Technology supporting the everyday life of people with dementia

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Abstract
People with dementia have increased needs for support when carrying out everyday tasks. Even mild forms of dementia are associated with a diminished quality of life, poor self-esteem, anxiety, and social isolation. Whereas in the past, technology research has largely focused on ensuring safety and security of dementia patients, the focus is increasingly on positively enhancing the quality of life of dementia patients living at home. More recent work, therefore, has adopted a needs-led approach to ensure that interactive devices are more usable and relevant to dementia patients. In line with this, the aim of the present study was to develop design concepts for technology supporting people with dementia in their independent living, based on interviews about the needs of users and their carers. The results show the need for both independence and social interaction as the main concern. From the carers’ point of view, technology for supporting social interaction is also seen as a major domain that technology development should focus on. A review of current research, the findings of our interview study, and resulting design scenarios are presented in this paper.

Keywords
Dementia, Inclusive design, Independent living, Social interaction.

Introduction
Dementia is a condition in which the way the brain functions is gradually lost. People usually think of it as being memory loss, but in fact dementia affects more than just memory. It affects the ability to use words and to carry out previously familiar tasks, like getting dressed or making a cup of tea. It affects recognition of places, people and objects, and people with dementia often feel lost in terms of time and place.

People with dementia have increased needs for support when carrying out everyday tasks. Even mild forms of dementia are associated with a diminished quality of life, poor self esteem, anxiety, and social isolation [1]. A number of studies have been looking into designing technology for people with dementia living at home. Whereas in the past,
research has largely focused on ensuring safety and security of the patients, mainly by providing alarm systems and barriers (e.g. against wandering about). Often, the focus has been on surveillance systems that can alert family, carers and medical staff if things go wrong. Increasingly, the focus is on positively enhancing the quality of life of dementia patients living at home, because surveillance and blocking off people from doing what they want to do raises ethical questions and does not receive much enthusiasm from patients [2,3]. More recent work has adopted a needs-led approach to ensure that interactive devices are more usable and relevant to dementia patients [4].

In a larger study that consisted of interviews and focus groups with carers and people with dementia, Wherton and Monk [1] derived several areas of daily living where designing supportive technology could help to maintain an independent lifestyle. This included daily activities like dressing, medication, eating and drinking, washing, toileting as well as domestic tasks like washing-up, locking-up, ironing, and cleaning. There was the area of risk mitigation, especially related to cooker safety and wandering. Leisure often consisted in watching television and was generally characterised by a loss of interest. Finally the large area of interpersonal interactions was identified as an area where technology could be useful. This included face-to-face and telephone conversations, keeping appointments, or help with recognising people.

The deficits in cognitive functioning underlying these problem areas are difficulties in sequencing actions (e.g. initiating actions, ordering actions and formulating procedures), learning (of new appliances and surroundings), memory and orientation (e.g. forgetting events, forgetting to do things, orienting in time and place, recognising people). The consequences of these deficits were identified to affect safety, security and health, but also the perceived well-being, stress, and social isolation of the people who suffer from dementia. The consequences for their caregivers are a heightened demand on supervision, worries and anxiety, but also a growing sense of frustration.

The challenge of designing technology for people with dementia is connected with the syndrome and the progressive worsening of cognitive functioning. Also, a crucial feature of dementia is that the recent memories and skills are the ones that are damaged or lost. Thus, people will have difficulty learning new technology and they will even gradually lose the ability to operate familiar devices, if they are too complex to use. One possibility is to make new technology look very familiar to what people already know or to attach it to already familiar items in their daily routines. New technology should be very simple to use, ideally have only one control, have clearly discernable controls with regard to their size and the surrounding visual clutter, feedback needs to be immediate and without delay, and direct interaction via touch-screen seems to be preferable [1,4,5].

As design for people with dementia can therefore be very challenging, our research tries to avoid introducing new technology to people with dementia. It rather focuses on designing devices that support older adults in their daily living before they get dementia. We think that such technologies gradually weave into everyday routines while the adults are healthy, so that the use of technology is already familiar when the first signs of
dementia set in. These devices then will continue to support the daily living of people with dementia – hopefully in a better way than current technology can.

To explore this idea a bit further, we conducted interviews with people with dementia and their carers on several domains of daily living. This resulted in some overarching themes that were used to develop design scenarios in which new forms of technology are explored that follow our general approach.

**Interview study**

**Method**

In order to find out more about the needs of people with dementia, an interview study was conducted at a British day centre that has a capacity for 15 people with dementia. Eight people from 76 to 86 years in an early to moderate state of dementia were interviewed (Table1). Six of them live on their own, one person lives with his spouse and another person lives in her own flat in a home for elderly people with a common room and care staff. In addition, two members of the day centre staff were asked about their ideas on technology supporting people with dementia in their independent living.

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The interviews with the people with dementia lasted between 30 and 70 minutes. The interview was semi-structured and covered several areas of daily living partly inspired by Wherton and Monk [1] and Sixsmith et al. [6]: Listening to music, social participation, community relationships, outdoor activities, household tasks, exercise, leisure activities, daily routines as well as the current and desired use of technology. The interviews were recorded with a voice recorder, transcribed and analysed to identify common themes across participants.

**Results**

One of the strongest findings was the need for independent living: “if I could I would be independent” (P1), “I like my independence because I think that’s the most important thing for anyone, you know. I don’t want to do that one, do that, eat that, or drink that. No.” (P4). Although this need for independence is felt quite strongly by almost everyone we interviewed, their (physical) illnesses make it necessary that other people provide help. This could be help with washing and cleaning, preparing meals or doing the shopping. Help sometimes was provided by professional carers or relatives. Being dependent on others therefore feels, to some of the participants, that they were a burden to others: “Yes, they [the carers] do everything, but I don’t want to be a burden. I am very
independent, I don’t want to be a burden…if I could I would be independent. Don’t ask anybody to help” (P1). Others are quite comfortable asking people for little favours. P5 who lives in the care home: “If I need anything. Say for instance I need buns, I’ll say ‘Well I need some buns can one of you…’ They’ll say ‘Alright’”.

Many participants retained responsibility for some small tasks like doing some shopping, walking the dog, preparing their meals, tidying up, etc. and that felt very important to them. It turned out that the urban environment is very good at supporting these tasks where shops, parks, the doctor’s, and the barber are near where people live, where the streets and the people are familiar. To have everything nearby is very helpful, because forgetting to buy something in the shop, for example, is not penalised highly. It can be easily made good the next day.

After the desire for independent living, the second largest area of concern was social interaction. This became obvious during the parts of the interview in which social interaction was the main topic of the conversation. But it also became apparent that many of the other topics of daily living had a significant social component. Social interaction always was interwoven with other activities and sometimes provided the only reason to engage in activities. For instance walking: there is the man (P6) who almost daily walks to The Regent’s Park. He knows some people there, “one gets to know them, I have a little bit of chat and all that with them” The people he meets remember his name and greet him, they are very friendly, he likes it. There is the woman (P2) who goes to the Bingo hall twice a week, because there she can meet people of her age. “I’ll speak to anybody. I mean if somebody comes and sits down next to me then I’ll… have a bit of a chat or something. Especially elderly people as well like myself you know”. And of course, one of the main reasons to go to the Day care centre for many is to see new people and have a chat.

The topic of music is very important to people with dementia, but it also is often connected to social events: listening to music and singing at the day centre, hearing Irish music at the Bingo hall where one can meet friends, etc. Although P2, for example, has a radio that she can easily operate, the music available at other places draws her to go out and see other people – especially if it is good old music from the past.

Satisfying social interaction is often superficial. A quick chat, a greeting, even waving at passers-by when sitting near the street are enough to make the day. Satisfying social interaction is often passive. S2 reports: “There is one lady who is Portuguese but she always requests Molly Malone the Irish song, which isn’t something I would image she knew when she was younger but because other people like it she likes seeing them enjoy it. […] maybe that is easier for her…Rather than singing it watching other people enjoy it.” Very often we heard from participants that they liked to receive phone calls, although they rarely take the initiative to phone others. It is not clear, why they would not take initiative. One thing is that initiative is slowly waning with the progression of dementia. Another is that they do not want to be a burden. One women asked why she did not phone her children, said that they had their own lives, their jobs and families, and she did not want to disturb them. She rather waited for them to call. The carers believe
that at least a few of the people with dementia are a little ashamed of their disease and are also afraid to lose track in the conversation.

A big issue in social interactions was trust. Knowing about their vulnerability, sometimes out of bad experience, participants were careful not to trust strangers too much. They were wary of constantly changing carers that came to their home. One man (P6) even decided to go to the Health Centre every day to get the pills himself rather than to let the carers bring them to his home, because “then anybody could come”. He felt that he couldn’t trust the people; going to the Health Centre he retains control and knows what is happening. Another man (P3), who lived alone, often goes to the pub around the corner. He says that he knows all the people there, that the barman introduces him to new people, and that he trusts the barman. But otherwise he is very careful to not go out alone. He thinks it is too dangerous.

A rather sad finding is that the people with dementia lose many opportunities for social interaction over time. That is the case when neighbours and acquaintances pass away or move into care homes. That is also the case when they themselves move into a care home. Entertainment venues may close. Children have their own families and lives and therefore not enough time to be available all the time. Because of the issues of trust, but also due to their illness that reduces the ability to recognise people or that reduces the ability to take initiative, they do not get to know new people. This can result also in great loneliness. For instance, P8 reports that she is not satisfied with the care she gets from her son. Her son would pick a programme on the TV, then he goes out with his mates and “leaves her there with nothing, looking at the ceiling”. Her other relatives are in Scotland but “they don’t come down for holidays” to visit her. She has no other friends: “Nowhere to go unless you made friends and I’ve never made friends”. Again, some of the people with dementia report they don’t want to be a burden to anyone. They are rather hesitant in calling family members because they don’t want to disturb them in their own daily life.

A third issue that did not pop up so automatically like independence and so pervasively like social interactions, but which we were very interested in, was the participant’s relation to technology and how they saw that technology could support an independent lifestyle as well as help fostering social relationships. It turned out that people with dementia rarely operate technology themselves. They find it too complicated to use. They say that they are confused when they don’t know which buttons to press (P3). Some switch their radio or TV only on and off and rarely change channels. Listening to CDs, for example, is very often not possible and someone else has to put the CD on for them. This seems to be a general pattern that was confirmed by the carers. The carers on behalf of the patients essentially operated each technology they tried at the day care centre, like applications for e-mail or chat or software for viewing photos. Only touch screens with single buttons would work at all. E-mail seemed to be too abstract and complicated, but there were early tests with Skype that went quite well, especially when the video picture of the other person was shown. The patients demanded bigger buttons on the phone, for example, and technology to be more easy to use in general. However, if asked if they would make more phone calls, if the technology was easier to use, the
people were not so sure. Sometimes they don't see the value of using technology and they are afraid of doing something wrong. P5 for example does not even make tea herself “because sometimes it might spill and you'll burn yourself.” Safety, of course, is another issue here.

**Summary and Discussion**

Of the many areas of daily living discussed in the interviews, the themes of independent living and social interaction were the most prevalent across participants. At the same time, the use of technology is very reduced to only single button presses, but most of technology use is delegated to other people. In addition, the progression of dementia makes it less likely to introduce new functions and new interaction paradigms to potential users of such devices. These findings are in line with previous research. Orpwood et al. [4] concluded that technology must be very simple to use and very obvious in its cause and effect relationships.

Our findings lead to the conclusion that a different approach is needed. So we were not looking for technologies that support the independent living for people with dementia but for the older adult who might in the future become a patient. This approach has several advantages. First, technology is introduced and learned while learning is still possible. Second, until the onset of dementia, devices have become familiar and the use of these devices has become automatic. Thus, technology can have a greater impact in supporting independent living of people with dementia early on.

In the following, we explore design scenarios and possible solutions that help older people staying or getting in contact with others and support independent living by new technology. As we have seen, from the carers' point of view, technology for supporting social interaction is also seen as a major domain that technology development should focus on. We would like to keep the independence of people in their daily life, support them in keeping their existing social contacts and help them in establishing new relationships. We think that in developing new technology, we should focus on such a preventive perspective. That means giving support to people with dementia in an early state of their illness before they lose abilities due to their disease.

**Design Concepts**

In the present paper, we would like to suggest information and communication technologies (ICT) that can serve elderly citizens to sustain social relations and create new contacts before dementia is setting in. The overall goal is to maintain self-determined lifestyles in older age for as long as possible. We contribute to basic approaches for the prevention of dementia and thereby focus on older adults that still stay self-dependent in private homes but are regularly visited by caregivers. The design concepts are based on the theoretical and empirical findings reported above.

When searching for solutions to support people with dementia we took into account that once the disease started, it is mostly irreversible and will likely worsen. Hence as a point
of departure we would like to foster situations that help to lighten the decline in cognitive abilities. Hence the suggested scenarios aim at preventive activities, related to the still healthy elderly adult. The hope is that there is a better prognosis for people with dementia living independently, when a stable social situation with regular and interactive social activities is established and nurtured. This should be done while we don’t have to deal with the constraints of the symptoms of the later disease. Furthermore we take into account that continuing routines and daily schedules can support people to maintain independent lifestyles more easily.

As a result of our interviews we learned that close family members play a prominent role for the people as trusted persons. In a phase of life, when people become aware that they struggle with certain deficits, people should be able to purposely share certain tasks with the people they trust. We assume that facilitating technologies could serve to mediate these relations and in effect unburden patients and carers from omnipresent concern and responsibility issues (cf. scenario shared diary, below).

Many old people don’t expect technology to improve their situation due to missing experiences in the use and so will not find reasons to integrate it into their everyday life. Our main concern was not to simply add existing technology to a situation but to suggest a technology that allows to change a social setting by adding forms of communication that are mediated by technology. For that reason we examined how a meeting functionality inspired by today’s office software should be modified so that it can support elderly people to arrange face-to-face meetings (cf. scenario meet me, below).

Before rolling out the scenarios we want to introduce four personas that serve to transfer important characteristics of the conducted interviews and other results from research into more concrete images of possible users.

**Personas**

In order to detail our concepts, we initially had to summarise our understanding of prototypic living situations and typical users of the applications that we want to suggest. We decided to achieve this by creating a set of personas. Personas are archetypical characterisations that allow generalising assumptions about people for making the researchers’ expectations about the users explicit. Our personas focused on three groups that we regarded as most relevant for the understanding of our target group: family, friends and home-care workers.

**Paula** is 82 years old and still lives at home on her own. Her husband died ten years ago. Since then she lives alone in a small town about a two hour’s drive from London, where her daughter **Helen** is living. Paula got used to living alone. She managed her household and her social life on her own. Since a few months her daughter Helen has been realising that her mother’s memory got worse and many things became difficult that used not to be a problem before. At one weekend when Helen visited Paula, she realised funny smells because the dustbin had not been emptied. Suddenly Helen became aware that her mother is less and less able to complete daily tasks on her own.
At the same time she would definitely reject the idea to put Paula into an elderly care home, yet.

**Judith** is a friend of Paula’s. She is 80 years old and in a very similar situation as Paula. She lives alone in the same town. She likes to meet people but doesn’t find the reasons to contact others.

**Helen**, Paula’s daughter, is 48 years old. She lives a two-hour’s car drive away from her mother, together with her family of four. Helen works as a manager in London. She feels sad about the situation of her mother, but can’t afford to visit her more often than once a week due to her demanding job and her two little kids.

**Rob**, 32, is a professional carer. He visits the two old ladies and supports them with their everyday activities to better manage their households. Rob loves his job, but complains that he can’t spend the time he would like to spend with his clients. They always put a heavier demand on his time-budget than he can afford to manage.

**Scenarios**

**Shared Diary**

A few months ago Paula started to feel that she struggles with the daily tasks that she needs to complete. Once she forgot to take her medicine, twice she forgot to turn off the stove after cooking. Although she decided not to tell anybody, Rob obviously found out. Paula knows this as he has begun to take extra care to ask her whether she has taken her medication or whether she plans to cook something for dinner. The difficulty for Helen is to check if her mother is doing all right because of the long distance. After Helen’s daughter introduced the concept of a *shared diary* to her, she decided to introduce it to her mother.

The shared diary is a digital calendar that allows two (or more) collaborators to share daily task-lists based on a simple digital application. The lists are displayed on a screen that is positioned on a living room table to remain visible during the day. In our case Helen supports her mother in arranging a weekly plan that contains all necessary tasks to be done. At the same time Paula can use the shared calendar as well to add tasks for her daughter including things she needs from the city. Every task Paula ticks as ‘Done’ is also marked on Helen’s calendar and the other way round.

A shared diary should be based on individually made arrangements and mainly target people that are still able to consciously engage in this kind of collaboration and that are able to decide which activities they want to share. Besides, family relations it would also be promising to test the tool with two older participants who could take care of each other. In this case, uneven dependencies could be avoided and the mutual exchange between the two older adults is encouraged. The application should be implemented on a device with a touch-screen that should integrate into the living environment. It shouldn’t need to be activated in order to display the task lists permanently.
Meet me
Paula and Judith share the same passion: for many years they used to play Bingo in the local club. For them it means the perfect event to chat with each other and to meet various other friends and acquaintances. However, since a few years the number of participants is constantly decreasing. Sometimes their friends simply don’t show up for health reasons, sometimes they just miss the gathering because no one prompts them to make the move to the club. Paula and Judith assume, that there are more people, who could be interested in participating in the regular meetings, but both feel not able to find out when their friends go to the club. They also wouldn’t know how to contact these people and activate them to join in. Judith and Paula feel that this problem is not restricted to organising outings to the Bingo club, but could help with choir meetings and meetings in the pub as well.

»Meet Me« is a collaborative tool that allows people to set up meetings, receive feedback from invited participants and prompt others before an event starts. The idea of the tool is to enable people with no computer knowledge to organise meetings with a small number of participants in a local environment. The application thereby focuses on one single feature of regular office software but reduces this to very few functionalities and intuitive interactions that are easy to learn and self-explanatory. It offers a discreet way to contact a number of people while avoiding the accompanying organisational efforts (calling a number of people, taking notes, managing replies, etc.). The application appears with few buttons and simple textual output. It intentionally is not able to transfer language, video or text as people are used to talk on telephones and we would not want to shift these activities to other new devices. Input happens with simple touch gestures.

The main functionalities of the application involve:
• setting up and inviting people for a gathering,
• confirming and rejecting requests made by others,
• permanently displaying the current status of confirmed invitations, and
• receiving feedback messages about the status of the meeting.

Setting up meetings with the “Meet Me” application is done in three simple steps guided by simple questions:
1. Schedule meeting by setting time and location (When? Where?).
2. Invite others or everybody (Who?).
3. Send invitation to participants (Send).

When a meeting is initiated, all linked persons will receive an invitation that appears prominently on theirs screens. In the following, the initiator will receive a visual feedback if people send positive answers or rejections. All participants will permanently be reminded that they admitted to the meeting by text message that appears before the meeting takes place (“You want to meet Mrs Black today at 12pm at the X-ways shopping centre”). People will be alerted in case overlaps with other activities occur. Other stakeholders could also be involved in the use of the tool. Care workers, for example, who actively take part in scheduling and organising meetings among different participants.
By providing a restricted functionality and a simple visual design, the application is accessible for people that would otherwise be excluded due to the various requirements existing to set up and configure complex office tools or complex applications on smart mobile phones.

Conclusion

People with dementia have a very strong motivation to remain independent. Their biggest concern, in all fields of life, is about good social relationships and not feeling lonely. Technology does not play a big part in their lives, because it is complicated to use and mostly unfamiliar to them. These are the main results of our literature study and the interviews with patients and their carers. From these findings we conclude that new technology that is able to support people with dementia needs to be provided before the onset of the disease. Only then it is able to interweave with daily habits and existing social relationships and remains being helpful later on. The design scenarios Shared diaries and Meet me are the first steps in exploring this approach and we are going to follow this up in our future research.

References


