Seeing the First-Person Perspective in Dementia: A Qualitative Personal Evaluation Game to Evaluate Assistive Technology for People Affected by Dementia in the Home Context

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The number of people with dementia is increasing rapidly. As a result, care has to be extended towards the home context. This increases the burden on both informal caregivers and persons affected by dementia. To support these people more effectively, technology could play an important role. However, it proves to be challenging to involve them in user-centred research with this purpose. Therefore, there is a need for more research approaches that gather first-hand experiences with technology from people with dementia directly. This research presents a personal evaluation game method, used in the home context to study assistive technology as experienced by its users. In parallel, a questionnaire was applied to explore the difference in data and experiences between both methods. In the study, 12 households participated, each with a person diagnosed with dementia and a partner still living with them as their informal caregiver. During a period of 3 weeks, participants experienced a dynamic lighting armature designed to improve the sleep–wake cycle and evaluated it through one of these methods. The results show that the newly developed method manages to capture the first-person perspective, and is a more appropriate research tool for people with dementia. The information gathered with the tool allowed the researchers to capture the daily lives of the participants in detail, mainly due to the diverse types of input. The personal evaluation game shows a first step towards an ecologically valid tool that includes people with dementia directly. As such the method proved to be qualitative and explorative, and able to provide insights into both the technology and the daily lives of people living with dementia.

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The growing population of people with dementia over the past decades has presented us with a significant societal challenge, affecting those struck by the disease, their loved ones, as well as society at large (Prince and Guerchet, 2013). People diagnosed with dementia suffer from progressive cognitive disabilities, characterized as early-, mid- or late stage (Timlin and Rysenbry, 2010). The cognitive disabilities salient in the early stage are typically memory problems, social anxiety and the loss of concentration. In the mid stage, we see impaired ability for activities of daily living, significant memory lapses, reduced people recognition and disturbed sleep patterns. As the disease progresses into the late stage, more cognition-related functions become impaired, for example communication, decision-making and even basic motor skills.

Over the course of the disease, care demands intensify gradually but severely (Langa et al., 2001). In the early stages most of this care is provided by informal caregivers, often a spouse, family member or friend. Towards the later stages, requests for professional care increase, as patients need more support. This trend will put further pressure on informal caregivers who already provide ~60% of the accumulated care for people with dementia. This number is expected to increase (Prince and Guerchet, 2013). Owing to the continued ageing of our population, it is estimated that the number of people with dementia will double by 2040 (Wimo et al., 2003). This place additional pressure on professional care and informal caregivers, and will likely result in an increase of care in the home environment, often referred to as ‘ageing in place’.

The World Alzheimer Report 2010 shows that worldwide the cost of dementia care accounts for more than US$604 billion, or 1% of the aggregated worldwide Gross Domestic Product. Reducing transitions into professional care environments and providing care at home for as long as possible is an important strategy of cost-containment for high-income country governments (Prince and Guerchet, 2013). Fortunately, these strategies generally align with the personal desire of the elderly to live at home for as long as possible as well as with the globally voiced movement towards person-centred care, in which care is personalized and adapted to the individual (Prince and Guerchet, 2013).

1. Assistive technology in dementia care

Currently, there is no cure for dementia; therefore innovative solutions are required to improve independence and quality of life (Cahill et al., 2007; Horgas and Abowd, 2004). Assistive technology is one of the means to achieve this. Although technological interventions can never replace person-to-person care, they can substantially support autonomy in daily activities (Hoey et al., 2010). Carefully designed innovations can answer unmet needs in various stages of dementia. However, existing products, systems and services are often difficult to use by people diagnosed with dementia (Astell et al., 2010). The usability and adaptability of such technological interventions therefore deserve more attention. These interventions only become truly useful when individual needs of people affected by dementia are met.

In spite of an increased understanding of the medical and physical implications of the disease, the design of assistive technology for this user group still proves challenging. For one, assistive technology for people living with dementia is seldom designed considering the users’ needs and context (Bharucha et al., 2009). Understanding the daily context of users in the development of new technologies is essential to cater to their, often complex, needs and the acceptance of the technology. Moreover, the first-hand perspective from the person with dementia itself is rarely sought in the design process of assistive technology (Topo, 2009). For cognitively impaired users, not only is the use of the proposed technology itself often challenging, but it may be difficult to actively participate in the evaluation of assistive technology as well (Astell et al., 2010). Instead, the designer or an informal caregiver generally voice
product or service evaluations on their behalf. This absence of a first-hand perspective in product conception and the need to develop and evaluate assistive technology as an integral part of the home context of people with dementia motivated the development of a new user-centred design method for this particular user group.

Evaluating assistive technology in the home context raises the ecological validity of the results (Koskinen et al., 2011). In their trusted home context users feel more at ease while participating in the design process. Moreover, because they are actively involved, the users are not subjects of study but co-creators in the innovation process (Brankaert and den Ouden, 2013). This case study aimed to explore a technological intervention and gather insights on the acceptance and usability of this technology from the user’s perspective (Almirall et al., 2012). The study presented in this paper is part of an overall development program of assistive technology for people living with dementia. In this a Living Lab approach is used, based on Bergvall-Kärneborn and Ståhlbröst (2009).

The aim of our research is to develop and assess a user-centred evaluation method to retrieve insights on the acceptance and usability of assistive technology and actively involve the users, people diagnosed with dementia and their informal caregivers, in the development process. In this research, the assistive technology used as a case is a dynamic lighting armature aimed at supporting the sleep/wake cycle.

1.2. Research rationale

In the current study, the possibilities of including the person with dementia in the evaluation of assistive technology will be explored. The aim is not only to assess the new proposition itself but also gather general insights about unmet user needs for future solutions. Therefore, the research question for this paper is: How can we successfully design a qualitative research method to collect first-hand evaluative data on the assistive technology from individuals in the early stages of dementia in the context of the home environment? The term ‘success’ in this question pertains both to the quality of data collection, and the experience of the participants, which should be one of fulfilment rather than being burdened. We therefore formulated three main criteria for the qualitative research method developed in this study:

(i) The method should extract first-hand experiences and perspectives from persons diagnosed with dementia. Hence it should be sensitive to the specific needs and cognitive limitations of this particular user group. This includes potential memory deficits, difficulties with language, lowered capacity to concentrate and trouble with maintaining an overview of the task at large.

(ii) The method should be attractive, appealing and fulfilling to the participants in the study. Even more so because the study is taking place in a Living Lab structure, with the aim to continuously develop new products and services for people living with dementia. Keeping participants motivated and involved in the research is therefore key to the process. It is imperative that the method place a minimal burden on the informal caregiver and the person diagnosed with dementia, and that both experience it as meaningful.

(iii) The method should generate useful evaluative data on the assistive technology. As such, the generated data should give insights for redesign of the evaluated assistive technology. Furthermore, it should facilitate the surfacing of additional unmet needs for the development of innovations and research in the future.

During earlier technology-evaluation studies a tablet-based questionnaire method was used (Brankaert and Den Ouden, 2013). Although the purpose of that study was not to evaluate the research method itself, the reflection afterwards resulted in a need for other evaluation methods, which better suited the user group. In the current study, we therefore explored a probing method and compared it with the more conventional questionnaire approach. Although we predict differences in types of gathered data, we expect to gain valuable insights with respect to both methods in the same evaluation context. The three criteria stated earlier are used to assess the newly introduced method since it was designed for addressing these specific criteria to be a successful first-hand perspective qualitative research tool.

1.3. The project context: the Dynamic Lighting Armature

The technological intervention selected for the current study was a high-fidelity prototype of a dynamic light application. The lamp is designed to improve the sleep/wake cycle, a common problem among people living with dementia, which places a heavy burden on informal caregivers (Bell et al. 2001). The lamp produces a high intensive bluish light that suppresses melatonin, similar to natural daylight, thereby intending to improve the sleep pattern. The lamp dynamically provides this stimulating effect during the day, while functioning as regular lighting in the evening.
et al., 2004; Topo et al., 2004), but unfortunately provide insufficient detail on the specific methodological considerations to understand how they managed to overcome the challenges of including people with dementia in research.

2.1. Related research involving people with dementia

Three studies that clearly explain the research method and properly reflect on the involvement of people with dementia are: a diary study by Bartlett (2012), a focus group study by Qureshi et al. (1998, reviewed in Wilkinson, 2002, Chapter 9) and an interview-based study by Nygård (2006). These studies were all ethnographical in nature, designed to broadly explore cultural phenomena. This deviates from the scope of the current research, which aims to generate personal evaluative data on assistive technology in the context of a Living Lab ecosystem. Nevertheless, the insights generated in these studies are very relevant for the current study.

Bartlett and Nygård both highlighted the importance of giving people with dementia a feeling of control during the research. Bartlett allowed users to select a specific type of diary. For example, she allowed participants to select from several options like a camera or a voice recorder to share their opinion. In addition, participants were free to choose when and where they made an entry in their diary. Furthermore, the context in which the research takes place also needs consideration; Nygård (2006) stressed the importance of providing a meaningful context during the interview. She employed a strategy labelled ‘reflection-by-doing’ (capturing the insights and feelings as they occur), thus avoiding retrospection, which is particularly difficult for this user group. Moreover, Nygård deliberated that this ‘reflection-by-doing’ is more stimulating when other people are involved. In addition, such a social aspect in a research activity increases the comfort for participants. The focus group studies of Qureshi and colleagues (2002) also provided a social setting during the inquiry.

An important insight from each of the three studies was that splitting up the research activity into smaller parts was beneficial to lower the burden of participation. The limited concentration span of people affected by dementia emphasizes the need for avoiding extensive sessions. By splitting the research into multiple smaller parts, participants can get used to the activity and a sort of ritual is created. According to Qureshi and colleagues (2002), this ritual made the participants aware that something was going to happen and potentially evoked memories about earlier focus group sessions. This all contributed to a pleasant setting where the persons with dementia felt at ease to share their thoughts and opinions.

Bartlett’s diary study (2012) captured insights for a couple of weeks without the direct influence of the researcher. When gathering data over a longer period of time, it is necessary to think about ways to create a holistic view of the entire period and context. Photographs can enhance the data through their contextualized and rich figurative nature. Taking photographs does not require language skills, a common problem for people with dementia and thus helpfully complements verbal feedback. Furthermore, the photographs can be used for elucidating and communicating the textual research findings. Bartlett found that audio could serve as a convenient and informative means to collect user input as well, since it reveals insights into the aural aspects of the participant’s life (Bartlett, 2012). In addition, it can enhance the understanding of language difficulties of people with dementia, more than written text can. An easy-to-use audio recorder provides flexibility and places the participant in control of what is said and when. The writing option was included to create an opportunity to write, which is an activity that is beneficial for people with early dementia who retain language skills as it helps to rediscover the self.

2.2. Inspired by probes

The current research aims at exploring the possibilities of getting first-hand evaluative data from persons diagnosed with dementia. Since it is unknown whether they would prefer to, for example, write, talk or take pictures, all options were provided. Flexibility and being in control should be the hallmarks of a new research method for dementia and we therefore integrated these aspects of probes in our method for non-intrusive research in the home context.

Cultural probes (Gaver et al., 2004) provide flexibility to participants because they typically provide several options to give input. Probe methods were used in research with older people before to facilitate the co-production of technologies (Wherton et al., 2012). Wherton et al. found that probes were most effective when used as a tool to facilitate communication and to develop a deeper understanding of older users’ needs. The flexibility of a probe method provides an opportunity to combine different types of answering options in a single method. In our method, we therefore aim to integrate several options to stimulate flexible and longitudinal input collection, providing holistic insights in the participant’s life and the use of the assistive technology.

Boehner et al. (2007) extrapolated on the use of probes in Human–Computer Interaction research and concluded that there are two ways to work with probes in this field; inspiration-oriented or information-oriented. The initial use of cultural probing (Gaver et al., 1999) was intended as a means for inspiration and opening up the design space. Their probes were specifically designed for this purpose. Wallace et al. (2013) used probes in the same way to design for people with dementia by focussing on the persons involved, showing such an approach can indeed open up the design space.

For the current study, however, getting inspirational data was not the main purpose, as the design of the assistive technology was already well advanced. Instead, we wanted to explore how to gather evaluative data about the technology from people with dementia directly at the moment they are using...
it. The choice of selecting elements of probing is grounded in
the flexibility that it creates; probes typically provide several
options to give input. As described earlier, Bartlett (2012)
points out the possible benefits of including such options for
people in the early stages of dementia. Another important
aspect of the probing method is that it can enhance the
involvement of people with dementia in research substantially
(Wallace et al., 2013). In this study, the key elements of
cultural probes are maintained; it is qualitative rather than
quantitative and it produces responses from users rather than dat
(Boehner et al. (2007)).

Playful probes are a variation on the probe method that allow
users to participate based on gaming principles (Bernhaupt
et al., 2007). The study by Bernhaupt et al. (2007) showed that,
by adding a playful aspect, a research tool could generate more
interesting and relevant responses. We felt that a game would
contribute to an informal setting, which is important for our
user group. Additionally, having the informal caregiver and the
person with dementia play the evaluation game together would
add a social aspect that could further stimulate discussions.
The resulting personal evaluation game should enable the person
with dementia to more easily partake in our research. Moreover,
the informal ambiance induced by the game-like format could
lower the burden on participants and engage them in the
study. This personal evaluation game could therefore generate
rich evaluative data providing a dynamic and contextualized
understanding of the lives of the participants in their home
context.

3. THE PERSONAL EVALUATION GAME

As a name for our personal evaluation game we used
‘Aangenaam’ (Dutch homonym for ‘Nice to meet you’
and ‘Pleasantly’). It had a set of question cards to evoke
discussions to evaluate the dynamic lighting armature that
potentially improves sleeping patterns. The type of questions
and wording used were in line with the suggestions from Nygård
(2006): clear, unambiguous and minimally retrospective. Open
questions were used in the personal evaluation game to stimulate
discussion even further. Asking questions about too detailed
knowledge, like time or sequences of activities, was avoided.
Instead, concrete questions that capture the direct experiences
were used. The question cards in ‘Aangenaam’ were divided
over four categories: experiences related to daily activities;
social and physical context; personal goals and events; and a
fourth class (a set that could be developed for the study at hand),
related to the dynamic lighting armature (Fig. 1). These different
categories were chosen to generate insights concerning the
context in which the lighting armature was placed. Besides, the
categories were intended to be flexible, allowing us to explore
what type of questions participants preferred.

As discussed earlier, the personal evaluation game had three
optional formats for answering: written answers in a notebook,
spoken input via an audio recorder and photographs taken with
a disposable camera. The question cards gave one of these three
options as a suggestion, although the participant was free to
select any alternative. Since this study focuses on people in the
early stage of dementia, we did not want to eliminate the options
of using language completely. People in this phase are in general
still able to perform such tasks.

The personal evaluation game itself did not have strict rules,
since it was important to let the participants be in control of the
activity (Bartlett, 2012; Nygård, 2006). We did choose to present
it as a game to the participants, with the remark to take turns
and to play it together. Furthermore, the appearance of the box
and the categorized cards created a game-like appearance. Such
a setting created an informal setting and relaxed experience,
without discomforting the person with dementia by adding a
competitive element. To evenly spread the research burden over
the measurement period, the participants were suggested to use
the method every day and to answer only a couple of questions
per session.
4. METHODOLOGY

4.1. Study design

In the study, two research methods were used: the newly developed personal evaluation game and a tablet-based questionnaire. Participants received one of the two research methods. Participants were assigned to one of the two methods randomly, alternating based on time of recruitment. As the main interest of the current study was the experience of the personal evaluation game and its answering options, a ratio of 2:1 (game:questionnaire) was chosen.

In the analysis, we looked at the experience participants had with both methods. Also the advantages and disadvantages of each of these methods concerning the value for evaluating assistive technology were considered. The entire test lasted 3 weeks: One baseline week and 2 weeks to evaluate the assistive technology. A semi-structured reflection interview on the final day of the study covered insights concerning the method and the assistive technology.

4.2. Participants

From March till June 2013, fourteen households participated in the study. Professional caregivers from a regional mental health-care institute recruited the participants, and ensured they were capable of participating in this study. Participants were only selected if they still lived at home with a partner (which we refer to as the informal caregiver), and preferably were in an early stage of dementia. Three households withdrew from the study after the first week due to worsening of the health situation. Only one of these three households provided enough data to be included in the analysis, since they actively played the personal evaluation game during this first week. This household is not included in the technology evaluation, as they never received the lighting system.

Eventually five females with dementia and seven males with dementia were part of the sample, aged between 66 and 87 ($M = 74.92$, $SD = 6.17$). In total, eight households received the personal evaluation game and four households worked with the tablet-based questionnaire. Research took place in the homes of the participants, all located in or near the city of Eindhoven, the Netherlands. All participating couples lived independently.

4.3. Informed consent

An informed consent raises questions when mentally impaired users are involved. The difficulty in dementia is that the impairment changes over time. Therefore the status has to be continuously assessed by designated independent consultants. If a person loses capacity, the participant would be withdrawn from the study, and no further data would be gathered. In this study, the care professionals and informal caregivers protected the integrity of the persons with dementia. Furthermore, the informed consent should be seen as a continuous dialogue (Coughlan et al., 2013). While all participants signed it at the start of the study, the participants were repeatedly asked to confirm it to ensure continued consent. Both participants and researchers experienced this as pleasant. The fact that three couples quit during the study further illustrates that participants felt the ability and freedom to do so.

4.4. Measurements and procedure

In the current study, we explored the possibilities of the personal evaluation game and whether it succeeded at capturing the user experience related to the dynamic lighting system. The participants received either the personal evaluation game ‘Aangaan’ (Fig. 2) or a tablet with a pre-installed questionnaire.

For the tablet-based questionnaire, iPads (generation 4, Wi-Fi Cellular, 16GB, Black, 9.7 inch) were configured in a way that the number of apps on the home screen was reduced to keep it simple for the participant. This app was a direct link to an online questionnaire. Two separate questionnaires were used, one for the baseline week and one for the 2 weeks of evaluation of the intelligent lighting system. Both questionnaires contained multiple choice questions and statements with six response categories.

With the questionnaire we aimed to evaluate the lighting armature. To do this, a question could, for example, be: ‘how many hours were spent today near the lamp?’, i.e. gathering insights in how the lamp was used. Other questions concerned the subjective perception of sleep quality and energy level for the person with dementia. To provide more freedom, a comment box allowed for additional input.

After the baseline week the dynamic lighting armature was placed and they received a new set of questions, both in the personal Evaluation Game and the questionnaire. During these 2 weeks of evaluation, the participants were contacted by phone once to make sure that there were no issues with
### Table 1. Factsheet results of the evaluation game and the tablet-based questionnaire.

<table>
<thead>
<tr>
<th>Method name</th>
<th>Objective data</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Evaluation game</strong></td>
<td><strong>Quantity</strong> We received 425 answers: 125 answers in the daily activities category, 124 answers in the environment category, 84 answers in the personal category and 92 answers in the dynamic light armature category. 345 answers were written down, 65 answers were audio taped and 15 answers were given via the disposable camera. This resulted in 4580 written words, 52 min and 32 s audio data and 26 photographs. One accidental audio recording of 3 h was not included in the analysis.</td>
</tr>
<tr>
<td><strong>People involved</strong></td>
<td>One of the informal caregivers worked individually on the evaluation game, three persons with dementia worked individually with the evaluation game and four couples actually played the evaluation game together. One of these couples reported that they played the game with a couple of friends once.</td>
</tr>
<tr>
<td><strong>Answer options</strong></td>
<td>Three participants only used the notebook to answer the questions. Another one used both the notebook and the photo camera. Two participants used all answer options. One of the individuals with dementia did not answer any of the questions in the personal evaluation game. The related informal caregiver delivered the answers digitally via a computer.</td>
</tr>
<tr>
<td><strong>Tablet-based questionnaire</strong></td>
<td><strong>Quantity</strong> We received 81 entries creating 927 answers to all questions. The remarks box was used for 65 times and a total of 1629 words were written down. Two participants were very elaborate in their remarks that explained the activities of the corresponding day.</td>
</tr>
<tr>
<td><strong>People Involved</strong></td>
<td>The informal caregivers made all entries in the tablet-based questionnaire. Two couples reported to have discussed all questions and answers throughout the study. One informal caregiver indicated to have had only minor discussions with the person with dementia when filling in the form. Finally, one informal caregiver did not have any discussions with his spouse about the questionnaire.</td>
</tr>
<tr>
<td><strong>Answer option</strong></td>
<td>Two households made all entries via the tablet, one household used a paper version solely and one household used the tablet, the paper version and their own laptop.</td>
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</tbody>
</table>

...the research. After the test period, a final reflection with the participants was conducted in their own homes in order to assess participants’ experiences with the method, the lighting armature and participating in the study in general.

### 4.5. Data analysis

We used manual methods to analyse the responses (Rose and Webb, 1998) get insights into the generated data. Thematic analysis was used as the main method (Braun and Clarke, 2006). In the thematic analysis, we included the written and audio data from the personal evaluation game, input data from the iPad questionnaire and comments made during the final reflection interview. A theoretical approach was used in extracting themes from the data, led by the three main criteria stated earlier in this paper. The focus was the level of engagement of the person with dementia, how they judged their participation and what type of evaluative data were generated. These main-overarching themes include sub-themes within them (Braun and Clarke, 2006).

Next to the thematic analysis, a content analysis of participants’ answers in the written vs. audio data was conducted. The focus lay on choice of words, prosody, repetition of words, extensiveness of answers and unanswered questions. This way, the latent preferences in how to use the method (questions, categories, answer option etc.) could be identified by looking at the exact behaviour of the participants.

The photographs from the personal evaluation game were compared within subjects to identify whether there were differences in types of photos in relation to question types. Furthermore, the majority of photos were used for illustrative purposes of the extracted themes.

Throughout the results section of this paper we use a code to identify the supporting quotes. This code consists of [fictive name of participant] – [IC (informal caregiver)/PwD (person with dementia)], [source]. For example:

This is an example quote of Beatrice, who is a person with dementia, coming from the audio recorder. (Beatrice-PwD, audio)

### 5. FINDINGS

The personal evaluation game ‘Aangenaam’ and the tablet-based questionnaire generated data that varied substantially between participants. Table 1 shows an overview of the input from both methods and how people handled the flexible answer options and question categories. Furthermore, we present the extracted themes from these results. These are structured according to the three main goals: The involvement of the participants, the importance of the participant–researcher relationship and the evaluative outcomes concerning the assistive technology. Furthermore, special attention is given to the three answering formats in the newly developed method.

#### 5.1. First-hand experience of people with dementia

In this study, we focused mainly on avoiding marginalization of dementia patients in research. To achieve this, we included
people with early dementia in our research. To make the method suitable for this user group, characteristics of the disease have to be considered. We evaluate whether people with dementia were able to participate and how the interaction between informal caregivers and dementia patients worked.

In the personal evaluation game, we see a high level of participation of the persons with dementia. There is clear evidence in both audio and written data that they contributed to the research directly. Some even explained that they experienced this as important, for example:

I am a considerate person, kind in interacting with others. I am a bit reserved but I do want to have my say (Beatrice-PwD, audio).

In previous research, we found that experiencing and evaluating together is beneficial to support dementia patients’ performance. Therefore, we looked at the amount of discussions with and support from the informal caregiver in both methods. Couples indicated that some questions indeed evoked discussions. However, the involvement of the dementia patient in these discussions appears to depend on the attitude of the informal caregiver. Some informal caregivers regarded this involvement as more important than others. One partner in the personal evaluation game, for instance, explicitly mentioned how she enjoyed the fact that her spouse was easily involved in the research activity:

Usually I have to do everything by myself, and friction might arise as he doesn’t understand it. Now he showed initiative by himself. (Geraldine-IC, final reflection (Aangenaam))

In addition, we learned that it took participants extra time and effort to partake in a research activity together. For the informal caregivers it was sometimes easier to just fill in the answers to the questions themselves. Whether they did seemed to depend partly on how important it was to informal caregivers that they elicited input directly from their partner with dementia, but also how demanding they felt it would be for their partner. Moreover, some felt that their intimate relation enabled them to validly respond in their spouse’s stead:

I have known him for 55 years, so sometimes I answered the question myself. (Harriet–IC, final reflection (Aangenaam))

Especially in the audio data, the role of the informal caregiver becomes apparent. The audio data give detailed insights into the interaction between the dementia patients and their partners. We found that informal caregivers applied several strategies to support the patient to actively participate. Such strategies could, for example, be supporting the structuring of an answer, breaking a question into smaller questions or reminding the dementia patient by suggesting the answer. For example:

[The question is: Do you listen to music often?] ‘Well, not that often. Maybe on television – a music broadcast.’ But you do listen to the radio very often? ‘Yes, I do listen to the radio’ That is music too isn’t it? You always search for the music channel, never for a talk show. ‘No? Then I listen to music often’ (Geraldine and George, Audio, (Aangenaam))

This data shows that the relationship between the two spouses is influential on different levels. One is the exact understanding of the needs of the partner, since everyday life together creates the knowledge about someone’s difficulties and how to overcome these. Another aspect is that the dementia patient accepts this help, because it comes from a familiar person.

Evaluating and experiencing together requires substantial time investments from the informal caregiver. They appear to balance the value of their partner’s personally voiced input against the extra time and effort it takes them to elicit this first-hand input. The informal caregiver’s role is therefore crucial in involving the dementia patient.

5.2. Involvement and motivation

Participants should not be or feel needlessly burdened by a research method. Therefore, the method should aim at creating feelings of involvement and long-lasting motivation for both the informal caregiver and the person with dementia. For this reason, we paid extra attention to factors that might indicate or illustrate these feelings of involvement and create motivation.

We started with looking into the direct answers the people gave when they were asked how they experienced participating in this research. During the final reflections, none of the participants reported any discomfort of participating in this study, independent of the method. Several aspects appeared to influence their feelings of involvement and motivation. First, the partaking in research sometimes seemed to remind participants of their loss of abilities due to the dementia, which potentially caused discomfort. Nevertheless, a feeling of fulfillment was achieved by being able to contribute and help future generations while having dementia. Secondly, the evaluation game was in general regarded as a fun activity that enhanced the motivation of the participants. A third factor influencing feelings of involvement and motivation was the participant–researcher relationship.

5.2.1. Reminder of ability loss

We expected that one of the aspects of keeping people motivated in a research activity was how much time it would take to participate. During the final reflection, none of the participants indicated that the study had been too time intensive. Nevertheless, two informal caregivers (both in the personal evaluation game) did indicate that 3 weeks of participating was enough for them. This comment was attributed to the confronting experience of seeing their spouse fail to understand and answer questions:

It confronts us yet again with the disease. (Evelyn–IC, final reflection (Aangenaam))

Besides their own perspective, the informal caregiver often considered the effects of participating in the study on their...
spouse. They have learned to protect their spouses, and know what upsets them, which can result in reluctance towards a new research method. This is, for example, shown in the following quote:

I do not want to affect her with those questions, she will be out of her comfort zone, and I do not want that. (Dick–IC, final reflection (Aangenaam))

The persons with dementia themselves do not specifically mention that they feel reminded about their ability loss in partaking in the current research. They do show an urge to be successful in participating, when they participate. For example:

At first we practiced the answering to the questions before actually recording the verbal account (Beatrice + Bernard, final reflection (Aangenaam))

This might mean that they wanted to provide the researcher with something useful, which indicates a good participant–researcher relationship. However, we expect this may also have served to cover up their inabilitys and therefore to not embarrass themselves or their partner. For example, one dementia patient did not deliver any data, as he indicated that he was afraid to fail:

I have troubles with concentrating and am not sure that I can contribute to this research in a useful way. (Charles – PwD, final reflection (Aangenaam)).

The importance of carefully constructing the questions and research guidelines, to avoid feelings of being tested, is evident.

5.2.2. Fun to participate

We aimed to enhance the motivation of the participants, by creating a joyful experience. Aspects that are regarded as fun in both research methods are elaborated on here. A few participants explicitly indicated how enjoyable the experience had been to them. One informal caregiver in the personal evaluation game condition explained that this shared involvement was an added value of the game over regular questionnaires:

In any case it is more enjoyable then a plain questionnaire. (Geraldine–IC, final reflection (Aangenaam)).

People who liked to play games were especially suitable participants for the personal evaluation game. The two couples who were most elaborate in their answering (and used all answer options) reported enjoying playing games in general. One of these couples even ‘played’ the game with friends, which is an indication that it was actually experienced as a game by the participants.

The use of humour in the answering of the questions is regarded as clear evidence that participants experienced enjoyment in their participation. Four participants used some humour in their answering by laughing during an audio recording, using silly remarks or jokes with a double meaning. Also, in the picture option some humour is shown, as there was a picture showing one of the participants and a friend laughing (Fig. 3).

5.2.3. Participant: researcher relationship

The level of involvement of the participants is reflected in the behaviour towards the researcher. Therefore, the attitude of the researcher in interaction with the participants is crucial for a good participant–researcher relationship. Participants wanted the interviewer to be more than just a distant researcher, and valued this:

When you left after your first visit we thought; finally somebody who can interact with people. (Vivian and Victor, final reflection (Tablet))

A good balance between talking about the objectives of the project and showing interest in the participants as human beings (and not just as participants) is relevant in the interaction. It is sometimes difficult to keep this balance. The final reflection, with one of the informal caregivers, illustrates this. The informal caregiver was too overwhelmed with all the events of the past weeks, making it impossible for the researchers to properly discuss all topics during this session. Instead, the researchers talked about the problems at hand and so forth. This shows that striking the right balance between talking about the project and about the people’s everyday life is crucial. The researcher should accept that discussing the project is sometimes not possible. This has to be expected, and over-structuring the research would be unwanted in such a situation. Eventually a good participant–researcher relation can motivate the participants to contribute more.

5.3. Generated evaluative insights

In this part, we reflect on the type of data we received. The generated data should be rich and give sufficient evaluative insights for the development of the assistive technology. Along this line, the input might potentially inspire new design directions, opening up the design space.
5.3.1. Reflection on input
We sought to gather data from a first-person perspective of persons with dementia. The personal evaluation game provided a more dynamic understanding of the lives of the participants, not only through written text, which in itself was already more vivid than the digital input received via the tablet, but also from the audio and photographic data. As such the data of the personal evaluation game offered more contextual richness, allowing the potential for new, unsolicited insights. For example, one user tried to support the designer of the lamp in how the lamp could be used:

People, who get headaches from the lamp, might try using sunglasses or a sunshade. (Geraldine-ic, notebook (Aangenaam)). [Researcher note: This of course would defeat the entire purpose of the lamp, and thus points to an important misperception of the lamp’s use from the part of the user.]

5.3.2. Written, audio and photographic input options
In the personal evaluation game three different answering formats were provided, each with their own benefits. In general, all types of data contained more information than just the answer to the question. For example, the written data clearly illustrated the language difficulties some dementia patients face. In the written and audio data, it was therefore easy to identify who made the entry. For the photographic input this was more difficult, and it was impossible for the digital data. This was important since we wanted to know what the dementia patients contributed directly. Furthermore, the audio data provided rich insights in the interaction between the dementia patient and the informal caregiver. These data also showed the possibilities of using a voice recorder to capture events in the home situation of people with dementia and their caregivers, unaffected by the presence of a researcher. In addition, the photographic data in this study showed the richness of pictures compared to plain text. For example, the photos of the current light situation in the home environment of the participant immediately showed that the look and feel of the dynamic lighting armature are incongruent with the interiors of many elderly (Fig. 4). Lastly, the pictures also supported input from the other options and contributed to a better understanding of what the participants meant.

The digital data in the current study did not provide more insights beyond those explicitly probed. The participants require self-motivation to use the remark box, especially since the data could not be reviewed later on. Despite that, there were some benefits as well. The data are already digitized and very clean, and so there is no need to decode any handwriting or listen to a 3-h audio recording. The final reflection revealed that some participants liked the easiness of correcting errors:

What the informal caregiver also liked was that the errors could be recovered quickly on the iPad in contrast to a paper questionnaire. (Vivian –IC, final reflection (Tablet))

5.3.3. Evaluative data
In both methods, insights were gained on the dynamic lighting fixture. The specific evaluation areas that are covered were different for the tablet-based questionnaire compared with the personal evaluation game. The personal evaluation game seemed to reveal more information on the aesthetics and what the exact context was in which the assistive technology was used. The questionnaire gave more functional insights, for example whether they noticed the effects of the light on a daily basis. Both these areas are relevant for the evaluation process, yet very different. The various input formats also provided a different value for developing the assistive technology. The audio data revealed insights into the interaction between the informal caregiver and the dementia patient. The photos provided, for example, more insights on the current lighting solutions and the aesthetical requirements of assistive technology in this domain. In contrast, the tablet-based questionnaire generated less qualitative data, and none directly from the dementia patients. The questionnaire did create very concrete user input concerning the light armature, yet was limited in opening up the design space.

6. DISCUSSION
The goal for this study was to explore the potential of a new evaluation method that captured first-hand experiences from persons with dementia itself. The reason for doing this was to complement the currently used caregiver-oriented questionnaire in a meaningful way. The newly developed probing-based evaluation game method, and a more conventional questionnaire approach were applied in this study. They were used to evaluate a high-fidelity prototype in the home environment for several weeks. We were well aware of the obvious differences in qualitative and quantitative data, and therefore we specifically focused on the experiences of the participant in using our newly developed research method. To use two different methods in the
same context was expected to give valuable insights into both pros and cons of the used methods when evaluating assistive technology for people with dementia.

In this study we had three main objectives. First, we wanted to make the dementia patient’s voice heard in the research when taking into account the aspects of dementia like memory deficits, language difficulties, and a reduced capacity to concentrate and follow longer trains of thought. Secondly, we focused on the experience of the participants. They should not be burdened by the method, and we therefore considered carefully the factors that might influence feelings of involvement and motivation. Finally, the generated data should be rich and give sufficient holistic insights to improve or develop new assistive technologies. We should be able to draw evaluative conclusions on the assistive technology and find unmet user needs as inspiration for future developments.

6.1. Findings from the current study

The experiences of the participants in the tablet-based questionnaire and the data collected through this method support the ideas that were the basis for our three main objectives. Some participants, both those with dementia and their informal caregivers, experienced problems working with the tablet and therefore the involvement of the persons with dementia was limited in this method. The questionnaire did provide specific insights, yet these were limited to functional parameters. The comments box allowed for additional input but users were not frequently inclined to do so.

In the personal evaluation game, we succeeded in gathering first-hand input directly from the people with dementia. Clear evidence for this could be found in both the audio and written input. Additionally, we found that real enjoyment in the research activity could be accomplished when the method was experienced as an informal and social activity. The shared involvement of both the informal caregiver and the person with dementia made participating pleasurable and at times even resulted in participants involving others in the research. The experience of playing a game also compelled users to try multiple answer options and to give answers that were more extensive.

Especially the audio data from the personal evaluation game gave insights into the interactions between the dementia patient and the informal caregiver to an extent that would not have been generated otherwise. The current study showed the possibilities of a voice recorder to capture events in the home situation of people with dementia and their caregivers, outside the researcher’s influence and scope.

Some questions in the personal evaluation game were left unanswered without any clear reason, these should be carefully adapted in future studies, were wording and syntax is further simplified. As preferences differed among participants, perhaps a greater variety of types of questions could be provided (open-ended/closed, with or without gradation and so forth). For the personal evaluation game, it is important that the questions that are more urgent for the project should be among the first set of questions in the stack of cards, as those were answered the most in the current study. However, it is not evident that the stack of cards itself had an added value in the evaluation game. Some participants lost track because of these stacks and the idea of answering all those questions could be overwhelming. Perhaps the more extensive discussion cards used by Huizing and Van Den Brandt-Van Heek (2009) in their game could be beneficial for the current evaluation game as well. This way people might be more stimulated to discuss the topics, instead of just answering the questions.

Others in the field of conducting research with people affected by dementia already pinpointed the importance of establishing a proper researcher–participant relationship (e.g. Lindsay, 2012; Wallace et al., 2013). The insights gathered during the current study corroborate these conclusions. Importantly, both the newly developed research method itself, as well as our research procedure in general supported this relationship substantially. A decent introduction by the recruiters; meeting the participants three times in their own home environment; checking on the participants by phone, all contributed to trusting the researcher. The home environment of the user is a private, secure place, which means the research conducted in this domestic domain should be sensitive and respectful. Ogonowski et al. (2013) emphasize the importance of a relaxed, friendly and social attitude from the researcher for a positive user motivation and research–participant relationship. Furthermore, it is important to note that by conducting research in a real-life context, the home environment will be disturbed (Coughlan et al., 2013), either by the research activity or the technological intervention. The goal should be to minimize this intrusion or make this a pleasant experience. A good research–participant relationship can contribute to this.

6.2. Limitations

The set-up of the current research was—in all honesty—a compromise. While investigating potential methods, it was inevitable to have two studies at once: evaluation of the assistive technology and the evaluation of the used method. To see whether the new method could generate evaluative data, there was simply a need for something to evaluate. Since one of the goals was finding a method that does not burden participants, doing two studies at once is contradicting. In this study participants were asked about both the assistive technology and the method employed. Asking the user about both could have increased the burden, even if this was exactly what we wanted to avoid.

The crucial role of the informal caregiver in the research activities raises questions about their exact influence on the answers given by the people with dementia and their motivation to participate individually. In both methods, the informal caregiver appeared to fulfil the role of an interviewer. This might not be easy for everyone. Some informal caregivers took
charge of the questions, while others gave full responsibility for participation to their partner. We do not know whether more interaction between caregivers and people with dementia results in more biased or less valid answers. It could also be that these answers represent the opinion of the person with dementia even better because of the long-term relationship and intimate familiarity between both participants. From the current study, we cannot conclude what the answer to this question would be. Therefore, we recommend this should be investigated further in future research.

6.3. Implications

In this study, the user group ‘people with dementia’ has a great variety on all kinds of levels (abilities, interests, relationships, dealing with the disease etc.). It is questionable if you could even define them as one user group. Generalization of user groups is always risky, but the current user group is prone to this generalization due to the shared illness. As Nygård (2006) puts it: ‘Big differences between people make it important to know WHO has the disease rather than just WHICH disease’. This was reflected in the great variety of input we received from the participants in both methods. Some liked to play with the game; others had great difficulties with it. Some were happy to have the tablet; others were not interested in the device. We are not only dealing with a dementia patient and an informal caregiver, but with people that have their own preferences and personhood (Wallace et al., 2013). How they experienced participating in the current study was therefore different for everyone as well. Accordingly, we cannot state that either the tablet-based questionnaire or the personal evaluation game is more suitable for persons with dementia than the other. That being said, the results of the current study do provide insights into the tools that researchers can use, and what they need to pay extra attention to, in order to involve people with dementia and informal caregivers comfortably in research. A flexible solution is important for this diverse user group, and further explorations are necessary to see how participation can be even more open and reflexive. One strategy could be to allow people who participate in research to offer as much or as little as they desire, while still letting them feel they have contributed sufficiently (Vines et al., 2012). A creative, more personal approach such as the design-led probe method by Wallace et al. (2013) can be a way to accomplish this. However, it is important to keep the balance between flexibility and letting the person with dementia be in control, as we found in the current study that the stacks of question cards can already cause problems.

In both methods, the informal caregiver is crucial for conducting successful research with this user group. Experiencing and evaluating together with a spouse is indeed increasing the involvement of dementia patients in research. The relationship between the two spouses is beneficial for the research activity. The informal caregiver has a complete understanding of the needs of their partner and is therefore capable to provide help where needed. On the other hand, the dementia patient seems to accept this help from the informal caregiver more easily because of the familiar relationship. As a researcher, it is important to not underestimate the time and effort that is requested from the informal caregiver. We even found that some informal caregivers experienced participating as more burdensome than the dementia patients did. It is therefore important that special attention should be given to how to include the informal caregivers.

Input from the personal evaluation game provided different insights concerning the assistive technology. The tablet-based questionnaire provided more feedback on functional aspects, and the newly developed method showed how the dynamic lighting armature was used in context. First of all, this ensured that the technology was evaluated in situ by both the patient and the informal caregiver. Second, the new answer options (for example, the camera) shows a very different perspective on the technology. For future research these can be adapted towards the specific requirements of a study.

In conclusion the personal evaluation game method showed the possibilities of including dementia patients in research. As already mentioned, the new method would not be suitable for every household. Several factors such as the abilities of the dementia patient and the attitude of the informal caregiver are crucial to the success of both methods. In addition, the personal evaluation game will not be suitable for every kind of evaluation. However, the personal evaluation game can be a method that gives insights for the researcher and the development of assistive technology, and above all enjoyment for the participants. ‘Aangenaam’ can be a pleasant way to meet your participants.

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