

Design **for** **Connectedness**

Designing a playful product for people living with moderate to severe dementia to support emotional well-being

Master Thesis by Maartje de Rond
April 2019

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MSc Design for Interaction

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Preface

This thesis presents the results of my master graduation project within the Design for Interaction master of the faculty of Industrial Design Engineering at Delft University of Technology.

This project formed a perfect combination of my interests in psychology, healthcare and playful design. Therefore, it was a great pleasure to work on this project and be able to contribute to the quality of life of people living with moderate to severe dementia.

It seems like yesterday that I started with this project, with only some basic knowledge about dementia. I, thankfully, did not have experience with this disease in my personal surroundings. Therefore, I spent many hours inside nursing homes to learn about the disease and empathize with stakeholders. This led to lots of personal stories, funny moments and inspiring insights.

We often only hear stories about the awful symptoms of dementia, and off course, dementia is a horrible disease. But we sometimes forget to see the person instead of the dementia. I experienced how a conversation, a touch or just some attention can brighten up the days of these people. This truly inspired and motivated me within this project.

Finally, I want to take this opportunity to compliment the care givers of nursing homes for people with dementia, as they do not always get the respect that they deserve. It was truly inspiring to see how they approach the situations they face every day with a positive mindset and strive to make life as pleasant as possible for their clients.

Enjoy reading my report!

Maartje

Executive summary

This project focuses on contributing to a feeling of connectedness for people in the mid to late stages of dementia living in a nursing home.

Feeling connected is still important for people living with dementia. They may suffer from disabilities caused by their disease, losing their memory and ability to make decisions, but there are also things that are not likely to be affected by dementia. A person with dementia stays capable of feeling negative emotions, like fear and pain, and positive emotions, like interest and happiness (Perrin, May, & Anderson, 2008a; Plaats & Kits, 2016). Therefore, it is important to contribute to feelings of connectedness, to support emotional well-being.

To analyze connectedness in the context of dementia, two studies were performed. One of these studies focused on forming a theory how connectedness can contribute to overall happiness and emotional well-being. The other study analyzes the context of daily life of people living with moderate to severe dementia in nursing homes, to discover opportunities to design for.

My theory on connectedness presents a framework which identifies that connectedness can be divided into three types:

- **Social connectedness** is about our interpersonal contacts and relationships, through which we feel connected to others. It relates to our needs for love and belonging, feeling related to, getting esteem from and being acknowledged by others.
- **Personal connectedness** is about feeling connected to your psychological self. It is about who you are as a person, about your beliefs and background. It is based on our basic needs for self-esteem, self-actualization, cognition, aesthetics, transcendence, purpose, competence, impact, morality, autonomy and ease.
- **Physical connectedness** is about feeling alive in the present moment. The human needs related to physical connectedness are all focused on bodily experiences: the need for physiological safety and survival, health, fitness, order and sensory stimulation. Therefore, physical connectedness focusses on what we experience through our senses and feel happening in our body that makes us feel alive.

Fulfilling one or more of the human needs related to a type of connectedness, leads to an increased feeling of being socially, personally or physically connected. It is possible to experience more than one type of connectedness at once, as they are all interconnected.

The analysis on the daily life of people with moderate to severe dementia living in a nursing home, reveals that these people spend a lot of their time in static environments every day. This means that they are surrounded by static objects and non-responsive, apathetic fellow residents. These static environments cause people to become apathetic or restless, which negatively impacts all three types of connectedness and hereby decreases emotional well-being (Alzheimer's Society, n.d.-a; Anderiesen Le Riche, 2017; T. P. Ettema et al., 2005; Perrin et al., 2008a).

As the moments where people spend time in static environments happen when care givers are busy with their caring duties, I envision to offer something for these moments that can be used by a resident without the help of care givers and can be used individually, without the need for fellow residents. Therefore, the design phase of this project focusses on the individual side of connectedness: personal and physical connectedness. The goal is to design a playful product that enables moments of physical and personal connectedness for people in the mid to late stages of dementia, to support emotional well-being in static nursing home environments.

To guide the design process, an interaction vision was created based on the design goal and an analysis on design principles suitable for people living with moderate to severe dementia. The interaction vision and its qualities are formulated as follows: The interaction should feel like playing with a ladybug: proactive, lively, explorative, enchanting, subtle and open-ended.

In an iterative design process, multiple idea directions were explored, and a concept was developed through the creation and evaluation of several prototypes. This resulted in the final concept: Twinkle.

Twinkle consists of a sphere, with an interactive dynamic light inside of it. This light can move across the surface of the sphere to proactively try to attract the attention of residents and trigger the curiosity in them to initiate interaction. When an interaction is started, the behavior of the light will change depending on the actions of the user. This way, it allows the user to explore the possibilities of the object. This way, Twinkle provides both cognitive and sensory stimulation to enhance personal and physical connectedness and thereby support emotional well-being for people living with moderate to severe dementia to bring back the twinkle in their eyes.

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1

Introduction

About 50 million people around the world are living with dementia. This number will increase with approximately 10 million new cases every year, which means that there is one new case every three seconds. It is expected that the number of people living with dementia will increase to 152 million in 2050 (World Health Organization, 2017a, 2017b).

While the number of people living with dementia keeps increasing rapidly, there currently is no cure for the disease nor a way to alter the progressive course of it (Alzheimer's Society, 2018; World Health Organization, 2017b). Dementia shortens the lives of those affected, but the greatest impact is on the quality of life of the person living with dementia and the lives of their family members and caregivers (Prince et al., 2015).

Given the fact that dementia is such an impactful disease, we should focus on how to optimize the quality of life of those affected by the disease, besides trying to find a cure (T. P. Ettema et al., 2005).

Because the disease is of a progressive nature, the lives of people in the early stages are affected in a different way than those of people in the later stages (Alzheimer's Society, 2019). Which is why a more specific focus is needed. This project is initiated by Active Cues, whose main target group is people with moderate to severe dementia living in a nursing home. Therefore, this target group was also chosen as the focus for this project.

1.1 Active Cues and the Tovertafel

This project was initiated by Active Cues; a Dutch company based in Utrecht. Active Cues develops games for specific target groups, like people with dementia and people with learning disabilities. They feel that everybody has the right to play because it can contribute to everyone's health and quality of life. Active Cues' mission is to create moments of happiness in residential care and education (Active Cues, n.d.-b).

The games Active Cues develops are especially made for their product called the Tovertafel (magic table) (see Figure 1). This product emerged from the PhD research of Hester Le Riche; one of the founders of Active Cues. The Tovertafel is an interactive projector in a casing that can be mounted on the ceiling above a table. This box projects the games on the table. The projections respond to hand and arm movements, which makes it possible to play with the light itself. In this way, the Tovertafel stimulates physical and cognitive activity and encourages social interaction (Active Cues, n.d.-a; Anderiesen Le Riche, 2017). For each target group, a different set of games is developed. The Tovertafel Original games are especially developed for and with people in the mid to late stages of dementia.

The Tovertafel was designed to stimulate people with moderate to severe dementia to become physically active. Dementia reduces people's capability to initiate activities, which is why they need external stimulation to remain active (Anderiesen Le Riche, 2017). 90% of people with dementia, living in a nursing home, suffer from apathy (Kolanowski, Litaker, & Buettner, 2005). This means that they are unwilling to take action and show no energy or interest. Apathy is a lack of feeling, emotion, interest or concern (Anderiesen Le Riche, 2017). Because carers do not have enough time to fulfil the task of taking the initiative and activate residents with dementia, the Tovertafel Original was designed to help in this process.

The games of the Tovertafel are based on intuitive interactions. It helps to activate people, preventing apathetic behavior, encourages social interactions and contributes to the quality of life of the person with dementia. It creates treasured moments with family members and carers (Active Cues, n.d.-a).



Figure 1: People with moderate to severe dementia playing with the Tovertafel.

1.2 Aim of this project

The Tovertafel Original has proven to be successful in preventing apathetic behavior, but there are still other areas which can be explored. An important aspect of the Tovertafel is the social interaction which is involved. However, social interaction is part of a broader research topic: connectedness. Therefore, this project is focused on exploring the theme 'connectedness' in the context of people in the mid to late stages of dementia living in a nursing home.

Connectedness can be described as: the state of being connected and having a close relationship with other things or people (Cambridge Dictionary, n.d.-a). We all experience feelings of connectedness. We feel connected to our family and friends, to our home, to the world we are living in and to life in general.

People living with dementia are not assured of this feeling anymore. Due to cognitive difficulties, it becomes harder for them to initiate actions, which makes them more dependent on the actions initiated by others and on the things their surroundings have to offer. Therefore, they cannot decide for themselves when and how to increase their feelings of connectedness.

However, it is still important for people living with dementia to feel connected. They may suffer from disabilities caused by the disease, losing their memory and ability to make decisions, but there are also things that are not likely to be affected by dementia. A person with dementia stays capable of feeling negative emotions, like fear and pain, and positive emotions, like interest and happiness (Perrin et al., 2008a; Plaats & Kits, 2016). Therefore, it is important to contribute to feelings of connectedness, to make people experience positive emotions and hereby support emotional well-being.

In this project, the concept of connectedness is explored to understand the concept in the context of people with dementia. The main aim of this project is to understand how we can contribute to a feeling of connectedness for people living with moderate to severe dementia in nursing homes to improve their quality of life. The insights that are gained through this research are translated into a design solution or concept.

1.3 Project approach

In this project, I worked with a user centered design (UCD) approach. This approach was also used in the development of the Tovertafel (Anderiesen Le Riche, 2017). UCD is an iterative design process which is focused on the users and their needs, capabilities and behavior. Users are involved throughout the process, first to get inspired through empathizing with the target group and gaining an explicit understanding of the context, later to evaluate the designs (IDEO.org, 2015; Sanders & Stappers, 2012). This project was divided into an analysis and design phase. Figure 2 shows an overview of the different stages, including their corresponding research questions.

1.3.1 Analysis phase

To understand what disconnectedness in dementia is, two studies were setup to generate knowledge. On the one hand, I created a theory that presents a framework about connectedness, through literature research (Hanington & Martin, 2012). On the other hand, the context of people living with moderate to severe dementia, residing in nursing homes was explored in two ways. First, literature was used to understand what happens when a person develops dementia. After this, I immersed myself in the context through exploratory field research techniques, like interviews and observations, to gain a deep understanding of the user and context (Hanington & Martin, 2012; IDEO.org, 2015). Combining both the knowledge about connectedness and dementia, I formed an understanding of what disconnectedness means in the context of people in the later stages of dementia living in a nursing home.

Dementia affects a person's cognitive, behavioral and emotional functioning, which influences product experience and interaction (Anderiesen Le Riche, 2017). Therefore, a separate study was performed in the analysis phase of this project to gain knowledge about design principles that can be used in designing for people in the mid to late stages of dementia.

The analysis phase of this project is concluded with a design brief, in which all insights were combined into a coherent design goal and interaction vision (Pasman, Boess, & Desmet, 2011). This design brief forms the basis for the design phase of the project.

1.3.2 Design phase

In the design phase of this project, idea generation was performed, based on the formulated design brief. This resulted in several idea directions. One of these directions was chosen to further develop in the iteration phase. In this phase, design and evaluation stages alternate to develop the concept. A user-centered evaluation process was used, where prototypes were tested with the user group (Anderiesen Le Riche, 2017; Hanington & Martin, 2012; IDEO.org, 2015). This resulted in the final concept: Twinkle.

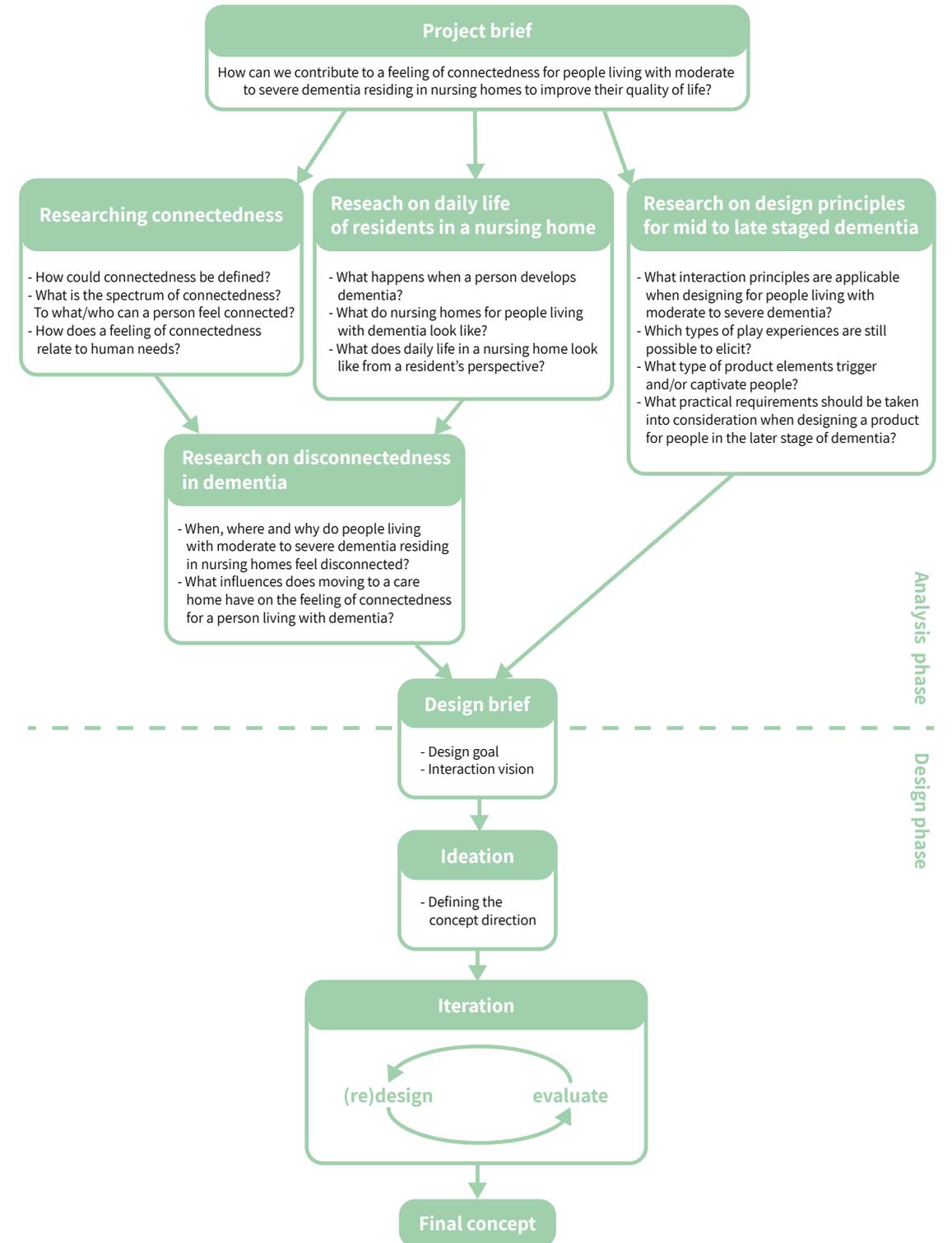


Figure 2: Process overview of the project

1.4 Structure of this report

The structure of this report is based on the project approach, which is grounded by two analysis studies. The analysis of connectedness in dementia is presented in chapter 2. Chapter 3 presents the analysis of design principles in dementia. These two chapters form the basis for the design brief, which is described in chapter 4. The design process, including the description of the final concept, is described in chapter 5. In chapter 6, the final concept is evaluated, based on the design brief of chapter 4. This chapter also discusses recommendation for the further development of the concept.

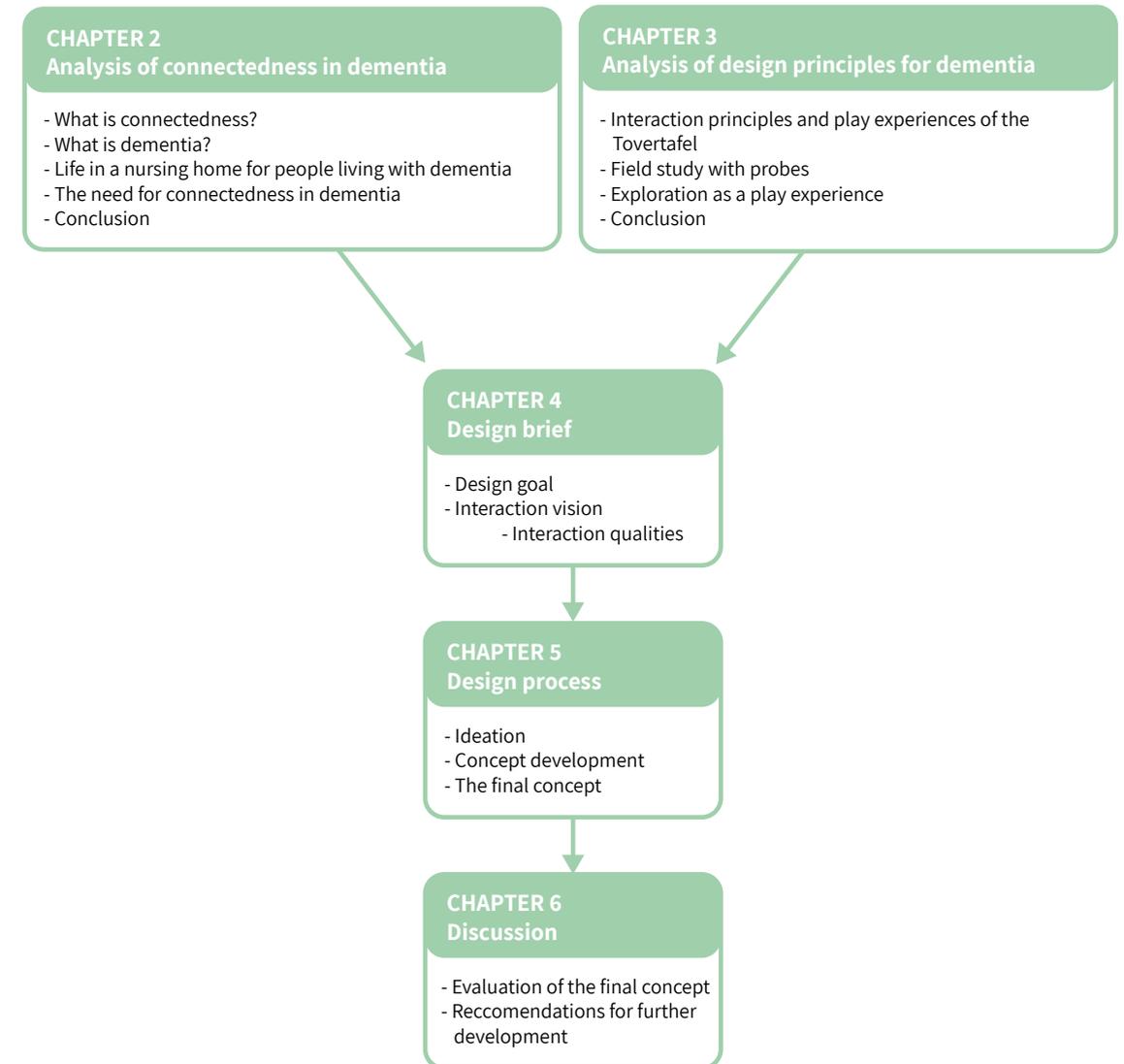


Figure 3: Overview of the structure of this report

2

Analysis of connectedness in dementia

This chapter presents the analyses of the need for connectedness in dementia. First, a theory on different types of connectedness is presented. After this, information is given about what dementia is and what life is like for people in the later stages of dementia living in a nursing home. The third part of this chapter is focused on combining the knowledge about connectedness with that on the daily life of someone with dementia living in a nursing home, to find insights on disconnectedness in dementia. The chapter is concluded with an overview of the most important insights and vision on how we could contribute to a feeling of connectedness for people with moderate to severe dementia and what the focus of this project is.

2.1 Connectedness

‘Connectedness’ is a term which can be used in diverse contexts and can have different meanings. But what does it mean in this project? This subchapter presents a universal theory about how ‘connectedness’ can contribute to our overall happiness and emotional well-being. This theory can be used in every context, regardless of culture, lifestyle and age.

2.1.1 Process of theory creation

The theory about connectedness was created through several steps and iterations. To guide this process, the following research questions were created:

- How could connectedness be defined?
- What is the spectrum of connectedness? With who/what can a person feel connected?
- How does a feeling of connectedness relate to human needs?

Connectedness can be described as: the state of being connected and having a close relationship with other things or people (Cambridge Dictionary, n.d.-b). With this as a starting point, the top of mind knowledge about connectedness was investigated through the creation of a mindmap, inventorying the concept (Hanington & Martin, 2012; Tassoul, 2009a). This mindmap was focused on to what or whom people can feel connected and in what way. To elaborate more on this top of mind knowledge, this mindmap was discussed with fellow students as well as with two of the coaches of this project to add things which were still missing.

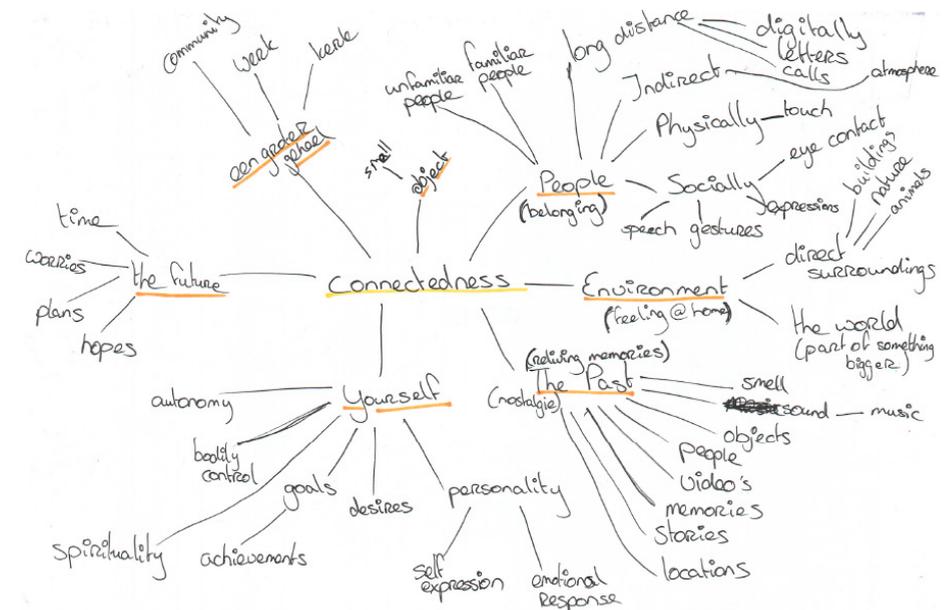


Figure 4: Mindmap about ‘connectedness’

Maslow's theory on human needs was used, because it describes fundamental human needs that are universal for everyone, regardless of culture, lifestyle and age (Maslow, 1943; McLeod, 2018). It is a psychological theory about human needs, put together in an eight-tier model shaped like a pyramid (See Figure 5) (Maslow, 1943; McLeod, 2018). The pyramid indicates that there is a certain hierarchy in fulfilling our needs, where for example survival takes precedence over others. In this research, the model is used because it shows clear categories. The order of these categories is less important in this project. Also, the order of needs is not rigid. It can be flexible based on personal differences and external circumstances (Maslow, 1943; McLeod, 2018). Attempts were made to combine the aspects of connectedness found in the mindmap, with the different categories of Maslow's human needs, but these did not convey a coherent theory. The attempts can be found in Appendix B.

Because the previous approach did not lead to a coherent framework, it was chosen to turn the process around and have human needs as a starting point and relate this back to a concept of connectedness. To broaden the scope on human needs and find qualities to form a concept of connectedness, an extra theory on human needs was used; the theory of Desmet and Fokkinga. Their theory on fundamental needs is seen as a collection of thirteen jars that need to be filled in order to achieve happiness (Desmet & Fokkinga, 2018).

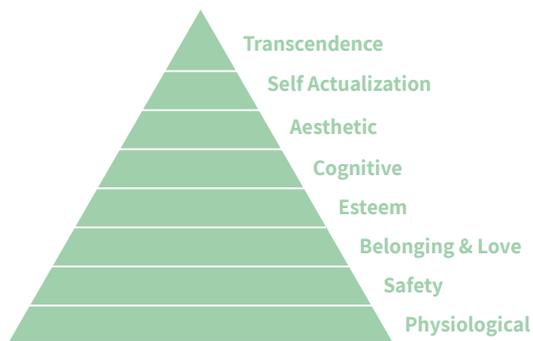


Figure 5: Maslow's hierarchy of human needs

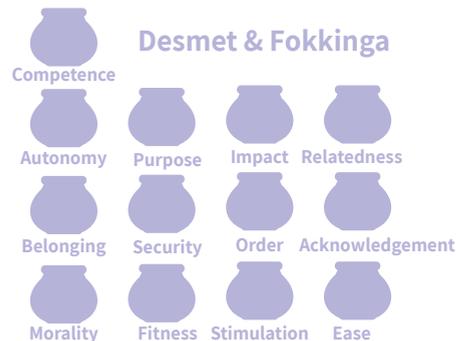


Figure 6: Desmet and Fokkinga's thirteen fundamental needs

With the elements of human needs of these two theories as a basis, clustering was done according to the way Marc Tassoul described it in Creative Facilitation (Tassoul, 2009b). The aim of this was to form clusters of needs that are closely related. This resulted in three clusters; one related to social interactions, one to the psychological self and one to the physical self (see Figure 7). These three clusters formed to bases for a theory which defines three types of connectedness: social, personal and physical. This final theory is explained in the next paragraph.

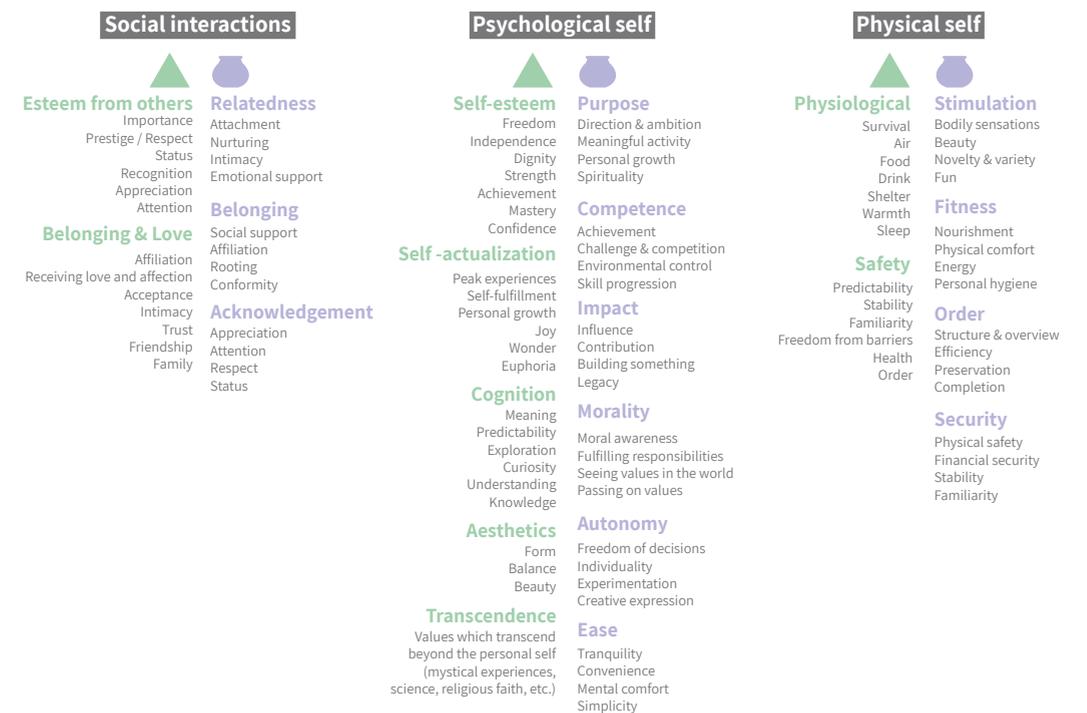


Figure 7: Result of clustering the human need categories of Maslow and Desmet & Fokkinga

2.1.2 Framework about connectedness

Through the analysis of human needs in relation to connectedness, I created a framework that divides the concept 'connectedness' into three different types: social, personal and physical connectedness. In the following section, each one of these types will be explained. While in this framework the three types are described separately, it is possible to experience more than one type of connectedness at once, as they are all interconnected.

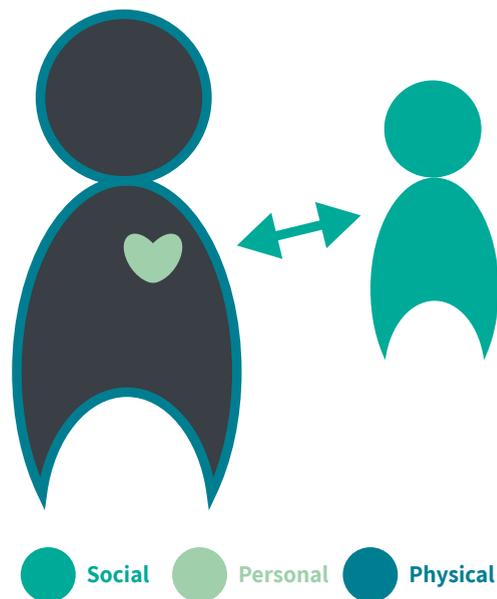


Figure 8: Three types of connectedness

Social connectedness

Social connectedness is about our interpersonal contacts and relationships, through which we feel connected to others. Human beings enjoy socializing (Sandstrom & Dunn, 2014a). Our prehistoric ancestors needed to live in herds to protect themselves from danger and survive. Our brains are still wired that way and therefore it pushes us to be in the company of others (Blanco-Suarez, 2017).

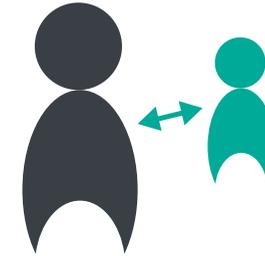


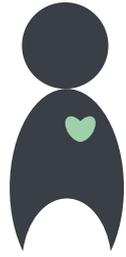
Figure 9: Social connectedness

Social connectedness is directly related to some of our human needs. We feel the need for love and belonging, want to feel related to others and feel the need to get esteem from and be acknowledged by other people (Desmet & Fokkinga, 2018; Maslow, 1943; McLeod, 2018). Figure 10 shows an overview of which fundamental human needs are related to social connectedness, including their underlying sub-needs. Fulfilment of one or multiple of these needs leads to a greater feeling of social connectedness. For example, when you become member of a sports association and are accepted by this group, your needs for belonging are a bit more fulfilled and therefore you will experience more social connectedness.

When talking about our social life, we tend to think about the interactions we have with close friends and family, but social connectedness is much broader than that. Not only your strong relationships, but also relationships involving less frequent contact, low emotional intensity, and limited intimacy belong to social connectedness. For example, a passer-by on the street. You will feel more socially connected when a passer-by makes eye contact with you instead of neglecting you by looking past you (Sandstrom & Dunn, 2014b). These type of interactions with weak relationships become especially more important and of greater impact when we have had less interaction with our strong relationships for some time (Sandstrom & Dunn, 2014a, 2014b).



Figure 10: Human needs related to social connectedness



Personal connectedness

Personal connectedness is about everything that has to do with who you are as a person. It is about feeling connected to your psychological self, your background and your beliefs. Every person has his own personal story about how he became who he is today and everything we experience builds up to that story. It is about our life history and memories that create our identity in the present and a sense of who we want to become.

Figure 11: Personal connectedness

Personal connectedness is based on our basic needs for self-esteem, self-actualization, cognition, aesthetics, transcendence, purpose, competence, impact, morality, autonomy and ease (see Figure 12) (Desmet & Fokkinga, 2018; Maslow, 1943; McLeod, 2018).

All the needs related to personal connectedness are related to who we are and what we believe we should do, be or become. Based on this we can say that fulfilling one or more of these needs results in a greater overall feeling of personal connectedness. For example, when someone can act upon his personal beliefs and values and is able to see them reflected in the world, we could say that the need for morality of this person is fulfilled (Desmet & Fokkinga, 2018) and therefore this person feels more connected to his personal self.

Another example is about searching for meaning in life. We want to have a purpose and be valuable to our sense of what makes life meaningful (Desmet & Fokkinga, 2018; McLeod, 2018). We set goals for ourselves about who we are or want to be to make life meaningful (Desmet & Fokkinga, 2018). When someone is able to live in such a way that one can get closer or even reach these goals, it touches upon almost all the needs related to personal connectedness. It is about being able to direct your own life, act autonomously, grow and achieve something as a person.



Figure 12: Human needs related to personal connectedness



Physical connectedness

Physical connectedness is about feeling alive in the present moment. The human needs related to physical connectedness are all focused on bodily experiences, such as the need for physiological safety and survival, health and sensory stimulation (see Figure 14). Therefore, physical connectedness focusses on what we experience through our senses and feel happening in our body.

Figure 13: Physical connectedness

Our senses (vision, hearing, smell, taste and touch) play a central role in experiencing physical connectedness. Our sensors receive input throughout each day, but sometimes, this sensory input is intensified for a moment, which makes us experience a peak of sensory stimulation. This can for example happen when cycling through the rain. You can feel the water and wind touching your skin and can hear the rain falling on the sidewalks and the wind blowing. It is a more intense sensory experience than sitting at a desk inside an office. One could therefore say that cycling through the rain results in a peak experience of sensory stimulation. Therefore, the need for bodily sensation and stimulation is fulfilled. This leads to a greater feeling of physical connectedness and makes us feel alive.

An increase in physical connectedness can also be experienced when the sun suddenly appears in between the clouds and it shines upon your face. You can feel the warmth of the sunlight and your eyes need to adapt to the sudden increase brightness of the light. This causes a peak of sensory input and therefore makes you feel your body in the present moment, which increases a feeling of physical connectedness.

Not only things that you can feel from outside in are able to increase our sense of physical connectedness, but also things we can feel happening inside our bodies contribute to this. For example, when doing a cardio training. You can feel your heartbeat raising, your body temperature rising and your blood streaming to every part of your body. This all raises your awareness of your physical body and therefore increases a sense of feeling alive in the present moment and feeling physical connected.



Figure 14: Human needs related to physical connectedness

Summary of main insights on connectedness

‘Connectedness’ is a term which can be used in diverse contexts and can have different meanings. To communicate the interpretation and meaning of connectedness in this project, a theory about how connectedness can contribute to our overall happiness and emotional well-being is created. This theory presents a framework that identifies three types of connectedness based on clusters of human needs: social, personal and physical connectedness.

- **Social connectedness** is about our interpersonal contacts and relationships, through which we feel connected to others. It relates to our needs for love and belonging, feeling related to, getting esteem from and being acknowledged by others.
- **Personal connectedness** is about feeling connected to your psychological self. It is about who you are as a person, about your beliefs and background. It is based on our basic needs for self-esteem, self-actualization, cognition, aesthetics, transcendence, purpose, competence, impact, morality, autonomy and ease.
- **Physical connectedness** is about feeling alive in the present moment. The human needs related to physical connectedness are all focused on bodily experiences: the need for physiological safety and survival, health, fitness, order and sensory stimulation. Therefore, physical connectedness focusses on what we experience through our senses and feel happening in our body that makes us feel alive.

Fulfilling one or more of the human needs related to a type of connectedness, leads to an increased feeling of being socially, personally or physically connected. It is possible to experience more than one type of connectedness at once, as they are all interconnected.

2.2 What is dementia?

Before explaining the concept of ‘connectedness’ in the context of dementia, a better understanding of this condition and the effects on daily life need to be understood. This subchapter presents a brief explanation of what dementia is.

Dementia is a collective term for a syndrome covering different types of diseases with similar symptoms caused by damage of the brain (Perrin, May, & Anderson, 2008b). When someone develops dementia there is deterioration in memory, thinking, behaviour and the ability to perform everyday activities. It has a progressive nature and currently there is no cure for it (World Health Organization, 2017b). The older someone gets, the more likely it is that they will develop a form of dementia. Although age is the biggest risk factor, dementia is not a normal part of aging (Alzheimer’s Research UK, 2018; World Health Organization, 2017a).

2.2.1 What happens in the brain?

To be able to understand the changes in health and behaviour that are caused by dementia, it is important to have a basic understanding of the functioning of our brain. In the following paragraphs, the structure and functions of the brain is explained, where after is described what happens when parts of the brain are damaged by dementia.

Structure and functions of the brain

Our brain is one of the most complex parts of our body. It can be divided into different structures with their own specialized functions (see Figure 15). In a healthy brain, all these different structures cooperate within the brain to regulate the body and behaviour of the person (Perrin et al., 2008b).

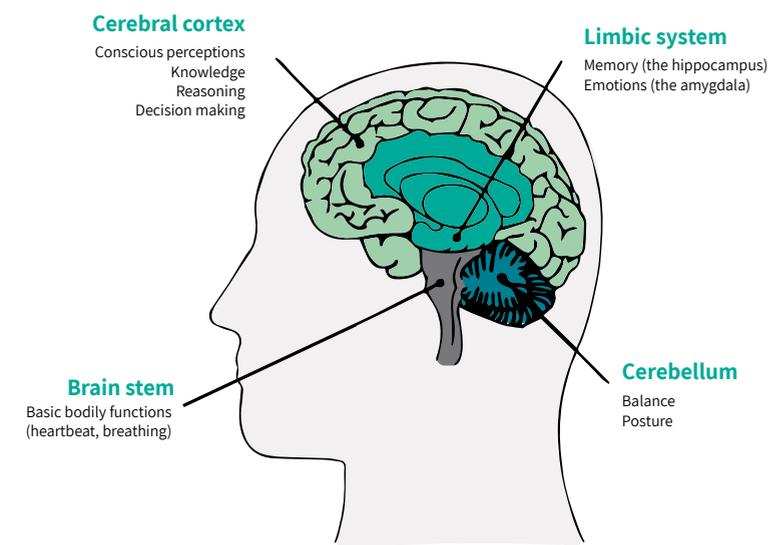


Figure 15: Parts of the brain and their functions (Alzheimer’s Society, 2014; Perrin et al., 2008b)

An important part to understand is the cerebral cortex, as it is responsible for supporting the more complex cognitive abilities such as consciousness, memory, reasoning, language and social skills and is particularly likely to be damaged by dementia (Perrin et al., 2008b). The parts that lie beneath the cerebral cortex are less likely to be badly affected by causes of dementia, especially in the mild to moderate phases of the disease (Perrin et al., 2008b).

The cerebral cortex is divided into two hemispheres. The left hemisphere is important for language functions and the right one for spatial understanding and emotional processing (Perrin et al., 2008b). Each hemisphere can again be divided into four separate lobes, with each lobe having its own specific abilities (see Figure 16) (Alzheimer's Society, 2014; Perrin et al., 2008b).

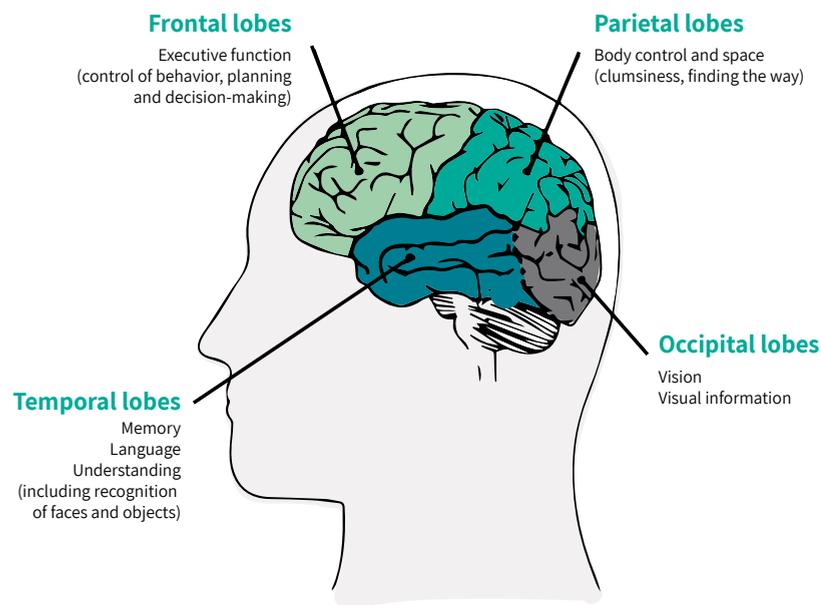


Figure 16 Lobes of the cerebral hemispheres and their functions (Alzheimer's Society, 2014; Perrin et al., 2008b)

2.2.2 What are the effects when parts of the brain get damaged by dementia?

When sections of the brain get damaged by a form of dementia (e.g. Alzheimer's disease), they will not be able to fully interact with each other and cognitive symptoms of dementia will become noticeable (Alzheimer's Society, 2017a). The specific symptoms that someone will experience depend on the exact parts of the brain that are damaged. This can be different per person, disease and stage of the disease (Alzheimer's Society, 2017). According to Perrin et al. (Perrin et al., 2008b), people suffering from dementia often experience some or all of the following symptoms:

- Memory loss
- Language difficulties
- Difficulties with spatial awareness and skilled movement
- A loss of knowledge and understanding of the world
- Problems with reasoning, planning and judgement
- Changes in personality, behavior and emotional control

In appendix C, each symptom is explained in more detail.

2.2.3 The course of the disease

Dementia is a progressive disease, which means that symptoms will increase and become worse over time (World Health Organization, 2017b). In the early stages of dementia, symptoms depend on the type of disease and which parts of the brain are typically affected by this disease. As the dementia develops further, damages spread to more areas of the brain and symptoms across different types of dementia tend to become more similar (Alzheimer's Society, 2014).

The progress of dementia can be divided into three stages (World Health Organization, 2017b). The World Health Organization created the following overview of signs and signals per stage.

“Early stage:

- *forgetfulness*
- *losing track of the time*
- *becoming lost in familiar places.*

Middle stage:

- *becoming forgetful of recent events and people's names*
- *becoming lost at home*
- *having increasing difficulty with communication*
- *needing help with personal care*
- *experiencing behavior changes, including wandering and repeated questioning.*

Late stage:

- *becoming unaware of the time and place*
- *having difficulty recognizing relatives and friends*
- *having an increasing need for assisted self-care*
- *having difficulty walking*
- *experiencing behavior changes that may escalate and include aggression.”*

(World Health Organization, 2017b)

2.2.4 What stays intact?

Besides only focusing on the disabilities caused by dementia, it is important to pay attention to what people with dementia are still capable of. They may lose their memory, but there are still things that stay intact.

The areas of the cortex that support the abilities of conscious awareness and feeling emotion are usually not damaged by dementia (Perrin et al., 2008b). Therefore, a person with dementia is still capable of feeling negative emotions, like fear and pain, and positive emotions, like interest and happiness (Perrin et al., 2008b; Plaats & Kits, 2016). Also, the capacity for sensation and action is not lost. It is just the understanding part in between that is damaged (Perrin et al., 2008b).

It is important to note that, people with dementia are still conscious human beings with a soul, needs, beliefs and feelings. They are still capable of knowing if they are treated as a 'PERSON with dementia' or a 'person with DEMENTIA' (Perrin et al., 2008b). Therefore, they deserve to be treated with care and dignity.

Summary of main insights on the effects of dementia

Dementia is a collective term for a syndrome covering different types of diseases with similar symptoms caused by damage of the brain (Perrin, May, & Anderson, 2008b). It has a progressive nature, which means that symptoms will increase and become worse over time. In the later stages of dementia, damages have spread across the areas of the brain, which means that symptoms across different types of dementia tend to become more similar in the later stages.

As people living with dementia suffer from multiple disabilities caused by dementia, it is also important to focus on what stays intact. People living with dementia stay capable of feeling negative and positive emotions, as well as feeling sensation and action. They are still capable of knowing if they are treated as a 'PERSON with dementia' or a 'person with DEMENTIA'. Therefore, they should be treated with care and dignity.

2.3 Quality of life and well-being in the later stages of dementia

The aim of this project is to improve the quality of life (QoL) of people with moderate to severe dementia, through creating a feeling of connectedness. To be able to achieve this, some knowledge about QoL and well-being in dementia is needed. In this chapter, the concepts of quality of life and well-being are explained in general and in the context of late stage dementia.

2.3.1 Definition of Quality of Life and well-being

While analyzing literature on this topic, it was noticed that the distinction between the terms well-being and QoL is not always clear. Research shows that there is a lot of subjectivity in the use and definition of the terms (Pinto et al., 2017). Also, the meanings of the terms are very similar, as they are both related to health and satisfaction in life.

*“Well-being: the state of feeling healthy and happy”
(Cambridge Dictionary, n.d.-f)*

“Quality of life: the level of satisfaction and comfort that a person or group enjoys” (Cambridge Dictionary, n.d.-e)

To make sure the terms are interpreted in the right way, I want to clarify how the terms are used in this project. The explanation of the terms is based on the research of Pinto et al. (Pinto et al., 2017) (Pinto et al., 2017), who reviewed a total of 18 studies in order to identify the differences between the terms (Pinto et al., 2017). The concept of QoL is seen as a broad multidimensional concept closely related to the overall definition and dimensions of health. Well-being can be divided into physical and emotional well-being. Physical well-being is about being safe and healthy and emotional well-being is the dimension of health, related to mental health. Thus, physical and emotional well-being are concepts that contribute to the overall concept of QoL.

There are two types of QoL: subjective and objective. In assessing our subjective QoL, our own opinion about our lives and life conditions are important, while in objective QoL general objective criteria are used (T. Ettema et al., 2005; Gerritsen et al., 2010).

2.3.2 Quality of Life in dementia

When assessing the QoL of life of people affected by dementia, the question arises to what extent they are capable of subjectively assessing their own QoL, as their cognitive abilities are increasingly limited (as explained in chapter 2.2). Literature emphasizes that only people with minimal levels of impairment are still able to do so (T. Ettema et al., 2005; T. P. Ettema et al., 2005; Perrin, 1997). This means that when assessing the QoL of people in the later stages of dementia, we are dependent on objective tools, which include observation and documentation of behavior (T. Ettema et al., 2005; Perrin, 1997).

The concept of QoL in dementia consists of a multidimensional model. In literature, models differ but mostly include the same type of domains. The relevancy of these domains can differ per stage of the disease (T. P. Ettema et al., 2005), therefore we need to identify which domains are relevant in the later stages.

I compared the theories on QoL of the World Health Organization, Gerritsen et al., Dröes and Ettema et al. and chose to focus on the adaptation-coping model of Dröes and the QUALIDEM model of Ettema et al., because they define the QoL domains for people with dementia as an adaptive process, which differs per stage of dementia (Dichter et al., 2016; T. Ettema et al., 2005; Gerritsen et al., 2010; World Health Organization, n.d.).

The adaption-coping model of Dröes consists of the following adaptive tasks: “developing an adequate care relationship with the staff, preserving an emotional balance, preserving a positive self-image, preparing for an uncertain future, developing and maintaining social relationships and dealing with the nursing home environment.” (T. P. Ettema et al., 2005) The QUALIDEM model of Ettema et al. is based on Dröes’ model of adaptive tasks for coping with dementia and provides a clear overview of what still can be assessed for people with severe dementia to measure their QoL (see Figure 17) (Dichter et al., 2016; T. P. Ettema et al., 2005).

The information provided by these two models indicates what elements contribute to the QoL for people in the mid to late stages of dementia. These elements are described in the next paragraphs.

Mild to severe dementia	Severe dementia
Positive affect	Positive affect
Is cheerful	Radiates satisfaction
Radiates satisfaction	Is capable of enjoying things in daily life
Is capable of enjoying things in daily life	
Is in a good mood	Has a smile around the mouth
Has a smile around the mouth	Mood can be influenced in positive sense
Mood can be influenced in positive sense	
Negative affect	Negative affect
Makes an anxious impression	Makes an anxious impression
Is sad	Cries
Cries	
Restless tense behavior	Restless tense behavior
Makes restless movements	Makes restless movements
Is restless	Is restless
Has tense body language	Has tense body language
Social relations	Social relations
Has contact with other residents	Has contact with other residents
responds positively when approached	responds positively when approached
Takes care of other residents	
Cuts himself/herself off from the environment	Cuts himself/herself off from the environment
Is on friendly terms with one or more residents	
Feels at ease in the company of others	
Social isolation	Social isolation
Is rejected by other residents	Is rejected by other residents
Openly rejects contact with others	Openly rejects contact with others
Calls out	Calls out
Care relationship	Care relationship
Rejects help from nursing assistants	Is angry
Is angry	Has conflicts with nursing assistants
Has conflicts with nursing assistants	
Accuses others	
Appreciates help that he or she receives	Accepts help
Accepts help	
Criticizes the daily routine	
Having something to do	
Finds things to do without help from others	
Enjoys helping with chores on the ward	
Positive self-image	
Indicates he or she would like more help	
Indicates not being able to do anything	
Indicates feeling worthless	
Feeling at home	
Indicates that he or she is bored	
Indicates feeling locked up	
Feels at home on the ward	
Wants to get off the ward	

Figure 17: Domains with subdomains of the QUALIDEM model (Dichter et al., 2016)

Emotional balance

Preserving an emotional balance is important for people with dementia, even in the latest stages of dementia (Dichter et al., 2016; T. Ettema et al., 2005). As described in chapter 2.2, a person living with dementia is still capable of feeling positive and negative emotions (Perrin et al., 2008b; Plaats & Kits, 2016). Therefore, it is important to analyze what contributes to a person's positive and negative affect. This way, elements that causes negative affect can be eliminated and the elements contributing to positive affect can be enhanced. This contributes to improving the QoL of people living with dementia (Dichter et al., 2016; T. Ettema et al., 2005; T. P. Ettema et al., 2005). Also signs of restless tense behavior can indicate emotional instability (Dichter et al., 2016).

Adequate care relationship

Also, an adequate care relationship with the staff is an important aspect of preserving a good QoL (Dichter et al., 2016; T. Ettema et al., 2005; T. P. Ettema et al., 2005). For the people living with severe dementia, this domain can only be assessed through signs of angriness, conflicts with nursing assistants and the acceptance of help (Dichter et al., 2016; T. Ettema et al., 2005). As explained in chapter 2.2, people with dementia are still capable of knowing if they are treated as a 'PERSON with dementia' or a 'person with DEMENTIA' (Perrin et al., 2008b). Therefore, in order to preserve a positive care relationship, care givers should approach residents humanely and treat them with dignity.

Social relationships

Social relations stay important, also with severe dementia. To enhance the QoL of people living with dementia, developing and maintaining social relationships, also when living in a nursing home, is an important domain (Dichter et al., 2016; T. Ettema et al., 2005; T. P. Ettema et al., 2005). It therefore is important to support the residents of a care home to interact socially. When someone cuts himself off from the social environment and/or rejects contact with others, it indicates that this person is not able to maintain social relationships and therefore has a decreased QoL (T. Ettema et al., 2005). Interventions should be done to enhance the acceptance and amount of social interaction of this person.

Positive self-image

For people living with mild to severe dementia, preserving a positive self-image contributes to a better QoL (Dichter et al., 2016; T. Ettema et al., 2005; T. P. Ettema et al., 2005). It therefore is important to treat these people with the dignity that they deserve. Also, caregivers can stimulate self-efficacy to emphasize the strengths and capabilities of the residents (Anderiesen Le Riche, 2017). The QUALIDEM model of Ettema et al. indicates that a the domain positive self-image cannot be assessed for people with severe dementia (Dichter et al., 2016; T. Ettema et al., 2005).

The nursing home environment

When a person living with dementia moves to a care home, it is important for them to be able to deal with the nursing home environment, as this contributes to the QoL of this person (Dichter et al., 2016; T. Ettema et al., 2005; T. P. Ettema et al., 2005). Dealing with the nursing home environment includes being able to feel at home and having something to do. Unfortunately, these two elements cannot be assessed for people with severe dementia (Dichter et al., 2016; T. Ettema et al., 2005). As seen in Figure 17, to make the residents of a nursing home feel at home, it is important that they do not feel locked up or bored.

2.3.3 Focus on emotional well-being

This project is about enhancing feelings of connectedness in people living with moderate to severe dementia to improve their QoL. As the word 'feelings' already indicates that it is about what a person experiences emotionally, the focus of this project within the topic QoL is on the psychological part of it, which is called emotional well-being.

In this chapter it is confirmed that preserving an emotional balance is important for people living with dementia, even in the latest stages of dementia (Dichter et al., 2016; T. Ettema et al., 2005). Therefore, it is important to analyze what contributes to a person's positive and negative affect. This way, elements that causes negative affect can be eliminated and the elements contributing to positive affect can be enhanced. Therefore, in the further course of this report, I will focus on how feelings of connectedness can support emotional well-being.

Summary of main insights on QoL and well-being in the later stages of dementia

The following elements that contribute to the QoL of people living with moderate to severe dementia are identified:

- Preserving an emotional balance
- Preserving an adequate care relationship with the nursing home staff
- Developing and maintaining social relationships
- Preserving a positive self-image (cannot be assessed for severe dementia)
- Dealing with the nursing home environment (cannot be assessed for severe dementia)

The aim of this project is to improve the quality of life (QoL) of people with moderate to severe dementia, through creating a feeling of connectedness. This means that this project is focused on the psychological aspect of QoL, which is called emotional well-being.

Therefore, the goal of this project is further specified: enhancing feelings of connectedness of people living with moderate to severe dementia, to support emotional well-being.

2.4 Life in a nursing home for people with dementia

This chapter will explain more about the exact context of this project, namely people with moderate to severe dementia living in a nursing home. First, the research methods are explained, where after an explanation of the nursing home environment is given. The chapter ends with an insight in the daily life of a person in the mid to late stages of dementia.

Due to the progressive nature of dementia, symptoms will worsen to the point that someone is not able to take care of himself anymore and full-time care is needed (Alzheimer's Association, n.d.-b; Alzheimer's Research UK, n.d.; Alzheimer's Society, 2017b). This can lead to the institutionalization of the person with dementia, which mostly occurs in the later stages of the disease (Alzheimer's Association, n.d.-a; Alzheimer's Society, 2017b).

In the Netherlands, 82.000 people over 65 years old had an indication for inpatient psychogeriatric care in 2013 (Volksgezondheidszorg.info, 2019). This is about 32% of people diagnosed with dementia. In the UK, 311.730 people with dementia (39%) are living in a care home (Alzheimer's Research UK, n.d.). Moving to a nursing home has a big impact on the life of the person with dementia, as well as on their relatives and informal caregivers (Alzheimer's Association, n.d.-b; Alzheimer's Society, 2017b; Omroep Human, 2018). Therefore, people with dementia tend to stay at home as long as possible to retain as much of their independence as possible (Alzheimer's Research UK, n.d.; Omroep Human, 2018).

2.4.1 Setup of the context study

To gain knowledge about the life in a nursing home, both desk and field research was performed. The research questions for guiding this process were as follows:

- What do nursing homes for people with dementia look like?
 - What is the thought behind this?
- What does daily life in a nursing home look like?
 - What is the general daily routine?
 - What effect does this routine have on the residents?

Desk research

The performed desk research includes literature, as well as documentaries and inspiring stories. The main goal of this exploratory desk research was preparing for the field research. Important elements to pay attention to were identified to guide the field research.

The work of Anderiesen Le Riche, Campo and Chaudhury and True doors were used to gain an understanding on the influences of the physical and social environment on the behavior, feelings and activities of daily life (Anderiesen Le Riche, 2017; Campo & Chaudhury, 2012; True doors, 2017). This includes interior design, as well as social interactions between residents and between residents and care givers. The documentary series 'in de Leeuwenhoek' and the book 'De dag door met dementie' by Plaats and Kits were used to empathize with the user group and get insights on how to interact with people with dementia (Omroep Human, 2018; Plaats & Kits, 2016).

Field research

The goal for the field research was to empathize with the stakeholders of this project (the people with dementia as well as formal and informal caregivers) and gain contextual knowledge to be able to form an understanding of what daily life in and the physical environment of a nursing home looks like.

A total of four nursing homes and one geriatrics department of a hospital were visited. All located in the Netherlands: in Heythuysen, Breda, Delft and Amersfoort. Three conferences were attended, which were used to empathize with the broader context of dementia. These conferences especially helped to feel the impact of dementia on someone's relatives. It taught me about the emotional aspects as well as worries and capabilities of care givers and relatives. Appendix D provides an overview of all field research moments.

To quickly gain hands on experience with the user group and observe the general context of a nursing home, two short exploratory visits to nursing homes were done in the beginning of the project. These visits were focused on the Tovertafel, as I joined a Tovertafel demo and a game evaluation. During these visits, I was able to observe the physical environment of these nursing homes and the social environment when interacting with Tovertafel. This immersion in the context helped me to empathize with the user group and understand better what living with dementia is like.

For the more thorough context research, a total of three nursing homes were repeatedly visited during different times of the day, altogether covering a hole day from morning till evening. The nursing homes included in this research are: Thebe Lucia in Breda, Nijestede in Amerfoort and Die Buytenweye in Delft. Insights were gathered through exploratory research methods, including semi-structured fly-on-the-wall and participant observation as well as unstructured interviews (Hanington & Martin, 2012; IDEO.org, 2015). The research was purposefully setup to be flexible to enable collection of information from spontaneous interactions and observations.

During the field studies, I started out with fly-on-the-wall observation (Hanington & Martin, 2012; IDEO.org, 2015). During these observations, residents and care givers in the nursing homes were observed without interfering in their daily routines. The aim of these observations was to gather insights with a minimal potential bias caused by interaction with the stakeholders. It was noticed that only fly-on-the-wall observations did only provide superficial insights. Therefore, this observation method was alternately used with participant observation. In participant observations, a design researcher actively participates in a community (Hanington & Martin, 2012; McLoad, 2015). This type of observation was used to gain deeper connections and empathy with the people with dementia and get a deeper understanding of things that are important to them in daily life.

To support the observations, short unstructured interviews with care givers were conducted in the nursing homes. Questions were asked to clarify and interpret certain behaviors and/or activities of the residents. As these unstructured interviews were often very short and conducted in the hallways in between the caring duties of the care givers, these interviews were not recorded and therefore could not be transcribed. Just like with the observations, written notes were made.

The results from the field research is gathered in appendix F. In the following chapters, the insights of both the desk and field research are combined, resulting in a description of the nursing home environment and the daily life of residents.

2.4.2 The nursing home environment

A nursing home for people with dementia provides round-the-clock specialized care for people living with dementia. Professional care givers are always around to help people with their personal care, like washing, dressing and eating, as well as supporting them in their daily activities and guiding them through the day.

In the Netherlands, each resident has his own bedroom, which they can decorate with their personal belongings, like pictures of relatives and furniture from their previous home. The bedrooms open onto a main hallway, to which the living/dining room(s) are also connected. Mostly, people get assigned to a specific living room, with a total of about 5 to 8 residents. In the shared areas, nursing homes pay attention to creating a home-like atmosphere, instead of a very clinical one. Therefore, these areas are filled with furniture and objects with aesthetics dating from the residents' youth (see Figure 18-21). This fits the perception of the residents, as their world perception is focused on the past, and will make them feel at home (Plaats & Kits, 2016; True doors, 2017). Some of the staff members, like the occupational therapists, wear normal clothes, instead of uniforms, to enhance the home-like atmosphere.

Overall, residents spend most of their time during the day in the living room. This is where they eat altogether and where daily activities take place, such as watching television, singing, playing games or reading the newspaper. Because people spend most time in the living room, this setting became the focus of this project.



Figure 18: Open kitchen in the living room



Figure 19: Sitting area of the living room



Figure 20: Dining area of the living room and a view into the main hallway to which the bed and bathrooms are connected



Figure 21: Hallway decorated with objects that fit the resident's world perspective

2.4.3 Daily life of a resident

As a result of the observations and interviews of the field research, a journey was created which gives insight in the daily life in a nursing home (see Figure 22). This journey is an example of what a day could look like. Some activities, like breakfast, lunch and dinner happen every day at approximately the same time. Others differ per day. Some days there are extra activities for residents like appointments with medical specialists or family visits. This journey does not include these extra activities, as they do not happen on a regular basis and differ per resident.

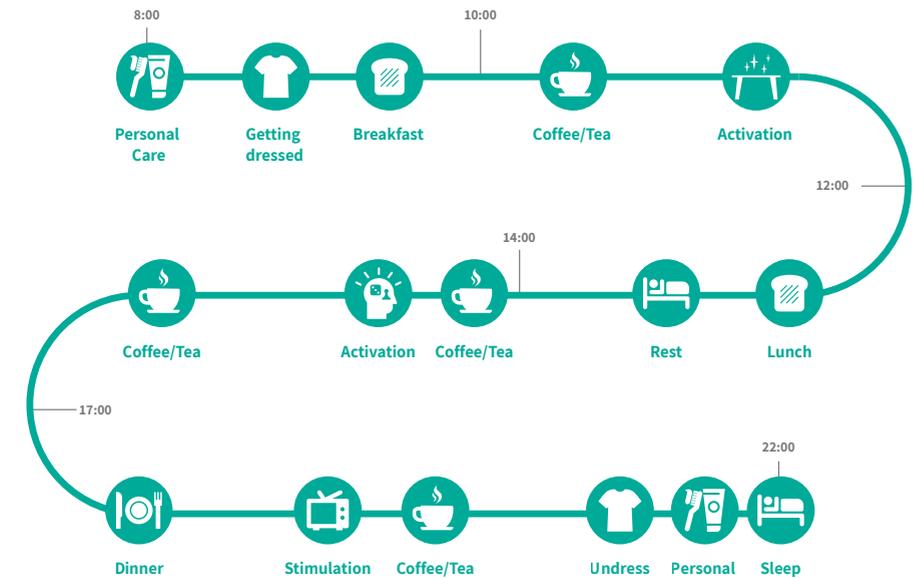


Figure 22: Overview of activities that take place on a daily basis

Besides this general overview of activities (see Figure 22), a more detailed journey was created (see pages 44-46) This detailed journey provides a general explanation of daily activities, as well as an example of a day in the life of two fictional residents. Following the analyses technique 'personas', as described by Hanington & Martin, the profiles of these fictional residents were put together from information collected from real residents of the different nursing homes (Hanington & Martin, 2012). A selection of residents in comparable situations and with comparable behaviors was used to create them.



Truus (85)

Gender female
Stage of dementia mid to late
Physical condition able to walk independently

Characteristics

wait-and-see	○○○●○	curious
easily distracted	○●○○○	focussed
fast responses	○●○○○	slow responses
needs little stimulation	○○○●○	needs much stimulation



- chatting with fellow residents
- music / singing
- animals



- being alone

Apathy

Truus is able to finish activities, but it is hard for her to initiate activities by herself.

Aphasia

She is still able to have and understand a conversation.

Figure 23: Persona of Truus; a fictional resident put together with insights from the field research

Truus (see Figure 23) is an optimistic 85-year-old lady, who is living with mid to late staged dementia. She is still able to walk independently and has a curious character. Truus is a social person who enjoys chatting with her fellow residents and the care givers. She is still well capable of having and understanding conversations. Because of her apathy level, it is hard for her to initiate activities by herself. Truus needs quite a bit of stimulation. When this is not provided, this can result in either apathetic or restless behavior, depending on the time of the day and environmental factors like her social surroundings. She doesn't like to be left alone in a room. When this happens, she feels lost and often starts wandering around, looking for social acknowledgement and stimuli.



Kees (90)

Gender male
Stage of dementia late
Physical condition wheelchair dependent

Characteristics

wait-and-see	●○○○○	curious
easily distracted	○●○○○	focussed
fast responses	○○○●○	slow responses
needs little stimulation	○○○●○	needs much stimulation



- nature
- technical objects
- puzzles



- bingo
- Dutch music

Apathy

Kees rarely initiates contact with his surroundings, but does react to contact initiated by others.

Aphasia

Kees hardly ever speaks. It is hard for him to understand conversations.

Figure 24: Persona of Kees; a fictional resident put together with insights from the field research

Kees (see Figure 24) is a 90-year-old man, who is living with late staged dementia. Because of his physical condition, he is wheelchair dependent. Kees sleeps a lot and suffers from apathy. This causes him to rarely initiate contact with his surroundings. He doesn't show curiosity. Kees does react to contact initiated by others, but his responses are slow. Because of his aphasia, Kees is not able to make sentences anymore and hardly understands conversations. Kees needs stimulation, but easily feels overwhelmed. When Kees is overstimulated he can become agitated, but most of the times he becomes apathetic or goes to sleep. He likes to explore technical objects and puzzles. He is passionate about nature and enjoys going outside. Dutch music is something Kees enjoys less, as well as playing bingo.

The entire journey, including those of Truus and Kees can be found on the next three pages.

Daily life in a nursing home for people living with dementia

General planning of the day



Truus (85)



Gender: female
Stage: mid to late

- able to walk independently
- social towards others

Truus gets out of bed at 8:30. She needs a **bit of guidance** in dressing and personal care. When moved to the living room, she is able to make her own breakfast with the things that are on the table. She is **awake and active**. Sometimes reacts to actions from her neighbor and talks about general things like you would do with an acquaintance.

+ Truus is **well capable of making her own breakfast** and grasping the things on the table that she needs for this. She is proactive in the activity of making and eating breakfast.

- When she is done with eating her breakfast, **she just sits, gazes around and waits**. She only reacts to actions from others, but does not initiate a conversation or some other action herself.

Truus sits at the table and **fidgits** with her watch and purse. She goes through her purse and looks at the things that are inside it. She **does this over and over again**. You can see that she really **enjoys the attention** in the coffee break. She **lives up** and is fully engaged in the coziness of the coffee moment. This also happens when playing with the Tovertafel. Truus mostly enjoys the **social part** of it.

+ Truus **lives up when the care givers actively pay attention** to the residents and create a cozy atmosphere. She enjoys the attention and has a satisfied expression on her face.

- When the atmosphere turns more quiet, Truus starts to **search for stimuli**. She has an emotionless expression on her face and her body seems a bit uptight.

Truus

During lunch, Truus is fully focused on her food and the task of eating. She quietly makes and eats her sandwiches. When she is done she **gazes around and waits** for the other residents to finish. She **does not need a rest** after the lunch. She does not go to her room, but stays in the living room.

+ Without distractions, Truus is **able to independently make and eat her lunch** with the things that are displayed on the table.

- When almost all other residents enjoy their rest, Truus starts **looking for stimuli**. She wanders around **looking for people and/or activities**. She seems a bit **lost and restless**. She doesn't seem to understand where everybody went.

Truus gets served a cup of coffee and is well capable of drinking it by herself. She sometimes forgets that she had coffee, but overall **manages to fulfill the activity of drinking coffee**. When the care givers start to play a game where they have to finish proverbs and sayings, Truus is one of the **first to join in** and finish the sentences. She is **aware of her social surroundings** and sometimes interacts with one of the other residents during the game. After the game has ended and the care givers got busy with other tasks, Truus is still **actively gazing around**. She read the time and date on the clock aloud, but **gets no respons**. She gazes around and repeats the time and date after 5 minutes.

+ Truus is **easily entertained and activated** with simple games and social contact. She creates a positive atmosphere which is contagious and positively influences the other residents as well.

- When there is no activity initiated by the care givers, Truus' **surroundings become static**, which causes her to **start looking for stimuli**. The date and time on the clock provide a bit of stimulation, but there is no interaction with this. When she reads it out loud, she **does not get a respons** and just **continues looking for stimuli**.

Kees (90)



Gender: male
Stage: late

- wheelchair dependent
- apathetic

Kees wakes up at 9:00. He **needs a lot of help** with dressing and personal care. He is put in his wheelchair and brought to the living room. He is **not capable of making his own breakfast**, but with some guidance he is still capable of bringing the food to his mouth. When he is done eating he seems to fall asleep.

+ Kees is still able to **eat without a lot of help**. This gives him a feeling of **independence**.

- He cannot decide to leave the breakfast table and go somewhere else, because he is in a wheelchair and **not able to move it by himself**.

After breakfast, Kees sits in his wheelchair at the table. His hands folded on his lap, his head hanging down. He seems to be asleep. When it's time for coffee a care giver touches his arm to ask what he wants to drink. The **touch and sound of the care giver wakes him up**. He enjoys the social activity. During the Tovertafel activity he becomes **physically active** for about 15 minutes. After this he goes back into his **apathetic, seemingly asleep** status.

+ When his surroundings take the initiative, Kees is **still able to react** and seems to **enjoy the interaction and attention**.

- Kees easily turns to a state of being apathetic. The **effect of activation rapidly decreases** when an activity comes to an end.

Kees

The lunch of Kees is prepared for him and precut into small pieces of bread. Kees is **able to eat it by himself**. It is a bit **messy** because his small and gross motor skills are not optimal. After lunch, the care givers take him to his room for a **rest**. After one hour, the care givers wake him up again and bring him back to the living room.

+ Kees is still able to eat by himself, although it is messy, it is still a bit of **self-reliance and autonomy**.

- Care givers **need to wake Kees up**, otherwise he would go into a deep sleep and as a result become more restless at night.

Kees gets served a cup of coffee and one of the care givers sits down next to him to help him with bringing the cup towards his mouth. He **enjoys the attention**, but is **not capable of fulfilling this task independently**. When they are playing a game he does not respond, but he is **aware of the activity** and sometimes gazes at the people who are asking questions or giving answers. When the activity of the game has ended, Kees becomes **apathetic** and sits in his wheelchair, with his **hands folded on his lap**.

+ Kees seems more awake and active when there is an activity going on. The **active, positive atmosphere seems to stimulate** him in a positive way.

- The **activating atmosphere** of an activity initiated by the care givers, has **no long-term effect** on Kees. Already during or right after the activity, Kees becomes **quiet, inactive and apathetic**. The static environment doesn't trigger or stimulate him.

Evening 17:00 - 22:00

Everyone is brought back into the eating setting. Residents are brought to their tables and **dinner gets served**. Residents do not need to put their food on their plate themselves, this is done for them. Some residents are able to eat themselves, others need help or need to be fed. After dinner, **care givers are busy with cleaning** up the table. Residents just **sit and watch the care givers, gaze around or fall asleep**. The **TV or radio** is turned on to provide some entertainment and/or stimulation and there is a **coffee/tea moment**. Around 7 pm, care givers start to prepare the first residents for the night and bring them back to their room. Around 10 pm the last person is brought to bed.

The people that do not go to bed that early are **left in the living room, mostly by themselves** because the care givers are busy with the other people. Residents that are still awake **do not have a lot of stimuli** in their surroundings, the living room becomes more and more **empty and quiet**. Some people start to **search for stimuli** by wandering around in search for people and/or something to do. Feelings of **loneliness and boredom** arise.



Dinner

Stimulation

Coffee/Tea

Undress

Personal Care

Sleep

Truus

During dinner, Truus is fully focused on her dinner. She appreciates the fact that the care givers cook and serve her food and thanks them for it. She seems to **enjoy the taste of the food**. When she is done eating, she just sits and gazes around, but **doesn't start a new activity**. She **fidgits** a bit with the blouse. When the care givers talk to her she responds immediately, but doesn't continue with a conversation. When the TV is turned on, Truus sometimes gazes at it, but **does not actively watch the program**. When care givers start to put more and more people to bed, Truus starts to feel **restless**. She is sometimes **left alone** in the living room, which causes her to start **wandering in a search for stimuli and people**. At about 21:30, Truus wants to go to bed and gets some help with undressing and her personal evening care.

+

Truus **appreciates all the help she gets**. She is friendly and social. In the evening, she still is actively looking for stimulation.

-

When the living room becomes more static and empty, Truus starts to feel restless. She doesn't know what to do with herself when she is left alone. Truus is **not capable of entertaining herself with her surroundings**. The TV is not captivating enough and care givers are busy. Truus is well aware of the time and doesn't want to go to sleep yet.

"I don't know what to do with myself... It's only 8:30, I'm not going to sleep yet, I'm not a child."

Kees

Kees is helped with his dinner. He has a **hard time handling cutlery**, which is why he needs help. After dinner, Kees sits in his wheelchair. **Gazes around and does not do anything**. He is one of the first ones who is brought to bed by the care givers. This is a big task for the care givers because he is in a wheelchair and not capable of standing anymore.

+

Kees is not able to feed himself anymore during dinner, but it is still visible that he **enjoys eating his dinner**. The **reflexes of opening his mouth are still smooth**, only handling the cutlery is not possible anymore.

-

After dinner, Kees becomes a bit **sleepy and doesn't initiate actions**. His evening ends early, because he goes to his room around 7 pm.

Summary of main insights on life in a nursing for people with dementia

Due to the progressive nature of dementia, symptoms will worsen to the point that someone is not able to take care of himself anymore and full-time care is needed. This can lead to the institutionalization of the person living with dementia, which mostly occurs in the later stages of the disease.

A nursing home for people with dementia provides round-the-clock specialized care for people living with dementia. In the Netherlands, each resident has his own bedroom, which opens onto a main hallway, to which the living/dining room(s) are connected. Overall, residents spend most of their time during the day in the shared living rooms, which is why this area became the focus of this project.

The daily life of a resident living in a nursing home is roughly structured in the same way every day.

- 08:00 – 10:00 personal care, getting dressed, breakfast
- 10:00 – 12:00 coffee/tea moment, activity for physical or cognitive activation
- 12:00 – 14:00 lunch, rest
- 14:00 – 17:00 coffee/tea moment, activity for physical or cognitive activation
- 17:00 – 22:00 dinner, stimulation, coffee/tea moment, going to/being brought to bed

2.5 Disconnectedness in dementia

This chapter is focused on the role of connectedness in dementia. The theory on connectedness, as discussed in chapter 2.1, described that connectedness can be divided into three types: social, personal and physical connectedness. In this chapter, this theory is used to analyze the field research results and gain insights on disconnectedness in the context of people living with dementia in a nursing home. The research questions that guided these insights were as follows:

- What influence does moving to a care home have on the feeling of connectedness for a person living with dementia?
- When, where and why do people with moderate to severe dementia feel disconnected on a daily basis?

2.5.1 Moving to a care home

One of the things that has a huge impact on the feeling of connectedness for people with dementia, is moving to a care facility. The consequences of moving to a care home mainly relate to whether people feel at home in the care home. When people do not feel at home, it can cause them to feel locked up or want to get off the ward (Dichter et al., 2016; T. Ettema et al., 2005).

Risk for social isolation

When someone moves to a care home, the risk for isolation increases. They are no longer surrounded by their familiar environment, are not familiar with the new one and have no connections with the people around them. Because of their cognitive decline, it is hard to impossible for people with dementia to build new relationships (Perrin et al., 2008b; Plaats & Kits, 2016; World Health Organization, 2017b). Only superficial interactions remain, while the more intimate ones disappear. This can result in feelings of loneliness (Perrin et al., 2008b; True doors, 2017) and negatively affects their need for relatedness, belonging and love and therefore the feeling of social connectedness.



Loss of identity and ownership

Your home shows your identity and is your legacy. You furnished it yourself, according to your sense of aesthetic pleasure and your rules apply. This all disappears when you are moved to an unfamiliar institutional environment that you don't own. This decreases the possibility for self-expression and therefore negatively impacts a feeling of personal connectedness.



Loss of outdoor sensory stimulation

When living at home, people with dementia can decide for themselves when they want to go outside, depending on the situation. This changes when they move to a closed unit of a nursing home. Here, people with dementia are not allowed to go outside on their own, for their own protection. This can cause a loss of multisensory and peak experiences that being outside and experiencing the weather, temperature and smells can provoke (Whear et al., 2014). Because these peak experiences are endangered, there's a risk for a decreased feeling of physical connectedness.



2.5.2 Static environments

As shown in the daily life journey (chapter 2.4), people in the moderate to severe stages of dementia spend a lot of their spare time in unstimulating, static environments. They are surrounded by static objects and non-responsive, apathetic fellow residents.

These static environments emerge in the moments between activities initiated by the care givers. Moments like this result in several possible behaviors, which strongly relate to under stimulation of senses and cognition. The behaviors that result from this and their impact on connectedness are discussed in the next paragraphs.

Apathy: withdrawn from the world

What is very apparent in the daily journey of people living with dementia is the inability to initiate action (see Figure 26). 90% of people with dementia, living in a nursing home, suffer from apathy (Kolanowski et al., 2005). This means that they are incapable to take action, show no energy and have a lack of feelings, emotions, interest or concern (Anderiesen, 2017). When a person doesn't take action they often are left doing nothing (see Figure 25). They get isolated from their feelings and life and are in a numb state. This state of no emotion negatively impacts the emotional balance of people, which results in a decreased level of emotional well-being (Dichter et al., 2016; T. P. Ettema et al., 2005).



Figure 25: A person is sitting on a chair with no stimuli in her surroundings. Without external triggers the person will just continue to sit here in a state without emotion and connection with her surroundings.

This behavior is clearly related to a decreased quality of life, since restless tense behavior is a domain that stays relevant, even in the latest stages of dementia (Dichter et al., 2016). Also, the quality of life domains ‘having something to do’ and ‘feeling at home’ are related to this lack of stimuli in someone’s environment, as people can feel bored and/or can’t find anything to do with the help from others (Dichter et al., 2016; T. Ettema et al., 2005). This generates negative emotions, as negatively impacts the emotional balance of people and therefore decreases emotional well-being (Dichter et al., 2016; T. P. Ettema et al., 2005).

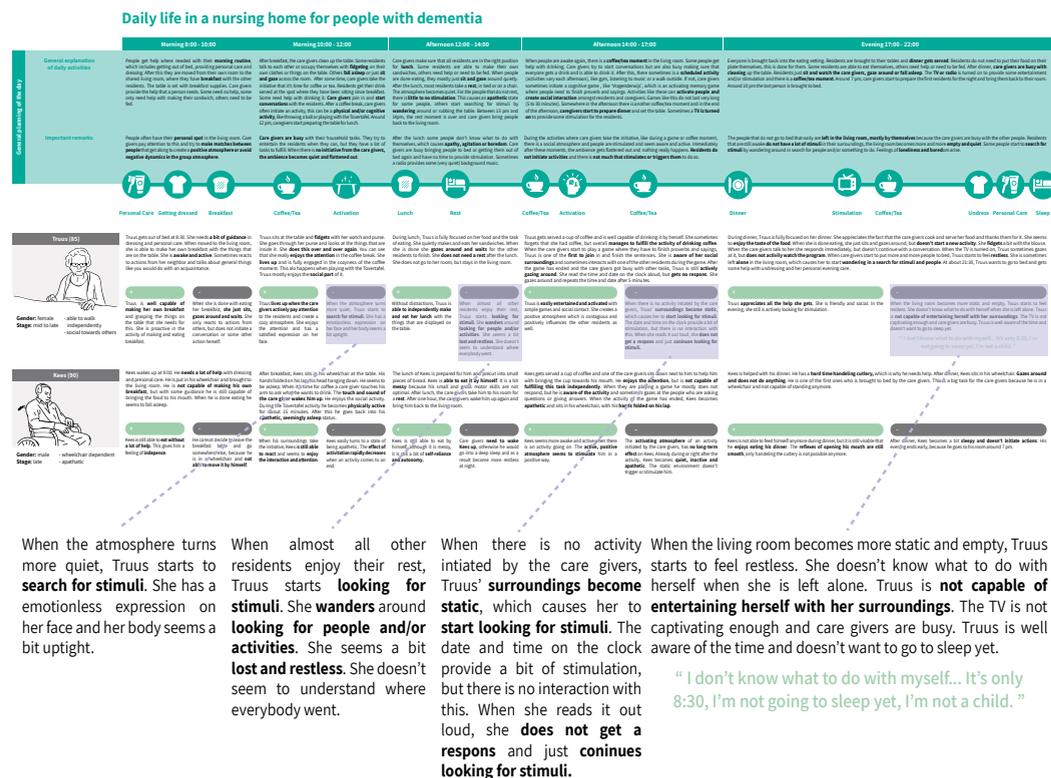
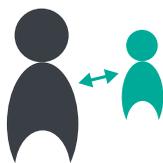


Figure 28: Restless moments in the journey of Truus

Search for social connection

Being left alone in an empty environment can cause feelings of social disconnectedness. Having no opportunities for social interaction, creates a lack in the fulfillment of our needs to belong, be acknowledged and receive esteem from others (Desmet & Fokkinga, 2018; Maslow, 1943). This can make a person feel socially isolated and not worthy of attention (see chapter 2.1). This can also happen when someone tries to make contact with a nurse or fellow resident, but instead of acknowledged, gets ignored.



Search for meaning

In a static environment, not only a person’s sensors are under stimulated, but also his cognition. A static room lacks novelty for people with moderate to severe dementia who are still capable of symbolic thinking (Perrin et al., 2008b). These people are still able to creatively relate stories from their past to objects or events in the present. When nothing happens in their surroundings, there is nothing to explore or find meaning in. Also, static objects are harder to interpreted for people living with dementia. Therefore, it is harder for them to recognize and relate to object in a static environment (Plaats & Kits, 2016). A person can feel bored in such a moment or start to develop a negative self-image, because he is not able to do anything (Dichter et al., 2016; T. Ettema et al., 2005). This search for novelty, purpose and meaning relates to feeling connected with yourself, being able to express who you are and find meaning in your life (see chapter 2.1).

Wanting to feel alive

Restless people are aware of their surroundings, but these surroundings do not give the supplies for fulfilling their needs. There are little to no sensory stimuli, which can cause people to start searching for them (Alzheimer’s Society, n.d.-a; Perrin et al., 2008b; Unforgettable, n.d.). They can for example start to fidget with objects or hit the table to fill this gap of under stimulation (Perrin et al., 2008b). This stimuli-seeking behavior can also be an attempt to feel alive; “I am alive. I must be alive, because I can hear myself making this noise” (Perrin et al., 2008b). This basic feeling of being alive is strongly related to the feeling of physical connectedness (see chapter 2.1).



Summary of main insights on disconnectedness in dementia

When applying the theory of connectedness to the context of people with moderate to severe dementia, two impactful elements were identified.

Moving to a care home has a huge impact on the feeling of connectedness.

- **Social:** risk for social isolation, resulting in feelings of loneliness.
- **Personal:** loss of identity and ownership reflected by your surroundings.
- **Physical:** loss of outdoor sensory stimulation, resulting in decreased multisensory and peak experiences.

Residents of nursing homes for dementia often spend time in unstimulating, static environments. This can cause both apathetic and restless behavior. These types of behavior impact the feeling of connectedness and decrease emotional well-being.

Apathy: withdrawn from the world, in a state without emotion

- **Social:** not being able to initiate contact creates an increased risk for social isolation.
- **Personal:** not being able to initiate meaningful or cognitively stimulating actions decreases the level of self-expression.
- **Physical:** as both the environment and the apathetic person are static, sensory stimulation is decreased to a minimal level.

Restlessness: searching for connection, leading to negative emotions

- **Social:** in a static environment, people have no opportunities for social interaction or get ignored, which can cause people to start searching for social connection.
- **Personal:** static environments can create a lack of cognitive stimulation, which can cause people to start searching for meaning.
- **Physical:** static environments provide little to no sensory stimuli, which can cause people to start searching for them, out of an urge to feel alive.

2.6 Conclusion

To conclude the analysis on connectedness in dementia, this chapter presents my vision on the project that serves as a basis for the design phase.

In this project, I focus on increasing the feeling of connectedness of people living with moderate to severe dementia in static care environments. In the analysis presented in this chapter, I found that people with moderate to severe dementia spend time in static environments every day. This means that they are surrounded by static objects and non-responsive, apathetic fellow residents (see chapter 2.5).

Due to cognitive impairments, it is difficult for people living with moderate to severe dementia to initiate action and make sense of the world around them (see chapter 2.2). Therefore, static environments cause people to become apathetic or restless. These types of behavior cause the level of feelings of connectedness to decrease, which negatively impact people's emotional well-being as apathy and restlessness involve states of no or negative emotions (see chapter 2.3 and 2.5).

As the moments where people spend time in static environments happen when care givers are busy with their caring duties, I envision to offer something for these moments that can be used by a resident without the help of care givers and can be used individually, without the need for fellow residents. Therefore, the design phase of this project focusses on the individual side of connectedness. This includes personal connectedness, where people feel connected to their psychological self, and physical connectedness, where people feel connected to their physical self (see chapter 2.1).

It is important to offer people with moderate to severe dementia the opportunity to engage with something when wanted. As they also like to rest and/or do nothing sometimes, they should be in charge of the interaction. The authors of the book 'Wellbeing in dementia' share this opinion and have described it as followed:

"We believe that it is a good practice for something to be offered. It might be rejected or ignored; that is not important – what is important is that we provide an opportunity for attaching to something that will assist, comfort and ease the journey towards absolute dependence." (Perrin et al., 2008b)

To provide something that increases the feelings of personal and physical connectedness in static environments, something should be offered that provides both sensory and cognitive stimulation. Therefore, a product should provide dynamic sensory stimulations that can be explored and trigger the curiosity in people. This way, physical connectedness is enhanced through the experience of sensory stimulations and the feeling of personal connectedness is enlarged through cognitive stimulation.

3

Analysis of design principles for dementia

Dementia affects a person's cognitive, behavioral and emotional functioning, which influences product experience and interaction (Anderiesen Le Riche, 2017). Therefore, this chapter investigates what type of design principles are suitable for this user group. Firstly, an analysis of the interaction principles and play experiences of the Tovertafel is presented. Thereafter, the method and results of a field study with probes that I performed are explained. The chapter ends with a conclusion on applicable design principles and play experiences that can be used when designing for people living with moderate to severe dementia.

The research questions for this chapter are the following:

- What interaction principles are applicable when designing for people living with moderate to severe dementia?
- Which types of play experiences are still possible to elicit for people living with moderate to severe dementia?
- What type of product elements trigger and/or captivate people living with moderate to severe dementia?
- What practical requirements should be taken into consideration when designing a product for people living with moderate to severe dementia?

3.1 Interaction principles and play experiences of the Tovertafel

In this chapter, the results of an analysis of the interaction principles and play experiences used in the development of the Tovertafel are described.

3.1.1 Interaction principles

During the iterative development process of the Tovertafel, multiple interaction principles were found which can stimulate and elicit a reaction from people with moderate to severe dementia. These interaction principles are used by Active Cues in designing new Tovertafel games (Active Cues, n.d.-c; Anderiesen Le Riche, 2017). In this research, these principles were analyzed to see which ones are applicable in the broader sense of designing for people with moderate to severe dementia. Principles that are very specific for the Tovertafel and less applicable to other design situations were excluded. This resulted in the following list of principles:

- A product should initiate the interaction
- Sensory triggers can stimulate people to interact
- A product can support people to lengthen their engagement time with an activity by frequently providing triggers. Especially at moments that the attention of the person drifts away.
- A product should provide participation at every level. A so called 'layered' design can ensure that most people living with dementia can participate and find joy at their own level.
- The product should provide sufficient time for people to react.
- A product should only provide positive feedback. This emphasizes people's abilities and creates a safe environment for people to interact freely with the product.
- The product should react to minimal and/or slow movements. (Active Cues, n.d.-c; Anderiesen Le Riche, 2017)

3.1.2 Play experiences

The results of a literature review on play experiences for people with Alzheimer's disease were also used in the developmental process of the Tovertafel (Anderiesen et al., 2015; Anderiesen Le Riche, 2017). This literature review identifies play experiences that are still suitable for people in the different stages of Alzheimer's disease (see Figure 29).

As shown in Figure 29, regardless of the severity of dementia, the play experiences relaxation, reminiscence and sensation are suitable. As this project focusses on designing for people living with moderate to severe dementia, one or more of these play experiences should be used.

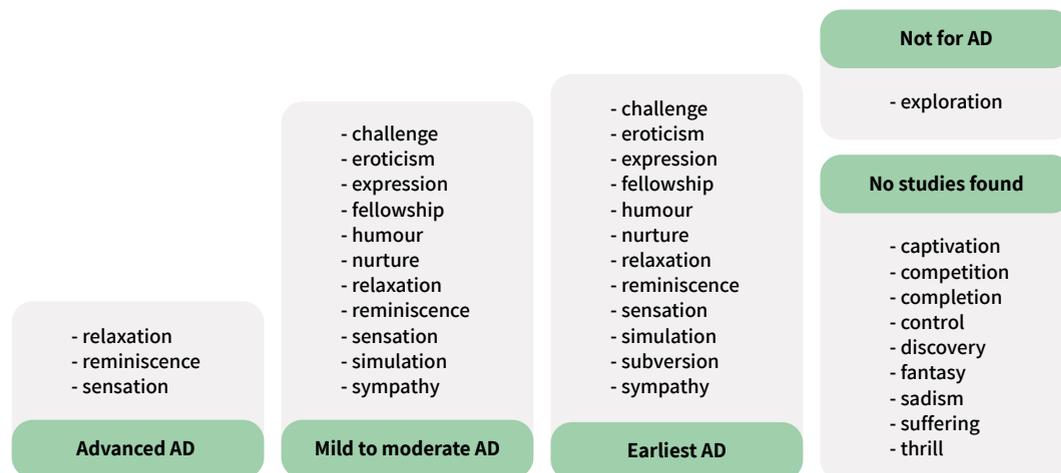


Figure 29: Play experiences for people with Alzheimer's Disease (AD) (Hester Anderiesen et al., 2015; Anderiesen Le Riche, 2017)

3.2 Field study with probes

This chapter describes insights from the field study in which probes with varying qualities were presented to the target group. The goal of this study is to investigate what type of product elements trigger and/or captivate people living with moderate to severe dementia. Besides design and play principles, this study also generated insights on practical concerns when designing for people living with moderate to severe dementia.

3.2.1 Research method

The goal of this research was to identify product elements that trigger and/or captivate people living with moderate to severe dementia. In order to achieve this, a set of probes was selected varying in textures, forms, colors and materials. This selection was based on the aim to offer elements that could stimulate different senses. The selection of probes not only differs in terms of sensory stimulation, but also in terms of potential for open-ended play, so attention was paid to freedom of interpretation and ambiguity of the objects (Bekker, de Valk, & Eggen, 2014; de Valk et al., 2015). Also objects that were present in the nursing homes, and were relevant for this study, were included. Figure 30 shows an overview of the probes included in this study.

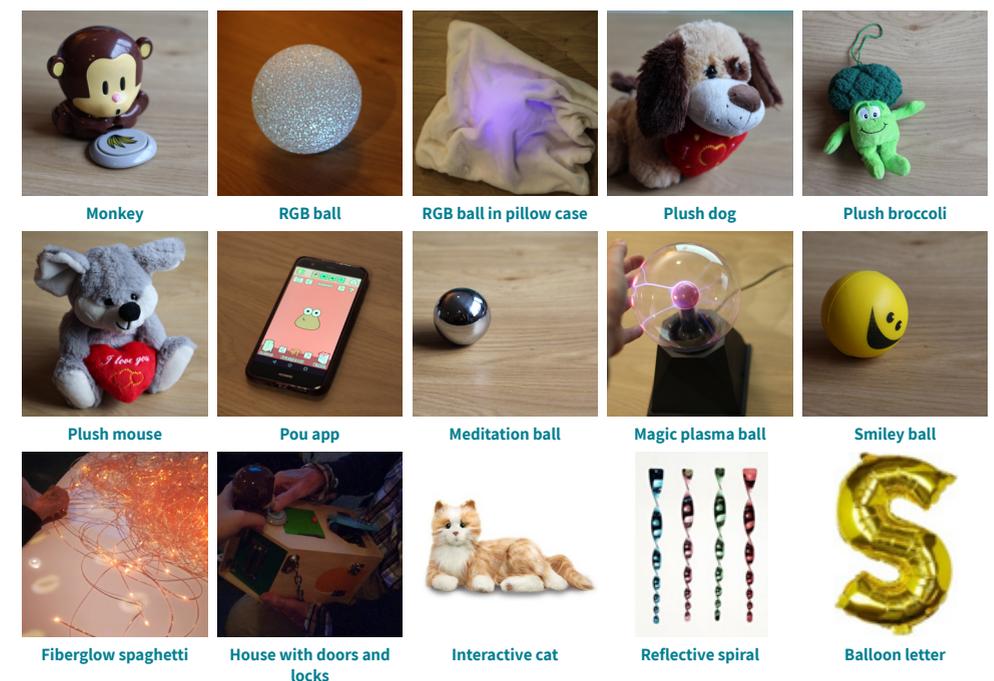


Figure 30: Probes involved in the research

Insights were gathered in three sessions divided over three nursing homes: Thebe Lucia in Breda, Nijstede in Amersfoort and Die Buytenweye in Delft. Insights were gathered through exploratory research methods, including semi-structured fly-on-the-wall observations and participant observation as well as unstructured interviews (Hanington & Martin, 2012; IDEO.org, 2015).

Probes were placed within the reach of one or multiple residents. For the fly-on-the-wall observations, no introduction of the product was given to research what intrinsically triggers the residents. Participant observations were used to deepen the insights. In these observations, conversations were conducted with the residents, making them explain and elaborate on the objects. To support the resident observations, short unstructured interviews with care givers were conducted to clarify and interpret the certain behaviors and/or activities of the residents. The research was purposefully setup to be flexible to enable collection of information from spontaneous interactions and observations.

The results were captured in observational notes and short video material. The gathered data was analyzed according to the method described by Sanders and Stappers in the book 'Convivial toolbox' (Sanders & Stappers, 2012). Data was interpreted and turned into an informational overview (see Appendix H), the interpretation of this information resulted in statements of knowledge. The goal of the analysis was to find similarities in triggers and captivation across the different nursing homes and probes. The results of the probes study can be found in appendices G & H.

3.2.2 Design principles for triggering and captivating

The probes research resulted in a series of statements with insights for design principles for triggering and captivating people with moderate to severe dementia and practical concerns. First the insights for design principles are explained, followed by the practical concerns.

People tend to fidget with what is in their surroundings

Fidgeting can be described as making continuous small movements because you are uncomfortable or bored (Cambridge Dictionary, n.d.-d). For example, a resident in Amersfoort, who was given the RGB ball inside a pillowcase liked to fidget with the pillowcase. She held it between thumb and index finger and made continuous small circles with these two fingers, rubbing the pillowcase across them. This movement was seen more often. Blankets and clothes are also used by residents for this type of fidgeting. Another type of fidgeting was found when a resident was wrapping the fiberglow spaghetti around her fingers like a ball of wool. The RGB ball was also used for fidgeting by a man who continuously rotated the ball in his hands, while exploring the texture.

People are attracted by elements of objects that deviate and/or stand out

Besides fidgeting, people were also attracted by the elements of an object that deviate and/or stand out. This results in touching the edges and corners of objects, as well as on/off switches. For example, a woman started to touch the edges of the black pedestal of the magic plasma ball. This also happened with the balloon letter; a woman stroked with her fingers over the edge of the letter as well as the edge between the head and torso of the monkey. Also, the attention of a man was caught by the on/off switch of the RGB ball.

Products that emit light draw people's attention, especially when the lights change color

Some of the objects included (color changing) lights. This caught the attention of people, even in the latest stage of dementia. One of the caregivers explained that objects that include lights are also easier to see for people with poor vision. The lights in the fiberglow spaghetti and RGB ball, both changed color in the same way; fading from one color to the next in a preset loop. People found it pleasant to watch this happen and were captivated and sometimes enchanted by it. Sometimes this color changing light effect became a topic for conversations initiated by the residents. They would name the colors and point at the object.

Products that allow for exploration can stimulate and captivate people

People tend to explore objects to figure out what it is and/or what you can do with it or just for the sake of the exploration experience itself. Especially male residents tend to try to figure out the technical details of objects. This, for example, happened with the wooden house with doors and locks. A man was trying to open one of the doors to find out what is behind it. Also, the reflective spiral triggered exploration. A man inspected it and found the elastic band at the end of it. This triggered him to hold it by the elastic band to see what would happen. Afterwards, he held the spiral next to the fiberglow and told me that it takes over the lights. This all indicated that he was exploring the possibilities of the reflective spiral. Some female residents carry around their purse. This is also an object which triggers exploration. Several women explored the contents of their purse. They would find something in it, observe the object and explore what else is inside the purse.

Sound originating from an object triggers people to interact

When a product makes a sound that matches the appearance of the product, it triggers people to interact with it. Also, when there is a more abstract sound, of which people don't know what it is, it triggers people's curiosity. The interactive cat makes meow and spinning noises. Each time the cat meowed, a woman started to pet the cat and talk to it. This meow was a trigger for her to start or continue interaction. The monkey starts to blow when the button in front of it is pressed. This made a sound that was unrecognizable for people. This caused people to interact with the product to figure out what this sound is and where it originates from.

People can be captivated by creature like objects and are often drawn to their faces

Several creaturelike probes were used in the probes study: a monkey, interactive cat, plush broccoli, baby doll, smiley ball, pou app, plush mouse and plush dog. People were drawn to the faces of these creatures and sometimes mimicked their expressions. Also, the noses caught attention. Several people carefully touched the noses of the plush dog, interactive cat and monkey. Caring behaviors were triggered by these products and conversations with or about the creatures were initiated by the residents.

Movement attracts people's attention and triggers them to interact

When a product falls over or moves by itself, this attracts people's attention and often triggers them to interact. For example, the interactive cat sometimes rolls over. This caused a woman to start petting it again and search for its face. In another case, the plush dog had the same effect. It is top heavy which makes it hard to make it sit up straight. A woman was fully focused on making it sit. When it felt over again, she would make sit up again and again. She each time explored what the best way would be to make it sit steady.

3.2.3 Practical concerns

This field study with probes also gave insights on some practical concerns when designing for people living with moderate to severe dementia. These concerns were found through the observations of people interacting with the probes and interviews with care givers.

- Products in common areas of the nursing homes are used by multiple residents consecutively. Which makes hygiene an important concern. Therefore, a product should be easy to clean.
- The fine motor skills of people living with moderate to severe dementia decline as the dementia progresses. Therefore, a product should not include interactions that are focused on fine motor skills only.
- People living with moderate to severe dementia tend to put objects in their mouth. Therefore, a product should not include small loose elements as this forms a risk for choking.
- Visuals should have a high contrast, as visual impairments are common for people living with moderate to severe dementia.
- Care givers have limited time besides their caring duties. Also, they already have to know how to handle lots of devices important for care giving. Therefore, it should be as easy and intuitive as possible to setup the product for a resident. This includes that if a product is electronically powered, it should be easy to charge or change the batteries.

3.3 Exploration as a play experience

Most findings of the two studies confirm and/or supplement each other. However, the play experience 'exploration' shows contradictory results when comparing the probes study with the literature findings of the Tovertafel. This contradiction is analyzed and explained in this chapter.

Exploration can be described as the experience of exploring or investigating a world, affordance, puzzle or situation (Anderiesen Le Riche, 2017; Bekker et al., 2014). According to Andriesen et al., exploration as a play experience is not suitable for people with Alzheimer's disease (Hester Anderiesen et al., 2015). However, in my field study with probes it was found that products that allow for exploration can stimulate and captivate people living with dementia. People actively tried to make sense of the products through exploring the possible interactions with it. This raises the question whether or not 'exploration' is suitable for people living with moderate to severe dementia.

Exploration is a crucial element in playful interactions. As described by Bekker et al. and de Valk et al., the interaction with a playful design has three stages: invitation, exploration and immersion (Bekker et al., 2014; de Valk et al., 2015). These stages are explained as follows:

- *“Invitation: potential players have to be seduced in order to start interacting with the design.*
- *Exploration: players need to get to know and try to understand what the possibilities of the design are.*
- *Immersion: players should be supported in creating rules and games resulting in fun and pleasurable experiences that make players forget about the world around them.”*

(de Valk et al., 2015)

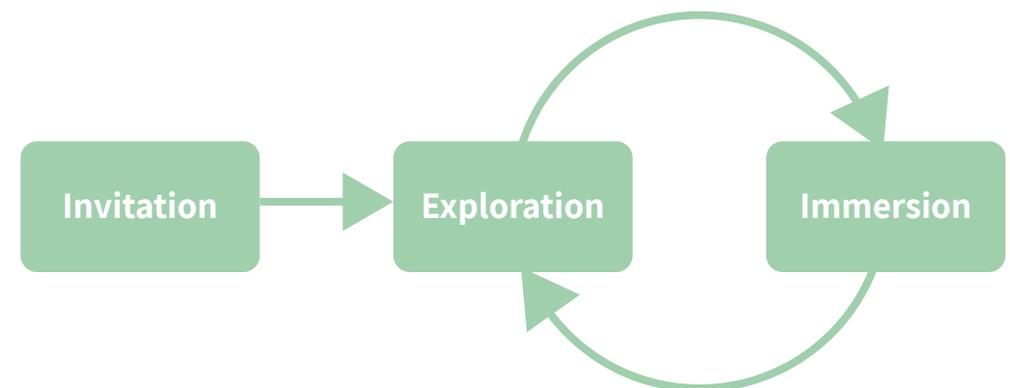


Figure 31: Stages of play in the interaction with a playful design (Bekker et al., 2014)

As shown in Figure 31, potential players should first of all be invited by the product, where after a stage of exploration starts. The stage of immersion can only be reached through exploration. When this is translated to the context of playful interactions for people living with moderate to severe dementia, it would mean that immersion in these interactions is not possible, as exploration was found to be not suitable for people living with Alzheimer's disease. But how is it then possible that people do get immersed in the interaction with the Tovertafel?

The recommendation of Anderiesen et al. is stated as follows: "Clinical studies show that the ability to take initiative is reduced in persons with Alzheimer's Disease, which is reflected in higher levels of apathy. We therefore recommend that game designers should not include exploratory elements appealing solely to a player's own initiative in games for all persons with Alzheimer's Disease." (Hester Anderiesen et al., 2015; Anderiesen Le Riche, 2017) This indicates that exploration is a suitable play experience to apply when exploratory elements are designed in such a way that the play experience does not only rely on the player's initiative. Therefore, I conclude that exploration is a play experience that can be suitable for people with moderate to severe dementia, as long as there is an external proactive trigger to invite the player to start and/or continue the exploration. This trigger could originate from the product itself and/or be initiated by a third party, like a care giver. This corresponds with the interaction principles of the Tovertafel that indicating that a product should initiate the interaction.

3.4 Conclusion

This conclusion combines all insights into a shortlist of answers per research question.

What interaction principles are applicable when designing for people living with moderate to severe dementia?

- A product should initiate the interaction
- Sensory triggers can stimulate people to interact
- A product can support people to lengthen their engagement time with an activity by frequently providing triggers. Especially at moments that the attention of the person drifts away.
- A product should provide participation at every level.
- A product should only provide positive feedback.
- The product should react to minimal and/or slow movements.

Which types of play experiences are still possible to elicit for people living with moderate to severe dementia?

- Exploration
- Relaxation
- Reminiscence
- Sensation

What type of product elements trigger and/or captivate people living with moderate to severe dementia?

- Color changing lights
- Sudden movement of or within an object
- Sound originating from an object
- Objects with flexible elements that allow for fidgeting
- Elements of an object that deviate and/or stand out
- Creature-like objects with faces

What practical requirements should be taken into consideration when designing a product for people living with moderate to severe dementia?

A product should:

- be easy to clean
- be usable with gross motor skills
- include no small loose elements
- include visuals with high contrast
- intuitive and easy for caregivers to setup

4

Design brief

In this chapter, the design brief of this project is described. This brings together the two analysis chapters: connectedness in dementia and design principles for mid to late stage dementia (chapter 2 and 3). First the design goal is formulated, after which the interaction vision and qualities are described. This design brief is later used as a point of reference in the design phase.

4.1 Design goal

Based on my vision on the project, which is described in chapter 2.6.2, the goal for the design phase of this project is formulated as follows:

“Designing a playful object that enables moments of physical and personal connectedness for people in the mid to late stages of dementia, to support emotional well-being in static nursing home environments.”

It is important to note that the object should be usable for people living with moderate to severe dementia without the help of care givers, as static environments are caused by the fact that care givers are busy with their caring duties. In Figure 32, the design goal is visualized in a storyboard.

Case 1 : Apathy



A person is sitting on a chair with no stimuli in her surroundings. Without external triggers the person will just continue to sit here in a state without emotion and connection with the surroundings.

Case 2 : Restlessness



A person is sitting on a chair with no stimuli in her surroundings. Restlessness arises in a search for stimuli. She becomes agitated and feels purposeless.

Case 3 : Connectedness



A person is sitting on a chair with an object in front of her on the table. The product gives a trigger at some point, which catches the person's attention. The person approaches the product, which responds to this, acknowledging the presence of the person. The person explores the interaction with the product for a while. After some time, the person decides to put down the product. A while later, the product will again give a trigger.

Figure 32: Storyboard about the current (case 1 & 2) and desired (case 3) situations

4.2 Interaction vision

Since this project is about designing an experience, an interaction vision was created (Pasman et al., 2011). This interaction vision uses a metaphor to represent the qualities of the interaction that should be transferred to the design. The interaction vision and qualities are based on insights from both the analysis of connectedness in dementia (chapter 2) and the analysis of design principles for dementia (chapter 3).

To provide something that increases the feelings of personal and physical connectedness in static environments, something should be offered that provides both sensory and cognitive stimulation (see chapter 2.1). Therefore, a product should provide dynamic sensory stimulations that can be explored and trigger the curiosity in people. This way, physical connectedness is enhanced through the experience of sensory stimulations and the feeling of personal connectedness is enlarged through cognitive stimulation.

Based on this, I formulated the following interaction vision:

“The interaction between user and product should feel like playing with a ladybug.”

This metaphor was chosen because there are several qualities about this interaction that are interesting to translate to the context of this project.



Figure 33: The interaction should feel like playing with a ladybug

4.2.1 Interaction qualities

Proactive

The ladybug takes the initiative by appearing in your eyesight or on your body. You decide whether to neglect or interact. In the context of this project, this is an important quality, as a product should initiate interaction with sensory triggers, to stimulate people to interact (see chapter 3) (H. Anderiesen, 2017).

Lively

Once you decide to interact with a ladybug, it will anticipate on what you do. You can see that it reacts on your actions, but also that it is not completely predictable. This makes it a lively interaction. Introducing a lively interaction like this into a static environment, increases the level of sensory stimulation which makes the setting more dynamic.

Explorative

When a ladybug approaches you, people can explore the possibilities. You can just look at it or decide to touch it. You can try to let it walk from one finger to the other or make it walk onto a leaf. This exploring of objects was found to stimulate and captivate people with moderate to severe dementia, as explained in chapter 3. Including factors in the object that can be explored and which react on the user's actions can have a positive effect on people with moderate to severe dementia, as they derive pleasure from being the cause of something (Perrin, May, & Anderson, 2008c) and fulfilling the need for exploration enhances feelings of personal connectedness, as it provides cognitive stimulation (see chapter 2.1).

Enchanting

Enchantment can be described as attracting or pleasing someone very much; a magical effect (Cambridge Dictionary, n.d.-c). A ladybug can suddenly appear in your eyesight, or open its wings, pretending to prepare for takeoff. This can be an unexpected trigger. In the context of this project it was found that in order to lengthen someone's engagement with a product, it should provide frequent triggers (see chapter 3). Moments with unexpected events can provide these triggers, as people with moderate to severe dementia enjoy the surprise of unexpected events (Anderiesen Le Riche, 2017). Moreover, enchantment also fits the positive design vision of Active Cues: to go beyond the functional solutions and evoke happiness and enchantment.

Subtle

Playing with a ladybug does not involve overwhelming, extreme interactions. It is present enough to notice and trigger, but is not too intrusive, so it can still be neglected. When you don't want to interact with the ladybug anymore, you can decide to blow to make it fly away or to start ignoring it. You have the control over it. This subtleness is an important quality in the context of dementia. When something is too intrusive it can become overwhelming and lead to overstimulation (Alzheimer's Society, n.d.-b, n.d.-a).

Open-ended

In open-ended play, players themselves can attach meaning to the design properties and the interactions while playing. It is play without predefined rules, which triggers the player's creativity by leaving room for interpretation (de Valk et al., 2013; de Valk et al., 2015). This open-endedness can enhance feelings of personal connectedness, as it is related to cognitive stimulation (see chapter 2.1). Playing with a ladybug is open-ended, as the person playing with it can create his own story and meaning through play. This open-endedness makes it possible to interact with the ladybug on different cognitive levels. This is important in the context of dementia, to make sure that people in different stages of dementia can participate and find joy at their own level (see chapter 3).

5

Design process

This chapter describes the design phase of this project. Based on the formulated design brief and interaction vision, idea generation was done, which resulted in three idea directions. One of these directions was chosen in which three prototype iterations were made to optimize the concept. This resulted in a final concept, which this chapter is concluded with.



5.1 Ideation

I started the idea generation phase with a brainstorm session based on the design brief. Several idea directions were explored through the creation of quick idea sketches. The ideas were focused on providing cognitive and sensory stimulation while taking the design principles for dementia into account, which are described in chapter 3. After the visual brainstorm session, the ideas were analyzed, which resulted in three idea directions.

Idea direction 1

Objects that provide sensory stimulation using different materials and textures and trigger people to interact through including flexible elements that allow for fidgeting.

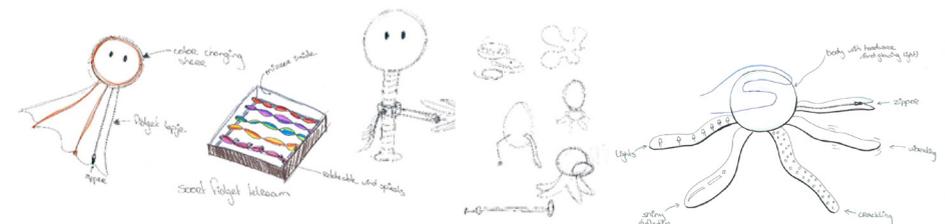


Figure 35: Sketches with ideas in direction 1

Idea direction 2

Creature-like objects that provide sensory stimulation using different textures and cognitively trigger people to interact through creating a character with a face.

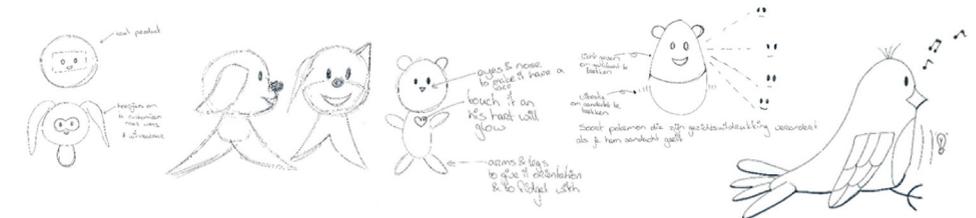


Figure 36: Sketches with ideas in direction 2

Idea direction 3

Abstract objects that provide triggers and sensory stimulation through color changing and/or moving lights that can be explored.

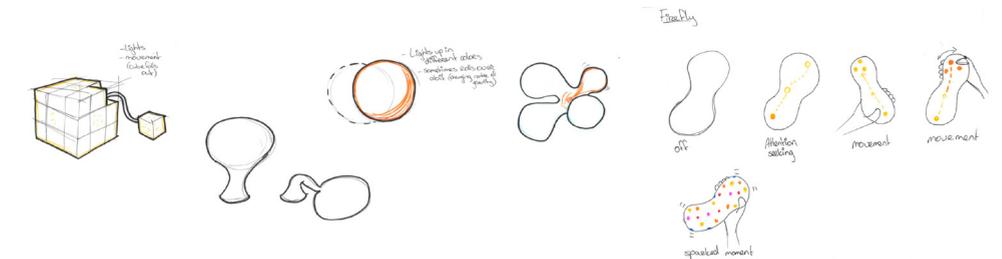


Figure 37: Sketches with ideas in direction 2

All ideas directions were assessed, using the interaction qualities of the design brief (see chapter 4.2). This made clear that idea direction one and two include too many different elements to trigger the users, which makes the object complex and takes away from the overall subtleness and enchantment of the experience. Also, the liveliness is not present in idea direction one. In idea direction two, this liveliness is interpreted as creature-like, which turned the ideas into realistic creatures. This leaves less room for the users to make their own interpretation, which makes the interaction less open-ended (Bekker et al., 2014; de Valk et al., 2013).

Idea direction three shows the most promising results, when comparing it to the interaction qualities of the design brief. While ideas in the other two directions include too many aspects, the ideas in this direction include more subtle triggers. Their abstract appearances make the ideas open-ended, as this makes them open for the interpretation of the user (Bekker et al., 2014; de Valk et al., 2013). One concept within idea direction three was chosen to develop further.

5.1.1 Final concept direction: firefly

The final concept direction is inspired by a firefly. A light, acting like a firefly, is present inside a three-dimensional object (see Figure 38). The light lights up and moves through the object, trying to catch the player's attention. When the player reacts to the fly by touching or picking up the product, the light will react to this movement. When rotating the object, the light will always 'fly' to the top, like a reversed hourglass.

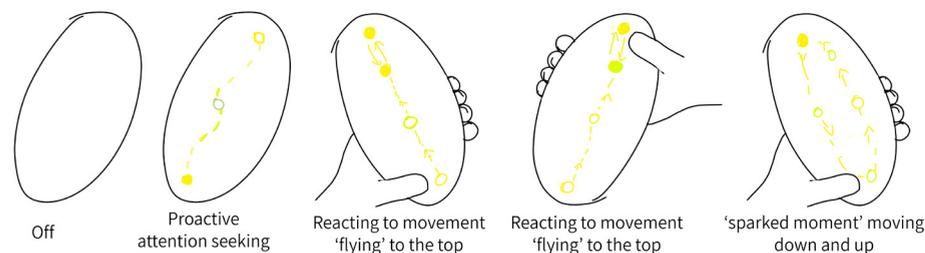


Figure 38: Sketch explaining the interaction of the 'firefly' idea

This concept direction shows to be promising to all interaction qualities:

Proactive

A light moves within the object and sometimes turns off and on again, to trigger the user to interact. Both light and movement showed to be suitable design principles for triggering interaction (see chapter 3).

Lively

The light moves as if it is a firefly. This means that there is a bit of randomness to it. It doesn't move with a fixed speed and is never stationary, which makes it dynamic.

Explorative

Once the proactive moving light has invited the player to interact, the interaction with the light can be explored. The user notices that the light reacts on his action of moving the object and can explore what he can do with it.

Enchanting

To enhance the enchantment of the product, the interaction can sometimes change when it has been the same for some amount of time. When this happens, the light goes to the bottom of the object and back up again. This unexpected change of events is implemented to make sure that the product provides frequent triggers to lengthen the interaction. Also, this unexpected change of events could enhance the enchantment of the interaction.

Subtle

There's only one firefly inside the object to make the interaction active, but not too intrusive. When the object detects there has been no interaction for a while, it turns off the light to provide a bit of rest. After a while it lights up for a short amount of time to subtly trigger the user to (re)start the interaction.

Open-ended

The form of the object is purposely ambiguous, to leave room for interpretation. Besides this, also the light itself is free to interpret. It was inspired on a firefly, but it can be explained as and related to more things, which can cognitively stimulate the user to use his interpretation and creativity.

5.2 Concept development

The concept direction of the firefly was further developed in three iterations. I created three prototypes consecutively and tested these with the user group to evaluate the concept. The first prototype focused on testing the basics of the envisioned interactions. The second and third prototype elaborated on these interactions as well as the embodiment of the product.

5.2.1 First iteration

The first iteration is focused on prototyping and testing the basic interaction with the light. The technical details of this prototype can be found in appendix I. Therefore, the embodiment of this prototype is only in service of realizing the interactions of the light.



Figure 39: First prototype

The iterations included in this prototype are the following:

- When the object is held vertically, the light moves up through the tube.
- When the light reaches the top of the tube, it keeps alternating between the last and the second-last LED.
- When the tube is turned upside down, the light moves to the top again.
- When the tube is held horizontally, the light moves from left to right in the middle part of the tube.
- When the product is not touched and has not been in motion for one minute, the light would be turned off.
- When the light is turned off and there is no motion for more than one minute, the light turns on again for one minute and perform the movement belonging to the current orientation of the tube.

This prototype was tested in two nursing homes with a total of 12 participants. The test setup and results can be found in appendix J. Based on the test results, I made a list of positive insights as well as insights on improvements, which is shown in Figure 40.

Positive insights

- People noticed the light and it attracted their attention, especially when it changes its behavior, by turning off or on.
 - When interacting with the object, people well understood that the light reacts to their movement.
 - When not interacting with the product, people did follow the movement of the light with their eyes and noticed when the light changed its behavior.
 - The light turning off, due to the product being motionless for a while, triggered curiosity in people. Some people would start to observe the object, until the light turned on again. Others actively started searching for it, by picking up the object, causing the light to turn on.
 - Two participants actively explored the object for a longer period of time (participant 5 & 7). They tried out different possibilities.
- "There are endless possibilities. I'm trying to figure out if there is a correlation between the blinking and the continuous light, but I can't figure it out yet." - participant 7
- People could easily pick up and hold the object, as the diameter of the tube fits into the palm of your hands.

Room for improvement

- The electronics inside the tube were visible, which distracted people from the interaction with the light.
- The flat surfaces of the tube caused people to put down the product, which ended the interaction.
- When the product was not actively introduced to the users by a caregiver, people did not seem to interpret the product as something to interact with. This can be caused by the shape of the object, as well as by the materials that make the object feel fragile.
- The liveliness of the light needs to be improved, as it was too subtle when the light altered between two LED's at the end of the tube and too predictable, which is probably why it did not captivate some participants.
- The trigger that happens when there has been no motion for a while was too subtle.

Figure 40: Insights gained from the user test with prototype 1

5.2.2 Second iteration

The second prototype is shown in Figure 41. The technical details of this prototype can be found in appendix I.



Figure 41: Second prototype

The following elements were altered in comparison with the first prototype:

- As the shape of the first prototype negatively affected the interaction with the object, I chose to change the shape of the product to a sphere to make the product more approachable and indicate it as being an interactive object.
- Another argument for the sphere is to avoid flat surfaces, as the flat surfaces in the first prototype, caused people to put down the product.
- The electronics within this prototype were concealed to avoid people from getting distracted by them.
- The movement of the light is amplified to make it more visible and less subtle. The amount of LED's was increased, so that the light always followed a path of at least 5 LED's in every position.
- The no-motion trigger was amplified to make it more triggering and less subtle. When the product would be motionless for more than one minute, the light would make a full round through the object with a higher speed than when the product is in motion.

This prototype was tested in one nursing home. The test setup and results can be found in appendix J. The test resulted in a list of positive insights as well as insights on improvements, which is shown in Figure 42.

Positive insights

- None of the people hesitated to touch the object.
- The trigger when there has been no motion for a while was less subtle and seems promising, as it had a positive effect on at least one participant (participant 2). Further testing is needed though.
- The liveliness of the interaction seems promising, as a lady interpreted the light as the sun that dynamically appears and disappears.
"And this is the sun (pointing at the light), but it goes away again and shows up somewhere else later (laughing)" - participant 4
- There was an indication that the product caused participant 2 to feel enchanted by it. This was made up out of here continuous positive comments.
"How nice! Oh dear! That's something for me ... really! I really enjoy it." - participant 2
- The diameter of the sphere was easy to grab and hold for most people.
- The battery within the sphere was a bit out of balance, sometimes resulted in an unexpected positive insight. The unbalance caused the sphere to move a bit when people tried to put it down. This unexpected movement, caused some people to grab the object again, lengthening the interaction with it.

Room for improvement

- The cotton that was used to cover the electronics was recognized as cotton by some residents. This took away from the experience with the light.
- The cotton did diffuse the light, but also made it less bright. Care takers questioned if all residents were still able to see the lights because of this.
- The surface of the sphere was shiny, which made it reflective. These reflections were distracting people from the envisioned interaction with the light. This may have caused that people did not seem to notice that the light sometimes turns off.
- The surface of the sphere was a bit slippery. This made it harder to grab the object for people, especially with small hands. Therefore, the material should provide a better grip and the diameter should be a bit smaller.
- Due to technical difficulties, the envisioned effect of the light following your movement and flying to the top of the object was not prototyped as envisioned. It caused the effect to be less noticeable.

Figure 42: Insights gained from the user test with prototype 2

5.2.3 Third iteration

The third prototype is shown in Figure 43. The technical details of this prototype can be found in appendix I.



Figure 43: Third prototype

The following elements were altered in comparison with the first prototype:

- The surface of the sphere was sandblasted to make it matt. This also replaced the light to diffuse the light.

This prototype was tested in one nursing home. The test setup and results can be found in appendix J. The test resulted in a list of positive insights as well as insights on improvements, which is shown in Figure 44.

Positive insights

- For most participants, the proactive light did capture their attention. Especially the moment when it goes into its sleeping state. This triggered participant 2, 3 and 7 to initiate action and give the object a nudge to explore where the light went.
- The interaction was focused on the light and movement of the ball, without distraction caused by electronics, cotton or reflections.
- The product did cause some people to be enchanted by it.

"It's a ball of wonder" - participant 3
(Dutch: "Het is een wonderbolleke.")
- People did explore the product. Some only by watching the light go on and off again, some further explored the object by picking it up.
- Not only the lights were explored, also the movement of the ball itself. Because the battery is not centered within the sphere, it moves in unexpected ways, when putting it down. This triggered two participants to lengthen their interaction with the object (participant 2 and 9).
- There were some indications that people did interpret it as a lively object. Participant 3 called it a stubborn thing, indicating that it is something with a will of its own. Participant 2 talked to the object saying that it should continue what it was doing, when it went into the sleeping state. This indicates that he appreciated the dynamic stimuli.
- The project does provide freedom of interpretation and interaction. Participants did interact with the object in different ways. Participant 9 interacted with it in a playful way, while participant 3 was more thoughtful about his actions as he tried to figure out the object. This open-endedness was also confirmed to be a positive thing by the comments of a care giver.

"I think that the fact that it's something unfamiliar attracts people. It's a positive thing that it's unfamiliar. It is pleasurable for people to explore it. To think of what it is and what you could do with it."
- Care giver
- Participants were very careful with the object. This carefulness fits the interaction vision, as playing with a ladybug also is playful, but very careful, as a ladybug is a fragile thing. Therefore, the carefulness is part of the interaction.
- Rotating the ball did happen a lot. Also, people seemed to enjoy rubbing the sphere in the palm of their hand. Participant 2, 8 and 9 all initiated this interaction.

Room for improvement

- Due to technical difficulties, the envisioned effect of the light following your movement and flying to the top of the object was not prototyped as envisioned. It caused the effect to be less noticeable. Further testing with an improved prototype is needed for this.
- Putting down the object sometimes caused problems due to the center of gravity. Since the battery within the sphere is the center of gravity, it not being in the center of the sphere makes the object unbalanced. This causes the ball to roll over when somebody puts it down. This did trigger interaction sometimes, but also caused the ball to fall, like in the test with participant 2. Therefore, this center of gravity should be oriented closer to the actual center of the ball. It can be slightly out of center to keep the surprising effect but make it subtler.
- The diameter of this prototype was 16 cm. Participants were able to pick up the object with one hand, but it was not effortless, because the surface of the sphere was a bit slippery. By making the ball a bit smaller and pick a material that is less slippery, the interaction could be made easier.

Figure 44: Insights gained from the user test with prototype 3

5.3 The final concept: Twinkle

All prototype iterations helped to develop the concept. This chapter describes the final concept of this project: Twinkle. First, the overall concept is described, after which the interactions and hardware development are discussed.

‘Twinkle’ provides sensory stimulation to people living with moderate to severe dementia in static care environments, to enhance physical and personal connectedness and hereby support emotional well-being and bring back the twinkle in people’s eyes.

The product is designed to be used by people living with moderate to severe dementia, without the help of caregivers. Therefore, the product should be present in the living room of a nursing home and within the reach of the resident. This way it can enable moments of physical and personal connectedness when the environment becomes static.

Twinkle consists of a sphere, with an interactive dynamic light inside of it. This light can move across the surface of the sphere to proactively try to attract the attention of residents and trigger the curiosity in them to initiate interaction. When an interaction is started, the behavior of the light will change depending on the actions of the user. This way, it allows the user to explore the possibilities of the object. Meanwhile the product provides sensory stimulations to the user. Their vision is stimulated through the sight of the object and the light and their touch is stimulated through the physical aspects of the product.

5.3.1 Interactions

Twinkle has several interactions, depending on the circumstances. Each interaction is explained below.

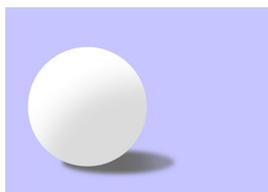


Figure 45: No motion

Sleep

When the object has been stationary for more than one minute, only the white shell is visible. All lights are turned off and there is no visible action within the product. The product seems to ‘sleep’ (see Figure 45).

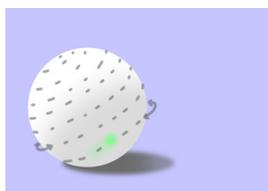


Figure 46: Trigger

Trigger

When the object has been asleep for more than one minute, a light will fly in circles around the sphere, from the bottom to the top and back down (see Figure 46). After this, it goes back to sleep again.



Figure 47: Interaction when in motion

Interaction when in motion

When the product is picked up, a light turns on and flies to the top of the object. When it has reached the top, it does not become stationary. It starts to flutter in an infinite loop shaped like an 8, until the object is turned into another orientation. In this case the light will again fly to the top in a straight line and start circling around again (see Figure 47).



Figure 48: Interaction when in motion for a while

Trigger when in motion for a while

When the product has been in motion for a while, the product provides an extra trigger to increase the interest in the product. This extra trigger happens after two minutes of constant motion. The light will suddenly disappear from top and appear at the bottom of the sphere. The light will fly in circles around the sphere, from the bottom to the top and back down again (see Figure 48). After this, the light will return to the top in a straight line and flutter in an eight-shaped loop (see Figure 47).

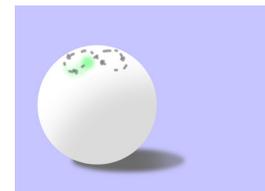


Figure 49: Action when motion ends

Action when motion ends

When the product is put down again, which stops the motion, the light will continue to flutter in an eight-shaped loop for a minute (see Figure 49). After one minute, the light turns off and the product will go into its sleeping state (see Figure 45).

General elements of the interaction:

- The color of the light changes slightly as it flies across the surface. The color changes gradually from yellow to green and back.
- The speed of the light is not fixed. It sometimes slows down or speeds up a bit to make it more dynamic.
- It takes the light approximately two seconds to fly from the bottom to the top in a straight line across the surface.
- The speed of the light in the trigger state is two times faster than the speed of the light of the in the 8-shaped loop, because it needs to travel across the whole surface of the sphere and should not be out of sight for too long.
- When the sphere is put to motion in the 'sleep' or 'trigger' state, the interaction will immediately switch to the 'interaction when in motion' state, to provide the user with instant feedback.
- When the sphere is rotated during the 'trigger when in motion for a while' state, the light will first finish its interaction, before switching back to the 'interaction when in motion' state.
- During the 'trigger when in motion for a while' state, the orientation of the bottom and top will be fixed. Rotating the object after this state has started, will have no effect on the light.

5.3.2 Product hardware

The product hardware is visualized in Figure 50. The product consists of a white sphere with a small flat surface, forming the outer shell of the object. This sphere has a diameter of 15 centimeters, to easily fit in the hands of the user. The outer shell contains a slightly smaller sphere of lights. The electronics that control the lights are in the core of this sphere. A charger outlet is located on the flat side of the object.

The outer shell serves as a layer to protect and cover up the electronics. It diffuses the lights to enhance a seemingly smooth motion when the light moves across the surface.

The object is spherically shaped to enable the interaction to create an endless surface, which is not interrupted by corners and edges. This way the interaction of the light flying to the top of the sphere can continue endlessly. Because of the spherical shape, the user also doesn't necessarily need to pick up the product to rotate it. It can be rolled over and rotated on a table as well.

One part of the sphere is flattened. This is introduced to prevent the object from falling. The center of gravity of the sphere should therefore be a little bit out of center, towards the flat surface. This way, the sphere will always roll towards the flat surface when released by a user. This stabilizes the object and prevents it from falling.

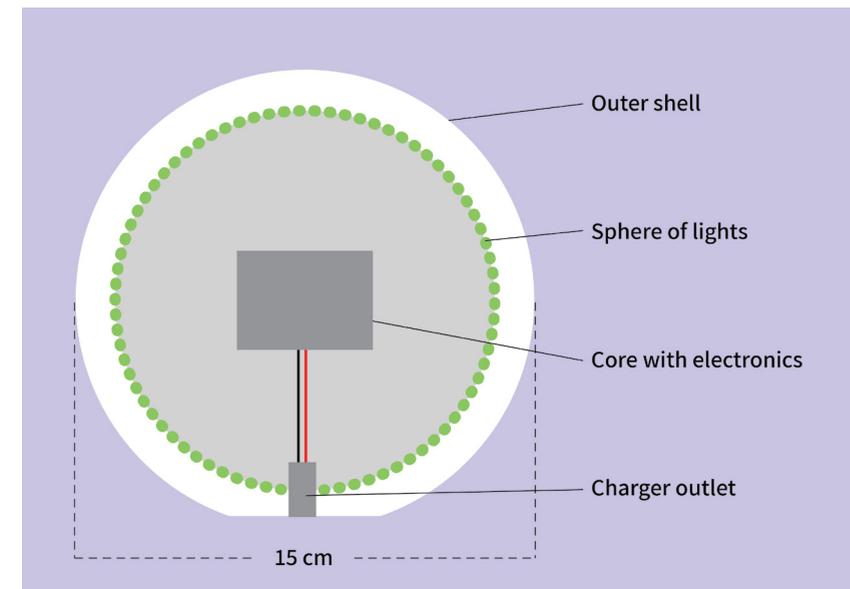


Figure 50: Cross-sectional view of the object

6

Discussion

In this chapter, the final concept that resulted from the design process is evaluated based on the design goal and interaction vision. Based on this evaluation, recommendations for the further development of the product are discussed in the second part of this chapter.

The research questions for this chapter are the following:

- Does the final concept fit the interaction vision and its qualities?
- Does the final concept fulfill the design goal?
- What can be recommended for the further development of the product?

6.1 Evaluation of the final concept

This subchapter evaluates the final concept, as presented in chapter 5.3, using the design brief of chapter 4. First, the concept is analyzed based on each individual interaction quality of the interaction vision. After this, an evaluation is presented, discussing whether the design goal is fulfilled by the envisioned product.

6.1.1 Does the final concept fit the interaction vision?

The interaction vision for the design phase of this project, as described in chapter 4.2, is the following:

“The interaction between user and product should feel like playing with a ladybug: proactive, lively, explorative, enchanting, subtle and open-ended.”

To answer the question whether the final concept fits the interaction vision, each interaction quality is separately evaluated in the next paragraphs. These evaluations are strengthened based on the insights gained in the user tests of the multiple prototypes.

Proactive

The ladybug takes the initiative by appearing in your eyesight or on your body. You decide whether to neglect or interact. In the context of this project, this is an important quality, as a product should initiate interaction with sensory triggers, to stimulate people to interact (see chapter 3) (H. Andersen, 2017).

A light moves within the object and sometimes turns off and on again, to trigger the user to interact. Both the light itself and the movement of the light serve as a proactive trigger to make the possible user initiate interaction. Light and movement showed to be suitable design principles for stimulating people with moderate to severe dementia to interact (see chapter 3).

In the prototype tests, it was shown that this light indeed catches the user's attention and initiates them to interact (see chapter 5.2 and appendix J). For most participants, the proactive light did capture their attention. The trigger when the product is motionless for a while was observed by people. But mostly the fact that the product went into its sleeping state, turning off the light, worked as a trigger for interaction. People wanted to get the light back on again, which caused people to nudge or grab the object.

Lively

Once you decide to interact with a ladybug, it will anticipate on what you do. You can see that it reacts on your actions, but also that it is not completely predictable. This makes it a lively interaction. Introducing a lively interaction like this into a static environment, increases the level of sensory stimulation which makes the setting more dynamic.

The light does not move with a fixed speed and color and is never stationary. This makes the interaction more dynamic and therefore livelier. This was confirmed by some comments of the residents who participated in the user test (see chapter 5.2 and appendix J).

“And this is the sun (pointing at the light), but it goes away again and shows up later again (laughing)” – Participant 4, user test prototype 2

In the user test of prototype 3, participant 3 called it a stubborn thing, indicating that it is something with a will of its own. Participant 2 talked to the object, saying that it should continue what it was doing, when it went into the sleeping state. This indicates that he appreciated the dynamic stimuli.

Explorative

When a ladybug approaches you, people can explore the possibilities. You can just look at it or decide to touch it. You can try to let it walk from one finger to the other or make it walk onto a leaf. This exploring of objects was found to stimulate and captivate people with moderate to severe dementia, as explained in chapter 3. Including factors in the object that can be explored and which react on the user's actions can have a positive effect on people with moderate to severe dementia, as they derive pleasure from being the cause of something (Perrin et al. , 2008c) and fulfilling the need for exploration enhances feelings of personal connectedness, as it provides cognitive stimulation (see chapter 2.1).

The user can already explore the product just by observing it. He can observe the light turning off and on, as the object alters between the sleep and trigger state. Once the user has been triggered to interact with the product, the behavior of the light can be further explored, through rotating the object.

This behavior was apparent in user test of prototype 3 (see chapter 5.2 and appendix J). Most participants in this user test clearly explored the object and its possibilities. For example, participant 3 extensively explored the object, trying to figure out what it was and what he could do with it. Participant 9 did also explore the object in extensively but interacted in a more playful way with it. He altered between several interactions, from rotating it on the table, to observing the movement of the light, to rubbing the ball in between his hands.

Enchanting

Enchantment can be described as attracting or pleasing someone very much; a magical effect (Cambridge Dictionary, n.d.-c). A ladybug can suddenly appear in your eyesight, or open its wings, pretending to prepare for takeoff. This can be an unexpected trigger. In the context of this project it was found that in order to lengthen someone's engagement with a product, it should provide frequent triggers (see chapter 3). Moments with unexpected events can provide these triggers, as people with moderate to severe dementia enjoy the surprise of unexpected events (Anderiesen Le Riche, 2017). Moreover, enchantment also fits the positive design vision of Active Cues: to go beyond the functional solutions and evoke happiness and enchantment.

The fact that there are lights within a ball that react to your actions is enchanting in itself. The insights gained with prototype 2 and 3 confirm that the product had an enchanting effect on multiple participants.

“How nice! Oh dear! That's something for me...really! I really enjoy it.” – Participant 2, user test prototype 2

In the user test of prototype three, a care giver explained that the resident was enchanted by the object, because the ball shape is something he recognizes, but the lights within the shape is something he has never seen before. He tried to figure out the object, which pleased him and therefore had an enchanting effect on him.

To enhance the enchantment of the product, in the final concept an additional interaction was implemented: the ‘trigger when in motion for a while’ state (see chapter 5.3.1). This state implements that the interaction can sometimes change when the product has been in motion for two minutes. This unexpected change of events is implemented to make sure that the product provides frequent triggers to lengthen the interaction and provide people with a surprise which they possibly can derive pleasure from. Further testing is needed to confirm this last part.

Subtle

Playing with a ladybug does not involve overwhelming, extreme interactions. It is present enough to notice and trigger, but is not too intrusive, so it can still be neglected. When you don't want to interact with the ladybug anymore, you can decide to blow to make it fly away or to start ignoring it. You have the control over it. This subtleness is an important quality in the context of dementia. When something is too intrusive it can become overwhelming and lead to overstimulation (Alzheimer's Society, n.d.-b, n.d.-a).

There's only one light inside the object to make the interaction active, but not too intrusive. When the object detects there has been no interaction for a while, it goes to the sleeping state, which can be a trigger in some situations, but is also implemented to prevent overstimulation. After a while the products tries to trigger the user for a short amount of time. When there is no response, the product will go back to the sleeping state. The results of the user tests confirm that the interaction is active enough to trigger people who are open to interaction, yet subtle enough for people to ignore the object (see chapter 5.3 and appendix J).

An additional aspect contributing to the subtleness of the interaction is the carefulness that was apparent in the user test of prototype 3. The participants did interact with the object in a very careful way.

"I think they notice that it is hard. I think they realize that it is fragile and that it can break. But maybe they are also careful because they think it is something special. That they think this is something special, something different, you have to be careful with it." – Care giver, user test prototype 3.

I conclude that this carefulness is a part of the subtle interaction quality. The interaction with a ladybug is playful, but also a very careful, as a ladybug is a fragile thing. Therefore, the carefulness is part of the envisioned interaction.

Open-ended

In open-ended play, players themselves can attach meaning to the design properties and the interactions while playing. It is play without predefined rules, which triggers the player's creativity by leaving room for interpretation (de Valk et al., 2013; de Valk et al., 2015). This open-endedness can enhance feelings of personal connectedness, as it is related to cognitive stimulation (see chapter 2.1). Playing with a ladybug is open-ended, as the person playing with it can create his own story and meaning through play. This open-endedness makes it possible to interact with the ladybug on different cognitive levels. This is important in the context of dementia, to make sure that people in different stages of dementia can participate and find joy at their own level (see chapter 3).

The product does provide freedom of interpretation as it provides a balance between recognizable and unfamiliar aspects. To provide a bit of structure, the product has a recognizable shape; a sphere. The light is the thing that makes the product interesting and unfamiliar. This balance was confirmed to be a positive aspect by the care giver in the user test of prototype 3. She explained that it also enhances the explorative and enchanting qualities of the interaction.

"I think it's a certain type of wonder. It's recognizable, but not really, because it has lights in it. I think that the fact that it's something unfamiliar attracts people. It's a positive thing that its unfamiliar. It is pleasurable for people to explore it. To think of what it is and what you could do with it." – Care giver, user test prototype 3.

The freedom of interpretation and interaction was confirmed in the user test of prototype 3 (see chapter 5.2 and appendix J). Participants did interact with the object in different ways. Participant 9 interacted with it in a playful way, while participant 3 was more thoughtful about his actions as he tried to figure out the object. The freedom of interpretation was confirmed in by several comments of participants.

"There it is again, the snow ball". - Participant 2, user test prototype 3

"It's a ball of wonder"- Participant 3, user test prototype 3

*"And this is the sun (pointing at the light), but it goes away again and shows up later again (laughing)"
– Participant 4, user test prototype 2*

Conclusion

Does the final concept fit the interaction vision?

Yes, it does. The evaluation of the interaction qualities confirms that each one of them is strongly represented in the final concept. Therefore, it can be concluded that the envisioned product does fulfill all interaction qualities and thus fits the interaction vision.

6.1.2 Does the final concept fulfill the design goal?

In chapter 4.1, the design goal of this project is formulated as follows:

“Designing a playful object that enables moments of physical and personal connectedness for people in the mid to late stages of dementia, to support emotional well-being in static nursing home environments.”

Enabling physical and personal connectedness

To make sure that the designed product enables moments of physical and personal connectedness, the interaction vision was chosen based on the fact that the design should provide both cognitive and sensory stimulation. This way, physical connectedness could be enhanced through the experience of sensory stimulations and the feeling of personal connectedness is enlarged through cognitive stimulation.

In the previous part of this chapter (6.1.1), I concluded that the final concept does include all the envisioned interaction qualities, that were needed to provide both cognitive and sensory stimulation. Therefore, I can conclude that the product does enable moments of physical and personal connectedness for people in the mid to late stages of dementia.

Usable without the help of care givers

In the envisioned situation of use, as formulated in chapter 4, the product should be usable for people living with moderate to severe dementia without the help of a care giver. This envisioned situation is shown in the storyboard that is presented in Figure 51.

In this envisioned situation, a nursing home resident is sitting on a chair with the product on the table in front of her on the table. The product gives a trigger at some point, which catches the person’s attention. The person approaches the product, which responds to this. The person explores the interaction with the product for a while. After some time, the person decides to put down the product. A while later, the product will again give a trigger, which at some point will catch the resident’s attention and will restart the interaction. This envisioned situation was clearly shown in the results of the user test with prototype 3 (see chapter 5.2 and Appendix J). In this test, this was also confirmed by the comment of a care giver:

“I think people will mostly hold it for a moment. Look at it. Put it back again and after a while it captures their attention again and they will start to think about what it is. This can cause them to pick it up again. And so on. I think it will work in this way.” – care giver (test with prototype 3)

This care giver did also express that the product should be introduced to a resident and tried out with the help of a care giver, to evaluate if it has a positive effect on the resident and make sure that it doesn’t cause negative emotions. She emphasizes that you can only know if something has a positive effect, through trying it out for each resident, as you can never certainly predict, how somebody will react. After this, the product can be used by a resident, individually.



Figure 51: Storyboard about the desired situation

Supporting emotional well-being

In general, observations made in the user tests indicate that the product did evoke positive emotions in people. However, the prototype evaluations were mainly focused on the interaction qualities. Therefore, no reliable conclusion can be formed about whether the product supports emotional well-being.

In theory, the product does contribute to the emotional well-being of people with moderate to severe dementia, as it is aimed to prevent apathy and restless behavior and thereby prevent states of no or negative emotions, but further research should be performed to confirm this.

Conclusion

Does the final concept fulfill the design goal?

The product clearly shows its potential of fulfilling the design goal, but it should be further developed and more thoroughly tested to be able to fully confirm this.

The evaluation of the design goal confirms that the product does enable moments of physical and personal connectedness, as it provides sensory and cognitive stimulation and that it is usable for people living with moderate to severe dementia without the help of a care giver. User tests with prototype 3 indicate that the product does evoke positive emotions, however no reliable conclusion can be formed based on this test. Further research is needed to confirm this aspect of the design goal.

6.2 Recommendations for further development

This chapter presents some of my recommendations for the further development of the product.

6.2.1 Embodiment design

The embodiment design of the product should be further researched, with the main focus on how the material used for the outer shell of the object influence the experience and interactions of the end user.

As explained in the evaluation of the interaction quality ‘subtle’, carefulness is a part of the interaction (see chapter 6.1). The care giver in the user test of prototype 3 explained that the fragileness could possibly have a negative effect on the interaction as well.

“It can also be negative. They may put it away sooner. That they think: I am not allowed to touch it... I have to be careful ... I should not do too much with it ...” – Care giver, user test prototype 3

This carefulness can be enhanced by finding the right balance between firm and fragile. The material used for the outer shell of the product should prevent the product from breaking and should have the right balance between firm and fragile. The ball should not be soft and squeezable, as this probably decreases the carefulness and thereby the subtleness of the interaction. To find the right balance of fragileness and firmness, the use of materials should be explored further in the future development of the product.

The requirements for the material of the outer shell are the following:

- It should provide an experience that has the right balance of fragileness and firmness.
- It should prevent the product from breaking when it falls.
- It should cover up the electronics.
- It should be transparent enough to let the light shine through.
- It should slightly diffuse the light to create the illusion of a smooth motion.

To be able to meet these requirements, further research should be performed on the embodiment of the product.

6.2.2 Improved prototype

Due to technical difficulties, which were caused by reaching the limits of my electronic prototyping skills, the envisioned behavior of the light, as described in the final concept, was not prototyped. Insights gained in the test of prototype 1, where the basics of the behavior were tested, did indicate that it has the potential to be captivating and explorative for the users. To be able to evaluate the effect of the envisioned behavior, an improved and more realistic prototype should be created, including all of the envisioned interactions as describe in chapter 5.3.

6.2.3 Visual and haptic senses

In this project, I purposely chose to focus on optimizing the visual feedback and interactions of the concept. I can imagine that adding elements like sound or vibration could enrich the interaction with the product. Therefore, I recommend researching the possibilities of adding elements that trigger senses other than the visual, to enrich the sensory and cognitive stimulation that the product provides.

7

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8

Personal reflection

When putting together what I was looking for in a graduation project, I defined for myself that I wanted something social with a specific, complex user group/context and a bit of playfulness. When reading Active Cues' assignment, I immediately got excited. It felt like a perfect fit.

This project has been a good challenge for me. I had experience with user centered design, gained through my previous projects and internships, but this project forced me to bring it to a new level. Where I would normally go into the field to interview my target group to discover design opportunities, this was not possible in this project. Not being able to ask your target group what their needs are was a new, yet refreshing, challenge for me.

I discovered that the key to success, when designing for people with dementia is time investment. By taking the time to immerse myself in the lives of these people, through observing and participating in their daily activities, I was able to empathize with the user group and gain insights for possible design opportunities.

At the beginning of this project, I set a goal for myself that I wanted to improve my skills of structuring my research to be able to create a coherent report in the end. I struggled with this throughout the project. In the first few weeks of the project, I was so focused on structuring everything that I sometimes lost contact with the way I naturally gather insights. I consciously reflected on my process along the way. Because of this, I was able to adapt it when needed.

The creation of this report has been an iterative design process in itself. Because of the complex context and user group, that involve lots of dimensions that need to be explained, it was a struggle to create a coherent story. If I would have to start over, I would advise myself to think of the structure of the report a bit earlier on in the process, as I experienced that this helped me to structure my insights and forced me to focus on the core of the project. Still, I was able to discover the core of my project and translate this into a coherent story within this report.

I had my ups and downs along the way, but overall it was a pleasure to work on this project!

9

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10

Appendices

The appendices of this report can be found in a separate document.

The appendices include the following information:

- A. Project brief
- B. Attempts of creating a theory about connectedness
- C. Explanation of most common symptoms of dementia
- D. Field research overview
- E. Results of field research
- F. Consent forms
- G. Results probes study
- H. Summarized interpretation of data from the probes study
- I. Technical details of all prototypes
- J. Test setup and results of each iteration

