Probing the Potential of Multimedia Artefacts to Support Communication of People with Dementia

Alina Huldtgren[1,3]([✉]), Fabian Mertl[1], Anja Vormann[2], and Chris Geiger[1]

[1] Department of Media, University of Applied Sciences Düsseldorf, Düsseldorf, Germany
{alina.huldtgren, fabian.mertl, geiger}
@fh-duesseldorf.de
[2] Department of Design, University of Applied Sciences Düsseldorf, Düsseldorf, Germany
anja.vormann@fh-duesseldorf.de
[3] Human-Technology Interaction Group,
Eindhoven University of Technology, Eindhoven, Netherlands

Abstract. Communication between people with dementia and others becomes increasingly difficult as the disease progresses. Symptoms such as memory loss, speech impairments and limitations in higher cognitive functions affect people's abilities for communication and social interaction. At the same time, meaningful interactions with others are important for the quality of life of people with dementia. In this paper, we describe our work in designing technology probes and testing them with target users to understand how multimedia could be utilized to support the communication of people with dementia through memories.

Keywords: Dementia · Multimedia · Reminiscence · Communication

1 Introduction

Demographic changes and longer life expectancy lead to a growing number of people with dementia (about 36 million people worldwide[1]). Dementia is an umbrella term for decline in mental ability. Primary dementias (90 % of all dementias) are caused by irreversible brain damage, while secondary dementias are caused by other diseases and can be treated. Alzheimer's disease is the primary dementia most prevalent in the population (about 60-80 % of people suffering from dementia[2]). Over the course of the disease, dementia severely impacts memory, speech, thinking, orientation and social behavior. As a result people with dementia have difficulties in all areas of daily life, often become frustrated and experience lower life quality. Unfortunately, there are no medical treatments available at this point to cure primary dementias. Instead, psychosocial interventions play an important role in order to increase the wellbeing of

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[1] www.alzheimers.net/resources/alzheimers-statistics/.
[2] www.alz.org/what-is-dementia.asp.

people with dementia. Psychosocial interventions, e.g. reminiscence, have proven to positively and sustainably influence behaviors of people with dementia [1].

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). From experience we found that many system designs, however, emerge from a technology-push and not from real needs of seniors and caregivers. In addition, few developments focus on people with dementia. However, "living with dementia presents a range of challenges ripe for creative applications of technology" [2]. We believe, that especially in the area of designing for reminiscence, maintaining personhood and communication new media technologies can be utilized in supportive ways. At the same time, user-centered design is not easy, because the target group is hard to access, communicate with, and rarely aware of the potential of new technology, making it difficult to co-design solutions. This is why we decided to combine the strengths of ethnographic field research and design-led research through the use of technology probes. Probes – designed based on insights from a first field research phase – acted as triggers for discussions with experts and allowed observations of how people with dementia approach new interactive artifacts. In particular, our interdisciplinary team investigated ways in which multimedia technologies can be utilized to support and enhance the experience of reminiscence and communication for people with mild to moderate dementia. The paper outlines our approach and provides first insights from the use of probes in the field and in expert focus groups.

2   Background

2.1   Reminiscence as a Cue to Communication

Dementia limits communication abilities in diverse ways. In the early stages forgetfulness (e.g. of people's names) and associated embarrassment leads people with dementia to withdraw from their social network. As dementia progresses individuals experience extreme memory loss, disorientation in time and place and in later stages a loss of their sense of self. Many also experience problems finding words (similar to aphasia) at the medium and later stages. As such, it becomes increasingly difficult for them to engage in meaningful activities, which is of high importance for life quality [3]. "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" [4]. Since remote memory is often 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 engaging with others [5].

2.2   Current Multimedia Applications for Dementia Patients

In the CIRCA project [6] researchers created a multimedia application using video, photo and music to support one-to-one reminiscence sessions. The authors reported

positive results from user testing. More recent work of the same research team [7] focused on computer-generated 3D environments providing means for people with dementia to enjoy environments they once liked, but cannot visit anymore. Similar is the work of [8], who created 3D environments for reminiscence and meaningful activities. However, people in later dementia stages had problems with the interaction. Several works [9, 10] investigated the television as a medium to provide media from the past or personalized media to people with dementia and [11] found in an observation that generic video triggered more diverse comments and a broader spectrum of conversation topics in people with dementia. Thus, research showed that contents targeted to the individuals were catalysts for reminiscence and communication with others. Overall, there is some proof that multimedia provides support in reminiscence; however, existing work contains mainly single case studies. Our approach aimed to explore aspects of interaction and content with a range of stakeholders instead.

3   Research Approach

Designing for and with people with dementia is sensitive and requires an empathic design approach. In the first step (Fig. 1) we gathered information about dementia through literature research, expert presentations and documentary films. The first field visits were organized in close collaboration with the dementia service network. We established contacts to several welfare organizations and were transferred to the key staff in a care home and two support groups for people with dementia living independently in their homes. Several team members conducted (participant) observations and interviews with people with mild dementia and caregivers. The collected data in form of video, photos, field notes and interview transcripts were discussed with the team and used to develop six technology probes [12] specifically focusing on abilities of people with mild to moderate dementia, when memory, speech, orientation and learning is affected, but people are not entirely dependent yet.
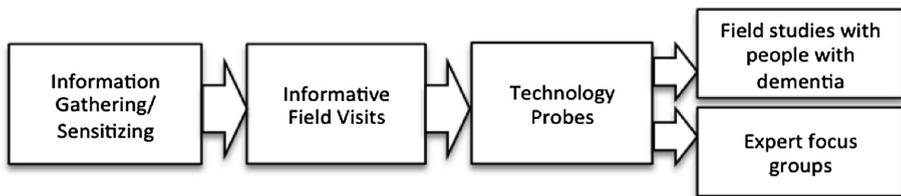

Fig. 1. Overall process of the research

4   Technology Probes

The collected material and first hand experiences served us to empathize with our target group, to understand their needs and challenges and, most importantly to inspire six designed probes (Fig. 2) that could be used in the diverse care contexts. The probes were designed as fully functional artifacts and underwent one review by a group of care

professionals followed by a design iteration that focused on improving the content, aesthetics and interaction. (For detailed information about the design and implementation of a single artifact, see e.g. our previous publication on the Reminiscence Map [13]). The probes cover a range of interaction styles as well as media content ranging from public material to completely personal stories.

Fig. 2. Probes: Top row, left to right: Chrono TV with TV programs sorted by decade, Interactive Book with sound output based on opened page, Icho-Sphere reacting to user's touch. Bottom row, left to right: Music-Teddy playing songs from the 30 s when lifted, Reminiscence Map with users' stories linked to time and place, Memory Window with scenes of familiar places.

4.1   Media Contents

Three artifacts cue reminiscence through general content from the past: (1) **Chrono TV** plays video snippets of TV programs from past decades (50 s-70 s) including news, commercials, and entertainment, (2) the **Interactive Book** has a travelling theme (Italy in the 50 s), and combines photographs of, e.g., cars, or popular music artists from the time with audio tracks, and (3) the **Music Teddy** plays back music from the 30 s. More personalized content is used in the **Memory Window** that provides virtual window views to familiar places. Completely personal content is used in the **Reminiscence Map,** which stores a collection of stories from a person linked to a time and place. More abstract sounds and colored light are used in the **Icho-Sphere**.

4.2   Interactions

A range of interaction styles is used in the probes. All aim to be intuitive either by providing a well known interface or providing affordances for basic human interaction skills such as grabbing, lifting, or shaking an object. **Chrono TV** comes with a simple remote control for people with dementia with an on-off button and buttons for changing the channel and volume and an advanced remote control for caregivers offering

functions to select a decade, a program or pausing a show, e.g. to be able to discuss the content with viewers. The **Interactive Book** can be used like a normal book by turning the pages. Additionally, it is augmented with different audio files per page (automatically recognized). The user can trigger the audio by pressing pictures in the book. The **Music Teddy** contains a gyroscope sensor, and plays back a random track when being sat up from a lying position. Users interact with the **Memory Window** by placing a postcard of choice on the windowsill. Thematic cards are provided with RFID chips that are recognized. The **Reminiscence Map** currently comes in two versions, a personal tangible object containing the story of one person. The user interacts with a time slider to select a year. LEDs light up in the places where the person was during that time. Respective stories can be listened to by clicking a speaker button. The digital version provides additional functionality to find out if people visited the same places. **Icho** is a sphere containing a range of sensors for measuring touch, movement and pressure. When touched it lights up, when shaken it plays ambient sounds, and when squeezed it vibrates. Icho was developed to provide sensory stimulation and engagement with an artifact (and possibly others).

5   Field Studies and Expert Feedback

5.1   Feedback from Testing the Probes in the Field

The design process of the probes was iterative with field tests involving people with mild to moderate dementia. These included, on the one hand, usability tests with small groups (e.g. three people tested the controls for Chrono TV). On the other hand, exploratory field studies were done, where we either deployed an artifact in the real context and reactions of people with dementia were observed (e.g. the Memory Window was placed in the common room of a care home, and groups of 3-5 users with mild to moderate dementia were observed throughout the day), or the artifact was actively integrated in a group activity (e.g. the Chrono TV in a dementia support group with six men with mild to moderate dementia). In addition, we organized a 2 h-workshop at a care home where all six probes were set up in the common room for residents to be tried out. About 20 people were present including residents (about 8 with dementia), relatives and caregivers. We collected written field notes.

5.2   Expert Workshop

Next, we conducted an expert workshop with 20 participants comprising caregivers, support group leaders, professionals from dementia research, social workers, and technology researchers. In the 1.5-h workshop participants first experienced all six probes in an interactive exhibition. They could discuss their experiences directly with developers and give voluntary feedback through a 5-item questionnaire about the user group, the attractiveness of the object, the expected potential to trigger communication, the expected effort to supervise the use, and the suitable care context. Afterwards, a 10-min presentation about the design of the probes was given. Then participants were divided into 4 discussion groups of five people with diverse backgrounds. Each

discussed a different aspects of communication of people with dementia: (1) fostering communication, (2) non-verbal communication, (3) verbal communication, and (4) communication between young and old. The discussions were structured in three steps: (1) current practice and problems, (2) possible role of probes in different settings and (3) brainstorming of new ideas. We audio-recorded and transcribed the discussions for analysis.

6 Insights and Considerations

In the following we provide our first overall insights and design considerations that we derived from the field notes, short questionnaire, and focus groups.

Catering for Diversity and Personalization. One recurring aspect was the variability of symptoms and progression of dementia. Unlike other diseases it is difficult to foresee the progression and communication problems arising at different stages. In addition, how people experience their limitations and how they react in interactions with others is closely related to their personality and past life experiences. To cater for this diversity, experts suggested a strong focus on familiarity and personalized content. The latter could range from media targeted to the preferences and interests of the people (e.g. providing virtual views into a museum for the art-interested user) to completely personal media, such as own photographs.

Application Types. Three general types of applications suitable to support communication emerged: applications that (1) allow people to virtually visit places they cannot visit anymore (such as going to the opera, a museum, the old town), (2) use biographic content and storytelling as a basis for communication (as the book, or the Reminiscence Map), and (3) stimulate the senses to trigger reminiscence and reactions (as the teddy or Icho). The first type would be suited best for people with limited mobility to allow them to keep memories of familiar places and activities alive that could then be communicated to others. Storytelling about the past was identified as a major activity older people engage in, when new experiences are limited. Therefore, using content that triggers stories about the past by showing old videos or photos is useful for providing a basis in the communication, especially in the communication between young and old. As verbal communication plays a major role, these applications would be suited only for early stage dementia. For the later stages the role of emotional triggers was considered more important. The teddy was a good example of this. We observed that people, who did not communicate verbally, still sang along with the teddy's music. In addition, a care manager mentioned that also the soft fur, the familiar looks of the teddy (from the 30 s) and the shape probably reminded the person of familiar things from the past, like their own stuffed animals, or even holding a baby. In one discussion, an expert called it the "emotional memory" and said that sensory input often directly triggers memories without people undergoing a cognitive process to understand them. This was also a topic in the focus group on non-verbal communication where the possibility of adding olfactory input to the book (e.g. paper producing smell when being rubbed) came up to trigger emotional memories.

Communication While, Through and After Interaction. Generally, experts reported that all people have the need to communicate. However, while people with mild dementia often start communication with others, this diminishes throughout the disease. One aspect that should be explicitly considered in the design of such systems is the goal of the communication. While our initial intention was to design probes that foster communication during interaction, e.g. while two people look at the content together, we observed in the field tests that this was mainly true for objects like the book, the map and the window. In these cases people either explored the content together, or commented on it. In the field test with the TV we found that people with dementia were very concentrated on the program and little conversation took place. Although we had implemented a pause function for the group leader he did not use it, as he did not want to disturb the people's viewing experience. He decided to refer back to the content after it was consumed. We also observed that communication can take part through the artifact itself, meaning that the shared interaction could be considered communication or as one expert said "the artifact becomes the communication medium". This was the case with the teddy and the Icho-sphere, which are suited for non-verbal communication of people with extreme dementia.

Familiar Actions. Especially people with dementia have limited capacity to learn new interactions with digital user interfaces. Physical objects, however, provide at least three advantages: (1) interactions are based on familiar and basic actions (such as grabbing, moving or lifting objects), (2) they provide haptic stimulation, and (3) they often allow for shared interaction in a social setting. In the workshop at the care home we could observe that especially the objects that looked most familiar (the book and the teddy) attracted seniors and could be used by people with dementia without supervision. Although the users did not immediately see the buttons in the book, they were eager to touch the pages on different spots to trigger the sound. Many experts also liked the interaction with the window via RFID-enhanced postcards, but we observed in the field, that in the current implementation (card has to be placed on the windowsill) mobility was a limiting factor.

Practical Considerations. Practical considerations that were mentioned during the expert workshop were (1) hygiene, (2) data security and personal rights of people with dementia, and (3) effort of the communication partners (i.e. caregivers, social workers, relatives). Hygiene is important for artifacts to be used in the care home and where the haptic interaction is prevalent, such as the Icho sphere, and the teddy. Data security was discussed in consideration of the Reminiscence Map, which stores personal stories. It was highlighted that recurring informed consent to use the data is important, but difficult to obtain from people with extreme dementia. In addition, some people were concerned that the window would deceive people who do not realize that it is not real. Some experts were worried that the effort of relatives or caregivers to enter the data would be too high for the map. On the other hand, if integrated well into the existing practice (e.g. biographic therapy), it could be feasible. In addition, many thought that the artifacts needed to be used under supervision of a caregiver or relative. Our field experiences, however, showed that simple artifacts, e.g., the teddy or the book, were used by people with dementia alone or among each other.

7   Conclusions

The work presented here provides a snapshot of our larger research endeavor to design interactive multimedia artifacts for people with dementia to support reminiscence and communication with others. We presented six probes that were designed based on a first phase of exploratory field research. The probes were used in several field studies to observe reactions from people with dementia as well as an organized workshop with stakeholders from the care domain. We presented our preliminary design insights from these studies. In the future we intend to extend our investigations and provide general guidelines for the design of interactive multimedia artifacts that support people with dementia in reminiscence and communication in different care settings.

References

1. Gallagher-Thompson, D., Tzuang, Y.M., Au, A., Brodaty, H., Charlesworth, G., Gupta, R., Lee, S.E., Losada, A., Shyu, Y.-I.: International perspectives on nonpharmacological best practices for dementia family caregivers: a review. Clin. Gerontologist **35**, 316–355 (2012)
2. Astell, A.J., Alm, N., Gowans, G., Ellis, M., Dye, R., Vaughan, P.: Involving older people with dementia and their carers in designing computer-based support systems: some methodological considerations. Univ. Access Inf. Soc. **8**(1), 49–59 (2009)
3. Wood, W., Womack, J., Hooper, B.: Dying of boredom: An exploratory case study of time use, apparent affect, and routine activity situations on two Alzheimer's special care units. Am. J. Occup. Ther. **63**(3), 337–350 (2009)
4. Kasl-Godley, J., Gatz, M.: Pschosocial interventions for individuals with dementia: an integration of theory, therapy, and a clinical understanding of dementia. Clin. Psychol. Rev. **20**(6), 755–782 (2000)
5. Woods, B., Portnoy, S., Head, D., Jones, G.: Reminiscence and life review with persons with dementia: Which way forward? In: Jones, G.M.M., Miesen, B.M.L. (eds.) Care-Giving in Dementia: Research and Applications, December 6, 1st edn., pp. 137–161. Routledge (1993)
6. Gowans, G., Campbell, J., Alm, N., Dye, R., Astell, A., Ellis, M.: Designing a multimedia conversation aid for reminiscence therapy in dementia care environments. In: CHI 2004 Extended Abstracts, pp. 825–836. ACM (2004)
7. Alm, N., Astell, A., Gowans, G., Dye, R., Ellis, M., Vaughan, P., Riley, P.: Engaging multimedia leisure for people with dementia. Gerontechnology **8**(4), 236–246 (2009)
8. Siriaraya, P., Ang, C.S.: Recreating living experiences from past memories through virtual worlds for people with dementia. In: Proceedings of the 32nd Annual ACM Conference on Human Factors in Computing Systems, pp. 3977–3986 (2014)
9. Waller, P.A., Östlund, B., Jönsson, B.: The extended television: Using tangible computing to meet the needs of older persons at a nursing home. Gerontechnology **7**(1), 36–47 (2008)
10. Wallace, J., Thieme, A., Wood, G., Schofield, G., Olivier, P.: Enabling self, intimacy and a sense of home in dementia: an enquiry into design in a hospital setting. In: Proceedings of the SIGCHI Conference on Human Factors in Computing Systems, pp. 2629–2638 (2012)
11. Davis, B.H., Shenk, D.: Beyond reminiscence using generic video to elicit conversational language. Am. J. Of Alzheimer's Dis. Other Dementias **30**(1), 61–68 (2014)

12. Hutchinson, H., Mackay, W., Westerlund, B., Bederson, B.B., Druin, A., Plaisant, C., Eiderbäck, B.: Technology probes: inspiring design for and with families. In: Proceedings of CHI 2003, pp. 17–24 (2003)
13. Huldtgren, A., Vormann, A., Geiger, C.: Reminiscence Map: Insights to design for people with dementia from a tangible prototype. In: Proceedings of ICT4AgeingWell, Lisbon, Portugal (forthcoming) (2015)