measurements [12]. Telemonitoring theoretically could eliminate the need for an in-person clinic visit, thereby increasing health care delivery efficiency, minimizing costs, and making the use of provider and patient time more efficient [12]. A meta-analysis of 23 randomized controlled trials (RCTs; 7037 patients) reported that home BP telemonitoring reduced BP by 5/3 mm Hg compared with usual care ( $P < 0.0001$  for both systolic and diastolic BP) [13]. This is a clinically important reduction in BP, as a 5-mm Hg reduction can decrease the risk of total cardiovascular disease by 17%, stroke by 18%, and myocardial infarction by 15% [14,15].

Adoption of telemonitoring will only occur if the process and technology are deemed usable and acceptable by patients and caregivers. Use of home BP telemonitoring may be particularly challenging in senior citizens, who, by virtue of being less technologically literate, may have greater difficulty using a telemonitoring device. Therefore, the purpose of this qualitative study, embedded within an ongoing RCT (trial registration Clinicaltrials.gov NCT02721667) examining the clinical and cost-effectiveness of telemonitoring among community-dwelling senior citizens with hypertension [16], was to examine the usability and acceptability of a home BP telemonitoring device within this particular patient population.

## Methods

### Study Design

A qualitative descriptive study was conducted [17,18] embedded within an RCT comparing BP telemonitoring plus pharmacist

case management with usual care to optimize BP control among senior citizens residing in supportive living. Half of the study sample will receive home BP telemonitoring, with measurements telemonitored to a pharmacist case manager, who will provide guideline-concordant, protocolized antihypertensive medication adjustment. Patients in the usual care arm will receive a home BP monitor that they can use to record their BP, but neither they nor their providers will receive access to telemonitored measurements or pharmacist case management. They will be asked to follow-up with their regular care providers as needed. A protocol paper has been published [16]; the most updated protocol can be found on clinicaltrials.gov (NCT02721667). The University of Alberta Research Ethics Board approved the study.

### Study Population

Participants were community-dwelling senior citizens (aged  $\geq 65$  years) with hypertension residing in a supportive living residence. The target sample size for this qualitative study was 5-8 participants based on a prior research demonstrating that the first 4-5 users typically identify 80% of all usability problems, including the most severe usability issues; beyond this, a higher sample size has low incremental yield as data saturation has been reached [19].

### Data Collection

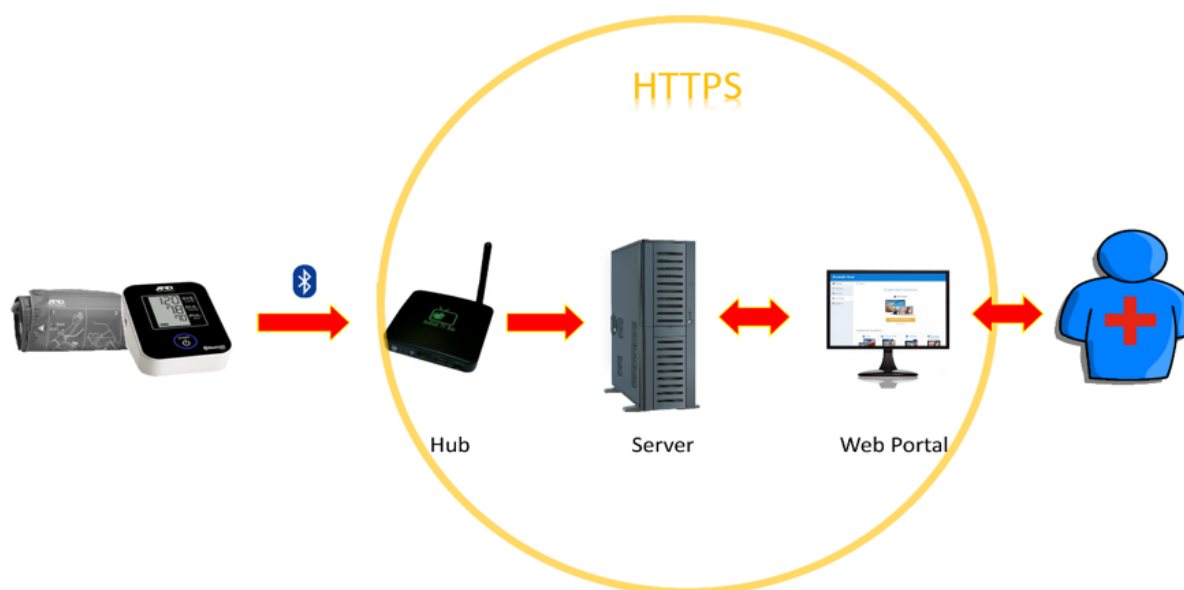
Participating senior citizens were instructed to use the home BP telemonitoring device and perform all measurements according to the recommended techniques for home BP measurement. To activate the device, the subject was required to initiate a BP measurement by pressing the appropriate device button. The remainder of the process was automated. Four measurements were taken daily (ie,  $2 \times$  am,  $2 \times$  pm) for 1 week [10]. Following this period of device use, participants completed individual, semistructured interviews (Multimedia Appendix 1) to obtain usability and acceptability information, probe participants' responses, and give participants freedom to respond and illustrate concepts in an open-ended fashion [20]. The interviews were conducted in-person and were audio recorded. Audio recordings were anonymized, de-identified, and transcribed verbatim.

### Telemonitoring System

The custom-built Technomed telemonitoring system consists of 5 components: (1) a commercially available, Bluetooth-enabled oscillometric BP monitor (A&D Medical UA-651BLE, supplied with cuff size medium [23-37 cm, UA-290] or large [31-45 cm, UA-291]); (2) a data transmission hub (Lamprey Networks Inc.); (3) a Web portal interface (Teled Diagnostic Management Inc); (4) an android-based interface for hub programming (Advanced Man Machine Interface Laboratory, University of Alberta); and (5) in patients with no existing internet access, a selectively deployed (based on home internet availability) Subscriber Identity Module (SIM)-based internet hotspot. Prior to operation, the system is set up by connecting the hub to the internet (hotspot or home internet), assigning a patient identification using the android app, and creating a patient profile on the Web portal.



**Figure 1.** System flowchart for Technomed telemonitoring blood pressure system. HTTPS: hypertext transfer protocol secure.



### Blood Pressure Measurements

Once the system is set up, the patient is instructed to follow the 7-day series BP protocol initiated by performing a measurement using the A&D device. This measurement is sent to the Web portal via the Bluetooth-connected hub (Figure 1). The data are summarized in a variety of formats including individual readings, averages (mean of all readings minus the first day, as recommended by current guidelines) [10], and graphed values to depict temporal trends. The case manager uses these data to adjust the patient's BP medication (uptitrate if BP is too high, downtitrate if BP too low, or leave unchanged if BP is within the optimal range).

### Data Analysis

Interview transcripts were managed and analyzed using NVivo data management software [21]. Thematic analysis was used to break interview text into small units for a detailed, nuanced account of the data [22-24]. Thematic analysis was guided by the hybrid approach of inductive and deductive coding and theme development described by Fereday & Muir-Cochrane

[25]. Deductive coding of the interview transcripts was done first using the semistructured interview guide as a framework; smaller units of data that emerged inductively were coded for increased granularity and specificity.

## Results

### Sample Demographics

Seven senior citizens participated in the usability testing of the home BP telemonitoring system from November 2016 to June 2017. Participants comprised females (n=4) and males (n=3) with a mean age of 86 years (range 70-95 years). Additional demographics are summarized in Table 1. The mean baseline home systolic BP of the 7 participants was 131 mm Hg (range 99-181 mm Hg) and the mean diastolic BP was 71 mm Hg (range, 47-125 mm Hg).

### Themes

Overall, eight main themes were identified and two main themes were further classified into subthemes for increased granularity and specificity (Table 2).

**Table 1.** Participant demographics.

Participant number	Sex	Age (years)	Partnered or single	Caregiver providing assistance (yes or no)	Notes
1	Male	89	Single	No	N/A <sup>a</sup>
2	Female	89	Single	No	N/A
3	Female	70	Single	No	Reported visual impairment
4	Male	86	Partnered	Yes	Reported hearing impairment
5	Female	91	Single	No	Reported mild dementia
6	Female	80	Partnered, lived alone	No	N/A
7	Male	95	Single	No	N/A

<sup>a</sup>N/A: not applicable.

**Table 2.** Main themes and subthemes

Main themes and subthemes	Number of interviews theme is referenced in	Number of overall references for theme
<b>Positive features of the device</b>	7	35
General positive comments about device	6	15
<b>Specific positives about device</b>	7	20
Cuff was appropriate	6	12
Start button worked well	6	7
Display screen worked well	3	3
No bruising after device use	1	1
<b>Difficulties or problems with device</b>	7	28
No difficulties or problems with device	2	2
General difficulties or problems with device	1	1
<b>Specific difficulties or problems with device</b>	7	25
Issues positioning and securing cuff	5	8
Cuff too large for arm	3	8
Knowing or remembering when to take blood pressure measurements	3	7
Error messages on display screen	2	4
Battery issues	1	2
Device was simple to use	6	16
Comments about wireless capability and components	6	8
Would recommend device to someone else	7	8
Would use device in future	6	6
Suggestions for improving the device	5	5
Assistance to use device	1	1

**Table 3.** Specific positive features of the device.

Feature	Description	Supporting quote from interview
Cuff was of appropriate tightness	All participants described the cuff to be of appropriate tightness. It only caused minimal pain for a short duration (ie, when the cuff was fully inflated), similar to other blood pressure cuffs they had used in the past.	<i>Participant: No, I think it was just right.</i> <i>Interviewer: Good, okay.</i> <i>Participant: Cause it didn't bother me that much. But it bothered me a little bit. [Laughing] [Participant 5]</i>
Start button worked well	Six participants noted that the start button was large enough to locate, easy to press to activate reading, and did not stick.	<i>But, yeah. So, other than that, it's...it's easy to use. The start and-and the stop. And, I mean, it's quite simple. [Participant 6]</i>
Display screen worked well	Three participants described the display screen as large enough and easy to read, even for those with visual impairments.	<i>Participant: Um...well, I-ah, I mean you know, it's um, it's got a...like, I'm legally blind.</i> <i>Interviewer: Okay.</i> <i>Participant: And-and so I-I have about 12 percent vision. So I mean, for me, like it-[stammers] it's ah-the-it's quite clear on the-on the screen and that. [Participant 3]</i>
No bruising after device use	One participant noted that he or she had no bruising after using the device.	—

## Theme Descriptions

### *Positive Features of the Device*

The interview guide included questions to ascertain the positive features of the device and elicit what worked for the participants.

A range of answers were given. These fell into 2 subthemes: (1) general positive comments about the device and (2) specific positive features of the device.

For the first subtheme, 6 participants described the device in general positive terms, including stating it “worked well” and “was a very good set-up.” All participants provided specific feedback on positive features of the device (subtheme 2). These fell into 4 subcategories: (1) cuff was of appropriate tightness; (2) start button worked well; (3) display screen worked well; and (4) no bruising after device use. These subcategories are described in detail in [Table 3](#).

### ***Difficulties or Problems With the Device***

The interview guide included questions to ascertain whether there were any difficulties or problems using the device. A range of answers were given. These fell into 3 subthemes: (1) no difficulties or problems with the device; (2) general difficulties or problems with the device; and (3) specific difficulties or problems with the device.

For the first subtheme, in response to a general question, 2 participants indicated that there were no difficulties or problems using the device. For the second subtheme, 1 participant indicated that using the device was “a little bit awkward” but that once you practice a few times, it worked well. However, all 7 participants identified specific difficulties or issues with the device (subtheme 3). These concerns fell into 5 subcategories: (1) issues positioning and securing cuff; (2) cuff too large for the arm; (3) knowing or remembering when to take BP measurements; (4) error messages on display screen; and (5) battery issues. These subcategories are described in detail in [Table 4](#).

### ***Device Was Simple to Use***

All 7 participants felt that the device was simple and straightforward to use, as demonstrated by the following conversation:

*Interviewer: So, did you find the device simple, to use?*

*Participant: Oh, yeah.*

*Interviewer: Yeah?*

*Participant: Yeah, I did. Yes.*

*Interviewer: And there was noth-was there anything about it that maybe was a bit tricky at first?*

*Participant: No, not-ah, not really. If you just followed the instructions, ah...the-all you gotta do is push the button and it-it goes, you know.*

*Interviewer: Yeah [laughing].*

*Participant: You don't have to figure it out. It's not like you're doing ah...puzzle or something like that. Ah...*

*Interviewer: Very true.*

*Participant: No, not at all. [Participant 1]*

### ***Comments About Wireless Capability and Components***

Six participants commented on the wireless technology aspect of the system. Overall, the participants knew that study staff had plugged in 1 or 2 peripheral devices to assist with the operation of the BP device, but they did not know what the peripheral devices did; they did not touch these pieces during their week of using the device.

### ***Would Recommend Device to Someone Else***

All participants indicated that they would recommend this device to someone else if they needed regular BP monitoring.

### ***Would Use Device in Future***

Six participants indicated a willingness to use this device in the future if their condition required regular BP monitoring.

### ***Suggestions for Improving the Device***

Two participants indicated that no improvements were needed in the BP device. One participant suggested that a helpful improvement would be a signal from the device to indicate when to take a BP measurement and another indicated that some form of feedback from the device to know whether the device was positioned and secured properly would be helpful. A third improvement would be decreased tightness of the cuff, if possible.

### ***Assistance to Use Device***

One participant required some assistance from his or her spouse to use the device. The spouse did not assist during the morning BP readings and assisted only during the afternoon or evening readings. The spouse helped to secure and position the device for the participant because it was difficult to do so with one hand.

**Table 4.** Specific difficulties or problems using the device.

Feature	Description	Supporting quote from interview
Issues positioning and securing cuff	Five participants found the cuff difficult to position and secure on the arm. This was largely an issue of having enough dexterity to pull the fabric tight and wrap it around the arm with only one hand. Participants indicated that while pulling and fastening, the cuff would slide back and forth, and the participants were unsure if it was properly placed on the arm. Participants used the crook of the elbow as well as the dot on the cuff as helpful guides but did not feel it was optimal.	<p><i>Participant: And so, then you-[stammers] you're trying to tighten it. And then you put your-in the meantime, you're struggling to try and get it...</i></p> <p><i>Interviewer: I see, yeah.</i></p> <p><i>Participant: ...and so you think, "Okay, can I pull it with this? No, that's not gonna work." So...I don't know how-and then, you raise your blood pressure trying to...</i></p> <p><i>Interviewer: [Laughing] I see, yes.</i></p> <p><i>Participant: To-to do that.</i></p> <p><i>Interviewer: Kind of a catch-22. [Participant 6]</i></p>
Cuff too large for arm	Three participants found that the cuff was too large and the extra material was cumbersome to manage with a single hand while securing the cuff.	<p><i>Participant: Yes. And the thing just slithered around. So it was not a good fit.</i></p> <p><i>Interviewer: Okay.</i></p> <p><i>Participant: It was a terrible fit.</i></p> <p><i>Interviewer: It was-</i></p> <p><i>Participant: A terrible choice.</i></p> <p><i>Interviewer: Too baggy?</i></p> <p><i>Participant: Oh, yeah.</i></p> <p><i>Interviewer: Yeah.</i></p> <p><i>Participant: I should have had a small cuff.</i></p> <p><i>Interviewer: Okay.</i></p> <p><i>Participant: They always use a small cuff on me at the...[chuckling] when I go to the doctor. [Participant 2]</i></p>
Knowing or remembering when to take blood pressure (BP) measurements	Five participants expressed uncertainty about knowing or remembering when to take the BP measurements. For one participant this meant forgetting to take two measurements at one time, and for the other 2 participants, this meant taking readings at different times than directed.	<p><i>Participant: Yes, but that was-trying to figure out that it was the right time.</i></p> <p><i>Interviewer: Uhum.</i></p> <p><i>Participant: You know, 10 to 12 hours apart. And I wasn't right in getting that every time.</i></p> <p><i>Interviewer: Uhum.</i></p> <p><i>Participant: I was a little bit...too short or too long, I'm not quite sure which. [Participant 5]</i></p>
Error messages on display screen	Two participants experienced error messages on the display screen. When an error message appeared on the device, both participants attempted to take another BP reading and repeated this process until it worked and a reading was displayed, which resulted in slight confusion.	<p><i>Participant: Ah, yeah. If I had an error message, I'd just...put-push the stop but-button, and push the Start again.</i></p> <p><i>Interviewer: Okay. And that worked?</i></p> <p><i>Participant: Uhum.</i></p> <p><i>Interviewer: Okay. Well, that's good.</i></p> <p><i>Participant: Yeah.</i></p> <p><i>Interviewer: Was it a little bit frustrating?</i></p> <p><i>Participant: Ah...oh, I was beginning to wonder if I'm doing it right.</i></p> <p><i>Interviewer: Yeah.</i></p> <p><i>Participant: Is there-is it my fault that it's getting the error message? I don't think so. But it might have been. [Participant 7]</i></p>
Battery issues	One participant experienced a battery issue with the device and did not know how to resolve it. The participant called study staff to resolve the issue; study staff replaced the battery, and the participant continued to use the device.	—

## Discussion

### Principal Findings

The purpose of this qualitative study, conducted concurrently with an RCT, was to assess the usability and acceptability of the home BP telemonitoring device among community-dwelling senior citizens with hypertension. Previous research has shown that 65% of the population aged  $\geq 65$  years would like to keep up-to-date with technological advancements, which includes health apps [26]; however, at present, there is a dearth of information on the unique needs and demands of senior citizens using medical devices at home [27]. In line with the results of a research conducted by Ehmen et al in which they concluded that mobile devices for measuring heart rate and electrocardiography were well accepted by participants aged  $\geq 55$  years [27], we hypothesized that participating senior citizens in this study would rate the home BP telemonitoring device as user friendly, acceptable, and useful for hypertension management. This hypothesis was supported by the study findings. However, a few issues were identified and potential solutions were explored in order to optimize device functionality and its successful future use.

One unique aspect of our study in comparison to prior studies is the advanced age of the participants (average age, 86 years). However, despite this difference, it is worth noting that our findings of high patient acceptability are consistent with the existing qualitative literature assessing patient views on BP telemonitoring systems [28-31]. Other studies have also included care providers in the qualitative assessment and have reported that while caregivers are generally supportive of the concept, they are concerned about the time required to view and act on telemonitored readings [30,31]. This underscores the need to develop systems and protocols that minimize provider time and replace (instead of adding to) existing workloads.

### User-Friendliness of the Device

In this study, all participants described the device as simple and straightforward to use. Specifically, the start button was large enough and easy to engage and the display screen was legible, even for those with visual impairments. This demonstrates that the design of this home BP telemonitoring is suitable for senior citizens of advanced age. Device acceptability and usability was enhanced by building a telemonitoring system that depended only on activating the home BP monitor. The remainder of the data transmission performed through communication between the monitor and the hub, and the hub and the cloud, was performed automatically. The fact that the monitor itself has been designed according to regulatory requirements and standards enhanced the probability that the users would find it usable and acceptable, as long as they were not required to perform additional steps besides activating a measurement.

Conversely, all participants identified one or more difficulties related to using the device. Specific issues were noted regarding the design and application of the BP cuff component. For example, it was described as being too large, having cumbersome extra material when pulled tight, and being difficult to place and secure with one hand. These concerns may be related to the features of normal, age-related decline in

psychomotor skills, including dexterity and hand-eye coordination [32]; however, it is critical to optimize the design by addressing these concerns to overcome the barriers to implementation and successful adoption of home telemonitoring technology.

Apart from the BP cuff component, participants noted that error messages on the display screen were confusing, and one participant did not know how to manage the device when the batteries ran out. While these issues are seen as normal features, albeit limitations, of current technology, older adults are more affected by the distracting context, including unfamiliar or unexpected error messages, making it challenging to perform concurrent tasks, including changing batteries at the same time as taking a BP measurement [32]. These challenges are related to cognitive load, and previous research has suggested that an initial facilitated learning experience, supplemented with support materials, can be used to train senior citizens in proper use and functioning of the device and to resolve any potential errors or issues that may arise [27].

An issue that arose that was peripheral to the BP device itself was the lack of understanding of the wireless technology required to enable the telemonitoring aspect of this system. Six of 7 participants had little awareness of the relevant technology. Participants knew, in general, that the hub assisted with the operation of the telemonitoring system, but they were not clear on specific functions and did not touch or interfere with these components during their week of using the device. This finding is not surprising as consumers often lack understanding of the inner workings of commonly used technologies such as mobile phones and computers, but this lack of knowledge does not preclude the use of these devices. In fact, rather than having an intimate understanding of how the technology works, it is more important that users have access to assistance with troubleshooting if the device is not working properly. Thus, it is important that telemonitoring system vendors provide such assistance.

### Acceptability and Usefulness of the Device

As proxies for the acceptability and usefulness of the device, participants were asked if they would use the device in the future and if they would recommend this device to a friend. All 7 participants indicated that they would recommend this device to a friend in need of regular BP monitoring. The majority ( $n=6$ ) indicated a willingness to use this device in the future if their health status required regular BP monitoring.

### Recommendations for Future Developments

It is worthwhile noting two specific factors that may influence future, appropriate use of this home BP telemonitoring device. First, 5 of 7 participants indicated some difficulty knowing when and how often to take measurements with the device. This could be addressed in both high- and low-tech approaches. For example, a high-tech solution could be a programmable device feature of either an audible signal or visual aid when it is time to take BP measurements. This is the advantage that mobile phone-connected strategies provide; however, these are not appropriate for populations with limited technology literacy. A low-tech solution could be to provide written, supporting



information, like a daily calendar containing these details. For 5 out of 7 of participants, detailed instructions were provided as part of the “study pack”; this may indicate that the provided information was not formatted optimally to disseminate operational instruction. The high-tech improvement (ie, a signal from the device) was suggested by a participant during the interview and would likely be acceptable to users.

Second, a number of participants indicated uncertainty about whether they were using the device properly. Other than the potential for an error message on the display screen, the device did not have the capacity to provide patients with feedback as to whether the device was properly positioned and secured for optimal readings or if the readings were being properly transmitted through the wireless connection. This concern was noted by a participant when asked about suggestions for improvement. Additionally, there was no explanation of the error messages. When these warnings occurred, participants repeatedly attempted to take additional BP readings until the error message disappeared. It could be worthwhile to explore

whether real-time feedback could be incorporated into the machine, which could include a written message on the display, an auditory message (voice, beep, etc) from the device, or a sensory message (squeeze, vibration, etc) in the cuff. This functionality may be especially important for successful, long-term use as the majority of participants lived alone and did not have any caregiver assistance to use the device.

## Conclusion

Overall, the home BP telemonitoring device had very good usability and acceptability among community-dwelling senior citizens with hypertension. This was illustrated by all participants indicating willingness to recommend this device to a friend and 6 of 7 participants stating they would use this device in the future. Additionally, all participants found the device to be simple and straightforward to use. To enhance its long-term use, a few improvements were noted that may mitigate some of the relatively minor challenges encountered by the target population.

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## Conflicts of Interest

RP is a director of a start-up company, mmHg Inc, focusing on innovations in blood pressure measurement.

Multimedia Appendix 1

Semistructured interview guide.

[[PDF File \(Adobe PDF File\), 25KB - aging\\_v1i2e10975\\_app1.pdf](#)]

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## Abbreviations

**BP:** blood pressure

**RCT:** randomized controlled trial

**SIM:** Subscriber Identity Module

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Original Paper

# Ambient Assisted Living as Support for Aging in Place: Quantitative Users' Acceptance Study on Ultrasonic Whistles

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## Abstract

**Background:** Given the fact of an aging society, new supply measures and living concepts are needed, especially as health impairments along with care dependency increase with age. As many elderly people wish to stay at home for as long as possible, ambient assisted living (AAL) represents a support for aging in place.

**Objective:** AAL combines medical and care technology within living environments and is, therefore, a promising approach to cope with demographic change in terms of fast-growing care needs and fewer skilled workers. Ultrasonic whistles represent one innovative technical possibility for such supportive housing solutions. Central fields of application are home automation, emergency service, and positioning. As AAL technologies affect sensitive areas of life, it is of great interest under which conditions they are accepted or rejected, taking individual user requirements into account. Hence, the aim of this study was to investigate users' perception and evaluation of ultrasonic whistles.

**Methods:** In this study, we examined the acceptance of ultrasonic whistles in home care by function and room using a Web-based questionnaire. Besides an evaluation of the overall usefulness, we focused on the intention to use ultrasonic whistles; 270 participants assessed home automation, emergency service, and positioning as specific functions of ultrasonic whistles. Furthermore, bathroom, bedroom, and living room were evaluated as specific usage locations (rooms). With regard to the user's perspective, the focus was set on age and attitudes toward aging of care receivers.

**Results:** This study revealed a significant influence of function ( $F_{2,269}=60.444$ ;  $P<.001$ ), room ( $F_{2,269}=41.388$ ;  $P<.001$ ), and the interaction of function and room ( $F_{4,269}=8.701$ ;  $P<.001$ ) on the acceptance of ultrasonic whistles. The use of emergency services within the bathroom represented the most accepted alternative, whereas positioning within the living room received the comparably lowest evaluations. Although user diversity played a minor role for acceptance overall, the assessment of single applications differed among user groups, particularly with regard to age differences ( $F_{20,500}=1.988$ ;  $P<.01$ ) in the evaluation of specific installation options such as automated doors.

**Conclusions:** The study revealed profound insights into the user-centered assessment of ultrasonic whistles in home care and discovered function and room as influencing acceptance parameters. Concerning user characteristics, age, and attitude toward aging partly affected these evaluations, forming the basis for and showing the importance of further investigations in this context.

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**KEYWORDS**

ambient assisted living; technology acceptance; user diversity; ultrasonic whistles; aging in place

## Introduction

### Background

Against the background of demographic change, today's society is affected by global shifts in population structure [1]. In Germany, for example, less young and a rising number of elderly people pose serious challenges, especially for health care [2]. Although better living conditions and medical progress extend life expectancy, the risk for health impairments increases with age [2]. In addition, chronic diseases (eg, diabetes) place new demands on the health care system [3]. Thus, nursing services face a growing amount of care-dependent people leading to shortcomings in the care supply [4]. As a consequence, it is observable that the majority of people in need of care are supplied with health services provided by relatives at home [5]. Hence, concepts referring to aging in place have become more important [6].

In this context, ambient assisted living (AAL) technologies and systems offer great potentials to simplify and enhance everyday life for both sides, patient and (family) caregiver, by means of technology assistance [7]. This refers to either individual devices (eg, stair lifts) or integrated systems (such as fall alarm systems). In addition, considering that many elderly people do not want to move out of their home [8], AAL technologies provide reliable prevention and rehabilitation measures to live independently despite physical or mental restrictions [7]. According to this, ultrasonic whistles—a specific technology to be used in supportive housing solutions (smart homes)—come up with new technical possibilities to support aging in place that are flexible in their application, retrofittable, cost-effective, and eco-friendly. The final ultrasonic whistle will be tiny and, thus, can be fitted in various places within the living environment such as furniture, textiles, or portable equipment on the body. Realizing an interconnectivity of infrastructure, major functions are home automation (eg, automated doors), safety prevention (eg, emergency services), and positioning (eg, fall detection) [9,10]. The handling is kept simple and also easy to use for people with disabilities, for example, by pressing a button. Technically, acoustic signals (ultrasound) are generated by actuation, coded by frequency, and inaudible to human ears. Referring to the durability of the ultrasonic whistle, first prototypes made of stiff plastic were quite damageable and sensitive when used in real-life scenarios. The air reservoir was frail toward fingernails when pushed from aside, the material got weak after several hundred times of pressing, and the reservoir got stuck down. In addition, the individual pressure strength and velocity lead to different frequencies. Using silicone as a softer raw material and adding a spring mechanism solved all problems toward reliability and durability; however, this prototype got a little bigger and needs to be scaled down for above-mentioned use cases. The decoding was taken over by receiving devices, installed in ceiling lights, for example, which activate the intended function and if required, forward data to third parties such as family caregivers, nursing services, or emergency centers. One major advantage of using this placing spot is that nearly all existing and new planned properties have ceiling lights; hence, you have electricity at a central point of each room. Concerning the microphones and receiving

technology, first prototypes used a 4-channel ultrasonic sensor wired to a personal computer via ethernet for real-time data processing, gaining a robust algorithm to detect ultrasonic whistles. Last prototypes were implemented in embedded systems into multisensors in the ceiling. Transmission for existing projects can be realized through the very robust DECT (wireless connection) standard or for new projects using Konnex (KNX) wiring (a standard for building automation), which can be connected to uninterruptible power supply systems, which are standard in hospitals or case-sensitive buildings.

As AAL technologies are used in sensible and intimate home care contexts, their acceptance is not given without restrictions and highly dependent on individual requirements, for example, related to needs for safety, privacy, and autonomy but also to the general willingness of individuals to accept technology at home. Thus, it needs to be considered to what extent user diversity gains an impact on AAL acceptance [11]. In this context, prior user studies examined decisive influencing factors, for instance, gender [12], age [13,14], and experience with care [15]. Provided that elderly people wish to decide on their living situation [8], it is of great interest under which conditions they are (not) willing to accept the implementation of AAL technologies for specific contexts of use. Concerning home care, previous research showed that technology types and installation sites affect AAL acceptance [16,17].

To the best of the authors' knowledge, there has been no empirical study directed to the acceptance of ultrasonic whistles in home care so far. Thus, this study aimed to examine the user's acceptance of ultrasonic whistles, with special regard to their functions and usage locations (rooms). With regard to the importance of users' diversity, we particularly focused on health status, user experience with (AAL) technologies, gender, age, and aging, and related their impact on the willingness to use AAL technologies.

### Ambient Assisted Living for Aging in Place

In this section, AAL is described as a chance for aging in place, with special attention given to ultrasonic whistles as an innovative technology. According to the current development of demographic change, growing potentials of AAL technologies in an aging society are outlined first. Thereafter, we discuss existing technology acceptance models, particularly focusing on a lack of knowledge referring to the influence of user diversity on the acceptance of specific AAL technologies. In this context, the focus is set on the factors of age and attitudes toward aging in relation to AAL acceptance.

### Ambient Assisted Living Potentials in an Aging Society

In Germany, demographic change causes an aging society combined with a declining population [18]. By 2060, the predicted number of inhabitants will range between 67.6 million and 73.1 million (depending on the scale of net immigration), provided that 1 out of 3 will be aged 65 years or older and the number of 70-year-olds will be almost twice of the newborns [2]. This shift in the age structure is because of persistently low birth rates and increasing life expectancy because of improved infrastructure and medical technological progress [18]. Aging involves the risk of health impairments such as physical or



mental diseases (eg, cardiac insufficiency and dementia). Hence, the growth of an aging society poses major challenges, especially affecting the health care sector. Although the need for long-term care increases sharply beyond the age of 75 years [18], nursing staff decreases, as there are fewer people in working age resulting in a lack of care [4]. In 2015, more than two-thirds (2.08 million) of all German care-dependent people (2.9 million) received domiciliary care, provided that the majority (1.38 million) was cared for exclusively by family caregivers [5].

AAL as a support for aging in place offers a great potential to enable frail and elderly people to handle daily life autonomously and relieve caregivers [7]. In general, aging in place is defined as “the ability to live in one’s own home and community safely, independently, and comfortably, regardless of age, income, or ability level” [19]. Next to individual perceptions of life satisfaction [20], well-being [21], and senses [8], research focus is set on supportive housing solutions [22], with special regard to smart homes [23]. Smart homes are commonly understood as “digital environments that are sensitive, adaptive, and responsive to human needs” [24]. According to this, they are particularly suited for AAL providing reliable measures aimed at prevention, rehabilitation, and practical support in everyday life by means of technology assistance [25]. Apart from single technologies (eg, blood pressure monitors and wheelchairs), intelligent (smart) home environments are provided with software for multipurpose usage that is integrated unobtrusively into the living space to operate infrastructure [26]. On the basis of the idea of ubiquitous computing [27], smart homes support daily life by monitoring users’ behavior, technically realized through wireless interconnectivity (eg, sensor technologies for home automation and fall detection) and operated via user-friendly devices that facilitate natural communication and interaction through speech, gestures, and familiar interfaces, for instance, mobile phones [7]. Major applications for home care are medical monitoring and rehabilitation (eg, medication reminder and vital parameter monitoring), safety prevention (eg, floor sensors for fall detection), and home automation (eg, automatic lighting) [28-31].

In that respect, ultrasonic whistles could offer innovative technical possibilities for supportive housing solutions. They are small and unobtrusive and can be integrated into a variety of home locations. Next to fixed and local installations (eg, wall switches), it is possible to integrate ultrasonic whistles into wearable devices (eg, emergency call wristband). Respective designs are variable too and can be used to prevent stigmatization, as for instance, covert and aesthetic installations with regard to (younger) users who are still mobile and able to move actively. However, accessibility—especially for users with physical or motoric disabilities—can be guaranteed on demand in terms of coarse buttons, for example, that are easy to use and robust without risks of injury. As it is possible to place the ultrasonic whistle in different spots within immediate reach, depending on users’ requirements and their living environment, its application—including emergency situations—is reliable and safe. As ultrasonic whistles are a holistic assistance system, they can be flexibly adapted to individual user’s needs such as the automation of household tasks, safety,

and fall prevention, as well as movement detection. In its specific function, the ultrasound is generated mechanically (eg, via button press), without using electricity or batteries. Hence, when using ultrasonic whistles, energy is produced in an environmentally friendly way, which represents a key feature [10], especially compared with equivalent assistance systems such as more complex and into-the-floor integrated sensor systems. However, there is only little knowledge about the user-centered perception and acceptance of ultrasonic whistles with regard to their technical possibilities in home care.

### **Technology Acceptance, Ambient Assisted Living, and User Diversity**

Previous research in the field of perception and acceptance of AAL technologies and systems revealed mainly positive evaluations by diverse user groups with regard to age, aging, and experience with disabilities [15,32,33]. At the center of those studies, perceived benefits in terms of a more independent, autonomous, and longer life at the own home environment contrast with perceived barriers, for example, feelings of surveillance, a perceived invasion of privacy, as well as feelings of isolation [34-36]. In particular, numerous qualitative studies (eg, interviews [32] and focus groups [17,37]) explored perceptions of AAL technologies in people older than 60 years. As key results, the older participants valued the opportunity given by AAL of staying longer at their own home, they understood the crisis in care (lack of caregivers and increasing proportions of people in need of care), as well as the potential of AAL technologies to relieve people in need of care, their caregivers, and the care sector itself. However, they also expressed concerns as they feared a dependency on not easy to control technologies, an invasion of privacy by storage or transfer of personal data, and a substitution of human caregivers by technology. Besides qualitative investigations, these motives and barriers have been confirmed by numerous quantitative surveys [15,16]. Predominately, generic AAL systems have been investigated so far (mostly not specific systems nor specific functions). However, there is a lack of knowledge about the interplay of specific AAL functions and application areas in home care and its importance for AAL acceptance.

For investigating the acceptance of assisting information and communication technologies and AAL technologies, well-known and widely spread acceptance models such as technology acceptance model [38], unified theory of acceptance and use of technology [39], and their adapted versions were frequently used in the past years. These models (in particular mentioned in David’s study [38]) are useful to predict the acceptance of innovative technologies by key constructs such as the perceived ease of use and the intention to use a specific technology. Those models are, however, quite generic and do not cover different contexts of use, usage situations, or specific user groups. Hence, the model has to be extended and specifically tailored to the ultrasonic whistle technology and their functions. For the application here, we added the functions (contrasting home automation, emergency service, and positioning) and the application areas (bathroom, bedroom, and living room) based on a preceding qualitative study to the ease-of-use and intention-to-use dimensions. In addition, previous studies and models showed the importance of integrating demographic user

factors and individual attitudes into technology acceptance research, in general and in research referring to AAL technology acceptance, in particular (eg, [39] and AAL-related research: eg, [15,40]).

### Age, Aging, and Their Impact on Ambient Assisted Living Acceptance

As the risk for health impairments increase with age [18], elderly people represent a major user group concerning AAL. Although AAL technologies facilitate everyday life offering great potentials for aging in place, their acceptance is not given without restrictions and is dependent on individual requirements and the extent to which innovative technology is perceived useful [14,16]. This is especially the case in older adults, which is a highly heterogeneous user group, with special regard to biological age, technical generations, and attitudes toward aging [13,41-44].

In general, there is evidence that the willingness to use AAL is high, refuting widespread stereotypes against technophobia among seniors [13,41,42]. However, it is also recognized that older users show comparatively low levels of expertise and confidence when dealing with technology, which can be explained against their generational background [42,43]. Hence, elderly people rather hesitate to adopt innovative technology compared with younger groups [45]. In addition, age-related motoric and cognitive impairments can make it difficult to handle technology and, thus, may limit its acceptance.

Recent studies indicate a link between attitudes toward aging (eg, related to quality of life, social integration, active aging, and dealing with change) and AAL acceptance, provided that people with positive aging concepts are more willing to accept AAL technologies than people with negative attitudes toward aging [40,44]. This leads to the assumption that individual attitudes and perceptions are at least as important as demographic factors in this context. Hence, it is worth considering whether and to what extent a connection between age, aging, and AAL acceptance exists. Concerning the adoption of innovative technology, special attention is required toward personal characteristics and requirements to reduce potential barriers for greater access and usage at older age.

## Methods

### Aim of Study and Research Questions

The aim of this study was to validate the influence of individual factors on the acceptance of ultrasonic whistles in home care, with special regard to function and room. Considering user diversity, we focused on age and attitudes toward aging in relation to AAL acceptance based on previously conducted interview studies [40]. To provide statistical evidence in this context, a quantitative online questionnaire study was conducted addressing the following research questions (RQ):

**RQ1:** In regard to which functions, contrasting home automation, emergency service, and positioning, is the use of ultrasonic whistles accepted or rejected?

**RQ2:** In regard to which rooms, contrasting bathroom, bedroom, and living room, is the use of ultrasonic whistles accepted or rejected?

**RQ3:** Do user diversity factors, in particular age and attitudes toward aging but also gender, affect the assessment of ultrasonic whistles with regard to function and room?

The questionnaire was conducted as an open survey in Germany in summer 2017. Concerning the sample construction, the focus was set on three different age groups, with special regard to young ( $\leq 40$  years), middle-aged (41-70 years), and elderly ( $\geq 71$  years) people as they may differ in their perception and acceptance of innovative technology against generation differences. Participation was voluntary and anonymous. The participants were acquired by personal contact, email, and social media without payment and provided with a link to access the questionnaire. To reach a broad sample, particularly with regard to elderly people, paper-and-pencil questionnaires were additionally used. Thereafter, the questionnaire design was outlined in detail, before a sample description was given.

### Questionnaire Design

The questionnaire items were based on literature review according to the current state of research and prestudy results [40]. Overall, the questionnaire covered 33 questions within different sections (illustrated in Figure 1).

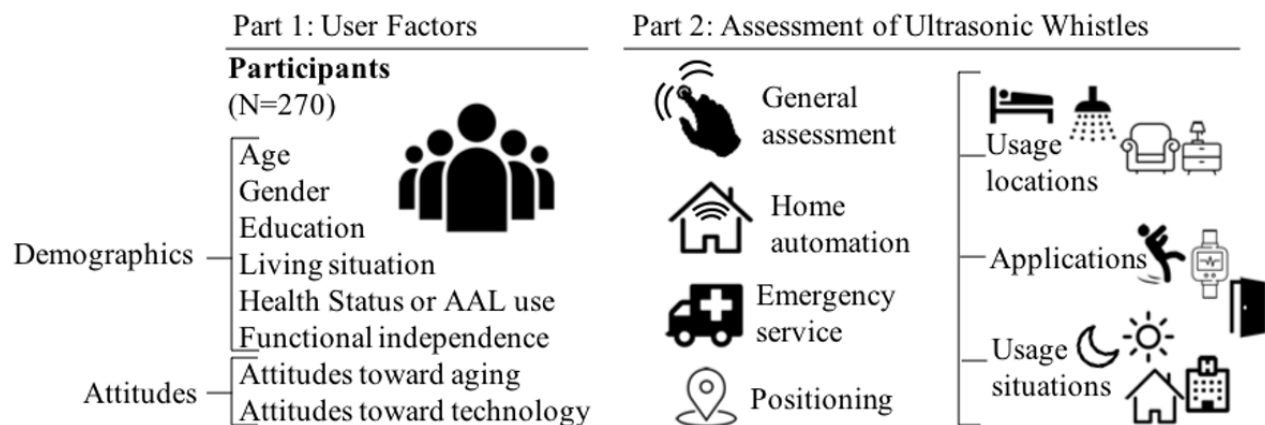
Initially, demographic data were collected such as age, gender, education, living situation, and health status. In connection with that, data about the current use of AAL technologies were collected, particularly with regard to blood pressure monitor, emergency service, bath lift, wheelchair, and motion sensor (answer options: yes or no). Subsequently, functional independence questions [46] were asked concerning the ability to handle activities of daily living, especially self-care, sphincter control, mobility, locomotion, communication, and social cognition (6 items; 7-point Likert scale with  $min=1$ : "in complete need of assistance" and  $max=7$ : "full autonomy"; Cronbach alpha=.907 by deleting the item *social cognition*).

Thereafter, the participants were asked to evaluate attitudes toward aging referring to the categories of health, dealing with change, active aging, social integration, and autonomy [40] on a 6-point Likert scale ( $min=1$ : "strongly disagree" and  $max=6$ : "strongly agree"). In total, 10 items (Cronbach alpha=.807;  $n=259$ ) were used to measure positive (4 items) and negative (6 items) attitudes toward aging (see Textbox 1).

In addition, the participants were asked to assess their attitude toward technology (ATT) [48], such as technical experience, interest, and trust when dealing with technology (5 items; 6-point Likert scale with  $min=1$ : "strongly disagree" and  $max=6$ : "strongly agree"; Cronbach alpha=.899).

The acceptance of ultrasonic whistles in home care was evaluated within four sections structured as follows: (1) the overall use of ultrasonic whistles and the assessment focused on specific functions, namely, (2) home automation, (3) emergency service, and (4) positioning, with special regard to different usage locations, which were bathroom, bedroom, and living room.

**Figure 1.** The illustration shows the questionnaire's structure divided into 2 parts: user factors (left) and the assessment of ultrasonic whistles (right). AAL: ambient assisted living.



**Textbox 1.** Categories and items (translated from German) referring to attitudes toward aging. Items measuring negative attitudes toward aging are coded reverse (R).

Health
<ul style="list-style-type: none"> <li>Decreasing health (R)</li> <li>Being less fit and lively (R) [47]</li> </ul>
Dealing with change
<ul style="list-style-type: none"> <li>Being more relaxed</li> <li>Less enjoyment (R) [47]</li> </ul>
Active aging
<ul style="list-style-type: none"> <li>Making plans</li> <li>Keep on learning [47]</li> </ul>
Social integration
<ul style="list-style-type: none"> <li>Staying in contact</li> <li>Loneliness (R) [47]</li> </ul>
Autonomy
<ul style="list-style-type: none"> <li>Being a burden to others</li> <li>Being dependent (R) [40]</li> </ul>

Overall, the assessment followed a two-step procedure within each section (1 to 4, provided that the sequence of sections was randomized). First, an evaluation of the perceived usefulness according to the rooms in question (bathroom, bedroom, and living room) was conducted using emoticons on a symbolic scale (3 items per section; see Table 1). Thereafter, the participants were asked to assess the respective use intention on a 6-point Likert scale (3 items per section, with all over Cronbach alpha>.9; see Table 1).

In addition, specific applications were evaluated on 6-point Likert scales (*min*=1: “strongly disagree” and *max*=6: “strongly agree”) such as applications at doors for home automation, wearables for emergency service, and floor applications for

positioning (16 items in total, with all over Cronbach alpha>.9; see Textbox 2).

At the end of each section, the participants were faced with a final decision concerning the acceptance or rejection of ultrasonic whistles with regard to different usage situations (see Textbox 3), measured on a 6-point Likert scale (*min*=1: “strongly disagree” and *max*=6: “strongly agree”; 3 items per section, with all over Cronbach alpha<.7 in sections 1 to 3 and alpha=.740 in section 4).

Overall, mean values above the scale center (mean>3.5) indicated acceptance, whereas mean values below the average (mean<3.5) were interpreted as rejection.

**Table 1.** Evaluation of ultrasonic whistles by function and room referring to their perceived usefulness and use intention. For the perceived usefulness, we used symbolic answering patterns (smileys indicating rejection, abstention, or acceptance). For the use intention, we used 6-point Likert scales (min=1 “strongly disagree” and max=6 “strongly agree”).

Assessment sections	Perceived usefulness	Use intention
Ultrasonic whistle	I consider ultrasonic whistles as useful in bathroom/bedroom/living room.	I would use ultrasonic whistles in bathroom/bedroom/living room.
Home automation	I consider home automation as useful in bathroom/bedroom/living room.	I would use home automation in bathroom/bedroom/living room.
Emergency service	I consider emergency service as useful in bathroom/bedroom/living room.	I would use emergency service in bathroom/bedroom/living room.
Positioning	I consider positioning as useful in bathroom/bedroom/living room.	I would use positioning in bathroom/bedroom/living room.

**Textbox 2.** Evaluation of ultrasonic whistles referring to specific installations and conditions.

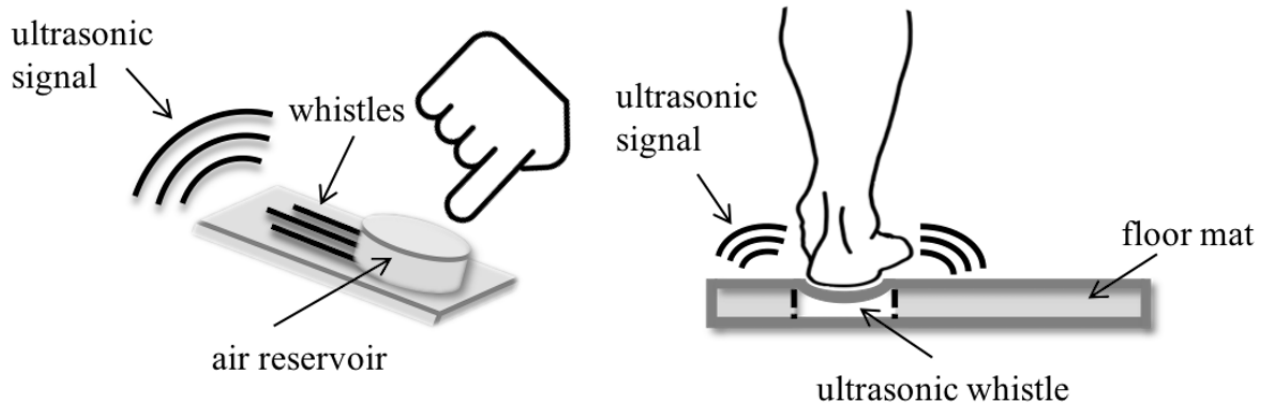
<p>I would use ultrasonic whistles</p> <ul style="list-style-type: none"> <li>... at doors</li> <li>... at windows</li> <li>... in cupboards</li> <li>... at chairs</li> <li>... in wall switches</li> <li>... in floor mats</li> </ul> <p>I would wear ultrasonic whistles in emergency call wristbands</p> <ul style="list-style-type: none"> <li>... during the day</li> <li>... at night</li> <li>... when I am alone</li> <li>... at any time</li> </ul> <p>I would use ultrasonic whistles in floors for fall detection</p> <ul style="list-style-type: none"> <li>... in floor mats (detection)</li> <li>... in doorsills</li> <li>... in floorboards or tiles</li> <li>... in carpets</li> <li>... in selected parts of the dwelling</li> <li>... throughout the home</li> </ul>
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**Textbox 3.** Evaluation of ultrasonic whistles referring to different usage situations.

<p>I would use ultrasonic whistles/home automation/emergency service/positioning</p> <ul style="list-style-type: none"> <li>... in personal care situations</li> <li>... for the care of relatives</li> <li>... at the present time</li> </ul>
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**Figure 2.** The illustration demonstrates the use of ultrasonic whistles by touch as for emergency service (left) and positioning (right).



### Instruction

As ultrasonic whistles represent an innovative assistance system, the participants were informed about technical core features and application options in advance. To reach a high understandability and to provide an idea of the functions of ultrasonic whistles, a drawing of the exemplary usage situations of ultrasonic whistles was given, see Figure 2: emergency buttons (left) and sensitive floors for fall detection (right, based on [9]). In addition, we provided a short scenario to ensure that all participants had the same level of knowledge in this context:

*Imagine that either you or relatives are in need of home care due to health restrictions. Ultrasonic whistles make it possible to live actively and autonomously, though. Its implementation is unobtrusive. As ultrasonic signals are generated by touch, no electrical power is needed. Based on diverse whistle lengths, each ultrasonic whistle produces an individual signal, which is transmitted by air towards a receiver (e.g., installed in ceiling lights) to activate a specific function defined in advance, such as automatic door opening or further home automated tasks, emergency calls to relatives or nursing services, and positioning to detect danger and fall situations.*

Pretests with participants in diverse ages ensured an overall understanding of the material and a maximum response time of 20 min with regard to all target groups.

### Sample Description

A total of 354 people participated in the questionnaire study. Of these, 84 had to be excluded from statistical analyses because of incomplete datasets. In all, a sample of 270 remained, of which 164 participants were female (164/270, 60.7%) and 106 were male (106/270, 39.3%). As the population share of women increases with age, especially concerning people aged 60 years

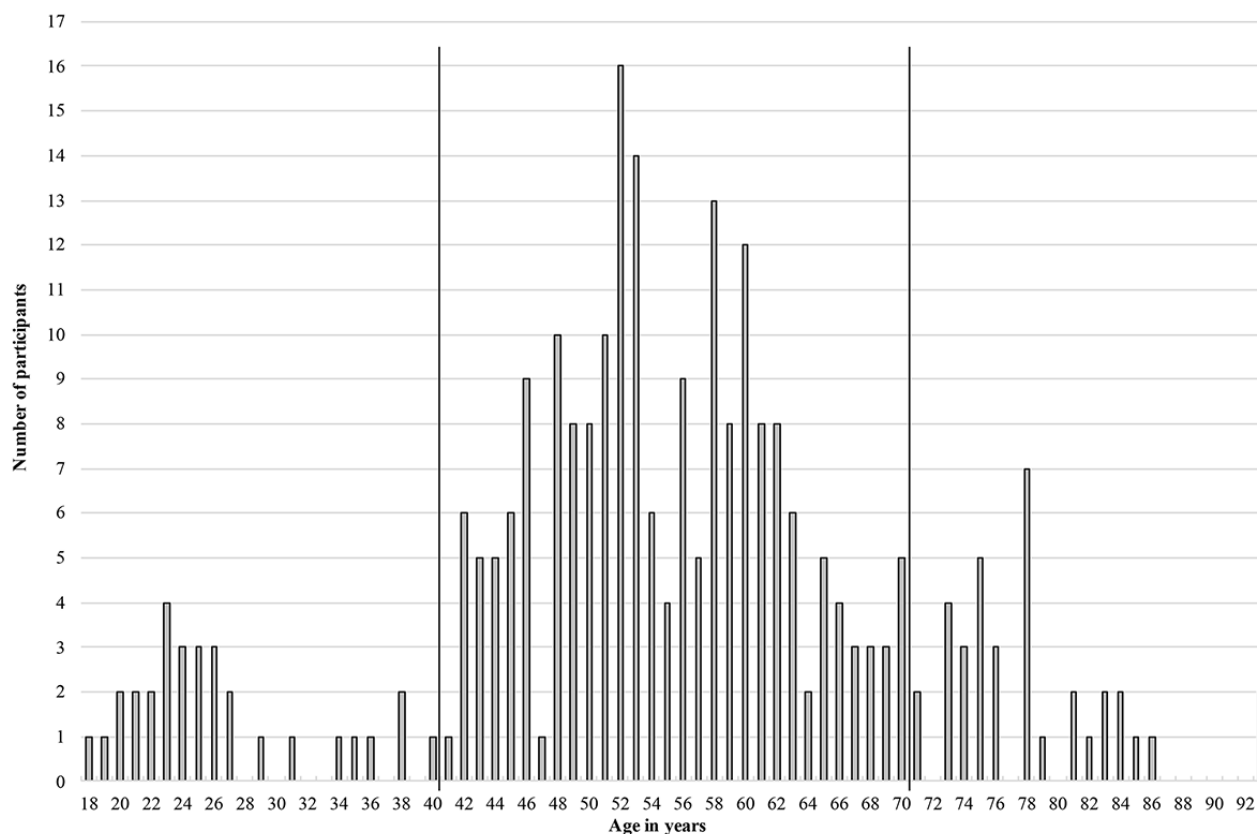
and older [18], gender distribution can be explained in terms of demographic change. The participants' age ranged from 18 to 93 years, with an average of 54.7 years (SD 14.67). According to the distribution (see Figure 3), we formed three age groups that showed peaks corresponding to the current age structure of Germany's population [49].

With 42.2% (114/270) holding a university degree, the participants were educated above average [50]. Regarding their housing situation, most of the participants (188/270, 69.9%) lived in residential communities.

The majority (251/270, 92.9%) indicated that they wanted to stay at home for as long as possible at older age. The overall health status was good; 34.1% (92/270) were affected by chronic diseases, 18.5% (50/270) reported current health issues, and 5.2% (14/270) were care dependent with the help of family caregivers or nursing services, for example. Functional independence was high (mean 6.86 [SD 0.65]) and the use of AAL technologies was rather low (86/270, 31.9%). Overall, blood pressure monitors were most commonly used (137/270, 50.7%), followed by motion sensors (43/270, 15.9%), wheelchairs (13/270, 4.8%), emergency services (10/270, 3.7%), and bath lifts (4/270, 1.5%). In general, attitudes toward technology (mean 4.55 [SD 1.00]) and aging (mean 4.1 [SD 0.71]) were positive.

Correlation analyses (see Table 2) revealed significant relations between attitude toward aging and functional independence ( $r_s=.138$ ;  $P<.05$ ). In addition, a relation between ATT and functional independence was observable ( $r_s=.129$ ;  $P<.05$ ). Besides, age correlated with ATT ( $r_s=-.227$ ;  $P<.001$ ) and functional independence ( $r_s=-.216$ ;  $P<.001$ ). Interestingly, age and attitude toward aging were not related ( $r_s=.005$ ;  $P=.94$ ); thus, older adults did not report different attitudes toward aging in comparison with younger adults.



**Figure 3.** Age distribution ranging from 18 to 93 years with separation in age groups.**Table 2.** Correlations of demographic and individual user factors.

User factors	Age	Attitude toward aging	Attitude toward technology	Functional independence
Age	— <sup>a</sup>	.005	-.227 <sup>b</sup>	-.216 <sup>b</sup>
Attitude toward aging	—	—	.092	.138 <sup>c</sup>
Attitude toward technology	—	—	—	.129 <sup>c</sup>
Functional independence	—	—	—	—

<sup>a</sup>Not applicable.

<sup>b</sup> $P < .001$ .

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

### Aging and Its Characteristics

Overall, aging has to be understood as a complex factor, not only because the population share of people in later age is steadily rising but also as the onset of aging and the forms and extent vary interindividually [11]. For the analysis of user factors, we compared young, middle-aged, and elderly age groups (see Table 3). Hence, younger users (mean 4.92 [SD 1.01]) shared rather positive ATT compared with middle-aged (mean 4.61 [SD 0.93]) and elderly people (mean 3.89 [SD 1.14]), which can be explained with regard to different technology generations [51]. Concerning this study's sample, the group of middle-aged people (born between 1947 and 1976) primarily experienced household and computer technologies, whereas the group of younger adults (born between 1977 and 1999) grew up with internet and social media as a part of the internet generation and so-called digital natives. By contrast,

the group of elderly people (born between 1924 and 1946) gained comparatively low experiences when dealing with technology because of the historical circumstances of their past.

Moreover, people with positive attitudes toward aging, who were optimistic about life quality in later age along with possibilities for living independently, active aging, fairly well health, and social inclusion, slightly tended to state more positive attitudes toward technology (mean 4.62 [SD 0.90]) compared with the group of participants with negative aging concepts (mean 4.29 [SD 1.29]), who were concerned about social isolation, dependency on others, restrictions on life quality, and reduced mobility because of physical and mental diseases (see Table 4).

Hence, it is not only important to explore single user factors but, in fact, to discover their interaction effects with regard to different contexts of use.

**Table 3.** Descriptive profiles of young ( $\leq 40$  years), middle-aged (41-70 years), and elderly ( $\geq 71$  years) age groups.

User factors	Young (n=31)	Middle-aged (n=203)	Elderly (n=36)
Age (years), mean (SD)	26.29 (6.00)	54.85 (7.28)	78.31 (5.40)
<b>Gender, n (%)</b>			
Female	20 (65)	126 (62.1)	18 (50)
Male	11 (36)	77 (37.9)	18 (50)
Attitude toward technology (max=6), mean (SD)	4.92 (1.01)	4.61 (0.93)	3.89 (1.14)
Attitude toward aging (max=6), mean (SD)	3.91 (0.89)	4.16 (0.65)	3.89 (0.80)
Functional independence (max=7), mean (SD)	6.99 (0.36)	6.88 (0.65)	6.64 (0.84)

**Table 4.** Descriptive profiles of aging groups with positive and negative attitudes.

User factors	Positive aging attitudes (n=214)	Negative aging attitudes (n=56)
Age (years), mean (SD)	54.46 (13.25)	55.61 (19.27)
<b>Gender, n (%)</b>		
Female	133 (62.1)	31 (55)
Male	81 (37.9)	25 (45)
Attitudes toward technology (max=6), mean (SD)	4.62 (0.90)	4.29 (1.29)
Attitudes toward aging (max=6), mean (SD)	4.35 (0.54)	3.13 (0.34)
Functional independence (max=7), mean (SD)	6.91 (0.57)	6.68 (0.86)

## Results

### Data Analysis

Next to descriptive analyses, inferential statistics were conducted by means of multivariate analysis of variance analyses (MANOVA) to analyze the impact of the factors function and room on the acceptance of ultrasonic whistles in home care as well as effects of user diversity. For analysis of age, we used the three age groups as independent variables. Concerning attitudes toward aging, two groups were formed as independent variables based on scale values, provided that means larger than the scale center (mean $>3.5$ ) were grouped as positive attitudes, whereas means smaller than the scale center (mean $<3.5$ ) were classified as negative attitudes toward aging. In this case, different group sizes were accepted to separate people with a more optimistic age attitude from people with a more pessimistic age attitude.

The level of significance ( $P$  value) was set at 5%. As aging is naturally heterogeneous, we reported findings within the less restrictive level as marginally significant. Post hoc comparisons were done by Bonferroni correction. Mauchly test for sphericity was performed. In addition, the Huynh-Feldt adjustment was used to correct violation of sphericity. As for effect sizes, the partial eta-squared ( $\eta^2$ ) was reported.

The description of the Results section is structured as follows: first, the overall assessment of ultrasonic whistles in home care is presented descriptively. Next, its acceptance by function and

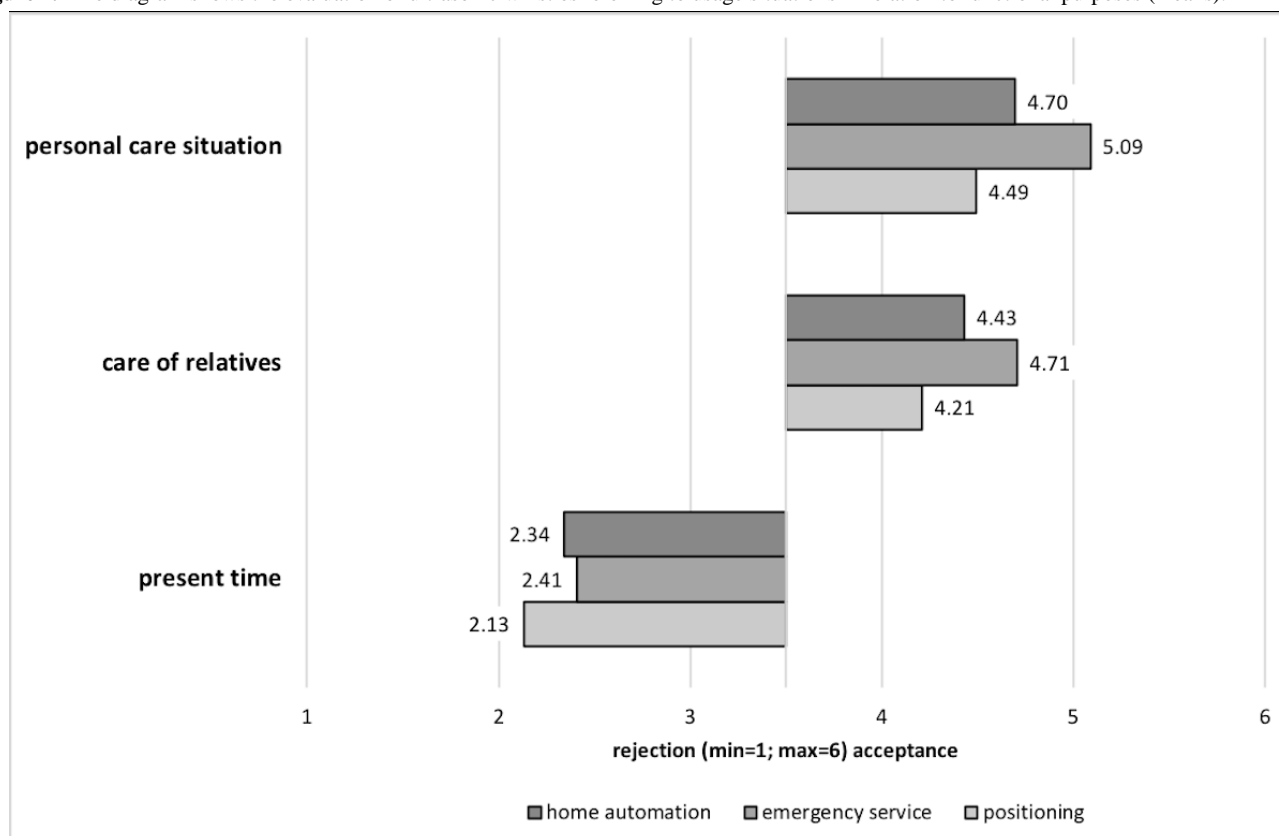
room is considered in detail. In addition, user diversity effects are outlined.

### Users' Assessment of Ultrasonic Whistles in Home Care

In general, the assessment of ultrasonic whistles in home care was positive (mean 4.09 [SD 1.25]). Considering different usage situations, the use of ultrasonic whistles was generally accepted concerning *personal care situations* (mean 4.90 [SD 1.07]) and the *care of relatives* (mean 4.53 [SD 1.32]), whereas it was rejected to be used at the *present time* (mean 2.09 [SD 1.40]). In detail, this pattern was likely to occur with regard to specific functions in question, provided that emergency services were preferred in all cases, followed by home automation and positioning (see [Figure 4](#)).

To examine whether user groups differ in their perception and evaluation of different usage situations (dependent variables), MANOVA analyses were conducted with age, gender, and attitudes toward aging as independent variables. Results revealed significant main effects of age ( $F_{18,502}=2.930$ ;  $P<.001$ ;  $\eta^2=0.095$ ) and gender ( $F_{9,250}=2.072$ ;  $P<.05$ ;  $\eta^2=0.069$ ). In contrast, the attitudes toward aging did not impact the willingness to use the whistles in either of the contexts under study. In detail, age influenced the assessment of *emergency service at the present time* ( $F_{2,258}=5.990$ ;  $P<.01$ ;  $\eta^2=0.044$ ), provided that elderly people (mean 3.11 [SD 1.79]) were more willing to adopt ultrasonic whistles for emergency situations immediately than the middle-aged group (mean 2.3 [SD 1.52]) and the younger group (mean 2.3 [SD 1.79]).

**Figure 4.** The diagram shows the evaluation of ultrasonic whistles referring to usage situations in relation to functional purposes (means).



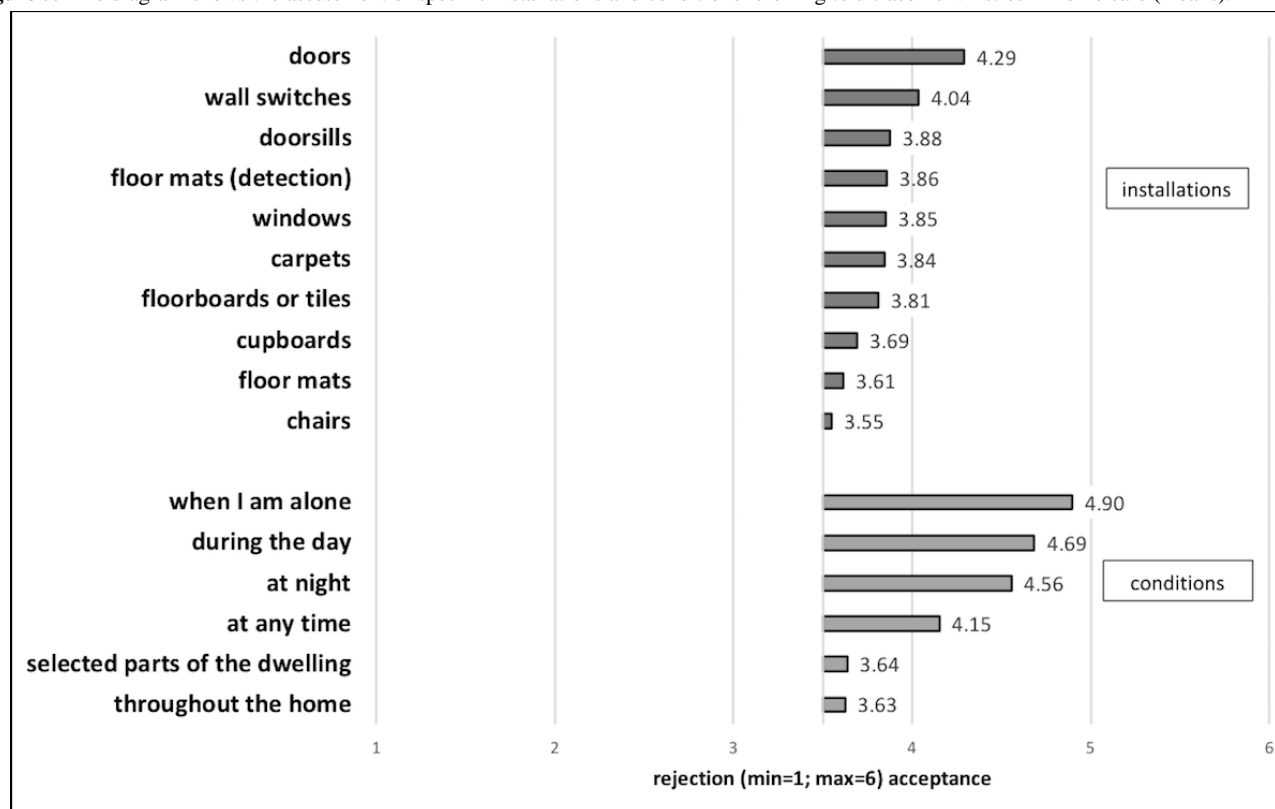
In addition, age gained an impact on the assessment of *positioning at the present time* ( $F_{2,258}=3.788$ ;  $P<.05$ ;  $\eta^2=0.029$ ). This indicated that older adults tended to give positive evaluations in this context in comparison with both other age groups (older adults: mean 2.52 [SD 1.52]; middle-aged adults: mean 2.11 [SD 1.34]; and younger adults: mean 1.74 [SD 1.43]).

In general, [Figure 5](#) shows that installations at *doors*, for example, for home automation, were valued the most (mean 4.29 [SD 1.49]), followed by *wall switches* (mean 4.04 [SD 1.52]), *windows* (mean 3.85 [SD 1.55]), *cupboards* (mean 3.69 [SD 1.56]), *floor mats* (mean 3.61 [SD 1.62]), and *chairs* (mean 3.55 [SD 1.55]). On average, the willingness to embed ultrasonic whistles in floors for fall detection was rather low (mean 3.78 [SD 1.41]). In this context, installations in *doorsills* (mean 3.88 [SD 1.64]) were rather more accepted than in *floor mats (detection; mean 3.86 [SD 1.66])*, *carpets* (mean 3.84 [SD 1.63]), and *floorboards or tiles* (mean 3.81 [SD 1.63]). Referring to specific conditions, the use of ultrasonic whistles in emergency call wristbands was most likely accepted (mean 4.57 [SD 1.26]), particularly concerning situations *when I am alone* (mean 4.9 [SD 1.3]) and *during the day* (mean 4.69 [SD 1.36]) compared with *at night* (mean 4.56 [SD 1.42]) and *at any time* (mean 4.15 [SD 1.56]). Moreover, assessments indicated that the acceptance of positioning systems, such as for fall detection, was slightly higher with regard to *selected parts of the dwelling* (mean 3.64 [SD 1.63]) than *throughout the home* (mean 3.63 [SD 1.65]).

For analyzing user diversity effects on the acceptance of specific installations and conditions as dependent variables, MANOVA analyses were conducted with age, gender, and attitudes toward aging as independent variables. For installations, analyses revealed a significant main effect of age as well as a significant interaction effect of age and attitudes toward aging (see [Table 5](#)). Assessments of installations options, for instance doors, were seen rather positive with regard to middle-aged (mean 4.42 [SD 1.37]) compared with young (mean 4.26 [SD 1.67]) and elderly users (mean 3.61 [SD 1.79]). For conditions, no significant omnibus effects were found (see [Table 5](#)).

### Users' Acceptance by Function and Room

Overall, the acceptance of ultrasonic whistles in home care was measured by its perceived usefulness and use intention referring to function and room. With regard to the perceived usefulness, ultrasonic whistles were commonly supported, particularly to be used in the bathroom (mean 73%, 197/270), followed by bedroom (mean 66.7%, 180/270) and living room (mean 63.3%, 171/270). In addition, taking into account specific functions, assessment results showed mean values above average (mean>50%), except for the use of positioning systems in bedroom and living room (mean 42.6%, 115/270; see [Figure 6](#), left). However, with regard to the use intention, all applications in question were accepted (mean>3.5) though (see [Figure 6](#), right). In total, the acceptance of emergency service reached peak levels across room boundaries, particularly in the bathroom (mean 4.98 [SD 1.24]). Slight restrictions were observable with regard to positioning in bedroom (mean 3.85 [SD 1.67]) and living room (mean 3.84 [SD 1.65]).

**Figure 5.** The diagram shows the assessment of specific installations and conditions referring to ultrasonic whistles in home care (means).**Table 5.** Multivariate analysis of variance analyses results with age, attitudes toward aging, and gender as independent variables and installations and conditions as dependent variables.

User factors	Installations			Conditions	
	<i>F</i> test ( <i>df</i> )	<i>P</i> value	$\eta^2$	<i>F</i> test ( <i>df</i> )	<i>P</i> value
Age	1.988 (20,500)	<.01	0.074	1.060 (12,508)	.39
Gender	1.308 (10,249)	.23	— <sup>a</sup>	1.949 (6,253)	.07
ATA <sup>b</sup>	0.660 (10,249)	.76	—	1.117 (6,253)	.35
Age × gender	0.942 (20,500)	.53	—	0.839 (12,508)	.61
Age × ATA	1.859 (20,500)	<.05	0.069	1.250 (12,508)	.25
Gender × ATA	1.559 (10,249)	.12	—	1.114 (6,253)	.36
Age × gender × ATA	1.017 (20,500)	.44	—	0.923 (12,508)	.52

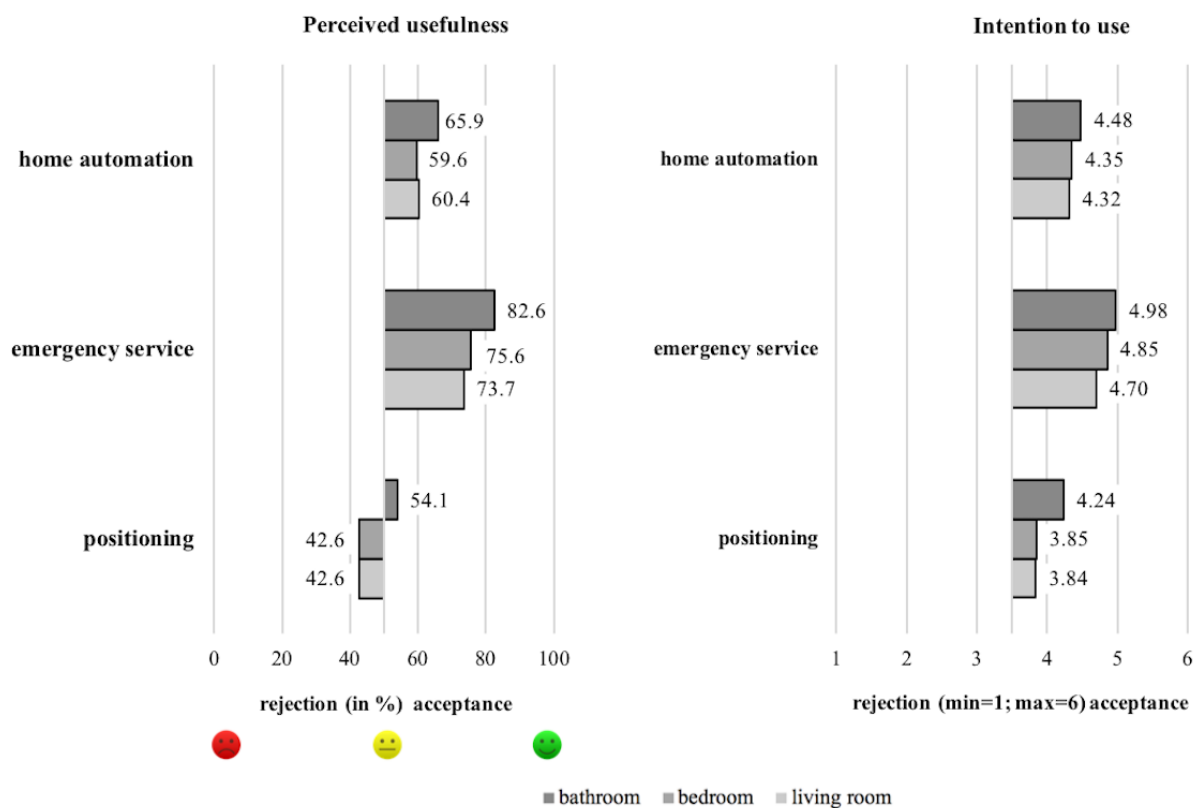
<sup>a</sup>Not applicable.<sup>b</sup>ATA: attitudes toward aging.

To test statistical significance of the factors function and room on the acceptance of ultrasonic whistles, a repeated measures analysis of variance was conducted. Overall, measurements revealed a significant main effect of function ( $F_{2,269}=60.444$ ;  $P<.001$ ;  $\eta^2=0.183$ ) and room ( $F_{2,269}=41.388$ ;  $P<.001$ ;  $\eta^2=0.133$ ) as well as a significant interaction effect of both factors ( $F_{4,269}=8.701$ ;  $P<.001$ ;  $\eta^2=0.031$ ). According to effect sizes, the factor function gained the highest impact on the acceptance. In detail, emergency service was valued the most (mean 4.84 [SE 0.08]), followed by home automation (mean 4.38 [SE 0.09]) and positioning (mean 3.98 [SE 0.10]). Considering the factor room, the use of ultrasonic whistles was most likely accepted

in the bathroom (mean 4.57 [SE 0.08]), followed by bedroom (mean 4.35 [SE 0.08]) and living room (mean 4.29 [SE 0.08]). With regard to the interaction of both factors, function and room, the use of emergency services in bathrooms influenced the acceptance of ultrasonic whistles in home care the most (see Figure 6, right).

As the factors function and room gain a significant influence on the acceptance of ultrasonic whistles in home care, it is of great interest whether and to what extent assessments differ with regard to diverse user groups, especially as the use of AAL technologies affects sensitive areas of life and, thus, is highly dependent on individual attitudes, demands, and concerns.

**Figure 6.** The diagrams show the perceived usefulness (left) and use intention (right) of ultrasonic whistles referring to function and room. For both scales, we used different response options. For the perceived usefulness, we used symbolic answering patterns (smileys, see bottom left), where participants gave their confirmation and rejection by percentages. For the use intention, we used 6-point Likert scales (min=1 “strongly disagree” and max=6 “strongly agree”), where mean values indicated acceptance or rejection (see bottom right).



To compare the effect of user characteristics on the acceptance of ultrasonic whistles with regard to different user groups, MANOVA analyses were conducted. Age and attitudes toward aging were taken as independent variables and acceptance as dependent variable. Overall, no age effects were observable. By contrast, analyses showed a significant impact of the factor attitude toward aging ( $F_{3,262}=3.098$ ;  $P<.05$ ;  $\eta^2=0.034$ ) as well as an interaction effect of age and aging ( $F_{6,526}=2.383$ ;  $P<.05$ ;  $\eta^2=0.026$ ) on the acceptance. According to this, the acceptance of home automation was related to attitude toward aging ( $F_{1,264}=3.214$ ;  $P<.1$ ;  $\eta^2=0.012$ ). In more detail, users with negative attitudes (mean 4.55 [SD 1.39]) accepted ultrasonic whistles more strongly than users with a positive attitude toward aging (mean 4.34 [SD 1.49]); however, these results were significant on the less restrictive level of 10 ( $P<.10$ ).

## Discussion

### Principal Findings

This study aimed to reveal deeper insights into the user-centered assessment of ultrasonic whistles in home care, with special attention to age and attitude toward aging as AAL installations have a huge potential in the support for elderly care at home. Ultrasonic whistles have the advantage to be installable in existing home environments, thus representing an unobtrusive form of technology support at home. Our main focus was laid on the questions, for what reasons ultrasonic whistles would be

perceived as useful at home (RQ1) and at which locations persons would accept ultrasonic whistles (RQ2). In addition, we explored whether user diversity factors, in particular, age and attitudes toward aging affect the assessment of ultrasonic whistles (RQ3).

### Acceptance of Ultrasonic Whistles

Overall, the assessment of ultrasonic whistles in home care is positive. In line with previous research, which shows that technology is accepted when the wish of older adults to age in place is respected [8,52] and the technology is perceived as useful [53,54], participants perceived ultrasonic whistles for home automation and for emergency services as highly useful and, as a consequence, reported to have a positive use intention for both contexts. Regarding the use of ultrasonic whistles for positioning, in contrast, the picture was more ambiguous. Participants' evaluated the usefulness of ultrasonic whistles for positioning not that positive, but still they reported their willingness to use it if necessary (although to a lesser extent compared with home automation and emergency; RQ1).

Considering different usage situations, the use of ultrasonic whistles is accepted referring to personal care situations and the care of relatives, whereas it is rejected to be used at the present time. Apparently, the perceived usefulness of AAL systems is limited to the specificity of the caring situation. Participants did not appreciate using the technology at that time, presumably because the majority was in overall good health status and a high functional independence. However, this could also possibly



be a kind of optimism bias, a psychological phenomenon, according to which individuals believe that they themselves are less vulnerable and less at risk in comparison with other people [55,56].

Confirming previous research on AAL acceptance [16,17], this study's outcomes validate an influence of the factors function and room (RQ2), revealing that the use of ultrasonic whistles as for emergency service in bathroom is commonly preferred, followed by home automation and positioning in bedroom and living room. In contrast, Himmel and Ziefle [16] demonstrated that AAL acceptance decreases from rather public to private domestic spaces, provided that visual monitoring is accepted least and positioning best. However, in the mentioned paper, AAL acceptance was examined generically, without specifying a particular technology. It might be reasonably assumed that other applications in question as well as the range of functional description cause different assessment results in this context. For example, considering the evaluation of abstract monitoring systems in Himmel and Ziefle's study [16], contrasting auditory, visual, and positioning technologies that have not been further specified, the acceptance of positioning turns out to be rather positive, whereas it is comparatively low when it comes to assessing a concrete technology such as the use of ultrasonic whistles for fall detection.

Furthermore, the outcomes of this study corroborate that the willingness to use ultrasonic whistles in home care is related to its perceived necessity along with commonly high safety needs, especially with regard to the broad acceptance of emergency services in bathrooms. This shows that older adults are not innovation-averse for age-related technology in general, but rather accept AAL technology that is perceived as useful and improves the quality of their daily life [52,53]. This was also confirmed by the findings in this study. As there is a general wish for aging in place [8,54], it is fair to assume that trade-offs between acceptance-related barriers, such as privacy concerns in intimate spaces, fall in favor of security and risk prevention as well as the opportunity to live independently and self-determined for as long as possible.

With regard to the user's perspective (RQ3), our study results reveal that user diversity plays a minor role in the acceptance of ultrasonic whistles in home care. Although, a trend can be seen that the assessment of single functions differs among user groups, predominantly depending on age and attitudes toward aging which confirms previous studies [13,44]. According to this, the willingness to use home automation is higher by users with negative aging concepts who tend to fear restrictions on health, autonomy, and social life. Hence, there is reason to believe that ultrasonic whistles address heterogeneous user groups, particularly depending on its multifunctionality related to individual attitudes, demands, and concerns.

## Methodology

In this research, we used questionnaires to reach a broader sample of participants, both online and as paper-pencil version for those older adults who are not used to using the computer and internet. As participation was voluntary and not gratified, we can rely on a sample that was interested to participate, and according to some comments at the end of the questionnaire,

participants were really motivated to contribute their opinions and expressed a high thematic involvement. Although one can assume honest and deliberate answering patterns by participants, one could critically argue that the sample reflects a group of symptomatic volunteers in terms of good aging, a comparably good health status, and high functional independence.

Having said that, we, thus, cannot exclude that the picture here reflects a kind of best case scenario, with a possible overestimation with respect to the acceptance of technology prevailing in a less biased sample. Future studies should, therefore, direct to including persons with a lesser health status, a more negative aging attitude, and with a lower level of functional interdependence to cover the full picture of aging and AAL technology acceptance.

Another aspect that should be critically considered is assessing the acceptance in scenario-based questionnaires reflects users' acceptance attitudes, which should not automatically be equated to the willingness to use the technology in the end. This might be because of the fact that the vision of using a technology might be impacted by different constraints, circumstances, and takes place at different points in time in comparison with the real use in context. This is of particular impact, as potential usage barriers and perceived benefits can only be reliably assessed if users can actively interact with the ambient environment and *feel* the impact of the ultrasonic whistles in the real context. However, we cannot exclude that users might over- or underemphasize the potentials and pitfalls of ultrasonic whistles if their judgments only rely on the imagination of using it [36,57].

To achieve an overall understanding of the user's acceptance in this context, further research is needed, particularly with regard to diverse user groups as well as perceived barriers and benefits. Only then it is possible to establish the potential for an accepted technology.

## Future Research

In total, the study revealed profound insights into the user-centered assessment of ultrasonic whistles in home care. However, the approach opens up a number of future research duties to complement the understanding of aging in place.

### *Validation in Real Ambient Assisted Living-Settings*

In particular, the comparison of cross-study results revealed assessment shifts concerning the acceptance of AAL technologies in home care. Hence, in line with Wilkowska et al [36], an interconnection between research methods and objects is presumably leading to the conclusion that some factors are more context sensitive than others. On the basis of the assumption that the user-centered assessment of ultrasonic whistles may differ with regard to diverse research models, a multimethod approach is needed, particularly focusing on experimental study designs such as real-life smart home environments. Only then it is possible to enhance user experience by allowing participants to transform their ideas and concepts into reality. In future studies, we will, therefore, investigate in real-life environments (care institutions and private home environments) to what extent hands-on experiences with diverse applications enabled by the implementation of ultrasonic

whistles change the perception and acceptance of ultrasonic whistles in home care.

### Sample Composition

Another point that needs further research is the understanding of user diversity. Although we placed great emphasis on diverse target groups, such as age and health status, the study participants did not represent the group of the very elderly persons, who are definitely a major user group of AAL technologies. In addition, personal experience with AAL technologies was limited to single applications, predominately blood pressure monitors, as the overall health status was rather good. Thus, key findings should be validated, especially considering elderly users with health impairments and disabilities as well as diverse user roles (caregivers vs patients). Furthermore, it would be interesting to address participants of younger age groups as future users to explore individual requirements concerning the use of AAL technologies, using the example of ultrasonic whistles, which may differ because of generational background.

### Intercultural Perspectives

Finally, the results of this study are shaped by culture- and country-specific norms, values, and standards of Germany. Beyond that, it would be insightful to compare assessment results against different cultural backgrounds with special attention given to diverse health care systems to contribute to a better understanding of acceptance-related factors in this context. In addition, especially the aging concepts and the value of aging varies across countries, social economies, and political systems [58]. As a consequence, also the extent of willingness of aged persons toward assistive technologies in the AAL context might vary. An intercultural picture of aging in place in combination with the study of the role and the functionality of AAL technologies is of paramount importance, not only for understanding the intercultural aging in place but also to inform technical designers, media, and policy about a responsible research and innovation, and last but not least, a public information strategy.

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### Conflicts of Interest

None declared.

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## Abbreviations

**AAL:** ambient assisted living

**ATA:** attitudes toward aging

**ATT:** attitude toward technology

**MANOVA:** multivariate analysis of variance analyses

**RQ:** research question

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Original Paper

# A Groupware Tool to Facilitate Caregiving for Home-Dwelling Frail Older Persons in the Netherlands: Mixed-Methods Study

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## Abstract

**Background:** Collaboration among informal and formal caregivers in a mixed care network of home-dwelling elderly may benefit from using a groupware app for digital networked communication (DNC).

**Objective:** This study aimed to describe and explain differences in the use and evaluation of a DNC app by members of the care network and to come up with a list of conditions that facilitate (or restrict) the implementation of a DNC app by a home care organization.

**Methods:** A pilot study collected information on digital communication in 7 care networks of clients of a home care organization in the Netherlands. Semistructured interviews with 4 care recipients, 7 informal carers (of which 3 spoke on behalf of the care receiver as well on account of receivers' suffering from dementia), 3 district nurses, 5 auxiliary nurses, and 3 managers were conducted 3 times in a period of 6 months. In addition, we observed relevant workshops initiated by the home care organization and studied log-in data created by the users of the DNC app.

**Results:** The qualitative data and the monthly retrieved quantitative log-in data revealed 3 types of digital care networks: arranging the care network, discuss the care network, and staying connected network. Differences between network types were attributed to health impairment and digital illiteracy of the care recipients, motivation of informal caregivers, and commitment of formal caregivers. The easy availability of up-to-date information, the ability to promote a sense of safety for the carers, and short communication lines in case of complex care situations were positively evaluated.

**Conclusions:** It is concluded that digital communication is beneficial for organizing and discussing the care within a care network. More research is needed to study its impact on care burden of informal carers, on quality of care, and on quality of life of home-dwelling frail older adults.

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**KEYWORDS**

devices; kinship networks; long-term care; home care organization; communication; health; elderly; digital care network; digital networked communication

## Introduction

**Background**

Frail community-dwelling older adults often receive care from formal and informal caregivers over a long period of time [1]. The presence of multiple types of caregivers and complex care

tasks requires adequate communication on care to optimize its quality. However, communication between formal and informal caregivers is generally low, particularly in care networks lacking a cohabiting informal caregiver [2]. Moreover, when the care recipient is in poor health and less able to manage his or her own care, the low frequency of communication among formal

caregivers and noncohabiting informal caregivers becomes a pressing issue for coordination tasks.

In the era of computer-supported cooperative work, the deployment of Web-based communication tools seems a logical way to organize care more efficiently around people at home [3]. Therefore, an increasing number of home care agencies are using a groupware tool to enable care coordination [4]. This type of software combines several functionalities such as registering goals and action plans, calendar managing, and networked communication. The empirical evidence regarding the effect of these apps on communication among different types of caregivers is limited. Most studies are only dealing with theoretical models of technology acceptance [5,6]. Moreover, a lot of studies are performed from a one-sided perspective only, such as the viewpoint of the care receiver [7]. Other computer-mediated health studies are limited to the communication in hospital care, for example, between the medical specialist and his patient at home [8].

To increase insight into how digital communication may improve communication between formal and informal caregivers in home settings, we conducted a pilot study among members of care networks around 7 clients of a home care organization in the Netherlands. The care recipients and their formal and informal caregivers were hooked onto an app developed for digital communication in a closed care network. We examined the use of the electronic tool (e-tool) for a period of 6 months using multiple ways of data collection. On the basis of acquired data, we aimed to (1) describe and explain differences in the use of the communication app by the members of the care network and (2) come up with a list of conditions that facilitate (or restrict) the implementation of such an app by a home care organization. The section below provides a short literature overview to identify conditions that predict differences in the actual use of the communication app and its effects on the process of caregiving.

### Online Care Networks

Crucial to all digital systems is the notion of networks. This is probably the most important distinguishing aspect of communication tools in comparison with other types of software [9]. Networked communication may help mixed home care networks to create online communities for coordinating care tasks and exchanging information. Similar to offline care networks, online care networks can be described according to their structural (size and composition) and functional characteristics (tasks, frequency, and content of discussion about care) [2]. In general, 3 types of offline mixed care networks are to be found among community-dwelling older care recipients: a small partner care network with few other helpers; the larger informal care network, composed of adult children, other relatives, nonkin, and formal caregivers; and the larger formal care network with few informal caregivers (mainly spouse or children) [10]. The type of care network present depends on the care needs and the economic, social, and psychological resources of the care recipient (eg, health status, income, partner status, and sense of self-efficacy). It can be expected that the composition of an online care network reflects the composition

of an offline care network, but there are 2 important arguments that nuance this expectation.

First, not everybody desires or is able to use online tools. There are differences in determinants such as age, the severity of an illness, and attitudes toward digital networked communication (DNC) [11]. A questionnaire study based on the constructs of the unified theory of acceptance and use of technology showed that physical frailty status is associated with older peoples' use of online tools, independent of age, education, and opinions on information and communications technology use [12]. Studies on care networks in which elderly were included showed that for people with mild dementia, technical errors and the unclearness of benefit lowered the initial trust in the groupware tool [13,14]. Such distrust in groupware tools may also be present among informal caregivers and home care professionals who are not common with these types of commercial tools. Another reason to refrain from DNC is that some highly valued characteristics of personal communication, for example, emotional support, do not translate into digital practices [15].

Second, offline communication between informal and formal caregivers largely depends on the meeting opportunities of the caregivers, defined by, for example, overlapping types of care activities and the coresidence of the informal caregiver [16]. In contrast, online communication provides ongoing meeting opportunities because any message communicated by any caregiver can be read by all other caregivers. However, assuming that for care recipients and informal caregivers there is no time limit to communication, this is limited for formal caregivers by their working hours and by how their organization has equipped teams to provide 24/7 attention to the needs of their clients [17]. In this line of reasoning, it is likely expected that an online care network represents only a part of the offline care network.

This leads to 2 main research questions (RQs) that guided our pilot study were:

RQ1: What are the characteristics of digital networked communication in terms of size and composition of the digital network and the frequency and content of communication?

RQ2: What might be the effects of using Web-based communication tools for the online and offline communication on care, the efforts from informal carers to help, and the perceived quality of care?

### The Role of the Home Care Organization and Usability of the Communication App

In addition to individual variation within the care network, there are several barriers and facilitators of success when implementing electronic health (eHealth) into care organizations. The extent to which the intervention fitted with the existing workflow and how well it is integrated within current working processes were found to influence implementation [18]. Nowadays, nurses experience a pressing responsibility of the economic aspect of their work; every task has to be done as efficiently as possible [19]. In addition, it is increasingly expected that they integrate informal caregiver involvement in formal work processes. Results of a study of 2 agencies and their clients in the Netherlands [20] show that the nurses were

aware of the organizational policy which stated that they should proactively keep connected with informal caregivers, yet most of them acknowledged that they hardly ever did so. The main reasons were lack of time, too little initiative from the informal carer, and no clarity on which team member is responsible and accountable for the informal caregiver involvement. An app for DNC may deal with some of these issues and can be assistive for formal caregivers in stimulating informal helpers to communicate within online care networks. Currently, those groupware tools used in home care organizations are more comparable with Facebook, WhatsApp, and Google Calendar than with eHealth record software. The apps look attractive and are comfortable to use, and swiping to activate these types of digital tools is considered to be pleasant [21]. As they are installed on vehicles as mobile phones, all the members of the care network can communicate with each other synchronous and/or asynchronous while being in the same or different place [22]. Furthermore, using these apps instead of visiting someone saves time, and in contrast to telephone use, the information can be reread [4]. The above elaboration leads to the third research question:

RQ3: Which organizational conditions facilitate or restrict the implementation of a communication app in a home care organization?

## Methods

### Sample and Design

The research team, the app developer and a home care organization in a rural area in the eastern part of the Netherlands, agreed to arrange a pilot study to monitor and examine among clients of one specific team the implementation of the DNC app.

The app was software developed for digital communication in a closed network. Using an internet browser, the software could be implemented on an iPad, iPhone, and/or personal computer. It contained a calendar to schedule meetings and tasks, and users could leave electronic messages (e-messages) and photos. Users received prompts to indicate that new messages were present. The district nurses and team manager asked clients and/or their informal carers to participate in the pilot, and finally, 7 care networks around clients agreed to use the app. These networks all met the criterion that at least one informal caregiver and one formal home caregiver could be hooked onto the app. Other criteria for selection were not used, and clients varied in health

conditions and living arrangements. Out of the 7 care receivers, 3 suffered from dementia to the extent that they could not participate themselves in interviews. In their case, informal caregivers spoke on their behalf. The 7 care networks started to use the app in February 2015 (T0). At the same time, information was collected on characteristics of the care recipient, the informal caregivers, and formal caregivers involved. The interviews were held face-to-face, by phone, or via Skype. Follow-ups were planned after 3 months (T1) and 6 months (T2). Monthly updates on log-in information were obtained from the developer of the tool. Auxiliary nurses who became members of the digital networks were interviewed during a focus group session, and field notes were made while observing 2 workshops to inform clients and/or their care network about the groupware tool. For the sake of completeness, 3 managers of the care agency were questioned about their vision and expectations on the DNC as part of the structural work of their staff. During the period of research, we conducted 42 semistructured interviews with 22 participants, consisting of 4 clients, 7 informal carers (of which 3 spoke on behalf of the care receiver as well), 3 district nurses, 5 auxiliary nurses, and 3 managers. Informed consents are obtained from the participants, and in field notes and transcriptions, their names are withheld for reasons of confidentiality.

### Procedure

Completed questionnaires were used to provide a short description of the clients and what type of care he or she got from whom. The gathered information was calculated using IBM SPSS version 23.0. Log-in data were provided monthly in an Excel sheet: actions, appointments, actors, and messages were coded (eg, action=entering text, appointment=going to the dentist, actor=district nurse, and message=care related/not care related), and the total number of different types of log-ins were counted. The audiotaped interviews were transcribed verbatim. For answering the 3 research questions, we investigated the transcriptions, field notes, and e-messages by using qualitative, directed content analysis [23]. The analysis consisted of reading and rereading the different types of data and writing down citations addressing the research questions. The next step was to search for linking themes and interpret them by means of constant comparison. Finally, the transcriptions are worked through by the qualitative research software Atlas.ti 7.5. Multiple ways of data collection have thus been used with multiple types of respondents. An overview of which information is provided by whom is given in Table 1.

**Table 1.** Overview of the data collection for answering the research questions.

Network, respondents, log data	T0	T1	T2
<b>NW<sup>a</sup>1</b>			
CL <sup>b</sup>	2 <sup>c</sup> , 5 <sup>d</sup>	3 <sup>e</sup>	3, 5
IC <sup>f</sup>	2, 5	3	3, 5
Log data	Yes	Yes	Yes
<b>NW2</b>			
IC on behalf of CL	2, 5	3	3, 5
IC	2, 5	3	3, 5
AN <sup>g</sup>	1 <sup>h</sup>	1	N/A <sup>i</sup>
Log data	Yes	Yes	Yes
<b>NW3</b>			
IC on behalf of CL	2, 5	1, 3	3, 5
IC	2, 5	3	3, 5
AN	1	1	3
Log data	Yes	Yes	Yes
<b>NW4</b>			
CL	2, 5	1, 3	3, 5
IC	3, 5	3	3, 5
AN	1	1	4 <sup>j</sup>
Log data	Yes	Yes	Yes
<b>NW5</b>			
IC on behalf of CL	2, 5	3	3, 5
IC	2, 5	3	3, 5
AN	1	1	3, 4
Log data	Yes	Yes	Yes
<b>NW6</b>			
CL	1, 5	2	3, 5
IC	1, 5	2	3, 5
DN <sup>k</sup>	1, 4, 5	1, 3	3, 5
AN	N/A	1	4
Log data	Yes	Yes	Yes
<b>NW7</b>			
CL	N/A	1, 3, 5	3, 5
IC	N/A	1, 3, 5	3, 5
DN	N/A	3, 5	3, 5
Log data	N/A	Yes	Yes
<b>NW1-5</b>			
DN	1, 4, 5	1, 3, 5	3, 5
DN of CL not started	N/A	3	N/A
AN of CL not started	3	N/A	4
Team manager	4	1	N/A
Division manager	3	N/A	N/A

Network, respondents, log data	T0	T1	T2
Sector manager	3	N/A	N/A

<sup>a</sup>NW: network.

<sup>b</sup>CL: client.

<sup>c</sup>2: face-to-face interview.

<sup>d</sup>5: questionnaires.

<sup>e</sup>3: telephone or Skype interview.

<sup>f</sup>IC: informal carer.

<sup>g</sup>AN: auxiliary nurse.

<sup>h</sup>1: observation.

<sup>i</sup>N/A: not applicable.

<sup>j</sup>4: focus group interview.

<sup>k</sup>DN: district nurse.

## Results

### Descriptions of the Care Recipients and Their Networks

The 7 networks (NW) that were involved in our research can be distinguished because of varieties between their care situations. Of 4 networks (NW1, NW4, NW6, and NW7), the clients needed care because of physical restrictions, but they were cognitively functioning well and capable of using the DNC app. Their networks consisted mainly of nurses who gave personal care. Informal carers were helping with transportation and arranging tasks and did some household work on an irregular basis. NW1 and NW7 comprised a cohabitated informal carer, a son and a partner, respectively. The client of NW7 had arranged several formal carers via the internet, such as the district nurse who was involved in our research as well. The other 3 networks (NW2, NW3, and NW5) comprised clients who had varying degrees of dementia and were therefore not capable of using the DNC app. They were all fragile, but the client in NW3 was especially restricted in her instrumental daily activities. Further details can be found in [Table 2](#).

### Functional Use of the App

The log-in data we collected over time showed how often communication occurred, who were central senders of e-messages, and who responded to senders. These data gave rise to the insight that the communication varied by the aim for which the app was used (RQ1). The 3 most dominating aims were to (1) arrange care tasks, (2) communicate about the circumstances of the care receiver, and (3) keep in touch/informed about the care situation. Together with characteristics of senders and content of information, 3 different types of online networks surfaced from the data: arranging the care network, discuss the care network, and staying connected network.

#### The “Arranging the Care” Network Type

This type of network is characterized by highly frequent (daily to weekly) usage of the digital agenda, which is used to plan care activities and shifts of caregivers (NW7). The one who

directed this digital network is the care recipient himself. His input was focused on making appointments with the formal caregivers. Digital communication occurred most often between the client and the district nurse. The characteristic of the content was pragmatic and concerned the organization of care. The log-in data revealed that the other DNC app members (other nurses, spouse, and relative) logged in regularly for checking information but rarely posted an e-message. During the period of our observation, there was no deterioration in the functional abilities of the client. Therefore, there was no need for additional hours of care over time, which explains the stable usage of the tool in the course of the time. The functional use of the app is clear from the following quote of the care recipient:

*...it depends on...is it a privacy issue or not. But if it is a task what can be changed in general, than undoubtedly...it has to be mentioned on the DNC-app, to make everyone aware. [Interview, NW7, client]*

#### The “Discuss the Care” Network Type

In this type of digital network, the client does not take part himself or herself because of severe cognitive impairments (NW2, NW3, and NW5), and the central informal carer and the district nurse or auxiliary nurse are communicating frequently with each other about the care situation. In NW3 and NW5, there is weekly to monthly activity on the DNC app. The central informal carer of NW2 uses it rarely because of lack of computer skills. In addition, 2 networks (NW2 and NW3) hardly used the digital agenda and action register, but conversely, NW5 used both often. Sometimes the e-messages contained information about housekeeping issues and public health care services concerning the client, such as the following two statements:

*As requested by XXX (the auxiliary nurse), I collected bandages from the pharmacy and brought them to mother (they are in the closet where the Care manual is also placed). [Log-in, NW3, informal caregiver]*

*This morning, I paid a visit to your mother. To me, she seemed cheerful. The wound heals well. I am glad that now her bed is at the proper height. [Log-in, NW3, auxiliary nurse]*



**Table 2.** Characteristics of the care networks at the beginning of the research, number of members of the DNC (digital networked communication) app, and the frequency of using the app during the whole period of observation.

Network	Client, type of helpers, amount and type of help	DNC app users	Frequency of using
1	Middle-aged man, sharing his home with his adult son, average level of education, cognitively functioning well, physically restricted, wheelchair dependent, socially active. Per week, 4 hours of private household work, 3 hours of formal household work, 5 hours of personal care by AN <sup>a</sup> .	1: DN <sup>b</sup>	3 times in the whole period
2	Woman, aged 70 to 75 years, widowed, lives on her own, suffering from dementia, socially active especially with family. Besides her daughter (IC <sup>c</sup> , aged 40 to 45 years), there are 5 family members helping with household work, transportation, and finances. One time a day, AN looks how she is doing. In the mixed care network, both a DN and a CM <sup>d</sup> are involved.	2: DN, IC	Less than once a month
3	Woman, aged 90 to 95 years, widowed, lives on her own, low level of education, suffering from dementia, restricted in her instrumental daily activities. Besides a son (IC, aged 65 to 70 years), there are 4 other family members helping with household work, transportation, and arranging tasks (3 hours a week). Every day ANs are taking care of heating the food in the microwave, intake of her medication, bathing, and dressing (13 hours a week).	5: DN, IC, AN, private household worker, FM <sup>e</sup>	Once a month
4	Woman, aged 80 to 85 years, widowed, lives on her own, average level of education, cognitively functioning well, physically restricted, wheelchair dependent, socially somewhat restricted. Her IC is an acquaintance (woman, aged 35 to 40 years); she assists the client with arranging tasks. She has a stepdaughter living abroad. Other relatives are a friend and neighbor; they do some household work. ANs come 5 times a day for helping her with meals, personal care, and nursing tasks.	5: CL, DN, IC, AN, FM	Once a week
5	Couple, both suffering from dementia. However, with some difficulty, the woman is able to support her husband a little bit. Aged 80 to 85 years, living on their own, low level of education. Besides a son (IC, aged 40 to 45 years), there are 6 other family members helping with household work, transportation, and arranging tasks. Per week, 3 hours of household work and 3 hours of helping with their medication intake by AN.	6: DN, AN, IC, CM, 2 FMs	Once a week
6	Woman, aged 85 to 90 years, widowed, lives on her own, low level of education, fragile. Besides a daughter (IC, aged 55 to 60 years), there is 1 other daughter helping with household work, transportation, and arranging tasks. Per week, 2 hours household work and 3.5 hours of personal care by AN.	5: CL, DN, IC, AN, FM	Since June more activity
7	Man, aged 60 to 65 years, cohabiting partner. Average level of education, substantial functional restricted, wheelchair dependent. Per week, 32 hours household work, 24 hours personal help, 4 hours nursing tasks, and 2 hours transportation by partner (IC, aged 55 to 60 years). A son, friend, and neighbor help with, for example, transportation and arranging tasks. Per week, 4 hours of household work, 11 hours of personal care, and 7 hours of nursing tasks by DN or/and AN from different agencies.	8: CL <sup>f</sup> , DN, IC, FM, 4 ANs of another agency	More than weekly

<sup>a</sup>AN: auxiliary nurse.

<sup>b</sup>DN: district nurse.

<sup>c</sup>IC: informal carer.

<sup>d</sup>CM: case manager.

<sup>e</sup>FM: family member.

<sup>f</sup>CL: client.

As in the type of network described above, log-in data of this type showed regular log-ins from other helpers just to inform themselves, mostly without leaving an e-message behind. It should be noted that all of the affiliated informal carers of NW3 met each other face-to-face on a regular basis, which reduced the need to actively take part in the DNC. During the study period, the functional abilities of the care recipients decreased, which required adjustment of care activities. This coincided with an increased use of the groupware tool in NW3 and NW5 and digital discussions on specific situations and care needs.

### **The “Staying Connected” Network Type**

Differing from the other 2 network types, this network type comprised an equal contribution in communication by the client, the informal carer, and the nurse (NW4 and NW6). During the

entire period of observation, the log-in data showed a low level of activity. Compared with the *discuss the care network*, the necessity for DNC seemed to be missing because the care recipients were still able to communicate themselves, and there was no deterioration in their functional abilities and no change in care needs in the period of observation. Therefore, quite a lot of e-messages were not about care but about leisure spending of the care recipients, periods of absence of the carers, and daily issues. Both care recipients explained that they experienced a lack of benefit of using the tool. They preferred communicating by phone or face-to-face to digital communication:

*If I want to go out this afternoon, I can put a message on the app, but she (the auxiliary nurse) might not see it on time. That's why I prefer to call her by phone. [Interview, NW4, client]*

The central informal carers of NW4 and NW6 articulated that the possibility to log in on to the DNC app increased the peace of mind. Although not living nearby, in a split second, the carers can be alarmed by receiving a push message if the health condition deteriorates. Otherwise, if everything is going well with their beloved one, they were reassured by reading e-messages such as this one:

*How kind of you sending me a message! I'm doing well, hope you're fine. Dear regards [Log-in, NW6, client]*

### Consequences of Using the Digital Communication App

During the interviews, we asked clients and their helpers what might be the effects of using the DNC app for communication on care, the efforts from informal carers to help, and the perceived quality of care (RQ2). The forms that were supplied to the clients and informal carers included relevant questions, with scales to measure changes herein during the period of observation.

#### Effects on Communication on Care

In general, the participants seemed to agree with each other that using the DNC app contributes to a quicker, better, and intensified connection between the affiliated members of the mixed home care network. Especially, the informal carers emphasized the advantage that everyone can be immediately aware of what is going on. By logging in, the information became visible, so everyone can be informed about which task has to be done by whom:

*Well, you see...for example...look here, here are the appointments [He shows the interface on his laptop]. This is an enumeration of work to do, we arranged that by mutual discussion. My brother, weekly he buys the groceries. My girlfriend and I are the back up. My other brother does the garden, and his sons are the back up. [Interview, NW5, informal carer]*

Despite their low use of the tool, the informal carers in the *staying connected* network type appreciated the opportunity to see online information that would have been otherwise obtained by reading the hard-copy dossier at the client's home. One of the informal carers, therefore, stressed that the ability to have short lines in the triangle of client-caregiver-professionals was the main motivator for her to use the DNC app:

*In the past week I have checked the app and it decreases the necessity for other modes of contact. We will use it more to maintain the communication within the triangle. [Interview, NW3, informal caregiver]*

In contrast, the client of NW7 mentioned several shortcomings of the tool that hindered coordination of caring tasks. Most of them were functional issues such as the inability to rehearse arrangements in the agenda in a simple way. Notably, the clients of NW4 and NW6 expressed that the DNC app would be an innovative idea for carers of people with dementia but not for themselves because they are cognitively still functioning well. Therefore, they prefer face-to-face or phone consultation rather

than digital contact to coordinate care. Finally, [Table 2](#) shows that during the period of observation, there was no mutual communication at all in NW1. The reason to not use the DNC app was their familiarity with other digital communication tools. Besides that, the helping family members lived nearby, so there was no need for them as well. Overall, for all the members of NW1, there were not enough triggers to use the groupware tool. However, till the end of the project, they were eager to provide information on effects of using mainly WhatsApp to coordinate all types of helping tasks. One of the consequences was that except for arranging transportation, they hardly communicated by phone anymore.

For the home care workers, the downside of the DNC app was the huge amount of posts to be read by them. A lot of the nurses read the e-messages in their spare time, especially the ones who had not yet received an appropriate mobile phone from the agency. Furthermore, during the period of observation, there was the disadvantage of the existence of various methods to submit the same information, such as via the DNC app, on the intranet of the care agency and in the dossier at client's home.

#### Effects on Degree of Help From Informal Carers

At the end of our period of observation of only 6 months, it was not possible to determine whether the e-tool had contributed to a statistically significant increase of informal help within the networks. The sample was too small to calculate differences. Neither was it possible to establish a significant decrease of formal help. If more helping hours per week were reported at T2 compared with T0, it seemed related to an increased demand for care of the client. However, by interviewing the informal carers 3 consecutive times, we can conclude that they became more engaged with the tool and that they felt more comfortable using the app later than in the beginning.

It is relevant to mention here that some home care workers expressed that they gained more insight into the degree of resilience of informal carers:

*Although we see on the DNC-app only elaborations about care situations, it's ok. It gives us a chance to determine their ability to care. [Interview, district nurse NW1-5]*

Moreover, not earlier than in the final phase of the study, we saw in the log-in data some cautious insinuations from nurses to get a task done by an informal carer:

*Would/could you discuss with the general practitioner which medical options there are to lessen the pain of your mother? Please, take into account that some medication increases the risk of falling. [Log-in, NW3, district nurse]*

On the other hand, one of the district nurses said she felt encumbered to ask for more help if only 1 informal carer is connected on the DNC app.

#### Effects on Quality of Experienced Care

Noticeably, the client who showed the highest degree of acceptance to use the groupware tool was the frailest of our research group. Due to his physical limitations and the large

number of caregivers, he was very enthusiastic about using the app:

*The app is the central point where carers can find the latest information. It gives me confidence that they know what to expect and how to handle.* [Interview, NW7, client]

His central formal carer confirmed this improvement in quality from her perspective:

*The DNC-app increases the client's self-efficacy on his life and caring tasks.* [Interview, NW7, district nurse]

The formal caregivers mostly admitted that the DNC app could be helpful when dealing with complex care and that the tool could also relieve their daily work practice:

*Before we go to the house of the client we can inform and prepare ourselves just by logging in on the DNC-app.* [Group session, auxiliary nurse]

Finally, to enhance the quality of care, some affiliated members suggested to invite other disciplines besides the participants of the mixed care network. For example, the general practitioner, dementia case manager, and physiotherapist could be hooked onto the DNC app as well. In this case, some nurses expressed, for example, that photos that provide insight into the healing tendency of wounds can be exchanged. At the same time, this elicited hesitations as photos and medical information provoke issues such as privacy and integrity.

### **Organizational Conditions Which Facilitate or Restrict the Implementation of the Digital Networked Communication App**

The data collected from home care workers and their managers showed that different factors contributed to (non)use of the DNC app (RQ3). The coordination of care was mentioned several times by the managers as an important potential benefit of the app but in the first place, they perceived this type of software to be a tool to monitor the care situation of their frail clients. Monitoring is necessary for safety reasons and for getting information about what can be done by the informal carers and when and how formal care is needed. However, the management also stressed to be cautious because the use of the DNC app is limited, given the data protection legislation.

Regarding the existing workflow of the home care workers, the recent reforms in long-term care are mentioned by auxiliary nurses several times as a barrier to implement the app. Due to a decrease in time for care provision, they see lesser opportunities to use the tool. Although their pessimism reduced in the course of time, during the T1 meeting, they were told to be distrustful because the DNC app would reduce their leisure time. They feared receiving a notification on their mobile phone after working hours, which needed to be taken care off. In addition, an auxiliary nurse expected that the app would lower the threshold for informal carers to ask nurses doing tasks that did not belong to their responsibilities (anymore). In contrast, the district nurses showed more enthusiasm from the start in adopting tools such as the DNC app. In a later stage of the implementation, the attitude toward the app of both types of

nurses became more similar. They saw as potential benefit that links between the informal and formal carers can be shortened by the app if appropriate agreements are made:

*If you have questions about their father or mother, and they just do not pick up the phone, then it may take too long before we have connection with each other. When they decide to use the app to communicate with us, then there is a commitment. In that case, they should at least once a week have to deal with the DNC-app.* [Focus group session, team manager]

The use of the app can be hampered when it is not clear who is responsible for assisting the informal carers in the use of the device. The following 2 statements make it clear that an informal carer had difficulties with the DNC app but was motivated to get instructions from the app developer:

*...and I had as well difficulties with another functionality. I tried a few times, without succeeding. Yeah, what to do about it.* [Interview, NW2, informal carer]

*The developer comes this week to help me, I hope he don't forget it. We have to wait again.* [Log-in, NW2, informal carer]

The district nurse of NW2 is, during the T2 interview, clear in her opinion that the developer failed to take his responsibility to instruct this client in using the DNC app:

*I thought he is the one who should have helped her till she knows how to use it.* [Interview, NW2, district nurse]

## **Discussion**

### **Principal Findings**

More reliance on informal caregivers of older people living at home asks for more connection and communication among all types of caregivers. Therefore, the main aim of this study was to explore the variety of DNC within different types of mixed home care networks. Studying the qualitative and quantitative information gave us insight into which aspects the 3 types of actors (clients, informal, and formal carers) showed similarities and differences in views on using a DNC app to communicate with each other and barriers and facilitators for its implementation.

Overall, such a digital tool in a closed network can facilitate communication on care between the client and informal and formal carers. How it will be used depends largely on the involvement of the client. If the client has a high capacity to use the tool and engagement to optimize the coordination, it may lead to more use of the agenda instead of communication about care. On the other hand, in case of lower involvement or absence of involvement of the client, the likelihood of communication between carers increases, especially when the informal helper has a strong motivation to use the digital tool. In small offline networks when the care situation is stable and the client has no or little involvement, a digital network surfaces, which exists but is not used very often. In that case, the informal

carer uses the tool for his peace of mind. Looking at these insights, there is a tendency to say that the sources and content of communication of online networks, in particular, reflect the needs, capabilities, and attitudes toward DNC of the care recipient and the informal caregivers, and to a lesser degree, the structure of the care network present.

However, the e-tool seems to be of particular use to mixed care networks with many different caregivers. In this type of network, it is not necessary that all participants are communicating online with each other, as care can be arranged among just a few of them; however, their e-messages are available for everybody when they log in. Therefore, the most important benefits of the tool for the client and his carers seem to be the easy availability of up-to-date information, the ability to give a sense of safety for the carers, and short communication lines in case of complex care situations. On the other hand, there is no clarity yet about whether electronic communication contributes to an increase of hours and types of informal help or to quality of life of clients and caregivers.

### Remarks and Recommendations

On the basis of our findings, several steps can be identified that home care organizations need to take when starting to use a groupware tool. The first step is to identify the targets that the use of the app may deliver. One such target could be to work more efficiently as face-to-face contact with affiliated members is replaced by online contact, which saves time. Other targets may be a larger involvement of informal carers and improved coordination of care within the mixed home care network. Second, the home care workers need to select clients and their caregivers for whom the groupware tool might work. This, in particular, concerns capable clients and caregivers who value digital communication [12]. The third step is to identify the mixed home care network around the determined client and arrange a meeting about who to invite to connect on the groupware tool, what type of communication is most appropriate, and how often communication is expected. The 3 types of digital care networks identified in this study can be used as examples for the home care staff in which different agreements with clients and caregivers can be made. Finally, continuous monitoring of the actual use of the app is warranted. Care situations change, which need to be reflected in the use of the app. For example, using only the calendar can be sufficient when the client is cognitively functioning well but may fall short as his or her health deteriorates. In that case, adjustments in the way of communicating are necessary because the digital *arranging the care* network may need to become a *discuss the care* network type.

### Strengths and Limitations of the Study

The strengths of our design are that multiple types of participants (clients, caregivers, and managers) were interviewed, thereby representing a wide range of perspectives. Furthermore, multiple ways of data collection made it possible to come up with rich information to answer our research questions and to contribute to the process of theorizing new sociological phenomena as DNC.

There are also limitations of the study. First, there were few specific inclusion criteria for the pilot study, so there is a high variability among the cases included. Second, the small size of the sample and the low use of the tool limited statistical analyses to corroborate our findings. Moreover, the period of observation was relatively short and did not allow for significant changes in structural and functional characteristics of the mixed care networks. It can be concluded that longitudinal large-scale studies are needed to examine how a tool such as the DNC app can indeed affect communication among caregivers.

### Conclusions

This small-scale study is one of the first to report on digital communication tools in mixed home care networks. Due to the information collected with multiple methods and from different types of actors, we were able to come up with (RQ1) 3 types of communication patterns in home care networks to illustrate the different functional uses of the groupware tool. These differences are clearly related to the physical frailty status of the care recipient, the motivation of client and informal caregivers, and the opportunities for the formal caregivers to use the tool and are less related to the structural features of the care network. Although the online care network may be rather comparable with the offline care network, digital communication is limited to specific network members and mostly focused on the arrangement of care in times that this was most needed. Those characteristics (RQ2) enhanced the care management of the digitally literate care recipients, the feelings of safety among informal caregivers, and efficiency of organization by the formal caregivers, which are all basic ingredients of good quality of care [24]. Before actually using an e-tool, it is important to (RQ3) consider the several barriers and facilitators of success when implementing it into home care organizations. For example, groupware tools have less privacy problems than eHealth and care records, which may be a trigger to implement the tools in home care organizations [25]. Finally, DNC may enhance the linkages in the triangle of client, informal caregiver, and professional caregiver and increase peace of mind among all users.

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### Conflicts of Interest

None declared.



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## Abbreviations

**AN:** auxiliary nurse  
**CM:** case manager  
**CL:** client  
**DN:** district nurse  
**DNC:** digital networked communication  
**eHealth:** electronic health  
**e-message:** electronic message  
**e-tool:** electronic tool  
**FM:** family member  
**IC:** informal carer  
**NW:** network  
**RQ:** research question

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Original Paper

# Informal Caregivers' Use of Internet-Based Health Resources: An Analysis of the Health Information National Trends Survey

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## Abstract

**Background:** Informal caregivers express strong interest in technology innovations to help them in their caregiving role; however, divides across sociodemographic characteristics in internet and technology access may preclude the most vulnerable caregivers from accessing such resources.

**Objective:** This study aims to examine caregivers' internet use, both generally and for seeking health-related information, and whether usage differs as a function of caregivers' characteristics.

**Methods:** Data were analyzed from the Health Information National Trends Survey 5 Cycle 1. Participants were included in analyses if they self-identified as providing uncompensated care to a close individual. Caregivers reported internet use factors, age, education, rurality, general health, distress, and objective caregiving burden. We used chi-square tests of independence with jackknife variance estimation to compare whether internet use factors differed by caregivers' characteristics.

**Results:** A total of 77.5% (303/391) caregivers surveyed reported ever using the internet. Of internet users, 88.1% (267/303) accessed from a home computer and 83.2% (252/303) from a mobile device. Most caregivers accessed health information for themselves (286/391, 73.1%) or others (264/391, 67.5%); fewer communicated with a doctor over the Web (148/391, 37.9%) or had a wellness app (171/391, 43.7%). Caregivers reporting younger age, more education, and good health were more likely to endorse any of these activities. Furthermore, two-thirds of caregivers (258/391, 66.0%) endorsed trust in health information from the internet.

**Conclusions:** Computers and mobile devices are practical platforms for disseminating caregiving-related information and supportive services to informal caregivers; these modalities may, however, have a more limited reach to caregivers who are older, have less education, and are in poorer health.

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**KEYWORDS**

caregivers; health education; internet; information dissemination; mobile phone; uncompensated care

## Introduction

Over 42 million Americans provided unpaid care to a loved one with serious illness in 2015 [1]; these informal caregivers

provide practical, medical, and emotional assistance to people with illness, often with little preparation [2,3] and risking the decline of their own mental and physical health [4-7]. Caregivers see technology (eg, computers, smartphones, and tablets) as

having the marked potential to assist them in their caregiver role by offering conveniently accessible information, support, and organizational tools [8]. Indeed, caregivers are more likely than noncaregivers to have internet access and access health-related information over the Web [9]. As such, psychosocial researchers and caregiver advocates are also turning to internet-based programs as resources for this population, given caregivers' high barriers to accessing traditional in-person supportive care [8,10-14]. Although inequalities are narrowing, prevailing disparities in internet and technology access suggest that digital tools and interventions may not be equivalently accessible by all caregivers [15,16]. Americans aged  $\geq 65$  years, with high school education or less, and living in rural areas are both less likely to report home internet access or own a smartphone [15] and more likely to experience poor health outcomes from caregiving [17-19]. These disparities suggest that some of the most vulnerable caregivers may be least likely to benefit from internet- and technology-delivered resources, warranting further investigation.

Informal caregivers are a high-risk population for poor mental and physical health outcomes. Compared with the general population, caregivers report higher rates of depression and anxiety [20-22], have poorer healthy lifestyle behaviors, such as diet, exercise, and sleep [23-25], and exhibit premature physical health decline [4,6,7]. Such discrepancies are likely related, in part, to the high stresses of caregiving. Caregivers report spending 24 hours per week on average on caregiving tasks [1], although demands can be markedly greater depending on the care recipient disease severity; caregivers for people with Alzheimer's disease are estimated to spend an average of 6 hours per day on caregiving [26], and cancer caregivers have described feeling "on-call" 24 hours per day [27]. Caregiving includes tasks such as assisting a loved one with activities of daily living and medical tasks, distributing information to family and friends, and navigating health care decisions [1]. Although in-person psychosocial interventions and educational tools have been effective in improving caregivers' well-being and role mastery [28-30], these interventions experience low enrollment, high dropout, and limited reach to caregivers of lower socioeconomic strata.

Disseminating caregiving resources through the internet may lower the barrier to entry and increase accessibility for caregivers by affording caregivers timely and convenient access to resources. Among the general US population, the internet fills an important gap in meeting health information needs; individuals with the highest barriers to health care access (ie, those who are traditionally underserved) are most likely to search for health-related information over the Web [31]. Over 90% of caregivers express interest in using internet- and technology-based tools to assist them in their caregiving role, with a particular interest in tools to help with managing medication refill and adherence, medical appointments, and emotional strain from caregiving [8]. While the acceptability of these tools seems apparent, <10% of caregivers report actually using any such tools that are currently available over the Web [8], raising questions regarding the extent to which all caregivers will be able to access and benefit equally from such internet- and technology-delivered resources. Such resources may range

in complexity from static informational websites to websites tailored based on user input, multicomponent programs and apps [13,14]. The uptake of these varying resources is influenced by caregivers' digital literacy (eg, personal capacity for technology use, including computer proficiency), accessibility of technology, caregiving needs, and stress [32]. Understanding how caregivers' sociodemographic factors may interact with their natural propensity to use different internet resources will help identify caregivers for whom internet-based tools may have the greatest, and least, reach.

Therefore, this study examines data from a large, nationally representative sample to better understand the potential reach of internet- and technology-delivered caregiving resources. The primary aims of this investigation are to characterize internet use among informal caregivers and examine whether internet usage differs according to certain sociodemographic, health, and caregiving-related factors. First, we characterize caregivers' self-reported internet use: both generally—whether they ever reported using the internet for any reason—and specifically for seeking health information. Next, we investigate whether such internet use differs according to factors potentially associated with disparities, namely caregivers' age, educational attainment, rurality, general health, distress, and caregiving burden.

## Methods

### Study Design and Participants

This is a cross-sectional study using data from the Health Information National Trends Survey (HINTS, 2017) [33] Version 5, Cycle 1, a nationally representative survey of civilian, noninstitutionalized adults aged  $\geq 18$  years in the United States. This survey is conducted by the National Cancer Institute (NCI) and assesses Americans' access to and use of health information. The HINTS was reviewed and approved by the Institutional Review Boards of the NCI Special Studies and the main contractor (Westat, Inc). Surveys were distributed by mail between January 2017 and May 2017. Of 13,360 surveys mailed, 3285 participants returned surveys (response rate, 32.4%). Additional methodology details are provided in the Methodology Report [34].

This analysis exclusively reports data from 391 participants who self-identified as a caregiver for an adult by answering affirmatively to the item "Are you currently caring for or making health care decisions for someone with a medical, behavioral, disability, or some other condition?" Caregivers could indicate that they were providing care to a spouse, parent, another family member, or another close individual; caregivers could select multiple responses to indicate they provided care for multiple individuals. Informal caregiving surveys typically focus on informal care to adults, given the anomalous, age-discordant nature of this caregiving [1,8]. Informal caregiving for a child is typically assessed with a denotation of atypical care provision, for example, "this kind of care is more than the normal care required for a child" [1]; no such specification was provided in the HINTS survey. As such, for this analysis, participants exclusively reporting caring for a child were not included ( $n=189$ ); however, individuals endorsing care for both a child and an adult were included ( $n=64$ ).

## Measures

The specific wording of all measures reported in this study is available on the Web [35].

### Internet Use Variables

Outcomes of interest were assessed by the following single-item questions.

#### Internet Use

Internet use was ascertained by participants responding to “Do you ever go on-line to access the Internet or World Wide Web, or to send and receive e-mail?” Response options were *Yes* or *No*.

#### Internet Use by Home Computer and/or Mobile Device

Those participants answering affirmatively to internet use were then asked, “How often do you access the Internet through each of the following...Computer at home?...On a mobile device (cell phone/smartphone/tablet)?” Response options were dichotomized to *Daily* and *Sometimes* versus *Never* and *Not applicable* for each item separately.

#### Wellness Mobile Apps

All participants were asked, “On your tablet or smartphone, do you have any ‘apps’ related to health and wellness?” Response options were *Yes*, *No*, *Don’t know*, or *Do not have a tablet or smartphone*. Participants who indicated that they did not have a tablet or smartphone were excluded from analyses with this variable (50/391, 12.8%). Remaining responses were dichotomized to *Yes* versus *No* and *Don’t know*.

#### Electronic Access of Health Information for Self and/or Someone Else and Contact With Doctor

All participants were asked, “In the past 12 months, have you used a computer, smartphone, or other electronic means to do any of the following...Looked for health or medical information for yourself?...Looked for health or medical information for someone else?...Used e-mail or the Internet to communicate with a doctor or a doctor’s office?” Response options were *Yes* or *No* for each item.

#### Trust in Health Information From the Internet

All participants were asked, “In general, how much would you trust information about health or medical topics from each of the following...Internet?” Response options were dichotomized to *Not at all* and *A little* versus *Some* and *A lot*.

### Caregiver Characteristics

Dichotomized variables for caregivers’ age (18-64 vs  $\geq 65$ ), level of education (*high school or less* vs *some college or more*), rurality (*metropolitan* vs *nonmetropolitan*), general health (self-reported as *excellent*, *very good*, or *good* vs *fair* or *poor*), distress [Patient Health Questionnaire (PHQ)-4 total score of  $\leq 2$  vs  $\geq 3$ ], and caregiving burden (time spent providing care  $< 5$  hours/week vs  $\geq 5$  hours/week) were examined for their relations to the internet use variables.

Age was dichotomized at 65 years (as reported previously [1]). Rurality was determined according to the National Center for Health Statistics Urban–Rural Classification Scheme for Counties, which was dichotomized to capture metropolitan

(large metro to small metro) versus nonmetropolitan (micropolitan and noncore) counties of participants’ residence. Distress was assessed by the PHQ-4 [36], which includes 2 items assessing anxiety and 2 items assessing depressed mood. Items are rated on a Likert scale score from 0 (*Not at all*) to 3 (*Nearly every day*). Higher sum scores indicate greater overall distress, with scores of  $\geq 3$  demarking clinically meaningful symptoms. The PHQ-4 has demonstrated strong reliability and validity for measuring depression and anxiety in the general population [36]. Caregivers’ reported hours spent caregiving per week (response options included “less than 5 hours per week,” “5-14 hours per week,” “15-20 hours per week,” “21-34 hours per week,” and “35 or more hours per week”) represented an approximate measure of the objective caregiving burden.

## Analytical Strategy

### Principal analyses

Descriptive statistics (means with SDs or frequencies, as appropriate) for study variables were conducted using SPSS version 25 (Tables 1 and 2). Research aims were addressed by weighted chi-square tests of independence that tested whether caregivers’ characteristics related to internet use variables. Data were analyzed using SAS 9.4 SURVEYFREQ procedures to account for the complex sampling design of the HINTS survey. Analyses were weighted using the full-sample weights provided in the public use datasets, yielding nationally representative population estimates. In addition, the jackknife variance estimation with repeated replications was used to estimate SEs, which reduces bias and, therefore, type I error. These procedures are in accordance with published HINTS analysis recommendations [37]. Furthermore, alpha of .05 was used to determine significance for all tests.

### Post-hoc analyses

Upon completion of principal analyses, we noted that 39 caregivers (10.0%) reported having accessed information or communicating with a doctor by internet-based or other electronic methods in the past year (ie, Information: Self, Information: Other, and/or Talk with Doctor=Yes), yet denied ever having used the internet (ie, Use Internet=No); this discrepancy suggests that some users may have incorrectly characterized themselves as noninternet users. To increase confidence that the planned analyses captured all caregivers who used the internet, a variable was computed that combined anyone who indicated affirmatively to any of the items—Information: Self, Information: Other, Talk with Doctor, and/or Use Internet. Then, weighted chi-square tests of independence were repeated, comparing the proportions of caregivers endorsing this expanded Use Internet variable by age, education, rurality, distress, and caregiving burden.

## Results

### Principal Results

Table 1 presents sample characteristics for participating caregivers’ sociodemographic, health, and caregiving factors. Caregivers’ average age was 58 (range: 24-101) years, 55.0% (215/391) of the sample self-identified as non-Hispanic white, 64.5% (252/391) identified as female, and 21.0% (82/391)

reported having children living in their home. Caregivers were most commonly (181/391, 46.3%) caring for a parent. Aging-related health issues (165/391, 42.2%) were most commonly reported as a reason that the care recipient required assistance. Most caregivers reported some college education or more (293/391, 74.9%), and lived in a metropolitan county (330/391, 84.4%). Most caregivers endorsed good health or better (319/391, 81.6%) and minimal distress (251/391, 64.2%). Caregivers most commonly reported spending  $\geq 5$  hours/week providing care to the care recipient(s) (228/391, 58.3%).

### **Aim 1: Characterize Internet Use Among Caregivers**

**Table 2** provides detailed descriptions of participating caregivers' internet use variables. Most caregivers indicated that they had used the internet (303/391, 77.5%); of these, most reported that they accessed the internet from a computer at home (267/391, 88.1%) and/or a mobile device (252/391, 83.2%). Among those with a tablet or smartphone, a similar percentage of caregivers endorsed having a wellness mobile app (171/391, 43.7%) versus not having one (165/391, 42.2%). Most caregivers reported having used electronic means to access health information for themselves (286/391, 73.1%) or someone else (264/391, 67.5%) in the past year; a few reported having communicated with a doctor using the internet or email (148/391, 37.9%). Furthermore, two-thirds of caregivers (258/391, 66.0%) endorsed mostly trusting medical information from the internet.

### **Aim 2: Examine Internet Use Across Caregiver Characteristics**

**Table 3** presents results for weighted chi-square tests comparing internet use generally (Use Internet) and internet use by home computer (Use Internet: Home) or mobile device (Use Internet: Mobile). Older age, less education, and metropolitan residence were associated with a lower likelihood of endorsing internet use. Among those caregivers endorsing internet use, worse general health was associated with a lower likelihood of accessing the internet from home computer, and older age was associated with a lower likelihood of accessing the internet from a mobile device.

**Table 4** presents results for weighted chi-square tests comparing a wellness mobile app use (Wellness App) and comparing electronic health information access for one's self (Information: Self) or another person (Information: Other). Among those owning a tablet or smartphone, older age was associated with a lower likelihood of having downloaded a wellness app. Only older age was associated with a lower likelihood of using the internet to access information for one's self. Furthermore, older age and less education were associated with a lower likelihood of using the internet to access information for someone else.

**Table 5** presents results for weighted chi-square tests, electronic communication with a doctor (Talk with doctor), and trust in health information from the internet (Trust internet information). Older age and worse general health were associated with a lower likelihood of electronic communication with a doctor. Worse general health was associated with less trust in health information from the internet.



**Table 1.** Sample description (N=391).

Characteristics	Value <sup>a</sup>
<b>Sample characteristics</b>	
Age, mean (SD)	58.3 (13.9)
Gender (Female), n (%)	252 (64.5)
<b>Race or ethnicity, n (%)</b>	
Non-Hispanic White	215 (55.0)
Non-Hispanic Black or African American	55 (14.1)
Hispanic	48 (12.3)
Non-Hispanic Asian	22 (5.6)
Non-Hispanic other	18 (4.6)
<b>Relationship to care recipient<sup>b</sup>, n (%)</b>	
Spouse	147 (37.6)
Child	181 (46.3)
Other family	77 (19.1)
Friend or other	38 (9.7)
<b>Care recipient condition<sup>c</sup>, n (%)</b>	
Cancer	65 (16.6)
Alzheimer's or dementia or cognitive impairment	132 (33.8)
Aging	165 (42.2)
<b>Children in home, n (%)</b>	
0	279 (71.4)
1-2	64 (16.4)
≥3	18 (4.6)
<b>Caregiver characteristics examined for impact</b>	
<b>Age group, n (%)</b>	
18-64	251 (64.2)
≥65	123 (31.5)
<b>Level of education, n (%)</b>	
High school or less	86 (22.0)
Some college or more	293 (74.9)
<b>Rurality, n (%)</b>	
Metropolitan	330 (84.4)
Nonmetropolitan	61 (15.6)
<b>General health, n (%)</b>	
Excellent, Very good, Good	319 (81.6)
Fair, poor	68 (17.4)
<b>Distress (Patient Health Questionnaire-4), n (%)</b>	
Minimal symptoms (≤2)	251 (64.2)
Mild symptoms or more (≥3)	128 (32.7)
<b>Caregiving burden, n (%)</b>	
<5 hours/week	136 (34.8)
≥5 hours/week	228 (58.3)

<sup>a</sup>Numbers may not total to N where data are missing.

<sup>b</sup>Caregivers may provide care to >1 relative.

<sup>c</sup>Care may be provided to care recipients for multiple conditions.

**Table 2.** Internet usage and electronic health information access among caregivers (N=391).

Questions	n <sup>a</sup> (%)
<b>Do you ever go online to access the internet or World Wide Web, or to send and receive email?</b>	
No	88 (22.5)
Yes	303 (77.5)
<b>If yes, how often do you access the internet by:<sup>b</sup></b>	
<b>A computer at home?</b>	
Daily or Sometimes	267 (88.1) <sup>c</sup>
Never or Nonapplicable	31 (10.2) <sup>c</sup>
<b>A mobile device?</b>	
Daily or Sometimes	252 (83.2) <sup>c</sup>
Never or Nonapplicable	38 (12.5) <sup>c</sup>
<b>On your tablet or smartphone, do you have any “apps” related to health and wellness?<sup>d</sup></b>	
Yes	171 (43.7)
No or Don't know	165 (42.2)
<b>In the past 12 months, have you used a computer, smartphone, or other electronic means to:</b>	
<b>Look for health/medical info for yourself?</b>	
Yes	286 (73.1)
No	105 (26.9)
<b>Look for health/medical info for someone else?</b>	
Yes	264 (67.5)
No	126 (32.2)
<b>Communicate with a doctor using email/internet?</b>	
Yes	148 (37.9)
No	242 (61.9)
<b>In general, how much would you trust information about health or medical topics from the internet?</b>	
A lot or Some	258 (66.0)
A little or Not at All	108 (27.6)

<sup>a</sup>Numbers may not total to N=391 where data are missing.

<sup>b</sup>Only caregivers indicating that they ever used the internet were eligible to respond.

<sup>c</sup>Percentage of those endorsing “Yes” to internet Use (ie, N=303).

<sup>d</sup>Caregivers who reported not having a tablet or smartphone were excluded.

**Table 3.** Differences in caregivers' internet usage by their characteristics.

Caregivers' characteristics	Use Internet			Use Internet: Home		Use Internet: Mobile			
	Yes, n (%) <sup>a</sup>	No, n (%)	<i>F</i> <sup>b</sup>	Yes, n (%)	No, n (%)	<i>F</i>	Yes, n (%)	No, n (%)	<i>F</i>
<b>Age (years)</b>			<i>8.80</i> <sup>c</sup>			0.34			<i>10.96</i>
18-64	212 (86.3)	39 (13.7)		192 (91.7)	18 (8.3)		193 (96.7)	16 (3.3)	
≥65	83 (59.6)	40 (40.4)		70 (87.2)	11 (12.8)		52 (68.8)	22 (31.2)	
<b>Education</b>			<i>5.44</i>			1.34			3.1
≤High school	53 (68.3)	33 (31.7)		45 (84.9)	7 (15.1)		39 (84.4)	11 (15.6)	
≥Some college	247 (83.8)	46 (16.2)		220 (92.8)	23 (7.2)		211 (95.1)	26 (4.9)	
<b>Rurality</b>			<i>7.07</i>			0.85			1.24
Metropolitan	253 (75.6)	77 (24.4)		225 (92.0)	25 (8.0)		215 (93.5)	28 (6.5)	
Nonmetropolitan	50 (90.5)	11 (9.5)		42 (85.3)	6 (14.7)		37 (85.8)	10 (14.2)	
<b>General health</b>			<i>2.54</i>			5.35			2.16
≥Good	264 (82.6)	55 (17.4)		237 (94.9)	22 (5.1)		222 (94.0)	30 (6.0)	
≤Fair	39 (63.9)	29 (36.1)		30 (67.0)	9 (33.0)		30 (81.5)	8 (18.5)	
<b>Distress (PHQ-4<sup>d</sup>)</b>			<i>1.36</i>			0			0.05
Minimal (≤2)	199 (75.5)	52 (24.5)		175 (90.7)	21 (9.3)		171 (92.5)	20 (7.5)	
Mild or more (≥3)	97 (83.0)	31 (17.0)		86 (90.7)	9 (9.3)		77 (91.7)	16 (8.3)	
<b>Caregiving burden</b>			<i>1.6</i>			0			2.81
<5 hours/week	114 (84.8)	22 (15.2)		99 (90.7)	13 (9.3)		97 (95.4)	11 (4.6)	
≥5 hours/week	177 (78.0)	51 (22.0)		158 (91.1)	16 (8.9)		144 (90.2)	26 (9.8)	

<sup>a</sup>Numbers may not match with totals reported in Table 2 where data are missing, and percentages are weighted using jackknife weighting.

<sup>b</sup>All chi-square tests have degree of freedom (1, 49)— $F > 4.04$ ,  $P < .05$ ;  $F > 7.19$ ,  $P < .01$ ;  $F > 12.37$ ,  $P < .001$ .

<sup>c</sup>Comparisons with  $P < .05$  are presented in italics for reference.

<sup>d</sup>PHQ-4: Patient Health Questionnaire-4.

**Table 4.** Differences in caregivers' use of wellness apps and access to electronic health information by their characteristics.

Caregivers' characteristics	Wellness App		<i>F</i> <sup>b</sup>	Information: Self			Information: Other		<i>F</i>
	Yes, n (%) <sup>a</sup>	No or don't know, n (%)		Yes, n (%)	No, n (%)	<i>F</i>	Yes, n (%)	No, n (%)	
<b>Age (years)</b>			<i>4.04</i> <sup>c</sup>			<i>9.89</i>			<i>13.82</i>
18-64	127 (59.4)	106 (40.6)		198 (80.2)	53 (19.8)		191 (79.8)	60 (20.2)	
≥65	36 (43.5)	57 (56.5)		76 (56.7)	47 (43.3)		64 (47.0)	59 (53.0)	
<b>Education</b>			1.63			2.83			6.54
≤High school	32 (48.7)	37 (51.3)		51 (65.0)	35 (35.0)		43 (56.1)	43 (43.9)	
≥Some college	138 (60.9)	126 (39.1)		229 (79.5)	64 (20.5)		217 (78.6)	76 (21.4)	
<b>Rurality</b>			1.98			1.24			0.09
Metropolitan	150 (59.6)	135 (40.4)		245 (76.2)	85 (23.8)		225 (71.5)	104 (28.5)	
Nonmetropolitan	21 (44.2)	30 (55.8)		41 (63.9)	20 (36.1)		39 (68.7)	22 (31.3)	
<b>General health</b>			3.72			0.55			1.05
≥Good	149 (60.6)	131 (39.4)		239 (76.8)	80 (23.2)		225 (73.8)	94 (26.2)	
≤Fair	22 (43.1)	32 (56.9)		47 (69.9)	21 (30.1)		38 (63.4)	29 (36.6)	
<b>Distress (PHQ-4<sup>d</sup>)</b>			0.11			0.12			0.30
Minimal (≤2)	114 (59.0)	104 (41.0)		186 (73.5)	65 (26.5)		175 (69.3)	75 (30.7)	
Mild or more (≥3)	55 (56.5)	54 (43.5)		92 (75.9)	36 (24.1)		46 (73.4)	82 (26.6)	
<b>Caregiving burden</b>			0.03			1.26			0.26
<5 hours/week	62 (58.1)	62 (41.9)		106 (81.1)	30 (18.9)		96 (75.1)	40 (24.9)	
≥5 hours/week	104 (59.5)	87 (40.5)		168 (73.4)	60 (26.6)		69 (71.9)	158 (28.1)	

<sup>a</sup>Numbers may not match with totals reported in Table 2 where data are missing, and percentages are weighted using jackknife weighting.

<sup>b</sup>All chi-square tests have degree of freedom (1, 49)— $F > 4.04$ ,  $P < .05$ ;  $F > 7.19$ ,  $P < .01$ ;  $F > 12.37$ ,  $P < .001$ .

<sup>c</sup>Comparisons with  $P < .05$  are presented in italics for reference.

<sup>d</sup>PHQ-4: Patient Health Questionnaire-4.

**Table 5.** Differences in caregivers' communication with doctors and trust in information from the internet by their characteristics.

Caregivers' characteristics	Talk with doctor			Trust internet information		
	Yes, n (%) <sup>a</sup>	No, n (%)	<i>F</i> <sup>b</sup>	A lot or Some, n (%)	A little or none, n (%)	<i>F</i>
<b>Age (years)</b>			<i>9.64</i> <sup>c</sup>			4.01
18-64	110 (45.9)	140 (54.1)		180 (73.3)	62 (26.7)	
≥65	35 (24.8)	88 (75.2)		72 (55.8)	38 (44.2)	
<b>Education</b>			2.19			
≤High school	25 (32.7)	61 (67.3)		47 (60.0)	30 (40.0)	
≥Some college	123 (44.1)	169 (55.9)		209 (72.3)	72 (27.7)	
<b>Rurality</b>			0.03			0.09
Metropolitan	126 (39.4)	203 (60.6)		219 (68.1)	87 (31.9)	
Nonmetropolitan	22 (41.1)	39 (58.9)		39 (65.3)	21 (34.7)	
<b>General health</b>			<i>6.37</i>			<i>6.77</i>
≥Good	132 (44.3)	187 (55.7)		225 (73.9)	77 (26.1)	
≤Fair	16 (21.6)	51 (78.4)		31 (42.7)	29 (57.3)	
<b>Distress (PHQ-4<sup>d</sup>)</b>			0.03			0.07
Minimal (≤2)	103 (39.6)	148 (60.4)		170 (68.3)	66 (31.7)	
Mild or more (≥3)	43 (40.9)	84 (59.1)		80 (66.3)	41 (33.7)	
<b>Caregiving burden</b>			2.28			1.85
<5 hours/week	63 (48.9)	73 (51.1)		99 (76.5)	29 (23.5)	
≥5 hours/week	81 (37.0)	146 (63.0)		150 (66.0)	66 (34.0)	

<sup>a</sup>Numbers may not match with totals reported in Table 2 where data are missing, and percentages are weighted using jackknife weighting.

<sup>b</sup>All chi-square tests have degree of freedom (1, 49)— $F > 4.04$ ,  $P < .05$ ;  $F > 7.19$ ,  $P < .01$ ;  $F > 12.37$ ,  $P < .001$ .

<sup>c</sup>Comparisons with  $P < .05$  are presented in italics for reference.

<sup>d</sup>PHQ-4: Patient Health Questionnaire-4.

## Post-Hoc Analyses

Weighted chi-square tests of independence were repeated for the expanded Use Internet item (ie, answering affirmatively to any of the items: Information: Self, Information: Other, Talk with Doctor, and/or Use Internet) that accounted for caregivers' potential misidentification as noninternet users. Results indicated a comparable pattern of findings between the original Use Internet and expanded Use Internet variables—older age ( $F_{1,49}=5.02$ ,  $P=.03$ ) and lower education ( $F_{1,49}=4.37$ ,  $P=.04$ ) were associated with lower reported internet use; general health ( $F_{1,49}=2.42$ ,  $P=.25$ ), distress ( $F_{1,49}=1.68$ ,  $P=.20$ ), and caregiving burden ( $F_{1,49}=3.74$ ,  $P=.06$ ) were not associated with the reported internet use. The only discrepant finding for the expanded Use Internet variable compared with the original Use Internet variable was that rurality was no longer significantly associated with internet use ( $F_{1,49}=2.42$ ,  $P=.13$ ).

## Discussion

### Principal Findings

Using data from a US nationally representative survey, this paper presents novel evidence regarding how internet use, both generally and specifically for accessing health-related

information, differs among informal caregivers according to certain key sociodemographic, health, and caregiving-related factors. Overall, the internet use, both by home computers and mobile devices, was common among caregivers, as was accessing health information for themselves and other people through the internet. The proportion of caregivers in this study who endorsed ever using the internet (303/391, 77.5%) was lower than prior estimates of internet use among the general population (89%) [15] or among caregivers (86%-92%) [8,9], although adjusting to include individuals who indicated any electronic access of health-related communication or information resulted in more comparable rates (342/391, 87.5%). The use of wellness mobile apps and communicating with a doctor's office by the internet were less common among caregivers. Older age, lower educational attainment, and poorer general health were associated with less frequent internet activity, as has been found among the general population [15]. Furthermore, rurality, distress, and caregiving burden were generally not related to internet activity.

From this survey data, caregivers aged ≥65 years tended to report lower overall internet use, with an estimated 40.4% of the population of older caregivers identifying as noninternet users, compared with 13.7% of caregivers under the age of 65 years. Among internet users, older caregivers did not differ from



younger caregivers in terms of home computer internet access but did endorse an approximately 10-fold lower likelihood to access the internet by a mobile device. Growth trends in mobile phone use are highest among older adults [38], however, suggesting the potential longer-term utility of mobile phones as a tool for enhancing older caregivers' well-being [13,39]. Fewer older caregivers reported having a wellness "app" downloaded, searching for health- or medical-related information, and communicating with a doctor's office using the internet. These findings regarding the disparity across the types of internet use by age are consistent with prior studies of both the general population [15,40] and caregivers [8], in which older adults are less likely to use the internet either in general or for health-related purposes. Low-barrier caregiving-related resources, such as those delivered by the internet, may be especially important for older caregivers, being particularly vulnerable owing to frequently having less help with caregiving, more medical problems of their own, and more barriers to accessing traditional in-person resources [1,17,18]. Importantly, older caregivers report being equally as interested in internet-based resources to assist them in their caregiving role as were younger caregivers [8], meaning older adults' lower internet use should not necessarily be interpreted as a lack of demand among this group. Interventions designed to enhance older caregivers' internet skills and digital literacy may help increase reach and benefit of internet- and technology-based health resources to this rapidly growing and especially vulnerable subset of informal caregivers (for review of similar programs, see Ref. [41]).

Caregivers reporting fair or poor overall health, another vulnerable caregiving population, were equally as likely to report internet use as caregivers reporting good or better health, yet reported 6-fold lower access from a home computer. In terms of dissemination of caregiver resources by the internet, ensuring that Web-based resources are compatible with both computer and mobile browsers will ensure the broadest reach of such resources. Many programs developed for caregivers, however, are not cross-platform appropriate (eg, disseminated through a native app vs a mobile-friendly website) [10-14], which would limit reach across caregivers. In addition, caregivers with poorer health were less likely to have communicated with a doctor or doctor's office through the internet and were twice as likely to distrust health-related information from the internet, despite being equally likely to access health information online. Notably, the HINTS survey did not qualify the item assessing trust in health information from the internet in terms of website reputability. It may be the case that caregivers in poorer health have had more experience finding "bad" information about health conditions online, thus expressing less trust in this modality. Overall, establishing reputability of internet- and technology-based caregiver resources, by ensuring the accuracy of information and creating a professional and appealing user experience, will be important to earn caregivers' trust and uptake [42].

Contrary to expectations, caregivers living in a rural area were more likely to report internet use than those in metropolitan areas, although this finding did not hold in post-hoc analyses when broadening the internet use variable to account for those

potentially misidentifying as noninternet users. The weighted percentage of internet use among the current sample of rural caregivers (90.5%) was substantively higher than prior nationally representative samples of adults living in rural areas (78%) [15], although the unweighted percentage (50/61, 82.0%) was more comparable. Given caregivers in rural areas have less access to traditional in-person health care resources, internet- and technology-based resources may help meet supportive care demand for these caregivers [31]. In addition, caregivers' internet activity did not differ according to caregivers' level of distress or caregiving burden. These findings contrast with previous qualitative findings among dementia caregivers, who had described stress and burden from caregiving as factors that interfered with their use of an internet-based intervention [32]. Further research into how caregiving stresses—both objective (eg, time and care tasks) and subjective (eg, perceived burden and impact of caregiving)—affect the uptake and use of internet-based resources will help to ensure the greatest reach and utility of these resources for caregivers who most need them.

### Strengths, Limitations, and Future Directions

This study reports findings from a cross-sectional survey that was designed to capture the attitudes of cancer-related health information from a representative sample of the general US adult population. As such, this survey was not designed to address research questions for this study specifically nor was sampling specifically targeted to family caregivers. Hence, this survey did not ascertain subjective caregiving burden or specific caregiving responsibilities, which may affect caregivers' motivation or need to access health information by the internet. In addition, it was not ascertained whether caregivers were utilizing the internet specifically to assist them in their caregiving role; however, this has been previously well-described [8], and this study extends the prior research to better understand what subsets of caregivers may be less likely to benefit from caregiver resources disseminated through the internet. Moreover, it should be noted that we analyzed a subset of the overall HINTS 5 cycle 1 sample (N=3285), namely those identifying as informal caregivers to adults (n=391), who were not representatively sampled among the national population of informal caregivers. This may reduce the reliability and generalizability of findings; however, robust analytical techniques that incorporate the complex survey weighting mitigates these concerns. Furthermore, these analytical techniques provide population estimates that are likely to be more representative than most prior research with caregivers, which has tended to disproportionately capture socioeconomically advantaged and non-Hispanic white individuals.

Ultimately, internet- and technology-based education, communication, and intervention hold significant promise to help caregivers be more active and connected participants in their care recipients', and their own, health care [12,39]. Although findings here suggest older caregivers, those with lower educational attainment, and those in poorer health are less likely to be using existing internet resources, it is not known why these individuals report less frequent use. Potential reasons explaining these discrepancies may include limited knowledge

of how to use technology, privacy concerns, costs of technology, lack of awareness of available internet resources, perception that the effort of using such resources would not outweigh potential benefits, or preferring more traditional resources, like print information or communicating with doctors by phone or at clinic appointments. Moreover, little is known about how such resources fit into caregivers' day-to-day lives or complement existing health care delivery systems [12], factors that may relate to caregivers' long-term use of and benefit from such tools. Continued research to understand caregivers' evolving needs, preferences for meeting those needs, and how needs and preferences differ among caregivers is necessary to ensure all caregivers may optimally benefit from internet- and technology-based caregiving resources.

## Conclusions

Most caregivers are internet users, both for general purposes and specifically to access health information. Caregivers over the age of 65 years, those with a high school education or less, and those reporting poor health report less internet activity, suggesting these vulnerable caregivers may not be equally benefited by internet- and technology-based caregiver resources without careful consideration of factors that might facilitate their use. In addition, caregivers' level of rurality, distress, and caregiving burden did not relate to their internet activity, suggesting these factors are not likely to impede caregivers' access to internet- and technology-based resources. Overall, internet- and technology-based resources to support informal caregivers are likely to have significant reach, yet close attention to the accessibility of such resources by the most vulnerable caregivers must be paid to ensure equal benefit.

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## Conflicts of Interest

None declared.

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## Abbreviations

**HINTS:** Health Information National Trends Survey

**NCI:** National Cancer Institute

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Original Paper

# Digital Media Recruitment for Fall Prevention Among Older Chinese-American Individuals: Observational, Cross-Sectional Study

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## Abstract

**Background:** Research in fall prevention programs has increased in recent years in response to the aging demographics of the United States. To date, limited research and outreach programs have focused on ethnic minorities due to increased cost, language barriers, and cultural differences. Digital media platforms may be a cost-effective avenue to initiate fall prevention programs for minority populations.

**Objective:** The objective of this study was to determine whether Facebook advertisements are a practical recruitment method for health education to the Chinese-speaking population.

**Methods:** This was an observational, cross-sectional study. We uploaded a video on fall education on YouTube and initiated an advertisement campaign on Facebook that was linked to the video. The target population was older adults aged >45 years who used Facebook and were presented with the advertisement (N=1039). We recorded metrics such as the number of unique individuals reached, the number of views of the advertisement, the number of clicks, user gender and age, and traffic sources to the advertisement. Data were analyzed with descriptive statistics.

**Results:** Our Facebook advertisement had 1087 views (1039 unique viewers). There were 121 link clicks with a click-through rate of 11.13% (121/1087). The cost per link click was approximately US \$0.06. Among the viewers, 91.41% (936/1024) were females and 8.59% (88/1024) were males. In the 45-54 age group, the ad reached 50 people, with 1 link click (2.00%). In the 55-64 age group, the ad reached 572 people, with 57 link clicks (9.97%). In the ≥65 age group, the ad reached 417 people, with 63 link clicks (15.11%).

**Conclusions:** Facebook was able to directly target the advertisement to the desired older ethnic population at a low cost. Engagement was highest among females and among those aged ≥65 years. Hence, our results suggest that Facebook can serve as an alternative platform for dissemination of health information to geriatric patients in addition to print-based and face-to-face communication.

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**KEYWORDS**

ethnic groups; falls; geriatrics; health education; social media; mobile phone

## Introduction

Falls are highly prevalent among older adults in the United States. Every year, 2.8 million older adults are admitted to emergency departments for fall injuries, and >800,000 patients

are hospitalized from fall-related injuries such as hip fracture or head injuries [1]. Falls can lead to devastating mental and physical consequences including fear for falling, low confidence, loss of independence, and premature death [2]. Furthermore, fall injuries place a tremendous economic burden on both patients and health care system [3]. As the percentage of older



adults in the United States continues to increase, it is estimated that the number of fatal falls among older adults is projected to reach 100,000 per year by 2030, with an associated cost of US \$100 billion [4].

In response to the aging demographics in the United States, new guidelines and outreach programs are being implemented and reformed. For example, the Centers for Disease Control and Prevention created the Stopping Elderly Accidents, Deaths, and Injuries initiative, a multiapproach program that aims to reduce fall injuries by improving screening and intervention rates at clinical settings. However, few programs were able to accommodate ethnic minorities with different culture and language backgrounds.

Minorities constitute the fastest growing segment in the rapid rise of older adults in the United States. Between 2001 and 2010, the older Asian American population increased by 145% [5]. Despite the rapidly changing demographics, research and medical services are lagging in identifying culturally influenced risk factors and in creating culturally sensitive resources [6]. Previous studies have shown that Chinese people commonly perceive falls as fatal, with low level of knowledge about fall prevention interventions, and often hide fall incidents from families and doctors [7,8]. Furthermore, Chinese-American individuals are more likely to underutilize health resources compared with Caucasians [9]. Hence, research and development of effective outreach methods is crucial in lessening the cultural and health knowledge gap among Chinese-American individuals.

Electronic health and Web-based outreach programs have shown substantial success in promoting awareness [10-14]. Popular digital marketing platforms such as Google, YouTube, and Facebook are increasingly being utilized to promote preventive medicine. A recent study showed that Facebook advertising was successful in improving the recruitment rate of older adults into a blood pressure clinical trial [10]. Another study showed that YouTube was effective in delivering dementia knowledge to older Chinese-American individuals [13]. However, few studies have investigated the role of Facebook in ethnic health outreach. Hence, we aimed to examine (1) whether Facebook advertising strategies are cost effective; (2) the ability of Facebook in targeting fall prevention and education to the Chinese geriatric populations; and (3) engagement among the targeted geriatric populations on Facebook compared with other social media platforms such as YouTube. We hope that this study can provide insights into the use of social media marketing in public health outreach for the geriatric populations.

## Methods

### Facebook Advertisement

We uploaded a recording of a 37-minute-long video of a medical education talk show at the radio station KMRB AM1430 in Los Angeles on YouTube in May 2016 [15]. The show was conducted entirely in Cantonese; contents included prevalence,

risk factors, prevention methods, and cultural factors and misconceptions about falls. An advertisement was then initiated on Facebook for 48 hours in September 2017, linking interested individuals to the video. The advertisement included a still of the video, an 11-character title, and a 23-character text body in traditional Chinese. The title can be translated into English as “What are the factors for loss of balance and falls among older adults?”

### Participants

The population sampled in this study included all viewers who saw the Facebook advertisement on Web during the 48-hour advertising campaign. According to the current literature, falls and related injuries are most prevalent in adults aged >65 years [1]. Therefore, we set the age of our target audience to be adults aged ≥45 years to include individuals who were beginning to enter the high-risk ages. These details were included as part of the initial Facebook advertisement registration process.

### Statistical Analysis

Data on the advertisement campaign were obtained via Facebook analytics. Parameters included the number of individuals reached (defined as unique advertisement viewers), the number of impressions (defined as the total number of views of the advertisement), the number of engagements (defined as the number of likes, clicks, or shares), the click-through rate (clicks/impressions), and the cost per click. In addition, demographic information including gender, age, and traffic sources was recorded. Data obtained via Facebook analytics were further confirmed using data directly obtained from the video link via YouTube analytics during the 48-hour campaign. Data were analyzed using descriptive statistics.

## Results

### Overall Ad Performance

Overall, the Facebook advertisement had 1087 impressions, of which 95.58% (1039/1087) views were by unique individuals (reach). Of 125 engagements recorded by Facebook analytics, 121 were link clicks, 3 were post reactions, and 1 was a post share. The click-through rate (clicks/impressions) was 11.13% (121/1087). The total cost of the advertisement for 48 hours was US \$6.82. The cost per 1000 impressions was US \$6.27, and the cost of the ad per link click was US \$0.06.

### Ad Performance by Gender, Age, and Traffic Sources

Table 1 presents the performance of the Facebook advertisement by different ages and gender. The advertisement reached 91.41% (936/1024) female viewers, with 112 link clicks (click-through rate, 11.97%). Conversely, the advertisement reached 8.59% (88/1024) male viewers, with 9 link clicks (click-through rate, 10.23%). Hence, the cost per link click among female viewers was US \$0.05, while the cost per link click among male viewers was US \$0.07.

**Table 1.** Descriptive summary of Facebook advertisement performance by gender and ages.

Variable	Reach, n (%)	Link clicks, n (%)	Cost per link click
<b>Gender</b>			
Female	936 (91.41)	112 (11.97)	US \$0.05
Male	88 (8.59)	9 (10.23)	US \$0.07
<b>Age (years)</b>			
45-54	50 (4.81)	1 (2.00)	US \$0.23
55-64	572 (55.05)	57 (9.97)	US \$0.07
≥65	417 (40.13)	63 (15.11)	US \$0.04

In the 45-54 years age group, the ad reached 4.81% (50/1039) viewers, with 1 (2.00%) link click. In the 55-64 years age group, the ad reached 55.05% (572/1039) people, with 57 (9.96%) link clicks. In the ≥65 years age group, the ad reached 40.13% (417/1039) people, with 63 (15.11%) link clicks. The costs per link click were US \$0.23, US \$0.07, and US \$0.04 for each group, respectively.

In the 45-54 years age group, 38 females and 12 males were reached; in the 55-64 years age group, 523 females and 43 males were reached; and in the ≥65 years age group, 375 females and 33 males were reached. There were 15 impressions with unknown gender. Only 1 female and no males clicked the advertisement in the 45-54 years age group; 52 females and 5 males clicked the advertisement in the 55-64 years age group; and 59 females and 3 males clicked in the ≥65 years age group.

With regards to device usage, the advertisement reached 99.62% (1035/1039) mobile device users, resulting in all 121 of the link clicks recorded. Only 4 users were reached through desktop devices, and there were no link clicks via desktop devices.

### Comparison With YouTube Data

During the first year when the same educational video was uploaded on YouTube, YouTube data showed 588 views with an average view duration of 27% (9.82/37.1 minutes) of the total video length. Mobile phones accounted for 52.2% (307/588) of the views.

In comparison, during the 48-hour advertisement run, the video had 75 views on YouTube, of which 66 viewers arrived from external websites. The total watch time was 440 minutes, and the average view duration was 16% (5.87/37.1 minutes) of the total video length. Data on audience retention revealed that 13% viewers (10/75 of viewers during this time period) finished all 37.1 minutes of the video. Mobile phones accounted for 85% (64/75) views.

## Discussion

### Principal Findings

This study demonstrates that Facebook was able to attract viewers to Web-based health education resources at low cost, as well as correctly target the advertisement at the desired older ethnic population. Engagement and cost-effectiveness were highest among those aged ≥55 years. This ultimately suggests that older Asian individuals may benefit from targeted

preventive health and educational interventions delivered through Facebook.

One advantage of using Facebook is its ability to directly target a certain demographic group; in our study, we were able to target our advertisement on fall education toward Chinese-American older adults with an above-average click-through rate (11.13% vs 0.90%) and a lower cost per click (US \$0.06 vs US \$1.72) compared with the Health and Medical Industry average [16]. On comparing with similar studies that were instead targeted toward younger adults, click-through rate of 11.13% (121/1087) of the older adults was almost 4 times as high as that of younger adults engaged with digital media advertising in other health outreach studies [17]; this suggests that older Chinese-American individuals have a relatively high interest in falls-related education, and they may be more receptive to remote health education compared with younger adults. In addition, this method of outreach is highly cost effective. Hence, our results suggest that Facebook could be an alternative way to reach this population despite the common belief that the geriatric population does not use social media.

A few other noteworthy patterns were also observed in this study. First, the advertisement disproportionately reached a very large number of female viewers compared with male viewers. Similar results have been noted in several previous studies on Facebook advertisements, which could be attributed to higher rates of Facebook usage by females across all ages [18-20]. In addition, the click-through rate for female viewers was slightly higher than that for male viewers. Moreover, click-through rates improved with the increasing age, causing cost efficiency to increase (as cost-per-click decreases) with the increasing age. The higher click-through rate among females and among older adults aged ≥65 years also suggest that these groups are more interested in obtaining health education through social media compared with males and other age groups. Furthermore, mobile devices accounted for a large amount of traffic through the linked advertisement.

Comparison of the data received from Facebook and the data gleaned from YouTube analytics during the 48-hour run of the advertisement revealed that the Facebook advertisement was able to increase traffic to the YouTube video. During the first year after uploading the video on YouTube, there were 588 views. During the 48 hours analyzed, there were 75 new views of the video, indicating that the advertisement was successful in directing traffic. Interestingly, the average view duration dropped from 9.82 minutes during the first year to 5.87 minutes

during the 48 hours. We speculate that this may be due to the fact that many Facebook users were not actively seeking out information on fall prevention when they came across the advertisement and, thus, may have a shorter engagement time than those who were actively searching for such information. However, the average view duration recorded from this advertisement coincides with the reported median engagement time of 6 minutes for Web-based educational videos, suggesting that the video was able to capture viewers' attention [21].

### Limitations

Limitations of this study include the inability of researchers to assess knowledge before and after viewing of the video. As such, the efficacy of the video in providing information on falls remains unknown. Additionally, because of the anonymity of internet users, as stated previously, there is no way of knowing the motivation of viewers for watching the video or their actual socioeconomic status. Furthermore, the study video was conducted in Cantonese; therefore, the audience reached was likely a selected group of Chinese-American individuals who are fluent in that language. Moreover, the advertisement only ran for 2 days, which qualifies as a short campaign. It remains unknown whether a longer campaign would have better or worse impact on the overall views of the video. Finally, the engagement time for the video was short. In the future, the video

should be shortened with more visual aids and focused content to improve viewers' engagement.

### Conclusions and Future Direction

Future studies should explore how to optimize advertisement descriptions to maximize the click-through rate. Owing to our result showing the high prevalence of female users in the older ethnic Facebook user population, we suggest that Facebook may provide an attractive platform for future distribution of information regarding women's health. In addition, future studies will likely have to address the increasing prevalence of mobile devices in exploring Web-based health care resources, as demonstrated by this study.

In this study, we were successful in engaging users; however, more research is needed in determining how to receive feedback regarding what this population may need in terms of health education information. Most viewers were older individuals belonging to an ethnic population; however, the very anonymity that attracts internet and social media users also makes it difficult for researchers to determine why this patient population is watching health education videos and to figure out the type of help they need. The question of how to bridge this gap between remote-based tools, internet anonymity, and clinical care is the next problem to solve in the internet and social media health information delivery research.

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### Conflicts of Interest

None declared.

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Original Paper

# A Fall Risk mHealth App for Older Adults: Development and Usability Study

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## Abstract

**Background:** Falls are the leading cause of injury-related death in older adults. Due to various constraints, objective fall risk screening is seldom performed in clinical settings. Smartphones offer a high potential to provide fall risk screening for older adults in home settings. However, there is limited understanding of whether smartphone technology for falls screening is usable by older adults who present age-related changes in perceptual, cognitive, and motor capabilities.

**Objective:** The aims of this study were to develop a fall risk mobile health (mHealth) app and to determine the usability of the fall risk app in healthy, older adults.

**Methods:** A fall risk app was developed that consists of a health history questionnaire and 5 progressively challenging mobility tasks to measure individual fall risk. An iterative design-evaluation process of semistructured interviews was performed to determine the usability of the app on a smartphone and tablet. Participants also completed a Systematic Usability Scale (SUS). In the first round of interviews, 6 older adults participated, and in the second round, 5 older adults participated. Interviews were videotaped and transcribed, and the data were coded to create themes. Average SUS scores were calculated for the smartphone and tablet.

**Results:** There were 2 themes identified from the first round of interviews, related to perceived ease of use and perceived usefulness. While instructions for the balance tasks were difficult to understand, participants found it beneficial to learn about their risk for falls, found the app easy to follow, and reported confidence in using the app on their own. Modifications were made to the app, and following the second round of interviews, participants reported high ease of use and usefulness in learning about their risk of falling. Few differences were reported between using a smartphone or tablet. Average SUS scores ranged from 79 to 84.

**Conclusions:** Our fall risk app was found to be highly usable by older adults as reported from interviews and high scores on the SUS. When designing a mHealth app for older adults, developers should include clear and simple instructions and preventative strategies to improve health. Furthermore, if the design accommodates for age-related sensory changes, smartphones can be as effective as tablets. A mobile app to assess fall risk has the potential to be used in home settings by older adults.

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**KEYWORDS**

usability; fall risk; mHealth app; mobile phone



## Introduction

In adults 65 years or older, 1 in 4 will fall per year [1]. Falls are also the leading cause of injury-related death in older adults [2]. The Centers for Disease Control and Prevention recommends annual falls screening for all older adults. However, objective fall screening is rarely assessed in clinical settings, in part because it requires expensive equipment, clinicians have time constraints, or they may not have the training or relevant expertise [3].

Mobile technology such as smartphones offer a potential solution for measuring fall risk objectively, inexpensively, and with minimal training required. Unlike gold-standard technology for fall risk assessment (ie, force plates, stand-alone accelerometers, and high-speed motion capture cameras), smartphones are commercially available and cost-efficient [4]. While smartphone technology may be useful, older adults tend to be slow to adopt new technologies [5]. However, having high perceived usefulness (the belief that using a system enhances performance) and high perceived ease of use (the belief that a system is free of effort) are foundational determinants of technology acceptance [6].

High perceived usefulness and perceived ease of use may explain why older adults are the fastest-growing population of smartphone users [7]. As of 2017, 42% of adults 65 years and older own a smartphone [8]. Moreover, 74% of adults aged 50-64 years own smartphones [8]. Furthermore, the use of health apps is growing among older adults, enabling these individuals to monitor and improve their health through their own device [9]. In addition to tracking health, apps can also provide feedback to help users reach health goals [10]. Therefore, the adoption of smartphone apps for older adults should be designed for high perceived ease of use and perceived usefulness.

There is growing evidence of the validity of smartphone usage for fall risk screening. There have been 2 recent systematic reviews that have indicated that smartphone accelerometers and smartphone apps have the potential to measure fall risk through quantifying gait and balance [11,12]. For instance, Ozinga and Alberts [13] found high correlations in root mean square acceleration and 95% volume of acceleration between an iPad and 3D-motion capture during static balance conditions. An app called the uTUG, which measures performance during the Timed Up and Go (TUG), was developed by 1 group [14]. Additionally, another study developed a fall risk app based on the Aachen Falls Prevention Scale and found their app to be related to users' self-reported history of falls [15]. The growing body of evidence for smartphone use to measure fall risk brings strong potential for falls screening in the home setting. This provides an opportunity for older adults to assess their individual fall risk, a necessary step in determining the type of fall prevention treatment needed.

Health apps targeting falls prevention are becoming more common, but previously developed apps center on a single task, such as the TUG or a specific questionnaire. Because fall risk is multifactorial, there is a need for an app to assess multiple influences on fall risk. These past apps provide an important foundation for mobile fall risk assessment, but an app that measures multiple risk factors helps determine which measures are useful for individualized fall risk. In addition to developing health apps to measure fall risk, a critical next step is to ensure usability by the target users. Our review of the literature indicated that the usability aspect is typically not part of the reported evaluations [13,16,17]. A smartphone can effectively address the issue of inadequate fall risk screening but only if older adults are able to use the app. A usable app must be designed to accommodate age-related changes in perceptual, cognitive, and motor capabilities [18]. Designing for accommodation of age-related changes is necessary but not sufficient for ensuring usability by older adults [19]. Usability testing with members of the target user group is needed to identify additional usability challenges. Therefore, the purpose of this study was to develop a fall risk app and test the usability of the app in healthy, older adults. A smartphone app that measures fall risk through a battery of assessments and is usable by our target population will improve falls screening and help identify those in need of fall prevention resources.

## Methods

### App Design and Development

The fall risk app, Steady, was developed in Android Studio 3.1.2 for smartphone and tablet devices. Steady consists of 2 components. The first is a 13-item questionnaire of health history (ie, age, gender, number of falls in the last year, and perceived balance confidence [20]; Figure 1). These questions were chosen because they are associated with falls and recurrent falls in community-dwelling older adults [21]. The second component is a progressive postural stability test (Figure 2), wherein the device guides participants through 5 progressively difficult tasks. These include 4 30-second balance tasks (eyes open, eyes closed, tandem, and single leg) plus a 30-second sit-to-stand test. These tasks were chosen because they have been shown to discriminate between high and low risk of falling in older adults [4,22]. Instructions prior to each balance task are provided through text, and users are asked to hold the phone against their chest for the duration of each test. Safety instructions to wear sturdy shoes and the option to skip a balance task were provided prior to the start of each task. On completion of each task, users report whether they attempted the task. If so, they then report whether they were able to complete the task (Figure 3). These data, alongside data from the health history questionnaire, are entered into a weighted algorithm to produce a score ranging from 0-100 and classified into a very low, low, moderate, high, or very high risk of falling (Figure 4). Lower scores represent a greater risk for falls.

**Figure 1.** Screenshot of the healthy history questionnaire.

Please answer the following questions

1. What is your current age in years?

76

2. What is your Gender?

Female

Male

3. Have you fallen in the last year?

Yes

No


How many times?

1.0

Did you suffer an injury?

~

**Figure 2.** Screenshot of the tandem stance task.

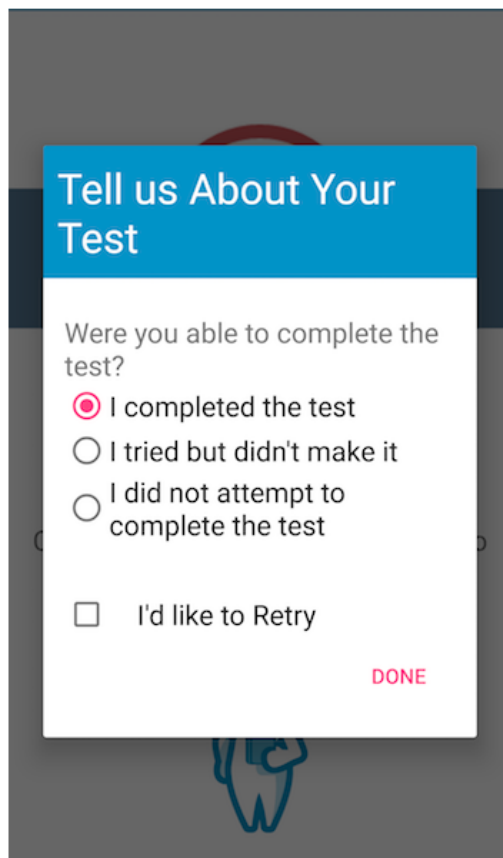
 Tandem Stand

For this test you will stand with your eyes open and one foot in front of the other, like you are on a balance beam.

After pressing start, place your phone to your chest, and stand in place until the final beep sounds.

**LET'S START** **SKIP**

**Figure 3.** Participants report their ability to complete each balance task.



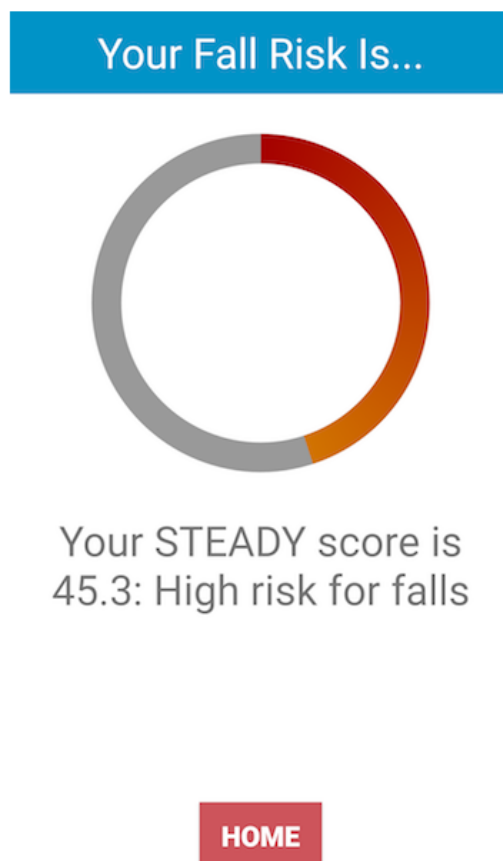
**Tell us About Your Test**

Were you able to complete the test?

- I completed the test
- I tried but didn't make it
- I did not attempt to complete the test
- I'd like to Retry

**DONE**

**Figure 4.** Final fall risk score; lower scores represent a greater risk for falls.



The first iteration of the app was developed with consideration for age-related changes that might influence usability. With respect to sensory changes, we ensured that the font was at least size 14 and sans serif, the recommended font size and type for older adults [23]. All text is black text on a white background to maximize contrast. The app also utilizes an audio component for the balance tasks. To begin each balance task, 5 identical beeps are presented, and the 30-second posture task begins at a unique (ie, higher) sixth beep. We ensured that the audio is loud enough for older adults to hear, and we added vibrations during each auditory tone for those hard of hearing. We minimized the cognitive demands by listing 1 set of instructions or task per screen. In doing so, we aimed to reduce working memory overload. In total, there are 10 screens to navigate before receiving a final fall risk score. Lastly, we accommodated motor capabilities of older adults by incorporating large buttons when entering information.

## Usability Testing

### *Participant Characteristics*

A total of 11 healthy, older adults participated in usability testing. Our approach was to have older adults interact with the app, identify usability issues, improve the design, and then have another group of older adults interact with the app. This iterative approach is ideal for identifying use challenges. Nielson [24] has argued that small numbers of participants (~5) are sufficient for identifying usability problems. Consequently, we included 6 older adults in our first iteration and 5 in our second. Inclusion criteria included being over 70 years of age, self-reported ability to swipe on a touchscreen device, and able to stand with or without aid. All procedures were approved by the University of Illinois at Urbana-Champaign Institutional Review Board, and all participants completed written informed consent prior to participation.

### *Testing Environment*

Usability testing was performed at 2 sites selected for convenience for the participants. The first was an unoccupied apartment at a local retirement community. Testing was performed in the living room of this apartment to mimic using the app in one's own home. We tested 5 participants from the first iteration and 3 participants from the second iteration at the apartment. The second site was a research laboratory on a University campus. This site used an open space in the research laboratory. We tested 1 participant from the first iteration and 2 participants from the second iteration at the research lab.

### *Procedures*

An iterative design-evaluation process of semistructured, videotaped interviews was used to determine the optimal usability of Steady [25]. Participants were presented with a smartphone (Samsung Galaxy S6) and tablet (Samsung Galaxy Tab S3) and asked to pick their choice of device to use first. After selecting a device, participants were asked to open the app and follow all instructions while thinking aloud and narrating their thoughts. In addition, a series of open-ended questions related to ease of use, recommendations for modifications, and feasibility were asked after completing the healthy history questionnaire, after completing the balance tasks,

and after receiving their final fall risk score. These questions are included in [Multimedia Appendix 1](#). After completion, participants repeated the testing measures with the alternate device and were asked to report differences in using the smartphone and tablet. Participants then completed the Systematic Usability Scale (SUS) [26] for both the smartphone and tablet. The SUS is widely used to quantify the usability of user-machine interfaces, consisting of 10 standard questions on a 5-point Likert scale, with higher scores indicating greater usability [26]. The SUS ranges from 0 to 100, with higher scores representing greater usability.

After the first iterative cycle, changes were made to the app based on identified issues from the interviews. The second iterative cycle was conducted on 5 older adults, following the same format as the first cycle. No new usability challenge themes emerged after the second cycle.

### *Data and Statistical Analysis*

All videotapes and field notes taken during the interview were transcribed verbatim. Qualitative data from transcripts and field notes were reviewed by KH to develop a coding system. Based on their content, data were assigned with codes, and codes with similar content were grouped into thematic categories.

Following a mixed-methods approach, SUS data were used to complement the qualitative results. SUS scores were averaged for each participant and transformed into a usability score out of 100, where the average score was 68 [27].

## Results

### **Participant Characteristics**

Demographic information of all participants is provided in [Table 1](#).

### **Iteration 1**

#### *Usability Testing Interviews*

Transcript analysis and coding revealed 2 distinct usability themes, namely, perceived ease of use and perceived usefulness.

#### **Perceived Ease of Use**

Overall, participants found the app easy to follow and free of clutter. Some participants found difficulties swiping between screens and answering the balance confidence questions in the health history questionnaire. In the first iteration, a slide bar was used to indicate a percentage for 0 through 100 ([Figure 5](#)). However, 4 participants were unable to drag the slide bar or needed multiple attempts. Therefore, the slide bar was replaced with a key-in entry ([Figure 6](#)), and forward and back arrows were added to each screen.

Participants reported confusion following the instructions to begin and end each balance task. The first 5 beeps prior to starting each balance task was programmed to allow time for participants set-up for each task. However, 4 of the 6 participants were confused about when to start or stop each task. Participants thought the task ended at the sixth beep instead of starting at the sixth beep. As a potential solution, instructions were added

prior to each balance task explaining when each task begins and ends within the second iteration of the app (Figure 7).

Additionally, participants completed the health history questionnaire and balance tasks in the incorrect order. In the first iteration, participants' fall risk would be displayed following the completion of the balance tasks, regardless of whether the health history questionnaire was completed. This resulted in an inaccurate initial score. This resulted because the button to initiate the balance tasks was displayed above the button for the health history, and participants often completed the balance tasks first. To address this issue in the second iteration, only the questionnaire button is displayed until the questionnaire is complete (Figure 8).

In comparing using the smartphone and the tablet, there were few differences reported. No differences between the 2 devices were reported by 3 participants. There was 1 participant who preferred holding the tablet for the balance tasks, and 2 participants preferred holding the phone for the balance tasks.

### Perceived Usefulness

Participants enjoyed learning their risk of falling from the app. There were 4 of the 6 participants who reported concerns and fear of falling, indicating that this app may address their concerns. For example, 1 participant mentioned that it helped her think about her balance and falls.

*I think this [the app] would be helpful for me because I wasn't too steady. This helps me think about balance exercises when I go to the gym. [Female, 74 years old]*

**Table 1.** Demographic information of all participants.

Characteristics	Iteration 1 (n=6)	Iteration 2 (n=5)
Age (years), mean (SD)	78.3 (7.3)	81 (3.7)
<b>Gender, n (%)</b>		
Males	1 (17)	1 (20)
Females	5 (83)	4 (80)
<b>Education, n (%)</b>		
High school diploma	N/A <sup>a</sup>	3 (60)
Bachelor's degree	1 (17)	N/A
Master's degree	2 (33)	2 (40)
PhD	3 (50)	N/A
Smartphone usage, n (%)	5 (83)	4 (80)
Tablet usage, n (%)	3 (50)	3 (60)
Falls in past year, range (median)	0-5 (2)	0-2 (0)

<sup>a</sup>N/A: not applicable.

It appeared that the greatest benefit for participants was to receive their fall risk and be more aware of falls. Half of the participants reported this benefit. Moreover, all participants who received a high risk of falls wanted to receive fall prevention strategies to lower their fall risk.

Participants also reported confidence and acceptance in using the app on their own if it were downloaded on their own device. There were 4 participants who explained that the app was easy to follow on their own. There was 1 participant who indicated that she may need assistance to start the app but could finish on her own. While a caregiver may not be needed, some participants mentioned they would want to be near a sturdy object in case they lose their balance. This was further included in the safety instructions provided at the start of each in-app testing session.

*I am comfortable using [the app] by myself. [Female, 77 years old]*

A summary of the main issues, with sample quotes, in the first iteration and the solutions implemented in the second iteration are described in Table 2.

### Usability Testing Questionnaire

The average score on the SUS for the smartphone was 79.17, and the average score on the SUS for the tablet was 77.92 (Figure 9). Blue bars represent scores for the tablet, and orange bars represent scores for the phone. These scores represent good usability for both devices [27]. Average scores on each of the 10 items are reported in Table 3. A 5-point Likert scale was used, with higher scores indicating greater usability.



**Figure 5.** In the first iteration, balance confidence was presented as a slide bar.

**Please answer the following questions**

10. How confident are you that you will not lose your balance or become unsteady when you are bumped into by people as you walk through the mall?

50% Confident

11. How confident are you that you will not lose your balance or become unsteady when you step onto or off an escalator while you are holding onto a railing?

60% Confident

12. How confident are you that you will not lose your balance or become unsteady when you step onto or off an escalator while holding onto parcels such that you cannot hold onto the railing?

70% Confident

13. How confident are you that you will not lose your balance or become unsteady when you walk outside on icy sidewalks?

0% Confident

**SAVE** **RETURN**

**Figure 6.** In the second iteration, the balance confidence questions were changed to key-in entries.

**Please answer the following questions**

8. On a scale from 0 to 100%, how confident are you that you will not lose your balance or become unsteady when you stand on your tiptoes and reach for something above your head?

100

100% Confident

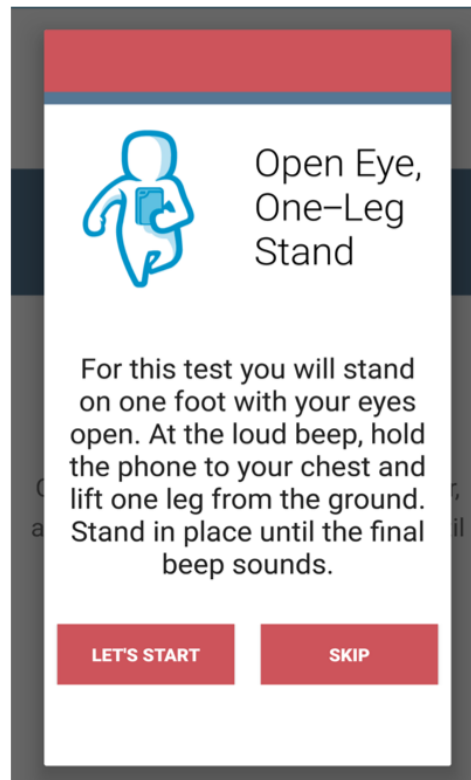
9. How confident are you that you will not lose your balance or become unsteady when you stand on a chair and reach for something?

100

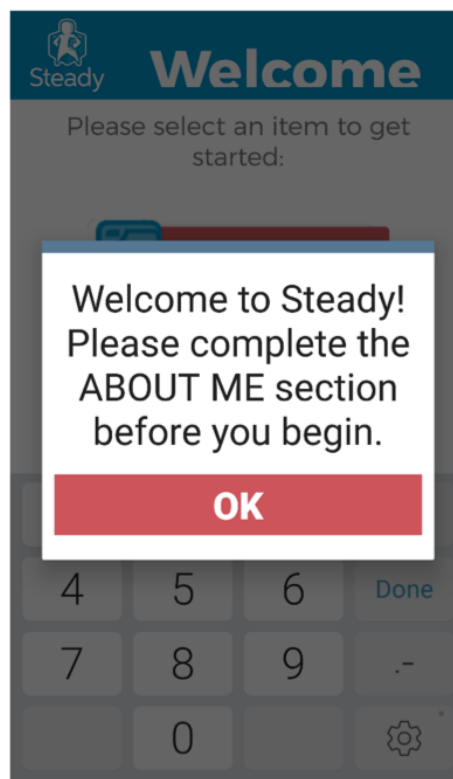
100% Confident

10. How confident are you that you will not lose your balance or become unsteady when you are bumped into by people as you

**Figure 7.** Instructions were added in the second iteration to clarify the start and end of each balance task.



**Figure 8.** To prevent users from receiving an inaccurate fall risk score, users are prompted to answer health history questions at start up.

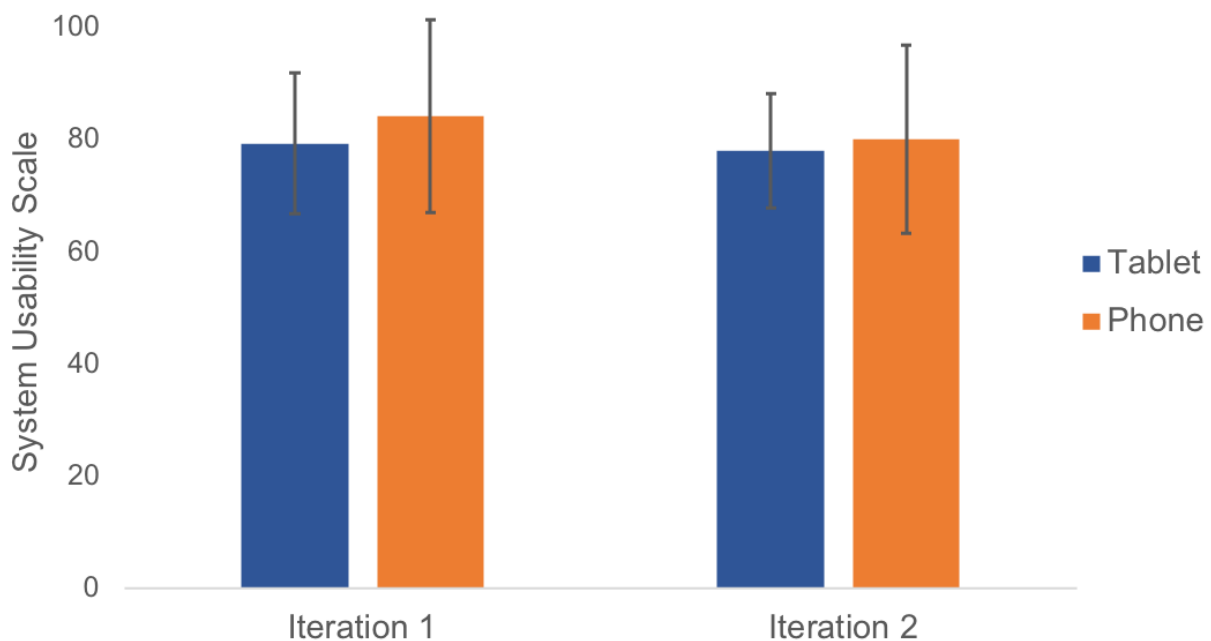


**Table 2.** Main issues, with sample quotes, identified from the first round of usability testing with solutions implemented in the second iteration of the app.

Domain and issue	Sample quotes	Solution
<b>Perceived ease of use</b>		
Instructions for beginning each balance task	<ul style="list-style-type: none"> <li>“The instructions should be in the beginning and say the first 5 beeps do the purpose to adjust the device. Then the sixth beep is when you start the test and you do it until a final beep after 30 seconds.”</li> </ul>	<ul style="list-style-type: none"> <li>Within the second iteration of the app, instructions were added prior to each balance task explaining when each task begins and ends.</li> </ul>
Inaccurate fall risk score	<ul style="list-style-type: none"> <li>“What do I do next?”</li> <li>“Do I go to Full Test?”</li> </ul>	<ul style="list-style-type: none"> <li>Only the questionnaire button is displayed until the questionnaire is complete. The Full Test button appears after the questionnaire is complete.</li> </ul>
Dragging a slide bar	<ul style="list-style-type: none"> <li>“How do I change the number?”</li> <li>“My fingers can’t move the bar.”</li> </ul>	<ul style="list-style-type: none"> <li>The slide bar was replaced with a key-in entry.</li> </ul>
Swiping between screens	<ul style="list-style-type: none"> <li>“You should indicate if I need to swipe left to right or up to down.”</li> </ul>	<ul style="list-style-type: none"> <li>Forward and back arrows were added to each screen.</li> </ul>
<b>Perceived usefulness</b>		
Fall prevention strategies	<ul style="list-style-type: none"> <li>“It was very beneficial to get your prediction for falling. I would, at the very end, provide a link to demonstrate preventative measures to reduce the risk of falling.”</li> </ul>	<ul style="list-style-type: none"> <li>N/A<sup>a</sup></li> </ul>

<sup>a</sup>N/A: not applicable.

**Figure 9.** Systematic Usability Scale scores for iterations 1 and 2.



**Table 3.** Average scores on each question of the Systematic Usability Scale for iterations 1 and 2.

Item number	Smartphone		Tablet	
	Iteration 1	Iteration 2	Iteration 1	Iteration 2
1	2.4	3.3	1.6	3.2
2	2.0	1.5	2	1.5
3	4.4	4.7	4.6	4.3
4	1.2	1.3	1.2	1.5
5	3.2	4.5	3.8	4.7
6	2.2	1.3	1.4	1.3
7	4.6	4.5	4.2	4.5
8	1.2	1.2	2.2	1.5
9	4.4	4.5	4.6	4.3
10	2.0	2.0	2.0	2.3

## Iteration 2

### Usability Testing Interviews

Transcript analysis and codes in the second round of interviews revealed 2 distinct themes, namely, perceived ease of use and perceived usefulness.

#### Perceived Ease of Use

In the second round of interviews, participants reported little to no difficulty in navigating through the app and understanding the instructions. Participants in the second round preferred the smartphone over the tablet. There were 3 participants who preferred the smartphone more because it was easier to hold against their chest. The tablet was preferred by 1 participant because it was easier to read, while 1 reported no differences. No other problems related to ease of use were identified during the second round of interviews.

#### Perceived Usefulness

Similar to responses from the first interviews, 4 participants reported a benefit of learning about their risk of falling. Participants also reported that Steady would be useful for them and other older adults, especially for those who do not have access to fall risk screening.

*In this place [retirement community] we have a lot of exercises and programs and balance tests, but I think there are a lot of people who are at home and who don't have access to all that, and I think it could be very helpful to them.* [Female, 83 years old]

After receiving their fall risk score, 4 participants also wanted to understand fall prevention strategies they could adopt. Participants suggested the app displaying simple exercises that they could practice at home.

Furthermore, not only did participants find Steady to be useful but they also reported that they would be able to use it on their own. Of the 5 participants, 4 reported that they could complete the app on their own. Because the tests are short, the instructions are clear, and the app is easy to follow, participants reported that they would be able to use Steady in their own homes. There

was 1 participant who indicated they would want a caregiver's help to assist in spotting during the balance tasks.

*The instructions were clear and I could download this on my own phone and use it on my own.* [Male, 85 years old].

### Usability Testing Questionnaire

The average score for the SUS on the smartphone was 84, and the average score for the SUS on the tablet was 80 (Figure 9). The average scores on each of the 10 items are reported in Table 3.

## Discussion

### Principal Findings

The purpose of this study was to develop a mobile app to measure fall risk in older adults and to test whether the app was usable by an older adult population. The iterative development and testing of a fall risk mobile app resulted in a usable device for older adults to measure their risk of falling. Through 2 rounds of usability testing, Steady accommodated for age-related perceptual, cognitive, and motor changes to promote use in older adults. When using Steady, participants reported that the app was easy to follow, they had little difficulty receiving a fall risk score (ie, positive ease of use), and the app was beneficial to bring awareness and knowledge of their risk of falling (ie, high perceived usefulness). High SUS scores also indicated high usability for both the smartphone and tablet, although older adults appeared to prefer using the phone for the balance activities.

This study suggests the potential for mobile technology to offer fall risk screening to older adults. The 2 themes generated from the interviews were perceived ease of use and perceived usefulness. Both perceived ease of use and perceived usefulness are factors that predict technology acceptance among older adults [5]. This suggests that older adults may have high acceptance of a fall risk app. Furthermore, a fall risk app that older adults find both usable and useful has high potential to provide falls screening to older adults outside a clinical setting. Along with previous studies that have found smartphones to

provide valid balance and fall risk screening, mobile technology may offer a solution to identify high fall risk older adults to seek fall prevention treatment.

Through iterative usability testing, we identified key lessons to use when developing a mobile health (mHealth) app for older adults. First, instructions should be as clear and simple as possible. This became evident when the 30-second balance task instructions were confusing for our participants. Rewording the instructions and maintaining the consistency of these instructions drastically improved performance. Second, measuring fall risk is a necessary step to prevent falls, but older adults also wanted to learn how to lower their fall risk. While participants reported high usefulness, there is potential to increase usefulness by adding prevention strategies. When developing a health app, both measurement and prevention strategies should be taken into consideration. Third, a smartphone can be just as effective as a tablet if the app has high perceived ease of use. We found that by incorporating large font sizes, keeping text consistent, and using contrasting colors, participants found no differences in reading or entering information in the phone or tablet. Because Steady involves holding the device to the chest, the smartphone was found to be the more feasible device. Following these lessons may help develop a highly usable mHealth app for older adults.

### Comparison With Prior Work

To the authors' knowledge, this is the first study to test the usability of an app that measures fall risk in older adults. Because fall risk screening is underutilized in clinical settings, this study suggests that a smartphone app can not only offer fall risk screening but also be used by older adults. Compared to previous studies, Steady provides a quick and understandable fall risk output. A previous study used a smartphone worn at the hip to monitor fall risk during a dancing game [28]. Another study tested the usability of mobile technology to detect falls in older adults [29]. Although both studies found high usability, neither the game nor the fall detection app provided a fall risk score for users. Providing fall risk knowledge to older adults is the first step to seeking treatments to lower their risk of falling.

A previous study developed and tested an app to measure fall risk based on the Aachen Fall Prevention Scale [15]. This app determines fall risk based on a set of questionnaires and completion of a 10-second balance task. Similarly, the Steady app also includes questionnaires and mobility tasks, but it utilizes valid and known predictors of fall risk and incorporates 5 balance tasks that are related to elevated fall risk in older adults. Furthermore, the previous study did not test the usability, and it is unclear whether older adults found the app easy to use on their own.

A recent study performed a survey of German-speaking internet users to identify features of a falls prevention app would increase user satisfaction, such as having fall risk treatments decided by a health care professional or having gaming elements incorporated for physical activity integration [30]. Steady accomplishes 1 of their findings, namely, to identify fall risk through a standardized test [30]. Because Steady is a fall risk identification app and currently does not include an intervention component, the other features do not apply. Future studies

should determine whether the design features reported from the survey are consistent with those identified in the United States, and future iterations of fall risk assessment and prevention apps should follow these guidelines.

### Limitations

A limitation in the design of Steady is that the balance tasks are constrained to individuals who can stand with or without aid. This limits older adults with significant mobility impairments (ie, wheelchair users) from using the app. Wheelchair users have shown to have an elevated fall risk [28], and future iterations of Steady should develop and test fall risk for wheelchair users. Steady also uses visual text to guide users through the app, which is a limitation for older adults with significant vision impairment. Future iterations of Steady should also include an auditory instruction to guide users through the app. It is also possible that individuals with pacemakers may find that holding a smartphone or tablet to their chest interferes with their pacemaker. Therefore, future efforts should also determine whether the phone can be placed at the hip or another area away from a pacemaker.

In addition, our sample of older adults is well-educated. Almost all participants had a college degree or higher. Those with higher education levels may also have greater technology experience, and they may perceive different issues with usability than older adults with lower education levels. Although smartphone and tablet usage were recorded from participants, the type of device (ie, Android, Apple, or Windows), was not recorded. Therefore, it is unclear if preference toward the smartphone was due to current usage of an Android smartphone. Future studies will collect the type of operating platform in addition to technology usage.

While the accelerometer embedded in the smartphone captured data during the balance tasks, the acceleration results were not incorporated into the final fall risk score. In the next iteration, the fall risk score will include both balance performance from acceleration data and health history questionnaire data. This will enhance the classification of low-, moderate-, and high-risk fallers. Furthermore, the next iteration will also include fall prevention strategies, as this was a common request among participants. Future directions should also include a long-term evaluation of Steady and determine its health impact on older adults. Next steps for Steady will be to determine the validity and reliability of the algorithm compared with standard fall risk tests in older adults. Ultimately, a fall risk app that is usable for older adults, valid compared with standard fall risk assessments, and reliable over time may provide a tool to increase knowledge of individual fall risk in older adults.

### Conclusions

In conclusion, through a mixed-methods, iterative design, we developed and tested an app on a smartphone and tablet to measure older adults' risk of falling. After 1 round of usability testing, confusion with task instructions and visual and tactile errors were corrected. After the second round of testing, older adults found the app useful and easy to use. High SUS scores for both the smartphone and tablet also indicated high usability, but participants preferred holding the smartphone over the tablet.



A fall risk app has the potential to be used by older adults to measure their risk of falling.

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## Conflicts of Interest

JJS has partial ownership in Sosnoff Technologies, LLC, a company that may be affected by the research reported in the enclosed paper. This conflict of interest is managed by a plan approved by the University of Illinois at Urbana-Champaign.

## Multimedia Appendix 1

Questions asked during semi-structured interviews for usability testing.

[PDF File (Adobe PDF File), 199 KB - [aging\\_v1i2e11569\\_app1.pdf](#)]

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## Abbreviations

**mHealth:** mobile health

**SUS:** Systematic Usability Scale

**TUG:** Timed Up and Go

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Original Paper

# An Interactive Home-Based Cognitive-Motor Step Training Program to Reduce Fall Risk in Older Adults: Qualitative Descriptive Study of Older Adults' Experiences and Requirements

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## Abstract

**Background:** Falls are a major contributor to the burden of disease in older adults. Home-based exercise programs are effective in reducing the rate and risk of falls in older adults. However, adherence to home-based exercise programs is low, limiting the efficacy of interventions. The implementation of technology-based exercise programs for older adults to use at home may increase exercise adherence and, thus, the effectiveness of fall prevention interventions. More information about older adults' experiences when using technologies at home is needed to enable the design of programs that are tailored to older adults' needs.

**Objective:** This study aimed to (1) explore older adults' experiences using *SureStep*, an interactive cognitive-motor step training program to reduce fall risk unsupervised at home; (2) explore program features that older adults found encouraged program uptake and adherence; (3) identify usability issues encountered by older adults when using the program; and (4) provide guidance for the design of a future technology-based exercise program tailored to older adults to use at home as a fall prevention strategy.

**Methods:** This study was part of a larger randomized controlled trial. The qualitative portion of the study and the focus of this paper used a qualitative descriptive design. Data collectors conducted structured, open-ended in-person interviews with study participants who were randomly allocated to use *SureStep* at home for 4 months. All interviews were audiotaped and ranged from 45 to 60 min. Thematic analysis was used to analyze collected data. This study was guided by Pender's Health Promotion Model.

**Results:** Overall, 24 older adults aged 70 to 97 years were interviewed. Findings suggest older adults are open to use technology-based exercise programs at home, and in the context of optimizing adherence to home-based exercise programs for the prevention of falls, findings suggest that program developers should develop exercise programs in ways that provide older adults with a fun and enjoyable experience (thus increasing intrinsic motivation to exercise), focus on improving outcomes that are significant to older adults (thus increasing self-determined extrinsic motivation), offer challenging yet attainable exercises (thus increasing perceived self-competence), provide positive feedback on performance (thus increasing self-efficacy), and are easy to use (thus reducing perceived barriers to technology use).

**Conclusions:** This study provides important considerations when designing technology-based programs so they are tailored to the needs of older adults, increasing both usability and acceptability of programs and potentially enhancing exercise participation

and long-term adherence to fall prevention interventions. Program uptake and adherence seem to be influenced by (1) older adults' perceived benefits of undertaking the program, (2) whether the program is stimulating, and (3) the perceived barriers to exercise and technology use. Older adults shared important recommendations for future development of technologies for older adults to use at home.

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## KEYWORDS

aged; community-dwelling; exercise; home-based training; adherence; motivation; exergame; active video games; falls; qualitative research

## Introduction

### Background

Accidental falls are a major contributor to the burden of disease in older adults and a major public health problem. One-third of people aged 65 years and above fall every year [1]. Falls and fractures account for over half of all injury-related health care costs [2]. Personal and community burden from falls is enormous due to mobility-related disability and loss of independence. Fall-related injuries lead to a reduction in quality of life [3] and independence in self-care [4] and can precipitate admission to long-term care facilities [5]. High-quality evidence shows that well-designed exercise programs can reduce falls by 42%, provided they are continued over a period of at least 6 months [6,7].

### Adherence to Fall Prevention Exercise Programs in Older Adults

Despite the robust evidence to support exercise as an effective fall prevention strategy among community-dwelling older adults [6-9], adherence to fall prevention exercise interventions is often low [10,11], suggesting some reluctance by older adults to take part in such programs [11,12]. Systematic review evidence indicates that adherence rates to home-based exercise programs for fall prevention are initially high at 82% over the first 2 to 4 months, but rates drop down to approximately 52% over 1 year [11].

A review of older adults' perspectives of fall prevention exercise programs found that social interaction was frequently suggested as a motivator to participate in group-based programs [13]. Qualitative data also suggest that exercising in the company of others provides older adults with pleasure and motivation to continue, and for some, social interaction is the primary reason for participating in such programs [14]. However, although some older adults value the professional supervision and social interaction and encouragement by peers [15,16], others perceive many barriers to participation in group programs. The existing evidence suggests that not all older adults wish to participate in group-based programs and that some older adults perceive it as a barrier to exercise participation. Examples of common barriers to attend group exercise programs away from home include the variety of skill levels within the group [14]; the requirement of assistance for some participants, meaning that others have to wait [14]; feeling uncomfortable about having the lowest skill level or not feeling equal within the group [14]; feeling intimidated to attend fitness facilities and other group exercise settings [17]; and environmental barriers such as lack

of transport [18,19], effort and costs associated with traveling [20,21], adverse weather conditions [15,22], and the need to care for an ill spouse [19]. Furthermore, factors including age older than 80 years, poor self-reported health status, recurrent falls, concerns about falls, and avoidance of activities have also been associated with an increased preference to undertake home-based programs [23]. Moreover, some older adults simply prefer the convenience, privacy, and autonomy that home-based exercise programs provide [21,24]. Technology has been used to address these barriers and promote exercise participation. This study is important in providing in-depth qualitative insight into older adults' experiences when using a technology-based fall prevention exercise program in their homes. Recommendations made by older adults will be valuable in shaping the development of future technologies to provide fall prevention interventions in older adults' homes.

### Use of New Technologies to Deliver Home-Based Exercise Programs for Older Adults

Technology-based exercise programs (also known as "exergames") offer several advantages over traditional exercise programs in that they can contribute to a more enjoyable and stimulating exercise experience. Some advantages include the opportunity to tailor the exercise modalities according to the abilities of each individual (balance, strength, functional exercises, etc), provide individualized progression of exercises by unlocking levels of difficulty according to each individual's performance, offer a wide variety of exercises to maintain engagement, provide users with reinforcement and real-time feedback while exercising, and monitor performance over time [25-27]. Exergames also allow the introduction of a fun gaming factor to enhance motivation and increase participation [28] and can offer combined training of sensory, cognitive, and physical functions by changing the tasks displayed on the screen [29]. These factors are important as declines in attention, psychomotor processing, and problem-solving have an important impact on postural control, gait, and falls in older adults [30,31].

Several systematic reviews have shown that it is safe and feasible for community-dwelling older adults to engage in exergames [32-37]. Furthermore, it has been reported that older adults report higher levels of motivation and engagement when exercising using exergames [33] and using exergames may also enhance social well-being [38]. Technology-based exercise programs have shown comparable improvements in physical function when compared with other exercise programs [36,39]; systematic review evidence suggests that older adults' adherence to technology-based exercise programs is similar—or slightly better—to traditional exercise programs [40].



These results suggest that technology-based exercise programs may be an effective alternative or complement to conventional exercise programs. The possibility of using these programs in older adults' homes may further increase exercise participation in the proportion of the community that is either unable or unwilling to take part in other exercise programs. However, it is important to consider that most randomized control studies in this area have been conducted under close supervision in laboratory or clinical settings, using mostly commercial game consoles such as Nintendo Wii console, Xbox, and PlayStation [40] that are not specifically designed for older adults. Factors such as the pace of gameplay, the amount of graphical information, and the instructions on how to use the program can make it difficult for older adults to use these programs on their own [25,27,36,37].

Only few randomized controlled trials (RCTs) have tried to overcome these usability problems and improve exercise adherence to home-based interventions by using technology-based exercise programs that have been custom-developed for older adults [25,41-43]. Results from these studies are encouraging as older adults have been able to independently use these technologies in their homes, and interventions have been effective at improving physical [41,42] and cognitive parameters of fall risk in older adults [41,43]. The implementation of technology-based exercise programs for older adults may increase exercise participation and adherence and, therefore, has the potential to increase the effectiveness of fall prevention exercise programs. However, as the implementation of custom-developed technologies for older adults is in its early stages, more information about older adults' experiences when using technologies independently in their homes is needed.

### **Description of Intervention: SureStep—a Home-Based Interactive Cognitive-Motor Training Program for Fall Prevention in Older Adults**

This study is part of a larger RCT [41,43]. The purpose of the RCT was to assess the feasibility and safety of older adults using *SureStep*—an interactive step training system designed for older adults to use unsupervised in the home setting—and determine the effectiveness of this intervention on stepping performance and associated fall risk in older adults compared with a nonexercise control group. The study showed that 16 weeks of unsupervised interactive cognitive-motor training using the *SureStep* system led to improvements in specific cognitive functions associated with falls in older people [43].

*SureStep* consists of a step pad that is connected to a computer unit and a television to present cognitive-motor training stimuli. The motor (stepping) component of *SureStep* aims to train people to take quick and accurate lateral and anterior-posterior steps, and the cognitive component, delivered as engaging *games*, aims to train specific executive functions including working memory, visuospatial skills, dual-tasking, inhibition, and attention. The combination of step training and video games makes it possible to increase the training complexity by adding challenging cognitive tasks. *SureStep* consists of 4 games (*StepMania*, *Stepper*, *Trail-stepping*, and *Tetris*) that are modified versions of popular video games (Figure 1). Although

the nature and objectives of the step exercises (games) differ, the basic action of making well-timed and directed steps to solve tasks is common to all games. Games were designed to provide the user with feedback on their performance and multiple levels were available, with the harder levels requiring higher cognitive capacity and physical effort to perform the tasks.

Participants were instructed on the use of the system during individualized sessions at the start of the study. In addition, participants received a manual with detailed instructions regarding the use of the system. To facilitate compliance and to resolve any difficulties with system use, participants were telephoned at the end of weeks 1, 4, 8, and 12. Participants could also call the research team at other times if required and additional home visits were offered if requested. Participants were asked to play each game at least once during each session as many times as they wished, with the recommended dose of 3 sessions of 20 min per week during the 16-week trial. The time and duration for system use and game performance were recorded, saved by the game computer, and uploaded to a custom-made website by the system. Participants not using the system for 2 consecutive weeks were contacted by telephone to solve any issues and encourage adherence. Adherence was measured using the recorded logs of the system use.

Participants required on average 2 instructional visits of 90 min each (mean 2.0, SD 1.2). During the 16 weeks of intervention, participants played on average 31.8 sessions (SD 21.9) with a mean duration of 27.4 min (SD 28.1) for a total of 1317 min (SD 2075). A total of 18 participants achieved the target of 960 min (16 weeks, 3 sessions per week, 20 min); however, only 1 participant performed each of the 4 tasks at least 3 times per week over 16 weeks. During the trial period, 32% (15/44) of the intervention participants withdrew or stopped training. Technical problems with the step training system led to 3 participants ceasing training and interfered with the training dose of others. Other reasons for withdrawal included death (n=1), medical reasons (n=8), and personal reasons (n=3).

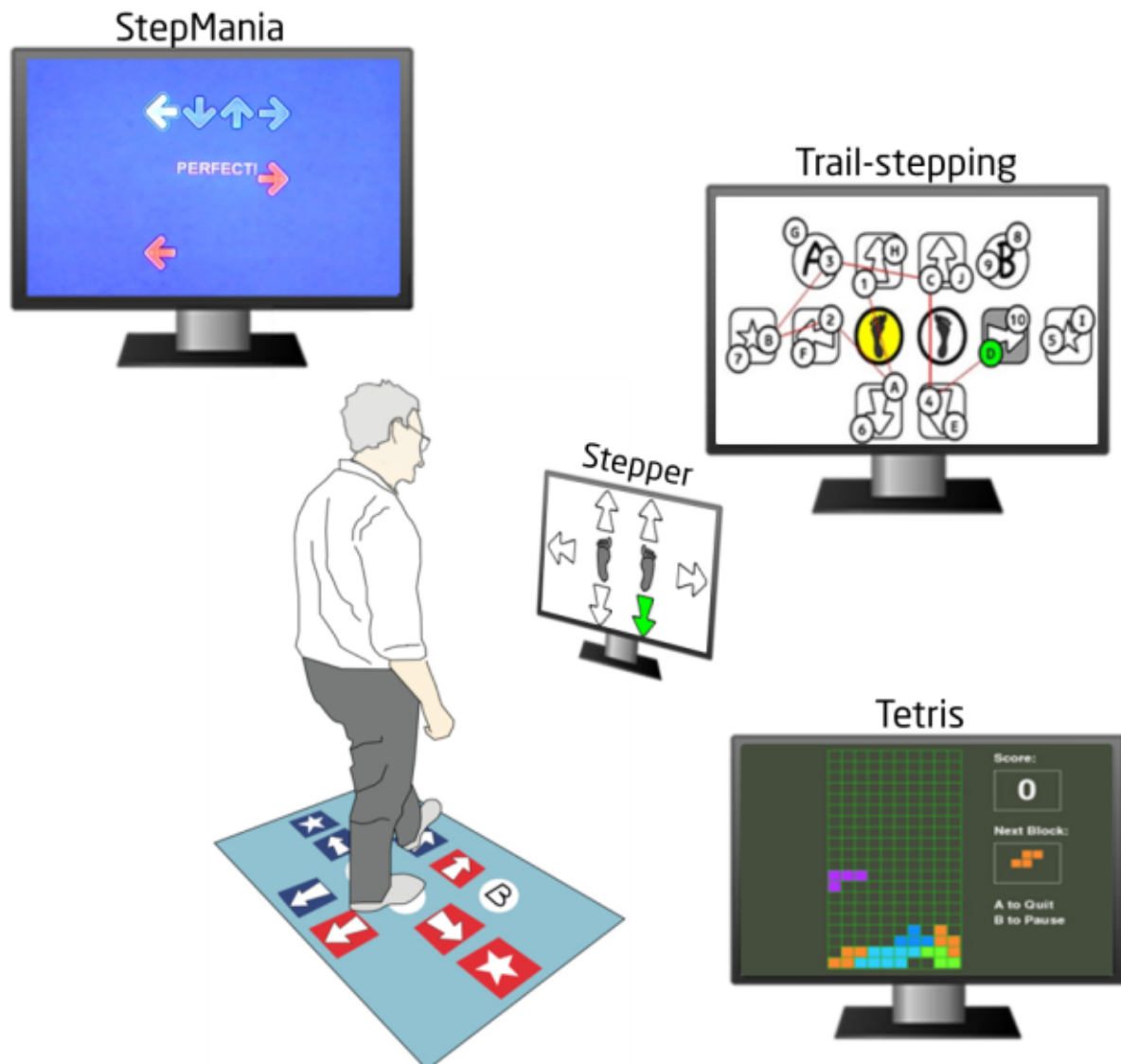
A comprehensive description of the interactive cognitive-motor step training program (*SureStep*) as well as the RCT and its effectiveness can be found in the protocol and main outcome papers [43,44]. An instructional video of the *SureStep* cognitive-motor training system can be found in [Multimedia Appendix 1](#).

### **Research Aims**

This paper reports on the qualitative findings from participants who were randomly assigned to use *SureStep* for 4 months as part of the larger RCT. The aims for the qualitative portion of the study were as follows: (1) to explore older adults' experiences using *SureStep*, an interactive cognitive-motor step training program to reduce fall risk unsupervised at home; (2) to explore which program features older adults considered encouraged program uptake and adherence; (3) to identify usability issues encountered by older adults when using the technology independently at home; and (4) to provide guidance for the design of a future technology-based exercise program tailored to older adults to use independently at home as a fall prevention strategy.



**Figure 1.** Schematic representation of SureStep: an interactive cognitive-motor step training program for fall prevention in older adults.



## Methods

### Study Design

A qualitative descriptive design was used [45,46]. Qualitative description is based on the theoretical foundation of naturalistic inquiry, which aims to study events and persons in their natural state. The methodology aims to provide an accurate description of the phenomenon using everyday language. Pender's Health Promotion Model (HPM) [47] was used as a theoretical framework to help design the research inquiry and guide the development of the interview. This study was approved by the Human Research Ethics Committee of the University of New South Wales (Reference number HREC 12316).

### Sample

Participants were selected from the intervention group participants that completed the *SureStep* training program. To ensure a range of viewpoints, maximum variation sampling [48] was used to purposively select participants that reflected different ages, gender, health status, familiarity with technologies, and adherence to the exercise program (N=24).

Residents of independent-living units of a retirement village in Sydney and from the community who met the following criteria were eligible to participate in the larger RCT: (1) aged 70 years or above; (2) living independently; (3) able to walk with or without a walking aid; (4) able to step unassisted on a step pad; and (5) have no severe lower extremity pain. Exclusion criteria were major cognitive impairment (Mini-Cog<3), diagnosis of degenerative disease, color-blindness, corrected vision of at least 6/16, or an unstable health condition.

### Data Collection

Structured interviews with open-ended questions were conducted within 30 days of participants completing the 4-month intervention using *SureStep*. The interview guide was pilot-tested with 3 older adults before administration to refine wording of the questions; these were not used in the analysis. The interviews focused on understanding older adults' motivations to use the *SureStep* program, perceived benefits of using the program, barriers and enablers to exercise participation and adherence, as well as program usability. The interview guide used at completion of the 4-month intervention period can be found in [Multimedia Appendix 2](#).

Interviews were conducted by the same researcher who instructed participants on the use of *SureStep* and provided assistance throughout the 4-month intervention study. This likely encouraged participants to talk more openly about both the positive and negative aspects of their experience (eg, technical difficulties they experienced) with someone familiar to them and who was aware of the technical difficulties some participants had experienced. During the training program, monthly logs of telephone contact and home visits, as well as detailed field notes from the home visits detailing problems encountered by each participant were maintained. These were used for data triangulation [49] as well as in the analysis to address the technical difficulties participants experienced when using the program unsupervised in their homes.

Following informed consent, interviews were audiorecorded to allow verbatim transcription and subsequent analysis of the data. Member checking [49] was performed at the end of each interview to ensure accuracy in data collection by summarizing the initial findings to the participant and gaining confirmation that the summary reflected their views, feelings, and experiences. Participants were also given the opportunity to add further information. Interview length varied between 45 and 60 min each. Collection of data continued until data saturation was achieved and no new information was revealed [49]. Interviews were transcribed verbatim by a third person not involved in the study and verified. All participants chose to have the interviews conducted in their homes.

### Data Analysis

Interview transcripts were analyzed using thematic analysis [48,50]. The data were analyzed by TV and HR. Initially, transcripts were read to become familiar with the data. Then, the transcripts were read again highlighting text that appeared to describe an emotional reaction to using the *SureStep* program. This was documented with a keyword that captured the emotional reaction—using the participant’s own words—on the margin of the text. After open-coding 4 transcripts, authors met to cross-check information and discuss any discrepancies. A consensus list of preliminary codes and a specified definition for each code was then generated and used as a guide for further coding. Transcripts were then imported into a computer software program (NVivo version 10, QRS International Pty, Doncaster, Victoria, Australia) to help manage the data and maintain an audit trail [51] of the steps and decisions taken during the analysis process. Throughout the coding of the interview transcripts, regular meetings took place to ensure rigor through a process of investigator triangulation [49]. As the coding progressed, some codes were combined, whereas others were split into subcategories. Final codes were then examined and organized into a hierarchical structure when possible. During data coding, the technique of constant comparison [48] was used to compare and contrast the categories within and across participants of different age groups, experience with the use of technology, level of physical activity, and self-reported health

status. This enabled exploration of the relationship between participants’ characteristics and their experience using the program.

## Results

### Older Adults’ Demographic Characteristics

All invited participants agreed to take part in the study. Overall, 24 interviews were conducted. Participants’ demographic and health characteristics are presented in Table 1. Out of the 24 interviewees, 74% (17/24) were women and ages ranged from 70 to 97 years. All participants resided in the Sydney metropolitan area; 78% (18/24) of the participants lived in independent apartments within a retirement village and 48% (11/24) of participants lived alone. Participants had a low number of comorbidities, were cognitively intact, and had low levels of depressive symptoms. Over half of the participants (65%, 15/24) had experienced a fall in the previous year and 30% (7/24) used walking aids when outdoors. Approximately half of the participants (48%, 11/24) reported having some previous experience using computers, and only 1 participant had previous experience using a commercial exergame (Nintendo Wii). Baseline self-reported levels of physical activity showed that 50% (12/24) of the participants were adhering to the general World Health Organization recommendation of 150 min of exercise per week [52]. Of the 24 participants interviewed, 18 participants (75%, 18/24) met the target recommendation of 960 min of exercise throughout the 4-month intervention period (20 min, 3 days per week, 16 weeks). Total time played over the 16-week intervention period ranged from 3.3 hours to 205.2 hours (mean 35, SD 47.6 hours). Reasons for not meeting the recommended exercise dose included prolonged hospitalization (n=2), pain that was aggravated by exercise (n=1), disinterest or lack of time (n=1), and difficulty using the system (n=2). Further follow-up visits were provided to the 2 participants who did not meet exercise recommendations due to technical difficulties, and further step-by-step instructions on program use were also provided. Participants were able to use the system under the supervision of the research staff; however, their inability to remember the instructions when unsupervised led them to stop using the program before the end of the intervention period.

### Qualitative Findings

Analysis of the interview transcripts generated 3 main themes that reflect older adults’ motivations as well as experiences and perceptions of using the *SureStep* program, as illustrated in Textbox 1. The results are presented according to the following 3 themes: (1) “It must be beneficial,” (2) “It must be stimulating,” and (3) “It must be accessible.” The words in italics or in quotes are sentences or expressions as spoken by the participants. Pseudonyms are used when making a reference to study participants to ensure participants’ confidentiality.

**Table 1.** Characteristics of the participants at study baseline.

Characteristics	Subsample of interviewed participants (n=24) <sup>a</sup>	Total sample of intervention group participants in the RCT <sup>b</sup> (n=47)
Age (years), mean (SD)	81.4 (7.5)	82 (7)
Female, n (%)	17 (74)	31 (66)
Body mass index in kg/m <sup>2</sup> , mean (SD)	26.3 (5.5)	27.1 (5.9)
Level of disability (WHODAS <sup>c</sup> 0-48), mean (SD)	15.6 (3.5)	17.1 (5.1)
Comorbidity (FCI <sup>d</sup> 0-18), mean (SD)	3 (2.2)	3.55 (2.2)
Number of medications, mean (SD)	4 (3.4)	4.55 (3.3)
Overall cognition (Mini-Cog), mean (SD)	4.3 (0.8)	4.4 (0.8)
Depression (PHQ <sup>e</sup> -9), mean (SD)	2 (2.5)	2.9 (4.1)
Concern about falling (Icon-FES <sup>f</sup> ), mean (SD)	48.3 (14.2)	53.9 (18.2)
Falls in the past year, n (%)	15 (65)	18 (38)
Use of walking aid outdoors, n (%)	7 (30)	13 (28)
Use walking aid indoor, n (%)	1 (4)	4 (9)
Computer literate, n (%)	11 (48)	— <sup>g</sup>
Resident of retirement village, n (%)	18 (78)	37 (78)
Single person in the household, n (%)	11 (48)	—
<b>Total physical activity, hours per week (IPEQ<sup>h</sup>), mean (SD)</b>	<b>25.3 (15.1)</b>	<b>26.4 (14.6)</b>
Planned Physical activity (hours/week), mean (SD)	2.8 (2.4)	2.6 (3.6)
Perform ≥150 min per week, n (%)	12 (52)	49 (54)
Incidental physical activity (hours/week), mean (SD)	21.9 (14.8)	22.1 (14.2)
Participants meeting recommended total exercise intervention dose of (960 min over 16 weeks), n (%)	18 (75)	18 (38)

<sup>a</sup>Values are for 24 participants except for body mass index, weight, and height (N=20) and IPEQ (N=22).

<sup>b</sup>RCT: randomized controlled trial.

<sup>c</sup>WHODAS: World Health Organization Disability Assessment Schedule.

<sup>d</sup>FCI: Functional Comorbidity Index.

<sup>e</sup>PHQ-9: Nine-item Patient Health Questionnaire.

<sup>f</sup>Icon-FES: Iconographical Fall-Efficacy Scale.

<sup>g</sup>Dashes indicate that data was not collected.

<sup>h</sup>IPEQ: Incidental and planned exercise questionnaire for older adults.

**Textbox 1.** Themes and subthemes generated from the interview transcripts.

<p>It must be beneficial</p> <ul style="list-style-type: none"> <li>Improving physical and cognitive functioning</li> <li>Being of help to others</li> </ul> <p>It must be stimulating</p> <ul style="list-style-type: none"> <li>Feeling physically and mentally challenged</li> <li>Importance of exercise variety and difficulty levels</li> <li>Seeing progress being made</li> </ul> <p>It must be accessible</p> <ul style="list-style-type: none"> <li>Benefits of home-based delivery</li> <li>Program design and usability</li> </ul>
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### **Theme 1: It Must Be Beneficial**

This theme relates to the different self-determined extrinsic motives by which older adults engaged in the *SureStep* training program. The interviews revealed that the main reasons why participants adhered to the program were to improve their physical and cognitive function and to help others.

#### **Subtheme 1.1: Improving Physical and Cognitive Functioning**

A feature that distinguishes *SureStep* from more conventional forms of exercise is that *SureStep* exercises were designed to provide older adults with combined cognitive and motor training. It was clear that participants appreciated this feature as they said *SureStep* was training both “their body and their mind.” When participants were asked about their motivations to use *SureStep*, it was apparent that those who had lower self-reported health status, poorer balance, and higher fear of falling wanted to do it “for [themselves]” as they thought that exercising would be “beneficial for them.” They seemed to be more conscious about the detrimental effect that inactivity can have on older adults. For example, they spoke of being aware of the “debilitating effects of lack of mobility,” which some described as “getting slow at doing things,” “losing [their] balance,” and “falling.” For Robert (aged 81 years), typical of the majority of study participants, having a fall represented a threat to his independence; thus, “preventing falls” and “remaining independent” were 2 of the most important motivators to take up and adhere to *SureStep*.

Perceived benefits attributed to using *SureStep* were the belief that using the program would help to *keep [them] healthy and improve [their] abilities*, including their *balance, reaction time, ability to walk further, and stay fit*. The perceived value of using *SureStep* seemed to rely on the belief that improving, or at least maintaining, their physical abilities would allow them to continue living independently for longer as portrayed in Thelma’s words. Thelma’s words also clearly indicate how important living independently is for these participants:

*[...] if you can save yourself from falling or tripping, you can still have your own shower; you can still get your own meals; you can still take yourself out and about. It’s worth everything to the individual to be able to do that. It doesn’t matter how old you are, being able to do that is just marvellous.* [Thelma, 87-year-old female]

For this group of participants, adhering to the *SureStep* training program was helping prevent cognitive decline and to keep their mind and body active:

*Well, I knew it would help me think faster and move faster. You don’t want to lose your faculties, you want to be able to remember people’s names, you want to be able to remember where you’re going and what you’re doing and remember things that happen.* [Agnes, 85-year-old female]

Some older adults seemed to feel an aversion to aging, as they feared they would lose their physical and cognitive capacities. The desire to *delay* the effects of aging came through in Bernice’s words:

*I thought it will keep me younger if I keep using my mind and my legs and arms [by doing SureStep training program].* [Bernice, 89-year-old female]

Higher adherence rates were attained by participants with lower self-perceived health status, poor balance ability, and fear of falling and by participants who were hoping to obtain health-related benefits. The improved physical and cognitive functioning participants spoke of reflects the notion of perceived benefits, which, according to HPM [53], helps promote positive health behavior. Even though on commencement of the study, adherence rates were mostly high for all participants, adherence rates for some participants declined over the duration of the trial. When participants were asked why their adherence declined, it was apparent that participants’ motivation to continue their engagement over time relied on them perceiving that they *needed* to perform the exercises. The notion that people adhere to actions from which they derive personally valued outcomes, such as health benefits, comes through in Donald’s words:

*[Interviewer: you said towards the end of the program you lost interest in the exercises, what do you think could have helped you stay motivated?] Yeah. Yes. The only thing I can think of is if—I was finding I was losing my physical fitness—that would motivate me because I’m going from here to the gym a few days still...I think that—yes, once people see they’re getting something out of it, yes, then you would take it on board. Yep. And that’s one of my problems, I can stand on one leg.* [Donald, 78-year-old male]

#### **Subtheme 1.2: Being of Help to Others**

In addition, 3 participants, all of whom rated their health and balance ability as good or very good, reported that even though they hoped to improve their physical and cognitive abilities using *SureStep*, their main motivation to engage in *SureStep* was not for health-related motives, but rather for the value they put on helping other people by contributing to research. Participants felt that by becoming research participants, they were helping researchers get the numbers they needed and thereby, in future, helping others:

*It was possibly helping somebody else that might be in an area where they are going to have problems with mobility. I think that was—that would be the number one driver as to why I did it; that it might benefit somebody that has had falls or suffered from some problem.* [Ron, 81-year-old male]

Ron who during the interview indicated he did not see himself as someone who was yet at risk of falling, was adhering to the program to help others as clearly reflected in his words. Similar to Ron, 78-year-old Donald who had described himself as being quite healthy and active was “committed to the program [*SureStep*]” to help with the research, “mainly because you need the numbers and you’re not getting them.”

It appears, overall adherence rates during the 16-week intervention period were higher in the group of participants whose main reasons to use *SureStep* were to improve their physical and cognitive function (n=17, mean time played 2103,



SD 2859 min) when compared with those whose main reason was to help others by contributing to research (n=3, mean playtime 1073, SD 158 min).

### **Theme 2: It Must Be Stimulating**

This theme relates to various features of *SureStep* that increased older adults' intrinsic motivation to engage in the training program. The interviews revealed that participants found the exercise experience enjoyable and stimulating when they felt physically and mentally challenged, when there was variety in both exercises and difficulty levels, and when they could see that they were making progress.

#### **Subtheme 2.1: Feeling Physically and Mentally Challenged**

Participants described *SureStep* as being *fun* and *challenging*. Ada's words below suggest that what distinguished *SureStep* from other forms of exercise was the design of the program, which challenged both cognitive and motor tasks simultaneously preventing users from getting bored:

*Well going to the gym bores me to tears, walking bores me to tears, that [SureStep program] keeps me active, my mind as well as my body and that is the main thing I enjoy.* [Ada, 76-year-old female]

For participants of this study, such as Doris (93 years), there were not many things that would present a challenge to them in their current daily activities. Engaging in *SureStep* was appealing as it presented a challenge to their otherwise routine life:

*Well, I think it's a challenge mentally for you to do it because as you get older there's not that many challenges that make you think—that makes you think quicker...Yep. Because it's very easy to let things slide, you know. You don't challenge yourself very much, particularly when you're living by yourself. If you have another person living with you they're challenging you but if you're living by yourself there's no challenge. So that was a bit of a challenge [referring to the exercise program].* [Doris, 93-year-old female]

#### **Subtheme 2.2: Importance of Exercise Variety and Difficulty Levels**

Participants expressed that having a *variety* of exercises and *different difficulty levels* was a good way to keep them engaged with the program as it made the experience more *interesting* and also made them want to *keep going from easy to more difficult and more difficult*. Furthermore, the ability to progress through different levels of difficulty made them feel *proud* and *good* about themselves and at the same time provided a *fun* way to exercise. These findings also suggest that older adults' self-efficacy and perceived competence to exercise with *SureStep* increased as they progressed from easier levels of gameplay to harder levels as depicted in Anna's words:

*Well, because if you are good at one level, then you can go up to the next. And then you feel, oh look you've done so well. Then you go up to the next one. And then you feel good. And you walk around saying, I did this and I did that.* [Anna, 72-year-old female]

The importance of varying difficulty levels was expressed by participants of different ages, perceived health status, and balance ability.

However, despite most participants finding the program fun and challenging, 3 participants found that as the weeks passed, the *novelty* wore off and they started to get bored with the exercises, which reduced their motivation to use the program. All 3 participants rated their balance to be "good" or "very good," had low concern about falling, were engaged in other activities (such as social activities, minding grandchildren, and doing voluntary work), and took part in other forms of exercise, for example, walking, going to exercise classes, and attending the gym. Two examples are the experiences of Ron and Donald:

*After you have done it for a couple of months, you sort of think, well, I have done that one, I have done another one [referring to the games]—and I can go up to level hard and that is about as far as I can go.*  
[Ron, 71-year-old male]

Like Ron, as time passed, 78-year-old Donald found he was "running out of challenge" and he "wasn't going to progress any further, [he] had reached the top," making Donald lose interest in the program.

For participants like Ron and Donald, their intrinsic motivation to use the program (ie, because it provided a fun and challenging experience) decreased as time passed, and instead, their motivation became driven by nonself-determined sources of motivation: they felt they *had* to do it because they had *committed to participating in the research*.

The loss of interest in the program due to lack of novelty did not prevent these participants from reaching the recommended exercise dose. However, it is important to consider that they all reported continuing to use *SureStep* because of their commitment to the research study. Thus, under other circumstances, a lack of novelty could lead to reduced adherence rates and program discontinuation.

Participants suggested that to prevent people from getting bored with the exercises and motivate them to continue, new games could progressively be introduced to the program to maintain *novelty*. The need to have a larger variety of games to maintain the challenging nature of the exercises and with that the feeling of enjoyment in the activities reflect the "activity related affect" construct of HPM. That is, older adults are more likely to engage and continue a behavior, such as exercise participation, if they associate the behavior (performing exercise) with positive feelings and emotions. However, when participants got used to the exercises, the novelty and challenge wore off and with that enjoyment.

#### **Subtheme 2.3: Seeing Progress Being Made**

Designing exercise programs in a way that older adults can see that *they are improving, they have made progress* was seen by all participants as an essential feature of the *SureStep* program. Before starting the program, some participants, particularly those with low self-reported health status and balance ability and moderate to high levels of fear of falling, questioned whether there was any point in starting an exercise program. They said "what's the good of me doing it [referring to exercise



in general],” as they thought they were already *too old, too slow*, and *not [sufficiently] well* to exercise. However, after having exercised with *SureStep* and having seen that they could progress to harder levels, they felt *good* and proud about themselves (eg, *I did this and I did that*), improving their self-esteem.

Participants indicated that feedback on their performance such as getting a score for their performance was *a great way of encouraging people to continue to exercise*. For 78-year-old Eva, getting a score motivated her to compete against herself *to get a bigger score* and this *made exercising fun*.

When comparing playtime between the 4 available games, it was apparent that *Stepper* was the least preferred game. Participants attributed this to the lack of feedback from *Stepper* game:

*[...] it doesn't tell you anything, you don't know if you are doing better or not. The others give you a score or tell you how long you are taking to solve it you know? There is no challenge in this one.* [Ada, 76-year-old female]

Feedback is, therefore, an important component of technology-based exercise programs, as it makes older adults feel they can still achieve their goals and *help themselves*. This is reflective of the construct of self-efficacy in HPM. According to this theory, the higher older adults perceived competence or self-efficacy to perform the *SureStep* exercises, the higher is the likelihood that they would commit to participating. Self-efficacy, in turn, was increased when participants saw they could successfully perform the exercises and improve their scores. According to HPM, greater self-efficacy results in fewer perceived barriers to exercises. Thus, the less likely it will be that feelings of *being too old, too slow*, and *not well* will interfere with their commitment to engage in exercise.

### **Theme 3: It Must Be Accessible**

This theme relates to the preference of participants to have a home-based exercise program and the importance of designing technology-based exercise programs that older adults can easily use independently in their homes. The interview responses revealed that participants liked having a home-based exercise program as it reduced common barriers to exercise. However, difficulties using *SureStep* led to 2 participants stopping the use of the program and other feeling frustrated with the system. This suggests that further development is needed to make the program more user-friendly for older adults to use unsupervised.

#### **Subtheme 3.1: Benefits of Home-Based Delivery**

When participants were asked about their perception of having *SureStep* as a home-based program, most participants conveyed that being able to exercise in their homes was very “convenient,” as it allowed them to exercise “when they liked and for as long as they liked” without having to be constrained to a schedule. Such convenience was important as many of these participants had a variety of caring, volunteering, social, and medical routines that impacted their availability to attend center-based exercise programs. For Gertrude (aged 97 years), a home-based program gave her flexibility as she poignantly expressed:

*This had all the elements that suited me. Because it was in my own home, because I didn't have to answer at half past six in the morning, because I could see and adjust myself to what was presented on the TV screen [referring to exercises], all that was going my way. I had often looked at—because there's four or five courses going all the time in this place, I'd often looked at them and thought no, I cannot make this body get up and be sure I'll be there half past eight every morning, which is what some of them require. So you see if it rains I can't go anywhere, because I can't take the scooter out in the rain and I can't walk. And buses only come at certain times, not when it suits you. So that I - this was absolutely handmade for me.* [Gertrude, 97-year-old female]

The importance of having the *SureStep* program as an “all-weather capability of moving your body around” comes through clearly in Gertrude’s words.

Being able to exercise in the *privacy* of their home was especially important to those who felt self-conscious about their bodies and their reduced abilities, as participants considered exercising in their home to be more *personal*.

Although most participants preferred to exercise in their home, for 3 participants, this was seen as a barrier to exercise participation, as they preferred other modes of exercise. For George (aged 87 years), who enjoyed being outdoors, using the program in his home was not appealing:

*Well, standing in front of the television and going backwards and forward, I get bored. Because before that and now, I generally go [out] every day, I go for a walk, I go through the bush. So I'd prefer going out. Because I like to get outside, so I'd rather go outside and do things outside and walk around.* [George, 87-year-old male]

Marion (86-year-old female), on the other hand, thought that joining an exercise class within the village would help her adhere to the program, as committing to a class would mean she had to attend, whereas at home she could “cheat and gradually stop exercising.”

For 84-year-old Evelyn, the social aspect of exercising seemed to be very important. She preferred to make exercise *a social thing* and thought it would be a good idea to set up the stepping mat exercise program in the retirement village, so people could go and exercise together.

In the context of exercise adherence, the higher the number of perceived barriers to exercise, the lower the likelihood is that individuals will adhere to an exercise program. This is in accordance with the perceived barriers to action construct of HPM.

#### **Subtheme 3.2: Program Design and Usability**

When designing technology-based exercise programs for older adults, it is important to take into account specific usability aspects of program design, as these can become a barrier to participation, especially for those without previous experience using technology. This subtheme is divided into participants’

experiences navigating through the program and the technical difficulties experienced.

### **Participants' Experiences Navigating Through the Program**

Participant accounts of their experiences when interacting with the *SureStep* program were varied, with some older adults finding it easy to use and others very difficult. When contrasting participants' experiences, it became apparent that those who described the program as being *quite easy to use* and *self-explanatory* were all accustomed to using other technologies (eg, computers, DVD player, and tablet computers), and they themselves talked about how their previous experience with technology may have facilitated the use of *SureStep*:

*It was only a few days [before I became familiar with the program]—see, I'd worked on computerised stuff for 20 odd years on different programs, different workings, different—seen how programs worked and that [SureStep] was probably much easier for me than [for] some other people. [Rubi, 78-year-old female]*

Although participants like Rubi found navigating through the program very easy, others experienced difficulties when trying to select a game, change from one game to another, and move between difficulty levels, which led to feelings of frustration. This is portrayed by Betty (aged 80 years), who described herself as “not being computer savvy,” but rather a “luddite” when it comes to using technology:

*Well I know it drove me mad because, I obviously, I grew to understand it [referring to how to navigate through the program]. But at the beginning when I didn't know that if I did that, that would fix that, so I had a lot of frustration at the beginning. Well I think it was mostly my fault, the problem was that I wasn't understanding computers. It might have taken me the first month [to learn how to navigate through the programs] because I know I fought with it for a long time. [Betty, 80-year-old female]*

Some participants, particularly those aged 80 years and over and those with low technology familiarity, spoke of having trouble using *SureStep* as they would often forget how to use the program. Participants were given a booklet with detailed instructions on how to operate the program; however, some did not use it because they “had forgotten [they] had it” or thought it was a “nuisance” having to stop and get the book because that “used up the time [they] had to exercise.” The frustration participants felt when forgetting how to operate the program is portrayed in Gertrude's words:

*It irritated me that I, 'cause I get irritated with myself, that I couldn't go straight into and do it, because I think my short term memory is a little bit weak and therefore, I was forgetting what you told me, by the time I tried to put it into practice. But that will happen to anybody of my age. [Gertrude, 97-year-old female]*

Gertrude's experience was quite typical of the difficulties that the study participants experienced when navigating through the

program to select an exercise game, change from one game to another, and move between difficulty levels. These were all common sources of frustration for some participants and can act as perceived barriers to action.

### **Technical Difficulties**

Participants encountered similar problems when navigating through the program interface. Again, this was more prevalent among participants aged 80 years and over and those who had limited experience using technologies. Some participants felt frustrated when unable to find a particular game they wished to play on the home screen. From observations made during home visits, it became evident that some participants were unable to remember that there were other game options in addition to what was presented on the screen and that by stepping right or left on the step mat they could access them. Future designs should ensure that all games are displayed on the home screen.

Similarly, participants reported often forgetting how to select a game from the home screen, how to return to the screen to change the level of difficulty of the game, and how to exit the game to play another game. The instructions were not consistent between games and participants said they would like to have all 4 games “work the same way” and have “explicit step by step instructions” on the screen to guide users in the operating of the program. This comes clearly in Eva's words:

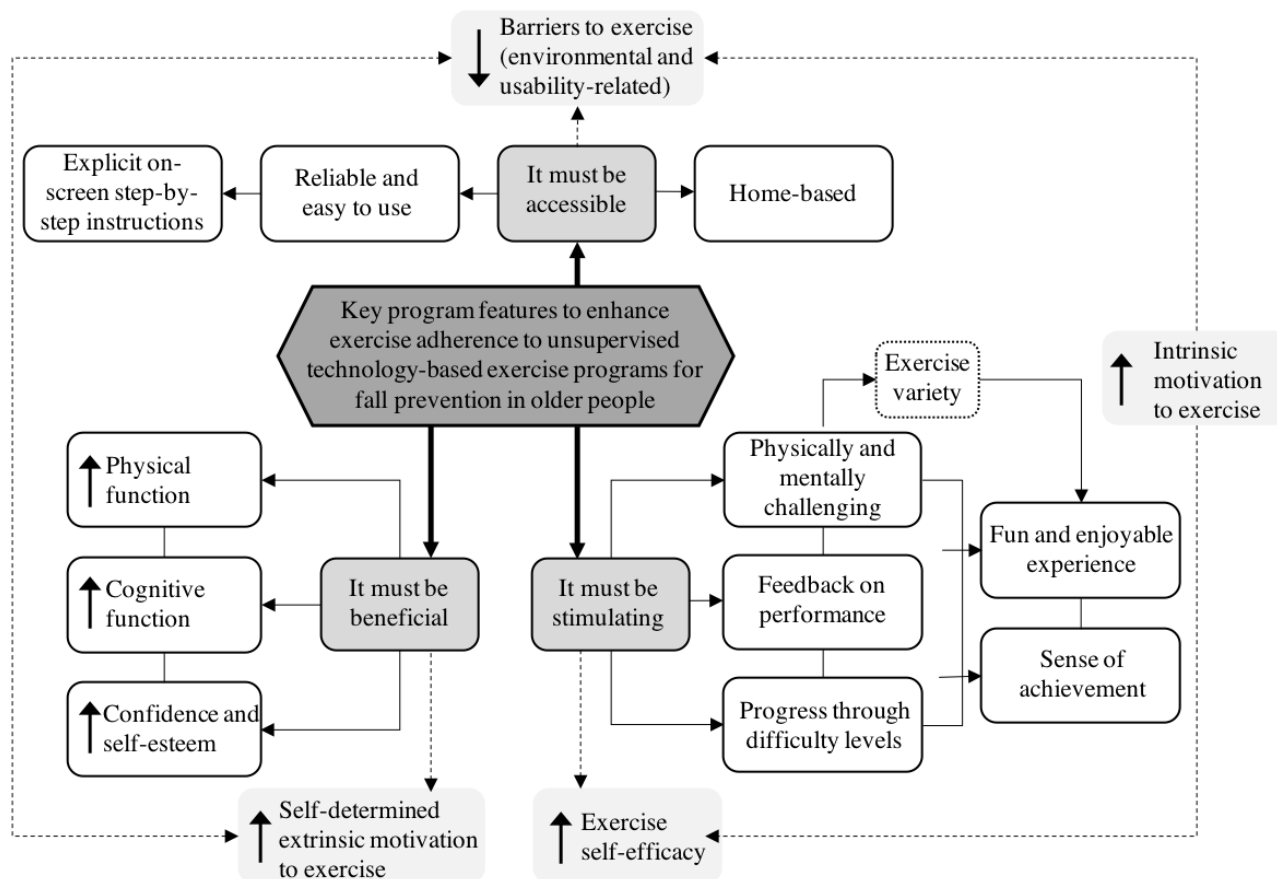
*I think perhaps the instructions could have been a bit more explicit, yes...I think it could have been a bit more, a bit more basic, not presuming that everybody could use computers...For non-computer literate people- and you're going to get a lot of them in this age group. A step-by-step [instruction] could have been better. [Eva, 78-year-old female]*

Finally, some participants also experienced technical problems such as the program temporarily not responding to the step mat or the program not starting correctly when turning it on. This impacted participants' willingness to use the program as portrayed by Thelma:

*I think that sort of put you off a bit [the program not functioning properly] and I thought oh well I won't do it now, it won't work. I haven't got time now to fiddle with it [...] you almost lost interest in it [the program] because it didn't operate immediately. It didn't matter what you did. And you thought, oh I haven't got time now and that's what you do. [Thelma, 87-year-old female]*

Difficulties were also encountered when moving from one game to another or changing difficulty levels, as the program would sometime flick through the different options too quickly. This was only experienced by a couple of participants due to faulty equipment and resolved after replacing the mat. However, this shows that it is of crucial importance to optimize the design and development before providing it to older adults, especially to those with limited prior experiences with technology.

**Figure 2.** Conceptual map of the 3 main themes identified from the thematic analysis of participants' interviews.



A conceptual map of the 3 main themes that were generated from the analysis of participants' interviews is summarized in Figure 2. Combined, the 3 themes emphasize the importance of implementing behavioral strategies in the development of technology-based exercise programs for older adults to use at home to optimize exercise adherence. The results of this study strongly suggest that self-efficacy, attitudes and beliefs, as well as the affective response to exercise participation enhance adherence to technology-based exercise programs. Therefore, it is important to assess an individual's needs and motivations to exercise to ensure appropriate exercise prescription.

## Discussion

### Principal Findings

This study explored older adults' perceptions of using a technology-based exercise program unsupervised in the home setting. Findings from this study suggest that older adults are open to using technology-based exercise programs in their home. Furthermore, program uptake and adherence seem to be enhanced by (1) older adults' perceived benefits of undertaking the program; (2) whether the program was stimulating; and (3) the perceived barriers to exercise and technology use.

Perceived benefits to health (both physical and mental health) were the most common reason for older adults to commence and continue their participation in the exercise program. Participants wanted to avoid having to rely on others and be able to care for themselves and felt that exercising would help maintain their independence and preserve their sense of

self-value. This is consistent with previous literature on exercise adherence, which suggests that maintaining good health and independence and reducing health risk factors are among the most common self-determined extrinsic motivators for exercise participation in older adults [54-60]. A systematic review of perspectives on fall prevention programs found that older adults were more likely to participate in exercise interventions if they believed that these would maintain or improve their health [61]. Similarly, a study looking at perceived benefits of and barriers to adherence to home-based exercise programs also found program adherence to be influenced by the perceived effect of programs on physical and mental health [62]. Furthermore, HPM construct of perceived benefits to action also suggests that individuals are more likely to commit and engage in behaviors, such as exercise, when they anticipate personally valued benefits [53]. The findings of this study confirm this relationship between an individual's perceived risk of future health-related problems and their commitment to exercise. Higher adherence rates were attained by participants with lower self-perceived health status, poor balance ability, fear of falling, and by participants who were hoping to obtain health-related benefits. Consistent with the findings of this study, a previous study also found poorer self-related health to predict adherence to balance exercises in older adults [63]. This motivational role of risk perception is consistent with a life-span perspective, which proposes that with advancing age, individuals become strongly driven by goals of preventive nature toward decreasing health risks and avoiding losses [64,65]. The prevalence of physical changes, health problems, and diseases can increase



older adults' perceived susceptibility to future illnesses and may lead to higher uptake of preventive health behaviors such as regular exercise participation [59]. Conversely, a lack of physical health benefits was reported by participants with higher self-perceived health status and balance ability; thus, participants reported other competing demands or preferences taking priority over following the prescribed stepping exercise program.

The importance of developing exercise programs that are stimulating to enhance exercise participation and adherence was clearly evident in this study with participants. Participants suggested a wide variety of exercises, with progressive difficulty levels, combining physical and cognitive tasks were key factors to make exercising fun, challenging, and enjoyable. Consistent with these findings, other studies have also found the enjoyment derived from exercising and the experience of personal satisfaction after exercising to be linked to older adults' motivation to continue exercise participation [25,62,66]. Our findings are also consistent with the activity-related affect construct of HPM, which suggests that people are more likely to engage in behaviors that invoke positive feelings or emotions [53]. Self-efficacy is also a crucial psychological determinant of adoption and long-term maintenance of physical activity [67-73]. Self-efficacy refers to an individual's judgment of their personal capabilities to execute a particular health behavior (such as engaging in exercise) and their self-confidence to perform the health behavior successfully [74]. Findings from this study suggest that *SureStep* increased participants' self-efficacy by providing a strong sense of achievement through successful completion of the exergames and progression to higher difficulty levels. Further findings from this study suggest that presenting older adults with positive feedback in the form of praise and scores further influenced their self-efficacy to exercise and increased their motivation to try and improve their scores. These findings emphasize the importance of an immediate positive experience when performing exercise. Tailoring the exercises to the individual's physical capacities and providing variety of exercises, opportunities for success, and positive feedback on performance are key considerations to increase program adherence.

Finally, our findings emphasize the importance of providing programs that are accessible to older adults. Participants liked the convenience of performing exercise at home, and the ability to select the amount of time spent exercising and when to exercise emerged as desirable aspects of the program. Home-based programs can reduce common barriers to exercise participation in this population, including lack of time, inability to travel, and dislike for group-based programs. By reducing perceived barriers to exercise, such programs may increase exercise participation and adherence in older adults. These findings are consistent with HPM, which postulates that perceived barriers can affect adults' commitment to action. However, it is important to consider that not all older adults prefer to exercise at home. For some participants, the self-reliance necessary to adhere to a home-exercise program and the lack of social opportunities were a concern. A study looking at the motivational determinants of exergame participation for older adults in assisted living facilities found that social interaction encouraged older adults to use the

exergame as it created competition that resulted in motivation to improve their score [75]. A previous systematic review and meta-analysis conducted on the impact of different program characteristics on adherence to home-based exercise programs found a higher proportion of older adults adhered fully to home exercise interventions that included moderate home visit support [10]. This suggests that it is equally important to promote autonomy in carrying out exercise interventions and provide support to facilitate program adherence. In this regard, technology-based exercise programs may benefit from incorporating an interactive platform through which older adults and health professionals could interact on a regular basis. This may provide opportunities to increase support while still reducing the cost associated with the provision of home-visit support. Finally, findings from this study suggest the importance of evaluating the acceptability, usability, and reliability of programs with a sample of older adults before implementing it as a home-based intervention [76]. Previous literature suggests that off-the-shelf programs that are not specifically designed for older adults may present a challenge for this population. Factors such as the pace of gameplay, the amount of graphical information, and the instructions on how to use the program can make it difficult for older adults to use these programs on their own [25,27,36,37]. *SureStep* was designed for older adults to use independently at home. The program was designed to deliver the training stimulus using a step pad connected to a computer unit and a television set. The step pad was designed to clearly indicate where the user should stand during game play, and large colored arrows were used to illustrate the different step directions the user could adopt. Two panels labeled "A" and "B" were used to access the home screen and select games and difficulty level, respectively. The program consisted of 4 games (*StepMania*, *Stepper*, *Trail-stepping*, and *Tetris*), which are modified versions of popular video games or converted neuropsychological tests. Parameters of game play including speed, color, object size, and drift rate of game elements were informed by an iterative process of design and testing involving collaboration between research staff, technologists, and older adults themselves such that the final exercise games delivered were appropriate for the physical, sensory, and cognitive abilities of an older population. As such, participants in this study did not report experiencing difficulties with factors such as the pace of gameplay or amount of graphical information displayed. However, results from our study revealed that participants with limited experience using technology experienced difficulties interacting with the program, including inability to access all available games, modify difficulty levels, and change from game to game. Older adults' inability to use technology conveyed feelings of frustration and apathy toward the program, thus affecting exercise adherence. To facilitate a more user-friendly interface, participants suggested the use of on-screen step-by-step instructions.

Furthermore, another element that requires attention to improve future implementation of *SureStep* is the need for a greater variety of games and greater range of difficulty levels to cater for older people of varied levels of physical and cognitive function and maintain older people's interest in the program. Results from our study showed that participants with better functional and cognitive abilities were able to successfully

complete all 4 games at the highest difficulty level within the intervention period. Thus, if the aim of technologies such as *SureStep* is to provide older people with exercise programs they can successfully use at home over prolonged periods, the provision of a wider range of games with extensive difficulty levels is warranted.

### Implications Toward Design of Technology-Based Programs for Older Adults

Findings from this study provide important considerations when designing technology-based programs, which are tailored to the needs of older adults and aimed at increasing both usability and acceptability of programs, which can ultimately enhance exercise participation and long-term adherence to fall prevention interventions. Findings from our study highlight the need for designers of technologies to work closely with older adults throughout the design and development process to learn how their preferences, attitudes, and capabilities relate to technology adoption and how products and services can be designed to promote their widespread and long-term use.

On the basis of this study's findings, future technology-based exercise programs should consider the following recommendations. First, hardware and software should be extensively tested before deployment into people's homes to avoid system malfunction leading to feelings of frustration and apathy toward the program, which can ultimately affect program adherence. Second, user testing to evaluate the ease of use of the program interface should be carried out during the development phase of the program, and explicit step-by-step instructions should be displayed on the screen to facilitate program use, especially among those with memory problems or cognitive impairment. Third, programs should incorporate a tailored exercise progression algorithm based on the user's performance, with increasing difficulty levels and unlocking of new games to ensure that the program remains challenging and enjoyable over time. Fourth, programs should provide a sufficient variety of games or exercises with a wide variety of difficulty levels, ideally training both cognitive and motor capacities, to maximize the perceived benefits of the program and maintain engagement. Fifth, programs that use equipment should ensure the equipment does not pose a tripping hazard, causing an increased risk of falling while stepping on or off the equipment.

### Limitations

Some limitations identified in this study need to be considered when interpreting the results. First, during the participant recruitment process, people were informed about the benefits of step training interventions in reducing fall risk factors; therefore, participants may have expected receiving health benefits from the program. Second, all participants volunteered to take part in the study knowing that if randomized to the intervention group, they would be required to use a technology-based exercise program; thus, all participants who

volunteered were open to try new technologies and may have more positive attitudes toward the intervention. Third, participants were selected from the sample of older adults that returned for reassessment after a 4-month intervention period. Therefore, the interviewed participants did not include older adults who withdrew or dropped out of the study. Interviewing some of these participants may have provided further information on the perceived barriers to using a technology-based exercise program unsupervised at home. However, efforts were made to interview individuals who had stopped using the program but did not withdraw entirely from the RCT. Fourth, the structured nature of the interview questions may have prevented obtaining more in-depth information on participants' experiences from the study. Finally, interviews were performed by the same person who provided assistance to participants during the RCT. Although this allowed for consistency and rapport building, it might have also allowed for demand characteristics, such as participants trying to provide more positive responses to the interviewer. However, data triangulation was performed using the logs from participants' visits, telephone calls, and support required to validate the participants' responses.

### Conclusions

Findings from this study suggest that it is feasible to use technology to deliver a home-based fall prevention intervention to community-dwelling older adults. However, to encourage uptake and long-term adherence, programs need to remain stimulating over time. Our results indicate that providing 4 different games with varying levels of difficulty did not offer sufficient variety, as over time, participants reported losing interest in the program as the novelty wore off. To maintain participants' engagement over prolonged periods, we therefore recommend providing a greater variety of games with increasing levels of difficulty to ensure exercises remain challenging. Technologies must also be designed in ways that are accessible to older adults regardless of their previous technology exposure. This study indicates that program usability could be improved by providing on-screen step-by-step instructions as older adults with low technology familiarity as well as those with memory problems or cognitive impairment had difficulty remembering how to use the program.

In light of this evidence and in the context of optimizing adherence to technology-based exercise programs for older adults to use at home, program developers should develop exercise programs in ways that provide older adults with a fun and enjoyable experience (thus increasing intrinsic motivation to exercise), focus on improving outcomes that are significant to older adults (thus increasing self-determined extrinsic motivation), offer challenging yet attainable exercises (thus increasing perceived self-competence), provide positive feedback on performance (thus increasing self-efficacy), and are easy to use (thus reducing perceived barriers to technology use).

### Conflicts of Interest

None declared.



## Multimedia Appendix 1

Instructional video of SureStep cognitive-motor stepping program and demonstration of study participant using SureStep. [MP4 File (MP4 Video), 116MB - [aging\\_v1i2e11975\\_app1.mp4](#) ]

## Multimedia Appendix 2

Interview guide for qualitative interviews with older people allocated to use SureStep at completion of 4-month intervention period.

[PDF File (Adobe PDF File), 24KB - [aging\\_v1i2e11975\\_app2.pdf](#) ]

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## Abbreviations

**FCI:** Functional Comorbidity Index

**HPM:** Health Promotion Model

**Icon-FES:** Iconographical Fall-Efficacy Scale

**IPEQ:** Incidental and planned exercise questionnaire for older adults

**PHQ-9:** Nine-item Patient Health Questionnaire

**RCT:** randomized controlled trial

**WHODAS:** World Health Organization Disability Assessment Schedule

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Original Paper

# Identifying Consumers Who Search for Long-Term Care on the Web: Latent Class Analysis

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## Abstract

**Background:** Because the internet has become a primary means of communication in the long-term care (LTC) and health care industry, an elevated understanding of market segmentation among LTC consumers is an indispensable step to responding to the informational needs of consumers.

**Objective:** This exploratory study was designed to identify underlying market segments of the LTC consumers who seek Web-based information.

**Methods:** Data on US adult internet users (n=2018) were derived from 2010 Pew Internet and America Life Project. Latent class analysis was employed to identify underlying market segments of LTC Web-based information seekers.

**Results:** Web-based LTC information seekers were classified into the following 2 subgroups: heavy and light Web-based information seekers. Overall, 1 in 4 heavy Web-based information seekers used the internet for LTC information, whereas only 2% of the light information seekers did so. The heavy information seekers were also significantly more likely than light users to search the internet for all other health information, such as a specific disease and treatment and medical facilities. The heavy Web-based information seekers were more likely to be younger, female, highly educated, chronic disease patients, caregivers, and frequent internet users in general than the light Web-based information seekers.

**Conclusions:** To effectively communicate with their consumers, providers who target Web-based LTC information seekers can more carefully align their informational offerings with the specific needs of each subsegment of LTC markets.

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**KEYWORDS**

internet; information seeking behavior; consumer health information; marketing of health services; public reporting

## Introduction

**Background**

It is widely acknowledged that the internet has become a primary marketplace for virtually all industries. Accordingly, potential consumers are now able to access necessary information for

their decision making [1]. Today, health care and long-term care (LTC) providers, as well as the federal government, are also heavily reliant upon the internet to provide information [2,3]. Accordingly, it is unsurprising that consumers also rely on the internet to inform their buying decisions. Likewise, providers can now acquire a wealth of data via the Web to guide their marketing efforts.



Current research on Web-based information and knowledge exchange in the LTC marketplace reveals the criticality of these processes. For example, the 5-star rating system of the US Centers for Medicare and Medicaid Services (CMS) as a Web-based information exchange has significantly impacted the way LTC information is presented to the public and the way individuals perceive such information [4]. Introduced as Nursing Home Compare, a US public reporting system in December 2008, the findings from these report cards were first made available via the internet. These researchers used a before-and-after design to determine whether published data on quality measures of nursing homes created a shift in demand or in quantity demanded across nursing homes once consumers had more access to relevant information. Their study revealed that consumers of nursing home services decreased their purchase of institutional care from poorly rated facilities and increased the share of services bought from highly rated (ie, 5-star) facilities. Accessing such nursing home quality data via the internet was the primary vehicle that altered this important retail market adjustment process.

Additional research indicates that LTC providers also have an opportunity to promote their facilities by being responsive to the informational needs of consumers in areas that extend beyond the mainstream quality measures such as the Nursing Home Compare of the CMS. On the basis of focus groups and key informant interviews with persons aged 65 years and older, as well as family members of nursing home residents, a study found that there is a far greater breadth of informational needs than that which now exists on Nursing Home Compare [5]. Moreover, the nature of informational needs of consumers differs across various demographic segments of the American population. Similarly, another study, in an analysis of the information-seeking nursing home behavior on Yahoo! Answers, identified a wide range of consumer-based informational needs and a market-based discordance between the informational needs of current or prospective consumers in the LTC market, and the information made available by the LTC providers [6]. Indeed, this study suggested that nursing home sites may also need to provide assurances of quality care to family members of potential LTC consumers.

In order for nursing homes and/or other LTC organizations to effectively communicate their informational contents to the prospective consumers who seek information via the internet, more refined marketing segmentation is needed. Research must move beyond mere demographic and/or socioeconomic data so that the psychographic, sociographic, and/or clinical informational needs of various subsets of consumers can be addressed. In this respect, an analytical approach that allows the identification of subgroup differences in the Web-based informational needs of consumers is useful [7].

The internet provides an opportunity for all marketplaces to function more optimally as a source of timely information. Yet, there is paucity of research that specifically examines how LTC information is accessed, and how the available Web-based information is in alignment with the information sought. This study seeks to initiate the process of remediating this void by advocating the use of market segmentation to better facilitate

the exchange of Web-based information between LTC consumers and providers.

## Objectives

Building upon the insights from previous research that focused on health and medical information-seeking behaviors [8-10], this exploratory study uses a large dataset of American adults to segment internet users who seek Web-based LTC information. Moreover, this research profiles the Web-based information-seeking behaviors of identified subgroups of internet users. Specifically, this study uses latent class analysis (LCA)—a person-centered approach—to accomplish this task. A content analysis of past studies reveals a sole reliance on the adoption of variable-centered approaches, such as linear regression and logistic regression, to determine whether significant differences in information-seeking activities occurred. This is not to say that such approaches are methodologically flawed. Indeed, the opposite is true.

Variable-centered approaches are sound when examining relationships between variables and developing the initial segmentation basis for internet users. However, such methodologies also embody several limitations in circumstances when more detailed segmentation data are required. First, the estimation and interpretation of models with more than one outcome variable can be a challenging task. As such, variable-centered approaches are generally not suitable for the simultaneous examination of multiple internet users' information-seeking behaviors (eg, the data we used for this study). Second, the extent to which such statistical models are capable of identifying the characteristics of target populations is also somewhat restricted. Specifically, the effect of one characteristic (eg, gender or education) on the outcome variable can only be examined while all other characteristics are held constant. Third, the traditionally used variable-centered approach measures an average effect of a predictor variable on the outcome variable by using the premise that all individuals were sampled from the same population. Such an approach explicitly bypasses underlying subpopulation differences. Finally, in conjunction with the first three limitations, variable-centered approaches do not clearly identify the consumer subpopulations to whom LTC providers must be responsive at a micro-level. Indeed, most studies on the information-seeking behavior of consumers fail to consider the need for providers to direct responsive *answers* to these information-seeking consumers so that overall health outcomes can improve.

This study used one of the first publicly available consumer survey datasets that include the questions of internet search for LTC. This study was specifically designed to address the limitations of the currently dominant variable-centered approaches while building upon the findings from previous studies on Web-based health or medical information-seeking. Moreover, this inquiry broadens dialogue by employing LCA [11]. LCA has been increasingly used in medical, health, social, and behavioral sciences [7]. The primary strength of this approach is the identification of underlying subpopulations that share similar sets of behaviors while separately developing profiles of multiple subpopulations. LCA assumes that unobserved groups (latent classes) are present and that these

groups have highly refined needs and behaviors [11]. Rather than modeling associations between variables, LCA first detects and then characterizes previously unobserved groups of persons (ie, subpopulations) within the larger sample.

The use of the person-centered approach supports the profiling of the internet users who seek LTC information while simultaneously taking other factors into account. These factors include (1) a summary description of the multiple health information-seeking behaviors displayed and (2) the construction of a sociodemographic profile of the internet users by identified subgroups. When LTC providers better understand the informational needs of each subgroup, they can better respond to these needs via their website and/or other marketing materials. This study was designed to answer the questions listed below:

1. Who are the subgroups or unique market segments that search the internet for LTC information?
2. What health, medical, and/or other knowledge is sought by the internet users who seek Web-based LTC information?
3. What are the sociodemographic and other characteristics of the internet users who search the internet for LTC information?

Based upon the answers to the above questions, recommendations can be made to LTC information providers regarding the type of information they should disseminate via Web-based resources.

## Methods

### Data Sources

Data from the 2010 Princeton Survey Research Associates International for the Pew Internet and American Life Project (Pew Internet) were used to answer the 3 described questions [12]. Collected through telephone interviews with adults aged 18 years and older in August and September of 2010, the samples for this study were drawn from a pool of 20,985 landline users and 12,699 cell phone holders by Survey

Sampling International, LLC [13]. The Pew Internet database explores the impact of the internet on children, families, communities, the work place, schools, health care, and civic or political life. In 2010, the Pew Internet and American Life Project included, for the first time ever, a question regarding LTC health information-seeking over the internet. The original survey item asked the respondents whether they had searched the Web for information about a series of health and medical topics. LTC was one of the response categories.

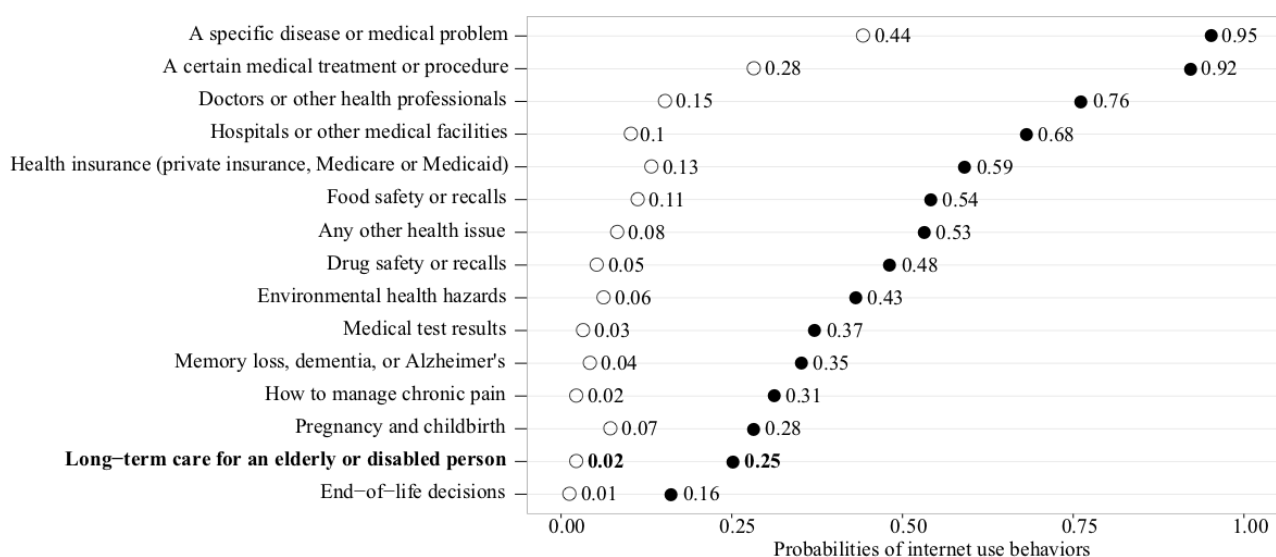
A series of survey items were included to assess key sociodemographic characteristics, internet use behaviors, and the health-related information sought by seekers of LTC information. Random digit dialing was used as a sampling strategy. Although not entirely representative of all of the US adult population, the data covered a large population of phone users [14]. Because this unique dataset collects Web-based health, medical, and LTC information-seeking behaviors, it provides a unique opportunity for researchers to conduct a market segmentation study based on internet use for LTC information. After excluding noninternet users (n=976) and missing values for key Web-based information-seeking behaviors (n=7) from the original sample (n=3001), the final sample size was 2018.

### Measures

#### Outcome Variable

The primary outcome of interest was a dichotomous measure indicating 2 identified latent classes (which is labeled as class 1 [light information seekers] vs class 2 [heavy information seekers, reference group]). Using LCA (described more in the next sections), these subgroups were identified based on a set of 15 Web-based health information-seeking behaviors with dichotomous responses (Yes or No; see Figure 1). The health information-seeking referred to looking for both the long-term information and other health-related information for themselves or for someone else.

**Figure 1.** Posterior probabilities for the online information-seeking behaviors by the identified latent classes.



### Predictor Variables

A variety of demographic, socioeconomic, health status, and caregiving status information was included for each model. Age was recorded in years. However, people older than 97 years were top-coded at 97. The more traditional demographic and socioeconomic segmentation variables were included as predictor variables. These included (1) gender (women vs men); (2) race or ethnicity (black vs white, Hispanic vs white, and others vs white); (3) marital status (married vs not married); and (4) employment status (employed vs not employed and retired vs not employed). These dichotomous measures were used for purposes of cross-classification. The number of people in each household was measured as the absolute count of total household members. Educational attainment was assessed based on a 5-point Likert-scale (1-5: None-Postgraduate degree). Household income was recorded using a 9-point Likert-scale ranging from less than US \$10,000 to US \$150,000 or more. Uneven rather than even increments were used. As a result, the income classes could not be treated as a continuous variable (eg, by US \$10,000, US \$25,000, and US \$50,000). Self-rated health was recorded based on a 4-point Likert-scale (1-4: Poor-Excellent). However, a range of clinical variables, as well as other segmentation factors were included. The number of self-reported chronic conditions was counted based on following 6 major diseases: diabetes mellitus, hypertension, lung disease, cardiovascular disease, cancer, and/or other chronic diseases. Disabilities were assessed using 6 disability indicators based on difficulties with hearing, vision, memory, walking, dressing, and running errands. Two dichotomous measures of caregivers were used as follows: (1) caregivers for 1 or more parents vs noncaregivers; (2) caregivers for adults who were not parent(s) vs noncaregivers (reference group). Finally, internet usage was recorded based on 7-point Likert-scale (1-7: Never-Several times a day) either at home or at work. Internet users who reported "Never" but still used email were classified as internet users in this study. Accordingly, the study included the potentiality for many subsegments based on various permutations and combinations of the included categories.

### Analytic Strategies

Two primary areas of inquiry guided this research. At the first level, this study sought to identify unique underlying subgroups or market subsegments that used the internet to address their needs relative to informational LTC. This study also sought to identify the health- or medical information-seeking activities of consumers across various subgroups. Accordingly, the first part of the analysis focused on the identification of the latent classes of users. Figure 2 presents a path diagram of the theoretical proposition that was applied for latent class analysis. The analysis was completed in 2 sequential steps using Mplus version 7 (Muthén and Muthén).

First, an LCA was conducted using the 15-Web-based health-related and medical information-seeking behaviors. LCA

is a special type of structural equation model (SEM) with unobserved or latent variable(s) [11]. Latent variables are commonly modeled with continuous observed variables (eg, measurement model) [15]. In other words, LCA is an SEM with a categorical latent variable [16]. The number of final groups was chosen based on the average posterior class membership probability, classification quality, and interpretability in view of possible implications of the findings for LTC providers relative to the type of information they should supply via Web-based mechanisms [7]. In the preliminary analysis, the number of groups ( $k$ ) was set between 2 and 6 in LCA, and full information maximum likelihood estimation was applied. With each *applicant*, several variables were analyzed, including (1) the specific group membership probability (0.7 or higher) [17]; (2) the percentage of people in the smallest class; (3) the classification quality indicator [11] (entropy>0.8); (4) bootstrap likelihood ratio test [18] (BLRT:  $k$  vs  $k-1$  specification); and (5) Akaike information criteria (AIC). Bayesian information criteria (BIC) and interpretability [19] were also evaluated (see Table 1).

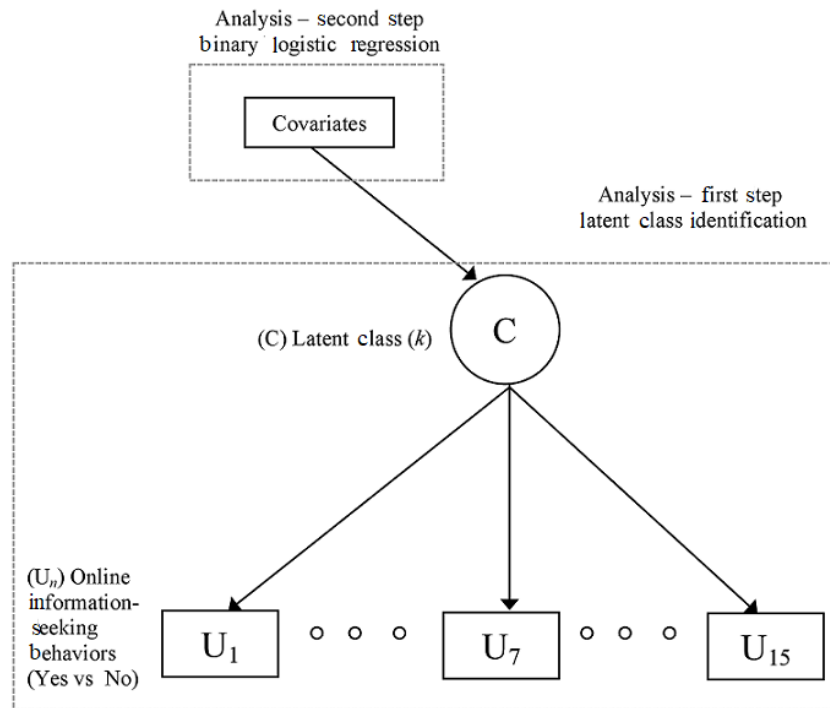
As a result, the model with 2 latent classes was determined to be optimal (the posterior membership probabilities>0.95; entropy=0.84, and BLRT  $P<.05$ ). Although AIC and BIC were smaller as the number of classes increased, other criteria indicated (eg, entropy) that the model with 2 or 3 classes was *finer*. However, the 2-class specification was chosen in view of the interpretability [19]. On a related note, the covariates were not included in the final LCA model because of unstable identification of the latent classes. However, given the high-quality classification [20] (entropy greater than 0.8) and the purpose of this study (ie, profiling) or segmentation, the effects of covariates on each class membership were examined in the second step of the analysis.

### Two Latent Subgroups

Each latent class corresponded with an underlying subgroup of internet users who visit the Web in search of information about the LTC marketplace. Figure 1 describes the percentages of internet information-seeking behaviors by the 2 classes. As can be seen, the class 1 members (black dots) are appreciably more likely to seek health, medical, and LTC information than the class 2 members (white dots). Moreover, for each specific Web-based information-seeking behavior, the pattern was consistent (ie, the class 1 is higher than the class 2).

In terms of LTC Web-based information-seeking, the difference between these 2 classes was evident. The first latent class is characterized by a high probability of internet use behavior. As a result, class 1 users were labeled as *heavy Web-based information seekers*. In contrast, class 2 is characterized by a low probability of internet use behavior. Thus, this segment of LTC current or prospective consumers was labeled as *light Web-based information seekers*.

**Figure 2.** Latent class analysis model and analytic approaches.



**Table 1.** Comparisons between the latent class analyses with different number of latent classes.

Model selection criteria	$k^a=2$	$k=3$	$k=4$	$k=5$	$k=6$
The minimum percentage of 1 class	44.50	22.8	15.46	10.50	7.17
The mean posterior class membership probability <sup>b</sup>	>0.96	>0.91	>0.83	>0.78	>0.77
Entropy	0.84	0.82	0.78	0.77	0.79
Bootstrap likelihood ratio test ( $k$ vs $k-1$ )-2 log likelihood (degrees of freedom)	5057.04 (16) <sup>c</sup>	1010.30 (16) <sup>c</sup>	274.03 (16) <sup>c</sup>	182.95 (16) <sup>c</sup>	141.77 (16) <sup>c</sup>
Akaike information criteria	27,465.22	26,486.93	26,244.90	26,093.95	25,984.18
Bayesian information criteria	27,639.12	26,750.59	26,598.32	26,537.13	26,517.12

<sup>a</sup> $k$ : number of latent classes.

<sup>b</sup>The model with  $k=2$  was selected as the final model considering the highest posterior class membership probability, entropy, statistically significant difference from the model with  $k=3$ , and interpretability (ie, more distinctive internet use behaviors between classes).

<sup>c</sup> $P < .001$ .

Table 2 represents a descriptive summary of both classes of users. The proportional odds binary logistic regression [21] was used to examine the effects of both sociodemographic and other market segmentation variables. Specifically, the impact of health status, caregiving status, and internet usage on membership of each primary class (ie, heavy vs light Web-based information seekers) was evaluated. It is important to note that SAS version

9.4 (SAS Institute Inc, Cary, NC, USA) was used because Mplus version 7 does not return the c-statistic [21,22] that was used to assess model quality. This fact assumes importance, given that SAS and Mplus, at the time of this study, do not use the identical estimation algorithms. Therefore, the computed c-statistic may require caution in its interpretation.

**Table 2.** Descriptive summary of internet users by the identified latent classes.

Characteristics	Latent class 1; heavy Web-based information seekers (n=1120)	Latent class 2; light Web-based information seekers (n=898)
Age in years, mean (SD)	44.30 (15.97)	45.03 (17.91)
<b>Gender, n (%)</b>		
Women <sup>a</sup>	713 (63.70)	479 (53.3)
<b>Race or ethnicity, n (%)</b>		
White <sup>b</sup>	754 (67.31)	547 (60.9)
Black <sup>c</sup>	173 (15.43)	176 (19.6)
Latino	132 (11.77)	122 (13.6)
Others	61 (5.49)	53 (5.9)
Married (vs not married) <sup>c</sup> , n (%)	604 (53.91)	417 (46.4)
Number of household members, mean (SD)	2.18 (0.92)	2.19 (0.98)
<b>Educational attainment<sup>a</sup>, n (%)</b>		
High school or less	41 (3.62)	84 (9.3)
Vocational school	246 (22.00)	317 (35.3)
Some college or associated degree	24 (2.17)	25 (2.8)
Bachelor's degree	405 (36.18)	279 (31.0)
Postgraduate degree	404 (36.03)	194 (21.6)
<b>Employment status, n (%)</b>		
Employed <sup>b</sup>	753 (67.19)	541 (60.2)
<b>Annual household income in US \$<sup>a</sup>, n (%)</b>		
Less than \$10,000	50 (4.45)	93 (10.3)
\$10,000 to under \$20,000	104 (9.28)	90 (10.0)
\$20,000 to under \$30,000	97 (8.64)	107 (12.0)
\$30,000 to under \$40,000	131 (11.69)	120 (13.4)
\$40,000 to under \$50,000	104 (9.28)	110 (12.3)
\$50,000 to under \$75,000	206 (18.42)	152 (16.9)
\$75,000 to under \$100,000	168 (14.99)	106 (11.9)
\$100,000 to under \$150,000	144 (12.83)	69 (7.7)
\$150,000 or more	117 (10.42)	52 (5.6)
Insured <sup>a</sup> , n (%)	1009 (90.12)	760 (84.6)
<b>Self-rated health, n (%)</b>		
Excellent	365 (32.55)	299 (33.3)
Good	609 (54.40)	475 (53.0)
Only fair	126 (11.27)	105 (11.7)
Poor	20 (1.78)	18 (2.1)
Number of chronic conditions <sup>c</sup> , mean (SD)	0.21 (0.50)	0.63 (0.93)
Number of disabilities, mean (SD)	0.33 (0.75)	0.33 (0.75)
<b>Caregivers for adults</b>		
Parents vs noncaregivers <sup>a</sup> , n (%)	178 (15.91)	77 (8.5)
Nonparents vs noncaregivers <sup>a</sup> , n (%)	250 (22.31)	127 (14.1)



Characteristics	Latent class 1; heavy Web-based information seekers (n=1120)	Latent class 2; light Web-based information seekers (n=898)
<b>Internet usage<sup>a</sup>, n (%)</b>		
Never <sup>d</sup>	22 (2.00)	31 (3.4)
Less often	11 (1.00)	35 (3.9)
Every few weeks	15 (1.34)	39 (4.4)
1-2 days a week	55 (4.90)	92 (10.3)
3-5 days a week	110 (9.80)	125 (14.0)
About once a day	147 (13.14)	177 (19.7)
Several times a day	760 (67.82)	398 (44.4)

<sup>a</sup> $P < .001$  for the *t* test or chi-square test.

<sup>b</sup> $P < .01$  for the *t* test or chi-square test.

<sup>c</sup> $P < .05$  for the *t* test or chi-square test.

<sup>d</sup>Internet usage: never, these respondents still used email and, therefore, classified as internet users.

## Results

### Findings From the Analysis of Posterior Probabilities

The findings from the analysis reveal a contrariety. Although a priori reasoning would suggest that people in need of LTC and/or individuals with a chronic disease would be more compelled to use the internet for information-seeking, this was not the case. As mentioned, 2 latent classes existed among the study participants: heavy Web-based information seekers (n=1120) and light Web-based information seekers (n=898). The heavy Web-based information seekers were more likely to be women (independent of race or ethnicity). These women were most often married, highly educated, employed, economically upper class, insured, less chronically ill, and in general, more active internet users.

Unsurprisingly, the heavy Web-based information seekers (15.91%, 178/1120) were more likely to be caregivers than the light Web-based information seekers (8.5%, 77/898). In this study, about 25% of the heavy Web-based information seekers reportedly looked for LTC information on the Web, whereas only about 2% of light Web-based information seekers did so (see Figure 1). Moreover, the individuals who sought LTC information on the Web were also more likely to use the internet to look for other health and medical information. Specifically, majority of the heavy Web-based information seekers looked for health and medical information related to a specific disease,

medical treatment, health care professionals, hospitals, insurance, food safety, and other health issues.

### Results of the Binary Logistic Regression

The results of the binary logistic regression were predictive of the latent class membership. This analysis revealed 8 statistically significant predictors (see Table 3). Interestingly, older adults were less likely to be the heavy Web-based information seekers and, therefore, less likely to seek Web-based LTC information, compared with younger adults. The membership of heavy Web-based information seekers was predicted by female gender, higher education, higher household income, and a greater number of chronic conditions. As expected, caregivers to parents and caregivers to adults who were not their parents had 1.94 times and 1.82 times odds of being the heavy Web-based information seekers than noncaregivers to any adult. That is, caregivers were significantly more likely to look for the LTC information, as well as other Web-based information than noncaregivers.

Finally, the adults who used the internet more often also tended to be in the category of heavy Web-based health-related as well as LTC information seekers. Overall, individuals who had health issues (either their own or someone else's) and/or caregiving responsibilities and particular characteristics (eg, gender and higher socioeconomic status) were significantly more active in terms of Web-based health and medical and LTC information-seeking behaviors.

**Table 3.** Estimated odds ratios from proportional odds binary logistic regression on the heavy Web-based information seekers (class 1) versus light Web-based information seekers (class 2).

Variables	Odds ratio (SE)
Age (years)	0.98 (0.01) <sup>a</sup>
Women (vs men)	1.90 (0.13) <sup>a</sup>
Black (vs white)	0.77 (0.17)
Latino (vs white)	0.89 (0.19)
Others (vs white)	0.64 (0.29)
Married (vs not married)	1.17 (0.15)
Number of household members	0.94 (0.07)
Educational attainment	1.34 (0.05) <sup>a</sup>
Employed (vs not employed)	1.02 (0.17)
Retired (vs not employed)	1.27 (0.26)
Annual household income	1.09 (0.03) <sup>b</sup>
Insured (vs uninsured)	1.09 (0.19)
Self-rated health	0.96 (0.10)
Number of chronic conditions	1.30 (0.08) <sup>a</sup>
Number of disabilities	1.06 (0.09)
Caregivers for adults (parent vs noncaregivers)	1.94 (0.20) <sup>a</sup>
Caregivers for adults (nonparent vs noncaregivers)	1.82 (0.17) <sup>a</sup>
Internet usage	1.20 (0.05) <sup>a</sup>

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

## Discussion

### Principal Findings

This exploratory study analyzed a large dataset of the internet users and identified the primary segments of users, as well the subsets within each larger segment of the adults who looked on the Web for LTC and other health and medical information. However, the implications of this study extend far beyond the defined areas of inquiry. Although multiple sources of LTC information exist on the Web, LTC providers as the *suppliers* in the markets can use findings from this study to ensure that the Web-based information that they provide is easily accessible by these various segments of users and includes the types of information that these various segments seek. The following sections provide brief discussions on the selected areas for future research.

### Heavy Versus Light Web-Based Information Seekers

One important finding from this study is the unobserved latent class memberships among the heavy and light Web-based information seekers. The latent class membership is informative of Web-based LTC of multiple individuals and other health and medical information-seeking behaviors. That is, when individuals seek LTC information on Web, there is a significantly greater chance that they also use the internet to look for other health and medical information. Moreover, with

the traditional variable-centered approach, findings are limited to the associations between two variables at a time while holding all other variables or covariates constant (ie, assuming all other variables are the same). Two practical implications can be drawn from the finding.

First, the volume of research on Web-based health and medical information is significantly greater than that of LTC information [23-26]. Accordingly, as LTC providers deliver knowledge and information to current and/or prospective users, this Web-based LTC information should be designed in alignment with the rich literature on Web-based health and medical information. Thus, this study provides a foundation for improvements in the *fit* between Web-based information-seeking by LTC consumers and the information made available by LTC providers. For example, given the heavy information seekers use the internet for multiple purposes, packaging the geriatric medical information (eg, aging-related disabilities and dementia) and associated LTC information in one place or website may help streamline efficient information-seeking experience.

Second, LTC providers, depending on the nature of their services, can literally target the specific subpopulations identified in this study. For example, if the goal is to provide Web-based LTC information to older adults who may need LTC services at some point in the future, LTC providers can target light Web-based information seekers who can be identified

based on a set of characteristics, including age, gender, educational attainment, household income level, number of chronic conditions, caregiving responsibilities, and general internet use. In other words, given that most of the light information seekers do not use the internet for health, medical, and LTC information, more aggressive marketing and outreach with the traditional health communication (eg, printed materials such as flyer and postcard) may be necessary.

Similarly, given the findings on the heavy Web-based information seekers, LTC providers can align their messages with non-LTC health and medical information sources. This is a highly effective strategy for reaching their audiences given that Web-based information seekers tend to simultaneously look for LTC and health and medical information. Finally, more practical strategies can also be used to better coordinate LTC providers and consumers' health and medical information as additional research of this type is completed.

### Younger Versus Older Adults

This study reconfirmed findings from other researchers, which indicated that older adults, despite their status as the primary LTC consumer segment, are significantly less likely to seek LTC information on the Web. Citing data from the Pew Internet Report, this research confirms that although internet use has been increasing among older adults, usage levels continue to remain below those of younger adults [27]. However, also using data from the Pew Research Center, another study found that in 2013, 53% of adults aged 65 years and older used the internet [28]. Yet, although 86% of this total communicated via email, a mere 27% used the internet for improving their health literacy through health-related information-seeking. The data suggest that there is an urgent need for LTC providers to assume a role of leadership in directing internet-based social marketing toward seniors. Munshi et al [29], describe the robust need for diabetes care among many LTC consumers. As this study reveals, health area-specific unique informational needs exist among LTC consumers with chronicities.

### Information Gaps Between Long-Term Care Consumers and Providers

A greater informational exchange between this subsegment of LTC consumers and providers can potentially improve outcomes via better informed decision making in LTC preplanning before the emergence of aging-related severe cognitive and/or physical disabilities that require LTC services. That is, a knowledge informational gap in the LTC marketplace that can only be addressed when providers and consumers of LTC experience better coordination in the online demand for, and supply of, LTC information [30]. As is known, the LTC marketplace as currently structured is one that is built upon minimum levels of dialogue between consumers and/or their representatives and LTC providers. This tendency is revealed as one reviews the US CMS document, *Your Guide to Choosing a Nursing Home or Other Long-Term Care* [31]. This document recommends the use of Eldercare Locator, Agency, and Disability Resource Centers (ADRCs), Long-Term Care Ombudsman, and other services. However, it also reveals the need for more direct informational linkages between LTC consumers and LTC

providers. Again, an awareness of the unique informational needs of LTC subsegments can be used to improve this dialogue.

### Women Versus Men as Seekers of Long-Term Care Information on the Web

One study using data from 7609 Medicare beneficiaries in the 2011 National Health and Aging Trends Study, found that, in general, males are more likely to use the internet than females [27]. Yet, the results from this study revealed that females, perhaps because of their over-representation among caregivers, were more likely to seek Web-based information on LTC than males. This finding suggests that if the LTC industry wishes to direct internet messaging to these unique segments of information seekers, separate messaging content and information dissemination strategies will be required. A similar pattern of research-driven market segmentation can also be found in any industry [32].

### Access to the Internet: People With Higher Versus Lower Socioeconomic Status

This study, as has been true with other analyses, also discovered that people with higher incomes and higher levels of education are more likely to access LTC information on Web. Yet, in some respects, people having lower income with disabilities that require LTC find themselves engaged in a more complex network of financial transactions as they engage in eligibility screening (eg, Medicaid), benefits establishment, and dual-eligibility [33]. People with lower income because of lack of exposure to technology or financial resources [34] are disproportionately likely to rely on cell phones rather than personal computers [35]. LTC providers may consider disseminating information to this group via mobile phone apps and/or mobile-friendly websites.

### People With More Versus Fewer Chronic Diseases

The findings also reveal that persons with chronic diseases are more likely to engage in LTC and health-related information-seeking on the internet (arguably out of necessity). This finding on chronic conditions and Web-based information-seeking suggests that LTC providers can disseminate reliable information to prospective residents regarding their services for managing various chronicities. One study criticizes the internet as a source of health information based upon fragilities, complexity of the information, and the observed frequency of inaccurate information [36]. Accordingly, LTC providers will need to ensure that the targeted market subsegments are delivered accurate information in a format compatible with their informational needs [37].

### Conclusions

This exploratory study applied LCA as a tool for the segmentation of LTC internet information-seeking into relevant subsegments. Such a person-centered approach can potentially improve the operations of LTC marketplace. The analysis of a large pool of data of American adults identified two underlying market segments—heavy and light Web-based information seekers—according to their Web-based LTC and health and medical information-seeking behaviors. The study also revealed that the segmentation basis for LTC consumers includes but

extends beyond demographic and socioeconomic variables such as age, gender, educational attainment, and household income level. Rather, chronic conditions, caregiving status, and general internet usage are predictive of class membership. Thus, identifying the latent classes with more or less usage of the internet for LTC and health and medical information was merely a starting point. The next step involves using the findings from this study to enhance Web-based communications between LTC

providers and current and prospective LTC consumers. In this respect, this exploratory analysis contributed to the framework for future research and provided a foundation to generate greater dialogue regarding how various subsegments of LTC information seekers via the internet can be better linked with LTC service providers, the group that is best positioned to deliver information essential for decision-making.

## Conflicts of Interest

None declared.

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## Abbreviations

- AIC:** Akaike information criteria
- BIC:** Bayesian information criteria
- BLRT:** bootstrap likelihood ratio test
- CMS:** Centers for Medicare and Medicaid Services
- LCA:** latent class analysis
- LTC:** long-term care
- SEM:** structural equation model



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Original Paper

# Evaluating the Use of Mobile Health Technology in Older Adults With Heart Failure: Mixed-Methods Study

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## Abstract

**Background:** Heart failure (HF) is associated with high rates of hospitalizations, morbidity, mortality, and costs. Remote patient monitoring (mobile health, mHealth) shows promise in improving self-care and HF management, thus increasing quality of care while reducing hospitalizations and costs; however, limited information exists regarding perceptions of older adults with HF about mHealth use.

**Objective:** This study aimed to compare perspectives of older adults with HF who were randomized to either (1) mHealth equipment connected to a 24-hour call center, (2) digital home equipment, or (3) standard care, with regard to ease and satisfaction with equipment, provider communication and engagement, and ability to self-monitor and manage their disease.

**Methods:** We performed a pilot study using a mixed-methods descriptive design with pre- and postsurveys, following participants for 12 weeks. We augmented these data with semistructured qualitative interviews to learn more about feasibility, satisfaction, communication, and self-management.

**Results:** We enrolled 28 patients with HF aged 55 years and above, with 57% (16/28) male, 79% (22/28) non-Hispanic white, and with multiple comorbid conditions. At baseline, 50% (14/28) rated their health fair or poor and 36% (10/28) and 25% (7/28) were very often/always frustrated and discouraged by their health. At baseline, 46% (13/28) did not monitor their weight, 29% (8/28) did not monitor their blood pressure, and 68% (19/28) did not monitor for symptoms. Post intervention, 100% of the equipment groups home monitored daily. For technology anxiety, 36% (10/28) indicated technology made them nervous, and 32% (9/28) reported fear of technology, without significant changes post intervention. Technology usability post intervention scored high (91/100), reflecting ease of use. A majority indicated that a health care provider should be managing their health, and 71% reported that one should trust and not question the provider. Moreover, 57% (16/28) believed it was better to seek professional help than caring for oneself. Post intervention, mHealth users relied more on themselves, which was not mirrored in the home equipment or standard care groups. Participants were satisfied with communication and engagement with providers, yet many described access problems. Distressing symptoms were unpredictable and prevailed over the 12 weeks with 79 provider visits and 7 visits to emergency departments. The nurse call center received 872 readings, and we completed 289 telephone calls with participants. Narrative data revealed the following main themes: (1) traditional communication and engagement with providers prevailed, delaying access to care; (2) home monitoring with technology was described as useful, and mHealth users felt secure

knowing that someone was observing them; (3) equipment groups felt more confident in self-monitoring and managing; and finally, (4) uncertainty and frustration with persistent health problems.

**Conclusions:** mHealth equipment is feasible with potential to improve patient-centered outcomes and increase self-management in older adults with HF.

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## KEYWORDS

heart failure; remote monitoring; mHealth; older adults; feasibility; self-management

## Introduction

### Background

Heart failure (HF) is a major health problem worldwide. HF accounts for approximately 20% of all hospital discharges in older adults—6.5 million people in the United States—and is increasing significantly as adults are living longer [1]. It is also associated with high symptom burden, comorbidity, and mortality [2-4]. Adults with HF challenge current health care systems because of the complexity of the disease, need for continuous management, coordination of care with multiple providers, and the need to support patients in community settings. Proactive symptom detection combined with earlier health care intervention provides a greater chance in reduction of poor outcomes than reactive treatment where patients wait until they have a serious symptom such as angina or dyspnea [3,4].

Self-care is the cornerstone to HF treatment [5], especially as related to home monitoring for subclinical congestion [6]; however, many patients do not understand how or what to self-monitor [7]. It is important for patients to implement ongoing assessment strategies to identify early indications of impending exacerbations through self-monitoring of weight, blood pressure (BP), and symptoms. Physiological changes that may indicate subclinical congestion may be monitored through a range of strategies ranging from home observation to routine monitoring of vital signs (such as BP and heart rate) to auto monitoring through implantable devices [6]. Patients with HF can prevent comorbidity, premature mortality, and costly hospitalizations through early recognition of decompensation and self-care strategies at home [8-10].

Effective communication with a care team is essential in the multifaceted management of patients with HF [5]. Systematic reviews and meta-analyses support that the care team is a primary characteristic associated with reduced morbidity and mortality [11], and patients who have improved communication with their health care team are known to have increased adherence to the treatment plan [12] and have increased satisfaction [13].

The increased utilization of remote monitoring, using connected mobile health (mHealth) devices at home, is one way to increase self-management and communication. The Center for Connected Health Policy defines remote patient monitoring as “the use of digital technologies to collect medical and other forms of health data that electronically transmits information securely to health care providers” [14]. Remote patient monitoring using mHealth equipment allows in-home monitoring of patient vital signs,

such as BP and weight, the same as monitoring in the exam room, allowing clinicians to monitor patients from almost anywhere. Studies using mHealth systems provide evidence that mobile monitoring reduces morbidity [2,3,15,16] and mortality [2]; however, a systematic review reports inconsistent outcomes [17]. In addition to improving morbidity and mortality, studies found fewer emergency department (ED) visits and hospitalizations with remote monitoring [16,18,19]. Despite a growing body of research demonstrating positive physiological outcomes and lower health care costs, few studies have considered the patient’s perspective on the potential benefits and burdens associated with the in-home monitoring of HF. In addition, inconsistent findings in the literature are likely related to variations in mHealth monitoring strategies [2-4,15,20]. This inconsistency demonstrates the need for more focused research in comparing approaches with the monitoring of patients with HF to determine which methods are most effective in improving overall patient outcomes, especially in older adults.

### Aims

The purposes of this pilot study were (1) to examine the feasibility of using mHealth equipment with community-dwelling older adults who suffer from HF and (2) to examine their perspectives as they used mHealth equipment compared with in-home equipment and standard care, specifically patient ease and satisfaction with using the equipment, health care team communication and engagement, and ability to self-monitor and manage their disease.

## Methods

### Design

This was a mixed-methods study using a descriptive explanatory design. We used survey methodology along with semistructured qualitative interviews to obtain a better understanding of patient experiences. The study was approved by the university institutional review board.

### Sampling and Recruitment

Participants were recruited from 2 cardiology clinics in a southern state. Provider’s office personnel identified potential participants who were interested in participating. A research assistant telephoned the participants and conducted a brief screening of the inclusion and exclusion criteria (see [Textbox 1](#)). If eligible, the research assistant scheduled an appointment to meet with the patient, and the caregiver(s) were also encouraged to attend. Participants were provided study information for fully informed consent.

**Textbox 1.** Research participants' inclusion and exclusion criteria.

**Inclusion criteria**

- Aged 55 years and above
- Current diagnosis of heart failure
- Successfully completes capacity to consent given during initial screening process
- At least 2 weeks of no hospitalizations before enrollment
- Able to stand to take daily weight measurements and read values independently or with the assistance of a caregiver
- Has working telephone reachable via text or call 24 hours/7 days a week
- English as primary language

**Exclusion criteria**

- Involved in other studies
- Involved in hospital case management
- Living in nursing home setting
- Diagnosis of dementia as indicated by a St Louis University Mental Status (SLUMS) score <20

### **Data Collection Randomization to Groups**

After baseline measures were taken, we randomized enrolled participants into 3 groups using statistician-generated random allocation cards that were sealed in envelopes: (1) mHealth equipment group, (2) in-home equipment group, and (3) standard care group. Each group received a different self-management intervention.

### **Self-Management Interventions**

Subjects in the mHealth group received a Cloud DX Connected Health Kit containing an Android Health Tablet with Bluetooth-paired body weight scale and the Pulsewave Universal Serial Bus BP wrist monitor. Subjects took daily BP and weight readings using the mHealth Cloud DX equipment. The equipment allowed real-time collection and monitoring of patients' values, instantly accessible 24 hours a day, 7 days a week by both patients and their clinicians, via a wireless gateway that transmitted results to a secure cloud-based clinician portal. The participants' daily weight and BP readings were remotely sent to the hospital's call center where we employed registered nurses specially trained to triage these patients using physician-study team-developed protocols. These protocols standardized the triage process, ensuring consistency in patient management.

Data collected from the call center included number of calls made by triage nurse staff, the patients, and the nature and outcomes of these calls. Readings falling outside predetermined parameters triggered notifications, alerting research staff and call center nurses. After receiving an alert, a call center nurse then contacted the patient and began the triage process based on alert type. For BP readings falling above or below set parameters, the call center nurse first directed the patient to relax for 15 min, then to retake their BP. If the second reading was in the normal range, no further action was required. If the reading remained outside of the parameters, the nurse asked a series of questions to determine patient needs. The nurse asked questions about physical symptoms (chest pain, shortness of

breath, and activity level), mental symptoms (stress levels and sleeping habits), medications (when BP readings or new medications were last taken), and dietary questions (does patient follow a low sodium diet and when did the patient last eat). An alert triggered by weight gain required additional questions about presence of edema, diuretics used, and fluid intake. This combination of questions and responses determined the next steps in triaging, whether it was to take medications and recheck BP in an hour, contacting the patients' physician's office for orders, or a recommendation to go to the local ED. Daily readings not received by 1 pm resulted in a reminder call from the call center. We used the compiled intervention data to record patient compliance, number and types of incidents requiring triage, adherence to triage protocols, and intervention outcomes.

The in-home equipment group received a standard Medline Plus digital BP wrist monitor, an Escali digital weight scale. Neither of these devices were connected to the call center or the software system. They were instructed to use this equipment and to record their daily BP and weight readings via pencil and paper using a log or diary that we supplied. They were also instructed of the parameters their provider specified for their BP and weight readings and to call their provider if readings were out of range.

The standard of care (SoC) group did not receive any equipment and were asked to continue following regular care instructions provided by their health care team and current self-monitoring routine. We did not encourage nor discourage the SoC subjects to change their daily self-management.

### **Survey Data and Instruments**

A total of 3 surveys were used in collecting participant data: (1) baseline survey, (2) postintervention survey, and (3) weekly symptom and status phone survey. The baseline survey captured demographic data and participant perceptions across 6 health domains: (1) general health and symptoms, (2) self-care perceptions, (3) provider care perceptions, (4) communication and engagement with health care team, (5) monitoring adherence, and (6) technology anxiety. See [Table 1](#) for a

description of the questionnaires adapted for use in the survey. The survey was administered in person by a research team member. All responses were entered directly into LimeSurvey, a Web-based service platform.

All participants received a weekly phone call over the course of the 12-week study to follow events prospectively. The weekly symptom and status survey for the 2 equipment groups consisted

of 22 questions across the following 6 domains: (1) current symptoms; (2) equipment status/issues; (3) medical visits/emergencies; (4) symptom changes; (5) adherence behavior for medication, diet, and exercise; and (6) BP and weight daily log adherence (see Table 2). The SoC group received a phone call to mimic attention but did not receive the survey; they were instead asked whether their health condition caused them to seek medical care (doctor or ED visit).

**Table 1.** Baseline/postsurvey questionnaire instruments.

Survey domain and instruments	Items, n	Measures
<b>General health and symptoms</b>		
Self-Rated Health Scale [21]	1	Patient's self-rated overall health
Health Distress Scale [22]	4	Distress levels triggered by current health problems/symptoms
<b>Self-care perceptions</b>		
Psychological Empowerment Scale [23], adapted	4	Importance of self-care, self-efficacy, decision-making abilities, and control over own health and health outcomes
<b>Provider care perceptions</b>		
Krantz Health Opinion Survey [24], adapted	5	Patient perceptions regarding provider care including active involvement in self-treatment and information seeking with regards to staying informed and a part of medical decisions
<b>Patient communication and engagement</b>		
Medicare Fee-for-Service Consumer Assessment of Health Plans Survey [25], adapted	4	Patient satisfaction with health plan, medical care, and overall communication with health care team
<b>Monitoring adherence</b>		
Morisky et al Medication Adherence Scale [26], adapted	3	Patient fidelity to self-monitoring upon receiving information from their health care provider on how to monitor signs and symptoms of heart failure
<b>Technology anxiety</b>		
Technology Acceptance Model [27], adapted	2	Patient anxiety/stress levels when working with technology
<b>Equipment usability and self-management (post survey only)</b>		
System Usability Scale [28]	10	Effectiveness, efficiency, and user satisfaction when using a system or piece of technology
Feasibility (author derived)	1	Feasibility of using equipment daily to monitor symptoms at home

**Table 2.** Weekly symptom and status survey.

Survey	Items, n	Measures
<b>Symptom Status Questionnaire-Heart Failure [29]</b>		
Frequency	1	Frequency of symptom occurrence
Severity	1	Severity of symptoms
Distress levels	1	Extent of symptom-induced stress
Equipment status/issues	2	Equipment problems and troubleshooting
Doctor/emergency department visits	2	Health-related clinic and/or emergency department visits; reason for visits
Lifestyle behaviors	5	General questions about sleep, daily activities, diet, exercise, and medications
Symptom improvement	2	Improvement in current symptoms and/or newly occurring symptoms
BP <sup>a</sup> /weight log adherence	2	Daily self-recording of BP and weight—home equipment group only
BP/weight changes	2	Notable changes in BP or weight readings—home equipment group only

<sup>a</sup>BP: blood pressure.



Finally, the postintervention survey was identical to the baseline survey except for removal of the demographic questions and addition of an equipment usability and self-monitoring questionnaire consisting of 11 questions. As the SoC group did not receive any equipment, they did not receive these additional questions. The postintervention survey was administered via telephone at 12-weeks in the same manner.

### Qualitative Methods

The purpose of the qualitative approach was to learn more about feasibility, satisfaction, communication, and self-management implications of using mHealth technology compared with in-home equipment and standard care in older adults with HF. A content analysis was used as the qualitative interpretive guide for these narratives according to criterion published by Boreus and Bergstrom [30]. This strategy is commonly used when one is looking for patterns in interviews and comparing different experiences. An interview guide was developed a priori to reflect the purposes of this study. The first author then completed 19 interviews via telephone with 2 more performed in-person using the interview guide. All interviews were digitally recorded, transcribed verbatim, checked for accuracy, and uploaded into a qualitative data software program, NVivo 11 Pro Software (QSR International, 2017). NVivo allows you to store, label, and categorize large quantities of narrative data to describe common experiences that the participants are elucidating.

Analysis involved reading all transcripts as a unit first, rereading, and then labeling segments of text that reflected similar ideas or experiences. A coding frame (method of categorizing the content) was developed so that the similar ideas or experiences could be successively labeled, defined, and sorted. Constant comparison technique was used as transcripts were compared with one another, and codes were added if new ideas emerged from successive transcripts. The initial transcripts were reviewed again and relabeled or recoded in this iterative process until no new ideas or experiences were found. In second-level analysis, narrative data were analyzed per coded groups to form categories of information that combined to form themes that aligned with the research purpose. Finally, recoding was performed 6 months after the original coding to check for intersubjectivity (or how close the results were to one another), and results were found

to be consistent, supporting validity and reliability of the findings.

## Results

### Participant Characteristics

A total of 151 potential subjects were identified, of which 28 were enrolled. Of those who were not enrolled, 76 did not return messages, 24 were ineligible, 17 could not be reached, and 6 were lost to follow-up. There were 7 participants randomized to the mHealth group, 11 in the home equipment group, and 10 in the SoC group. We had attrition of 3 subjects before completing their 12-week enrollment, 1 from the mHealth group and 2 from the in-home equipment group citing they were too busy or sick to continue, leaving 25 participants at study conclusion. We aimed to enroll 60 participants to be able to compare each group. Due to limitations in the funding period and 1 clinic reorganizing management, we did not meet this goal and thus are not powered sufficiently to determine between-group differences via inferential statistics; however, within-group changes from pre to post survey were tested to indicate feasibility for future clinical trial(s).

All participants had a diagnosis of chronic HF, and this was confirmed by medical record audit. Of note, our participants' educational attainment is below national averages (eg, 18% [5/28] with bachelor's degree), with substantial comorbid conditions such as 32% (9/28) with diabetes and 68% (19/28) with hypertension. Table 3 reflects the general demographics of the participants.

### Results of Survey Data

We asked about home monitoring of BP, weight, and symptoms. At baseline, 29% (8/28) of participants did not monitor their BP, 46% (13/28) did not monitor their weight, and 68% (19/28) did not monitor for other symptoms at home. Postintervention data demonstrated that 100% of both the mHealth and in-home groups were monitoring their BP and weight, whereas, only 75% (6/8) of the SoC group monitored their BP and 88% (7/8) monitored their weight—although not often on a daily basis. We report frequencies and trends in differences between groups; see Table 4.

**Table 3.** Study demographics (baseline N=28).

Characteristic	n (%)
<b>Age (years)</b>	
55-59	5 (18)
60-64	6 (21)
65-69	7 (25)
Above 70	10 (36)
<b>Gender</b>	
Female	12 (43)
Male	16 (57)
<b>Race/ethnicity</b>	
Black, non-Hispanic	5 (18)
White, non-Hispanic	22 (79)
American-Indian/Alaskan native	1 (4)
<b>Educational level</b>	
Some high school/high school graduate/GED (General Educational Development)	11 (39)
Some college/associate's degree	12 (43)
Bachelor's degree	5 (18)
<b>Marital status</b>	
Single/never married	3 (11)
Married	13 (46)
Separated/divorced/widowed	12 (43)
<b>Chronic conditions</b>	
Diabetes	9 (32)
Asthma	3 (11)
Lung disease	12 (43)
Heart disease	28 (100)
Hypertension	19 (68)
Arthritis or other rheumatic disease	15 (54)
Cancer	8 (29)

**Table 4.** Home monitoring.

Characteristic	Baseline			Post intervention		
	mH <sup>a</sup> (n=7)	HE <sup>b</sup> (n=11)	SoC <sup>c</sup> (n=10)	mH (n=6)	HE (n=9)	SoC (n=10)
<b>Do you currently monitor your blood pressure, weight, or other health symptoms related to your risk for heart failure at home?, n (%)</b>						
Yes	5 (71)	10 (91)	7 (70)	6 (100)	9 (100)	8 (80)
No	2 (29)	1 (9)	30 (3)	0 (0)	0 (0)	2 (20)
<b>Which of the following do you currently monitor at home?, n (%)</b>						
<b>Blood pressure</b>						
Yes	5 (71)	10 (91)	5 (50)	6 (100)	9 (100)	6 (75)
No	2 (29)	1 (9)	50 (5)	0 (0)	0 (0)	2 (25)
<b>Weight</b>						
Yes	2 (29)	7 (64)	6 (60)	6 (100)	9 (100)	7 (88)
No	5 (71)	4 (36)	4 (40)	0 (0)	0 (0)	1 (13)
<b>Health symptoms</b>						
Yes	3 (43)	5 (45)	1 (10)	3 (50)	8 (89)	7 (88)
No	4 (57)	6 (55)	9 (90)	3 (50)	1 (11)	1 (13)

<sup>a</sup>mH: mobile health group.

<sup>b</sup>HE: home equipment group.

<sup>c</sup>SoC: standard care group.

### General Health and Health Distress

On the health and health distress scales, at baseline, 50% (14/28) of the participants rated their health as poor or fair, 25% (7/28) and 36% (10/28) were very often/always discouraged and frustrated by their health, with 21% (6/28) very often/always fearful for their health. Only the mHealth group trended toward a change in very often/always discouraged by their health, with 43% (3/7) reporting discouragement at baseline and 0% post intervention (0/6). In our exploratory analysis for our feasibility aim, we examined if our interventions with the older participants living with HF added to their distress. A repeated measures analysis of variance showed a marginally significant main effect of time for the health distress items ( $F_{1,22}=4.080$ ;  $P=.056$ ;  $\eta^2=0.156$ ; power=0.489), indicating that overall, participants' scores showed less health distress (ie, discouragement, fear, worry, and frustration) in their last assessment (mean 2.01, SD

0.81) than in their first assessment (mean 2.36, SD 1.24). Moreover, 15.6% of the variability among our observations can be attributed to time. See [Table 5](#).

### Self-Care and Provider Care Perceptions

The Self-Care Perceptions scale indicated that 89% (25/28) of participants were confident about their ability to care for their health at baseline, with 79% (22/28) strongly/somewhat agreeing that they should decide how to manage and control their health (see [Table 6](#)). However, when we queried about provider care perceptions, the majority of the participants believed that the provider/doctors should be managing their health rather than themselves, and 71% (21/28) reported that one should trust and not question the doctor or nurse. However, when we look at group differences, the mHealth equipment users seemed to become more empowered as they relied more on themselves post intervention. These changes were not mirrored in the home equipment or SoC group (see [Table 7](#)).

**Table 5.** Self-rated health and health distress scales.

Characteristic	Baseline			Post intervention		
	mH <sup>a</sup> (n=7)	HE <sup>b</sup> (n=11)	SoC <sup>c</sup> (n=10)	mH (n=6)	HE (n=9)	SoC (n=10)
<b>In general, would you say your health is, n (%)</b>						
Excellent/very good	2 (29)	2 (18)	2 (20)	1 (17)	1 (11)	2 (20)
Good	3 (43)	2 (18)	3 (30)	3 (50)	3 (33)	5 (50)
Fair/poor	2 (29)	7 (64)	5 (50)	2 (33)	5 (56)	3 (30)
<b>How much time during the past 2 weeks were you discouraged by your health problems?, n (%)</b>						
Very often/always	3 (43)	3 (27)	1 (10)	0 (0)	1 (11)	1 (10)
Sometimes	2 (29)	3 (27)	3 (30)	2 (33)	4 (44)	5 (50)
Never/seldom	2 (29)	5 (45)	6 (60)	4 (67)	4 (44)	4 (40)
<b>How much time during the past 2 weeks were you fearful about your health?, n (%)</b>						
Very often/always	2 (29)	3 (27)	1 (10)	0 (0)	2 (22)	2 (20)
Sometimes	0 (0)	0 (0)	1 (10)	0 (0)	1 (11)	2 (20)
Never/seldom	5 (71)	8 (73)	8 (80)	6(100)	6 (67)	6 (60)
<b>How much time during the past 2 weeks was your health a worry to your life?, n (%)</b>						
Very often/always	1 (14)	2 (18)	1 (10 )	0 (0)	0 (0)	1 (10)
Sometimes	0 (0)	1 (9)	2 (20)	1 (17)	3 (33)	1 (10)
Never/seldom	6 (86)	8 (73)	7 (70)	5 (83)	6 (67)	8 (80)
<b>How much time during the past 2 weeks were you frustrated by your health problems?, n (%)</b>						
Very often/always	3 (43)	5 (45)	2 (20)	0 (0)	1 (11)	1 (10)
Sometimes	1 (14)	1 (9)	2 (20)	3 (50)	5 (56)	2 (20)
Never/seldom	3 (43)	5 (45)	6 (60)	3 (50)	3 (33)	7 (70)

<sup>a</sup>mH: mobile health group.

<sup>b</sup>HE: home equipment group.

<sup>c</sup>SoC: standard care group.

**Table 6.** Self-care perceptions.

Characteristic	Baseline			Post intervention		
	mH <sup>a</sup> (n=7)	HE <sup>b</sup> (n=11)	SoC <sup>c</sup> (n=10)	mH (n=6)	HE (n=9)	SoC (n=10)
<b>The way I care for my health is important to me, n (%)</b>						
Strongly/somewhat agree	6 (86)	10 (91)	10 (100)	5 (83)	8 (89)	9 (90)
Neutral	0 (0)	1 (9)	0 (0)	1 (17)	1 (11)	0 (0)
Somewhat/strongly disagree	1 (14)	0 (0)	0 (0)	0 (0)	0 (0)	1 (10)
<b>I am confident about my ability to care for my health, n (%)</b>						
Strongly/somewhat agree	6 (86)	11 (100)	8 (80)	5 (83)	9 (100)	10 (100)
Neutral	0 (0)	0 (0)	1 (10)	1 (17)	0 (0)	0 (0)
Somewhat/strongly disagree	1 (14)	0 (0)	1 (10)	0 (0)	0 (0)	0 (0)
<b>I can decide on my own how to go about managing my health, n (%)</b>						
Strongly/somewhat agree	6 (86)	9 (82)	7 (70)	5 (83)	5 (56)	7 (77)
Neutral	1 (14)	1 (9)	0 (0)	0 (0)	0 (0)	0 (0)
Somewhat/strongly disagree	0 (0)	1 (9)	3 (30)	1 (17)	4 (44)	3 (30)
<b>I have a great deal of control over what happens to my health, n (%)</b>						
Strongly/somewhat agree	5 (71)	8 (73)	9 (90)	5 (83)	7 (78)	9 (90)
Neutral	1 (14)	0 (0)	1 (10)	0 (0)	1 (11)	0 (0)
Somewhat/strongly disagree	1 (14)	3 (27)	0 (0)	1 (17)	1 (11)	1 (10)

<sup>a</sup>mH: mobile health group.

<sup>b</sup>HE: home equipment group.

<sup>c</sup>SoC: standard care group.



**Table 7.** Provider care perceptions.

Characteristic	Baseline			Post intervention		
	mH <sup>a</sup> (n=7)	HE <sup>b</sup> (n=11)	SoC <sup>c</sup> (n=10)	mH (n=6)	HE (n=9)	SoC (n=10)
<b>Except for serious illness, it is better to take care of your own health than to seek professional help, n (%)</b>						
Strongly/somewhat agree	2 (29)	5 (45)	4 (40)	2 (33)	3 (33)	3 (30)
Neutral	0 (0)	0 (0)	1 (10)	0 (0)	0 (0)	1 (10)
Somewhat/strongly disagree	5 (71)	6 (55)	5 (50)	4 (67)	6 (67)	6 (60)
<b>It is better to rely on the judgments of doctors (who are experts) than to rely on “common sense” in taking care of you own body, n (%)</b>						
Strongly/somewhat agree	6 (86)	5 (45)	6 (60)	3 (50)	7 (78)	9 (90)
Neutral	0 (0)	1 (9)	1 (10)	0 (0)	2 (22)	0 (0)
Somewhat/strongly disagree	1 (14)	5 (46)	3 (30)	3 (50)	0 (0)	1 (10)
<b>Recovery is usually quicker under the care of a doctor or nurse than when patients take care of themselves, n (%)</b>						
Strongly/somewhat agree	5 (71)	11 (100)	10 (100)	4 (67)	9 (100)	10 (100)
Neutral	1 (14)	0 (0)	0 (0)	2 (33)	0 (0)	0 (0)
Somewhat/strongly disagree	1 (14)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
<b>It is better to trust the doctor or nurse in charge of a medical procedure than to question what they are doing, n (%)</b>						
Strongly/somewhat agree	5 (71)	8 (73)	7 (70)	3 (50)	4 (44)	10 (100)
Neutral	1 (14)	0 (0)	1 (10)	1 (17)	1 (11)	0 (0)
Somewhat/strongly disagree	1 (14)	3 (27)	2 (20)	2 (33)	4 (44)	0 (0)
<b>I'd rather be given many choices about what's best for my health than have the doctor make the decisions for me, n (%)</b>						
Strongly/somewhat agree	5 (71)	10 (91)	10 (100)	4 (67)	5 (56)	8 (80)
Neutral	0 (0)	0 (0)	0 (0)	2 (33)	0 (0)	0 (0)
Somewhat/strongly disagree	2 (29)	1 (9)	0 (0)	0 (0)	4 (44)	2 (20)

<sup>a</sup>mH: mobile health group.

<sup>b</sup>HE: Home equipment group.

<sup>c</sup>SoC: standard care group.

**Table 8.** Patient communication and engagement.

Characteristic	Baseline			Post intervention		
	mH <sup>a</sup> (n=7)	HE <sup>b</sup> (n=11)	SoC <sup>c</sup> (n=10)	mH (n=6)	HE (n=9)	SoC (n=10)
<b>How often does your health care team listen carefully to you?, n (%)</b>						
Very often/always	4 (57)	9 (82)	10 (100)	3 (50)	8 (89)	9 (90)
Sometimes	2 (29)	1 (9)	0 (0)	3 (50)	0 (0)	1 (10)
Never/seldom	1 (14)	1 (9)	0 (0)	0 (0)	1 (11)	0 (0)
<b>How often does your health care team explain in a way you can understand?, n (%)</b>						
Very often/always	5 (71)	11 (100)	9 (90)	4 (67)	8 (89)	10 (100)
Sometimes	1 (14)	0 (0)	1 (10)	1 (17)	1 (11)	0 (0)
Never/seldom	1 (14)	0 (0)	0 (0)	1 (17)	0 (0)	0 (0)
<b>How often does your health care team show respect for what you say?, n (%)</b>						
Very often/always	4 (57)	8 (73)	10 (100)	4 (67)	8 (89)	10 (100)
Sometimes	2 (29)	2 (18)	0 (0)	2 (33)	1 (11)	0 (0)
Never/seldom	1 (14)	1 (9)	0 (0)	0 (0)	0 (0)	0 (0)
<b>How often does your health care team spend enough time with you?, n (%)</b>						
Very often/always	5 (71)	10 (91)	10 (100)	6 (100)	8 (89)	9 (90)
Sometimes	1 (14)	1 (9)	0 (0)	0 (0)	1 (11)	1 (10)
Never/seldom	1 (14)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)

<sup>a</sup>mH: mobile health group.

<sup>b</sup>HE: home equipment group.

<sup>c</sup>SoC: standard care group.

### **Patient Communication and Engagement**

We asked about the participant's communication and engagement with providers. Overall, participants indicated that they experienced good communication/engagement with providers, which did not change appreciably after 12 weeks with satisfaction scores ranging from 80% to 92% from pre intervention to post intervention. See [Table 8](#).

### **Monitoring Adherence**

We asked participants about adherence to self-monitoring for signs and symptoms of HF complications at baseline and post intervention. All but 3 of the participants told us that they had received instructions from their provider about monitoring for signs and symptoms of HF complications (these 3 were excluded from further questions). Questions were concerned with how often did you forget or were careless or stopped monitoring your signs and symptoms. At baseline, 44% (11/25) sometimes or very often forgot to monitor, 40% (10/25) were careless, and 52% (13/25) stopped monitoring when they felt better. Postsurvey data revealed that 100% (15/15) of participants receiving either the mHealth or home equipment reported never/seldom forgetting to monitor their symptoms daily, a 50% increase from baseline. In the standard care group, 67% (6/9) of participants reported never/seldom forgetting to monitor their daily symptoms at baseline, whereas post intervention, this

number decreased to 22% (2/9). At baseline, 50% (8/16) of mHealth and home equipment users reported they sometimes/very often/always stopped monitoring their symptoms when feeling better. This number decreased to 14% (2/15) post intervention. The SoC group remained unchanged from baseline to post intervention, with 55% (5/9) of participants reporting they sometimes/very often/always stopped monitoring when feeling better (data not included in tables). Furthermore, a Pearson chi-square test on data captured post intervention showed a trend toward significance ( $\chi^2_{(4)} = 7.852$ ;  $P = .097$ ), indicating that group membership and monitoring adherence were associated.

### **Technology and Equipment Usability Survey**

For the technology anxiety portion of the pre and post survey, 36% (10/28) and 32% (9/28) of our older adults indicated that technology made them nervous or fearful at baseline without significant change post intervention. For equipment usability and self-management, 12 of 15 participants ranked equipment usability at 90 points or above (on a 100-point scale), with an overall mean score of 91.1. The mean score was 84.2 for mHealth users and 95.8 for the home equipment group. When asked about the feasibility of using the mHealth and home equipment regularly to monitor their symptoms, 93% (14/15) of participants agreed that the equipment was easy enough to use on a daily basis.

**Table 9.** Summary findings using mean baseline and postintervention scores.

Scale	Baseline			Post intervention		
	mH <sup>a</sup> (n=7), mean (SD)	HE <sup>b</sup> (n=11), mean (SD)	SoC <sup>c</sup> (n=10), mean (SD)	mH (n=6), mean (SD)	HE (n=9), mean (SD)	SoC (n=10), mean (SD)
Health distress	2.40 (1.04)	2.39 (1.38)	2.14 (1.06)	1.75 (0.47)	2.11 (0.85)	2.08 (0.96)
Self-care perceptions	4.05 (0.91)	4.45 (0.69)	4.19 (0.48)	4.46 (0.98)	4.22 (0.51)	4.20 (0.61)
Provider care perceptions	2.60 (0.87)	2.69 (0.55)	2.60 (0.57)	2.77 (0.95)	2.22 (0.78)	2.22 (0.65)
Communication/engagement	4.30 (0.74)	4.36 (0.57)	4.61 (0.31)	4.21 (0.87)	4.64 (0.75)	4.60 (0.47)
Monitoring adherence	3.80 (1.50)	3.55 (0.82)	3.78 (0.85)	4.72 (0.53)	4.37 (0.61)	3.56 (1.07)
Technology anxiety	2.00 (0.79)	3.18 (1.23)	2.00 (1.32)	1.75 (0.88)	2.83 (1.32)	1.75 (1.14)

<sup>a</sup>mH: mobile health group.

<sup>b</sup>HE: home equipment group.

<sup>c</sup>SoC: standard care group.

**Table 10.** Symptoms of heart failure scale (SSQ-HF).

During the past week did you have	Week 1 percentage positive <sup>a</sup> (N=17)	Week 6 percentage positive (N=15)	Week 12 percentage positive (N=14)
Shortness of breath during the daytime	35	33	57
Shortness of breath when you lay down	6	7	21
Fatigue or lack of energy	53	53	57
Chest pain	0	0	14
Leg or ankle swelling	35	27	36
Difficulty sleeping at night	41	20	14
Dizziness or loss of balance	35	40	39

<sup>a</sup>Percentage positive=percentage of participants reporting symptoms that week.

## Summary of Survey Findings Using Mean Scores

The mean scores of all surveys at baseline compared with post intervention in each group have been presented in [Table 9](#). As noted earlier, sample sizes were not sufficient to show statistical significance, although trends in differences before and after the intervention may be clinically meaningful and provide estimates for future study.

## Weekly Symptom and Health Status Survey

We made 289 telephone calls to the participants over 12 weeks. For the equipment groups (mHealth and home equipment), we checked for common HF symptoms, provider/hospital visits, and lifestyle and activity patterns. For the standard care patients, we only queried about provider/hospital visits.

For HF symptoms, multiple symptoms were experienced each week. They varied throughout the study with no discernible patterns emerging. [Table 10](#) (Symptoms of heart failure scale; SSQ-HF [29]) shows the percentage of subjects reporting symptoms cross-sectionally at 3 time points: week 1-baseline, week 6-midpoint, and week 12-completion. We asked 4 questions weekly about improvements and changes in symptoms, BP, and weight. Overall symptom improvements were reported 48 times (out of 177 or 27% of the time), with participants describing less fatigue and higher energy levels or improved sleep, less dizziness, reduced swelling, and medication

changes, again demonstrating waxing and waning of symptoms from week to week. In the home equipment group, we asked about changes in BP and weight. Overall, 20% of the home equipment participants reported changes in BP or weight during the 12 weeks. Finally, we asked about provider and ED visits; there were 79 provider visits in 12 weeks with 7 visits to the ED (mean of 3.4 visits per person). There were no differences found between groups.

## Equipment Status and Issues

We asked each week about equipment problems, and 23.2% (41/177) of the time, problems were reported. Most common complaints were about the automated wrist BP cuff in the home equipment group, the scale reading slightly different weights when repeated measures were taken by the participants, and mHealth equipment connectivity problems (the Bluetooth function of the scales). We asked if participants' needed us to retrain them in using their equipment and did this 4.5% (8/177) of the time, home equipment users answered affirmatively 2 times, and there were 6 requests from the mHealth users. Interestingly, there were essentially an equal number of problems with home equipment when compared with mHealth internet connected equipment.

## Lifestyle Behaviors

We asked a few questions each week about lifestyle adherence behaviors of diet, medication, and exercise. Overall, 67% (19/28) of the participants indicated they were on a low-sodium diet, although the methods of this diet varied greatly and most reported they just “did not add salt” to most of their food (but did not necessarily buy low-sodium foods). For adherence to medications, 97% (27/28) told us they were adherent; however, 15% (4/25) later said they were skipping medications some days, with no differences seen between groups. When asked about participation in exercise, 68% (19/28) of the participants reported they were exercising each week; however, when asked what type of exercise, many participants included walking “every now and then,” “getting out of the house,” house cleaning, or physical therapy as qualifiers for exercise. Other exercise regimens included weekly exercise classes at a fitness center, stationary biking, strength training, and taking daily 30-min walks. There were no differences seen between groups.

## Nurse Call Center Data and Adherence to Daily Readings

The call center nurses received 872 total mHealth readings throughout the 12-week study, 500 for BP and 372 for weight, demonstrating that participants were largely adherent to our instructions with an 85.15% (872/1024) overall adherence rate. Of those readings, 50 triggered alerts, meaning the submitted readings fell outside doctor-provided parameters. BP readings accounted for 30 alerts, 26 of which resulted in 14 triage calls. However, most of these were to 1 participant who had multiple alerts for high BP readings. Of the 4 alerts remaining that were not triaged, 2 were due to mHealth equipment error and 2 due to call center nurse error. Moreover, 2 abnormal BP readings failed to trigger any alerts; reasons for this remain undetermined, but this may have been probably due to a connectivity issue. Weight gain triggered 20 alerts and 6 triage calls. Of the 14 alerts not triaged, 11 were related to equipment problems (the call center was aware of this) and 3 were errors by the call center. A total of 7 weight readings did not trigger alerts for reasons undetermined.

During the 12 weeks, 224 readings were missing, 71 for BP and 153 for weight. Call center nurses phoned participants when daily readings were not transmitted. Moreover, 2 participants were responsible for 168 of the missed readings, 1 who suffered a leg injury and could not weight-bear to stand on the scales and 1 participant who was essentially nonadherent due to continued mHealth equipment tampering by grandchildren (ie, disassembling). Call center nurses were instructed to discontinue calls to these participants. Of the remaining 56 missed readings, call center nurses placed 50 reminder calls to participants, and there were 6 instances where calls were not placed due to error. Ultimately, 89% of the time, patients were contacted correctly for missed readings.

## Home Equipment Group Daily Log and Monitoring Adherence

The home equipment group was instructed to take daily BP and weight measures and record them in a log provided by the study team. Out of the 11 participants in this group, 4 (36%, 4/11) did not return their logs as per protocol; we received 1137 readings (62% adherence rate). The log data demonstrated the results were out of range, similar to the mHealth group, 63 times for BP and 60 times for weight; that is, alerts would have been triggered for these same values in the mHealth group participants. Although we did not collect information on whether the providers were contacted by the participants as a result of these physiologic changes, participants may have needed intervention from their provider.

## Qualitative Results

Of the 21 participants engaged in the qualitative study, 9 were in the home equipment group, 6 in the mHealth group, and 6 in standard care group. We identified 4 key themes from the narrative analysis, *Communication and Engagement with Health Care Providers*, *Home Monitoring with Technology*, *Awareness of the Importance of Self-Monitoring and Management*, and *Persistent Health Problems*. Themes were based on the analysis of the narratives, which demonstrated repetition of common participants' experiences. The themes, categories, and exemplary narratives that support each are included in [Table 11](#).

### *Theme 1: Traditional Communication and Engagement With Health Care Providers*

Most participants were satisfied with their established methods of communication with their providers, specifically, they used phone calls to the clinic and in-person clinic visits during office hours, although several had the burden of arranging for transportation. Communication and engagement were specified in 3 ways: health care system issues, both good and bad provider communication, and by routine ED visits. Only 1 participant utilized the communication internet portal that was provided by the health care system. All other participants did not envision other methods of care communication other than traditional phone calls or in-person visits. As seen in [Table 11](#), narratives described health care system problems and both good and poor communication with providers. Unexpectedly, participants described using the ED as a routine practice for accessing care. Narratives describing self-management of their HF symptoms were uncommon before their participation in this study, participants would wait until a symptom was unmanageable and then relied on their provider to take care of the problem.

### *Theme 2: Home Monitoring With Technology*

When questioned about home monitoring with the mHealth equipment or the home equipment, they described it by 3 categories: as helpful, problematic, and for the mHealth equipment participants, “like someone was watching over me.”

**Table 11.** Results from qualitative analysis: themes, categories, and participant narratives. Numbers that follow the narrative represent distinct study participants and group to which they were randomized: mHealth (mobile health) connected technology, home equipment, or standard of care.

Themes and categories	Narrative
<b>Traditional communication and engagement with health care providers</b>	
Health care system problems	<ul style="list-style-type: none"> <li>“I actually made a formal complaint to the hospital. I don’t know how many calls I’ve made and they essentially said ‘well there is nothing we can do about it.’ and I said, ‘Well there is something I can do about it, I can go somewhere else...’” [Participant 14, mHealth]</li> </ul>
Provider communication: good	<ul style="list-style-type: none"> <li>“They usually call us back in the next 30 minutes or an hour. You don’t get nobody, I mean, when you call, you just have to leave a message. But usually, they call you back in the next 30 minutes to an hour. But they are good to us, they are very good to us... [The communication] is pretty good.” [Participant 16, home equipment]</li> </ul>
Provider communication: poor	<ul style="list-style-type: none"> <li>“If I’m feeling that bad now, then I want to see a doctor. I need to see a doctor now. Not 2 or 3 weeks from now when I might be feeling fine. I’m feeling so bad now, I want to see what’s going on. I want you to see me now” [Participant 27, home equipment]</li> <li>“[is it easy to communicate with your doctor] No, it’s really not...I didn’t want it to get really bad, so I had an appointment with my heart doctor...they wanted me to make an appointment and come back in...and I didn’t want to...because it takes several hours to do that.” [Participant 22, home equipment]</li> </ul>
Emergency room visits are routine	<ul style="list-style-type: none"> <li>“I went to Emergency. Yeah. They are really, really good here and it’s much quicker than anything else.” [Participant 1, home equipment]</li> <li>“I went twice this month [to the ER], I didn’t go last month.” [Participant 23, standard care]</li> </ul>
<b>Home monitoring with technology</b>	
Helpful	<ul style="list-style-type: none"> <li>“It helped me with my blood pressure and my weight, It told me what I needed, you know.” [Participant 18, mHealth]</li> <li>“I think that it’s a good thing and that it would help people that live a distance away because they see that there is a problem, that they can either contact the doctor’s office or get up to the hospital as quick as they can. It doesn’t make me nervous or anything, I am used to this stuff [technology].” [Participant 11, mHealth]</li> </ul>
Problematic	<ul style="list-style-type: none"> <li>“I didn’t like the equipment. It was ok except for the scales. It was so hard to set it up and everything to get the weight. By the time you turned the iPad on, got the scale on the floor on a level spot, pushed the button underneath it to get it to weigh you, the iPad had kicked off, and by the time you reset it, the scales kicked off. So you literally had to have someone help you do it.” [Participant 12, mHealth]</li> </ul>
Watching over me	<ul style="list-style-type: none"> <li>“Well that was good, knowing that somebody was there, watching over it, who actually knew something about medicine. It was kind of a plus.” [Participant 14, mHealth]</li> <li>“It was good. It didn’t bother me none. I liked people checking, you know, to see how I was doing.” [Participant 18, mHealth]</li> </ul>
<b>Patient awareness of the importance of self-monitoring and management</b>	
Symptom surveillance	<ul style="list-style-type: none"> <li>“...it keeps my mind focused on what I have to eat and if I eat this stuff with too much salt...it is going to make me have to retain fluid...you’re stuck with a situation where you can’t take a breath of air, you know, I couldn’t even blow my nose. My lungs were being squished so much that I couldn’t even take a breath enough to blow my nose.” [Participant 9, home equipment]</li> <li>“The equipment helps...you know if you gained weight overnight you know to take Lasix. If I’m about 4 or 5 pounds over, I take a little more Lasix.” [Participant 17, home equipment]</li> </ul>
Becoming a routine practice	<ul style="list-style-type: none"> <li>“It brought a level of comfort ...a baseline reading, kind of what was normal for me. Then if I saw something abnormal, I would try to identify what did I do?...So it gave me an idea of what was causing the changes. But, yeah, it did help. It made me more aware of my own health... I got in the habit of taking my blood pressure every day.” [Participant 3, home equipment]</li> <li>“...because it gets you used to monitoring yourself and then you start realizing just what it means when you see them numbers off...never did realize before how much difference it made.” [Participant 25, home equipment]</li> </ul>
<b>Persistent health problems</b>	
Uncertainty	<ul style="list-style-type: none"> <li>“...changed my blood pressure medicine after the congestive heart failure episode. They increased my blood pressure, changed it, and increased it, he thought after that, that it was probably the diuretic that was causing the problem. Or maybe, I don’t know, may have been the heart, the blood pressure medicine. The Lasix should have gotten rid of it, so, anyway it didn’t go away...So I’m not sure what’s going on.” [Participant 1, home equipment]</li> </ul>



Themes and categories	Narrative
Frustration	<ul style="list-style-type: none"> <li>“I just felt like it was just too much with...And nurses were coming in to check me out make sure that everything was going right and just seemed like a lot was going on and I thought I'd just go ahead and drop out of this [study].” [Participant 2, mHealth]</li> </ul>

Exemplary narratives that described their perspectives about the monitoring technology are listed in [Table 11](#). Findings from narratives supported that most participants in the equipment groups appreciated the equipment and found it helpful in monitoring for signs and symptoms of decompensation. An exemplary narrative:

*I think you would have probably found this weight gain, Yeah, if you were monitoring the scale, you would have seen. I think it's probably happened over a 10, 15 day period. So, I think it would have been very evident had I been one of the ones that got the telemetry [Participant 1; home equipment]*

Several participants discussed that monitoring increased their confidence in themselves, and they were less fearful of HF exacerbations. However, 2 participants in the equipment groups did not like or want to monitor their BP or weight at home, instead they recognized impending crises by other methods, such as feeling “dizzy, tired, or short-of-breath,” and as a result, they self-treated with a diuretic or visited their provider or ED for care. For example:

*If I get real short of breath, I mean, I call the doctor. Generally, if my fluid is building up, I have to take an extra Lasix.” [Participant 25, home equipment]*

When these and the standard care participants were asked why they did not home-monitor before this study, most replied that they did not own a scale or BP cuff, they were not interested, or they did not see the need. For instance:

*I've weighed the same for about 12 years, so I don't need to check it [Participant 8, standard care]*

*I don't have the equipment for one thing and if I did, I really don't know how to run it. [[Participant 26, standard care].]*

Narratives demonstrated that the mHealth group experienced a feeling of security and alliance to our research team that was very encouraging to them. For example:

*it brought a level of comfort to me...it was like a friend calling rather than an annoyance...to know if I am in trouble or if I have a new problem...it is a wonderful idea [Participant 2, mHealth]*

### **Theme 3: Awareness of the Importance of Self-Monitoring and Management**

Participants in the 2 equipment groups overwhelmingly reported that they became more aware of the importance of monitoring their weight, BP, and symptoms because of this study. Narratives described that symptom surveillance became a routine practice during the 12 weeks of this study that was likely to prevail going forward. Reasons expressed that our weekly reiteration of the symptom survey and status check taught them which symptoms to watch for and encouraged them to self-manage. For example:

*I never thought of whether my feet get swollen or not...then they asked me almost every week when they called, now I know to watch for it [Participant 6, mHealth]*

An exemplary narrative:

*The whole thing just makes you realize that you've got to keep a close eye on what your weight and blood pressures because those are the factors that are going to get you...it is so important that I do it every day. [Participant 9, home equipment]*

### **Theme 4: Persistent Health Problems**

Participants repeatedly told us they suffered from persistent health problems and challenges associated with their HF, although this was not included as part of the interview guide questions. They described continuous uncertainty and frustration from living with chronic HF and described instances that were traumatizing to them:

*People don't understand how it feels, that I couldn't even bend over to tie my shoes. It was the hardest thing for me to do...everything in there is so full, your belly is full and you haven't even eaten, I would have to stop trying and take a breath. [[Participant 9, home equipment].]*

See [Table 11](#) for other narratives.

## **Discussion**

### **Principal Findings**

The main aim of this mixed-methods study was to examine the feasibility of older adults with HF using connected mHealth technologies at home. Specifically, we looked at patients' ease and satisfaction with the equipment, communication patterns with their providers, and their engagement in HF self-monitoring and management as an essential first step before designing a clinical trial to test such an intervention. Results demonstrated the feasibility of older adults with HF using the equipment, completing the surveys, maintaining study engagement, and even improving self-management. Interviews augmented the survey data by providing synergistic information that helped clarify and explain the survey data and should be considered a strength of this study.

Before this study, participants more often monitored their BP rather than their weight at home, and most did not monitor for symptoms. We also discovered that this monitoring was not done routinely or on a daily basis for most of the participants despite their poor health status and persistent symptoms. They often forgot or skipped days, especially when they felt better. Postintervention data on monitoring adherence showed a change in consistent monitoring to 100% in both of the equipment groups for daily self-monitoring, and 100% said they did not

forget to monitor or skip days. In the SoC group, 78% of the time, they forgot to monitor their symptoms post intervention. This is an important finding partially explained by our interview data, which may demonstrate that the equipment groups, through training and recurring messages given by our weekly status calls, increased knowledge and skill development in self-management. It is established that HF, like many other chronic diseases, can be better managed when the patient exhibits self-care behavior [9]. HF self-management involves lifestyle adjustments [10] and physiological monitoring and surveillance [9]. It is frequently reported that these are difficult skills for HF patients to acquire because of the complexity of their treatment plan, cognitive changes, poor health literacy, and patient inclinations [9]. Individuals with HF most often have multiple comorbid conditions, affecting their ability to manage this multiplicity; thus, the interventions for the comorbidities must be a priority as well [31].

This study showed that the general health of our participants was mostly fair or poor at baseline with no real differences between the groups, which is consistent with data demonstrating poor quality of life in these individuals [9]. They reported discouragement, frustration, and fear regarding their health, emotions that reduce quality of life. However, post intervention, the mHealth group showed less discouragement, fear, and frustration regarding their health. This finding is supported by other research describing that home telehealth is found to increase quality of life for these individuals [32].

We aimed to examine perspectives of these older adults while they used the equipment and self-managed their HF. Although older adults may require training on technology literacy [33], mHealth monitoring is designed to foster autonomy and independence in chronic disease self-management and may have improved their feelings of distress. Research demonstrates similar responses in a study of community-dwelling older adults with poor health as they similarly shared feelings of powerlessness that emerged during the process of regaining independence [34]. Not surprising in these older adults, about one-third of them were nervous or fearful about using technology; however, when asking our participants about whether they thought home monitoring was feasible, easy to use, and helped them manage their symptoms, equipment usability and ease both scored in the 90 percentiles (out of 100), indicating they would use this on a daily basis. A 2017 report from the Pew Foundation found that the percentage of older adults using technology, such as the internet, smartphones, tablets, and social media, has increased steadily since 2000 [35]. Seniors who are more affluent and have a higher educational level have similar rates of use to adults younger than 65 years [35]. Our baseline findings related to fear of using the technology (36%) may be, in part, due to our participants' educational levels (18% bachelor's degree). Even though use of technology is increasing, the Pew Report stated that 73% of older adults say "they need someone else to set it up or show me how to use it" [35]. These findings are consistent with other studies related to utilization rates in older adults to monitor HF [36] and positive perceptions of use of technology to monitor HF [37].

We found that our participants ranked communication with their providers as quite satisfactory using traditional methods of phone calls and clinic visits, although qualitative data described participants having both good communication and substandard experiences with communication and obtaining access to care. mHealth technology is supported as a method to increase communication and access to care [38,39]. It was interesting that we found the participants mostly relied on their provider to manage their health—instead of themselves. Under the traditional model of health care, older adults are more accustomed to a paternalistic approach and interact with providers in a clinic or hospital setting to meet their needs. The dependency initially indicated from results on the provider care perception survey and decreasing post intervention may actually reflect a transition from the traditional model of health care to a more decentralized environment [40,41]. Research supports that HF patients will experience improved quality of life [42] and positive behavioral changes in BP and weight monitoring as they demonstrate confidence for self-management of HF [41,42].

The weekly symptoms and health status survey provided insights into symptoms, adherence to lifestyle recommendations, and provider visits. Our participants experienced persistent struggles with distressing HF symptoms that exhibited no pattern in this study. Interview data described uncertainty and frustration with ongoing symptoms. However, the participants described that home monitoring was helpful and those that had mHealth equipment described a feeling of security knowing someone was available to them. This phenomenon has been reported by others [43].

We also wanted some insight into how these patients were currently managing their HF at home. National HF guidelines recommend developing a care management plan to include appropriate levels of physical activity and dietary adherence, especially for sodium intake [44,45]. Studies demonstrate that lower sodium intake is associated with improved status in those with symptomatic HF [46]; however, HF patients have difficulty adhering to this restriction [47]. Moreover, 67% of our participants self-reported a low-sodium diet, which is quite high given the objective measure of approximately 34% in a recent study [46]. In this study, we asked about these lifestyle parameters weekly in both equipment groups and found that self-reported physical activity was also likely overstated, similar to other studies that measure with self-reported questionnaires [48]. For example, Yates et al report that 38% of HF patients self-reported meeting physical activity recommendations, but when measured objectively, 0% met recommendations.

Gilorta et al [49] found HF knowledge gaps that were identified through surveys given to HF patients post discharge, along with identifying reasons for nonadherence. Patients reported that (1) they did not know they had HF despite being informed of this diagnosis while in the hospital or (2) they strayed from their strict dietary restrictions as they felt better and did not have symptoms. Similar patterns were reported in this study. The Heart Failure Society of America Guidelines recommend continuing education over time because of lack of efficacy with a single educational session that commonly occurs during a hospital discharge [49]. Telehealth interventions have potential

for real-time education and symptom support in addition to monitoring for physiological alterations [50].

The nurse call center received 872 readings, and we completed 289 telephone calls following our participants on a weekly basis. Overall, we found that the call center triaged the calls accurately with only a few errors made. We had patients in very rural areas but had only a few missed transmissions, likely a result of cellular connection interruption. From these data, it appears that it is quite feasible to use this technology in rural as well as urban areas.

Our participants reported 79 provider visits and 7 ED visits in 12 weeks, that is, an average of 3.44 visits per person. HF is a syndrome that places a substantial burden on the health care system as well as the patient [1], with over 1 million hospitalizations annually and estimated 7.4 million ED visits [51]. The Centers for Medicare and Medicaid require public reporting of HF admissions and have established penalties for hospitals with high readmission rates. Primary reasons for ED visits are breathing difficulties (88% of patients) followed by chest discomfort (35%) and fatigue (16%) [52]. Recently, mHealth was supported for reducing hospital readmissions [32,53,54] but not necessarily ED visits [51].

### Study Limitations

With this study, we examined feasibility of our mHealth approach and perceptions of older patients using technology so that our findings could be used in future research. An initial limitation is that we did not collect demographic data on the

potential participants who did not respond to our invitation to participate. Our sample size was small; thus, we described trends in findings, reported frequencies, and did not have the power to determine significance in group outcomes. We augmented our survey data with interviews from 21 participants to help explain and understand the data, partially mitigating some limitations. This study was performed in 1 state with 2 geographically diverse health clinics and limits generalizability. We hope to have furnished valuable insights for future study.

### Conclusions

We examined the feasibility of using mHealth and automated digital equipment in older adults with HF who mostly resided in rural areas. Most participants described ease of use and satisfaction with the equipment, and problems with the equipment were essentially the same with the connected mHealth and the home equipment. We learned how older adults engage and communicate with their providers in hopes of augmenting their communication and engagement with mHealth technology in future studies. Many had problems with access to care and relied heavily on the ED for access. Our call center was acceptable to participants and their health care providers and a feasible method of promoting self-management. We found that these older adults tended to increase knowledge and skills related to self-care and could and would self-monitor for HF indices that predict decompensation and pending crises. mHealth equipment is feasible with potential to improve patient-centered outcomes and improve self-management in older adults with HF.

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### Conflicts of Interest

SJR has received royalties from Angel Eye Camera System, LLC.

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## Abbreviations

- BP:** blood pressure
- ED:** emergency department
- HF:** heart failure
- mHealth:** mobile health
- SoC:** standard of care

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Original Paper

# Mobile Technology for Healthy Aging Among Older HIV-Positive Black Men Who Have Sex with Men: Qualitative Study

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## Abstract

**Background:** People living with HIV are living longer in the United States as a result of antiretroviral therapy. Black men who have sex with men (MSM) are disproportionately affected by HIV and have low rates of engagement in HIV care and treatment. Mobile technology holds promise as an intervention platform; however, little is known regarding its use among older black MSM living with HIV.

**Objective:** The goal of this study was to explore mobile technology use and narratives of aging with HIV among older black MSM to inform mobile health intervention development.

**Methods:** A total of 12 black MSM living with HIV, aged 50 years or older, completed in-person, semistructured interviews exploring the issues of aging, HIV care engagement, and mobile technology use. The interviews were audiotaped, transcribed, and analyzed using qualitative research methods.

**Results:** Men appreciated having survived the AIDS epidemic, but some expressed discomfort and ambivalence toward aging. Men described various levels of engagement in HIV care and treatment; challenges included social isolation and need for support that was not focused on HIV. Almost all described using mobile technology to engage in health care, whereas some referenced important barriers and challenges to technology use.

**Conclusions:** Findings highlighted a high level of interest toward a mobile technology-based intervention targeting older black men but also identified barriers and challenges to using mobile technology for health care engagement. Mobile technology is well incorporated into older black MSM's lives and shows potential as an intervention platform for addressing aging issues to enhance engagement in HIV care and treatment.

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**KEYWORDS**

aging; HIV; black men who have sex with men; mHealth; HIV care and treatment

## Introduction

**Background**

Black gay, bisexual, and other men who have sex with men (MSM) are among the most disproportionately impacted by

HIV and have some of the worst HIV care and treatment outcomes [1-3]. Due to biomedical advances such as antiretroviral therapy (ART), HIV has gone from a terminal disease to a manageable, chronic illness. A high rate of adherence (ie, >95%) to ART is required for suppression of

HIV, and retention in HIV care prevents opportunistic illnesses [4]. Black MSM accounted for 26.00% (10,343) of the 39,782 new HIV diagnoses in the United States in 2016 [5]. Black MSM show the least favorable HIV care engagement outcomes relative to other racial or ethnic groups of MSM with suboptimal adherence to ART [3,6,7]. On the basis of current diagnoses rates, it is estimated that 1 in 2 black MSM will be diagnosed with HIV during their lifetime [8].

The population of individuals living with HIV is growing, aging, and experiencing a widening spectrum of diseases and conditions that compromise successful aging [9]. By 2030, as many as 73% (7503) of people living with HIV will be older than 50 years [10]. People living with HIV age earlier due to HIV infection; they exhibit multimorbidity, polypharmacy, and geriatric syndromes at a rate equivalent to those observed much later in life in HIV-uninfected persons [11-13]. Chronic inflammation and immune activation among those living with HIV are likely important in the high prevalence of aging-related conditions among individuals living with HIV [14,15]. The accelerated or premature aging has a deleterious impact on quality of life [11]. Despite an increased focus on aging with HIV and the subsequent decline in the quality of life, evidence for older black MSM living with HIV remains scant. Research is needed to inform innovative interventions that maximize functioning and quality of life as more people are living longer with HIV [16,17].

Mobile technology use among black Americans has increased with the ubiquity of mobile devices. According to a recent poll, the vast majority of black Americans own mobile devices and access the internet: 98% own a cell phone and 75% own a smartphone [18,19]. Black Americans were also more likely than whites to rely on their mobile phone for Web access [19]. Furthermore, the use of mobile technology for health, or mobile health (mHealth), is on the rise among seniors in the United States [20-22]. mHealth is a promising intervention platform, given its capabilities to mitigate traditional intervention barriers with older populations (eg, mobility) while transcending social and cultural barriers (eg, HIV stigma) [23,24].

Mobile phone-based HIV interventions have been developed for young black MSM [25,26]. However, mHealth interventions remain underdeveloped for aging populations, perhaps due to misconceptions about user capability despite evidence to the contrary [27-29]. A recent study showed that older black men indicated high willingness to participate in mHealth interventions, despite never having participated in them [30]. Furthermore, older black men were willing to participate in mHealth if they were offered more information about the topic or if they trusted that the research targeted and benefitted racial/ethnic minorities [30]. Another study found that the association between age and technology use was mediated by the effect of computer-related anxiety, self-efficacy, and confidence, suggesting that interventions that address these psychological factors can improve use of mHealth among older adults [31].

## Objectives

To our knowledge, there are no technology-based interventions specifically developed for improving HIV care and treatment

among older black MSM [25,32,33,34]. Research must first characterize the needs and preferences of older black MSM living with HIV who are increasingly in need of viable innovations adaptable to various social and behavioral factors that promote healthy aging. Formative research can help identify critical factors that could affect intervention feasibility, acceptability, and retention/attrition. Therefore, the goals of this study are to explore using qualitative research methods, to assess the issues involved in aging with HIV, and to understand the unique needs and preferences among black MSM to inform mHealth intervention development for enhancing HIV treatment outcomes.

## Methods

### Participants

Participants were recruited using purposive sampling to participate in a one-time in-person interview to explore the role of mobile technology in care engagement among older black MSM living with HIV. During a 3-month period, recruiters distributed study materials containing a dedicated study phone number at AIDS service and community-based organizations serving black MSM in (blinded for review) and social venues (eg, local bars and cafes). Potential participants were screened by trained research staff on the phone for eligibility. Individuals were eligible if they identified as black or African-American and as cisgender men at the time of the study, were currently living with HIV, owned a personal mobile telephone device, and were aged 50 years or older. We chose this age threshold because overwhelming evidence demonstrates that aging syndromes (eg, frailty and HIV-associated neurocognitive disorders) occur earlier (ie, by age 50 years) in people living with HIV. HIV status was verified by a letter of diagnosis or by a labeled pill bottle of their HIV medicine.

Eligible participants were interviewed in a private room located at a community-based research site accessible by public transportation. An interview guide was used to explore overlaps among the topics of aging, HIV care and treatment, and mobile technology. Sample interview questions include “In a typical day, what do you use your mobile phone to do,” “What does aging mean to you,” “What does living with HIV mean to you,” and “How do you use your mobile phone in your health care?” Each interview lasted approximately 1.5 hours and was audiotaped and transcribed for analysis. All study procedures and materials were approved by the lead author’s institutional human research review board.

### Approach

The main goal of the study was to explore the intersection of aging, living with HIV, and mobile technology to inform mHealth intervention development for improving HIV care engagement among older black men living with HIV. Qualitative analysis entailed reading all transcripts, highlighting sections of texts to derive themes based on narratives of aging and technology use in the context of HIV, and care engagement. Next, each transcript was summarized, and themes and subthemes emerged under the domains of mobile technology use in general and for HIV care engagement and aging with HIV as a black man. The themes and subthemes were reviewed

by the senior author and coauthors (with supporting excerpts from the text) and revised as needed. Thereafter, the first author coded and created analytic memos based on emergent findings.

## Results

### Overview

A total of 12 black cisgender men (mean 57.7 [SD 6.5] years) living with HIV participated in one-on-one, semistructured interviews. Of these, 9 men reported receiving or applying for social security disability benefits; 3 men had full-time employment. The annual household income ranged from less than US \$10,000 to \$55,000. Moreover, 6 men (50%, 6/12) reported having a primary relationship partner. All men reported taking antiretroviral medications currently. The length of time on ART ranged from 3 to over 22 years.

We identified 4 major themes (with subthemes): (1) use of mobile technology, (2) use of mobile technology in HIV care, (3) the meanings associated with aging with HIV, and (4) mHealth design implications. In the following sections, we first present how men described using mobile phone technology, particularly with respect to HIV care engagement, and the barriers and challenges to its use. We present how men engaged in HIV care and treatment, including barriers and challenges the men referenced. Next, we present findings of what it means to age with HIV. Finally, we present mHealth design needs and considerations.

### Use of Mobile Technology

Mobile technology literacy, reliance, and habits ranged widely. Some participants described being very technologically savvy and reliant on their phone. Some had at least two mobile devices. For example, a 50-year-old participant reported having 2 mobile phones, 1 for business purposes and the other to listen to music. Another participant also reported owning 2 mobile phones, an iPhone and an Android (ie, the *Obama phone* for eligible Medicaid recipients in California); he preferred the iPhone but has the other phone because he could not always pay for the service on the iPhone. He explained that he mostly used texting as a form of communication but used an iPad for email. He has other apps on his phone for accessing the news (eg, Huffington Post and BBC), social media (eg, YouTube), and dating sites (eg, Grindr). Other than calling and texting, the most common use of the mobile phone was to listen to music. One man explained that it is easy to use music apps relative to other features:

*I really like my music. It's really easy. I use Spotify. And it's really easy to get along and navigate through the different prompts. I hate texting. I'm not that fast of a typer. I don't even like to use emails. [I use my phone for] calls and music and semi-texting.*

### Challenges to Mobile Technology Use

Participants perceived the following barriers or challenges to using mobile technology: having low technology literacy, feeling uncomfortable using mobile technology, having limited access to data (affordability of data plans), and having privacy concerns. Some lamented being unfamiliar with features and

described frustrating experiences, including the use of social media apps. One man referred to feeling overwhelmed when using Facebook:

*With my [previous] Android, I had contact with people on Facebook. I was overwhelmed. I couldn't go on it anymore. Have not even adapted my [current] phone to do a Facebook. I'm overwhelmed by the number of conversations. Well, no. I don't worry about some-my sister. She Facebooks everything and I don't need to know everything. I don't want to know everything.*

Of the 12 men, 6 men between the ages of 50 and 69 reported using social media apps. Of these 6 men, 2 referred to using both Facebook and Instagram or Twitter and Instagram. Moreover, 1 participant mentioned that he was “not very tech savvy” and used his phone primarily for texting, calling, and listening to music:

*It can be a headache, my phone. I'm not all that savvy when it comes to technology and what not. But I use it for the basic necessities. I'm not glued to my phone daily.*

Despite frustrations, many participants described that they “cannot live without the phone.” A 66-year-old man with an iPhone described still learning how to use all of the features and occasional challenges. However, he described his phone as indispensable to everyday life. He used mobile apps to stream music, email, and keep track of his appointments. He also owned a tablet at home that he used to surf the Web.

Frustration with using mobile technology was almost always related with unfamiliarity with various features and navigating certain *bells and whistles*. Other challenges to using mobile technology included the hassle of having to register a user name and password. For example:

*Sometime it's complicated to find different things, how to work it, what you have to do to this, downloads and that kind of stuff. I'm not good with that kind of stuff. I'm not patient with that kind of stuff. I hate like going to sites where you have to register and all that kind of crap. If I have to do all that, forget it.*

### Use of Mobile Technology in HIV Care

Regarding use of technology related to health care, most participants reported using mobile apps in addition to making phone calls to engage in health care. In addition, 1 man indicated that he kept track of his medical appointments by setting reminders on his mobile phone devices. He explained that he used a pharmacy app to keep track of his medication refills and will receive a text alert when his medications are ready for pickup. He mentioned that he receives his lab test results via email and discusses them with his doctor. Some men used their mobile phone to Google information on symptoms or to stay on top of medical news such as the newest ART. One participant expressed:

*Well, first of all, I'm an avid news fanatic. If anything comes up, and it catches my eye, I'll check into it. I mean, the progress with cure stuff is coming. But if I*



*see something, I'll bring it up to a physician and say, what do you think about this, or what do you think about that?*

It is important to note that although many participants were reliant on and somewhat proficient with advanced mobile technology features, there were a few men who used the bare minimum. A few men were unable to access apps and other features because they did not own a smartphone, highlighting barriers to mobile technology for health care.

Despite a wide range in proficiency, almost all described mobile technology use in HIV care engagement. A 68-year-old man described not being too savvy and having an outdated phone but also showed some advanced use of technology for engaging in health care: he explained that he accessed all of his labs and physicians via their websites. Another man described his technology use to be very minimal; he nevertheless described using the app from his pharmacy, which sends him a reminder for prescription refills. Another man described using various apps, such as housing apps to find housing and a music app. He stays organized by using the calendar on his phone to set reminders. A 64-year-old man described using his mobile phone to research medications, conduct banking, and find social support group meeting times. He referred to using several apps, including the calendar on his phone, and social media (eg, WhatsApp and Facebook).

## Aging With HIV

### Loss of Opportunity

For several men, living through the HIV epidemic meant a loss of real opportunity and time to think and plan ahead. For the most part, these men accepted the widely held belief in the early days of the epidemic that they would never have to face getting older because they would die of AIDS first. For some, expecting to die young precluded putting hopes on one's future, as a 57-year-old man expressed:

*Yeah, I don't think that far ahead, though. I can't. I have to think day by day and what I'm going to do today or tomorrow or next week. I don't like to think too far ahead. But I hope I'll be in a good place. I hope I'll be in a good place mentally. I hope my health still be holding up.*

For the generation of men who expected to die of AIDS before ART, having lived through the epidemic only to now face the inevitability of aging was bittersweet. Some expressed regret and disappointment at the years lost. For example, a 51-year-old man described his disappointment in realizing that he would have lived differently if he had known HIV would not be a death sentence:

*I didn't think I would be alive at this point. I expect to get older now versus I didn't in the past. It's amazing to me, so it's great to age, to be alive when so many people have passed away. I was mad at the doctor forever, because he told me I wouldn't live to be 30. Oh, I wasted so much time. I could've finished school and everything. I started like spending my retirement money and going to Europe. [But I was] not getting sick. And ten years go by, it's like, oh,*

*yeah, you're a long-term non-progressor. Ooooh, that doctor.*

### Avoidance

Some men held the idea that aging meant becoming infirm, being an invalid, and growing surly and mean over time. This was in contrast with how they viewed themselves currently, representing a separation between aging as a negative concept and their self-perception. One participant described aging as "gray hair, disappointment at what you have not achieved, going forward with what you have, and trying to make the best of the rest of your life." Another 50-year-old participant expressed his dismay when someone younger referred to him as *Pops*:

*And a kid called me Pops. He got up. I was on the bus, and he said, here, "Pops, here's a seat for you." I said, now I look old? I don't want to look all old, and I just don't want to be old and mean like my parents did when they got older.*

The concept of aging was often synonymous with dying. A 56-year-old man explained avoiding thinking about aging and the impending *move toward death*:

*It's the end-of-life thing is what I get reminded of as getting older. And I don't like to think about that, even though I'm living it and moving toward that. And I guess that's my way of not liking it so much. Because I don't want to progress and move forward towards death and dying. I just don't. I just-I don't look forward to it. I know that it's inevitably going to happen. But I try to erase some of that in my thinking...*

Some men admitted the increasing number of challenges in getting older and facing multimorbidity, including HIV. A 68-year-old cancer survivor explained that he was "not a friend of aging":

*It just means the body wants to fall apart. And how am I dealing with it? Well, I have struggles. I have good days and bad days with aging. I've had two health issues that [have had to do with me] aging. So I have my good days and my bad days. I'm not a friend of aging so much.*

Some participants avoided thinking about aging and HIV. One man reported that he did not like to think about aging and the changes it inevitably brings. He became sad when referring to his HIV status. When asked if he attended support groups, he explained:

*I don't really go to any support groups...because I don't like really talking about it. I very seldom talk about my HIV problem. I done came to terms in myself that I have it, and I have to take care of myself. But I don't really like talking about it. It depresses me.*

He referred to receiving drug counseling, which has helped him with his mental state. He mentioned that it was difficult for him to find a partner because he does not like talking about his HIV status:

*I don't want nothing to remind me that I have HIV. I know I have it, but I don't want to be talking about*



*it. I'm going to take my medicine, and that'd be it. I don't even like to think about it, which is probably not a good thing, but I haven't been stressed over it. So I don't really trip off of it. The only thing I regret is - the only thing that hurts me about it is like finding a partner. Simple fact that I don't like talking about it, and I would have to tell them.*

### Acceptance

In contrast, some men appeared to accept the idea of getting older and the inevitability of death. Many were thankful that they were able to manage HIV as a chronic disease, emphasizing the pointlessness in dwelling on the negative. A 63-year old described viewing aging with HIV as just part of life:

*I have a good positive attitude about it. I don't think negative about it. It's nothing you can do about aging. It's just life. You just have to deal with it and make the best of it you can. And when you don't dwell on it. Sometime you may get a little bit depressed, but I kind of get out of that depression because I think stuff could be worse. And I'm lucky to get around and do what I have to do... You got to keep yourself motivated, keep yourself going. You just got to keep moving.*

Another man described how he maintains perspective on living with a chronic but manageable disease like HIV in terms of how things could be so much worse:

*There's a lot of other things could be going on if I lived in a different part of the world. What is it like living in a poor neighborhood in Libya? What is it like in Syria for kids right now? Some people would do anything to be in my position or live on this planet. So I don't take it lightly, but I appreciate that it could be so much worse.*

Some men understood aging in the context of surviving or defying HIV and expressed pride in having survived HIV. A 68-year-old man expressed appreciation for being alive when so many of his peers died during the AIDS epidemic:

*Well, I was diagnosed in '85, so I've pretty much got the kinks out of the HIV craziness because I-many years of craziness around HIV, many years. So now I just take my medication. Actually, my relationship with HIV is, I'm really glad. Last Tuesday was my 68th birthday, so I'm really glad to be alive.*

In addition, 1 man cited having a fighter attitude and admitted that he still looked forward to living a healthy and full life:

*Because I ain't ready to die. I feel I still got things to do and people to hang out with. So, yeah, I'm just not ready... I looked at so many people died because they didn't [take care of their health]. I don't want to go out like that. I don't want to be all messed up because I didn't take care of myself. I just want to -I want to live. That's what motivates me. Because if you don't, you die. I ain't trying to go out like that. I'm a fighter, literally.*

Some appreciated the opportunity to see old age. One man recounted an early memory of his aging mother describing to him what it was like to grow old and now appreciating being able to reflect on his own experience in aging:

*I'm quite comfortable with being 50. I'm surprised I made it this far. And I remember when my mother was 50, had turned 50. And I was thinking about all the things that she was trying to tell me that was going to happen when you turn 50. I just don't find a lot of pleasure in things I used to when I was 40. I look at -some of them I think are stupid now. And I'm set in a certain way. I'm comfortable with it.*

When asked how he feels about aging, one man described finding *unmerited favor* in living into old age with HIV:

*Participant: It means finding grace in the midst of-let's say the physical, emotional, and spiritual condition, because I realize that there are things that have changed from my youth, and to make sure that I continue to focus on not what is leaving, but what I can still do.*

*Interviewer: What do you mean by grace*

*Participant: I mean unmerited favor. I mean the opportunities to live through wisdom, to be able to tap into a power source greater than the circumstances and situations, having faith in a process that relieves me from anxiety and fear.*

Some participants expressed that attitude was a major factor in aging. One man considered himself a healthy individual despite living with HIV. He mentioned that having a good attitude was the key to staying healthy:

*It's not what's thrown at you, but how you deal with it, and that all resorts back to state of mind-just to be able to not let those things affect you to the point where you're stressing, because that's a silent killer. Yeah, I think the longevity issue is how you deal with a situation that you're dealt.*

Spirituality and religion appeared to play a role in some men's viewpoints on aging. One man used to attend a gay-friendly church to *take bits and pieces* of religion. He wanted to make the most of what the time he has left in life, referring to the universality of aging:

*It's getting better, understanding life a little better, knowing that one day I'm not going to be here. So do the best I can with what I got and face it. I'm still here. I've been positive since 1990. As long as I could walk and talk and get around to the best of my ability, I'm fine. I'm going to die. All of us are going to die one day.*

## Mobile Health Design Implications

### Willingness and Acceptability

There was a moderate level of acceptability of a mobile technology-based tool, such as an app, that would be designed for older men living with HIV to support care engagement. One participant appreciated the mHealth research focus on older

men of color living with HIV (“I think what you guys are doing is an asset. And I think [an app for us] would be great. It would be nice to see that. I definitely would support that.”). Many participants were interested in using a mobile app to organize care engagement and access information in 1 central place. However, interest in using an app was qualified by an emphasis that the app would have to be easy to use:

*[I would be interested] if it's user-friendly. I get frustrated with difficult prompts, and I'm not that - I don't have the patience for that. But if it's user-friendly, yes, I would be interested in it.*

Given memory loss, most men saw the value in using an app as an additional tool in helping to remember things like medical appointments or social engagements:

*I would be interested [in using an] app might have a weekly or monthly reminder of something, you know. Because truth be told, to be reminded of something, I think it's very important and very helpful to a lot of us that are out there. Because, like, when you got your medicine and all this other stuff on your mind, the little reminders [would help]. For instance, I have my yearly housing thing coming up where, they sent me a thing in the mail which I got up on my bulletin board, but...you get a lot of mail sometimes, you know. I'm 62 and my brain's kind of working still, but I can sense [that] the older I get—I could appreciate prompts and reminders with a lot of things.*

### Connecting With Similar Others

Overall, 4 of the participants reported belonging to a social support group of older men living with HIV. Acceptance of older age appeared to be associated with being connected with similar others. Furthermore, 1 man explained that socializing with similar others helped him learn about or understand some of his own aging experiences:

*I'm still trying to identify with [getting older]. I mean, that's why I go to my groups. Then we all speak about it. Then I learn from there. My body is aging a little bit because I'm starting to feel it...we have a weekly Wednesday group which is like a support group...it's the little social things we do that really make me feel good and the camaraderie, you know.*

A few men mentioned the need for the existence of such social networks for older men living with HIV. One participant mentioned it would be helpful for a mobile tool such as an app to connect men with each other and remind them to attend groups:

*Just something to ring a bell once [that] this group is going on at a certain time. And maybe anything that that group is doing...[like] get little notes about certain functions that group is doing. And because a lot of us are getting older it's hard to get sociable, but...I think if they knew things were going on [and] got reminded, they would go out. But yeah, something like [a way to connect socially and get reminders] that [is] simple and steady, I could appreciate it.*

Other men who did not belong to a formal social gathering expressed interest in attending support groups devoted to older folks living with HIV for the purpose of learning from others and contextualizing their experiences about aging with HIV. For example, 1 man expressed interest in app features that would provide reminders and connect him to others living with HIV from whom he could learn their experiences with HIV care. He mentioned that although he did not see a need for reminders to take his medications, he saw the value of getting reminders for his medical appointments:

*[I want to know] how are they taking their medication? Are they going through anything, like side effects? Because I don't forget to take my medicine. I think that probably [I] might need something like a reminder for a doctor's appointment.*

Health concerns among older men living with HIV were mostly unrelated to HIV but rather on the lack of guidance and focus on healthy aging. Men expressed a need for targeted messages that focus on their resilience in having survived the epidemic and on friends and family. Men who had been living with and managing their HIV for many years indicated that social support should not focus solely on HIV but rather on overall health and addressing barriers to healthy aging. These men emphasized that social spaces for older men living with HIV should have a *positive spin on golden years* because they felt that the focus these days was all on being and staying undetectable. Social groups that focus on healthy aging (physical and mental health) and the golden years may be a way to attract men who would otherwise be averse to interventions that focus solely on HIV:

*I very seldom talk about my HIV problem. I done came to terms in myself that I have it, and I have to take care of myself. I had been going to drug counseling, actually, that was helping a lot as far as my mental state.*

Several men who were less engaged in care and treatment reported being somewhat isolated, underscoring a critical gap that mobile tools may fill by facilitating access to necessary resources. When asked whether he would be interested in using app features to connect with others, one man explained:

*Simple fact that I don't like talking about [my HIV status]. So basically I'll be by myself. That's one reason why I be by myself a lot... I haven't been with anybody because I'm too scared of rejection. So yeah. And I probably would [be interested]. I probably would. Because sometimes I just be needing somebody to talk to about various issues. So that may work. I'm just a quiet person, and I don't really like to [talk] on the phone.*

### Support for Self-Management

Participants voiced preferences for educational content on communication and self-management. Some men mentioned wanting to learn skills to manage stress and anger. Furthermore, 1 man explained the need for having tools, such as a daily planner and reminders, to support better time management:

*For me, time management is important. We have so many things to do within a day that we don't get done.*

*So if we could design an app that would take you from the time you get up to the time you lay down, things you need to do, a to-do list, contacts, implementing those, check off, and just feeling like you got through the day and you got some things done, I think that would be awesome. That would be also helpful to know that I got an alarm that will wake me up, maybe a scheduled time every morning, if I have certain things I do, a regimen, get up, walk the dog, have my coffee, breakfast, phone calls. Then I'll make my way to work. If I got appointment reminders, just little stuff that would kind of be in your ear every day, that would be great. Sometimes I do forget [to take my medicine]. Right now I'm switching meds, so it's important for me not to miss a dose. So, yeah, reminders would be great.*

### Concerns About Confidentiality

A majority of the participants mentioned using passcodes on their mobile devices. A few men appeared reticent to use an app that would contain personal health data due to concerns about confidentiality. Furthermore, 1 man explained his concern about a loss of confidentiality trumping his desire to access his medical information in 1 central place on his mobile device:

*I'd be worried about why all that information's in one place. Why would I want to have all my information linked where if I make a mistake, all of it'll be out there? With all this hacking and nonsense, I don't know if I would want to use it or if it would even be necessary, because right now it's not.*

## Discussion

### Principal Findings

This study explored mobile technology use and narratives of aging with HIV among older black MSM to inform mHealth intervention development. The findings centered on 4 themes: (1) mobile technology use in general and (2) in HIV care, (3) aging with HIV, and (4) mHealth design implications. Conceptualizations of aging with HIV were often situated within narratives of the early AIDS epidemic and what it means to be a long-term survivor when many others have perished from it. Many considered themselves to be fortunate to live long enough to age, with several of these men accepting the inevitability and universality of aging. By contrast, others viewed aging negatively as becoming infirm and unable to live life to the fullest extent. Findings underscored a need for promoting models of healthy aging relevant to black men living with HIV, given findings that conceptions of aging are culture- and context-dependent [35]. Many men aging and living with HIV may lack visible and positive role models, perhaps due to the death of peers and social isolation exacerbated by social factors related to HIV stigma, aging, or both [36-38].

Findings also showed a wide range in the level of comfort and skill in using mobile technology. Many older black men relied heavily on their mobile phones to access entertainment such as music. The findings were encouraging of leveraging mobile technology as an HIV intervention platform: older black men

relied on their mobile phones specifically in their HIV care, such as ordering their medications via drugstore apps or calling their providers to schedule appointments. Several reported using self-management apps (eg, calendar) and functionality (eg, reminders) to organize HIV care and treatment. Finally, we found evidence of acceptability of an mHealth intervention in the form of an app for enhancing HIV care and treatment among older black MSM.

These findings show where needs of older black MSM are similar to or different from those of young black MSM [39]. Similar to young black MSM, older black men considered confidentiality and privacy in mobile technology to be paramount [39]. Younger black men preferred a holistic approach to health in an mHealth intervention rather than one solely focused on HIV [39]. Similarly, older black men desired access to information on successful aging and health concerns unrelated to HIV. Regardless of age, men cited self-management as an important reason for using mobile technology. In contrast, although younger men relied heavily on apps [39], our findings with older men showed variability in the level of reliance on and comfort with using certain mobile phone features. Although some younger black men wanted to seek experienced *sponsors* for guidance and support [39], older black men were more varied on their desire for Web-based social connections. Future mHealth research should explore how a mentorship model facilitated by mHealth may be appropriate for connecting younger and older black MSM toward achieving better health.

### Implications for Intervention

Our findings point to specific content areas that an mHealth HIV intervention should address with older black MSM. Interventions that promote positive conceptions of aging with HIV may be particularly impactful. Promoting ideas about resiliency and the *golden years* may help men who otherwise avoid the topic incorporate holistic and dynamic models of aging into their self-concepts. Social isolation among the elderly is common, but among those living with HIV who are also sexual and/or gender minorities, social ties may be even more tenuous [40,41]. Areas for focus include information on healthy aging, connecting socially to similar others, and self-help aspects such as managing psychosocial distress. Men who wish to connect in person with others for social support may already belong to formal groups; those who are more socially isolated may want the option of connecting remotely to potential social groups at first. Thus, access to existing social support networks should be remote as well as in person [18]. Since many older men had been engaged in care and treatment for some time, content around HIV may be deemed irrelevant. In addition, some men expressed being tired of HIV prevention and health intervention messaging solely on HIV. mHealth interventions should focus on helping users define and achieve goals of aging along with promoting HIV care engagement.

Findings also guide the design of mHealth features. App features should be easy to navigate and focus on being operable right off the shelf, minimizing user burdens and cognitive loads. For example, usernames could be set to mobile telephone numbers rather than a unique username that may be hard for many to remember. The number of features should also be minimal, with



a focus on simplicity and enhancing user experience. The tool should include reminding and camera functions the users are most likely to be familiar operating. Additional features may include day planners. Incorporating mobile phone capabilities such as music, social media, and video streaming may be a viable way to engage older black men [42].

### Limitations

The findings are limited to a small sample size due to the pilot nature of the study. This study did not extensively explore how challenges to using mobile technology might be associated with specific aging-related cognitive, physical, perception, and motivation barriers to mobile technology [21]. Given the goal of the study, the small sample size, and sampling method, findings cannot be generalized. Eligibility for the study participation included owning a mobile phone, although ownership of a smartphone was not a criterion. A small minority of participants did not own a smartphone, even as smartphone devices are affordable through safety net, state-subsidized programs. Even as rates of adoption increase among older

racial/ethnic and sexual and gender minorities, researchers are cautioned to consider existing constraints on mobile technology access.

### Conclusions

Adoption of digital technology among older black MSM living with HIV is likely influenced by a multitude of issues [22]. This study adds to the scant literature specific to older black MSM living with HIV, a population showing health disparities and for whom no mHealth interventions exist [42]. Mobile technology for promoting healthy aging with HIV among older black MSM appears acceptable and is likely to be feasible based on extant digital technology for advancing black men's health [18]. mHealth interventions for older black men living with HIV can educate and promote healthy concepts of aging with HIV and support self-management skills and behavior around HIV care, such as adhering to ART [18]. It is paramount that future research to develop mHealth interventions work with black MSM to explore culturally relevant mHealth strategies rather than apply a *one-size-fits-all* approach.

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### Conflicts of Interest

None declared.

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## Abbreviations

**ART:** antiretroviral therapy

**mHealth:** mobile health

**MSM:** men who have sex with men

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Original Paper

# Analyzing Twitter as a Platform for Alzheimer-Related Dementia Awareness: Thematic Analyses of Tweets

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## Abstract

**Background:** Dementia is a prevalent disorder among adults and often subjects an individual and his or her family. Social media websites may serve as a platform to raise awareness for dementia and allow researchers to explore health-related data.

**Objective:** The objective of this study was to utilize Twitter, a social media website, to examine the content and location of tweets containing the keyword “dementia” to better understand the reasons why individuals discuss dementia. We adopted an approach that analyzed user location, user category, and tweet content subcategories to classify large publicly available datasets.

**Methods:** A total of 398 tweets were collected using the Twitter search application programming interface with the keyword “dementia,” circulated between January and February 2018. Twitter users were categorized into 4 categories: general public, health care field, advocacy organization, and public broadcasting. Tweets posted by “general public” users were further subcategorized into 5 categories: mental health advocate, affected persons, stigmatization, marketing, and other. Placement into the categories was done through thematic analysis.

**Results:** A total of 398 tweets were written by 359 different screen names from 28 different countries. The largest number of Twitter users were from the United States and the United Kingdom. Within the United States, the largest number of users were from California and Texas. The majority (281/398, 70.6%) of Twitter users were categorized into the “general public” category. Content analysis of tweets from the “general public” category revealed stigmatization (113/281, 40.2%) and mental health advocacy (102/281, 36.3%) as the most common themes. Among tweets from California and Texas, California had more stigmatization tweets, while Texas had more mental health advocacy tweets.

**Conclusions:** Themes from the content of tweets highlight the mixture of the political climate and the supportive network present on Twitter. The ability to use Twitter to combat stigma and raise awareness of mental health indicates the benefits that can potentially be facilitated via the platform, but negative stigmatizing tweets may interfere with the effectiveness of this social support.

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**KEYWORDS**

social media; Twitter; dementia; social support

## Introduction

Dementia is a neurocognitive disorder that affects cognitive function and performance of daily activities, such as going to the bathroom, eating, and communicating. In 2017, an estimated 5.5 million people in the United States had Alzheimer-related

dementia, one of the most common forms of dementia, with 96% of them being adults aged  $\geq 65$  years [1]. The increasing number of adults living with dementia has simultaneously caused an increase in awareness for the mentally debilitating disease. However, this recognition of dementia as a problem among the elderly has caused both negative stigmatization and

positive support among communities. For instance, those living with dementia have reported experiencing various degrees of shame, including avoidance, negative self-perceptions, and uncertainty [2]. Interviews with individuals affected by dementia have shown that these individuals often feel perceived as “stupid” [3]. These perceptions of individuals affected by dementia have been perpetuated by the increased use of the internet as a source of information and social commentary. A study examining stigma associated with Alzheimer disease on Twitter found that 21% of Alzheimer-related tweets used related keywords (ie, “Alzheimer’s,” “senile,” “memory loss,” and more) to perpetuate public stigma [4].

Nonetheless, technology has also become a platform for disseminating information about dementia and the creation of education and support programs. This most often occurs in the form of blogs written by dementia caregivers about their experiences and the impact of caring for affected persons. These platforms have aided the development of intervention programs and services for caregivers [5]. Additionally, these platforms have also helped in the creation of these same programs for affected persons. Studies discovered that a dementia awareness campaign may be useful in decreasing mental health disparities [6] while media outlets such as public radio stations would be helpful in promoting dementia awareness [7].

Twitter has been used as a Web-based source for people to receive support [8] and for physicians to share scientific information with the public [9]. Thus, upon analysis of tweets mentioning the term “dementia,” we expect to find supportive Web-based Twitter discussions about dementia. This study is notable for analyzing geotags associated with each tweet to determine the worldwide usage of “dementia” in tweets. As the Western world has become more involved in mental health advocacy, we specifically focus on states within the United States to evaluate whether states that have more open discussions on mental health and mental health policy have more users involved in positive conversations.

The aim of this paper was to develop a better understanding of the Web-based Twitter discussion about dementia and to analyze the applicability of using Twitter as a Web-based support system for individuals with dementia and their families.

## Methods

### Data Collection

A total of 398 publicly available tweets were collected on 4 different dates and times during the months of January and

February in 2018 (Table 1). Given the vast majority of tweets available on the Web and the ability of two researchers to manually code each tweet, a sample of 398 tweets was chosen, which is comparable to the 311 tweets manually coded in a similar paper [4]. The Twitter search application programming interface (API) and Postman API Development Environment (San Francisco, CA) were used to collect data endpoints from Twitter that contain the keyword “dementia.” Furthermore, ≤100 tweets were collected at each time point, a limit that is imposed on the Twitter search API. Thus, we accessed only a portion of the tweets posted during each of the 4 time points. For each tweet, we collected data on the date, time, location, username, and tweet body text including hashtags, links, and emojis. Tweets were collected at various time points to account for differences in usage time on the Web and events that may occur, such as political occasions or book publications.

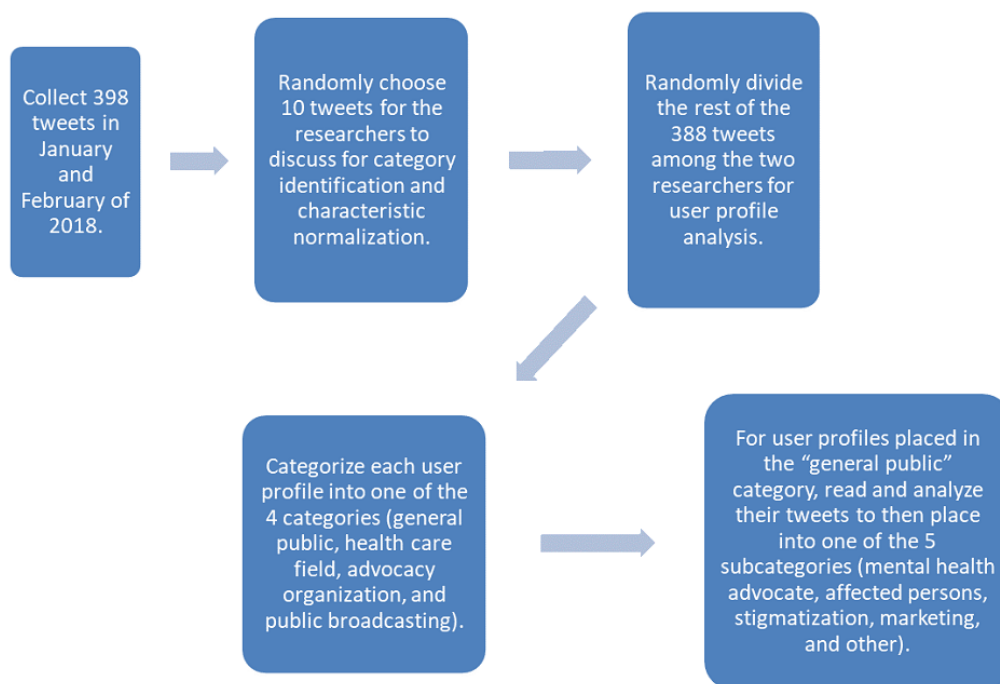
### Data Analysis and Manual Coding

Upon completion of data collection, all tweets were imported into a password-protected Excel (Microsoft) file for analysis. Retweets were considered as individual data points because the more retweets a particular tweet has, the more likely it is to appear at the top of a Twitter search. Thus, retweets are vital for understanding which category of tweets is more readily visible and available for users searching for “dementia” and the diffusion of tweets through follower-friend connections [10]. Tweets in languages other than English were inputted into Google Translate to identify subject matter.

User profile information was used to determine the location of the Twitter user. Tweets coming from the United States were further categorized by state. Thematic analysis performed by two of the researchers was utilized to determine the key purpose of each tweet. A few randomly chosen tweets were discussed between the two researchers to determine what category they should be placed in. After tweets from each category were identified and characteristics of each category were discussed, the rest of the tweets were randomly divided to be read by either researcher. Tweets that one researcher was unsure about were then discussed with the other researcher until a category was decided and agreed upon. A hierarchical structure of categories and subcategories was produced to normalize the comparison between tweets. Tweets were divided into 4 categories based on user profile information: general public, health care field, advocacy organization, and public broadcasting. Further classifications were made if the user was considered general public, explained in further detail below. This process is also further illustrated in Figure 1.

**Table 1.** Time points of collection.

Date	Time (Greenwich Mean Time)	Tweets collected (N)
Friday, January 5, 2018	10:12-10:23	100
Thursday, January 11, 2018	6:59-7:16	98
Thursday, February 8, 2018	20:05-20:12	100
Tuesday, February 13, 2018	16:29-16:41	100

**Figure 1.** Schematic illustrating the approach to analysis.

For the first category, general public, a user was placed into it if the user was mainly an individual posting about his or her life, thoughts, or interests, and did not have a user description that would place them in any of the other categories. These tweets were subsequently divided into 5 categories based on the content of the tweet itself: mental health advocate (posting about ways to prevent dementia, raising money for dementia), affected persons (persons living with dementia, or family members or friends of a person living with dementia), stigmatization (using the word “dementia” to accuse people of certain qualities), marketing (using dementia to promote a business), and other (not belonging to any of the above named subsections). In the health care field category, the researchers looked for keywords in the users’ profiles that would indicate provider-patient interactions. The users were analyzed for a link to their website on their profile or an explicit statement in the description. For the advocacy organization category, researchers looked for a profile that focused on raising awareness for dementia. Public broadcasting users typically had news-related profiles or usernames. Examples of the users and tweets in the categories can be found in [Multimedia Appendix 1](#). A few words and identifying information have been altered and removed, respectively, to preserve user identity and privacy. This technique has been recommended in prior research on analyzing Twitter data [11].

## Results

### Data Collection

A total of 398 tweets were collected. Of them, 228 (57.3%) were retweets and 359 (90.2%) were posted by different user screen names; furthermore, 29 (7.3%) tweets were posted by the same user screen name at least two or more times.

### Data Analysis and Manual Coding

Upon analysis of geotag locations, tweets were found to be posted from 28 different countries. The top 2 countries with the most tweets were the United States (119/398, 29.9%, tweets) and United Kingdom (111/398, 27.9%, tweets). Of the 119 tweets from the United States, the top 2 states with most tweets were California (22, 18.5%, tweets) and Texas (12, 10.1%, tweets).

Categorization of Twitter users showed that of 398, a majority were classified as general public (281, 70.6%, tweets) and advocacy organizations (57, 14.3%, tweets); moreover, 41 (10.3%) tweets were from users associated with the health care field, such as psychologists, nurses, and researchers, while 14 (3.5%) tweets were associated with public broadcasting, such as newspapers and radio stations. Of the 398 Twitter user profiles, 5 (1.3%) were deleted when analysis began and, thus, could not be classified.

Further analysis of the “general public” category demonstrated that of 281, a majority of the tweets were identified as stigmatization (113, 40.2%, tweets) or mental health advocate (102, 36.3%, tweets); furthermore, 26 (9.3%) tweets were tweeted by affected persons, while 13 (4.6%) tweets were tweeted for marketing purposes. Of 281, 25 (8.9%) tweets could not be classified under the 4 main subcategories and were subsequently placed in the “other” category. A list of keywords used commonly in each subcategory can be found in [Multimedia Appendix 2](#).

Analysis of tweets from the top 2 states in the United States, after adjusting for missing data values, showed that Californians, with 14 tweets, had more stigmatization-related tweets ( $n=9$ ), while Texans, with 5 tweets, had more mental health advocate-related tweets ( $n=3$ ).



## Discussion

### Principal Findings

Less than a third of the tweets were posted by advocacy organizations or health professionals. These tweets generally aim to raise awareness about dementia, provide dementia prevention information, and give advice for caretakers. However, many of these tweets are eclipsed by the many more tweets generated by the general public. Web users seeking support from dementia tweets may not see all of the information offered to them by advocacy organizations or health professionals but instead see information provided by the general public. This leads to dangers of misinformation through the Web as many are willing to believe news that align with their own beliefs and provide them with a greater sense of hope and control [12]. While many of the posts from the general public may be helpful, posts from organizations or professionals are more likely to contain credible and trustworthy information that will be better received and followed by the public.

Furthermore, many of the tweets posted by the general public in the “mental health advocate” and “affected persons” subcategories provide sentimental tweets that raise awareness and seek support, respectively. Having these become eclipsed by negative tweets reduces the effectiveness of using Twitter as a supportive Web-based community for dementia.

In 2009, the National Alliance on Mental Illness produced a report card for each state, grading them in 4 categories related to their mental health policies [13]. This standard was utilized to compare the mental health system in both California and Texas (Table 2). Because California has a higher grade in each category, it demonstrates that California has more resources and ability to advocate for those living with mental illnesses. Thus, we would expect a larger amount of mental health advocates among Twitter users residing in California rather than in Texas. However, results demonstrate that there are more stigmatization posts from Twitter users residing in California than those in Texas. This contradicts what is expected based on the grades given to each state.

**Table 2.** The 2009 National Alliance on Mental Illness category grades.

Category <sup>a</sup>	California grade	Texas grade
I. Health Promotion & Measurement	B	F
II. Financing & Core Treatment/Recovery Services	C	D
III. Consumer and Family Empowerment	D	F
IV. Community Integration & Social Inclusion	B	D

<sup>a</sup>National Alliance on Mental Illness category grades are based on 4 categories: Health Promotion and Measurement considers the services states provide, the development of mental health policy planning, and data collection; Financing and Core Treatment/Recovery Services entails the accessibility and availability of mental health services, reimbursement for these services through state Medicaid programs, the severity of current shortages in the mental health workforce, and state efforts to improve the cultural competence of their mental health care systems; Consumer and Family Empowerment grades are determined by the states’ opportunities for family and consumer education and empowerment; and Community Integration and Social Inclusion determines whether states are compensating for extreme mental illnesses that go beyond those addressed by mental health agencies (this includes data on public health education and housing resources).

### Limitations

In exploring the global conversation surrounding dementia, a majority of the tweets were posted from the United States and United Kingdom. Although the United States and United Kingdom are among the top countries that have the most Twitter users, there are other countries such as Japan and Spain that may engage in the dementia conversation [14]. Since the search term used was “dementia” in English, this may have limited the searched tweets to those written in English. Furthermore, the United States and United Kingdom are often at the forefront of increasing awareness for mental health awareness. As one of the first countries to establish a mental health policy in 1996, the United States has seen its residents hold increasingly positive attitudes toward seeking professional help for mental health problems over time [15]. Another factor to consider is the role of culture in mental health awareness and seeking professional help [16]. This may influence the lack of other countries actively participating in the dementia discussion.

In relation to the deviance from data suggesting that California would generally have more mental health advocates than Texas, data collected during the month of January followed large political events or wrongdoings. Thus, Twitter users might have used the term “dementia” to express negative attitudes toward those involved in the political event.

### Comparison to Prior Works

A similar study on Twitter that was performed in 2012 studying types of social media users and dementia themes found that most of the information on Twitter came from health professionals, health information sites, new organizations, and commercial entities and that most tweets contained links to news and health information sites [17]. From 2012, the number of worldwide active Twitter users has greatly increased from 167 million users to 335 million users in 2018 [18]. Now that there are more users, there can be more actively voiced, differing opinions and misinformation that may affect how others perceive dementia and bar access to dementia support systems. Thus, as the world uses more technology, it becomes more relevant and important to study how the Web-based Twitter discussion may have changed over time.



## Clinical Implications

As media outlets have played an important role in communicating popular opinion in the general public [19], researchers have further shown that the Web-based community shows a greater preference for talking about mental health conditions compared with nonpsychiatric diseases, such as cancer, stroke, or HIV infection [20]. Tweeting about mental health can foster communication among the Twitter community [21], especially anonymous communication that allows individuals to express themselves openly and honestly [22]. Twitter surveillance of these discussions may help health care providers, health institutions, and policy makers see how dementia is discussed and what issues are there in their own communities, allowing them to tailor their services to local, current issues presented in Web-based culture of dementia [23].

Furthermore, while platforms such as Twitter can allow for access to pertinent, critical information, medical misinformation on the Web may lead to potential rifts in patient-health care provider relationships. Web-based information that differs from that provided by health care providers can lead to unanticipated consequences, such as raising false hopes or increasing patient anxiety. To combat distribution of misinformation, especially on a large social media platform, health care providers should actively address and recommend websites with information that they deem is qualitatively informative and accurate. [24] This would encourage patients to ignore information on popular social media that is more likely filled with opinionated statements than factual evidence.

## Conclusion

Twitter as a social media platform has great potential for disseminating information on care, creating support systems, and raising awareness for Alzheimer-related dementia. With the popularity of the internet growing with each generation, future generations may turn to Twitter to seek comfort and knowledge about the onset of this disease. However, it has thus far been used as a readily available method for perpetuating stigma by attributing traits associated with dementia to normal, healthy people that Twitter users may find disagreeable.

Further research is warranted to determine the full impact and number of tweets addressing dementia in a negative light or as a method to raise awareness. In particular, older generations that may actually be affected by dementia do not use the internet as a platform for discussion as much as younger generations do. Thus, research on dementia on social media platforms should also be pursued in the future as younger generations grow older. The search for tweets would also have to be broadened to be more inclusive in addressing language differences in tweets ("dementia" in different languages), the time of day the tweets were posted, and the time of year. Furthermore, in the efforts to raise awareness of mental health issues, the conversations surrounding dementia should be expanded from the United States and United Kingdom, changing cultural beliefs that affect views on mental health. With more than 330 million users on Twitter, understanding the ability of Twitter as a readily available, popular, free source of information to better disseminate important information about Alzheimer-related dementia may be the key in building supportive and knowledgeable communities for the future.

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## Authors' Contributions

TYMC and LL contributed to study inception, data collection, data analysis and interpretation, and drafting of the manuscript. BKPW contributed to study inception and provided valuable insights and critical revision of the manuscript.

## Conflicts of Interest

None declared.

### Multimedia Appendix 1

Examples of Twitter users and Twitter posts.

[PDF File (Adobe PDF File), 21KB - [aging\\_v1i2e11542\\_app1.pdf](#) ]

### Multimedia Appendix 2

List of key words used common in the different types of posts in the general public category.

[PDF File (Adobe PDF File), 21KB - [aging\\_v1i2e11542\\_app2.pdf](#) ]

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## Abbreviations

**API:** application programming interface

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Original Paper

# Health Care Cost Analyses for Exploring Cost Savings Opportunities in Older Patients: Longitudinal Retrospective Study

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## Abstract

**Background:** Half of Medicare reimbursement goes toward caring for the top 5% of the most expensive patients. However, little is known about these patients prior to reaching the top or how their costs change annually. To address these gaps, we analyzed patient flow and associated health care cost trends over 5 years.

**Objective:** To evaluate the cost of health care utilization in older patients by analyzing changes in their long-term expenditures.

**Methods:** This was a retrospective, longitudinal, multicenter study to evaluate health care costs of 2643 older patients from 2011 to 2015. All patients had at least one episode of home health care during the study period and used a personal emergency response service (PERS) at home for any length of time during the observation period. We segmented all patients into top (5%), middle (6%-50%), and bottom (51%-100%) segments by their annual expenditures and built cost pyramids based thereon. The longitudinal health care expenditure trends of the complete study population and each segment were assessed by linear regression models. Patient flows throughout the segments of the cost acuity pyramids from year to year were modeled by Markov chains.

**Results:** Total health care costs of the study population nearly doubled from US \$17.7M in 2011 to US \$33.0M in 2015 with an expected annual cost increase of US \$3.6M ( $P=0.003$ ). This growth was primarily driven by a significantly higher cost increases in the middle segment (US \$2.3M,  $P=0.003$ ). The expected annual cost increases in the top and bottom segments were US \$1.2M ( $P=0.008$ ) and US \$0.1M ( $P=0.004$ ), respectively. Patient and cost flow analyses showed that 18% of patients moved up the cost acuity pyramid yearly, and their costs increased by 672%. This was in contrast to 22% of patients that moved down with a cost decrease of 86%. The remaining 60% of patients stayed in the same segment from year to year, though their costs also increased by 18%.

**Conclusions:** Although many health care organizations target intensive and costly interventions to their most expensive patients, this analysis unveiled potential cost savings opportunities by managing the patients in the lower cost segments that are at risk of moving up the cost acuity pyramid. To achieve this, data analytics integrating longitudinal data from electronic health records and home monitoring devices may help health care organizations optimize resources by enabling clinicians to proactively manage patients in their home or community environments beyond institutional settings and 30- and 60-day telehealth services.

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**KEYWORDS**

health care cost analysis; cost acuity pyramid; patient segmentation; multicenter study; Markov chains

## Introduction

The United States spends more on health care per person than any other country in the world [1]. National health care expenditures increased by 5.8% to US \$3.2 trillion from 2014 to 2015, or US \$9990 per person, and accounted for 17.8% of gross domestic product [2]. A recent study [3] on 5 fundamental factors associated with increases in US health care spending, including population size, population age structure, disease prevalence or incidence, service utilization, and service price and intensity, found that increases in service price and intensity were associated with a 50% health care spending increase. Increases in population size and age were also positively associated with increased health care spending, whereas changes in disease prevalence or incidence were negatively associated.

A sizable proportion (20%) of all national health care expenditures are due to Medicare spending, a federal health insurance program for US citizens who are 65 years and older, younger people with certain disabilities, and those who suffer from end stage renal disease [4]. For each consecutive year from 2011 to 2015, national average Medicare expenditures per enrollee steadily increased from US \$11,408, US \$11,465, US \$11,509, US \$11,711, to US \$11,951 [5]. Factors contributing to this growth included rising medical costs and an expansion of health insurance from 2014 to 2015, which increased the use of health services [5]. Among Medicare beneficiaries, older patients are among the groups that spend the most, and this is driven largely by inpatient (including emergency care) and postacute care costs [6]. In fact, in 2015, 35.9 per 100 individuals between the ages of 65 to 74 years had an emergency visit compared with 60.5 per 100 individuals aged 75 years and older [7]. Medicare beneficiaries are nearly twice as likely as the privately insured to be admitted 4 or more times per year to the emergency department (ED) [8]. Further, readmissions are common among Medicare patients and cost US \$26 billion annually, as estimated by the Agency for Healthcare Research and Quality [9]. Nearly a quarter of these Medicare readmissions are considered potentially avoidable [10,11] by the Centers for Medicare & Medicaid Services (CMS), the federal agency that administers Medicare.

Unsustainable health care costs and the need to improve overall efficiency is the driving force for the introduction of value-based care, wherein clinicians aim to cost effectively monitor, diagnose, and treat patients. Many health care organizations (HCOs) now use value-based care strategies [12], such as connected solutions that seamlessly integrate sources of big data and data analytics to identify and manage high-risk and high-cost patients [13]. An example of technology that is used worldwide for older patients is the personal emergency response service (PERS). PERS is designed to promote independent living in older adults by providing help in case of medical emergencies that could lead to costly ED visits and hospitalizations. Although PERS has been widely used for many years to monitor older patients, only recently has PERS data been utilized to develop CareSage [14], a data analytics engine that utilizes PERS device data to identify older patients at risk of ED transports/visits. Further, the unique combination of electronic health records (EHRs) and PERS data improved the

existing ED transports predictive model and facilitated the development of new models predicting emergency care [15]. However, to enable the development of cost-effective population health programs for older patients utilizing PERS, there is a need to better understand their health care utilization costs.

Health care expenditures in the United States are unevenly distributed across individuals and different segments of the population [16-20]. For example, the bottom 50% of the population (B segment which includes the 50% less expensive patients) spends only 3%-4% on health care, whereas the top 5% of the population (T segment, which includes the 5% most expensive patients) spends 50% of the total expenditures. The middle 45% of the population (M segment) accounts for the remaining 45% of the total cost. Accordingly, most HCOs focus on developing population health management programs targeting the most expensive patients in the T segment. The persistence in the health care cost of the T segment has been explored in a few studies that justify the use of targeted interventions [21-24]. However, none of these studies have examined the nonpersistence of health care costs, (ie, the full dynamics of patient and cost flows between the different segments from year to year). Furthermore, little is known about patient and cost flow prior to reaching the top 5%. To address these gaps and enable HCOs to deliver targeted and cost-effective interventions, we analyzed patient flow throughout the cost segments and associated annual health care cost changes.

## Methods

### Aims

The primary aim of this study was to evaluate the health care costs of older patients using PERS over a period of 5 years. Specifically, to answer the following questions:

- What is the total health care cost of the study population from fiscal year 2011 to fiscal year 2015 (FY11-FY15) and its distribution across specific cost segments?
- Are there longitudinal trends in health care cost across the cost segments?
- How many patients are moving up/down the cost segments and how do their health care costs vary annually?

### Design

This was a retrospective, longitudinal, multicenter study to evaluate health care costs of inpatient and outpatient hospital encounters in patients using PERS for any length of time during the study period of 5 years (FY11-FY15). The study was conducted using US data and was approved by the Partners Human Research Committee, the Institutional Review Board for Partners Healthcare hospitals.

### Settings

Study participants were identified from Partners Healthcare at Home (PHH), a home health agency that offers general care as well as specialized services to help patients within the Partners Healthcare System (PHS) network of hospitals to manage chronic conditions while at home. Patients are usually referred to the PHH service by their care providers after discharge from the hospital. In addition to in-person home visits, PHH utilizes



a variety of health care technologies to manage their patients. One of these technologies is the Lifeline PERS, which PHH care providers routinely recommend to chronically ill patients who are at risk of falls or other health-related emergencies. Detailed descriptions of PHH and PERS were described in a previous paper [25].

### Subject Selection

Subjects included in this study received health care at any of the 5 PHS affiliated hospitals and had at least one inpatient and/or outpatient encounter. Study subjects had at least one episode of PHH care with average duration of 2-3 months and were enrolled to PERS through PHH for any length of time during FY11-FY15. Initially, there were 4290 patients identified as PERS users from the Lifeline database, as illustrated in Figure 1. We excluded patients that were unmatched (by first name, last name, and date of birth) in the PHS data warehouse and those without any health care utilization record in the study period because their health care costs were zero without any variation. This resulted in 2643 patients included in the data analysis. All data were deidentified before analyses.

### Data Sources

The primary data source for this study was the enterprise data warehouse (EDW), an electronic medical record data repository for hospitals within the PHS network. It includes data such as patient demographics, medical conditions, clinical encounters, and health care costs. Health care cost data in EDW is obtained from the PHS costing system (ie, billing and internal cost to the hospital); it does not refer to insurer payment or cost to the patient. "Total cost" is the sum of variable and fixed costs for direct and indirect patient care during hospital inpatient and outpatient encounters. Hospital costing data are divided into fiscal years (FYs), as opposed to calendar years, with the fiscal year beginning Oct 1, (eg, FY11 begins on 2010 Oct 1). All mention of "year" herein refers to the fiscal year.

The PERS database included patient demographics, living situation, caregiver network, self-reported medical conditions, and medical alert data. The latter included all information gathered during the interactions of the patients with Lifeline call center associates when the PERS help button was pressed, including the reasons for pressing and the outcomes of the interactions.

### Subject Segmentation

The subject segmentation was based on the following steps performed for each fiscal year (FY11-FY15). Firstly, we selected

the patients that had any health care costs in a particular FY from all 2643 patients included in the study. Secondly, we calculated the annual cost of each patient as the sum of the total costs of their inpatient and outpatient encounters. Third, we ranked subjects by their annual health care costs from highest to lowest. Finally, we grouped them into the following segments: T segment constitutes the top 5% (0%-5%) most expensive patients; M segment comprises the middle 45% (5%-50%) of all patients; B segment includes the bottom 50% (50%-100%) least expensive patients. We visualized these 3 segments for each fiscal year by an annual cost acuity pyramid, as illustrated in Figure 2. The cost acuity pyramid is a core visual in this paper and is instrumental in illustrating the disproportion between the size of the segments and their health care costs.

### Outcomes

To address the aforementioned study objectives, our primary outcomes were to quantify patients who moved up, down, or stayed in the same segment of cost acuity pyramids over a 2-year period and to evaluate the costs associated with these flows.

Prior to analyzing the primary outcomes, we conducted exploratory analyses to evaluate a secondary outcome of the total health care cost of the study population and its distribution across the segments of the cost acuity pyramids for each available fiscal year. In addition, we performed inferential analysis to identify longitudinal trends in the total health care costs of the complete study population and each segment of the cost acuity pyramid.

### Statistical Analysis

Demographic and health care utilization data for FY11-FY15 were extracted from EDW using Microsoft Structured Query Language Server Management Studio (SSMS) 2014. Data management and deidentification were achieved through SSMS and Microsoft Excel 2007. The statistical analysis described below was performed via R version 3.4.1 [26].

To evaluate our primary outcomes, we applied a 3-step analysis, which included the following steps: model the patients' flow between the T, M, and B segments of the cost acuity pyramid over each 2-year period, group these flows to quantify patients moving up, down, or staying at the same segment of the cost acuity pyramid, and estimate the cost flow associated with the patient flow.

**Figure 1.** Flow chart diagram of the study subjects.

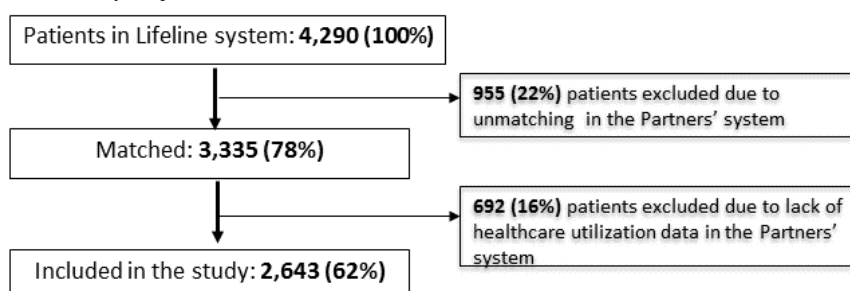


Figure 2. Cost acuity pyramid based on health care cost in 2015.

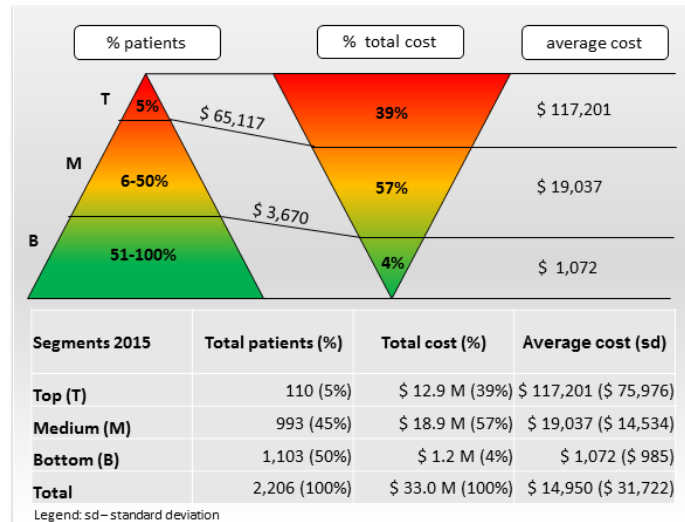
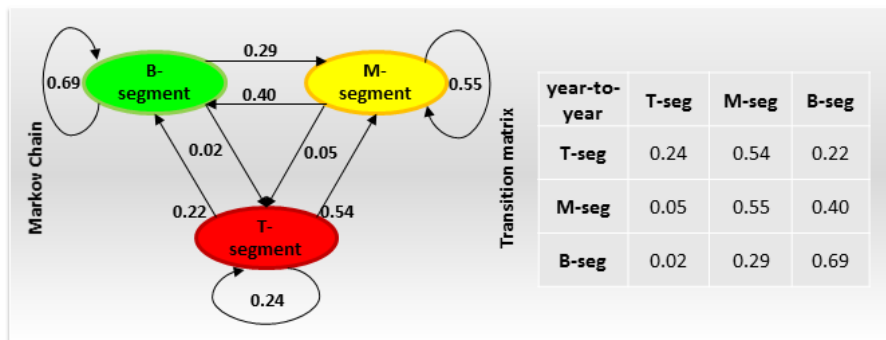


Figure 3. Markov chain of the patient flow and associated transition matrix.



To model the patients' flows in step 1 above, we created a Markov chain of the flow from each segment to all others over 2 successive FYs. A Markov chain describes a sequence of possible events, in which the probability of each event depends only on the state attained in the previous event. Markov chains have been used in the economic evaluation of health care [27] but not to examine the flow between the T, M, and B segments of the cost acuity pyramid. The Markov chain we built in this study included 3 states (B, M, or T segment) and 9 transitions (B to B, B to M, B to T, M to B, M to M, M to T, T to B, T to M, and T to T). These transitions could be grouped into 3 persistent (B to B, M to M, and T to T) and the remaining 6 nonpersistent transitions. The states represent the patient segments of the cost acuity pyramid, whereas the transitions indicate the probability that a patient will move from one segment to another over a 2-year period. The probability of transition change is an average of the flow percentages over 4 sequential pairs of FYs, that is, FY11-FY12, FY12-FY13, FY13-FY14, and FY14-FY15. The 9 probabilities constitute a 3x3 transition matrix associated with the Markov chain, as illustrated in Figure 3. This transition matrix was used in step 2 of the analysis described above. Namely, the probabilities in the lower triangular, upper triangular, and diagonal of this matrix were multiplied by the size of the corresponding segments and summed to quantify patient movements throughout the segments of the cost acuity pyramid.

To evaluate health care expenditure trends, we conducted linear regression analyses. Four linear regression models were built with health care costs of the total study population and T, M, and B segments as the dependent variables with each available fiscal year serving as the independent variable. Each model provided an estimate of the expected annual cost increases/decreases.

## Results

### Characteristics of Study Population

The study population was, on average, 79 years old, predominately female (1990/2643, 75.29%), white (2312/2643, 93.41%), living alone (2483/2643, 93.95%), without family caregivers (2629/2643, 99.47%), and at least 86.70% (1310/1511) had a high school education (Table 1). The majority of the patients (1728/2643, 65.38%) had multiple medical conditions.

### Health Care Cost Distribution and Trends

Health care costs were unevenly distributed across the segments of the cost acuity pyramid for each fiscal year. For example, there were 2206 patients with any health care utilization in 2015, as illustrated in Figure 2. Their total health care costs were US \$33.0M and the average cost per patient was US \$14,950 (SD US \$31,722). The T segment in 2015 (in total 110 patients with annual cost above US \$65,117) constituted 39% (US \$12.9M)

of the total health care expenditures and the average cost per patient was US \$117,201 (SD US \$75,976). The M segment (in total 993 patients with annual cost above US \$3670) accounted for 57% (US \$18.9M) of the total health care expenditures and the average cost per patient was US \$19,037 (SD US \$14,534). The B segment (in total 1103 patients) comprised only 4% (US \$1.2M) of the total health care expenditures and the average cost per patient was US \$1072 (SD US \$985).

The total health care expenditure of the study population nearly doubled from US \$17.7M in FY11 to US \$33.0M in FY15, although the number of patients per year having any costs remained similar, as illustrated in [Figure 4](#). About two thirds of the total expenditure (ranging from 63% to 71% throughout FY11-FY15) included hospital admissions costs, which doubled from US \$11.4M in FY11 to US \$23.4M in FY15. The remaining one third of the total expenditure was outpatient encounters costs, which also increased from US \$6.3M in FY11 to US \$9.6M in FY15.

The M segment was the most expensive with total costs increasing from US \$9.1M in FY11 to US \$18.9M in FY15, as illustrated in [Figure 4](#). Moreover, the relative contribution of the M segment to the total cost increased from 51% in FY11 to 57% in FY15. Next was the T segment, the costs of which increased from US \$8.0M in FY11 to US \$12.9M in FY15. The relative contribution of the T segment to the total cost decreased from 45% in FY11 to 39% in FY15, and this was in contrast to the M segment. The cost of the B segment increased from US \$0.6M in FY11 to US \$1.2M in FY15. However, the relative contribution of the B segment to the total cost remained steady at 3%-4% over the 5 years. Further, linear regression analysis showed that the increasing trend in total health care costs of the study population was statistically significant ( $P=.003$ ) with an expected annual cost increase of US \$3.6M, as illustrated in [Figure 4](#). This growth was driven primarily by the significant cost increase of US \$2.3M in the M segment ( $P=.003$ ). The expected annual cost also increased significantly in the T and B segments with US \$1.2M ( $P=.008$ ) and US \$0.1M ( $P=.004$ ), respectively. The trends in both components of total cost, inpatient and outpatient costs, were similar to those illustrated in [Figure 4](#).

### Patients and Cost Flow Throughout Segments of the Cost Pyramids

The Markov model of the patient flow throughout the segments of the cost acuity pyramid is illustrated in [Figure 3](#).

An alternative visualization using the cost acuity pyramids is shown in the upper part of [Figure 5](#). Both figures highlight several important insights. First, the B segment was the most stable of all 3 segments. A majority (69%) of the patients in the B segment stayed in the same segment during the next fiscal year, 2% moved up to the T segment, and the remaining 29% of the patients moved up to the M segment of the cost acuity

pyramid during the next fiscal year. Second, the M segment was more dynamic than the B segment. A majority (55%) of the patients in the M segment stayed in the same segment during the next fiscal year, 5% moved up to the T segment, and the remaining 40% moved down to the B segment of the cost acuity pyramid in next fiscal year. Third, the T segment was the most dynamic of all 3 segments. Only 24% of the patients in the T segment stayed in the same segment next fiscal year, whereas 54% and 22% of the patients moved down to the M and B segments of the cost acuity pyramid during the next fiscal year, respectively.

The cost flow associated with the patient flow is depicted in the lower part of [Figure 5](#), specifically for the two most recent FYs, FY14 and FY15. The cost of 1112 patients in the B segment increased from US \$1M in FY14 to US \$8.7M in FY15 (+770%) owing to their movement up to the M and T segments, as depicted in the upper part of [Figure 5](#). Similarly, the cost of 1000 patients in the M segment increased from US \$15.7M in FY14 to US \$16.5M in FY15 (+5%) owing to their movements to the B and T segments. The cost of 111 patients in the T segment decreased from US \$12.1M in FY14 to US \$5.4M in FY15 (-55%) owing to their movement down to the lower segments.

We evaluated the potential demographic differences between patients who moved up, stayed, or moved down the cost acuity pyramid, as detailed in [Table 2](#). Using the patient flow from FY14 to FY15 as an example, the patient groups were statistically similar to each other, except for likelihood of living alone and the number of comorbid medical conditions. More specifically, patients who stayed in the same segment were most likely to live alone and those who moved down being least likely to live alone ( $P=.02$ ). Further, patients who stayed in the same segment were higher in proportion with none of the selected comorbidities compared with patients who moved up or down ( $P<.01$ ). Patients who moved up were more likely to have 4 or more of the selected comorbid conditions ( $P=.03$ ) than those who stayed or moved down.

After quantifying the patient and cost flows throughout the segments of the cost acuity pyramids, we evaluated the primary outcome of how many patients moved up, down, or stayed in the same segment the following year, as illustrated in [Figure 6](#). In total, 22.18% (493/2223) of the patients moved at least one segment down the cost acuity pyramid yearly and their costs decreased from US \$14.5M in FY14 to US \$2.0M in FY15 (-86%). Another 18.13% (403/2223) of the patients moved at least one segment up the cost acuity pyramid yearly and their costs increased from US \$1.8M in FY14 to US \$13.9M in FY15 (+672%). Overall, 59.70% (1327/2223) of patients stayed in the same segment of the cost acuity pyramid yearly; however, their costs also increased from US \$12.5M in FY14 to US \$14.8M in FY15 (+18%).

**Table 1.** Characteristics of the study population.

Variables	Study population (N=2643), mean (SD) or n (%) <sup>a</sup>
Age, mean (SD)	79 (11)
<b>Age category, n (%)</b>	
<65	303 (11.46)
65+	2340 (88.54)
<b>Gender, n (%)</b>	
Female	1990 (75.29)
<b>Race (N=2475)<sup>b</sup>, n (%)</b>	
White	2312 (93.41)
Hispanic	9 (0.36)
Black/African American	128 (5.17)
Other	26 (1.05)
<b>Family caregivers, n (%)</b>	
0	2629 (99.47)
1	14 (0.53)
<b>Live alone, n (%)</b>	
Yes	2483 (93.95)
No	160 (6.05)
<b>Education (N=1511)<sup>c</sup>, n (%)</b>	
≥College	551 (36.47)
Some college	102 (6.75)
High school	657 (43.48)
<High school	201 (13.30)
<b>Marital status (N=2374)<sup>d</sup>, n (%)</b>	
Married	695 (29.28)
Divorced	317 (13.35)
Single	475 (20.00)
Widowed	887 (37.36)
<b>Medical condition, n (%)<sup>e</sup></b>	
0	386 (14.60)
1	529 (20.02)
2	562 (21.26)
3	473 (17.90)
≥4	693 (26.22)

<sup>a</sup>Percentages may not add to 100 due to rounding.

<sup>b</sup>Unknown: n=168.

<sup>c</sup>Unknown: n=1132.

<sup>d</sup>Unknown: n=269.

<sup>e</sup>Selected medical conditions included disordered lipid metabolism, atrial fibrillation, congestive heart failure, chronic obstructive pulmonary disease, malignant cancer, fractures, pneumonia, obesity, and acute myocardial infarction.

Figure 4. Health care cost trends of total population, top (T), middle (M), and bottom (B) segments from 2011 to 2015.

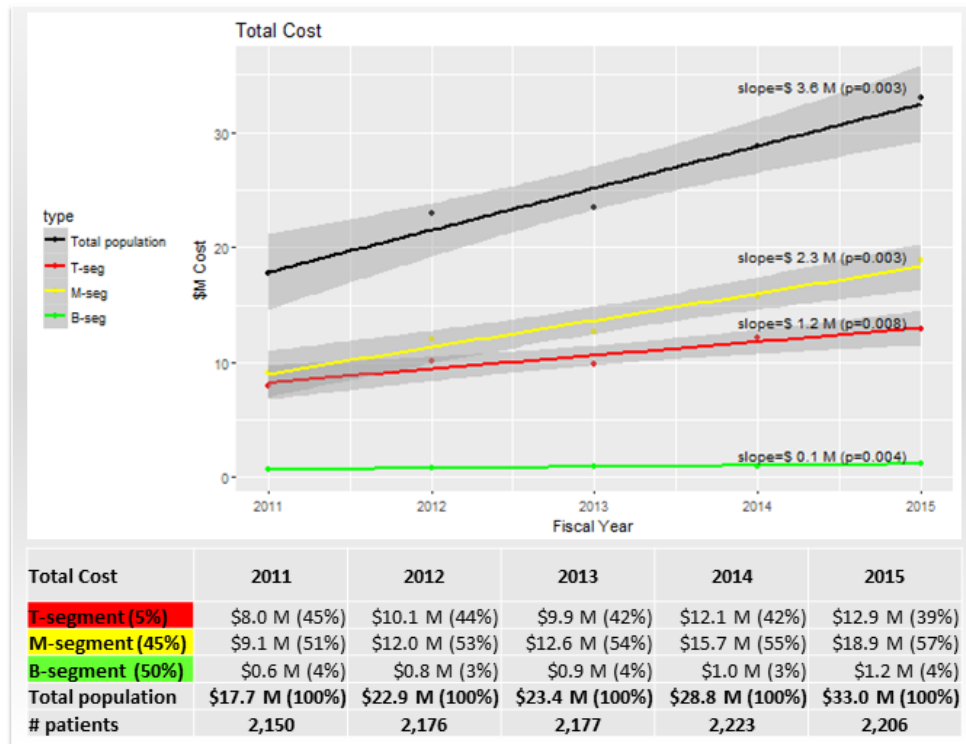
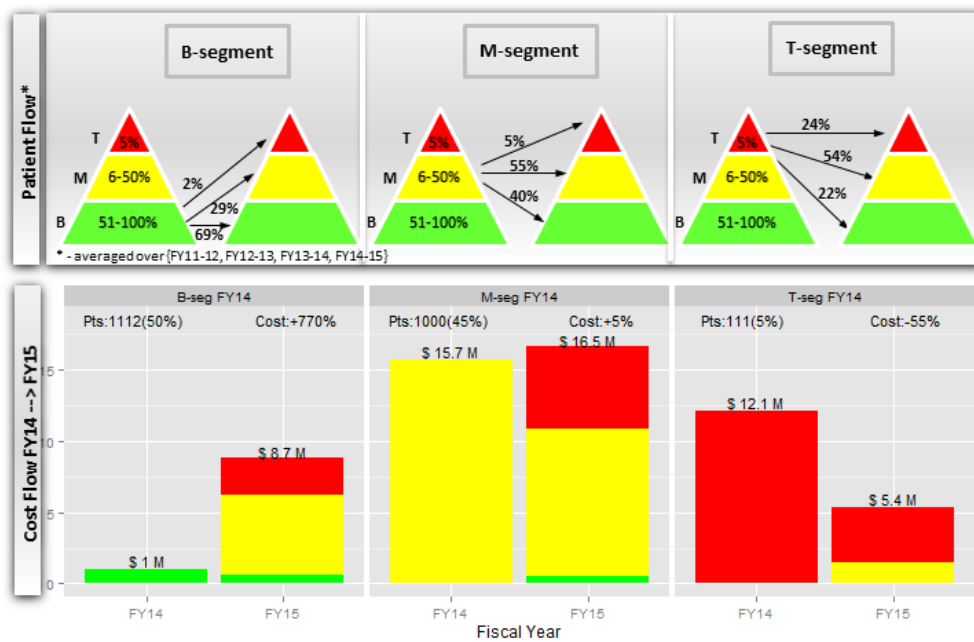


Figure 5. Patient and cost flows of top (T), middle (M), and bottom (B) segments of cost acuity pyramid.





**Table 2.** Characteristics of study population (N=2223) who moved up, stayed, or moved down the cost acuity pyramid from fiscal year 2014 to fiscal year 2015.

Variables	Moved up <sup>a</sup>	Stayed <sup>a</sup>	Moved down <sup>a</sup>	P value
Total, N (%)	403 (18)	1327 (60)	493 (22)	
Age, mean (SD)	10.9 (78.9)	11 (78.8)	11 (78.6)	.91
<b>Age category, n (%)</b>				.96
<65	48 (11.91)	162 (12.21)	58 (11.76)	
65+	355 (88.09)	1165 (87.79)	435 (88.24)	
<b>Gender, n (%)</b>				.73
Female	306 (75.93)	1000 (75.36)	364 (73.83)	
<b>Race, n (%)<sup>b</sup></b>	<b>N=391</b>	<b>N=1259</b>	<b>N=468</b>	.86
White	368 (94.12)	1169 (92.85)	433 (92.52)	
Hispanic	1 (0.26)	6 (0.48)	1 (0.21)	
Black/African American	17 (4.35)	71 (5.64)	30 (6.41)	
Other	5 (1.28)	13 (1.03)	4 (0.85)	
<b>Family caregivers, n (%)</b>				.42
None	402 (99.75)	1319 (99.40)	492 (99.80)	
<b>Live alone, n (%)</b>				.02
Yes	375 (93)	1255 (95)	449 (91)	
<b>Education, n (%)<sup>c</sup></b>	<b>N=255</b>	<b>N=758</b>	<b>N=295</b>	.86
≥College	98 (38.43)	282 (37.20)	104 (35.25)	
Some college	19 (7.45)	38 (5.01)	21 (7.12)	
High school	103 (40.39)	330 (43.54)	126 (42.71)	
<High school	35 (13.73)	108 (14.25)	44 (14.92)	
<b>Marital status, n (%)<sup>d</sup></b>	<b>N=366</b>	<b>N=1200</b>	<b>N=444</b>	.94
Married	109 (29.78)	352 (29.33)	126 (28.38)	
Divorced	49 (13.39)	166 (13.83)	65 (14.64)	
Single	64 (17.49)	237 (19.75)	90 (20.27)	
Widowed	144 (39.34)	445 (37.08)	163 (36.71)	
<b>Medical condition, n (%)<sup>e</sup></b>				<.01
0	16 (3.97)	149 (11.23)	31 (6.29)	<.01
1	55 (13.65)	249 (18.76)	91 (18.46)	.06
2	94 (23.33)	297 (22.38)	112 (22.72)	.92
3	92 (22.83)	245 (18.46)	109 (22.11)	.07
≥4	146 (36.23)	387 (29.16)	150 (30.43)	.03

<sup>a</sup>Percentages may not add to 100 due to rounding.

<sup>b</sup>Unknowns: moved up: n=12; stayed: n=68; moved down: n=25.

<sup>c</sup>Unknowns: moved up: n=148; stayed: n=569; moved down: n=198.

<sup>d</sup>Unknowns: moved up: n=37; stayed: n=127; moved down: n=49.

<sup>e</sup>Selected medical conditions included disordered lipid metabolism, atrial fibrillation, congestive heart failure, chronic obstructive pulmonary disease, malignant cancer, fractures, pneumonia, obesity, and acute myocardial infarction.

**Figure 6.** Patients moving throughout the cost acuity pyramid and associated cost flow.

## Discussion

### Principal Findings

This study is the first to quantify patients' annual movements through the segments of the cost acuity pyramid and associated changes in health care costs. We discovered 3 main findings. First, the total health care cost of the study population doubled from US \$17.7M to US \$33.0M (FY11-FY15) with an expected annual increase of US \$3.6M ( $P=.003$ ). Second, patients in the M segment were major contributors to the increased cost with an expected annual increase of US \$2.3M ( $P=.003$ ). The M segment was consistently the costliest throughout all 5 FYs. Third, the patient and cost flow analysis showed that 18% of patients moved up the cost acuity pyramid yearly and their costs increased by 672%. In contrast, 22% of patients moved down with cost reductions of 86%. Although the remaining 60% of patients stayed in the same segment from year to year, their health care costs also increased by 18%.

Our first finding is consistent with those of the prior studies characterizing high-cost users as predominantly older patients with functional limitations and multiple chronic conditions [28-30], yet the magnitude of this annual increase of 20% (US \$3.6 M) was notably 3 times higher than the national average of 6% per year projected by CMS [31]. This discrepancy can be explained, in part, by the fact that our population was significantly older than the national CMS population (79 vs 71 years old) [25]. Nevertheless, we found in a previous study [25] that 37% of all costly admissions were due to medical conditions leading to potentially avoidable admissions [10,11]. Taken together, this suggests that interventions targeting these conditions may be an effective strategy for in older adults.

The second finding that the M segment (not the T segment) of the cost acuity pyramid was the most expensive each year is a new insight that reveals the importance of the M segment for cost management. Currently, most HCOs develop population health management programs targeting the T segment of the

cost acuity pyramid [32-34]. Although these programs have demonstrated improvement in clinical outcomes, evidence supporting their impact on health care costs is inconclusive [35]. Often, these studies compare health care expenditures pre- and postprogram introduction. The lack of randomized control trials raises the question of whether the reported cost savings can be attributed to the effect of the interventions or a statistical phenomenon known as regression to the mean [36]. Figure 5 supports the latter, illustrating that a majority (76%) of patients in the T segment tended to move to the M and B segments the following fiscal year and consequently, their costs dropped by US \$6.7M (-55%). However, this cost reduction can be completely phased out by the US \$7.7M (770%) cost increase of the B segment owing to patients moving up. Therefore, for all cost reduction initiatives, the unforeseen costs of patients moving up the cost acuity pyramid, which are hidden within an overall budget, may seem to invalidate the work being done to manage the costs of the T segment.

The third finding illustrates how health care expenditures of the different segments of the cost acuity pyramid changed over the 2-year period. Previous work [25] analyzing the persistence of expenditures over a 2-year period reported a slightly higher percentage of patients remaining in the T segment (34% vs 24%) and B segments (73% vs 69%) than that reported by us. However, this study involved the general US population, which is much younger than our study population. Our study is the first one that quantifies not only the patients staying at the same cost segment (persistent flows) but also those moving up and down throughout the segments of the cost acuity pyramid (nonpersistent flows) over the sequential 2-year period as well as their cost changes. Analyzing cost persistence over 3-, 4-, or 5-year periods is more appealing than over a 2-year period. However, our choice to analyze over a 2-year period was imposed by the growing complexity of the nonpersistent flows. Each subsequent year the number of nonpersistent flows tripled from 6 to 18 to 54 to 162 over 2-, 3-, 4-, and 5-year periods, respectively, whereas the number of persistent flows stayed the

same at 3. Further, analyzing over a 2-year period kept the number of patients in the nonpersistent flows still meaningful for statistical analyses.

In evaluating potential group differences in patients who moved up, stayed, or moved down the cost acuity pyramids, we observed that patients who stayed in the same segment were more likely to live alone and to have fewer comorbid conditions. Patients who moved up the cost acuity pyramid had the highest proportion of comorbid conditions. Future work will examine additional patient characteristics.

In summary, our findings demonstrate that a holistic cost management approach is needed to attenuate the overall increases in total health care costs, taking into account the dynamic flows between all segments of the cost acuity pyramid, rather than the T segment only. This approach would target interventions to patients at risk of moving up the cost acuity pyramids.

### Limitations

This study had a number of limitations. Firstly, PERS used by this population was self-paid and may limit the study generalizability to patients that could afford the service. Secondly, our analyses did not include the costs of patients' clinical encounters that may have occurred outside the Partners Health care network. Further, information about patients' alignment with insurers accepted by PHS at the time of their health care utilization was not available because the dataset was derived from EHR, rather than the insurance claims. Thirdly, other types of health care costs, such as skilled nursing facilities and home health agencies, are not included in our analysis

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### Authors' Contributions

All authors read and approved the final manuscript. SA, MS, SG, JodB, and LS designed the research. MS and SG performed the statistical analyses; SA, LS, JK, KJ, AO, NF, and JF provided feedback on analyses and interpretation of results; MS, SG, SA, JF, NF, and JodB wrote the paper; and SA had primary responsibility for the final content.

### Conflicts of Interest

Philips provided funding for this study and four Philips employees (MS, JB, LS and AO) played a role in the design of the study, data collection, analysis, interpretation and writing of the manuscript.

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## Abbreviations

**CMS:** Centers for Medicaid and Medicare Services  
**ED:** emergency department  
**EDW:** enterprise data warehouse  
**EHR:** electronic health record  
**FY:** fiscal year  
**HCO:** health care organizations  
**PERS:** personal emergency response service  
**PHH:** Partners Healthcare at Home  
**PHS:** Partners Healthcare System  
**SSMS:** structured query language server management studio

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Original Paper

# Testing a Photo Story Intervention in Paper Versus Electronic Tablet Format Compared to a Traditional Brochure Among Older Adults in Germany: Randomized Controlled Trial

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## Abstract

**Background:** To increase effective communication in primary care consultations among older adults in Germany, the photo story is considered to be a useful tool based on Bandura's social cognitive theory. With information technology helping to increase effective communication, the use of tablets is gaining attention in health care settings, especially with older adults. However, the effectiveness of tablet technology and photo stories has rarely been tested.

**Objective:** The aim is to compare the effectiveness of a photo story intervention to a traditional brochure. Both were delivered either in paper or tablet format.

**Methods:** A trial was conducted with 126 older adults, aged 50 years and older, who were approached and recruited by researchers and administrative staff from senior day care, doctors in rehabilitation centers, and trainers in sports clubs in Germany. Open and face-to-face assessment methodologies were used. Participants were randomly assigned to one of four intervention conditions: traditional brochure in paper format (condition 1) and tablet format (condition 2), and photo story in paper format (condition 3) and tablet format (condition 4). Each participant received a questionnaire and either the traditional brochure or photo story in a paper or tablet version. To evaluate the effectiveness of each intervention, participants completed evaluation questionnaires before and after each intervention. The second part of the questionnaire measured different indicators of health literacy, communication skills, health measurements, and possible underlying mechanisms.

**Results:** Compared to the traditional brochure, participants considered the photo story easier to understand ( $t_{124}=2.62, P=.01$ ) and more informative ( $t_{124}=-2.17, P=.03$ ). Participants preferred the paper format because they found it less monotonous ( $t_{124}=-3.05, P=.003$ ), less boring ( $t_{124}=-2.65, P=.009$ ), and not too long ( $t_{124}=-2.26, P=.03$ ) compared to the tablet format. Among all conditions, the traditional brochure with a tablet (condition 2) was also perceived as more monotonous (mean 3.07, SD 1.08), boring (mean 2.77, SD 1.19), and too long to read (mean 2.50, SD 1.33) in comparison to the traditional brochure in paper format (condition 1). Moreover, the participants scored significantly higher on self-referencing on the traditional brochure in paper format (condition 1) than tablet format for both types of the brochure (conditions 2 and 4).

**Conclusions:** Traditional brochures on a tablet seem to be the least effective communication option in primary care consultations among all conditions for older adults. The findings might be specific for the current generation of older adults in Germany and need to be replicated in other countries with larger sample sizes. Although information technology brings advantages, such as effective interventions in different fields and settings, it may also come with several disadvantages, such as technical requirements of the users and devices. These should be considered when integrating information technology into wider situations and populations.

**Trial Registration:** ClinicalTrials.gov NCT02502292; <https://clinicaltrials.gov/ct2/show/NCT02502292> (Archived by Webcite at <http://www.webcitation.org/747jdJ8pU>)

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## KEYWORDS

photo story; traditional brochure; health literacy; communication; older adults; tablet intervention; electronic/information technology; primary care consultation

## Introduction

The involvement of older people in medical decision making and the barriers they experience during conversations with health care professionals have been a prominent focus in clinical settings [1]. One study revealed that the most common barriers include difficulties understanding medical information [1]. Almost half of the patients preferred to play a passive role in medical decision making, but still might want more information about their health care, and 27.5% of patients were not asked for their opinion at all. Therefore, this study concluded that information and communication are basic requirements for everyone to participate in medical decision making. According to Clayman and colleagues [2], the ability to efficiently communicate with health care providers is an important element of proper self-care. This is especially important for individuals with limited health literacy: to be able to obtain, understand, and recall information from their doctors. Therefore, this study aims to develop relevant and beneficial interventions, which address the aforementioned aspects including useful information and communication, to assist older adults with low health literacy during their care consultations and increase their ability to comprehend health-related information.

Narrative communication as a tool has been strongly recommended in previous studies [3], as it is an effective approach to interaction regardless of literacy level. This assumption is based on Bandura's social cognitive theory [4] because a photo story with a comic layout, modeled pictures, and bubble conversations addresses the three main sources of self-efficacy and outcome expectations. In his self-efficacy theory, Bandura hypothesized that self-efficacy influences choice of activities, goal setting, and initiation of behavior, as well as coping efforts after commencement of the behavior (maintenance). Self-efficacy controls how much effort one invests and how persistent one is in investing more effort to deal with obstacles and adverse experiences. In addition, performance feeds back to self-efficacy expectation creating a reciprocal effect. Self-efficacy is linked with goals in that the higher self-efficacy is, the more likely people are to set a goal. Self-efficacy also affects outcome expectations: individuals with higher self-efficacy are more likely to perceive outcomes as more favorable [4,5].

Bandura's self-efficacy theory describes four different influence procedures or sources of self-efficacy: performance accomplishments, vicarious experience, verbal persuasion, and emotional arousal. They can all directly influence self-efficacy and thereby have a mediated effect on behavior [4,5]. Thus, they represent targets of interventions to create or alter

self-efficacy and enable people to perform a behavior to attain a set goal.

Personal experiences or performance accomplishments are often called *mastery experiences*. Personal experiences have been found to have the highest impact on self-efficacy beliefs and thereby on future behavior. However, an avatar would only provide this experience when using information technology, but not personal contact. Thus, of higher importance are the other sources. Vicarious experience is the second source and includes all experiences observed by the individual, like in a photo story or in a traditional brochure on a tablet. Model learning builds on vicarious experiences by observing others and drawing conclusions for one's own behavior and its predictors. The more similar the model (ie, the observed other person) is to the individual, the more likely it is that the observations have an impact on the individual [4,5].

The third and weaker factor, compared to the first two sources, is verbal persuasion. Verbal feedback and instruction can come from other people, texts, or self-instruction [4,5]. Such feedback is not usually possible with photo stories or in a traditional brochure on a tablet. However, the last and least strong source is a physiological state of emotional arousal; such arousal can be elicited by material such as a photo story or in a traditional brochure on a tablet.

Photo Story is an alternative tool in a comic layout with modeled pictures and bubble conversation [6], which is considered to be one of the most useful health literacy strategies to engage people in effective communication through the process of reflection and critical thinking [7]. This tool has been used in several contexts; for example, to promote healthy eating in a Latino community [8], to support older adults with limited health literacy during doctor-patient communication [9], and to improve depression literacy and help-seeking behaviors [6]. Moreover, a previous study highlighted the value of comic strips, which share similar characteristics with photo stories, as a format for health information [10]. Despite this, there is a lack of systematic studies that examine the effectiveness of photo story interventions, especially in older adults. This study aims at filling this gap.

The usefulness of information technology electronic devices, such as tablets, in the context of primary care consultations for older adults is not yet well understood [11]. A systematic review and meta-analysis suggested older adults have the potential to benefit from the use of tablet technology, especially in health care settings [12]. Information technology can be used in different ways to promote health literacy among people with low literacy. A study by Wang and colleagues [13] tested the effectiveness of a story-based video as an educational tool to

increase people's comprehension of prostate health terminology. Their findings showed that comprehension significantly increased for 13 of 32 terms. The researchers concluded that story-based education by means of videos has the potential to increase comprehension and support shared decision making [13].

Another previous study tested the readability of discharge instructions for hospital patients, either by means of electronic templates for specific diagnoses or by doctors for whom no templates were made available. Results showed that the readability of electronic diagnosis-specific templates was better than the instructions generated by the doctors [14]. Yet another study compared tablet and paper formats of a tablet-based consent process for a mock clinical trial among older adults. The results showed that the older adults accepted the tablet-based consent process and it was feasible to implement, although they took a longer time to complete the tablet format compared to the paper format [15].

Despite the wide range of studies available, there is a visible lack of research, especially randomized controlled trials with study interventions, to test the effectiveness of the photo story for increasing health-related understanding and the usefulness of electronic devices, such as tablets [12]. A systematic review assessing the evidence for the effectiveness of such interventions concluded that there is a lack of consistent evidence for effective interventions [16].

Based on the presented evidence, it seems that older adults with low health literacy can gain from innovative solutions that help to improve understanding and communication in health settings. Such innovative solutions can make use of the advances in technology occurring today but require interventions to test effectiveness and find the right solution for the target population. This study therefore provides insight into a photo story intervention as a potentially effective communication tool. The following research questions were tested:

1. Which intervention do older adults appreciate more: the photo story or the traditional brochure?
2. Which format do older adults prefer in the intervention: the paper format or the tablet format?
3. Which condition of the interventions (the photo story or the traditional brochure provided on paper or on a tablet) is more effective in increasing older adults' communicational self-efficacy and behavioral intentions in the context of primary care consultations in Germany, and has effects on different aspects of health literacy (transportation, identification, self-referencing)?

## Methods

### Participants

Participants were approached and recruited by researchers via administrative staff of senior day care, rehabilitation centers, and sports clubs in Germany. Data collection took place in 2015. Only participants who met the following inclusion criteria were approached to participate in the study: (1) aged 50 years or older, (2) no cognitive impairments with average literacy

enabling them to complete a questionnaire without help, and (3) German language proficiency.

### Procedure

To guarantee a standardized approach, all researchers completed training before the start of the data collection process. Following training, each researcher was assigned to a sports club or rehabilitation center, and then they contacted the facility to arrange appointments with the participants to collect the data. The researchers introduced themselves to participants and provided information sheets, which contained both the aim and basic information about the study.

Ethical approval was applied for and received from the Deutsche Gesellschaft für Psychologie (German Association for Psychology). It was conducted in line with the American Psychological Association's ethical principles and the 1964 Helsinki Declaration and its later amendments or comparable ethical standards. The study was registered at ClinicalTrials.gov (NCT02502292), where the description of this study with its objectives, designs, methodologies, and interventions were submitted with several purposes: to decrease publication and outcome reporting biases, and to promote the implementation of ethical obligations to participants [17].

After signing the consent form, each participant received a questionnaire and either the traditional brochure or photo story in a paper or tablet version. The researcher was present to answer participants' questions or concerns. The intervention was developed by partners of the Intervention Research on Health Literacy among the Ageing Population consortium to improve older adults' health literacy and communication skills during care consultations. The photo story and traditional brochure used in this study were developed based on both previous literature [3,6,8] and the outcomes of focus group discussions conducted in the Netherlands and Hungary [9,16]. The traditional brochure contained only text health information, whereas the photo story contained storylines and sketches with photographs in a clinic setting between a doctor and a patient, with added speech and thought bubbles according to the scripts. More details have been published elsewhere [9,16], but are distinct from this study. Participants in the two tablet conditions were shown the traditional brochure and the photo story in the form of a PDF (Portable Document Format). After they returned their brochures, the second part of the questionnaire was given to the participants to complete. At the end of the study, all participants received a debriefing statement with the researchers' contact details in case they had questions or suggestions regarding the study.

### Measures

The questionnaire consisted of two parts: the first part contained questions regarding sociodemographics, perceived health and well-being measurements, morbidities, and the frequency of doctor consultations. The health literacy Set of Brief Screening Questions was also utilized, with three 5-point Likert scale questions (eg, "How often do you need help to read the information papers from the hospital?" [18]). In addition, questions regarding the general level of communicative self-efficacy (Ask, Understand, Remember Assessment; AURA)

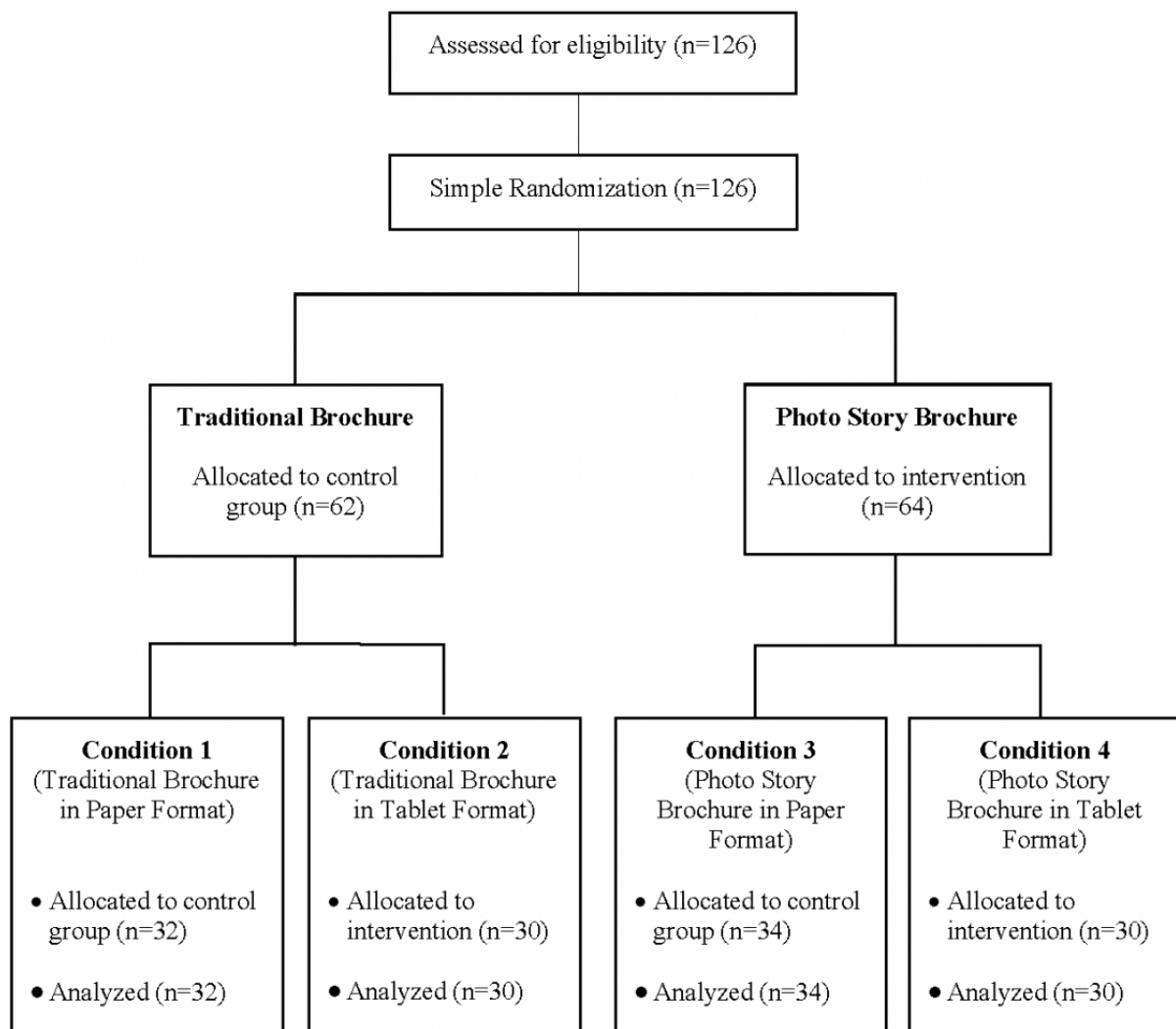
were included, such as “Is it easy for you to ask your doctor questions?”; Cronbach alpha was .83 [2].

In the second part, questions related to each story of the traditional brochure, including domain-specific self-efficacies (eg, “You have the feeling that your doctor might not give you enough attention, is it easy for you to make him aware of it?” rated from 1=no, not at all to 5=yes, absolutely) and behavioral intentions items (eg, “You have the feeling that your doctor doesn’t give you enough attention, would you make him aware of this feeling?”) [19-21]. The questions regarding self-efficacy included aspects of attention calling, social support mobility, clarifications, medication help seeking, instruction checking, question asking, and question developing. Cronbach alpha was determined to be .70 for self-efficacy and .77 for behavioral intention. To investigate the underlying mechanisms of effective communication, questions about self-referencing [22], identification, and transportation [23] were also included. This was followed by evaluation questions regarding the traditional brochure and photo story, such as “Did you find the booklet hard to understand?”

## Analyses

Statistical analyses were carried out with SPSS version 25. As shown in Figure 1, simple randomization checks were performed between participants of the control groups (traditional brochure and paper format) and the interventions (photo story and tablet format). We used multivariate analyses of variance to (1) to investigate perceived health, frequency of doctor visits, and communication self-efficacy across the four conditions; (2) to gain insight into the evaluations of the effectiveness of the interventions across all four conditions; and (3) to examine the intervention’s effectiveness in increasing older adults’ communication self-efficacy and behavioral intentions, as well as the underlying mechanisms (ie, self-referencing, identification, and transportation) across all four conditions. These analyses were followed by polynomial contrasts and post hoc multiple comparisons. In addition, we conducted two independent *t* tests with seven evaluation variables to compare the means of the two independent groups: photo story and traditional brochure, as well as the mean differences between paper and tablet formats.

**Figure 1.** Consolidated Standards of Reporting Trials (CONSORT) flow chart.





## Results

A total of 126 participants, aged 50 years and older (mean 71.85, SD 10.13 years), were recruited and randomly assigned with simple randomization to one of four test conditions. In total, 61.9% (78/126) of the participants were female and 38.1% (48/126) were male. Further, 45.2% (57/126) of the participants had no chronic disease, 35.7% (45/126) had one chronic disease, and 17.5% (22/126) had more than one chronic disease, including cardiovascular disease, respiratory disease, diabetes, rheumatism, or diseases of the musculoskeletal system. In total, 67.5% (85/126) were married and/or in a long-term relationship, and 78.6% (99/126) were retired.

### Health Measurements

Both means and standard deviations for perceived health, frequency of doctor visits, and communication self-efficacy (AURA) across the four conditions are displayed in Table 1.

As can be seen in Table 1, the participants perceived their health average to be between “satisfactory” and “well” and, on average, participants consulted their doctors between every 3 and 6 months. Regarding their communication self-efficacy, during their doctor visits, participants perceived themselves to be able to understand their doctors’ instructions. However, there was no statistically significant difference in perceived health,

frequency of doctor visits, and communication self-efficacy between the four different conditions ( $F_{9,292}=0.597$ ,  $P=.79$ , Wilk  $\lambda=0.96$ , partial  $\eta^2=.015$ ). There was also no significant effect among different groups for perceived health ( $F_{3,122}=0.95$ ,  $P=.42$ , partial  $\eta^2=.023$ ), frequency of doctor visits ( $F_{3,122}=1.20$ ,  $P=.31$ , partial  $\eta^2=.029$ ), and communication self-efficacy ( $F_{3,122}=0.20$ ,  $P=.89$ , partial  $\eta^2=.005$ ).

### Photo Story Versus Traditional Brochure

Three significant differences between the two groups of the photo story and traditional brochure conditions were found indicating that participants considered the photo story to be easier to understand ( $t_{124}=2.62$ ,  $P=.01$ ) and more informative ( $t_{124}=-2.17$ ,  $P=.03$ ) in comparison to the traditional brochure (see Table 2).

### Paper Versus Tablet Format

Comparing the paper format (n=66) with the tablet format (n=60) across the same seven variables, three significant differences between these two groups were seen: participants preferred the paper format because they found it less monotonous ( $t_{124}=-3.05$ ,  $P=.003$ ), less boring ( $t_{124}=-2.65$ ,  $P=.009$ ), and not too long ( $t_{124}=-2.26$ ,  $P=.03$ ) compared to the tablet format (see Table 3).

**Table 1.** Means and standard deviations of perceived health, frequency of visit to doctor and communicative self-efficacy, across four conditions.

Types of brochures	Traditional, mean (SD)		Photo story, mean (SD)		Total (N=126)	P value
	Paper (n=32)	Tablet (n=30)	Paper (n=34)	Tablet (n=30)		
Perceived health	3.28 (0.96)	3.60 (0.93)	3.35 (0.85)	3.57 (0.86)	3.44 (0.90)	.42
Frequency visit doctor	4.34 (0.97)	4.60 (1.13)	4.38 (0.99)	4.77 (0.94)	4.52 (1.01)	.31
Communicative self-efficacy (AURA <sup>a</sup> )	4.06 (0.73)	4.06 (0.67)	3.94 (0.91)	4.08 (0.79)	4.03 (0.77)	.89

<sup>a</sup>AURA: Ask, Understand, Remember Assessment.

**Table 2.** Means and standard deviations of the evaluations between the traditional brochure (conditions 1 and 2) and photo story (conditions 3 and 4) tool (N=126).

“Did you find the booklet...” <sup>a</sup>	Traditional brochure (n=62), mean (SD)	Photo story brochure (n=64), mean (SD)	P value
Hard to understand?	2.03 (1.25)	1.52 (0.94)	.01
Interesting?	3.56 (1.22)	3.63 (1.23)	.78
Monotonous?	2.66 (1.23)	2.48 (1.16)	.41
Boring?	2.34 (1.21)	2.28 (1.20)	.79
Enjoyable?	2.42 (1.22)	2.56 (1.15)	.50
Informative?	3.37 (1.39)	3.86 (1.13)	.03
Too long?	2.13 (1.34)	2.23 (1.24)	.65

<sup>a</sup>Answers were given on a five-point rating scale with 1=no, not at all; 2=rather not; 3=neither; 4=yes to some extent; 5=yes, completely.



**Table 3.** Means and standard deviations of the evaluations between paper (conditions 1 and 3) and tablet (conditions 2 and 4) formats (N=126).

“Did you find the booklet...” <sup>a</sup>	Paper format (n=66), mean (SD)	Tablet format (n=60), mean (SD)	P value
Hard to understand?	1.77 (1.12)	1.77 (1.16)	.98
Interesting?	3.68 (1.33)	3.50 (1.10)	.41
Monotonous?	2.27 (1.18)	2.90 (1.12)	.003
Boring?	2.05 (1.18)	2.60 (1.17)	.009
Enjoyable?	2.56 (1.31)	2.42 (1.03)	.49
Informative?	3.77 (1.35)	3.45 (1.20)	.16
Too long?	1.94 (1.24)	2.45 (1.29)	.03

<sup>a</sup>Answers were given on a five-point rating scale with 1=no, not at all, 2=rather not, 3=neither; 4=yes to some extent, 5=yes, completely.

### Traditional Brochure Versus Photo Story in Paper and Tablet Formats

There were no statistically significant group differences among the conditions in the evaluation variables ( $F_{21,334}=1.34$ ,  $P=.15$ , Wilk's  $\lambda=0.79$ , partial  $\eta^2=.075$ ). Nonetheless, the results showed significant differences in the variables of the evaluation item that assessed the understanding of the condition of brochure and format ( $F_{3,122}=2.91$ ,  $P=.04$ , partial  $\eta^2=.067$ ), the item that assessed whether the condition of brochure and format was monotonous ( $F_{3,122}=3.51$ ,  $P=.02$ , partial  $\eta^2=.079$ ), and the item that assessed whether the condition of brochure and format was boring ( $F_{3,122}=2.90$ ,  $P=.04$ , partial  $\eta^2=.067$ ).

In addition, polynomial contrasts revealed that there was a significant cubic trend for the item of evaluation that assessed whether the condition of brochure and format was informative ( $F_{1,122}=6.72$ ,  $P=.01$ , partial  $\eta^2=.055$ ) and a significant linear trend for the item of evaluation that assessed whether the condition of brochure and format was too long ( $F_{1,122}=5.00$ ,  $P=.03$ , partial  $\eta^2=.048$ ; see Table 4).

When testing for differences among the four conditions, a traditional brochure with a tablet (condition 2) was perceived significantly less positively than a photo story on a tablet (condition 4), as it was harder to understand. Moreover, the traditional brochure shown on paper (condition 1) was also perceived as being less monotonous, less boring, and less lengthy to read in comparison to the traditional brochure with a tablet (condition 2). The traditional brochure with a tablet (condition 2) was also perceived as being significantly more monotonous and less informative than the photo story shown on paper (condition 3).

### Self-Efficacy, Behavioral Intentions, and the Underlying Mechanisms

There was no statistically significant difference in self-efficacy, behavioral intentions, self-referencing, identification and transportation based on the four different conditions ( $F_{15,326}=1.18$ ,  $P=.28$ , Wilk's  $\lambda=0.86$ , partial  $\eta^2=.048$ ). However, the findings showed a significant difference among groups ( $F_{3,122}=3.44$ ,  $P=.02$ , partial  $\eta^2=.078$ ) in that the participants deliberately considered that the contents could be related to their own experiences.

**Table 4.** Means and standard deviations of the evaluations of the traditional brochure and photo story in paper and tablet formats in the study (N=126).

“Did you find the booklet...”	Traditional, mean (SD)		Photo story, mean (SD)		P value <sup>a</sup>	Multiple comparisons <sup>b</sup> (conditions)
	Paper (n=32)	Tablet (n=30)	Paper (n=34)	Tablet (n=30)		
Hard to understand?	1.91 (1.17)	2.17 (1.34)	1.65 (1.07)	1.37 (0.77)	.02 <sup>c</sup>	2>4
Interesting?	3.69 (1.36)	3.43 (1.07)	3.68 (1.32)	3.57 (1.14)	.54	— <sup>d</sup>
Monotonous?	2.28 (1.25)	3.07 (1.08)	2.26 (1.14)	2.73 (1.14)	.02	2>1&3
Boring?	1.94 (1.11)	2.77 (1.19)	2.15 (1.26)	2.43 (1.14)	.03	2>1
Enjoyable?	2.47 (1.37)	2.37 (1.07)	2.65 (1.28)	2.47 (1.01)	.77	—
Informative?	3.59 (1.54)	3.13 (1.20)	3.94 (1.13)	3.77 (1.14)	.01 <sup>c</sup>	3>2
Too long?	1.78 (1.26)	2.50 (1.33)	2.09 (1.22)	2.40 (1.28)	.03	2>1

<sup>a</sup>Statistically significant linear trends based on polynomial contrast.

<sup>b</sup>Only significant multiple comparisons are displayed ( $P<.05$ ).

<sup>c</sup>Statistically significant cubic trend. Otherwise, statistically significant linear trend.

<sup>d</sup>Not significant.

**Table 5.** Means and standard deviations of self-efficacy, behavioral intention, self-referencing, identification, and transportation across four conditions.

Item	Traditional, mean (SD)		Photo story, mean (SD)		Total, mean (SD)
	Paper (n=32)	Tablet (n=30)	Paper (n=34)	Tablet (n=30)	
Self-efficacy	3.98 (0.68)	3.90 (0.75)	3.97 (0.76)	3.88 (0.85)	3.94 (0.75)
Behavioral intention	4.34 (0.53)	4.14 (0.65)	4.32 (0.62)	4.21 (0.75)	4.26 (0.64)
Self-referencing <sup>a</sup>	3.63 (1.01)	2.90 (1.12)	3.05 (1.14)	2.84 (1.05)	3.11 (1.11)
Identification	3.56 (0.72)	3.31 (0.53)	3.61 (0.93)	3.49 (0.85)	3.50 (0.78)
Transportation	2.84 (0.78)	2.67 (0.72)	2.68 (0.76)	2.70 (0.58)	2.72 (0.71)

<sup>a</sup>Significant difference with  $P=.02$ .

Self-referencing consisted of three items measuring whether the display format of the brochure encouraged participants to think or recall their own experience and reflect on their own conversation with their doctors [22]. In multiple comparisons, the traditional brochure in paper format was significantly the best condition for self-referencing compared to both the traditional brochure and photo story in tablet intervention (see Table 5). It was particularly significant for the item “Did the brochure make you think about yourself and about the conversations with your doctor?” ( $F_{3,122}=6.096$ ,  $P=.001$ , partial  $\eta^2=.130$ ).

For self-efficacy, intention, identification, and transportation, health literacy aspects of the interventions were examined and the results revealed no significant effects of the conditions ( $F_{3,122}=0.14$ ,  $P=.94$ , partial  $\eta^2=.003$ ;  $F_{3,122}=0.68$ ,  $P=.57$ , partial  $\eta^2=.016$ ;  $F_{3,122}=0.90$ ,  $P=.44$ , partial  $\eta^2=.022$ , and  $F_{3,122}=0.43$ ,  $P=.73$ , partial  $\eta^2=.010$ , respectively).

## Discussion

### Summary of Main Findings

This study aimed to compare the effectiveness of a photo story intervention presented in different conditions in comparison to a traditional brochure. An evaluation of different forms of patient interventions with 126 older adults in Germany revealed that the photo story intervention was more positively evaluated in comparison to traditional brochures: participants claimed that a photo story is easier to understand and more informative than a traditional brochure. Furthermore, this study found that older adults preferred the paper format to the tablet format due to paper being less monotonous, less boring, and the length of the contents being judged as appropriate.

Regarding older adults' communicational self-efficacy and behavioral intentions, self-referencing, identification, and transportation, only self-referencing showed significant differences among the different conditions. The participants in the traditional brochure in paper format group (condition 1) scored higher on self-referencing than those in the tablet format for both types of brochure (conditions 2 and 4).

The results that emerged in this study are consistent with the literature that a photo story intervention is an effective communication tool for health information [3,10]. The photo story showed its potential in health behavior application as an

encouraging method for individuals to learn certain behaviors by observing a model (in line with Bandura's social cognitive theory [4]). This effect appeared stronger in the photo story version than in the traditional version. As suggested in previous studies [3,10], the narrative format is not only an uncomplicated and less effortful way to deliver messages through words, but also potentially offers opportunities for self-awareness, reassurance, empathy, and a safe and neutral way to explore the impact of illness in family relationships. This could also be relevant to doctor-patient communication, particularly in primary care consultations when discussing illness, prevention, awareness, and self-care.

Regarding the use of tablets among older adults regardless of the types of brochure, this study showed that participants preferred a paper format, as they found reading a brochure on tablets to be more monotonous, boring, and too lengthy. The results of this study did not corroborate the findings of previous studies [11,24], in which older adults reported more positive than negative attitudes about the technologies they used to obtain health information and the research consent process. Our findings highlight the concern of the potential barriers and challenges older adults face regarding rapid changes in information technology. This is important to keep in mind when translating previous interventions into versions that are meant to be delivered via information technology. Although technology use might generally be considered more effective, this may not be the case for older adults. There is a wide range of explanations for the challenges of using information technology among older adults. For example, lack of instructions and support, lack of clarity in giving instructions and support, lack of knowledge and self-confidence in their personal capabilities to use a tablet, health-related barriers, and high cost of technological equipment [25]. The usage of information technology is also highly influenced by gender, age, (health) literacy, health condition, and educational background [24]. However, solutions are possible. For example, a previous study found that co-creation of interventions using information technology with older adults was appealing and understandable [9]. Such a co-creation approach with interventions like those in this study may help to alleviate some of the challenges faced by the target group.

Considering all conditions in the study, the traditional brochure in tablet format appeared to be the least effective. This can be explained by the preference for the photo story over the traditional brochure, together with the challenges of technology

use. Unless the intervention of a photo story was used in tablet format, participants rated reading the traditional brochure on a tablet as hard to understand. This is in line with a previous study, in which older adults in a focus group admitted tablet technology was too complicated and expressed a preference for simpler devices [25]. On the other hand, the participants from the same study expressed the likelihood of using a tablet in the future, and they enjoyed the tablet experience [25]. Therefore, the use of a photo story in health interventions, and the use of technology, are worth investigating further in the future.

Although many positive aspects of technology use have been identified in the literature, the negative aspects of technology use among older adults are also highly relevant. It is especially important to increase the understanding of older adults' points of view and attitudes toward the use of technology, which is essential to help with introducing technology to this target group and maximizing the potential of technology, particularly to facilitate effective communication in primary care consultations [25]. A previous study showed that older adults recognized that information technology can be discouraging in some ways; therefore, it is essential to have appropriate skills or measures to tackle the difficulties associated with technology use [26].

Although this study did not find significant effects on this photo story intervention regarding participants' health literacy, communicational self-efficacy, or behavioral intention, it found significant differences among the different conditions regarding self-referencing. This particularly refers to the traditional brochure in paper format (condition 1). This outcome is consistent with findings of a previous study by de Graaf [27]. Older adults might have felt more comfortable with the classic paper format than the electronic device, making it easier to encourage them to think about their personal experiences and conversations with their doctors [27]. There were nonsignificant outcomes for both identification and transportation. For identification, it was more challenging for the participants in this study because of their mean frequencies of doctor visits: most were between every 3 and 6 months, which is perhaps not frequent enough to provoke recognition of the characters as similar or build a social relationship [18]. Most of the participants reported few difficulties in communication with their doctors and few difficulties with transportation, which refers to when participants focused on the events happening in the stories. With fewer relevancies to the story, the participants were less likely to be transported [23].

### Strengths and Limitations

To our knowledge, this study is one of the few studies that investigated the effectiveness of a photo story intervention and the use of tablet technology. The materials were designed and constructed based on the outcomes of pilot studies and focus group discussions, as well as previous studies [19-21]. Conducting a pilot study before the main data collection and analyses ensured that the content was both comprehensible and relevant to the participants, and the reliability and validity of the results was strengthened. One further strength was the randomized assignment of participants to minimize the effect of confounding variables on the systematic variation, thus reducing errors due to measurement or other preventable

influences on variation in addition to that of the independent variable [28]. The comparisons of traditional brochures displayed in paper and tablet format were useful in providing additional insights into the health literacy levels of older adults and intervention design for effective communication, especially in primary care consultation. Moreover, the reported outcomes are outlined with the intention to provide an overview of the general trends of the variables among this specific group of participants: older adults aged 50 years and older in clinical settings. This is especially meaningful because this set of variables, to our knowledge, has not yet been widely examined in the literature.

Despite the study having a reasonable sample size, more participants for the different conditions would have been preferable to obtain better power to detect statistical significance [29]. In future studies, in addition to larger sample sizes, longer follow-up measurement points should also be aimed for to enable better intervention checks and analyses of changes over time, as well as collection of more reliable data (eg, objective data from tracking devices). In addition, information technology itself can bring several disadvantages, such as the technical requirements of the users in terms of the need to be technologically health literate, able to read and write, and open to using information technologies and innovations. In addition, user fear of fraud and misuse of their data should be considered. Moreover, devices need to be available and well-functioning, which can be an obstacle for individuals without proper support systems. Another limitation is that the operational definitions of the main variables in the questionnaires are unclear, such as the items of self-efficacy and behavioral intention. Therefore, it is strongly recommended to improve the comprehensiveness of the questionnaire in future studies. Finally, these findings might be specific for the current generation of older adults in Germany and should be investigated with other target groups in different locations.

### Conclusion

In conclusion, when different types of brochure (traditional brochure vs photo story) and display formats (paper vs tablet format) were examined, the photo story and paper formats were found to be effective among older adults aged 50 years and older. Overall, a traditional brochure on a tablet appeared to be the least effective, with higher preference for the photo story instead.

The findings of this study indicate that the use of electronic devices is less helpful for older adults. Several aspects should be taken into consideration in future studies; for example, health literacy, educational background, gender, previous experience with technology, behavioral outcomes, and generational differences to gain further insight into potential influencers [11]. The rise of information technology brings advantages since more people can be addressed and attracted in various fields, such as health care. Different target groups can also be addressed more effectively by tailoring the intervention to their needs.

Information technology can also, however, bring several disadvantages, such as the need to be technologically health literate, able to read and write, and open to using modern technologies. This study highlighted the relevance of some of

these aspects with older adults in Germany. These factors should be considered when integrating information/electronic technology into wider situations and populations, globally and individually.

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## Authors' Contributions

SLT and SL contributed to the conception and design of the study. SLT performed data collection and performed the statistical analyses. SL provided guidance to the data collection and presentation of results. SLT, AM, and SL were involved in the interpretation of the data and in drafting and revising the manuscript. All authors read and approved the final manuscript. We would also like to thank Christian Preißner (Jacobs University Bremen) for extensively editing and proofreading this manuscript.

## Conflicts of Interest

None declared.

Multimedia Appendix 1

CONSORT - EHEALTH checklist (V 1.6.1).

[[PDF File \(Adobe PDF File\), 305KB - aging\\_v1i2e12145\\_app1.pdf](#)]

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## Abbreviations

**AURA:** Ask, Understand, Remember Assessment

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Original Paper

# Commercially Available Mobile Apps for Caregivers of People With Alzheimer Disease or Other Related Dementias: Systematic Search

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## Abstract

**Background:** More than 15 million Americans provide unpaid care for persons with Alzheimer disease or other related dementias (ADRD). While there is good evidence to suggest that caregivers benefit from psychosocial interventions, these have primarily been delivered via face-to-face individual or group format. Alternatively, offering electronic health (eHealth) interventions may assist caregivers in providing quality care while remaining in good health. Research to date has generated little knowledge about what app features support ADRD caregivers' behavioral changes and how developers might optimize features over the long term.

**Objective:** There is an evident knowledge gap in the current landscape of commercially available apps, their integration of behavioral techniques, content focus, and compliance with usability recommendations. This paper systematically reviews and inventories the apps caregivers might typically be exposed to and determines the support integrated into the apps and their functionality for older adults.

**Methods:** The search strategy was designed to mimic typical Web-based health information-seeking behavior for adults. Apps were included based on their explicit focus on ADRD caregiver knowledge and skill improvement. Two coders with expertise in behavioral interventions and eHealth pilot-tested the data extraction. One coder retained app characteristics and design features. Techniques used to promote change were determined, and 2 questions from the Mobile App Rating Scale were used to assess the app credibility and evidence base. Content topics were evaluated using a thematic framing technique, and each app was assessed using a usability heuristic checklist.

**Results:** The search results generated 18 unique apps that met the inclusion criteria. Some apps were unavailable, and only 8 unique apps were reviewed. Of the 8, 7 (88%) apps did not state which scientific orientation was followed to develop their content. None of the apps made clinical claims of improving caregivers' and care recipients' overall health. All apps relied on textual information to disseminate their contents. None of the apps was trialed and evidence based. Apps included on average 7 out of 10 behavioral change techniques, 5 out of 10 C.A.R.E. (Caregivers, Aspirations, Realities, and Expectations) features, and 10 out of 18 features on the usability heuristics checklist.

**Conclusions:** Our findings suggest that caregivers are likely to discover apps that are not actually accessible and have low or no evidence base. Apps were found to be largely static, text-based informational resources, and few supported behaviors needed to maintain caregivers' health. While apps may be providing a high volume of information, caregivers must still navigate what

resources they need with limited guidance. Finally, the commercial marketplace is addressing some of the major usability elements, but many design elements are not addressed.

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## KEYWORDS

alzheimer and other related dementias; apps; caregivers; eHealth; mobile phone

## Introduction

### Background Rationale

More than 15 million Americans provide unpaid care for persons who have reduced abilities due to Alzheimer disease or other related dementias (ADRD) [1], ranging from activities of daily living, personal care needs, shopping, and transportation. It is estimated that the 18.1 billion hours of care provided by family members or others represents a contribution of US \$221.3 billion (in 2015) in unpaid support [2]. ADRD caregivers report substantial financial, emotional, and physical difficulties caring for another person [3]. Reportedly, 59% of these caregivers report that the emotional stress of caregiving is high or very high [4]. Approximately 40% report depressive symptoms, compared with 5%-17% of similar noncaregivers [5].

To help alleviate the burden associated with caregiving, health professionals, researchers, and other agencies recommend that ADRD caregivers seek support and assistance from family and friends and organize support groups [6]. While there is good evidence to suggest that caregivers benefit from psychosocial interventions, these have primarily been delivered via face-to-face individual or group format. Electronic health (eHealth) is of growing interest in expanding convenient access to information and support services. Offering eHealth to caregivers may assist them in providing quality care while remaining in good health [7].

A 2018 systematic review of eHealth interventions for family carers of people with long-term illness found that 46% (33/72) of the included studies involved ADRD caregivers [8]. The reviewer concluded that eHealth interventions for this population are “becoming more popular, and are generally perceived as acceptable, desirable and helpful” [8]. Most of the interventions in their review involved a Web-based platform with electronic or phone-based coaching support. There is evidence that caregivers may be open to lower-intensity mobile apps (mobile health) as an intervention delivery method. In 2016, 40% of caregivers reported using an app to help them manage their caregiving tasks. Caregivers aged 18-24 years are 12% of the caregiver population and account for half of the app users [9]. While older adults are slower to adopt new technologies than younger adults, they are open to using technologies that appear to have value, for example, in maintaining their quality of life [10,11].

The academic literature around mobile health for caregivers is growing and evolving somewhat analogously to the proliferation of mobile apps available in the commercial marketplace. While systematic reviews provide a snapshot of the evidence base, they do not capture the range of apps ADRD caregivers can access and download. Studies have shown that 80% of adult

app downloaders rely on a rather simple “take the first” decision-making heuristic. Once they have an idea of the type of app they “need,” they pick the first one that has been well rated or ranked [12]. This rating of “top apps” is often presented through unfiltered and nonmoderated patient experience blogs, chat rooms, or testimonials from friends and family members. While the value of peer-approved resources is important, there has been concern that if unmoderated, they may expose caregivers to aggressive marketing or even unintentionally promote health behaviors that are not evidence informed [13].

Generally speaking, health apps contain low levels of behavioral change support or are not adequately designed for long-term behavioral changes [14,15]. These apps function largely as mobile information resources and do little to prompt self-care actions, lifestyle, and communication behaviors needed to successfully navigate caregiving over the long term. The complex process of family caregiving may last >20 years, suggesting that a variety of caregiver interventions are needed to support the care recipient and avoid a deleterious and compounding impact on caregivers’ health [16]. Research to date has generated little knowledge about what app features support ADRD caregivers’ behavioral changes and how developers might optimize features for adaptive and flexible behavioral skills over the long term.

Recognition of caregivers evolving needs is also underscored in recent research showing older adults have specific usability needs that influence interaction with mobile apps, but the scarce implementation of usability design guidelines for older adults has been reported [17]. Generally, the current literature suggests that although older adults are open to using technology, there may be age-related (eg, cognitive decline) as well as technology-related (eg, interface usability), barriers. As 19% of caregivers are >65 years of age [18], apps in development now must be designed with these barriers in mind. Organizations responsible for setting usability standards for eHealth tools are beginning to recommend changes to design features to make them more accessible to older adults [19], such as larger font size, no use of scrolling, use of tactile feedback (vibration), low-frequency spectrum sounds, lengthening sound signals, avoiding monochromatic color schemes, etc. Validated usability heuristics tailored for technologies involving older adults are lacking, so effort must be taken to testing and refining emerging ways of evaluating mobile apps for ADRD caregivers [20-22].

### Research Aims and Questions

These converging issues and trends highlight a knowledge gap in the current landscape of commercially available apps, their integration of behavioral techniques, content focus, and compliance with usability recommendations. A minimum starting point for improving the design of apps for this

population is to systematically review and inventory the apps caregivers might typically be exposed to, not just those studied and reported on in the academic literature. The review is guided by the following questions:

1. What are the main features and functionality of apps for caregivers of people with dementia?
2. What types of behavioral techniques are integrated into these apps?
3. What is the evidence base of apps caregivers are likely to find out about on the Web?
4. Which caregiver needs are addressed in these apps?
5. Do the apps comply with recommended usability features for older adults?

## Methods

### Search Strategy

The search strategy was designed to mimic typical Web-based health information-seeking behavior for adults as follows: (1) we chose Google, the most used search engine by adults for health information [23]; (2) we used 5 keywords per search without applying search modifiers typically used in academic reviews (eg, Boolean operators like “OR” and “AND”) as these are not commonly used by the public; (3) we conservatively reviewed the first 2 pages of search results (40 results per search) as research suggests 91% of searchers do not go past the first page of results [24]; and (4) for each search result, we limited deep navigation and only identified apps that were mentioned within 5 clicks (submenus, secondary pages, and drop-down menus) as typical users normally only proceed through 3 layers before leaving a site [25]. Overall, 5 unique searches were conducted involving combinations of keywords for the population of interest (“caregiver,” “caretaker,” “carer,” and “family”); health condition (“dementia” and “Alzheimer’s”); and technology modality (“app” and “mobile phone”). Searchers signed out of their personal Google account before conducting the search. To reduce the likelihood of locating apps that are no longer available, we filtered our search to content generated within the last 12 months. As search engine results are updated and optimized routinely, searches were conducted on the same day. Additionally, the searches were performed on a designated device and the same network to obtain consistent search results and avoid deviations by personalized search results. Searches were conducted in April 2018.

### Inclusion Criteria

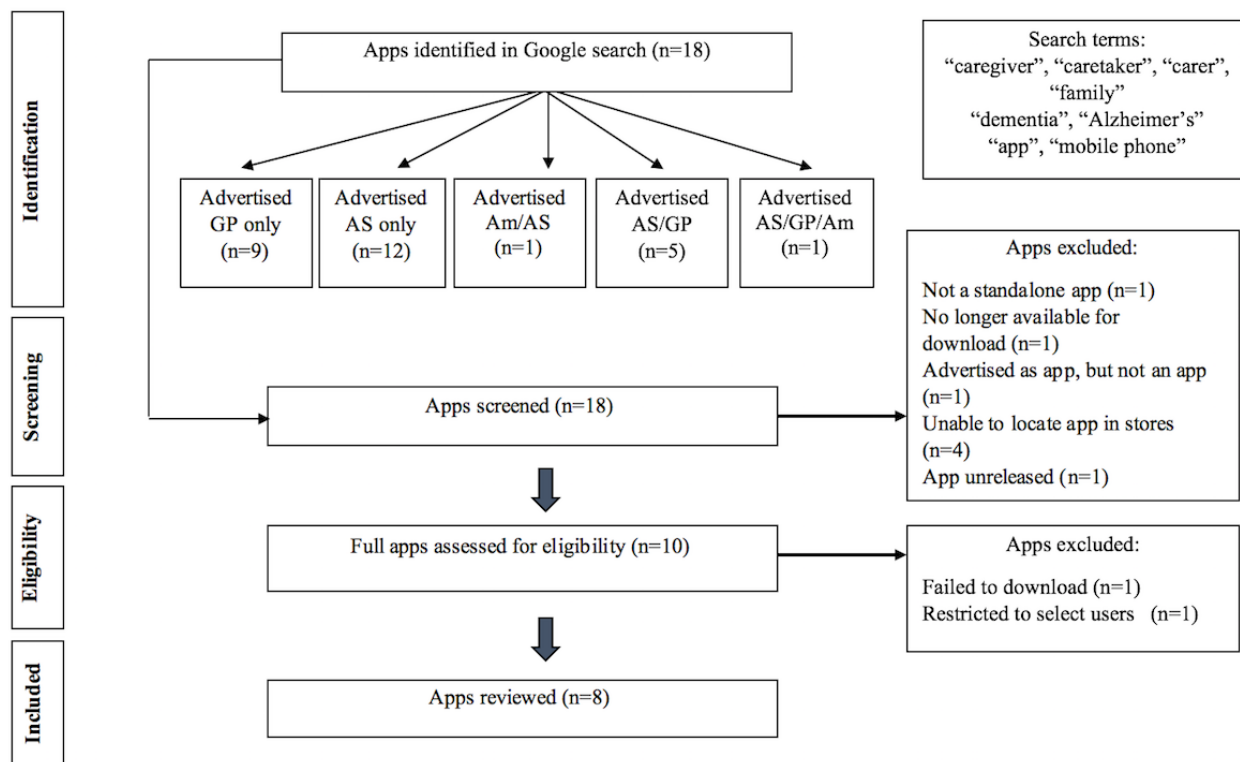
The following criteria were applied for app inclusion: (1) apps focused explicitly on improving caregivers’ knowledge or skills and (2) apps available in English. We did not exclude apps based on price, operating system (iOS, Android, Amazon, etc); popularity; or research evidence base. We excluded apps that (1) were not applicable to caregivers of people with dementia (eg, specifically for caregivers of people with cancer); apps where the target user was the care recipient and not the caregiver (eg, memory skills training app); apps where the caregiver was

only tracking a single component of a care recipients’ routine (ie, medication reminder); apps that were not standalone (eg, multicomponent training program with a proprietary companion app); app that were related to generic stress, anxiety, or depression (ie, not tailored to caregivers); and apps that were no longer available for download (as of April 2018). The selection process for apps included in this study is summarized in Figure 1.

### Data Extraction

App store descriptions were scanned first to extract as much information as possible. One author (LMFdS) then downloaded each app and used it for approximately 2 days to familiarize with the features and functionality. If the app was available in multiple stores, we downloaded the one with the most recent update. Each app was navigated from the presentation screen to each menu component. The data extraction form was pilot-tested independently by 2 coders who have expertise in behavioral interventions and eHealth design (LMFdS and EK). Disagreement and discrepancies were resolved through discussion and revision of coding instructions. Data extraction was undertaken by a coder (LMFdS) for the remainder of apps with concerns and issues discussed and resolved through collaborative consensus.

For descriptive purposes, *app characteristics*, including name, identification number (ID), version, producer, price, operating system, privacy policy statement, number of downloads, and year of the last update, were retained. We extracted information on *design features*, including the use of multimedia; social interaction features; feedback and reminders; use of a persona, guide, or navigator; and instructional design elements (ie, timing, sequence, and structure of information). The presence or absence of *techniques used to promote change* was categorized using the Theoretical Domains Framework (TDF). TDF was derived from a synthesis of 33 psychological theories and 128 key theoretical constructs relevant for behavioral change [26]. It is widely used in behavioral health-related implementation and intervention research. In addition to behavioral change techniques (BCTs), we also recorded if the app endorsed a particular therapeutic (eg, cognitive behavioral therapy, behavioral activation) or theoretical approach. Two questions from the Mobile App Rating Scale [27] were used to assess app *credibility* and *evidence base*. To assess the *content topics* that each app addressed, we used the 10 C.A.R.E. Tool domains as a thematic organizing framework [28]. The C.A.R.E. Tool was developed with Health Canada as a validated psychosocial assessment tool for caregivers needs [29]. Finally, each app was assessed using a modified mobile app usability heuristic checklist for older adults proposed by Silva et al [30]. The heuristic is a composite of general and older adult-specific design recommendations and contains 18 selected items to analyze if each app considers age-related issues regarding cognition, content, dexterity, navigation, perception, and visual design. This guideline-based approach of usability testing is in accordance with the proposals of Nielsen [31].

**Figure 1.** Flowchart of the selection process for apps included in the review. GP: Google Play; AS: Apple Store; Am: Advertised Amazon.

## Results

### Principal Results

A total of 400 Google search results (10 searches x 40 results per search) returned a variety of results, including blog posts, app store advertisements, news articles, YouTube videos, and organizational websites. Close reading of these results generated a list of 18 unique app names that met the inclusion criteria. We noted 4 apps (ie, Elder411; Caregivers in the community, Small circles, and Silverline) in the search results but could not locate these in iTunes, Google Play, or Amazon apps. Several apps were referenced or cited multiple times across different search sites. A number of apps were advertised as apps for caregivers of people with dementia but were either a social network or an app to pay for health care and well-being services (eg, Huddol and WEMA Life). One app (eg, eCare) was restricted to select users only and other failed to be downloaded (eg, CaringBridge). In total, 8 unique apps were included in this review.

### General Characteristics of the Selected Apps

Of the 8 apps fully reviewed, 2 were paid. The average price of paid apps was Can \$2.49 (before tax). The majority of apps (n=5) stated their privacy policy though it was unclear how clients' data are shared with third parties. In total, 2 apps did not report a privacy statement and 1 stated that clients' information is not shared with third parties. Moreover, 3 apps were updated in 2018, 3 in 2016, and 2 in 2015. All apps were available for download on a tablet. Notably, 1 app is developed by a Canadian organization and has its content available in English and French. A total of 6 apps targeted caregivers of people with Alzheimer and other related dementias, while 2

were generic to all caregivers. Table 1 summarizes general information of the reviewed apps.

### Main Features and Functionality of the Selected Apps

#### Content and Educational Features

In total, 7 apps (7/8, 88%) did not state which scientific orientation was followed to develop their content and 1 (1/8, 13%) app reported using "therapeutic reasoning" to recommend care strategies to caregivers. None of the apps made clinical claims of improving caregivers' and care recipients' emotional, mental, and physical health. Half of apps (n=4) presented content tailored for both the person with ADRD and caregivers, 2 focused on care strategies for the person with ADRD, 1 targeted the level of care to be provided to the person with ADRD, and 1 aimed to help caregivers to organize and share multiple care tasks (eg, send reminders of medication time, take the person with ADRD to a doctor appointment or stroll, and buy groceries) with a network of care supporters.

All apps relied on textual information to disseminate their content and allowed clients to select the content to be navigated; 4 apps included hyperlinks to organizations' websites (eg, Alzheimer's Association, American Association of Retired Persons, Mount Sinai Hospital/Reitman Centre, Home Instead Senior Care); 1 included 1-2-minute videos (ie, videos featured a professional caregiver assisting seniors with ADRD in a nursing home); 1 included audios; and 1 had animations. Only 1 app (Dementia Advisor) included an avatar, that is, a photo of the psychiatrist who had sanctioned the content of the app. Overall, 3 apps (3/8, 38%) drew on case scenarios and testimonials to build caregivers' skills on how to deal with a person with ADRD. Notably, 7 apps did not recommend the timing of app use to caregivers (e.g. daily, weekly, or longer);



1 recommended daily access. Most apps (n=6) did not allow progress tracking, 1 used charts to demonstrate client's progress, and 1 used textual feedback.

### Social Media Features

Overall, 5 apps allowed the sharing of experiences in social media (e.g. closed app communities, Facebook groups, and Twitter); 1 had a discussion forum. A total of 3 apps (3/8, 38%) offered live help through helpline and texting and 1 (1/8, 13%) facilitated contact with professional caregivers and shared information with a physician. Moreover, 1 app included feedback messages (eg, automatic messages displayed in the app device) in their features; 3 apps sent reminders to clients inviting them to engage with the app (eg, to include more information about the caregiver's needs, set care tasks, build own network—also called village).

### Credibility and Evidence Base

In total, 4 apps (4/8, 50%) were developed by nongovernment organizations, and 1 of these organizations was granted funding by the Government of Canada's Social Development Partnership Program, Children and Families Component; 3 (3/8, 38%) apps were developed by associations and centers for people with ADRD or retired persons; and 1 (1/8, 13%) was created by a commercial business. None of the apps has been trialed or, at least, has not published peer-reviewed research establishing their evidence base in terms of direct impact on caregiver outcomes.

### Behavioral Change Technique Categories

The average number of change techniques observed per app was 7 out of 14 categories, ranging from 2 (Lotsa Helping Hands) to 12 (Balance: Alzheimer's Caregiver and Dementia Advisor). Detailed distribution of BCTs across the apps is shown in Figure 2. The most frequent change techniques included in the apps were knowledge (n=6), skills (n=6), optimism (n=6), beliefs about consequences (n=6), and environmental context and resources (n=6). In contrast, reinforcement (n=1), goals (n=2), and behavioral regulation (n=2) were found in less frequency.

### C.A.R.E. Features

On average, apps included 5 out of 10 C.A.R.E. features, ranging from 1 (Lotsa Helping Hands) to 9 (Alzheimer's Daily Companion). The most included features were support and coordination (n=8), physical care (n=6), personal health (n=6), planning or crisis (n=6), whereas juggling responsibilities (n=2) and financial costs (n=1) were rarely included in the apps. Distribution of C.A.R.E. features across apps is presented in Figure 3.

### Usability Heuristics for Older Adults

Table 2 presents the distribution of usability heuristics for older adults' features across the reviewed apps. On average, 10 out of 18 features of the modified checklist of usability heuristics for older adults were found in each app.

**Table 1.** General information of the reviewed apps.

App name	App ID number	Advertised	Developer (company name)	Operating system	Downloads (N)	Price (Can \$)	Privacy statement
Alzheimer's Daily Companion	1	Yes, Apple Store	Home Instead Senior Care	iOS and Android	500+	Free	Yes
Balance: Alzheimer's Caregivers	2	Yes, National Alzheimer's Centre, and Apple Store	The Hebrew Home for the Aged	iOS	NR <sup>a</sup>	0.99-1.39	No
Caregiver Buddy	3	Yes, Alzheimer's Association, Apple Store, Google Play, and Amazon	Alzheimer's Association	iOS and Android	NR	Free	Yes
Caregivers Matter <sup>b</sup>	4	Yes, Jewishjournal.org, Apple Store, and Google Play	Greater Lynn Senior Services (GLSS)	iOS	NR	Free	Yes
Caring Village	5	Yes, Caring.com, Google Play, and Apple Store	Caring Village	iOS and Android	1000+	Free	Yes
Dementia Advisor <sup>c</sup>	6	Yes, Reitman Centre, Apple Store, and Google Play	Sinai Health System-Reitman Centre	iOS	NR	Free	Yes
Dementia Caregiver Solutions <sup>d</sup>	7	Yes, American Seniors Housing Association, Apple Store	Lorenzo Gentile	iOS	NR	3.99	No
Lotsa Helping Hands	8	Yes, American Association of Retired Persons, Apple Store, and Google Play	Lotsa Helping Hands	Android, Web-app, and iOS	100+ <sup>e</sup>	Free	Yes

<sup>a</sup>NR: not reported.

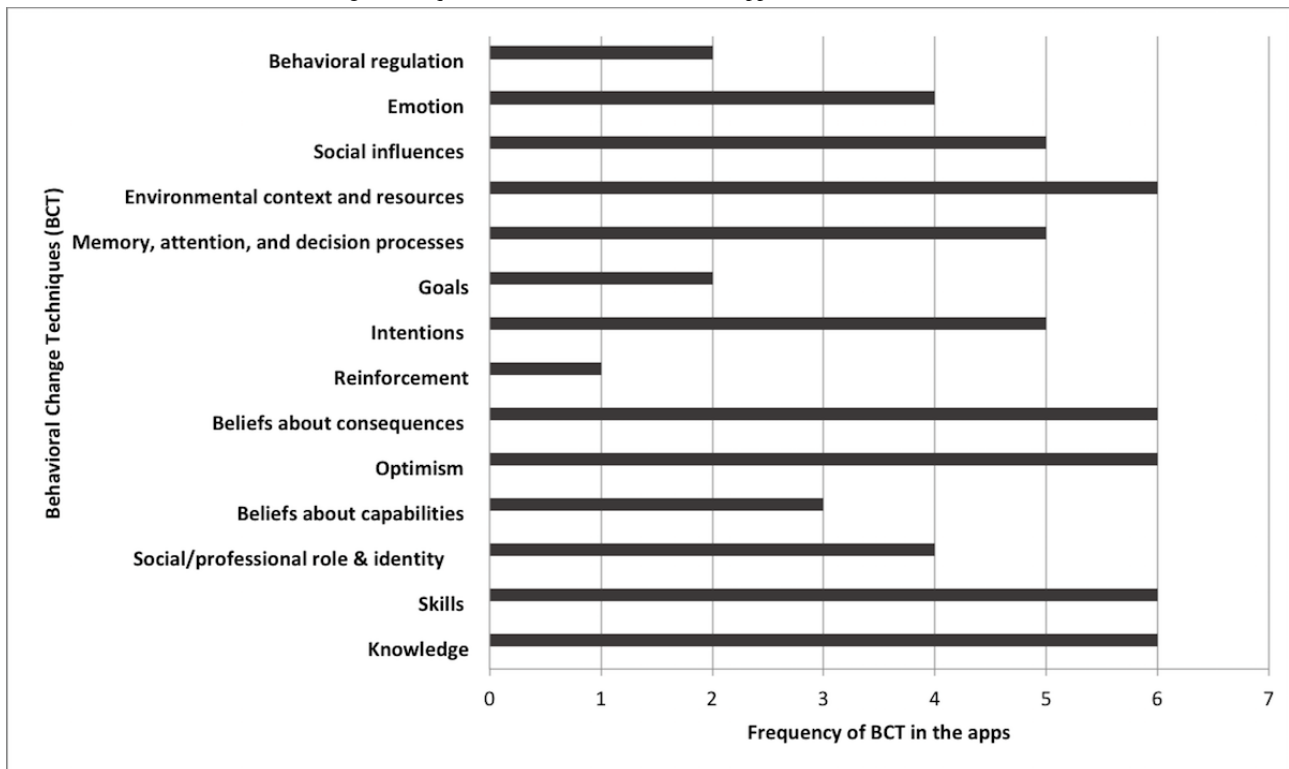
<sup>b</sup>App was advertised in Google Play but not found.

<sup>c</sup>App is also available in French.

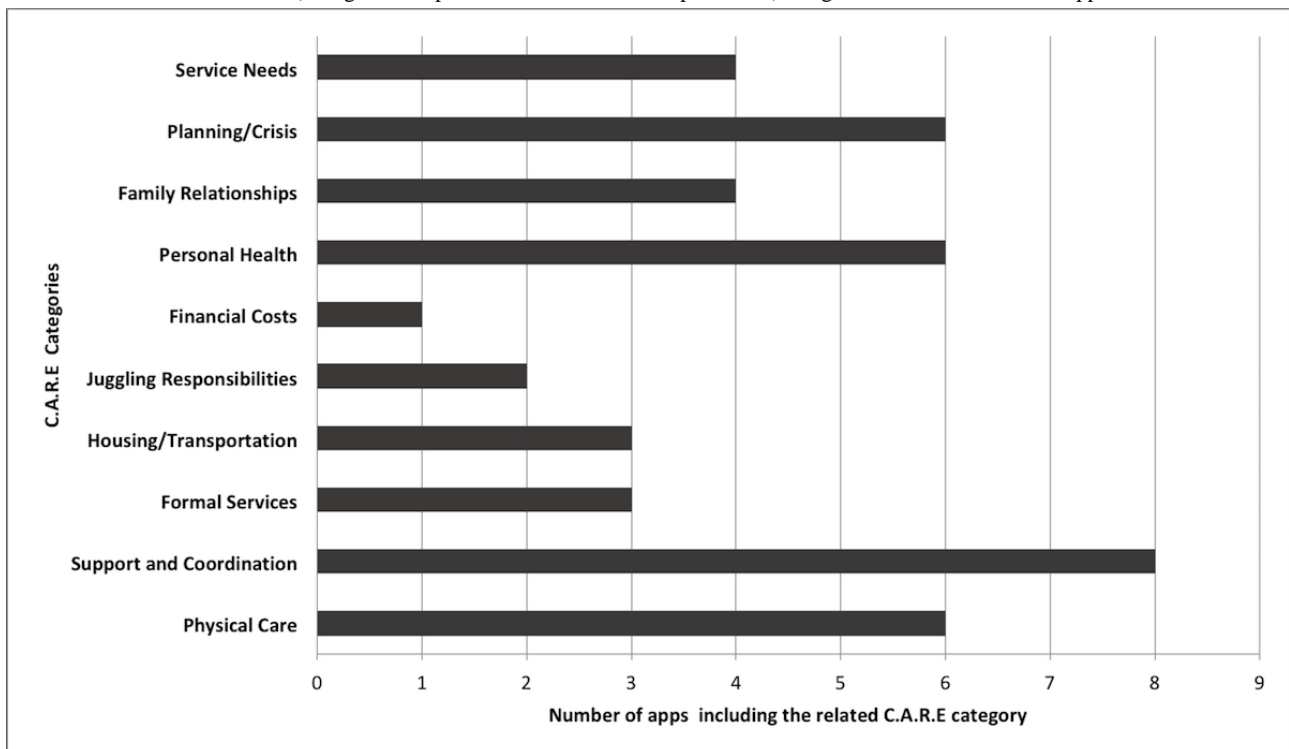
<sup>d</sup>The app is related to moderate-to-severe dementia.

<sup>e</sup>Number of downloads on Google Play.

**Figure 2.** Distribution of behavioral change techniques (BCTs) across the reviewed apps.



**Figure 3.** Distribution of C.A.R.E. (Caregivers, Aspirations, Realities, and Expectations) categories across the reviewed apps.



The most inclusive app (app 1: Alzheimer’s Daily Companion) presented 13 of 18 usability features. A feature, “content written in a language simple, clear, and adequate to older adults,” was observed in all reviewed apps. Usability principles related to cognition, dexterity, navigation, and visual design were consistently addressed across most apps.

A total of 2 apps gave instructions on how to navigate their content, presented the button “back” to facilitate app navigation, and allowed users to enlarge the font size. Only 1 app provided clear feedback when providing error messages. Overall, 3 apps (3/8, 38%) were found to use simple and meaningful icons, to make information accessible through different ways, and to aim at creating an esthetical user interface. No apps provided visual as well as tactile and auditory feedback.

**Table 2.** Distribution of usability heuristics for older adults features across the reviewed apps.

Feature	App ID number							
	1 <sup>a</sup>	2 <sup>b</sup>	3 <sup>c</sup>	4 <sup>d</sup>	5 <sup>e</sup>	6 <sup>f</sup>	7 <sup>g</sup>	8 <sup>h</sup>
<b>Cognition</b>								
Focus on 1 task at a time instead of requiring the user to actively monitor $\geq 2$ tasks and clearly indicate the name and status of the task at all times.	✓	✓	✓	✓	✓	✓	✓	N/A <sup>i</sup>
Avoid the use of animation and fast-moving objects.	✓	✓	✓	✓	✓	N/A	✓	✓
Aim at creating an esthetical user interface by using pictures and graphics purposefully and adequately to minimize user interface clutter and avoid extraneous details.	N/A	N/A	N/A	✓	✓	✓	N/A	N/A
<b>Content</b>								
Give specific and clear instructions and make help and documentation available. Remember that it is better to prevent an error than to recover from it.	N/A	N/A	N/A	✓	N/A	N/A	N/A	N/A
Provide clear feedback and when presenting error messages make them simple and easy to follow.	N/A	✓	N/A	N/A	N/A	N/A	N/A	N/A
Write in a language that is simple, clear, and adequate to the audience.	✓	✓	✓	✓	✓	✓	✓	✓
<b>Dexterity</b>								
Avoid pull-down menus.	✓	✓	✓	N/A	✓	✓	✓	✓
Avoid the use of scrolling.	✓	N/A	✓	✓	✓	✓	✓	✓
Enlarge the size of user interface elements in general; targets should be, at least, 14 mm <sup>2</sup> .	N/A	✓	N/A	N/A	N/A	✓	N/A	N/A
<b>Navigation</b>								
Keep the user interface navigation structure narrow, simple, and straightforward.	✓	✓	✓	✓	✓	✓	✓	N/A
Make sure that the “Back” button behaves predictably.	✓	N/A	N/A	N/A	N/A	✓	N/A	N/A
<b>Perception</b>								
Provide not only visual but also tactile and auditory feedback.	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
Make information accessible through different modalities.	✓	N/A	✓	N/A	N/A	✓	N/A	N/A
<b>Visual Design</b>								
Use high-contrast color combinations of font and graphics and background to ensure readability and perceptibility; avoid using blue, green, and yellow in close proximity.	✓	N/A	N/A	✓	✓	✓	✓	✓
Use color conservatively, limiting the maximum number of colors in use to ~4.	✓	N/A	✓	✓	✓	✓	✓	✓
Make links and buttons clearly visible and distinguishable from other user interface elements.	✓	✓	N/A	N/A	✓	✓	✓	N/A
Use user interface elements consistently and adhere to standards and conventions if those exist.	✓	✓	N/A	N/A	N/A	✓	✓	N/A
Use simple and meaningful icons.	✓	✓	N/A	N/A	N/A	✓	N/A	N/A
Total features	13	10	8	9	10	14	10	6

<sup>a</sup>App 1: Alzheimer’s Daily Companion.

<sup>b</sup>App 2: Balance: Alzheimer’s Caregivers.

<sup>c</sup>App 3: Caregiver Buddy.

<sup>d</sup>App 4: Caregivers Matter.

<sup>e</sup>App 5: Caring Village.

<sup>f</sup>App 6: Dementia Advisor.

<sup>g</sup>App 7: Dementia Caregiver Solution.

<sup>h</sup>App 8: Lotsa Helping Hands.

<sup>i</sup>N/A: not applicable.

## Discussion

### Principal Findings

This study aimed to systematically review apps that caregivers of persons with dementia might typically encounter in the commercial marketplace. Our findings suggest that when looking for apps to support them in their role, caregivers are likely to discover apps that are not actually accessible or available in the app store or are linked to specific services or programs they cannot access. For this reason, our review provides only a snapshot of what was available at the time of our search. Even when the app store logo was present on a website, it did not ensure that the app was still available for download. This would likely be frustrating, confusing, and potentially create barriers to future health information seeking. Our review also showed that the evidence base for commercially available apps for this population is low or none at the time of our review. While the app might still be perceived as useful or helpful to caregivers, it is unclear how to manage caregivers' expectations about if and how these apps might help given the lack of rigorous outcome monitoring.

Apps in our review were found to be largely static, text-based informational resources focusing on relaying factual information and providing common-sense tips and ideas for coping. Few of the apps emphasized goal setting, action planning, or self-monitoring, but they did not provide tailored feedback or reinforcement techniques that support lifestyle or behavioral changes needed to maintain their own health. Some of the apps did provide a Web-based community for all users of the app to connect and share, but it is unclear as to the content of these interactions, their perceived utility, or restrictions (eg, geographic location, language, etc) that might limit users' access. Closed groups in which users can share information with a preset list of approved family members or friends were one of the more common design features. Apps employed limited multimedia outside of hyperlinks to additional textual information or websites.

As mainly informational resources, it is not surprising that, overall, apps covered significant breadth of caregiving-related topics within the C.A.R.E. (Caregivers, Aspirations, Realities, and Expectations) Tool domains. While diverse topics were covered, there was no evidence that these apps were able to tailor or personalize the informational needs to specific users, type of dementia, stage of disease, or other caregiving scenarios (eg, coresiding vs living apart). This suggests that while apps may be providing high volume of information, caregivers must still filter, navigate, and adjudicate what resources they need with limited feedback and guidance in navigation aside from key search terms or alphabetized lists of topics.

Finally, this review of usability heuristics suggests that the commercial marketplace is addressing some of the major usability elements (clear, simple language) but that many perceptual and visual design elements are not addressed. Importantly, this is an emerging field with new understandings evolving rapidly about what older adults typically need to support their interaction with mobile apps and how unique

cognitive, motivational, and developmental realities of that population should be incorporated into the design.

### Limitations

Our review has some limitations. Approximating typical search strategies was based on research about how adults access information on the Web. While we conservatively reviewed more search engine results to account for divergent approaches, it is possible that caregivers might employ different or more diverse strategies and may locate or identify different apps than those we captured. Search location algorithms used by Google may have also unintentionally biased results geographically. While an adjudication process with at least 2 authors was used to find consensus on inclusion screening and app data extraction, interrater reliability or kappa was not calculated. TDF is a framework for exploring behavioral change, but we only applied it to the global domains level, which limits the level of specificity that we could speak to. Finally, we did not evaluate the accuracy or evidence base of the information being relayed within the apps—only general information about topics, design features, and usability.

### Future Directions

Our findings point to 4 key areas for innovative research and future intervention development. First, moving beyond informational apps to harnessing new functionality of apps to deliver a much more tailored and personally relevant learning experience is possible. Information is only valuable if caregivers can mobilize it to improve their quality of life. Apps that not only provide information but also help caregivers think about ways to put that information into action may support better self-management. Second, the field of gerontechnology needs to rapidly develop industry guidelines around Web design that is sensitive to the unique, visual, perceptual, cognitive, and motivational attributes of older adults that typically act as caregivers. Best practices in usability should be a priority as one size does not fit all in design for adults. Older adults need their user experience to be better understood by developers and should not be assumed to operate in the same ways as younger adults. Third, prioritizing or weighting of informational needs is an important line of future research. While apps may provide comprehensive information, not all caregivers need all of it at the same time. Learning more about when different informational needs present along the caregiver journey, which needs are more critical or impactful on the quality of life, and how different types of dementia or stage of disease make information more or less relevant is vital. Mapping of caregiver journey typologies could help ensure designers move away from information repositories toward truly personalized “just-in-time” interventions. Finally, this review highlights the importance of co-design for mobile app development. Caregivers of persons with dementia face incredibly complex informational needs. True design partnerships for mobile apps with this population should be built holistically—taking into account not just what they need but how they want to interact with the app, why and where they find value in different features, and how best to make the apps accessible and available to them.

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## Conflicts of Interest

None declared.

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## Abbreviations

- ADRD:** Alzheimer disease or other related dementias  
**BCT:** behavioral change technique  
**C.A.R.E.:** Caregivers, Aspirations, Realities, and Expectations  
**eHealth:** electronic health  
**TDF:** Theoretical Domains Framework

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Original Paper

# The Impact of the Virtual Cognitive Health Program on the Cognition and Mental Health of Older Adults: Pre-Post 12-Month Pilot Study

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## Abstract

**Background:** Face-to-face multidomain lifestyle interventions have shown to be effective for improving or maintaining cognitive function in older adults at risk for dementia. Remotely delivered interventions could increase access to such solutions but first require evidence to support that these programs can successfully impact health outcomes.

**Objective:** The objective of this study was to evaluate the impact of a remotely delivered multidomain lifestyle intervention, the virtual cognitive health (VC Health) program, on the cognitive function and mental health of older adults with subjective cognitive decline (SCD).

**Methods:** A 52-week, prospective, single-arm, pre-post, remote nationwide clinical trial was conducted to measure the change in cognitive function, depression, and anxiety levels for older adults at risk of developing dementia who participated in the VC Health program. A Web-based study platform was used to screen, consent, and enroll participants across the United States. Participants completed the Repeatable Battery for the Assessment of Neuropsychological Status (RBANS) test and Web-based assessments (which included the Patient Health Questionnaire [PHQ-9] and Generalized Anxiety Disorder [GAD-7] surveys) at baseline and weeks 12, 24, and 52; all data were collected remotely. Changes in RBANS, PHQ-9, and GAD-7 were assessed using 2-tailed paired *t* tests and nonparametric signed-rank tests.

**Results:** Participants (N=82) were, on average, aged 64 years (range 60.0-74.9 years), 74% (61/82) female, 88% (72/82) white, and 67% (55/82) had a college degree or higher. At baseline, participants had a mean and median RBANS Total Index score of 95.9 (SD 11.1) and 95.5 (interquartile range, IQR=13). Participants experienced a mean and median increase of 5.8 (SD 7.4) and 6 (IQR=11) in RBANS Total Index score from baseline to week 52 ( $P<.001$ ). Participants had a mean and median PHQ-9 score of 8.5 (SD 4.9) and 8 (IQR=6) at baseline and experienced a mean and median decrease of 3.8 (SD 4.1) and 4 (IQR=6) units in PHQ-9 score from baseline to week 52 ( $P<.001$ ). At baseline, participants had a mean and median GAD-7 score of 6.2 (SD 4.5) and 5.5 (IQR=6) and experienced a mean and median decrease of 2.9 (SD 4.1) and 2 (IQR=5) units in GAD-7 score from baseline to week 52 ( $P<.001$ ). Participants were engaged and very satisfied with various program components.

**Conclusions:** In this study, older adults with SCD who were at risk for dementia experienced statistically significant improvements in their cognitive function, depression, and anxiety levels. These findings serve as initial evidence for the overall feasibility and effectiveness of the VC Health program to improve or maintain cognitive function in older adults who are experiencing SCD. Further research should be conducted to understand the degree to which the improvements are attributable to specific components of the intervention.

**Trial Registration:** ClinicalTrials.gov NCT02969460; <https://clinicaltrials.gov/ct2/show/NCT02969460> (Archived by WebCite at <http://www.webcitation.org/73XOph9Qm>)

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## KEYWORDS

cognitive impairment; dementia; Alzheimer disease; mental health

## Introduction

### Background

By 2035, the number of individuals older than 65 years in the United States is projected to outnumber those younger than 18 years [1]. With age, many individuals begin to experience cognitive changes that affect memory, learning, language, and judgment, all of which can impact the ability to perform daily tasks [2]. In the early stages of cognitive change, individuals may experience subjective cognitive decline (SCD), in which subjective changes in memory and cognition are perceived but are not associated with clinically measurable abnormalities [3,4]. These individuals are considered at-risk for developing dementia, particularly Alzheimer disease (AD) [5-7]. If cognitive decline continues to worsen, SCD can progress to mild cognitive impairment, an intermediate state between normal cognition and dementia, in which there are clinically observable changes in measures of cognitive function [4-8].

Dementia places a significant burden on the health care system in terms of cost and caregiver hours. With a lifetime cost of care estimated at US \$341,000 per individual, dementia is considered to be one of the world's costliest health conditions [9]. Total health care expenditures for AD and other dementias in 2018 was estimated at US \$277 billion, and this cost is expected to be more than US \$1 trillion by 2050 [9]. In addition, family and other unpaid caregivers provided an estimated 18.4 billion hours of care (valued at over US \$232 billion) to individuals with dementia [9]. Given the high burden of dementia and current lack of efficacious pharmaceutical agents, there is significant value in developing early interventions to help prevent or delay the onset and progression of disease.

Multidomain interventions that target modifiable lifestyle-related risk factors (eg, nutritional intake, physical activity, and cognitive engagement) can be useful prevention tools, as many studies have linked vascular and lifestyle-related risk factors to an increased risk of cognitive impairment and dementia [10-12]. The Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability (FINGER) found that a 2-year multidomain intervention of diet, exercise, vascular risk monitoring, and cognitive training could help at-risk older individuals improve or maintain their cognitive functioning [13,14]. Following the success of the FINGER study, numerous replication studies have been launched globally, including the Singapore Intervention Study to Prevent Cognitive Impairment and Disability, Multimodal Intervention to Delay Dementia and Disability in Rural China, and United States Study to Protect Brain Health Through Lifestyle Intervention to Reduce Risk studies [15-17]. However, many challenges related to access, cost, and other logistical constraints remain for these multidomain programs. In the current format, individuals are

required to visit an office for in-person coaching and assessment, limiting the scalability and reach of the intervention. As new technological developments change the way health care services are delivered, digitally administered lifestyle programs can be an effective and efficient way to help older individuals at risk for developing dementia improve or maintain their cognitive function [18].

### The Virtual Cognitive Health Program

The Virtual Cognitive (VC) Health program, which was modeled after the FINGER study, is a commercially available, multidomain digital lifestyle intervention for the prevention or delay of cognitive impairment in at-risk aging adults. The year-long digital intervention includes exercise and nutritional guidance, cognitive training, social engagement, and personalized health coaching. The VC Health study aimed to understand the feasibility and effectiveness of the VC Health program, specifically examining the long-term impact this program may have on cognitive function and mental health.

## Methods

### Study Overview

The VC Health study was a 52-week, prospective, intention-to-treat (ITT), single-arm, pre-post, remote nationwide clinical trial that aimed to evaluate change in cognitive function and mental health of individuals at-risk for dementia with SCD. A Web-based study platform (Achievement Studies, Evidation Health; San Mateo, CA) was used to screen, consent, and enroll study participants across the United States. The platform was also used to collect study data and monitor completion of study tasks. Participants were able to complete all study procedures from their own homes using a computer with internet access and a webcam. The full details of the study design have been published previously [19], and the study was registered on ClinicalTrials.gov (NCT02969460). The trial was reviewed and approved by the Solutions institutional review board (Little Rock, AR).

### Recruitment and Screening

Various digital platforms (eg, online patient communities, social media, and targeted advertisements) were utilized to recruit study participants. All interested candidates were asked to complete a Web-based screener via the study platform to assess eligibility. Eligible individuals were aged between 60 and 75 years and showed signs of SCD as assessed by scoring  $\geq 1$  on the Subjective Cognitive Decline Questionnaire (SCD-9) [20] and endorsing the 1-item subjective cognitive decline with worry item ("Do you feel like your memory is becoming worse?" Possible responses were "No," "Yes, but this does not worry me," or "Yes, this worries me") [21]. Individuals also needed

to have the ability to make and receive phone calls and text messages; have access to a desktop computer with video conferencing and a reliable internet connection, which were required to access the intervention and complete the study procedures; and be motivated to use a daily coaching program, as assessed by self-reported willingness (on a 5-point scale from extremely willing to not at all willing) to participate in the virtual cognitive training coaching program. Individuals were excluded if they had a significant history of dementia, mental illness, substance abuse, learning disability, or neurologic conditions, had ophthalmologic or visual problems (eg, legal blindness, detached retinas, and occlusive cataracts) that prevented them from viewing a computer screen at a normal distance, were currently participating in a formal cognitive-training coaching program, or were currently pregnant.

### Enrollment and Study Procedures

All eligible participants completed an electronic informed consent form through the Web-based study platform and were asked to complete a Web-based baseline assessment that included questions about demographics, average nightly sleep hours, and weekly diet and exercise habits. Depression and anxiety severity scores from the Patient Health Questionnaire (PHQ-9) and Generalized Anxiety Disorder (GAD-7) survey were also assessed at baseline [22-24]. Upon completion of the baseline assessment, participants were scheduled to complete a 30-min baseline Repeatable Battery for the Assessment of Neuropsychological Status (RBANS) test [25]. A licensed psychologist used video teleconferencing to administer the RBANS test to qualified candidates (the Echelon Group; Woodstock, GA). The validity of digitally administered neuropsychological tests, including RBANS, has been supported by multiple studies [25-28]. After completing the RBANS test, participants began an initial VC Health coaching session over the phone with a program coach. Individuals were considered enrolled in the VC Health study once this initial coaching session was complete.

Throughout the study, the participants were asked to complete follow-up RBANS tests and Web-based assessments at weeks 12, 24, and 52. To reduce practice effects due to repeated testing over time, alternate forms of the RBANS test were used at each time point. The Web-based assessments included questions about sleep, activity levels, depression and anxiety symptom severity (PHQ-9 and GAD-7, respectively), and experience with the VC Health program. Participants also completed coaching sessions focused on nutrition, physical activity, and cognitive training as part of the VC Health program during the first 6 months of the study.

### Intervention: Virtual Cognitive Health Program

The VC Health program is a multidomain lifestyle intervention designed to prevent or delay cognitive decline and impairment in older at-risk adults and comprises 2 phases. The first 6 months of the program (active phase) emphasize lifestyle change, whereas the last 6 months of the program (maintenance phase) emphasize habit reinforcement. The program consists of individually tailored coaching sessions focused on nutrition, physical exercise, and cognitive training. The cognitive training program (provided by MindAgilis; London, England) focused

on processing speed, executive function, working memory, episodic memory, and mental speed, which are tasks shown to be associated with improved cognitive ability and less difficulty with instrumental activities of daily living [29,30].

All program coaches were certified as personal trainers with mastery of exercise physiology safety and nutritional health practices. Coaches were available via telephone, email, and text messaging. To promote social engagement, participants were encouraged to participate in an internal social network with communal support and directed life review prompts adapted from life review protocols moderated by a licensed clinical psychologist.

### Study Outcomes

The primary outcome of the VC Health study was change in RBANS Total Index score from baseline to week 24 and week 52. The RBANS test has demonstrated strong efficacy as a dementia assessment tool and can also detect cognitive impairment associated with AD [31-33]. Secondary outcomes included change in PHQ-9 depression severity scores and change in GAD-7 anxiety severity scores from baseline to week 24 and week 52, as both depression and anxiety are risk factors for AD [34,35]. RBANS, PHQ-9, and GAD-7 data were also collected at week 12 to allow for interim nonprimary analysis. Exploratory analyses assessed the association between various engagement measures with the VC Health program and change in RBANS, PHQ-9, and GAD-7 scores.

### Sample Size and Statistical Analyses

Due to its preliminary nature, the VC Health study was not powered to detect any specific difference in RBANS score. On the basis of the overall capacity of the VC Health program, 85 participants were enrolled in the study.

Baseline sociodemographic characteristics were collected for all individuals in the ITT population. For the primary analysis, mean and median change in RBANS Total Index score from baseline to week 24 and baseline to week 52 were compared using a 2-tailed paired *t* test and a nonparametric signed-rank test. Similar analyses were conducted to evaluate the mean and median changes in RBANS Total Index score and the 5 RBANS Sub-Index scores (immediate memory, visuospatial, language, attention, and delayed memory) across various time points (baseline to week 24, baseline to week 52, and week 24 to week 52).

For the secondary analysis, mean and median change in PHQ-9 and GAD-7 from baseline to week 24 and baseline to week 52 were assessed using a 2-tailed paired *t* test and a nonparametric signed-rank test. Similar analyses were conducted to measure the mean and median changes in PHQ-9 and GAD-7 across additional time points (baseline to week 24, baseline to week 52, and week 24 to week 52).

We also conducted an unadjusted repeated measures analysis using a linear mixed model with a random intercept specific for each participant to account for intraparticipant correlation. The model used baseline; weeks 12, 24, and 52 RBANS; PHQ-9; and GAD-7 scores for the repeated measures analysis. This analysis included all individuals in the analysis set and was not



limited to those individuals with complete data at baseline and week 52. Results for RBANS Total Index score, PHQ-9, and GAD-7 were stratified by key participant characteristics, including sex (female vs male), ethnicity (white vs nonwhite), and education level (college degree or higher vs less than college degree). Supplemental analyses used a linear regression model to explore the relationship between various user engagement metrics such as number of coaching calls and changes in RBANS, PHQ-9, and GAD-7 scores. All analyses were conducted in Stata version 14.2 or R version 3.5.0, with an alpha of .05 for assessment of statistical significance.

## Results

### Study Sample

Of the 4255 individuals who initiated the Web-based screening process, 28.08% (1195/4255) did not complete the screener, 62.40% (2655/4255) completed the screener but were deemed ineligible for the study, and 9.52% (405/4255) completed the screener and were eligible for the study. Among all 3060 individuals who completed the screener, the top reasons for study ineligibility included not endorsing the 1-item subjective cognitive decline with worry question (80.03%, 2449/3060), not willing to use a virtual coaching program (14.28%, 437/3060), and an SCD-9 score <1 (11.96%, 366/3060). Of the 405 individuals who completed the screener, 57.8% (234/405) did not complete the informed consent process. Of the 171 individuals who completed informed consent, the majority (95.3%, 163/171) completed the baseline survey. A total of 68 individuals (41.7%, 68/163) of the 163 participants who

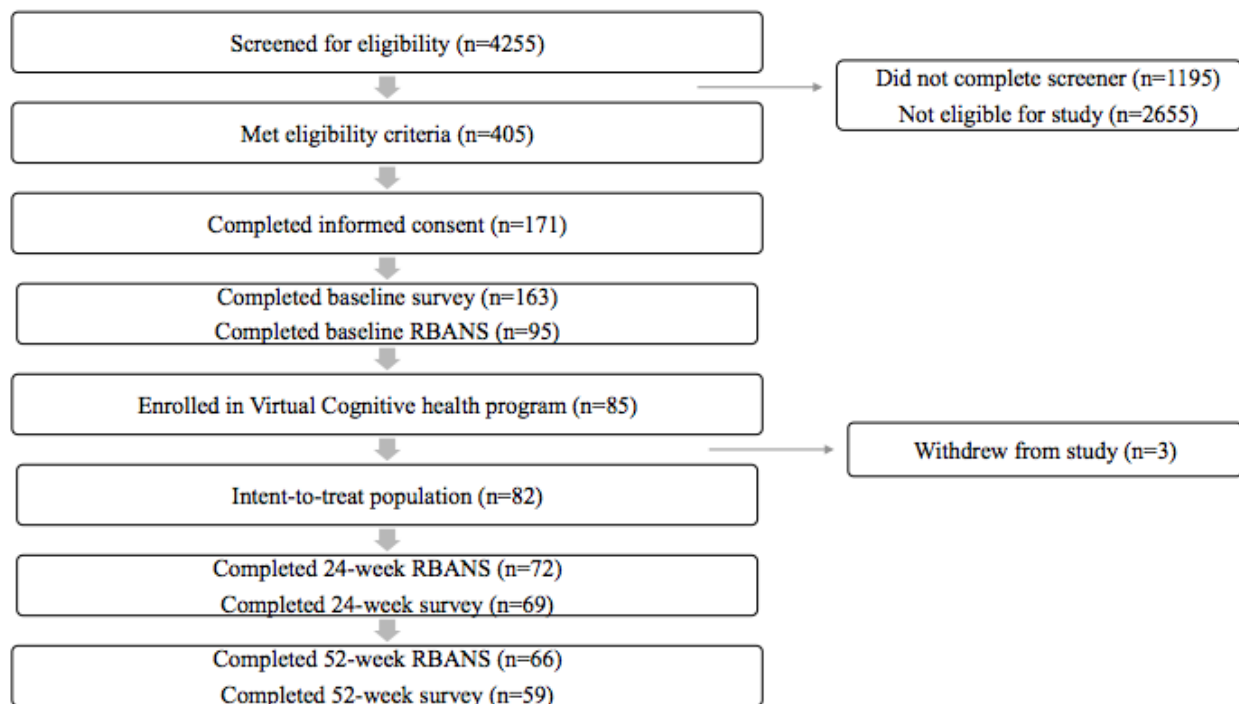
completed the baseline survey did not schedule or complete the initial RBANS test. Of the 95 individuals who completed the initial RBANS test, 11% (10/95) never scheduled or completed their initial VC Health program coaching session. A total of 85 individuals completed all of the required steps, including the initial coaching session, and enrolled in the study. A total of 3 participants withdrew from the study because they no longer wanted to participate in the program or study. As such, 82 participants were included in the analysis set (Figure 1).

Table 1 details the characteristics of the study population. A majority of the study population was female (74%, 61/82), white (88%, 72/82), and had a college degree or higher (67%, 55/82). Mean age of the population was 64 years (range 60-74.9 years). The ITT population represented a geographically diverse population comprising 29 different states in the United States [19].

### Primary Outcome: Cognition

At the 24-week time point, RBANS Total Index score decreased from baseline, but the change was not statistically significant ( $P=.15$ ). Among the 72 participants who completed both their baseline and week 24 RBANS test, mean and median RBANS Total Index score was 96.3 (SD 11.2) and 96 (IQR=13) at baseline, and 95.0 (SD 9.3) and 95 (IQR=13) at week 24, respectively, for an unadjusted mean and median change of -1.4 (SD 8.1) and 0 (IQR=10) units (Table 2). Of the 5 Sub-Index scores, participants experienced a statistically significant change (a slight decrease) in the immediate memory domain ( $P=.02$ ; Table 2).

**Figure 1.** Study diagram. RBANS: Repeatable Battery for the Assessment of Neuropsychological Status.





**Table 1.** Baseline characteristics of study population (N=82).

Characteristics at baseline	Statistics
Age in years, mean (SD)	64 (4)
<b>Gender, n (%)</b>	
Male	20 (24)
Female	61 (74)
Other	1 (1)
<b>Education, n (%)</b>	
High school graduate or general education development degree	3 (4)
Trade, technical or vocational training	2 (2)
Some college, no degree	22 (27)
College graduate, associate's or bachelor's	29 (35)
Graduate degree	19 (23)
Doctorate degree	7 (9)
<b>Race/ethnicity, n (%)</b>	
African American	5 (6)
Asian	1 (1)
White	72 (88)
Hispanic	3 (4)
Other	1 (1)
<b>BMI<sup>a</sup>, n (%)</b>	
Underweight, <18.5 kg/m <sup>2</sup>	0 (0)
Healthy weight, 18.5-24.9 kg/m <sup>2</sup>	16 (20)
Overweight, 25.0-29.9 kg/m <sup>2</sup>	24 (29)
Obese, 30-34.9 kg/m <sup>2</sup>	25 (30)
Very obese, ≥35 kg/m <sup>2</sup>	15 (18)
<b>Average nightly sleep duration, n (%)</b>	
<3 hours	1 (1)
4 to 5 hours	4 (5)
5 to 6 hours	18 (22)
6 to 7 hours	35 (43)
7 to 8 hours	16 (20)
8 to 9 hours	6 (7)
9 to 10 hours	0 (0)
>10 hours	2 (2)

<sup>a</sup>BMI: body mass index.

At the 52-week time point, participants experienced a statistically significant increase in RBANS Total Index score from baseline ( $P<.001$ ). Among the 66 participants who completed both their baseline and week 52 RBANS test, mean and median RBANS Total Index score was 96.9 (SD 10.7) and 97 (IQR=15) at baseline, and 102.7 (SD 9.9) and 101.5 (IQR=13) at week 52, respectively, for an unadjusted mean and median increase of 5.8 (SD 7.4) and 6 (IQR=11) units ( $P<.001$ ;

Table 2). Of the 5 Sub-Index scores, participants experienced a statistically significant increase from baseline to week 52 in immediate memory, language, and delayed memory Sub-Index scores ( $P<.001$ ; Table 2).

Comprehensive mean and median RBANS Total Index scores for all individuals who completed the RBANS test at each study time point are shown in Table 3 and Figure 2.

**Table 2.** Change in mean and median Repeatable Battery for the Assessment of Neuropsychological Status (RBANS) scores.

Metric	N	Mean (SD) <sup>a</sup>	Median (IQR) <sup>b,c</sup>
<b>Total Index score</b>			
Baseline to week 24 change	72	-1.4 (8.1)	0 (10)
Baseline to week 52 change	66	5.8 (7.4) <sup>d</sup>	6 (11) <sup>d</sup>
Week 24 to week 52 change	64	6.8 (6.3) <sup>d</sup>	6 (8) <sup>d</sup>
<b>Immediate memory</b>			
Baseline to week 24 change	72	-3.7 (12.7) <sup>f</sup>	-3.5 (14.5) <sup>e</sup>
Baseline to week 52 change	66	7.8 (11.4) <sup>d</sup>	8 (15) <sup>d</sup>
Week 24 to week 52 change	64	12.2 (11.3) <sup>d</sup>	12 (17) <sup>d</sup>
<b>Visuospatial</b>			
Baseline to week 24 change	72	-0.5 (14.9)	0 (21.5)
Baseline to week 52 change	66	0.5 (13.7)	0 (22)
Week 24 to week 52 change	64	0.3 (11.1)	0 (16)
<b>Language</b>			
Baseline to week 24 change	72	0.9 (11.0)	2 (11.5)
Baseline to week 52 change	66	5.7 (12.5) <sup>d</sup>	5.5 (15) <sup>d</sup>
Week 24 to week 52 change	64	4.5 (9.7) <sup>d</sup>	5 (11.5) <sup>d</sup>
<b>Attention</b>			
Baseline to week 24 change	72	-1.5 (12.1)	-3 (13)
Baseline to week 52 change	66	2.0 (12.6)	0 (16)
Week 24 to week 52 change	64	3.5 (9.7) <sup>e</sup>	3 (13) <sup>e</sup>
<b>Delayed memory</b>			
Baseline to week 24 change	72	0.9 (10.5)	0 (9.5)
Baseline to week 52 change	66	5.4 (12.5) <sup>d</sup>	4 (14) <sup>d</sup>
Week 24 to week 52 change	64	3.6 (9.0) <sup>e</sup>	4 (7) <sup>d</sup>

<sup>a</sup>*P* values in the mean column are calculated using 2-sided paired *t* tests to compare means at the 2 time points.

<sup>b</sup>IQR: interquartile range.

<sup>c</sup>*P* values in the median column are calculated using 2-sided nonparametric signed-rank tests to compare distributions at the 2 time points.

<sup>d</sup>*P*<.001.

<sup>e</sup>*P*<.01.

<sup>f</sup>*P*=.02.

## Secondary Outcomes: Mental Health

Depression symptom levels (as measured by PHQ-9) decreased from baseline to week 24. Among the 69 participants who completed both their baseline and week 24 PHQ-9 tests, mean and median PHQ-9 was 8.6 (SD 4.8) and 8 (IQR=6) at baseline and 5.5 (SD 5.2) and 4 (IQR=6) at week 24, respectively, for a statistically significant unadjusted mean and median PHQ-9 change of -3.1 (SD 4.7) and -3 (IQR=6) units (*P*<.001; Table 4). At the 52-week time point, depression symptom levels also decreased from baseline. Among the 59 participants who completed both their baseline and week 52 PHQ-9 test, mean and median PHQ-9 were 8.3 (SD 5.0) and 8.0 (IQR=6) at baseline and 4.5 (SD 4.5) and 3.0 (IQR=5) at week 52,

respectively, for a statistically significant unadjusted mean and median PHQ-9 change of -3.8 (SD 4.1) and -4 (IQR=6) units (*P*<.001; Table 4).

Similar results were observed with anxiety symptom levels (as measured by GAD-7). Among the 69 participants who completed both their baseline and week 24 GAD-7 tests, mean and median GAD-7 were 6.2 (SD 4.4) and 6 (IQR=6) at baseline and 3.9 (SD 4.6) and 3 (IQR=4) at week 24, respectively, for a statistically significant unadjusted mean and median GAD-7 change of -2.3 (SD 4.3) and -2 (IQR=4) units (*P*<.001; Table 4). Among the 59 participants who completed both their baseline and week 52 GAD-7 test, mean and median GAD-7 were 6.0 (SD 4.7) and 5 (IQR=7) at baseline and 3.1 (SD 4.1) and 2 (IQR=4) at week 52, respectively, for a statistically significant

unadjusted mean and median GAD-7 change of  $-2.9$  (SD 4.1) and  $-2$  (IQR=5) units ( $P<.001$ ; Table 4).

Comprehensive mean and median PHQ-9 and GAD-7 scores for all individuals who completed the assessments at each study time point are shown in Table 5 and Figures 3 and 4.

### Primary and Secondary Outcomes: Mixed-Effects Model Analysis

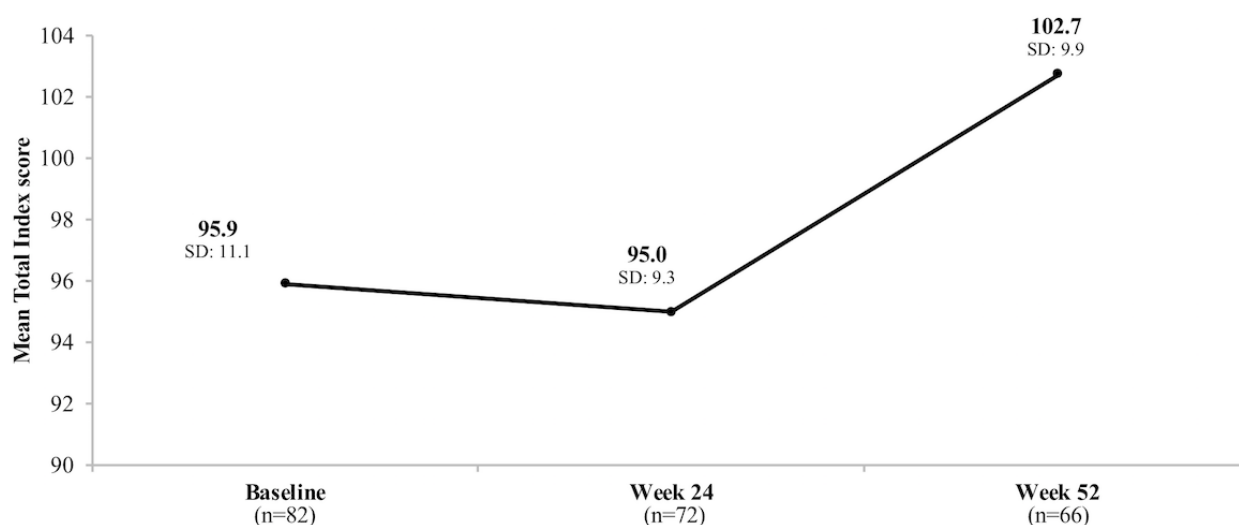
In the repeated measures analysis using a mixed-effects model with a random intercept specific for each participant in the study

population (N=82), we found that the marginal mean change in RBANS Total Index score was consistent with our results from the primary analysis. Using a mixed-effects model, we found that the marginal mean change in RBANS Total Index score was  $-1.3$  (95% CI  $-3.0$  to  $0.4$ ) from baseline to week 24 ( $P=.14$ ) and  $5.7$  (95% CI  $3.9$  to  $7.5$ ) from baseline to week 52 ( $P<.001$ ).

**Table 3.** Mean and median Repeatable Battery for the Assessment of Neuropsychological Status (RBANS) scores.

Metric	N	Mean (SD)	Median (IQR <sup>a</sup> )
<b>Total Index score</b>			
Baseline	82	95.9 (11.1)	95.5 (13)
Week 12	73	100.8 (11.7)	100 (18)
Week 24	72	95.0 (9.3)	95 (13)
Week 52	66	102.7 (9.9)	101.5 (13)
<b>Immediate memory</b>			
Baseline	82	99.4 (12.5)	103 (22)
Week 12	73	100.8 (13.0)	103 (19)
Week 24	72	95.4 (13.2)	97 (21)
Week 52	66	107.4 (10.8)	109 (11)
<b>Visuospatial</b>			
Baseline	82	90.4 (14.3)	87 (19)
Week 12	73	95.5 (13.2)	96 (16)
Week 24	72	90.1 (12.1)	89 (18.5)
Week 52	66	91.2 (12.2)	92 (21)
<b>Language</b>			
Baseline	82	97.2 (10.2)	96 (9)
Week 12	73	104 (10.7)	104 (13)
Week 24	72	98.9 (8.1)	98 (10.5)
Week 52	66	103.8 (9.3)	101 (12)
<b>Attention</b>			
Baseline	82	102.8 (14.8)	101.5 (24)
Week 12	73	103.3 (16.5)	103 (21)
Week 24	72	102.1 (12.7)	103 (19.5)
Week 52	66	107.1 (14.7)	106 (18)
<b>Delayed memory</b>			
Baseline	82	96.6 (12.5)	98 (20)
Week 12	73	100.8 (13.3)	102 (15)
Week 24	72	97.6 (9.4)	98 (7)
Week 52	66	102.2 (10.4)	102 (12)

<sup>a</sup>IQR: interquartile range.

**Figure 2.** Change in mean Repeatable Battery for the Assessment of Neuropsychological Status (RBANS) Total Index score over time.**Table 4.** Change in mean and median Patient Health Questionnaire-9 (PHQ-9) and Generalized Anxiety Disorder-7 survey (GAD-7) scores.

Metric	N	Mean (SD) <sup>a</sup>	Median (IQR) <sup>b,c</sup>
<b>PHQ-9 total score</b>			
Baseline to week 24 change	69	-3.1 (4.7) <sup>d</sup>	-3 (6) <sup>d</sup>
Baseline to week 52 change	59	-3.8 (4.1) <sup>d</sup>	-4 (6) <sup>d</sup>
Week 24 to week 52 change	56	-0.8 (3.6)	-1 (4) <sup>e</sup>
<b>GAD-7 total score</b>			
Baseline to week 24 change	69	-2.3 (4.3) <sup>d</sup>	-2 (4) <sup>d</sup>
Baseline to week 52 change	59	-2.9 (4.1) <sup>d</sup>	-2 (5) <sup>d</sup>
Week 24 to week 52 change	56	-0.8 (3.7)	0 (3.5)

<sup>a</sup>*P* values in the mean column are calculated using two-sided paired *t* tests to compare means at the 2 time points.

<sup>b</sup>IQR: interquartile range.

<sup>c</sup>*P* values in the median column are calculated using two-sided nonparametric signed-rank tests to compare distributions at the 2 time points.

<sup>d</sup>*P*<.001.

<sup>e</sup>*P*=.01.

We conducted similar analyses for PHQ-9 and GAD-7 scores. Using a mixed-effects model, we found that the marginal mean change in PHQ-9 score was -3.0 (95% CI -4.1 to -2.0) from baseline to week 24 (*P*<.001) and -3.8 (95% CI -4.8 to -2.9) from baseline to week 52 (*P*<.001). The marginal mean change in GAD-7 score was -2.3 (95% CI -3.3 to -1.4) from baseline to week 24 (*P*<.001) and -3.0 (95% CI -4.0 to -2.1) from baseline to week 52 (*P*<.001). These marginal mean changes in PHQ-9 and GAD-7 from the mixed-effects model were similar to the mean changes from our primary analysis.

### Primary and Secondary Outcomes: Stratified by Key Characteristics

Baseline RBANS, PHQ-9, and GAD-7 scores were similar across all demographic subgroups analyzed (Table 6). Mean change in RBANS Total Index score from baseline to week 24 was similar between each respective cohort (Table 7). The increase in RBANS score between baseline and week 52 was

significantly higher for females (mean change 7.2 [SD 6.9]) compared with males (mean change 1.1 [SD 7.0]; Table 7); however, the difference in mean change was not significant when stratified by race or education. Stratification did not show any differences when looking at difference in mean change in PHQ-9 and GAD-7 scores from baseline to week 24 and baseline to week 52.

### Exploratory Analyses: Lifestyle Factors, Program Satisfaction, and Program Engagement

Participants reported high satisfaction rates with the program. Of study participants who completed the study end questionnaire at 52 weeks (n=59), 86% (51/59) reported that the VC Health program was at least moderately helpful in improving their cognitive ability. Almost 69% (41/59) of participants felt the VC Health program was at least moderately helpful in improving their sleep habits. At baseline, participants reported sleeping on average 6.5 hours (SD 1.3) per night, whereas at week 52,

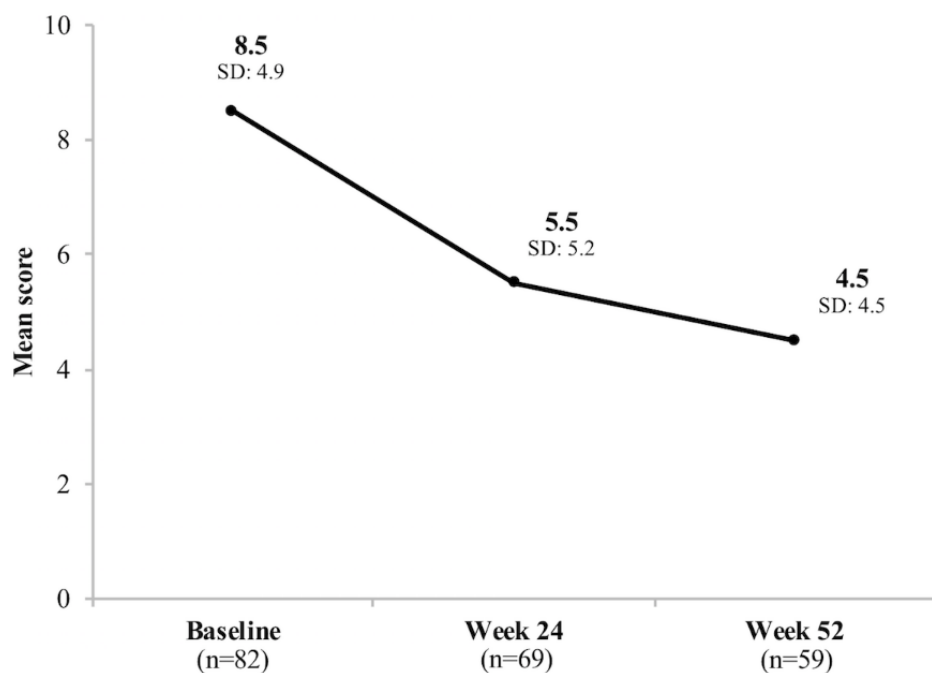
participants reported sleeping 6.6 hours per night (SD 1.2;  $P=.50$ ).

**Table 5.** Mean and median Patient Health Questionnaire-9 (PHQ-9) and Generalized Anxiety Disorder-7 survey (GAD-7) scores.

Metric	N	Mean (SD)	Median (IQR <sup>a</sup> )
<b>PHQ-9 score</b>			
Baseline	82	8.5 (4.9)	8 (6)
Week 12	54	4.8 (4.0)	3.5 (5)
Week 24	69	5.5 (5.2)	4 (6)
Week 52	59	4.5 (4.5)	3 (5)
<b>GAD-7 score</b>			
Baseline	82	6.2 (4.5)	5.5 (6)
Week 12	54	3.0 (3.4)	2 (5)
Week 24	69	3.9 (4.6)	3 (4)
Week 52	59	3.1 (4.1)	2 (4)

<sup>a</sup>IQR: interquartile range.

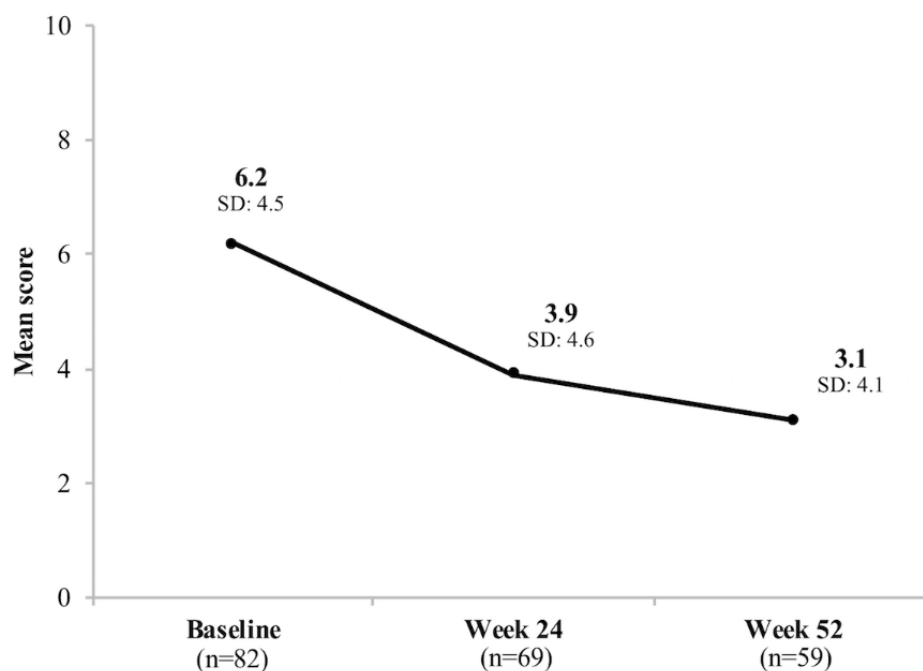
**Figure 3.** Change in Patient Health Questionnaire-9 (PHQ-9) scores over time.



A total of 86% (51/59) and 80% (47/59) of participants reported that the VC Health program was at least moderately helpful in improving their diet and eating habits, and physical activity levels, respectively. At baseline, participants reported exercising an average of 2.8 days per week (SD 2.4), whereas at week 52, participants reported exercising 3.9 days per week (SD 1.8;  $P=.01$ ). A total of 93% (55/59) of study participants reported that the program made at least some impact on their daily food

decisions. Average body mass index (BMI; based on self-reported height and weight) also decreased in the 52-week study period, but this change was not statistically significant; at baseline, BMI was 29.9 kg/m<sup>2</sup> (SD 6.3), and at the end of the study, BMI was 29.2 kg/m<sup>2</sup> (SD 5.7;  $P=.07$ ). A majority of participants (75%, 44/59) reported that the VC Health program at least moderately improved their stress levels.



**Figure 4.** Change in Generalized Anxiety Disorder-7 (GAD-7) scores over time.**Table 6.** Change in mean Repeatable Battery for the Assessment of Neuropsychological Status (RBANS), Patient Health Questionnaire-9 (PHQ-9), and Generalized Anxiety Disorder-7 survey (GAD-7) scores stratified by sex, race, and education level.

Outcome	Stratification by sex <sup>a</sup>				Stratification by race				Stratification by education level			
	Female		Male		White		Nonwhite		College degree or above		Below college degree	
	N	Mean change (SD)	N	Mean change (SD)	N	Mean change (SD)	N	Mean change (SD)	N	Mean change (SD)	N	Mean change (SD)
<b>Total Index score</b>												
Baseline to week 24 change	53	-0.9 (8.4)	18	-3.1 (7.4)	64	-1.1 (7.8)	8	-3.5 (10.8)	48	-0.6 (7.7)	24	-2.8 (8.8)
Baseline to week 52 change	50	7.2 <sup>b</sup> (7.1)	15	1.1 <sup>b</sup> (7.0)	59	6.1 (7.0)	7	2.6 (10.7)	45	6.8 (7.0)	21	3.6 (8.0)
<b>PHQ-9 total score</b>												
Baseline to week 24 change	52	-2.8 (5.0)	16	-4.1 (3.2)	60	-3.2 (4.4)	9	-2.9 (6.3)	46	-3.1 (5.1)	23	-3.1 (3.6)
Baseline to week 52 change	45	-3.6 (4.3)	13	-4.3 (3.7)	54	-3.9 (4.2)	5	-2.6 (3.6)	42	-4.0 (4.2)	17	-3.2 (4.0)
<b>GAD-7 total score</b>												
Baseline to week 24 change	52	-2.0 (4.6)	16	-2.9 (2.8)	60	-2.0 (4.3)	9	-4.4 (3.7)	46	-2.5 (4.8)	23	-1.8 (2.8)
Baseline to week 52 change	45	-2.7 (4.4)	13	-3.5 (3.0)	54	-2.8 (4.1)	5	-4.0 (4.1)	42	-3.0 (4.4)	17	-2.6 (3.5)

<sup>a</sup>One participant identified as *other* sex; thus, we do not report data for the *other* category.

<sup>b</sup> $P=.005$  when comparing the difference between females and males.

**Table 7.** Mean Repeatable Battery for the Assessment of Neuropsychological Status (RBANS), Patient Health Questionnaire-9 (PHQ-9), and Generalized Anxiety Disorder-7 survey (GAD-7) scores stratified by sex, race, and education level.

Outcome	Stratification by sex <sup>a</sup>				Stratification by race				Stratification by education level			
	Female		Male		White		Nonwhite		College degree or above		Below college degree	
	N	Mean (SD)	N	Mean (SD)	N	Mean (SD)	N	Mean (SD)	N	Mean (SD)	N	Mean (SD)
<b>Total Index score</b>												
Baseline	61	96.4 (11.0)	20	93.7 (11.1)	72	95.9 (10.6)	10	96.1 (14.9)	55	96.2 (11.2)	27	95.2 (10.9)
Week 12	55	102.4 (11.2)	17	95.6 (12.2)	66	101.3 (11.1)	7	96.1 (16.4)	48	101.8 (12.2)	25	99.0 (10.5)
Week 24	53	95.8 (9.2)	18	91.8 (8.7)	64	95.2 (9.0)	8	93.1 (12.1)	48	96.0 (9.6)	24	92.9 (8.6)
Week 52	50	103.9 (10.4)	15	98.1 (6.8)	59	102.5 (10.1)	7	104.4 (8.7)	45	103.6 (10.1)	21	100.8 (9.5)
<b>PHQ-9 total score</b>												
Baseline	61	8.4 (5.1)	20	9.0 (4.4)	72	8.8 (5.1)	10	6.6 (3.0)	55	8.4 (5.0)	27	8.8 (4.8)
Week 12	39	4.5 (3.4)	14	5.6 (5.5)	47	5.1 (4.1)	7	3.0 (2.7)	38	4.5 (3.6)	16	5.5 (5.0)
Week 24	52	5.9 (5.7)	16	4.3 (3.0)	60	5.8 (4.9)	9	3.6 (6.7)	46	5.3 (5.2)	23	5.9 (5.3)
Week 52	45	4.7 (4.8)	13	3.8 (3.5)	54	4.8 (4.5)	5	2.2 (3.8)	42	4.4 (3.9)	17	4.9 (5.7)
<b>GAD-7 total score</b>												
Baseline	61	6.0 (4.7)	20	6.7 (3.9)	72	6.2 (4.7)	10	6.3 (2.8)	55	6.2 (4.8)	27	6.1 (4.1)
Week 12	39	3.1 (3.4)	14	3.0 (3.7)	47	3.2 (3.5)	7	2.0 (2.1)	38	2.7 (3.0)	16	3.9 (4.1)
Week 24	52	3.9 (4.8)	16	3.8 (3.9)	60	4.2 (4.7)	9	1.7 (2.4)	46	3.5 (4.6)	23	4.6 (4.5)
Week 52	45	3.0 (4.3)	13	2.9 (3.6)	54	3.2 (4.2)	5	2.0 (2.8)	42	3.0 (4.0)	17	3.3 (4.3)

<sup>a</sup>One participant identified as *other* sex; thus, we do not report data for the *other* category.

Overall, the mean and median numbers of coaching calls completed by study participants over the 12-month study period were 16.5 (SD 9.6) and 16.0 (IQR=12.3), respectively. The mean and median call length was 12.9 min (SD 5.9) and 11.7 min (IQR=6.9), respectively. When comparing program engagement and change in RBANS Total Index score, we found no statistically significant association between change in Total RBANS Index score and number of phone calls, number of interactions with the program's social media platform, or number of participant food and exercise logs. We found a statistically significant inverse association with the number of completed phone calls and change in PHQ-9 (beta=-.16,  $P=.01$ ) and GAD-7 (beta=-.17,  $P=.008$ ) between baseline and week 52. For each additional call, PHQ-9 scores improved by 0.16 units and GAD-7 scores improved by 0.17 units. Lower PHQ-9 and GAD-7 scores correspond to lower levels of depression and anxiety; therefore, a negative change in average PHQ-9 and GAD-7 score from baseline to week 52 indicates an improvement in mental health status. There was also an inverse association between the number of food and exercise logs entered by the participant and change in PHQ-9 (beta=-.01,  $P=.03$ ) and GAD-7 (beta=-.01,  $P=.002$ ). For each additional day that a participant logged their food or exercise, the average PHQ-9 and GAD-7 scores improved by 0.01 units.

## Discussion

### Principal Findings

This study provides a number of key insights into the feasibility and effectiveness of the VC Health program, a remotely delivered multidomain lifestyle intervention designed for the prevention or delay of cognitive impairment in older adults at risk of developing AD. One of the strengths of this study was the 52-week study duration, which allowed us to examine the long-term impact of the VC Health program. Participants did not experience a statistically significant change in cognitive ability from baseline to week 24, but cognitive function was significantly increased from baseline to week 52. On the basis of RBANS scoring guidelines, participants at baseline had an *Average* RBANS Total Index score (scores between 90 and 109 are considered to be *Average*) [36]. By the end of the study, participants experienced an average increase in RBANS Total Index score of 5.8 units, remaining in the *Average* category. It is possible that the full impact of the VC Health program on cognitive ability may completely manifest in the longer term, over the course of multiple years. Future longitudinal studies should assess whether this increase in cognitive function can be sustained or further improved after 1 year, as well as how cognitive function would be expected to change in the absence of an intervention (in a control group).

Study participants also experienced statistically and clinically significant improvements in symptoms of depression and anxiety, as measured by PHQ-9 and GAD-7 scores. At baseline,

participants were considered on average to have *Mild Depression* and *Mild Anxiety* based on PHQ-9 and GAD-7 scoring guidelines [22,24]. By the end of the study, their PHQ-9 and GAD-7 scores decreased on average by 3.8 and 2.9 points, respectively, moving participants into the *Minimal or No Depression* and *Minimal or No Anxiety* categories [22,24]. Participants experienced the largest improvement in PHQ-9 and GAD-7 from baseline to week 24, after which they did not experience any additional statistically significant benefits between week 24 and 52. This suggests that the VC Health program's impact on mental health is more immediate than its impact on cognitive function. At the beginning of the program, the immediate exposure to psychoeducation, cognitive stimulation, and/or frequent coaching sessions may have had an instant positive impact on a participant's daily life, resulting in improved mental health. Given that depression and anxiety symptoms are known risk factors for AD, mitigating these symptoms in the first half of the program may play a role in the observed long-term improvements in cognitive function. Future longitudinal studies should be conducted to further understand the longer-term effects of the program on depression and anxiety.

When we examined various components of program engagement, there was no association between the number of coaching calls a participant completed and change in RBANS Total Index score over time, but there was an association between number of calls completed and improvement in both PHQ-9 and GAD-7 scores. Coaching calls are only 1 component of the overall program experience, and different participants may require various levels of attention and frequency of interactions with their coach to gain the same benefit in cognitive function from the program. This finding that more calls completed correlates to mental health improvements further supports the hypothesis that coaching sessions may have a positive impact on an individual's daily life. Change in depression and anxiety symptoms did not differ by sex, race, or education levels. Given that the sample size of 82 individuals was relatively small for this subgroup analysis, this finding should be further explored in future larger studies.

The results from this study indicate that participants had overall high satisfaction with the program. The majority of study participants reported the VC Health program improved their diet and eating habits, physical activity, cognitive ability, sleep habits, and stress levels. In addition, despite this being a year-long program, participants were engaged with the VC Health program throughout the study and averaged 16.5 coaching sessions over the 12-month period with an average of 12.9 min per coaching session.

A number of prospective clinical studies have been previously conducted to measure the impact of digital solutions on chronic

disease prevention and management [37-40]; however, there have been a limited number of studies and solutions focused on older adults. In this study, we observed high compliance and engagement with study-related activities (eg, completion of RBANS tests, Web-based assessments) and high engagement and satisfaction with the digital technology-based VC Health program for a population of older at-risk adults with SCD. This suggests that older adults may also enjoy and benefit from new technology-based health solutions, such as the VC Health program, and can successfully participate in remote studies.

### Limitations

This study had a number of limitations, some of which have been previously discussed in the publication detailing this study's methods and design [19]. First, given that this was a pre-post study design and there was no control arm, we were unable to compare the changes in cognitive ability and mental health experienced by individuals using the VC Health program with individuals who did not use the program. Therefore, we are unable to fully attribute the observed changes in cognitive ability and mental health to the VC Health program. However, previously conducted observational and longitudinal studies have shown that over a course of a 52-week period, older community-dwelling adults experienced a decline in cognitive ability (as measured by RBANS) over time [32,41]. This suggests that study participants' cognitive ability may have declined over time in the absence of the VC Health program. Even if participants in the VC Health program just maintained cognitive ability over the course of the 52-week period, this would still be considered a better outcome than what would be seen in the absence of an intervention.

As a pilot study, the sample size was relatively small, primarily female, white, and well-educated. Although we did stratify results based on sex, race, and education levels in our analyses to explore differences in subgroups, sample sizes for each subpopulation were fairly small; therefore, conclusions based on stratified results are limited.

### Conclusions

In this pilot study, older adults at risk of developing AD experienced statistically significant improvements in their cognitive function and mental health after participating in the VC Health program. These results serve as initial evidence for the feasibility and effectiveness of this fully digital multidomain lifestyle change program (consisting of health coaching, diet, exercise, cognitive training, and social engagement components) to delay or prevent cognitive impairment in older adults at risk for developing AD. This initial evidence can be used to inform future longitudinal randomized controlled studies measuring the impact of the VC Health program on the prevention or delay of cognitive impairment.

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## Conflicts of Interest

Neurotrack makes and owns the VC Health program examined in this study. NB, KC, JMG, and ENM are employed by Neurotrack and receive a salary and stock options. Evidation Health collected and analyzed all study data. SK, JT, HM, CT, and JLJ are employed by Evidation Health and have no financial interest in Neurotrack.

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## Abbreviations

**AD:** Alzheimer disease

**BMI:** body mass index

**FINGER:** Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability

**GAD-7:** Generalized Anxiety Disorder-7 survey

**ITT:** intention-to-treat

**IQR:** interquartile range

**PHQ-9:** Patient Health Questionnaire-9

**RBANS:** Repeatable Battery for the Assessment of Neuropsychological Status

**SCD-9:** Subjective Cognitive Decline questionnaire

**VC Health:** Virtual Cognitive Health

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Original Paper

# Feasibility and Conceptualization of an e-Mental Health Treatment for Depression in Older Adults: Mixed-Methods Study

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## Abstract

**Background:** Depression is one of the most common mental disorders in older adults. Unfortunately, it often goes unrecognized in the older population.

**Objective:** The aim of this study was to identify how Web-based apps can recognize and help treat depression in older adults.

**Methods:** Focus groups were conducted with mental health care experts. A Web-based survey of 56 older adults suffering from depression was conducted. Qualitative interviews were conducted with 2 individuals.

**Results:** Results of the focus groups highlighted that there is a need for a collaborative care platform for depression in old age. Findings from the Web-based study showed that younger participants (aged 50 to 64 years) used electronic media more often than older participants (aged 65 years and older). The interviews pointed in a comparable direction.

**Conclusions:** Overall, an e-mental (electronic mental) health treatment for depression in older adults would be well accepted. Web-based care platforms should be developed, evaluated, and in case of evidence for their effectiveness, integrated into the everyday clinic.

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**KEYWORDS**

depression; online therapy; e-mental health

## Introduction

In 2014, about 18.5% of the approximately 506.8 million inhabitants of the European Union were aged over 65 years. By 2050, this number is expected to rise to 28.1% [1]. The population growth in this age group is not only evident for Europe but can be observed worldwide. Depression is the second-most common type of mental illness in older people [2].

Current prevalence rates for depression range from 1% to 6% of the total population. [3] Prevalence rates (between 6% and 16%) are significantly higher among older people [4] and dementia patients [3]. The occurrence of subclinical symptoms

in the elderly is much more common in comparison with clinical depression, and prevalence rates range from 10% to 16.5% [5].

Depression in old age is diagnosed according to the Diagnostic and Statistical Manual of Mental Disorders (DSM) [6] and the International Classification of Diseases (ICD) system [7]. Depressive episodes can be classified as *easy*, *moderate*, or *severe*. To meet the diagnostic criteria for depression, the depressive episode should last for at least 2 weeks. The main symptoms of a depressive episode according to ICD-10 are depressive mood, loss of interest or pleasure in activities, and a diminished drive. Additional symptoms are loss of self-confidence, unsubstantiated self-reproaches, recurring thoughts of death or suicide, difficulties in concentrating, and psychomotor agitation. Differences in clinical symptoms

between elderly people with depression and younger adults with depression are very well reported. Suicide rates in the elderly are higher than in younger adults and more closely associated with depression. Depressed older adults are less likely to endorse affective symptoms and more likely to display a loss of interest than younger adults [8]. Depression in old age is associated with cognitive impairments, as well as other somatic comorbidities [9]. Many studies identified personality traits [10] and a negative self-image [11] to be risk factors for depressive symptoms and disorders. Several studies show a link between depression and quantitative and qualitative aspects of social network [12].

Only about 25% of patients with depression in old age receive psychotherapy [13]. Dakin and Areán [13] reason that because of the fact that treatment guidelines for age-related depression are often lacking, psychotherapy is seldom prescribed. Espinoza and Kaufman [14] point to further reasons why an elderly patient with depression seldom receives psychotherapy, namely, a potentially difficult access to qualified staff, limitations in mobility for older people, and the inability of therapists to tailor a therapy adequately to the elderly. The lack of psychotherapeutic care for depression in old age is being criticized, and the call for innovative treatment options is becoming bigger [15]. Early detection and treatment help to reduce symptoms, improve the quality of life, and prevent an unfavorable prognosis. Therefore, early detection of people who are likely to develop a depressive disorder is desirable. A possible solution for early detection, management, and treatment of depression in old age is an electronic mental (e-mental) health program [16]. The area is constantly evolving and has significantly expanded conventional services such as *face-to-face* interventions. E-mental health offers range from providing health-related information via Web 2.0 interventions to mobile phone apps [17]. According to Wicks and colleagues [18], e-mental health offers the following 3 particular advantages: (1) improving the efficiency of care through better communication and diagnostics possibilities while reducing costs, (2) improving quality of care, and (3) promoting active cooperation and autonomy of the patient.

A large number of innovative interventions in the e-mental health sector for the prevention and treatment of depression have been developed. E-mental health research projects are mostly focused on the monitoring of symptoms [19], the early detection of depression [20], and sensors and devices that record vital data.

Most e-mental health projects that include some form of intervention are based on cognitive behavioral therapy (CBT); therefore, they are also called computerized cognitive behavioral therapy (cCBT). The effectiveness of cCBT therapy is well documented for mental illness [21]. There are more than 100 studies on cCBT for various mental disorders [22]. Particularly, cCBT for depression and anxiety disorders is well researched and has been proven to be effective [23]. A review of cCBT in depression reported an average effect size ( $d$ ) of 0.56 for 19 included randomized controlled trials [24]. Similarly, a study by Spek and colleagues [23] that specifically looked at elderly (aged 50 years and older) showed that cCBT was at least as effective as a commonly used group CBT intervention for

subthreshold depression. In addition to the efficacy studies of individual cCBT interventions, there are now several international meta-analyses that provide sufficient evidence that computer-assisted cognitive behavioral interventions are generally effective [25]. In 17 of the 19 analyzed studies, positive evidence of effectiveness was found. Averaged across all disorder patterns and forms of intervention, the average treatment effect was 0.53, which is quite similar to effect sizes for traditional outpatient treatment [25].

Examples of cCBT include Help4Mood, an agent-based decision support system, for severely depressed patients [26]; THIS WAY UP, an Australian online training program [27]; or MasterMind, a European project that consists of a 10-week training program based on cCBT [28]. SeniorEngage is a project from the organization Second Ambient Assisted Living-Call, which has developed Web 2.0 tools for social networking to prevent isolation and depression of people in retirement [29]. Beating the Blues is an example of an English online platform with CBT as its methodical base. Beating the Blues integrates storytelling elements into its 8 modules [30]. Considering German-speaking countries, a very prominent example is the online program Deprexis, which consists of behavioral modules for behavioral activation or cognitive restructuring [31].

Unfortunately, these projects fundamentally neglect discussed age-related issues of depression. eHealth programs to reduce depressive symptoms in elderly people are not readily available despite the many benefits of such interventions. Therefore, there is a need for a collaborative care platform for people with depression in old age addressing the special circumstances and needs of the elderly, as well as the needs and requirements of those caring for them and treating them.

Therefore, the goal of this study was to identify the development of a collaborative Web-based care platform for people with depression in old age, addressing the special circumstances and needs of the elderly, as well as the needs and requirements of those caring for them and treating them. In particular, the following aspects will be examined to elucidate the research question:

1. How common and regular is the use of information and communication technology (ICT) in the elderly in general and in elderly patients with depression?
2. What are the contents and requirements for a collaborative Web-based care platform for self-management and early detection and interventions of depression in old age?
3. How willing are elderly patients with depression to use such a collaborative Web-based supply platform?

## Methods

### Study Design

In a series of 3 consecutive studies, the feasibility and conceptualization of an e-mental health treatment for depression in older adults were investigated. First, focus groups with mental health care experts were conducted. An online study was launched in forums and depression-related online platforms. Finally, to allow for more in-depth insights, a series of

interviews was conducted. Ethical approval was obtained from the Sigmund Freud University Vienna ethics committee.

### Focus Groups

Two focus group discussions were held in February and March 2016. The groups were recruited by personal contacts within medical care organizations in Austria. Focus groups were supposed to consist of a maximum of 8 and at least 3 people. A guideline prepared in advance served as a basis for the questions posed. Each focus group lasted for around 90 min. With the consent of participants, the 2 focus group discussions were recorded. After the discussions, the material was transcribed.

### Online Study

Furthermore, an online study was conducted. The data collection period lasted 12 weeks. Filling out the questionnaire took about 15 to 25 min.

Data collection took place in 2 phases. Phase 1 started in March 2016. The questionnaire was posted in an online forum. As a result of this pretest, the questionnaire was revised regarding its practicability, comprehensibility, and completeness of item formulation. Phase 2 started a week later. The questionnaire was published in 14 online forums and websites focusing on depression or forums for the elderly.

### Interviews

Participants of the online questionnaire were able to leave their contact data if they were willing to participate in a follow-up interview study. Participants from both samples (50- to 64-year-olds or 65-year-olds and older people) were selected for the interviews. They were then contacted and invited to participate in the interviews.

The interviews were conducted by telephone in June 2017. A guideline prepared in advance served as a basis for the questions posed in the interviews. With the consent of the participants, interviews were recorded. The recorded material was transcribed. Interviews lasted between 60 and 90 min.

### Instruments

#### Focus Groups

To secure a structured and standardized structure for the focus groups, a guideline was predefined. Information included in the guideline was the objectives of the focus groups, open questions, and explanatory remarks. Organizational information was also included. The method of qualitative content analysis according to Mayring was chosen for the analysis of transcripts.

#### Online Study

Due to a lack of research in the area being investigated, no suitable standardized scales were available to use. On the basis of a comprehensive literature search, a questionnaire was constructed. The questionnaire included the following 6 subjects:

1. Sociodemographic data and mental health status
2. Previous experience with offline as well as online therapy for depression
3. Social support
4. Media behavior

5. Self-management strategies for coping with depressive symptoms
6. Possible features of an online care platform

Two standardized tests were part of the questionnaire to assess the severity of depression and personality of participants.

The severity of the depression was assessed with the Patient Health Questionnaire (PHQ). The PHQ-9 is a 9-question instrument that takes less than 3 min to complete. Results of the PHQ-9 may be used to make a depression diagnosis according to DSM-4 criteria. As part of the PHQ-9, the severity of depression is scaled (from 0-27) and categorized (minimal, mild, moderate, and heavy). In general, a total of 10 or above is suggestive of the presence of depression. A Cronbach alpha of .89 indicates acceptable reliability [32]. Personality dimensions of participants were recorded using the 10-item Big Five Inventory (BFI-10). The BFI-10 consists of 10 items, 2 for each dimension of personality. Interviewees indicate their response on a 5-point Likert scale ranging from *does not apply at all* (rated as 1) to *fully applies* (rated as 5). It takes about 2 min to complete the BFI-10. The test is interpreted by averaging the answers on the 2 items per personality dimension. Obtained values ranged from 1 to 10. Results from multiple samples and for 2 languages, namely English and German, suggest that the BFI-10 possesses acceptable psychometric properties [33]. Statistical analyses were conducted using SPSS 23.

### Interviews

The guideline for the half-structured interviews was developed with reference to relevant research questions that remained unanswered in the previous online survey. The following research questions were formulated:

1. What do participants know about and what are their experiences with electronic support and support?
2. Which features are essential for an online care platform to be actively used by elderly patients with depression?

For this study, the method of qualitative content analysis according to Mayring was chosen for the analysis of transcripts.

### Sample

#### Focus Group

For the 2 focus groups, 8 experts in mobile and stationary health care, mental health care, day care, and psychosocial services, as well as gerontopsychiatry were recruited (see Table 1). The first focus group consisted of 3 participants, whereas 5 experts were part of the second focus group.

#### Online Study

The final sample consisted of 56 participants, including 35 (35/56, 63%) women and 21 (21/56, 38%) men. Mean age of the participants was 61.77 years (SD 8.74). A majority of participants (43/56, 77%) came from Germany, 20% (11/56) from Switzerland, and 4% (2/56) from Austria. There were 43% (24/56) married participants, whereas 18% (10/56) were divorced, 16% (9/56) lived in a partnership, and 14% (8/56) were single. Only 5% (3/56) were widowed, and 4% (2/56) were currently living separated.

**Table 1.** Focus groups participants.

Sex	Profession
Female	Nursing director and head of palliative care
Male	Case manager at Fonds Soziales Wien
Male	Nursing director of the Vienna Social Services
Female	Head of a nursing home
Male	Psychosocial service
Male	Mobile individual nursing
Male	Mobile individual nursing
Male	Board member at the Institute of Ethics and Law in Medicine

Considering that individuals aged 55 to 64 years (66%) use the internet more than people aged 65 to 74 (45%, for people aged 74 and older there is no data available), statistical analysis was conducted separately for the 2 age groups to allow for more in-depth findings [34].

### Interviews

Unfortunately, only 2 people agreed to participate in the interviews. A 51-year-old, divorced, early retiree participated from the age group of 50 to 64 years. The interviewee had been suffering from severe, recurring depressive episodes for more than 10 years. Person A had experience in different forms of psychotherapy. Of the sample group 65 years and older, Person B, aged 70 years participated. Person B suffered from various depressive symptoms for more than 24 years. Therapeutically, Person B made use of outpatient psychotherapy, psychiatry, and medication.

## Results

### Focus Groups

The focus groups investigated what experts consider is required for a collaborative online care platform to work and how experts rate the benefits of a collaborative internet-based care platform for older and depressed individuals. Following the analysis of the transcribed focus group material, the following 8 categories were formed: perception of depression in old age in society, factors that influence depression, self-management of depression, usability of existing internet-based interventions, support of relatives, support of therapists, definition of the potential user group for a collaborative care platform, and third parties and ethical issues.

The need to develop a collaborative care platform for depression in old age was repeatedly emphasized during both focus groups. This becomes particularly important when taking into account that use of new media will become even more commonplace in the future. In nowadays' society, depression in old age frequently goes undiagnosed. The impact of depression on general health is underestimated. Experts emphasized that there is a plethora of illnesses that facilitate the development of a depression, such as dementia or cancer. However, social factors, for example, social isolation, cannot be ignored.

A focus group participant remarked: "I believe that many relatives are going through hell." Taking into account that

relatives of old patients with depression are often left alone and seldom get help, the experts unanimously concluded that a collaborative care-platform where caregiving family members find relief would be very beneficial. Furthermore, this could ease the therapeutic process by providing vital information to medical and psychological therapists involved.

It was questioned whether the motivation of depressed elderly was high enough to use corresponding online offers. For an internet-based collaborative care-platform to be practical, focus group participants suggested several critical factors: the system must be integrated into the lives of those affected, instructions for handling the platform need to be described accurately and adequately, and the validity of the product should be empirically proven. Experts highlighted that it is important to provide a precise definition of depression in old age, the user group, and the form and scope of the platform. Ethical and legal consequences that involve the inclusion of additional persons to support the stakeholders in the internet-based platform need to be considered.

### Online Study

#### Depressive Symptoms

More than 90% (50/56) of all participants indicated to suffer from some form of depressive symptoms at some point in their lives. For 8.9% (5/56) of the participants, depressive symptoms started in the last 12 months. Another 45% (25/56) of the participants reported having depressive symptoms for 1 to 10 years. For 35.8% (20/56) of the sample, depressive symptoms began more than 11 years ago. Results of the PHQ-9 revealed a mean score of 12.36 (SD 6.33) of the total sample (a score of 10 or above indicating depression). The mean depression score of the participants aged 50 to 64 years was 13.90 (SD 6.52). In comparison, the mean depression score of the participants aged 65 years and older was 10.58 (SD 5.73). A *t* test revealed a significant difference between the 2 groups ( $t_{54}=2.03$ ,  $P=.04$ ,  $d=0.54$ ). Considering the descriptive results, it can be concluded that the severity of depression is more pronounced in the younger age group. Currently, 58.8% (33/56) were in treatment for depression.

#### Personality

For the total sample, mean values for the 5 personality dimensions were between 5.11 (Conscientiousness) and 6.34



(Neuroticism), suggesting normally pronounced personality traits.

### **Use of Information and Communication Technology**

Although more than half (34/56, 61%) of participants indicated to use a computer on a daily basis, about half (28/56, 50%) of participants used a mobile phone daily. Tablets were least frequently used, with 52% (29/56) of participants stating that they are not using this device at all. With regard to the purpose of ICT use, sending email (51/56, 93%) and finding information online (50/56, 91%) were most common, followed by health-related purposes (34/56, 62%) and visits to internet forums (43/56, 62%). Internet games (11/56, 20%) proved to be the least used form of ICTs. Looking at the participants from the age group 50 to 64 years, it can be seen that 83% (25/30) of this group use a computer or laptop and a mobile phone (25/30, 83%) daily. By contrast, 47% of this group said they never use a tablet. All participants (30/30, 100%) of this age group indicated that they use an ICT device at least once a week. A computer or laptop was used by only 38% (10/26) and a mobile phone by 38% (10/26) of those aged 65 years and older every day. This group also reported using tablets least frequently. Almost all participants (25/26, 96%) of this age group reported that they use ICT devices less frequently than once a week.

Correlations between the use of ICT and age groups were investigated using chi-square tests. There was a significant relationship between age groups and the use of computers or laptops ( $P < .001$ ). As expected, participants aged 50 to 64 years tend to use computers or laptops more frequently than those

aged 65 years (see Table 2). Most participants in each media category stated that their media use did not change during a depressive period. Participants who reported a change were less likely to use ICT (see Table 3). There was a significant correlation between the use of ICT for finding information and coping with depressive symptoms and the severity of depression ( $r = .346$ ,  $P = .01$ ); particularly, patients with a more pronounced depressive episode used ICTs more frequently.

### **Previous Experience With Offline and Online Therapy**

In terms of previous experience with offline services, it can be concluded that participants had the most experience with individual psychotherapy or psychological counseling (45/56, 80%). The most popular offline support therapy option was prescription drugs (54/56, 96%). Overall, only 25% (14/56) of participants were aware of internet-based interventions. Only 4% (2/56) of the people reported that they already tried internet-based therapy. However, some participants had experience with online self-help platforms (13/56, 23%).

### **Social Support**

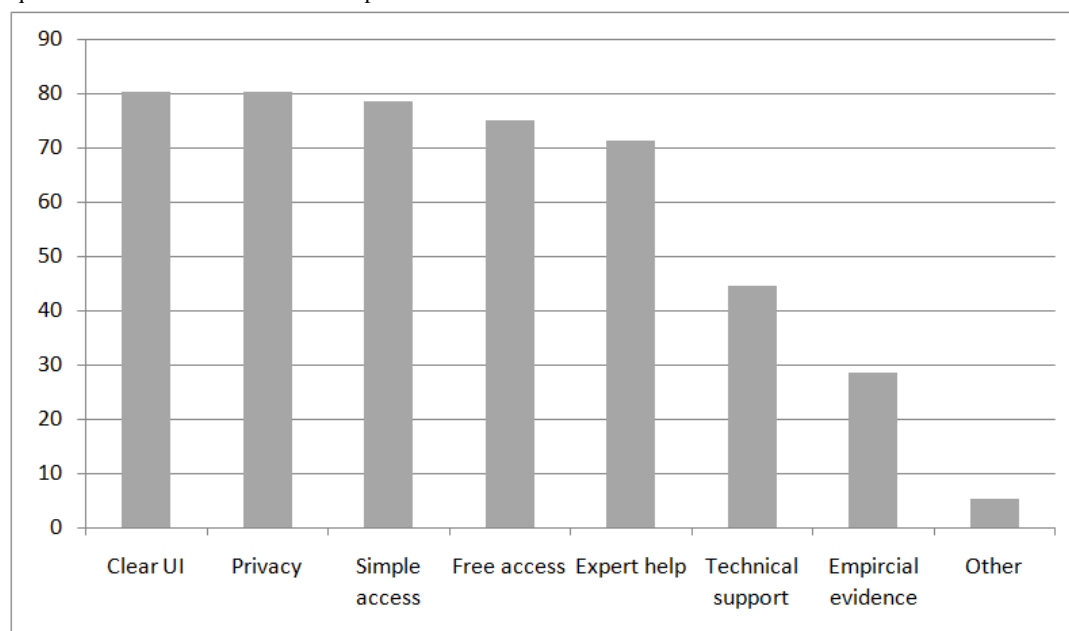
Looking at the entire sample, friends are the main source of potential help during depressive episodes (33/56, 59%), followed by partners (25/56, 45%) and children (20/56, 36%). A total of 14% (8/56) said they did not have anyone they could reliably get their hands on. More than half (33/56, 59%) of the sample was satisfied with their current level of social support (eg, practical or emotional assistance). Another 38% (21/56) reported that the support from their friends and family was improvable, whereas 4% (2/56) wanted less social support.

**Table 2.** Use of information and communication technology.

Frequency of use	50-64 years (n=30), n (%)	65 years and older (n=26), n (%)	Total (N=56), n (%)
<b>Mobile phone</b>			
On a daily basis	18 (60)	10 (38)	28 (50)
More than once a week	3 (10)	3 (12)	6 (11)
Once a week	1 (3)	0 (0)	1 (2)
Less frequently than once a week	0 (0)	1 (4)	1 (2)
Never	8 (27)	12 (46)	20 (36)
<b>Tablet</b>			
On a daily basis	5 (17)	3 (12)	8 (14)
More than once a week	7 (23)	5 (19)	12 (21)
Once a week	1 (3)	2 (7)	3 (5)
Less frequently than once a week	3 (10)	1 (4)	4 (7)
Never	14 (47)	15 (58)	29 (52)
<b>Computer</b>			
On a daily basis	25 (83)	9 (35)	34 (61)
More than once a week	2 (7)	4 (15)	6 (11)
Once a week	1 (3)	5 (19)	6 (11)
Less frequently than once a week	2 (7)	2 (8)	4 (7)
Never	0 (0)	6 (23)	6 (11)

**Table 3.** Change of media use during depressive episodes.

Media	n (%)
<b>Mobile phone</b>	
Less likely	20 (35)
No change	29 (51)
More frequently	8 (15)
<b>Tablet</b>	
Less likely	25 (44)
No change	27 (49)
More frequently	4 (7)
<b>Computer</b>	
Less likely	14 (25)
No change	30 (53)
More frequently	12 (22)

**Figure 1.** Prerequisites for a collaborative online care platform. UI: user interface.

### Prerequisites for a Collaborative Online Care Platform

For most participants (45/56, 80%), online privacy as well as a clear user interface (45/56, 80%) were of particular importance. Other factors that were considered important included simple (44/56, 79%) and free access (43/56, 75%) to the platform. By contrast, scientific evidence for the effectiveness of the platform was important only for 29% (16/56) of the sample (see Figure 1).

For 91% (51/56) of participants, the most important content a potential platform should have was *self-help strategies* for coping with depressive symptoms. Similarly, 88% (49/56) thought that *Information on Early Detection* of depressive symptoms should be included. On the other hand, only 45% (25/56) of the participants considered *self-management applications* (eg, online diary of positive and negative thoughts) important or very important. Furthermore, 57% (32/56) of

respondents indicated that *internet-based psychotherapy* (eg, online behavioral therapy to treat depression) is important or very important for a platform. A majority (47/56, 84%) of participants thought that a delineated part to which only those affected and other authorized persons (eg, therapist or general physician) would have access would be helpful. A further 41% (23/56) of participants welcomed a separate part for relatives of the patient.

### Willingness to Use a Collaborative Online Care Platform

Willingness to use a collaborative care platform of participants was assessed with 6 items (3 positive and 3 negative poled items). Three-quarters (42/56, 75%) of the participants indicated that it was likely that they would register and use an online care platform. When considering the 2 distinct age groups, a majority of the participants aged 50 to 64 years (27/30, 90%) said they would be willing to register and use an online care platform. Among those aged 65 years and older, 58% (15/26)

indicated that they would register for and use an online care platform. Whether a platform would be helpful in managing depressive symptoms was answered positively by 80% (45/56) of the sample. Another 91% (51/56) believed that online care platforms could enable more people to connect with fellow sufferers and professionals.

A *t* test was conducted to investigate the differences in the willingness of the 2 groups to use a collaborative care platform ( $t_{54}=3.59$ ,  $P=.002$ ,  $d=0.94$ ). Considering that Levene test indicated unequal variances ( $F_{54}=6.831$ ,  $P=.01$ ), findings have to be interpreted with care. It was found that 50- to 64-year-olds (mean 3.08 [SD 0.42]) were significantly more willing to use an online platform than those in the age group of 65 years and older (mean 2.56 [SD 0.66]). Interactions between willingness to use and other variables were examined. There was a positive correlation between the current use of ICT for depression-related purposes and the willingness to use an online care platform ( $r=.442$ ,  $P<.001$ ). Unsurprisingly, current users were more willing to try out another online platform. Another correlation was found between severity of depression and willingness to use an online platform, with a more pronounced depression going along with an increased willingness to use an online platform ( $r=.340$ ,  $P=.01$ ). There was a weak correlation between the degree of extraversion and the readiness for use ( $r=.272$ ,  $P=.04$ ). More extraverted people were more open toward using an online platform. Finally, another weak correlation could be found between the level of desired social support and the willingness to use an online care platform ( $r=-.226$ ,  $P=.04$ ); a higher level of desired social support was a sign of a higher willingness to use an online supply platform.

## Interviews

The text was pooled into the following 3 categories: resources, experience with online interventions, and prerequisites for a collaborative online care platform. First, it was assessed what helped interviewees in dealing with their depression. Most notable were social support, psychoeducation and hobbies, such as reading, sports, or volunteering, *but that only helps to a certain degree*. Another goal of the individual interviews was to examine what experiences with online therapy elderly patients with depression had. Although Person B reported having never used any form of online therapy, Person A had limited experience with online therapy. However, so far person A used the internet primarily for information and research purposes.

In addition, the question, “which criteria respondents consider a necessity for an online care platform to be effective?” was asked. Interestingly, Person A thought that some form of acute online instructions “such as lie down and listen to a bit of relaxing music, and then the person can listen to some for free” would be ideal. The following specific wishes were expressed: unlimited access, easy usability, psychoeducational information, opportunity to exchange information, motivation, platform-independent access, suitable for slow internet connections, and privacy.

## Discussion

### Principal Findings

Focus groups, online surveys, and interviews were conducted to allow an accurate assessment of the prerequisites and willingness to use a collaborative online care platform addressing the special circumstances and needs of the elderly, as well as the needs and requirements of those caring for them and treating them.

The results of the focus groups highlighted that there is a need for a collaborative care platform for depression in old age. However, it was already apparent in the focus group discussion that depressed seniors could be overwhelmed with computer-aided measures. Only future generations could have sufficient skills in their old age to make meaningful use of such offers. This picture was confirmed in the online survey. A comparison of the 2 age groups revealed that younger participants used electronic media more often than older participants. The findings are in line with previous research that has also shown different usage patterns between younger and older participants [35]. Nonetheless, the results of this study underline that the use of ICT was relatively widespread. Consequently, it can be concluded that online interventions could well have the potential [36].

A similar trend can be seen when analyzing the willingness to use: younger participants were more willing to use an online care platform. This finding can in part be explained by another finding of this study; more severe depression was associated with higher willingness to use online services. As younger patients showed more symptoms of depression, they might be more open to online therapy options. Nonetheless, this difference was also found in previous research on the role of age in the willingness to use online interventions [35]. It remains unclear whether in future, older patients will be more receptive because of greater ICT knowledge and experience, or whether they will show less willingness because of other barriers.

The positive correlation between willingness to use an online intervention and extraversion is no surprise, considering extraversion and the influence of this personality dimension on help-seeking behavior. Previous studies already established that extraversion is a predictor of help-seeking behavior in different life situations [36]. In addition, the positive correlation between the desired level of support and the willingness to use an online care platform reflects past research, indicating a link between social isolation and increased readiness to receive benefits [37].

Finally, the interpretation of the interviews points in a comparable direction. Although the younger participant not only had limited experience with online services, the older respondent had no idea of the possibilities of online therapy. From these very uniform findings, it can be concluded that older depressive participants (65 years and older) not only have very limited knowledge about the possibilities of an internet supply platform but are currently unwilling to use a corresponding offer.

With regard to prerequisites to use an online care platform, the focus group formulates particularly low costs, integration into

everyday life, and easy handling as important features. In the user survey, privacy and data protection emerged as the most significant factors. Other features mentioned not only in the online survey but also during interviews included ease of use and free access. In addition, the opportunity to network with other stakeholders, as well as comprehensive information and support in acute crisis situations were highlighted. To conclude, the following factors can be summarized as particularly important for an online care platform: simple use, data protection, and costs.

### Methodological Limitations

There are some methodological limitations to this study. Due to the small sample size, the results of this study are to be interpreted with care. Only a few participants could be recruited both for the online survey as well as for the interviews. However, the reduced participation in epidemiological studies has been extensively shown in the literature [38]. In particular, response rates for telephone interviews have been decreasing rapidly [39]. This might be explained by an oversaturation of online forums and self-help groups with inquiries to take part in yet another online study. A more optimistic perspective might be that only a few visitors of investigated forums and websites belong to the target group. Therefore, the small number of responders represents the digital-savvy portion of this particular age cohort. As the usage of the internet is rapidly increasing,

this study could be well understood as a road sign for a growing group in the future. These difficulties in recruiting subjects also confirm discussed results, in the sense that older depressive people are overwhelmed with online offers. Nonetheless, this study presents a comprehensive picture of the conditions and willingness to use a potential online care platform for elderly patients with depression. Further research on the willingness of older people to use e-mental health apps is necessary. For example, the willingness to use face-to-face therapy versus the willingness to use online services should be compared. It would also be important to measure the willingness to use eHealth services after participants were able to collect some experience themselves so that assessment can be based on concrete experiences and not on an abstract concept as was the case in this study.

### Conclusions

In conclusion, elderly patients with depression are willing to use a collaborative online care platform for depression. Age plays a significant role whereby younger elders are significantly more willing. When designing an online care platform, a particular focus should be on making the intervention simple to use, ensuring online privacy, and making the service as affordable as possible. Online care platforms seem to constitute a viable intervention for older patients. Further research is needed to extend our findings to the overall population.

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### Conflicts of Interest

None declared.

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## Abbreviations

**BFI-10:** 10-item Big Five Inventory  
**CBT:** cognitive behavioral therapy  
**cCBT:** computerized cognitive behavioral therapy  
**DSM:** Diagnostic and Statistical Manual of Mental Disorders  
**e-mental health:** electronic mental health  
**ICD:** international classification of diseases  
**ICT:** information and communication technology  
**PHQ:** Patient Health Questionnaire

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Original Paper

# Digital Access in Working-Age and Older Adults and Their Caregivers Attending Psychiatry Outpatient Clinics: Quantitative Survey

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## Abstract

**Background:** It has been suggested that improving access to mental health services, supporting self-management, and increasing clinical productivity can be achieved through the delivery of technology-enabled care by personal mobile-based and internet-based services. There is little evidence available about whether working-age and older adults with mental health problems or their caregivers have access to these technologies or their confidence with these technologies.

**Objective:** This study aimed to ascertain the prevalence and range of devices used to access the internet in patients and caregivers attending general and older adult psychiatry outpatient services and their confidence in using these technologies.

**Methods:** We conducted an anonymous survey of 77 patients and caregivers from a general psychiatry and old age psychiatry clinic to determine rates of internet access and device ownership, and attitudes to technology-enabled care.

**Results:** We found high levels of internet access and confidence in using the internet in working-age adults, their caregivers, and older adult caregivers but not in older adult patients. The smartphone usage predominated in working-age adults and their caregivers. Older adult caregivers were more likely to use desktop or laptop computers. In our sample, tablets were the least popular form factor.

**Conclusions:** Access rates and uptake of internet-based services have the potential to be high in working-age adults and their caregivers but are likely to be markedly lower among older adult patients attending psychiatry clinics. Applications designed for tablets are likely to have low uptake. All groups identified appointment reminders as likely to be beneficial.

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## KEYWORDS

general psychiatry; internet access; memory assessment and treatment service; mobile phone; old age psychiatry

## Introduction

It is recognized that although the majority of people with mental health problems never seek help [1], current United Kingdom (UK) services are struggling with rising demand in a time of severely constricted resources [2]. One strategy that seeks to address these dilemmas is to improve access to mental health services, support self-management, and increase clinical productivity, through the adoption of technology-enabled care [3].

The launch of iPhone in 2007, Android handsets in 2008, followed by Apple's iPad tablet computers in 2010, combined with the increasing prevalence of Wi-Fi and mobile broadband, have led to the widespread public adoption of powerful mobile technology. Smartphones overtook all other computing devices in popularity in the UK in 2015. As many as 90% of young adults now own a smartphone, and adults use a smartphone for nearly 2 hours a day on average.

In older adults, the situation is more complex; in the United Kingdom, 3 in 10 adults aged 65-74 years, two-thirds of those aged  $\geq 75$  years, and a quarter of those in the lowest socioeconomic group of older adults do not use the internet at all [4]. In 2015, a large US study [5] of 3116 adults aged  $>65$  years found that only 15.1% had access to the internet through a handheld device. Among those aged  $>65$  years, the youngest, wealthiest, and best-educated participants were most likely to have internet access, but the study did not describe the mental health status of participants. Given that many people living with mental health problems are older, and suffer socioeconomic disadvantage [6] it is a concern that digital exclusion could mean that ambitions to revolutionize mental health care through technology may fall at the first hurdle.

Given the lack of available data on internet access among people with mental illness and that estimates of technology use that do exist vary markedly and do not tend to include considerations of internet access [7], we decided to survey our general psychiatry clinic (which included a mix of patients aged from 18 to 65 years and caregivers attending for psychological therapy, planned and emergency psychiatric assessment and follow-up, and a clozapine phlebotomy service) and a separate specialist older adults (aged  $>65$  years) memory clinic. We compare our findings to general population data collected by Ofcom [4] and explore the implications.

## Methods

Our project was reviewed by the local Ethics Committee, which determined that full ethical approval was not required. The study was approved by the Royal Edinburgh Hospital Quality Improvement Team. An anonymous survey (see [Multimedia Appendix 1](#)) was conducted by inviting all those attending the Royal Edinburgh Hospital Outpatient Department and the Memory Assessment and Treatment Service (MATS) from April 8, 2016 to May 6, 2016. Both patients and their caregivers were surveyed. Respondents were asked whether the appointment they were attending was for themselves or for someone they were accompanying. The survey was administered by clerical staff at each outpatient clinic and was also available on tables in the waiting rooms with posters inviting patients to participate. One of the authors (CC) visited the general psychiatry outpatient clinic and directly brought the survey to the attention of patients. Survey questions were written in simple English, taking care to avoid technical jargon, using a mix of dichotomous questions, free response questions, and 5-point Likert scales. This survey was designed to be short and easy to understand, especially for people with dementia. Moreover, exact wording was chosen with reference to questions in adults' media use and attitudes to ensure responses were comparable.

## Results

In the general psychiatry outpatient clinic, there were 11 male and 13 female patient attendees whose ages spanned from 18 and  $>75$  years and 6 male and 12 female caregiver attendees

whose ages spanned from 24 and 74 years. In the MATS clinic, there were 8 male and 5 female patient attendees aged  $>75$  years and 9 male and 13 female caregiver attendees whose ages spanned from 18 and  $>75$  years.

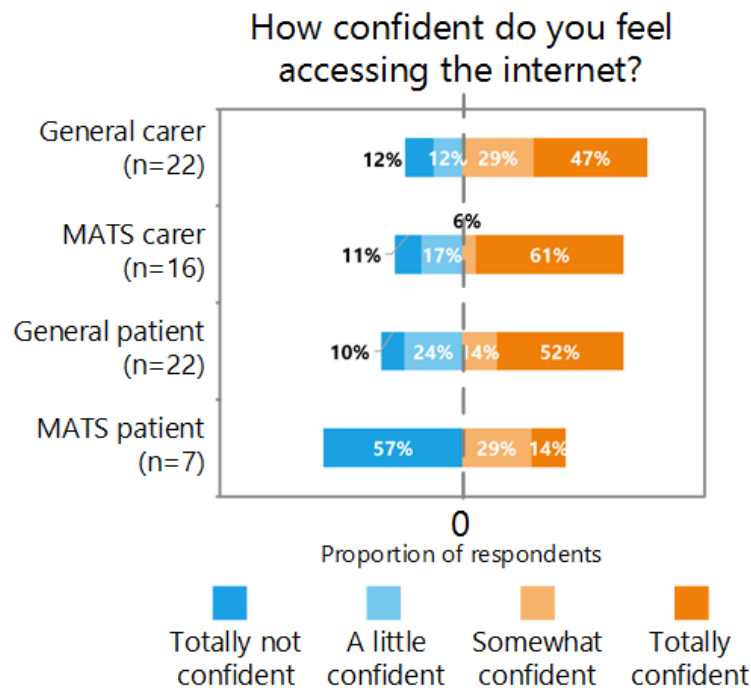
The overall prevalence of internet access was high, with 85% (63/74) respondents reporting access to the internet. Of note, 95% (35/37) of caregivers and 75% (28/36) of patients had access to the internet. However, only 54% (7/13) of the patient group attending MATS had any internet access, compared with 88% (21/24) of the general psychiatry group (general psychiatry outpatient clinic). Of those with the internet, the majority had an internet connection in their home, and the remaining 2 had access at public libraries.

In addition, the mobile phone ownership was high, with 90% (66/73) respondents owning a mobile phone. Notably, 96% (22/23) of general psychiatry patients and 70% (9/13) of MATS patients owned a mobile phone. Similarly, all general psychiatry caregivers ( $n=18$ ) had mobile phones, while 89% (17/18) of MATS caregivers did. Most respondents were able to access the internet on their phones; however, 27% (20/74) were not able to because they did not own a phone or because their phone could not connect to the internet. This was true for 77% (10/13) of MATS patients and 21% (4/19) of MATS caregivers, but only for 6% (1/18) of general psychiatry caregivers and 21% (4/19) of general psychiatry patients.

Mobile phones were the most popular device in all groups, other than MATS caregivers, where personal computers or laptops were ubiquitous ( $n=19$ ). Even in that group, 90% (17/19) had a mobile phone in the household, and the same number had a tablet. Overall though, tablets were the least popular device with fewer than half of general psychiatry patients (11/24) and caregivers (8/18) and MATS patients (6/13) having access to one. For general psychiatry patients and caregivers and MATS patients, personal computers and laptops were available to 75% (18/24), 78% (14/18), and 62% (8/13), respectively.

Caregivers were more confident using the internet than patients, and the general psychiatry group tended to be more confident than the MATS group.

Within the MATS group, 56% (10/18) of respondents had a mobile phone, but only 22% (4/18) of respondents had a phone that could connect to the internet. The overall internet access was higher with 50% (9/18) reporting access to the internet. Only 11 of those aged  $>75$  years rated their confidence with accessing the internet, but 6 stated they were totally not confident, 2 a little confident, and 3 totally confident. This limited sample suggests they do not feel confident accessing the internet. Furthermore, personal computer and tablet ownership was similar to that of mobile phones among those aged  $>75$  years in the MATS group with 10 and 8 of 18 respondents, respectively, owning those devices. [Figure 1](#) shows the ratings provided by the respondents on a Likert scale regarding their confidence in accessing the internet. No respondent answered "neither," and no MATS patient responded "A little confident." These values are not shown.

**Figure 1.** Respondents' ratings on a Likert scale regarding their confidence in accessing the internet. MATS: memory assessment and treatment service.

Several patients commented on the survey as follows:

*Fine for younger caregivers but no use for older patients. There could be no confidence that messages, etc, would be picked up. [MATS Caregiver, 55-64]*

*Father would be completely unable to use technology, but would think that he could. [MATS patient, 75+ (completed on behalf of father)]*

*A vital part of being kept informed. Mobile phone iPad PC emails. [MATS patient, 75+]*

*Appointment reminders via email/text would be very useful [18-24, general psychiatry patient]*

## Discussion

### Principal Findings

The overall finding of this paper is encouraging—(63/74) 85% of patients and caregivers attending psychiatric clinics in Edinburgh reported that they had access to the internet; overall, (61/74) 82% had access to the internet at home. This is broadly similar to the UK general population rate of 86% and 84%, respectively.

### Older Adult Clinic

At our older adults' clinic (MATS), in the patient group, 46% (6/13) did not have access to the internet; in this group, all were all aged over 75 years, while the caregiver group at the older adults clinic was aged from 18-24 to >75 years. Our findings are in line with recent UK general population surveys, which report that the >75 age group is the least likely to have internet access, and up to two-thirds had no access at all [4].

In our sample, MATS patients were also the least likely to be able to access the internet on their phone (3/13), suggesting that they would not be able to access the internet in the waiting room or a clinic. Our sample is again in line with UK population

estimates, which report that only 18% of those aged 65-74 years and 4% of those aged >75 years accessed the internet through a smartphone [4], and with Shahrokni et al [5] who found that 15.6% of those aged >65 years in their survey of 3116 people had accessed the internet through a handheld device. In addition, they found that the group that had accessed the internet using a handheld device comprised the youngest, wealthiest, and best-educated participants. This is of great concern given that people with mental health conditions are likely to belong to lower socioeconomic groups [6] and people with dementia are likely to be older. This may place patients with dementia as among the least likely to access the internet through handheld devices.

Ofcom [4] found that those aged 65-74 years and >75 years used tablets more often than smartphones, but this only accounted for 23% and 13%, respectively, suggesting that services developed for tablets may not be currently able to best address the needs of older adults; this may impact the types of services they are able to access. If older adults are to use internet-based services, they may have to be directly targeted at this group to overcome these particular barriers, something which is not happening at present [8].

### General (Working Age) Clinic

In a survey of 100 patients at a general psychiatry outpatient clinic in the United Kingdom, Glick et al [8] found that while 85% of patients with serious mental illness had a mobile phone, only 37% owned a smartphone. Firth et al [9] conducted a meta-analysis and found the rates to be 81.4% and 35%. However, in our general psychiatry sample, (22/23) 96% were found to own a mobile phone, and (19/23) 83% had internet-enabled phones. Tablet computers were the least popular computing device in our general sample, although 57% (42/74) had access to a tablet. In sharp contrast to the older adult clinics, rates of internet access here are high, suggesting that

internet-dependent services may be more widely used within this group.

### Socioeconomic and Geographic Factors

Internet access rates vary with the socioeconomic status and are likely to be lower in more rural areas. Handley et al surveyed 1246 patients in rural Australia in 2014 to determine the feasibility of internet-based mental health treatments using 2 feasibility criteria—(1) internet access and (2) willingness to use internet services. This Australian study found that only 7% of those who would consider using an internet service cited lack of internet access as a barrier [10], but that rates of internet access decreased markedly with increasing rurality, which is also true in Scotland [11].

### Qualitative Feedback: Attitudinal Factors

The second barrier to uptake identified by Handley et al was the willingness to use internet-based services. As well as having poorer internet access, older adult clinic attendees may be the less likely to see value in using digital services. Qualitative feedback in our survey, which prompted “If there’s anything you’d like to say about the use of technology in care, please do so here,” included remarks such as:

*Fine for younger caregivers but no use for older patients. There could be no confidence that messages, etc, would be picked up.* [MATS Caregiver, 55-64]

It is recognized that if users are unwilling or simply uninterested in using digital technology, then they will not integrate it into their daily routines [12]. Conversely, we also found concern expressed that older adult patients may overestimate their capability:

*Father would be completely unable to use technology, but would think that he could* [Caregiver of patient aged 75+]

Sourbati [12] found that, in general, older people had very little idea how internet-based services might benefit them.

Clearly, health care needs to be tailored to the needs of an individual. One older adult commented:

*A vital part of being kept informed. Mobile phone iPad PC emails.* [MATS patient, 75+]

In general, we found younger patients and caregivers were more enthusiastic about the benefits of internet-based services and identified clear, practical benefits, such as appointment reminders and the provision of additional information, as beneficial. In addition, Firth et al [9] found appointment

reminders and enhanced communication with health services to be the most sought after use for technology. Moreover, respondents in our study valued digital communication with our services. However, a recurring theme is service users’ concern that implementing technology may be used as an excuse to reduce services and, in particular, face-to-face contact [13,14], although some studies suggest social benefits [15].

### Trust and Equity

Another recurring theme in digital health care is trust. Despite their abundance, the regulation of digital health apps is still being developed [16]. Given the potential pitfalls of misinformation and poor health advice, it seems appropriate that health care services should have a role in identifying and curating technology-enabled care. Patients in this sample identified a difference between apps and “helping care,” suggesting a lack of trust:

*I have no knowledge of what “technology in care” is—is it helping care through technology or is it apps?* [35-44, general psychiatry caregiver]

At present, there is conflicting advice on apps for mental health. Bennion et al [7] collected data on internet-based services used to treat or manage stress, anxiety, or depression in English health trusts using freedom of information requests, finding 41 different apps or services recommended by the National Health Service (NHS) in England. They highlighted the lack of uniformity in making these recommendations and that there were no apps designed for people over the age of 65 years.

Furthermore, in moving to greater use of digital services, barriers to adoption must be recognized and efforts made to ensure equitable access. Our study suggests that, at present, older adult patients and caregivers attending psychiatry clinics are less likely to use digital services, particularly if these are tablet or smartphone based; however, if these tools are personalized to an individual’s circumstances, uptake is still possible.

### Limitations

The principal limitation of this study is geography. Further research with samples across a range of locations would be informative. Second, there is a risk of selection bias, and efforts to capture a more representative sample would improve the reliability; however, the alignment of our findings with larger Ofcom surveys [4] suggests that this study was broadly in line with the existing literature. The survey design was pragmatic. Furthermore, survey codesign with patient and caregiver involvement could improve the uptake and validity.

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### Conflicts of Interest

None declared.

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Multimedia Appendix 1



Survey.

[[PDF File \(Adobe PDF File\), 83KB - aging\\_v1i2e4\\_app1.pdf](#)]

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## Abbreviations

**MATS:** memory assessment and treatment service

**NHS:** National Health Service

**UK:** United Kingdom

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