Designing 'De Klessebessers': a Leisure Game for People with Dementia

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Abstract—Providing leisure to people with dementia is a serious challenge. This paper shows insights from the design project of 'de Klessebessers', a leisure game for group use. The game, of which the name freely translates as 'the chitchatters', aims to stimulate social interaction among people with dementia. Different stakeholders, such as care professionals, relatives, and the people with dementia themselves were involved in the process to give insight into the experiential world of dementia. This paper presents (1) what we learnt from the stakeholders about social interactions, (2) how we applied these insights into a product design which we evaluated with the target group, and (3) lessons we drew about what are appropriate ways to involve the different stakeholders in this type of design process.

I. INTRODUCTION

THE provision of leisure and pleasant activities to people with dementia in group-living environments is a serious challenge within the domains of care and gerontechnology [1]. Most games and leisure products are unfit to these people, due to diminished cognitive capacities and other symptoms accompanying dementia syndrome. Within the WHO's International Classification of Functioning (Fig. 1), leisure devices influence a person's health condition at the participation level.
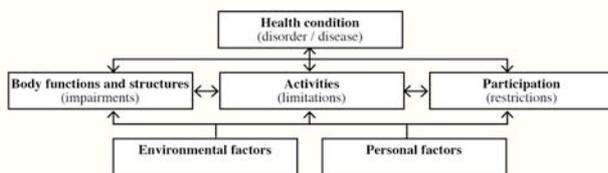

Fig.1. International Classification of Functioning of the World Health Organization describing a person's health condition.

The design team realised that designing for this target group (people with dementia) is not easy, because their world of experience is unlike anything the designers had experienced before. Therefore, the team used participatory design techniques that aimed specifically at 'designing for others' by involving those others as informants or participants in the design process, such as cultural probes

[2], generative techniques [3], and contextmapping [4]. But these techniques rely on expressive abilities and communication skills, which make them difficult to apply for this target group.

This paper describes what we learnt about dementia and collaborating with care professionals, relatives, and people with dementia during designing 'de Klessebessers'.

II. DEMENTIA

Worldwide, an estimated 24.3 million people cope with a decline in intellectual functioning called dementia [5]. According to the Netherlands Alzheimer's Foundation, there are an estimated 250,000 people with dementia in the Netherlands [6]. People with dementia often feel isolated, which makes them rather passive, meaning they are no longer, or to a lesser degree than before, taking initiative for interactions. Technology often addresses a health condition on the impairment or limitation level by supporting body functions and activities, e.g., [7]. In this project we addressed the health condition on participation level by supporting restrictions.

In understanding the experience of dementia, the team kept in mind the syndrome forces the person into a specific time frame, for example 30 years back in their past, depending on the stage of dementia and personal factors [8]. Professional and informal carers (such as family and friends) need to find out which time frame their clients or loved-ones are in to understand to some extent the way they think and behave.

Many have realised the importance of reminiscing as a therapy or meaningful activity [9], shown in Fig. 2. Orpwood et al. [10] list other challenges for design, such interactions that do not require learning, are familiar, do not take away control, and reassure the user.

Fig. 2. Recalling shared memories by triggers from the past can result in enjoyable social interactions among people with dementia.

III. Designing for dementia

The goal was to design a leisure game that stimulates social interaction among people with dementia. The design team consisted of the first author, who is an MSc graduate of the faculty of Industrial Design Engineering of TU Delft, and an MSc student of that same Faculty. The project lasted for three months. People with dementia, below referred to as 'our target group', their relatives, and care professionals were involved to provide insight in the experiences and needs of the target group. In the following paragraphs, we describe chronologically our design process for 'de Klessebessers' (Fig. 3). First, we participated in activities at a day care centre for psychogeriatric clients, involved care professionals, and relatives (A-C). Next we formulated design insights and generated ideas (D-F). Finally, we developed this into a concept, and built an experiential prototype, which was evaluated at the day care centre with psychogeriatric residents (G-H). We will address both the insights for the game itself, and the learnt lessons about involving the different stakeholders in the design process.

Fig. 3. The prototype of 'De Klessebessers' in use at the care centre with psychogeriatric clients. The prototype consists of four archetypal products, each marked by a lamp that indicates it is 'ready for action'.

A. Participating in activities at a day care centre

Before this project started, the design team had never before interacted with the target group. The team was aware that these people had to deal with memory loss, but had no idea what that would mean to them and their environment, such as relatives and care professionals.

The first step in getting acquainted with the target group, was visiting a day care centre for psychogeriatric clients. For two days the design team took part in activities, such as pouring coffee and tea, facilitating the people to the activity room, helping them with preparing lunch, and joining in conversations about the newspaper. The most valuable lesson was to see how much the target group enjoyed personal attention, but also how suspicious they could be about the team's intentions. The design team quickly understood that newly-met people remain strangers to them for a long time, because the target group tends to forget about the meeting. After a while, though, the target group would get used to design team, even if they could not recall their names.

During the first visit, the design team took some notes, while sitting at the couch among the people. This kind of 'observations' made them feel nervous. The people asked about the intentions of their writing. The best way to make them feel at ease with the design team was by joining in the daily activities, talking along, and helping them, as if the team was made up of staff that worked there.

Moreover, the team talked with the target group to get to know them better and learn how to interact with them. They discussed their hobbies, favourite activities, family, or any other topic they had in mind. The team observed the conversation covers the topic the people choose to express, meaning the people's expressions were not often an answer to the team's questions. Realising the difficulties of having a conversation for these people was an important insight for the design process. The team members could experience those difficulties of the target group from first hand experience through being their conversation partner.

At one point the design team introduced a new element: an application on their laptop allowed people to see themselves and take a picture. The design team assumed the target group would enjoy seeing themselves on the laptop, as if it were a mirror. Moreover, the team was curious how they would react on technology they had never seen before. The first two people were amazed by the magic of the laptop. But the third person asked, 'what is this about, and can I please go back to the couch?' This woman was truly scared of the team and their strange device, and after this incident the team decided to only talk to the people when they sat at the couch with the rest of the group.

The first two days the team noticed that people in the group searched for attention. A person sometimes grabbed the hand of a team member out of the blue. The people also tried very hard to belong to the group. They seemed to place very high value on 'being normal' and 'fitting in'. Unfortunately, their memory problems make this difficult sometimes. They cannot easily have conversations, because they forget what happened before. Often, someone at the centre would point at another who forgot something. In that way, he showed the rest of the group that he still remembered – ironically, a minute later he could have forgotten something him selves. The team realised that the game should stimulate the best in the users, so they can show off to others about their skills.

B. Probing with relatives

Although the target group themselves could not readily be approached with participatory techniques such as interviews, the design team expected that these techniques could well be applied with their relatives. Relatives probably learn effective tricks for interacting with their demented family member. Moreover, a relative may know from close experience what moves his or her loved-one, because he or she knows part of the loved-one's history. Therefore, the design team came up with booklets containing small assignments or questions about their personal experiences with dementia, comparable with cultural probes [2] or sensitize booklets of contextmapping techniques [4]. The booklet contained assignments, such as how a relative keeps a conversation going, what they like to talk about, or what their favourite memories are together (Fig. 4). Two relatives each received three booklets, for the loved-one's partner, child, and grandchild.

The technique did not work as well as expected. After two weeks, only one family returned two of the three booklets. The other family told us that some questions were confronting them too much with the severity of the disease. They did not dare to give the booklet to their parent, who had a partner with dementia. Eventually, this family did not return any booklet at all. The design team concluded that they had made the questions too confronting by asking too focused about the person dementia. A less confronting approach might have been to ask about their history together.

Fig. 4. A page from a probe completed by son of a person with dementia. He expresses that pictures from the house he grew up initiates conversations with his mother about that house, the neighbourhood, and related memories.

C. Notebooks for care professionals

Care professionals are experts on interacting with people with dementia. These experts have been trained to provide their clients with meaningful and pleasurable activities throughout the day. The design team left behind four notebooks at the day care centre (Fig. 5). Each notebook had a specific question on its cover, such as 'What makes the people happy?', 'What goes on in the people's mind and how do you know?', 'What makes something ideal for the people?', and 'How do you make the people feel connected?'. The notebook was blank inside. Carers could freely add their own remarks, thoughts, and ideas, and react to the ones of their colleagues. An advantage over an interview was that the carers could think a while on their answers without the team being around. Moreover, the notebooks reminded the carers of their involvement in the design process. The care professionals enjoyed teaching the team valuable lessons. For instance, a carer wrote serving cake makes the people happy, because cake is 'party'. Another carer expressed that she helps the people feeling connected by searching and providing for a common topic to talk about. Moreover, the carers said products and interactions should be clear and consistence. Sometimes, people feel at ease if they have a personal chair, or coffee cup. Many people value a big clock or time and date display in the room, informing them about the current time and date.

D. Design insights

Based on our visits, talks, diaries, and notebooks, we formulated the following insights that served as basis for idea generation and development of the game.

Fig. 5. Notebooks in which care professionals wrote down examples and advise on people with dementia

The product or interaction should:
- Stimulate social contact
- Provide a trigger for interaction
- Feel familiar
- Help people to fit in the group
- Give them confidence
- Make them feel proud and useful
- Make use of strengths (e.g., long-term memory)
- Establish a shared 'wavelength'
- Connect to their time frame (1950's-1970's)

E. Idea generation

Next, the team started to generate ideas. Ideas were for example, products helping people to have physical contact with each other, or products providing pleasure with triggers from the past to get the target group re-experience nice memories. An important insight was that these triggers could provide a basis for a conversation, and thereby stimulate social interaction. These people all shared certain historical events, such as the first television broadcast, the introduction of cars, and radio shows. These long-term memories are still present. Thereby, triggers about these memories can put people at the same wavelength and provide a common topic to talk about. This idea was used in the final concept of 'de Klessebessers'.

The game consisted of objects that recall happy experiences or memories from the past. Ideas for these objects were, for example, a cat in a basket that would begin to snore when it was touched, a radio with music from their youth, a treasure box with antique objects such as silver spoons and jewellery, a music box with melodies, picture frames with photos from the old times, and a television with TV shows from their youth. The users should perform a physical action to obtain the memory or happy experiences; in this way they would become more active, gain self-confidence, and take the opportunity to show off to others about their skills.

F. Evaluating the idea with care professionals

The design team discussed this idea with the care professionals by means of a sketch (Fig. 6), who gave their opinions and suggestions to improve the idea. Moreover, the professionals knew pleasant triggers for memories. They told the design team that their clients enjoyed classical music, and popular music from their youth, and stressed that triggers should recall pleasant memories. For example, one person had traumatic experiences from

World War II. These memories should of course not be recalled. Moreover, the professionals invited the team to find inspiration in their collection of CD's, books, and objects. The carers' enthusiastic reaction, made the team feel confident that further concept development would lead to a joyful product for the care clients. However, most valuable for the team was probably sitting among the people in the day care centre with the idea already in mind, and imagining how they would use the game together.

Fig. 6. The first sketch of 'De Klessebessers', which the design team shared with care professionals of the day care centre.

G. Concept development: 'De Klessebessers'

Using this feedback on their ideas, the design team started to further develop the concept into a prototype (Fig. 7). In this concept, four products were elaborated with an emphasis on clear interaction and feasibility.

Fig. 7. Prototype building at the ID-StudioLab

The concept 'De Klessebessers' [11] consist of four every day objects, a television, radio, telephone, and a treasure box, as shown in Fig. 8. These would be put in the circle of people, as was shown in Fig. 2.

These objects were given an old-fashioned, somewhat cartoonesque, appearance to make them look and feel familiar. The brown colours deliberately made them part of the background. The design team thought the new product should fit in, i.e., feel as if it had always been there for these people. The people should be able to trust on their previous knowledge on operating a television, radio, telephone, or treasure box. Pushing a television button, or picking up the receiver of a telephone are interactions with which they have been familiar for decades.

Each product triggers memories in its own specific way. The television shows movies, the radio plays songs, the telephone tells poems, and the treasure box reveals objects. One by one, a specific object asks for attention of the group by lighting the lamp that is placed next to it. Only one object is active at any time, to prevent chaos.

The product does not reveal its content immediately, but waits for a simple action by a participant in the circle, such as pushing the television button, or turning on the radio's volume. The team wanted to stimulate the participants to become physically active. In that way, the participants can show others their competences in providing songs or movies.

The design team imagined dementia feels as if everything in time happens in random order. Therefore, the designers let objects randomly take turn and reveal their content. The team expected carers to enjoy this surprise. Fig. 8 shows each object's way of asking for attention and desired action to reveal its content.

H. Prototype testing at the day care centre

The working prototype of 'de Klessebessers' was tested with a group of 12 people at the day care centre. Before the participants were present, the design team prepared the game in the circle. One man had arrived early, as was his habit, and sat down in a chair. He watched the team connecting the cables and already saw the test. The funny thing was that he did not ask what they were doing. He said 'the phone rings', when the telephone was tested before the game started. He said he was looking forward to the game, and was not suspicious at all. He even remembered the name of one team member. None of the other people entering the room paid any attention to the newly placed objects. When everyone was present and had received a cup of coffee, the care professionals introduced the team, who explained the game. Next, the game was started, and when a carer asked, the woman next to the radio turned the volume on. The radio played a song by the 1960s Dutch comedian 'Wim Sonneveld'. We saw the twinkle in their eyes, and this gave goosebumps to both the team and the carers.

During the visits to the day care centre in the beginning of the project, the team already realised the people need a trigger to elicit them to take action. Testing 'de Klessebessers' confirmed the difficulty of designing a product that elicits them to interact with it, without any intervention from carers. For instance, during the game the telephone rang when its light was turned on, meaning it asked for someone to pick it up. Even in that case, the carer needed to ask what they normally do when the phone rings. As response some said, 'Pick it up', on which the carer said, 'So what shall we do now?' All answered together, 'Pick it up!' On that the care professional asked, 'Who likes to do it?' One visitor volunteered and in the end after the phone had been ringing for fifteen times someone finally answered it. This example shows they need a pull to do the last step. So, the care professional also needs to interact with the game.

The telephone

1. When the lamp turns on, the phone starts ringing. Someone from the group can *answer the phone themselves*.

2. Next this person can *individually enjoy from a poem*. The others cannot hear what is said.

3. After listening she can tell the others what she heard. Next they can together talk more about it.

The radio

1. When the lamp turns on, someone can put on some music by turning on the volume.

2. Next, the group can enjoy a song from the old times.

3. After listening, they can talk about the song and their associations.

The treasure box

1. When the lamp turns on, someone can open the treasure box.

2. The group is curious about its content. After opening, the whole group can see what is inside.

3. After everyone has seen and held the content, people can tell where they had to think about.

The television

1. When the lamp turns on, someone can play a movie by pushing the button.

2. The group can enjoy a movie from the old times.

3. After seeing the movie, they can talk about what they just saw and their associations with it.

Fig. 8. An overview of the four products, and their specific way of (1) triggering use and desired action, (2) providing a pleasant experience or memory, and (3) providing a common topic as basis for a group conversation.

Surprisingly, another time the people did not need help from outside the group all the time. For instance, a 92-year-old woman asked the man next to her to turn on the volume since she is a bit deaf. In that sense the curiosity of the woman and the easiness of the product helped the people to use the game themselves. All people were able to use the product right away. The people were flushed with joy when putting on some happy music or discovered a yellow toy car from the treasure box. The design team and carers also enjoyed listening to the stories told by the people, and one trigger could be the basis of a 30-minute conversation.

The prototype test showed that the people enjoyed interacting together with help of 'de Klessebessers', because they could themselves generate happy moments.

IV. DISCUSSION

Designing 'de Klessebessers' with the help of people with dementia, relatives, and care professionals resulted in insights we used in the product and were largely found effective in testing the prototype in practice. This discussion describes our insights on collaborating with the different stakeholders.

The design team learnt the importance of building on a relationship of trust, especially with those people suffering from dementia. The team got to know the people by visiting them for several times. This helped them to know what to expect. Although most of the target group could not remember the team's names, they did recognise them. This familiarity was important for both for the people with dementia in order to trust the designers' intentions, and for the designers to feel confident in the situation. When the team approached them confidently, the people also felt more at ease with them. So, a relationship of trust worked in two directions.

The visits also build on a relationship of trust with the care professionals. Making an effort to understand their profession gives motivation to help the design team as well. The care professionals were willing to contribute to the project. In general, the team saw these people are very enthusiastic for many activities. Part of their everyday work is being positive and complimenting. This may explain why the team sometimes felt that their reactions to our design were not very critical: they are geared to being encouraging rather than criticising. The carers mainly gave signs that they appreciated the efforts. This might be alleviated if the design team had presented multiple alternatives, by which they would show the carers that they themselves had not yet decided, thereby encouraging more critical feedback.

The people with dementia really enjoyed participating in the design project. Talking with the team members was for them an extra activity on the day. Because of the designers' young age, the target group expected them to have no memory problems, and expected continuous attention from both of them. So, the design team was not only gathering design information, but became activity providers as well, and we think this is inevitable. Four months after the project, the care professionals reported that some people still ask about the designers.

The design team had found that the families that were approached with questions about dementia found these too confronting. For next time, the team would not exclude them from the process, but be more careful with what they ask and how they involve them. The designers would probably more ask about their overall situation and history, and less about their direct experience with the disease itself.

VI. CONCLUSION

There is a need for more leisure products for people with dementia. The current project aimed to provide an example of this. During the project, the design team learnt that different stakeholders each need to be approached in a different way. We hope our experiences in designing for people with dementia can help others as well. This project shows how technology can facilitate people in leisure activities, when provided in a friendly and familiar manner. We believe that it is only a first step, and hope others can build further on our experience.

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