Enabling Positive Moments to People in the Last Stages of Dementia

A personalised approach to multi sensory experiences

Master Thesis by Hannah Pak

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Colophon

Master Thesis
Delft University of Technology
Faculty of Industrial Design Engineering
MSc Design for Interaction

Author
Hannah L. Pak

Graduation committee
Chair
Dr. Ir. M.H. Sonneveld (Marieke)

Mentor
Ir. A.C. Ruiter (Anna)

Company mentor
Ir. Drs. H.M. Van Zuthem (Hester)

Company
Active Cues
Hamburgerstraat 28a
3512 NS Utrecht
Tovertafel.nl

Date
October 8, 2020

Executive Summary

The aim of this thesis was to enable people in the last stage of dementia, that are confined to their bed or room, and the people around them with shared positive moments.
In order to design an experimental concept proposal that could accomplish that aim, the emotional needs of people living with dementia and the people around them were explored.

Research activities consisting of a literature review, documentaries review and conducting interviews were conducted to generate understanding of the context. Analysing the findings from these activities resulted in identifying the emotional needs and an overview was presented in a stakeholder journey map.

It was discovered that due to dementia, people start to live in another 'inner past world' that looks a lot like the past. This causes a lot of anxiety to people living with dementia.
It was revealed that by bringing back their personal memories from the past, people living with dementia are able to get out of their "inner past world' and get back to the actual world. This causes them to feel at ease and happy. These personal memories are part of their identity, so focussing on their identity is very crucial in reducing their anxiety.

However, bringing back memory events is not easy for people living with dementia. In the last phase, people living with dementia are only able to communicate when their senses are activated. Stimulating their senses is essential for them to connect with their identity and thus to get that at ease and happy feeling.

From these insights the following design goal was formulated:
"Making the Person living with Dementia to feel at ease by giving them the ability to reconnect with their identity and interests."

From this design goal and the findings in the analysis, a concept direction was driven. The concept direction describes that the concept consists of three parts: an input, an internal part and an output. The different parts are connected to each other over time. The concept starts with an input where the identity of the person living with dementia is explored with a tool, specifically

focussing on personal experiences. The information gained during the input will be internally turned into sensory elements that are placed in the output's part of the concept. When people living with dementia are in the last stage of dementia the concept's output can stimulate them with the identity events gathered during the input. By presenting this output with sensory stimulation, people living with dementia are able to connect with the event.

The concept direction was the foundation of the exploration during ideation. By combining findings from different ideation activities, ideas on how the input and the output of the concept could possibly look like were generated.

The input of the concept should be in the shape of an interview with assignments. The person living with dementia should be supported during this interview by a family member/ the informal caregiver. The interview focuses on gaining information about the background and general likes, but goes deeper into activities that they enjoyed while aged 15 to 25 years old.

The output of the concept should focus on stimulating as many senses as possible. Therefore the output consists of a digital element for visual and auditory stimulation and of a physical element for tactile and olfactory stimulation.
These decisions were summarized in the concept's scenario.

The scenario was used to evaluate the feasibility of the concept. According to the addressed experts, the concept is very feasible. This is due to the fact that the concept stimulates the senses of people living with dementia to reconnect them with their most memorable memories.

In order to clarify what the presented output could look like, examples from multi sensory environments were presented. The elements used in multi sensory environments can be used in the output of the concept, but in a personalised way. Also in comparison to the multi sensory environment, the concept's output should be an experience brought to the person, instead of bringing the person to the experience.

Based on the validation, it could be concluded that the proposed concept could serve as a base to further develop, test and research the possibilities of personalised multi sensory stimulation within the private room environment.

“Rather than slowing the course of the disease, stimulating people in the last stages of dementia should focus more on improving the quality of daily life.”

Anderiesen, 2017

Preface

This project is the final step of my master Design for Interaction at the Technical University of Delft. During my graduation project I explored the complex topic of people living with dementia and encountered a lot of great learning experiences. I could have never completed this project alone and would like to thank all the people who have helped and supported me throughout my studies and my graduation project.

First I would like to thank the people who participated in the interviews, the brainstorm session and the evaluations. I loved hearing your stories and you have brought me countless valuable insights.

I would like to thank my supervisory team from the TU Delft for guiding me throughout this project.
Marieke, thank you for always managing to have time for a meeting and giving me your good advice and honest opinion, but always in a sensitive manner. I loved our conversations and the open feeling you gave me.
Anna, thank you for always bringing the best guidance and being my mentor during this project even while struggling on your maternity leave. I appreciated how you were always able to give clear advice and ended a meeting with asking me if I had enough information to move forward.

I would like to thank Hester from Active Cues for our lovely weekly meetings. Thank you for sharing your knowledge and always helping, advising and supporting me during the project. It would not have been the same without you, you were wonderful.

I would like to thank Ileana for working together during the analysis. I enjoyed our collaboration and all the great talks we had. I had a wonderful time with you.

Additionally a special acknowledgement to my friends who helped me throughout my studies. Especially Maartje, my online study buddy who was always available for a good chat over a “coffee”. Eva, thank you for helping me set-up the creative session and teaching me a new approach. Charlotte, thank you for sharing your experience and helping me manage my expectations.

I would like to thank my boyfriend Luka for supporting me, correcting my countless spelling mistakes and even being willing to move in with me during this sometimes-difficult time. You always managed to put a smile on my face eventually.

Last but not least I would like to thank my mother and brother. You always believed in me and supported me throughout my studies. Mom, you were always there to help me, even with ideating and by sharing your network to find my participants.

I look back on an amazing project with beautiful people involved. I enjoyed your presence to the fullest.

Enjoy the read,

Hannah

Table of Contents

1 Introduction 10
1.1 Active Cues and Tovertafel 12
1.2 Project Aim 14
1.3 Project Approach 16

2 Literature Research 18
2.1 What is Dementia? 20
2.2 Quality of Life and Dementia 24

3 Context Research 28
3.1 Research Aim 30
3.2 Method and Set-up 31
3.3 Analysis 36
3.4 Journey Map 39
3.5 Insights 48
3.6 Conclusion 63

4 Design Brief 64
4.1 Design Goal 66
4.2 Interaction Vision 70

5 Concept Development 72
5.1 Concept Direction 74
5.2 Informative call Caregiver 77
5.3 Brainstorm Session 79

5.4 List of Requirements & Wishes 80
5.5 Ideation 82
5.6 Scenario 86
5.87 Conclusion 90

6 Iteration 92
6.1 Evaluation Scenario 94
6.2 Multi Sensory Environment 98

7 Final Concept 100
7.1 Concept Overview 102
7.2 Desired Journey map 105

8 Conclusion 112
8.1 Recommendations 114
8.2 Project Conclusion 118

9 References 120

10 Appendices 126

Introduction

Many people live with dementia; approximately 280.000 people in the Netherlands alone and this number increases each year. Dementia is a syndrome caused by brain disorders or brain disease, which causes people to no longer act independently.

On average people live with dementia for 8 years. During these years the amount and seriousness of the conditions increases. There is no cure and people will eventually pass away while living with the disease (Alzheimer-Nederland, 2019)

Improving their health in general may prolong their life, but people in the last stages of dementia typically experience severe deterioration in physical and cognitive function (Anderiesen, 2017). So instead of focusing on stretching out the last phase of their life, there should be more focus on improving the quality of their daily life and eventually increase their overall happiness.

In the later stages of dementia people lose their ability to walk and are confined to either their room or bed. Although their live is very individually and tough in this phase, this project is focused on finding a solution to still provide them with meaningful moments in their life.

1

1.1 Active Cues and Tovertafel

This graduation project is initiated by Active Cues. They develop games for specific target groups, like people with dementia and people with other disabilities. Although there are so many people living with dementia, this user group is easily forgotten. Active Cues however is paying attention to people living with dementia, because they believe that everyone has the right to play. They aim to give moments of happiness to people in residential care and education by investing in their Quality of Life.

Their first product; the Tovertafel Original (figure 1) was developed during the PhD research of Hester Le Riche, which is one of the founders of Active Cues. The Tovertafel Original is a playful care innovation that connects elderly people in the middle and late stages of dementia with each other and with their environment (Active Cues, 2020).

The Tovertafel consists of an interactive projector that can be mounted onto the ceiling. The projector projects games on a table below. The projections respond to movement that is picked up by the sensors. The responsiveness of the Tovertafel makes it possible to play with the projections. With this interaction the Tovertafel stimulates people living with dementia with continuous triggers to initiate activation. This helps them to socialize, to reduce their apathy and most of all it creates meaningful moments together with family members and caregivers.

Figure 1, Tovertafel.

1.2 Project Aim

The Tovertafel focuses on the middle and late stages of dementia where people living with dementia are still mobile. In the later stage people living with dementia lose their mobility completely and are confined to their room or even their bed. Because they are confined to their room or bed, they are not able to enjoy the happy moments provided by the Tovertafel.

At the moment this user group is still not being addressed and although it is the last stage in their life, anybody needs a life worth living. So Active Cues is looking for new opportunities to offer the same meaningful moments to people living with dementia that are confined to their room or bed.

This project's aim is to understand these users and people around them in order to find opportunities to still enable people in the last stages of dementia with positive moments while confined to their room or bed.
That is why in this project the emotional needs of people in last stages of dementia confined to their room or their bed are explored, in order to find opportunities to improve their quality of life.

Although the focus is on people living with dementia themselves, other users will be involved during the project as well. This project does not only focus on exploring the needs of the patients themselves, but also the needs of the informal caretakers, family and health professionals are taken into account. All stakeholders are involved throughout the project.

Within the found opportunities, a playful experimental concept will be created that may not be used by the patient himself/ herself, but will eventually enable the patients to experience positive moment(s) with the ones around them.
The Tovertafel shows that the help of either a caretaker or family member is always needed. They can both carry the experience, making it a shared positive moment.

This project will focus on the following research questions:

- What are the emotional needs of all stakeholders; patients in the last stage of dementia, informal caregivers, family and health professionals?

- What is quality of life for people in the last/final stage of dementia, living in a nursing home environment, and what is the influence/role of the people around them?

- Design vision: How can interactive, playful technology be used to enable people in the last stage of dementia, confined to their bed or room, and the people around them with shared positive moments?

1.3 Project Approach

The emotional needs of people in the last stage of dementia that are confined to their room are explored, by involving all stakeholders within the process. Design interventions have been developed, evaluated and iterated on, to eventually develop a playful and experimental concept that enables the users with positive moments. An overview of the project process is shown in figure 2.

This project is divided in 4 main phases. 1: Research and analysis, 2: Concept development, 3: Evaluation & 4: Finalization.

During phase 1: Research and analysis. This phase is about gaining knowledge about living with dementia, quality of life, game design and co-design to understand these aspects in the context of dementia. This is done by a literature review.
With this knowledge in mind interviews and observations are done with the target group and other stakeholders to explore and understand their emotional needs. All the data will be analysed and concluded into a journey map including all stakeholders.

In phase 2: Ideation. From all the knowledge gained in the first phase and the journey map, a design vision and design goal was created. With this vision in mind a brainstorm session took place. Also the stakeholders were involved and the ideas were discussed with them.

During phase 3: Iteration, the interventions will be designed and evaluated during an iterative process. All results will be concluded into a final experimental concept. The functionality of the concept will be prototyped and tested.

Finally in phase 4: Finalization, from the final evaluation the concept will receive its final recommendations and will be visualized. Final conclusions will be drawn as for conclusions and recommendations.

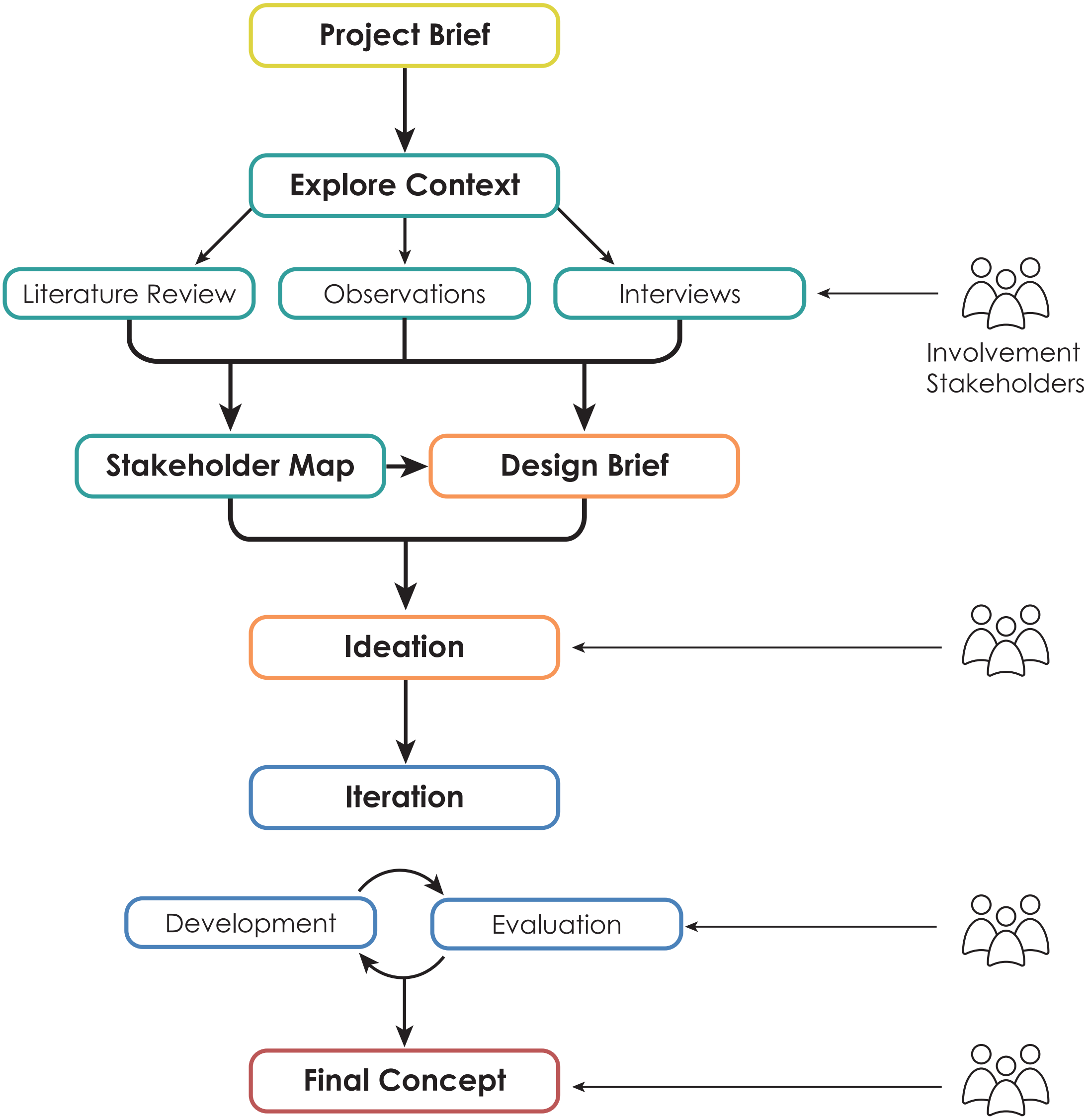


Figure 2, Project Approah Overview.

Literature Research

This chapter is focussed on providing information about what dementia is, the different stages that are defined and what the capabilities are of people living with dementia, specifically on the final stage.

Also the concept of quality of life for people living with dementia (PlwD) is addressed. This knowledge is valuable background knowledge to design for people living with dementia and to accordingly analyse the context further.

2

2.1 What is Dementia?

This chapter is focussed on providing information about what dementia is, the different stages that are defined and what the capabilities are of people living with dementia, specifically on the final stage. Also the concept of quality of life for people living with dementia (PlwD) is addressed. This knowledge is valuable background knowledge to design for people living with dementia and to accordingly analyse the context further.

What is Dementia?
This chapter is set to answer the following research questions:
- What is dementia?
- What are the different stages within dementia?
- How does dementia affect a person's capabilities?

"Dementia is an overall term for diseases and conditions characterized by a decline in memory, language, problem-solving and other thinking skills that affect a person's ability to perform everyday activities. Memory loss is an example. Alzheimer's is the most common cause of dementia."(Association, 2020).
Dementia is not a single disease; it's an overall term. Disorders grouped under the general term "dementia" are caused by abnormal brain changes. These changes trigger a decline in thinking skills, also known as cognitive abilities, severe enough to impair daily life and independent function. They also affect behaviour, feelings and relationships Alzheimer's (Association, 2020).

Dementia is caused by damage to brain cells. This damage interferes with the ability of brain cells to communicate with each other. When brain cells cannot communicate normally, thinking, behaviour and feelings can be affected (Alzheimer's Association, 2020).
It has a progressive nature and currently there is no cure for it (World Health Organization, 2017).

Stages of Dementia

The Global Deterioration Scale (GDS), developed by Dr. Barry Reisberg, divided the stages of cognitive function for primary degenerative dementia into 7 stages. Stages 1-3 are the pre-dementia stages. Stages 4-7 are the dementia stages. Starting in stage 5 an individual can no longer survive without assistance. With the progression of the last stage, stage 7: Very severe cognitive decline, basic psychomotor skills like the ability of walking are lost within the progression of this stage and people are confined to their bed. The brain appears to no longer be able to tell the body what to do. Generalized rigidity and developmental neurologic reflexes are frequently present. Also all verbal abilities are lost over the course of this stage. Frequently there is no speech at all -only unintelligible utterances and rare emergence of seemingly forgotten words and phrases. (Reisberg, Ferris, de Leon and Crook, 1982).

Capabilities with last stage Dementia

The later stages can be hard to define and everyone will go through them in their own way. Nevertheless Dementia is a progressive condition. This means it will get worse over time because of damage to the person's brain, and this will have a big impact on the person's mental abilities (Including memory and communication).

People in the later stages of dementia become increasingly frail and depend more on other people for support. As dementia progresses and causes changes to the person's brain, they may struggle to do many of the things they used to. However some of their abilities may return temporarily, the person's reactions are likely to be influenced by their environment and how they feel (Alzheimers society, 2017).

People in the later stages of dementia often experience problems with the following:

Memory & cognitive difficulties:

Recent memories are lost completely, only parts from the past. Believe to be living in an earlier time period from their life. They can act and behave towards this time period. Get frustrated when being held from activities they believe they need to do. The person's reactions are likely to be influenced by their environment and how they feel. For example, they may react more positively if they are in a familiar environment or one where they feel comfortable (Alzheimers society, 2017).

Concentration, planning and orientation:
They become only capable to carry out simple activities. There is no concentration for too long. Increased disorientation and no longer recognising where they are. Limited understanding of time (Alzheimers society, 2017).

Meaningful activities:
They can still experience enjoyment from past hobbies, interests and activities. Although they may not be able anymore to completely do the activity, they may enjoy feeling, hearing, smelling, tasting or looking at the activity they enjoyed in the past. Focus on stimulating their senses (Alzheimers society, 2017).

Communication:
In the later stages of dementia the person is likely to have more problems with verbal communication. No understanding of what is being said to them, less likely to be able to respond verbally, due to limited or no speech. They can repeat the same phrase, sound or couple of words.

Although verbal communication is limited, they may still be able to show their needs in other ways. They can use behaviour, facial expressions, gestures and sounds to communicate. Observe their body language, behaviour and facial expressions.

Tips for communication:
- keep eye contact when communicating
- non-verbal communication (such as gestures, facial expression and body language) can help, smile
- use appropriate physical contact (such as holding hands) to let the person know you are there and offer reassurance
- don’t rush – allow plenty of time and look for non-verbal clues from the person
- even if you don’t think the person can follow what you’re saying, continue talking to them clearly. They may still feel a certain way even if they don’t fully understand what you’re saying
- consider responding to them in the way they respond to you (‘mirroring’ them) (Alzheimers society, 2017).

Mobility:

People in the last stages of dementia may lose their ability to walk, stand or get themselves up from the chair or bed. They are also more likely to fall.

Many people with dementia find themselves staying in one position for a long time and not moving around much. They are at risk of pressure ulcers (Bedsores).

They are also at risk of infections and blood clots (Alzheimers society, 2017).

Changes in Behaviour: People in the later stages of dementia may behave in ways that are out of character. These behaviours can be difficult to understand and there are often different reasons for them. Either their need is not being met (pain), or they are confused or distressed (Alzheimers society, 2017).

Apathy is the most common behavioural change experienced by people with dementia. These findings are worrisome, as the absence of physical activity is related to the decline of physical health and cognitive capacities (Colcombe & Kramer, 2003)

Location: If you're thinking about the person moving in the later stages consider the impact this will have on them. Adjusting to a new environment in the later stages can be challenging. It's important that the person lives somewhere suitable for them where their needs can be met (Alzheimers society, 2017).

Figure 3, Last stage dementia overview.

2.2 Quality of Life and Dementia

This project aims to improve the quality of life for people living with dementia, instead of improving their health and possibly prolonging their life. In order to achieve this, knowledge on the concept of Quality of life in dementia is needed. This chapter describes the concept of quality of life for people living with dementia and how it can be measured with people living with dementia.

Although the term ‘quality of life’ (QoL) has many definitions, it is defined as a conscious cognitive judgment of satisfaction with one’s life by Pavot & Diener(1993).

Quality of life (QoL) is a multidimensional concept encompassing social, psychological, and physical domains. The multidimensionality of the concept shows a need to assess QOL subjectively as well as objectively.
The objective sector is about our own opinion about our lives and life conditions. Domains such as behavioral symptoms, agitation, depression, self-care abilities, meaningful time-use, social engagement, and emotional expression are important behavioral competences.
The subjective sector of perceived QOL, uses general objective criteria. Domains such as spirituality, satisfaction with health care, family, friends, spare time, and housing are important behavioral competences.
Affect state, happiness, morale and self-esteem are examples of subjective domains in the sector of psychological well-being, while objective environmental quality may be assessed in domains such as physical safety, presence of amenities, privacy and stimulating or esthetic quality (Brod, et al., 1999).

Brod et al. (1999) found that dementia affects all traditional domains of QoL, confirming our belief that the impact is multidimensional. They created a conceptual framework of all QOL domains for people living with dementia. This framework is shown in table 1.

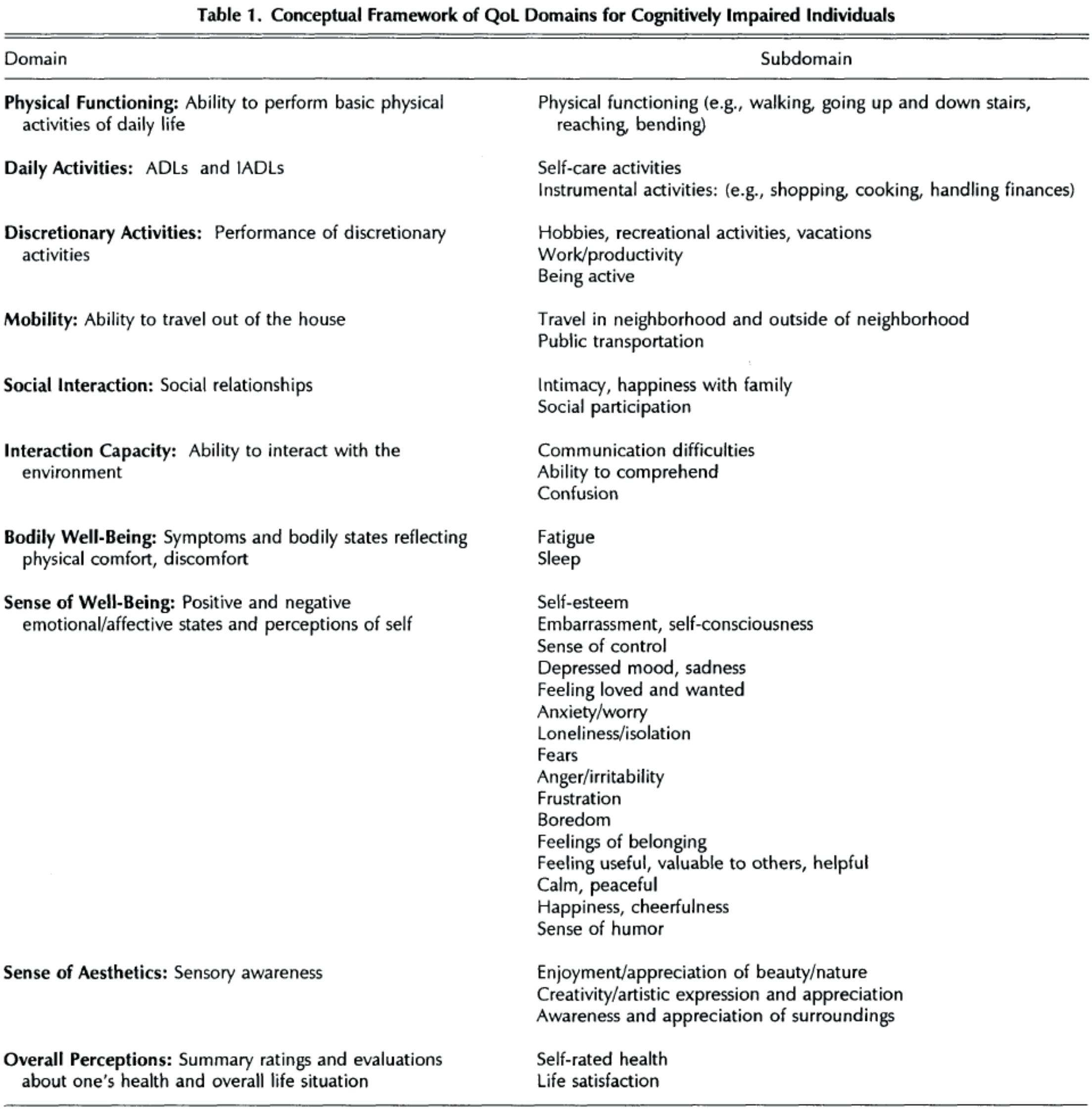


Table 1. Conceptual Framework of QoL Domains for Cognitively Impaired Individuals

Domain	Subdomain
Physical Functioning: Ability to perform basic physical activities of daily life	Physical functioning (e.g., walking, going up and down stairs, reaching, bending)
Daily Activities: ADLs and IADLs	Self-care activities Instrumental activities: (e.g., shopping, cooking, handling finances)
Discretionary Activities: Performance of discretionary activities	Hobbies, recreational activities, vacations Work/productivity Being active
Mobility: Ability to travel out of the house	Travel in neighborhood and outside of neighborhood Public transportation
Social Interaction: Social relationships	Intimacy, happiness with family Social participation
Interaction Capacity: Ability to interact with the environment	Communication difficulties Ability to comprehend Confusion
Bodily Well-Being: Symptoms and bodily states reflecting physical comfort, discomfort	Fatigue Sleep
Sense of Well-Being: Positive and negative emotional/affective states and perceptions of self	Self-esteem Embarrassment, self-consciousness Sense of control Depressed mood, sadness Feeling loved and wanted Anxiety/worry Loneliness/isolation Fears Anger/irritability Frustration Boredom Feelings of belonging Feeling useful, valuable to others, helpful Calm, peaceful Happiness, cheerfulness Sense of humor
Sense of Aesthetics: Sensory awareness	Enjoyment/appreciation of beauty/nature Creativity/artistic expression and appreciation Awareness and appreciation of surroundings
Overall Perceptions: Summary ratings and evaluations about one's health and overall life situation	Self-rated health Life satisfaction

Table 1, Conceptual framework for QoL domains for cognitively impaired individuals.

Measuring Quality of Life with Dementia

To measure the QoL of people living with dementia, it is questionable if they are capable of subjectively assessing their own life. Dröes (1991) developed the adaptation-coping model for explaining and understanding psychosocial problems of people living with dementia. The model proved to be a useful theoretical framework for designing and evaluating psychosocial interventions for people with dementia, such as psychomotor therapy (Dröes, 1991). This model shows the fundamentals for assessing the QoL of people living with dementia. 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
- Dealing with the nursing home environment.

Although the framework provides a strong overview of how to assess the QoL, it is still questionable whether people living with dementia are reliable and valid informants on (aspects of) their QoL.
The cognitive deficit is a problem not only for self-report in advanced dementia but also for some people with mild dementia (Ettema et al., 2005).
Ettema, et al. (2005) state that a particular problem in longitudinal dementia research using self-report measures is missing values in the subsequent measurements due to the progression of dementia in participants. And even if the participants still respond to the questions, their deteriorated cognitive deficit may cause their perception of the content of the questions to differ from that of the first measurement. This would be a serious threat to internal validity of the design of an experiment. A fear of missing values can be a reason to apply proxy measures.

Studies by (Novella et al. (2001) and Logsdon et al. (2002) indicated a systematic bias by proxy, in the sense that they reported lower levels of (aspects of) QoL. The bias might be influenced by the burden on caregivers. Despite the disagreement, other research shows that proxies are almost as good as patients in detecting changes in some QOL domains over time (Sneeuw et al., 1997). Although proxies report lower levels of QoL for patients, they are able to detect

changes in QoL. They can be valuable while assessing the effect an intervention with people living with dementia, even if the subjects perceive their QoL on a different level.
So for people in the later stages of dementia, or people who are unable to answer questions, it might still be possible to have proxies observe a level of adaptation on the basis of their behavior and to asses their QoL.

Context Research

In order to understand how to provide happy moments to people in the last stage of dementia, their needs, experiences and daily life interactions need to be researched. By conducting context research, designers are able to understand and empathise with the patients, professional caregivers, informal caregivers and family members and are therefore better suited to design for them.

This chapter provides an overview of the context analysis done within this project; the aim and set-up will be explained, how the research was conducted, the information gained by the research will be discussed, a summary of the information will be giving in the shape of a journey map and finally all valuable insights that were found will be addressed.

3

3.1 Research Aim

The aim of this research is to understand the context of people living in the last stage of dementia and their emotional needs and to identify opportunities to provide them with happy moments.

The research was led by the following research questions:

- What are the emotional needs of all stakeholders; patients in the last stage of dementia, informal caregivers, family and health professionals?

- How does living in a nursing home environment for people in the last/ final stage of dementia and the people around them look and feel like? (Journey)
    - Which shared positive moments are already present in the journey of the patients, caregivers and family members?
    - Which challenging moments are already present in the journey of the patients, caregivers and family members?

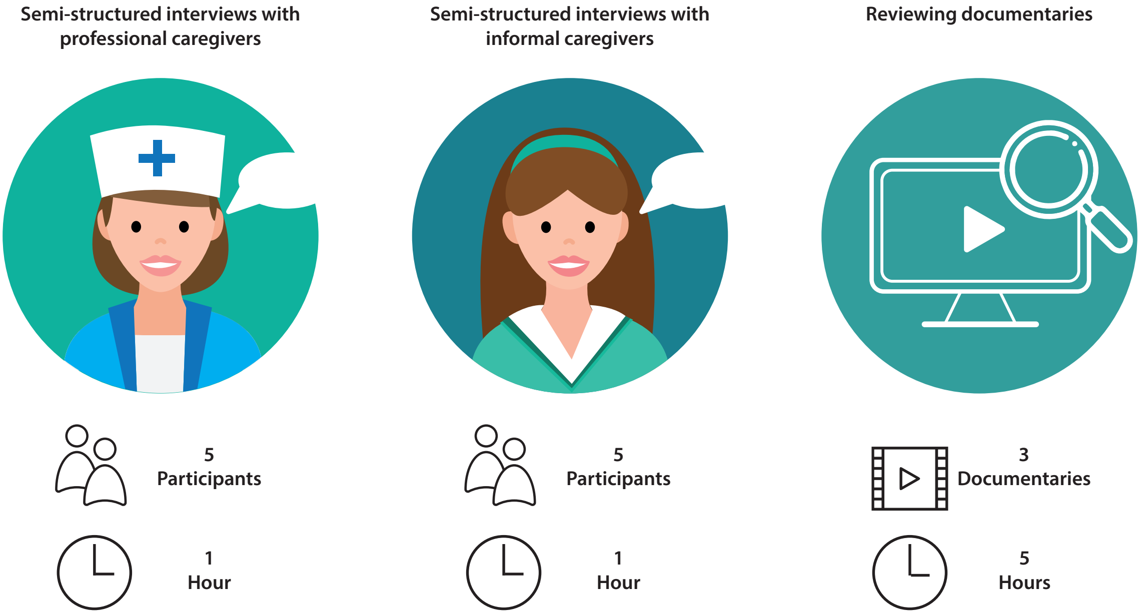


Figure 4, Method overview.

3.2 Method and Set-up

In order to answer the research questions, several qualitative research methods have been used; semi-structured interviews with professional caregivers, semi-structured interviews with informal caregivers and documentaries. *(Unfortunately this study was not able to include observations in care homes or interviews with people living with dementia, due to the measurements against Covid-19)*. For an overview of the method, see figure 4.

The semi-structured interviews with professional caregivers and with informal caregivers were done simultaneously. 5 semi-structured qualitative interviews with professional caregivers were conducted and 5 semi-structured qualitative interviews with informal caregivers. More information on the participants can be found in appendix B1.

Prior to the interviews, the participants received sensitizing material (figure 5 and 6) consisting of 3 sheets with a total of 6 assignments they needed to fill in before the interview. This material was provided to them as a way to already think about the subject, which led to more in depth information during the interviews.

Together with the sensitizing material the participants received an introduction letter and a consent form for their participation in the study, both can be found in appendix B2 and B3.

Sensitizing Material

Because the professional and informal caregivers needed a different approach during the interviews, 2 types of sensitizing material were developed; one for the professional caregivers and one for the informal caregivers.
The sensitizing material for the professional caregivers is shown in figure 5 and the sensitizing material for the informal caregivers is shown in figure 6.
The sensitizing material starts with an introduction where the material is explained and where the participants were asked to fill in the material over 2 days.
The structure of the assignments was as followed: It started with basic

informative questions that were easy for the participant to answer.
Following we asked all participants to describe a day in the care home.
The professional caregivers were asked to make the timeline from their own perspective and the informal caregivers were asked to make the timeline from their parent's perspective.
Furthermore the participants were asked to mark the positive and challenging experiences and to explain why those moments were positive and challenging.
Finally the participants were asked to look back at their experience.

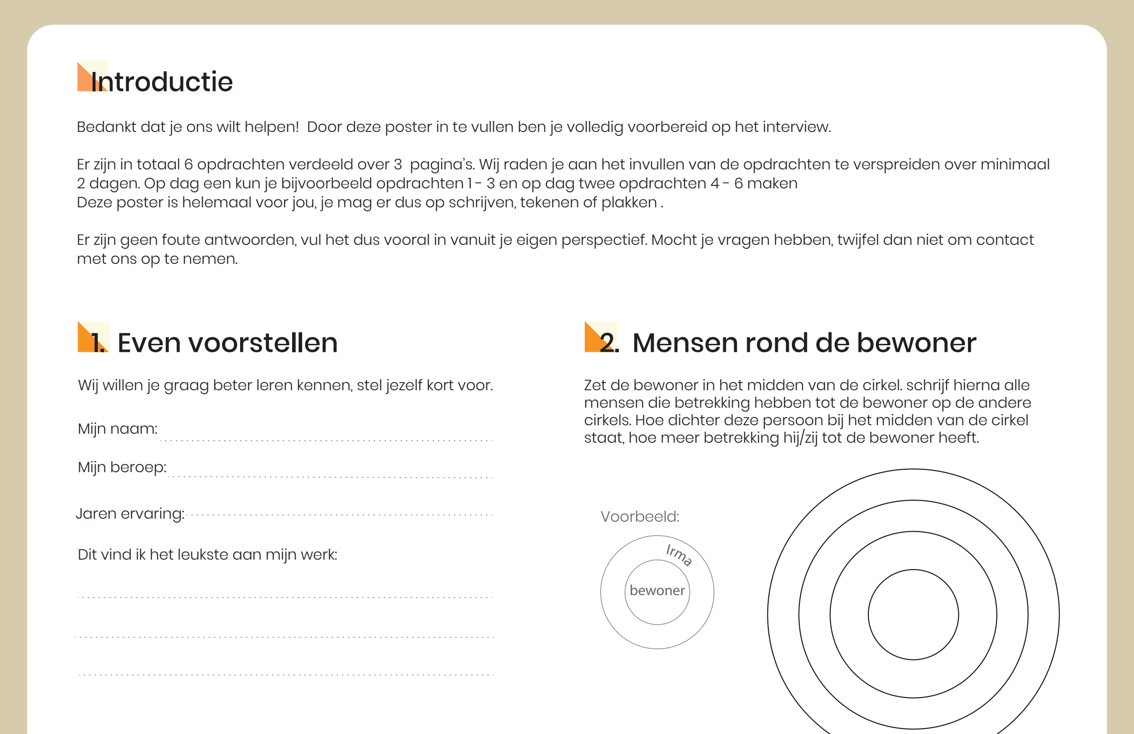
Interviews

The following procedure was applied during the semi-structured interviews with both the professional caregivers and the informal caregivers: First the goal of the study was explained to the participants. The participants were told that they are the experts of their own experiences, so during the interview there were no wrong or right answers. Next the consent form was discussed. Like on the consent form that the participants received prior to the interview, the handling of the data was explained again and the participants were asked if they agreed and if they signed the consent form. When all information was provided, the participants were asked if they managed to fill in the sensitizing material and if they had it on them during the interview. Finally the participants were asked if they had any questions, then the interview started.
The interview questions roughly followed the themes of the sensitizing material. The set-up questions can be found in appendix B4.
All interviews were conducted by video calling. This was required due to the measurements against Covid-19.

Documentaries

Since there was no possibility to visit nursing homes for this study, three documentaries were watched to provide an image of what the nursing home environment looks like to the researcher.
The following documentaries were addressed:

- "In de leeuwenhoek" by Hugo Borst & Adelheid Roosen
- "Wat ik nog ben" by Gerard Smit
- "Alive inside" by Michael Rossato-Benett



Introductie

Bedankt dat je ons wilt helpen! Door deze poster in te vullen ben je volledig voorbereid op het interview.

Er zijn in totaal 6 opdrachten verdeeld over 3 pagina's. Wij raden je aan het invullen van de opdrachten te verspreiden over minimaal 2 dagen. Op dag een kun je bijvoorbeeld opdrachten 1 - 3 en op dag twee opdrachten 4 - 6 maken
Deze poster is helemaal voor jou, je mag er dus op schrijven, tekenen of plakken .

Er zijn geen foute antwoorden, vul het dus vooral in vanuit je eigen perspectief. Mocht je vragen hebben, twijfel dan niet om contact met ons op te nemen.

1. Even voorstellen

Wij willen je graag beter leren kennen, stel jezelf kort voor.

Mijn naam: ……………………………………

Mijn beroep: ……………………………………

Jaren ervaring: ……………………………………

Dit vind ik het leukste aan mijn werk:

……………………………………

……………………………………

……………………………………

2. Mensen rond de bewoner

Zet de bewoner in het midden van de cirkel. schrijf hierna alle mensen die betrekking hebben tot de bewoner op de andere cirkels. Hoe dichter deze persoon bij het midden van de cirkel staat, hoe meer betrekking hij/zij tot de bewoner heeft.

Voorbeeld:

Figure 5.1, Sensitizing Material Professional Caregiver page 1.

3. Mijn leven als een verzorger

Schrijf en teken op de tijdlijn hoe een dag in jouw leven als verzorger er uit ziet.

Voorbeeld:

4. Moment waarderen: Positief en uitdagend

Kijk terug naar de tijdlijn. Noteer een ✧ bij ieder positief moment en een ⚐ bij ieder uitdagend moment in de tijdlijn.

Figure 5.2, Sensitizing Material Professional Caregiver page 2.

5. Beredeneren

Kies de twee meest positieve en meest uitdagende momenten uit die in de vorige oefening zijn aangegeven. Leg uit waarom deze momenten zo fijn of uitdagend waren.

Positief ✧

1

2

Uitdagend ⚐

1

2

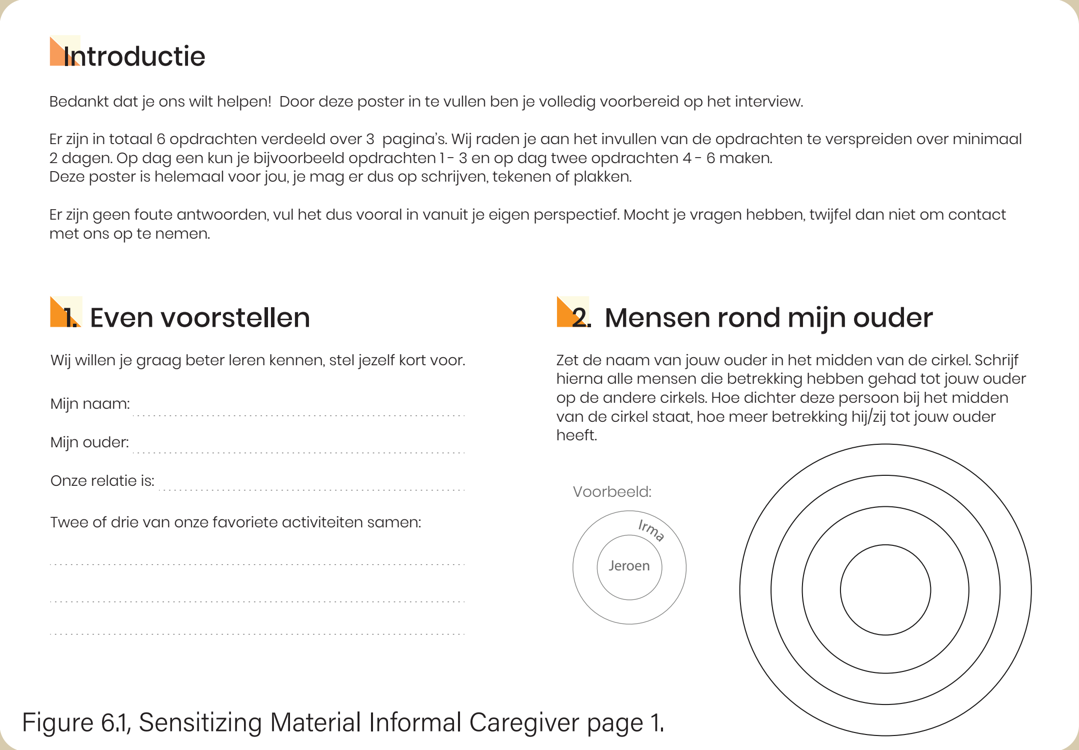
6. Mijn ervaringen

Terugkijkend naar je eigen ervaringen:
Wat zijn een of twee memorabelen ervaringen van de gehele tijd dat je in deze sector werkt?

Wat zou je graag geweten willen hebben toen je met dit werk begon?

Bedankt voor je medewerking en tot bij het interview!

Figure 5.3, Sensitizing Material Professional Caregiver page 3.



Introductie

Bedankt dat je ons wilt helpen! Door deze poster in te vullen ben je volledig voorbereid op het interview.

Er zijn in totaal 6 opdrachten verdeeld over 3 pagina's. Wij raden je aan het invullen van de opdrachten te verspreiden over minimaal 2 dagen. Op dag een kun je bijvoorbeeld opdrachten 1 - 3 en op dag twee opdrachten 4 - 6 maken.
Deze poster is helemaal voor jou, je mag er dus op schrijven, tekenen of plakken.

Er zijn geen foute antwoorden, vul het dus vooral in vanuit je eigen perspectief. Mocht je vragen hebben, twijfel dan niet om contact met ons op te nemen.

1. Even voorstellen

Wij willen je graag beter leren kennen, stel jezelf kort voor.

Mijn naam:

Mijn ouder:

Onze relatie is:

Twee of drie van onze favoriete activiteiten samen:

2. Mensen rond mijn ouder

Zet de naam van jouw ouder in het midden van de cirkel. Schrijf hierna alle mensen die betrekking hebben gehad tot jouw ouder op de andere cirkels. Hoe dichter deze persoon bij het midden van de cirkel staat, hoe meer betrekking hij/zij tot jouw ouder heeft.

Figure 6.1, Sensitizing Material Informal Caregiver page 1.

3. Het traject van mijn ouder

Schrijf en teken op de tijdlijn hoe een dag in het leven van je ouder was in het verzorgingstehuis.

Voorbeeld:

4. Moment waarderen: Positief en uitdagend

Kijk terug naar de tijdlijn. Noteer een ✧ bij ieder positief moment en een ⚐ bij ieder uitdagend moment in de tijdlijn.

Figure 6.2, Sensitizing Material Informal Caregiver page 2.

5. Beredeneren

Kies de twee meest positieve en meest uitdagende momenten uit die in de vorige oefening zijn aangegeven. Leg uit waarom deze momenten zo fijn of uitdagend waren.

Positief ✧

1

2

Uitdagend ⚐

1

2

6. Mijn ervaringen

Terugkijkend naar je eigen ervaringen:
Wat was een van jouw favoriete momenten tijdens het bezoeken van je ouder?

Wat zou je andere families aanraden met een ouder met dementie die in een verzorgingstehuis woont ?

Bedankt voor je medewerking en tot bij het interview!

Figure 6.3, Sensitizing Material Informal Caregiver page 3.

3.3 Analysis

In order to translate the data from the interviews into insights, the audio recording of each interview was listened to again. While listening to the participants, quotes or interpretations that were remarkable or informative were listed

A tool called "Miro" was used, to preform the analysis online. Miro is an interactive digital whiteboard. All quotes and interpretations were placed on digital post-its, see figure 7. Figure 7 shows the richness of the insights and gives an example of quotes. Each individual participant had it's own distinctive colour, so it was always clear to whom the quote or information belonged. Also a division was made between the professional caregivers and the informal caregivers. The same procedure was also done for all documentaries addressed in this study.

To analyse all the information, the post-its that had a similar subject or meaning were clustered together, but still within their category; professional caregiver or informal caregiver.

When a cluster became too big, a sub-cluster was made within the cluster. The overview can be found in figure 8, which shows the amount of clusters and the approximate size of each cluster. This overview resulted in a better understanding of all aspects that are relevant to people living with dementia.

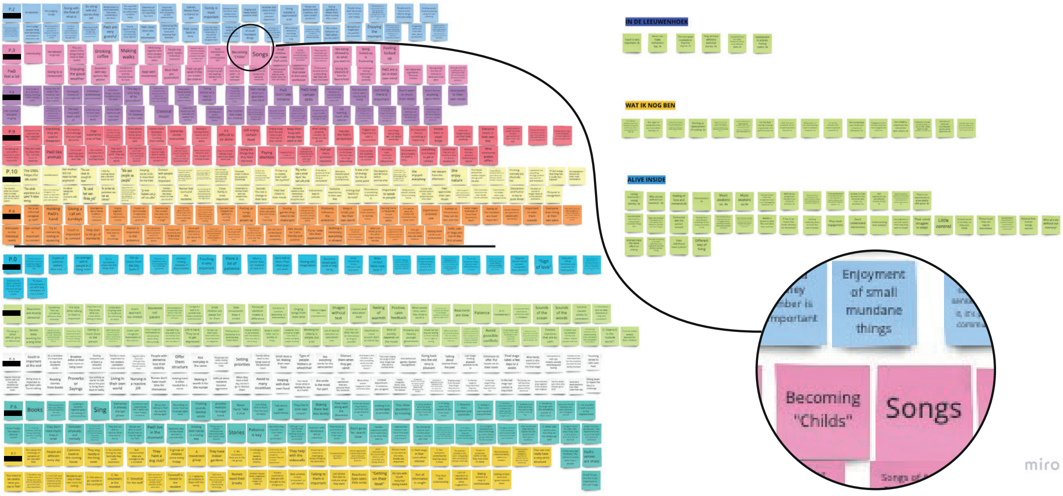


Figure 7, Post-its pre clustering.

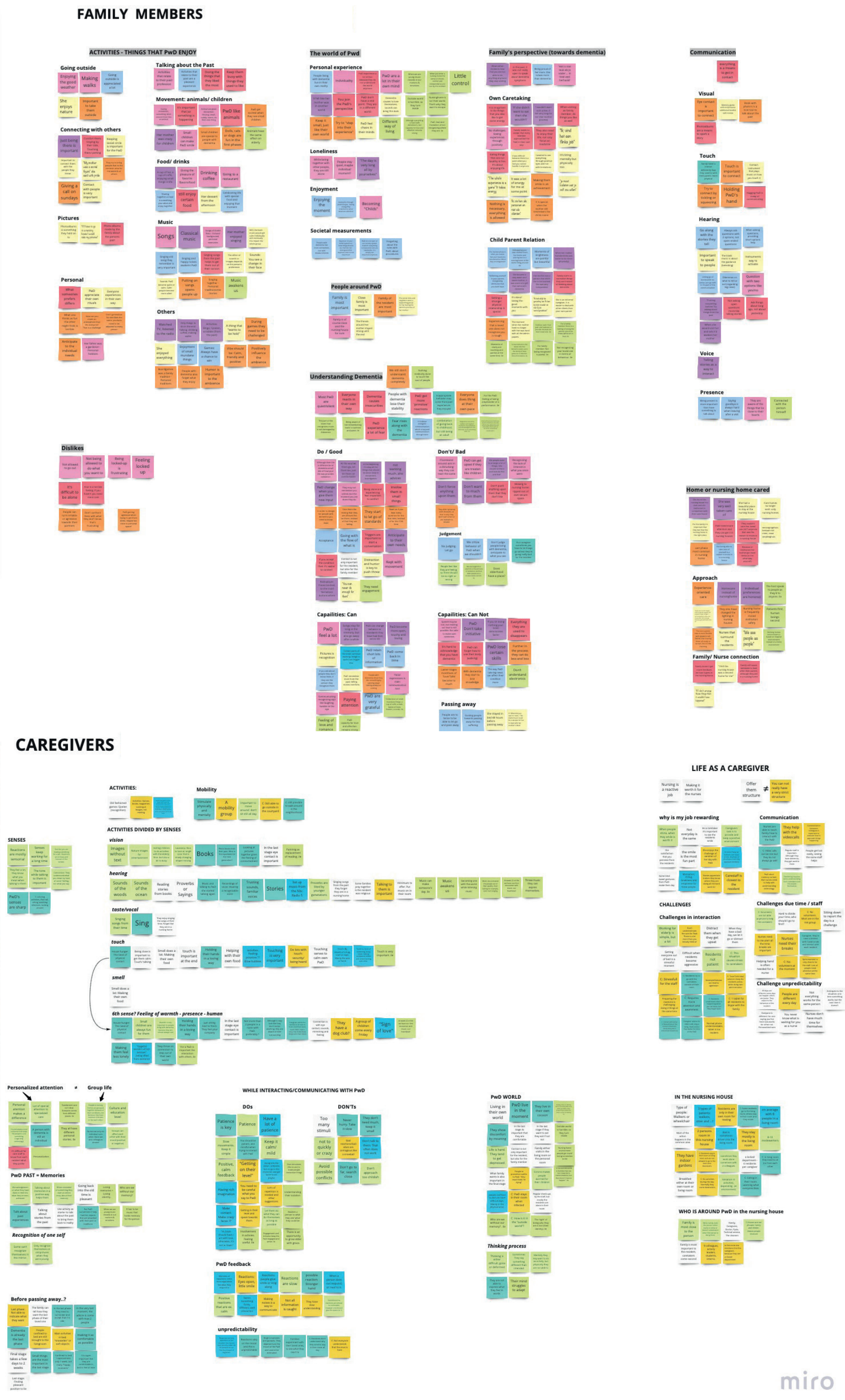


Figure 8, Post-its after clustering.

Informal caregivers		**Professional caregivers**	
Cluster	**Sub-cluster**	**Cluster**	**Sub-cluster**
Professional caregivers	Going outside, Talking about the past, Connecting with others, Food/ Drinks, Pictures, Music, Personal & Others	Activities by Senses	Vision, Hearing, Taste/ Vocal, Touch, Smell & Presence
Dislikes		Senses	
The world of PlwD	Personal experience, Loneliness, Enjoyment & Societal measurements	Personalized attention vs. Group life	
People around PlwD		PlwD Past (memories)	Recognition of one self
Family's perspective (towards dementia)	Own Caretaking & Child Parent Relation	Before passing away	
Communication	Visual, Touch, Hearing, Voice & Presence	While interacting/ communicating with PlwD	Do's & Don't's
Home or nursing home cared	Approach & Family/ Nurse connection	PlwD World	Thinking process
Understanding Dementia	Do/Good, Don't/ Bad, Capabilities: Can, Capabilities: Can not & Passing away	Life as a caregiver	Why my job is rewarding, Communication & Challenges; interaction, time/ staff & unpredictability
		In the nursing home	
		Who is around PlwD in the nursing home	

Table 2, Clusters overview.

3.4 Stakeholder Journey Map

The clusters present a good overview of all aspects that are important to people living with dementia and the people around them, however it does not provide a clear answer to the research questions stated in the beginning of this chapter yet. To structure all the information and to get a clear overview of the needs and the living environment, a journey map was made.
The customer journey map is a method to analyse and communicate the process a user goes through. The map provides a graphic representation of all the steps a user encounters, together with their emotions, pains, gains and needs. By mapping all parts of the context it helps to understand the complex experiences over time and to find opportunities to meet the user's needs.

When a customer journey is used within the healthcare context and is from a patient's perspective, it is called a patient journey. However in this report the map also includes the other stakeholders; the professional and informal caregivers perspective. Therefore the word stakeholder journey map is used to describe the method.

The stakeholder journey map is presented in figure 10. On the top of the map all activities that people living with dementia go through are stated. The activities range from the early beginning where someone is noticing symptoms related to dementia and performing a test, to the end where someone eventually passes away with dementia.

Below the activities, the thoughts and needs are stated for each individual stakeholder for every activity. The thoughts and needs of the stakeholder are only stated when they are involved in the activity. That explains the unfilled gaps at some of the activities.
The needs stated in the map are the human needs and sub-needs from the Human experience catalog by Desmet and Fokkinga, 2018 (figure 9).

Next, there is the emotion curve for each stakeholder. The blue line represents the person living with dementia, the green line represents the professional caregiver and the yellow line represents the informal caregiver. The emotion curve shows for each activity if the need connected to that activity is met or not making it either a pain point or a gain point within the stakeholder journey map.

For some of the activities a quote is stated from one of the interviewees to construct more understanding why there is a pain or a gain point. Because the data is based purely on caregivers, the quotes are from their perspective and not from the person living with dementia.

Finally at the bottom there are possible opportunities that could lift the pain point or increase the gain point even further. The opportunities are very broad going from already applied methods, towards very psychological and not easy to change aspects. Colours indicate to which stakeholder the opportunity applies.

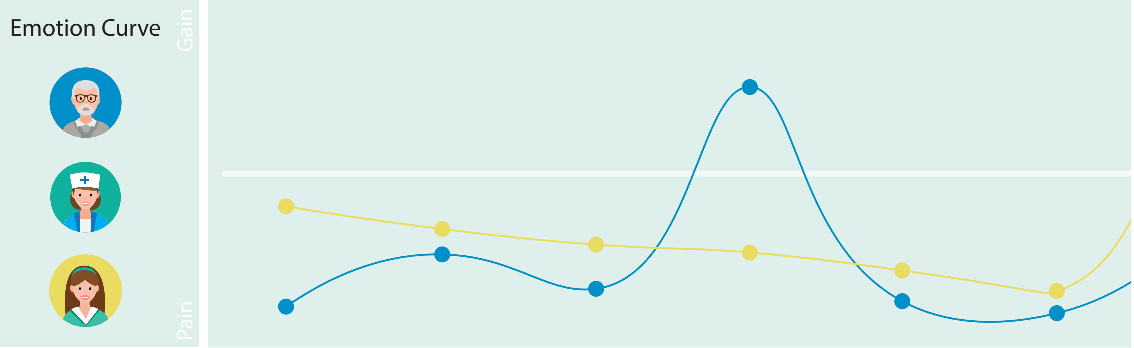
Fundamental Needs Diagram (Desmet)

Need	Sub-Needs	Explanation
Competence	Achievement Challenge & Competition Environmental Control Skill Progression	Having control over your environment and being able to exercise your skills to master challenges. Rather than feeling incompetent or ineffective.
Autonomy	Freedom of Decision Individuality Experimentation Creative Expression	Being the cause of your own actions and feeling that you can do things your own way. Rather than feeling that external conditions and other people are the cause of your actions.
Purpose	Direction & Ambition Meaningful Activity Personal Growth Sprituality	Having a clear ense of what makes life meaningful and valuable. Rather than lacking direction, purpose, or meaning in your life.
Impact	Influence Contribution Building something Legacy	Seeing that your actions or ideas have an impact on the world and contribute something. Rather than seeing that you do not influence or contribute anything.
Relatedness	Attachment Nurturing Intimacy Emotional Support	Having warm, mutual and trusting relationships with people that you care about. Rather than feeling isolated or unable to make personal connections.
Belonging	Social Support Affiliation Rooting Conformity	Being part of and accepted by a social group or entity that is important to you. Rather than not belonging anywhere and having no social structure to rely on.
Acknowledgment	Appreciation Attention Respect Statur	Getting attention and appreciation for what you do and respect for who you are. Rather than being disrespected, underappreciated or ignored.
Security	Physical Safety Financial Security Stability Familiarity	Feeling that your conditions and environment keep you safe from harm and threats. Rather than feeling unsafe, at risk or uncertain.
Order	Strucuture & Overview Efficiency Preservation Completion	Feeling that your life is structured, organized and harmonious. Rather than feeling that your life is disoganized, messy and obscure.
Morality	Moral Awareness Fulfilling Responsibilities Seeing Values in World Passing on Values	Being able to act on your personal values, passing them on to others and seeing them reflected in the world. Rather than feeling that you canoot recognize or act on your values.
Fitness	Nourishment Physical Comfort Energy Personal Hygiene	Having and using a body that is healthy, comfortable and full of energy. Rather than feeling ill, uncomfortable or listless.
Stimulation	Bodily Sensations Beauty Novelty & Variety Fun	Being mentally an physically stimulated by novel, varied and relevant impulses. Rather than feeling bored, indifferent or apathic.
Ease	Tranquility Convenience Mental Comfort Simplicity	Having an easy, simple and relaxing life. Rather than experiencing hardship, hassle or everstimulation.

Figure 9, Needs and sub-needs overview.

Journey		**Getting Diagnosed**					
Activities		**Noticing Dementia Symptomes**	**Talk about possible dementia**	**Go to the Doctor**	**Perform a Test**	**Receive the Results**	**Accepting living with dementia**
	Thoughts	“Is there something wrong with me?”	“Am i getting this right?” Confused	Nervous “Is this really necessary?”	“That was quite easy.” Doubting	Vulnerable	“This is my life now.”
	Needs	Security	Familiarity	Physical Safety	Simplicity	Tranquility	Purpose Simplicity
	Thoughts						
	Needs						
	Thoughts	‘I hope it’s not dementia” Uncertain	Hesitant/ affraid to talk about it	Insecure, but determined	Impatient, Eager, Doubt	Powerles, Vulnerable, Confirmed	Overwhelmed, Sad, Accepting
	Needs	Security	Ease	Impact	Stability	Emotional Support	Tranquility Stability

Emotion Curve

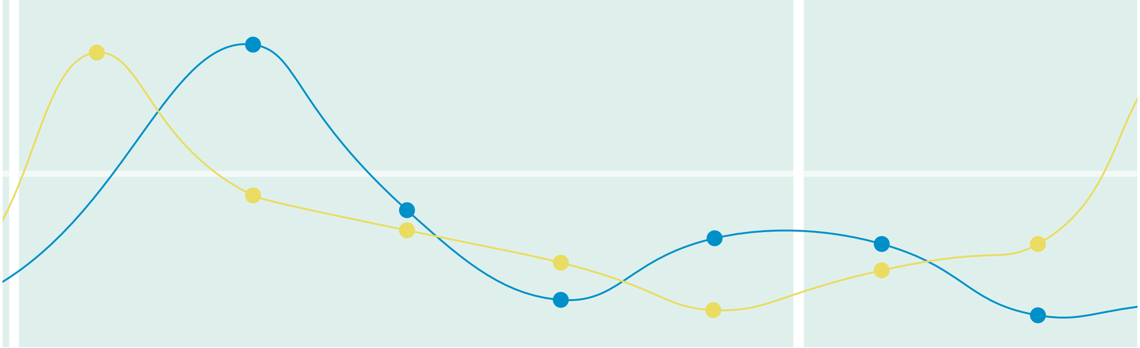


Quote’s			“You contantly doubt if you have it wrong” (about dementia)			“The transition from no dementia to dementia is the hardest part”
Opportunities	Crash course about dementia 🟡	Ability to talk with others about experiences. DIY Test on dementia 🔵 🟡		Information on how life looks like with dementia 🔵 🟡	Step by step doctors visit quide with reminder to ask questions. Information on how to get support 🔵 🟡	Highlighting positive sides/ Support Group 🔵 🟡

Figure 10, Stakeholder journey map.

Family Being Caregiver

Gather information/ help needed	**Trying to set a routine**	**Chaning interaction child - parent**	**Not everything is possible anymore**	**Ackowledging more help needed**	**Talk about moving to nursing home**	**Deciding to move to nursing home**
	Helped Taken care of	“I prefer a different aproach now” Other likes	Discomfort	“I don’t want a stranger taking care of me”	Confused	“I don’t want to leave my home” Worried
	Familiarity	Respect, Rooting Nourishment	Physical Safety Mental Comfort	Stability Familiarity	Simplicity	Freedom of decision
“Where do I start?” Determined	Determined	Reluctanct, infamiliarity, adapting	Overwhelmed, Grief	Powerless “It’s to much for me”	“I can’t handle this anymore”	Hesitant, Accepting
Fulfilling responsibilities	Convenience	Familiarity Attachment	Familiarity	Competence Experimentation	Ease Social Support	Morality

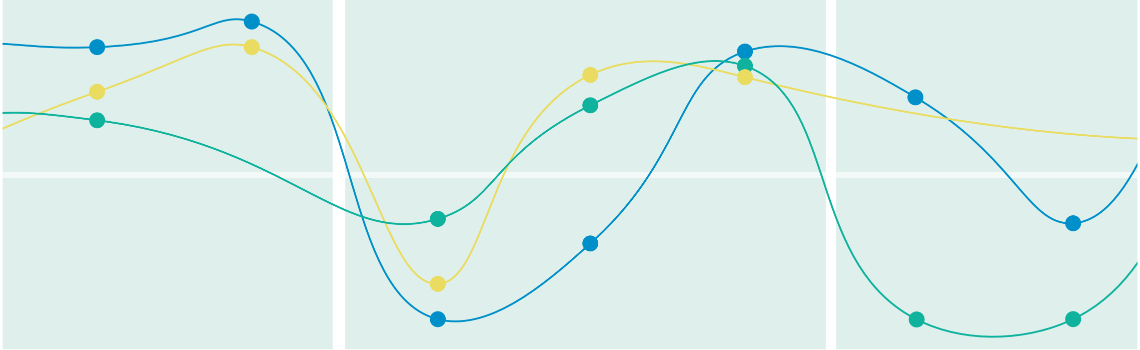


		“The parent you knew all this time is gone. She is a different person now”			“You don’t want to kidnap them from their own home”	
Having a non-judgemental buddy ●	Keep an open conversation with the focus on own capabilities ● ●	Acknowledge that personalities change with time and approach the changes in a positive way ● ●	Keepin focus on what is still possible. Leaving judgement behing: (no right or wrong) ● ●	Accepting that having limitations is okay ●	Keep an open conversation and hint to PwD that more care is needed ● ●	Involve PwD in decision making process. Validation checklist for decision making ● ●

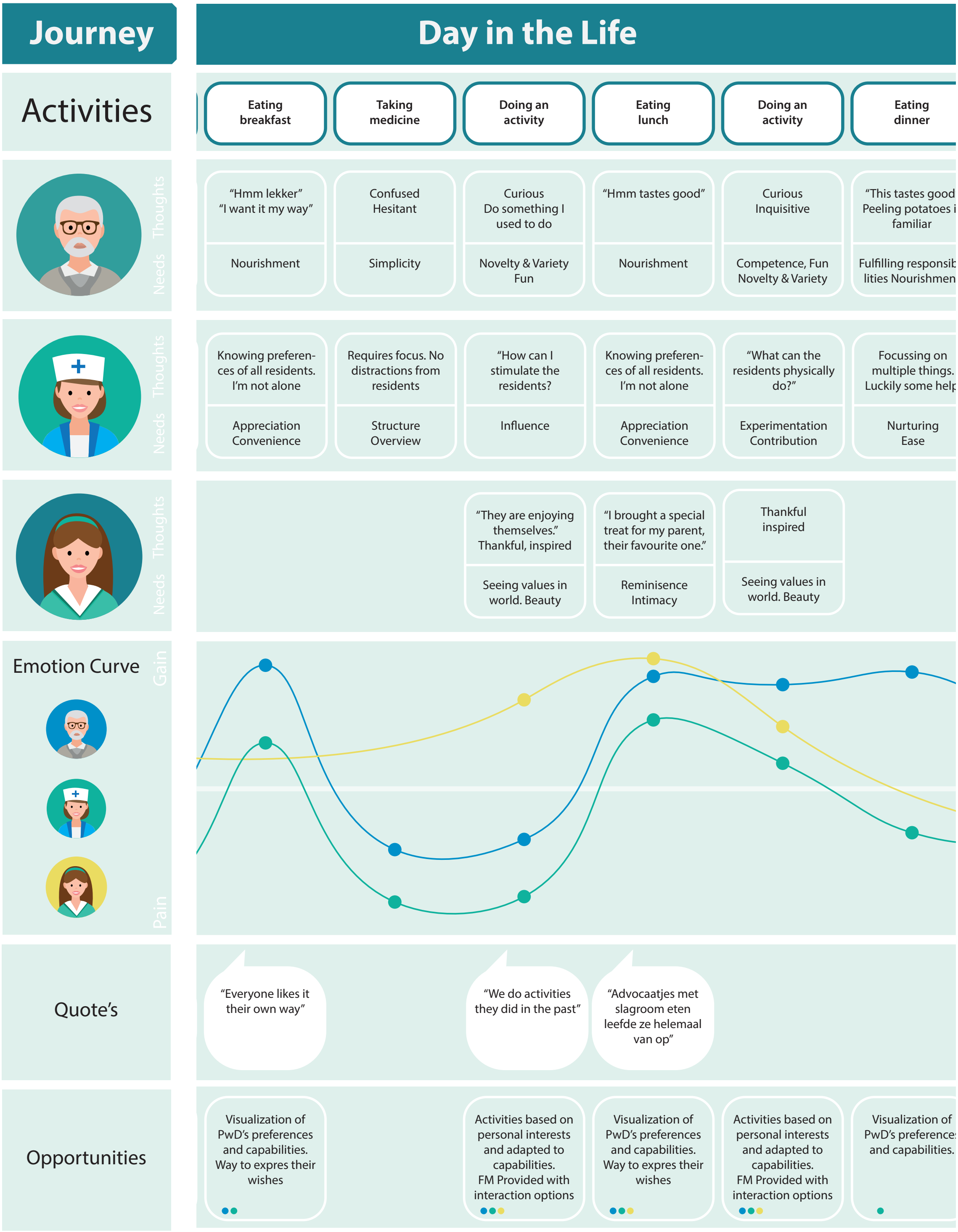
Journey	Transition to Nurse Care					
Activities	**Finding right nursing home**	**Moving into nursing home**	**Inform nurse on PlwD preferences**	**Getting used to new situation**	**Daily Health Care**	**Doing physical activities**
Thoughts	This looks like a hospital and not a home	“Moving might be unnecessary? I don’t understand it.”	“I hope this stranger will listen to my whishes.”	“This doesn’t feel like my home.”	“I habe good and bad days like everyone.”	Free Joyful
Needs	Attachment	Familiarity Social Support	Attention	Familiarity Social Support	Stimulation Familiarity	Bodily sensations
Thoughts	Is our place the right place for this person?	Curious	Inspired	Anticipating to resident’s needs	Trying to do everything at the same time	Making residents feel at ease
Needs	Impact Purpose	Purpose	Stimulation	Ease Competence	Order Convenienve	Acknowledgement
Thoughts	Determined, Content, Relieved	Upset, Remorseful, Relieved	Determined “As a child you need to be on-top of it”	Supported, Guilt, “Did I do the right thing?”		
Needs	Affiliation	Emotional Support	Attention	Emotional support Morality		
Emotion Curve Gain Pain						
Quote’s	“Some nursing homes look more like hospitals then homes”		“I need to constantly remind the care staff how she likes her coffee”			“You try to stimulate them”
Opportunities	Way to present care values and practicalities from nursing homes ●●●	Provide communication options for personal preferences ● ●	Provide ways for PwD to express their wishes and for FM way to visualize them to communicate to CG ●●●	Visualization for CG to be reminded of resident’s needs to give resident more recognition at common areas ●●●		Taking into account personal preferences ●

Figure 10, Stakeholder journey map.

At Nurse Care		Reduced Mobility				
Playing games	**Family visits**	**Losing mobility: Difficult to move**	**Finding alternatives**	**Adjusting to bed or wheelchair**	**Waking Up**	**Getting dressed**
Aroused Playful	"Most of the time this makes me shine."	"Ouch" Physical pain	"What is going on?"	"This is not so bad"	Calm	Confused "I can do this myself" Offended
Creative Expression	Valued Intimate	Physical Safety	Physical Safety	Individuality	Physical Comfort Purpose	Autonomy
"How can I stimulate the residents?"		"The resident must be in pain/ Frigtenend"	Find solutions for mobility	"Is this a good solution?" Doubt, optimistic	"How am I going to get everyone out of bed?" Overwhelmd	"Will the resident not be aggressive?"
Impact		Nurturing	Contribution. Influence	Achievement Appreciation	Ease Order	Physical Safety
Creative, Loving, Judgmental, "To childish"	Loving, Sensitive, Intimate	Stressed, Worried	Determined	"This is the best option, but I want him to stay mobile."		
Intimacy	Intimacy Rooting	Moral Awarenes Convenience	Tranquility Preservation	Preservation Familiarity		



"They become "Childs", but don't approach them childisch"	"You try to make them feel at ease, because they are very restless"		"You try to give them some sort of freedom where possible"		"Doing it all at once is very hard"	"When they get aggressive I need to protect myself"
Taking into account personal preferences during games. Provide interaction options ●●●	Provide FM with handles to communicate: Stimulate senses to trigger interaction/ communication ● ●	Accepting physical limitations. Keep focus on what is still possible. ●●●	Overview of alternatives: Pro's and con's on resident and nuring house level ●●●	Clear validation moment. Seeing the aid alternative as an extension of themselves . ●●●	Provide PwD with reminder of something to look forward to ●	Collaboration approach between PwD and Caregiver" "Help me help you" ●●

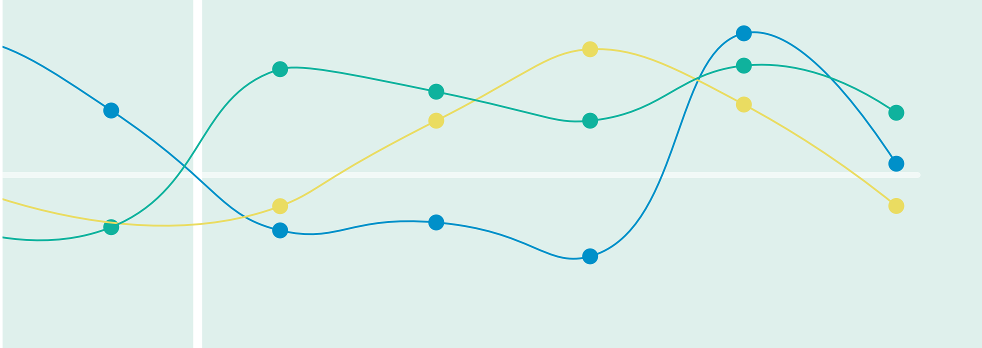


Journey	Day in the Life					
Activities	**Eating breakfast**	**Taking medicine**	**Doing an activity**	**Eating lunch**	**Doing an activity**	**Eating dinner**
Thoughts	"Hmm lekker" "I want it my way"	Confused Hesitant	Curious Do something I used to do	"Hmm tastes good"	Curious Inquisitive	"This tastes good Peeling potatoes i familiar
Needs	Nourishment	Simplicity	Novelty & Variety Fun	Nourishment	Competence, Fun Novelty & Variety	Fulfilling responsib lities Nourishmen
Thoughts	Knowing preferences of all residents. I'm not alone	Requires focus. No distractions from residents	"How can I stimulate the residents?	Knowing preferences of all residents. I'm not alone	"What can the residents physically do?"	Focussing on multiple things. Luckily some help
Needs	Appreciation Convenience	Structure Overview	Influence	Appreciation Convenience	Experimentation Contribution	Nurturing Ease
Thoughts			"They are enjoying themselves." Thankful, inspired	"I brought a special treat for my parent, their favourite one."	Thankful inspired	
Needs			Seeing values in world. Beauty	Reminisence Intimacy	Seeing values in world. Beauty	
Quote's	"Everyone likes it their own way"		"We do activities they did in the past"	"Advocaatjes met slagroom eten leefde ze helemaal van op"		
Opportunities	Visualization of PwD's preferences and capabilities. Way to expres their wishes ●●		Activities based on personal interests and adapted to capabilities. FM Provided with interaction options ●●●	Visualization of PwD's preferences and capabilities. Way to expres their wishes ●●●	Activities based on personal interests and adapted to capabilities. FM Provided with interaction options ●●●	Visualization of PwD's preference and capabilities. ●

Figure 10, Stakeholder journey map.

Final Days

	Going to bed	Lying in bed as comfortable as can	Long lonely days	Losing appetite	Family visits	Passing away
d” is ibi- nt	“Sometimes it is painful when they help me move.” individuality Physical Comfort	Vulnerable Tired Peaceful Physical Comfort Tranquility	Lonely Fragile Appreciation Intimacy, Support	“Iii’m not hungry” Integrity, Respect their will	“I feel when someone is with me” Relatedness Physical Safety	Peace Ease
. lp.	“Will the resident get aggressive?” Nervous Security	“How can we make the resident comfortable?” Acknowledgement Experimentation	Visit resident as often as possible Impact	Do we force residents to eat? How to stimulate? Nurturing	“Make sure not to many people are in the room” Security Overview	Supporting family Powerless Respect
		“What else can I do for my parent to feel comfortable?” Emotional Support	Grief “I need to comfort her” Impact	“If she doesn’t want to eat, she doesn’t eat” Morality	“I’m here with you” Simplicity, Rooting, Spirituality	Grief Respect Emotional Support



		“We try different positions to let them lie as comfortable as possible”	“We come by their room a few times a day. Just feeling your company is important”			“I wanted to preform a mantra to her, but was affraid the staff would find it weird. But I was there for my mother, so I just did it and it really calmed her down”
f es .	More user friendly bed-lifts for the PwD. Collaboration approach ●●	Reminder for changing positions Open mind for experimenting ●●	Way to interact with PwD for them to feel company ●●●	Showing that their will is respected and accepted. Understanding values ●●●	Guidelines for connection. ● ●	Stimulation to do what feels right how weird it may look. Stimulate PwD to feel at ease to go. ●●●

3.5 Insights

Project Scope

During the interviews it became clear that people living with dementia are not necessarily confined to their room or experiencing a lot of loneliness while losing their mobility. In a lot of cases people living with dementia that lose their mobility are put in wheelchairs during the day by the help of an electronic bed lift. Even when people living with dementia are confined to their bed, those beds are still mobilised and caregivers bring the people while in bed to the living room area.

With this new information the scope of the project was slightly adjusted. Although the cases are rare, it was clear that there still is a need for a design that worked for individuals while being in their private room and in their own bed. People living with dementia experience so called 'bad days' and when those days occur they don't want to be in the living room area. On those moments an individual design for the personal room could be of great value.

Stakeholder Needs

In order to get a better understanding of the needs of all stakeholders, which is one of the main research questions, the needs stated in the stakeholder journey map are visualised.
Figure 11, 12 and 13 show all the user needs for each stakeholder.
The journey map only shows the entire trajectory and this project is mainly focussed on the final phase. So the bright circles in the visualisation are the needs that occur in the last phase of the journey map and the light circles are the needs that occur in the other phases of the journey map.
The size of the circle represents the amount of times they occur.
To improve the understanding of where the needs come from, quotes corresponding to the specific need are added.

Person living with Dementia’s Needs

For the person living with dementia it is very important that their personal needs are being taken into account and respected. This comes back in their need for nourishment and physical comfort. There is an opportunity in a way for them to express their wishes/ preferences, which is quite hard since they forget what their preferences are.

People living with dementia also show a need for individuality, autonomy, purpose and competence. They can be confused about needing help and want to do things themselves, although they are not able to anymore. There is an opportunity to approach people living with dementia with a collaborative approach.

The need for simplicity plays a big role in their life. Due to the dementia they forget a lot about their life and they start to live in their own reality. Because they are so much in their own mind and do not understand the world around them anymore, they experience a lot of fear. Helping them with bringing up memories helps to calm them down and to feel at ease.

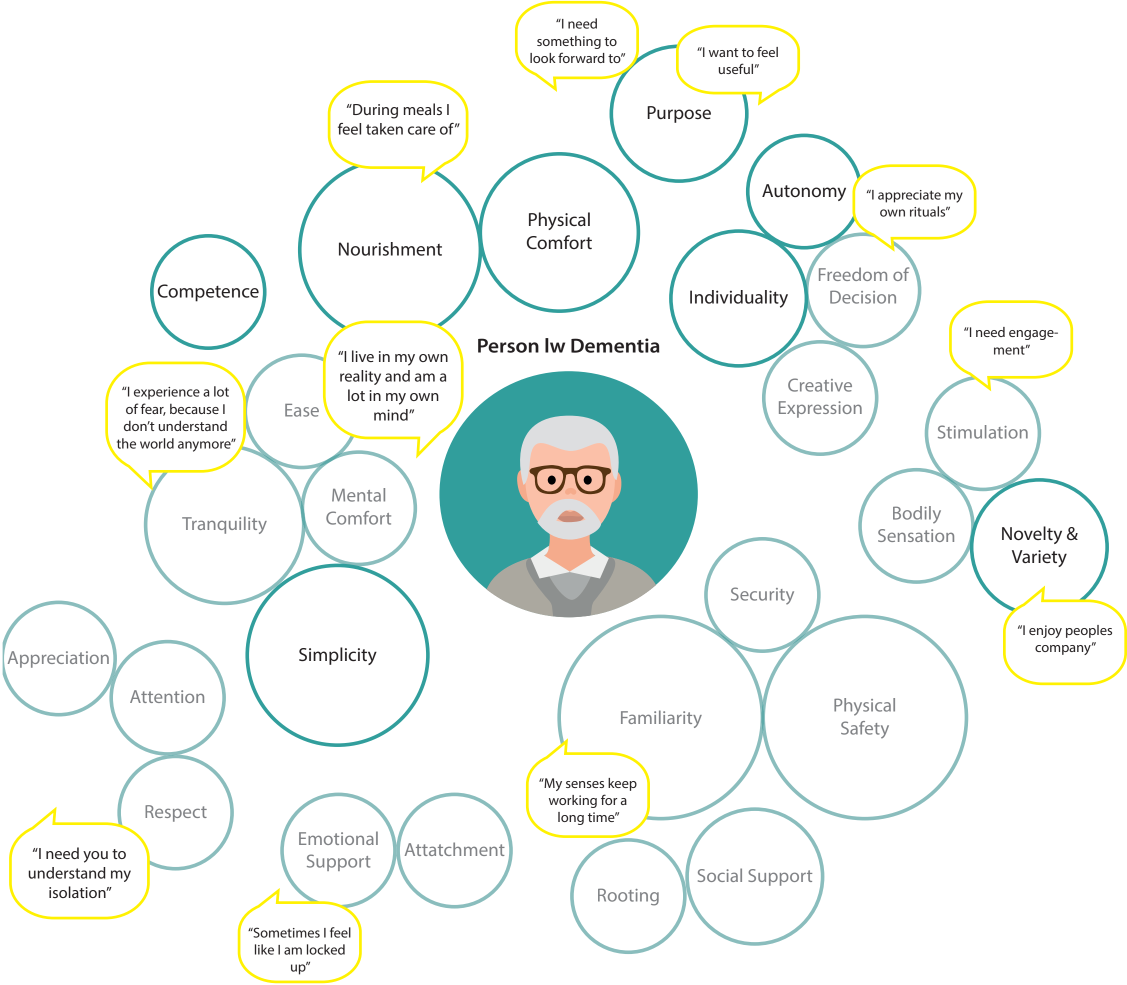


Figure 11, Person living with Dementia Needs.

Professional Caregiver’s Needs

In the last phase the caretaker shows a big need for nurturing, ease and competence. This comes mostly from their work activities and how overwhelming they can be. Taking care of multiple people at the same time can be very tough. Especially taking into account everyone’s preferences and wishes is not always easy. An opportunity would be a way to visualize the needs, wishes and preferences of the residents for the caretakers to be reminded by them quickly and easily.

They also show a need for contribution and influence. When they see that their hard work pays off it really stimulates them. They also see that personal attention in care really makes a difference and that they want to fill the loneliness for the people living with dementia. This feeling can be increased to focus on activities that come from a preference perspective instead of a capabilities perspective.

Finally the caretakers have a big need for security and physical safety. Residents can become confused and aggressive, which makes it hard to take care of them. The need of safety can be increased by a collaborative approach, where the caretaker supports the resident while helping them, instead of completely taking over.

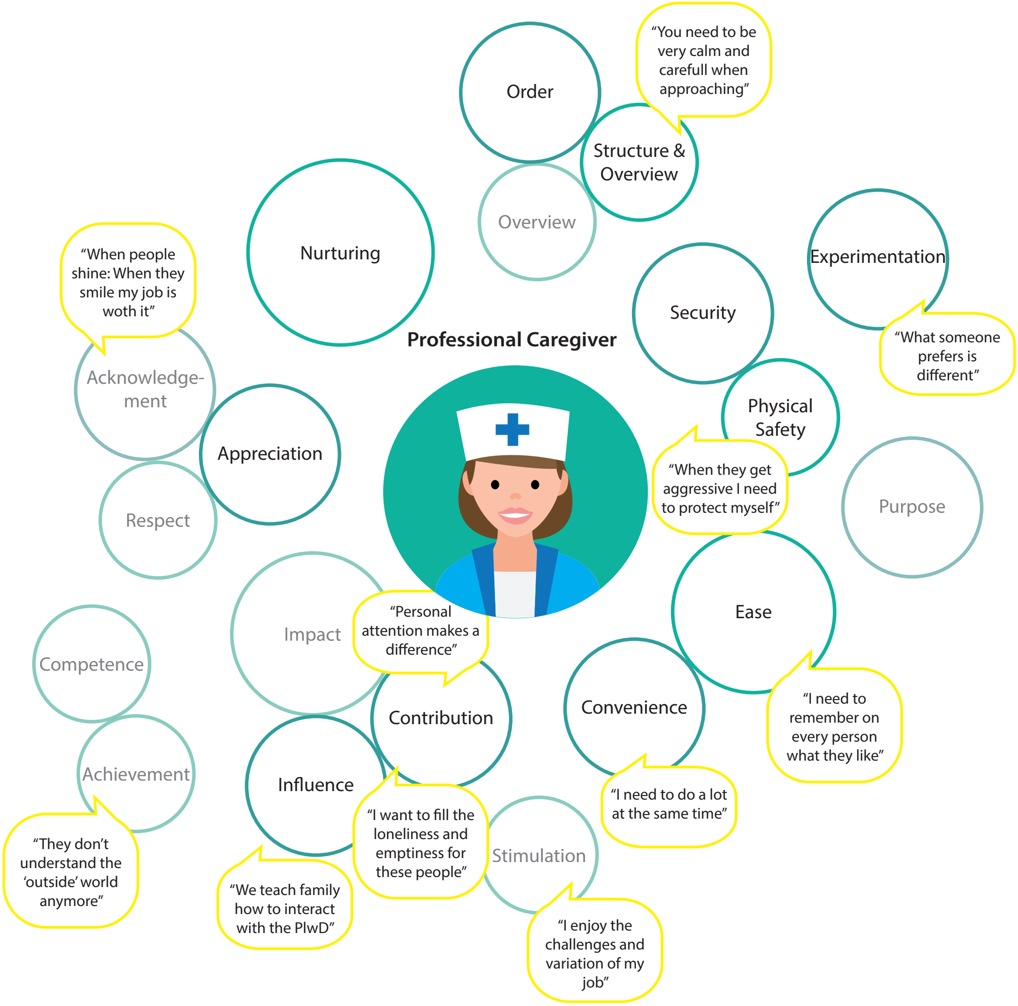


Figure 12, Professional caregiver Needs.

Informal Caregiver’s Needs

While visiting their loved one the informal caregiver shows a big need for emotional support, intimacy, seeing values in the world and beauty. During their visits they need to interact in a different way with their parent then they are used to, which is quite painful to experience. Providing them with communication/ interaction options could increase the impact of their visits and fulfil their needs.

They also show a need for impact. They put a lot of time and effort in taking care of their loved one and would like to see that they are being taken care of properly. They feel like they need to be on top of things, to get the right care. An opportunity would be a tool that helps them to communicate the preferences of their loved one to the nursing home.

There is also a big need for familiarity and preservation. They start to lose their loved one as they always knew him or her. There is unfortunately no way to prevent this from happening, but they could be provided with a way on how to adapt to the new situation.

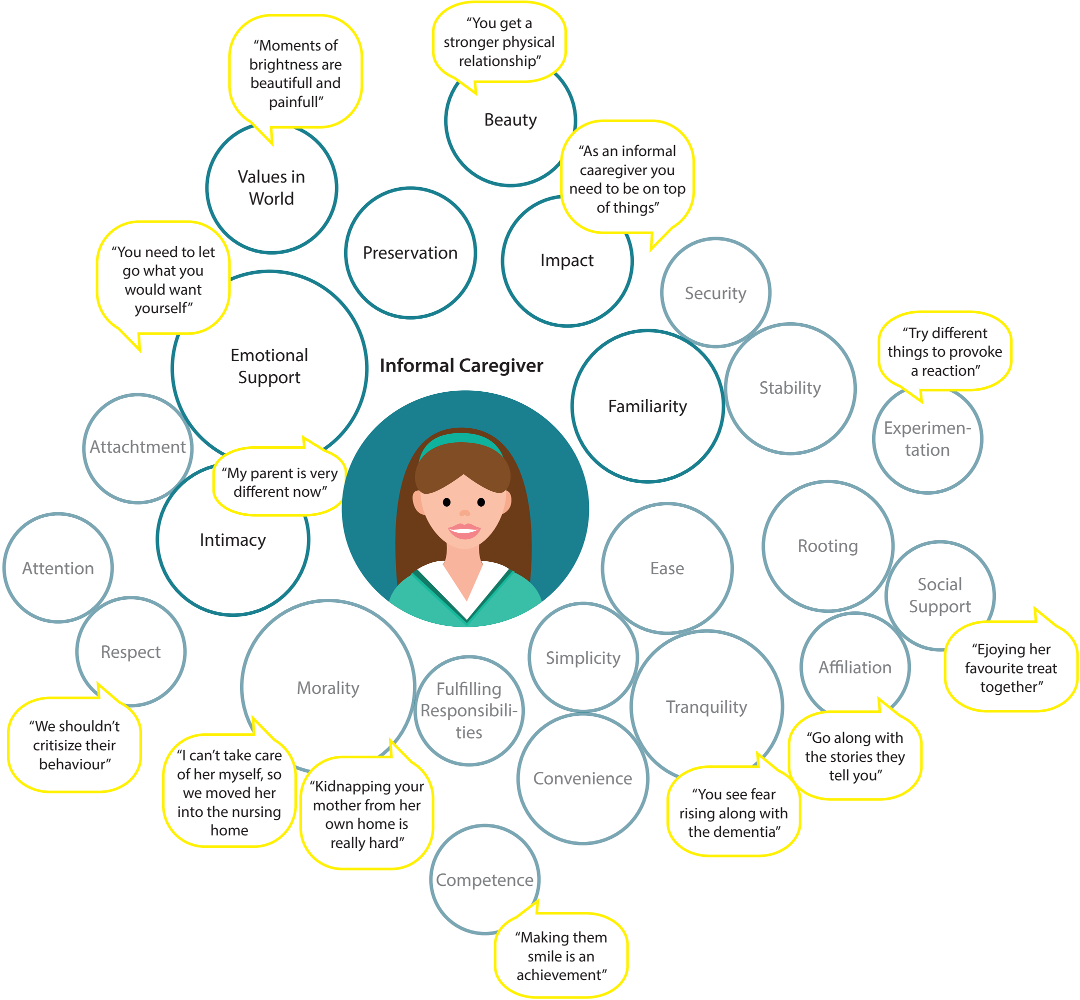


Figure 13, Informal caregiver Needs.

The Perception Model & Communication Model

People living with dementia can feel very frustrated or not understood. That is because we simply do not completely understand what dementia does to people. One of the things that the research showed is that due to dementia, people living with dementia start to live in their own personal experience of the world, their from now on called "inner past world", instead of the real world (see figure 14). This 'inner past world' looks a lot like their childhood, but is not completely the same and is very individualistically oriented. The present they see around them doesn't fit anymore with what they remember. The main thing is that they feel disconnected from the real world: That is where their frustration and confusion comes from.
By talking about the past with others, they relive certain parts of their past and are able to reconnect again with the real world. This reconnection is necessary to calm them down and make them feel as ease. This calm and reconnected feeling can be experienced as a happy moment for people living with dementia.

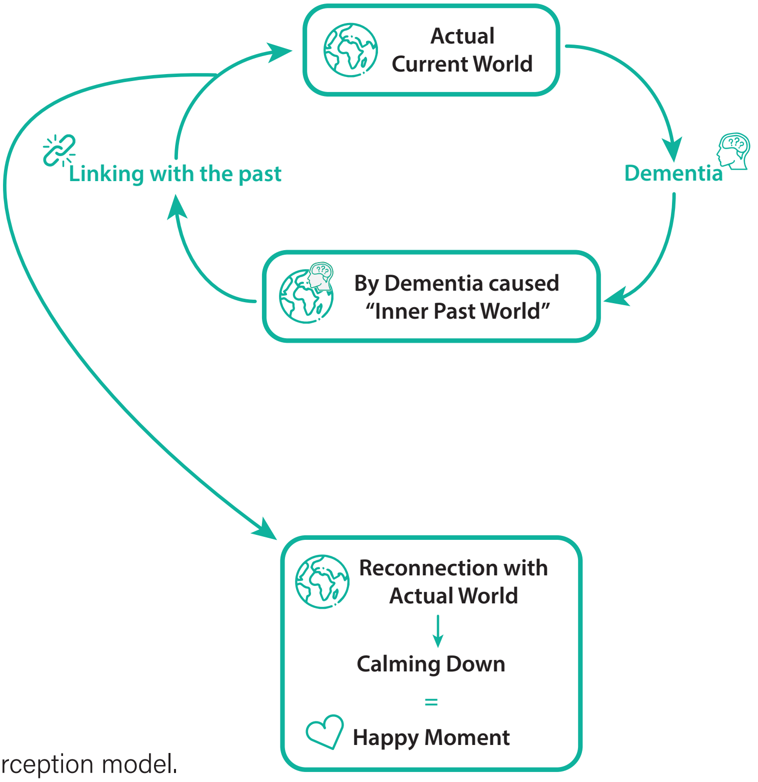


Figure 14, Perception model.

However in order for people to communicate with someone living with dementia and to help them talk about their past, they need to go through a few steps (figure 15). First their senses need to be stimulated. Mostly haptic or hearing works very well to stimulate people living with dementia. This can be done by touching them or putting on some music they prefer.
By stimulating their senses, person living with dementia is activated. They get into a different state and are ready to connect or interact with you. From this state you are able to communicate with the person living with dementia.

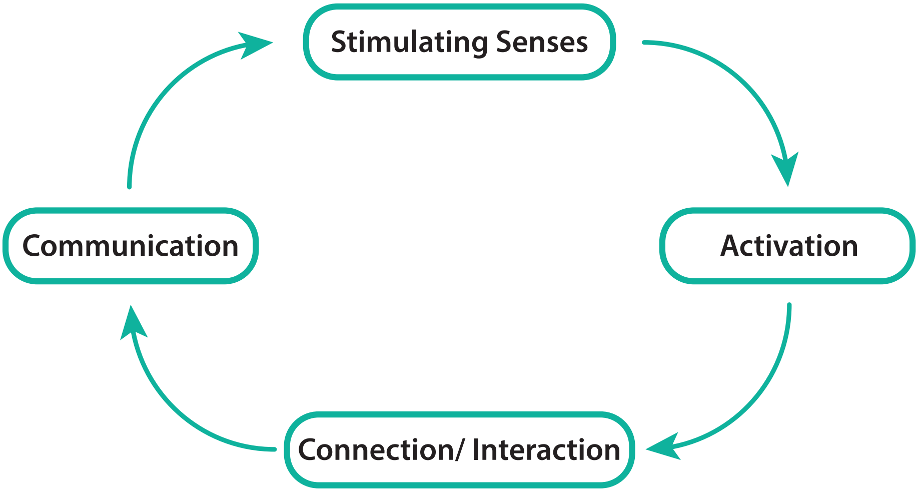


Figure 15, Communication Model.

Combining both these models allows for understanding on how to provide people living with dementia with a calm and at ease feeling.
However this is purely based on the connection between people living with dementia and another person. Another person is not around all the time at the moment's people living with dementia experience fear. Then they do not have the possibility to feel calm and at ease by the help of another person. It would be a great opportunity if a system could provide these models with the effect to decrease their anxiety.

Activities Design Approach

Another thing found during the research was that activities that are currently being provided to people living with dementia are primarily based purely on the capabilities of people living with dementia. This leads towards capabilities based activities. Most of these activities are not enjoyable for everyone living with dementia and in some cases there are no suitable activities to their liking available. In nursing homes people are either forced to participate in activities they don't enjoy or they are not stimulated by an activity, which both is negative to their quality of life.

As figure 16 shows, there could be an opportunity to first focus on the personal interests of people living with dementia. From those personal interest, interest based activities can be found. Taking into account both the interest based activities and the dementia capabilities while designing activities for people living with dementia could lead to interest based activities tailored to capabilities. Designing from this approach and with this outcome would be very beneficial to the quality of life of people living with dementia.

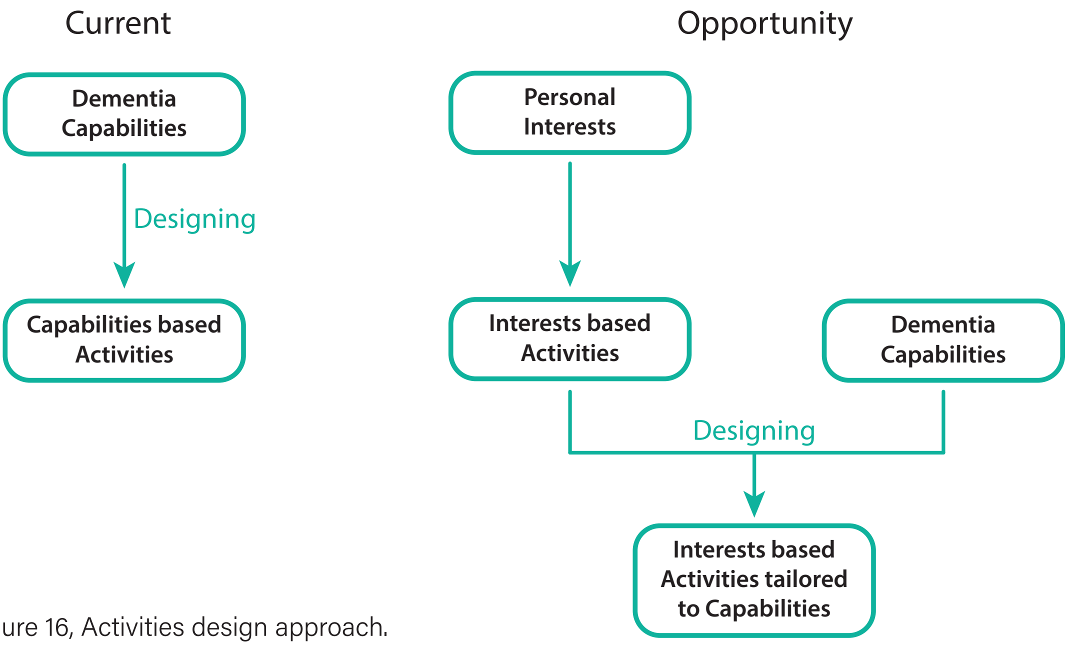


Figure 16, Activities design approach.

Personal Interests

Because the theme of personal interests frequently came back in the insights of this research, especially within the stakeholder journey map, the relations between the three stakeholders was looked into. This resulted in the triangle visualisation in figure 17.
This triangle shows that for the person living with dementia their main priority is that their preferences and wishes are being taken into account, but for someone living with dementia it is already a challenge to remember what those are. So for themselves it is important to find their identity in order for their identity to be taken into account by their caregivers.

The informal caregiver luckily already knows a lot about their loved one's identity. However, it is very hard for them to inform the professional caregiver about it. This is due to the fact that not only a lot of different caregivers take care of one resident, but also because one caregiver takes care of a lot of different residents. It is simply very hard for them to remember everyone's wishes.
On the other hand the informal caregiver can have a big role in supporting the person living with dementia in finding their identity. They have a very special relationship with them, but they still struggle in communicating with their loved one. People living with dementia need a different approach for communication. Luckily this is something the professional caregiver is very experienced with. Professional caregivers are able to teach informal caregivers on how to communicate effectively.

So when all stakeholders work together they should be able communicate with the person living with dementia, to discover their identity and eventually provide them with activities based on their interests. Of course in practise this is easier said than done.

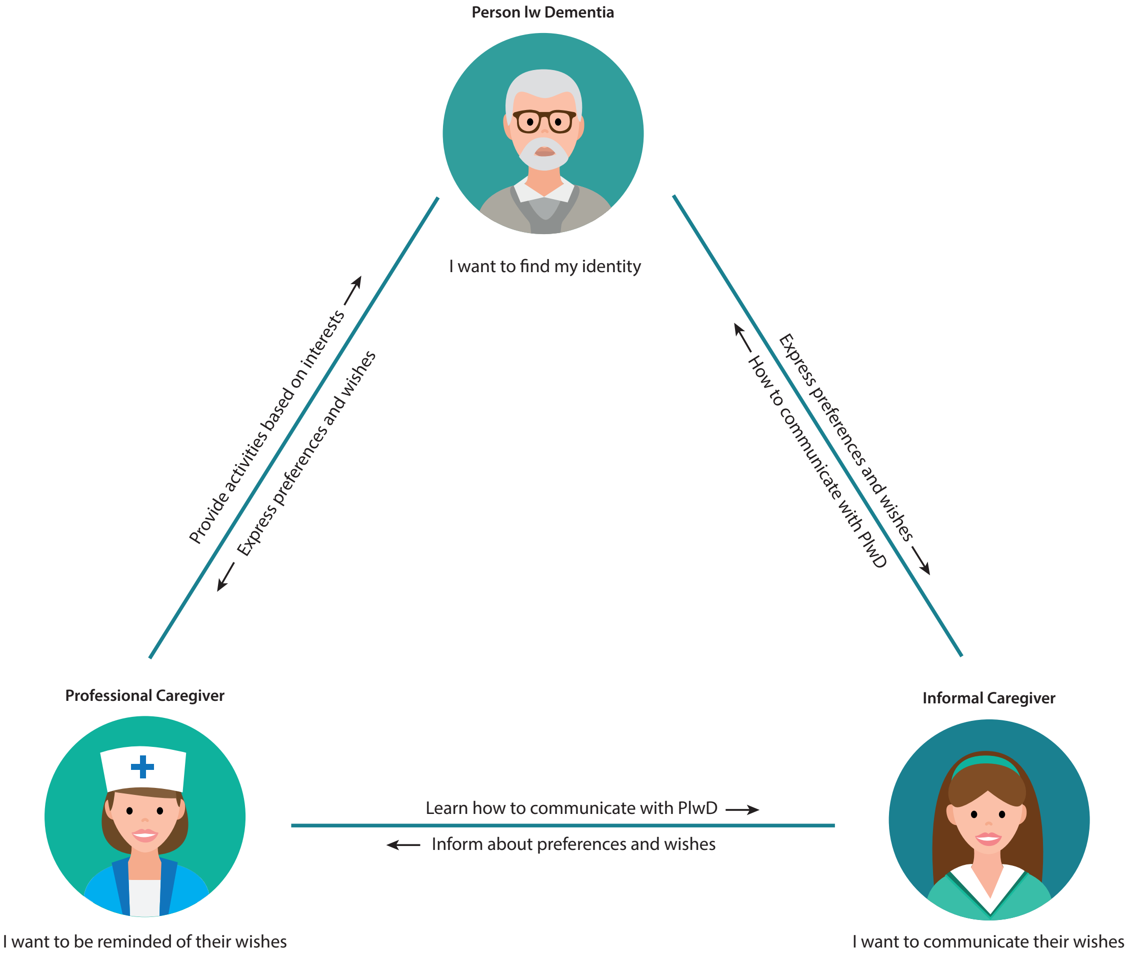


Figure 17, Personal interests triangle.

Anxiety

Besides the theme personal interests, also the theme anxiety came back frequently within this research. The relation between the three stakeholders on the subject of anxiety was also looked into and is shown in figure 18.
The visualisation goes in on the previous mentioned perception model where the person living with dementia experiences a lot of anxiety, because they don't understand the world around them anymore.
The informal caregiver tries always has the feeling that they need to make their loved one to feel at ease. Not only do they have this feeling while visiting them, but also when they are not around. The only way to help their loved one to feel

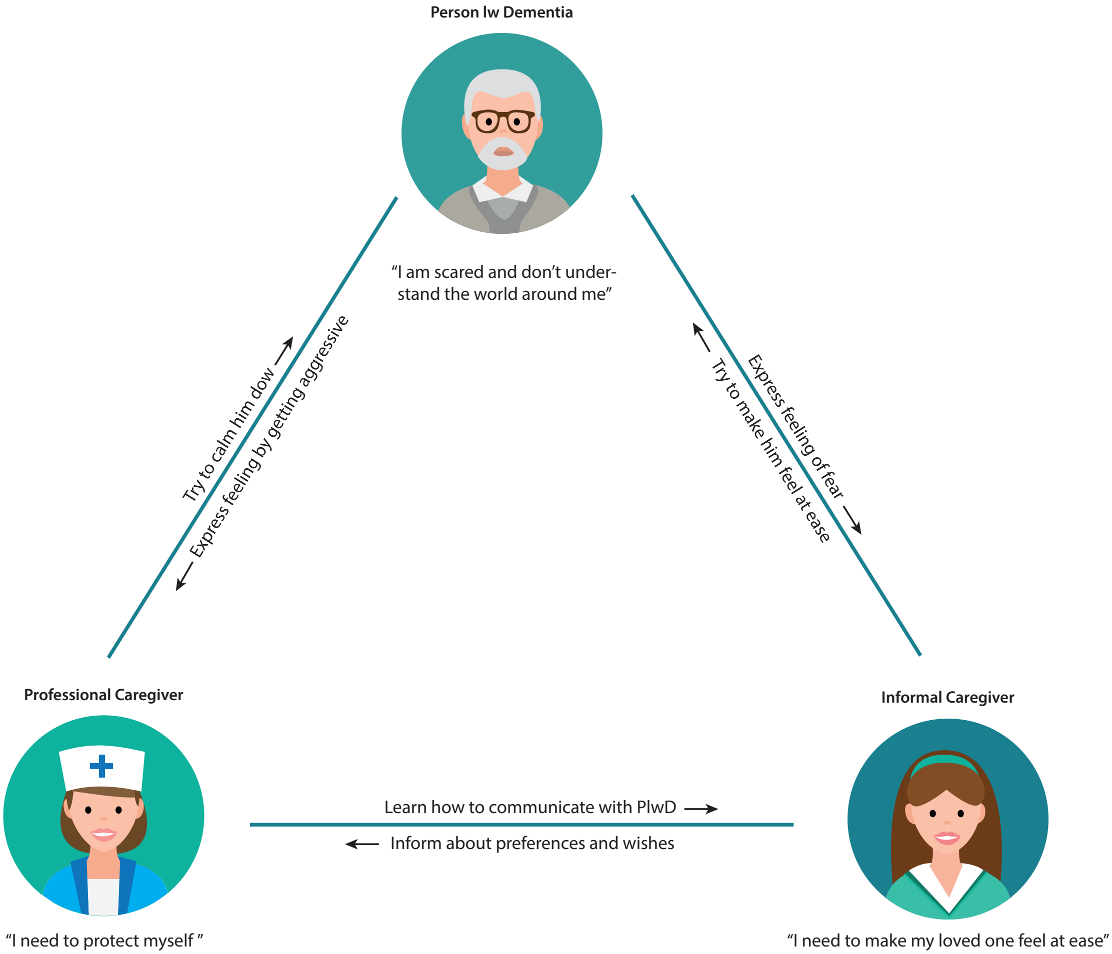


Figure 18, Anxiety triangle.

at ease when they are not around is to inform the professional caregiver on their preferences and wished.
On the other hand the person living with dementia can express their feeling of anxiety in an aggressive way towards the professional caregiver. This could lead towards risky situations where they are forced to protect themselves.

Looking at both visualisations on the theme of personal interests and on anxiety, gives the realisation that there is a connection between the feeling of anxiety and the need for finding the identity of the person living with dementia for all stakeholders. Taking their identity into account could decrease the person living with dementia experiencing anxiety.

Side Note

The research that is conducted is through the eyes of the caretaker and family member. Although they tried to tell from the perspective of the person living with dementia, it is still from their own perspective. That is also why a lot of the insights found focuses on the connection of the person living with dementia with someone else.

Someone else can simply not know how it feels for a person living with dementia to be alone. Because there was no ability to visit the nursing homes, there was also no ability to ask the people living with dementia themselves how it is for them to be lonely.

Although the research is from this connection perspective, we cannot deny that the connection with other people is very important for people living with dementia.

3.6 Conclusion

All insights gathered through this researched show that there is a large need of all stakeholders for the person living with dementia to feel at ease. Taking away their feeling of anxiety is not only beneficial for the person living with dementia themselves, but also for the professional caregiver and the informal caregiver. This can be done by focussing on the identity of the person living with dementia: by finding out what their identity includes and to give their identity back to them. However this can only be accomplished when the person living with dementia is ‘activated’ by stimulating their senses. During the concept development not only the effect on the person living with dementia should be taken into account, but also the effect on the professional caregiver and the informal caregiver. All stakeholders have their own role within providing positive moments to the person living with dementia.

Design Brief

This chapter describes the design brief formulated for this project based on the findings in the previous analysis chapters. First the interaction vision of the current situation is presented. Then the desired interaction vision is presented and the qualities of both are described. Finally the design goal is presented, which is a leading point of reference throughout the concept development.

4

4.1 Interaction Vision

The Interaction vision is a technique that uses a metaphor for generating and communicating interaction qualities. The main objective of this technique is to create a rich representation of the moods, feelings or experiences that the interactions with the future product should bring for the user (Pasman et al., 2011).

Before looking into how the desired interaction should feel like, the feeling of the current interaction is described. The current interaction comes from the perception model presented in the previous chapter. The perception model shows that people start living in a disconnected 'inner past world' that they don't understand, due to the dementia. That feeling is described in the current interaction.

Current Interaction

"Being locked up in a cage and
you can't look through the bars"

Interaction Qualities:
- Fear
- Restless
- Own world
- Alone

The vision and figure 19 describe the current interaction. It described how people living with dementia feel in their own 'inner past world.' They feel locked up in that world, because they don't understand the world around them anymore. Sometimes there are small breakthroughs, but even those are blurry and they can't grasp what is outside of the 'cage.'

Figure 19, Current interaction.

Desired Interaction

"Lying in the pool on an inflatable ring"

Interaction Qualities:

- Calm
- Safe
- Free
- Supported

The vision and figure 20, describes the desired interaction. Instead of feeling anxious, people living with dementia should feel calm and safe. Instead of feeling locked up in their own 'inner past world' , they should feel free and instead of feeling alone, they should feel supported. The inflatable ring represents this supported feeling and the large pool represents the feeling of being free and the ability to go wherever you want. While lying in a pool people are able to completely relax and feel calm. The fact that the person is in a pool and on an inflatable ring makes the interaction feel safe.
The interaction vision can also be interpreted that the water is the identity of the person and the inflatable ring is a playful tool that helps the person living with dementia to discover their identity.

Figure 20, Desired interaction.

4.2 Design Goal

The insights of the previous chapter and the interaction vision were the foundation for the creation of the design goal. The design goal represents the connection between reducing anxiety by reconnecting people living with dementia with their past, discovering people's identity and a more personalised and interest-based approach.

"Making the Person living with Dementia to ***feel at ease*** *by giving them the ability to* ***reconnect*** *with their* ***identity*** *and* ***interests.****"*

Concept Development

This chapter describes how the design goal of the previous chapter will be realised into a concept. First the overall concept direction will be explained, together with some preliminary requirements. From the concept direction several research questions are drawn. These research questions are answered by gaining more knowledge for professional caregivers and by conducting a brainstorm session with designers. This resulted in a broader list of requirements and wishes. With that information in mind ideas were generated for the concept direction. Finally a scenario was created to illustrate the overall concept.

5

5.1 Concept Direction

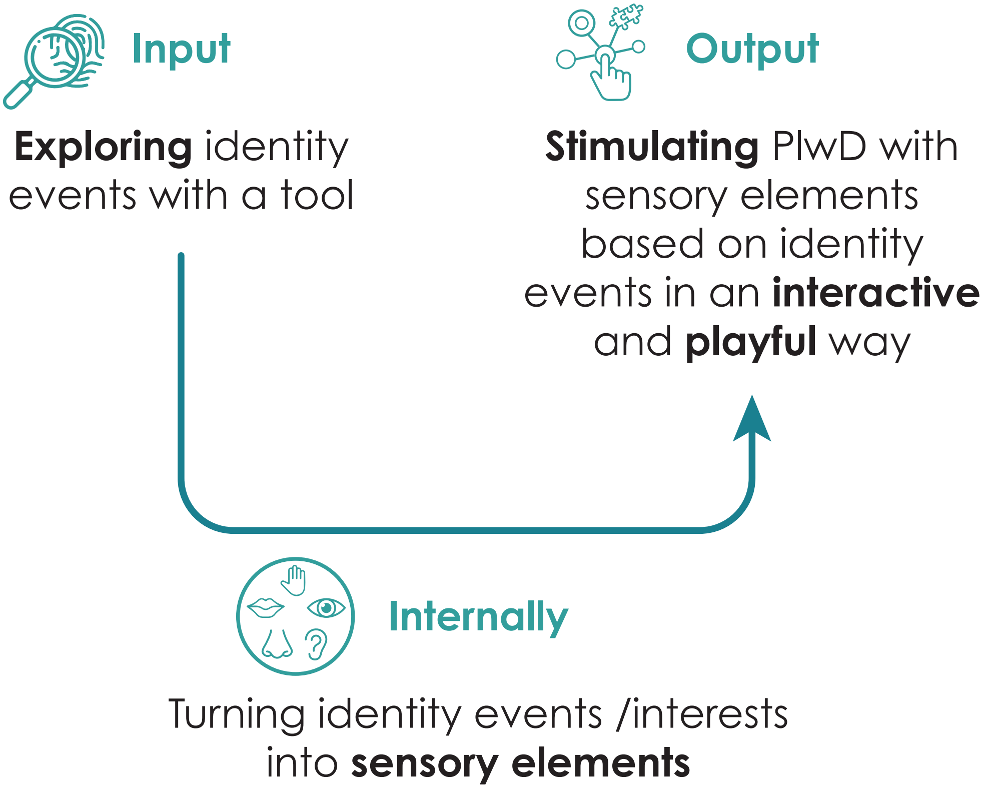
To acquire a better understanding on how the design goal could be achieved before going into ideation, the concept direction was worked out a bit more thoroughly.
Looking back at the insights and with the design goal in mind the following concept direction was made, see figure 21.

The figure shows that the concept starts with an input where the identity and specifically identity events of the person living with dementia are explored with a tool. Ideally people should use this tool before they even have signs of dementia. But looking realistically and at the stakeholder journey map, this tool can be implemented at the moment people sign in at a nursing home. The tool could be added to the introduction conversations between the nursing home and the future resident.

Later when people living with dementia are in the final stage the concept's output can stimulate them with the identity events gathered during the input. By presenting this output in a playful and interactive way, people can stay engaged with the output of the concept.

The research showed that people living with dementia are only able to communicate when activated by their senses. So the concept should use the senses, in order to make the reconnection with their identity happen. That is why internally the concept needs to turn the identity events gathered during the input into sensory elements. By turning the identity events into sensory elements, these can be provided to the person living with dementia and they will actually respond to it.

Making the Person living with Dementia to feel **at ease** *by giving them the ability to* **reconnect** *with their* **identity** *and* **interests**



Input

Exploring identity events with a tool

Output

Stimulating PlwD with sensory elements based on identity events in an **interactive** and **playful** way

Internally

Turning identity events /interests into **sensory elements**

Figure 21, Concept direction.

While working out this concept direction, some preliminary requirements occurred:

- The Internal part is an updatable service from Active Cues
- The moment of implementation: signing in to nursing home
- The product is sold to nursing homes, not necessarily to individuals
- There is one product with several profiles for each resident
- The product is used in the bedroom, but not necessarily alone
- The product should be movable from room to room
- The product doesn't use static images: it should be dynamic

Research Questions

To understand what is needed for each part of the concept direction, research questions were set-up. Each part has its own set of research questions. The questions are also divided in where the information would come from; the brainstorm session with designers or from an informative call with a professional caregiver. Other research questions would be looked into during the ideation.

Part 1: Exploring identity

- What is part of someone's identity? (Brainstorm)
- How can you discover someone's identity? (Brainstorm)
- How can you grasp what is most relevant (events)?
- What do nursing homes already do to get to know their residents? (Caregiver)
- What do nursing homes already know about their resident? (Caregiver)

Part 2: Turning identity into sensory elements

- What can sensory elements look like? (Brainstorm)
- How can sensory elements represent an identity event?
- How can you make sensory stimulation easily adjustable to a personal profile?

Part 3: Making sensory elements playful and interactive

- How can you turn sensory elements into something interactive? (Brainstorm)
- How can you make sensory stimulation playful? (Brainstorm)
- How can you provide sensory stimulation interactive between multiple people? (Brainstorm)
- How can you make the interaction interesting for a single user, but also for multiple users?

5.2 Informative call Caregiver

In order to gather more information for the research questions stated, an informative call with a professional caregiver was made. The questions asked during the call are stated below, together with a short summary from the information that was provided.

- *When a resident applies to the nursing home, what would be the steps that you take?*

The resident gets assigned an individual caregiver that takes care of the introduction of the resident. That caregiver has a meeting with the resident and in most cases with the informal caregiver. During the meeting the caregiver shares information.

- *How do you get to know a new resident?*

This is purely dependent on the motivations of the assigned caregiver. The nursing home does not have a clear structure that the caretaker has to follow. Some caregivers do not take any initiative to get to know the resident besides their name and age. Luckily some caregivers do take initiative to get to know more about the resident's background.

- *How do you get to know certain preferences and the background of a resident?*

A lot of the times this information about the resident is gained over time. During the resident's stay at the nursing home, the caregivers get to know more while encountering special moments with the resident.

- *I assume that you have a file for every resident. What is stated in the file about a resident?*

First the nursing home had information documented on paper, but since a while they document everything online. In the beginning only some basic information is included in the file, like on a passport. During the resident's stay, more in-depth information is added to the file. Unfortunately that information is mixed with the general information caregivers need to document for each day, so the in-depth information gained over time mostly gets lost.

When the files converted to an online environment, the informal caregiver also gained access to the file. This way the informal caregiver can be easily updated on the conditions of the resident. However the professional caregivers need to be very careful with not only what they put in the file, but also how they phrase it. The caregiver mentioned that she does not think the file reaches its full potential with making it accessible for the informal caregiver.

5.3 Brainstorm Session

To get initial ideas on what each part of the overall concept could be like and to get answers to the previous set of research questions, a creative brainstorm session was done with other designers.

The Set-up of the brainstorm session and all results can be found in appendix C1. The main results that were taken from the brainstorm session into the ideation were on what is part of someone's identity. The results showed that especially the roots of someone are very important to their identity. And the fact that preferences are also part of someone's identity came forward.

To discover someone's identity interviews turned out to work the best. It is a bit straightforward, but the best way to get to know people's stories. This could of course be supported with other methods like sensitizing materials.

The results also showed that experiencing moments together is a good way to get to know someone. This could not be done with an interview, but other people connected to the person living with dementia that experienced moments with them could play a very important role in discovering their identity.

The results on the other parts of the brainstorm session were unfortunately not extensive enough to be of value to the project. The results however can be found in appendix C2.

5.4 List of Requirements & Wishes

From all the information previously gained during the research of this project a list of requirements and wishes was made. The list states the import characteristics that the concept must meet in order to be successful. The list describes concretely all the intentions of the concept and can be used later in the project to eliminate ideas that do not meet the requirements or to select the most promising ideas. The list of requirements has been updated along further development of the concept.

Performance

- The product uses the techniques from Active Cues
- The product uses reminiscence to reconnect people with their identity
- The product provides a multisensory experience
- The product can be used solo, but also with multiple users
- The product can switch between several profiles
- The product has profiles for each specific resident
- The product uses visual and audio stimulation based on the techniques of Active Cues

Environment

- The product is used within nursing home environment
- The product can be used in a resident's personal room
- The product is movable from room to room

Interaction

- The product provides triggers to stimulate interaction
- The product only provides positive feedback
- The product can be used by people in the last stage of dementia
- The product is usable with gross motor skills

Safety

- The product is safe to use in a bed
- The product is safe to use with gross motor skills
- The product does not have any loose parts

Installation and initiation of use

- Installation can be done by a (informal) caregiver
- The product itself does the initiation of use

Ergonomics

- Operating the product from bed is comfortable
- The cognitive ergonomics of the product are understandable for people in the last stage of dementia

Maintenance

- Cleaning the product can be done daily within 10 minutes
- All parts that need to be touched of the product can be washed or hygienically cleaned
- Updating the profiles is a service done by Active Cues

Wishes

- The product fits with the brand identity of Active Cues
- The product uses a combination of visual, audio and tactile stimulation
- The product has a physical and a digital element
- The product is intuitive to use for people in the last stage of dementia
- The product allows for a good representation of their personal memories
- The product feels very personal to the user
- The product can be used in bed while sitting, but also when lying down

5.5 Ideation

Ideas Input

The input should be a tool that provides the person living with dementia to explore their identity. From the information gained from the caregiver and during the brainstorm session, the idea of conducting a playful interview occurred quite early. Additional to the interview the person living with dementia could perform some assignments, like sensitizing material.

As for what kind of input would be gained with the interview, that is of course very dependent on what is needed for the output of the concept. On the other hand, the output can also be designed from the input that can be obtained. From the brainstorm session it became very clear that someone's background is very important to his or her identity. The relevance of the background to the identity came also forward during a talk with professional life-story writer Melle Knulst. He writes life-stories for elderly and always puts emphasis on the background when writing someone' life-story.
So this should nonetheless be taken into account in the input. Just like their career path and general things that they like on all kinds of subjects could be valuable information for the caregiver to understand the resident.

Looking closer at the need to discover identity events that could be given to the person living with dementia in a later phase, the question on what event in their life they really enjoyed occurred. By reflecting on this question the meaning behind the event could be found.
However people living with dementia go back to their memories from their 15 to 25 years old, so while gaining the input there should be more focus on this time period. That is when the question had arisen to ask them to look back at when they were 15 to 25 years old and what they enjoyed to do at that age.

Besides asking these questions people could also deliver materials like pictures, movies, sound fragments, etc. The value of these materials is very dependent from the output.

Last there was the thought of not only involving the person living with dementia during the input, but also the informal caregiver, other family members or close friends. They could participate in the interview together at the same time. They could be inspired by each other and gain more meaningful information. Or they could be interviewed separately, so they will not influence the perspective of the person living with dementia.

The first version of the input was evaluated as described in appendix D. Unfortunately due to the measurements against Covid-19, there was no ability to properly evaluate the input. This will be discussed in the recommendations chapter.

Ideas Output

The output should be a product that stimulates the person living with dementia with sensory elements that are based on the identity events gained during the input, in an interactive and playful way.
Although people living with dementia experience an increasing loss of cognitive brain function, the sensory and emotional areas of the brain remain relatively untouched. Hence sensory experiences in everyday life can provide ongoing pleasure and cues for active responses contributing to the individual's wellbeing (Bowlby, 1993).
This could be achieved in two main ways; creating a database for all kinds of input scenarios that could be possible outcomes from the input, or the family could give materials like pictures, movies, sound fragments, etc.
Because the triggers provided to people living with dementia need to be very subtle, it would be best to reform the material into abstract elements that are still recognizable for the event, like colours and shapes. These abstract elements could be given to trigger the people living with dementia.

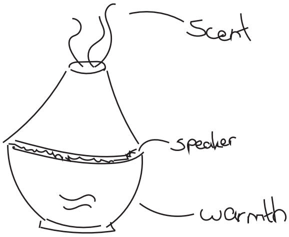
Figure 22 shows the first ideas for the output.
For all ideas there was searched for a way to integrate a tactile element to the interaction, since people living with dementia respond very well to touching tactile objects especially textiles. Applying textiles as a material to enhance spatial design can create a warm, comfortable and calm atmosphere reducing negative sensory stimuli (Jakob & Collier, 2017).

Figure 22 provides an overview of possible ideas for the output. The ideas should be seen as suggestions, because of course other outcomes or also possible. To assess the most valuable ideas, the list of requirements was addressed. First the ideas that did not fit completely within the set requirements were eliminated. Also the decision was made to focus on the techniques of Active Cues; using light projections and sounds. After this elimination only the ideas ‘path memories’, ‘digital/ physical photo album’ and ‘tactile memories’ were left.
Looking also at the wishes, the idea ‘path memories’ did not allow for personalisation on the tactile element. Eventually only the ideas ‘digital/ physical photo album’ and ‘tactile memories’ turned out to be suitable ideas for the aim of the project.

The first version of the output was evaluated as described in appendix E. Unfortunately due to the measurements against Covid-19, there was no ability to properly evaluate the second version of the input. This will be discussed in the recommendations chapter.

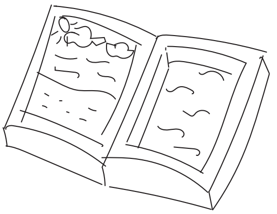
“Aroma hugger”

A heated aroma diffuser that produces different scents and produces background noice (like nature sounds). The scent and sound gets stronger when hugging it.



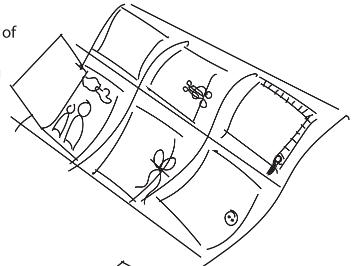
“Digital/physical photoalbum”

Photoalbum with on one side a projection of a picture or movie and on the other side a sensory pouch filled with an object related to the picture.



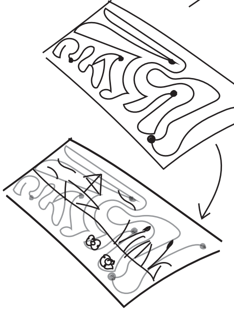
“Sensory blanket”

A quilt blanket with all kinds of fabric boxer that can be opened. Behing the opening there is a picture. The boxes can be opened with: Buttons, ribbons, zippers, pressure button, hook, velcrow, etc..



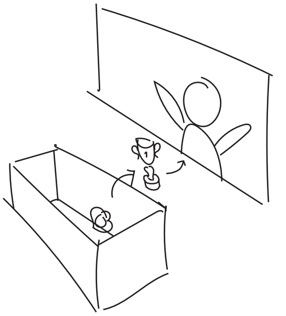
“Path Memories”

A brain path board that can be places on the lap. While tracing the path with the finger, certrain trigger points are allong the path. When a trigger point is touched, a memory is projected onto the board.



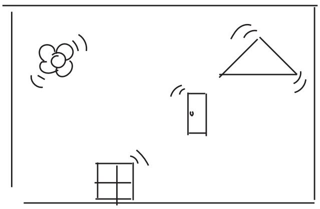
“Memory Box”

A box filled with all kinds of items from their past. When an item is pulled out of the box a visual connected to that item is shown.



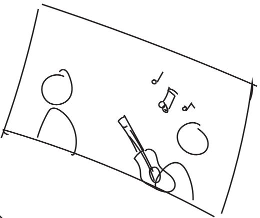
“Digital old puzzleboard”

Elements of an old picture float around. Picture is very vague in the background. Person can place the elements in the right place. However picture increases to get sharper and elements go to the right spot.



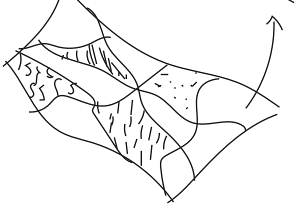
“Tactile Memories”

A sensory blanket with different textures is placed on the lap. When a certain area is touched, a visual is shown that is connected to that tactile stimulation.

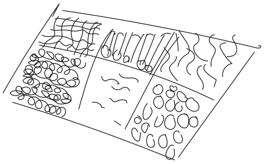


“Texture Matching Game”

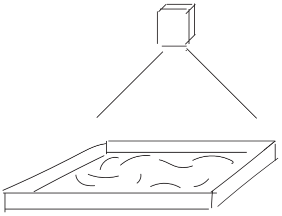
An image/ visual is projected and the resident needs to connect the visual with the right texture on the sensory blanket.



Board will different kindes of textures to touch



Case with water, sand or other shape changing substance like gel closed off. People can touch and shape the material how they like. A projection is placed on top of the shape and transforms to the shape.



“Digital painting”

image of a photo appears when you go over it with your hand. like painting.

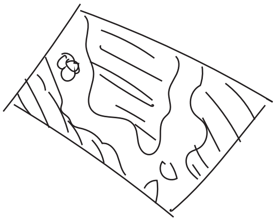


Figure 22, First output ideas.

5.6 Scenario

In order to illustrate all the different elements of the concept, a scenario was created, see figure 23. The scenario shows the different moments where the concept takes place, the various users that are involved during those moments and what their role is and mostly the scenario shows the emotional effect that the concept has on the users.

First we see the main character Leny who lives with dementia. Her daughter took care of her as her informal caregiver. Unfortunately Leny's symptoms have progressed and she needs day-to-day care. So Leny and her daughter decided that she is going to move to a nursing home where she can get the care she needs.
During the first conversation at the nursing home, her assigned personal mentor tells her about a special program the nursing home applies. The program is from a company called Active Cues and it will provide her with positive moments when her dementia progresses. Leny and her daughter are very enthusiastic about the program and they agree to participate.

Together with Leny's personal mentor, Leny and her daughter have an interview that is supported by assignments. The assignments help Leny to discover her identity and, most importanty, the events she enjoyed a lot. In order to understand those events on a deeper level, the assignments help Leny to describe the events on the senses.
Back at home Leny and her daughter search for items related to the discovered activities. Items such as photos, (short) movies, sounds, music or physical objects.
With all the information gained Active Cues makes a profile for Leny, which provides a clear overview of who Leny is and what her preferences are, but mainly it captures her most meaningful events.

A few years later and the dementia of Leny has progressed even further. She is now in the last phase of dementia where she is declined to her bed. The dementia has caused her to live in her own 'inner past world', like explained in figure 14, where she doesn't understand the world around her anymore. Often she is alone and feels very anxious.

Luckily for Leny the product of Active Cues is there. Either the professional caregiver can turn it on during the daily care or her daughter can put it on during her visit.
When the product is turned on, a preferred event can be chosen and the product will create a multi sensory experience around this event. The experience is created by a physical element providing tactile stimulation and could also provide olfactory stimulation and there is a digital element providing visual stimulation and auditory stimulation.

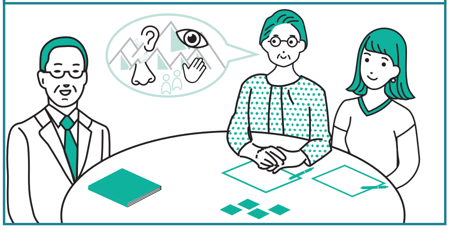
The sensory stimulation activates Leny and helps her to be able to connect and communicate again with the people around her, see figure 15, on the event that she used to love so much. The experience makes her anxiety disappear and she is able to feel calm and at ease again.

This is Leny, she lives with dementia and loves to drink eggnog.

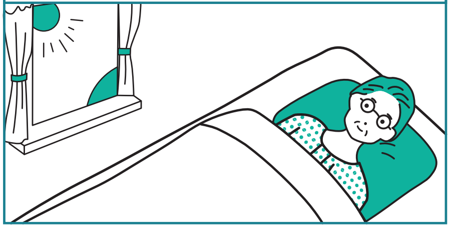
For the past 3 years her daughter took care of her, but now she is moving into a care home.

They discover that she really loved walking through the mountains while on holiday.

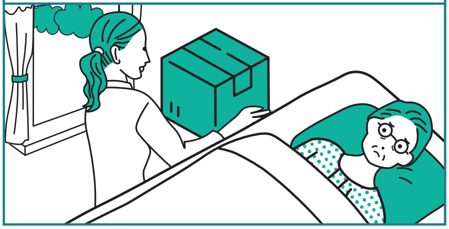
The exersices help Leny to describe the activity thoroughly on the senses.



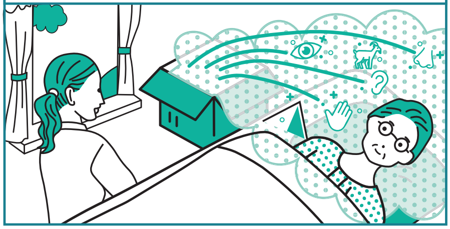
A few years later, the dementia of Leny progresses and she gets into last stage dementia.



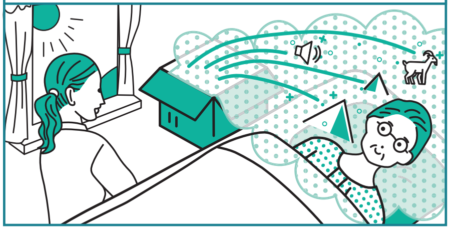
The caretaker places the product of Active Cues in Leny's room and turns it on.



The product provides personalised sensory stimulation based on the explored activity.



Leny experiences walking through the mountains again.



Leny feels calm and at ease.

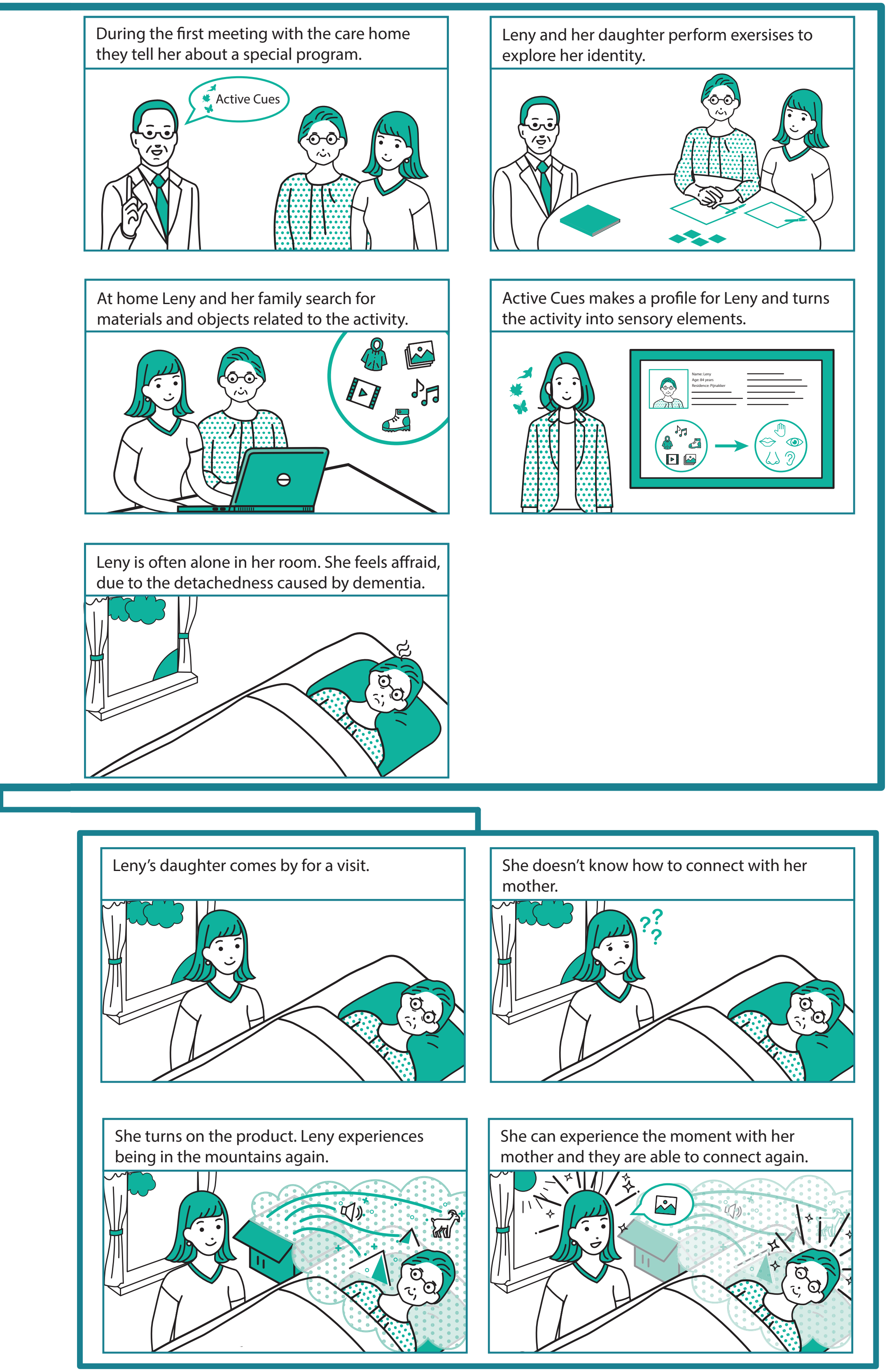


Figure 23, Scenario.

5.7 Conclusion

This chapter showed and explained all steps taken from the design goal to initial ideas of the concept and concluded with a scenario of the entire concept. With research through caregivers and designers, information was gained that shaped the concept.

The overall concept consists of an input where the identity of the person living with dementia is explored. This input will be implemented when the person living with dementia requests residency to the nursing home. This will be done by an interview with sensitizing-like assignments. The assignments will focus on the background of the person living with dementia, the general preferences and will go more in depth on memorable events from when they were 15 to 25 years old.

The memorable events will be transformed into sensory elements. Those sensory elements will be the output part of the concept. The output will be presented to the person living with dementia during their stay at the nursing home, especially in the last phase.

The output shall consist of a physical element to stimulate the tactile and olfactory senses and to give a personal touch to the output, and a digital element like the Tovertafel provides to stimulate the visual and auditory senses.

Iteration

This chapter is about validating the scenario presented in the previous chapter together with people that have experience with people living with last stage dementia.

During the time that this project took place unfortunately there was no opportunity to visit nursing homes due to the Covid-19 pandemic. Working closely with the people in this environment is crucial when designing the input and the output of the concept in an effective manner.

Therefore it was decided to validate the probability of the concept being realistic through the scenario. The scenario illustrates the different steps of the concept, the people involved and the effect on the person living with dementia and is therefore the best representation of the concept to use during the concept validation.

6

6.1 Evaluation Scenario

Research Aim

The aim of this research is to validate the scenario of the concept. The scenario is validated on two subjects: the clarity of the scenario itself and the feasibility of the scenario within the context.

The research was led by the following research questions:

Scenario clarity
- Does the scenario clearly communicate the potential of the concept?
- Are their any un-clarities within the scenario?

Concept feasibility
- Is the desired scenario realistic within the context?
- Are their any insecurities within the concept?

Method and Set-up

In order to answer the research questions, semi-structured interviews with professional caregivers that have experience with last stage dementia were done. A total of 5 participants participated in the study. See appendix F1 for an overview of the participants.

Prior to the interviews, the participants received the scenario as shown in figure 23 and some additional information about the research. The additional information can be found in appendix F2.
By receiving the scenario prior to the interviews, the participants were able to review the scenario at their own pace, without any pressure from the interviewee.
The participants also received a consent form (appendix F3) for their participation in the study.

A complete transcript of the interview itself is presented in appendix F4. There were some questions set to provide information on the clarity of the scenario and feasibility of the scenario, but further the interview was open and anything that came to the table was discussed. This approach resulted in an extensive set of results.

Results

Scenario Clarity

The scenario turned out to be very clear during the validation. The various steps of the scenario are clearly stated and the effect is noticeable as well. The scenario is also very recognizable for people that have experiences with people in the last stage of dementia, because it shows what they experience in practise. They notice that it is difficult to connect and the scenario describes the problem very well.

The only thing that is not very clear in the scenario is the output itself. What exactly comes out of the 'box' or what it does on a concrete level was not obvious from the scenario.
Of course the output of the scenario was kept a bit ambiguous on purpose, but it should be clear what kind of stimuli the output could give.

Concept feasibility

As far as the feasibility of the scenario goes, it sounds very promising according to the addressed experts. The scenario is especially promising because the connection with people living with dementia is made by using sensory stimulation. In the last stage of dementia this is the only way to 'speak' to these people.
That is also why the concept is very promising to be helpful for either professional caregivers as informal caregivers. It could provide a clear and easy way for them to connect with people living with dementia.

Although people living with dementia would respond to the concept, the responses will be minimal and for a short term only. This is due to the fact that people in the last stage of dementia are not capable of focusing for a long period of time. However it is believed that the concept will provide a long-term improvement of their quality of life, just like the Tovertafel does. The Tovertafel provides a short term positive moment, but the research of Bruil (2018) showed that the positive effects on their quality of life is long term.

The only downfall in the scenario that the experts mentioned was the moment of identifying the special moments. This moment is set when people living with dementia assign to a nursing home. At this moment their dementia has already progressed for a while and some memories might be already lost. So the effectiveness of gaining the identity information at that point is debatable and could be argued too be too late. Of course an informal caregiver can help with gaining those memories, but it would be preferred to have the input session of the concept at an earlier moment in the journey. The moment of the diagnosis would be ideal.

Other point of attention
During the validation of the scenario, also other points came across that were worth mentioning. One of those points was, that an expert mentioned that the output of the concept could be partly generalised with the help of a database, but that there still needs to be room for real personalisation of a specific individual. Real personalisation could be in the shape of their own images of their old home or the specific park they loved to walk.

It was also mentioned that the concept should provide the possibility to bring back more than just one special event. So not only during the input there should be a focus on gaining several events, but also the output should allow for showing multiple events where either the caregiver or the person living with dementia themselves could choose between.

Another thing mentioned was that with people living with dementia you always need another person to activate the device and also another person that needs to keep an eye on the person living with dementia. They need to guard the stimulants, for when they become too much for someone. So a person living with dementia could never use the product completely solo.

The final thing that came forward during the validation was that people of an older generation are not used to talk about their feelings. This could be an issue during the exploration of the identity. However the input is luckily designed in a

way that it asks the person living with dementia to describe the positive events in a concrete way on the senses. Their feelings are not necessarily taken into account, only if they are open to mention those as well. But the main source of information is the description of the senses. Hopefully this fact will not be of any issue for the concept.
A complete overview of the results can be found in appendix F5

6.2 Multi Sensory Environment

Since the output is still too ambiguous, it was explored a bit further. Inspiration for what the output could look like came from looking into Multi Sensory Environments (MSE). The MSE – sometimes also referred to as "Sensory Room" or "Snoezelen" – is a designated space that aims to provide an enabling, stress-free, positive environment offering sensory enriched experiences and activities – either for stimulation or helping to relax to enhance feelings of comfort and wellbeing and to maximize a person's potential to focus. It addresses the senses of vision, touch, hearing, smell, taste, and movement with limited or no need for higher cognitive processing (Jakob & Collier, 2017).
The MSE should create opportunities for exploring and engaging in/wit appropriate and meaningful activities/objects giving the person a sense of purpose (Jakob & Collier, 2017).

As shown in figure 24, multi sensory environments are truly a space on its own. They provide soft furniture to sit on in a relaxed position. The room itself is quite dark, which makes the visual elements that are mostly sparkly to stand out. They use projections, reflections and moving objects like lava lamps and columns with air bubbles. The space could also provide different textures that the visitors can touch and feel. All the different elements of the room make it multi sensory.

The potential of the multi sensory environment is great, but the different elements of the room are not tied in with each other very well. Besides it is an additional room in the nursing home that people have to go to. When the mobility has decreased, this would not be preferred. Bringing the possibilities of the multi sensory environment all together into one product and into someone's private room is a great opportunity. Also this opportunity is in line with the vision for the output of the concept presented in this project.

To make the envisioned output more concrete, the product consists of a physical element with a digital element. The physical element will provide tactile and olfactory stimulation by using different textures and scents. The digital element will provide visual and auditory stimulation by using light projections and sounds, like the Tovertafel. All stimulations will be connected and will be focused around the event. It is very important is that the stimuli are dynamical and not static.

Figure 24, Examples of MSE.

Final Concept

The information gained during the validation of the scenario is concluded within an overview of the entire concept. This overview describes the concept on a deeper level and clarifies any insecurities mentioned previously.
To conclude, the effect of the concept is presented by projecting the desired journey map over the current journey map.

7

7.1 Concept Overview

The concept overview of figure 25 shows all components of the concept. Where figure 21 showed the three different parts of the concept direction, the concept overview also shows substantive information of the different parts.

For the input, the figure shows the method that is used to gain the information and the kind of information that is gained; a playful interview with assignments. This interview is done together with a family member that knows a lot about the person living with dementia. The interview starts with the generic questions about the subjects of the person's background, the people around them, their education and career path and general things they like for all kinds of categories. This is followed by events that are special to someone. Starting with an age range from 15 to 25 years, since those memories last the longest, and later going into events from their entire life. All events mentioned are explored on the senses; what they see, what they hear, what they feel and what they smell. Besides the senses, there are also questions that focus on understanding why that event is so special and what makes it positive.

For the internal part of the concept, the figure shows the different ways Active Cues van use the gained information and implemented it into creating a personalised output. The decision was made to use a pre-made database by Active Cues of all kinds of events. When an event of the database matches with an event described during the input phase, this event will be set in the output. The decision for a database was made, due to the fact that it requires too much effort to design completely new outputs for every individual.
However the research showed, that there still needs to be room within the concept to implement real personalisation. This can be in the shape of importing images or movies into the pre-made database event or using an object that is owned by the person in question.

The figure clearly shows that the output consists of a physical element with digital elements in it and their focus on the senses like described in the previous chapter. The figure also shows two images that represent examples of how the multi sensory environment could be turned into a multi sensory experiences

Input **Exploring** identity events +

- **Playful interview with assignments**
- **Starting with generic questions**
  - Background
  - People around them
  - Education & Career
  - General Likes
- **Most positive Activity from when 15 - 25 years**
  - Explore activity on senses
  - Understand importance
- **Most positive Activity outside age range**

Internally Turn identity into **sensory elements**

Active Cues Database

- Database of multi sensory experiences on all kinds of activities: Selection of experiences related to discovered activity

Family Materials

- Images, movies or objects related to discovered activity are collected

Materials from family are placed within preset experience of Active Cues

Output **Personalised** Multi Sensory Environment

Physical Element with **Digital Elements**

- Tactile
- Olfactory
- Visual
- Auditory

Figure 25, Concept overview.

within the environment of someone's personal room. The two images show that, although it has the same product, it can create different environments. The images also show the different type of people that can be involved during the experience.

The left image shows a very calm and peacefully environment, where the moment is shared with a professional caregiver. The right images shows a playful and bright environment, where the moment is shared with a family member.

7.2 Desired Journey Map

The desired journey map of figure 26 is based upon the stakeholder journey map presented earlier in figure 10. The input and output parts of the scenario are placed within the timeline of the journey map. This presents a good overview of the different points of action within the dementia trajectory.

For the input there are two points on where the input could take place. These points depend on the business model Active Cues will approach when launching the eventual product. When the product is sold to individuals, the ideal moment to implement the input would be when the person living with dementia receives their diagnosis. When the product is sold to nursing homes, the ideal moment to implement the input would be when the person living with dementia is moving into the nursing home.

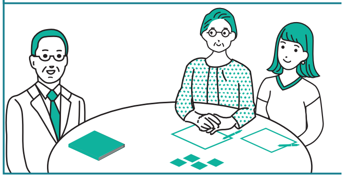
The output is placed in the timeline in the “day in the life” category after the mobility is reduced. Within the category the most forward moments to use the concept would be during an activity, but the concept could also be used during family visits or other open moments during the day to provide positive moments to the person living with dementia.

The desired journey map also shows the effects of the concept on the emotion curve. The new curve is projected upon the current curve. The current curve is made transparrent, so a comparison between the two could be made. The positive effect of the concept is already visible when the input takes place. Discovering their identity can help people living with dementia to better understand themselves. It also gives them the feeling that people are giving attention to their personal needs. Especially when assigning to the nursing home this effect is visible. The positive effect is also shown during family visits, but mostly in the later stage.

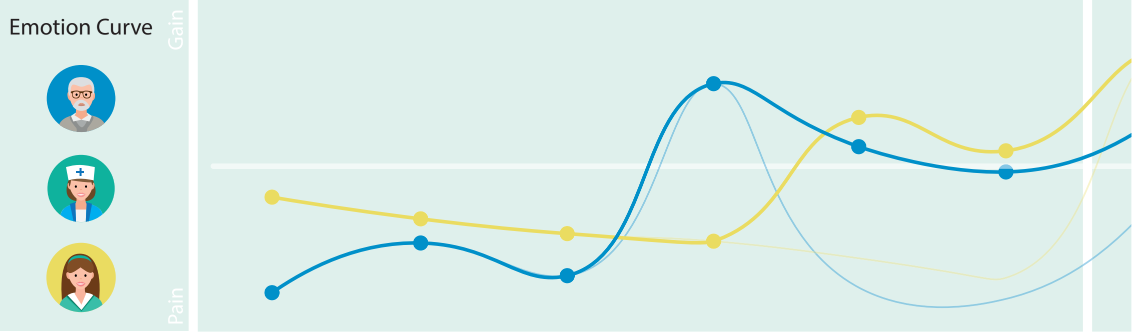
The positive effect is not only visible during the activity moment, but also in the moments after the activity took place. The positive moment caused by the concept may be short, but the effect continues during the rest of the day. Not only the person living with dementia has a better quality of life, but this also makes it easier for the professional caregiver to provide good care in a safe way.

Figure 26, Desired journey map

Leny and her daughter perform exersises to explore her identity.

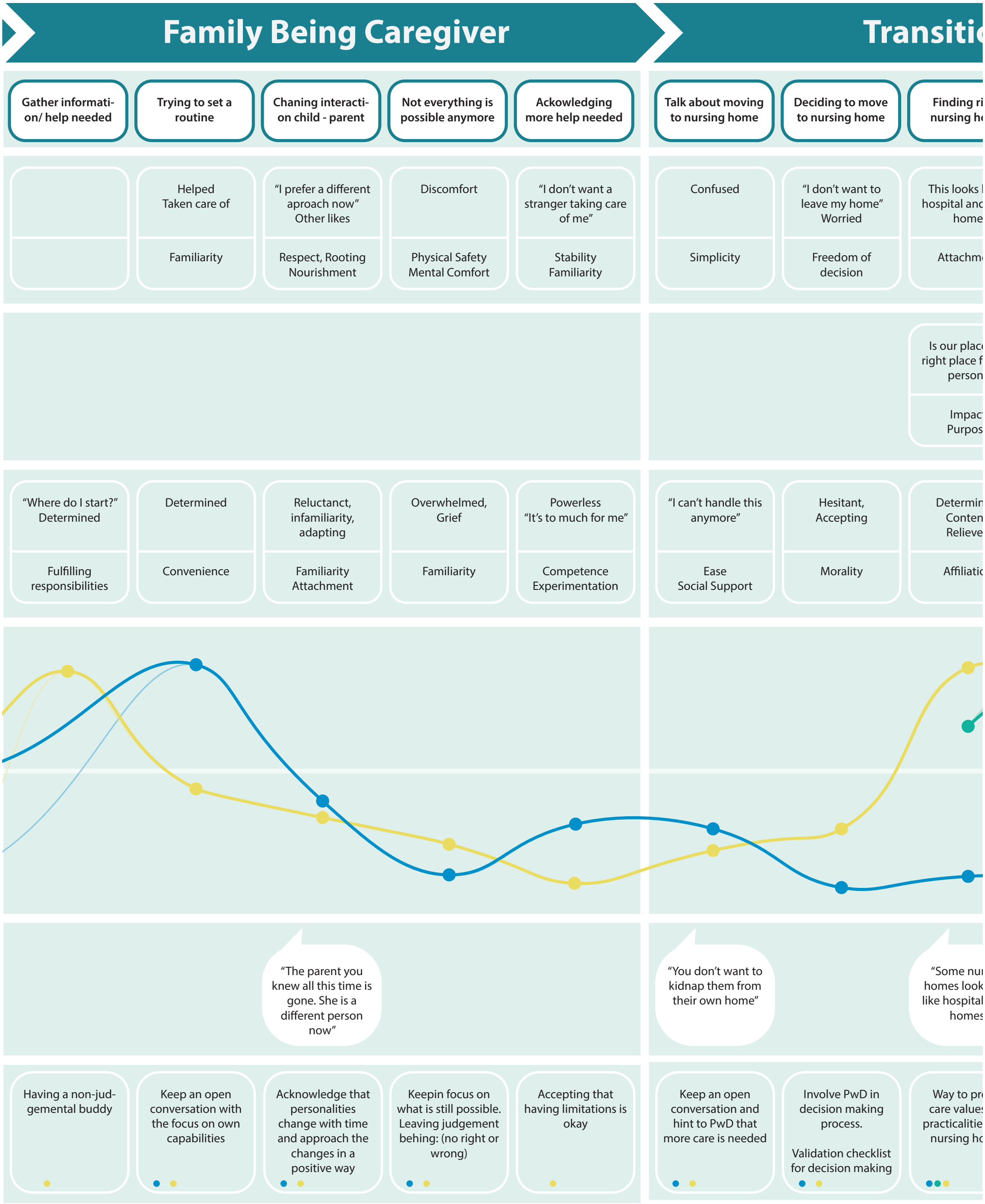


Journey	Getting Diagnosed						
Activities	**Noticing Dementia Symptomes**	**Talk about possible dementia**	**Go to the Doctor**	**Perform a Test**	**Receive the Results**	**Accepting living with dementia**	**Ga on**
 Thoughts	“Is there something wrong with me?”	“Am i getting this right?” Confused	Nervous “Is this really necessary?”	“That was quite easy.” Doubting	Vulnerable	“This is my life now.”	
Needs	Security	Familiarity	Physical Safety	Simplicity	Tranquility	Purpose Simplicity	
 Thoughts							
Needs							
 Thoughts	‘I hope it’s not dementia” Uncertain	Hesitant/ affraid to talk about it	Insecure, but determined	Impatient, Eager, Doubt	Powerles, Vulnerable, Confirmed	Overwhelmed, Sad, Accepting	“W
Needs	Security	Ease	Impact	Stability	Emotional Support	Tranquility Stability	re



Quote’s			“You contantly doubt if you have it wrong” (about dementia)			“The transition from no dementia to dementia is the hardest part”	
Opportunities	Crash course about dementia	Ability to talk with others about experiences. DIY Test on dementia		Information on how life looks like with dementia	Step by step doctors visit quide with reminder to ask questions. Information on how to get support	Highlighting positive sides/ Support Group	Ha ge

Best moment of implementing input, when product is sold to **individuals.**

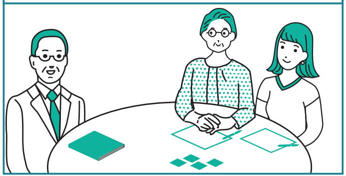


Family Being Caregiver					Transiti		
Gather information/ help needed	**Trying to set a routine**	**Chaning interaction child - parent**	**Not everything is possible anymore**	**Ackowledging more help needed**	**Talk about moving to nursing home**	**Deciding to move to nursing home**	**Finding ri nursing h**
	Helped Taken care of	"I prefer a different aproach now" Other likes	Discomfort	"I don't want a stranger taking care of me"	Confused	"I don't want to leave my home" Worried	This looks l hospital anc home
	Familiarity	Respect, Rooting Nourishment	Physical Safety Mental Comfort	Stability Familiarity	Simplicity	Freedom of decision	Attachm
							Is our plac right place f person
							Impac Purpos
"Where do I start?" Determined	Determined	Reluctant, infamiliarity, adapting	Overwhelmed, Grief	Powerless "It's to much for me"	"I can't handle this anymore"	Hesitant, Accepting	Determin Conten Relieve
Fulfilling responsibilities	Convenience	Familiarity Attachment	Familiarity	Competence Experimentation	Ease Social Support	Morality	Affiliati

		"The parent you knew all this time is gone. She is a different person now"			"You don't want to kidnap them from their own home"		"Some nu homes look like hospital homes
Having a non-judgemental buddy ●	Keep an open conversation with the focus on own capabilities ● ●	Acknowledge that personalities change with time and approach the changes in a positive way ● ●	Keepin focus on what is still possible. Leaving judgement behing: (no right or wrong) ● ●	Accepting that having limitations is okay ●	Keep an open conversation and hint to PwD that more care is needed ● ●	Involve PwD in decision making process. Validation checklist for decision making ● ●	Way to pr care value practicalitie nursing hc ● ● ●

Best moment of
implementing input,
when product is sold to
Nursing homes.

Leny and her daughter perform exersises to explore her identity.



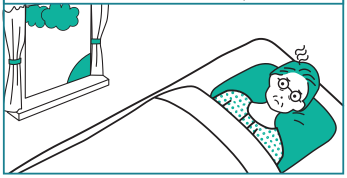
nsition to Nurse Care

At Nurse Care

Finding right nursing home	Moving into nursing home	Inform nurse on PlwD preferences	Getting used to new situation	Daily Health Care	Doing physical activities	Playing games	Family visits
This looks like a hospital and not a home	“Moving might be unnecessary? I don’t understand it.”	“I hope this stranger will listen to my whishes.”	“This doesn’t feel like my home.”	“I habe good and bad days like everyone.”	Free Joyful	Aroused Playful	“Most of the t this makes n shine.”
Attachment	Familiarity Social Support	Attention	Familiarity Social Support	Stimulation Familiarity	Bodily sensations	Creative Expression	Valued Intimate
Is our place the right place for this person?	Curious	Inspired	Anticipating to resident’s needs	Trying to do everything at the same time	Making residents feel at ease	“How can I stimulate the residents?”	
Impact Purpose	Purpose	Stimulation	Ease Competence	Order Convenienve	Acknowledgement	Impact	
Determined, Content, Relieved	Upset, Remorseful, Relieved	Determined “As a child you need to be on-top of it”	Supported, Guilt, “Did I do the right thing?”			Creative, Loving, Judgmental, “To childish”	Loving, Sensit Intimate
Affiliation	Emotional Support	Attention	Emotional support Morality			Intimacy	Intimacy Rooting

Finding right nursing home	Moving into nursing home	Inform nurse on PlwD preferences	Getting used to new situation	Daily Health Care	Doing physical activities	Playing games	Family visits
“Some nursing homes look more like hospitals then homes”		“I need to constantly remind the care staff how she likes her coffee”			“You try to stimulate them”	“They become ”Childs”, but don’t approach them childisch”	“You try to ma them feel at e because they very restles
Way to present care values and practicalities from nursing homes ●●●	Provide communication options for personal preferences ● ●	Provide ways for PwD to express their wishes and for FM way to visualize them to communicate to CG ●●●	Visualization for CG to be reminded of resident’s needs to give resident more recognition at common areas ●●●		Taking into account personal preferences ●	Taking into account personal preferences during games. Provide interaction options ●●●	Provide FM w handles to communicat Stimulate sens trigger interact communicati ● ●

Leny is often alone in her room. She feels affraid, due to the detachedness caused by dementia.



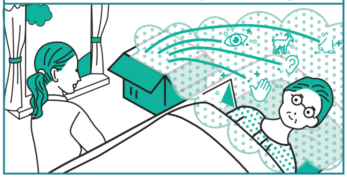
Reduced Mobility

Day

	Losing mobility: Difficult to move	Finding alternatives	Adjusting to bed or wheelchair	Waking Up	Getting dressed	Eating breakfast	Taking medicine
ime ne	“Ouch” Physical pain Physical Safety	“What is going on?” Physical Safety	“This is not so bad” Individuality	Calm Physical Comfort Purpose	Confused “I can do this myself” Offended Autonomy	“Hmm lekker” “I want it my way” Nourishment	Confused Hesitant Simplicity
	“The resident must be in pain/ Frigtenend” Nurturing	Find solutions for mobility Contribution. Influence	“Is this a good solution?” Doubt, optimistic Achievement Appreciation	“How am I going to get everyone out of bed?” Overwhelmd Ease Order	“Will the resident not be aggressive?” Physical Safety	Knowing preferences of all residents. I’m not alone Appreciation Convenience	Requires focus. No distractions from residents Structure Overview
ive,	Stressed, Worried Moral Awarenes Convenience	Determined Tranquility Preservation	“This is the best option, but I want him to stay mobile.” Preservation Familiarity				

ake ase, are s”		“You try to give them some sort of freedom where possible”		“Doing it all at once is very hard”	“When they get aggressive I need to protect myself”	“Everyone likes it their own way”	
ith . te: es to tion/ on	Accepting physical limitations. Keep focus on what is still possible. ●●●	Overview of alternatives: Pro’s and con’s on resident and nuring house level ●●●	Clear validation moment. Seeing the aid alternative as an extension of themselves . ●●●	Provide PwD with reminder of something to look forward to ●	Collaboration approach between PwD and Caregiver” “Help me help you” ●●	Visualization of PwD’s preferences and capabilities. Way to expres their wishes ●●	

The product provides personalised sensory stimulation based on the explored activity.

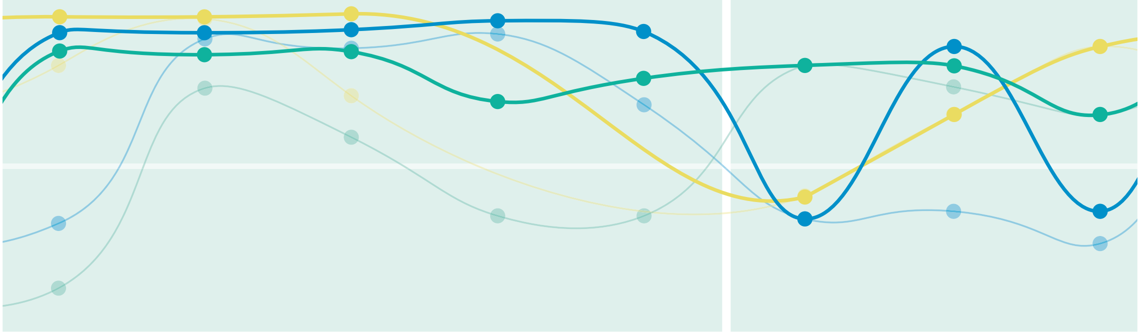


Leny feels calm and at ease.

in the Life

Final D

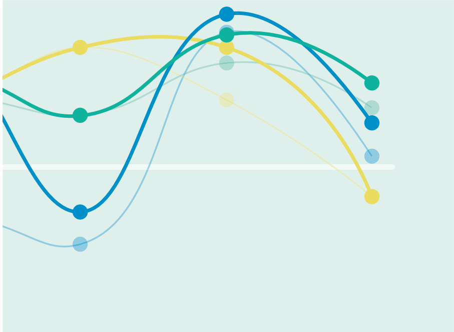
Doing an activity	Eating lunch	Doing an activity	Eating dinner	Going to bed	Lying in bed as comfortable as can	Long lonely days	Losing appetite
Curious Do something I used to do	“Hmm tastes good”	Curious Inquisitive	“This tastes good” Peeling potatoes is familiar	“Sometimes it is painful when they help me move.”	Vulnerable Tired Peaceful	Lonely Fragile	“Iii’m not hung
Novelty & Variety Fun	Nourishment	Competence, Fun Novelty & Variety	Fulfilling responsibilities Nourishment	individuality Physical Comfort	Physical Comfort Tranquility	Appreciation Intimacy, Support	Integrity, Respe their will
“How can I stimulate the residents?	Knowing preferences of all residents. I’m not alone	“What can the residents physically do?”	Focussing on multiple things. Luckily some help.	“Will the resident get aggressive?” Nervous	“How can we make the resident comfortable?”	Visit resident as often as possible	Do we force residents to ea How to stimula
Influence	Appreciation Convenience	Experimentation Contribution	Nurturing Ease	Security	Acknowledgement Experimentation	Impact	Nurturing
“They are enjoying themselves.” Thankful, inspired	“I brought a special treat for my parent, their favourite one.”	Thankful inspired			“What else can I do for my parent to feel comfortable?”	Grief “I need to comfort her”	“If she doesn’t w to eat, she does eat”
Seeing values in world. Beauty	Reminisence Intimacy	Seeing values in world. Beauty			Emotional Support	Impact	Morality



“We do activities they did in the past”	“Advocaatjes met slagroom eten leefde ze helemaal van op”				“We try different positions to let them lie as comfortable as possible”	“We come by their room a few times a day. Just feeling your company is important”	
Activities based on personal interests and adapted to capabilities. FM Provided with interaction options ●●●	Visualization of PwD’s preferences and capabilities. Way to expres their wishes ●●●	Activities based on personal interests and adapted to capabilities. FM Provided with interaction options ●●●	Visualization of PwD’s preferences and capabilities. ●	More user friendly bed-lifts for the PwD. Collaboration approach ●●	Reminder for changing positions Open mind for experimenting ●●	Way to interact with PwD for them to feel company ●●●	Showing that th will is respected accepted. Understandin values ●●●

Final Days

Losing appetite	**Family visits**	**Passing away**
“Iii’m not hungry” Integrity, Respect their will	“I feel when someone is with me” Relatedness Physical Safety	Peace Ease
Do we force residents to eat? How to stimulate? Nurturing	“Make sure not to many people are in the room” Security Overview	Supporting family Powerless Respect
“If she doesn’t want to eat, she doesn’t eat” Morality	“I’m here with you” Simplicity, Rooting, Spirituality	Grief Respect Emotional Support



“I wanted to preform a mantra to her, but was affraid the staff would find it weird. But I was there for my mother, so I just did it and it really calmed her down”

Showing that their will is respected and accepted. Understanding values ●●●	Guidelines for connection. ● ●	Stimulation to do what feels right how weird it may look. Stimulate PwD to feel at ease to go. ●●●

Conclusion

This chapter presents the conlusion of this project, consisting of the recommendations that need to be looked into when further developing the concept and its different elements and the project conclusion. The presented recommendations are discussed for each topic.

8

8.1 recommendations

Input and Output design

This project presented a concept with promising effects for people in the last stages of dementia. In order to achieve the desired effects, the input and output of the concept need to be designed on a tangible level. This project already presented a base for these designs, but these preliminary ideas need to be properly validated. During this validation there should be a close collaboration with the user context; people living with dementia, professional caregivers and informal caregivers, to make sure that these ideas deliver the envisioned effects. During the developments of the input and the output of the concept a rapid prototyping method would be recommended. With this method different kinds of prototypes could be tested, in order to find what works for the user group and what does not work.

For the design of the input it would be suggested to look into the kind of questions and the amount of questions that are suitable for people living with dementia. This is suggested because for the output of the concept, the right kind of information is necessary. It should be investigated which kind of information is obtained with those questions by people living with dementia.

For the design of the output it would be suggested to look into different types of sensory stimulation in the context of the personal living environment. As presented, MSEs are a good example. It should be investigated how people in the last stage of dementia respond to these stimulations. Also personalizing the stimulations should be looked into further: when is something recognizable as their own memory by someone in the last stage of dementia?

As mentioned earlier, the input and the output of the concept are very dependent from on each other. So the design process of these two elements should be done simultaneously.

Last phase dementia focus

When looking at the trajectory of people living with dementia, like presented in the desired journey map, it could be stated that when the input already takes place early in the trajectory, the output can be given earlier as well. In a way it is true that the output could be given to people in the early stage of dementia, but people in the last phase of dementia require different stimuli than people in the early stage of dementia. In order to provide the intended effect to people in the last stage of dementia, the development of the concept's output should focus mainly on designing it for people in the last stage of dementia. When this development has been completed, it could be further investigated if the design also appeals to early stage dementia. If research shows that people in the early stage of dementia also benefit from the design, the concept could also be used earlier.

To emphasize, the main focus of this project is people in the last stage of dementia, so the design should be optimized for the late stage first.

Kinds of sensory stimulation

The Tovertafel as it currently is, provides visual and auditory stimulation, which are great stimuli to activate people living with dementia. However, people have five different kinds of senses and with only focussing on two of them, there are three senses unused. Multi Sensory Environments proved that focussing on more senses offers great benefits to people living with dementia. Besides, every individual prefers different kinds of stimulation. That is why this project also looked into adding tactile stimulation to provide an even greater multi sensory stimulation than the Tovertafel does at the moment. Ideas were made as suggestions to implement tactile stimulation into the experience. Adding only tactile stimulation still leaves two senses unaddressed. Several professional caregivers talked about the importance of olfactory stimulation. They mentioned that scents are a powerful tool that is often underestimated. Designing olfactory stimulation might look difficult, which could be the reason why it has not been used yet within sensory stimulation environments. However, to provide a thorough multi sensory experience, it would be outstanding if there could be found a way to also incorporate olfactory stimulation into the final design. So it would be recommended when designing the output of the concept to not only look into adding tactile stimulation, but also olfactory stimulation to the current stimulations of the Tovertafel. Addressing these types of stimulations could provide a thorough multi sensory experience.

Business & Implementation plan

With the first thoughts of the concept direction, came the business plan of a product service system. Within that system the physical product would be sold to nursing homes and residents of the nursing home could get their own personal profile from a membership with a monthly payment. The membership would be the service along with the product, where the profile would be made and would be updated over time.

With this business plan in mind the moment of implementation for the input in the dementia trajectory, seemed obvious to be at the point of when people assign to a nursing home. Since Active Cues currently focuses on selling the Tovertafel to nursing homes, it appeared desirable to stay within their known market. Staying within the same market provides to maintain the current marketing techniques.

However as described in the desired journey map, the research showed that placing the input at the point of when people living with dementia assign to the nursing home, is quite late. At that point their dementia has already progressed to a state that they need day to day care. So it is very likely that some important memories are already lost. Some memories could still be retrieved by the proposed input method, but probably not all of them.

To be able to acquire as many memorable activities as possible, it would actually be ideal to implement the input around the time people are diagnosed. At this point there are still a lot of memories intact and there is a motivation for the person living with dementia to invest in a product like the proposed concept.

But as mentioned this would change the initial business plan into selling to individuals, rather than an entire nursing home. This new market could provide an even bigger benefit, since not only the service, but also the physical product would be sold to individuals. The possible benefits of both business plans should be calculated before making any decisions in which point of implementation should be preferred. In conclusion, further research should be conducted on which market sounds more promising or if another approach should be taken.

8.2 Project Conclusion

The aim of this thesis was to enable people in the last stage of dementia, that are confined to their bed or room, and the people around them with shared positive moments.

This project showed that due to dementia, people start to live in another 'inner past world.' It was discovered that this causes a lot of anxiety to people living with dementia. By bringing back their personal memories from the past, people living with dementia are able to get out of their "inner past world' and get back to the actual world. This causes them to feel at ease and happy. These personal memories are part of their identity, so focussing on their identity is very crucial in reducing their anxiety.
However, bringing back identity events is not easy for people living with dementia. In the last phase, people living with dementia are only able to communicate when their senses are activated. Stimulating their senses is essential for them to connect with their identity and thus to get that at ease and happy feeling.

Based upon these findings and the validation of the scenario, it could be concluded that the proposed concept is very promising. The focus of the concept on people's identity events and bringing those back to them, by stimulating their senses, sounds very effective to enable people in the last stage of dementia with shared positive moments.

During this project it was found that there is an increasing need from care staff to approach their residents as people with a life story and not as just every other patient. They feel the need for a more personal approach, but they do not have the ability or the recourses to make this happen.

The proposed concept could serve as a base to further develop, test and research the possibilities of personalised multi sensory stimulation within the private room environment.
There is already a lot of information about multi sensory stimulation within multi sensory environments. It would be a great challenge not only to bring

this experience into a smaller scale of a private room environment, but also to especially personalise this stimulation.
Although it sounds like a big challenge, the possibility and the demand are present.

This project showed some examples that could be realised, however further research is needed to elaborate on the proposed input and output of the concept.
Nursing homes and people living with dementia should be involved, to actually justify the concept in the context of the private room environment.
Although this project was not able to evaluate the outcome of the proposed concept, the project did show that the desired effects are promising.

References

This chapter presents all the references that were used within this project as supporting information.

9

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Appendices

The appendices include the following information:

A Project Brief
B Interview Set-up
C Brainstorm Session
D Evaluation Input
E Evaluation Output
F Evaluation Scenario

10

A Project Brief

DESIGN FOR our future

TU Delft

IDE Master Graduation

Project team, Procedural checks and personal Project brief

This document contains the agreements made between student and supervisory team about the student's IDE Master Graduation Project. This document can also include the involvement of an external organisation, however, it does not cover any legal employment relationship that the student and the client (might) agree upon. Next to that, this document facilitates the required procedural checks. In this document:

- The student defines the team, what he/she is going to do/deliver and how that will come about.
- SSC E&SA (Shared Service Center, Education & Student Affairs) reports on the student's registration and study progress.
- IDE's Board of Examiners confirms if the student is allowed to start the Graduation Project.

USE ADOBE ACROBAT READER TO OPEN, EDIT AND SAVE THIS DOCUMENT

Download again and reopen in case you tried other software, such as Preview (Mac) or a webbrowser.

STUDENT DATA & MASTER PROGRAMME

Save this form according the format "IDE Master Graduation Project Brief_familyname_firstname_studentnumber_dd-mm-yyyy".
Complete all blue parts of the form and include the approved Project Brief in your Graduation Report as Appendix 1 !

family name: Pak
initials: H.L. given name: Hannah
student number: 4283643
street & no.:
zipcode & city:
country:
phone:
email:

Your master programme (only select the options that apply to you):

IDE master(s): ○ IPD ○ DfI ○ SPD
2nd non-IDE master:
individual programme: - - (give date of approval)
honours programme: ○ Honours Programme Master
specialisation / annotation: ○ Medisign
○ Tech. in Sustainable Design
○ Entrepeneurship

SUPERVISORY TEAM **

Fill in the required data for the supervisory team members. Please check the instructions on the right !

** chair: Marieke Sonneveld dept. / section: ID/ AED
** mentor: Anna Ruiter dept. / section: ID/ AED
2nd mentor: Hester van Zuthem
organisation: Active Cues
city: Utrecht country: The Netherlands

comments (optional): Although both members of the supervisory team are from the same department, Marieke has expertise in research and Anna provides expertise on design.

Chair should request the IDE Board of Examiners for approval of a non-IDE mentor, including a motivation letter and c.v..

Second mentor only applies in case the assignment is hosted by an external organisation.

Ensure a heterogeneous team. In case you wish to include two team members from the same section, please explain why.

Procedural Checks - IDE Master Graduation

APPROVAL PROJECT BRIEF
To be filled in by the chair of the supervisory team.

chair Marieke Sonneveld date - - signature

CHECK STUDY PROGRESS
To be filled in by the SSC E&SA (Shared Service Center, Education & Student Affairs), after approval of the project brief by the Chair.
The study progress will be checked for a 2nd time just before the green light meeting.

Master electives no. of EC accumulated in total: ______ EC
Of which, taking the conditional requirements into account, can be part of the exam programme ______ EC
List of electives obtained before the third semester without approval of the BoE ______

○ YES all 1st year master courses passed
○ NO missing 1st year master courses are:

name ______ date - - signature ______

FORMAL APPROVAL GRADUATION PROJECT
To be filled in by the Board of Examiners of IDE TU Delft. Please check the supervisory team and study the parts of the brief marked **.
Next, please assess, (dis)approve and sign this Project Brief, by using the criteria below.

- Does the project fit within the (MSc)-programme of the student (taking into account, if described, the activities done next to the obligatory MSc specific courses)?
- Is the level of the project challenging enough for a MSc IDE graduating student?
- Is the project expected to be doable within 100 working days/20 weeks ?
- Does the composition of the supervisory team comply with the regulations and fit the assignment ?

Content: ○ APPROVED ○ NOT APPROVED
Procedure: ○ APPROVED ○ NOT APPROVED

comments

name ______ date - - signature ______

Initials & Name H.L. Pak Student number 4283643
Title of Project Enabling Positive Moments to People in the Last Stages of Dementia

Personal Project Brief - IDE Master Graduation

Enabling Positive Moments to People in the Last Stages of Dementia project title

Please state the title of your graduation project (above) and the start date and end date (below). Keep the title compact and simple. Do not use abbreviations. The remainder of this document allows you to define and clarify your graduation project.

start date 04 - 03 - 2020 08 - 09 - 2020 end date

INTRODUCTION **

Please describe, the context of your project, and address the main stakeholders (interests) within this context in a concise yet complete manner. Who are involved, what do they value and how do they currently operate within the given context? What are the main opportunities and limitations you are currently aware of (cultural- and social norms, resources (time, money,...), technology, ...).

Many people live with dementia; approximately 280.000 people in the Netherlands alone and this number increases each year. Dementia is a syndrome caused by brain disorders or brain disease, which causes people to no longer act independently. On average people live with dementia for 8 years. During these years the amount and seriousness of the conditions increases. There is no cure and people will eventually pass away while living with the disease [1].

Although there are so many people living with dementia, this user group is easily forgotten. Active Cues however is paying attention to people with dementia, because they believe that everyone has the right to play. They aim to create moments of happiness for people in residential care and education by investing in their quality of life. Improving health in general may prolong one's life, but people in the last stages of dementia typically experience severe deterioration in physical and cognitive functioning [2]. So instead of focusing on stretching out the last phase of their life, there should be more focus on improving the quality of their daily life and eventually increase their overall happiness.

In order to realize this, Active Cues develops games for specific target groups, like people living with dementia. Their first product; the Tovertafel Original (figure 1) was developed during the PhD research of Hester Le Riche. The Tovertafel Original is a playful care innovation that connects elderly people in the middle and late stages of dementia with each other and with their environment and stimulates movement [3].

The Global Deterioration Scale divided the severities of primary degenerative dementia conditions into 7 stages. Stages 1-3 are the pre-dementia stages and stages 4-7 are the dementia stages. Beginning in stage 5 an individual can no longer survive without assistance. With the progression of the last stage, stage 7, basic psychomotor skills like the ability of walking are lost and people are confined to their bed [4].

The Tovertafel stimulates people living with dementia with continuous triggers to initiate activation. This helps them to socialize and to reduce their apathy. However the Tovertafel focuses on the middle and late stages of dementia where people are still mobile.
In the later stage people living with dementia lose their mobility completely and are confined to their room or even their bed. At the moment this user group is still not being addressed, so Active Cues is looking for new opportunities to offer the same meaningful moments to people living with dementia in the last stage.

That is why in this project I will explore the emotional needs of people in last stages of dementia confined to their room or their bed, in order to find opportunities to improve their quality of life.
This project does not only focus on exploring the needs of the patients themselves, but also the needs of the informal caretakers, family and health professionals. All stakeholders will be involved throughout the project.
Within the found opportunities a playful experimental concept will be created that may not be used by the patient him/ her selves, but will eventually enable the patients to experience positive moment(s) with the ones around them.

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introduction (continued): space for images

image / figure 1: The Tovertafel Original in use

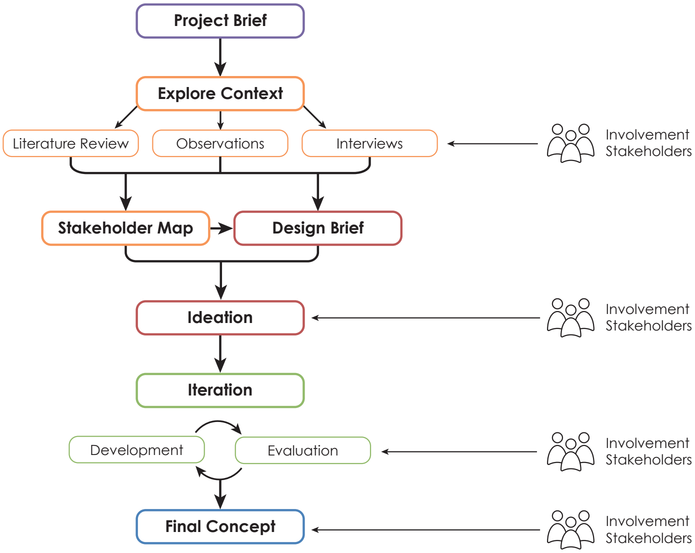


image / figure 2: Project Process

Personal Project Brief - IDE Master Graduation

TUDelft

PROBLEM DEFINITION **
Limit and define the scope and solution space of your project to one that is manageable within one Master Graduation Project of 30 EC (= 20 full time weeks or 100 working days) and clearly indicate what issue(s) should be addressed in this project.

In the last stages of dementia people experience apathy and lose their mobility. Because they are confined to their room or bed, they are not able to enjoy the happy moments provided by the Tovertafel. Although it is the last stage in their life, anybody needs a life worth living.
This project's aim is to understand these users and people around them in order to find opportunities to still enable people in the last stages of dementia with positive moments while confined to their room or bed.

Although the focus is on people living with dementia themselves, other users will be involved during the project as well. The Tovertafel shows that the help of either a caretaker or family member is always needed. They can both carry the experience, making it a shared positive moment.

This project will focus on the following research questions:
- What are the emotional needs of all stakeholders; patients in the last stage of dementia, informal caregivers, family and health professionals?
- What is quality of life for people in the last/final stage of dementia, living in a nursing home environment, and what is the influence/role of the people around them?
- Design vision: How can interactive, playful technology be used to enable people in the last stage of dementia, confined to their bed or room, and the people around them with shared positive moments?

ASSIGNMENT **
State in 2 or 3 sentences what you are going to research, design, create and / or generate, that will solve (part of) the issue(s) pointed out in "problem definition". Then illustrate this assignment by indicating what kind of solution you expect and / or aim to deliver, for instance: a product, a product-service combination, a strategy illustrated through product or product-service combination ideas, ... In case of a Specialisation and/or Annotation, make sure the assignment reflects this/these.

I will explore the emotional needs of people in the last stage of dementia that are confined to their room, by involving all stakeholders within the process. I will create design interventions that will be evaluated and iterated on, to eventually develop a playful and experimental concept that enables the users with positive moments.

- First knowledge about living with dementia, quality of life, game design and co-design will be gained during a literature review.
- Through interviews and observations with the target group and other stakeholders in the context their emotional needs will be explored.
- With this information a service blueprint and journey map of all stakeholders will be developed.
- This map will be the foundation for the vision on how to create positive moments for the stakeholders.
- With this vision in mind, playful design interventions will be created and iterated together with the stakeholders.
- All design research will be concluded into a final experimental concept. The main functions of the concept will be prototyped and tested with the end users.

An overview of the project process is shown in figure 2.

During my project I will be working parallel with Ileana Diaz Couder Breceda. She is working a project within the same context for Active Cues. We will collaborate during the interviews and observations of our projects, but draw our own conclusions.

Initials & Name H.L. Pak Student number 4283643

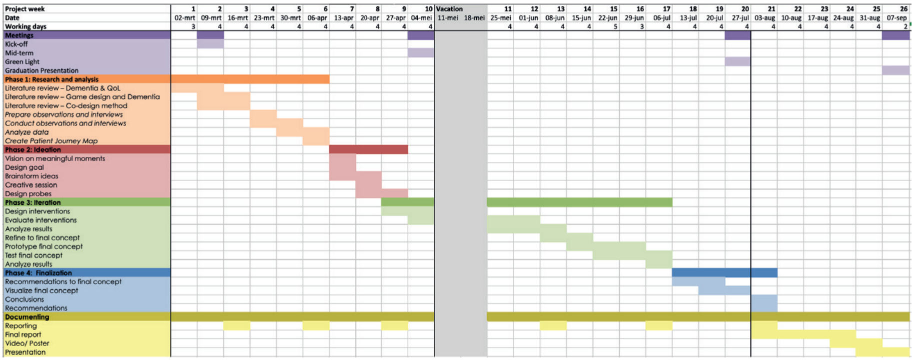
Title of Project Enabling Positive Moments to People in the Last Stages of Dementia

PLANNING AND APPROACH **

Include a Gantt Chart (replace the example below - more examples can be found in Manual 2) that shows the different phases of your project, deliverables you have in mind, meetings, and how you plan to spend your time. Please note that all activities should fit within the given net time of 30 EC = 20 full time weeks or 100 working days, and your planning should include a kick-off meeting, mid-term meeting, green light meeting and graduation ceremony. Illustrate your Gantt Chart by, for instance, explaining your approach, and please indicate periods of part-time activities and/or periods of not spending time on your graduation project, if any, for instance because of holidays or parallel activities.

start date 4 - 3 - 2020

8 - 9 - 2020 end date



I will work on the project part-time 4 days a week. This project is divided in 4 main phases. 1: Research and analysis, 2: Concept development, 3: Evaluation & 4: Finalization.

During phase 1: Research and analysis, I will be conducting literature reviews on dementia, game design with dementia and on the co-design method with people living with dementia. Together with Ileana Diaz Couder Breceda I will conduct observations and interviews with all stakeholders. I will analyze the data and create a journey map of all stakeholders.

In phase 2: Ideation, I will start with creating the design vision and design goal. With this vision in mind I will brainstorm ideas and use a creative session with the stakeholders to come with design probes that could turn into design interventions.

During phase 3: Iteration, the interventions will be designed an evaluated during an iterative process. All results will be concluded into a final experimental concept. The functionality of the concept will be prototyped and tested.

Finally in phase 4: Finalization, from the final evaluation the concept will receive its final recommendations and will be visualized. Final conclusions will be drawn as for conclusions and recommendations.

Meeting Dates:

Kick-off meeting	11-03-2020	Greenlight meeting:	29-07-2020
Midterm meeting:	06-05-2020	Graduation presentation:	08-09-2020

MOTIVATION AND PERSONAL AMBITIONS

Explain why you set up this project, what competences you want to prove and learn. For example: acquired competences from your MSc programme, the elective semester, extra-curricular activities (etc.) and point out the competences you have yet developed. Optionally, describe which personal learning ambitions you explicitly want to address in this project, on top of the learning objectives of the Graduation Project, such as: in depth knowledge a on specific subject, broadening your competences or experimenting with a specific tool and/or methodology, ... Stick to no more than five ambitions.

With designing I would like to bring more joy to people in general, but this project gives the ability to bring joy to a part of our population that is easily overlooked.
Although this is a difficult user group I would like to challenge myself to work together with them during my project. Working closely with the patients will be confronting, but it will give me the opportunity to involve the project with real people. Hopefully this will give me the ability to actual bring meaning to their lives.

Besides this motivation I am also interested in learning more about the co-design approach. What especially excites me to learn to use the co-design method during this project is that I will not only be working with the end-users, but also caretakers and family members. Having these multiple stakeholders involved in the project, will give the process a very broad perspective. During my studies I heard often that when you only collaborate with the end-user, they find it hard to look critically at themselves and that I often helps to involve other parties, because they bring a different perspective toward the end-user. So I look forward to applying this method during my project with several stakeholders and to conduct tests in a real environment.

Also using game design, as a starting point to design from is something I have not experienced before during my studies, but is something that always intrigued me. I want to know how focusing on play experiences works for me and how it affects the end users.

During this project I want to challenge myself to work more visually. I know I can do it when I put the time and effort in it, but within a big project I easily forget to focus on the visual aspects.

Besides acquiring new competences during this project I also want to focus on competences I already developed. During projects I love making prototypes with all kinds of materials and tool. So that is something I definitely want to use during this project. However I can lose myself into prototyping as well, so I will need to push myself to focus more on the functionality of the prototype and less on the looks, in order to manage my time well.

Sources:
1 Alzheimer-Nederland. (2019, May). Factsheet cijfers en feiten over dementie. Retrieved 20 februari 2020, from https://www.alzheimer-nederland.nl/factsheet-cijfers-en-feiten-over-dementie
2 Anderiesen, H. (2017). Playful Design for Activation: Co-designing serious games for people with moderate to severe dementia to reduce apathy. https://doi.org/10.4233/uuid:ebeef0fa-46fe-4947-86c1-c765a583770a
3 Active Cues. Tovertafel Original. Retrieved 09 march 2020, from https://tovertafel.nl/original/
4 Reisberg, B., Ferris, S.H., de Leon, M.J., and Crook, T. The global deterioration scale for assessment of primary degenerative dementia. American Journal of Psychiatry, 1982, 139: 1136-1139.

FINAL COMMENTS

In case your project brief needs final comments, please add any information you think is relevant.

Initials & Name H.L. Pak
Student number 4283643
Title of Project Enabling Positive Moments to People in the Last Stages of Dementia

B Interview Set-up

1 Participants

Recruiting participants

The participants were recruited in two ways. Active Cues searched within their co-design location contacts for caregivers that were willing to participate. If the caregiver agreed to Active Cues, the researcher made contact with the caregiver. Other participants were recruited by sending out a message to possible connections. The message contained some information about the project and invited caregivers or family members from people living with dementia to participate in an interview. When participants contacted the researcher, more information about the project was given and an explanation that the interview would be online.

Professional caregivers

#	M/F	Function	Years of experience
P1	F	Caregiver	30 years
P2	F	Activity supervisor	8 years (within this function)
P3	F	Activity supervisor	26 years
P4	F	Caregiver	2 years (previous 5 years as help)
P5	M	Dementia Clown	1 year

Informal caregivers

#	M/F	Mother or Father	Extra function
I1	F	Mother	Volunteers at Alzheimer café
I2	F	Mother	-
I3	M	Mother	-
I4	M	Mother	Volunteers at trips for PlwD
I5	F	Father	-
I6	F	Mother	Provides sound healing to PlwD

2 Introduction Letter

Bedankt voor het meedoen

Bedankt voor je interesse om deel te nemen aan ons onderzoek voor onze afstudeerprojecten met betrekking tot mensen in de laatste fasen van dementie in verzorgingstehuizen.

Het doel van dit onderzoek is:

- Om beter te kunnen begrijpen wat de emotionele behoeften zijn en
- Hoe de kwaliteit van leven er uit ziet in de laatste fasen van dementie in verzorgingstehuizen

Daarom is jouw input zeer waardevol en belangrijk.

De interviews voor dit onderzoek zullen worden afgenomen tussen 30 maart en 17 april 2020. De data die tijdens dit onderzoek gebruikt worden, zullen verzameld worden door middel van een geschreven poster voorafgaand aan het interview en een audio-opgenomen interview. Om van deze data gebruik te kunnen maken hebben wij uw toestemming nodig. De data zal anoniem behandeld worden, enige informatie die de participant zou kunnen identificeren zal niet gedeeld worden met derden. Alle originele ruwe data zal in september aan het einde van dit project vernietigd worden.

Omdat dit onderzoek onderdeel is van het afstuderen van de MSc Design for Interaction aan de TU Delft, zullen de resultaten en conclusies publiekelijk gepubliceerd worden op de online repository van deze institutie.

U kunt te allen tijde weigeren een vraag te beantwoorden en u kunt op ieder moment uw deelname tot het onderzoek intrekken, zonder een reden op te geven.

Mocht u nog enige vragen hebben, twijfel dan niet om contact met ons op te nemen via h.l.pak@student.tudelft.nl of 06 17 212123

Bedankt,

Hannah Pak en
Ileana Diaz Couder Breceda

MSc Design for Interaction studenten aan de TUDelft

3 Consent From

Toestemmingsformulier voor ‘Mensen in de laatste fasen van dementie’

Vink aan wat van toepassing is	**Ja**	**Nee**
Deelnemen aan dit onderzoek		
Ik heb de onderzoeksinformatie van 30/03/2020 tot 17/04/2020 gelezen en begrepen, of het is aan mij verteld. Ik heb de mogelijkheid gehad om vragen te stellen over het onderzoek en mijn vragen zijn naar mijn wens beantwoord.	☐	☐
Ik geef mijn vrijwillige toestemming om deel te nemen aan dit onderzoek en begrijp dat ik kan weigeren om vragen te beantwoorden en mij op ieder moment terug kan trekken uit het onderzoek, zonder een reden op te geven.	☐	☐
Ik begrijp dat deelnemen aan dit onderzoek bestaat uit een geschreven poster voorafgaand aan het interview en een audio-opgenomen interview.	☐	☐
Gebruik van de informatie in het onderzoek		
Ik begrijp dat de informatie die ik aanlever gebruikt zal worden voor het eindverslag van de twee afstudeerprojecten en dat deze gepubliceerd zullen worden op de repository van de TU Delft.	☐	☐
Ik begrijp dat persoonlijke informatie die over mij wordt verzameld anoniem zal worden behandeld	☐	☐
Ik ga ermee akkoord dat mijn informatie geciteerd kan worden in onderzoekspublicaties.	☐	☐

Handtekeningen

Naam onderzoekers en handtekening:

Hannah Pak & Ileana Diaz Couder Breceda

Date: ______________________

Naam participant en handtekening:

____

Date: ____________________________

4 Interview Questions

Professional Caregiver

0. Inleiden

Hoi ....
Wat fijn dat je tijd kon maken om een interview met ons te doen. Ik ben Hannah en dit is mijn mede student Ileana. Wij studeren beide design for interaction aan de TU Delft en zijn momenteel bezig met ons afstudeerproject omtrent geluksmomenten voor mensen in de laatste, bedlegerige fase van dementie.

Voor we aan het interview beginnen willen we je nog een aantal dingen vertellen.
Wij zien onszelf niet als experts op het gebied van Mensen met dementie, voor ons ben jij de expert van jouw ervaringen op dit gebied. Wij zijn benieuwd wat jouw ervaringen zijn. Er zijn dus geen foute of goede antwoorden.
Zoals beschreven staat in het toestemmingsformulier zal alle informatie die je ons geeft tijdens dit interview anoniem verwerkt worden.
De resultaten van het onderzoek zullen worden gedeeld in de TUDelft repository.

Heb je verder nog vragen voor we aan het interview beginnen?

Wij willen het interview doen aan de hand van de poster die je voor ons hebt ingevuld.

1. Voorstellen

- Kun je ons vertellen wat je bij de eerste opdracht hebt ingevuld, om jezelf voor te stellen?

Naam
Beroep
Jaren ervaring
Leukste aan werk

- Kun je ons vertellen hoe het verzorgingstehuis waar je werkt uit ziet?
  - Aantal mensen die er werken?
  - Aantal patiënten
  - Leefomstandigheden/ ruimten

2. Mensen rond de bewoner

- Wie is het meest belangrijk voor de bewoner?
- Wat betekent die persoon voor de bewoner?
- Is er een persoon die weinig betrekking heeft op de bewoner, maar wel een belangrijke bijdrage levert aan de gemoedstoestand van de bewoner?

3. Mijn leven als een verzorger

- Waarom heb je besloten om in een verzorgingstehuis te gaan werken?
- Op welk moment begint jouw tijdlijn?
- Hoe ziet de verzorging van een bewoner uit? Wat voor zorg hebben ze nodig?
- Wat zou je nooit doen tijdens de verzorging van een bewoner?
- Wat is je meest waardevolle activiteit?
- Wat was de voornaamste reden om mensen in het verzorgingstehuis te plaatsen?

Bedlegerigheids fase

- Kun je omschrijven hoe het voor iemand is om op bed te liggen in de laatste fase?
- Hoe ziet hun dag er uit?
- Wat is de hoogtepunt van hun dag?
- Wat voor activiteiten doe je om de bewoner heen?
- Hoe communiceer(de) je met een bewoner?
- Waar reageert een bewoner positief op?
- Waar reageert een bewoner geïrriteerd op?

Hoe gaan jullie momenteel met de corona maatregelen om?

5. Beredeneren

- Welke 2 positieve momenten heb je uitgekozen?
- Waarom waren deze momenten het meest positief?
- Wat denk je dat de belangrijkste factor was voor dit positieve moment?
- Welke 2 uitdagende momenten heb je uitgekozen?
- Waarom waren deze momenten het meest uitdagend?
- Wat denk je dat de belangrijkste factor was voor dit uitdagende moment?
- Wat had volgens jou dit uitdagende moment kunnen verlichten?

6. Mijn ervaringen

- Wat is jouw meest memorabele ervaring in de gehele tijd dat je in deze sector werkt?
- Wat maakte dit je meest memorabele ervaring?
- Wat zou je graag geweten willen hebben toen je met dit werk begon?
- Waarom had je dit graag willen weten?
- Zou je dit als advies geven aan mensen die nu beginnen met werken in deze sector?

Informal caregiver
0. Inleiden

Hoi ....
Wat fijn dat je tijd kon maken om een interview met ons te doen. Ik ben Hannah en dit is mijn mede student Ileana. Wij studeren beide design for interaction aan de TU Delft en zijn momenteel bezig met ons afstudeerproject omtrent geluksmomenten voor mensen in de laatste, bedlegerige fase van dementie.

Dit interview is onderdeel van ons onderzoek om de emotionele behoeften en de kwaliteit van leven in kaart te brengen.

Voor we aan het interview beginnen willen we je nog een aantal dingen vertellen.
Wij zijn geen experts op het gebied van Mensen met dementie, wij zien jou als de expert van je eigen ervaringen op dit gebied. Wij zijn benieuwd wat jouw ervaringen zijn. Er zijn dus geen foute of goede antwoorden.
Zoals beschreven staat in het toestemmingsformulier zal alle informatie die je ons geeft tijdens dit interview anoniem verwerkt worden.
De resultaten van het onderzoek zullen worden gedeeld in de TUDelft repository, wij en anderen willen van jouw ervaringen leren om hiermee andere mensen met dementie te kunnen helpen.
Ga je akkoord met deze voorwaarden en heb je het toestemmingsformulier ondertekend?
Dan zullen we nu beginnen met het opnemen van het interview.

Is het gelukt om de poster in te vullen? En heb je hem momenteel bij de hand.

Heb je verder nog vragen voor we aan het interview beginnen?

We zullen het interview afnemen aan de hand van de poster. We beginnen bij de eerste opdracht.

1. Voorstellen
- Kun je ons vertellen wat je bij de eerste opdracht hebt ingevuld, om jezelf voor te stellen?

Naam
Ouder
Activiteit: waarom was/is dit je favoriete activiteit?

- Kun je ons vertellen hoe het verzorgingstehuis waar je ouder woonde er uit zag?
    - Aantal mensen die er werken
    - Aantal bewoners
    - Leefomstandigheden/ ruimten

2. Mensen rond mijn ouders
- Wie is het meest belangrijk geweest voor jouw ouder?
- Wat heeft die persoon voor jouw ouder betekent?
- Is er een persoon die weinig betrekking heeft (gehad) tot jouw ouder, maar wel een bijzondere relatie heeft (gehad) tot jouw ouder?

3. Het traject van mijn ouder
- Kun je ons vertellen hoe je de tijdlijn hebt ingevuld.
- Wat was de voornaamste reden om jouw ouder in het verzorgingstehuis te plaatsen?
- Hoe lang heeft jouw ouder in het verzorgingstehuis gewoond?
- Wat waren de voornaamste momenten in de tijd in het verzorgingstehuis?
- Heeft jouw ouder een fase van bedlegerigheid meegemaakt?
- Was er een speciale gebeurtenis waardoor jouw ouder op bed kwam te liggen?
- Hoe was de transitie van nog mobiel te zijn, naar bedlegerig zijn?
- Hoe communiceer(de) je met je ouder? Is daar een verandering in opgetreden nadat je ouder bedlegerig werd?
- Waar reageerde jouw ouder positief op?
- Waar reageerde jouw ouder geïrriteerd op?

5. Beredeneren

- Welke 2 positieve momenten heb je uitgekozen?
- Waarom waren deze momenten het meest positief?
- Wat denk je dat de belangrijkste factor was voor dit positieve moment?
- Welke 2 uitdagende momenten heb je uitgekozen?
  - Geen -> en wat gebeurde er dan tijdens slechte dagen?
- Waarom waren deze momenten het meest uitdagend?
- Wat denk je dat de belangrijkste factor was voor dit uitdagende moment?
- Wat had volgens jou dit uitdagende moment kunnen verlichten?

6. Mijn ervaringen

- Wat was je meest favoriete ervaring?
- Wat maakte dit je meest favoriete moment?
- Wat zou je andere families in dezelfde situatie aanraden?
- Waarom raadt je dit andere families aan?
- Had je dit advies graag zelf gehad?

5 Recruitment Message

"Voor mijn afstudeerproject aan de TU Delft ben ik op zoek naar familieleden en/of verzorgers van ouderen die leven in de laatste fasen van dementie en hierdoor beperkt zijn tot hun bed. Het onderwerp van mijn project is namelijk: "Het creëren van geluksmomenten voor mensen in de laatste, bedlegerige fasen van dementie." Mocht U binnen deze doelgroep vallen, dan zou ik graag een interview met U af willen nemen. Ik ben te bereiken door te mailen naar h.l.pak@student.tudelft.nl of door de bellen of appen naar 0617212123."

C Brainstorm Session

1 Set-up

The set-up for the brainstorm session was as shown in table 3 together with the time that was given for each part. The table shows that there were assignments and brainstorms for each part of the concept direction. The assignments were done to make the designers think about the subject close to themselves first, as an inspiration for the brainstorm questions that followed. Most of the brainstorm questions where phrased like the “how can you” method for brainstorming.

Because the brainstorm session needed to be fully online, the tool ‘miro’ was used again for the designers to collaborate on. Also the video-calling tool ‘zoom’ was used for communication during the brainstorm session. In ‘miro’ a board was made prior to the brainstorm session. The board was organized in the same structure as the set-up. With having a set board, the designers could be guided through the brainstorm session and knew where they needed to work. Every designer was assigned their own individual workspace during the assignments and their own individual colour during the brainstorm questions. By having their own space and colour, there were no conflicts on clarities on where to work during the session.

2 Results

Figure 27 shows the results of the brainstorm session. Because the brainstorm session was online, only a few participants were preferred to participate in order to prevent the session from becoming chaotic. So the number of designers was at first limited to 4. Unfortunately one of the designers was last minute not able to join the session, bringing the number of designer that participated to 3. This was sadly a bit too low. It would be recommended to have at least 5 or 6 participants during an online session, so in case one participant drops out there still is a good number of participants.

The first part of the brainstorm session was nicely done. The participants enjoyed the assignment prior to the questions. The questions gained good insights on what is part of someone’s identity, especially that the roots of

Time	Activity
2	Explanation of project & session set-up
5	Introduction – introduce yourself
	Part 1: Exploring Identity
3	Assignment: Could you draw or describe a moment in your life that meant a lot to you?
3	Discussion: Can you find similarities on how this defines your identity? How could someone discover this from you?
5	Brainstorm 1: What could be part of someone's identity?
5	Brainstorm 2: How can you discover someone's identity?
	Part 2: Turning identity into sensory elements
10	Brainstorm: What could sensory stimulation look like? (Seeing, Hearing, Touching, Smelling, Tasting) on each for 2 minutes x5
	Part 3: Making sensory elements playful and interactive
4	Assignment: What would/ do you like to play with?
5	Discussion/ clustering
3	Brainstorm 1: How can you make sensory stimulation playful?
3	Brainstorm 2: How can you make sensory stimulation interactive?
3	Brainstorm 3: How can you provide a sensory stimulation interaction between multiple people?
	Closing: Any tips and/ or tops?

Table 3, Brainstorm session set-up.

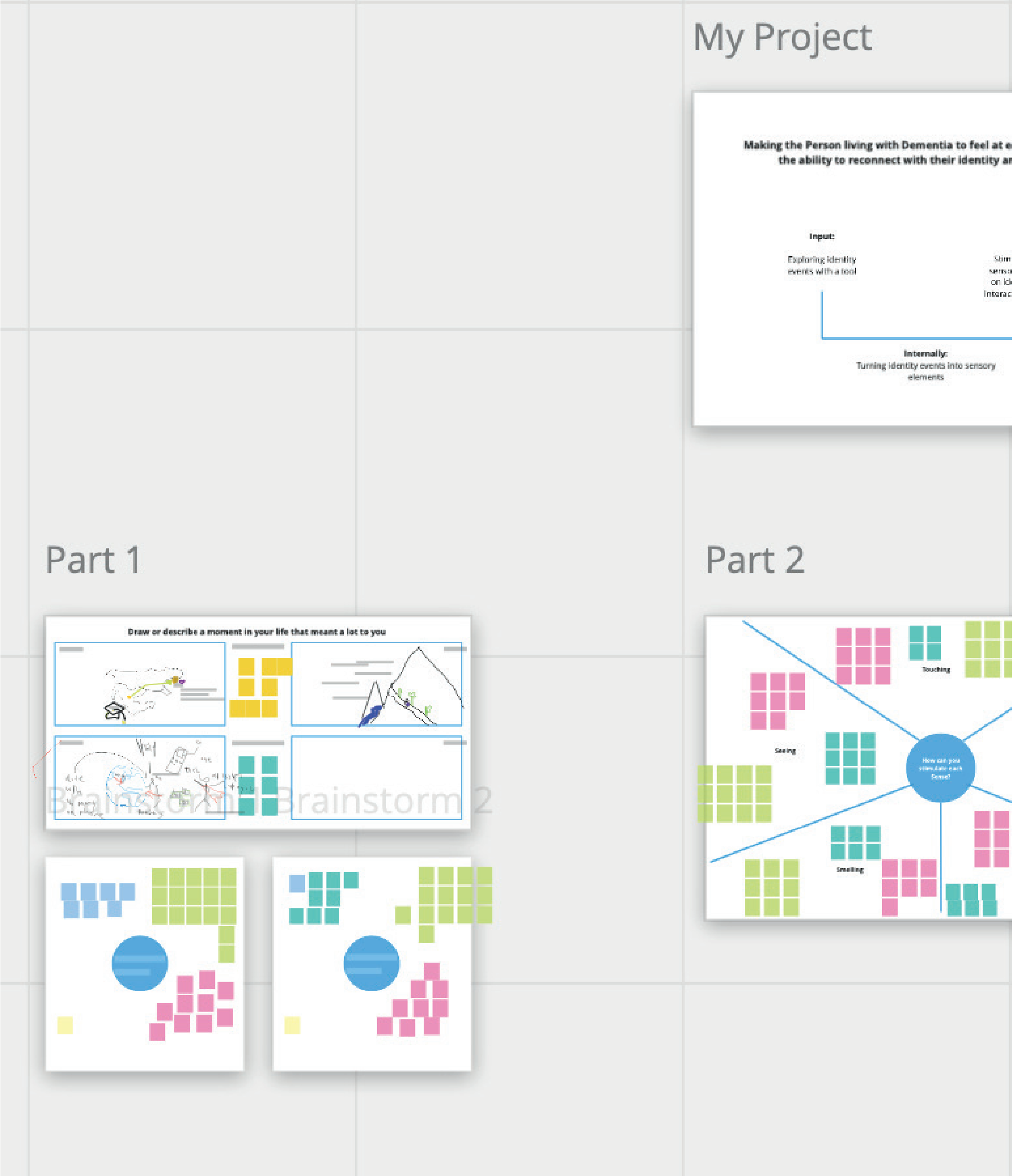
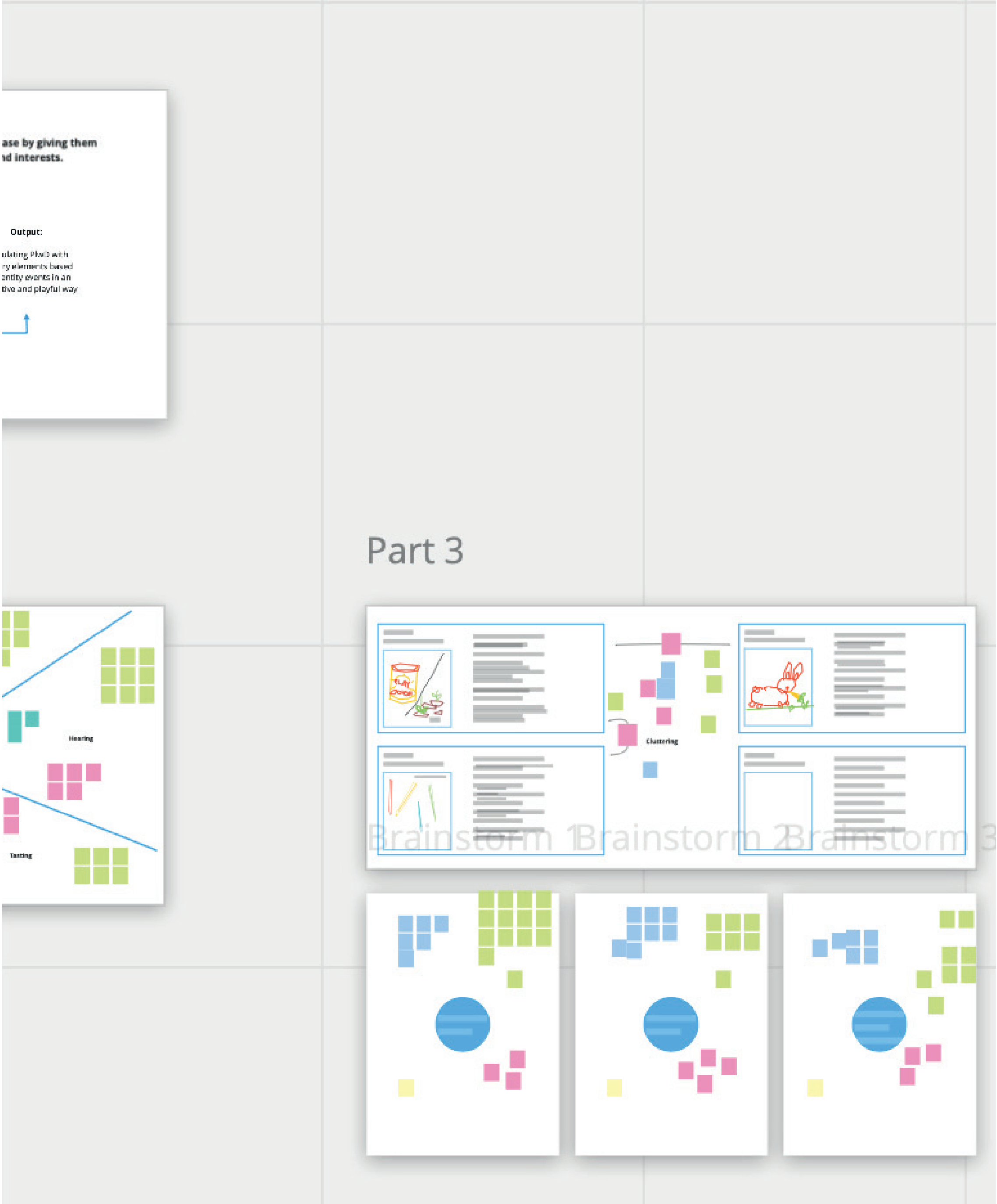


Figure 27, Results brainstorm session.



ase by giving them
nd interests.

Output:

ulating PlaiD with
ry elements based
entity events in an
tive and playful way

someone are very important to their identity. And the fact that preferences are also part of someone's identity came forward.
To discover someone's identity interviews turned out to work the best. It is a bit straightforward, but the best way to get to know people's stories. This could of course be supported with other methods like sensitizing materials.
The results also showed that experiencing moments together is a good way to get to know someone. This could not be done with an interview, but other people connected to the person living with dementia that experienced moments with them could play a very important role in discovering their identity.

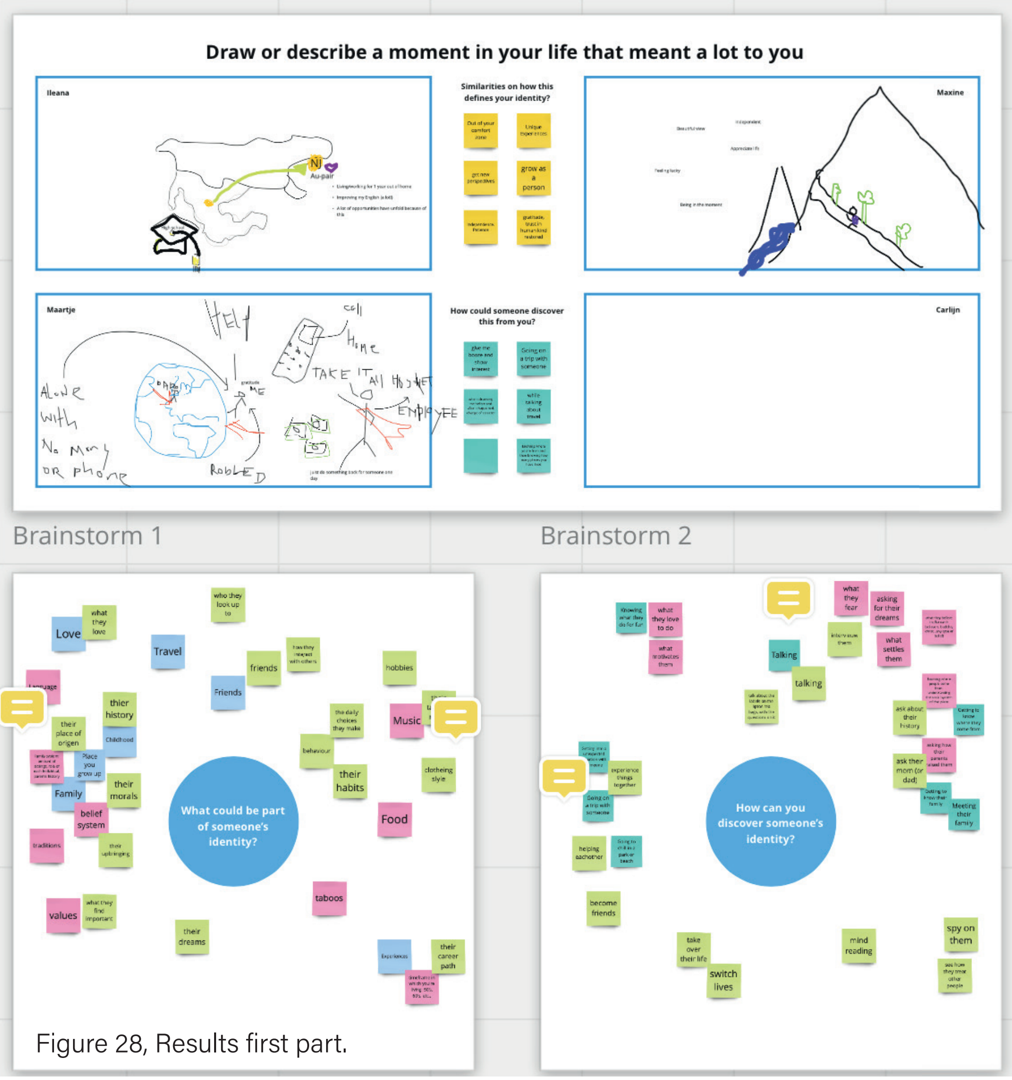


Figure 28, Results first part.

The second part of the brainstorm session turned out to be a bit broad. The questions resulted in all kinds of ways to stimulate people on their senses. However people living with dementia respond differently on their senses than people without dementia, they need very subtle stimulations. The questions should have been more focussed toward stimulating the senses of people living with dementia in order to give valuable initial ideas.

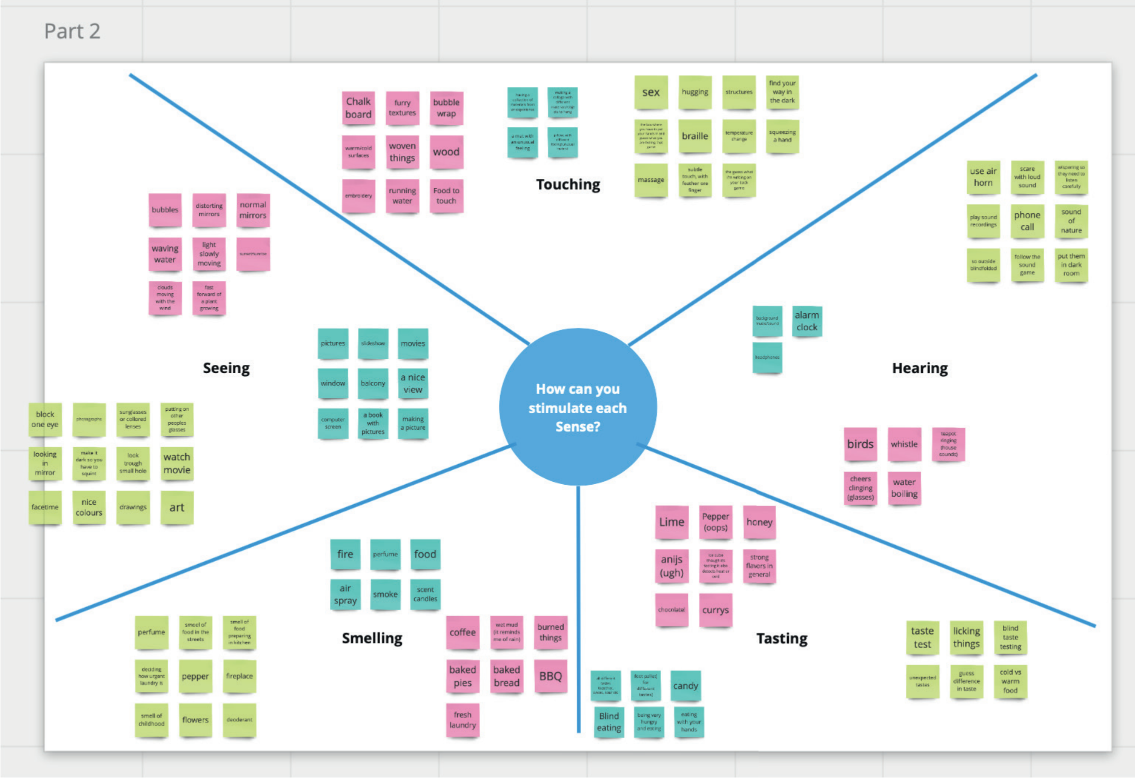
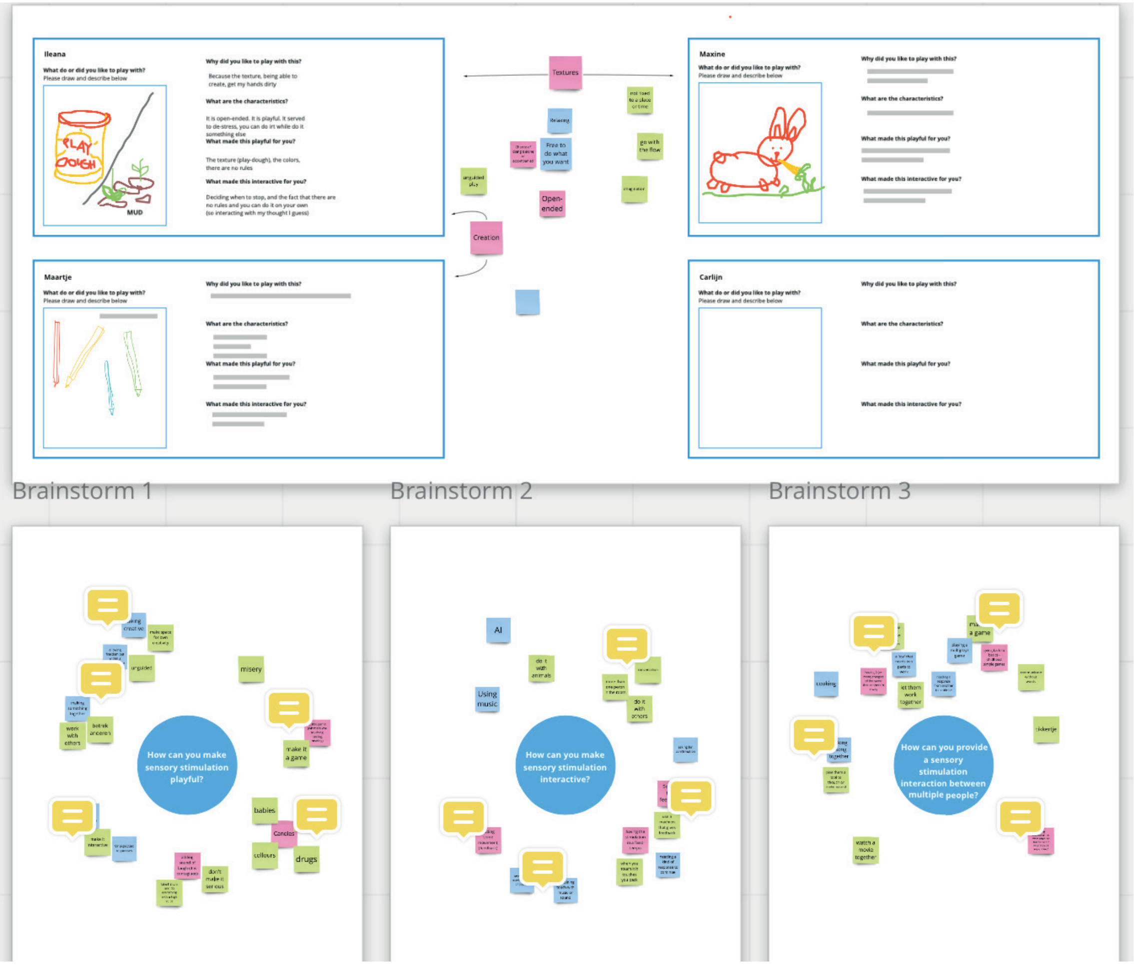


Figure 29, Results second part.

The results of the third part of the brainstorm session also did not turn out as intended. The questions were again too broad and/ or it was due to the fact that the questions came at the end of the session and the participants were not in a creative flow anymore. It presented some initial ideas, but not as valuable as hoped for.



Ileana

What do or did you like to play with?
Please draw and describe below

Why did you like to play with this?

Because the texture, being able to create, get my hands dirty

What are the characteristics?

It is open-ended. It is playful. It served to de-stress, you can do irt while do it something else

What made this playful for you?

The texture (play-dough), the colors, there are no rules

What made this interactive for you?

Deciding when to stop, and the fact that there are no rules and you can do it on your own (so interacting with my thought I guess)

Maxine

What do or did you like to play with?
Please draw and describe below

Why did you like to play with this?

What are the characteristics?

What made this playful for you?

What made this interactive for you?

Maartje

What do or did you like to play with?
Please draw and describe below

Why did you like to play with this?

What are the characteristics?

What made this playful for you?

What made this interactive for you?

Carlijn

What do or did you like to play with?
Please draw and describe below

Why did you like to play with this?

What are the characteristics?

What made this playful for you?

What made this interactive for you?

Figure 30, Results third part.

D Evaluation Input

For testing the input the following research questions were set-up:
- Do these questions map the identity of the participant?
- Is the way of execution pleasant for the participant?
- Is the presence of a child supportive in gaining information or does it hinder?
- Do the assignments provide sensory elements of the identity events?

1 Set-up of Evaluation

The test consisted of a total of six participants: one mother together with her son, one father together with his son and two individual mothers. This mixture of participants was chosen to see the effect of the presence of a child. The two kinds of participants could be compared, to see the difference that the presence of a child makes.

Before the test began the participants received some information about the project and information about the test, see appendix D3. They were told that during the test they are the experts of their own experience, so that there were no right or wrong answers to the questions. Also they were asked to speak out loud during the test and that after completing all the assignments there would be a few evaluative questions.

The assignments were handed to the participant and the participant could fill in all assignments by themselves. The researcher only guided the participant when a question was unclear. The researcher also asked follow-up questions when participants told stories, to gain more in-depth information on the identity events. After the participant completed the assignments, some evaluative questions were asked.

2 Research Questions

Vraagblad 1
- Welke vragen zijn onduidelijk (en hebben meer uitleg nodig)?
- Hoe reageren de participanten op de vragen?

- Is er belangrijke informatie die de participant deelt, maar niet is opgenomen in de vragen?

Stamboom
- Is de structuur van de stamboom voldoende naar waarheid van een gemiddeld persoon?
- Is de stamboom gemakkelijk in te vullen?

Jeugd
- Hoe reageren participanten op de vraag?
- Geeft het beeld wat de participanten schetsen hun identiteit weer?
- Voelen participanten zich gemakkelijk genoeg om dit beeld te tekenen?
- Hoeveel participanten maken gebruik van de afbeeldingen?
- Wat is de mening van de participant over het gebruik van de afbeeldingen?
- Wat vinden de participanten van de beschikbaar gestelde afbeeldingen?

Evenement
- Hoe reageren participanten op de vraag?
- Geeft het beeld wat de participanten schetsen hun identiteit weer?
- Geeft de vraag aanvullende informatie op de voorgaande vraag?

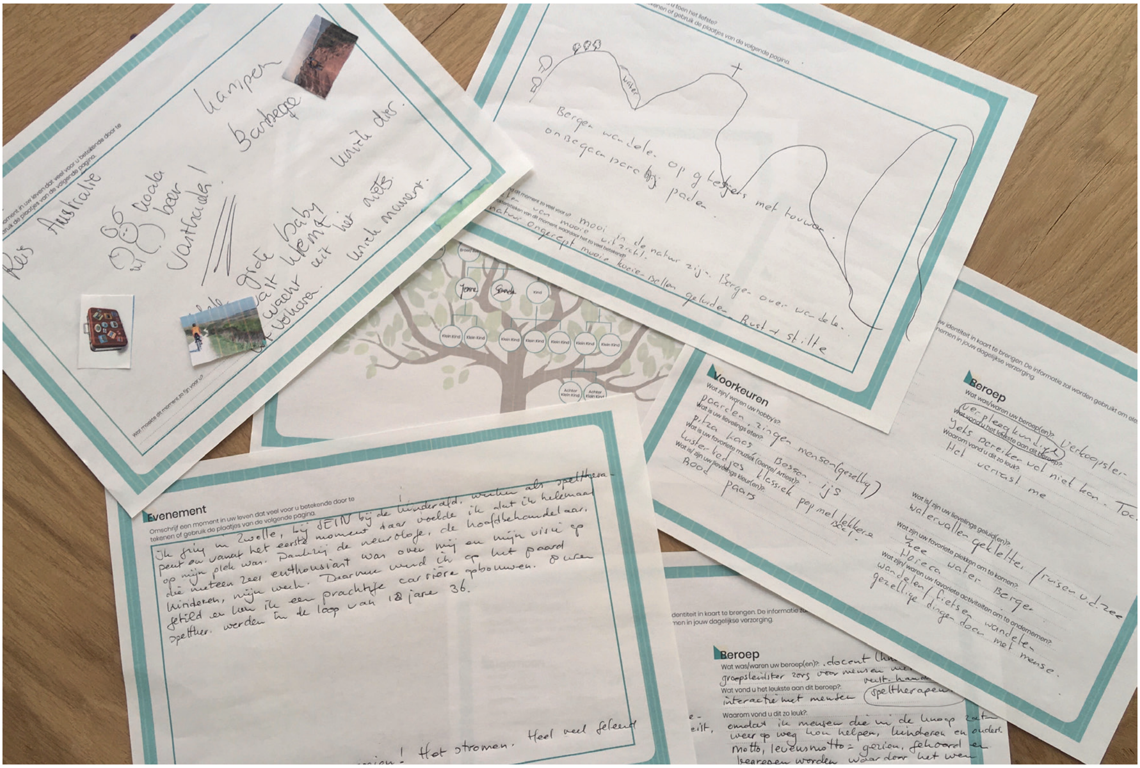
Overig
- Hoeveel participanten hadden nog een evenement ingevuld bij overig?
- Vonden de participanten het overbodig om deze vraag nog te hebben of vonden ze het fijn om nog meer evenementen te kunnen benoemen?

3 Evaluative Questions
- Wat vonden de participanten van de opdrachten in het algemeen?
- Heeft u het gevoel dat dit uw identiteit weerspiegeld?
- Ontbreken er bepaalde vragen?
- Zijn bepaalde vragen overbodig/ waren irrelevant voor u?
- Hoe voelde het om deze opdrachten te doen?
- Zou u de vragen liever alleen thuis willen doen of op deze manier met een “begeleider” erbij?

4 Information given before test

Voor mijn afstudeerproject doe ik onderzoek naar hoe ik mensen in de laatste fase van dementie van geluksmomenten kan voorzien. Dit wil ik bereiken door hun identiteit in kaart te brengen, om deze vervolgens aan hun terug te koppelen op een speelse en interactieve manier.
Momenteel ben ik voor dit eerste deel aan het onderzoeken hoe ik hun identiteit in kaart kan brengen. Ik heb een aantal opdrachten opgesteld die ik u wil vragen om (samen met uw kind) uit te voeren.
De oefeningen zijn bedoeld om uw behoeften en belangen naar boven te brengen. Tijdens het invullen van de oefeningen bent u dus de expert van uw eigen ervaringen, wat betekend dat er geen goede of foute antwoorden zijn.
Mocht u een vraag onprettig vinden om te beantwoorden, dan wordt dat gerespecteerd en kunt u de vraag overslaan.
Aan het eind van de oefeningen zal ik u nog wat vragen stellen.
Heeft u verder nog vragen voor we aan de test beginnen?

5 Results



…moment in uw leven dat veel voor u betekende door te … gebruik de plaatjes van de volgende pagina.

Wat maakte dit moment zo fijn voor u?

…u toen het liefste? …tekenen of gebruik de plaatjes van de volgende pagina.

Bergen wandelen op gletsjers met touwen. onbegaanbare paden.

…dit moment zo veel voor u? mooi in de natuur zijn. Bergen over wandelen.

…karakteristieken van dit moment, waardoor het zo veel betekend? …van mooie uitzicht. natuur ongerept mooie koeie-bellen geluiden. Rust + stilte

Evenement

Omschrijf een moment in uw leven dat veel voor u betekende door te tekenen of gebruik de plaatjes van de volgende pagina.

Ik ging in Zwolle, bij SEIN bij de kinderafd. werken als speltherapeut en vanaf het eerste moment daar voelde ik dat ik helemaal op mijn plek was. Dankzij de neuroloog, de hoofdbehandelaar, die meteen zeer enthousiast was over mij en mijn visie op kinderen, mijn werk. Daarna werd ik op het paard getild en kon ik een prachtige carrière opbouwen. … speltherap. werden in de loop van 18 jaar 36.

…! Het stromen. Heel veel geleerd

Voorkeuren

Wat zijn/ waren uw hobby's? paarden, zingen mensen (gezellig)
Wat is uw lievelings eten? pizza kaas Bessen. ijs
Wat is uw favoriete muziek (Genre/ Artiest)? Luisterliedjes klassiek pop met lekkere beat.
Wat is/ zijn uw lievelings kleur(en)? Rood paars

…w identiteit in kaart te brengen. De informatie zal worden gebruikt om … …nomen in jouw dagelijkse verzorging.

Beroep

Wat was/waren uw beroep(en)? verpleegkundige Verkoopster
Wat vond u het leukste aan dit beroep? Iets bereiken wat niet kon. Toc…
Waarom vond u dit zo leuk? Het verrast me

Wat is/ zijn uw lievelings geluid(en)? watervallen gekletter, / ruisen v.d. zee
Wat zijn uw favoriete plekken om te komen? Zee Horeca water Bergen.
Wat zijn/ waren uw favoriete activiteiten om te ondernemen? wandelen / fietsen wandelen gezellige dingen doen met mense.

…dentiteit in kaart te brengen. De informatie … …men in jouw dagelijkse verzorging.

Beroep

Wat was/waren uw beroep(en)? docent … groepsleidster zorg voor mensen met … verst. hand…
Wat vond u het leukste aan dit beroep? interactie met mensen (speltherapeut)
Waarom vond u dit zo leuk? omdat ik mensen die in de knoop zat… weer op weg kon helpen, kinderen en ouders. motto, levensmotto = gezien, gehoord en begrepen worden waardoor het wer…

Figure 32, Results Input validation.

Onderzoeksvragen:	Antwoorden via Testen
Brengen deze vragen de identiteit van de participant in kaart?	Een groot gedeelte van de identiteit wordt in kaart gebracht. Zeker voor de hoeveelheid tijd en moeite die er in wordt gestopt.
Ontbreken er belangrijke vragen of zijn er vragen overbodig?	Sommige elementen ontbreken nog op het gebied van eigenschappen, oorsprong en geluk. Kijken of dit relevante input is voor de output. Hobby's, favoriete plekken en favoriete activiteiten voelen voor sommigen dubbel.
Is de aanwezigheid van een kind bevorderend voor informatie verschaffen of werkt het juist tegen?	Ja dit is zeer bevorderend. Sowieso is het voor de participant prettiger om de opdrachten niet alleen of alleen met een onbekende te doen. De sfeer wordt een stuk gezelliger en prettiger. Ook helpt het kind om discussie te stimuleren en met meer diepgang te komen.
Is de manier van uitvoeren prettig voor de participant?	Ja de manier van uitvoeren wordt als zeer prettig ervaren. Dit ligt ook zeer aan hoe de begeleider de opdrachten presenteert en hoe hij/zij zich tijdens het invullen opstelt. Een open en toegankelijke sfeer is erg belangrijk zodat de participanten zich op hun gemak voelen.

Vraagblad 1	
Welke vragen zijn onduidelijk (en hebben meer uitleg nodig)?	De beroeps vervolg vragen hebben verduidelijking nodig dat het om 1 beroep gaat.
Hoe reageren de participanten op de vragen?	Goed, soms zet het ze wel aan het nadenken maar over het algemeen vullen de participanten de vragen zonder moeite in.

Table 4, Evaluation Results.

Is er belangrijke informatie die de participant deelt, maar niet is opgenomen in de vragen?	Soms vertellen de participanten meer dan ze opschrijven. Opnemen van de sessie is dus belangrijk.

Stamboom	
Is de structuur van de stamboom voldoende naar waarheid van een gemiddeld persoon?	Ja. Het is beter om te veel vakjes te hebben, dan te weinig.
Is de stamboom gemakkelijk in te vullen?	Nee, Er moet ruimte zijn om eigen namen in te vullen naast de structuur namen.

Jeugd	
Hoe reageren participanten op de vraag?	De participanten zijn verbaasd en vinden het een hele sprong. Ze moeten erg nadenken, maar er komen vrij snel herinneringen naar boven. Niet duidelijk dat het om één moment gaat.
Geeft het beeld wat de participanten schetsen hun identiteit weer?	Het beeld sluit vaak aan op wat de participanten op blad 1 genoemd hebben.
Voelen participanten zich gemakkelijk genoeg om dit beeld te tekenen?	Ja, ondanks dat participanten aangeven niet te kunnen tekenen, doen ze het toch allemaal zonder ongemak.
Hoeveel participanten maken gebruik van de afbeeldingen?	2/3 gebruikten de afbeeldingen.
Wat is de mening van de participant over het gebruik van de afbeeldingen?	Fijn als suggestie, soms overbodig, uitknippen vervelend.
Wat vinden de participanten van de beschikbaar gestelde afbeeldingen?	Goede mix van verschillende triggers.

Evenement	
Hoe reageren participanten op de vraag?	Alle participanten moeten even nadenken, maar komen al snel met een moment. Momenten wisselen van betekenis.

Table 4, Evaluation Results.

Geeft het beeld wat de participanten schetsen hun identiteit weer?	Het beeld zelf niet altijd, maar de extra vragen geven meer duidelijkheid in de betekenis achter het beeld. Aanvullende vragen zijn dus erg belangrijk.
Geeft de vraag aanvullende informatie op de voorgaande vraag?	Ja, door het verschil in tijd komen er andere herinneringen met andere waarden uit.

Overig	
Hoeveel participanten hadden nog een evenement ingevuld bij overig?	2/3
Vonden de participanten het overbodig om deze vraag nog te hebben of vonden ze het fijn om nog meer evenementen te kunnen benoemen?	Een participant vond het overbodig nog meer in te vullen. De andere participanten kwamen met zelfs meer evenementen dan 2.

Afsluitend	
Wat vonden de participanten van de opdrachten in het algemeen?	Goed, fijn en prima. Daarnaast ook makkelijk en laagdrempelig. Ze verwachten iets heel ingewikkelds, maar het was erg makkelijk en toegankelijk.
Heeft u het gevoel dat dit uw identiteit weerspiegeld?	Ja, het geeft een deel van de identiteit goed weer. Zeker voor de hoeveelheid moeite die er in gestoken wordt.
Ontbreken er bepaalde vragen?	Ja, eigenschappen, oorsprong en elementen als trots, geluk en blijdschap ontbreken.
Zijn bepaalde vragen overbodig/ waren irrelevant voor u?	Sommige vragen voelen dubbelop. Zoals hobby’s, favoriete plekken en favoriete activiteiten voelen dubbel.
Hoe voelde het om deze opdrachten te doen?	Goed en makkelijk.
Zou u de vragen liever alleen thuis willen doen of op deze manier met een “begeleider” erbij?	Liever met een begeleider erbij. De opdrachten worden serieuzer ingevuld. Ook kan de begeleider ondersteuning bieden en aanvullende vragen stellen voor meer diepgang.

Table 4, Evaluation Results.

Based on the findings the following adjustments will be made to the input:

In the chapter of profession it will be clarified that one profession should be chosen to answer the following questions within the chapter. This chapter could also be broadened with their educations or other classes followed.

The preferences chapter can be broadened with questions about their characteristics, bad and good ones. Also questions on what makes them happy of what makes them proud can be added. The question on what they prefer to do was very similar to the questions of what their hobbies are, so one of these questions will be left out.

The family tree needs to be bigger and there should be empty spots were the names of family members can be written. Besides focussing on family members, other important people within their life can also be addressed within another assignment.

Within the question about there youth it should be clearer that the question is about one specific moment. This also goes for the events assignment.
The question of "what are the characteristic elements of this moment, why it meant so much" was intended to acquire the sensory elements from the experience. This question was unfortunately confusing and the participants did not reflect on the sensory elements. Thus this question should be better defined.

E Evaluation Output

During the evaluation of the input, some of the participants who had experience with people living with dementia as well mentioned that providing people living with dementia with decisions helps them to feel in control.
Literature also states that: Encouraging and empowering the user to play a more active role increases confidence and feelings of self-worth (Valenzuela, 2008) and is considered a more effective care method than passive (receptive) interventions (Sánchez et al., 2016).
This gave the idea to the output to give the opportunity to make decisions between different events to activate. In order to let the person living with dementia to be in control of what is happening. In the beginning there could be a choice between only two different events, but later this could be expanded.

With this interaction in mind it was decided to go further with the book idea, because it provides more options to adjust over time for each resident.
Each resident could have their own book, their own personal possession, which results in a more personal experience.
Pages of events that are not being used by the person living with dementia can be taken out of the book and new pages can be added to the book.
Off course it should be tested during the second evaluation if it is in deed preferable to make the concept in the shape of a book and to give people the ability to make decisions between events.

F Evaluation Scenario

1 Participants

#	M/F	Function	Years of experience
P1	F	Caregiver	6 years
P2	F	Activity supe rvisor	8 years (within this function)
P3	M	Activity supervisor	8 years
P4	F	Caregiver	2 years (previous 5 years as help)

2 Introduction Letter

Bedankt dat je mij wilt helpen bij het validatie onderzoek van mijn afstudeerproject.
Ik doe een afstudeerproject om mensen in de laatste fase van dementie van geluksmomenten te voorzien. Na het afronden van mijn analysefase heb ik een overkoepelend concept bedacht waarmee ik dit wil gaan bereiken.

Dit concept heb ik uitgewerkt in een scenario. Het scenario zou ik graag met je willen bespreken om het te valideren. Dit zal in de vorm zijn van een open interview.

De data die tijdens dit validatie onderzoek gebruikt worden, zullen verzameld worden door middel van een audio-opgenomen interview. Om van deze data gebruik te kunnen maken hebben wij uw toestemming nodig. De data zal anoniem behandeld worden, enige informatie die de participant zou kunnen identificeren zal niet gedeeld worden met derden. Alle originele ruwe data zal in Oktober aan het einde van dit project vernietigd worden.

Omdat dit onderzoek onderdeel is van het afstuderen van de MSc Design for Interaction aan
de TU Delft, zullen de resultaten en conclusies publiekelijk gepubliceerd worden op de online repository van deze institutie.

U kunt te allen tijde weigeren een vraag te beantwoorden en u kunt op ieder

moment uw
deelname tot het validatie onderzoek intrekken, zonder een reden op te geven. Mocht u nog enige vragen hebben, twijfel dan niet om contact met ons op te nemen via
h.l.pak@student.tudelft.nl of 06 17 212123

Als bijlage in deze mail vindt u het toestemmingsformulier en het scenario. Zou u het toestemmingsformulier ondertekend terug willen sturen en het scenario voorafgaand aan het interview willen bestuderen?

Met vriendelijke groet,

Hannah Pak
MSc Design for Interaction studenten aan de TUDelft

3 Consent Form

Toestemmingsformulier voor ‘Scenario Validatie’

Vink aan wat van toepassing is	**Ja**	**Nee**
Deelnemen aan dit onderzoek		
Ik heb de onderzoeksinformatie gelezen en begrepen, of het is aan mij verteld. Ik heb de mogelijkheid gehad om vragen te stellen over het onderzoek en mijn vragen zijn naar mijn wens beantwoord.	☐	☐
Ik geef mijn vrijwillige toestemming om deel te nemen aan dit onderzoek en begrijp dat ik kan weigeren om vragen te beantwoorden en mij op ieder moment terug kan trekken uit het onderzoek, zonder een reden op te geven.	☐	☐
Ik begrijp dat deelnemen aan dit onderzoek bestaat uit een audio-opgenomen interview.	☐	☐
Gebruik van de informatie in het onderzoek		
Ik begrijp dat de informatie die ik aanlever gebruikt zal worden voor het eindverslag van het afstudeerproject en dat deze gepubliceerd zal worden op de repository van de TU Delft.	☐	☐
Ik begrijp dat persoonlijke informatie die over mij wordt verzameld anoniem zal worden behandeld	☐	☐
Ik ga ermee akkoord dat mijn informatie geciteerd kan worden in onderzoek publicaties.	☐	☐
Scenario Ik zal het scenario dat mij is toegestuurd vertrouwelijk behandelen en niet delen met derden.	☐	☐

Handtekeningen

Naam onderzoekers en handtekening:	Naam participant en handtekening:
Hannah Pak	______________________________
Date: ________________________	Date: ______________________________

4 Interview Transcript

Wat fijn dat je tijd kon maken om een interview te doen. Ik ben Hannah en ik studeer design for interaction aan de TU Delft en werk momenteel aan mijn afstudeerproject omtrent geluksmomenten voor mensen in de laatste, bedlegerige fase van dementie.

Voor we aan het interview beginnen wil ik je nog een aantal dingen vertellen. Het interview is bestemd om het concept te valideren. Dit zal gedaan worden door middel van vragen aan de hand van het scenario wat je hebt ontvangen. Zoals beschreven staat in het toestemmingsformulier zal alle informatie die je ons geeft tijdens dit interview anoniem verwerkt worden.
Heb je verder nog vragen voor we aan het interview beginnen?
Dan zal ik nu de opname starten.

De eerste vragen zijn bedoeld om te valideren of het scenario het concept duidelijk weergeeft. Er zijn dus geen goede of foute antwoorden op de vragen.

Vragen Deel 1:
- Wat zie je in het scenario?
- Worden de stappen van het concept logisch weergegeven?
- Zijn er onderdelen in het scenario die je niet (goed) begrijpt?

De volgende vragen zijn bedoeld om aan de hand van jouw expertise het concept zelf te valideren. Om het concept iets te verduidelijken zal ik nog wat aanvullende informatie geven.
Zoals je hopelijk in het scenario hebt kunnen zien bestaat het concept uit een input en een output gedeelte. De input draait om het ontdekken van de identiteit in de begin fase van dementie. De output is gericht op de laatste fase van dementie om mensen gepersonaliseerde multi-sensorische stimulatie te geven, gebaseerd op de activiteiten die ontdekt zijn tijdens de input fase. Deze gepersonaliseerde stimulatie heeft als doel om de persoon met dementie het gevoel te geven van hun favoriete activiteit, om hun gevoel van angst weg te halen en ze weer tot rust te brengen.

- Denk je dat de uitkomst van het concept dat geschetst wordt realistisch is?
- Hoe denk je dat mensen in de laatste fase van dementie op het concept zullen reageren?

▪ Zie je knelpunten in het scenario waar meer aandacht aan geschonken moet worden?

We zijn aan het einde gekomen van het interview. Heb je zelf nog vragen?

5 Results

Vraag	Conclusie
Worden de stappen in het concept logisch weergegeven?	Het scenario is heel duidelijk. De verschillende stappen en onderdelen worden goed belicht en het effect is ook erg helder. Het scenario spreekt de participanten ook erg aan, omdat ze dit zelf ook zo meemaken en in de praktijk zien dat het lastig is om contact te maken met mensen met dementie. Scenario is heel duidelijk en beschrijft het verhaal. Scenario is kort en krachtig. Omslag van deel 1 naar deel 2 is ook duidelijk.
Zijn er onderdelen in het scenario die je niet (goed) begrijpt?	Wat de output concreet doet is nog vaag, dit kan concreter. Wat komt er uit die doos? Wat kun je met die tool? Het is moeilijk voor te stellen wat de doos doet.
Denk je dat de uitkomst van het concept dat geschetst wordt realistisch is?	Het beeld is erg realistisch. In het begin weten mensen nog erg veel, dus het is goed om dat dan vast te leggen. Mensen met dementie reageren in de laatste fase niet meer op woorden, maar wel op hun zintuigen. Het is dus zeker realistisch om via de zintuigen contact te maken en op die manier de herinnering op te halen.

Table 5, Scenario Evaluation Results.

Hoe denk je dat mensen in de laatste fase van dementie op het concept zullen reageren?	Omdat de zintuigen aangesproken worden, zullen mensen met dementie er goed op reageren. Het ophalen van de herinnering is wel een moment, een kort moment. Dus er moet niet gedacht worden dat dit fijne moment een uur duurt. Per persoon verschillend wat nog aansluit. Eventueel al eerder de output geven en kijken of het wat is, ipv wachten tot de laatste fase. Reacties zullen minimaal en non-verbaal zijn, maar je zult zeker de ontspanning in het lichaam zien.
Zie je knelpunten in het scenario waar meer aandacht aan geschonken moet worden?	Het moment van de herinneringen vastleggen zit wel net op de grens. Dit zou idealiter eerder plaats moeten vinden. Het moment van vastleggen is vrij laat, het kan beter eerder plaats vinden, bv. Tijdens diagnose. Het mensen leven is breed, dus er moeten meerdere herinneringen aangehaald worden. Het concept staat er op of mensen er voor open staan. Het moet geen product zijn dat in de hoek van de kamer staat, aangezet wordt en dat iemand dan achtergelaten wordt. Het moet gecombineerd worden met de mantelzorger of verpleegkundige. Dmv het apparaat connectie maken.

Table 5, Scenario Evaluation Results.

Andere opmerkingen	- Het is fijn dat mantelzorgers en professionals handvaten krijgen om contact te maken of om meer te bieden wanneer hier ruimte voor is. - De output kan deels gegeneraliseerd worden, maar zal ook ruimte moeten bieden voor specifieke personalisatie. - Er moet de mogelijkheid zijn om meerdere momenten aan te halen. De mantelzorger of verpleegkundige zou dit dan moeten inschatten of de persoon met dementie moet zelf keuzes kunnen maken dmv drukknoppen. - Je hebt een ander persoon nodig om het apparaat te activeren en die zal ook een oogje in het zeil moeten houden, om de prikkels te bewaken. - Mensen van een oudere generatie zijn niet gewend om over hun gevoelens te praten - Zouden geuren ook mogelijk kunnen zijn? Een belangrijke prikkel die weinig wordt toegepast, maar wel veel zou kunnen bieden.

Table 5, Scenario Evaluation Results.

Enabling Positive Moments to People in the Last Stages of Dementia

A personalised approach to multi sensory experiences

Master Thesis | Hannah Pak