Designing for Reminiscence with People with Dementia

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ABSTRACT

We investigate how technology can be used to support people with dementia to engage in Reminiscence Therapy. We used a participatory design approach carried out over three stages: scope, design and evaluation, involving five participants with dementia. We also engaged professionals and caregivers through a survey. We provide initial recommendations for engaging participants with dementia on how they wish to reminisce and what technology may support this.

KEYWORDS

Dementia; Reminiscence; Care Homes; User Centred Design; Interactive Prototypes

INTRODUCTION

Most technology designed to support people with dementia tends to focus on impairments that characterize dementia, e.g. ensuring safety and security of dementia patients [12], at the expense of the experiential consequences of design choices [7]. Whereas, research that examines the use of technology as a means for supporting memory loss often place a significant emphasis on caregivers and family input (e.g. [3]) or decide on the technology without participants input (e.g. [13]). This can lead to assumptions being made about the issues the individuals face and what technology is

Caregivers
Four caregivers with between 2 and 14 years experience in the home.

Occupational Therapists
Twelve Occupational Therapists with between 4 and 25 years experience

Social Workers
Five Social Workers with between 3 and 30 years experience.

Outcomes
- Music, photographs and story telling all were used successfully for reminiscence sessions
- Items were non-personalised, mostly from a reminiscence magazine
- Most participants struggle to learn new technology

Sidebar 1: Professionals who completed the survey and its outcomes.

Table 1: Participants with dementia and stage of their participation.

	Scope	Design	Evaluation
Mary	✓	✓	✓
Doris	✓	✓	✓
Hugh	✓	✓	✓
Vera	✓	✗	✗
Maureen	✓	✗	✗

appropriate to address such issues, which in turn could compromise the suitably of technology for the individual users. Focusing on enhancing quality of life for people with dementia, we present an approach exploring the use of participatory design to develop technology that supports reminiscence. We thus demonstrate methods for engaging with people living with dementia through participatory design that led to tailored solutions for the participants. Here we find that development in this manner can provide choice to the participants over how they wish to reminisce and what technology they are comfortable using. In addition we provide suggestions to further researchers on how they can carry out Participatory Design projects involving people with dementia.

RELATED WORK

Technology to support reminiscence is a growing field of research [15]. The CIRCA project [2] showed that technology can play an important role in supporting reminiscence. It aimed to support interaction between caregivers and the people with dementia, relying on caregivers feedback to develop such support. This highlights a common issue with research into dementia support where there is a heavy reliance on the input of the caregivers who can take control of the sessions [6, 8]. This is problematic as caregivers can be risk adverse which can reduce opportunities for the person with dementia [9]. These risk adverse strategy, recognised by the CIRCA project [1], reduces opportunity for the participants.

Personalised memorabilia has been used by other projects which record more positive experiences as a result for the participants [13]. However, this project decided the technology to use without the participants input, choosing DVDs and TVs on the basis that this was common technology that participants would be familiar with. It was found that some participants had difficulty in controlling the DVDs introducing a different limitation, one of accessibility.

The KITE project followed a participatory design methodology to develop technology to aid independence for people with dementia [8, 11]. Engaging with people with dementia to explore barriers they faced when independently going outside, they found that most participants had mobile phones but rarely turned them on or would leave them at home and were therefore unsuitable as a basis for potential solutions [11]. This highlights the difference in experience between the person with dementia and the researcher, which can lead to the researcher's intuition misleading them. Lindsay et al. [8] suggest that this should be overcome through an empathic approach to participatory design that empowers the person with dementia rather than emphasise their impairment.

APPROACH

Working in partnership with a medium-sized nursing home (20 residents) we developed a participatory design approach that involves both professionals and participants with dementia in three stages: scope, design, and evaluation (see Table 1 for participation in each stage).

Scope:
- Semi-structured interviews
- Exploration of memorabilia bought by the researchers and the participants (see figure 1)
- Open Conversations.

Design:
- Session 1: Focused Exploration of Memorabilia, both personalised and non-personalised (see figure 2).
- Session 2: Exploration of Technology focusing on audio and visual prompts. Technologies allowed for interaction with obvious and hidden technologies.
  - iPad storyteller application
  - Photograph Frame that plays audio when touched
  - Cushions with QR codes that play sound when scanned
  - Laptop application that displays pictures and sound
  - Cushions with hidden buttons linked to screen via blue tooth
  - Tablet to access internet to source picture and music

Evaluation:
- Session 1: Demonstration of prototypes
- Session 2: Demonstration, participant exploration of prototypes, semi-structured interview
- Session 3: Participant exploration, semi-structured interview

Responses coded as per [3, 5, 10].

Sidebar 2: Methodology for each stage

Four women and one man participated in the project ranging in age from 86 to 94 years old. Our only criteria for inclusion was that each participant had a diagnosis of dementia but retained the mental capacity to agree to participate in the project. Three participants had lived in the home for over two years, one for over five years and one for three months. Three of the participants had limited mobility and required caregiver support to move locations. For outline of Methodology see Sidebar 2.

Professionals were recruited to complete questionnaires prior to the workshops to help further understanding of current practices and technology use with this user group (See Sidebar 1 for professionals involved and outcomes). The outcomes from the professionals' participation meant that we focused on both personalised and non-personalised music, photographs and storytelling as means to engage the participants in reminisce for the scoping sessions.

SCOPE

We used thematic analysis to analyse the data we collected following the 6 point process outlined by Braun and Clarke [4], this was inclusive of the feedback from professionals as per Sidebar 1. Three major themes captured the barriers to reminiscence that participants identified:

(1) Personalization, lack of own memorabilia in the care home and reliance on others to gather memorabilia.
(2) Lack of control, inability to initiate reminiscence sessions and accessibility of memorabilia.
(3) Difference in professional and participants focus, caregivers trying to avoid subjects which might prompt negative memories, such as war.

DESIGN

Session one highlighted that all options would prompt reminiscence but photographs and music, particularly when combined would elicit the strongest responses. Mary, when listening to music and looking at photographs of an orchestra, stated that she had sung in the Albert Hall and proceeded to sing Ave Maria in Latin in the session, something her carers were not aware of. Doris stated that *"with music there is always reminiscence and it seems to strike out of the blue!"*.

Session two highlighted a clear barrier with technology with two participants, Mary and Hugh, not wanting to touch any of the technology involved. Hugh stated that he had owned seven computers in his life but that everything looked too advanced and he did not want to learn at his age. This reinforced the professionals' input as per Sidebar 1.

PROTOTYPES

Two prototypes were developed following these sessions: MyStory, an interactive photograph album where each page has a picture and the ability to record stories or play sound; SharedMemories, a
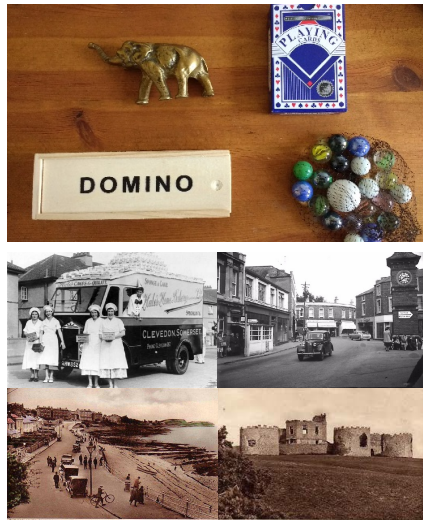
Figure 1: Example Objects and Images Used for Scope sessions

Figure 2: Example Objects and Images Used for Design sessions

web-based digital photograph frame where each picture has the ability to record stories, play audio which others can upload to (see figure 3). These allowed for a personalised approach to reminiscence, including images and audio which were the preferred choices, and an exploration of whether and how low-fidelity and higher-fidelity prototypes can overcome the barrier of technology.

EVALUATION

All participants were able to independently use MyStory, including in the third session with no demonstration; however, the touch screen interface proved more difficult for all and required repeated demonstrations for successful use. The coded responses showed MyStory was also more positively viewed than SharedMemories, with all users explicitly choosing this as the preferred option in the second session. Doris stated that she is *"more used to it"* and Mary that it was *"beautifully put together"*. However, in the third session both Hugh and Mary chose SharedMemories as the preferred choice as they could see it better. This was of interest as neither wanted to touch any obvious technology in the design sessions yet chose it as the option they would rather use. It was also interesting that the day of the third sessions was much darker due to poor weather which affected visibility and, therefore, the backlit screen did aid visibility.

DISCUSSION

The two prototypes developed both showed potential as technological support for reminiscence with the familiarity of MyStory eliciting the most positive responses. However, the support for the digital SharedMemories where visibility is an issue suggests that, for these participants, a range of options would be preferable to support them in different circumstances. What was clear from the early scoping stage was that a combination of audio and images was the preferred choice for reminiscence, and the ability to share one's own personalised story was important to all the participants.

This project highlighted a number of recommendations for future participatory design researchers undertaking projects involving people with dementia.

Firstly, **avoid assumptions**. Unlike prior work, we demonstrate that this is particularly crucial for people with dementia and needs to be practically implemented. In this study the caregivers' assumption that potential negative memories should be avoided, specifically discussions about World War 2, was proved unfounded. All participants wished to discuss this period in their lives as it had such a significant impact on them. The caregivers suggested this approach due to concerns for the participants well-being, however, as Waycott et al. [14] have suggested research should challenge 'decisions that we perhaps perceive as caring for participants'. In this context caring for the participant is not protecting them from their own memories but allowing the opportunity to reminisce about any subject.
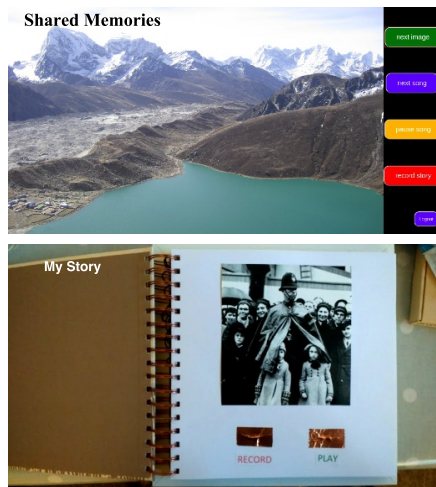
Figure 3: MyStory and SharedMemories

Secondly, **limit family or caregivers input**. Limiting input beyond the scoping stage allowed us to avoid issues raised by other researchers over the influence caregivers can have on the direction of the research [6, 8]. This allowed stories to be shared that family were not aware of. This is not a call to ignore caregivers input but to manage it explicitly and to be cognisant of its potential adverse effects on the direction of design given that it could overwhelm participants input.

Thirdly, **avoid pre-determination of the technology**. This allowed for the lack of recent technological experience of the participants to be overcome. Although two participants refused at the design stage to interact with technology they would engage with more novel forms of technology. This strength of feeling towards technology was not expected and through exploration with the participants we were able to find options they wanted to engage with. However, we found that involvement with design of technology is not enough. All participants were willing to engage with the digital prototype only when it became meaningful to them. The difficulties with abstract thought that people with dementia face meant that some participants could not see the potential impact of the technologies until it was personalized.

Fourthly, **engagement in the process itself can be a positive experience for the participants**. Participants enjoyed the interactions referring to researchers on arrival in the home as *"the memory people"* and, on end of the meetings, asked when the researchers would return to see them again. Mary highlighted this by stating during one meeting that she would *"never forget this"* and, at another, *"This is a day I shall never forget"*. All participants wanted to discuss their memories and as these were recorded and images gathered wanted to share these and discuss with family and caregivers. These findings are in contrast to those of Hendriks et al. [6] who found that most of the participants in their study engaged as a 'favour' to the researchers or family members. In our study the participants wanted to engage in the research.

CONCLUSION

This project showed that potential technology to support reminiscence for people with dementia can be successfully developed following a Participatory Design approach. Although a longer investigation would be needed to take these prototypes further and make more definitive assertions as to the suitability of the technology proposed and the set of recommendations for designing with for people with dementia, this project is able to suggest ways of approaching research of this kind which may be of interest to other researchers.

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