

MASTER

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a new method to involve people with dementia in research in the context of a Living Lab

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Eindhoven, september 2013

NICE TO MEET YOUR PARTICIPANTS
*A new method to involve people with dementia
in research in the context of a Living Lab*

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identity number 0618502

in partial fulfilment of the requirements for the degree of

**Master of Science
in Human-Technology Interaction**

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PREFACE

This is it. My time as a student has passed. It took a couple of years longer than expected, but I don't regret any of them. I've had wonderful experiences in both my Bachelor and Master, and I am truly happy with the choices I've made for the education trajectory I followed. I was able to find a place for my creativity and curiosity in both studies. After all, I feel that it all comes back in my graduation project. The fascination for people with special abilities and in irregular situations, mostly healthcare-related, grew during my time at Industrial Design and there was plenty of room in the Human-Technology Interaction master to continue with this focus. The choice to graduate within the Innovate Dementia project was therefore easy to make; it was exactly my cup of tea. I enjoyed the project and I have to thank a couple of people as they were definitely part of this enjoyment.

First, my supervisors Yvonne de Kort and Mariëlle Aarts. Both real light gurus who have taught me a lot about this topic in a widespread area. It was very valuable for me to get feedback from someone from a different department to enhance my writing and research set-up. Yvonne acted as a true mentor when the piles of data scared me and she ensured me that I was doing something interesting. Secondly the people at the Industrial Design department, especially Rens Brankaert who's enthusiasm for the project was contagious. With his experiences in the field and with the project, he helped me substantially to conduct my research. I also want to thank Maarten Voorhuis for providing me with the set of Vitaallicht lamps. Without his help, this research would have been way less interesting and above all I would not have been able to perform this research logistically. I wish him all the best with the further development of the lamps. The people from the GGzE, Liselore Snaphaan, Eveline Berben, Monique Peeters and Harriët Verbeek in particular, were invaluable for the project. Next to the sharing of their professional knowledge, they also acted as recruiters for finding the most important people in my research; my participants. I was warmly welcomed at every household and I learned even more from them than I could describe in one thesis. The participants made me realize again, why I like working in this field.

Moreover, this half year I experienced the value of the important people in my life including my parents, my siblings and their spouses and my lovely nieces Nikki & Marinke and nephew Jerome. I am grateful for their unconditional support (or in the latter three, their extreme cuteness). That support is also the kind of support I get from both Irene and Amber who will always be my best friends. Thanks for being there for me, whenever or wherever I need you!

The last people I would like to thank are the people who were looking for the word 'Awesome' in my preface; well here it is! The last couple of months were full of awesome events, awesome discussions and above all, awesome friendship.

Sandra Suijkerbuijk

September 2013

SUMMARY

In 2012, the INTERREG IVB project 'Innovate Dementia' started in order to find innovative (care) solutions for people living with dementia. The main goal is to provide solutions for the societal challenges we face related to dementia. As the number of people suffering from dementia increases and the governmental support for the healthcare sector is declining, there is a necessity for research and innovation for this user group. The Dutch delegate of the Innovate Dementia Project is researching innovations that have a special focus on the positive effects of light on the sleep-wake cycle of people with dementia. In order to research and develop new meaningful solutions, the Innovate Dementia project is based on the idea of the Living Lab with a special focus on user-centered research in real life contexts. However, up until now there do not seem to be conclusive ideas on which data gathering methods are appropriate for people in the early stages of dementia.

In the current project, we focused on a successful design of a qualitative research method to collect first-hand evaluative data from individuals in the early stages of dementia in the context of a Living Lab. Three main objectives for a successful research method are related to the dementia characteristics, the feelings of involvement and motivation of the participants, and the benefits for the researcher. A unique aspect of the current study was that we compared two methods: A newly developed method (the probe game 'Aangenaam') and a more conventional method (iPad questionnaire). The probe game contained question cards that could be answered by using a notebook, a voice recorder or a photo camera. The intention was to evoke and capture discussions between dementia patient and informal caregiver, instead of just questioning the informal caregiver. The two methods were used in the current study to evaluate an innovation in the area of light.

The generated data from the twelve participating households, were divided into two results sections. On the one hand, we present the intrinsic data. These included insights in daily life of the participants, their vitality, and how they used light and the Vitaallichtlamp. We dealt with a group of people with wide interests in activities, creating a great diversity between participants. This affects how they judge a new innovation, such as the Vitaallicht lamp. Since troubles with forgetting are in general more apparent than sleeping problems, people do not see a need in buying an innovation with a focus on problems they do not experience (yet). Especially if this innovation is expensive and is dominating their home environment in design and light intensity. Some participants did rate the Vitaallicht lamp as pleasant, when they needed viewing accuracy in their activities. This can be explained by the most important function they currently attribute to light: enhance visual performance.

On the other hand, we have the data regarding the actual research question. This includes an in depth evaluation of the two research methods based on how well they suited the dementia patients' abilities, how the participants were involved and motivated, and what the benefits for the researcher were. The probe game showed possibilities of including dementia patients in research, since there was clear evidence of their involvement. However, not for every household the probe game would be suitable. Several factors such as the abilities of the dementia patient and the attitude of the informal caregiver were crucial for a successful use of the method. In addition, the probe game mainly revealed insights in the user experience of the new innovation, which might not cover the full spectrum of evaluation.

Nevertheless, the probe game can be a method that gives insights for the researcher and enjoyment for the participants. Written data showed the troubles people with dementia have with language, but also how different these troubles are among different patients. Furthermore, audio recordings revealed the interaction between informal caregiver and dementia patient in an invaluable way. The audio recorder showed to be an option for gaining a dynamic understanding of the lives of the participants. The use of humor in some answers showed the potential enjoyment of playing the probe game. 'Aangenaam' can be a pleasant way to meet your participants.

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Dementia is a growing socio-economic problem that is devastating for the patients and their families. The disease itself is characterized by short-term memory problems and changes in personality. A dementia patient will repeatedly have trouble with daily activities and these difficulties will increase along the progression of the disease. Special care is needed and as long as the patient stays at home, a close relative mostly provides this care: the informal caregiver. Prolonging the time that people can stay at home is cost efficient for public health services, it is often the desired option for the dementia patient, and informal caregiver as home is a secure place. However, the close relative who became a caregiver is resigned to an arduous task. As the dementia disease progresses, the caregiver's job intensifies.

Solutions to support the dementia patient and the informal caregiver in the home environment are therefore a necessity. The current graduation study is part of the European project Innovate Dementia, which was started to create and evaluate innovations for this cause (<http://www.innovatedementia.eu>). Most of these innovations focus on people in the early and middle stages of dementia, as they are the ones who still live at home. In order to create meaningful solutions, a close cooperation with the dementia patient and the informal caregiver is needed throughout the entire research and design process. As the home environment is an important aspect of the innovations as well, the Living Lab approach was chosen for the project, which is based on participatory research methods in real life contexts. The question, however, is how this should be implemented in the current context where the end user has problems that include memory deficits and language difficulties.

Research in this field is in its infancy and people with dementia were marginalized in many studies. A common approach is to question the informal caregiver solely, although the insights of the dementia patients could contribute to a more complete picture of the situation at hand. Especially people in the early stage of the dementia disease are able to give their opinions and viewpoints. The challenge is to get this information in such a way that it is useful for the project and that the person's abilities are taken into account and respected. Up until now, there are no conclusive ideas on which data gathering methods are appropriate for people with dementia. This will be the focus for the current project that uses the Vitaallicht lamp (<http://www.vitaallicht.nl>) as a case to find out if useful evaluative information can be collected via a specially designed research method.

This introduction section elucidates the rationale of this study by an exploratory overview of the relevant subjects including dementia, the Innovate Dementia Project, light, the Living Lab approach and qualitative research methods for people suffering from dementia.

1.1 What is dementia?

The dementia disease is characterized by memory deficits, which are often accompanied by aphasia, apraxia, agnosia or disturbances in executive functioning (Alzheimer Nederland, 2013). This means that people suffering from dementia have difficulties understanding verbal and written language, making deliberate choices, recognizing people and objects, keeping track of ongoing activities and making new memories. These difficulties get usually more salient over the progression of the disease. We use the three stages of ISAO (Internationale Stichting Alzheimer Onderzoek, 2012) to identify how far the dementia disease is progressed for a specific patient, which includes: the early stage, the middle stage and the later stage (Figure 1). Especially in the middle and later stages, the person with dementia can suffer from secondary symptoms including hallucinations, aggression, passivity, depressions, behavioral problems and a disturbed sleep/wake cycle. In the case of the progressive dementias, which include Alzheimer's disease and vascular dementia, there is currently no known cure and no treatment that slows or stops the progression (Alzheimer's Association, 2013).

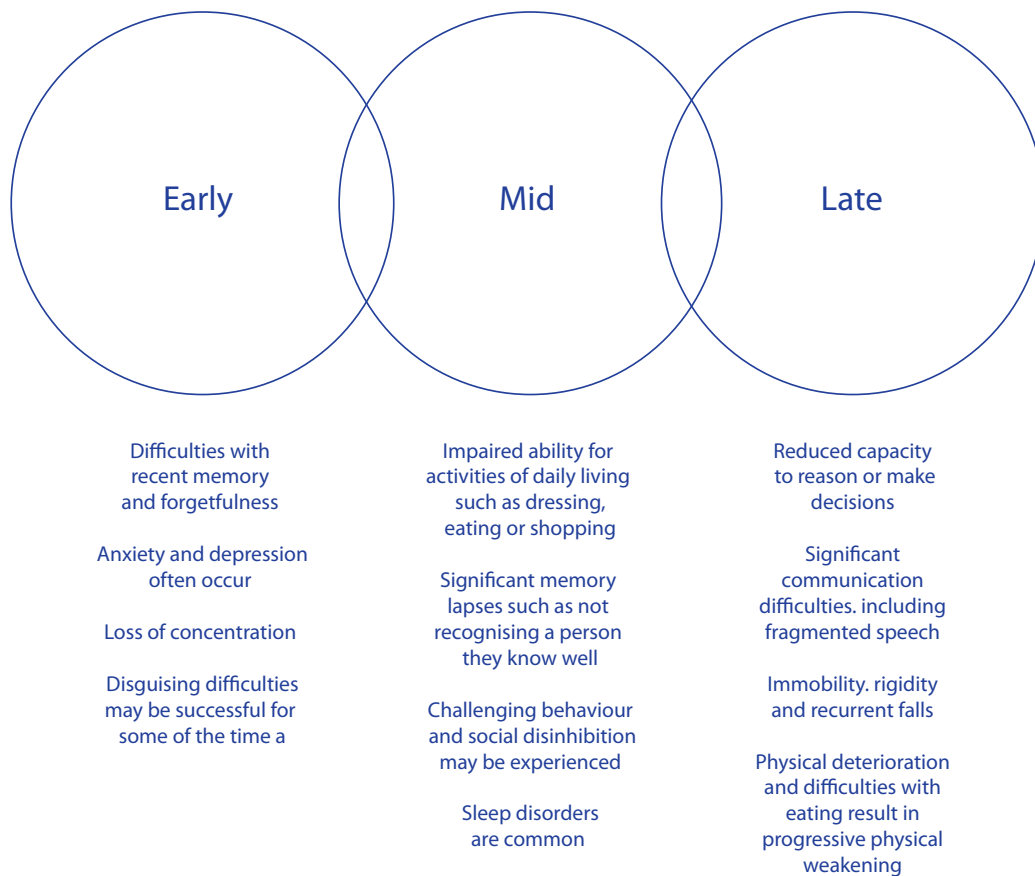


Figure 1. Design for dementia – Timlin & Rysenbry (2010)

This disease affects more people every day as the number of dementia patients is growing steeply. Currently there are 256.000 people with dementia in the Netherlands, 6.000.000 in Europe and 36.000.000 worldwide. It is expected that this worldwide number doubles in the upcoming 20 years, which implies that there is a new case of dementia somewhere in the world every four seconds (Alzheimer Disease International, 2013). Alzheimer Disease International also estimated the worldwide annual cost of dementia to be US\$604 billion in 2010. About 70% of these costs are made in Western Europe and North America where the amount of people suffering from dementia is larger than in the rest of the world. A large percentage of the estimated costs go to residential care. Gray et al. (2008) conclude in their study that the need for residential care would greatly decline, and therefore costs will be reduced, if people with moderate to severe dementia could continue living in their own homes for a longer period.

Currently, 70% of the dementia patients in the Netherlands live at home. The special care that they need is often provided by their spouse or a family member. This informal caregiver eventually becomes a full-time caregiver as their role intensifies when the severity of dementia increases (Langa et al., 2001). So next to the tragedy of having a seriously ill loved one, close relatives get a very different relationship with this person. 82% of the 300.000 informal caregivers in the Netherlands are (or have a risk of becoming) overburdened, which is often caused by a combination of physical, psychological, emotional, social and/or financial stressors (Kasuya, Polgar-Baily & Takeuchi, 2000). Especially the secondary symptoms, such as the disturbed sleep/wake cycle of the dementia patient, contribute to these stressors. Eventually, the main reason for institutionalization of the person suffering from dementia is the overburden of the informal caregiver. Supporting the informal caregiver and the dementia patient in their own homes is therefore necessary to be able to prolong the time people can stay at home.

Since there is currently no cure either, innovative approaches need to be developed to help promote independence and maximize quality of life (Cahilla, Macijauskieneb, Nygård, Faulkner & Hagen, 2007). Assistive technology seems to be one tool to accomplish this. Four main categories in assistive technologies, as they are in the market right now, can be identified. Those used to promote safety (examples here might

include night lamps, flood detectors, cooker switch off devices), foster communication and address memory loss problems (picture button telephones), provide multi-sensory stimulation (picture-gramophone) and act as memory enhancers (reminder messages, electronic calendars, item locators, and medicine reminders). Other technology that is developed for people living with dementia includes technology for stimulation, relaxation, behavior management and control assistance for relatives (Marshall, 1996).

The nature of dementia may make people cautious and suspicious of trying out new devices, which makes it important to consider the right time for introduction of the new technology. An assessment of needs and proper user testing is therefore of great importance. As Cahilla et al. (2007) state that open and in-depth discussion with the individual and his or her family caregiver must always be a priority.

1.2 Innovate Dementia Project

In 2012, the INTERREG IVB project 'Innovate Dementia' (ID) started in order to find innovative (care) solutions for people living with dementia. The main goal is to provide solutions for the societal challenges we face related to dementia. In the ID project, four regions in the NWE area cooperate to explore, develop and evaluate new innovative propositions by setting up a Living Lab. The exact interpretation of the Living Lab as used in the ID project is given in paragraph 1.4 of this chapter. The regions in the Innovate Dementia project are Liverpool in England, Krefeld in Germany, Leuven in Belgium and Eindhoven in the Netherlands.

Every country has its own focus area: the use of intelligent lighting (NL), nutrition and exercise (UK), living environments (BE) and innovative care models (DU). The results from this program are shared among the different countries to create benefits on a European level and become the center of knowledge for applied innovations for people living with dementia (<http://www.innovatedementia.eu>).

The Dutch division of the Innovate Dementia Project includes four partners, which are the GGzE, Brainport development, Eindhoven municipality and the TU/e. This graduation project is part of the TU/e activities within the project.

1.3 Light

The focus for the Dutch division of the Innovate Dementia project is to innovate in the area of intelligent lighting. They are responsible for the research with a focus on the potential effects of light for people living with dementia, but also in a broader perspective such as how people experience extra light inside their home environment. It is therefore important to understand the reasoning why and how light might be used to prolong the time that people can continue living at home.

Light is important for every human being. It fulfills different needs and effects: visual needs or image forming (IF) effects, and non-visual needs or non-image forming (NIF) effects. Visual needs pertain to visual performance, which refers to the ability to perform a task that requires sight, such as reading or small domestic tasks like preparing food etc. Another visual need is visual comfort that includes having a pleasurable sight in a pleasant and suitable ambiance. Functional light fulfills these visual needs (van Putten en Zonneveldt, 2005 as cited in TNO, 2010). If functional light is lacking, problems can occur, including; stumbling and falling, wrong medicine intake, headaches, fatigue and irritated eyes.

Light also helps controlling several bodily processes, which are referred to as NIF effects. The suprachiasmatic nucleus (SCN) is a small part of the brain that functions as the biological clock (Miller, 1998). The SCN needs to

synchronize with the Earth's 24 hours clock. Research shows that the day-night cycle is the main synchronizer of the circadian rhythm (Czeisler et al, 1986). Examples of bodily processes with a circadian rhythm, and with that examples that benefit from light, include hormone levels, body temperature, alertness, urine output and composition, sleep/wake cycle, mood and performance (Someren en Riemersma-van der Lek, 2007). Especially the sleep/wake cycle is influenced by light, because exposure to, specifically short wavelength, light results in suppressing nocturnal melatonin synthesis. (Brainard et al., 2001; Thapan et al., 2001)

For the current project, research with a special focus on the effects of light on dementia patients is particularly relevant. Given that a disturbed sleep/wake cycle is a secondary symptom of the dementia disease, and that light has an important influence on this sleep/wake cycle, it can be assumed that light is beneficial for dementia patients. This is what the existing research indeed shows. Satlin and colleagues (1992) and Van Someren and colleagues (1997) found improvements in the stability of the circadian activity rhythm of people living with dementia when more and brighter light was induced. They measured this by means of actigraphy, a wrist-worn device that measures physical activity levels. Mishima and colleagues (1994) reported an increase in mean sleep time during light therapy treatment by having people fill in a sleeping log. Other studies focus on the effects of light on nocturnal unrest and restless and agitated behavior (Rheaume, 1998) or on cognitive functioning (Riemersma-van der Lek et al., 2008). Likewise, they find positive effects when dementia patients are exposed to more light with higher light levels. Riemersma-van der Lek and colleagues (2008) found a slower decline in scores of the Mini-Mental State Examination (MMSE), which is used to identify cognitive functioning of the dementia patient, and the Cornell Scale for Depression in Dementia, which is an indication of depressive symptoms. Especially this last study, which was also a long-term study, indicates that people with dementia benefit from extra light.

However, there does not seem to be consensus on the specific characteristics for effective light for people suffering from dementia. The luminance levels used in the given studies ranged from 1500 up to 10.000 lx, and it is not always reported whether this is measured at eye level or not. Next to that, the duration differs from 2 hours per 10 days to all day long for 28 days, while time of treatment is also varied. Some studies suffer from methodological flaws, including lack of control groups, blind evaluations, and objective outcome measures, as well as small sample sizes (Kim, Song & Yoo, 2003). A study by Hoof, Schoutens and Aarts (2009) indicate that color temperature might be an important characteristic too, as high color temperature lighting is expected to have an influence on the melatonin suppression. However, establishing the right color temperature appears to be difficult as many factors influence this characteristic (light levels of the light source and the attributes of the location). As most of the studies focusing on light and dementia patients take place in institutions, these studies only research the inhabitants of these institutions who are people with more severe dementia. It is of interest what the influences of light in the home environment can be, where people in the earlier stages of dementia live. In addition, the effects of light for these people might be interesting to research as the neurobiological basis of circadian rhythmicity may be more intact and thus more responsive to treatment (Skjerve, Bjørn Bjorvatn & Holsten, 2004).

In general, people with dementia are part of an age group who do not receive enough light (Aarts & Westerlaken, 2005; Sinoo, van Hoof, & Kort 2011). Elderly homes are poorly lit and older people do not spend much time outdoors (where light levels are higher). This is a problem, as more light is needed due to the changes in vision because of biological ageing. These changes are caused by the opacification and yellowing of the vitreous body and the lens (Abbott, 2003). Projects, like ALADIN in 2009 (<https://etc.fhv.at/ambientlighting/>), are initiated to find the possibilities of extra lighting in senior housing. The ALADIN project developed an intelligent lighting system with light panels (Figure 2). This system responded to biofeedback of the user and was aimed at improve feelings of wellbeing. Households that tried the system for a period of time, did report an increase in ability to relax and cognitive performance as well as in overall wellbeing. The exact research procedure is ill defined so it is not clear whether these results are generalizable. TNO (2010) published a review of this ALADIN project and similar projects and concluded that although these projects



Figure 2. Is this the solution? ALADIN lighting system.

report interesting findings, the question remains what kind of effective lighting systems will be accepted by elderly in their own home environment. Effects on cognitive performance, wellbeing etc. might not be immediately apparent, so how willing are older people to change their own home environment tremendously by high intensity, or bluish, light to evoke these effects?

It is obvious that light is a relevant focus for research in the field of dementia. On the one hand, people with dementia are part of an age group that is not receiving enough light, although they need more light due to the aging of the eye. On the other hand, it seems that dementia patients benefit from light to alleviate secondary symptoms of their disease. How to accomplish that people with dementia are exposed to beneficial light, however, is not clear. The exact specifications for effective lighting systems are not known, both regarding to technical aspects such as amount of lux as well as to aspects that improve acceptance of bright light in-home environments. The latter is of particular interest for the Innovate Dementia Project, as light could be a non-medical intervention, which increases the length of time that dementia patients can stay at their own home. The Vitaallicht lamp, which is used as the case for this graduation project, is developed to create a normal looking lamp with a high level and high color temperature lighting. The question is how people experience this lamp in their own homes. The user's perspective is in this case of great importance.

1.4 Living Lab

The ID project sees possibilities to innovate in the broad area of lighting and is still looking for new directions and insights. In order to do this in a meaningful way, the ID project is based on the European Living Lab approach (European Network of Living Labs, 2013). In this project, the Living Lab is a structure in which different research approaches can be applied with a strong focus on user-centered research methods for discovering, exploring, evaluating and validating product and services in real life contexts. The user is continuously involved in an iterative design process (Ogonowski, Benedikt & Stevens, 2013).

Innovations are placed in the everyday life of the user, mostly their own home environment, to make them co-designers of the eventual innovation. This is aimed to create insights in the acceptance and usability of the design from the user's perspective (Almirall, Lee & Wareham, 2012). The Living Lab is a commonly used approach in designing for networks, as needs, wishes and benefits of different stakeholders need to be taken into account. This is also applicable in the dementia care sector where users (both patients and

informal caregivers), care providers and potential business partners are involved in the development of innovations (Brankaert & den Ouden, 2013). In this network (Figure 3) a lot of knowledge is available, but is distributed among different (groups of) people, e.g. during which activities does the dementia patient had the most difficulties or what kind of care takes the most amount of time. On the other hand, when new innovations are in use, the other stakeholders are affected as well. Hypothetically, when the dementia patient has a better sleep/wake cycle by means of a new lighting system, the burden on the informal caregiver declines and less professional care is needed. The importance of every stakeholder in this network, and with that in research in this area, is therefore evident.

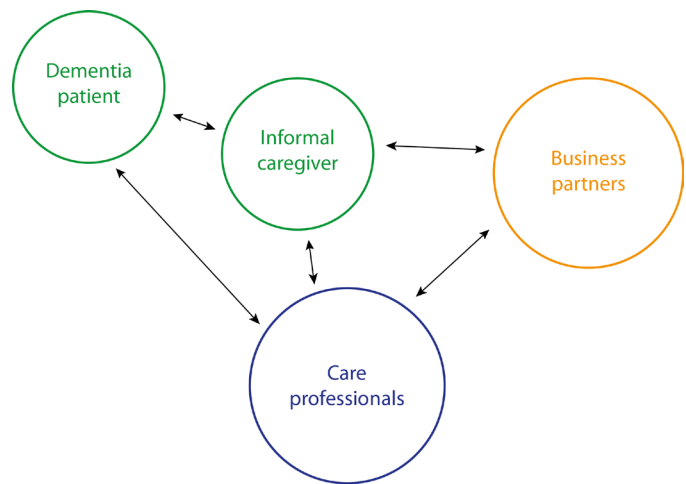


Figure 3.. Simplified representation of stakeholder network in dementia care sector

The challenge for the Living Lab as a context is that the researcher enters, or even intrudes, upon the home environment of the user. This is a private, secure place, which means the research conducted in this domestic domain should be sensitive and respectful. Ogonowski and colleagues (2013) emphasize the importance of a relaxed, friendly and social attitude from the researcher for a positive user motivation and research-participant relationship.

Since the user is seen as a co-designer in the Living Lab approach, their motivation should be positive throughout the entire project.

The Living Lab as a research structure is new and even unique in the field of dementia research. Consequently, it is still unknown how to apply it in a way that every stakeholder, including the dementia patient, is involved in the entire project. Thorough deliberation in choosing specific research methods that can be used in the home environment is needed. These methods should motivate the dementia patient to be part of a longitudinal project, so sensitive and respectful approaches are crucial to capture the valuable firsthand experiences that the person with dementia can provide.

1.5 The methodological challenge

The current study will take a closer look on the possibilities of light in the home environment of people with dementia. For people with dementia the home environment is of great value, as it becomes the most important place for preserving and presenting the person's identity (Topo & östlund, 2009). This can provide researchers and designers with a thorough understanding of the life of the person with dementia, if the right way of researching is chosen. An infinite list of factors including daily activities, light preferences, acceptance of new products and other personality traits, can have an important influence on the potential benefits one can experience from an intervention with light in the home environment. These factors are related to the persons with dementia themselves, but other factors which are related to the specific environment need special attention too (Topo, 2009). These include housing characteristics and the opinion and preferences of other people in the context. It is of interest to gain insights in these two types of factors that might influence the acceptance and usage of a potential beneficial lighting system in the home environment. An understanding of the entire context is needed.

It would perhaps appear to be obvious to ask all relevant people in the home environment, including the dementia patients themselves, about these factors. Nevertheless, this involvement of people with dementia in research is not that common. A literature review of different studies that investigate several technological innovations, by Topo (2009) shows some remarkable insights in this matter. In most of these reviewed studies the informal or formal caregivers are the main information sources to rate the usability and usefulness of technological innovations. Instead of studying people living with dementia, the focus often lays on people living with a person with dementia. What Topo shows in his overview, which is also concluded in earlier research by Zimmerman & Magaziner (1994), is that there is discrepancy between the caregiver's opinion and the opinion of the patient. Zimmerman & Magaziner (1994) attribute this to characteristics such as the nature of the relationship and time spent with the patient, the degree of objectiveness of the questions, and the level of impairment of the patient. Both opinions are relevant, but the opinion of the dementia patient is marginalized in most studies (Topo, 2009).

This marginalization is something that we want to avoid in the Living Lab of the ID project, especially since the aim is to create a strong longitudinal research-participant relationship.

Research shows that many early and moderate stage dementia patients are able to give their opinion about their current situation (Grut, Jorm, Fratiglioni, Forsell, Viitanen, & Winblad, as cited in Brod, Stewart, Sands, & Walton, 1999; Kiyak, Teri, & Borson, as cited in Brod et al., 1999). Some studies therefore do involve people suffering from dementia, mostly in a passive way by means of observation (Lucero et al., 2000; Margot-Cattin & Nygård, 2006; Nygård & Johansson, 2001). When a participatory way is chosen, researchers use interviews (Baruch, Downs, Baldwin, & Bruce, 2004; McConatha et al., 1994; Öhman, Josephsson & Nygård, 2008), although people suffering from dementia might experience a traditional research interview as stressful (McKillop & Wilkinson, 2004). A few studies use adapted methods such as a diary study (Bartlett, 2012) or focus group with patients (Qureshi et al., as cited by Wilkinson, 2002). These adapted methods, however, have limitations to apply it in the current study. For example, they were applied without evaluative purposes, reported respondent's fatigue or non-disclose agreements were violated in the group session with dementia patients. These and more limitations are further elaborated in the next chapter.

The methodological challenge to include dementia patients in research needs exploration, which is a reason to use a qualitative research method in the current study. Since research protocols as used by the Innovative Dementia Project are still in their infancy, a qualitative research method fits with the goal of this project. These methods have the central purpose of contributing to revision and enrichment of understanding (Elliott, Fischer & Rennie, 1999) which is needed in the area of intelligent lighting in the home environment of people with dementia.

In order to create a pleasant reserach experience, which is part of the objectives of the Living Lab, standard approaches of data collections need to be adapted.

The neurological effects of dementia, such as memory deficits and expressive language difficulties (Morris & Becker, 2004), need to be considered in the development of a new data collection tool.

Next to the fact that this new data collection tool respects the abilities of the dementia patient and enables their participation, the tool should give meaningful insights for the project.

1.6 Research Question

The goal for this project is to develop a qualitative research tool that captures first-hand experiences from the person with dementia to complement the currently used caregiver-questionnaires in a meaningful and unique way. The overall research question is how one can successfully design a qualitative research method to collect first-hand evaluative data from individuals in the early stages of Dementia in the context of a Living Lab. The term 'success' in this question pertains both to the quality of data collected, and the experience of the participants as burdening and/or fulfilling.

There are three main objectives for this qualitative research tool:

1. The focus for this project is to make the dementia patient's voice heard in the research. The method should have a special focus on aspects of the dementia disease to make it suitable for the current user group. This includes taking into account the memory deficits, the difficulties with language, the lowered capacity to concentrate and troubles with seeing the complete picture.
2. The objectives of the Living Lab include the experience of participating as an important factor to be taken into account. Participants should not be burdened by the method and the method should aim at creating feelings of involvement and long-lasting motivation for both informal caregiver and the person with dementia. Extra care should be taken as the research takes place in the private home environment.
3. In addition, the researcher should benefit from the generated data in order to be able to draw evaluative conclusions. The generated data should be rich and give all insights needed for redesigning innovations. Aspects of doing research, such as time intensity, need consideration.

In this thesis a closer look at existing qualitative research methods and previous work in the field of involving dementia patients in research (Bartlett, 2012; Qureshi et al. 1998, as cited in Wilkinson, 2002 ; Nygård, 2006) can be found. This will uncover what elements of existing methods need adaptation to follow the three main objectives of the current study. This is elaborated in in the next chapter. The next chapter also elucidates on the development of the new method.

Another unique aspect of the current study is that we compare this newly developed method with a more conventional method. Previous work in this field only used one adapted method, which makes it hard to exactly identify the advantages and disadvantages of the method. The two methods in the current study are used to evaluate a new innovation in the area of light.

Afterwards the collected data will be compared to see the difference in type and quality depending on the design of the method. Furthermore, the experiences of the participants and their informal caregivers, about participating in research by the given method, are studied.

METHOD DEVELOPMENT 2

Studies with a focus on the methodology in research with dementia patients are rare. Especially those where the dementia patient has an active role in the study, seem to be few and far between. This is remarkable as the number of existing qualitative research methods is large and it seems unlikely that none of these methods could fit the abilities of a person with dementia. Some studies report to have conducted interviews with people with dementia (Baruch, Downs, Baldwin, & Bruce, 2004, Topo et al., 2004), although the exact procedures and questions of these interviews are ill defined. Three studies that do reflect on specifically designed methods are the diary study by Bartlett (2012), the focus group study by Qureshi et al. (Qureshi et al. 1998, reviewed in Wilkinson, 2002, Chapter 9) and interviews and observations by Nygård (2006). Next to that, we found applied knowledge on this matter in a game designed for people with dementia (Huizing & Van Den Brandt-Van Heek, 2009). Their deliberate choices and eventual insights were used in the development of the probe game 'Aangenaam' which was the method created and used in the current study. 'Aangenaam' is based on existing methods that were combined and refined to reach the three main objectives.

2.1 Insights from previous studies

By evaluating previous work in the field of including dementia patients in research, strengths and weaknesses of the chosen methods can be identified.

2.1.1 Bartlett's diaries (2012)

Bartlett (2012) chose the diary method, as she was interested in creating and representing knowledge on people's experiences during their everyday activities. The diary provides insights into a person's thinking which cannot be derived from participant observations alone. Bartlett felt that in the diaries, there is no retrospection involved as people can make an entry when thoughts and feelings occur. As recall is a problem for people with dementia, this way the memory errors can be lessened.

Bartlett studied people with dementia who were still active in public life by means of written, audio or photo diaries. She let her 16 participants choose between one or more types of diaries to give them a feeling of control. It was assumed that audio and photo diaries would create a more dynamic understanding of people's lives than just plain text, as visual and auditive input can complement text for richer insights. The diaries contained instructions on what to discuss in the written or audio data and what to photograph, but they were not specifically structured.

Bartlett assumed that the option to make an entry in their own way, in their own time, and wherever they felt comfortable, would minimize the burden on the participants. Furthermore, the written diary created 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.

Bartlett did indeed find that people felt in control due to the option to choose which diary to use, when to use it etc. Participants also had some control over how they represented themselves. 'Although instructions were provided, ultimately each participant decided what to emphasize and record in his or her diary'. As a researcher, Bartlett was not actively involved during the data gathering process. Therefore, she felt to get more time to support the participants. Another valuable insight was that participants mentioned that they liked the ability to rethink the entries in the written diaries. Expansions and details could be supplemented in a later moment. A more general finding by Bartlett was that a method that needs input on a regular basis improved the feelings of involvement with the research. Lastly, the gathered results could be placed in the context of someone's personal lifestyle and concerns.

One of the weaknesses of this study was that the sample might have been biased. A group of participants who were active in organizations and media carried out Bartlett's diaries. This indicates that they might have been used to share opinions openly and therefore might not reflect the dementia population properly. Bartlett indicated that some of her participants felt that the written diary was a tangible, reviewable reminder of the language and writing skills one has lost or is losing which might be experienced as confronting. Some

participants indicated respondent fatigue as reporting about life on a daily basis could be boring after a while. Especially since the diaries were unstructured, the self-motivation of the participants should be high at all times.

2.1.2 Qureshi et al's focus group study (in Wilkinson, 2002, Chapter 9)

Qureshi and colleagues (in Wilkinson, 2002, Chapter 9) studied the outcomes of social home care by means of a series of focus groups. The focus groups were constructed with the deliberative approach to make people understand the purposes of the topics. The choice was made to have multiple sessions over a period of time. This enabled the participant to consider, discuss and change their opinions over time, as most participants were new to the topics of the focus groups. People with dementia might benefit from this procedure as they have difficulties with forming cumulative value judgments. Fifteen older people with dementia participated in the study, two of whom attended all five sessions.

The choice for a focus group was based on several reasons coming from earlier research. In a group, a person feels more in control over the level of participating compared to individual interviews, as the individual level of participating is less apparent in a group. If you do not feel like talking during one of the sessions, another person can fill this silence easily without the research activity to fail. The group setting also creates feelings of support and empowerment, especially when others in the group share similar experiences. When these experiences are shared, recall of similar events or feelings might occur which increase access to memories outside the current context. This last advantage of a focus group is of extra interest when dealing with participants with memory deficits.

Interestingly enough, Qureshi and colleagues used special scents in the room where the focus group took place and started with singing together in order to make the participants aware that something special was going to happen. This also created a sort of ritual to evoke possible memories about earlier focus group sessions. This approach eased the transition to a new activity, although hard conclusions on the effects of these actions could not be drawn.

The focus group study, as conducted by Qureshi and colleagues, showed that multiple smaller sessions lowered the burden of participating. This way, participants were not forced to attend long exhaustive discussions, but rather participate in smaller talks with a period in between to reconsider ones thoughts. Another strength was the use of the later sessions to feeding back the drawn conclusions from earlier sessions. This helped validating the results with the participants' help. Photographs proved to be useful in managing a focus group with dementia patients. These photographs helped to talk about other settings and were used as elicitation material. Case studies were also used to give examples about certain topics but these might only be useful stimulus material when adjusted according to the characteristics of the group. This means that when you have a group full of females, an example about a man in a given situation will evoke comments related to the gender differences instead of the situation that was of interest. As people were sitting in groups, the interaction between participants helped remembering feelings and thoughts. Qureshi and colleagues found that people encouraged each other to participate in discussions.

However, participation selection in focus groups with dementia patients was very crucial. Communication difficulties or disruptive behavior, which might occur with people with dementia, could hinder group discussions. As Qureshi and colleagues used existing groups in their focus groups, social relations between participants appeared to restrict the feeling of freedom of opinion. Sometimes interaction between group members was seriously lacking respect, which did not contribute to the general ambiance of the discussions. Another weakness about focus groups with people with dementia was that confidentiality of what is said in the group was hard to guarantee. People forgot the non-disclosure agreement. In addition, if talks were set up to be informal, to create a casual atmosphere for the discussion, it was hard for the participants to keep focused on the topic. Idealized accounts and telling stories were common off topic behaviors, which cost a lot of time.

2.1.3 Nygård's interviews (2006)

Nygård had been conducting interviews with people with dementia for over 15 years when she wrote a guideline reflecting her lessons learned in 2006. She states that a combination of interviews and observations will give insights from the perspectives of the dementia patients when conducted correctly.

The choice for interviews is challenging as interviews rely on cognitive and verbal functions, which deteriorate as the disease progresses. Nygård states the importance of the context of the interview. When performed in a natural context, the comments made will be more closely connected to the experience as things in the environment can help as a reminder and support. Furthermore, 'reflection-by-doing' reveals sudden insights or feelings, which would not be generated by solely asking questions. The example Nygård provides illustrates this action-based interviewing well: a woman with dementia was not able to pinpoint difficulties she had with the washing machine, up until the researcher was present at the washing ritual and the woman did not know how to handle when the machine made a certain sound. This experiencing and evaluating together can also be accomplished to some extent by using photographs. These might help someone to show what they mean when verbal accounts are troublesome.

During the interview, it is important to take one's time as it might take longer for someone with dementia to prove his point. Several short sessions might also be beneficial as an interview can be a tiring activity for the dementia patient, which was also a finding of Qureshi and colleagues. Pauses and relaxed small talks are crucial for the participant to take rests.

In addition, the construction of the questions needs thorough consideration. If it becomes apparent that the question is not clear to the participant, slight changes in form and wording or complete repetition can be advantageous. Although open questions may be difficult for people with dementia, Nygård experiences that concrete open questions have the strength to create elaborate accounts. These questions should not require recall of the exact characteristics of events or sequences. Instead, open questions regarding what the person with dementia usually does and what he thinks about particular issues in their daily life may be more appropriate.

2.2 Existing methods

The insights of these three studies show the strengths and weaknesses in a diary study, a focus group study or an interview with dementia patients. As there is a great variety of qualitative research methods, it seemed relevant to explore other methods to see what these might contribute to the research with dementia patients. Especially since only the diaries of Bartlett (2012) seem to be able to capture experiences over a moment of time in the daily life of the participant, there is room to find a method that could enhance this data gathering in the home environment. With this in mind, the field of existing qualitative research method was explored. Eventually the following list was created:

Audio Diary: The participants receive an audio recorder. They can record themselves telling about their experiences, but they can also interview others or record sounds in their environment.

Cultural Probes: A wide variety of tools carries the name of a cultural probe. Often there is a set of tools combined in a probe-kit, which is given to the participant to work with for a period. Data can serve as a conversation starter and surprising insights can be gained as a participant's creativity is stimulated. Tools can be priority trees, mood cards, clay, post cards, scrapbook, cameras, post-its, experience flows, maps etc. A variation is *Playful probing* where games are developed to enhance participants' involvement in the probe studies (Bernhaupt, Weiss, Obrist, & Tscheligi, 2007).

Day Reconstruction Method: The DRM is designed to collect data describing the experiences a person has on a given day, through a systematic reconstruction conducted on the following day. Participants are asked to

reconstruct the preceding day's activities, indicating the approximate start and end times and then questions of interests about these activities are asked (how people felt, why they performed these activities etc.)

Digital Storytelling: Video, audio, interactive system, web, games, animation, narrative voice etc. that tells the story of life of the participant.

Elicitation Studies: Most of the times these are interviews based on certain media (photos, videos, music, tangible objects etc.) which elicit the conversation between researcher and participant. Visual ethnographer Pink (2007) explains that e.g. photographs can inspire people to represent and then articulate embodied and material experiences that they do not usually recall in verbal interviewing.

Experience Sampling Method: The most common version of this method is the signal-based version where the participant receives a notification when to make an entry in a diary. ESM is, compared to conventional methods of observation, a rather "unobtrusive" method, and ESM-data does not, unlike conventional survey-data, rely on retrospective information (Borell, 1999).

Lomography: This method is the unstructured version of the photo diary. People just get a camera to make spontaneous pictures, which are analyzed afterwards.

Photo Diary: The participants receive a photo camera/device that can make photos. They receive instructions on what to capture, ranging from things that are important to them to which steps they undertake during a certain activity. The photos can be used in subsequent elicitation studies, to gain more information data.

Physiological Diary: The participants wear a physiological data measurement device, such as actigraphy, in order to capture information about physical movement, heart rate, GSR, blood pressure etc.

Semi-structured Interview: An interview that is open, allowing new ideas to be brought up during the interview as a result of what the interviewee says.

Structured Interview: The researcher prepares a set of questions which are exactly the same for every participant and there is no to little room for deviating from these questions.

Tangible Objects Diary: The participants receive instructions to collect physical objects in a given environment, on given moments that represent a certain activity or feeling. The tangible objects can be used in elicitation studies, to gain more information data.

Telephone Diary: There are two options for this diary type. Either the researcher calls the participant, or the participants call the researcher on a predefined interval or event basis. The conversation can be one way, when the participant just tells the story of the day, or the conversation can be more like an interview when the researcher has a more active role.

Time Budget Studies: Surveys and other studies that require participants to keep time-use diaries, to report the activities occupying each hour of each day for a fixed period, such as a week or month.

Video Diary: The participants receive a video recorder/device that can capture video. They can record themselves telling about their experiences, but they can also video record others or their environment.

Visual Anthropology: This covers several methods such as ethnography, physical traces and observation in which the participant does not have an active role in research. The data is an interpretation of the environment of the participant and can be as abstract as interpretation of visiting behavior of museums, preferences in art, what kind of media is produced, what kind of jewelry people wear etc.

Voicemail Diary: The participant calls the voicemail box of the researcher on a predefined interval or event basis.

Written Diary: There are several options for this diary type: digital online, digital offline or analog offline. The digital versions might exclude people who are not used to work with computers/PDA/iPad or any other electronic device. Entries in the digital versions do not have the issue of unreadable handwriting. The online version creates direct access to the generated data, as well as exact information about time/place of entry. The analog version does not limit the participant to be creative in their entries (strikethrough text and doodling can give extra insights in the way the participant thinks).

All methods appear to have their advantages and disadvantages. Some seem to be immediately unsuitable for the current user group due to the media used (digital storytelling) or when it is based on participant's remembering (time budget series and day reconstruction method). Some methods are not participatory (physiological diary and visual anthropology), which does not really include someone's own perspective so those do not suit the current project objectives. Interesting methods are those that are not fully based on language skills (lomography, photo dairy) or have a degree of freedom (cultural probes, semi-structured interview) that might result in a more relaxed research setting.

2.3 Suitable methods

2.3.1 Considerations

To make a choice in all methods provided, our considerations should be structured. First, we have our own three main objectives:

1. Making the dementia patient's voice heard in the research when taking into account the memory deficits, the difficulties with language, the lowered capacity to concentrate and troubles with seeing the complete picture.
2. Participants should not be burdened by the method and the method should aim at creating feelings of involvement and long-lasting motivation for both informal caregiver and the person with dementia. Extra care should be taken as the research takes place in the private home environment.
3. The generated data should be rich and give all insights needed to draw evaluative conclusions. Aspects of doing research, such as time intensity, need consideration.

These objectives are complemented by the lessons learned from Bartlett (2012), Qureshi and colleagues (as cited in Wilkinson, 2002), and Nygård (2006). The discussed studies were all conducted with an ethnographical intention, which is different from the intention of the current study. We focus on generating evaluative data of new innovations in the context of a Living Lab. Nevertheless the insights of these studies are important for the current project, as studies that do claim on getting evaluative data from dementia patients in interviews (Astell, Alm, Gowans, Ellis, Dye, & Vaughan, 2009; Orpwood et al., 2004) do not provide clear guidelines as their procedures are ill defined.

What we learned was that it is beneficial to give the participants a feeling of control, for example by providing several options. Participants are also in control when they are free to choose when to make an entry, they can find their own way, their own time and place. These feelings of control are also apparent in the focus group study, where people can decide for themselves what their level of contribution to the group talk is.

Furthermore, the context of the research needs consideration. As we work within the Living Lab structure, the context is the home environment of the participants. This is where everyday activities take place which need to be captured in this context as well to get a dynamic understanding. Nygård states the benefits of this context on the comments related to the activities in the context. The context will help reminding and supporting the thoughts of the person with dementia. Reminding can be accomplished by 'reflection-by-

doing' (capturing the insights and feelings as they occur), or using stimulus material such as photographs. This way retrospection is largely avoided.

The research activity should exist out of smaller parts, as this will lower the burden for participating. Especially the problems with concentration emphasize the need for avoiding long extensive talks. By multiple smaller parts, the participant can get used to the research activity and a sort of ritual can be created, which Qureshi and colleagues aimed for as well.

2.3.2 Rating the methods

To get an insight in which of the given methods would be suitable, a list of requirements is created. These requirements were structured in line with the three main objectives of the current study and they included the insights of the previous discussed studies.

1. Putting the dementia patient in control and keeping his or her difficulties into account. For example, retrospection avoiding techniques or techniques that remind the participant to contribute in the research get higher scores. Bartlett found that writing was a good practice for people in the early stage of dementia, although methods that are not based on language can be more suitable for people who experience the language difficulties.

Not based on language

Opportunity to write (Bartlett)

No retrospection is needed from the participant (Nygård)

The participant is reminded to make an entry

Participant is in control (Bartlett, Qureshi and colleagues & Nygård)

Experiencing and evaluating together (Nygård)

No reminder of loss of abilities (Bartlett)

Multiple smaller parts for concentration decline (Qureshi and colleagues)

Also includes participants who are unable to write

2. People should feel involved throughout the current study and beyond. The research activity takes place in the home environment and should therefore feel as an unobtrusive, natural activity. Participants can be supported by others, who can also help them remember certain events. The method will be better when it is not fully based on self-motivation and is fun to use. This will avoid respondent fatigue.

- Participants can add details later (Bartlett)

- Natural activity

- Not very time consuming for participant

- Fun to participate (Bartlett)

- Reflection on earlier entries possible (Bartlett)

- Not fully based on self-motivation (structure is provided) (Bartlett)

- Regular basis to create feelings of involvement (Bartlett)

- Supported by social influences (Qureshi and colleagues)

- Research activity becomes ritual (Qureshi and colleagues)

- Method captures event in the home environment

- Room for taking time and moment to relax (Nygård)

3. The researcher should benefit from the data gathered by the method in order to make evaluative conclusions. Everyday activities should be captured to get all possible insights in the lives of the participants. Most requirements are time-related.

- Everyday activities are captured (Bartlett)

- Dynamic understanding of people's live (Bartlett)

- Direct access to data

- Entry lengths are created by researcher, to avoid enormous piles of data

- Not expensive

- Interpretation of data is relatively easy

- Can capture information that the participant is not aware off

- Data (without analysis) can be used in other contexts/purposes (such as illustration)

- Can be used to evaluate new innovation

- Most experiences/feelings are easily captured

- Exact design of method is not substantially affecting results

- Low social desirability bias / no direct contact with researcher or others

- Not very time consuming for researcher

- Includes options for elicitation (e.g. photographs) (Qureshi and colleagues)

All methods, including the diaries, focus groups and interviews, were scored on these requirements ranging from not applicable at all (--), to very applicable (++). This scoring was conducted to see the extremes and these were highlighted in Table 1 on the next page.

Table 1. Rating the methods

	Audio Diary	Cultural Probes / Payroll probing	Day Reconstruction Method	Digital Storytelling	Elicitation Studies	Experience Sampling Method	Focus Groups	Longmography	Photo Diary	Physiological Diary	Semi-structured Diary	Structured Interview	Targeted Interview	Telephone Diary	Time Budget Studies	Video Diary	Visual Anthropology	VoiceMail Diary	Written Diary
Not based on language	-	+	-	+	0	0	-	++	++	-	-	+	-	0	+	++	-	-	-
Opportunity to write	--	0	+	--	-	0	--	--	--	--	--	-	-	0	--	--	--	--	++
No retrospection is needed from the participant	+	+	0	0	0	+	+	+	++	-	-	++	++	0	+	+	++	+	+
The participant is reminded to make an entry	-	-	-	0	+	+	-	-	N.A.	+	+	-	-	-	-	N.A.	-	-	-
Participant is in control	++	+	-	0	0	+	+	++	++	0	0	++	0	-	++	++	+	+	+
Experiencing and evaluating together	0	+	-	+	0	0	++	0	--	0	0	-	+	-	0	--	--	-	-
No reminder of loss of abilities	++	+	--	0	0	0	+	+	+	0	0	0	0	0	++	++	+	+	--
Multiple smaller parts for concentration decline	+	++	-	0	0	+	++	++	++	+	+	+	+	0	0	++	++	++	++
Also includes participants who are unable to write	+	0	-	+	-	+	+	+	+	+	+	+	+	-	+	+	+	+	+
Participants can add details later	0	+	0	+	0	0	-	0	N.A.	0	-	0	0	+	0	N.A.	0	0	++
Natural activity	+	0	-	0	+	-	+	+	-	+	0	++	-	-	+	N.A.	++	+	+
Not very time consuming for participant	0	0	-	0	0	0	+	++	0	0	+	0	0	-	0	++	0	0	0
Fun to participate	0	++	-	+	0	-	+	0	0	0	0	0	+	--	0	N.A.	0	0	0
Reflection on earlier entries possible	0	+	+	0	0	+	0	0	--	0	0	0	+	+	0	N.A.	-	+	+
Not fully based on self-motivation (structure is provided)	+	0	0	-	++	+	++	0	++	+	+	++	++	+	0	++	++	+	+
Regular basis to create feelings of involvement	++	+	+	-	+	0	+	++	-	+	+	++	++	+	++	--	--	++	++
Supported by social influences	0	+	0	+	0	++	-	0	--	+	+	0	0	0	0	0	0	0	0
Research activity becomes ritual	+	++	+	0	0	+	+	0	-	0	0	+	+	+	+	+	+	+	+
Method captures event in the home environment	++	+	+	0	0	+	+	+	+	0	0	0	+	+	+	0	+	+	++
Room for taking time and moment to relax	++	++	+	0	0	0	++	++	++	+	0	++	+	+	+	+	+	+	++
Everyday activities are captured	++	+	++	0	0	++	0	++	+	0	0	+	++	+	++	0	++	++	++
Dynamic understanding of people's live	++	0	++	0	0	+	++	0	0	0	+	+	-	-	++	++	+	+	0
Direct access to data	0	-	0	0	+	0	++	0	0	+	+	-	+	0	0	+	+	+	0
Entry lengths are created by researcher	0	0	+	0	0	+	0	0	0	0	0	N.A.	+	+	0	N.A.	+	+	+
Not expensive	0	-	0	0	0	0	0	0	-	0	+	+	-	0	0	0	+	-	0
Interpretation of data is relatively easy	+	0	+	+	++	+	0	0	--	++	++	++	++	0	+	-	+	+	+
Can capture information that the participant is not aware of	0	+	0	-	0	+	0	0	++	-	-	0	0	0	0	++	0	0	0
Data (without analysis) can be used in other contexts/purposes (such as illustrative)	-	0	-	+	0	-	--	0	--	--	0	0	-	0	0	0	0	0	-
Can be used to evaluate new innovation	+	+	0	0	+	+	0	0	0	+	+	0	+	0	+	0	+	0	+
Most experiences/feelings are easily captured	+	+	+	++	+	0	0	0	0	+	+	--	+	+	+	0	+	+	+
Exact design of method is not substantially affecting results	+	0	0	-	0	0	+	+	+	+	+	++	++	0	0	++	++	++	0
Low social desirability bias / direct contact with researcher or others	+	0	0	0	-	0	--	+	++	--	+	+	+	0	+	++	++	+	0
Not very time consuming for researcher	0	0	0	-	0	0	-	0	0	0	0	+	-	0	0	0	0	0	0
Includes options for elicitation (e.g. photographs)	0	+	0	++	0	++	++	-	+	++	+	++	0	-	+	-	-	-	0

2.4 Combining the methods

Table 1 shows that there is no single method that meets all requirements. A couple of methods do show some striking advantages over the other methods. We expected that combining several aspects of different methods, would result in a higher chance of meeting more requirements. Besides, it would provide insights whether these methods in itself were appropriate to use with dementia patients.

Three methods from Table 1 appear to be interesting for applying in the Living Lab of the Innovate Dementia project: photo elicitation study, cultural (playful) probes and the audio diary. If we would complement these methods with interviews and an option to write, a large set of requirements will be covered.

In all three studies by Bartlett, Qureshi et al. and Nygård, photographs enhanced the research, either as dynamic input about the context (Bartlett, 2012), in talks as stimulus material (Qureshi et al., as cited by Wilkinson, 2002), or as a communicative tool (Nygård, 2006). It is not based on language skills and the data can be used for illustrative purposes. The idea is to find out how these pictures can be used as an elicitation in interviews, as it will lower the need for retrospection.

Furthermore, audio can serve as a dynamic 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 just written text does. The participant is in control with the audio recorder of what is said and when. This creates the flexibility and the importance of putting the participant in control, as Bartlett was highlighting.

Cultural (playful) probes also generate flexibility because these probes often exist out of several options to give input. Probe methods were used in research with older people before to build a rich picture of their lives which facilitated the co-production of technologies (Wherton et al., 2012). Wherton and colleagues found that probes are most effective when used as a tool to facilitate communication and to develop a deeper understanding of older people's needs. The flexibility of the probes seemed a way to combine the photo elicitation, audio diary and written option and still create coherence. By choosing the probes as main method, the other methods could serve as input options.

This main probe method was further considered and we chose to work with playful probing. This variation aims to support active participation by using games as integral research tool (Bernhaupt, Weiss, Obrist, & Tscheligi, 2007). The study by Bernhaupt and colleagues showed that adding a playful aspect, the probes generated more data. We felt that a game would suit the context and objectives of the current study. The game could be played in the safety of the own home environment. Furthermore, it puts the participants in control as the game can be played in time and moments that the participants prefer. This also results in what appears to be the 'smaller sessions'. The choice is made to let the informal caregiver and the dementia patient play the probe game to stimulate discussions. The social interaction between two partners that have respect for each other can be beneficial to empower and support the dementia patient during the research activity.

This combined method will enable the dementia patient to partake in a research activity that considers their abilities. By providing a comfortable ambiance by means of a game to play with the informal caregiver, it is expected that the dementia patient feels less burdened and more involved with the study. When designed properly, the probe game will generate rich evaluative data that gives a dynamic understanding of the lives of the participants.

2.5 Probe game 'Aangenaam'

The probe game 'Aangenaam' (Dutch homonym for 'Nice to meet you' and 'Pleasantly') consisted out of a set of question cards to evoke discussions between informal caregiver and dementia patients. We wanted to spread the intensiveness of the research activity, so therefore the participants were instructed to play the game every day and to answer only a couple of questions each time. This relaxed, game setting was expected to lower the burden of participating.

The questions in the probe game were based on the questions in the game 'Mijn leven in fragmenten' by Huizing & Van Den Brandt-Van Heek (2009), which is a game especially developed for people with dementia. Both game-developers work in the care sector, with Huizing as theologian to support people with telling their life story and Van Den Brandt-Van Heek as specialist in dementia. Therefore, their game was a very suitable inspiration for the probe game in the current project. Questions that would generate evaluative data were also needed so those were created in the same fashion. The type of questions is in accordance with the insights retained from Nygård (2006) who stressed the importance of well-considered questions. Open questions are used in 'Aangenaam' to evoke discussion between informal caregiver and dementia patient for elaboration on a topic. Inquiring about detailed knowledge, like time or sequences of activities, is avoided. Instead of retrospective information about events in the recent past, concrete questions will capture in situ experiences.

The question cards contain questions that are directed to the dementia patient. Questions are designed to capture opinions about all kinds of topics, or evaluation of matters in the current situation and moment (examples below). The questions in 'Aangenaam' are divided over four categories (Figure 4). Three categories are standard and one category has questions specifically designed for the prototype that needs evaluation. In the current study, this is the Vitaallicht lamp.

Category 1 (blue cards): Daily activities, includes questions about sleeping, using the telephone, playing a game etc.

Category 2 (green cards): Environment, includes questions about their city and street, what their ideal home would look like, whether they need a garden etc.




Category 3 (red cards): Personal, includes questions about what makes them happy, what gives them energy, what is important to them etc.

Category 4 (orange cards): Vitaallicht lamp, includes questions about when they make use of the lamp, whether it fits their home environment, how much they would pay for the lamp etc.



Figure 4. Four cards of the probe game from four categories.

The questions in 'Aangenaam' could be answered by means of:

-  taking a photograph
-  recording the answer in an audio recorder
-  writing the answer down in a notebook

These three items are referred to as 'answer option' throughout this thesis. The cards have a suggestion, which answer option to use, although participants were instructed to choose the answer option they felt most comfortable with. The notebook was an A5-format basic notebook with ruled paper. The audio recorder was an Olympus Memorecorder DP-211 (2GB) and buttons that were not needed to make an entry were taped to limit the options for the participant. (Figure 5). The photo camera was a simple disposable camera. The participants also received a booklet that they had to fill in every time they played 'Aangenaam'. This booklet contained short questions about who played, when they played, which questions they answered and which questions were skipped. There was room for remarks as well. All items were placed in a wooden box named 'Aangenaam' and pens from the University of Technology, Eindhoven were provided as final addition (Figure 6 & 7).



Figure 5. The audio recorders with the taped buttons



Figure 6 & 7. The probe game 'Aangenaam'

3 METHOD

3.1 Design

The current study was of qualitative nature. We compared two research methods, a newly developed method (a probe game) and a more conventional one (iPad questionnaire). Participants received one of the two research methods. Differences in results and experiences between subjects would give insights in advantages and disadvantages of each method. Extra attention was given to the three answer options in the probe game (notebook, audio recorder, and a photo camera). The entire test period was three weeks. In addition, the sleep quality over this period was measured by a repeated questionnaire, which was the same for every participant. Within subject differences would be used to identify possible changes in sleeping patterns. A final interview would reveal insights in the experiences with the Vitaallicht lamp and how the participants felt about participating in the study.

Participants were assigned to one of the methods based on time of recruitment. As we were especially interested in the experiences of the probe game method, the ratio of 2:1 for method division was chosen. This results in the following distribution: probe game – iPad – probe game – probe game – iPad – probe game etc. The study took place from the end of April until the end of July 2013.

3.2 Participants

Fourteen households, each with one informal caregiver and one dementia patient, started the study. Four different employees of the GGzE, who were case managers or otherwise connected to the Innovate Dementia Project, did the recruiting of the participants. Participants were selected when they still lived at home with a partner, preferably in the earlier stages of dementia. Some of the participants knew each other as they were selected from the same dementia-related training, provided by the GGzE earlier in the year.

Three households withdrew from the study after the first week due to worsening of the health situation and apparent unsuitability to continue with the Vitaallicht lamp. Only one of these three households provided data that is included in the analysis, as the contribution is relevant for some of the findings. Eventually five female dementia patients and seven male dementia patients were included in the sample, aged between 66 and 87 ($M=74,92$, $SD=6,17$). One participant was in the later stage of dementia; all other participants were in the early to middle stages. Eight participants were diagnosed with Alzheimer disease, three with vascular dementia and one with dementia not otherwise specified (NOS). Table 2 & 3 show more information and the distribution of the participants over the two methods.

Table 2. Information of participants in iPad condition

<i>Gender</i>	<i>Age</i>	<i>Dementia</i>	<i>Description of household</i>
Female	72	Alzheimer disease	Living in a village near Eindhoven, in a larger older townhouse with a big garden. Windows with lace curtain. Higher class. She gave sewing lessons in home school. Close family ties.
Male	72	Dementia NOS, Middle stage	Living in village near Eindhoven, in a larger townhouse with a big garden. Few windows. Higher class. Slightly artistic people, he made stained glass frames as a hobby
Female	71	Vascular dementia, Middle stage	Living in a village near Eindhoven, in a ground level elderly apartment with neighborhood association. Few windows. Lower income. He was a janitor at a high school. Close family ties.
Male	79	Vascular dementia	Living in Eindhoven, in an elderly apartment in an older apartment building on the third floor. Few windows. Middle class. He was a primary school teacher.

Table 3. Information of participants in probe game 'Aangenaam' condition

Gender	Age	Dementia	Description of household
Female	70	Alzheimer disease Later stage	Living in Eindhoven, in a regular older townhouse with a regular garden. Windows with lace curtain. Lower class. He was an electrician.
Female	66	Alzheimer disease	Living in small village near Eindhoven, in a regular older townhouse with a big garden. Few windows. Middle class. She quit school when she got married. He was an primary school teacher. Close family ties.
Male	77	Alzheimer disease Early stage	Living in Eindhoven, in a regular older townhouse with a small garden. Few windows. Middle class. She is his second wife. He lived in Australia for a couple of years. He worked all around the world, but was educated for a hairdresser, and owned a salon.
Female	72	Alzheimer disease Early stage	Living in Eindhoven, in a newer elderly apartment with a small garden. With many windows. Higher class. She was a nurse. He worked for a big company in Eindhoven.
Male	84	Vascular dementia	Living in a village near Eindhoven, in a newer ground level elderly apartment with no garden, but a small balcony. Big windows. Middle class. Close family ties.
Male	87	Alzheimer disease Early stage	Living in a village near Eindhoven, in an elderly apartment in a new apartment building on the top floor with big windows with few lace curtains. Middle class. He served the army.
Male	71	Alzheimer disease Early stage	Living in a small village near Eindhoven, in a regular townhouse with a garden. One large window. Middle class. He build boats and was a draftsman.
Male	78	Alzheimer disease Middle stage	Living in a small village near Eindhoven, in a newer ground level elderly apartment with no garden, but a balcony. Windows with lace curtain. Middle class. He was an employee at Eindhoven University of Technology. She is a volunteer in a nearby elderly home.

All participants were supported by their informal caregiver: their spouse. Both the participant and the informal caregiver gave a written consent for taking part in the study.

3.3 Setting & Materials

Research took place in the own homes of the participants, which were all located in or near the city of Eindhoven, the Netherlands. All participating couples lived independently.

The Vitaallicht lamp is the product that is evaluated in the current study. It is an example of an intelligent lighting solution for the Innovate Dementia Project, although it was not specifically designed for people living with dementia. The Vitaallicht lamp contains 186 LEDs (62 2700K LEDs and 124 6500K LEDs, Type STW8Q14BE, Produced by Seoul Semiconductor) that together create high-intensity light. Measurements in a dark room with the Vitaallicht lamp show that in a distance of 1 meter on average 1268,00 lux is created on the vertical axis at eyelevel (Dubois, de Vries, & Roskam, 2013). This is the illuminance level of the lamp during daytime between 7:00/8:00 a.m. and 4:00/7:00 p.m., which depends on seasonal daylight changes. During this timeslot, the lamp creates bluish light, with a color temperature of approximately 4400 K. In the

earlier and later hours, the light intensity and color temperature decrease gradually (Figure 8). Exact light intensity and color temperature in these hours is not known.

In most households, the lamp was placed near the favorite armchair of the dementia patient in the living room, although one household chose the kitchen table as location where the most time was spent during the day. One of the participants received a charcoal colored luminaire, while all others got a white version of the Vitaallicht lamp. The lamp will be for sale for around €2500,-. Figure 9 shows the exact dimensions of the lamp.



Figure 8. Gradual colortemperature change of Vitaallicht lamp (retrieved from <http://www.vitaallicht.nl>)

3.4 Measurements

Two methods for capturing the usage and experiences of the participants with the Vitaallicht lamp were compared in this study: the newly developed probe game 'Aangenaam' and the iPad questionnaire. In addition, a sleep quality questionnaire was used to capture objective data on possible changes in sleeping routine. A final reflection with the participants was conducted in order to assess participants' experiences with the lamp and with participating in the study.

3.4.1 Probe game 'Aangenaam'

The probe game consisted a wooden box with question cards and three answer options (photo camera, audio recorder and notebook). The questions were divided over four categories, with each 36 questions. Three categories (daily activities, environment and personal) were provided in the baseline week and one category (Vitaallicht lamp) was added to the box for the actual evaluation weeks.

Some questions, which were regarded as important, were asked repeatedly in the game but with different answer option suggestions and later in the stack of cards. This way we hoped to see whether there were differences in answering between answer options and in time. All questions can be found in Appendix A, questions that were repeated have a *.

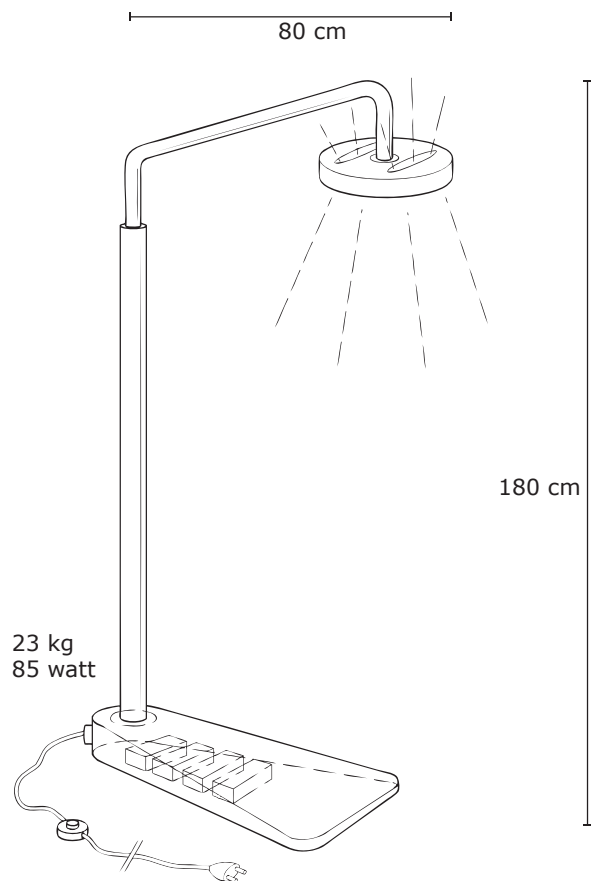


Figure 9. Dimensions of Vitaallicht lamp

The exact procedure of a game of 'Aangenaam' was described on an explanation sheet for the participants in Appendix B. 'Aangenaam' is preferably played every day, although once in two days was also acceptable. More information on the probe game and its development can be found in 2. Method Development.

3.4.2 Ipad

The iPads (Wi-Fi Cellular, 16GB, Black) were configured in a way that the number of apps in the home screen was limited to three, one being the direct link to the online questionnaire (Figure 10). A SIM card was placed in order to make a connection to mobile internet, although in two households an internet Wi-Fi connection was present and used as it was more stable. The questionnaire was hosted by the online survey application LimeSurvey (<http://www.limesurvey.org/nl>).

Another researcher in the Innovate Dementia Project prepared the questions, to represent the kind of questions that were used in earlier evaluation sessions. Two separate questionnaires were used, one (A) for the baseline week and one (B) for the two weeks of evaluation of the Vitaallicht lamp.

Questionnaire A contained one multiple choice question about the amount of time people spent outside that day. Furthermore seven statements were given. Participants were asked to indicate whether they agreed or disagreed with these statements using six response categories, labeled 'disagree', 'slightly disagree', 'neutral', 'slightly agree', 'agree', and 'no answer'. These statements covered the subjects of enough physical movement, a good night sleep, feelings of fitness and how one felt about participating in the study. All statements were either about the informal caregiver or the dementia patient (framed as 'I' and 'my partner'). The questionnaire ended with a box for remarks.

Questionnaire B had all of these items plus some extra: one multiple-choice question about the amount of time people spent near the Vitaallicht lamp that day, and three statements were added. These covered the subjects of the pleasantness to have the lamp in the home environment, whether more energetic feelings

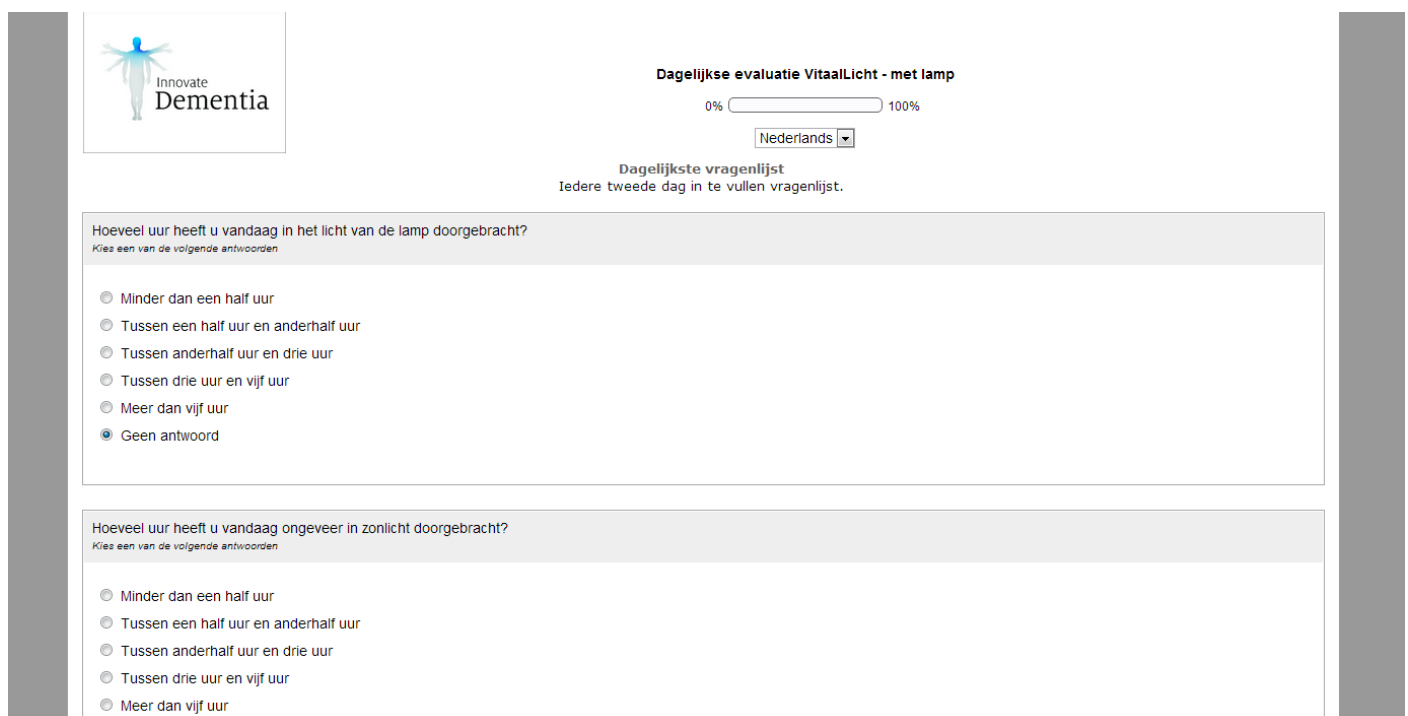


Figure 10. Printscreen of iPad questionnaire

could be attributed to the lamp and whether the participants mind having the lamp in their homes. The entire set-up of the questions can be found in Appendix C

The informal caregiver was the intended respondent of the questionnaire and was instructed to try to fill it out every day, although one in two days was also acceptable. The total amount of time to fill in the questionnaire was estimated to be no more than 10 minutes. The participants also received a paper version of the daily questionnaire, which they could use when they were not able to use the iPad.

3.4.3 Sleep quality questionnaire

The subjective sleep quality was measured by means of questions adopted from the Karolinska sleep diary (KSD; Akerstedt, Hume, Minors & Waterhouse, 1994) and the Pittsburg Sleep Quality Index (PSQI; Buysse, Reynolds, Monk, Berman & Kupfer, 1988). The questions included ratings of the quality of sleep, the amount of sleep, easiness of falling asleep and waking up, the calmness of sleep etc. These were rated on five-point scales that resembled the notions of 'disagree', 'slightly disagree', 'neutral', 'slightly agree', and 'agree'. The entire questionnaire can be found in Appendix D. The questions were asked by the researcher three times; after week 1, after week 2 (telephone interview) and after week 3. The sleep quality score was identified per week, by averaging the answers on the five-point scales ('disagree' = 1, 'slightly disagree' = 2, ... , 'agree' = 5).

3.4.4. Final reflection

The final reflection was a semi-structured interview with the intention to give insights in the experiences of the participants with the Vitaallicht lamp, as well as with the given method. The researcher took notes during the interview, with literal citations when they seemed remarkable by use of words or if the citation contained a valuable new insight. Also remarks during earlier talks, when relevant, are included in the final reflection data resulting in data that has the structure of field notes.

After some small talk, the discussion started with questions regarding the use of the lamp, for example, when the participants used the lamp, during which activities and for how long, and what they liked or disliked about the design and the light intensity. The participants were asked whether they felt differently when using the lamp, what other people who came by thought of the lamp and whether the participants would miss the Vitaallicht lamp in their home.

The second part of the interview consisted of questions regarding participating. It started with asking the reason why people decided to partake in the study, what their expectations were and whether these expectations were fulfilled. Furthermore, there were questions about the time intensity of participating, whether questions were unclear or too personal, and how they judge the approach during this study of the meetings in their own homes and the interview via telephone. The researcher inquired how participants rated their involvement with the study and whether they felt that their contribution was useful. Participants were asked whether they would want to participate in a future study with the same set-up as the current one.

All questions were both addressed to the informal caregiver and the dementia patient. Other subjects that were put forward by the participants were elaborated during the talk. In all talks with the participants, the researcher actively evades the words 'dementia' or 'Alzheimer disease' and uses 'memory problems' instead, as earlier research showed that deliberate inclusion of these terms may cause unnecessary harm or burden and should be used only when introduced by the participants (Bartlett & Martin, n.d., in Wilkinson, 2002).

3.5 Procedure

Participants and their informal caregivers first met one of the recruiters, in four of these meetings the researcher was present as well, who conducted a needs assessment which is not further used in this graduation project but was necessary for the GGzE administration and possible future studies in the Innovate Dementia Project. The contact details of the participants were handed to the researcher who called the participants or their informal caregivers to schedule a new meeting. During this meeting, which took place at the home of the participant, the evaluation method (either the iPad or the probe game) was introduced and the baseline week started (Number 1 in figure 11).

In both conditions, participants were asked to try to interact with the evaluation method on a daily basis for the entire three weeks. The participant and their informal caregiver signed a consent form (Appendix E) and received an information letter from the GGzE (Appendix F), an information leaflet from the Vitaallicht lamp (Appendix G) and detailed information about the study written by the researcher (Appendix H). During this meeting the participant and the researcher agreed on a new appointment for the placement of the Vitaallicht lamp, which was scheduled a week later. (Number 2 in figure 11).

When the Vitaallicht lamp was being placed, someone accompanied the researcher in carrying the luminaire. This was either the producer of the lamp or another researcher from the Innovate Dementia Project, who were instructed not to interfere with the work of the researcher. They were asked to use the Vitaallicht lamp just how they wanted to use it, with a suggestion to also turn on the light during the daily activities. The researcher asked questions about the experiences with the evaluation method and the sleep quality questionnaire was conducted. In this meeting, the researcher changed the direct link to questionnaire B in the iPad condition, or gave the participant an extra set of questions (Vitaallicht lamp category) in the probe game condition.

A week later (Number 3 in figure 11) the participants were called and the researcher repeated the questions

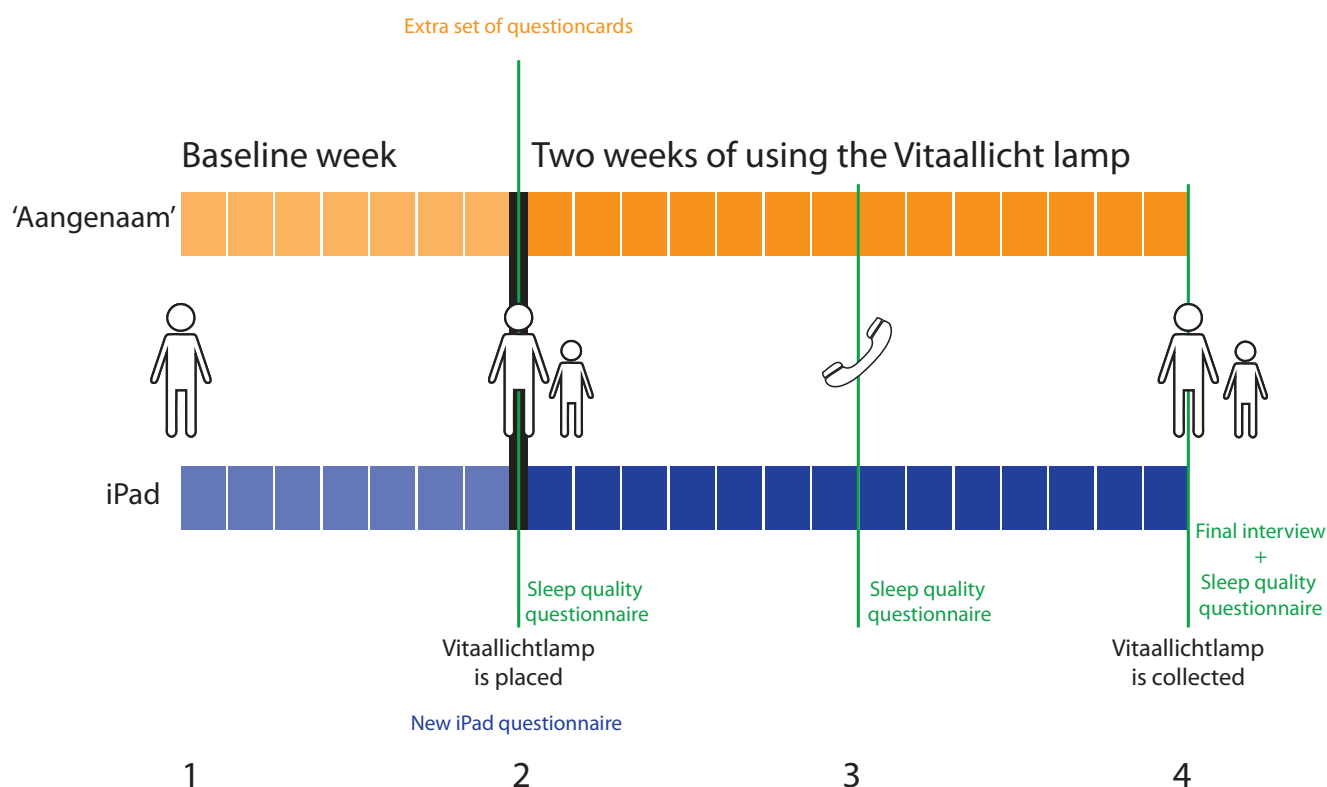


Figure 11. Graphical representation of procedure

asked in the previous meeting. An appointment for recollecting the Vitaallicht lamp was made during this telephone call.

During the last meeting with the participants, the Vitaallicht lamp was collected by the researcher and the accompanier (Number 4 in figure 11). Again, the same questions about the experiences and the sleep quality were asked. The final interview was conducted as well. Eventually the participants and their informal caregivers were thanked for their contribution to the project with some flowers and a thank you card.

3.6 Data Analysis

First the audio data was transcribed and with the notebook data from the probe game, digitized in an excel datasheet. The data was sorted by date, participant number and question number. A color was used for linking the used answer option to the answer. Photographs were developed and delivered digitally on a CD-ROM.

The data from the iPad was recoded: the amount of time spent ('less than a half an hour' = 1, 'between an half an hour and an hour and a half' = 2, ..., 'more than five hours' = 5, 'no answer' = 99) and the labels in the statement questions ('disagree' = 1, 'slightly disagree' = 2, ... , 'agree' = 5, and 'no answer' = 99). The input per question was averaged per week. Graphs were made of every question with the week numbers on the x-axis and all the participants' data was plotted in the same graph to identify possible trends over time.

To get a first insight in the generated data, a thematic overview of the answers was created. Data was printed and rewritten on post-it's to force the researcher to learn the data. Written and audio data from the probe game was included and recurring wording (coming from frequency counts, generated via <http://www.wordcounter.net/>) was used to create the themes, which were also based on the questions asked. As not all questions in the probe game were answered by all participants, this thematizing was relevant to get insights in the answers given. Answers that were overlapping between themes, were indications that themes were linked and a broader theme was created. This iterative process stopped when themes became largely mutually exclusive. Remarks from the iPad data and the data from the final reflection were separately analyzed in the same manner. Eventually themes were combined if applicable.

Next to the thematic analysis, a closer look was taken on how participants answered the questions in the written and audio data. The focus lay on choice of words, prosody, repetition of words and answers, extensiveness of answers and not answered questions. We hoped to find out the preferences in the method (questions, categories, answer option etc.) by studying the exact behavior of the participants as flexibility was provided. It was assumed that looking at the answers on the repeated questions was contributing to this as well.

Photographs are compared within subjects to identify whether there are differences in types of photos in relation to questions. Furthermore we tried to see whether the photos could serve for illustrative purposes in the extracted themes.

Eventually the data was divided into two results sections, with both their own discussion, in order to show the division of the study clearly. On the one hand we present the actual informative data (including insights in daily life of the participants, and vitality, light and the Vitaallichtlamp) and on the other hand we have the data regarding the actual research question of this thesis (including an in depth evaluation of the two methods based on how well they suit the dementia patients' abilities, how the participants are involved and motivated and what the benefits for the researcher is)

4 RESULTS, PART 1

4.1 General remarks about results and quote identification

We received a great variety of responses in both methods.

Probe game:

We received a total of 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 Vitaallicht category.

340 answers were written down, 65 answers were audio taped and 15 answers were given via the disposable camera. This creates 4580 written words, 52 minutes and 32 seconds audio data and 26 photographs. There was also an accidental audio recording lasting for 3 hours and gave insights in the television watching behavior of this participant. The latter was not included in the further analysis.

One of the informal caregivers decided to hand in the answers himself, three dementia patients worked individually with the probe game and four couples actually played the probe game together. One of these couples reported that they played the game with a couple of friends once.

Three participants used the notebook solely to answer the questions. One used the photo camera as well. Two participants used all answer options. One of the individual dementia patients did not answer any of the questions in the probe game. The individual informal caregiver made his own printed handout with typed answers as he felt more at ease working with a computer.

iPad:

We received 81 entries creating 927 answers to all questions. The remarks box was used for 65 times and a total of 1629 words was written down. Especially participant 2 and 8 were very elaborate in their remarks which explained the activities of the corresponding day.

All entries in the iPad questionnaire were made by the informal caregivers. Two couples reported to have discussed all questions and answers throughout the study. One informal caregiver indicated to have only minor discussions with the dementia patient when filling out the form. The last informal caregiver did not have any discussions with his wife about the questionnaire.

Two households managed to make all entries via the iPad, one household used the paper version solely and one household used the iPad, the paper version and their own laptop.

Throughout 4. Results, part 1 and 5. Results, part 2 we used a code to identify the supporting quotes. This code consists out of [fictive name of participant] – [IC / DP], [source]. For example:

This is an example quote of dementia patient Beatrice coming from the audio recorder (Beatrice-dp, audio)

This is an example quote of the informal caregiver Thomas coming from the iPad (Thomas-ic, iPad)

This is an example of an ambiguous quote where the informal caregiver Evelyn wrote the entry, but from the perspective of the dementia patient Edwin (Evelyn + Edwin , notebook).

For Alfred, who handed in the answers of the probe game in printed format, the choice is made to report it as the notebook answer option. The entries of the participants that used the printed version of the iPad questionnaire, are reported as coming from the iPad.

4.2 Introduction of results, part 1

As already explained in 3.6 Data Analysis we divided our data in themes and these themes were again divided over two main parts. The current part (part 1) is where we present the actual informative data. This includes the insights in daily life of the participants, how vital the participant judge themselves, and how they experience light and in particular the Vitaallicht lamp. Figure 12 highlights the main themes we discuss in this part. The subthemes are divided over these main themes.

Figure 12 serves as a graphical overview of what you can expect in the coming paragraphs.

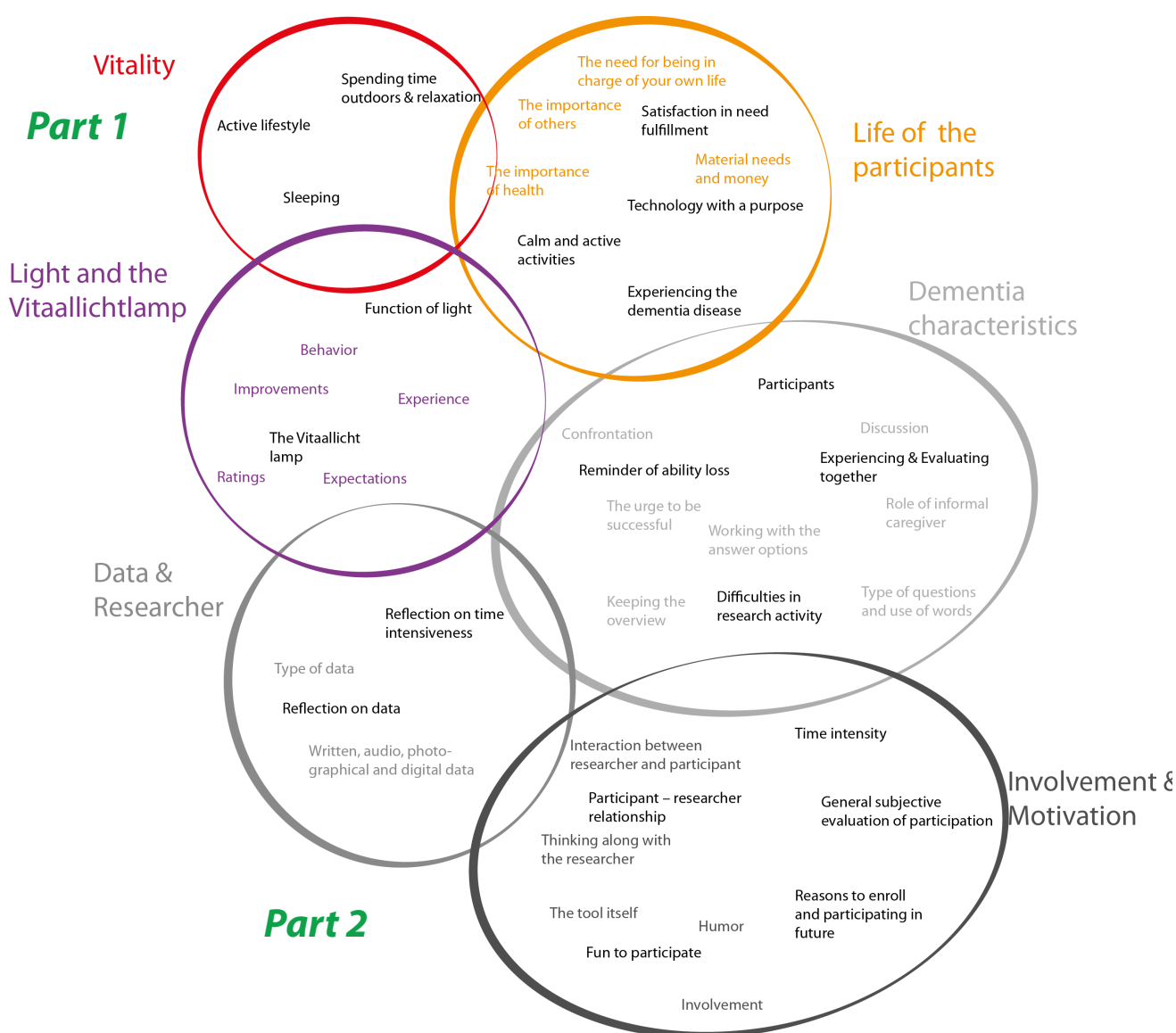


Figure 12. Graphical representation of results. Results for part 1 are in color, results for part 2 are in grayscale.

4.3 Life of the participants

To get an understanding of the everyday life of the participants, several aspects that people report doing, using or what they find important are identified. This is relevant as evaluative data since this can predict whether people would benefit from a new innovation. In addition, it can explain why they rate a certain product as useful or not. As we are placing a new product in the home environment of the participants, it is of interest to see if it fits their current lives.

4.3.1 Calm and active activities

There are two main categories in the activities that people choose to spend their free time: calm activities and more active activities. Most of the participants like to do things that are typically calm, such as reading, puzzling, watching television or small crafts. There is no big difference between men and women, or informal caregivers and dementia patients.

Lezen, puzzelen, handwerken en het huis schoonhouden (Frederick-dp, notebook)

Wordfeuden, handwerken, krant lezen. (Beatrice-dp, notebook)

At least one of the participants likes to engage in activities that are more physical as well, such as painting and doing carpentry. These activities resemble the profession he practiced in his early days.

Binnen doe ik graag schilderen, en boven knutselen, timmeren. (George-dp, audio)



Figure 13. Dementia patient solving puzzles (left) and painting as activity (right) (Geraldine + George, photo camera)

Almost every participant indicated that they like the active activity of going for a walk or exercise. Furthermore, they spent a lot of time at different types of day care centers. These activities are elaborated in the next themes.

Some activities that people enjoyed doing in the early days are not possible anymore for everyone. The reasons for this are physical deterioration, causing troubles with active activities and mental deterioration causing troubles with mainly the calmer activities. Watching television or reading a book, can be difficult

as storylines are hard to follow. One of the participants talked about the inability to conduct his hobby, stained glass processing, because he was not able to perform the step-by-step procedure anymore.

Vroeger speelde ik [Harold] graag 'n spelletje. En sporten, zoals voetballen vond ik leuk. Maar nu kan ik dit niet meer. (Harriet + Harold, notebook)

Ik maakte altijd glas-in-lood kunstwerken, maar wat ik vroeger in een paar weken deed, doe ik nu anderhalf jaar over. Dan is de lol er wel vanaf. (Simon-dp, final reflection(iPad))

It seems that the participants know how to spend their free time in their own homes. Most people engage in calmer activities, which are rather similar across participants. The active hobbies appear to be more unique, except for the activity of going out for a walk. Even though some activities cause troubles, people are keen to hold on to their hobbies as long as possible. When people are not able to perform an activity anymore, this results in distress. This might be a reason to engage more in the calmer or easier activities.

4.3.2 Technology with a purpose

Since new innovations might have technological components, it is of interest how people currently make use of technology in their home environment.

On the question what people find essential technological devices in their houses, participants include both devices for housekeeping and for entertainment. As watching television is one of the important daily activities, this device is indispensable for the home environment.

Wasmachine, droger, koelkast en vriezer, je hebt ook veel plezier aan televisie en radio (Frederick-dp, notebook)

Wasmachine, wasdroger, koffie-apparaat, TV, vaatwasser enz. Ja, is altijd [onmisbaar] geweest. (Harriet + Harold , notebook)



Figure 14. Three photos from technological devices in the home environment (Beatrice + Bernard, photo camera)

Besides these essential devices, technology does not seem to be an important aspect of the lives of the participants. Nevertheless, some participants do show a higher interest than the others. These informal caregivers, both male and female.

[over interesse in nieuwe dingen leren] Ja in [van] alles, Kwantum mechanica [...]. Nano techniek (Alfred-ic, notebook)

Het huishouden heeft een grote Mac maar ook een windowslaptop, een ereader en mevrouw gaf ook aan dat ze aan het twijfelen was om een ipad aan te schaffen. (Vivian - ic, final reflection(iPad))

The lack of interest in technology is resulting in accepting the fact that working with technological devices is troublesome, which is reflected in the troubles the dementia patients experience with the telephone. Often help of the informal caregiver is needed.

Ik [Harold] telefoneer nooit. Vind ik niet prettig omdat ik er niet meer zo goed mee kan omgaan. Mijn vrouw helpt mij heel vaak. (Harriet + Harold, notebook)

[over telefoneren] Mijn handen weten niet hoe ik dat moet doen. Dit laat ik aan [Flora] over (Frederick-dp, notebook)

Although there are some differences among the participants, the general attitude towards technology seems a bit reluctant. Technological devices that are used, are already part of the home environment for many years. These devices have a clear purpose: housekeeping and entertainment. None of the participants mention lighting, which might be an indication that people do not identify lighting as a technological device or that light is taken for granted as an integral part of the home environment. The dementia patients themselves seem to be even more reluctant towards technology, especially as the interface causes them troubles in use. The informal caregiver is the main user.

4.3.3 Satisfaction in need fulfillment

Satisfaction refers to what people identify as important needs in their lives and how they judge the fulfillment of these needs.

4.3.3.1 Material needs and money

The participants were asked whether they missed something in their homes. This was to uncover the unfulfilled material needs of the participants. If these were present, the information might serve as inspiration for new products. However, the participants report that they are satisfied with their home environment. People have no specific wishes for improvement.

[over wat te veranderen in omgeving] Niets, we zijn heel tevreden (Frederick - dp, notebook)

[over extra geld hebben] Niet voor luxe, ik ben snel tevreden met wat ik heb. (Beatrice - dp, notebook)

Since the material needs seem to be fulfilled, people are keen in keeping this need fulfilled. They do not do this by buying new products all the time, but instead they are frugal with their current possession. As the current possessions are satisfactory and important to the participants, they do not feel the urge to change these. People in either lower class, middle class or higher class are keen on their money. It seems to be more related to their age category instead of to their budgets.

De foto's van onze ouders en onze kinderen (eigenlijk zijn we overal zuinig op) (Frederick-dp, notebook)

Wij wonen nu 45 jaar in dit huis. Het is goedkoop wonen daarmee gemakkelijk leven (Alfred-ic, notebook)

Meneer geeft aan dat ze van de generatie van zuinig leven zijn. (Dick – ic , final reflection(Aangenaam))

This frugality, probably in combination with the lack of interest in technology, is also reflected in their buying behavior of new products. None of the participants report to be early adopters when it comes to new inventions. Again money is an issue, as one of the informal caregivers states that cheap inventions might be considered nevertheless.

Ik [Harold] kijk liever de kat uit de boom en koop daarna pas 'n nieuw product. (Harriet + Harold, notebook)
Ik wacht liever even af totdat ik zeker weet dat de kinderziekten eruit zijn, behalve als iets goedkoop is dan is er nog geen man overboord (Bernard-ic, notebook)

The participants are satisfied with what they have and do not claim to need anything in their environment. They are not keen on spending money, especially not on products that are not proven to improve their lives. The possessions they currently have, are satisfactory enough.

4.3.3.2 The importance of health

If people would have had extra money, they would not spend this to improve anything in their home environment or to buy luxurious items. Luxury is not a need that need fulfillment. Instead, their health situation seems to be important. Remarkably is the fact that the dementia disease is not part of this health need to some of the patients, as they report that the need is fulfilled.

[Over wat belangrijk is in het leven] Dat ik nog gezond ben,[...] Dat zijn belangrijke dingen voor mij. Ja. (George - dp, notebook)

[Over extra geld hebben] Als ik ernstig ziek was en met geld beter zou worden. Omdat mijn gezondheid boven alles gaat. (Beatrice - dp, notebook)

In addition, only one informal caregiver seems to suffer from bad health conditions as visiting the hospital is a large part of his life. For all other participants their health need appears to be fulfilled, as they do not specifically mention anything about it.

"Even naar de huisarts geweest daar de informatie opgehaald van de foto die vrijdag was gemaakt van mijn longen en naar het [naam ziekenhuis] gebeld en 'n afspraak gemaakt en kon pas 21 juni terecht dus afwachten!" (Thomas - ic,ipad)

Their health is important to the participants. Both time and money is well spent when it contributes to their general health. Most participants judge themselves as healthy, both informal caregivers and dementia patients.

4.3.3.3 The importance of others

Participants spent much time with others and report about these others a lot. This indicates the relevance of other people in the lives of the participants, which is a social need. The most important people are close family such as children and grandchildren, but also friends and siblings. They are an important aspect of activities in daily life as people visit others on a regular basis. Participants report being thankful for having them. This is indifferent for men and women, or informal caregivers and dementia patients.

Ik[Harold] word blij van alle goedheid, die ik in mijn omgeving ondervind. Ook van leuke reizen die ik in mijn leven gemaakt heb met dierbaren en vrienden. (Harriet + Harold, notebook)

Mijn man en mijn kinderen, dus mijn gezin [zijn onmisbaar], omdat ik van hun liefde krijg en ik hun liefde kan geven en dat maakt mijn leven compleet. (Beatrice-dp, audio)

There are individual differences whether participants say it is important what others think about them or not. It is not apparent if this is more important for the dementia patients or the informal caregivers. Therefore, we cannot say whether the dementia patients are afraid of being judged for their inabilities. Perhaps women are more sensitive to the opinions of others.

Ik heb wel een idee wat anderen van me vinden [Bernard; wat dan?] Ze vinden me wel aardig, vind ik dat belangrijk? Ja dat vind ik heel erg belangrijk. (Beatrice-dp, audio)

"Ik heb geen flauw idee wat anderen van mij vinden en ik vind het ook helemaal niet zo belangrijk wat dat ze van me vinden. Ik hoop niet dat ze, ja., niet leuke dingen van me vinden. Ik zou het anders niet weten. (George-dp, audio)

[wat anderen van me vinden] Waarschijnlijk een kankeraar, heb daar totaal geen last van. (Alfred - ic, notebook)

Close family and friends are important to all participants. They play a huge part in everyday life. It might be that people judge the opinion of family and friends to be more important, but the importance of the opinions of undefined others is judge differently among the participants. This shows that people are concentrating on their own lives and ties with the people they know for a longer period of time fulfill their social needs.

4.3.3.4 Dissatisfaction in the need for being in charge of your own life

Next to all the needs that are reported to be fulfilled to a satisfactory level, the most dissatisfaction is connected to things that changed over the years. Most changes are direct or indirect related to the dementia disease. The direct changes are elaborated in 4.1.5 Experiencing the dementia disease, and are more from the patient's perspective. The indirect changes are reported by the informal caregivers, who experience changes in their lives because of the change of their spouse. As their spouse is not able to take initiatives in activities or the housekeeping, the informal caregiver needs to fill this gap. The changes result in a lack of fulfillment in the need for being in charge of your own life.

Geen animo meer om iets te doen, ook geen initiatieven nemen (Harriet + Harold, notebook)

In het huishouden moet ik alles doen. Koken gaat, de rest met tegenzin (Alfred – ic, notebook)

Also informal caregivers who are not explicitly mention these changes in their lives, do claim the importance of being in charge of your own life. This is reflected in the demand of having enough space in their homes to be able to perform the activities one prefers.

Ja ik vind een ruim huis wel belangrijk, zo kan iedereen zijn hobby uitoefenen (Geraldine-ic, notebook)

Ik vind de grootte van een huis belangrijk omdat iedereen dan een eigen kamer heeft om zich terug te trekken. (Bernard-ic, notebook)

This need is especially important for the informal caregiver, who feels to be losing this charge of the own life. The dementia patients might experience this as well, but they are not specifically mentioning it.

People do not report to miss anything in their daily life environment. As long as both health needs and the social needs are fulfilled, participants seem to be satisfied. Money is saved, perhaps for worse times when health conditions become a bigger issue. Especially if these health conditions are substantially affecting their everyday life, and the lives of the informal caregiver in particular, people might want to take measures.

4.3.4 Experiencing the dementia disease

As the dementia disease is prominent in the lives of the participants, it is of interest how they actually experience this disease. In 4.3.3.2 The importance of health, we already saw that the dementia patients themselves do not explicitly judge their health conditions as poor. In everyday life however, they do report

difficulties of which the most common one is the forgetting. What appears to be simple to remember, such as the day, is easily forgotten by the dementia patient. Participants have different ways to cope with that, which are not always successful as these coping strategies are sometimes forgotten too. The informal caregiver has an invaluable role in helping the dementia patient.

Ik vergeet de dag, afspraken en waar ik dingen heb neergelegd. Ja, dat vind ik erg vervelend. Heeft u hier een oplossing voor? Ja, mijn man helpt mij hiermee, bovendien hebben we een klok waar de tijd, dag en maand op staat. (Beatrice-dp, audio)

*"Typische dingen die ik vergeet. ... Dat kan ik nou niet zo in ene bedenken, moet jij mij helpen. Jou valt dat beter op dan als ik zelf wat vergeet. " **Je vraagt elke dag; Wat voor dag is het.** "Jaa, ja.. Dan vergeet ik wat voor dag het is." **en wat je deze dag moet doen.** "En wat ik die dag moet doen, vergeet ik ook. [...]" **Ja, jij staat op en het eerste wat uit jouw mond komt is.. "Wat voor dag is het vandaag?"** Wat voor dag is het vandaag en [George en Geraldine tegelijkertijd:] wat gaan we doen? "Ja, klopt" **Vind je dat vervelend?** "Nee" **Heeft u hier een oplossing voor?** "Nee, ik zou niet weten hoe dat moest doen." **Het zou heel simpel kunnen zijn door op te staan, naar beneden te gaan, dan kun je het op het memobord zien.** "Jaa.." **Dan zou je het niet hoeven te vragen.** "Dat is wel een oplossing ja" **Maar dat komt niet in jou op.** "Nee, daar heb ik niet aan gedacht nee. Dat ik helemaal niet kijk op dat memobord en wat erop staat. Dan weet ik wel op tijd wat we gaan doen." (George-dp & Geraldine - ic, audio)*

In total six participants mention that they visit the day care center at least once a week. None of the participants elaborates on what they exactly do at the center, although it is in most cases very tiresome. Different naming is used, which gives an idea on what type of activities take place

Na de akkers [= dagbesteding] te zijn geweest, ben ik zo weer vertrokken [=in slaap vallen] (Frederick-dp, notebook)

Vanmorgen voelde ik[Edwin] opgeladen. Ik had wat problemen met m'n vrouw maar op de boerderij [= dagbesteding] was dat weer over. (Evelyn + Edwin, notebook)

The experiences with the dementia disease are different when the disease is further progressed. The informal caregivers of the persons in the middle to later stages of dementia indicate how difficult it sometimes is for them. Their partner is changed in person (more rebellious, emotionally flattened, losing sense of reality) and drastically in abilities (no ability for conversation, memory loss).

Ja, ik ben veranderd door mijn ziekte van Alzheimer. Daardoor ben ik soms bozer en opstandiger geworden. Maar ook emotioneel afgevlakt. (Harriet + Harold, notebook)

Mijn vrouw is ziek vanaf donderdag, kan dan niet naar de dagopvang [wat zij ziet als werk] en dat is nou net niet de bedoeling voor de partner. [Nu krijg ik geen rust] (Thomas - ic, ipad)

Vroeger na het eten de dag doornemen, maar dat gaat nu niet meer. (Alfred-ic, notebook)

Ik zelf heb wel eens moeite [met dingen onthouden] Ik kan [m'n] geheugen locatie soms niet vinden. Maar [Agnes] kan helaas niets meer vinden (Alfred-ic, notebook)

The people with dementia in the earlier stages are especially keen on showing themselves as a person and not, solely, as a patient. One participant states that she is not ashamed of her illness, but she wants to be seen as more than that. This seems to be more apparent in the female patients, than in the male patients. This might be because men seem to be less caring about other people's opinion as discussed in 4.5.2.1 The importance of others.

Sommige mensen hebben moeite met toegeven van de ziekte. Zelf heb ik niet echt schaamte, maar ik ben ook niet op zoek naar een plakkertje. (Danielle -dp, notebook)

Ik ben uh zorgzaam, vriendelijk in omgang met mensen, sta niet voorop maar wil wel mijn zegje doen. (Beatrice-dp, audio)

There are large differences in experiencing the dementia disease, which is mainly connected to the progression of the disease. People in the early stage of the disease are looking for coping strategies for everyday problems. These are the people who find it important that they are seen as more than a patient. The informal caregivers of people in the middle to later stage, need to take their time and rest to learn to live with their changed partner.

Participants have different needs and problems. One has troubles with physical activities, which are tiresome, and another reports to be especially bothered with memory deficits. We have to take into account that we are dealing with individuals with their own needs, abilities and interests.

A returning aspect in the life of the participants, both informal caregiver and dementia patient, can be identified. People are keen on holding on to hobbies, objects and activities one is familiar with. As everyday life changes slowly, because of the dementia disease, these familiar things help them to keep in control of their lives. Feelings of distress occur when these familiar things get lost. New things in their lives, which include products but also hobbies or even people, are scary. Especially when these things cost money, the participants will be reluctant towards it. As soon as this new item has a clear function that helps them in their important needs (health, social, and control of life) they might become interested but the informal caregiver will probably be the decision maker.

4.4 Vitality

Next to getting an insight in the daily life of the participants, there is a specific interest in the vitality of the people involved in this study. Since the evaluated prototype in the current study (Vitaallicht lamp) aims at improving this vitality, we need to understand the actual vitality of the participants and how they judge it themselves. Three main aspects are considered: the active lifestyle of the participants, how much time they spent outdoors and what their sleep quality is. Especially the latter two might give indications whether the Vitaallicht lamp can support the user.

4.4.1 Active lifestyle

One key aspect of being vital is that one has enough physical exercise. Participants have different opinions on what is included in this physical exercise. There is no clear division among men and women or informal caregivers and patients. Some people judge their everyday activities, such as housekeeping but also active hobbies, as part of the physical exercise. This indicates that these people do not feel the urge to find other activities (such as sports) to keep in shape. It can also be that they already find these activities tiresome, so they find themselves unfit for 'real sports'.

Zij vindt dat stofzuigen al genoeg beweging oplevert, terwijl ik meer denk aan wandelingen maken. (Raymond-ic, final reflection(iPad))

*"Sporten doe ik helemaal niks mee, ik doe wel graag wandelen, een eind lopen en ik doe nog veel werken. Aan mijn boot werken, maar sporten doe ik niet [...] "[Dat zijn] bezigheden ja," **Hoe hou je dan je conditie?** "Door te werken, dan maak ik genoeg lichamelijk bewegingen, timmeren en" (Geraldine-ic and George-dp, audio)*

Ik vind sport niet zo belangrijk en ik hou me toch wel in conditie door heel de dag bezig te zijn. Ik zie de hele dag door praktisch geen stoel. [in another comment =]Ook poetsen, traplopen en wandelen zijn voor mij vermoeiend. Omdat dit voor mij veel energie kost. (Beatrice-dp, notebook)

Others are more consciously practicing physical exercise by means of sports so they might be more willing to improve (or keep) their physical abilities. This physical exercise takes a more prominent place in their lives.

Nou ik vind het heel belangrijk om mijn lichaam in conditie te houden, ik vind sowieso bewegen altijd al fijn. Ik volleybal graag, we wandelen heel veel. Ik zit maar heel weinig, ik ben eigenlijk altijd wel bezig met 't een of 't ander. Dus ik vind bewegen heel belangrijk (Geraldine-ic, audio)

's morgens gymoefeningen om in conditie te blijven (Frederick-dp, notebook)

There is no clear difference in the people who are doing sports and those who do not, based on physical attributes (such as body weight or physical ailments).

Several participants mention going for a walk as a physical exercise activity. People actually like it, mostly because of the surroundings they enjoy.

Wij vinden het heel plezierig om te genieten van de prachtige bomen (Frederick-dp, notebook)

Yet some participants state that it is a tiresome activity or that the walks should be shorter. However, this will not stop them from engaging in a walk. Walking seems to be an active activity that is possible for a long period of time, even when other activities such as cycling are too hard. Walking-aids can prolong this period of time even further.

Lange wandelingen [kunnen niet meer]. Omdat ik geen goede conditie meer heb. (Harriet + Harold, notebook)
[Ik doe niet veel aan sport], alleen wandelen, fietsen gaat niet meer. [Agnes] beheerst dat niet meer (Alfred-ic, notebook)

Onze zoon kwam in een rollator brengen zo maar [...] dat was 'n verrassing. Nu komt [Tamera] meer buiten en loopt meer. Ze voelt zich beter dan eerst,[...] (Thomas - ic, ipad)

A majority of the participants seem to judge their amount of exercises as enough, although others actively search for more exercise based on their bigger need for physical activities. What we learn from the iPad data is that the amount of physical exercise seems to be judged as rather similar between informal caregiver and dementia patient. This can be an indication that partners are engaging in physical exercise together. What the lower ratings in the amount of physical exercise mean is not easy to define as we already notice the differences in what people include as physical exercise.

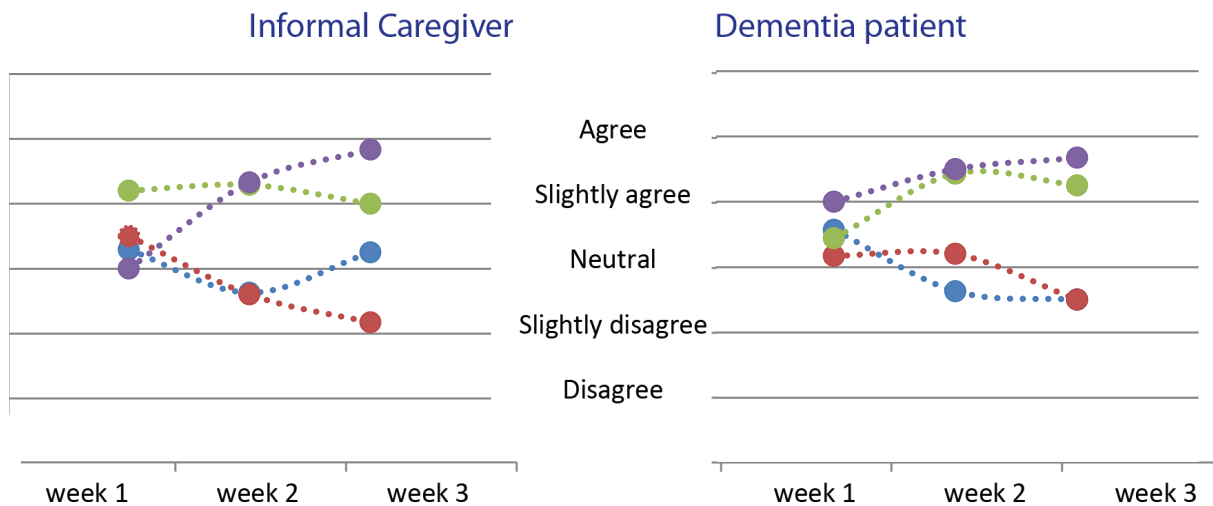


Figure 15. Ratings of physical activities of the informal caregiver (left) and dementia patient (right)

There are large individual differences in engaging in physical exercises. The results do not give insights in what exactly influences this need for physical exercise. This makes it hard to identify how one judges their amount of physical exercise. Participants especially enjoy the active activity of going for a walk, which might be because it is a pleasant experience that can be shared with the significant other.

4.4.2 Spending time outdoors & relaxation

Another aspect of a vital lifestyle is the amount that people spend outdoors, where they perceive sunlight, fresh air and sometimes natural surroundings. This is expected to contribute to the feelings of fitness. The amount of time spent outdoor, and especially the amount of light the participant receive, could give an indication what the Vitaallicht lamp can contribute to the household.

Participants in the iPad condition report to spent on average between 30 minutes and 90 minutes outdoors every day (30-90 minutes is coded as 2, Mean = 1.99, SD = 0.47) It is not clear how they judge this amount. The rest of the participants in general do not mention that they want to increase the time they spend outdoors, which might be an indication that they are fine with the current amount.

Participants enjoy being outdoors, especially for the scenery. It is an important aspect of their lives and they do judge it as part of their vital lifestyle. For some it is even a way to come to rest or escape the hectic of daily life.

Liefst buiten, frisse lucht, natuurmens (Danielle-dp, notebook)

Buiten werk ik het liefste met de natuur (Edwin-dp, notebook)

Ik maak me niet zo vaak druk, [anders][...] ik ga naar buiten, soms fietsen. (Bernard-ic, notebook)

Spending time outside is regarded as an important aspect of people lives and it linked to one of the active activities they like: going for a walk. People are not actively seeking to increase the time they spend outside. There is no big difference in the people that live in the city compared to the people that live in smaller villages. If for some reason these people were not able to go outside anymore, the tendency is to think that they would miss it much. It appears that the natural surrounding is most important in the experience of going outside. This indicates that people might not miss the outside light which may be because they do not rate it as important or because they take it for granted.

4.4.3 Sleeping

Perhaps the most relevant part of this vitality paragraph, is how the dementia patients sleep and how they judge their sleep. If the sleep quality is poor, a solution with light (the Vitaallicht lamp) can be beneficial.

Looking at the sleep quality measures, on average the dementia patients' sleep is scored a 3.48 (SD = 0.59) on a scale from 1 to 5, in the baseline week (N=11). This can be considered as not problematic. Three dementia patients have a remarkably lower score. The people with lower scores either are in the middle stage of dementia or seem to be unfit due to other conditions (heart problems). They report to have restless sleep, with nights full of dreams, movement and snoring. One informal caregiver explicitly mentions a night (not in the baseline week) where her partner was up all night and made a fuss about the loiterers outside who were goofing around with the trashcans. However, this was totally imaginary but it kept the dementia patient awake all night. The amount of sleep per night varies much for the people with sleep problems. We do not have sleep quality measures of the participant who withdrew after the first week, but the informal caregiver did mention that the dementia patient wanders during the night.

Nou [slaapproblemen] heb ik behoorlijk, [ik slaap heel licht en waakzaam]. Mijn vrouw wil 's nachts nog al dwalen (Alfred – ic, notebook)

These results indicate that 4 out of 12 dementia patients in our sample have a poor sleep quality. This number does not include the patients who have (sleep) medication. One patient has Mirtazapine (which is sleep medication) and another patient has tranquilizers for his autism spectrum disorder. Both have a high sleep quality score but this might be attributed to the medication. For all dementia patients, the average amount of sleep per night in the baseline week is seven to ten hours (Mean = 8.41, SD = 1.16), which is judged as enough to a bit too much. Some patients report to have a set time for a daytime nap, others indicate to fall irregularly asleep during the day and only two patients do not sleep during the day. This daytime sleeping is mainly because the people with dementia mention that they get tired easily, especially after being at the adult day care center during the day. Some also mention that it is tiresome when people visit them. It is not only the activity itself, but also the excitement on forehand that costs energy.

Op dit moment ben ik wel vrolijk, maar ook een beetje moe i.v.m. het bezoek dat ik vanmorgen heb gehad (Beatrice – dp, notebook)

Door bezoek van oudste dochter met drie drukke kinderen [is Ruth] op voorhand al onrustiger. Bezoek is altijd wat spannend (Raymond – ic, ipad)

There seems to be a difference between the two measures of sleep quality. In the iPad questionnaire two of the poor quality sleepers, have on average a maximum and an almost maximum score on their judgment of sleep quality (5 out of 5 and 4.7 out of 5). On the other hand, someone with a sleep quality score of 3 judged the sleep a lot lower (2.7 out of 5). This might be because the sleep quality score is based on several factors, while the sleep question in the iPad questionnaire was just asking how well someone judges their sleep the preceding night.

The memory deficits of the dementia disease can affect the judgment of the sleep quality. This is shown by one of the patients who receives sleep medication every evening, but does not remember this.

Wat krijg je om 11 uur 's avonds? "Slaap" Wat krijg je.. wat moet je pakken 's avonds om 11 uur? "Oh een pilleke" En waarom slaap je dan snel? "Door dat pilleke denk ik, oh dat wist ik niet meer dat dat daarvoor was." (Geraldine – ic + George, audio)

Two informal caregivers mention that they have sleeping problems, of which one has a poor sleep quality due to the wandering of his partner. The other informal caregiver does not give a reason for her troubles with sleeping. A way to cope with the sleeping problems is to think pleasant thoughts, for example about holiday plans. This was also a coping strategy of an informal caregiver with former sleeping problems.

Ja ik kan me voorstellen [hoe het is om slaapproblemen te hebben] want ik slaap zelf slecht. Ik probeer me te ontspannen en aan leuke dingen te denken. (Geraldine– ic, notebook)

Ja, ik heb ook wel eens slaapproblemen gehad. Ik vond dat zeer vervelend en vermoeiend. Ik begon dan aan vakantieplannen te denken, of inrichting van de tuin, kortom aan prettige dingen (Bernard – ic, notebook)

Two informal caregivers explicitly show that they take a daytime nap as well. This napping takes place on the couch, which might be an indication that it happens sporadically and it does not take long.



Figure 16. Two informal caregiver napping on the couch (Geraldine, photo camera & Bernard, photo camera)

When the dementia disease progresses, the chances of getting sleeping problems will grow. Other ailments such as heart problems, can affect the quality of sleep too. Since we are dealing with people in an older age group, these ailments might be more apparent. Besides, the aging itself can cause tiredness so it is not merely a symptom of the dementia disease. Sleep medication can solve the problems, although other solutions might be welcomed as well. Current non-medical solutions are daytime naps (for complementing the nighttime sleep) and thinking pleasant thoughts (for falling back asleep during the nights). There might be a difference in the ratings of the sleep quality, which may be caused by the memory deficits of the dementia patient.

There are large differences between the participants regarding their vitality. Most indicate to have enough physical exercise, spend much time outdoors and do not judge their sleeping quality as poor. The question on how people judge their general fitness in the sleep quality questionnaire is scored with an average of 3 (SD = 0.89) out of 5 which is a neutral rating in the baseline week. For three out of four participants of the iPad questionnaire the judgment of feeling fit are quite similar in the averages of the iPad questionnaire and the question in the sleep quality questionnaire (4 and 4, 2.10 and 2, 3.50 and 4). This is an indication that the ratings about fitness in the sleep quality questionnaire can represent the feelings of fitness of the preceding week.

Nevertheless, many people report to be tired during the day and some have sleep medication to have a good night sleep. In addition, four dementia patients have a poor sleep quality as well. A couple of informal caregivers seem to have sleeping problems too, or need at least some daytime napping. This all shows that in the area of sleeping, improvements in these households might be possible. One should keep in mind that the subjective ratings might not fully resemble the objective ratings. This appears to be true in at least the sleep quality, but might also be apparent in the judgments of enough physical exercise and spending time outdoors.

4.5 Light & Vitaallicht

The actual evaluation of the Vitaallicht lamp can be found in this paragraph. To judge the usages and experiences of the Vitaallicht lamp, we elaborate on how the participants experience lights and lamps currently in their houses. It is expected that this influences how people made their judgments over the Vitaallicht lamp.

4.5.1 Function of light

In general, the participants judge light to be most important for a purely functional purpose: light is used to brighten a dark room. This helps them to practice their hobbies throughout the day, especially the hobbies that need accuracy such as reading and crafts.

Alle lampen gaan in een keer aan als het donker wordt (Alfred-ic, notebook)

[Lampen zijn nodig] [...] voor handwerken + lezen (Danielle-dp, notebook)

This shows that the participants are not used to turn on a light during the day, because then light cannot fulfill the purpose of brightening a dark room. People do not experience their houses to be dark during the day. The fact that people do not use lighting during the day can also be explained because of the frugal living of the participants, which we encountered in 4.3.3.1 Material needs and money. Turning on a light during the day can be experienced as needless.

Meneer geeft aan dat ze van de generatie van zuinig leven zijn, dan is het onnodig om een lamp aan te zetten gedurende de dag. (Dick – ic , final reflection(Aangenaam))

Next to the functional purpose, a vast majority of the people agree with the fact that light is important for the atmosphere and coziness of a room as well. What the exact characteristics of cozy light are, is not defined.

Ja, de lampen zijn er natuurlijk om licht te verspreiden en voor de sfeer. Dit laatste is ook belangrijk. (Harriet + Harold, notebook)

Photographs on the next page show what the currently used lamps in the houses of Evelyn & Edwin and Geraldine & George look like (Figure 17). These might indicate the differences in cozy lamps and functional lamps too. The cozy lamps are placed in corners and seem to be placed in a lower spot. Functional lamps are placed near chairs and tables and the looks of those are statelier.



Figure 17. Currently used lamps in the houses of two participants

Two persons are mentioning other functions of light. One is an informal caregiver who mentions that light is positively influencing her mood. More light makes her more active. One of the dementia patients has a similar comment about his early days when he was a teacher and he noticed that light helped his students to pay attention.

Licht is voor mij belangrijk, uhhhh... mijne... humeur wordt daar beter van. Ik vind dat wel gezellig. Licht geeft mij een goed gevoel. Dan ben ik veel actiever dan als het minder licht is (Geraldine-ic, audio)

Meneer zegt dat hij lampen en licht heel belangrijk vindt en dat dat komt vanuit vroeger toen hij voor de klas stond. Daar vond hij het ook belangrijk dat zijn leerlingen alles goed konden zien en geconcentreerd konden werken. (Victor - dp, final reflection(iPad))

In general, light means two things for the participants: the function to brighten a room and the ability to increase the coziness of a room. Different types of lamps are used to fulfill these meanings. The lamps are only used during the evenings, which might be an indication that the brightening function comes first or that the brightening function comes along with the ability to increase the coziness. Either way, people are not used to turn on a light during the day, which is a main issue when a product (the Vitaallicht lamp) is intended to be turned on during the day.

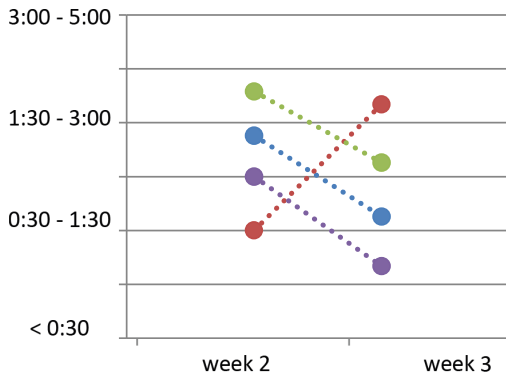


Figure 18. Amount of time spent near the Vitaallicht lamp

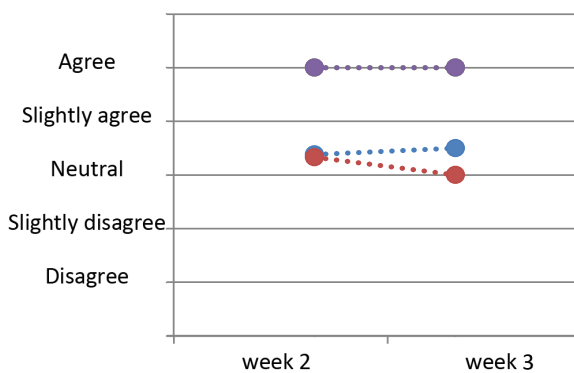


Figure 19. Using the lamp during daytime hours is appealing

4.5.2 Vitaallicht

In this section, we discuss the evaluation of the Vitaallicht lamp. Several aspects are discussed: the behavior of the participants during usage, the experiences during usage, the expectation fulfillment, rating of design and lighting, and ideas for improvement.

4.5.2.1 Behavior during usage

Participants in the iPad condition report to spend at least 90 minutes in proximity of the lamp a day during the first week of testing (30-90 minutes is coded as 2, Mean = 2.67, SD = 0.54). The amount of time spending next to the lamp is increasing in the next week for one household, and decreasing for the other three (Mean = 2.40, SD = 0.65). This can be seen in figure 18. Nobody spends more than 5 hours near the lamp a day, but some manage to be in the proximity of the lamp for more than 3 hours a couple of times during the test period. Two participants of the entire group explicitly mention that they felt spending much time near the lamp.

Meneer heeft er veel onder gezeten en ook mevrouw heeft onder de lamp zitten lezen "Toen was jij op de boerderij!" (Clara + Charles, final reflection(Aangenaam))

The time of using the lamp was different among participants. Some used it especially in the evening, others in the morning or during the entire day. This variety in preferences is also shown in the ratings of how appealing people (in the iPad condition) judge the use of the light during the day (Figure 19). Two people judge it as very appealing (5 out of 5), while the others were less enthusiastic (average of 3.3 out of 5). This is not changing over the two weeks, which might be an indication that it has nothing to do with acclimatization but only individual differences.

The good/warm weather outside is both a reason to use the lamp during the day as well as during the evening. This might be because some people judge it to be too warm to sit outside during the day and curtains might be closed to keep it cool inside. Therefore, light is needed to brighten up the dark room during daytime. On the other hand, people like to spend time outside during the day when the weather is good. They will probably only use the Vitaallicht lamp during the evenings.

Tijdens het onderzoek zijn de mensen veel buiten geweest, veel weg geweest en de lamp heeft voornamelijk aangestaan tijdens het tv kijken 's avonds. (Shannon + Simon, final reflection(iPad))

Het licht is juist overdag prettig, en 's avonds hebben ze 'm niet vaak aangehad in verband met het lekkere weer (Vivian + Victor, final reflection(iPad))

The exact functioning that people attribute to the lamp might influence this time of using the lamp. Most participants see the light as useful for performing activities that need accuracy such as reading and handcrafts. They are the people who mainly use the lamp during the evening hours.

Ja, ik ga graag onder de lamp zitten. Ik ga dan lezen of puzzels oplossen. (Beatrice-dp, notebook)

One participant's extra notes in the notebook clearly show this household sees the lamp as a therapy (Figure 20). This resulted in specific behavior near the lamp, which was scheduled during the morning and in the late afternoon.

Ook in de manier waarop men van de lamp gebruik maakt, lijkt een therapie verwachting; zitten in de juiste stoel, de lamp aan zetten en wat puzzelen en lezen en dan de lamp weer uit zetten zodra ze iets anders gaan doen. (Flora + Frederick, final reflection(Aangenaam))

One remarkable finding was that two households explicitly mentioned that the lamp changed their usual behavior. They report to sit near the lamp most of the times instead of sitting somewhere else. One of these couples rated the usage of the lamp during the day as less appealing, so it is remarkable that they still changed their behiuro. Perhaps the function they attribute to the lamp is affecting their behavior (e.g. seeing it as a therapy).

De plaatsing van de lamp veranderde het gedrag, daar er eerst veel in de voorkamer wordt gezeten, ging men deze weken voornamelijk aan de keukentafel zitten. (Ruth + Raymond, final reflection(iPad))

Men ging expres in de stoelen zitten bij de lamp, terwijl ze overdag normaliter in andere stoelen (dichtbij het raam) gaan zitten. (Vivian + Victor, final reflection(iPad))

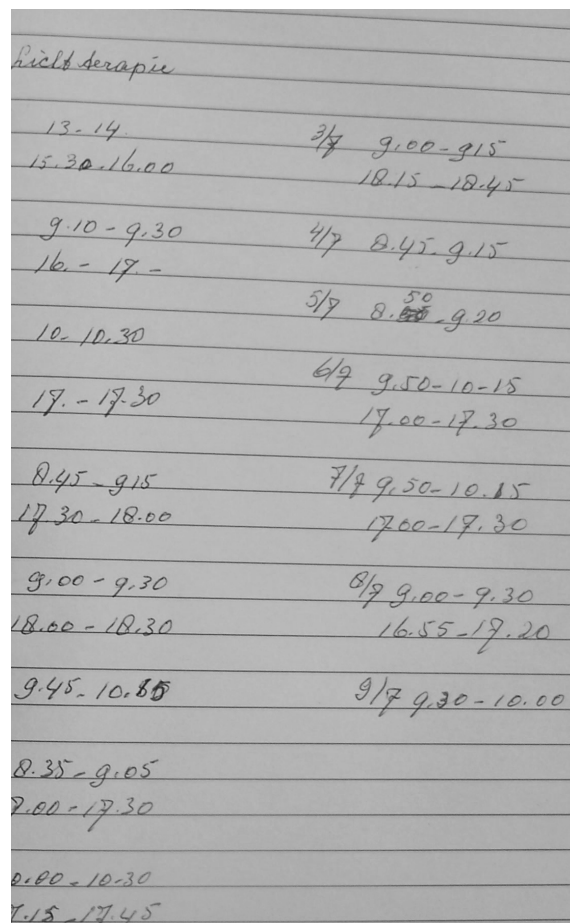


Figure 20. One informal caregiver wrote down the exact hours of usage, titled 'Lighting therapy'

People used the Vitaallicht lamp in the weeks of evaluating in a great divers manner. This was mainly driven by the function the participants attributed to the lamp. When they see it as a form of therapy, they changed their usual behavior and used the lamp during the day. If the weather outside was good, people spent the day or the evenings outside which affected the usage of the lamp as well.

4.5.2.2 Experiences during usage

People do not report to experience anything else than purely functional qualities of the lamp, although one participant in the iPad condition does indicate that his partner is more energetic because of the Vitaallicht lamp (Figure 21). However, in the final reflection he is not confirming this. The fact that people do not experience more energy because of the lamp, might be influenced by the expectations of the lamp. These are further elaborated in 4.5.2.3 Expectation fulfillment. There are no differences in these results among people who are in the middle stages of dementia compared to the people in the earlier stages.

[De] neiging [om onder de lamp te gaan zitten] heb ik helemaal niet tenzij ik meer licht nodig heb bijvoorbeeld lezen. Anders geen andere uitwerking. (Evelyn + Edwin, notebook)

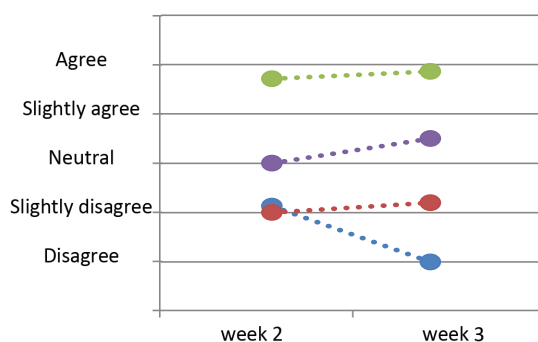


Figure 21. Partner has more energy because of the Vitaallicht lamp

De lamp heeft geen invloed op mij. In mij wijzigt zich niets door deze lamp. (Harriet + Harold, notebook)

Verder merkt meneer geen merkbaar verschil in fitheid door de lamp, ze kan bijvoorbeeld echt geen tv programma's meer bijhouden en valt tevens in slaap onder de lamp. (Thomas - ic, final reflection(iPad))

De vraag is wel gewekt wanneer zoiets nou 'helpt', nu is de ervaring dat het voornamelijk handig is in gebruik bij zaken waar je precies bezig moet zijn. (Ruth + Raymond, final reflection(iPad))

A closer look is taken to the changes in the sleep quality measures and the differences over the weeks in the iPad questionnaire. In the first week of testing the average sleep quality measure is the same as in the baseline week (3.48 of 5). In the second week the average sleeping quality has a slight increase (3.52 of 5, SD = 0.70) but this no big change. That might be because a majority of the people did not report real sleeping problems or the small sample size. The graph with the sleep quality scores of all participants (N=11), does not show any clear differences either.

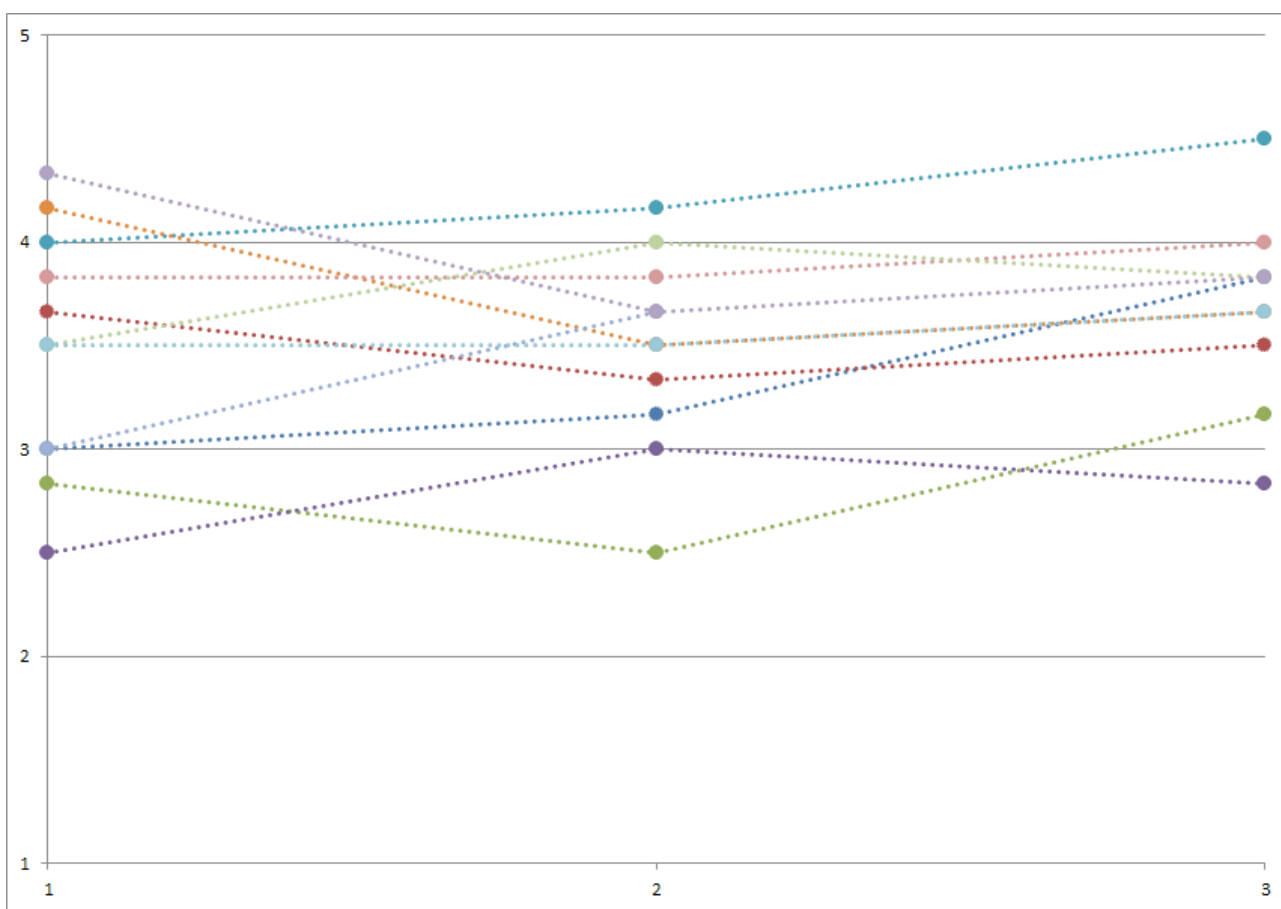


Figure 22. Measures of sleep quality per participant over the entire test period (ratings range from 1 = low sleep quality to 5 = high sleep quality)

In addition, the iPad questionnaire does not show any trends in either judgments of quality of sleep or judgments of feeling fit (figure 23 and figure 24 on the next page). This was rather expected as more factors than just the Vitaallicht lamp, affect these judgments. The fact that we did not find a trend among all participants is an indication that the possible effects of the Vitaallicht lamp are not that large that we can identify them in two weeks of testing.

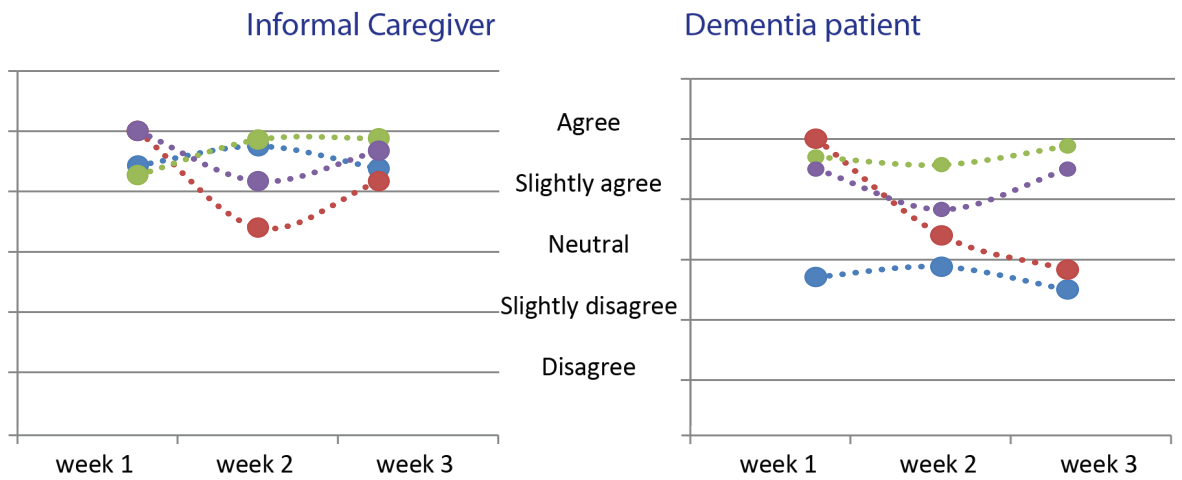


Figure 23. "Quality of sleep is good" ratings of informal caregiver (left) and dementia patient (right)

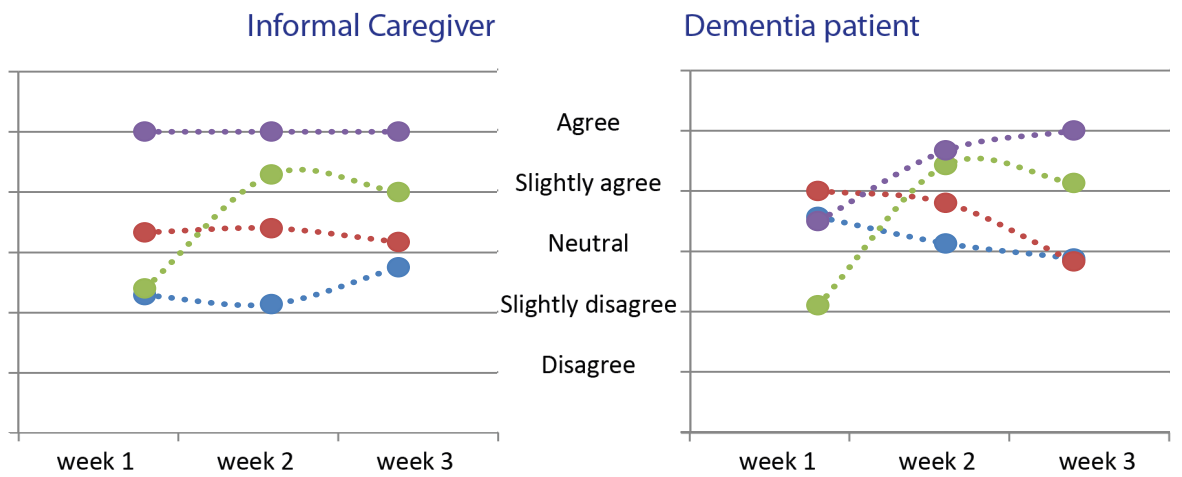


Figure 24. "I feel fit" ratings of informal caregiver (left) and dementia patient (right)

An important reported experience is that two participants (one dementia patient and one informal caregiver) have headaches that they attribute to the light of the Vitaallicht lamp. Both indicate that they tried their best to use the lamp a couple of times. One participant even reported to have used sunglasses during usage of the lamp (Figure 25). Their first main attitude towards the lamp was positive, but they stopped using the lamp because of the returning headaches.

[Eerste dag van evaluatie] Hoe voelt het licht? "Heerlijk, echt heel fijn licht, helemaal niet storend dus.. ik vind het echt heel fijn" (Geraldine + George, audio)

[Een paar dagen later] Ik ben op dit moment een beetje moe en ik heb last van hoofdpijn, ik denk dat het door de lamp komt." **Hoelang heb je onder de lamp gezeten vanmorgen? Anderhalf uur?** "Anderhalf uur, zoiets ja" (Geraldine + George, audio)

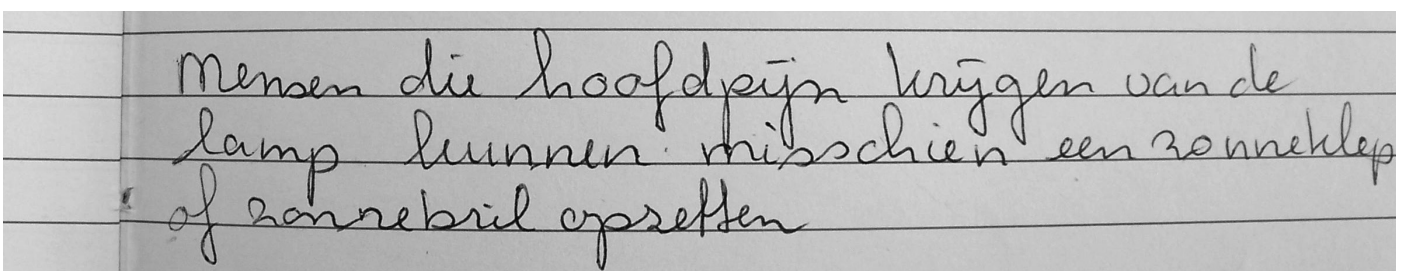


Figure 25. "People who get headaches from the lamp, might try using sunglasses or a sunshade"

Mevrouw geeft aan dat ze blijvende hoofdpijn kreeg van het licht van de lamp, die pas na een paar dagen echt weg was. Ze heeft het twee of drie dagen geprobeerd en is toen ergens anders gaan zitten als de lamp aanstond. (Flora - ic, final reflection(Aangenaam))

The participants do not report to feel different when using the lamp, except two people who identified to get headaches they attributed to the light of the Vitaallicht lamp. The sleep quality scores are not confirming any large effect of the Vitaallicht lamp.

4.5.2.3 Expectation fulfillment

It seemed that the expectations of the Vitaallicht lamp were different among the participants, and the question was raised what the effect of these expectations would be on the general experience with the lamp. Expectations of the functionality of the lamp differed. One participant wanted to overcome his inertia, while another hoped to improve her memory deficits with the lamp. These expectations are linked to the problems the people mention to be most important to them. As these problems are largely evident the expectation are rather unfeasible.

Meneer had al eens eerder het advies gekregen om een lichttherapie lamp te nemen en gebruiken. Hij had verwacht/gehoopt dat hij "niet zo lam" zou opstaan en "vlotter uit bed zou springen". (Simon - dp, final reflection(iPad))

"Het grootste euvel is het vergeten". Lichamelijk is alles goed, maar ze hoopt mentale verbetering te vinden met de lamp. (Danielle - dp, final reflection(Aangenaam))

For them the eventual effects of the lamp will be disappointing. Others did not have a large expectation, which was mostly caused by the limited time of the Vitaallicht lamp test period. Most of them believe that the study is not performed in the right season and that they will use the Vitaallicht lamp more in the winter season.

Ondanks dat ze wel bewust was van het effect van licht bij mensen met een depressie was haar eerste reactie bij het horen van dit onderzoek "Dat kan toch niet met een lamp!" Naderhand geeft ze aan: "Misschien doet het iets, dat kan ik nu niet zeggen." Tijdens het onderzoek was het warm weer en hebben meneer en mevrouw veel buiten door gebracht. In de winter, verwacht mevrouw, zou ze meer van de lamp genieten. (Harriet - ic, final reflection(Aangenaam))

Next to the expectations of the effects of the Vitaallicht lamp, other expectations seem to influence the experiences with the lamp as well. A couple of informal caregivers talked about the heat of the lamp and their expectations and experiences differed largely. One expected to feel heat and she was surprised that the heating was low. Another expected the heat to be low and experienced it as low, and the last one expected nothing in particular but experienced the lamp as hot.

Ook geeft mevrouw aan dat ze verrast was dat de lamp geen warmte afgeeft, dus dat het niet hetzelfde is als een hoogtezon. Dat was verder niet erg, ze vond het juist wel prettig want zo was het langer uit te houden. (Evelyn - ic, final reflection(Aangenaam))

Mevrouw geeft aan dat ze het gebruik van LED fijn vindt omdat het nauwelijks warmte afgeeft. (Vivian - ic, final reflection(iPad))

Ik vind het licht niet onaangenaam maar ik vind de lamp wel veel warmte afgeven. (Geraldine-ic, notebook(Aangenaam))

This shows that expectations are not always logically linked to the experiences. The other way around also occurred with one dementia patient, who seem to had a real remarkable expectation of the lamp itself. She expected that the lamp would be like a hood dryer, so she felt relieved when her expectations were not

met. This was especially remarkable as the leaflet they received before the test period, include an image of the Vitaallicht lamp.

"Ik had een droogkap verwacht waar ik de hele tijd onder moest zitten, maar dit is een gewone lamp". (Danielle - dp, final reflection(Aangenaam))

The dementia patients in particular seem to have had more unfeasible expectations of the evaluated product before the actual testing. The eventual experiences can be influenced by these expectations, especially when the expectations are high. This might results in disappointment. However, it is not always the case that these expectations influence the true experiences.

4.5.2.4 Rating of design

An important aspect of the experiences with the Vitaallicht lamp is the rating of its design, especially since many comments about the design were made. A vast majority of the participants explicitly mention that the lamp is too big for their living room. The placement of the lamp seems to be of influence as one informal caregiver states that the way it is placed, it does not need much space. Despite the fact that the placement was considered thoughtfully in every household, people might think differently after a couple of days. The dominant lighting (which is discussed in 4.5.2.5 Rating of lighting) might have an effect on this size matter too. During the placement the light was turned off, so than only one dominant aspect (the size) was apparent and not directly unsatisfactory.

De lamp past niet in ons huis. Hij is te groot, kap is erg groot en de voet lomp voor altijd in de kamer te hebben. (Evelyn + Edwin, notebook)

De vitaallichtlamp staat op een goede plek. Zo neemt hij niet veel ruimte in beslag en geeft optimaal verlichting]. (Bernard-ic, notebook)

Other remarks are reflecting personal taste. Most people do not think the lamp, both design and color, fits their interior design. This can be explained when taken a look at the pictures of the current lamps in the home environment (4.5.1 Function of light) Only one household seems to like the looks of the Vitaallicht lamp, but they were in general very enthusiastic about the lamp.

Fijn licht, vormgeving niet mooi. Past niet in mijn interieur.(Clara - dp, notebook) . *Op deze manier valt de lamp zo op.* (Clara -dp, final reflection(Aangenaam))

[De vormgeving is mooi en straalt rust uit. In ons interieur past de witte kleur niet (Harriet + Harold , notebook)

Ik vind [de lamp] niet fijn omdat die veel ruimte in beslag neemt en [de kleur is een] beetje donker en somber is (Beatrice-dp, audio) (This participant had the charcoal colored luminaire)

"Sommige (andere participanten) zeggen dat het niet in de kamer staat, maar hier staat die prima". Van mevrouw zou er niet persé een nieuw ontwerp van de lamp hoeven komen; "Hij is goed zoals hij is." (Clara + Charles, final reflection(Aangenaam))

The current costs of the lamp (€2500,-) are too high for the people who were asked what they would pay for the Vitaallicht lamp. This is not only linked to the design or the lighting of the lamp, but also to the functionality that people attribute to the lamp. Therefore the cost might be not that high, as we saw earlier that the participants did not experience any large effects of the Vitaallichtlamp (4.5.2.2 Experiences during usage). This is also reflected in their comments that the price of the Vitaallicht lamp should not extent the price of a proper regular twilight lamp. Nevertheless, the household that is more enthusiastic about the lamp is willing to give up a holiday to spend the saved money on the Vitaallicht lamp.

De kostprijs zou niet hoger mogen zijn dan een goede schemerlamp (Evelyn + Edwin, notebook)

Voor de vitaallichtlamp compleet zou ik €100,- betalen (Beatrice-dp, notebook)

De kosten zijn echter wel te veel, mevrouw geeft aan dat ze best een vakantie over zou willen slaan maar dit bedrag zou betekenen dat ze 4 vakanties over zou moeten slaan. (Clara + Charles, final reflection(Aangenaam))

The rating of the design is based on individual preferences but there are remarkable similar comments provided by the participants. The size and the looks are not fitting the interior design of the people in this study. This becomes apparent when the looks of the Vitaallicht lamp are compared with the looks of the lamps currently in the homes of the participants. Misschien nog een foto? If the lamp does not fit the interior design of the participants and is not showing particular effects, the costs should not be too high for people.

4.5.2.5 Rating of lighting

As the lighting of the Vitaallicht lamp is different from regular lamps, we were interested in how the participants judge this lighting. It appears to vary considerably. A couple of people are enthusiastic about the intensity of the lamp, while others comment that they did not like it and claim that the light is too bright. This could be attributed to the differences in lighting preferences in general, as some houses were darker compared to others. People who have less light in their homes, will probably judge the intensity of a bright light as more bright. Only one participant had a specific comment about the reverberation of the light, which was not always pleasant. Other people did not comment on this.

De eerste indruk van het licht is goed; "Geweldig", wat is het prettig en mooi licht. (Clara - ic, final reflection(Aangenaam))

Als ik wat zou veranderen als hij van mij was zou het licht wat minder fel zijn. (Evelyn + Edwin, notebook)

The ratings of the color temperature of the light are covering a great range from cold to cozy. Not a lot of comments are made on this color temperature, so it is not clear what most people think about the bluish light of the Vitaallichtlamp.

De kleur van het licht is prettig en knus (Harriet + Harold, notebook)

Het licht is erg koud en de weerkaatsing op papier was niet altijd fijn. (Ruth + Raymond, final reflection(iPad))

Next to the brightness of the Vitaallicht lamp, two participants have a comment on the dispersion of the light but these are not in accordance with one another. One couple experience a pleasant, wide dispersion of the light, due to the height of the lamp. This results in a lack of annoying shadows during reading activities. The other couple experiences the light dispersion as very narrow. In combination with the brightness of the light, this is one of the reasons to limit the use of the lamp if they have visitors.

Wat men prettig vindt aan het licht is dat je helemaal in het licht zit, dat is een andere beleving dan gewoon een leeslamp wat gericht extra licht geeft op een boek o.i.d. Het levert dan ook geen vervelende schaduwen op, wat mevrouw toegeëigend aan de hoogte van de lamp. (Vivian + Victor, final reflection(iPad))

Ze vinden het licht erg gecentreerd en in combinatie met de felheid, is het zo erg dominant. "Ja, ik ga dat ding niet aan zetten als er bezoek is". (Shannon + Simon, final reflection(iPad))

The rating of the light is varied among the participants. This is probably due to individual light preferences as people who live in darker houses, experience the light as more bright than others. This is true for all aspects covered: light intensity, light color and light dispersion. One remark shows that the ratings of these light characteristics might be less important when the positive effect of the light outweighs the negative ratings of the characteristics. It is, however, not clear whether this is true for all people.

Mevrouw geeft later wel aan dat de felheid wel te overkomen is als de lamp verder een effect blijkt te hebben. Het is uiteindelijk niet te vergelijken met een gewone schemerlamp (Evelyn + Edwin, final reflection(Aangenaam))

4.5.2.6 Ideas for improvements

People showed in their comments to have ideas for improvements. These ideas might also explain the general experiences with the Vitaallicht lamp as these are characteristics that people currently indicate to be insufficient or lacking. In the participants' opinion, the first thing to improve is obviously the size of the luminaire. One reason for this is that it would provide the option of portability. This is mainly linked to the functional purposes of the bright light to be used in hobbies and activities that need accuracy.

Omdat de lamp niet draagbaar is, wordt men verplicht om te zitten waar de lamp staat terwijl ze hem misschien wel zouden willen verslepen naar de ruimtes waar ze hun hobby's uitoefenen (schilderen, weven etc.). (Geraldine + George, final reflection(Aangenaam))

Tijdens het schilderen van de kamer, hadden ze graag de lamp verplaatst om het felle licht te gebruiken. (Beatrice + Bernard, final reflection(Aangenaam))

Another idea for improvement is linked to the fact that people are not used to turning on the light during the day. This informal caregiver has the idea to automatize the on/off switch. This automation could be based on the presence of people in the room, in order to save energy. The automation could also be based on the current amount of lux, so that the Vitaallicht light complements this amount to the light level that is needed.

Meneer heeft nog het idee om er een sensor in te bouwen die de hoeveelheid licht meet of de aanwezigheid en zodoende de lamp automatisch aan of uit schakelt (Dick - ic, final reflection(Aangenaam))

Two ideas that are both given by dementia patients, seem to be linked. One idea for improving the ambiance the lamp is creating, is to have a few smaller luminaires. This would also decrease the dominance of the lighting. In addition, the other suggestion is to sell the lamp in a regular store. Both ideas seem to avoid feelings of stereotyping.

Het idee wordt geopperd of er niet misschien verschillende kleine lampen zouden kunnen komen, dat zou bijdragen aan de sfeer. (Simon - dp, final reflection(iPad))

Voor het verkooppunt van de lamp stelt mevrouw voor het niet in een hulpmiddelenwinkel te verkopen. (Danielle - dp, final reflection(Aangenaam))

The most important aspect to improve is the size of the lamp, because not only it would fit the interior design of the participants more but it makes the lamp easier to move as well. Perhaps a few smaller luminaires could serve this function too, although this idea seems to be suggested for another cause. Some of the dementia patients do not like to be stereotyped and with this dominant lamp, they might feel a bit as if they are.

In general, light means two things for the participants: the function to brighten a room and the ability to increase the coziness of a room. Whatever the lamp is intended to do, it is usually not turned on during the day. The remarkable finding in the current study is that a couple of participants used the Vitaallicht lamp during the day. This was mainly driven by the function the participants attributed to the Vitaallicht lamp. When they see it as a form of therapy, they changed their usual behavior and used the lamp during the day. However, there were still a lot of people who did not use the lamp during the day. This was also ascribed to the season of testing, as participants expected to use the lamp differently during the winter months. They also expect that the effects of the Vitaallicht lamp would be greater in the winter, as now no large effects on sleep quality or feelings of fitness can be reported.

The ratings of the design and lighting of the Vitaallichtlamp are based on individual preferences but there are remarkable similar comments provided by the participants. The most important aspect to improve is the size of the lamp. This is not only because it would fit the interior design of the participants more or that it improves the portability, but it could mean that a less dominant lamp avoid feelings of stereotyping of the dementia patients. In general, one can conclude that the ratings of design and lighting are based on what people experience as regular. E.g. people who live in darker houses (Figure 26), experience the light as more bright than others. If effects of the lamp are positive, people might be able to overcome negative ratings of characteristics and might be willing to pay more for the lamp as well.



Figure 26. A darker home environment with the Vitaallicht lamp. (Bernard + Beatrice, photo camera)

4.6 Discussion, part 1

The focus of this results part was to get a grasp on the daily life of the participants. We expected that understanding the everyday lives of people with dementia and their informal caregivers, would help us to judge how people evaluate a new innovation in their lives. Several aspects, such as what people do, use and find important were identified in the preceding results section. The vitality of the participants was also studied to be able to see whether people would benefit from an innovation that was intended to improve this vitality. We ended with the evaluation of the actual innovation which was placed for two weeks in the home environment of the participants: the Vitaallicht lamp.

There is a great diversity between participants. One has troubles with physical exercise, while the other reports to be especially bothered by memory deficits. As we are researching a group that is, mostly, in the early stage, the differences between the individuals are evident. The dementia disease is not progressed that far that someone's personality is obscured. We are dealing with individuals with their own needs, abilities and interests. As all the participants still live at home, their daily lives are more diverse compared to patients who are institutionalized and have less freedom (and capability) to choose their activities and surroundings.

Similarities between participants are identified as well. Almost everyone mentioned that going for a walk is a favorite activity. Furthermore, the importance of friends and families is also a frequently mentioned subject. Previous research indicates that these activities place a person in a context and provide him or her with a sense of coherence with social bonding, and aspects of time and existence (Öhman & Nygård, 2005). Walking for example create feelings that are supportive and encouraging which are linked to geographical location with familiar surroundings. Engaging with friends and family gives the feeling of contributing to the social context. Such common activities give meaning to everyday life. The interesting thing about the activities people report to perform, especially reading, is the fact that difficulties with these activities are also reported. It appears that people want to hold on to the activities they are familiar with to keep in control of their lives, even though these activities causes them troubles.

Participants are part of the generation that experienced World War II, which might be a reason why they live frugal and are satisfied with their current economic situation. They do not need more luxury, and therefore a majority of the participants is a bit reluctant towards new innovations and technology. These new innovations should be functional and contribute to improve their lives. The costs of buying and using should not be too high. As soon as this new item has a clear function that helps them in their important needs (health, social, and control of life) they might become interested but the informal caregiver will probably be the decision maker.

In general, light means two things for the participants: the function to brighten a room and the ability to increase the coziness of a room. Whatever the lamp is intended to do, it is usually not turned on during the day. The remarkable finding in the current study is that a couple of participants used the Vitaallicht lamp during the day. This was mainly driven by the function the participants attributed to the Vitaallicht lamp. When they see it as a form of therapy, they changed their usual behavior and used the lamp during the day. However, there were still a lot of people who only used the lamp in the evenings.

As the effect of the Vitaallicht lamp is not that apparent, the enthusiasm among participants is not great except for the people that like the brightness of the lamp to perform activities that need accuracy. This is a direct functional benefit of the Vitaallicht lamp. The time of test period of the current study is probably too short to be able to get any clear ideas on the effects of the Vitaallicht lamp on the sleep/wake cycle of the participants. Some studies have shown that it may take months until effects of light on day-night

rhythms become evident (Riemersma-van der Lek et al., 2008). Others, however, already found reduced daytime sleep in two weeks in institutionalized dementia patients, which was attributed to bright light's acute alerting effects (Fetveit & Bjorvatn, 2005). From the current study, we know that the participants spent a lot of time outside their homes (visiting family and friends, going to the adult day care center etc.) which gives an indication that two weeks in the home environment is not enough. In addition, the current study was not designed to test the effects of light and was perhaps not scheduled in the right season.

Most of the participants did not report any sleeping problems either. However, people do report to feel tired during the day and a couple of participants score low on the measure of sleep quality (one even wanders during the night). Therefore, objectively we could say that there is room for improvement. The fact that people do not see a problem, or that problems might occur in the near future, is an important aspect of acceptance of solutions (the Vitaallicht lamp). As forgetting everyday things is seen as more problematic at this point, a solution for a less important (or non-existing) problem is somewhat meaningless. This is especially the case for the dementia patients, as informal caregivers seem more willing to try new things that have the slightest probability to enhance the situation. This is seen in the fact that they seem to be more positive in general about the Vitaallicht lamp, both on effects of the lamp as well as on the design and lighting.

Another important thing to realize is the effect of the presentation of a new innovation for people with dementia. Especially the people who still live at home, in the early stages of the disease, are in denial of their problems caused by the dementia. They are experiencing troubles throughout the day and are not looking for more signs that there is something wrong with them. People with dementia do not want to be seen as a patient, but as a human being so something that is stereotyping will be regarded as offensive. The Vitaallicht lamp had the benefits of being functional for the informal caregiver as well, resulting it to be less dementia-related. For some seeing the lamp as a therapy works well, but others are relieved that it is not stereotyping them as patients.

To create a higher acceptance level, the looks of the design are crucial too. The Vitaallicht lamp is dominating the living room by its light and design. The dominating lighting is not easy to change but the design can be more subtle. An unordinary looking lamp will evoke questions by other people, which might create feelings of embarrassment. People prefer a product that can integrate with their personal interior design. If effects of the lamp are more prominent and positive, people might be able to overcome negative ratings of design and lighting characteristics.

Finally, we would like to stress that two people in our study reported to experience headaches, which they attributed to the light of the Vitaallicht lamp. This is a serious result that needs more research on what the exact cause might be. One assumption is that certain medicine intake can cause hypersensitivity to light. Especially since we are dealing with an age group that has a greater chance of having medication, this needs further attention. However, some people are in general more light-sensitive than others, even without medication.

5 RESULTS, PART 2

5.1 Introduction of results, part 2

As already explained in 3.6 Data Analysis we divided our data in themes and these themes were again divided over two main parts. The current part (part 2) is where we present data regarding the actual research question of this thesis. These results will give us insights in how successful the iPad questionnaire and the probe game 'Aangenaam' were in functioning as a qualitative research method to collect first-hand evaluative data from individuals in the early stages of Dementia. The results include insights that are linked to the three main objectives for this qualitative research method:

1. Making the dementia patient's voice heard in the research when taking into account the memory deficits, the difficulties with language, the lowered capacity to concentrate and troubles with seeing the complete picture.
2. Participants should not be burdened by the method and the method should aim at creating feelings of involvement and long-lasting motivation for both informal caregiver and the person with dementia. Extra care should be taken as the research takes place in the private home environment.
3. The generated data should be rich and give all insights needed to draw evaluative conclusions. Aspects of doing research, such as time intensity, need consideration.

The highlighted parts of Figure 27 show the themes we discuss within these three main objectives.

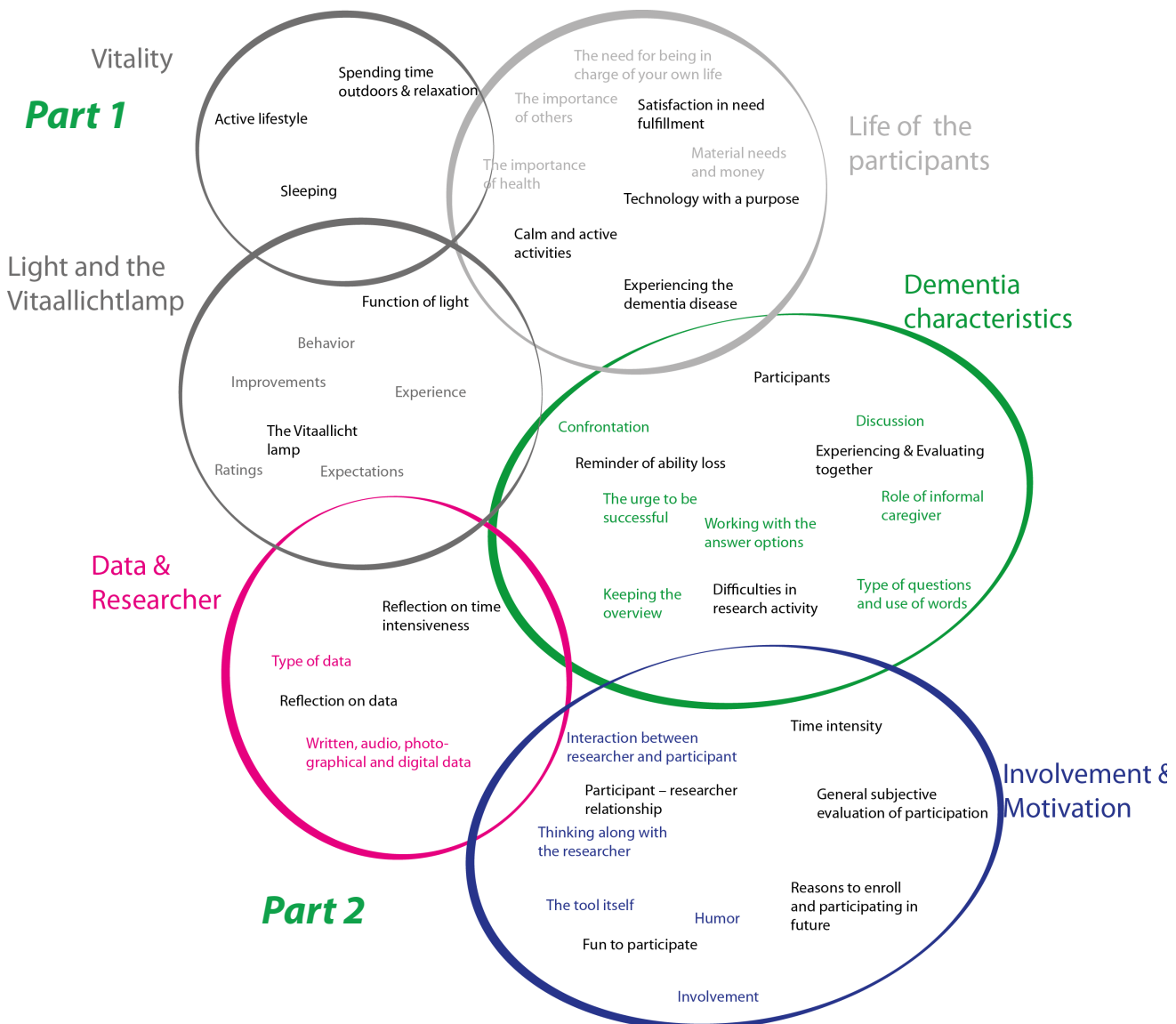


Figure 27. Graphical representation of results. Results for part 2 are in color, results for part 1 are in grayscale.

5.2 Dementia characteristics

We wanted to avoid the marginalization of the dementia patient in the current project. One of the main objectives for a successful research method for people in the early stage of dementia is to have a special focus on aspects of the dementia disease to make the method suitable for the current user group. This includes taking into account the memory deficits, the difficulties with language, the lowered capacity to concentrate and troubles with seeing the complete picture. In this theme, insights and remarks regarding specific dementia-related aspects are considered in both iPad questionnaire and probe game 'Aangenaam' data.

5.2.1 Participants

To be able to say which method is including the dementia patients, we have to identify the actual participants in both methods.

The most important result of the comparison between the iPad and the probe game data is the fact that there is a higher certainty of the participation of the dementia patient in the probe game. There is clear evidence in both audio and written data, that the dementia patients have contributed to the research themselves. Some dementia patients were even individually partaking in this research activity. These facts cannot be identified in the iPad data, as this method generated digital data and it is therefore harder to ascertain who made an entry. From the final reflection, it appeared that the informal caregivers were the only ones who worked with the iPad.

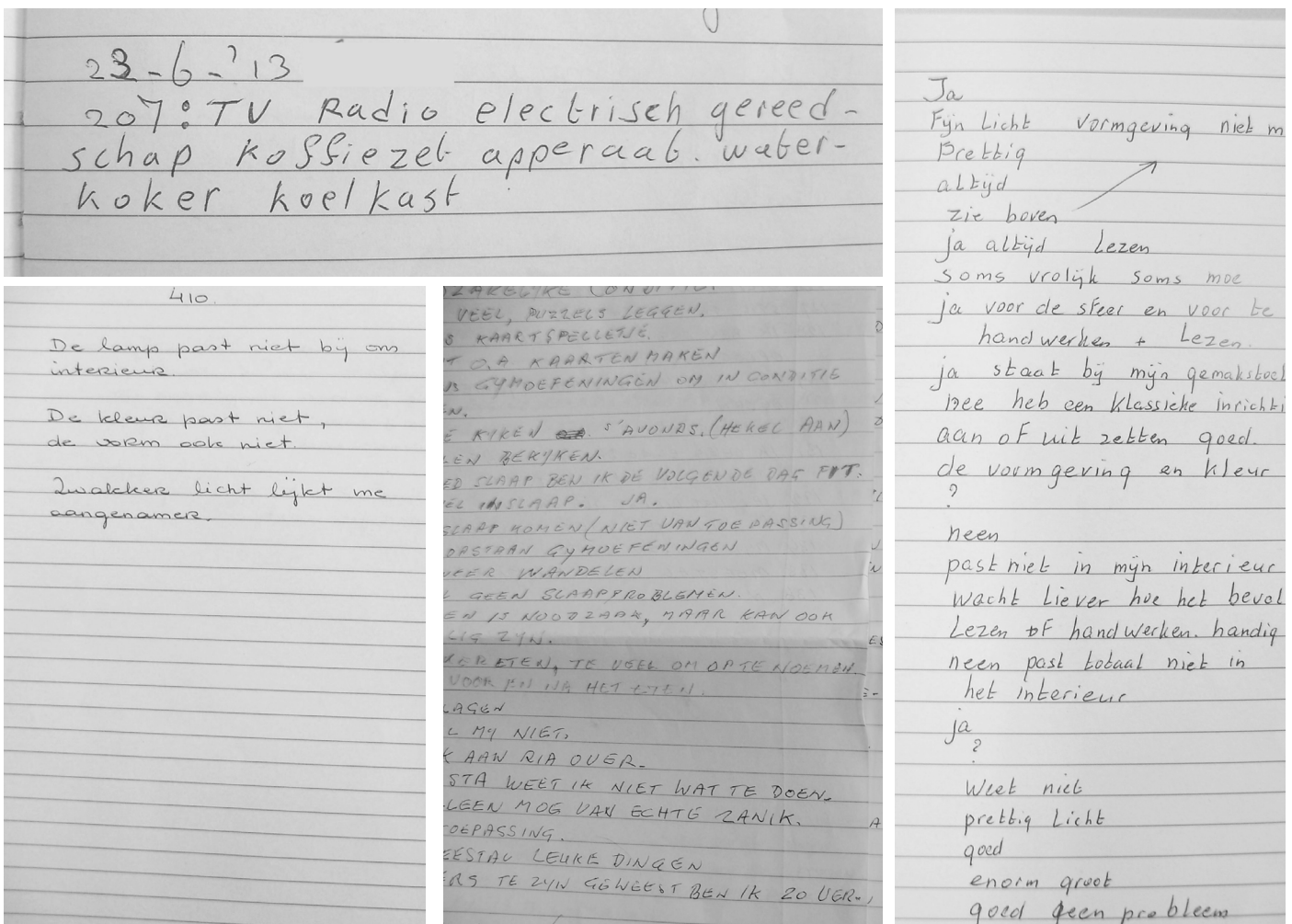


Figure 28. Written evidence of dementia patients partake in probe game themselves.

Two informal caregivers, both with a different method, indicate the incapability of their spouse to actively contribute to the research as the progression of the disease is already too far. They are not able to contribute actively to any discussion anymore. Both methods can be used by individuals too so data was still generated. However, this data is obviously coming from the informal caregiver only. It is not clear how these informal caregivers actually experienced this individual working with the method. It might be that the probe game, which is especially intended to use together, is reminding the informal caregiver about the loss of abilities of his spouse more than the iPad questionnaire.

Ook is mevrouw al te verheer, dus voor haar is een spel geen meerwaarde. (Alfred-ic, final reflection(Aangenaam))
Mevrouw kon niet meehelpen met invullen omdat ze hard achteruit gaat. Ze heeft zelf een beperkte realiteitsbesef, denkt dat ze nog gaat werken. (Thomas - ic, final reflection(iPad))

Several participants were specifically doubting whether the iPad questionnaire would be suitable for households where only a dementia patient would live. This remark was only made by the people who were in the iPad condition, which might be an indication that it is regarded as something difficult. Two of the four informal caregivers in the iPad condition mentioned to have troubles with the iPad, of whom one was not even able to make a single entry with that device. This might not be solely related to the dementia disease, but with the ageing of the participants in general.

M.b.t. het huidige project vraagt ze zich af hoe dat we omgaan met huishoudens waar de dementerende alleen is, aangezien een iPad dan niet mogelijk zou zijn. (Shannon-ic, final reflection(iPad))

Ik heb moeite om de iPad te bedienen, terwijl dat [naam onderzoeker] [dat] toch goed aan mij heeft uitgelegd. Ik probeer dan de vragenlijst zo goed mogelijk in te vullen (Thomas-ic, iPad)

More individual contributions of the dementia patients was shown in the probe game data compared to the iPad data. On the one hand, this is because the iPad generates digital data where it is harder to verify the source, but on the other hand, the iPad itself is a device that is not common in the age group of the participants. Both methods can be used by individuals, although informal caregivers might be confronted with the inabilities of their spouses.

5.2.2 Experiencing and evaluating together

We saw that both methods can be used individually, but what we found in previous research was that experiencing and evaluating together would be beneficial to support the dementia patient's remembering. The amount of discussions with and support of the informal caregiver in each method are identified.

5.2.2.1 Discussion

Some couples indicate that participating in the current study evoked discussions about the subjects that were asked. This was slightly more apparent in the probe game. However, the involvement of the dementia patient in the discussions appears to be most dependable on the attitude of the informal caregiver. Some informal caregivers, in both methods, regard this as more important than other informal caregivers. This is shown in behavior such as using the speaker function during the telephone-interview to include the patient in that conversation with the researcher as well. One informal caregiver in the probe game condition explicitly mentions that she enjoyed the fact that her spouse was easily involved in the research activity.

"Anders moet ik alles zelf doen en er ontstaat vaak wrovel bij meneer omdat hij het niet begrijpt." Nu was er actie vanuit zichzelf. (Geraldine - ic, final reflection(Aangenaam))

Of course, it was not always possible or desirable to talk about the answers with the patient. Therefore, the informal caregivers sometimes answered the questions by means of observing the dementia patient (iPad) or by the years of knowledge, they had about their spouse (probe game).

Mevrouw heeft met de iPad gewerkt en niet direct aan meneer gevraagd of hij zich fit voelde of goed geslapen had. Ze bekeek vooral zijn activiteiten, bijv. hoe hij in de tuin werkte.(Shannon + Simon, final reflection(iPad))

Mevrouw geeft aan dat ze er veel over gepraat hebben samen en ook met kinderen. Ook bij het invullen van de vragen dat dat lastig is om te begrijpen wat meneer vindt. "Hij ziet dingen heel anders dan ik. Soms heb ik wel wat anders opgeschreven dan dat hij het zei. Wel op de manier dat ik dacht dat hij het dan bedoelde". (Evelyn - ic, final reflection(Aangenaam))

"Ik ken hem al 55 jaar lang, dus zei ik soms ik denk wel dat het zo is". (Harriet - ic, final reflection(Aangenaam))

It takes extra time and effort to partake in a research activity together. For the informal caregivers it sometimes seems to be easier to just fill in the answers to the questions themselves. This behavior is apparent in both methods and seems to be linked to how important the informal caregiver rates the input of the patient, but also how intense the gathering of input from the dementia patient is. This is complemented with the years of knowledge about their spouse.

5.2.2.2 Role of informal caregiver

It was expected that the informal caregiver had an important role in the research activity. In the iPad questionnaire, this main role is to actually make an entry and work with the device. In the probe game 'Aangenaam', we discovered the greater role of the informal caregiver, which resembles what the importance of the informal caregiver is in the daily life of the dementia patient.

Especially in the audio data of the probe game, this role of the informal caregiver becomes apparent. The audio data gives insights in the interaction between the dementia patient and the informal caregiver. Ways to help the patient to actively partake in the research activity are the structuring of an answer, breaking an extensive question in smaller questions, or reminding the dementia patient, by for example whispering the answer. This data shows that the relationship between the two spouses is beneficial on several aspects. One is the exact understanding of the need 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 as it comes from a familiar person and it is familiar help.

*[Wat zou voor u een ideaal huis zijn?] "...ja.... Ik vind waar we nu wonen ook wel een ideaal huis dus... [...]" **Ja maar dat kan toch misschien wel idealer? ... Waar zou het huis dan staan, als je ideaal huis had? Waar zou je het willen hebben?** "Ja, toch eigenlijk wel een beetje in de natuur eigenlijk, niet te ver van een dorp of stad af, in de bossen [...]" **Ja en dan je ideale huis, wat dan in de bossen zou staan, zou dat dit huis zijn of een ander?** "Ja, een ander" **Wat voor iets dan?** "Nou een houten huisje, of stenen huis met een fijne kamer,... [...etc.] (Geraldine + George, audio)*

*[Luistert u vaak muziek?]"Nou, niet zo vaak. [onverstaanbaar] Wellicht op de televisie ergens op.. Een muziekprogramma." **Maar je luistert toch heel vaak naar de radio?** "Ja, naar de radio luister ik wel" **Dat is toch ook muziek? Je zoekt altijd de muziekzender hoor, nooit een praatprogramma.** "Nee? Oh dan luister ik wel vaak naar muziek" (Geraldine + George, audio)*

*[Bent u nieuwsgierig naar nieuwe uitvindingen? Waarom wel/niet?] "Ja, ik ben nieuwsgierig naar nieuwe uitvindingen. Waarom wel of niet.... [Fluisterend = wat zei ik nou net?] Nieuwe uitvindingen die...." **Als de levensomstandigheden, dat zei jij net..** "Als de levensomstandigheden verbeteren, dan ben ik daarvoor." (Beatrice + Bernard, audio)*

In the written data of the probe game this role of the informal caregivers is also apparent, but on a different level. Now the exact interaction between informal caregiver and patient is not clear anymore, but the result of these interactions is given. One example shows the structuring of the answers again, by breaking up a question, numbering it and connect the why answers with the what (Figure 28 on the next page). Another example shows that the informal caregiver takes the lead in writing as the dementia

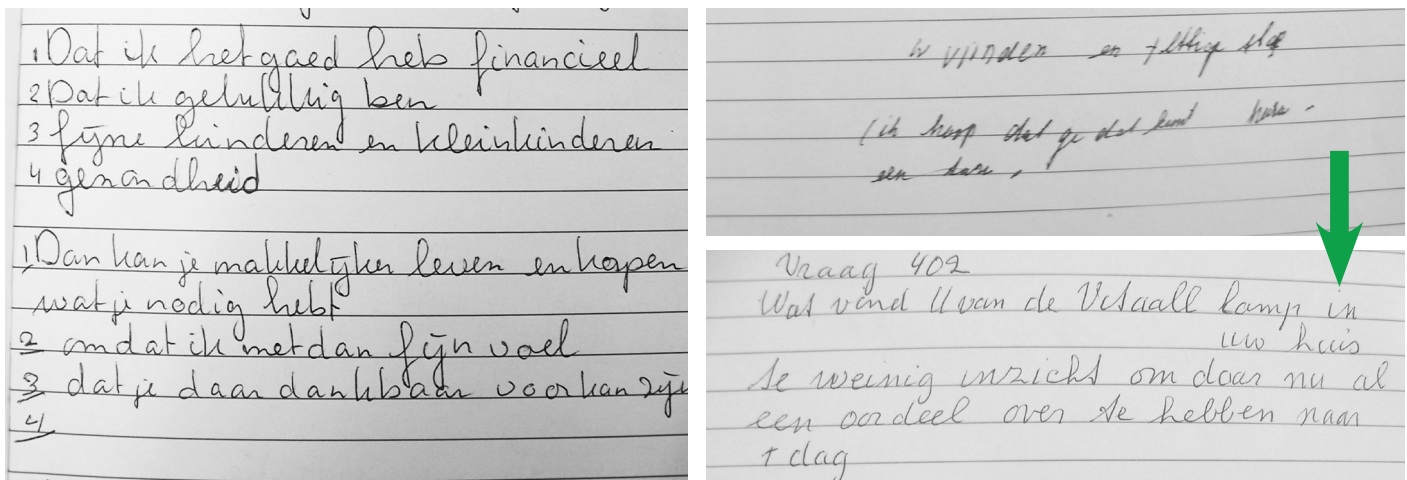


Figure 28. Structuring of question by informal caregiver (left) and difficulties with writing (top right) taking lead in writing (bottom right)

patient showed difficulties (Figure 28 on the next page). The extensiveness of the written answers is greater in the participants where there was an interaction between patient and informal caregiver. This can be concluded from comparing the average number of words used in sentences by only the dementia patients (6.35) or dementia patients who were supported by their informal caregiver (18.48).

Next to the fact that these examples illustrate the role of the informal caregiver, it also shows some of the difficulties the dementia patients face when playing the probe game 'Aangenaam'. These are further elaborated in 5.2.4. Difficulties in research activity.

The role of the informal caregiver becomes more evident in the probe game data than in the iPad data. The informal caregiver helps the dementia patient by restructuring extensive questions, helps them with remembering their answers or takes the lead in writing the answers down. In general, the answers given by the patients supported by their informal caregiver were more extensive. The audio data is showing the interaction between the informal caregiver and dementia patients on these difficulties, while the written data gives the results of these interactions.

Evaluating and experiencing together cost extra time and effort from the informal caregiver. It is sometimes difficult to get input from the dementia patient, which results in the fact that the informal caregivers will generate the data themselves. An important part in this matter is how important the informal caregiver rates the input of the dementia patient compared to the extra time and effort it takes. The informal caregiver is needed to help the dementia patient in structuring and remembering answers. As the informal caregiver is the partner of the dementia patient, the years of knowledge about the spouse helps them to practice their role or generate the data themselves.

5.2.3 Reminder of ability loss

One key aspect of a successful qualitative research method for people with dementia is that the research activity does not remind them about their ability loss. People experience this as embarrassing which is not what we would like to evoke. This potential experience is inevitably linked with the second main objective that focusses on the motivation of the dementia patient (5.3 Motivation & Involvement). However, the ability loss itself is connected to the dementia disease so therefore we discuss in this chapter. Two aspects of this reminder appear from the data: one being the confrontation experienced during the research and the other is the urge to be successful.

5.2.3.1 Confrontation

The level of confrontation identified by the participants gives insights to what extent the research reminded them of their current situation. The interesting thing is that this was mainly coming from the informal caregivers as some indicated that three weeks was enough for the research activity. The main reason for them was that participating in research for people with dementia, reminded them of the fact that their spouse is a dementia patient. The incapability of answering questions is experienced every time they work with the probe game or iPad.

Het confronteert toch weer met de ziekte. (Evelyn - ic, final reflection(Aangenaam))

Besides their own perspective, the informal caregiver is also thinking about the effects of participating in the study on their spouse. This seems to be more apparent in the probe game, as the involvement of the dementia patient is more intense. The informal caregiver is used to protect his spouse, and knows what upsets her, which results in reluctance towards a new research method.

Die vragen wil ik haar niet aandoen, haar drie weken uit haar doen laten zijn, dat wil ik niet. (Dick-ic, final reflection(Aangenaam))

One of the informal caregivers in the iPad conditions made a more general remark regarding reviewing the generated data. In the iPad questionnaire, there is no possibility to look back at the entries. On the one hand this can be seen as a limitation (as this informal caregiver indicates too) because it does not give any idea on what kind of data they generated over a week. On the other hand, it might also be experienced as relieving to not being able to see the possible confronting data one created over a period of time. This is especially apparent in the iPad questionnaire.

Na de eerste week vroeg meneer ook of hij de antwoorden nog in kon zien naderhand omdat hij het zelf interessant vond om te zien wat bepaalde antwoorden teweegbracht, wat was er dan die dag gebeurt. (Raymond - ic, final reflection(iPad))

Participating in research for people with dementia, is in itself confronting the participants with their situation of living with dementia. Especially when it is a daily activity and the involvement of the dementia patient is requested, the informal caregiver might be faced with the reality of the incompetence of his or her spouse. It is therefore that it seems to be more apparent in the probe game condition. The patients themselves, however, do not specifically mention this but show it more in their behavior that is discussed in the next paragraph.

5.2.3.2 The urge to be successful

The dementia patients do not specifically mention that they feel reminded about their ability loss in partaking in the current research. They do show to have an urge to be successful in participating, primarily in the probe game. This might mean that they want to provide the researcher with something useful, which indicates a good participant-researcher relationship. However, we expect it has more to do with covering up their inabilities and therefore to not embarrass themselves or their informal caregiver. For example, one dementia patient did not deliver any data, as he indicated that he was afraid to fail. Others are reporting with pride that they answered all questions or tried their best to deliver a good answer (Figure 29). The latter is apparent in both written and audio data, which indicates that the reminder of losing the abilities can be experienced in both ways. At least the written data can be revised when participants want to.

Meneer heeft problemen met concentreren en is bang dat hij het toch niet goed zou doen, ondanks dat hij aangeeft nog steeds leergierig te zijn. (Charles - dp, final reflection(Aangenaam))

Bij het ophalen van de lamp en ook aan de telefoon geeft mevrouw, een beetje trots aan, dat ze alle vragen heeft ingevuld. Mevrouw geeft aan dat ze het boekje prettig vond, omdat ze het nog eens kon overdenken. (Danielle - dp, final reflection(Aangenaam))

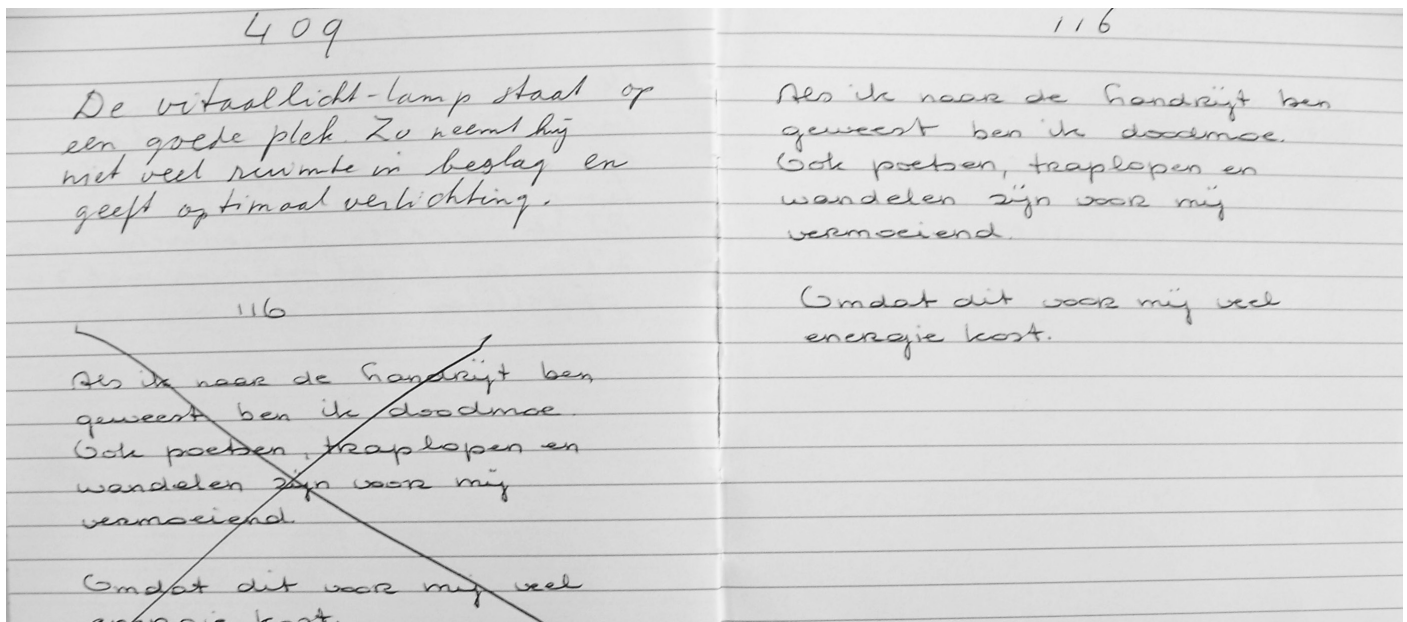


Figure 28. One of the dementia patients follows the rules of the game precisely (write the answer to the question on a new page)

In het begin vond de cliënt de audio vragen wel een beetje lastig, het kostte tijd om te winnen. Vaak oefenden ze even met het beantwoorden van de vraag voordat de recorder aanging. (Beatrice + Bernard, final reflection(Aangenaam))

This shows the importance of special care in constructing questions as these should avoid that the participants feel tested. Even some slight instructions, such as to write the answer on a new page, can make the dementia patient insecure. Endorsement from the researcher, and probably the informal caregiver as well, can be very helpful. The question remains whether data should be revisable or not.

Even though partaking in research is not intended to remind the participants about the dementia disease, and the loss of abilities, it is an inevitable side effect of researching people with dementia. Especially for the informal caregiver, this might be experienced as confronting. The probe game seems to evoke this more than the iPad, since the active involvement of the dementia patient is requested. That is why the loss in abilities, such as answering a question, becomes more apparent. The dementia patients themselves try to cover this by doing their best in participating, and follow every rule. The importance of the construction of the questions and guidelines, to avoid feelings of being tested, is evident.

5.2.4 Difficulties in research activity

An important aspect of a suitable research method for people in the early stage of dementia, is that it takes the inabilities of these people into account. Not only to avoid the reminder of this loss in ability (which we discussed in the previous paragraph) but also to increase the possibility that the person is able to give his or her insight about the research topic. Identifying the difficulties give insights in improvements of the currently used methods.

5.2.4.1 Type of questions and use of words

There are different types of questions, e.g. open and closed. It is of interest to see whether some types of questions generated difficulties and why that is the case. In the iPad questionnaire, the questions were mainly closed, while in the probe game the questions were open.

In the iPad condition, nobody had any remarks about the type of questions. This might be because the informal caregivers were the main respondents of this questionnaire and they did not experience difficulties. It is not clear if during discussions the questions were framed differently for the dementia patient.

In the probe game condition, several remarks were given about the type of questions. It appears that individual differences are evident. One of the informal caregivers report to prefer closed questions, because that makes it clearer what kind of answer is expected. On the other hand, a dementia patient is identifying the troubles he faced with closed questions as they usually contain gradations which he finds hard to understand (e.g. How do you rate your sleep quality? Good, slightly good, neutral ... etc.). A balance in directing the participant towards the answer is needed.

Soms zouden gesloten vragen prettiger zijn, omdat het niet altijd duidelijk is wat voor antwoord er gezocht wordt. (Dick-ic, final reflection(Aangenaam))

Meneer vindt definiëren moeilijk, vooral als over gradaties gaat. Bijv. hoe makkelijk is iets.. een beetje makkelijk? Wat is een beetje makkelijk? (Edwin-dp, final reflection(Aangenaam))

The probe game questions were sometimes experienced as too elaborative or too abstract in the phrasing. This was not done on purpose, although multiple questions in one card were intended to evoke a discussion (*Aan wie zou u de Vitaallicht lamp aanraden? Waarom? Wie zou u de Vitaallicht afraden?*). However, since the dementia patient has troubles concentrating and keeping the overview, this seemed to become an issue for some participants. The informal caregiver was necessary to guide the dementia patient. The more abstract questions, e.g. about someone's ideal home, seem to be hard for the dementia patient as well. Some might be troubled by imagining such an abstract theme, as it is not available in the current moment or time. This was not the case with all questions, since no troubles were identified with for example the question one would do with extra money. In these cases the informal caregiver needed to 'translate' the questions in words that the patient did understand, or the dementia patient themselves could rethink the answer when it was written down in the notebook.

Voor meneer was het soms lastig en is de eerste reactie vaak ja of nee, pas later valt het muntje en kan er echt gesproken worden over het onderwerp. Bijv: "Wat is je ideale huis?" is lastig, maar als het dan gaat over "Wil je een boven en beneden?" dan wordt het concreter en is het ook makkelijker aangeven waarom bepaalde dingen zo zijn. Zo kun je verder door praten, "je begint eigenlijk achterste voren". (Geraldine-ic, final reflection(Aangenaam))

"Toch zijn er wel wat woorden gebruikt in de vragen die onduidelijk zijn (bijv. ritueel) en die een soort vertaling nodig hadden." (Geraldine - ic, final reflection(Aangenaam))

Soms was het onduidelijk of de vraag over de lamp ging of over het licht van de lamp. (Beatrice – dp, final reflection(Aangenaam))

"Daarnaast was de vraag over zonlicht ook vaag. Wordt daar buiten mee bedoeld of echt zonlicht? Dat is nogal een verschil in Nederland." (Raymond - ic, final reflection(iPad))

If involvement of the dementia patient is required, special attention is needed for the construction of questions. The probe game questions were not always clear enough, as even an informal caregiver commented to be unsure what kind of answers the researcher expected. People with dementia have difficulties with certain words, especially in sentences that are very long. This resulted in the needing of help of the informal caregiver who restructured the questions or rephrased some of the wordings. This shows that questions need to be framed more clearly and without degrees in answers. Furthermore, the wording in questions should be specific. Individual differences in abilities are apparent as not all participants reported to have troubles with the questions. The informal caregiver will be the one who knows how to adjust the questions, which indicates the importance of the informal caregiver again.

5.2.4.2 Keeping the overview

One of the aspects of the dementia disease is the difficulty with keeping the overview. In the probe game, this seems to be an issue only when the dementia patient is not sufficiently supported by the informal caregiver. This is not reported by every dementia patient who worked with the probe game individually but one participant explicitly mentions this. He found it difficult to get an overview over the question cards, even though he judged their appearance to be appealing. This participant states to prefer a questionnaire, to avoid the cluttering of questions. Another individual dementia patient received an adapted version of the probe game (with only the Vitaallicht category cards and the notebook), as her informal caregiver expected his wife to lose the overview as well.

Met een vragenlijst zou het overzichtelijker zijn. Door deze kaartjes lijkt het geheel wat rommeliger, hoewel het verder wel goed in elkaar zit. (Charles - dp, final reflection(Aangenaam))

In the couples where the informal caregiver was actively involved in playing the game, the caregivers have the task to keep the overview for the dementia patients. This resulted in the fact that the dementia patients in these settings did not report to be unable to keep the overview. This way the dementia patient was able to focus on the actual answering of the questions.

5.2.4.3 Working with the answer options

We provided the people in the probe game with three options for answering: a notebook, a voice recorder and a photo camera. People mainly used the notebook, which might be because they are more familiar with writing. Despite that, some of the dementia patients themselves seem to have difficulties with writing as the informal caregiver wrote the answers to the questions down. These dementia patients (both in middle stage of dementia) also showed to have difficulties with speaking during the reflection with the researcher, so that might be a reason why they did not make use of the voice recorder either. One of these dementia patients used the photo camera, which might be an indication that he judged that as a way to be involved in the research.

Others, who did not use the voice recorder, were two dementia patients and one informal caregiver who worked individually with the probe game. For the dementia patients it might be difficult to use the voice recorder by themselves. This is a pity as multiple people (informal caregiver and dementia patient) did indicate that they preferred talking over writing. It seems that they felt that they had to talk to the voice recorder, instead of just recording the conversation between people as they indicate that they like to talk to someone.

Meneer geeft aan dat hij het prettiger vindt om vragen direct te krijgen en daar antwoord op te geven. (Charles - dp, final reflection(Aangenaam))

Praten tegen iemand prefereert ze over schrijven, dat is makkelijker en prettiger uitdrukken. (Harriet - ic, final reflection(Aangenaam))

In general, the people who did not use all answer options might not have experienced the probe game as a game activity. This could have caused them to be limited to try the device or did not see the use of trying it by themselves. Both reasonings might also explain why these participants did not use the photo cameras either.

The people who did use the voice recorder did not mention any difficulties with the device. Only one dementia patient stated that she needed some time to get used to the device. She practiced her answering before the actual recording started. This is an indication on how such a new device can be experienced by the dementia patients, which was not expected to happen beforehand. After a period of time, people get used working with the probe game and things get easier.

In het begin vond de dementerende de audio vragen wel een beetje lastig, het kostte tijd om te wennen. Vaak oefenden ze even met het beantwoorden van de vraag voordat de recorder aanging. (Beatrice + Bernard, final reflection(Aangenaam))

The notebook seems to be the most favorite answer option in the probe game, as it does not require the participants (both informal caregiver and dementia patient) to put extra energy in understanding a new device. Especially when the dementia patient shows language deterioration, the usefulness of such a voice recorder is not evident for the informal caregiver. Yet, this still might have given interesting insights in understanding the difficulties of the dementia patients for the researcher. The informal caregiver is needed to help the dementia patient in using a new device. This new device (voice recorder in the current study) can be a bit daunting for the dementia patient at first, so they need some time to become accustomed to the research activity.

Language difficulties seem to be apparent in the contribution of the dementia patients in the probe game. This might result in problems with certain questions that use abstract or difficult words, but it is also shown in the handling of the answer options. The informal caregiver has an invaluable role to help the patients understand the questions, to keep the overview and sometimes also to write down the answers as well.

The iPad questionnaire did not involve the dementia patient clearly in the research activity, or the extent of their involvement is at least hard to identify because of the digital nature of the data. The iPad is not a device that could be used by a dementia patient solely, unlike the probe game which was used by some individual dementia patients.

As the involvement of the dementia patient is more apparent in the probe game, their inabilities become more apparent too. This might be experienced as confronting by their spouses. The dementia patients themselves are actively trying to cover their inabilities, which can become burdensome if it gets hard to do. The importance of the construction of the questions and guidelines, to avoid feelings of being tested, is evident. People with dementia have difficulties with certain words, especially in sentences that are very long. This resulted in the needing of help of the informal caregiver who restructured the questions or rephrased some of the wordings. In the audio data, the exact interaction between patient and informal caregiver becomes evident.

Next to the research format, the extent of involvement of the dementia patient in research seems to be based on two things: the progression of the disease as well as the attitude of the informal caregiver. People in the middle to later stadium are less able to take an active role in research, so they are either involved via non-participatory methods (observation by e.g. informal caregiver) or other options should be provided that do not include language production (photo cameras can serve this purpose) or understanding. The attitude of the informal caregiver should be positive towards including the dementia patient. A right balance is needed between the ability to get useful input of the dementia patient compared to the extra time and effort it takes for the informal caregiver.

5.3 Involvement & Motivation

The objectives of the Living Lab include the experience of participating as an important factor to be taken into account. Participants should not be burdened by the method and the method should aim at creating feelings of involvement and long-lasting motivation for both informal caregiver and the person with dementia. Therefore, we pay extra attention to factors that might influence these feelings of involvement and create motivation.

5.3.1 General subjective evaluation of participation

We start 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 real discomfort of participating in this study, independent of the method used. The probe game did not have a question about how people rated their participation but the iPad questionnaire did.

In the iPad questionnaire, the people were asked how they experienced participating in the study. This gives us insight how the people felt during the actual participation over the entire period of testing. None of the participants in the iPad condition indicated to mind participating in the research, although one participant rates it as neutral over the entire test period. The other three participants seem to rate participating in the study as somewhat more enjoyable after the Vitaallicht lamp is placed. This can be seen as an indication that people in the iPad condition did not see the exact use of the baseline week. It was also a remarked by one of the participants in the comment box who did not make many entries in the first week.

Ik zie hier de zin niet zo van in (Vivian – ic, iPad)

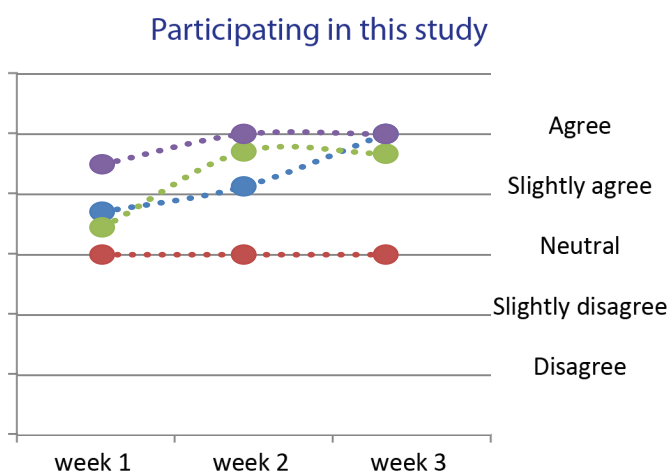


Figure 29. 'I do not mind participating in this study' ratings from iPad questionnaire

It is important to ask how people judge the participation, as that will be the main feeling that people have with the research. The results show that there is not a big discrepancy between the ratings of the people in the probe game compared to the people in the iPad questionnaire. The iPad data shows a better insight compared to the probe game, since the design of the iPad questionnaire method gives the opportunity to ask such a question on a regular basis. It is not clear whether the baseline week in the probe game was also regarded as less interesting, which appeared from the iPad data.

5.2.2 Time intensity for participant

One of the aspects that keep people motivated in a research activity is how much time it takes to participate. During the final reflection, none of the participants indicated that the study was too time intensive. Nevertheless two informal caregivers (both in probe game) did indicate that three weeks of participating was enough. This comment was attributed to the fact we earlier explained in 5.1.3.1 Confrontation, about the experience of the failure of understanding and answering questions of their spouse. This is especially apparent in the probe game.

Het confronteert toch weer met de ziekte. (Evelyn - ic, final reflection(Aangenaam))

A couple of people in the probe game answered the questions in the game all at once. This is an indication that people preferred to get them done instead of spreading the possible burden, which was the intention

of the probe game. As the answers do not change overnight and can be answered in a couple of words, it seems to be illogical for the participants to not spend a bit more time and finish it at once. A remarkable fact about the people who answered the questions all at once is that these were all people who participated individually.

De dingen die je vraagt veranderen niet naar verloop van tijd, dus ik kan ze net zo goed direct allemaal invullen. (Alfred-ic, final reflection(Aangenaam))

In the iPad condition, one remark was made about the time intensity of the participation as well. This informal caregiver especially mentioned that he has a busy schedule, so every extra task can be seen as a burden. This was only one comment in the three weeks of testing and none of the other participants in the iPad condition made any comments about the time intensity of the research activity. This might indicate that it is more a general comment than on the method specifically.

[Met al die ziekenhuisbezoeken] heb ik het heel erg druk en dan dit [meedoen met onderzoek] erbij, volgens mijn vrouw loop ik wel 'ns over (Thomas - ic, ipad)

Three weeks of testing was not judged as being too much. Some informal caregivers in the probe game thought it was enough as it confronted them with the loss in abilities of their spouse on a daily basis. Furthermore people who participated in the game alone, preferred to answer the questions all at once to save time. Since they experience the game differently from the people who actually play it together, this answer behavior seem to be more logical. In general, the lives of the participants can be hectic, which might affect the experience of time intensity. Some days the time intensity of participation might be judged differently than on another day.

5.3.3 Fun to participate

To keep a long-lasting motivation in the participants, it is expected that the enjoyment one experiences during participating can be influencing this motivation. Aspects that are regarded as fun in both methods are elaborated.

5.3.3.1 Involvement

There were a couple of participants explicitly indicating how enjoyable they judged their involvement in participation. One of the informal caregivers in the iPad condition, did not understand why some of the questions were about her. This might indicate that it was not totally clear that we were interested in both the experiences of the informal caregiver as well as the experiences of the dementia patient. The misunderstanding resulted in a bit of offended feeling in this informal caregiver, causing less enjoyment in participating.

Mevrouw vraagt zich wel af waarom de vraag wordt gesteld waarom zij zich fit voelt. "Ik mankeer toch niets? Ik zit niet onder die lamp, wij zijn niet twee oude besjes onder een lamp"[...] "Ik denk niet hoi-hoi, wat leuk dat ik weer mee mag doen". (Shannon - ic, final reflection(iPad))

Others did not mention this misunderstanding, in neither the iPad condition nor the probe game. Instead, one informal caregiver in the probe game condition explains that she felt the shared involvement of her and her partner was an added value of the game compared to regular questionnaires. This contributed to the feelings of enjoyment in the research activity.

Mevrouw ziet ook de meerwaarde t.o.v. een vragenlijst. "Anders moet ik alles zelf doen en er ontstaat vaak wrevel bij meneer omdat hij het niet begrijpt." Nu was er actie vanuit zichzelf[...]. Het is hoe dan ook leuker dan een vragenlijst. (Geraldine-ic, final reflection(Aangenaam))

The purpose of research, so that there is an interest in both dementia patient and informal caregiver, should be clear to the participants to appreciate the required involvement. If this is clear, or supported such as in the probe game, it can be an extra factor in the enjoyment of participating.

5.3.3.2 *The tool itself*

In both methods there were remarks about the actual tool (the game or the iPad device) and how people judge this. People who like to play games are especially suitable participants for the probe game. The two couples who were most elaborate in their answering (and used all answer options) reported to enjoy playing games in general. One of these couples even played the game with friends, which is an indication that probe game was actually experienced as a game by the participants.

Wij zijn gek op spelletjes. (Beatrice + Bernard, final reflection(Aangenaam))

Over het algemeen zijn de mensen enthousiast over het spel, ze hebben het zelfs een keer met vrienden gespeeld en toen hebben ze vreselijk gelachen. [Geraldine] is een spelletjesmens, maar [George] eigenlijk niet. Toch sloot het goed aan. (Geraldine + George, final reflection(Aangenaam))

In the iPad condition, it is important to have at least a bit of interest in new technologies to be able to enjoy working with the device. If this is the case, than the participants might especially like the fact that they can try out this new device. The informal caregiver that reported this, however, was not more extensive in filling the comment box. Most participants also reported that children and grandchildren were surprised to see the iPad and liked to play with it as well.

Ik heb moeite om de iPad te bedienen, terwijl dat [naam onderzoeker] [dat] toch goed aan mij heeft uitgelegd. Ik probeer dan de vragenlijst zo goed mogelijk in te vullen (Thomas-ic, ipad)

Mevrouw is erg techsavvy ; een grote Mac maar ook een windowslaptop, een ereader en mevrouw gaf ook aan dat ze aan het twijfelen was om een ipad aan te schaffen dus vond het erg leuk een tijdje gebruik te kunnen maken van eentje tijdens het onderzoek. (Vivian - ic, final reflection(Aangenaam))

Both methods have a tool that can serve as interesting for people who are not participating in research. The enjoyable aspect of the tool can improve the extent that people contribute in research, although this was not noticeable in the iPad condition.

5.3.3.3 *Humor*

The use of humor in the answering of the questions, is regarded as clear evidence that participants experienced enjoyment in their participation. This was solely found in the probe game data. Four participants use some humor in their answering, by laughing during an audio recording, using silly remarks or jokes with a double meaning. All answer options give the possibility to use humor, as there was also a random photo made where one of the participants and a friend are laughing (Figure 30). It seems that people especially show humor in their answering when they are with people who are not involved in the research themselves.

[over geluiden in huis] Huis is van 1960 en stenen binnenmuren dus gehorig. Maar alles went, zelfs een vent. (Alfred - ic, notebook)

[over of mensen spelletjes spelen leuk vinden] "Eerlijk antwoorden!" -gelach- "Ja dat doe ik graag." En wat vind je dan een leuk spel? - gelach - Zeg op! "[onverstaanbaar]" -gelach- Ja ik kan dit niet wissen.(Geraldine + friend, audio)

Mooie spullen vind ik een piano, orgel, kortom muziekinstrumenten, bladmuziek en niet te vergeten mijn vrouw. (Bernard - ic, audio)

[geroezemoes op de achtergrond Vriend spreekt in] Zo nu ken ik opnemen. Hallo? [zet deftige stem op] Dit is [Clara] en [Charles] [Clara op achtergrond: "Dat hoort ze allemaal hoor, mergen.. zij luistert dat allemaal

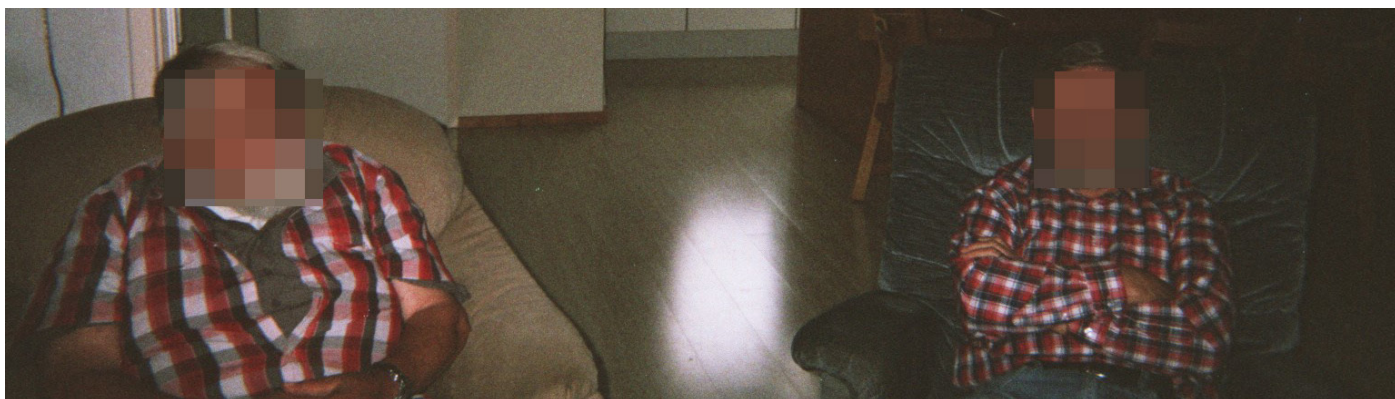


Figure 30. Random picture when playing with friends, laughing faces. (Geraldine + George, photo camera)

af. *Vriendin: "Zet dan stop!' Nee da geeft niks, ze mag da gerust heuren haha] We zijn net teruggekomen uit Spanje [Charles lacht] en we wensen u nog een fijne dag [Charles lacht] [Clara: pinksterdag!]. En morgen ook nog zo'n fijne dag, pinksterdag. [Clara: Ik hoop dat het goei weer is] Ik hoop voor u dat het mooi weer wordt - gelach- (Clara + Charles + friends, audio)*

What the exact reason for this humor is, is not clear from the data. The latter example is from the participant who did not deliver any probe game data, and of whom the informal caregiver was not specifically interested in the probe game during meetings with the researcher. The same goes for Alfred, who individually answered all questions at once. They might have not taken the answering of at least some of the questions seriously. The other examples are from the people who delivered much data, so we expect that they were mainly having fun with the answers options or questions. Whatever the reason is, all examples show that people had fun during the answering of these specific questions.

The shared involvement in the probe game can increase the enjoyment level of participants. Both tools in the used methods (the game and the iPad device) can enhance the fun in participating, especially when other people can be involved. In the probe game, this can lead to more extensive partaking in the research activity, as well as having clear fun when using humor in answering. The understanding of the method should be clear at all times to avoid offended feelings or people who do not take participating seriously.

5.3.4 Participant – researcher relationship

The involvement of the participant with the research is expected to also be reflected in the behavior toward the researcher and how they judged the interaction.

5.3.4.1 Thinking along with the researcher

In both conditions people thought along with the researcher. This is an indication that the people feel connected to the research and the results. These ideas were covering a wide variety of subjects, from ideas to ease the data analysis to ideas for follow-up studies. One informal caregiver in the iPad condition thought that the data analysis for the researcher was easier when working with an iPad instead of paper versions. A similar remark was made in the probe game condition when an informal caregiver adjusted the way of playing the game to help the easing of the data analysis as well. These examples indicate that people felt connected with the researcher as they did not want to increase the workload.

De iPad lijkt wel een handig middel voor de data verwerking oppert meneer. (Raymond - ic, final reflection(Pad))
De eerste keer hield hij de vragen in een soort waaier om er 1 uit te kiezen maar toen bedacht hij dat het voor de onderzoeker makkelijker zou zijn om het vraag na vraag te doen [door de nummering van de kaartjes].(Bernard - ic, final reflection(Aangenaam))

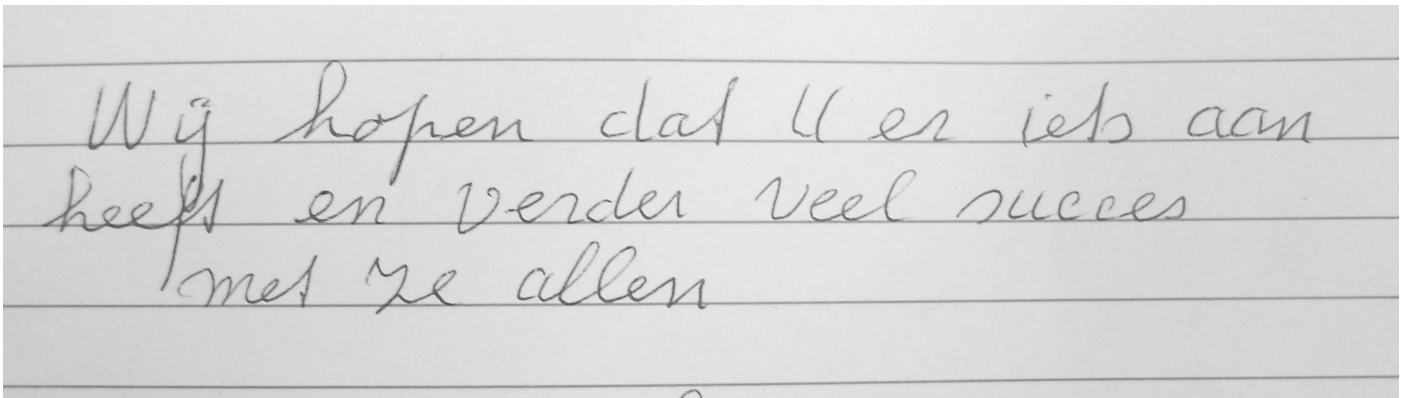


Figure 30. "We hope that our contribution is valuable for you. Good luck, everyone!"(Evelyn + Edwin, notebook)

Another remark was about an improvement for future studies, to include a picture of the researcher onto the information letter. This would be useful for the dementia patient to remember who the researcher was. This is not only an indication that this participant thought along with the researcher, but also that she regarded the dementia patient-researcher relationship as important too.

Mevrouw gaf aan dat het handig zou zijn als er een foto van de onderzoeker op de informatiebrief zou staan voor de dementerende is dat handig.(Geraldine - ic, final reflection(Aangenaam))

In both methods there were participants actively thinking along with the researcher. This shows that the people felt involved with the study. People are keen on contributing that is useful for the research (Figure 30). This might be more because the interaction between researcher and participant was regarded as pleasant (which we cover in the following subparagraph) instead of the exact design of the method.

5.3.4.2 Interaction between researcher and participant

The attitude of the researcher in interaction with the participants is crucial for a good participant-researcher relationship. Participants want the researcher to be more than a researcher. 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.

Verder vonden ze de benadering ook prettig "Toen jij na de eerste keer weg was dachten we, zo eindelijk iemand die met mensen om kan gaan". (Vivian + Victor, final reflection(iPad))

It is sometimes difficult to keep this balance. The final interview with one of the informal caregivers illustrates this. He was so overwhelmed with all the events of the last weeks that the researchers were unable to properly discuss all topics of the final interview, and instead talked about his life and his problems.

Tijdens het eindgesprek is mevrouw niet aanwezig, waardoor meneer voluit praat. Uiteindelijk een uur geweest, maar weinig over het onderzoek kunnen praten omdat meneer veel vertelde over zijn eigen gezondheid en die van mevrouw. (Thomas-ic, final reflection(iPad))

For the feelings of involvement, the interaction between participants and researcher is important. A right balance between talking about the project and about the people's everyday life is crucial. The researcher should be prepared that keeping this balance is not always possible when working with people who face troubles with the dementia disease in their lives.

When a proper participant-researcher relationship is established, participants are willing to think along with the researcher. This relationship is mainly created when the researcher finds a good balance between

the topics in meetings. The focus should not only be the objectives of the study, but should also include the topics that the participants want to discuss.

5.3.5 Reasons to enroll and participating in future

If people feel involved and motivated, it is assumed that they would like to participate in future research again. Since the reasons to enroll in research seem to differ among the participants, these are of interest to identify as those reasons might influence the re-enrollment in future research as well.

5.3.5.1 Reasons to enroll

There are two main categories of reasons why people participate in the current study: personal benefits or reasons to do good for the dementia community. Personal benefits are related to the effects of the prototype on themselves as well as that they have the feeling to benefit in a later moment in time. Reasons to do good for the dementia community are to contribute to the general understanding of the dementia disease and provide insights for possible products. These particular reasons are inseparable from the feelings of useful contribution of participating.

Personal reasoning:

“Uiteindelijk profiteer ik ook van mijn eigen bijdrage”.(Charles - dp, final reflection(Aangenaam))

Men vond de lichttherapielamp geen succes dus wilden ze kijken of dat het op een ander manier wellicht wel werkt. (Shannon + Simon, final reflection(iPad))

“Als je eenmaal een keer hebt meegedaan, dan zit je in de loop en wordt je weer benaderd. Dat is prettig voor het geval als er echt iets wordt gevonden.” (Thomas - ic, final reflection(iPad))

For the dementia community:

Ze hoopt dat haar bijdrage nuttig is geweest voor het onderzoek want dat vind ze belangrijk. Alles wat je ermee wint, is mooi meegenomen. Er [de lamp] kan iemand veel plezier van hebben. (Danielle - dp, final reflection(Aangenaam))

De reden waarom mensen meedoen met het onderzoek is dat als niemand het doet, het ook niets oplevert. Als we iets kunnen bijdragen dan is het goed. (Evelyn + Edwin, final reflection(Aangenaam))

“Ik ben blij dat ik mee mag doen, zo hopen we dat er iets gevonden wordt want er hebben zoveel mensen last van deze ziekte.” (Flora-ic, final reflection(Aangenaam))

If people are approached for research, it is key to understand why they would want to enroll. If they have personal reasons, a prototype that does not show immediate benefits will cause more dissatisfaction with the participation. Special care is needed to provide them with information why their contribution is relevant, in order to increase their motivation for future research. This information should focus on personal benefits, while the information for people who are participating for the dementia community should focus on the benefits on community levels.

5.3.5.2 Participating in future

All the participants indicated that they would enroll in future research from the Innovate Dementia project when they were invited again. Only one informal caregiver, in the probe game condition, attached a proviso that the method should be made more brief. He was also one of the informal caregivers who might have experienced the partaking in research as confronting (as discussed in 5.1.3.1 Confrontation) and is eager to protect his spouse.

Als het een beknopte methode is, dan zijn de mensen bereid nog eens mee te doen met een onderzoek. Men doet over het algemeen veel mee met onderzoeken zoals o.a. van de gemeente Eindhoven [..], zolang het niet te langdradig is. (Dick - ic, final reflection(Aangenaam))

Ondanks dat dit product niet werkte voor deze mensen, vonden ze het toch niet erg om mee te doen. Ze zouden zo weer mee doen met een onderzoek (Geraldine + George, final reflection(Aangenaam))

Ze zouden zo weer meedoen met een volgend onderzoek "Maar bij de derde keer moet je betalen" [lacherig]. (Vivian + Victor, final reflection(iPad))

This result can be seen as a validation of the results from 5.3.1 General subjective evaluation of participation, as people indeed did not judge their participation in the current study as inconvenient because they would enroll in future similar research too. This is true for people who worked with the probe game as well as with the iPad.

It is important to know why people enroll in research to be able to provide the right type of information about the project and about the value of their contribution. This will keep the participants involved and motivated to participate in future research as well. The amount of confrontation people experienced during the study, might be influencing their future participation.

We found that a couple of factors influenced the feelings of involvement and motivation in both informal caregiver and dementia patient. There were no big differences between the people in the probe game and the iPad questionnaire on how they judged the participation. All people are also willing to partake in future research of the Innovate Dementia project as well. The three weeks of testing was not judged as being too much either, although informal caregivers of the probe game felt that this period was enough. In the probe game, the loss in abilities of the dementia patients are more apparent, which might be regarded as confronting for the informal caregivers. This might also influence future participation. Providing conclusive and suitable information on what people might expect from the study, is vital.

It is important how the participant experienced the probe game. If they did not experience it as a game, their answering behavior was different as they answered all questions at once. Others showed real enjoyment in the research activity as humor was used in some of the answers. The shared involvement enabled the fun in participating and it even resulted in involving people from outside the research as well. The iPad device also involved people from outside the research, but only as the function of an interesting gadget.

For the feelings of involvement, the interaction between participants and researcher is important. A right balance between talking about the project and about the people's everyday life is crucial. The researcher should be prepared to keeping this balance is not always possible when working with people who face troubles with the dementia disease in their lives. Eventually a good participant-researcher can enhance the contribution the participants want to deliver.

5.4 Data & Researcher

The researcher should benefit from the generated data in order to be able to draw evaluative conclusions. The generated data should be rich and give all insights needed for redesigning innovations. Aspects of doing research, such as time intensity of the conducting and analysis of research, need consideration.

5.4.1 Reflection on time intensiveness

One aspect that needs consideration is the time intensiveness of the research activity for the researcher. During the actual test period, the difference in time intensiveness between the two methods is not apparent. In both the iPad and the probe game condition, the number of meetings with the participants is the same. The process of the probe game is, however, more time intense since the development of the method took more time than for the iPad questionnaire. This was because it was the first time that the probe game was used, while the iPad was used in previous evaluation rounds. Besides, the actual making of the question cards cost more time compared with the construction of the digital questionnaire. After the test period, the probe game was again more time intensive compared to the iPad questionnaire. Since the data from the latter was already digitalized and stored online, no extra time was needed to make the data usable. The data from the probe game needed digitalization of written, audio and photographic data. Transcribing the audio data and the development of the photos can be considered as time intensive.

The research process of the probe game is more time intensive than the process of the iPad questionnaire.

5.4.2 Reflection on data

Different aspects of the data are considered in this subparagraph in order to qualify the data coming from both methods. The following aspects are elaborated: type of data, and the difference in data between answer options and digital data.

5.4.2.1 Type of data

The type of data we were aiming for in the current study was qualitative, first-hand evaluative data. The data of the probe game seems to be more qualitative in nature, compared to the data from the iPad. This was mainly due to the type of questions in the iPad questionnaire, which were closed-ended. If the participant was not elaborative in the remarks box, the exact reason for giving certain answers seems to be unclear. The probe game data increased the dynamic understanding of the lives of the participants. Not only the written text (which is richer than digital text) but also the input of audio and photographic data, shows who the participants are in multiple ways.

First-hand data from the people with dementia themselves is generated more in the probe game than in the iPad questionnaire. There is clear evidence in both audio and written data, that the dementia patients have contributed to the research themselves. This cannot be concluded from the iPad data, as this method generated digital data and it is therefore harder to identify who made an entry. From the final interviews, it appeared that the informal caregivers were the only ones who worked with the iPad.

From both methods in the current study, we gained insights in the evaluation of the Vitaallicht lamp (details in 4. Results, part 1). The specific evaluation areas that are covered are different for the iPad questionnaire compared to the probe game. The probe game data seems to reveal more information on how the user rates the aesthetics and what the exact context is where the prototype is placed. The iPad data gives insights in how often people used the lamp and whether they noticed effects on a daily basis. These areas are all relevant for the evaluation process, but it is an evident difference.

5.4.2.2 Written, audio, photographic and digital data

In the current study, we dealt with four kinds of data: written, audio, photographic (from the probe game) and digital data (from the iPad). Each kind of data had its own benefits.

In the written and audio data, it is easy to identify who made the entry, this is more difficult in the photographic data and in the current digital data, it was impossible. For this study, this was important since we wanted to know what the exact contribution was of the dementia patient.

Data from the three different answer options in the probe game contained more than just the answer to the question. For example, the written data clearly showed some of the language difficulties and troubles a dementia patient faced with writing. It also showed that another dementia patient was still very capable in writing her answers down. Although we did not ask how people judge their language abilities, we got clear evidence in the variety of problems.

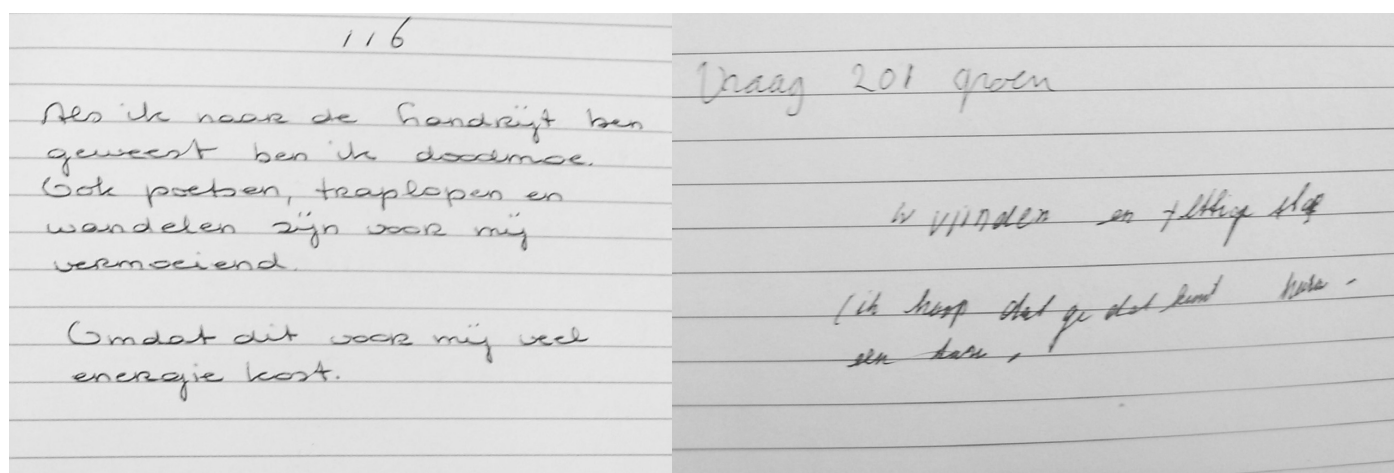


Figure 31. Written data shows differences in writing abilities among dementia patients.

The audio data gave insights in the interaction between the dementia patient and the informal caregiver to an extent that would not have been generated otherwise (more information in 5.2.2.2 Role of informal caregiver). This insight showed the possibilities of a voice recorder to capture events in the home situation of people with dementia and their caregivers, without researcher influences. For the Living Lab methodology, this is an invaluable insight. The number of words was counted in the notebook and audio

Table 4. Average number of words per answer

Average of words in written text	Average of words in spoken text
Dementia patients: 19.00	Dementia patients: 34.66
Informal caregivers: 26.91	Informal caregivers: 46.96

data of participants who used both answer options. There is an apparent difference between the average number of words used per answer in the written text in the notebooks compared to the spoken text in the audio data among both dementia patients and informal caregivers. This indicates the richness of the audio data in a more objective way.

The photographic data in this study showed the richness of pictures compared to plain text. For example, the photos of the current lamps in the home environment of the participant, immediately show that the looks of the Vitaallichtlamp are not congruent with the interior design. The pictures support the other data to contribute to a better understanding of what the participants mean. Since the photos were not used as elicitation material (which was the intention), it is sometimes hard to identify what the photo exactly represents. This photo elicitation is still something to consider in interviewing people with dementia.

The digital data in the current study did not contain any extra insights than just plain answers. This was mainly due to the limited functionality of the used questionnaire. Self-motivation from the participants is needed to make extensive use of the remark box, especially since data cannot be reviewed later on. Despite that, there were some benefits in this data as well. The research was able to access the data as soon as the participants made an entry. This was used only to check whether people might have had difficulties, but it could have been served as discussion guidelines during the meetings. Next to that, the data is very clean so there is no need to decode any handwriting or listening to a three hour audio recording. The fact that the data is clean is due to the easiness of rectifying errors. That was a reason for one informal caregiver in the probe game to use his computer instead of one of the answer options provided and he handed his answers in via printed handouts. He indicated to be insecure about his language skills. Another informal caregiver also indicated that she liked this functionality of digital entries.

Wat mevrouw ook prettig vond, was dat ze fouten snel kon herstellen op de ipad i.t.t. een papieren vragenlijst.
(Vivian - ic, final reflection(iPad))

The probe game generated qualitative, first hand evaluative data. The evaluation areas covered by this method were mainly specific evaluations on design, lighting and context. The written data from the probe game shows insights in the problems that dementia patients face with language and writing. It also showed that there are differences in these problems among participants. The written data and the audio data help to identify who the producer is. Furthermore, the audio data shows unique insights in the interaction between informal caregiver and dementia patient, within the context of the own home environment. The audio data is rich data, which is more extensive than the written text in general. The photographic data from the probe game supports the input via other answer options. In the current study, the photos were not used in elicitation, which might have created more value in this data.

The ipad data is generating less qualitative data, which is, to our knowledge, not directly coming from the dementia patients themselves. It did create evaluative data, mainly about the exact use of the prototype and how the people rated this use concerning different aspects. The iPad questionnaire did not make use of many digital opportunities. Self-motivation of the participants needs to be high in order to get more insight from the remark box. The data of the iPad questionnaire was directly accessible for the researcher and could have been used during discussions with the participants. The data from the iPad is clean, since the rectification of errors is easier for the participant. One distinct advantage of the iPad method is the lower amount of time required from the researcher.

6 DISCUSSION

The goal for this project was to find a new research activity that captured first-hand experiences from the person with dementia to complement the currently used caregiver-questionnaires in a meaningful and unique way. These individuals in the early stages of Dementia were researched in their own home environment as part of the research structure of a Living Lab. Three main objectives were the focus for this new qualitative research method. First, we wanted to make the dementia patient's voice heard in the research when taking into account the memory deficits, the difficulties with language, the lowered capacity to concentrate and troubles with seeing the complete picture. The second objective pertains to the experience of participating as an important factor. Participants should not be burdened by the method and we paid extra attention to factors that might influence feelings of involvement and create motivation. Lastly, the researcher should benefit from the generated data in order to be able to draw evaluative conclusions. The generated data should be rich and give all insights needed to draw evaluative conclusions. Aspects of doing research, such as time intensity of the conducting and analysis of research, needed consideration.

We combined several existing qualitative research methods into one probe game 'Aangenaam', which is the new research method in the current study. We compared the probe game with the more conventional iPad questionnaire, which was intended for the caregiver. We expected that combining several aspects of different methods in one research activity, would provide insights whether aspects of these methods were beneficial for dementia patients. Three methods appeared to be interesting for applying in the Living Lab of the Innovate Dementia project: photo elicitation study, cultural (playful) probes and the audio diary. By complementing these methods with interviews and an option to write, we expected to have a complete set of options that suited the dementia patients. The flexibility of the combined methods was expected to enable the dementia patient to partake in a research activity that considered their abilities. By providing a comfortable ambiance by means of a game to play with the informal caregiver, it was assumed that the dementia patient would feel less burdened and more involved with the study. With a right set of questions, the probe game would generate rich evaluative data that gives a dynamic understanding of the lives of the participants.

6.1 Findings from the current study

First-hand data from the people with dementia themselves is generated more in the probe game than in the iPad questionnaire. There is clear evidence in both audio and written data, that the dementia patients have contributed to the research themselves. This cannot be concluded from the iPad data, as this method generated digital data and it is therefore harder to identify who made an entry. From the final reflections, it appeared that the informal caregivers were the only ones who worked with the iPad. The iPad is not a device that could be used by a dementia patient individually, unlike the probe game that was used by some dementia patients individually.

One of the objectives of the method was that it would generate evaluative data. From both methods in the current study, we gained insights in the evaluation of the Vitaallicht lamp. The specific evaluation areas that are covered are different for the iPad questionnaire compared to the probe game. As the probe game data revealed more information on the user experience (aesthetics and context), the iPad data seem to be about functionality (how often did people use the lamp and did the lamp heighten their energy levels). These two areas are both relevant for the evaluation process (McNamara & Kirakowski, 2006), so the choice should be made what type of information is more needed at the particular development phase of the evaluated prototype.

The involvement of the dementia patient is more apparent in the probe game than in the iPad questionnaire. The inabilities of the participating dementia patients become more apparent in the probe game too. Their spouses might be experience this as confronting. Participating in research about dementia will always

prompt people with the fact that this disease is a part of their lives. The amount of confrontation the informal caregivers experienced during the study, might be influencing how they experienced the time intensity of participating and how willing they are to re-enrol in future studies. Since the probe game was mainly focusing on how the dementia patients would experience participating, we did not take into account that the involvement of the dementia patient could cause this confrontation for the informal caregiver. Couples with a dementia patient in the middle to later stage, or couples who did not experience the probe game as a game activity, experienced this confrontation to a greater extent. Extra care is needed to provide the informal caregivers with clear insights in what they can expect when their spouses participate actively in a research activity. Real enjoyment in the research activity can be accomplished, when the probe game is experienced as a game. The shared involvement of both informal caregiver as well as dementia patient, enabled the fun in participating and it sometimes even resulted in involving people from outside the research. The experience of playing a game also supported the use of multiple answer options and to give answers that are more extensive.

In both methods we saw that the involvement of the dementia patient was based on two things: the progression of the disease and the attitude of the informal caregiver. The progression of the disease can be the reason for choosing different types of methods that are not participatory, such as observation. Or other options are required that do not include language production or understanding. In the probe game we tried to accomplish this by means of providing a photo camera for the participant, although not all participants seem to make use of this.

The dementia patients themselves try to cover their inabilities. As dementia patients have a history of failing in daily life (Topo & östlund, 2009), they might experience extra burden to be successful in answering question in research, as was evident in the current study too. For this reason, the questions and guidelines in the methods should be constructed with care in order to avoid feelings of being tested. People with dementia can have troubles understanding certain words or keeping the overview in sentences that are very long. The informal caregiver can help them by rephrasing words or restructuring extensive questions.

The audio data gave insights in these 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, without researcher influences. For the Living Lab methodology, this is an invaluable insight. Since we provided the participants with three answer options, most people chose to work with the notebook solely. This is because people are already familiar with writing they might be a bit reluctant to try something they do not know. Especially when the dementia patient shows language deterioration, the usefulness of a voice recorder is not evident for the informal caregiver. Besides, a new device (voice recorder in the current study) can be a bit scary for the dementia patient at first. Extra time is needed to become accustomed to the research activity. The photo camera was useful for creating photos for illustrative purposes but the pictures were not used as elicitation, which was the intention. This was mainly due to the time intensive recruitment of the participants, resulting in limited time for scheduling extra interviews. This photo elicitation is still something to consider in interviewing people with dementia.

In general, in qualitative research the participant-research relationship is of great importance to create trust and enable the participants to open up towards the researcher (Charmaz, 2004). For the current project, with the Living Lab approach, extra attention was paid to create this positive participant-research relationship. Building a relationship with participants with dementia requires that the researcher dedicates time, is flexible and is willing to remind the participants repeatedly who he or she is, why he or she is there, and what the aim is (Nygård, 2006). A right balance between talking about the project and about the people's everyday life is crucial. This balance is not always possible as people, who face troubles with

the dementia disease in their lives, sometimes need to tell their stories. A strong participant-researcher relationship can enhance the contribution the participants want to deliver. We still believe that developing a specially designed research method strengthens this researcher-participant relationship.

6.2 Limitations

Some factors might have influenced the findings in the current study. The researcher's standpoint, which affects the interpretation of the data, is elaborated in the next chapter (7. Reflexivity) .

The informed consent discussion in this field of research was not extensively part of the current study. As the participants have memory deficits, it is debatable how to ensure informed consent and with that, ethical issues on including dementia patients in research are raised. Traditional consent, as Dewing (2002) calls it, is based on a standard cognitive ability that is not present in people with dementia. This 'one size fits all' approach of informed consent is not sufficient for the great variety of abilities in people with dementia and should therefore be replaced by a more individual approach, which actively seeks consent by not only including verbal but also non-verbal and behavioral cues into account.

In the current study, we did not pay a lot of attention to this informed consent, although we emphasize the urgency of this part of doing research with possible vulnerable people. We do feel however that our participants were well aware about the purpose of the study and of their ability to quit at any point in time. The most important reason for this assumption is the extent of the gatekeeper involvement in the current project. The gatekeepers (according to Pratt, in Wilkinson, 2002) are informal and formal caregivers whose contribution should be valued because they may provide additional insights into the experiences of persons with dementia. By recruiting the participants via the GGzE and asking the informal caregiver to give their consent too, it is believed that the wellbeing of the patient was safeguarded. The households were provided with an explanation of the project and they were instructed to call the researcher whenever they felt uncomfortable or if something was not clear. Given that three households withdrew from the study, can be seen as evidence that people felt free to do so. However, the fact that caregivers might have a vested interest in convincing the person with dementia to participate, might not be underestimated in future studies (Bjørneby et al., 2004).

The crucial partaking of the informal caregiver is also creating doubts about their exact influence on the answers given by the dementia patient. In both conditions, the informal caregiver appears to fulfill the role of a researcher, or interviewer. This might not be easy for everyone. The informal caregivers of couples, who show a clear interaction during playing the probe game, can be identified as dominant partners. For them this interaction might be easier than for other couples with a different relationship. Some are especially careful with their spouse, others take charge of answering and another is given full responsibility for participation to their partner. The question remains what the effect of the interaction with the informal caregiver is on the answers of the dementia patients. Is more interaction resulting in answers that are too guided or are these answers representing the opinions of the patients especially well because of the relationship of many years' standing between the spouses?

The sample in the current study can be evaluated as biased because of a couple of reasons. First, the sample was recruited by members of the GGzE and with that included only people from the GGzE's database of clients. Clients from the GGzE usually have complex cases with multiple problems. In the current group of people, one was diagnosed with Autism Spectrum Disorders (ASD) and another with Posttraumatic stress disorder (PTSD). Other reported to have sleep apnea (one dementia patient and one informal caregiver). This might have affected the data from these participants, as not only dementia-related disabilities were present. However, we feel that the results did not differ much between these people so we therefore did

not treat their generated data differently. Secondly, several participants knew each other and were aware of the others' participation in the study as well. During the test period, they had an informal meeting where they also discussed the study so this might have had some influences on their feelings of participation. As we were not present during this meeting, we do not know what they exactly discussed.

Another thing that needs attention is the set-up of the current research. In researching the methodology, it was inevitable to have two studies at once: evaluation of the Vitaallicht lamp and the evaluation of the used method. In order to judge whether the used method could generate evaluative data, there was a need for something to evaluate. Since one of the focusses was to find a method that was not burdening the participants, doing two studies at once is contradicting this focus. As participants were asked about both the Vitaallicht lamp and the used method, this might have been contributing to the feelings of burden we wanted to avoid.

The final reflections would have been more valuable when scheduled later in the procedure. It would have created an extra check of the interpretation of the data with the people who created the data. This "member checking" is one way of validating qualitative data (Lincoln & Guba, 1985, cited in Creswell & Miller, 2000). Especially the use of elicitation with this user group could have been evaluated, to see the exact benefits of this tactic on the interview session. As the test periods of all participants were widespread over a couple of months, it would have been difficult to first analyze all data and then schedule the final interviews.

6.3 Implications

A couple of key lessons learned in the current study include the need for flexibility, the importance of informal caregiver and researcher, and the use of the probe game.

What can be concluded from the current study, is that the user group 'dementia patients' has a great variety in all sorts of areas (abilities, interests, relationships, how they experience problems, how they solve problems etc.). The question is almost raised whether you could define these people as one 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 (cited in Topo & östlund, 2009) puts it: "Big difference between people makes it important to know WHO has the disease rather than just WHICH disease". This is reflected in the great variety we received from the participants in either of the two methods. Some liked to play with the game, others had great difficulties. Some were happy to have the iPad; 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. How they experienced partaking in the current study is therefore different for everyone as well. Accordingly, we cannot state that either the iPad or the probe game is suitable for every person with dementia and his or her caregiver. That being said, the results of the current study do show insights in what researchers can try to use, and need to pay attention to, in order to involve dementia patients and informal caregivers in a comfortable way in research. A flexible solution is key for this diverse user group.

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 very able to give the help that is needed. On the other hand, the dementia patient seems to accept this help easily because of the familiar relationship. As a researcher, it is key to not underestimate the time and effort needed from the informal caregiver to do this. They were the people that experienced participating as more burdensome than the dementia patients did in general. It is therefore that special care is needed to inform the caregivers and support them in every way that is possible. The need to be aware of their value

and contribution to the project, which relates to the discussion about informed consent. This is needed from the informal caregiver too.

From the talks with the participants, it became apparent that it is important that the researcher pays enough attention to and spends enough time with them, in order to create a positive experience with participating in research. The role of the researcher should not be underestimated in any case to judge whether participating is not burdening the participant (both dementia patient and informal caregiver). As the reason to partake in the study might be that people are desperate to find some solution for their situation, they will not easily admit that they are unable to participate. During the meetings with the participants, the researcher should pay serious attention to signals, such as having a hard time focusing on the interview questions, talking about intense personal experiences and showing fatigue during the talk, and decide whether continuing would be distressing for the participant. In order to do so, sufficient time is needed to build a steady participant-research relationship.

Some questions in the game were unanswered without any clear reason, so therefore the questions should need more consideration on forehand, based on type of words and syntax. As preferences differed among participants, perhaps a greater variety of types of questions could be provided (open-ended/closed, with or without gradation etc.). For the probe game, it is of high importance 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. However, it is not evident that the stack of cards itself had an added value in the probe game. Some participants lost track because of these stacks and the idea of answering all those questions could be demotivating. It seems that the more extensive discussion cards used by Huizing & Van Den Brandt-Van Heek (2009) in their game could be beneficial for the current probe game as well. This way people might be more stimulated to discuss the topics, instead of just answering the questions.

The probe game showed the possibilities of including dementia patients in research. As already mentioned, not for every household the probe game would be suitable. Several factors such as the abilities of the dementia patient and the attitude of the informal caregiver are crucial for a successful use of the method. In addition, not for every type of evaluation round the probe game will be useful. However, the probe game can be a method that gives insights for the researcher and enjoyment for the participants. 'Aangenaam' can be a pleasant way to meet your participants.

To judge the interpretation of the qualitative data in the current study, it is of great importance to know the standpoint from the researcher.

The researcher has a background in Industrial Design and she is therefore interested in iterative design processes with an user-centered approach. She has had experiences with dementia patients in the later stage of dementia in a design project during her internship in 2009. From that project onwards, she got fascinated with the involvement of people in research, who need a special approach due to their situation or disease. During her Human-Technology Interaction master's she conducted research with children with Autism, parents in a Neonatal Intensive Care Unit and eventually with people with dementia in the early stage (the current study). This is her first research study with a special focus on the methodology. The researcher does not have personal experiences with dementia in her family or friends. She has a keen interest in the healthcare sector, as close relatives are working in this field. Based on their stories, the researcher feels the urge to contribute to the improvement of the healthcare system in the Netherlands in an almost idealistic fashion.

The researcher feels that she is objective, albeit she sometimes has difficulties with having an objective attitude during personal talks with participants. The fact that the Vitaallicht lamp is not her own design, helps to practice objectivity in questioning. Feedback rounds with several supervisors guarantees a critical understanding of the current research. The researcher feels that she benefits from her age (25 years old) in this research, as it helps avoiding possible power inequalities between participants and researcher (Wilkinson, 2002).

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9 APPENDIX

Appendix A - Questions of probe game

- 101 Wat zijn activiteiten die u graag buiten doet?
- 102* Wat zijn activiteiten die u graag binnen doet?
- 103 Wat zijn activiteiten die u graag 's ochtends doet? Zijn er activiteiten die u niet graag 's ochtends doet?
- 104 Wat zijn activiteiten die u graag 's avonds doet? Zijn er activiteiten die u niet graag 's avonds doet?
- 105 Hoe belangrijk is een goede nachtrust voor u?
- 106* Valt u snel in slaap? Wat doet u als u niet in slaap kunt komen?
- 107* Hoe belangrijk vindt u het om te sporten of uw lichaam in conditie te houden? Wat doet u dan zoal?
- 108 Kunt u zich voorstellen hoe het is om slaapproblemen te hebben?
- 109 Ziet u eten als pure noodzaak of als gezellige bezigheid?
- 110 Houdt u van lekker eten? Wat eet u graag?
- 111 Heeft u een ritueel voor, tijdens of na het eten?
- 112 Wat zou u nog weleens willen doen/leren?
- 113 Verveelt u zich weleens? Wat gaat u dan doen?
- 114* Telefooneert u vaak op een dag? Vindt u dat een prettige manier van communiceren?
- 115 Wat zijn typische dingen die u vergeet? Vindt u dat vervelend? Heeft u hier een oplossing voor?
- 116 Waar wordt u moe van? Waarom wordt u daar moe van?
- 117 Staat u graag vroeg op of slaapt u liever even uit? Gaat u graag vroeg naar bed of blijft u graag lekker lang op?
- 118 Zijn er activiteiten op een dag die vervelend zijn, maar "die nou eenmaal moeten gebeuren?"
- 119* Hoe rust u uit van een zware klus of een dag werken?
- 120 Speelt u graag een spelletje? Wat vindt u een leuk spel?
- 121 Wat zijn activiteiten die u graag met anderen doet? Met wie doet u wat?
- 122 Heeft u bepaalde rituelen?
- 123 Luistert u vaak muziek? Op wat voor momenten luistert u graag muziek? Wat voor muziek luistert u dan?
- 124 Kijkt u vaak tv? Op wat voor momenten kijkt u graag tv? Wat voor tv programma's kijkt u dan?
- 125 Welke taken heeft u in het huishouden? Wat is leuk in het huishouden? Waaraan heeft u een hekel?
- 126 Wat vindt u prettig om te doen als u alleen bent?
- 127 Wat vindt u prettig om te doen als er anderen om u heen zijn?
- 128 Zijn er dingen die u moeilijk vindt om te doen?
- 129* Hoe belangrijk vindt u het om te sporten of uw lichaam in conditie te houden? Wat doet u dan zoal?
- 130 Bent u creatief? Waarin bent u creatief? Schilderen/naaien/meubels maken?
- 131 Leest u elke dag de krant? Zo ja, is dat om bij te blijven wat er allemaal gebeurt in de wereld, ter ontspanning of uit gewoonte?
- 132 Kunt u genieten van een goed boek? Wanneer leest u het liefst?
- 133 Vindt u het leuk om boodschappen te doen?
- 134* Telefooneert u vaak op een dag? Vindt u dat een prettige manier van communiceren?

- 135* Valt u snel in slaap? Wat doet u als u niet in slaap kunt komen?
- 136* Hoe rust u uit van een zware klus of een dag werken?
- 201 Wat vindt u prettig aan de stad waar u nu in woont? Zijn er ook dingen minder prettig?
- 202 Wat vindt u prettig aan de straat waar u nu in woont? Zijn er ook dingen minder prettig?
- 203 Bent u iemand die graag thuis is of gaat u graag naar buiten?
- 204 Wat zijn activiteiten die u graag buiten doet?
- 205 Hoe voelt u zich in deze omgeving? Waar komt dat door?
- 206* Vindt u het belangrijk om veel ramen te hebben in uw huis? Waarom wel/niet?
- 207 Welke technische apparaten in huis zijn onmisbaar voor u?
- 208 Vindt u het belangrijk om veel planten te hebben in uw huis? Waarom wel/niet?
- 209 Ziet u iets in deze ruimte waar u zuinig op bent?
- 210 Ziet u iets in deze ruimte wat eigenlijk wel weg zou mogen?
- 211 Ziet u hier voorwerpen die u een huiselijk gevoel geven?
- 212 Heeft het huis waar u woont geuren of geluiden die kenmerkend zijn voor uw huis?
- 213 Heeft u altijd in het huis gewoond waar u nu in woont? Waarom heeft u besloten (niet) te verhuizen?
- 214* Vindt u deze ruimte comfortabel? Wat maakt een ruimte comfortabel?
- 215 Hoe zou uw ideale huis eruit zien? Waar zou het staan?
- 216* Heeft u verschillende lampen in huis staan? Wanneer gaat welke lamp aan?
- 217 Hoe belangrijk is een tuin of een balkon voor u?
- 218 Vindt u de grootte van een huis belangrijk? Waarom wel/niet?
- 219 Vindt u het belangrijk om veel mooie spullen om u heen te hebben?
- 220 Welke technische apparaten in huis zijn onmisbaar voor u?
- 221* Vindt u het belangrijk om veel ramen te hebben in uw huis? Waarom wel/niet?
- 222 Wat mist u in uw huis?
- 223 Wat maakt uw huis een vertrouwde omgeving?
- 224* Welke kleuren ziet u veel in deze omgeving? Heeft u bewust voor deze kleuren gekozen?
- 225 Wat is uw lievelingsvoorwerp in deze ruimte?
- 226 Wat is een voorwerp in deze ruimte die voor u persoonlijk heel waardevol is, maar voor een onbekende wellicht niet?
- 227 Hoe voelt u zich in deze omgeving? Waar komt dat door?
- 228 Wat zijn activiteiten die u graag binnen doet?
- 229 Wat zou u willen veranderen aan deze omgeving? Waarom?
- 230 Is er genoeg licht in deze ruimte? Waarom wel/niet?
- 231 Is er genoeg gezelligheid in deze ruimte? Waarom wel/niet? Zo niet, hoe zou u dat kunnen veranderen?
- 232 Stoort u zich ergens aan in deze omgeving?
- 233 Vindt u het belangrijk om een plekje voor uzelf te hebben?
- 234* Vindt u deze ruimte comfortabel? Wat maakt een ruimte comfortabel?
- 235* Heeft u verschillende lampen in huis staan? Wanneer gaat welke lamp aan?
- 236* Welke kleuren ziet u veel in deze omgeving? Heeft u bewust voor deze kleuren gekozen?

- 301 Welke opleiding heeft u gevolgd? Waren er speciale vakken waar u in uitblonk? Waren dit ook de leukste vakken?
- 302 Wat vindt u belangrijk in het leven? Waarom is dit belangrijk voor u? Is het altijd belangrijk geweest?
- 303 Waar kunt u boos over worden? Waarom? Bent u hier vaak boos over? Hoe komt u over uw boosheid heen?
- 304 Waar kunt u verdrietig over worden? Waarom? Bent u hier vaak verdrietig over? Hoe wordt u dan weer vrolijk?
- 305 Waar kunt u blij van worden? Waarom? Bent u hier vaak blij om?
- 306 Waar bent u dankbaar voor in uw leven? Waarom? Bent u hier altijd dankbaar voor geweest?
- 307* Wat zou u nog weleens willen doen/leren?
- 308 Kunt u zich voorstellen hoe het is om heel arm / heel rijk te zijn?
- 309* Bent u iemand die graag nieuwe uitvindingen koopt of wacht u liever een tijdje om te kijken hoe een nieuw product bevalt?
- 310 Waar krijgt u energie van?
- 311* Hoe voelt u zich op dit moment? Bent u vrolijk? Bent u moe?
- 312 Bent u nieuwsgierig naar nieuwe uitvindingen?
- 313 Als u zichzelf mag omschrijven, wat vertelt u dan?
- 314 Waar kunt u boos over worden? Waarom? Bent u hier vaak boos over? Hoe komt u over uw boosheid heen?
- 315 Vindt u dat u in uw leven veranderd bent? Kunt u zeggen waarin?
- 316* Waarover kunt u zich wel eens druk maken?
- 317 Heeft u een idee wat ánderen van u vinden? Vindt u dat belangrijk?
- 318 Waar bent u goed in?
- 319 Wat geeft u houvast in uw leven?
- 320 Wat vindt u onmisbaar in uw leven?
- 321* Speelt u graag een spelletje? Wat vindt u een leuk spel?
- 322 Zijn er mensen die voor u een groot voorbeeld zijn?
- 323 Welke ervaringen in uw leven hebben grote indruk op u gemaakt?
- 324 Waar heeft u veel geld voor over?
- 325 Heeft u weleens spijt gehad van een bepaalde aankoop?
- 326 Wat vindt u dingen waarop je best kunt besparen?
- 327* Wat zou u nog weleens willen doen/leren?
- 328* Bent u iemand die graag nieuwe uitvindingen koopt of wacht u liever een tijdje om te kijken hoe een nieuw product bevalt?
- 329 Waar bent u fan van?
- 330 Vindt u het leuk om nieuwe mensen te leren kennen? Waar leert u nieuwe mensen kennen?
- 331 Bent u tevreden met hoe u eruit ziet? Is dat belangrijk voor u?
- 332* Speelt u graag een spelletje? Wat vindt u een leuk spel?
- 333 Wat zou u doen als u de loterij zou winnen?
- 334 Wat doet (heeft) u voor werk (gedaan)?
- 335* Hoe voelt u zich op dit moment? Bent u vrolijk? Bent u moe?

- 336* Waarover kunt u zich wel eens druk maken?
- 401 Heeft u verschillende lampen in huis staan? Wanneer gaat welke lamp aan?
- 402* Wat vindt u van de Vitaallicht lamp in uw huis?
- 403 Vindt u het licht van de Vitaallicht lamp nu prettig?
- 404 Wanneer is licht belangrijk voor u?
- 405 Wat vindt u mooi aan de Vitaallicht lamp? Wat vindt u niet mooi aan de Vitaallicht lamp?
- 406 Heeft u weleens de neiging om onder de lamp te gaan zitten? Wat gaat u dan doen?
- 407 Hoe voelt u zich op dit moment? Bent u vrolijk? Bent u moe?
- 408 Vindt u licht belangrijk voor de sfeer in huis? Is licht nog belangrijk voor andere dingen?
- 409 Staat de Vitaallicht lamp op de juiste plek?
- 410* Past de Vitaallicht lamp in uw huis?
- 411 Wat vindt u ervan dat de Vitaallicht lamp aan en uitgezet moet worden? Zou het fijn zijn als het automatisch ging?
- 412 Wat zou u willen veranderen aan de Vitaallicht lamp?
- 413 Hoeveel zou u betalen voor de Vitaallicht lamp?
- 414* Zou u een reden kunnen bedenken waarom de Vitaallicht lamp voor u beter/slechter is dan een reguliere lamp?
- 415 Vindt u het fijn om de Vitaallicht lamp in uw huis te hebben staan?
- 416 Bent u iemand die graag nieuwe uitvindingen koopt of wacht u liever een tijdje om te kijken hoe een nieuw product bevalt?
- 417* Bij welke activiteiten zou de Vitaallicht lamp u kunnen helpen? Bij welke activiteiten is de Vitaallicht lamp juist onhandig?
- 418* Heeft u het idee dat de Vitaallicht lamp iets bijdraagt in uw huis?
- 419 Vindt u de Vitaallicht lamp makkelijk in gebruik? Zijn er dingen onduidelijk aan de lamp?
- 420 Aan wie zou u de Vitaallicht lamp aanraden? Waarom? Wie zou u de Vitaallicht afraden?
- 421* Wat vindt u van de Vitaallicht lamp in uw huis?
- 422 Wat vindt u van de kleur van het licht van de Vitaallicht lamp?
- 423 Wat vindt u van de intensiteit van het licht van de Vitaallicht lamp?
- 424 Wat vindt u van de grootte van de Vitaallicht lamp?
- 425 Wat vindt u van de bediening van de Vitaallicht lamp?
- 426 Bent u liever binnenshuis of liever buitenshuis? Waarom?
- 427 Welke plekken in huis zijn licht? Welke plekken in huis zijn donker?
- 428* Heeft u het idee dat de Vitaallicht lamp iets bijdraagt in uw huis?
- 429 Op wat voor manier komt er nu licht in uw huis?
- 430 Vindt u het licht van de Vitaallicht lamp vergelijkbaar met zonlicht? Waarom wel/niet?
- 431 Waarom denkt u dat de lamp Vitaallicht heet? Waar denkt u nog meer aan bij die naam?
- 432 Hoe voelt u zich op dit moment? Bent u vrolijk? Bent u moe?
- 433 Kan een lamp mooi zijn? Of is een lamp puur functioneel? Zou een lamp nog meer functies kunnen hebben dan alleen licht geven?
- 434* Zou u een reden kunnen bedenken waarom de Vitaallicht lamp beter/slechter is dan een

reguliere lamp?

435* Past de Vitaallicht lamp in uw huis?

436* Bij welke activiteiten zou de Vitaallicht lamp u kunnen helpen? Bij welke activiteiten is de Vitaallicht lamp juist onhandig?

Appendix B - The exact procedure of a game of 'Aangenaam'

UITLEGBLAD "Aangenaam"

1. Kies een categorie
2. Pak een kaart van de categorie stapel en bepaal of u deze vraag wilt beantwoorden
3. Welk voorwerp staat er op de kaart:



De foto camera

Draai het rolletje door, d.m.v. het draaiwiel. Richt de camera en druk op de knop.



Het Notitieboekje

Gebruik voor elk antwoord een nieuw blad. Schrijf het nummer van de vraag op en vervolg met het antwoord op de vraag.



De voice recorder

Zet de voice recorder aan (ON) met het onderste schuifknopje (POWER) aan de linkerkant. Druk op de rode REC knop en vertel het nummer van de vraag en uw antwoord. Druk op STOP als u klaar bent met opnemen.

Vergeet niet de voice recorder weer uit (OFF/HOLD) te zetten na gebruik met het onderste schuifknopje (POWER) aan de linkerkant.

4. Stap 1 t/m 3 kunt u zo vaak herhalen als u wilt.
5. Bent u klaar met vragen beantwoorden voor vandaag? Noteer dan in het invulboekje de gegevens (zoals datum, tijdstip enz.). Er is hier ook ruimte om de vragen te evalueren.

Appendix C - iPad questionnaire

Vragenlijst Vitaallicht (A)

1. Hoeveel uur heeft u vandaag ongeveer buiten doorgebracht?

- Minder dan een half uur
- Tussen een half uur en anderhalf uur
- Tussen anderhalf uur en drie uur
- Tussen drie uur en vijf uur
- Meer dan vijf uur
- N.V.T.

2. Geef van de volgende stelling aan in hoeverre u dat vandaag ervaren heeft.

	Mee eens	Gedeeltelijk mee eens	Neutraal	Gedeeltelijk mee oneens	Mee oneens	N.V.T.
Vandaag heb ik voldoende beweging gehad:						
Vandaag heeft mijn partner voldoende beweging gehad:						
Afgelopen nacht heb ik goed geslapen:						
Afgelopen nacht heeft mijn partner goed geslapen:						
Ik voel me vandaag niet zo fit:						
Mijn partner is vandaag niet zo fit:						
Vandaag vond ik het prettig om mee te doen aan dit onderzoek:						

3. Verdere op of aanmerking: _____

Vragenlijst Vitaallicht (B)

1. Hoeveel uur heeft u vandaag in het licht van de lamp doorgebracht?

- Minder dan een half uur
- Tussen een half uur en anderhalf uur
- Tussen anderhalf uur en drie uur
- Tussen drie uur en vijf uur
- Meer dan vijf uur
- N.V.T.

2. Hoeveel uur heeft u vandaag in zonlicht doorgebracht?

- Minder dan een half uur
- Tussen een half uur en anderhalf uur
- Tussen anderhalf uur en drie uur

- o Tussen drie uur en vijf uur
- o Meer dan vijf uur
- o N.V.T.

3. Geef van de volgende stelling aan in hoeverre u dat vandaag ervaren heeft.

	Mee eens	Gedeeltelijk mee eens	Neutraal	Gedeeltelijk mee oneens	Mee oneens	N.V.T.
Vandaag heb ik voldoende beweging gehad:						
Vandaag heeft mijn partner voldoende beweging gehad:						
Afgelopen nacht heb ik goed geslapen:						
Afgelopen nacht heeft mijn partner goed geslapen:						
Ik voel me vandaag fit:						
Mijn partner is vandaag fit:						
Het is prettig om de VitaalLicht lamp overdag te gebruiken:						
Door de VitaalLicht lamp krijg ik meer energie:						
Het is niet erg om de VitaalLicht lamp in huis te hebben:						
Vandaag vond ik het prettig om mee te doen aan dit onderzoek:						

3. Verdere op of aanmerking: _____

Appendix D - Sleep quality questionnaire

Datum: _____

Proefpersoon nr: _____

Hoelaat bent u deze week gemiddeld naar bed gegaan 's avonds? _____

Viel u moeilijk/gemakkelijk in slaap? Erg moeilijk/Moeilijk/Gewoon/Gemakkelijk/Erg gemakkelijk

Hoelang duurde het deze week gemiddeld voordat u in slaap viel? _____

Hoelaat bent u deze week gemiddeld uit bed gegaan 's ochtends? _____

Werd u moeilijk/gemakkelijk wakker? Erg moeilijk/Moeilijk/Gewoon/Gemakkelijk/Erg gemakkelijk

Hoeveel uur per nacht heeft u deze week daadwerkelijk geslapen? _____

Wat vindt u van deze hoeveelheid slaap Absoluut te weinig/Te weinig/Genoeg/Veel/Absoluut te veel

Hoe rustig heeft u gemiddeld geslapen? Erg rusteloos/Rusteloos/Gewoon/Kalm/Erg kalm

Hoe uitgerust wordt u wakker? Absoluut niet/Niet/Gewoon/Wel/Helemaal

Bent u van de week 's nachts wakker geweest? Zo ja, wat was de reden?

Heeft u deze week gebruik gemaakt van slaap medicatie? Zo ja, wat was de reden?

Heeft u deze week overdag geslapen? Hoe vaak? _____

Heeft u deze week moeite gehad met wakker blijven tijdens bepaalde activiteiten? Zo ja, welke activiteiten?

Hoe fit voelde u zich deze week gemiddeld? Helemaal niet/Niet/Gewoon/Wel/Helemaal wel

Appendix E - Consent form

Toestemmingsverklaring
(Cliënt)

Innovate Dementia

Ik heb de informatiebrief voor de proefpersoon gelezen. Ik kon aanvullende vragen stellen. Mijn vragen zijn genoeg beantwoord. Ik had genoeg tijd om te beslissen of ik meedoe.

Ik weet dat meedoen helemaal vrijwillig is. Ik weet dat ik op ieder moment kan beslissen om toch niet mee te doen. Daarvoor hoef ik geen reden te geven.

Ik weet dat sommige mensen mijn gegevens kunnen zien. Die mensen horen allen bij de projectgroep Innovate Dementia.

Ik geef toestemming om mijn gegevens te gebruiken, voor de doelen die in de informatiebrief staan.

Ik geef toestemming om mijn onderzoeksgegevens 15 jaar na afloop van dit onderzoek te bewaren.

Ik wil meedoen aan dit onderzoek.

Naam proefpersoon:

Handtekening:

Datum : __ / __ / __

Ik verklaar hierbij dat ik deze proefpersoon volledig heb geïnformeerd over het genoemde onderzoek.

Als er tijdens het onderzoek informatie bekend wordt die de toestemming van de proefpersoon zou kunnen beïnvloeden, dan breng ik hem/haar daarvan tijdig op de hoogte.

Naam onderzoeker (of diens vertegenwoordiger):

Handtekening:

Datum: __ / __ / __

Aanvullende informatie is gegeven door (indien van toepassing):

Naam:

Functie:

Handtekening:

Datum: __ / __ / __

Toestemmingsverklaring
(mantelzorger)

Innovate Dementia

Ik ben gevraagd om toestemming te geven voor de volgende persoon, zodat hij meedoet aan dit project:
Naam proefpersoon: _____ Geboortedatum: __ / __ / __

Ik heb de informatiebrief voor de proefpersoon gelezen. Ik kon aanvullende vragen stellen. Deze vragen zijn naar tevredenheid beantwoord. Ik heb voldoende tijd gehad om te beslissen of deze persoon meedoet.

Ik weet dat meedoen helemaal vrijwillig is. Ik weet dat ik op ieder moment kan beslissen dat deze persoon toch niet meedoet. Daarvoor hoef ik geen reden te geven.

Ik weet dat sommige mensen de gegevens van deze persoon kunnen zien. Die mensen horen alleen bij de projectgroep Innovate Dementia.

Ik geef toestemming om de gegevens te gebruiken voor de doelen die in de informatiebrief staan.

Ik geef toestemming om de onderzoeksgegevens van deze persoon 15 jaar na afloop van dit onderzoek te bewaren.

Ik vind het goed dat deze persoon meedoet aan dit onderzoek.

Naam wettelijk vertegenwoordiger:

Relatie tot de proefpersoon:

Handtekening:

Datum: __ / __ / __

Ik verklaar hierbij dat ik deze persoon/personen volledig heb geïnformeerd over het genoemde onderzoek.

Als er tijdens het onderzoek informatie bekend wordt die de toestemming van de wettelijk vertegenwoordiger zou kunnen beïnvloeden, dan breng ik hem/haar daarvan tijdig op de hoogte.

Naam onderzoeker (of diens vertegenwoordiger):

Handtekening:

Datum: __ / __ / __

Aanvullende informatie is gegeven door (indien van toepassing):

Naam:

Functie:

Handtekening:

Datum: __ / __ / __

Appendix F - Information letter from the GGzE



Informatiebrief belangstellenden Innovate Dementia

Innovate Dementia Dementiezorg voor morgen

Geachte heer, mevrouw,

Dank voor uw belangstelling voor het project Innovate Dementia. Graag informeren wij u over deelname aan het project.

Door de vergrijzing neemt het aantal mensen met dementie sterk toe. Mensen die met dementie te maken krijgen geven aan graag zo lang mogelijk thuis te willen wonen in plaats van in een verzorgingshuis. Dat is plezieriger voor alle betrokkenen, maar ook nodig om zorgkosten te beperken.

Innovate Dementia ontwikkelt mogelijkheden voor mensen met dementie om langer thuis te kunnen blijven wonen. Dat kan niet zonder uw hulp. Innovate Dementia is daarom op zoek naar u!

Zonder uw ervaringen kunnen wij geen goede producten ontwikkelen. Wij hebben u hard nodig bij het in kaart brengen van behoeften en het testen van producten die de zorg voor dementie in de thuisomgeving vergemakkelijkt. U kunt deelnemen aan het project als u thuiswonend bent, leeft met dementie en/of zorgt voor iemand met dementie.

Innovate Dementia is een project waarbij producten thuis worden getest bij mensen met dementie én hun naasten. Dit wordt gedaan door een netwerk van organisaties uit het binnen- en buitenland, waaronder GGZ Eindhoven en De Kempen (GGzE) en TU/e. Meer informatie over het project leest u op de site <http://innovatedementia.id.tue.nl>.

Deelnemen aan Innovate Dementia

U kunt op verschillende wijze deelnemen aan Innovate Dementia:

- Door het invullen van vragenlijsten over uw dagelijkse bezigheden.
- Door het uitproberen van hulpmiddelen.
- Door het bespreken van mogelijke hulpmiddelen met ontwerpers.
- Als vrijwilliger, door mensen met dementie te begeleiden in project Innovate Dementia.

Deelname aan het project bestaat uit drie contactmomenten met de onderzoeker, ontwerper of projectmedewerker:

1. Tijdens het eerste bezoek krijgt u uitgebreide informatie over het project en kunt u de onderzoeker/ontwerper hierover vragen stellen. Wanneer u besluit om mee te werken, wordt u gevraagd de bijgesloten toestemmingsverklaring te ondertekenen. Daarna vragen wij u om samen een aantal vragenlijsten in te vullen. Dit duurt ongeveer een uur.

2. Tijdens de tweede week van het project krijgt u uitleg over het hulpmiddel. Deze wordt bij u thuis neergezet en gedemonstreerd. Tussentijds (maximaal 1x per dag) wordt u gevraagd om dit hulpmiddel te beoordelen via een vragenlijst.
3. In de daaropvolgende week wordt het hulpmiddel bij u thuis opgehaald en wordt samen met u besproken wat uw mening over dit hulpmiddel is. Ook dit duurt ongeveer een uur.

Na ongeveer 3 maanden wordt u benaderd om opnieuw een hulpmiddel uit te proberen. Uiteraard bent u vrij om hieraan mee te doen.

Wat vergt uw inzet?

Uw deelname aan dit project vergt enige tijd, onder andere door de contactmomenten met de projectmedewerkers van Innovate Dementia. We trachten hulpmiddelen te ontwikkelen die uw dagelijkse bezigheden vergemakkelijken en u tijd besparen.

Het tijdstip van de contactmomenten wordt vanzelfsprekend in overleg met u vastgesteld.

Wat levert het op?

Een belangrijk voordeel is, dat door uw deelname aan Innovate Dementia, u een bijdrage levert aan ontwikkelingen, waardoor mensen die leven met dementie mogelijk langer thuis kunnen blijven wonen.

Goed om te weten

- Deelname aan het project is geheel vrijwillig. U kunt op ieder moment stoppen.
- Er is geen vergoeding verbonden aan dit project, deelname is volstrekt vrijwillig.
- Er is een standaardverzekering afgesloten voor deelnemers die meedoen aan dit project (zie bijlage 1)
- De verzamelde gegevens worden vertrouwelijk behandeld. De resultaten worden anoniem verwerkt. In rapportages zal uitsluitend met geanonimiseerde gegevens worden gewerkt.
- Als u besluit mee te doen zal gevraagd worden om een toestemmingsverklaring te tekenen. Daarmee geeft u aan dat u voldoende geïnformeerd bent over dit project.

Informatie

Heeft u vragen over Innovate Dementia? Dan kunt u contact opnemen met een van de projectmedewerkers:

Specialistische Verpleegkundigen

Specialistische Verpleegkundigen

Bijlage 1

INFORMATIE OVER DE VERZEKERING

Voor iedereen die meedoet aan dit project is een verzekering afgesloten. De verzekering dekt schade, die het gevolg is van deelname aan het onderzoek. Dit geldt voor schade die naar boven komt tijdens het onderzoek, of binnen vier jaar na beëindiging van deelname aan het onderzoek. U moet de schade ook binnen die vier jaar aan de verzekeraar hebben gemeld.

In geval van schade kunt u zich direct wenden tot de verzekeraar of schaderegelaar. In het kader van Innovate Dementia is dit de volgende verzekeraar:

Naam:
Adres:
Telefoonnummer:
E-mail:

De verzekering biedt een maximumdekking van € (ten minste 450.000) per proefpersoon en € (ten minste 3.500.000) voor het gehele onderzoek, en € (ten minste 5.000.000) per jaar voor alle onderzoeken van GGzE. De dekking van specifieke schades en kosten is verder tot bepaalde bedragen beperkt. Deze vindt u in het Besluit verplichte verzekering bij medisch-wetenschappelijk onderzoek met mensen. Informatie hierover kunt u vinden op de website van de Centrale Commissie Mensgebonden Onderzoek: www.ccmo.nl.

Voor deze verzekering gelden een aantal uitsluitingen. De verzekering dekt de volgende schade niet:

- schade waarvan op grond van de aard van het onderzoek (nagenoeg) zeker was dat deze zich zou voordoen;
- schade aan de gezondheid die ook zou zijn ontstaan als u niet aan het onderzoek had deelgenomen;
- schade die het gevolg is van het niet (volledig) nakomen van aanwijzingen of instructies;
- schade aan nakomelingen, als gevolg van een nadelige inwerking van het onderzoek op u of uw nakomeling;
- bij onderzoek naar bestaande behandelmethoden: schade die het gevolg is van één van deze behandelmethoden;
- bij onderzoek naar de behandeling van specifieke gezondheidsproblemen: schade die het gevolg is van uitblijvende verbetering of van verslechtering van deze gezondheidsproblemen.

Appendix G. Information leaflet from the Vitaallicht lamp



Gebruikerstest Vitaallicht

Geachte gebruiker,

Vitaallicht wil u bedanken voor uw bereidheid tot deelname aan de Vitaallicht Gebruikerstest. Het doel is uw mening te krijgen over de werking, het uiterlijk en de gebruiksvriendelijkheid van het product.

Middels deze test willen we kijken of u dankzij de Vitaallicht lamp beter slaapt, overdag alerter, actiever of opgewekter bent en of u meer energie heeft.

Het gebruik van Vitaallicht:

- Wij adviseren u om **minimaal** 1 uur per dag (meer mag ook), tussen 8 uur 's morgens en 6 uur 's avonds, de lamp te gebruiken. Op andere tijden mag u de lamp naar wens gebruiken, maar heeft hij geen activerende werking meer. Daarnaast adviseren wij u met regelmaat naar buiten te gaan, want zonlicht is altijd nog gezonder dan binnen verlichting.
- De lamp heeft een aan/uit voetschakelaar, waarmee u de lamp kunt bedienen. Mocht de lamp niet goed opstarten, dan dient u de lamp opnieuw aan en uit zetten. Werkt de lamp vervolgens nog steeds niet, neem dan contact op met Maarten

Verder:

- De lamp is een demonstrator, oftewel het is de eerste speciaal gemaakte serie. Hierbij zijn zoveel mogelijk CE goedgekeurde componenten gebruikt, maar helaas nog niet allemaal.
- Het stroomverbruik van de lamp is relatief laag, zo'n 85 watt opgenomen vermogen. Dat is iets meer dan een 60 watt gloeilamp, terwijl er 20 keer meer licht wordt gemaakt. Als u van huis weg gaat, adviseren wij wel om hem uit te zetten.

Samenvattend adviseren we u om minimaal 1 uur per dag van Vitaallicht gebruik te maken. Wij wensen u veel plezier met het actieve genieten!

Getekend voor ontvangst,

Naam & handtekening

Datum

Appendix H. Information letter by the researcher

Beste

Wat fijn dat u mee wilt doen aan het onderzoeksproject met het spel "Aangenaam" en Vitaallicht! Op deze pagina's vindt u meer informatie over mij en over de studie. Mocht u verder nog vragen hebben, dan vindt u ook mijn contactgegevens op de volgende pagina.

Ik ben Sandra Suijkerbuijk en ben een student op de Technische Universiteit van Eindhoven. Bij mijn studie, Mens-Techniek Interactie, ligt de focus op de effecten van techniek op mensen.

Afstudeerproject

Op dit moment ben ik met mijn afstudeerproject bezig en ik richt mij in dit project op het ontwikkelen van een evaluatie methode voor mensen met dementie. Het idee is dat deze methode inzichten geeft over het dagelijkse leven vanuit het perspectief van de cliënt. Deze inzichten zouden ontwerpers kunnen helpen bij het ontwikkelen van nieuwe producten voor mensen met geheugenproblemen. Een voorbeeld van een nieuw product is de Vitaallicht lamp. Deze lamp zal worden gebruikt in het onderzoeksproject waar u aan deelneemt. We onderzoeken in dit project dus eigenlijk twee dingen: hoe dat de Vitaallicht lamp bevalt bij mensen thuis én welke evaluatie methode dit het beste meet. Uw deelname aan het onderzoek is daarom heel waardevol, want u bent degene die hier inzicht in kan geven! Hartelijk bedankt dat u meedoet!

Mijn afstudeerproject is onderdeel van het grotere project Innovate Dementia, waar ook de GGzE, de gemeente Eindhoven en verschillende faculteiten van de Technische Universiteit Eindhoven aan meewerken.

De Evaluatie methode

De evaluatie methode die u gaat gebruiken tijdens de duur van het onderzoek is het spel "Aangenaam". De bedoeling is dat het spel "Aangenaam" gespeeld wordt in de ruimte waar de Vitaallicht lamp geplaatst wordt, dit kan bijvoorbeeld de woonkamer zijn. Het spel bestaat uit verschillende vragenkaartjes in verschillende categorieën: Persoonlijk, Omgeving, Dagelijkse Bezigheden en Vitaallicht. De Vitaallicht kaartjes ontvangt u tegelijk met de lamp. De vragenkaartjes zijn bedoeld om een discussie te starten tussen de spelers over een bepaald onderwerp. Sommige vragen komen meerdere keren voor in het spel. Zoals u kunt zien, zitten er nog wat voorwerpen in de doos van het spel: een fotocamera, een memorecorder en een notitieboekje. Dat zijn de 3 verschillende manieren waarop u uw antwoord vast kunt leggen. Op de vragenkaartjes staat aangegeven welk voorwerp u moet gebruiken. Op het uitleg blad ziet u hoe alle voorwerpen te gebruiken zijn. Tevens vindt u in

de doos van het spel nog een boekje waarin u aangeeft wanneer u het spel gespeeld heeft, welke vragen u beantwoordt heeft en wat u van de vragen vond.

Het zou fijn zijn als u dagelijks een vraag van elke categorie behandelt (dus 3/4 vragen per dag), maar het is begrijpelijk als dat niet altijd lukt en dat u een dag overslaat. Wellicht dat u de vragen in sommige categorieën niet prettig vindt, of dat u het lastig vindt om met de fotocamera uw antwoord vast te leggen, dan bent u geheel vrij om een andere vraag te pakken van de stapel. Het uitgangspunt is dat u plezier heeft met het spel "Aangenaam" en dat wij door middel van de antwoorden de spelers beter leren kennen en de ervaringen met de Vitaallicht lamp ontdekken!

Belangrijk

Het is belangrijk voor u om te onthouden dat wij het spel "Aangenaam" en de Vitaallicht lamp testen en NIET hoe goed u om kunt gaan met deze zaken. Alle antwoorden die u geeft op de vragen zijn altijd goed en u mag zeker ook kritisch zijn! Daar leren we het meeste van. Alle informatie wordt natuurlijk anoniem behandeld en alleen gebruikt voor het onderzoek, uw naam zal dus nooit ergens worden genoemd.

Planning

In onderstaande schema kunt u zien hoe dat de studie zal verlopen, de data zijn richtlijnen en zullen met u persoonlijk afgestemd worden.

<i>Wat?</i>	<i>Wanneer?</i>	<i>Hoe laat?</i>
Start met spel	3 – 5 – 2013	
Plaatsing lamp, kaartjes Vitaallicht categorie en kort vraaggesprek	10 – 5 – 2013	
Kort vraaggesprek (wellicht telefonisch)	17 – 5 – 2013	
Ophalen lamp en afsluitend vraaggesprek	24 – 5 – 2013	

Verdere vragen?

Mocht u verder nog vragen hebben over het onderzoek, het spel "Aangenaam", de Vitaallicht lamp of iets anders dan kunt u mij altijd bereiken via (

Hartelijke groet,
Sandra



