Reminiscence Map: 
Insights to design for people with dementia from a tangible prototype

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Abstract: With higher life expectancy and an increasing number of older people, the number of people suffering from dementia continues to grow. Dementia impacts all areas of daily life and, in particular, communication with other people and maintenance of personhood. Technology is a promising means to address these challenges, yet approaches to design with and for people with dementia remain sparse. In our work we aim specifically to design interactive systems that can be used by people with dementia, e.g. as part of reminiscence therapy or generally to remember the past and communicate with others. In this paper we present our research and design approach and exemplify one design case: the interactive Reminiscence Map, which was developed together with a person with early stage dementia. We show how this design served us as a lens into the thoughts, and daily life of the care home residents and caregivers and provide design insights.

1. INTRODUCTION

Demographic changes and longer life expectancy lead to a growing number of people with dementia. In 2014, about 36 million people worldwide have Alzheimer’s or a related form of dementia, the highest percentage living in Western Europe (Alzheimers.net, 2014). Over the course of the disease, dementia severely impacts memory, speech/language, thinking, orientation and social behaviour. As a result people with dementia have difficulties in all areas of daily life, often become frustrated and experience lower life quality. In extreme cases such frustrations can even lead to challenging behaviours such as unrest, aggression or apathy (Ferri et al., 2004). Unfortunately, there are no medical treatments available at this point to cure the disease. Instead psychosocial interventions play an important role in order to increase the wellbeing of people with dementia. Psychosocial interventions include among others reminiscence, reality orientation or memory training, which have proven to positively and sustainably influence challenging behaviours of people with dementia (Gallagher-Thompson et al., 2012).

Technology has recently started to play an important role in the area of care, mostly in the form of assistive systems for the home care context (AAL). Systems for people with dementia have mainly put users in a passive role, e.g., when using GPS systems (Miskelly, 2005). However, “[l]iving with dementia presents a range of challenges ripe for creative applications of technology” (Astell, 2009).

We believe, that the currently prevailing technology-led developments miss some important values and needs of people with dementia and that approaches involving the target group that result in technical artefacts to be used by people with dementia have higher potential to address these people’s needs. Especially in the area of designing for reminiscence, maintaining personhood and communication new media technologies can be utilized in supportive ways.

In an on-going project our interdisciplinary team investigates ways in which multimedia technologies can be utilized to support and enhance the experience of reminiscence and communication for people with dementia. Until now, we conducted exploratory field research in different settings (e.g. a care home, day care and support groups) and developed a number of interactive multimedia artefacts to be deployed in these settings for
observation and discussion with people with dementia and caregivers. We intend to identify design possibilities for multimedia technologies that integrate smoothly into people’s daily lives.

In this paper we focus, in particular, on one design case that emerged from our field research in a local care home. We describe the development of a tangible interface called Reminiscence Map – a physical map allowing the user to select a timespan and remember places and stories from that time. The map was co-developed with a person with early-stage dementia as a personalized artefact and discussed in an interview with the person and a focus group with the caregivers in the institution.

Our intention was not to evaluate this particular design for the purpose of generalization, but to use the interactive artefact (like other prototypes created in the project) as a lens into the lived world of people with dementia. Similar to Wallace et al., our Reminiscence Map “[a]s a tool of enquiry it revealed valuable spaces for design in dementia that have wider implications for interaction design” (Wallace et al., 2012). In particular, the analysis of the case surfaced themes for technology design (e.g., leaving a legacy) that had not originally been considered.

2. RELATED WORK

2.1 Psychosocial Interventions for People with Dementia

Researchers investigating dementia, especially those following a person-centred perspective (Kitwood & Bredin, 1992), believe that “the symptoms [e.g. depression and fears] and behaviours [e.g. unrest, aggression, wandering] of demented individuals are not solely a manifestation of the underlying disease process, but also reflect the social and environmental context, as well as the demented individual’s perceptions and reactions. Psychosocial interventions can address these factors.” (Kasl-Godley & Gatz, 2000) Psychosocial interventions are even more important in light of the limited success of pharmaceutical interventions for dementia. Kasl-Godley and Gatz (2000) reviewed the six main psychosocial interventions for people with dementia: psychodynamic approaches, reminiscence and life review therapy, support groups, reality orientation, memory training and cognitive/behavioural approaches. Each intervention targets particular factors and addresses different goals. For instance, while psychodynamic approaches are helpful for gaining insight in the intra-psychic experiences of the individual, reminiscence and life review help with creating interpersonal connections. Behavioural approaches as well as memory training, on the other hand, are less concerned with the subjective experiences, but target specific cognitive deficits. It is recommended to involve others in these interventions in order to “increase social contact, interpersonal communication and psychological health” (Godley & Gatz, 2000).

2.1.1 The role of reminiscence

As dementia progresses individuals experience memory loss, disorientation and in later stages a loss of their sense of self. As such, it becomes increasingly difficult for them to engage in meaningful activities, although this is of high importance for life quality (Wood et al., 2009). „It is argued that reminiscence may be particularly important for demented individuals’ psychological health given that the progressive deteriorating nature of the disease erodes the ability to achieve present successes and makes individuals increasingly dependent on past accomplishments for a sense of competency“ (Godley & Gatz, 2000). Since remote memory is usually spared for large parts of the dementia process, people are able to recall events from the past. While processing memories may be compromised due to brain damage, reminiscence can still provide structure in developing relationships or engaging with others (Woods et al., 1992).

2.2 Multimedia and Dementia

Especially when it comes to providing a window into the past, and thereby triggering memories, technologies have a supportive role. Multimedia including music, digital photographs and video can be used for reminiscence. Moreover, advanced technologies such as touch displays or tangible interfaces provide new opportunities to make media materials more easily accessible.

In the CIRCA project (Gowans et al., 2004) researchers created a multimedia application using video, photo and music to support one-to-one reminiscence sessions. The interface was intended to be used by caregivers initiating conversations with people with dementia. The authors reported positive results from user testing and even people with dementia being able to use the touch screen. More recent work of the same research team (Alm et al., 2009) focused on multimedia for leisure. For
instance, computer-generated 3D environments provided means for people with dementia to enjoy environments they once liked, but cannot visit anymore, e.g. a garden or a pub. Immersive 3D technology was also utilized by Siriaraya and Ang (2014), who used Unity3D and the Kinect to create environments for reminiscence and meaningful activities (like gardening). However, people in later dementia stages had problems with the interaction. Davis and colleagues (2014) examined, in particular, which type of video content elicited conversation in people with dementia. The authors found in an observation that generic video triggered more diverse comments and a broader spectrum of conversation topics. Several works (Waller et al., 2008; Wallace et al, 2012) investigated the television as a medium to provide media from the past or personalized media to people with dementia. This research showed that contents targeted to the individuals were catalysts for reminiscence and communication with relatives or caregivers.

Many of the works above prove that multimedia has indeed desired effects of supporting reminiscence and communication. However, the majority of systems were either not meant to be used by people with dementia or posed difficulties in interaction for them – an aspect we focus on.

3. PROJECT CONTEXT

In our project, researchers and designers from four disciplines (Media Technologies, Design, Electrical Engineering and Social Sciences) collaborate on solutions for people with dementia. Our research focuses on empowering people with dementia, on the one hand, through active integration in the design processes of new care technologies, and, on the other, by designing solutions adapted to their needs, values and abilities.

While from the perspective of informal caregivers providing safety is one of the most important functionalities of technology (Topo 2009), experiences from studies with people with dementia emphasized other values. For instance, communication with their surrounding, having a meaningful activity and establishing a connection with biographic aspects were identified to be of highest relevance for good life quality (Astell et al. 2009, Wood et al. 2009, Orpwood et al. 2007). Therefore, we focus on the design of technical aids to improve communication of people with dementia and their surrounding people, preferably through the use of biographic aspects.

3.1 Research and Design Approach

Designing for and with people with dementia is a sensitive endeavour and requires an empathic design approach (Lindsay et al., 2012). Creating trust is a first step. This is why we had a relatively long phase in the beginning of the research process (Fig.1) in which we gathered information about dementia through literature research, expert presentations and documentary films about dementia to sensitize the design team. Before visiting the field to get a first hand perspective we engaged in an activity where all design team members reflected about their own ways to reminisce, which objects trigger memories and in what ways. The first field visits were organized in close collaboration with the dementia service network in our city. We established contacts to several welfare organizations and were transferred to the key personnel in a care home (with stationary and day care) and in two support groups for people with dementia. In the first round of field visits several team members did participant observations and conducted narrative interviews (Rosenthal & Loch, 2002) with people with dementia and caregivers in order to allow for the target group to give us insights into their lived world. The collected data in form of video, photos, field notes and interview transcripts were discussed with the team and used in the ideation phase, where several group brainstorming sessions were held. The result was a large number of ideas ranging from interactive furniture (mirrors, carpets), technology-enhanced everyday objects (stuffed animals, books) to completely newly designed artefacts. While some ideas focused more on functional aspects such as day planning, we selected a final set of ideas that all used multimedia content (video, audio, light and sound), either as original content from the past, recorded stories about the past, or recorded content from today that reminded of places of personal significance. Six prototypes were built in the next phase that have been or are currently being tested.
with people with dementia in the field. We also conducted a focus group with four caregivers (two working as care managers) in the care home we collaborate with, where we presented all prototypes and discussed ideas for further development. Each prototype was assigned to a caregiver in the home, who helped with the further development and provided test settings with residents.

In the following, we will discuss one of the designs in detail to show how this interactive object gave us insights into the thoughts and values of a person with dementia and into the care practice in the care home. These perspectives are valuable for interaction design in this domain (Section 5).

4. DESIGN CASE: INTERACTIVE REMINISCENCE MAP

4.1 Design Concept

In one of the interviews in the first field research phase, a person suffering from mild dementia (called Mrs. Smith in this paper) expressed the wish to own a world map to mark all places that she had visited to use it as a memory aid for later.

A map is a well-known visual representation of countries and cities. While physical maps provided guidance to people in the past, people use digital maps today. In the brainstorming session the idea was developed to create an interactive map for Mrs. Smith to not only support memories of places, but also have a way to link Mrs. Smith’s stories to the right places and time (Fig. 2). While this could easily be built as, e.g., a tablet app, we decided to use a physical map, in order to create an intuitive user interface that does not require another digital device. A common representation for time is a vertical time bar. To set a certain time span of a person’s life, we therefore, used a vertical time slider with a big handle. To indicate visited cities in the chosen time span we used LED lights.

The stories told by Mrs. Smith in a first interview about each place were audio-recorded and could be played back for the chosen time span by pressing a physical button with a speaker icon. When analysing the first interview we realized that some important temporal information was missing to place all narratives onto the timeline. Therefore, a second interview was conducted to focus on the stories and missing dates and to reconstruct all events in Mrs. Smith’s life. Some difficulties occurred in this process due to memory deficits, but overall most narratives could be placed in time. To support the

4.2 Prototype Implementation

The prototype was developed as a tangible interface. The basis is a printed map of 60x40cm that was glued onto a corkboard (Fig. 4). The size was chosen as a balance between providing a good resolution and portability. The lightweight material allowed the map to be easily held with one or two hands.

The heart of the technical backend (Fig. 4 bottom) is an Arduino Uno microcontroller equipped with an audio-shield. All places were marked on the map using coloured 3mm LEDs to be controlled through the time slider, which was build from 6 mm cardboard (Fig. 5), a material used in advanced prototyping. We used two parallel rods on the backside of the slider, one made from copper and a plastic one wrapped with resistance wire (10 Ω). The current of 5V sent through the wire drops depending on the position of the handle, which makes the electricity flow back through the copper rod that is connected to the analogue input of the Arduino. When a new position is retrieved, the respective LEDs are controlled via the PWM output of the Arduino (using a shift register to control several LEDs in parallel). The speaker button is implemented as a simple push button with a cardboard interface. For each time span an audio file is saved on the micro SD card inside the audio-shield. When the speaker button is pushed, the position of the time slider is used to access the particular audio file. We used two miniature speakers (1 Watt) hidden on the backside of the map for audio output.
4.3 Feedback from field visits

4.3.1 Mrs. Smith’s feedback

We visited Mrs. Smith a third time after the prototypical interactive map was built. We did not intend to do a controlled user test, but to elicit her feedback in an unstructured interview. The following vignette (based on the first author’s field notes) presents what happened.

We enter Mrs. Smith’s room together with a caregiver. We greet Mrs. Smith and she immediately recognizes my colleague. I introduce myself and take a seat. Mrs. Smith asks curiously if there was already something to see. My colleague brought her a map as a gift to keep, where he marked all her visited cities. Mrs. Smith is surprised to find all the places on it. “Even Breslau is on it!” Then she says proudly, “but I was also in Africa.” It seems that she hadn’t immediately seen that Africa was also on the map. My colleague points it out to her and Mrs Smith starts telling a story about her stay in Africa. When her story is told my colleague demonstrates the interactive prototype and shows how it works by setting the slider on 1920. An LED lights up. “That’s when I was born!” Mrs. Smith exclaims. After the demonstration Mrs. Smith teases the caregiver in the room “That’s great! Do you also have a map like this?” He says jokingly that there would not be any lamps lighting up on a map for him, because he has not seen much of the world. “What are you going to do with the map? Will it be in an exhibition?” Mrs. Smith asks. My colleague is irritated and says that our intention was to improve the map and maybe give it to her, but Mrs. likes her idea of making the map and her stories publicly available. “It could be interesting to other people to hear my stories,” she says. Later in the conversation Mrs. Smith suggests that we could also give the map to her GP, who seems to be dear to her, after she passed away. “Then he can remember my stories” she says – her eyes filling with tears.

The conversation stops, it is quiet. Mrs. Smith looks at the marked places on the map and suddenly begins a new story about when she was crossing the border between the GDR and West Germany and was held captive at the border. A bit later, we hear another story about Mrs. Smith crossing the Atlantic Ocean by boat, to which we listen reverently.

When my colleague invites her to try out the map herself she takes it in her hand (Fig. 5). With shaky fingers she moves the slider and places it on a timespan. She presses the speaker button to start the audio, but the sound is a little low, so that she has to move the map closer. When we ask her whether it is strange to hear her own voice telling the stories, she says that she doesn’t care. The caregiver suggests that we take a photo together. When he lifts her bed, she starts fiddling with her t-shirt to get ready for the picture.

Throughout our visit Mrs. Smith looks at the map several times and starts telling different stories about the places marked on the map. In another conversation break, I take the initiative to learn something about Mrs. Smith. I see on the map that

Figure 4: Prototype (top: backside, bottom: front side)

Figure 5: Cardboard Modelling of the time slider.
she has also visited Scandinavia, where I once lived. I ask her about a place there, and she tells us an exciting story about a bus trip through Scandinavia.

In many of her stories she mentions ‘her children’, but when I ask her about how many children she had, she says surprised “None! I took care of children of rich people.” She reflects for a while and continues, “Others had families and I travelled around a lot. That’s life. I made the best of mine.” In this moment she looks content.

After 30 minutes had passed since we arrived, she seems tired and we politely say our goodbyes and tell her that we will improve the map further and show her the results again, if we may. She smiles and says “Of course, if I can be of help. You are always welcome.”

Figure 5: Visiting Mrs. Smith

We will return to different aspects from this field visit in the discussion section.

4.3.2 Feedback from Caregivers

Besides discussing the interactive objects with people with dementia we also conducted a focus group with four caregiver/managers in the care home. In a two-hour session we first explained the goals of our research and then showcased all interactive prototypes, among these the Interactive Reminiscence Map. Each object led to discussions about its multimedia contents, the user interface and possible uses in different contexts in the care home. The complete results will be published elsewhere. Instead we focus here on the feedback that we received for the Reminiscence Map. Two aspects about the map were highlighted in the discussion: (1) its potential as a communication trigger via places and (2) its appearance (virtual/physical).

Although the map was originally as a person-tailored object for Mrs. Smith, her comment about sharing her story with others, led to a reflection that the map could be developed further in a way that it holds several residents’ life stories. With extended functionality it could then highlight places where several people have once been. “That sounds good, because it is often like that. ... I often visit places and then I usually find a conversation partner, one person was also in Austria, the other knows Mallorca, the other Southern Germany. It is great [to communicate] via the cities.” (female caregiver).

Another aspect is that people may have visited the same places, but at different times, which would allow for conversations about how places changed over time. “I think this is great, because it connects people. There is this outsider status that people with dementia still have – that would be released a bit, because there are places where everyone has once been. Places, everyone has memories about. Even if some loose their memories slowly, there are still points that connect people. I think this is a great picture.” (female care home manager).

Adding functionality to the map, such as finding overlap between users or showing additional media content (e.g. photos from the times people visited places) would be easier if the map was developed as a digital system using a screen. While the caregivers were not entirely against this idea, it was mentioned that the old physical maps (that were used in geography classes school) would also be great, as residents still remember them. At least such old maps could serve as an inspiration, one caregiver said, even if the interface was digital. Another option could be a mixed reality solution projecting media content on a physical map.

5 DISCUSSION

In the following we present the themes that emerged from the field research, and, in particular, the feedback we received from Mrs. Smith and the caregivers on the Reminiscence Map.

TRIGGER OF MEMORIES

In the session with Mrs. Smith we have noticed that even the non-interactive world map with the marked places triggered a conversation. At least at this early stage in dementia it was easy for her to recognize the places on the map as places that were important in her life and she immediately started telling stories about them. The interactive map added the time dimension to this. When we set the time slider to a
certain time Mrs. Smith saw the places light up and it referred to the time in the narratives. Given our experiences from the first two interviews with Mrs. Smith, in which it was sometimes hard to match the stories to the correct timespans, the map would be supportive in remembering places and time.

COMMUNICATION POINTS FOR OTHERS
Equally important to the memory support for the person with dementia, we experienced ourselves the benefit of the interactive map in conversations with someone we know little about. One of the researchers who had not met Mrs. Smith beforehand, could easily see on the map where Mrs. Smith was born and which places she had visited at which times in her life. Especially in the case of places that the researcher had also lived in, it was easy to begin a conversation with Mrs. Smith. It was also confirmed in the focus group that caregivers would use, for instance recent holiday trips to start a conversation with residents, e.g., asking if they had been there.

EQUAL LEVEL COMMUNICATION
Places provide a good means to trigger conversations with people with dementia, not simply because many people have visited the same places in their lives, but also because places are deeply intertwined with one’s life story, which allows residents to (1) share their knowledge and (2) supports their life review. Keeping in mind that “[d]espite experiencing degeneration of short-term memory function, people with dementia (including individuals who are severely impaired) can very often retain a facility for long term memory that will function strongly given appropriate stimulation” (Gowans et al., 2004), communication about their past should be possible for people with dementia until the later dementia stage.

As the care manager said in the focus group, an interactive map showing several people’s places changed over time allows them to feel empowered. It puts emphasis on the vast experiences from the first two interviews with Mrs. Smith, in which it was sometimes hard to match the stories to the correct timespans. The interactive artefact would support the identification of interesting conversation topics between people, who, e.g., visited the same city or country at the same time or different times.

LEAVING A LEGACY
Closely linked to sharing one’s life story with others in current conversations, is the aspect of leaving a legacy. For us, as designers of technology to support everyday life for people with dementia, Mrs. Smith’s reaction in the try-out session was rather surprising. While we expected the Reminiscence Map to be a tool for remembering for Mrs. Smith herself, it became clear in the conversation that Mrs. Smith was more concerned with preserving her life story for others after she cannot tell it herself anymore. Several times in the conversation she talked about placing the map in an exhibition for others to see or bequeathing it to someone she knows. She explicitly pointed out that it would be interesting for others to hear the stories, because she had travelled the world so much. While it remains unclear to us whether traveling the world was her own choice or simply a result of her life circumstances, her reflections on her life seemed to make her content and leaving her stories as a legacy beyond her own life span seemed important to her. Maybe especially because she has few people left and no family of her own to continue telling her stories this becomes even more important.

Important for the design of interactive artefacts, is to revise our assumptions of what is important for our target group – even if based on interviews – and seeing the possibilities interactive technology can play in addressing their needs. While we assumed that communication in everyday life is an important need that technology should support, in this case, providing a means for casting one’s experiences into an artefact that can be made accessible to others beyond one’s life, surfaced as an important need, not in the first interviews, but in the session with an interactive prototype. Thus, the technology becomes to tool for a very different type of communication.

6 CONCLUSION AND OUTLOOK
The work presented here provides a snapshot of our larger research endeavour to design interactive multimedia artefacts for people with dementia to support their reminiscence and communication with others. In this paper we put the focus on only one of the designed artefacts to show how this prototype could give us insights into the experiential world of a person with dementia and at the same time could be used in a focus group with caregivers as a probe triggering new ideas for designs in the care context.

Based on the feedback we got we are currently developing a more sophisticated multimedia system that can be used in the care home to support the communication between several residents and caregivers. It will store profiles and stories of the residents and provide functionality to identify places that were visited by several people, presumably at different time spans. The system will also provide more media content, such as photographs, of the
different places to trigger further communication. The content as well as the design is currently being co-developed with a caregiver in the care home.

Besides this specific design case we are also field-testing several other designs (e.g. an interactive book and a TV program for reminiscence). In the future, we intend to provide general guidelines for the design of interactive multimedia artefacts that support people with dementia in communication. We should take into account that communication is manifold, and can also refer to communication beyond one’s own life. In any case, we learned from the current case that we need to carefully look into the communication needs of people with dementia to check our own design assumptions.

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