

Technological Interventions to Increase Mobility of Older Adults with Dementia

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Abstract—Since lack of movement constitutes a risk factor for dementia, increasing mobility of older adults is important. We present three technological prototypes, which gear towards increasing mobility, while considering issues such as privacy, autonomy, daily routines, accessibility and shared responsibility, raised in a series of workshops. An expert review of the prototypes especially highlights the importance of considering privacy and autonomy and the need for a holistic perspective when designing technology for older adults with dementia as well as their relatives and other caregivers.

I. INTRODUCTION

Lack of movement is considered to be one of the primary risk factors for dementia in the USA and Europe [1]. Maintaining a mobile and active lifestyle can at least contribute to delay the advance of dementia symptoms. Encouraging mobility of people with dementia also increases risks like getting lost or falling. Because of this, technological solutions often concentrate on monitoring and restricting mobility of persons with dementia. People with dementia are often only considered passively while stakeholders such as care personnel and relatives are considered primarily when designing and implementing technological solutions. Attempts to increase independent mobility of people with dementia mostly focus on smartphones or smartwatches, both of which are difficult to handle for this user group.

In the project Way-Key [2] we follow the approach of promoting mobility. For persons with light to medium grades of dementia independent mobility can be considered a feasible and legitimate need to lead a self-determined lifestyle. Technology is intended to support people to the necessary extent, to guide them to where they want to go and back home safely, and to encourage mobility in general. Older adults, relatives and care personnel are involved in the design. To avoid problems with acceptance and to facilitate everyday use, the developed technological interventions will be connected to an item of daily use to make it likely to be carried along by users when leaving home. Privacy protection, human dignity, ethics by

design, usability and non-discrimination are central topics of the project as well [3].

In the following we present three prototypes of technological interventions to encourage and further mobility of older adults. The design of the prototypes was shaped by workshops with older adults, relatives and caregivers. The prototypes were then reviewed by experts. We conclude by presenting a series of insights on how to design technology to further mobility of older adults with dementia.

II. RELATED WORK

Emergency systems that can help locate a lost or wandering person with dementia are often based on GPS location data [4], [5]. Some systems are even offered by the local emergency medical services (EMS). When pressing a button, they automatically connect to the EMS headquarters [6], [7]. This results in either a phone call or, if the caller is unable to speak, transmits the location data to authorised entities [6], [7]. Because of the availability of different system, a basic understanding of the various components may be lacking, as well as the perceived usefulness of these technologies, which require additional usability studies with the primary user group [4], [8].

In order to fully comprehend such technologies and allow for a correct usage, it is recommended that older adults start utilising them early on [9]. One of the most important implications to consider for tracking technologies is privacy [10]. Security settings should allow to decide to whom or when access is granted [10]. The availability of information can make family members and care personnel perceive the technologies as a safety measure for their loved ones [9], [11].

The design of such technologies should be easily understandable, desirable [12] and consistent, but not stigmatising or portraying weaknesses of the user [13]. With regard to people with dementia, the most important guidelines include: customisable, life-enhancing, extending the users capabilities, intuitive and easily accessible [14].

Design recommendations also include keeping the user interface simple, so that even non tech-savvy older adults can use the basic functionalities, but include extended options or an expert view [15]. At the same time, the tracking technology should ensure that its usage provides advantages for the user, meaning that the design should focus on the primary user and not people in their surroundings [16].

Potentially useful features mentioned in literature are a daily planner, a reminder function [17], [18] or information on the weather citeSchneider:2013. Another useful feature would be to log walked routes, if the user is at risk of getting lost often [19]. This could especially support people with dementia to find reasons for their wandering or help search for them when being lost [10].

While these features could assist helpers to locate someone who is lost, older adults should also be given the possibility to actively request help via a phone call [15]. If connected through a phone call, ideally a family member or an aid should be contacted [15].

Interviews show that family members and care personnel are familiar with the use of a computer or a smartphone [9], [10], [11], [15], and that a mobile device is more preferred, due to its handy size and allows a use on the go [10]. As almost a third of the adults over 50 provide unpaid care [20], the design and functionalities of a mobile application have to be straightforward and concentrate on a navigational or localisation purpose, as this appears to be the most used function [10], [11]. However, as the main application of tracking technologies is perceived as a method of reassurance for these secondary users [21], more direct advantages for the older adults need to be discovered.

III. METHOD

We used a series of 3 workshops to gather data about the context of living with dementia and to better understand findings from related literature. Each workshop was geared towards a different group of stakeholders:

- Older adults without dementia: This group was invited to better understand different living situations of older adults and to learn from members of a possible future target group.
- Care personnel: Care personnel can provide a deeper insight into dealing with special situations when caring for patients with dementia and introduce us to strategies applied in such situations.
- Relatives of/and people with dementia: This group provided first and second hand experiences of dealing with dementia in their everyday life.

While we were in direct contact with one person with dementia in the presence of their caretaker, it was hard to get first hand accounts due to an ethical dilemma with the informed consent. In our opinion an informed consent signed by a person with dementia can only be seen as temporary consent, due to the cognitive decline during the different stages of dementia. Hence, directly working with people with

dementia needs to be approached with care and collected data needs to be handled prudently.

Based on the lessons learned during the workshops, we designed 3 prototypes geared towards supporting autonomous mobility for people with dementia. While a larger scale evaluation of each prototype is in progress, we did a preliminary evaluation in a workshop, in which we introduced the prototypes to a group of health and computing experts and discussed possible issues and pitfalls concerning the prototypes. Descriptions of the prototypes along with the preliminary evaluation will be presented in this paper.

IV. WORKSHOP RESULTS

During the first months of the Way-Key project we conducted a series of workshops. While we learned a lot from these workshops and the participants' different viewpoints, our most interesting takeaways came from discussions around the topic of autonomy, privacy, adapting to new things while having dementia, and security.

The first workshop with older adults without dementia gave us a better idea of existing daily routines, things they usually take with them when going out and their use of technology. Participants openly discussed their stance on privacy and security, which highly differed from person to person, from an openness towards being tracked at all time to a hesitation of carrying around hidden items marked with personal data. They also commented on the need for a more informed and helpful neighborhood and a more sensitised society to issues of aging and its effect on autonomy and mobility.

The second workshop introduced us to the viewpoint of professional caretakers from institutions and home care environments. Participants talked about situations, in which people with dementia could potentially be supported by a technical intervention, be it for everyday household chores or for situations related to mobility. An important takeaway from this workshop was an emphasis on the immense difference of the constitution of older people who can still live at home, even with difficulties, to people who are admitted to care facilities, whose dementia is much more severe and who are not able to autonomously take even a short trip. Furthermore, we talked about the still existing curiosity of older adults with dementia to try out new things and the need to keep up this curiosity when introducing them to new technology tools.

In the third workshop we talked to relatives of people with dementia as well as a dementia patient. Most of the workshop was spent with the exchange of experiences of caring for relatives with dementia or being cared for by family. Relatives talked about their difficulty to accept the fact that their loved ones did not deliberately forget about certain things or were not on purpose not able to do things they had done their whole lives. They also brought up the issue of sharing the responsibility of caring for their loved ones with others and accepting help. We also discussed the introduction of new technology, the difficulty to learn new things and the necessity for easily accessible interfaces when developing new tools.



Fig. 1. This Figure shows the first haptic prototype of the day planner. The left side shows the time of day. Blocks can be placed on the right side and are labelled with activities. A glowing LED shows the current time of the day.

V. PROTOTYPES

A. Day Planner

Our first prototype is a cooperative day planner. The idea is to provide people with dementia and their care personnel or family with a means to discuss and communicate about the day's structure, preferably in the morning, and to reflect upon upcoming plans. This reflection might serve to activate the patient's memory and form emotional connections with certain to-dos and hence heighten commitment for daily chores.

Several situations in the workshop lead to this idea. Older adults in the first workshop talked about the importance of staying connected to their family, even throughout their busy, work-driven lives and finding some time to talk about and share their own daily lives. Care personnel in the second workshop mentioned that daily chores are becoming more important for people with dementia with certain events coming up, e.g., showering for a doctors appointment, cleaning up before family members visit. In the third workshop, the person with dementia mentioned that they were aware of asking similar questions constantly and hence being a burden on their family, however, if they had one place to look up information, they might remember to go there first before asking and hence feeling like less of a burden.

The day planner is a haptic input device where to-dos can be arranged on a board with blocks representing appointments, see the picture in Figure 1. The blocks are designed to be easily graspable and are magnetic to latch onto time slots on the board. Each block is associated with an activity such as shopping, or a visit to the doctor and some blocks can be labelled freely. The board has a digital up-link to a home device, which can make planned activities available for family and care personnel in emergency situations and to other applications such as our Red Alert or Context Aware prototypes.

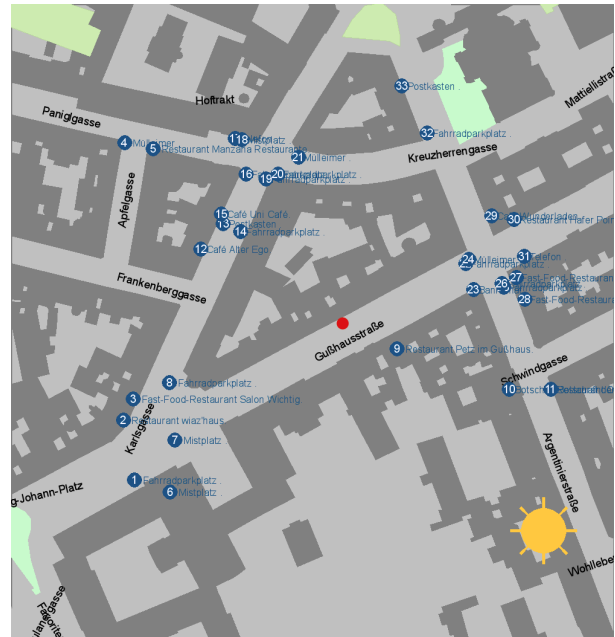


Fig. 2. This Figure shows the interface of the Context Aware prototype, which is displayed to relatives or caregivers. The person needing assistance is located in the middle of the map. The caregiver is shown landmarks in the close environment, which could help guide the person to safety.

B. Context Aware

The second prototype is the context aware guide shown in Figure 2. The idea is to help people with momentary disorientation either find their way back home or stay calm and safe until someone can pick them up.

The idea for this prototype came up in workshops when talking about momentary disorientation. The situation was described from slightly stressful to being on the verge of a panic attack. Workshop participants agreed that autonomously finding a way home or to a certain point was close to impossible. Relatives mentioned that they usually had to pick up their loved ones in such situation, but feeling concerned about their safety in the meantime.

The prototype consists of two parts, an emergency button with which the person with dementia can call for help, and an automatically generated 'conversation script' for the caller.

The emergency button should be a stand alone tool only for this type of situation. It can either be a simple button to be carried around, integrated in a mobile cover, or be attached to jewellery such as a watch or a necklace. When pressing the emergency button, the system tries to reach supporters from a pre-defined list of people until someone picks up and is connected to the person in need. At this point, the conversation script is activated.

A conversation script is made available for the helper. The script is a mix of calming the disoriented person with dementia and then, based on their location, finding a solution for the current situation. Depending on their location, the system can retrieve context aware data from applications such as the AccessibleMap to better understand the surroundings of the

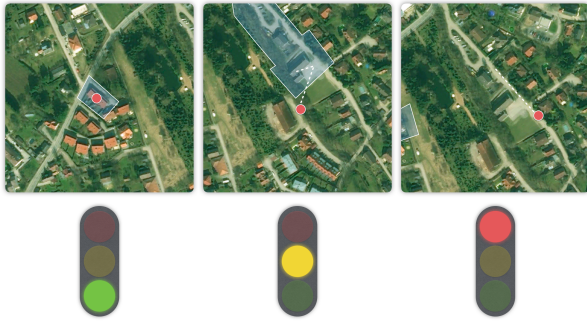


Fig. 3. This Figure shows three different states of the Red Alert prototype. In the first image the person might be visiting their sister, a location stored in the system as safe. In the second image they might just take a different route home but are still close to their familiar surrounding and the system might learn to identify this way as normal in the future if used more regularly. The third image shows an instance of wandering and would need outside intervention.

person with dementia. Based on this information, callers might be able to either see the person in need for help through to more familiar surroundings, or help them find a good place to stay and wait for help. A caller could for example tell them, "Do you see the fountain in the middle of the square? Behind that is a bench. Sit down, relax, I'll be there in 10 minutes!".

C. Red Alert

The next prototype is a smart geofencing application. The product will not use a predefined geofence but will analyse movement data on the go, learn the users habits and update accordingly. The prototype only simulates this behaviour by creating a predefined geofence around a person's 'normal' environment and reacting as soon as this predefined area is left. Ideally this area is not only defined based on a location, but also based on time limits, e.g., the supermarket is within the geofence, however, at 3am it is not a good sign if someone goes there.

The idea is based on discussions in the workshop where participants talked about owning smart phones and carrying them along, but not being able to use most of their functions. They did, however, mention usually picking up if someone was calling them. This creates the possibility to use these devices for tracking purposes with the advantage of users not needing to think of additional gadgets to take along when leaving the house. Additionally, most participants agreed that they wouldn't mind relatives accessing their GPS data if there seemed to be a problem or emergency. This openness to freely share their whereabouts puts an obligation on developers to make sure that the privacy of users is protected.

The data will be used to build a system capable of differentiating 'normal' movement patterns from unusual ones, examples of which can be seen in Figure 3. Family and care personnel will not have direct access to the data to protect the user's privacy, however, they can receive status messages indicating that everything is alright, that there are slight changes to normal behaviour or that something might

be wrong. These status messages can for example be used to contact the person with dementia to see if they are okay.

The idea for the Red Alert prototype originated in the first workshops where we learned that senior citizens are already used to carry a mobile phone, in most cases even a smart phone along when they leave their home. While people with dementia might arguably not be able to use the phone in a situation of disorientation and stress to call for help, they are used to pick up the phone when it rings. Hence, if a call is initiated by a family member or care personnel who offer help, this might overcome the shortcomings of too complicated technical devices and support people in a moment of need.

VI. EXPERT EVALUATION OF THE PROTOTYPES

The last workshop of the series took part in the context of the eHealth conference in Vienna [22]. The conference is attended by a mix of participants from academia, industry, government and health care organisations, which was an interesting target group for our project. We introduced first ideas for possible prototypes and discussed their design and possible issues, particularly security of the tools and surveillance, as well as compliance and free will of potential users.

A. Day Planner

During later workshops we introduced the general idea of the cooperative day planner to workshop participants to get an idea of how such an intervention would be received. While the reception was mixed depending on which group of stakeholders we asked, the overall feedback confirmed the value of testing the idea in real life.

The day planner was considered to be a social tool to facilitate communication between older adults and their relatives. Workshop participants talked about issues, which could arise with putting too much structure in a day and making the planning and reflecting phase obligatory for their family, hence being a chore itself. Having a shared day plan can also lead to the feeling of surveillance and hence could lead to leaving out certain appointments they don't want to share and consequently forgetting about them. There were also discussions about putting on reminders and hence increasing the pressure to do something one might not want to do. Also, when collaboratively planning a person's day, everyone might put different value on certain chores which can influence people with dementia and might inadvertently be considered disruptive. Last but not least, the intervention of collaboratively planning a day might be interesting at first, but lose its novelty over time, making it less attractive to use.

B. Context Aware

All interventions used in this prototype should be familiar for people with dementia, many of which already use an emergency button for situations such as falling down. Also operating and answering a mobile phone is a known activity, and ideally they should be connected with a familiar person who has a normal conversation with them. However, talking to people with dementia, they were still not sure they would

even think of operating an emergency button in a situation of stress and disorientation. This concern might be picked up for future iterations of the prototype where we plan on merging the context aware prototype with the red alert prototype and try to automatically initiate a call based on unfamiliar tracking data.

Another issue that needs to be dealt with is the presentation of the context data for someone who does not already know the surroundings. The system in the background needs to automatically filter out relevant data that can be shown to the caregiver to give them an idea about the immediate environment of the person in need. This context information can be vital to guide a possibly distraught person to safety, hence, a sensible selection is vital for the system to support rather than distract the caregivers.

C. Red Alert

Participants in the workshop were concerned about privacy and possible hacker attacks divulging sensitive data to perpetrators. Furthermore, some argued that the wrong type of notifications for family and care personnel could lead to a constant feeling of emergency. For example, even indicating only slight changes in behaviour can lead to uncertainty and nervousness among the carers, and 'red alert' can create a panic that might be for naught in most cases. Hence, the system has to be designed accordingly to not be an additional burden on its users.

Another issue that was discussed is that of responsibility on misinterpretation of the data. Who would, for example, be responsible if the system showed that everything was okay even though there was an emergency? In this case the system would convey a false sense of security. The metaphors picked to convey a person's status hence need to be selected carefully to convey the right message.

Using biographic data could also help the system to better judge a person's status, e.g., when a person is within their geofenced area, but is standing in front of their former workplace for a long time. This could be a sign of wondering and the person should maybe be checked on by a relative.

VII. DISCUSSION

The workshops held before designing the interventions confirmed the importance of privacy when working with tracking technology (also pointed out by Wan et al. [10]), albeit sensibility for this area greatly varies among participants. Another important point raised in the workshops includes balancing autonomy of older adults with dementia with the desire for safety and security by relatives and caregivers (also see [9], [11] and [21]). Further technology should be embedded in daily routines (confirming the suggestions of Carmien and Fischer [17] as well as Lee and Dey [18]), cater to varying degrees of dementia and be easily accessible to users and caregivers alike, as also pointed out by Angelini et al. [12]. Also articulated in the workshops was a need for accepting more help and sharing responsibility among relatives, caregivers and neighbours. Overall, the workshops

confirm the issues relevant to designing technology in this space raised in the relevant literature of the field.

The expert evaluation of the three prototypes further confirmed the importance of a holistic perspective, which considers users, their relatives and caregivers as stakeholders in the design process. In the opinion of experts, the day planner succeeds in establishing a tight integration with daily routines but might not provide the life- and capability-enhancing functions expressed as important by Astell [14] after novelty effects wear off. The inclusion of an emergency button in the context aware prototype follows recommendations made in the literature [10], but experts and workshop participants raised concerns over older adults with dementia's ability to recall the button's existence in an actual emergency situation. Thus, while technology might be designed for everyday use and accessibility [12], especially in designing technologies for users with dementia it is important to also focus on extreme and emergency situations. The expert review of the Red Alert prototype further underlined the importance of privacy discussed earlier and raised ethical concerns over possible misrepresentation of data and ensuing concerns over conveying a false sense of security or emergency.

VIII. CONCLUSION

We identified a series of design issues including privacy, autonomy, daily routines, accessibility and shared responsibility, building on literature and a series of workshops with older adults and caregivers as well as relatives of older adults with dementia. These issues led to the design and implementation of three technological prototypes built to encourage mobility of older adults with dementia: a cooperative day planner, a context aware guiding solution and an emergency tracking system. The subsequent expert review of these technologies further confirmed the importance of considering privacy and autonomy in the design. Furthermore, a holistic perspective is needed to design technology that is primarily focused at older adults with dementia and only secondarily geared towards their relatives and other caregivers.

Future work will encompass an iterative revision of the presented prototypes and testing them with the actual target group. In these revisions the functions of prototypes will be interlaced and used to inform each other. For example, the data put into the day planner can be used as a basis for creating a geofence in the other prototypes. The expert review was a good sense check of current prototypes and a security layer before testing the prototypes in the wild. Testing them with the older adults with dementia will bring deeper and more specific results but we will also need to sensibly tackle challenges with responsibility for and informed consent of a vulnerable target audience.

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