

Featured Article

Technology for home dementia care: A prototype locating system put to the test

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Abstract

Introduction: The user experience of persons with dementia and their primary caregivers with locating systems is not firmly established.

Methods: Eighteen dyads used a prototype locating system during 4 weeks. Primary outcome measures were ratings of usability, and product functions and features. Secondary outcome measures were caregiver burden, perceived self-efficacy, frequency of use, and willingness to purchase the prototype. Changes in scores between baseline (T₁) and end of testing period (T₂) were compared by performing independent and dependent samples correlations and descriptive statistics.

Results: Seventeen dyads made up the final sample. Ratings of usability and product functions and features were fair, but usability ratings were significantly reduced after 4 weeks. Although the prototype was used infrequently by majority of the participants, most caregivers would be willing to purchase the prototype, with men more willing than women. No significant change in technological willingness, caregiver burden, or perceived self-efficacy was found between T₁ and T₂. Perceived self-efficacy significantly negatively correlated with willingness to purchase the prototype after 4 weeks.

Discussion: Results highlight the importance of including end users in the research and development phase of locating systems to improve the user experience in home dementia care. Necessary indications for further research are carrying out randomized controlled trials with larger, more representative samples and developing innovative software and hardware solutions.

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Keywords:

Assistive living technologies; Technology; Caregivers; Dementia; Locating systems; Tracking systems; User experience; Usability

1. Introduction

In 2015, the number of persons diagnosed with dementia (PwD) was estimated at almost 47 million worldwide [1]. By 2050, this number is projected to increase about 135 million owing primarily to aging populations [2]. Currently, most

care received by PwD is provided by informal, primary caregivers, such as family members, friends, or others [3]. Research to date has overwhelmingly shown that informal care places a high amount of mental, physical and financial stress, and burden on caregivers, including suffering from anxiety, depression, sleep disturbances, reduced immune function, and job loss [4]. Accordingly, investing in research to develop innovative, promising, as well as equitable care solutions for home and residential dementia care is considered an essential component of a global dementia care plan [2]. To this end, developing assistive living technologies that particularly aid PwD to maintain their ability to

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independently carry out activities of daily living is regarded as a key research area [5], with much research to date focusing on the use of tracking or locating systems.

By using global positioning system (GPS) technology, locating systems make it possible to address one of the first significant sources of stress and burden faced by PwD and caregivers alike in the early stages of dementia, namely disorientation or getting lost while outside the home environment alone [6]. This is done by determining the location of PwD in real time and by providing assistance with orientation to PwD and caregivers when needed. In recent years, research on the user experience of locating systems by PwD and caregivers has gained increasing attention [7,8], yet differences in the definition of user experience between studies make comparing results difficult.

At present, a large number of locating systems, such as watches, tracking pagers, or shoe soles, are commercially available [9]. However, their adoption and long-term use remains low outside research and clinical settings [10,11]. It has been described that methodological limitations such as relying on proxy evaluations of user experience by having caregivers or professionals answer in place of PwD help contribute to the observed underutilization of locating systems [12]. Furthermore, the importance of adequate knowledge on using locating systems was emphasized [13]. Other studies using GPS technology focused on research questions regarding mobility and cognitive impairment. Their results indicated life space parameters may contribute to monitor functional decline in dementia [14], and caregiver burden was closely correlated to challenging walking behavior of PwD [15,16].

Accordingly, the aim of the present study was to evaluate the user experience regarding a prototype locating system in home dementia care to better understand the needs and preferences of PwD and their caregivers. User experience within this study is defined based on the ISONORM 9241/210 [17]. As user experience is a multifaceted construct that comprises users' affective, cognitive, and behavioral attitudes toward a product [17–19], we set out to assess participants' responses to the following variables: usability, ratings of the prototype's functions and features, caregiver burden, perceived self-efficacy, subjective frequency of use, and willingness to purchase the prototype.

2. Methods

2.1. Sample

A total of 18 dyads of PwD and their primary caregivers participated in our user study. Recruitment was done following a convenience sampling technique from eligible patients and their primary caregivers of the Charité University Hospital's Memory Clinic. To ensure having a more representative user evaluation, PwD with different dementia severities were included. In total, three (16.7%) had a mild cognitive impairment, six (33.3%) had a mild disease severity, and

nine (50%) had a moderate disease severity based on their Mini-Mental State Examination (MMSE) scores obtained no longer than one month before inclusion, performed by an experienced neuropsychologist. Similarly, primary caregivers were made up of ten husbands (55.6%), six wives (33.3%), and two daughters (11.1%). Participants provided their written informed consent at baseline. Ethics approval was obtained by the Charité Ethics Board, number EA4/033/13.

2.2. Materials

2.2.1. Prototype locating system

The locating system used was a mobile application (app; webXells GmbH, Potsdam, Germany) featuring four main functions: locating, call, alarm, and service hotline, and two sub functions: zone mapping and zone sharing. As the name implies, the locating function allows to remotely locate PwD using GPS technology. In real time, a city map mapping the user's location is created (i.e., zone mapping). Caregivers are able to create individual habitual zones for PwD with the Geofencing function. Should the app locate a PwD as entering or leaving a habitual zone, a notification message can be sent to their caregiver (SMS; i.e., zone sharing). The call function allows users to come into telephone contact, whereas the alarm function allows PwD to call their caregiver when they need more urgent assistance, and the service hotline function enables users to obtain ongoing technological assistance. Our team selected this prototype as we have previously conducted a user study with an earlier version of the prototype with caregivers [20]. In short, the prototype was positively rated overall, suggesting its promising future research and development potential.

2.2.2. Additional products

To use the app, PwD received a Samsung Galaxy xCover smartphone with the prototype preinstalled. We recommended to wear the smartphone in an adjustable waistband, but depending on individual preferences, any other kind of wearing the device nearby and safely secured within clothing or handbag was optional. Caregivers received either a Samsung Galaxy Tab II tablet personal computer (PC; $n = 9$) or a Samsung Galaxy Note II smartphone ($n = 9$) with the prototype preinstalled. These products were selected as they feature a touch screen with a large display and are devoid of unnecessary functions. Fig. 1 shows the tablet PC and the smartphone, both with the installed prototype.

2.3. Study design

2.3.1. Baseline (T_1)

The entire testing period lasted for 4 weeks from baseline (T_1) to the end of the testing period (T_2). All questionnaires at T_1 and T_2 were completed by caregivers.



Fig. 1. Tablet PC for caregiver and smartphone for PwD, both with the installed prototype.

During the first meeting, caregivers completed a demographics questionnaire, the short version of the Zarit Burden Interview (ZBI) [21], and the General Self-Efficacy (GSE) scale [22]. The ZBI short version contains 12 questions, each scored on a five-point Likert scale ranging from 0 = never to 4 = nearly always. Total scores range from 0 to 48, where higher scores indicate higher subjective burden. The GSE scale was used to measure how caregivers perceive themselves when handling stressful situations. Questions follow a four-point Likert scale ranging from 1 = not true at all to 4 = exactly true. Total scores range from 1 to 40, with higher scores indicating higher perceived self-efficacy. The demographics questionnaire included questions on PwD's walking behavior, impairments in orientation, and the number of times caregivers had to search PwD outside the home environment. Two questions also assessed subjective technological experience, namely: (1) "How much experience do you have with the following products: cell phone without Internet, smartphone, tablet PC, and computer?" and (2) "How often do you use the following functions: SMS, e-mail, telephone, Internet, navigation system?" Each question used a four-point Likert scale ranging from 1 = none/never to 4 = a lot/very often, and total scores ranged from 9 to 36, with higher scores indicating a higher subjective technological experience. To measure technological commitment, four select questions of the German Technology Commitment Scale were used [23]. The questions specifically measured acceptance or openness toward technological products ($n = 3$) and perceived self-competence with regards to using such tools ($n = 1$) on five-point Likert scales ranging from 0 = not at all true to 4 = completely true. Final scores range from a possible 0 to 16, with higher scores indicating higher subjective technological commitment.

Dyads then participated in an interactive educational training session of 30 minutes during which they received their products and information on how to use them. Depending on preexisting technological experience, the training sessions lasted longer or were even shorter than 30 minutes. To verify whether the provided information was understood, caregivers completed these four tasks: (1) use the locating function to locate PwD; (2) use zone mapping function to map out the location of PwD; (3) use the call function to call PwD; and (4) call the service hotline. Afterward, caregivers completed the ISONORM 9241/10 questionnaire [24] to assess their usability rating of the prototype. This questionnaire measures seven areas of usability, including the following: (1) suitability for the task, (2) self-descriptiveness, (3) controllability, (4) conformity with user expectations, (5) error tolerance, (6) suitability for individualization, and (7) suitability for learning. Answers follow a seven-point Likert scale ranging from 1 = not at all satisfied to 7 = very satisfied, and the maximum number of points a person can obtain is 210. To examine whether dyads used the prototype on a regular basis, and to assess their ongoing experience, they received a user diary. Dyads were asked to specify a situation where they had used the prototype, describe any difficulties experienced, list the attitudes of the PwD toward the prototype, and report on how satisfied they were with the prototype overall on a scale ranging from 0 = not at all satisfied to 4 = very satisfied.

2.3.2. End of testing period (T_2)

Caregivers completed the ZBI, GSE, and ISONORM 9241/10 a second time to assess any possible changes from baseline. Furthermore, dyads completed a 40-minute semistructured interview to rate the prototype's

product functions and features. The product functions and the main product features (i.e., font style, font size, font color, overall colors displayed, icons used to represent product functions, and labels given to product functions), were rated on a five-point Likert scale ranging from 0 to 4, with higher numbers indicating more positive ratings (0 = very poor, 1 = poor, 2 = fair, 3 = good, 4 = very good). Furthermore, caregivers reported their subjective frequency of use of the prototype on a scale ranging from 0 = never used to 4 = used very often. In addition, participants commented on their quantitative ratings within the interview. To examine whether caregivers' ability to use the prototype had improved over the 4 weeks, the same four practical tasks at baseline were readministered. Finally, the caregivers were asked if they would purchase the prototype (0 = yes, 1 = no) and for the maximum amount of money they would spend for a system covering all individual needs. Possible answers covered the amounts of 39.99€, 59.99€, 79.99€, and 99.99€.

2.4. Statistical analysis

SPSS Statistics 23 was used to analyze data. T_1 and T_2 results were compared by performing independent samples t-tests, paired samples t-tests, Pearson's correlations, chi-square tests, and descriptive statistics.

3. Results

3.1. Participant characteristics

Before data analysis, data were inspected for outliers and were not detected. Of the 18 dyads included at T_1 , one dyad dropped out for reasons unrelated to study involvement (dropout rate: 5.6%). Unless otherwise specified, the reported results are from these 17 dyads. Participant characteristics at baseline are presented in Table 1.

As expected, MMSE scores correlated with baseline caregiver burden scores, $r = -0.53$, $P = .024$. No other significant findings between other demographic variables were found at baseline. Regarding PwD's walking behavior, the majority were able to walk outside alone at study inclusion ($n = 14$; 82.4%), but several were rated as displaying impairments with orientation, ranging from none ($n = 3$; 17.6%), mild ($n = 4$; 23.5%), moderate ($n = 7$; 41.2%), to severe ($n = 3$; 17.6%). Almost all caregivers never had to search PwD outside the home environment ($n = 15$; 88.2%), and only one caregiver (5.9%) had used a locating system in the past.

3.2. Primary outcome measures

3.2.1. Usability

The total usability rating of the prototype declined significantly from T_1 to T_2 , $t(16) = 2.34$, $P = .032$. The variation in range of scores is also larger at T_2 , indicating that

Table 1
Participant characteristics at baseline (T_1)

Characteristic	PwD ($n = 18$)	Caregivers ($n = 18$)
Gender ratio (male/female)	7/11	10/8
Age (years); range	71.94 ± 5.01; 62–82	66.89 ± 10.65; 41–78
MMSE score (out of 30)	18.89 ± 7.49 (5–29)	
MCI (cutoff 28)	3	—
Mild (cutoff < 28 > 20)	7	—
Moderate (cutoff ≤ 20)	8	—
Number of years diagnosed with dementia		
Two or less	6	—
Three or more	12	—
Educational attainment		
High school	—	5
College	—	2
University	—	11
Living with PwD	—	16
Technological experience (out of 36)	—	23.1 ± 6.0 (9–32)
TCS (out of 16)	—	9.9 ± 3.3 (5–16)
GSE (out of 40)	—	29.7 ± 4.8 (19–36)
ZBI (out of 48)	—	13.4 ± 7.2 (0–28)

Abbreviations: PwD, persons diagnosed with dementia; MMSE, Mini-Mental State Examination; MCI, mild cognitive impairment; Technological experience, higher scores indicate higher technological experience; TCS, Technology Commitment Scale—higher scores indicate higher technological commitment; GSE, General Self-Efficacy Scale—higher scores indicate higher perceived self-efficacy; ZBI, Zarit Burden Interview—higher scores indicate higher burden.

NOTE. Continuous variables are displayed as mean value ± standard deviation, with minimum and maximum scores in parentheses.

caregivers' usability rating was more similar at T_1 and more widespread at T_2 . Results are displayed in Fig. 2. Concerning the seven usability subcategories, all scores decreased from T_1 to T_2 , with categories one (i.e., suitability

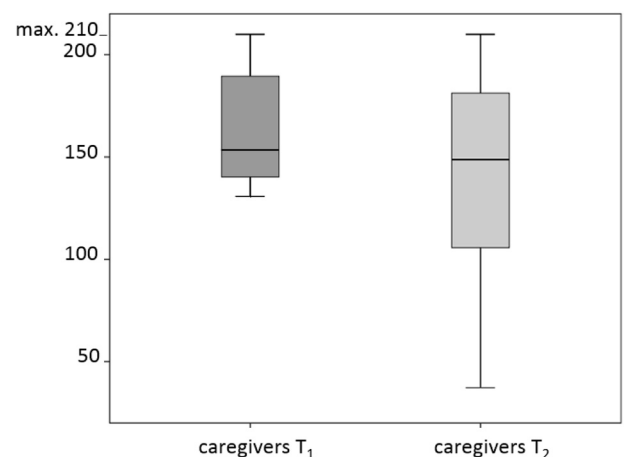


Fig. 2. Total usability evaluation of the prototype with the ISONORM 9241/10: scores ranging from 0 to 210; higher scores indicate better usability ratings. T_1 : $M = 163.5 \pm 28.7$; min/max = 130.75/210. T_2 : $M = 139.94 \pm 46.5$; min/max = 37.25/210. Continuous variables are displayed as mean value ± standard deviation. Abbreviations: min, minimum; max, maximum; M, mean value.

for the task), three (i.e., controllability), four (i.e., conformity with user expectations), and six (i.e., suitability for individualization) significantly reducing, where $t(16) = 2.37, P = .031$; $t(16) = 2.27, P = .037$; $t(16) = 2.17, P = .045$; and $t(16) = 2.12, P = .05$, respectively. Usability rating at T_1 or T_2 did not correlate with any relevant variable at either time point.

3.2.2. Ratings of product functions and features

3.2.2.1. Product functions

Overall, the prototype was rated fairly with respect to product functions ($M = 2.4$; standard deviation [SD] = 0.9; min/max = 0/4). Of the functions to be rated, the locating function was rated most positively ($M = 2.8$; SD = 1.1; min/max = 0/4), followed by the zone mapping function ($M = 2.6$; SD = 1.2; min/max = 0/4), the service hotline function ($M = 2.4$; SD = 1.3; min/max = 0/4), the call function ($M = 2.3$; SD = 1.2; min/max = 0/4), and the zone sharing function ($M = 2.2$; SD = 1.5; min/max = 0/4). The alarm function was rated most negatively ($M = 2.0$; SD = 1.7; min/max = 0/4). No significant differences between function ratings were found. Comments made by participants identified three specific areas of dissatisfaction with the zone mapping function, namely the number of steps needed to take to map zones ($n = 3$; 17.6%), the complexity of these steps ($n = 3$; 17.6%), and the reliability of this function ($n = 4$; 23.5%). In addition, five caregivers (29.4%) explicitly stated the overall functioning of the prototype as unreliable due to technological problems. In general, they complained about the complex functions and lacking reliability. In detail, they criticized the not precisely working Geofencing. One caregiver mentioned that the prototype had helped them locate the PwD three times during the study.

3.2.2.2. Product features

Similarly, the prototype's product features were fairly rated ($M = 2.3$; SD = 0.9; min/max = 0/4). Of the features to be rated, the overall colors displayed received the best rating ($M = 2.9$; SD = 0.9; min/max = 1/4), followed by the labels given to the different product functions ($M = 2.7$; SD = 0.7; min/max = 2/4), the font style ($M = 2.6$; SD = 0.9; min/max = 1/4), and the icons used ($M = 2.5$; SD = 0.9; min/max = 1/4). The font size and font colors were rated equally least positively ($M = 2.1$; SD = 1.1; min/max = 0/4; min/max = 1/4, respectively). A significant difference was found between the overall colors displayed and the font colors, $t(16) = 3.25, P = .005$, as well as with font size, $t(16) = 2.64, P = .018$. Some participants ($n = 4$; 23.5%) would have preferred to wear the prototype integrated into a watch or another small device avoiding to stigmatize the PwD.

Ratings of the product functions or features did not correlate with any relevant variable at T_1 or T_2 , and dyads' overall weekly satisfaction ratings of the prototype furthermore show that it was fairly rated

each week ($M_{\text{range}} = 1.83\text{--}2.3$; $SD_{\text{range}} = 0.82\text{--}1.2$; min/max_{range} = 0/3), with no significant difference found between any given week. Further reports from the user diary revealed a list of difficult situations while using the prototype. One caregiver reported on removal of the smartphone from the waistband by the PwD. The locating device was temporarily lost and by this caused additional burden. In terms of the acceptance of the PwD to constantly wear the device, $n = 4$ (23.5%) reported overall positive and $n = 2$ (11.8%) negative attitudes. If the caregiver received a tablet PC or a smartphone did neither influence the primary outcome measures nor the time to complete tasks.

3.3. Secondary outcome measures

3.3.1. Caregiver burden and perceived self-efficacy

No significant difference in caregiver burden from T_1 ($M = 13.4$; SD = 7.2; min/max = 0/28) to T_2 ($M = 12.4$; SD = 7.6; min/max = 0/28) or in perceived self-efficacy from T_1 ($M = 29.7$; SD = 4.8; min/max = 19/36) to T_2 ($M = 28.3$; SD = 4.8; min/max = 18/38) was found.

3.3.2. Subjective frequency of use and time to complete tasks

Dyads believed to have used the prototype a moderate number of times during the testing period ($M = 2.3$; SD = 1.1; min/max = 1/4), and most mentioned having used it when going for a walk ($n = 8$; 47.1%), visiting family and friends ($n = 5$; 29.4%), and for grocery shopping ($n = 5$; 29.4%). Although the time required to complete the four practical tasks decreased from T_1 ($M = 5:24$ minutes; SD = 4:27; min/max = 1:17/19:24) to T_2 ($M = 3:45$ minutes; SD = 2:05; min/max = 0:37/9:15), no significant difference between both time points was found.

3.3.3. Willingness to purchase the prototype

Most caregivers ($n = 13$; 76.5%) mentioned being willing to purchase the prototype, and results of our chi-square test show that men were more willing than women, $\chi^2(1, N = 17) = 7.46, P = .029$. Concerning the pricing for a system that covers all needs, the largest proportion of participants chose 39.99€ ($n = 8$; 47%) as suitable. Followed by 23.5% ($n = 4$), who would pay up to 59.99€, 11.8% ($n = 2$) up to 79.99€, and 17.6% ($n = 3$) up to 99.99€. In addition, a significant negative correlation between perceived self-efficacy at T_2 and willingness to purchase the prototype was found, $r = -0.483, P = .049$.

4. Discussion

The present study reports on the user experience with a prototype locating system in home dementia care. As expected, baseline MMSE and caregiver burden scores

were significantly correlated. Regarding user experience, usability ratings show that the prototype was rated fairly at both time points, although surprisingly ratings significantly decreased over time. This indicates several experienced technical deficiencies affecting usability and underlines the importance of reliable systems (e.g., regarding GPS accuracy and Geofencing). Other studies already stated challenges concerning complex GPS-locating systems [25]. Reliability and user-friendliness are of highest importance, especially for the caregiver, but also for the PwD. In addition to this, our results show that potential users have to be trained. This indicates the need to develop training manuals and programs for users with few technological experience, also stated by other authors [13].

Furthermore, we found that four subcategories of usability (i.e., suitability for the task, controllability, conformity with user expectations, and suitability for individualization) significantly diminished after time. Focusing on these four areas of usability when developing locating systems may contribute toward improving usability scores, especially after users acquire more experience. This suggestion seems particularly relevant given that usability ratings were not significantly associated with any other variable, implying that the inherent characteristics of the prototype influenced usability ratings rather than the external characteristics of participants (e.g., caregiver burden, or technological experience and commitment). The fair ratings of the product's functions and features reported here are encouraging, considering that the locating system was merely a prototype. Although these results are largely descriptive, this type of information regarding usability is surprisingly limited in the available literature, which limits our knowledge on the needs and preferences of potential users. As expected, participants preferred the locating function, but no function was rated significantly better than another.

In any case, the fair ratings of the prototype are at odds with the finding that it was used infrequently by most of the participants. One way to interpret this discrepancy is that PwD and caregivers are open to the idea of receiving additional forms of support in home dementia care and accordingly rated the prototype fairly overall. Other studies suggest the high potential of assistive technologies in home dementia care similarly [25], in particular, the positive effects of locating systems for caregivers were mentioned [6]. Interestingly, we additionally found that most caregivers, men more than women, would be willing to purchase the prototype. Those who rate themselves as handling stressful situations well are more inclined to purchase a locating system. This is reflected by a significant negative correlation between self-efficacy at T₂ and willingness to purchase the prototype.

The statistical power of this study is limited by the small sample size. Furthermore, PwD were not directly in focus

of our research, which might be a methodological limitation [12]. Nevertheless, aiming to explore the dyad as an entity, we gathered some interesting insights on PwD indirectly. Because the assessment of the user experience of cognitively impaired is a challenge, we recommend to focus on qualitative methods, such as problem-centered interview [26] and participatory design approaches [27]. Including dyads in early development would additionally support recommendations with the aim to provide a person-centered approach for dementia care [28]. A further limitation of our study is the lack of data with respect to the frequency of use, which was caused by a technological limitation of the tested system. Also other small user studies have experienced challenges, leading to comparable limitations [6,25]. Finally, it can be speculated that the duration of our study was too short and PwD were not sufficiently impaired to investigate the usefulness of the tested system in depth.

In summary, our study could be seen rather as a pilot study in this very young research area, focusing on implications for further research obtainable from these findings. Thus, developing innovative software solutions for caregivers and hardware solutions for PwD is one relevant implication. In this context, future experiments should also focus on locating systems already available and evaluating their current quality. Nevertheless, the most important conclusion is the high relevance of carrying out randomized controlled trials with larger, more representative samples in a real environment. This recommendation was also stated by other authors [12,29]. Proposed suitable outcome measures in earlier studies were "time spent searching" and "days until long-term admission" [29] as well as caregivers' well-being and quality of life [15]. Because technological limitations often inhibit to investigate the usefulness of assistive technology, we recommend to focus on the usability, until these kinds of limitations have been overcome. In addition, future studies that include different stakeholders will likely help us gain more insights into how to better address the needs and preferences of PwD and caregivers to improve their user experience with locating systems. As this kind of research addresses many disciplines such as business, design, gerontology, neurology, and psychiatry, focusing on interdisciplinary research is required.

Taken together, our findings highlight the importance of including end users in the research and development phase of locating systems to improve user experience of locating systems in home dementia care.

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RESEARCH IN CONTEXT

1. Systematic review: The authors reviewed the literature (e.g., PubMed) and meeting abstracts and presentations. Although a number of locating systems exist, their adoption in home dementia care remains low, and the inclusion of persons with dementia in user experience studies is limited. These relevant citations are appropriately cited.
2. Interpretation: Our findings highlight the importance of including persons with dementia and their primary caregivers in the research and development phase of locating systems to improve use experience in home dementia care.
3. Future directions: Recommendations to improve user experience are provided based on ratings of usability, and product functions and features. Future studies more heavily involving persons with dementia, as well as different stakeholders, are welcomed.

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