Reminiscence of people with dementia mediated by a tangible multimedia book

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Abstract: With the growing senior population the number of people with dementia is rising rapidly. Besides – currently limited – pharmaceutical treatments, psychosocial interventions play a major role in ensuring the life quality for people with dementia. Among these is reminiscence therapy, which helps people to remember episodes of their past life and maintain their identity, while the disease progresses. The research presented in this paper explores the role of a tangible multimedia artifact to support reminiscence sessions. We describe the development of an interactive book that was tested in a care home with people with dementia and caregivers. We present findings on the interaction with the book, its potential to mediate reminiscence and communication, and on the perspective of caregivers using the book in the sessions.

1 INTRODUCTION

Due to the demographic changes and associated population aging, the number of people suffering from dementia is rapidly increasing (Alzheimers.Net). Dementia is a condition commonly associated with memory decline, however, the disease also impacts other cognitive functions such as speech, decision making, reasoning, or learning, thereby making it more and more difficult for people with dementia to engage in meaningful and social activities. This in turn impacts their self-confidence and quality of life (Wood et al., 2009).

Caregivers, on the other hand, often suffer from stress and frustration, when caring for people with dementia. Especially in more advanced stages of the disease challenging behaviors such as apathy or aggression impact the social interaction (Van der Linde et al., 2012) and stimulating a conversation can be very difficult. Until now pharmaceutical interventions are rather limited. “Currently, five drugs have been approved by the FDA for use in AD […]. These five drugs are supportive or palliative rather than curative or disease-modifying therapies, and they do not appear to alter the final outcome of the disease.”(Casey et al., 2010) Therefore, psychosocial interventions have gained in importance over the last years. These include, e.g., memory training, reality orientation and reminiscence therapy. Especially the latter is considered a promising intervention for people with dementia to improve mood, cognition, and behavior (Woods et al., 1992). Furthermore, reminiscence can increase interpersonal communication (Kasl-Godley et al., 2000).

In our work we were interested in which way advanced user interfaces and media technologies could play a supporting role. We hypothesized that the new opportunities that come with embedding sensors and microcontrollers into everyday artifacts, allow for the design of tangible interfaces in combination with multimedia to be used by people with dementia with little technological skills and caregivers to stimulate reminiscence and communication. In particular, haptics, images, audio, and possibly other modalities like smell seem to offer ways to stimulate affective memories.

In our research program, researchers and designers from four disciplines (Media Technologies, Design, Electrical Engineering and Social Sciences) collaborate on socio-technical solutions for people with dementia. Our research aims at 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 and abilities. In the following, we describe our work following a research-through-design approach. In particular, we...
describe the design of an interactive book that was used in several field studies with people with dementia of different degrees and their caregivers. We provide insights derived from a field study into how tangible user interfaces can support reminiscence and communication between a caregiver and a person with dementia and considerations to be taken into account.

2 BACKGROUND

2.1 Reminiscence Therapy

Researchers investigating dementia, especially those following a person-centered 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 et al., 2000). Psychosocial interventions are even more important in light of the limited success of pharmaceutical interventions for dementia. Kasl-Godley and Gatz 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/behavioral 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. Behavioral approaches as well as memory training, on the other hand, are less concerned with the subjective experiences, but target specific cognitive deficits. Generally, it is recommended to involve others in these interventions in order to “increase social contact, interpersonal communication and psychological health” (Kasl-Godley et al., 2000).

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 their quality of life (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” (Kasl-Godley et al., 2000). Since remote memory is usually spared for large parts of the dementia process, people are often able to recall events from the past. Furthermore, abilities like sensory awareness (response to stimuli like visual, audio and tactile), musical responsiveness and emotional memory (ability to experience rich emotions) are thought to persist in dementia (Lawton et al., 2000), making reminiscence through audio-visual and tactile media possible. Even while processing memories may be compromised due to the brain damage, reminiscence can still provide structure in developing relationships or engaging with others (Woods et al., 1992).

2.2 Technologies in Reminiscence Therapy

A recent literature review (Lazar et al., 2014) on technologies used in reminiscence therapy points to many research projects in which ICT was used, e.g. in the form of displaying media on touch screens or projections. The purposes of using technology in reminiscence, as analyzed by Lazar et al. are two-fold: either to account for deficits such as motoric problems or memory loss or to harness strengths, such as emotional memory.

One big project in the area is the the CIRCA project (Gowans et al., 2004), in which researchers created a multimedia application using video, photo and music to support one-to-one reminiscence sessions. The interface was meant to be used by caregivers initiating conversations with people with dementia. The authors reported positive results from user testing. 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. Similarly, (Siriaraya et al., 2014) utilized immersive 3D technology, in particular Unity3D and the Kinect, to create environments for reminiscence and meaningful activities (like gardening). However, people with progressed dementia had problems with the interaction. Lazar and colleagues (2014) found that “[c]hallenges include that many of the systems described in the study require technical expertise for setup or operation and may not be ready for independent use.” We would like to address this specifically in our project by designing tangible everyday objects that hide the technology in a way...
that users do not need any technical expertise and people with dementia can interact with them without support.

2.3 Tangible Computing for Seniors’ Reminiscence

Although it has already been recognized (Waller et al., 2008) that tangible computing is a way to approach a person-centered model for designing technology for seniors, the exploration of tangible computing within the area of reminiscence is so far limited to a handful of examples that we briefly outline.

One of the early works on using tangible interfaces designed specifically for older adults to trigger reminiscence was Nostalgia (Nilsson et al., 2003), which consisted of an old radio and an interactive textile runner with a diamond pattern. The runner was augmented with hidden switches that could be pressed to select music and news from different timespans ranging from 1930 to 1980. A preliminary evaluation showed that people at the care home were able to interact with the device and that it triggered discussions about the old news and singing along with the music. The television was another familiar medium, which was deemed suitable for broadcasting information for reminiscence to people in a care home. For instance, Waller and colleagues (Waller et al., 2008) designed a television that extended the regular TV program with specific care home internal and personal programs. The TVs were installed in the rooms of the residents as well as the communal rooms to allow for private reflection as well as communication between residents about the programs, which showed among others, old TV series, pictures from the care home and events, and personal photographs. In the unstructured evaluations, the authors found some proof that people used the TVs and also discussed the contents. However, especially people with dementia had problems using the standard remote controls. For one person a tangible remote in form of a photo frame was built. This could be used by the person, but was rarely approached by her without a caregiver.

More recent work targeted specifically to people with dementia was done by Wallace and colleagues (Wallace et al., 2012) (Wallace et al., 2013). In the "Tales of I" project (Wallace et al., 2012) they designed a system comprised of a wall cabinet holding several snow globes that encased objects relating to topics like soccer, holidays or local and a television cabinet with a mold to hold a globe. Through RFID tags in the globe the TV could read the correct topic and start the corresponding film. Films were created from footage ranging back to the 1930s. In addition, personal content for each client could be played via a USB stick. In this project authors found that in the hospital setting, where the system was installed in a common living room, it provided a sense of home for clients and visiting relatives, which was often lacking in the sterile rooms. Through a sense of home and familiarity anxiety and challenging behaviors could be reduced. In addition, staff members were able to see a client more as full person, when that person reconnected to a sense of self through the films.

In the "Personhood" project (Wallace et al., 2013), in-depth research into the lived experiences of people with dementia was done through designing probes with and for a couple, in which the wife suffered from dementia. Based on this research interactive jewelry was designed for reminiscence and providing a sense of self, through old media (like personal photographs in a locket) and personalized tangible artifacts (like a brooch made of old dresses).

These projects were exploratory inquiries into how tangible computing can be used to trigger reminiscence, and through that support a sense of self for people with dementia. Inspired by these works our work focuses more strongly on developing a medium that can be used equally by caregivers and people with dementia in reminiscence sessions, and can be personalized to care home residents.

2.4 Augmented Books

Within HCI the idea of augmenting books with sound or video is not new. For instance, “Books with Voices” (Klemmer et al., 2003) links video recordings to transcripts of oral histories. This book, however, needed an additional device to display the videos. This was also the case with the MagicBook (Billinghurst et al., 2001), which came with a handheld AR device to watch additional 3D content emerging from the pages of the book.

Although studies of the above artifacts show that the combination of a physical book for easy access and browsing and the possibilities of additional multimedia or 3D are beneficial, until now augmented books have not been used in reminiscence work for people with dementia.

Our work, however, differs from the above as we intended to focus the interaction only on the book itself, and avoid additional technology for accessing the additional content, as this may be to difficult for people with dementia.


3 DESIGN CASE: INTERACTIVE MULTIMEDIA BOOK

3.1 Design Concept

During initial design explorations the project team engaged in a collection of artifacts that trigger memories, and field research in dementia care centers to understand what artifacts were used by caregivers to stimulate memories in people with dementia. Photo books, or postcards, were one type of artifacts that often serve as reminiscence triggers. Images alone, however, require people to perceive the content through one sense only, i.e. vision, which can lead to frustrating situations if the person does not recognize the content. Music and sound on the other hand, has a stronger impact on people’s memories, as it connects to affect. Therefore, we chose for a combination of images and sound, implemented in an interactive book (Fig. 1), whereas the sound can be triggered by the user through simple touch gestures on three parts of the pages.

Reminiscence content can be very personal; something that triggers memories in one person does not necessarily do so in another. Therefore, we decided to develop the book in such a way that the contents and the theme of the book can be changed easily. While the technology is installed permanently inside the book, the image content is a printed inlay (Fig. 1 bottom) that can be changed and the matching sound files per page are stored on a removable SD card. The book can recognize different inlays through RFID. Besides the possibility of creating very personal content, there are themes that refer to a collective memory of a generation. For the prototype we chose ‘traveling to Italy’ to exemplify one such theme. The book consists of five double pages, each dedicated to another aspect of Italy trips in the 50s/60s. The first double page sets the scene by showing a map of Italy and playing sounds like typical Italian music, and street sounds. The second double page was devoted to the transportation means showing cars and mobile homes of the time. Accompanying sounds were the engine roar or car commercials. The third double page showed a beach scene with people dressed in 50s beachwear and it played, e.g., ocean sounds. The fourth page was devoted to Italian foods like pasta and sounds from Italian commercials and a song about wine from the that time. The last double page shows album covers of typical music of the 50s/60s, which could be played by pressing on the covers. One famous song’s lyrics are also printed on that page.

3.2 Implementation

The goal was to embed the technology in such a way that the look and feel of the artifact is so close to a real book that it would be perceived by people with dementia as such, and thereby reduce possible barriers to use. A real book was used with the pages glued together and small cavities cut out to fit the technology (Fig 2, right). The book contains an Arduino Nano V3, which recognizes magnets embedded each double page through linear Hall
sensors and is thereby able to identify the opened page. Furthermore, an RFID reader is built into the back of the book, which reads the RFID tag of each designed inlay and thereby enables the exchange of the book’s contents. Three push buttons are positioned in the back of the book (Fig. 2, left). On pressing one of these through the pages of the book (positions were indicated by green points) a message containing the selected audio file is sent to an MP3-player module, which reads the file from an SD card and outputs it. The book is powered via a mini-USB port and has a headphone jack to attach external speakers, as the quality was insufficient with embedded speakers.

4 USER TESTING

4.1 Setting

Dementia care takes place in diverse settings, such as home care, institutional care and daycare/dementia support groups. The focus in this paper lies on the institutional setting, where a majority of people with dementia resides and caregivers are confronted with the daily task of engaging with residents in activities. First, we got in touch with a local welfare organization. After discussing the project with the lead social worker in one of their care homes we were invited to an introductory session involving her and five caregivers in the care home, who are responsible for the social care (as opposed to physical care) of the residents and engage in activities with them, among these reminiscence sessions, on a regular basis. The artifact was introduced in this meeting to get caregivers acquainted with it, discuss an appropriate set-up and recruit suitable participants. Instead of defining all study parameters beforehand, we allowed the caregivers to bring in their own ideas of how to fit the book into their practice to also derive their own insights from the user tests. The final set-up was agreed upon together. For instance, while we initially intended to have test participants suffering all from the same level of dementia (i.e., first stage), the caregivers saw more value in trying the book with a range of people with different degrees of dementia. In fact, they were very curious if it worked with people with advanced dementia. We did not see this as a problem in the study, since we chose for a qualitative methodology and did not expect to be able to generalize the findings over the whole population of people with dementia. Another discussion point was the setting in which the book was presented. We agreed on using different communal rooms in the care home depending on where each resident would be most comfortable. However, caregivers commonly use additional decorations in the room to induce a certain atmosphere linked to the conversation theme. We agreed not to do this, since we did not want the effect of the book diffused by other props.

4.2 Participants

In total, eight people with dementia (1 male, 7 female, aged 80+) and four caregivers took part in the study. The lead social worker attended all sessions and took notes for her keeping. Participants suffered from different levels of Alzheimer’s. Additional, handicaps such as mobility problems, hearing problems, speech impairments (related to strokes) and tremors also occurred (see table 1).

<table>
<thead>
<tr>
<th>#</th>
<th>Gender</th>
<th>Characteristics</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>female</td>
<td>wheelchair, no glasses, slightly impaired hearing and vocal articulation</td>
</tr>
<tr>
<td>2</td>
<td>female</td>
<td>wheelchair, slight vision impairment</td>
</tr>
<tr>
<td>3</td>
<td>female</td>
<td>wheelchair, shaky hands and torso, motoric problems</td>
</tr>
<tr>
<td>4</td>
<td>female</td>
<td>wheelchair, apathetic</td>
</tr>
<tr>
<td>5</td>
<td>female</td>
<td>wheelchair, impaired hearing, shaky hands</td>
</tr>
<tr>
<td>6</td>
<td>female</td>
<td>wheelchair, one arm is paralyzed, speech impairment</td>
</tr>
<tr>
<td>7</td>
<td>female</td>
<td>wheelchair</td>
</tr>
<tr>
<td>8</td>
<td>male</td>
<td>wheelchair</td>
</tr>
</tbody>
</table>

4.3 Materials and Data Collection

We used the interactive book with an external battery pack and miniature speaker. We were not allowed to do video recordings, as this was seen problematic.
with people with dementia, especially in the first stages, as they can be very suspicious of camera equipment. Therefore, sound recording was done through a smartphone and additional information was collected in observations using an observation scheme to guide the observations according to interactions with the book, interactions between people, and physical reactions of participants.

4.4 Procedure

We first briefed the caregivers in how the book works and informed participants of the study conditions. Informed consent was provided by care workers, also on behalf of the people with dementia.

4.4.1 Reminiscence Sessions

In each session, one caregiver engaged a resident and they looked at the book together, while two researchers took observational notes sitting at a separate table in the room. Caregivers were instructed to engage with the participant as usual and use the book as they would use other materials in reminiscence sessions. Sessions lasted between 15 min and 30 min depending on when the person with dementia wanted to stop. After each session we asked the person with dementia for some spontaneous feedback.

4.4.2 Focus Group with Caregivers

After the sessions we were curious about the caregivers’ feedback. For this purpose we ran a 70-min focus group with all four caregivers and the lead social worker. Questions were prepared relating to spontaneous feedback from the sessions, communication normally and compared to using the book, media normally used in reminiscence, other topics for the book, interaction with the book, and improvements. However, the set of questions served us only as a guide, and was not strictly followed.

4.5 Data Analysis

The collected data was analyzed using a qualitative content analysis (Schreier, 2012). All audio-recordings of the sessions were transcribed verbatim in the first step. The transcripts were then complemented with field notes from the observation about people’s interactions with each other and with the book, as well as emotional expressions, gestures and posture. A coding frame was developed in a two-step procedure, (1) the higher level codes were concept-driven based on the focus of our observation of the sessions (Reaction of PWD (person with dementia), Reaction of Caregiver, Interaction of PWD with book, Interaction of Caregiver with Book and Communication between both), and (2) sub-codes were based on reading the transcripts.

The data of the focus group with the caregivers was coded directly in a data-driven way, as the themes/questions used in the focus group were not followed strictly. After an initial coding of the complete transcript, codes were categorized in the tree structure shown in Fig. 4. After coding all data two researchers discussed and derived higher-level themes from the coding combining results from the single sessions and the focus group. Next, we provide our findings by elaborating on the themes exemplified through quotes (translated from German).

![Figure 4: Data-driven Coding Frame for Focus Group.](https://via.placeholder.com/150)

5 FINDINGS

5.1 The Book as an Interaction Device

The book afforded several actions including touching, turning pages, pressing on pages (to trigger sound), viewing pages, reading text on pages. We observed that most of the time the caregiver turned the pages. However, some interesting exceptions occurred, e.g. when P3 did not want to listen to the sounds anymore and went to the next page by herself to make the music stop. This example shows that the book empowers
people with dementia to take initiative in steering the output of the book and thereby the conversation.

With regard to pressing the buttons to play back sounds, we observed a diversity of reactions of the residents. Some were curious and pressed the buttons themselves without an invitation by the caregivers. The majority, however, waited until the caregiver asked them to push another button. None of them seemed to be afraid of the technology or refused it completely. P3, however, stated clearly that she did not want to push anymore, which may be related to the problems it had caused her to hit the buttons correctly. P5, the only man, pressed the buttons mainly himself and figured out without explanation that he could stop the music by pressing a button a second time.

### 5.1.1 Usability Problems

During the sessions several usability problems were observed. Many participants were sitting in wheelchairs, which made it difficult to get close to the table and the book lying on the table. Since the book was rather heavy, people could not easily put it in their lap or lift it. Some were leaning forward to be able to read better. In several cases, caregivers lifted the book up a little by putting other books underneath the backside. In two occasions people had trouble hitting the buttons. P3 due to a tremor and P8 due to perception problems (she sometimes mistook other circles on the pages for a button). When the sound was too quiet some participants pressed the button again, which, however, stopped the music altogether causing confusion.

In some cases pages stuck together. Generally, it was advised to have thicker or laminated paper, which would also be more hygienic in the care setting. When participants reached the last page of the inlay they tended to try to turn the page, as the book gives the impression that there are more pages. Caregivers also criticized the clutter of the graphics on some pages, which confuses people with dementia, and suggested to use fewer images per page and add additional textual information instead. Text should generally not be used as a graphical element (e.g. some background texts in Italian), because people tend to read them and get frustrated if they cannot understand them.

### 5.2 The Book as a Medium to Support Reminiscence

#### 5.2.1 Types of Memories and Triggers

Several types of memories could be observed. Some were of factual nature in response to something in the book, either triggered by an image (“Yes, that is like a camper, they had those trailers and they slept in them, when they drove to Italy.”), a sound (“Do you know what you can do in San Remo? Go to the casino!”) or a question of the caregiver (“Did you use that [Fondor]”–“My parents, yes”).

Others were more personal narratives triggered by an image or sound. “Right, these are tomatoes. Also typically Italian, right?” (CG4) … “They also grow in Turkey” (P8). “Yes”(CG4) “They were hanging on the trees, I saw it. We were even allowed to pick them and eat them. They allowed it. On the street there were also small peaches or something that we were also allowed to pick.” (P8)

In two cases memory chains were triggered by the book’s content that led to memories or complete narratives that were unrelated to Italy. In the case of P2 a sound that was interpreted by her as zither music made her think of a country (Austria). She could unfortunately not remember the country’s name, and started talking about Peter Alexander (a famous musician from Austria). Once the caregiver dropped the name Austria, the person continued talking about her ski vacations there. Similarly, P8 started telling stories about her trips to Norway even after the session with the book ended. According to the social worker the book still achieved its purpose to trigger memories in these cases.

#### 5.2.2 Searching for Help

We observed that in some cases people looked at the texts to remember something, e.g. in case of the Isetta car (logo in the book) or when a song was playing that had the lyrics printed in the book. P2 also pressed a button for supportive sounds when the caregiver asked a question: [P2 reads] “A trip across the Alps. Messerschmidt. That reminds me of something” “Yeah? Of what” (CG2) [P2 ignores the question and presses another button on the page.]”

#### 5.2.3 Emotional Reactions

Especially the music acted as a trigger to affective memories. One of the last songs was outstanding, as every participant knew it and even people with speech problems sang along. P5 even started crying during this song, which was interpreted by the caregiver as a sentimental, but still positive reminiscence. Other reactions to the book were laughing together. P2 made many jokes and was generally very talkative, but also others, who were more reserved, like P5 or P6, joked at some points in reaction to the images. It was also common for people
to sigh in what could be interpreted as a sentimental way, especially after enjoying the music, which may have brought up memories.

5.3 The Book as a Medium to Support Communication

As we did not set up the study to compare reminiscence sessions with and without the book in a within-subject set up, we rely on the accounts of caregivers about the mediating power of the book in the communication. Especially the focus group revealed the difficulties of engaging people with dementia in activities. “And Mrs S. is also difficult. It is hard to connect to her, she is very introverted and impulsive.” (CG2) “Normally, she does not go to any activities. She mostly stays in her room with her roommate and is very hard to get out.” (CG3) Several caregivers reported that they were very surprised that the residents were willing to come along and even seemed to be engaged and enjoy looking at the book together.

One caregiver told us that the book acts as a medium to learn something about the other person and their time. „And you learn something about the people, depending on what they react to, then you know their preferences. In that sense it was exciting, how the people would react. Just asking someone you don’t find out very much. But with such a medium, I wished to just see their reactions.” (CG2)

5.3.1 Styles of Leading the Communication with the Book

We observed two apparent styles of using the book in a conversation. Some caregivers directed the conversation strongly through asking questions closely related to the content (e.g. What is this sound? Which image do you like?), while others left it open to participants to react and engaged in a more natural conversation. We noticed that in the first cases, conversations quickly led to a question-answer turn taking, in which people with dementia seemed less engaged, but rather briefly answered the posed questions, while less questions led to more engaged conversation, as the following excerpts exemplify:

[Fondor Commercial plays] “As in the old days” (P1) “As in the old days?” (CG1) “Yes, Fondor” (P1) “Did you use that?” (CG1) “My parents, yes” (P1) “To spice up food? What kind of food?” (CG1) “Everything.” (P1) “Pasta?” (CG1) “Yes, yes, pasta, too, of course.” (P1)

[Fondor Commercial plays] “Enjoy your meal! Do you know Barilla?” (CG3) “Mmmh, pasta.” (P5) “Pasta! I know you like Spaghetti.” (CG3) “No, not Spaghetti. I don’t always have scissors on me!” (P5) “What? But with lots of tomato sauce.” (CG3) “Yes, with sauce. Yes, mmm, tomato sauce.” (P5) “Yes, that is something simple you can make quickly. And then a glass of red wine with it.” (CG3)

In the case of P2 we also observed a playful back and forth between her and the caregiver ordering each other to press a button, then guess what the sound is. In this case the book clearly facilitated an equal turn taking in the conversation and a playful engagement between the two.

The lead social worker added in the focus group that she could imagine more storytelling from the side of the caregiver in response to the book, which could in turn animate the person with dementia to tell stories, too. This style was, however, not observed in the sessions, which was due to the fact that caregivers felt that they should not intervene too much in this way. CG3 insisted that it would be helpful to have more time and background information about the different aspects of the book (like the sounds or details about the cars) before using it in a session, and that telling own stories would become easier with more preparation, too.

5.4 Composition & Atmosphere Creation

An important theme that came from the focus group was the composition of the book’s content in order to create a certain atmosphere. Caregivers told us that this is very important for people with dementia in order to reminisce. Therefore, they often use extra decoration as well as food or smells for people to experience in such sessions. In this case one could think of red wine and pasta to taste, lemons to feel and smell, etc. Caregivers evaluated the last page of the book (Fig. 3) with the music, and fitting graphics that infer an atmosphere very positively. They suggested that this or a similar page should be placed at the beginning of the book to set the scene and get people in the right mood.

Furthermore, it was discussed to include music on each page, to guide the person through the book while maintaining the feeling. Further ideas were scented papers or papers with textures to give haptic feedback.

5.5 Accounting for the Individuality of the Resident

During the sessions we could observe that the caregivers were very sensitive to the reactions of the
participants, even if the cues were very subtle. In one case, for instance, we thought P8 seemed very disengaged while a song played, but in the focus group the caregiver (CG4) reported that the woman was still tapping her finger a little bit to the music and therefore left it playing. In another case, a participant started crying while the music played. In the focus group CG3 reported the following: “I thought should I stop it, but that was a nice memory, sentimental, but nice, and then I thought, I would let her enjoy it, although it is sad to reminisce.” Being sensitive to the person is often only possible if one knows the person’s background well enough. “Mrs S. trembles a bit and she is incredibly embarrassed about it, because she is very proud. That is why I asked ‘should I do it?’ just to relieve her. Not to do it for her, but because I know she would be embarrassed, if she was trembling and it did not work.” (CG2)

Knowing the person’s background is also crucial to interpret their reactions. In several occasions we thought participants were disinterested, negative or even aggressive, but in most cases the participants said in the end that they liked the book and the caregivers reported that certain reactions are normal for the participants. “Well for being her, she actually concentrated long on this. She is rather sour and rejects a lot.” (CG4) “That is her way. In the same way she can tell you trembling and screaming ‘Yes, of course, I would like to go outside!’” (CG2)

The sessions also showed that even though the theme was about Italy, the variety of the content (cars, food, etc.) allowed people to talk about their own memories, even if they had not visited Italy, as e.g. in the case mentioned earlier where P8 talked about Norway instead. In addition, the implementation of the book also allows for completely personalized content, as the inlay can be exchanged.

6 DISCUSSION

6.1 Tangibles for People with Dementia

In the previous section we described many detailed findings on how people interacted with the book. From these we would like to highlight three aspects that proof, in our view, the suitability of tangible computing for this target group. First of all, familiarity with the artifact enabled participants to approach the book without fear and the level of technical skills did not matter at all. After short explanations all participants understood the concept of pressing on the pages to trigger sounds. This was also not considered strange. Two people with dementia referred to the book as an audio book or a talking book. A second aspect we could observe in the sessions was that the book enabled self-direction for people with dementia. As described, people used the functionality of lifting a page or pressing a button twice to stop the sounds they did not like to listen to anymore, thereby steering the conversation themselves. Last, an interesting observation was made by one caregiver in the focus group regarding the agency of people with dementia using the book by themselves to turn on music, as opposed to the caregiver playing music from a CD player. “But also [her] surprise, when she pressed for the first time. This surprise was of course very extraordinary. You cannot achieve this when you start [playing] something [music at a CD player] elsewhere. That is something that only happens when they press themselves.” (CG3) This integration of input and output spaces, inherent in tangible computing, seemed to trigger emotional reactions in the participants that traditional technology is not able to trigger.

6.2 Design Recommendations

From the findings of the study we recommend the following design considerations for interactive reminiscence books:

- Make the book more manageable by reducing original (unused) pages and weight.
- Use few and distinct images on the pages to avoid clutter.
- Provide buttons with different texture than the rest of the page and bigger surfaces.
- Start with a page that creates an atmosphere to set the scene by using music and possibly other sensual output like scents.
- Add information to the visual content (mostly for caregiver as background information).
- Increase reminiscence potential through emotional content like music or poems.
- Provide contents people with dementia can easily relate to, e.g. local things or content linking to collective memories of the generation (e.g. TV shows).

6.3 Limitations

Drawing generalizable conclusions from the sessions on how a medium like the book works for people with dementia is hard due to the inherent diversity of
symptoms, personalities, and capabilities of the target group. This, however, is not specific to this study, but rather a general concern in doing qualitative field research with people with dementia, since the disease develops differently in people depending on which brain areas are affected. Although we did ask people with dementia to give us direct feedback on their experience, some were too tired or had forgotten parts of the content already. In these cases we have to rely on our observations and caregivers’ accounts on how to interpret the reactions. Another limiting factor in this respect is the lack of video recordings, which would have allowed us to look back at certain reactions with the caregivers.

Overall, the observations need to be interpreted in the context of interaction styles of caregivers and backgrounds of residents (see Findings). Yet, we believe that the rich accounts of the qualitative data give many insights into the role of tangible multimedia in this setting.

6.4 Future Work

In accordance with the findings on the usability of the book, we intent to implement the recommendations described above including making it less heavy, increasing the button size and changing their texture, using scented paper for additional sensual output, as well as improving the graphics and general composition of the content. In addition, the book was created in a way to allow for easy switch of content. Together with the caregivers we explored which content would work best for reminiscence sessions and we identified, besides others, two themes for new content: local content about our city (including, e.g., traditional events) and a TV theme including TV moderators/actors, shows etc.

7 DISCUSSION

We investigated the use of tangible multimedia in reminiscence with people with dementia. In particular, we presented a design case, i.e. an interactive book that can be operated by people with dementia and their caregivers created with the goal to support memories from the past through images and associated sounds. In the field study we found that the book had potential to act as a medium for reminiscence and communication between a caregiver and resident. Some usability problems were found and design recommendations provided to mitigate those. Overall, we observed that people had no hesitation to approach the device and people with dementia were empowered to steer the conversation pointing to a great potential for tangible interfaces in this domain. Especially, given the importance of psychosocial interventions for people with dementia, their lack of technical knowledge and the new possibilities tangible UIs offer, we should consider the combination of digital multimedia content and familiar physical objects as an effective way to improve therapy with people with dementia.

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REFERENCES


