



DOOR MIJN OGEN
TREASURING QUALITY OF LIFE
WITH THE FRAIL ELDERLY

Thesis of Lana Klok

Colofon

*Master thesis:
Door mijn ogen
Treasuring the quality of life with frail elderly*

*Defended on 14 march 2019
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Preface

This graduation project for me has not started in September 2018, but developed slowly over the years through personal experiences. Therefore it seems important to share with you, the reader of this graduation report, why I believe we should listen more closely to the elderly, than we are currently doing.

My personal motivation for this project has to do with my grandmas, oma Greet en oma Marian. The passing of my grandmothers has taught me a lot about the quality of life and how they experienced the end of it. In Dutch I would say they have taught me: “*Hoe mooi het leven kan zijn en hoe het leven ook mooi geweest kan zijn.*” To explain what I mean with this, I will share my story with you about how they passed away.

Both my grandmothers have always played an important role in my life. They used to babysit when I was little, I had ‘*logeerpartijtjes*’ at their houses and hold many precious memories of all the other things I have experienced with them.

Oma Marian was the kind of grandmother that always spoiled you with love, attention and ‘*wat lekkers*’. It was nice when she moved to a nursing home nearby our house. She fell in her room at the nursing home and ended up in the hospital with artificial respiration. In the hallway my parents, uncle and aunt were discussing whether to stop her treatment or not. My brother, cousins and I were in the hospital room with my grandmother, who was already in a deep sleep. I took her hand and suddenly she woke up. Before we knew, she wanted to go outside. So we brought her downstairs in a wheelchair without artificial respiration to enjoy the nice weather with the whole family.

I cherish how oma Marian taught me that life can be so good that you do not want to let go, but also how important it can be to let life go where and when you want to. A couple of months after the hospital admission she passed away in her nursing room home in the presence of my mother.

I admire my oma Greet for her braveness and honesty. My grandmother had been by herself since she and my grandfather split up when my father was 12. She was always very active and the grandmother with whom you went swimming or midgetgolfing. Eventually she started answering the ‘how are you’ question with; ‘I just carry on’. It seemed as if she starting to loose some of the quality in her life. At the end of her life she had the courage to say that she did not want to live anymore. I was very sad to hear this, but when looking back now I think it has been very important she shared this powerful message with my father. This way he was able to ensure her wishes could be fulfilled. She passed away in her home on the quay, where I will always remember her sitting in her window enjoying the view of all the boats passing by. Oma Greet taught me that life can be enough and how valuable it can be to share this feeling.

My grandmothers taught me a different way of looking at the difficulties of the aging society. However, not all elderly feel free to express themselves. This is why I believe that by helping the elderly to express what they desire, we can better understand what living means for them and thereby prevent care decisions that do not contribute to their personal quality of life.

Executive summary

The frail elderly struggle with mental, physical and/or social limitations and due to their deteriorating health have an increased risk to get involved with care. To ensure that care contributes to the elderly's quality of life, the care professional and the elderly should focus on the desires of the elderly to acknowledge which treatments are desirable and undesirable (shared decision making). To achieve useful communication it is necessary that the elderly are able to express their desired quality of life, however, especially for the frail elderly this is difficult. Therefore, it is useful to prepare these elderly for potential care decisions and help them to express themselves, in order to only provide them with care that actually contributes to their quality of life.

The aim of this project is:

“To design a tool for the frail elderly to help them timely express their desired quality of life, so that care can contribute to their actual quality of life.”

The desired quality of life is defined as what someone desires to do, whereas actual quality of life addresses their abilities.

To design a tool from an elderly-centered perspective, the frail elderly, and also care professionals, are closely involved in the project. This is achieved through explorative research; including interviews, observations and design interventions (research through design).

The research helped to understand desired quality of life from the perspective of the frail elderly and define it as a combination of their current happiness (meaning and connection), and their beliefs (values and character traits), which together form their wishes. For these elderly expressing their desired quality of life without aid is difficult, particularly because they perceive their future as limited. Furthermore existing tools and methods often trigger the frail elderly to think about the negative aspects of their future, such as their deteriorating health, the loss of autonomy, potential illness and mortality.

This unintended negativity is what inspired the vision to start communication with the frail elderly, when they are still relatively autonomous, and support them in portraying their desired quality of life in a tangible manner. This way they are equipped and have a means to express themselves when future care decisions need to be made.

The chosen design context for this vision is the meeting center, a day care facility supporting the socially frail elderly, who still live at home, to have a meaningful day. The meeting center employees are care professionals, who through their regular, personal contact become familiar with the elderly visitors, which makes them a suitable conversation partner. Furthermore helping a frail elderly visitor to express themselves does not only contribute to personalized care, but also helps the visitor to connect with a meeting center employee and build a relationship. In this way a conversation tool becomes a relation-centered design.

This results in the following design goal:
“**Spark** a socially frail visitor to **collect & create** their own *Quality of life Portrait* together with a meeting center employee, so the visitor can **reflect** upon their desired quality of life & **share** their wishes with others in order to treasure them together for the future.”

The design goal also presents five conversation elements, which are illustrated in a framework:

Spark - a conversation starter

Reflect - upon your life

Collect - happiness, beliefs and wishes,

Create - quality of life portrait

Share - desired quality of life.

Nine design guidelines give insight in how to achieve these conversation elements and design for the conversation's interaction, content and tool. Throughout the conversation, the desired interaction qualities are: trustful, encouraging and invigorating.

The final design ‘Door mijn ogen’ is a conversation package that contains instructions for the care professional and a booklet for the frail elderly. Thereby the tool helps the meeting center employee to prepare for their role as listener and encourages the visitor to become the narrator and writer of their desired quality of life story.

The tool was evaluated with the two collaborating companies (elderly care institution Pieter van Foreest and service design bureau Muzus), which resulted in opportunities for future development and application of the tool. The vision and design brief are as relevant as the conversation tool, and hold the potential to inspire further design and research. This project shows a way to help the frail elderly express their desired quality of life in order to improve their actual quality of life by preparing them for personalized care decisions.

Glossary

Advance Care Planning

Abbreviation: ACP;

A conversation driven approach which promotes care professionals and patients to start communicating about their values, desires and goals, to be able to anticipate upon potential care decisions

Advance Health Care Directives

Abbreviation: AHD;

A tool for people to document their end of life wishes and boundaries regarding care, i.e. non-resuscitation, treatment interdictions, euthanasia and a designated representative

Care

All the formal and informal care that supports the elderly in their physical, mental and social well-being.

Informal caregiver

People from the social network of the elderly that perform care activities

Formal caregiver

People with a relevant professional background that perform care activities

Medical care professional

Formal caregiver that focusses on the physical and mental health of the elderly by providing treatments and/or medication

Psychological care professional

Formal caregiver that focusses on mental and social well-being of elderly by improving these through conversations

Spiritual care professional

Formal caregiver that focusses on social and mental well-being of elderly by helping them to reflect on their life

Daily care professional

Formal caregiver that support elderly 's social, mental and physical well-being through personal, daily care contact

Care decision

The moment when the elderly and care professional decide upon further care

Communication

Personal communication between a frail elderly and a care professional.

Conversation elements

Essential elements to reach the purpose of the conversation

Frail elderly

older people of over 75 years of age, who experience limitations in their mental, physical and/or social well-being and therefore have an increased need for additional care

Meeting center

Day care facility for frail elderly people, who can not stay independently at home each day of the week due to their physical, social or mental limitations

Meeting center employee

Daily care professional that is responsible for the activities and a group of elderly at the meeting center

Multi disciplinary meeting

Abbreviation: MDO;

A meeting between multiple caregivers including formal and informal to discuss the state of the elderly

Person-oriented care

Providing care that is appropriate for an individual person

Pieter van Foreest

Care institute focussed on elderly people,
located in the surroundings of Delft

Quality of life

An individual's perception upon their
quality of life, which is defined in the
following components:

Happiness

meaning & connection

Beliefs

values & character traits

Health

social, physical and mental well-being

Independence

autonomy vs. dependency

Shared decision making

A form of communication in which care
professionals and patients acknowledge
together which treatments are (un)
desirable by focussing on the desires of
the patients

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PART II

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STEPPE CARE IN DE PRAKTIJK

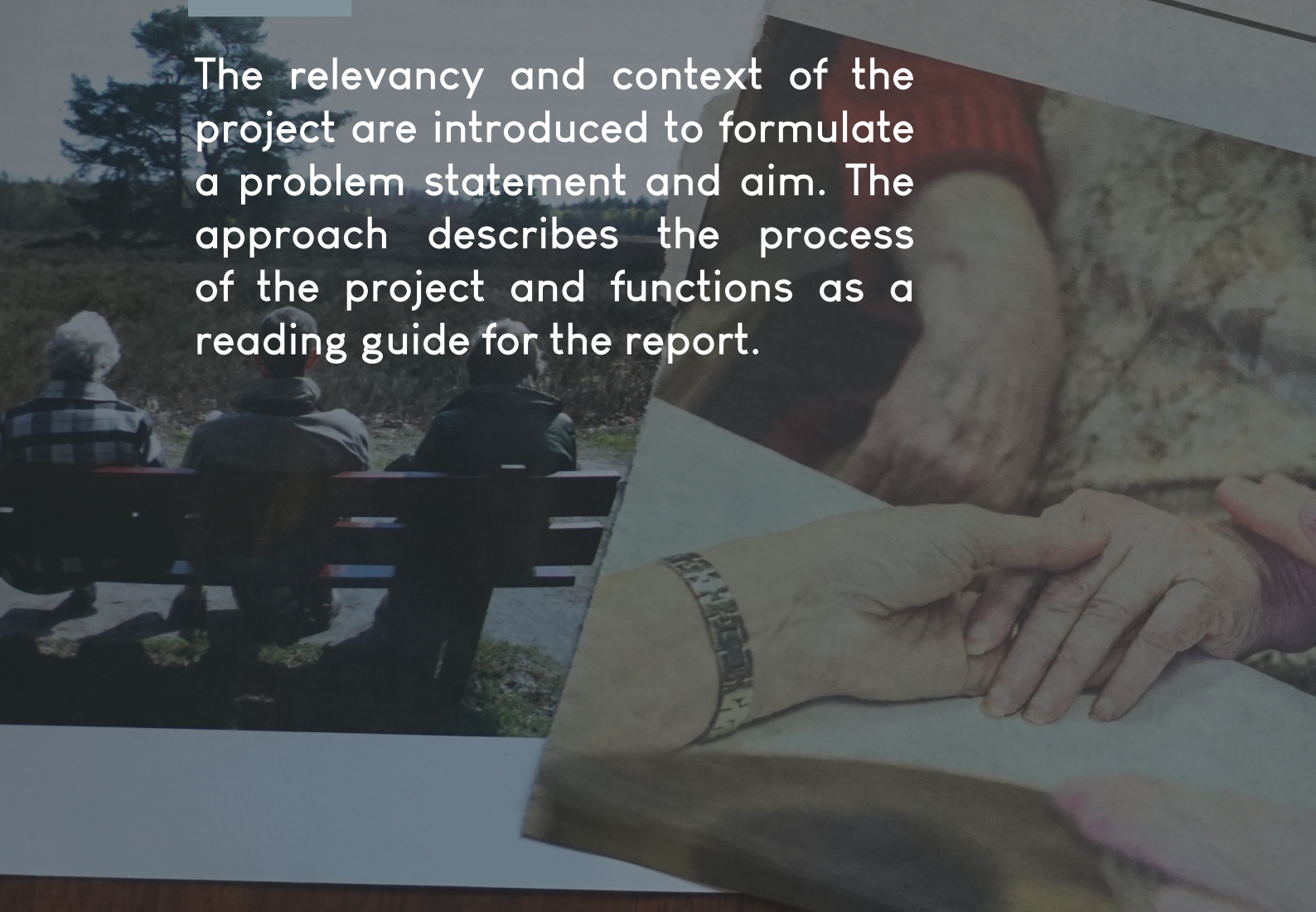
Thuis als het kan

de toekomst is nu

De Velp is het aandeel senioren onder de bevolking
in Nederland over twee tot drie decennia het geval
onbedoeld tot een proeftuin voor de vraag hoe
men bij deze mate van vergrijzing. Een goede reden
om erop te bekijken.

1. INTRO

The relevancy and context of the project are introduced to formulate a problem statement and aim. The approach describes the process of the project and functions as a reading guide for the report.





4 In het nieuws

Ouderenzorg

INTERVIEW **CORINNE ELLEMEET**

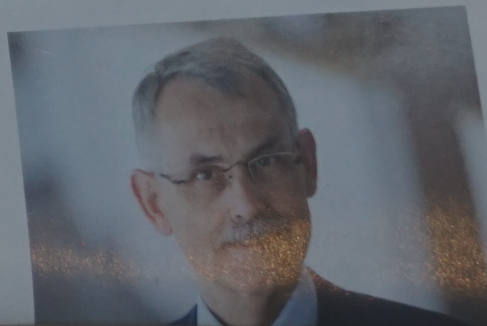
'De beste zorg is soms ook om ouderen niet te behandelen'

Veel ouderen hebben het zwaar - of ze thuis wonen of niet, stelt GroenLinks in een initiatiefnota. Aan eindeloos behandelen is niet a behoefte. En ja, minder medisch ingrijpen kan ook geld schelen.

FEDERATIENIEUWS

'De dood is geen nederlaag. Een dood is dat wel'

Tijdens het congres kwaliteitskader palliatieve zorg Nederland sprak KNMG-voorzitter René Héman in een videoboodschap over zorg die niet gericht is op genezen, maar op het verlichten van lijden. Lees hieronder zijn speech.



bevestigt ook dat zijn boodschap nog altijd geen gemeengoed is.

Zijn boodschap is samen te vatten in drie punten:

- Palliatieve zorg moet al veel eerder in het ziekteproces worden gegeven.
- Alle zorgverleners, betrokken bij het sterven, moeten in palliatieve zorg worden getraind.
- Zorgverleners moeten nooit verg...

1.1

Prologue

We are living in an aging society, in which medical treatments have the potential to extend the life of many (Centraal Bureau voor de Statistiek, 2018; Smits, van den Beld, Aartsen, & Schroots, 2014). The rapid aging of the population also burdens healthcare. Especially in the final stages of people's lives, a large increase in personal health expenditure is found (Alemayehu and Warner, 2004).

Extended quantity of life does not always imply quality of life (Groen links & Ellemeet, 2018; Van Steenberg, 2018; Weeda, 2018). To ensure the quality of a longer life, it is important to help the elderly communicate what they really desire, instead of only providing them with care possibilities to prolong their life (KNMG, 2015; Plaisier, Broese van Groenou, Deeg, 2011).

Shared decision making is a form of communication in which care professionals and patients acknowledge together which treatments are desirable and undesirable by focussing on the desires of the patients (Barry & Edgman-Levitan, 2012). This form of care communication differs from more traditional approaches in which the medical care professional decides what is best for the patient or has an informative role to help the patient decide, thereby holding the potential for a patient centered approach. Furthermore supporting people in shared decision making could potentially lead to fewer hospital admissions (Veroff, Marr & Wennberg, 2013) .

Shared decision making for frail elderly is only just at the initial stage (Van de Pol, Fluit, Lagro, Lagro-Janssen en Olde Rikkert, 2017). Especially for this target group the process requires preparation to enable a useful conversation (Van de Pol, Fluit, Lagro, Lagro-Janssen en Olde Rikkert, 2017; Vilans, 2018). For these elderly shared decision making could play an important role to ensure they only receive care that contributes to their quality of life.

1.2

Relevance

Shared decision making with frail elderly

A good preparation, appropriate communication and a person-oriented approach are important to enable shared decision making with the frail elderly (Pel-Littel, van de Pol, de Boer, & Delmee, 2018; Van de Pol et al., 2017). This preparation should take place before urgent care decisions have to be made.

Timing

A timely conversation about quality of life and the future gives the frail elderly time to think and holds potential for an elderly-centered approach. So later on care decisions can be made based on the elderly's desires together with their relatives and care professionals (My Futures, 2018; Singer et al., 1998; van Soest-Poortvliet et al., 2015).

Approach

Literature shows that current approaches should be reconsidered to ensure future care communication better suits the perspective of the elderly and is employed in a timely way (Sudore and Fried, 2010; Singer et al., 1998; Robinson et al., 2011).

Advance healthcare directives, also referred to as living wills, help the elderly declare which treatments they do (not) desire, when their health deteriorates beyond a certain point (KNMG, 2017). In recent years question marks have been placed regarding the usefulness of such a document driven approach (Hertogh, 2017; Singer et al., 1998). Advance Care Planning, which is a communication driven approach, seems to hold potential (Mullick, Martin and Salnow, 2013; Hertogh, 2017).

Advance Care Planning (ACP, or in Dutch "vooruit kijken op zorg") includes a series of conversations between a medical care professional and an elderly person, possibly also involving relatives (Van Soest-Poortvliet et al., 2015).

Mullick et al. (2013) state that: "*Advance care planning discussions should be centered around the beliefs, goals and values of patients, rather than on specific outcomes or interventions.*"

The purpose of this approach is to encourage timely conversations to give the elderly some autonomy in potential care decisions (Mullick et al., 2013).

Although advance care planning seems to be a step towards timely and elderly-centered conversations, this approach still faces some hurdles. First of all the conversations often start too late, since advance care planning is usually applied when the patient has an advanced stage of frailty, such as a progressive illness, or are facing the end of life (Van Soest-Poortvliet et al., 2015; Singer et al., 1998; Robinson et al.; 2011).

Secondly, even though literature describes the potential benefits of also applying advance care planning outside of the medical context, it usually takes place in a hospital environment (Caplan, Meller, Squires, Chan, & Willett, 2006; Van Soest-Poortvliet et al., 2015).

Sensitive topic

Besides the timing and the approach, the future quality of life is also a sensitive topic. Not only because people prefer not to think about the negative aspects of aging, but also because it is difficult to express desires for the future (My Futures, 2018; WRR, 2017)

1.3

Context

Topics and collaborating partners

The context of this project is defined by the following topics: frail elderly, quality of life, care and communication, as well as the collaboration with elderly care institution Pieter van Foreest.

Frail elderly

The frail elderly can be described as older people who experience a multitude of limitations in their health, which results in a growing vulnerability (Fried, Ferrucci, Darer, Williamson, & Anderson, 2004). As a consequence, their risk of becoming dependent on additional care increases (Van Iersel, Jansen, & Olde Rikkert, 2009).

Since the term frailty does not have a standard definition nor a set list of criteria, besides being related to health limitations, health and the elderly are further defined (Fried et al., 2004; van Iersel et al., 2009). Health is defined as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” by the World Health Organization (1948).

Furthermore, the definition for elderly is reviewed and it is proposed to define them as people over 75 years of age (Orimo, Ito, Suzuki, Araki, Hosoi & Sawabe., 2006).

In this project the frail elderly are older people of over 75 years of age, who experience limitations in their mental, physical and/or social well-being and therefore have an increased need for additional care.

Quality of life

The WHO (1997) defines quality of life (QoL) as “an individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns.”

This project makes a distinction between a person’s actual and desired quality of life based on Fayers & Sprangers (2002). Desired quality of life addresses what someone would like to do, whereas actual quality of life implies what they are able to do (Figure 1). The desired and actual quality of life relate to each other and together form the individual’s perception of their quality of life. In this project a satisfactory quality of life is defined as the moment when an individual experiences that their actual quality of life meets their desired quality of life (Figure 1).

To measure quality of life the WHO (1997) formulated six domains: physical health, psychological, level of independence, social relations, environment, spirituality/religion/personal beliefs. These six domains are combined into four components, which in this project form a basis to describe quality of life (Figure 2). Figure 2 also shows how the components are dependent on one another and how they together form the quality of life.

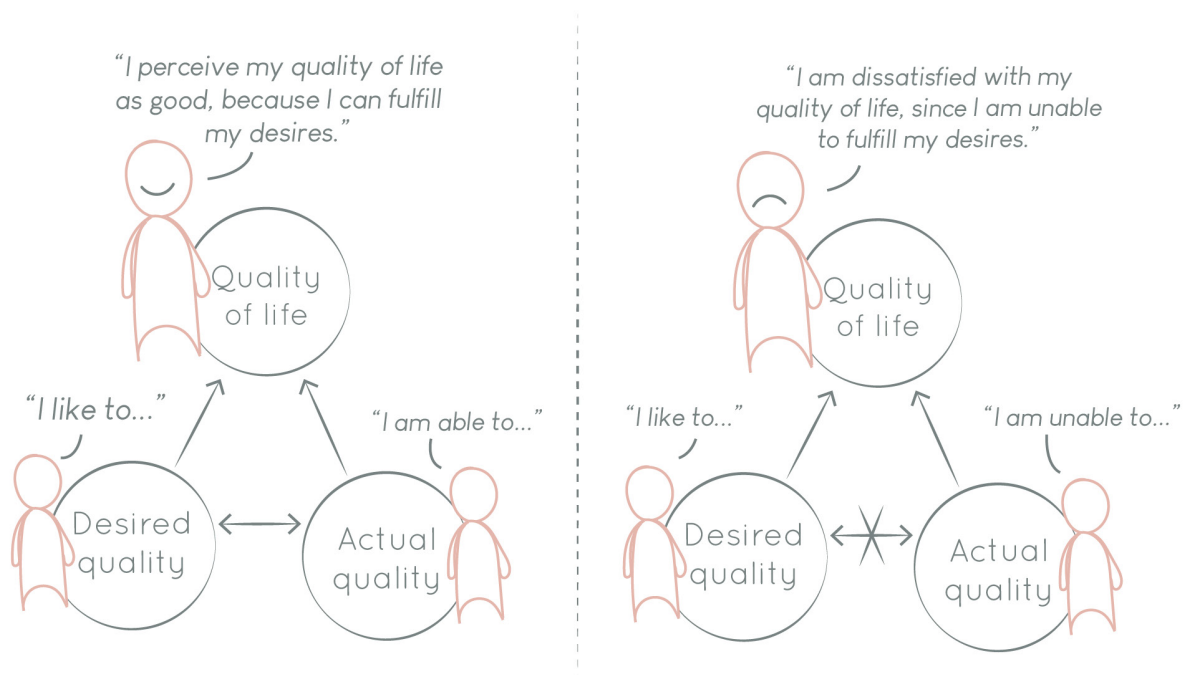


Figure 1. Perception of quality of life based upon desired and undesired quality of life.

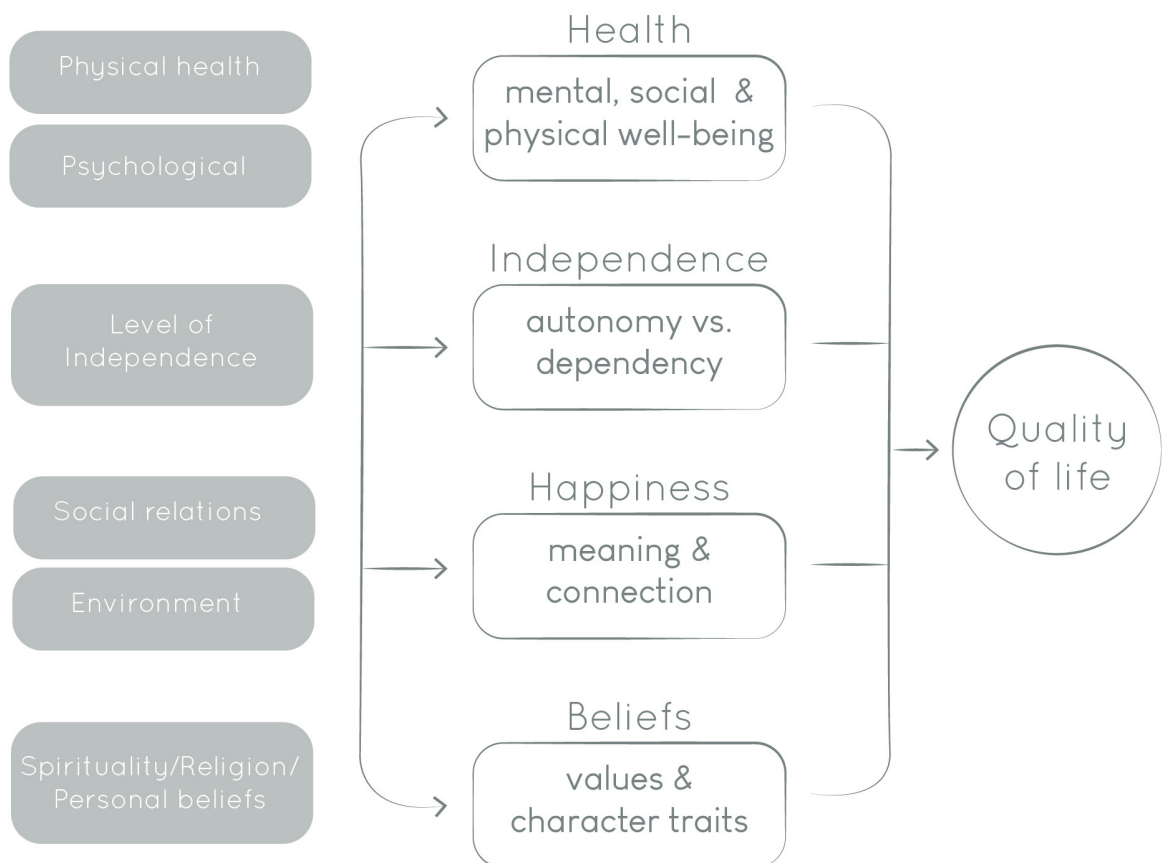


Figure 2. Combining the domains of the WHO (1997) into four components to describe quality of life.

"My health does not hinder me in my daily being."

Health

mental, social & physical well-being



"I am able to make my own decisions and go my own way."

Independence

autonomy vs. dependency



"I am happy, when I can do what matters to me and be with people that are important to me."

Happiness

meaning & connection



"I can stay true to who I am."

Beliefs

values & character traits



Health

The WHO (1997) describes the physical health and psychological domain, which is combined into the component health. Health is a dynamic principle, which fluctuates during someone's life. The elderly have already passed their optimum point of physical, mental and social well-being, as their health only deteriorates as they age. Health is defined as a physical, mental and social state of being of the elderly.

Independence

The WHO (1997) also formulates the level of independence as a domain of quality of life. The personal experience of independence is a balance between someone's autonomy and their dependency on other people and means.

Happiness

The domains social relations and environment, among others, describe personal relationships, someone's living environment and leisure activities (WHO, 1997). Feeling connected to people and places, as well as being able to participate in activities, can give someone's life meaning, and thereby make them happy (Stavrova & Luhmann, 2016; Gabriel & Bowling, 2004).

Beliefs

The WHO (1997) defines the domain religion, spirituality and personal beliefs. These beliefs include values that motivate and guide people in their life (Schwartz, 2012). The beliefs of someone are also represented in the unique set of character traits that describe their personality (Allport, 1937).

Care

Care is defined as all the formal and informal care that supports the elderly in their physical, mental and social well-being. Formal caregivers are people with a professional background, whereas informal caregivers are people from the social network of the elderly.

Communication

The communication described in this project is a conversation between elderly and caregivers, which might involve tools that support the interaction.

Collaborating partners

This project was executed in collaboration with elderly care institution Pieter van Foreest and service design bureau Muzus.

Muzus

Muzus is a service design bureau that closely involves the target group through qualitative research (Muzus, n.d.). They design for solutions with a positive impact for both the company and their clients. These solutions among others are client journeys, personas and conversation tools.

Pieter van Foreest

The collaboration with Pieter van Foreest creates a practical context for this project. This organization specializes in elderly care in the region of Delft (Pieter van Foreest, n.d.-a). Pieter van Foreest offers care services at home and intramural care (nursing homes) for the frail elderly, and is representative for other traditional elderly care institutions in the Netherlands, of which Cordaan and Laurens are some examples.

Pieter van Foreest strives to provide person-oriented care meaning that the elderly are seen as individuals and so a personalized care package can be made. Among others this package could include home care, meeting centers for day care and nursing homes.

Furthermore Pieter van Foreest sees these elderly and their social network as a whole and tries to support both. By professionally taking care of the elderly, they also ease the burden of their informal care givers. Their vision is “*Being yourself, together, exceeding expectations*”.

**“Samen jezelf zijn,
boven verwachting.”**

Vision Pieter van Foreest

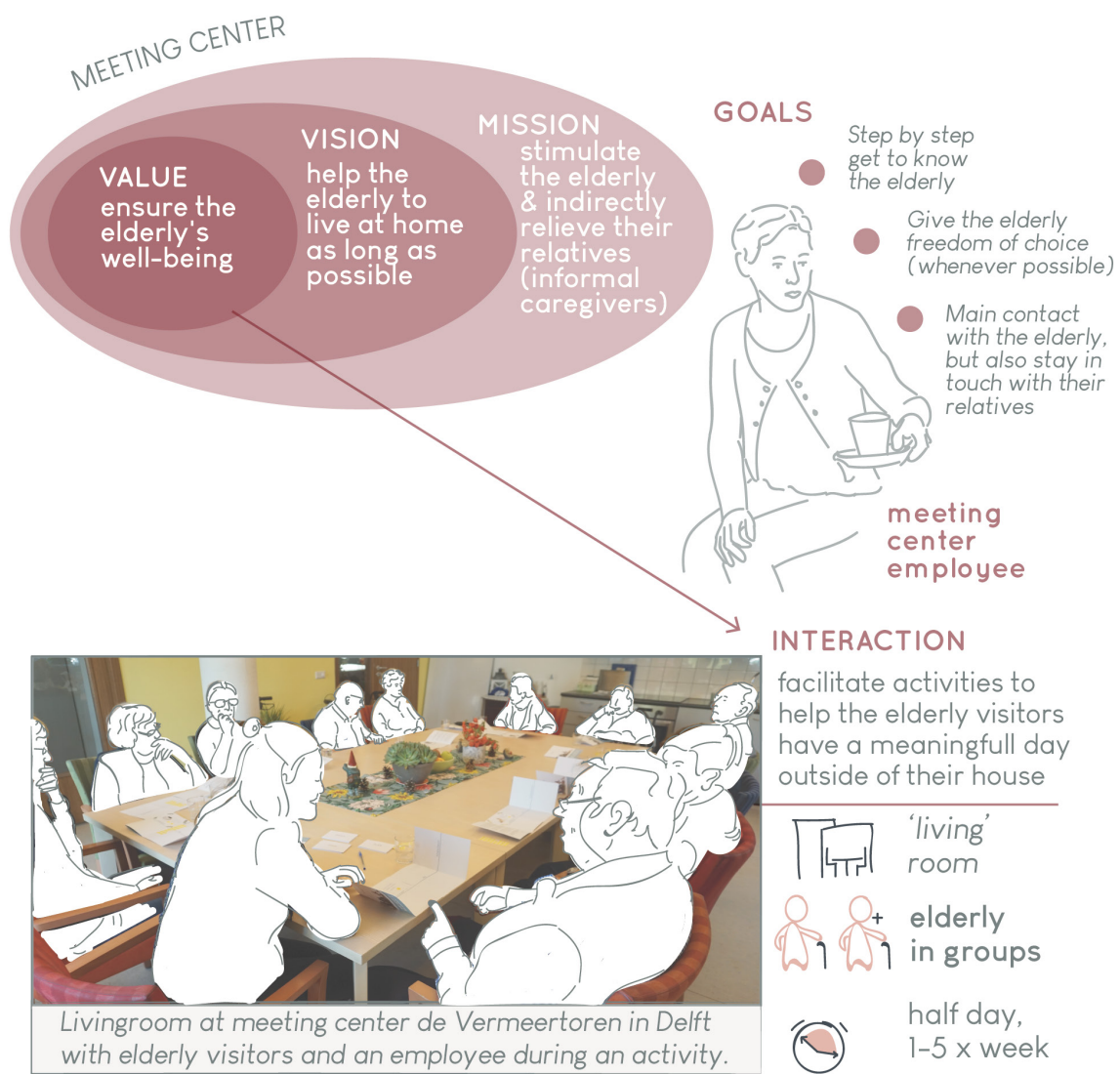


Figure 3. The meeting center; a day care facility for frail elderly.

The meeting center is a facility that offers day care for frail elderly, who still live at home, but struggle with mental, physical and/or social disabilities (Figure 3). The meeting center employees strive to help these elderly have a meaningful day by organizing group activities and providing them with a hot meal at noon.

The elderly visit the meeting center multiple days a week from the morning till the afternoon. In their living room they meet other elderly and follow a day program led by a meeting center employee. Every morning the elderly can choose an activity of their choice, including memory training, movement exercises and creativity practices. In this project the focus lies on the elderly with social and physical limitations, not on those with mental disorders, such as dementia.

1.4

Problem statement & aim

Problem statement

Shared decision making has the potential to help the frail elderly acknowledge which care corresponds with their desired quality of life. However, for frail elderly this process requires preparation and time. Currently the timing of such conversations is often too late and the approaches originate from a medical perspective, which defines the elderly as patients rather than people. *Furthermore quality of life is a sensitive topic, because it is difficult to express desires for the future.*

Aim

This project researches and designs for an opportunity to enable elderly-centered communication about desired quality of life, which serves as a basis for shared decision making and results in person-oriented care. The aim of the project is:

“To design a tool to help the frail elderly timely express their desired quality of life, so they receive care that contributes to their actual quality of life.”

1.5

Approach

Part I, II & III

This project has an explorative nature. To enable an elderly-centered design the project closely involves target group, the frail elderly, and also care professionals through various qualitative research methods. The project is divided into three parts: Part I Research, Part II Design research and Part III Design. Figure 4 shows a schematic representation of the process and project.

Part I: Research

By analysing the current context an opportunity for the design is defined. This results in a vision, which is simplified and specified in a conceptual frame. Part I answers the following question: *“When and how should the communication about quality of life with the frail elderly take place?”*

The analysis answers four sub-research questions to define the current context:

1. Who are the frail elderly?
2. How do the frail elderly perceive quality of life?
3. What is the care context for the frail elderly?
4. What shapes the care communication with the frail elderly?

To answer these questions, the following activities took place: observations at elderly care services, interviews with the frail elderly, interviews with care professionals, an evaluation of existing tools and methods, and literature research.

Part II: Design research

The defined opportunity is explored in a specific case: the meeting center. This results in a design brief that combines the insights of the exploration, the vision and the conceptual frame. Part II answers the following question:

“How to design for the initial desired quality of life conversation in the meeting center?”

The exploration helps to further define the conceptual frame and answers the following three questions:

1. What is the right interaction for the conversation?
2. How to address the topic desired quality of life?
3. How to design a tool for the conversation?

To gather knowledge three interventions took place with visitors of the meeting center using design prototypes based upon ideation activities. Also, a feedback session was held with employees of the meeting center and the company mentor of Pieter van Foreest.

Part III: Design

In the third part of this report the formulated design brief is used to design a conversation tool for the frail elderly and meeting center employees. This tool is evaluated with representatives of both Pieter van Foreest and Muzus.

Reflection

Finally a reflection upon the contributions of the project, the process limitations and recommendations and personal learnings is presented.

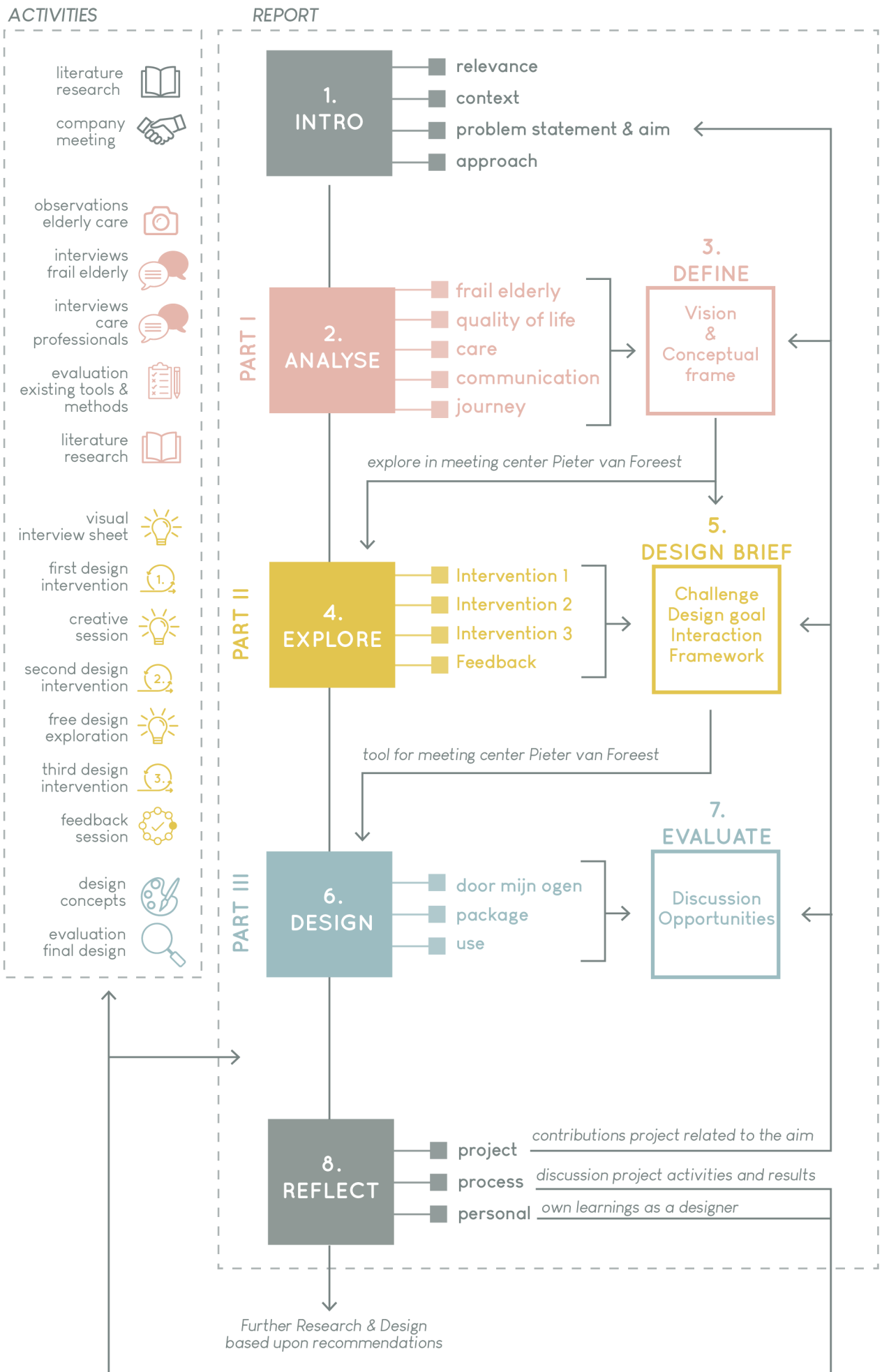


Figure 4. The project explained through its activities and the results in the report.

2. ANALYSIS

The analysis describes who frail elderly are and how they perceive quality of life, and gives insight in the current care context and communication, in order to define design opportunities.





> Verloskundige

> Huisartsen
Fysiotherapie

< Centrum voor Jeugd & Gezin
Careyn Thuiszorg / Dienst

2.1

Frail elderly

Who are the frail elderly?

Observations at elderly care services and interviews with four frail elderly took place to become acquainted with the target group (Appendix A, Appendix B). These findings are concluded in the persona *Tine* to make the target group come alive in the report.

Confrontations with frailty

While the elderly do not always identify themselves as old people, on the other hand they are confronted with their age in their everyday lives.

“We zijn oude mensen, we kunnen altijd wat krijgen.”

visitor of meeting center

Frailty comes with age and could cover a combination of mental, social and also physical health aspects that limit the elderly in their everyday being. To illustrate, the frail elderly experience feelings of loneliness due to little social interaction or have difficulties performing their daily routines because of physical inabilities.

“Ik ben kwetsbaarder geworden. Als ik struikel over de drempel dan stort mijn wereld in.”

elderly man (observations)

To overcome some of these limitations the frail elderly have to rely on the help of others to live their day to day lives.

When the support of their social network, such as their partner, family or relatives, becomes insufficient, they become dependent on additional professional care services. The more the elderly have to rely on others and care services, the less free they are to make their own decisions and plan their lives. An increasing dependency results in a loss of their autonomy. In time this expresses itself in three phases related to the elderly's living situation and care (Figure 5).

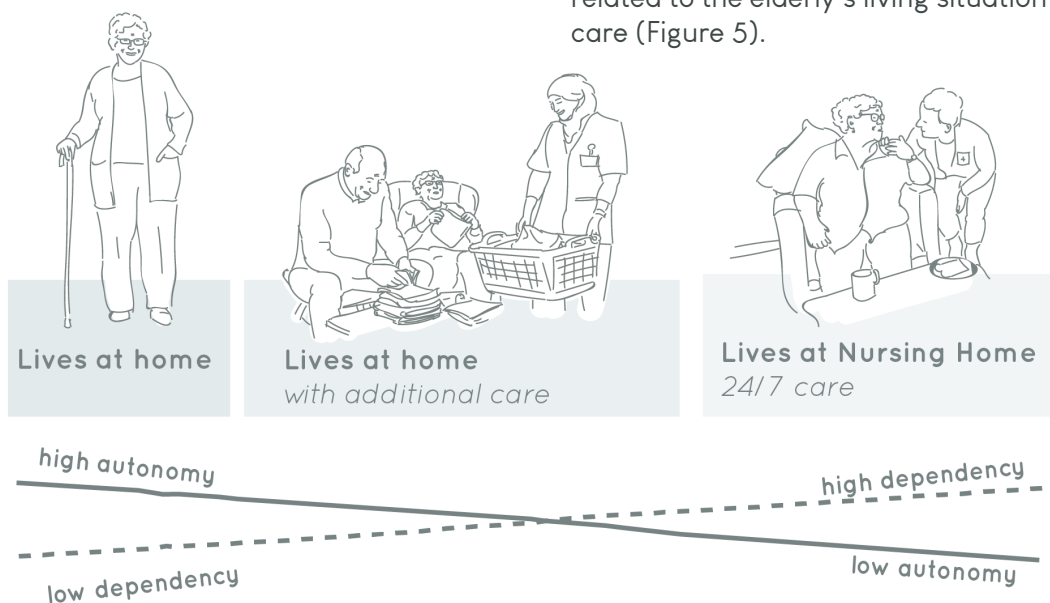


Figure 5. Three care and living phases in the life of an elderly person with increasing frailty.

Past, present and future

Frail elderly have lived the largest part of their life. Their past forms their perception of the now and influences their perspective on the future.

Listening to their stories learns that a lot of their values and character traits from the past are still visible in their current beliefs. But how their beliefs express itself now in what matters to them, differs from how it used to be.

“Vroeger waren dingen belangrijk, die dat nu niet meer zijn.”

visitor of meeting center

The dynamics of life, among others, express itself in the elderly's loss in abilities, as well as the people around them. For this reason the elderly readjust their meaning and connection in life and try to find their happiness in things they are still able to do and spend time with people who are still around.

In the interviews the elderly also express that they experience their future to be limited and when this becomes a topic of conversation they often only address their mortality (Laureiro-Martinez, Trujillo, & Unda, 2017).

“Ik heb toch niet het eeuwige leven.”

elderly woman (interviews)

Introducing four frail elderly

The four interviewed elderly are briefly presented to illustrate how they find their happiness in their daily lives, and how their past influences their beliefs and future perspective (Figure 6, page 26-27),

Saar is a real family person. She grew up as one of the youngest in a family of eleven. She still values the presence of family and enjoys it a lot when her children and grandchildren come to visit. But her (grand)children would rather not talk about her funeral.

Lianne is a caring type, and independent woman. When her husband became ill, she got a job to take care of her family. She loves to cook for her children and grandchildren, but she would never want to become a burden to them.

Gerrit is an adventurous elderly man who finds it important to keep developing himself. He used to discover new worlds through diving and flying. Now he enjoys watching documentaries and being surrounded by youngsters, to keep exploring in his current life. Gerrit has already thought about a farewell ritual, but it is not the time for it yet.

Jaap is a hard working man, who values tradition. He followed the steps of his father and grandfather, and worked in the same factory as them. The factory was his work and social network, so after his retirement he felt a void in his life. Now he makes photographs and CD's, and tries to keep enjoying his life.



GROWING UP

ADULT LIFE

CONNECTION

Saar, 95
enjoys her ever-growing family // writes poems

Heeft 7 broers en 3 zussen "Mijn oudste zus had een hele andere jeugd. Ik kon altijd buitenspelen."

Heeft van jongs af aan gezwommen tot haar 90e.

"Elke donderdag eet ik bij mijn zoon. (...) Mijn dochter komt elke week langs."

Lianne, 85
connector of the family // shares her cooked food

Vader overleed toen ze 11 was. "Ik was echt een vaderskindje."

"Toen [man ziek werd] ben ik gaan werken. En 1 jaar werd 30 jaar."

"De meiden weten alles." [over dochters]

Gerrit, 84
curious // likes to discover "new" worlds

"Ik heb diepe respect voor mijn vader."

"Ik heb alles gedaan, parachute springen, vliegen, sportduiken."

"Mijn dierbare dochter."

Jaap, 77
is never bored // likes to make photos and cd's

Vader en opa werkten ook bij de Gist fabriek.

"Ik werk van begin af aan bij de Gist [fabriek]."

"Het belangrijkste weten zij [kinderen] van mij."



MEANING

TODAY

FUTURE

MORTALITY

"Ik ga dan liever een keer [naar blijdorp] met de kleintjes [achterkleinkinderen]."

"Het is zo'n leuk kado [persoonlijk foto boek familie] je hebt verder niks meer nodig."

"Ik heb het wel eens over mijn uitvaart, maar daar willen ze [familie] het liever niet over hebben."

"Ik wil weten hoe ze wonen." [over kleinkids]

"Ik draag nooit broeken, altijd rokken."

"Ik wil niemand belasten. (...) Ik hoef niet zo [lamledig] in de stoel te zitten."

"Ik heb toch niet 't eeuwige leven."

"Ik heb tot mijn 81e gewerkt in het onderzoek."

"De mooiste herinneringen heb ik van boven af."

"Ik heb al een afscheidsritueel bedacht."

"Het is nog niet heel actueel."

"Als je werk wegvalt, val je in een leegte."

"Ik ben een mens van de dag"

"Ik wil nooit bij mijn kinderen intrekken. Ik wil ze niet tot last zijn."

"Leven is voor mij niet zo belangrijk, kwaliteit wel. (...) Als je plezier in het leven verliest."

Figure 6. The four elderly who were interviewed presented through their quotes.

Persona: Meet Tine

The insights from the interviews and observations inspired the persona, Tine. (Figure 7). This persona illustrates the beliefs and happiness of an elderly woman, and also shows how her physical and social health limits her daily life and influences her autonomy.

Conclusion

Elderly are confronted with their frailty through their deteriorating health and the decreasing autonomy. Getting to know these elderly involves learning how their past relates to their beliefs, listening to how they currently perceive happiness in their lives and respecting that their future time perspective is limited.

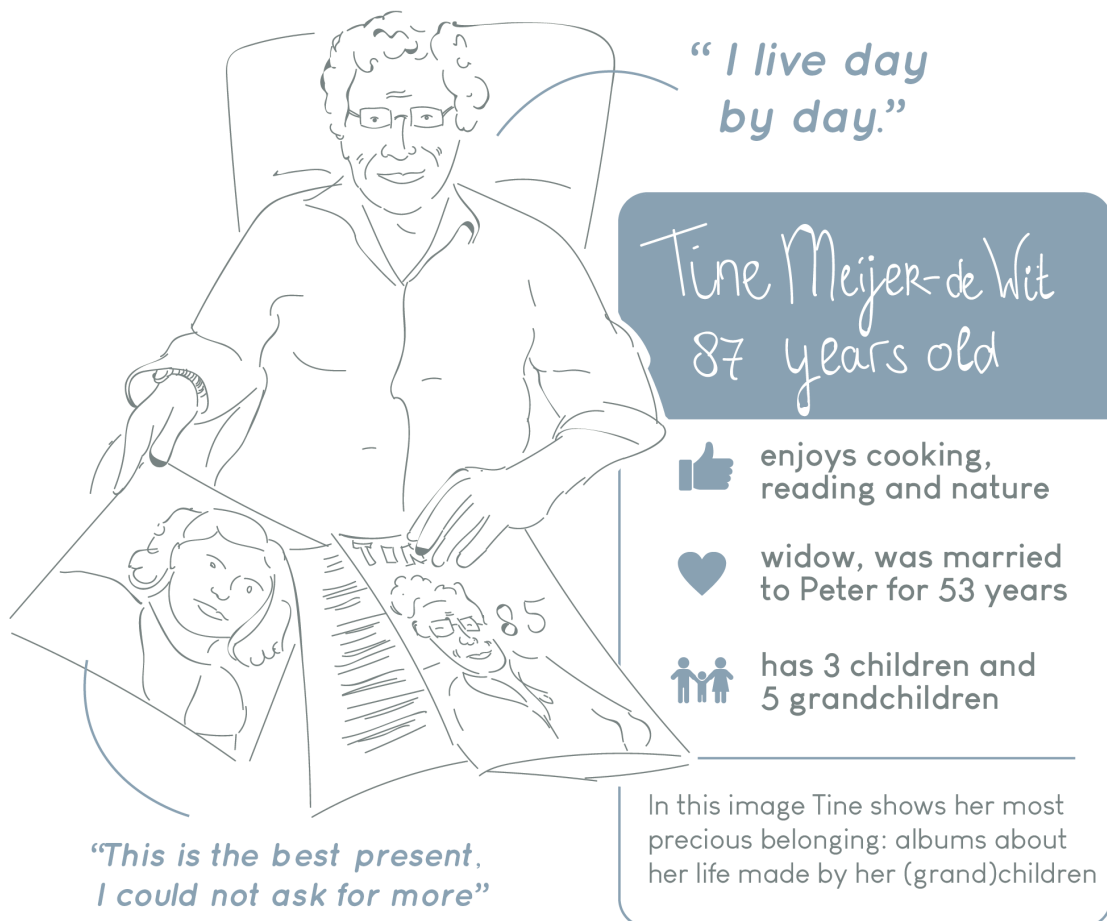


Figure 7. Persona Tine, including a day in her life.

A day in Tine's life

7:30	a nice long shower This relaxes my worn knees. So on days when I don't visit the meeting center, I do this.	<i>"I cannot clean my house anymore, due to my sore knees"</i>
8:00	sitting by the window I watch the children go to school. The neighbourhood has changed, I am almost the only old lady around.	<i>"I have lived in my house for over fifty years "</i>
9:00	coffee with home care Every morning the lady from home care comes to help me with my stockings and medication.	<i>"I prefer to wear skirts."</i>
11:00	call with my daughter One of my daughters works as a teacher. I try to call her during the morning break. She has a busy life.	<i>"My girls know the most important things about me"</i>
12:30	read a book and have lunch I usually make myself a sandwich around noon. I eat in my comfortable chair, while reading a book.	<i>"I use to work as a secretary. I know my way with words."</i>
15:00	walk through the park Peter and I used to love taking a stroll, when we went to do our grocery shopping. I really miss him.	<i>"I really miss him, we use to do everything together."</i>
17:00	cooking for my grandchildren My granddaughter loves my recipe for 'stoofpeertjes' so I always make those when she visits on wednesday.	<i>"I was raised in a large family. I really enjoy having family around."</i>
20:00	watch the news Not everybody is interested in the news, but I like to know what is going on. After the news I get ready for bed.	<i>"I like to stay up to date."</i>

2.2

Quality of Life

How do the frail elderly perceive quality of life?

To enable the elderly to express their desired quality of life, the project explores how they perceive quality of life. Through interviews with the frail elderly and literature research a distinction is made between their actual and desired quality of life, to support the elderly in seeing their limited future from a positive perspective.

Actual and desired quality

The interviews with the elderly teach us that quality of life is important for them. While they sometimes struggle to further define what it means to stay happy and healthy.

“Het leven is niet zo belangrijk, kwaliteit wel (...) Als je plezier in het leven verliest.”

elderly man (interview)

Furthermore the elderly also assume that others know what they want. So helping the elderly become aware of their desired quality of life could not only help them, but also others to better understand their wishes.

“Het belangrijkste van mij weten ze [de kinderen] wel.”

elderly man (interview)

Throughout the interviews the elderly often mention people or activities that bring them joy. This could be social activities, like catching up with their relatives, or more individual activities, such as cooking a meal or practicing a hobby. These positive aspects in their life give an idea of their personal view of meaning and connection. They indirectly address their desired quality of life by describing their happiness and beliefs.

On the other hand the elderly also mention the inability to do certain things, like putting on their own stockings, or describe a physical limitation, which they relate to an unsatisfactory quality of life. This way the elderly describe the (potential) limitations in their actual quality of life, referring to their health, as well as their level of independence

“Ik wil niemand belasten (...). Ik hoef niet zo lamleendig in een stoel te zitten.”

elderly woman (interview)

As long as these limitations do not have too much impact on their desired quality, the elderly are satisfied with their quality of life. If it does affect their desired quality they can either cope with their actual quality of life by adjusting their desires, or accept help, for example by receiving appropriate care to improve their actual quality of life. This illustrates that quality of life is dynamic and relates to the elderly's desired and actual quality of life.

Defining desired quality

Based upon the findings considering the elderly's actual and desired quality of life three questions are proposed. These questions help to understand the desired quality of life from the perspective of the elderly and introduce related themes. By helping the elderly express their desired quality of life it is easier to understand how their actual quality might limit them in their being. Therefore these questions take a positive stance towards their future, by focussing on the elderly's happiness and beliefs, rather than on their limitations. To illustrate a possible interpretation of these themes, Tine's persona is used as an example (Figure 8).

Who are you?

Beliefs: values and character traits

This question refers to the elderly's character traits and values, which are shaped by the now and their past.

What matters to you?

Happiness: connection and meaning

This question refers to the present of the elderly person and how they currently perceive meaning and connection in their life.

What do you desire?

Wishes for now and the future

The final question refers to wishes for now and the future. The elderly's answers to the other two question form a positive basis to think about later.

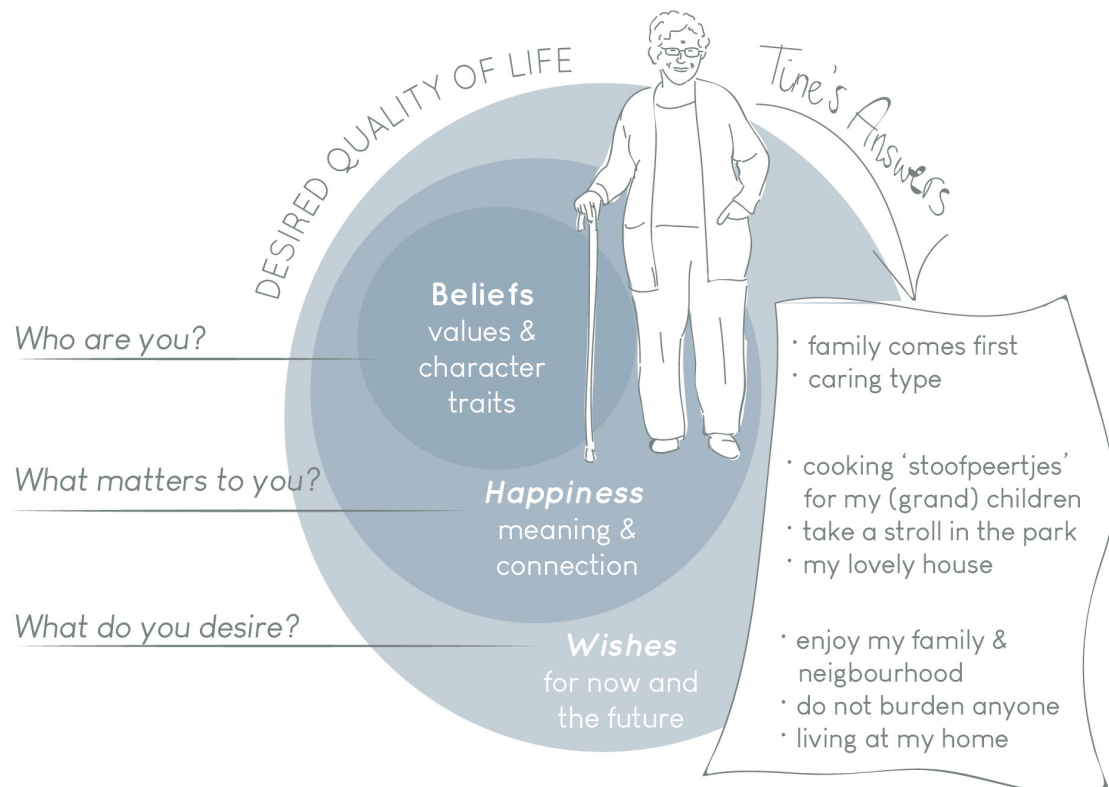


Figure 8. Desired quality of life questions and themes, also showing Tine her answers.

Conclusion

Actual quality is defined by the (in)abilities of the elderly, and mainly address their health and independence. While desired quality of life evolves around their happiness and beliefs.

Since the elderly's actual quality of life changes over time, also their desired quality of life is dynamic.

The following questions and themes can help the frail elderly define their desired quality of life:

- Who are you?
(Beliefs: values & character traits)
- What matters to you?
(Happiness: meaning & connection)
- What do you desire?
(Wishes for now and the future)

Helping the frail elderly to express their desired quality of life, also helps others to understand their perspective. This helps to clarify how limitations influence the elderly's perception of their quality of life, and if they might benefit from receiving care.

2.3

Care

What is the care context for the frail elderly?

The formal and informal care context is mapped to clarify who is involved in caring for the frail elderly and how. A better understanding of the different types of care helps to understand their relationship to the elderly. The information was gathered through interviews with different care professional, the interviews with elderly and observations at elderly care services (respectively Appendix C; Appendix B; Appendix A).

Formal care clusters

The interviews with care professionals resulted in four formal care clusters: medical, spiritual, psychological and daily (Figure 9). The criteria for this clustering is based upon how the care professionals contribute to the health of the elderly – mental, physical or social well-being – their professional objective, and the characteristics and context of the interaction.

On pages 34–35 the four clusters are explained. For a more detailed description per interviewed professional, and how and why the elderly get in touch with them, see Figure 14 pages 36–37.

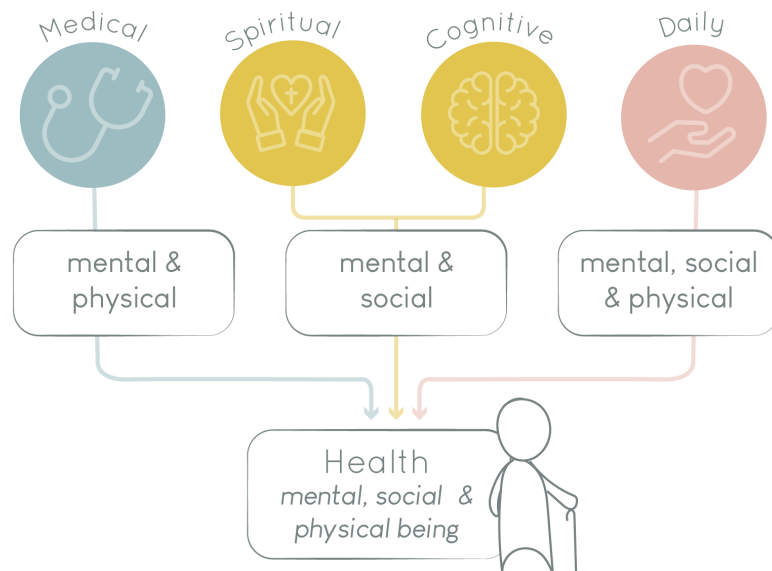


Figure 9. How the care clusters relate to the health of the elderly.

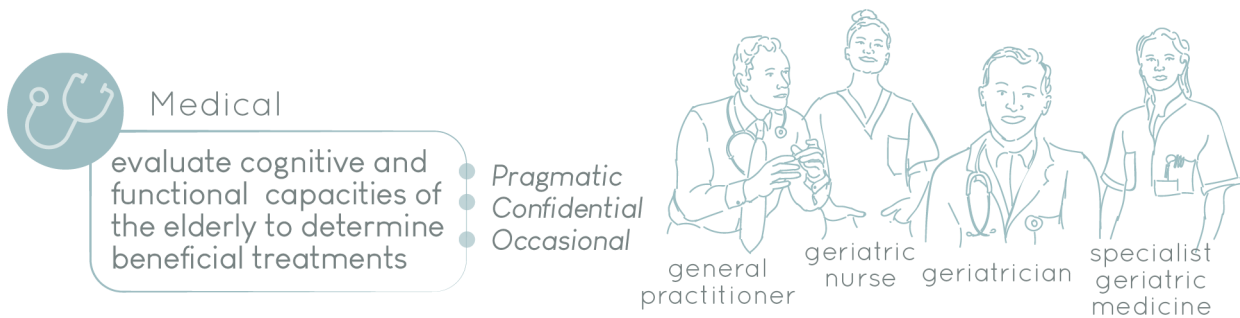


Figure 10. Medical care cluster: role, characteristics, professionals

The interviews with a geriatrician, geriatric nurse and specialist geriatric medicine resulted in the medical care cluster (Figure 10). This cluster focusses on the physical and mental health of the elderly by providing treatments and/or medication. Medical professionals are doctors and nurses, who meet the elderly, and usually also their relatives, in the general practitioner's office, the hospital or the nursing home. Their approach is characterized by direct, to the point, questions in order to define a suitable treatment plan (*pragmatic*). Their contact with the elderly is based upon doctor-patient confidentiality (*confidential*). Finally, the trigger for the interaction is a negative change in the health of the elderly (*occasional*).



Figure 11. Psychological care cluster: role, characteristics, professional.

The interview with a psychologist specialized in clinical neuropsychology forms the basis for the psychological care cluster (Figure 11). Psychological care diagnoses the frail elderly based upon their mental and social well-being and strives to improve these through conversations. The professionals in this cluster have a psychological education, which they use to understand behavioural issues of elderly residents of the nursing home (*understanding*). The trigger for this interaction are other people around these elderly who observe a negative change in their behaviour. Their contact with the elderly is confidential, frequent over a short time span and preferably one on one (*confidential, periodic*).



Figure 12. Spiritual care cluster: role, characteristics, professional.

The interview with a spiritual caregiver defined this cluster (Figure 12). Spiritual care addresses the social and mental well-being of elderly by helping them to reflect upon their life. These professionals come from a religious background. From this angle they consider existence. They visit the elderly in the nursing home in their room and give them time and space to freely express themselves (*non judgemental*). Their contact in the first place focusses on the elderly, and they strive to only involve others and share information if the elderly want that (*confidential*). Elderly often get in touch with a spiritual caregiver, when they experience negative emotions, because they are facing the end of their life. For a short period these professionals have intense contact with the elderly (*periodic*).



Figure 13. Daily care cluster: role, characteristics, professionals.

Interviews with a nurse of a nursing home and a meeting center employee helped to define the daily care cluster (Figure 13). This cluster support elderly, living at home and in nursing home, in their day to day lives by caring for their social, mental and physical well-being through personal contact. Among others this includes stimulating them to move, having a chat with them or training their memory in activities. The professionals in this cluster are a diverse group and do not all support the elderly in the same way. The nursing staff and home care employees provide individual care, while meeting center and activity employees focus on group contact. This contact takes place either in the home of the elderly or in an environment with a similar atmosphere, such as the living rooms in the meeting center and nursing home. Whether other elderly or relatives are involved depends on the context. The daily care professionals all have in common that they have (almost) daily contact with the elderly (*regular*). This frequent contact makes it possible for them to get to know the elderly person, besides their professional objectives (*personal, familiar*).

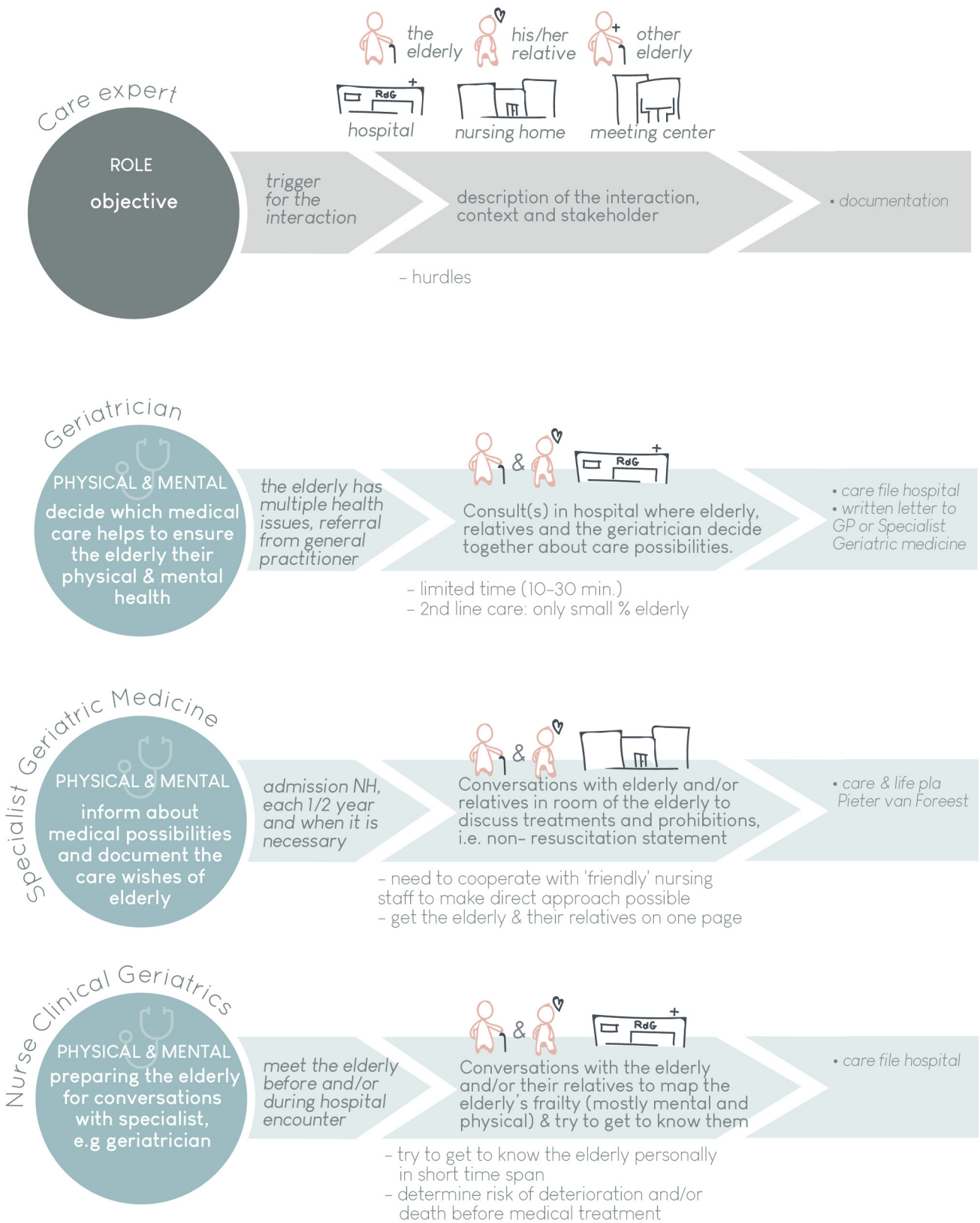


Figure 14. Detailed description of the interviewed professionals and their interaction with the elderly.

Spiritual Caregiver

MENTAL & SOCIAL

give the elderly space to help them become aware of their personal life and beliefs

when the elderly are in a negative state, i.e. sad, anxious



Give elderly a space to share their personal stories in their own room in order to help them relieve and live their life to fullest

• care & life plan Pieter van Foreest (only when it relates treatment goals)

- meet the elderly a bit too late
- get to know the elderly in relatively short period and in emotional unstable state

Psychologist

MENTAL & SOCIAL

place the resident first in order to help them function better after analysing their behaviour

change in behaviour or functioning of the elderly



Multiple conversations with the elderly (and relatives) & observations in room/department to improve current situation

• care & life plan Pieter van Foreest
• MDO

- only meet the elderly with 'issues'
- meet the elderly a bit too late
- get to know elderly (and their past) quickly to understand behaviour
- family co-operation

Nursing staff

PHYSICAL, MENTAL & SOCIAL support and stimulate the elderly in their daily routines through personal contact

from admission until passing away, 24/7 daily care



Contact evolves around the daily care routine of the elderly, i.e. washing, during which casual conversations happen.

• care & life plan Pieter van Foreest
• 1/2 yearly MDO
• share info about elderly on 'familynet'

- limited time per elderly person
- balancing involvement relatives

Meeting centre employee

PHYSICAL, MENTAL & SOCIAL

facilitate activities for the elderly to enable them to have a meaningful day

elderly with who cannot stay alone at home every day



Casual conversations and activities evolve around a structured day planning with other elderly or individually in 'living rooms'

• care & life plan Pieter van Foreest
• 1/2 yearly MDO
• phone/email contact relatives

- limited amount employees hinders individual contact
- keep relatives involved

Informal care

The informal caregivers are relatives of the elderly, such as a partner, children, other family, friends or neighbours. These people are all to a certain extent emotionally invested in the elderly person, and unlike the formal care they act from a personal interest instead of a professional objective to care for their health. These informal caregivers might remind the elderly to take their medication, stimulate the elderly to stay in motion or just stop by for a cup of coffee.

Collaboration

The various formal care professionals strive to improve and sustain the elderly's health so it remains at a satisfactory level. The informal caregivers complement the formal care and also support the elderly in their daily being (Chappell & Blandford, 1991).

In other words by caring for the elderly's social, mental and physical well-being, care contributes to their actual quality of life to ensure their health limitations affect their desired quality of life as little as possible.

Overview

The formal and informal caregivers support the elderly throughout their life. An increase in care professionals becomes visible as the elderly's autonomy decreases (Figure 15).

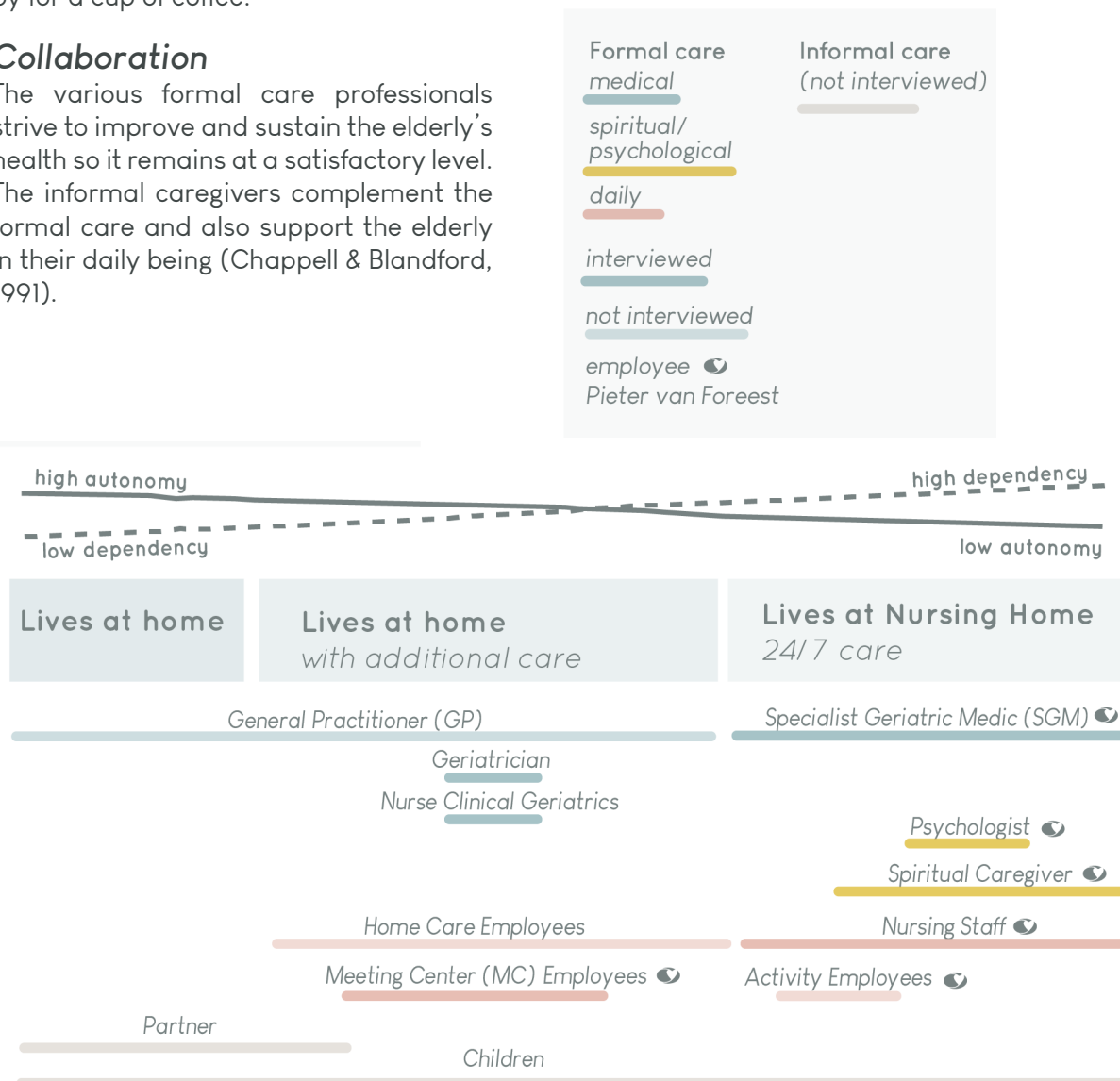


Figure 15. Overview informal and formal care related to the living and care phases of the elderly.

Conclusion

The care context for the frail elderly includes formal care, which are care professionals, and informal care, the people who have a personal bond with the elderly.

The formal care professionals are divided in four clusters:

- **Medical:** mental and physical health
(*pragmatic, confidential, occasional*)
geriatrician, general practitioner,
geriatric nurse, specialist geriatric
medic
- **Spiritual:** mental and social health
(*non judgemental, confidential, periodic*)
spiritual caregiver
- **Psychological:** mental and social health
(*understanding, confidential, occasional*)
psychologist clinical neuropsychology
- **Daily:** mental, social and physical health
(*personal, familiar, regular*)
home care employees, meeting center
employees, nursing staff, activity
employees

Daily care professionals start from a professional objective, but their care contact with the elderly is characterised as personal, familiar and regular.

Considering these characteristics the daily care seems to be tied to both the formal and informal care.

Furthermore the daily care supports the elderly in their total well-being, supporting their social, mental and physical health.

2.4

Communication

What shapes the care communication with the frail elderly?

To design for communication with frail elderly about their quality of life and future, first the challenges and the opportunities in the current situation should be clarified. This includes considering both the conversation hurdles of formal and informal care givers, and finding potential to address the future by reviewing current approaches of care professional, methods and tools.

Communication challenges

To offer care which suits elderly individuals the formal care strives towards shared decision making (Van de Pol et al., 2017). In this process it is essential to get to know the elderly, in order to balance whether providing care is desired or not, in relation to their quality of life .

Formal care

The interviews with care professionals gave insights in their communication hurdles. From their perspective time is one of the biggest issues. It is also a negative trigger, and the difficulty to let the elderly express their desired quality of life could hinder shared decision making.

All four of the formal care clusters face the issue of time. The time of medical consultations is restricted, however the nursing staff and meeting center employees have more time in total to interact with the elderly. But these daily care professionals have to divide their time and attention over a group of elderly. For the psychologist and spiritual caregiver it is not necessarily the interaction time, but especially the timing of the initial contact that is too late. Since they often deal with the elderly at a late stage in their life, in which they are not very autonomous anymore (see Figure 15, page 38).

“Het verpleegtehuis kan gezien worden als het laatste station.”

Specialist Geriatric Medicine (interview)

Secondly, a negative change in the elderly's well-being is often the initial trigger for contact with formal care, especially for the medical care. This results in a situation in which decisions need to be made quickly , and time to think and talk is often limited. Especially if it involve the frail elderly, who might find it more difficult to express themselves, this reduces the possibilities for shared decision making (Van de Pol et al., 2017).

“De huidige focus in de ouderenzorg is om te weten wat je moet doen in het geval van een noodsituatie.”

Geriatrician (interview)

Furthermore, providing care does not always imply improved quality of life (Van Steenberghe, 2018). To illustrate this a quote from the interview with the geriatrician is discussed (Figure 17).

“Goed geformuleerde levensdoelen zijn veel meer waard dan behandelverboden.”

Geriatrican (interview)

A knee or hip injury is an often occurring physical complication for the frail elderly. Such a disability could be solved with an operation, which also includes a recovery period. Whether it is a good decision if the elderly enters this medical trajectory, depends on more factors than only their fitness. It is especially important to discuss the wishes and personal happiness (connection and meaning) of the elderly, because these provide a reason for the medical intervention. The pros and cons for a procedure can then be weighed in relation to their perception of quality of life.

Figure 16. Why someone's life goals are more informative than treatment interdictions.

Informal care

For informal caregivers their personal bond with an elderly person is their incentive to care for him or her. Even though the relationship between an informal caregiver and the elderly could be seen as a pro, it also has a flipside. During the observations and interviews with the elderly it was learned that the communication regarding care decisions not always benefits from the involvement of informal caregivers, exactly because these people are emotionally invested.

First of all the future of the elderly is also a sensitive topic for their relatives. So even if the elderly themselves would like to discuss their future, the relatives might hinder the conversation to avoid discussing negative outcomes.

“Ik heb het wel eens over mijn uitvaart maar daar willen zij [de kinderen] het niet over hebben.”

elderly woman (interviews)

Secondly it was observed that relatives sometimes take over the conversation, and try to speak in the name of the elderly.

“Ik luister aandachtig naar wat jullie over mij bespreken.”

elderly man (observations)

Furthermore, giving informal care could put a lot of pressure on a relative. This could result in care decisions that relieve the informal caregiver, rather than respond to the wishes of the elderly.

“Drie vragen die ik stel zijn:
1. Hoe oud bent u?
2. Hoe oud voelt u zich?
3. Hoe oud wilt u worden?”

“Ik vraag de eerste dag
in het verzorging tehuis
of ouderen gereanimeerd
willen worden.”

“Wat als u morgen
niet meer wakker
zou worden?”



nurse clinical
geriatrics



geriatrician



specialist geriatric
medicine

Figure 17. Approaches of care professionals to talk about the future and quality of life with elderly.

Communication opportunities

To achieve shared decision making in the care context the elderly should be prepared and have formulated their wishes and prior to the conversation have thought about their desired future. The geriatrician indicated that, therefore, the elderly are prepared to evaluate care possibilities together with a care professional in order to make a shared decision.

The observations at the care services and interviews with the elderly showed that the elderly need to be triggered to start thinking about their future, especially when looking at it from a positive perspective. This can be explained by their limited future time perspective and the fact that they usually think about their mortality when mentioning the future (Laureiro-Martinez et al., 2017).

“Het is nog niet actueel.”

elderly man (interviews)

**“Ik word bijna 90, dus
zoveel toekomst zal ik niet
meer hebben.”**

visitor of meeting center
(observations)



Approaches of care professionals

Most interviewed care professionals have their own approach to start a conversation with the elderly about their quality of life and/or their future (Figure 17). The pragmatic approach of the medical care professionals clearly differs from that of the psychologist and spiritual caregiver, who in an indirect way try to learn more about the elderly’s desires.

The daily care professionals strive to place the elderly at the heart of the conversation, but from the observations was learned that the topic addresses their present or past. These examples again illustrate the differences between the clusters, and shows how their professional background and relation to the elderly influences the communication approach.

“Om over de toekomst na te denken moet je eerst reflecteren op je huidige situatie.”

Psychologist (interview)

Methods & tools

Next to a conversation partner, also tools or methods could support elderly in expressing their desires for the future. Six existing tools and methods that support future thoughts were selected as inspiration, and evaluated upon whether they:

- > use a communication or documentation driven approach
- > if the future focus relates to an undesired quality of life (*illness and mortality*) or if it addresses desired quality of life
- > focus on elderly as a target group

The evaluated tools and methods are discussed on page 44-45 and the outcome of the evaluation is visualized in Figure 18. The latter shows a potential design gap that combines a document and communication driven approach, and stimulate elderly to think about their desired quality of life for the future.

Evaluated tools and methods

Advance Care Planning (ACP)

ACP is a conversation driven approach which promotes care professionals and patients to start communicating about their values, desires and goals, to be able to anticipate upon potential care decisions (Mullick et al., 2013). These conversations usually take place in a medical environment with people who have either a progressive illness or a serious deteriorating health.

Advance Healthcare Directive (AHD)

This tool helps people to document their end of life wishes and boundaries regarding care, i.e. non-resuscitation, treatment interdictions, euthanasia and a designated representative. People can either draft these Advance Healthcare Directives by themselves or use a standardized format from a paid service such as Stichting Zorgverklaring (2019).

My futures

My Futures (2018) is a research project of Industrial Design Engineering of the TU Delft, the Design Academy Eindhoven and various design agencies focussed on how to help people imagine and prepare for their potential futures. The result is a method for designers that describes:

- > two ways to stimulate future thoughts (*perspective and reflection*)
- > six conversation elements to take into account (*motivation, others, time & place, topic & goal, content and tools*)

My futures (2018) state that tools should provide guidance, overview and ownership.

Schrijf een brief (write a letter)

This tool gives the user guidelines how to write a letter to a person of their choice about their end of life wishes regarding care and dying, and potentially start a conversation. The format is a free of charge download of the campaign ikwilmetjepraten.nl, which is a part of the coalition 'Van betekenis naar eind' (2019).

3 goede vragen (3 good questions)

This initiative of Patiënten Federatie Nederland, Medische Specialisten and other organizations (2015) strives to start a good conversation during a doctor's visit by helping people prepare through the following questions:

1. What are my possibilities?
2. What are the pros and cons?
3. What does that mean for me?

5 sterfstijlen (5 styles of dying)

This tool is an online personality test from Stichting STEM (2010), where a set of questions give insight in how people view and approach end of life. People could use this tool, when they or a relative of them are facing the end of their life. The tool has a goal to facilitate a conversation and help those involved to better understand each other's perspectives.

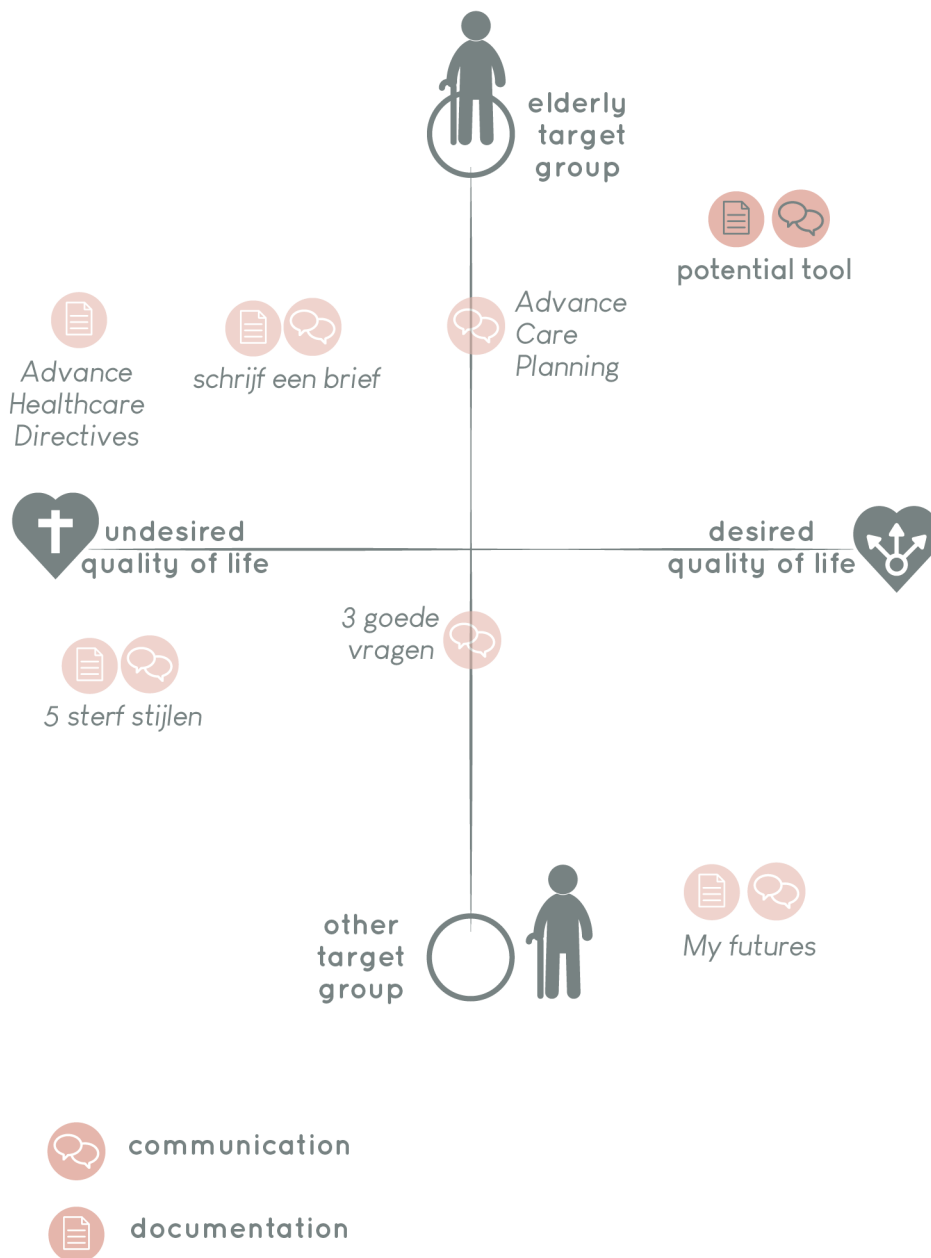


Figure 18. Potential design gap for a future tool; using documentation and communication, and focussed on an elderly target group and desired quality of life.

Conclusion

The challenges of the communication with the frail elderly about quality of life and the future were defined for the current care context:

- Formal care professionals struggle with a lack of time, the negative trigger for the interaction, and the difficulty to let elderly express their desired quality of life in the moment, when care decisions need to be made.
- Considering informal caregivers' personal bond with the elderly, their emotional investment could hinder the communication.

These challenges show why it could be difficult to make shared decisions with the elderly about potential care.

Besides challenges also the opportunities of the current situation were analysed. Inspiration can be found in the approaches of the psychologist and spiritual caregiver, who in an indirect manner stimulate elderly to think about their quality of life. Furthermore existing tools and methods that help to address the future were evaluated. It was found that there is no tool yet that focusses on stimulating the elderly to think about their desired quality of life and includes both documentation and communication.

2.5

Conclusion

Frail elderly experience deteriorating health, which leads to a loss of autonomy and increased dependency on others. This expresses itself in their care and living situation, in which they over time have to accept the support of both informal caregivers (people with whom they have a personal bond) and formal caregivers (medical, spiritual, psychological or daily care professionals) to support them in their daily being and prevent their health affecting their desired quality of life.

To help elderly express their desired quality of life the following questions and themes are useful:

- Who are you?
(Beliefs: values & character traits)
- What matters to you?
(Happiness: meaning & connection)
- What do you desire?
(Wishes for now and the future)

Thereby respecting how the elderly's past and present influences their future perspective and taking into account that desired quality of life is dynamic.

The elderly's desired quality of life should be the focus to ensure that care contributes to the elderly's actual quality of life. However since the frail elderly experience their future to be limited, they often do not communicate about it, besides mentioning their mortality.

A conversation partner and a potential tool could help the elderly to trigger positive thoughts about their potential future.

The daily care professionals support the elderly in their social, mental and physical well-being. Their objective for the regular contact with the elderly is professional, while it is also characterized as personal and familiar.

Furthermore there is no tool yet for the elderly that focusses on desired quality of life, and combines a document and communication driven approach.

Also, when frail elderly prior to a decisive care conversation have considered their desired future it is possible to achieve shared care decisions that are centered around the wishes of the elderly,

“Goed geformuleerde levensdoelen zijn veel meer waard dan behandelverboden.”

Geriatrican (interview)

To illustrate the findings of the analysis phase a journey was made that presents the potential life of a frail elderly person (Page 48, Figure 19). This woman, Tine, experiences deteriorating health leading to a loss of autonomy. Her need for care increases and she is confronted with decisions that address not only care, but also have an impact on her life. These moments are described in events, which show the current touchpoints for communication about care. These events present moments in which a conversation about desired quality of life is relevant, while often this is not the topic of communication.

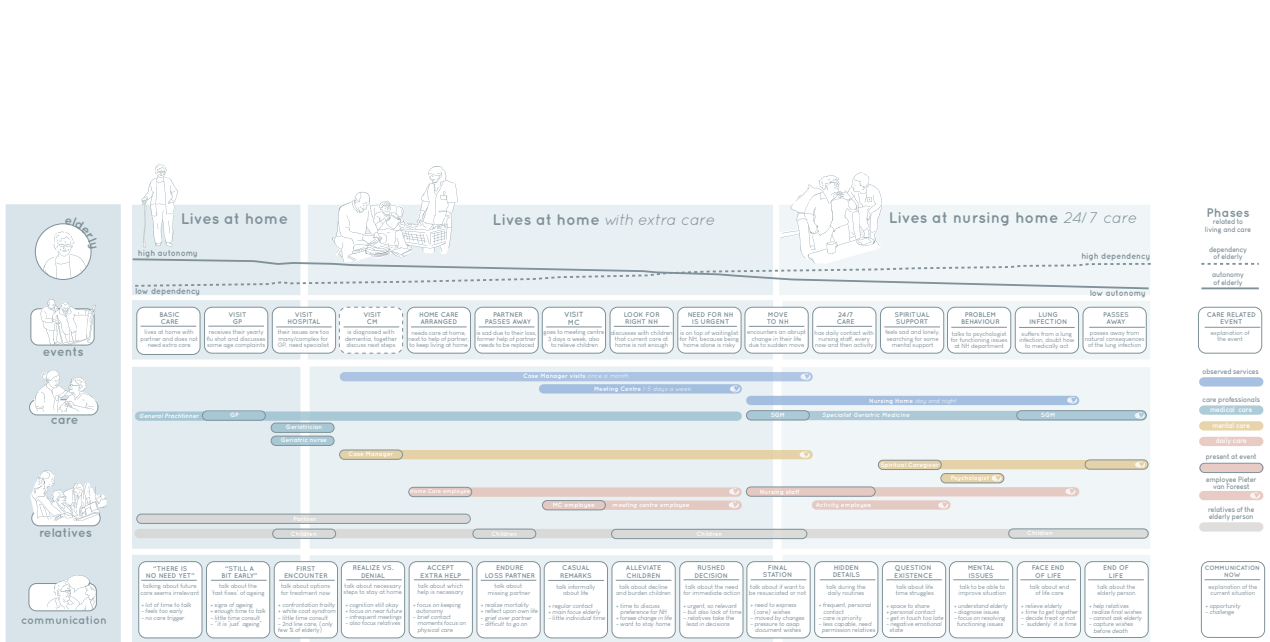


Figure 19. Journey of a frail elderly woman describing care and life events, who is involved (informal & formal care) and the communication.

3. DEFINE

The results of the analysis were interpreted to formulate a vision, which answers the following research question:

When and how to communicate about quality of life with the frail elderly?

Based upon this vision a conceptual framework is developed that defines a context and characteristics for the design-research explorations in Chapter 4.

3.1

Vision

A quality of life portrait for the frail elderly

Starting the communication about quality of life makes it possible to place the elderly on center stage and base care decisions on their desired quality. The earlier the conversation takes place the better, but often in an earlier stage there is no trigger present to start the communication. However it should take place before the elderly's dependency becomes higher than their autonomy. It is proposed to let the elderly during a conversation with a daily care professional make a tangible representation of their happiness, beliefs and wishes. This way the elderly can adjust the representation of their desired quality later on, and are prepared when they need to make care decisions in the future.

This results in the following vision (Figure 20):

Stimulate the **autonomous frail elderly**
to **timely portray their desired quality** of life
in an **exploratory conversation**
with a **daily care professional**.

...

So the elderly are **equipped to express themselves** and
their wishes to formal and informal caregivers,
in order to make **shared decisions** about **care**
that contributes to the elderly's **quality of life**.

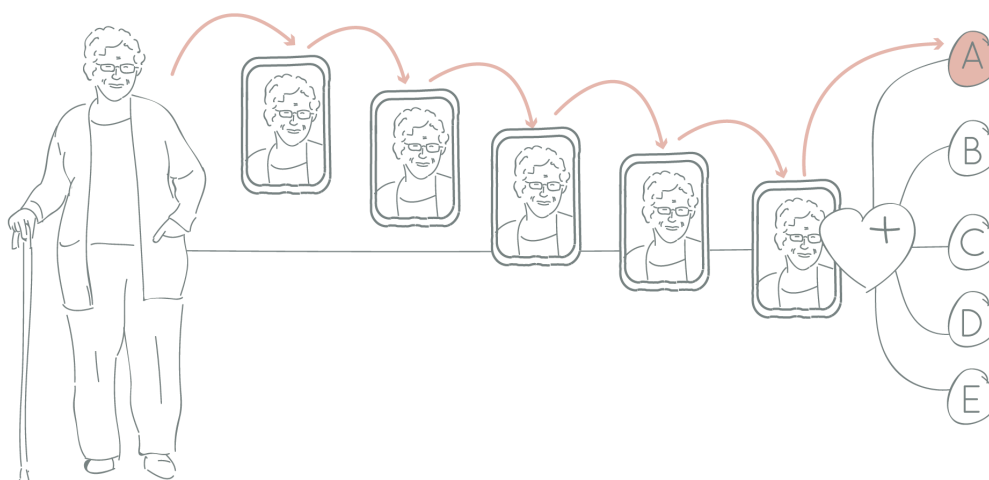


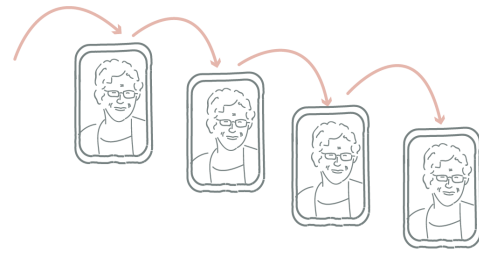
Figure 20.

Vision timely communication about desired quality of life to create a quality of life portrait as an aid for the elderly for future care decisions.



Stimulate the autonomous frail elderly, to timely portray their desired quality of life

The interaction should **create** a dynamic representation by stimulating the elderly to **collect** their *beliefs, happiness and wishes*. This documentation respects that the perception of the elderly changes over time and that their *future* perspective is influenced by their *present and past*.



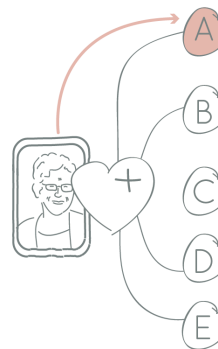
...in an exploratory conversation with a daily care professional.

A **timely** conversation with someone who balances a **professional and personal** approach could **spark** the frail elderly. By helping them to **reflect** upon their desired quality of life and **share** their wishes, allowing a **positive future perspective**.



So the elderly are equipped to express themselves and their wishes to formal and informal caregivers ...

If the elderly are **aware** of their desired **quality of life** prior to a care intervention they can **actively participate** in the decision making. The portrait supports the elderly in a tangible manner to **express** who they are, what matters to them and what they desire.



... in order to make shared decisions about care that contributes to the elderly's quality of life.

This facilitates **shared understanding** between the elderly and the others about the actual goal of care, contributing to the elderly's **quality of life**. Thereby enabling them to together guard the elderly's quality of life for now and the future.

3.2

Conceptual frame

From vision to design: the first portrait

The vision is translated into a conceptual frame. This conceptual frame is the bridge between the vision and the design explorations in Chapter 4.

Design

The design in this project is two-fold, focussing on both the communication and the creation of a quality of life portrait. The vision is summarized below describing the communication, the portrait, and the relevant elements of the conversation.

Communication...

> is a timely conversation, which combines a professional and personal approach, and helps the elderly to look at the future from a positive perspective.

> lets the elderly actively participate to make them aware of their desired quality of life and enable them to express it.

> as a result leads to connection and shared understanding between the elderly and those involved.

A quality of life portrait....

Is a dynamic representation of the elderly's beliefs, happiness and wishes, involving their past, present and future perspective.

Conversation elements

spark	start the communication
reflect	present and past
collect	desired quality of life
create	a personal portrait
share	wishes for the future

Context

The journey (page 48) is used to find a suitable moment to design for the vision within the collaboration of Pieter van Foreest. To decide upon a suitable context the following three elements of the vision are leading: autonomous frail elderly, exploratory conversation, timely portray desired quality.

Autonomous frail elderly

The autonomy of the elderly should be sufficient. The journey presents the urgent need for nursing home admission as a tipping point, when the dependency becomes higher than the autonomy.

Timely

Timely is preferably as early as possible. But the conversation should at least take place before the elderly faces a medical care decision. The hospital visit in the journey illustrates such an event.

Exploratory conversation

For an exploratory conversation the duration and frequency of the interaction are important. The journey shows that from the formal care professionals, only those of the daily care have regular contact over a longer time span with the elderly.

Portray desired quality of life

The elderly and their perception upon quality of life should be the focus point. Since this is such a personal topic, familiarity with the conversation partner is important. However someone who is too emotionally involved, which could be the case with a relative, could hinder the elderly to express themselves.

Taking into account these elements, as well as the involvement of care professionals of Pieter van Foreest, the journey presents the meeting center as a suiting moment because:

- The elderly visit the center, when they are still autonomous to a certain extent.
- The elderly are in contact with professionals of the daily care, which offers potential for a personal and professional approach.
- The elderly visit the center for a certain part of the day. Their interaction with the meeting center employees, as well as with the other elderly in the center is regular.
- The elderly have the time to become familiar with the meeting center employees and connect with them personally, without their relatives being present.

“De ouderen zijn het middelpunt.”

Meeting center employee

Focus

The initial conversation in which the elderly start making their quality of life portrait is the beginning of the vision and therefore also a logical starting point for the design. This leads to the following design question for the explorations in Chapter 4:

“How to design for the initial desired quality of life conversation in the meeting center?”

Besides the conceptual frame, also other takeaways for the exploration phase have been gathered throughout the analysis. These are summarized in Appendix D.

4. EXPLORE



Hallo,

Wat fijn dat u samen met mij vandaag uw geheugen komt trainen! Ik ben Lana en studeer af bij Pieter van Foreest. Tijdens mijn project ga ik op zoek naar wat de toekomst wensen van ouderen zijn. Dit doe ik samen met u, de bezoekers van de Vermeertoren.

Vandaag gaan we met behulp van foto kaartjes praten over wat belangrijk was, is of gaat zijn. De kaartjes die u krijgt en dit boekje mag u mee naar huis nemen.

Op de achterkant van dit boekje zit ook een leeg kaartje. Daarop is plek voor een eigen tekst, plaatje of foto, van iets wat belangrijk voor u is. Dit mag alles zijn, een persoon, een voorwerp of een plek.

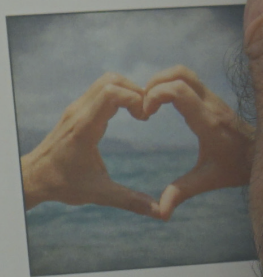
Neemt u uw *ingevulde* kaartje en het boekje *volgende week maandag 15 oktober* weer mee naar de vermeertoren?

Groeten, an

4. EXPLORE

Through design interventions with the target group the conversation's interaction, content and tool are explored in the context of the meeting center. This way insights are gathered to formulate the design brief.

VROEC



4.1

Process

Interventions, ideation and feedback

Interventions, ideation and a feedback session took place to explore the first part of the vision with elderly visitors at the meeting center (Figure 21). Prior to each intervention an ideation activity took place to inspire the design of a prototype. The exploration phase ends with a feedback session to evaluate the findings of the interventions and discuss remaining questions.

The goal of interventions and feedback session is to answer the following questions:

1. **Interaction:** What is the right interaction for the conversation?
2. **Content:** How to address the topic 'desired quality of life'?
3. **Tool:** How to design a tool for the conversation?

Per intervention the goal, the results (including the research set up, see), the findings and a discussion are presented.

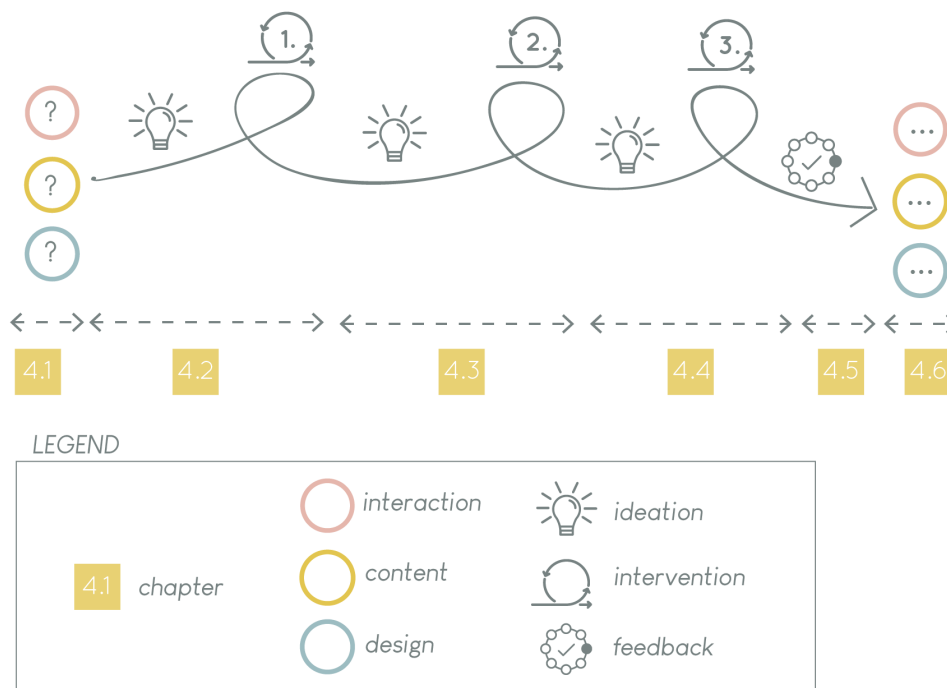


Figure 21. Exploration process.

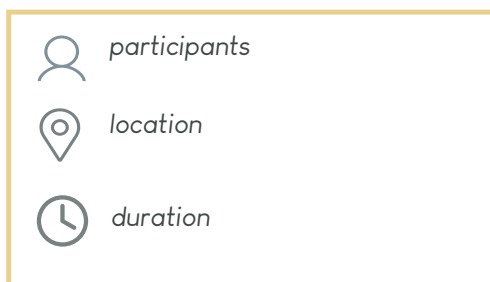


Figure 22. Research set up.

Intervention methods

For the interventions three prototypes were developed and user tested with elderly visitors of meeting center de Vermeertoren in Delft. For these interventions the methods Research through Design and generative design techniques were used.

Research through Design includes design activities, in this case the development of prototypes, whose making and researching helps to further define the project's challenge (Stappers & Giaccardi, 2013).

“The designing act of creating prototypes is in itself a potential generator of knowledge.”

Stappers & Giaccardi, 2013

Generative design helps to understand what people know, feel and dream (Sanders & Stappers, 2012).

Generative design techniques are applied to the prototypes designed for the interventions (Figure 23). This includes the use of toolkits, triggersets and the path of expression (Sanders & Stappers, 2012).

Toolkits in this case, include materials that help the elderly express their past experiences, present feelings and/or their aspirations for the future. The materials used in the prototypes are e.g. photographs and emotion stickers. In all prototypes the perspective of time is used to motivate the elderly to express their perception of the past, present and future. This relates to the path of expression, which explains how the current moment connects to someone's past and future through memories and dreams.



Figure 23. Overview of the prototypes used during the interventions.

4.2

Intervention 1

“Wat belangrijk is voor mij”

Goal

The goal of the the first intervention was to explore:

1. **Interaction:** Can the conversation can become a group activity?
2. **Content:** Does using the perspective of time (past, present, future) and asking “How important is it to you?” help to address desired quality of life?
3. **Tool:** Could “Wat belangrijk is voor mij” be a potential tool?

On the next pages the protoype, the results, findings and discussion of the first intervention are explained. For more information on the prototype see Appendix E.

...t u samen met mij vandaag uw
... komt trainen! Ik ben Lana en
... bij Pieter van Foreest. Tijdens mijn
... ik op zoek naar wat de toekomst
... an ouderen zijn. Dit doe ik samen
... bezoekers van de Vermeertoren.

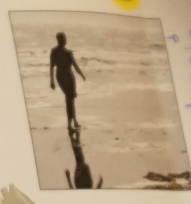
...g gaan we met behulp van foto
... praten over wat belangrijk was, is
... zijn. De kaartjes die u krijgt en dit
... mag u mee naar huis nemen.

...achterkant van dit boekje zit ook een
... kaartje. Daarop is plek voor een eigen
... plaatje of foto, van iets wat belangrijk
... u is. Dit mag alles zijn, een persoon,
... voorwerp of een plek.

...mt u uw ingevulde kaartje en het boekje
...ende week maandag 15 oktober weer
...e naar de vermeertoren?

Groeten, Lana

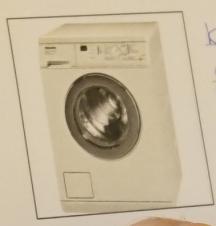
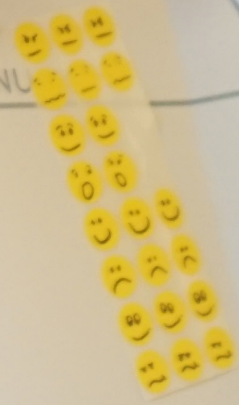
PLEK



me foto
→ Strand
Schevening
→ Huister Dajn

VROEGE

NU



kado bij het
gaan samen
-wonen



Prototype

The prototype is inspired by the 'praatplaat' used in the interviews with elderly. Figure 24 gives an idea of the ideation and shows the prototype. The storyboard the next page shows how the prototype was used.

The following points inspired the prototype design:

To learn more about the Praatplaat and its use see Appendix B.

> Timeline and pictures

A physical timeline and pictures help to structure a conversation.

> Invite elderly to engage

The elderly did not actively engage with the 'praatplaat', unless it was brought to their attention. A prototype design should be more interactive.

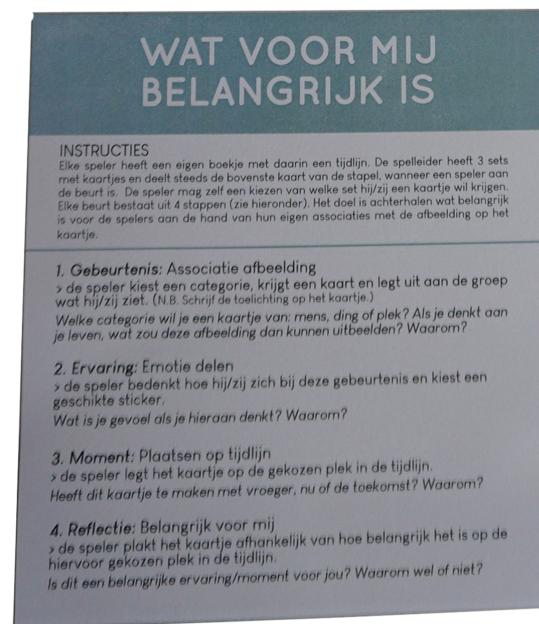


Figure 24. From ideation to the design of the first prototype.

personal booklet with
timeline & empty card



3 categories:
image cards



Instructions for
meeting center employee

Set of 8 different
emotion stickers

Results

The research activity is visualized in a storyboard in Figure 25. The results of the intervention are:

1. **Interaction:** In a group activity the elderly do not feel totally free to express themselves and there is little time to let each visitor tell their story.

2. **Content:** The conversations mainly focus on important memories, instead of what matters for the elderly now or could matter in the future.

3. **Tool:** The tool engaged the elderly to tell stories about their past, and they enjoyed receiving a personal booklet.



11 elderly, both male and female, and an employee



living room at the meeting center during memory activity



45 minutes



Figure 25. Storyboard first intervention.

Findings: interaction, content, design



personal contact

Individual attention is necessary to give the elderly enough time to express themselves.

"Ik laat gewoon niet het achterste van mijn tong zien" elderly man (intervention 1)



mixed feelings

Stories evoke mixed feelings, a pleasant memory with someone, could remind them of the current loss of this person.



sensitive future

Carefully approach the future in a subtle manner, instead of directly mentioning it.

"De toekomst is ook volgende week, maand of morgen." meeting center employee



meaning and connection

What and who makes the elderly happy in the present.



reflective questions

Stimulate the elderly by asking "you" or "your life" questions, such as: "What does that mean for you?"



associative images

Seeing images evokes stories of the past (and sometimes present).

"Er komt zo van alles weer naar boven. (...) Een blij gevoel natuurlijk." elderly woman



ownership

A personal item creates a feeling of belonging and could motivate sharing.

Discussions

The following points of discussion were highlighted:

1. ***Interaction:*** In an evaluation after the intervention with the meeting center employee, she stated that group dynamics can be valuable. Especially if the group is smaller, leaving more time for personal contact.

2. ***Content:*** The fact that mainly the past was addressed could be explained, by the activity usually being a memory activity, but might also have to do with the way the future should be presented in a more subtle manner.

3. ***Tool:*** A tool that helps the elderly to go from the past and present towards the future step by step, might make the latter more approachable.

Taking the tool home not only creates a feeling of ownership for the elderly, but also makes it possible to share it with their relatives. Furthermore the card gave them the opportunity to create personal input.

Note that only three of the eleven participants remembered the activity and took the booklet back to the center. This could be explained by the fact that a majority of the participants suffered from dementia.

4.3

Intervention 2

“Terugblik” and “Mijn ideale dagboek”

Goal

The goal of the the first intervention was to explore:

1. **Interaction:** How are the dynamics in a smaller group, and do these result in the right interaction?
2. **Content:** Does it help to divide desired quality of life in different sessions (*past, present and future*) to slowly approach the future?
3. **Tool:** Are “Terugblik” and “mijn ideale dagboek” (session 1) potential tools?

On the next pages the prototype, the results, findings and discussion of the second intervention are explained. For more information on the prototype see Appendix G.



Prototype

A creative session inspired the design of this prototype. Figure 26 gives an overview of the prototype and the storyboard the next page shows how it was used.

To explore how to design a desired quality of life conversation tool a creative session with four industrial designers took place (Appendix F).



The following points inspired the prototype design:

> "Blik op de tijd"

Use objects which embody a metaphor to trigger time (and future) in a subtle manner.

> "Invulverhalen"

Letting the elderly literally fill in the dots to trigger them to think and create personal stories.

> Idea clusters

The ideation resulted in multiple idea clusters to inspire future designs (see Appendix F).

Figure 26. From ideation to the design of the second prototype.



Terugblik:
talk about your
past associations
& what they mean

Mijn ideale dagboek:
write down how your
perfect day looks like

Blik op nu:
talk about what
and who matters
to you & why

Verlanglijstje voor later:
write down what you desire
in the near future

Vooruitblik:
talk about your hopes
& fears for the future

Results

The research activity is visualized in a storyboard in Figure 27. The intervention results are:

1. **Interaction:** The elderly build upon each other's stories. They also give their opinion, which sometimes results in judging another one's story.

2. **Content:** In the conversation the elderly share stories from both their past and present. In these stories they express what they enjoy in their lives, as well as their current limitations. When you take the time to ask what this means for the elderly person, they share their feelings.

3. **Tool:** The elderly need to be motivated to engage with the prototype "Terugblik". Eventually they selected images that evoke personal stories. Only one elderly woman took the prototype "Mijn ideale dagboek" back to the meeting center. In a follow up conversation with her was learned how little things in life bring joy to her day.



2 elderly women, 1 elderly man (no employee present)



seperate room at the meeting center



45 min.

SPARK	"Terugblik" is placed on table.
SPARK	With a little push elderly explore "terugblik" and "gespreksstof".

REFLECT & COLLECT	Select images that you find interesting..
SHARE	... and explain how they relate to your life.

SHARE	Discussion how certain things are valued differently by and matter to each person.
-------	--

REFLECT, COLLECT & CREATE	fill in "diary" at home by yourself
SHARE	show and explain personal "diary"

Figure 27. Storyboard of the second intervention

Findings: interaction, content, design



personal truth

The elderly should not feel like they are being judged or have to justify their stories.

"That is not normal."

elderly man responds to the story of elderly woman (intervention 2)



layered content

Keep discovering more about the elderly by asking them questions.



abilities & feelings

The elderly experience emotions that link to the (in) ability to fulfill a daily activity.

"Dan valt er zoveel weg."

elderly woman, about not being able to cycle anymore (intervention 2)



simple design

Less is more: too many sub elements in the design could be confusing and miss the mark.



clear in a glance

The purpose of the conversation should be immediately clarified by the design.

"Het zegt mij niks. Een lappie stof met 'n fotootje erop en 'n oud blikkie."

elderly woman about the prototype (intervention2)

Discussions

The following points of discussion were highlighted:

1. **Interaction:** Group dynamics are difficult to control and could positively and negatively influence the conversation. It is questionable if a group activity is the right interaction, since judgement should be avoided.

2. **Content:** The content addressed in the conversation related to things that mattered in the elderly's past and present, but the future was no topic of conversation. Since the remaining sessions with the prototypes "Blik op nu" and "Vooruitblik" never took place it is impossible to say if these would have made the elderly's desired future a topic of conversation.

3. **Tool:** The remaining two sessions were not executed, since it was learned that the elderly do not find the prototype design engaging and the conversation does not support a tangible outcome. "Mijn ideale dagboek", however, seems to have potential to result in a representation of the elderly's happiness.

4.4

Intervention 3

Ook dat is toekomst

Goal

The goal of the third intervention was to explore:

1. **Interaction:** Is a one on one conversation the right interaction?
2. **Content:** Does it work if all three desired quality of life questions (*Who are you, What matters to you & What do you desire?*) are addressed in one conversation?
3. **Tool:** Do the poem “Ook dat is toekomst” and profile booklet have potential?

On the next pages the prototype, the results, findings and discussion of the third intervention are explained. For more information on the prototype see Appendix I.

praktisch
niet
theoretisch

wie ik
ben

Volle aandacht
is noodzakelijk
meer op
lichaal
en het gevoel
met andere

niette shapening
altijd een goede ding

Ook dat is toekomst

DE OUDERE



Prototype

An individual ideation session resulted in the design of this prototype. Figure 28 gives an overview of the prototype and the storyboard the next page shows how it was used.

A poem was written to better understand the perspective of the elderly and the goal of the conversation for them.

A second version of the poem was written to describe the role of the conversation partner of the elderly. See Appendix H for the two poems. The poem "Ook dat is toekomst" proposes two roles for the ones involved. The tool should support them in connecting to each other and building a relation.

The following points inspired the prototype design:

> poem "Ook dat is toekomst"

The poem for the elderly is used to start the conversation.

> Relation-centered design

The position of a tool in a one on one conversation can be to connect those involved and support shared understanding.

*"Om ervoor te zorgen
Dat jullie weten
Wat ik graag wil
Mijn wil niet vergeten"*

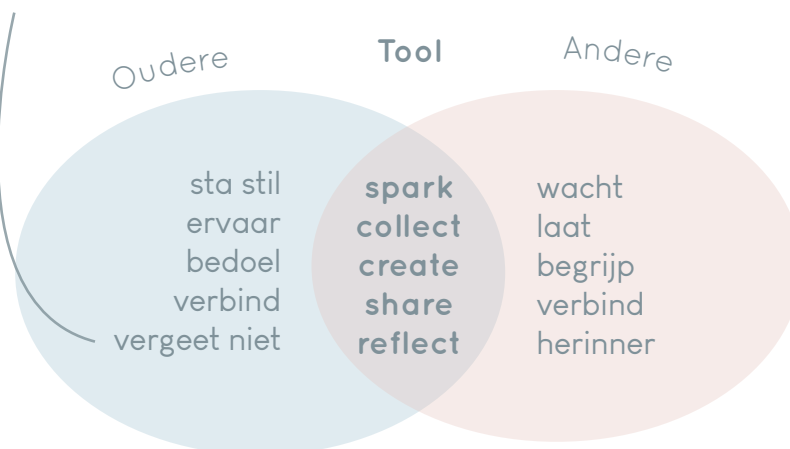


Figure 28.

From ideation to the design of the third prototype.

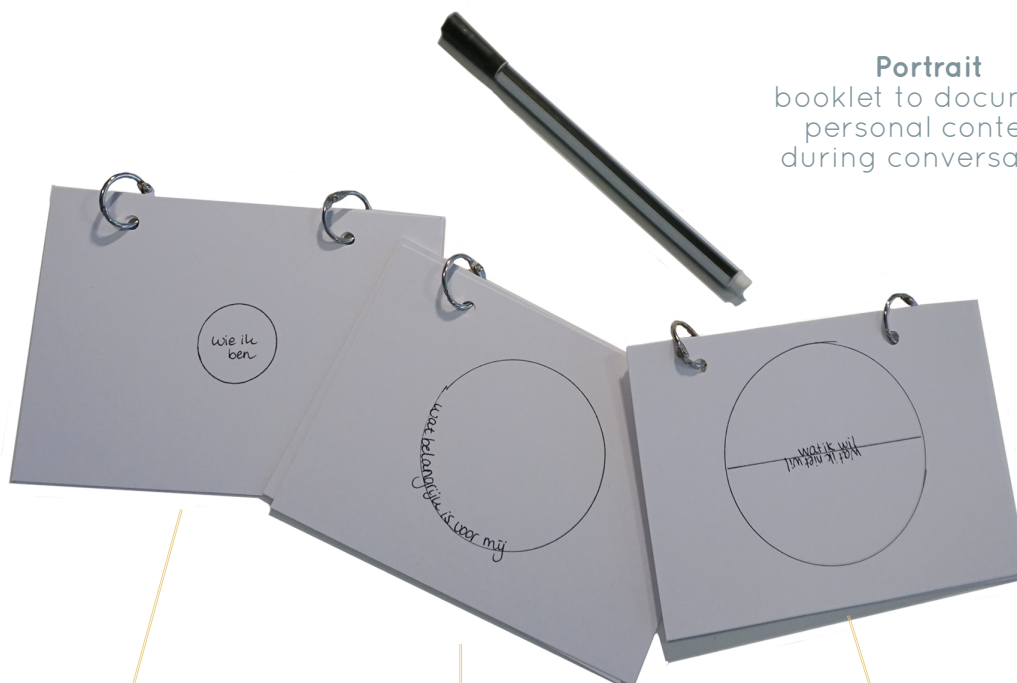
Ook dat is toekomst
booklets with poems
and purpose of the
conversation



poem in
perspective
of elderly

characteristics
and roles in the
conversation

Portrait
booklet to document
personal content
during conversation



Who I am

What matters to me

What I (not) desire


Results


The research activity is visualized in a storyboard in Figure 29. The intervention results are:

1. **Interaction:** A one on one conversation gives the elderly person the time to express themselves and helps the listener to better understand their perspective.

2. **Content:** The conversation first addresses what matters to the elderly person in the present. Thereafter he or she often mention aspects related to who they are. This collected content is used to stimulate them to formulate wishes for their future.

3. **Tool:** The poem seems to touch the elderly their narrative competency and helps them reflect upon their life and potential future (Westerhof, 2018). Asking questions helps them to express their thoughts. They are happy to receive the conversation in a booklet and take it home.

 2 elderly women, 1 elderly man
(no employee present)

 one on one conversations
in a private room

 30-45 min

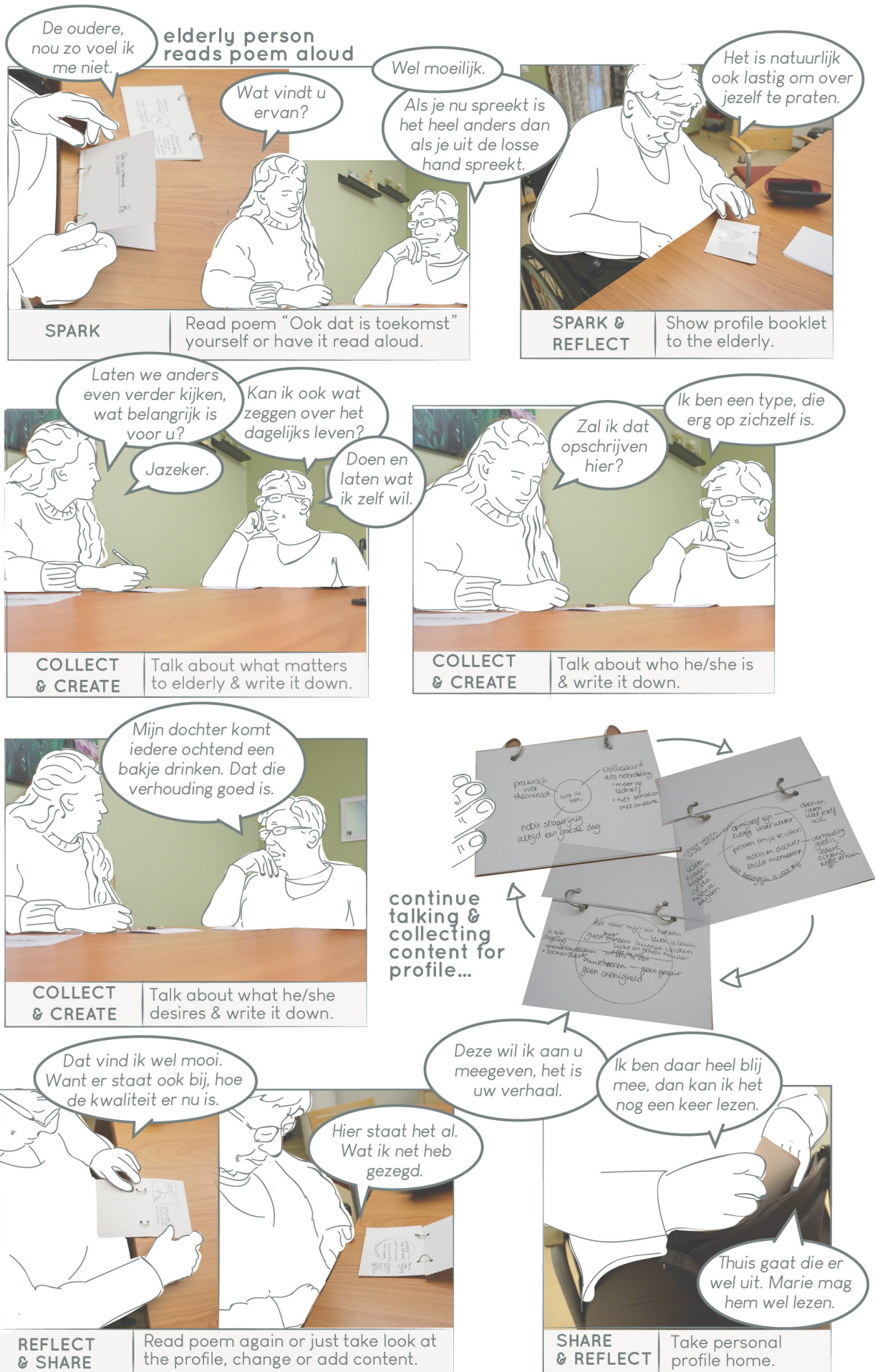


Figure 29. Storyboard of the third intervention.

Findings: interaction, content, design



collaborative storytelling →

Introduce two roles:
· narrator – elderly person
· listener – conversation partner
Then capture the story together.

"Ik vind het fijn dat u dit met mij wilde delen, dat ik u nu in een korte periode..."
"Met andere ogen zie." elderly woman finishes the sentence (intervention 3)



meaningful silence

Give the elderly room for thought, this gives them the space to express themselves and fill in the dots.



now as a center

The present helps to prevent the elderly from dwelling in the past and is a starting point to think about the future.



future vs. faith →

Practical objections hinder future thoughts, but *what if* ...

"Dat kun je niet vermijden."
elderly woman about the future (intervention 3)



power of poetry →

The right words can empower elderly's thoughts and feelings, and thereby spark imagination.

"Een waarheid als een koe."
elderly man after reading the poem (Intervention 3)



essential structure

Make sure to address all topics of desired quality of life: happiness, beliefs & wishes

"Als ik een normaal gesprek zou hebben, dat is anders als nu."
elderly woman (intervention 3)



my story

Capturing desired quality of life in a tangible and personal form, helps the elderly to later on reflect upon it and share it.

Discussions

The following points of discussion were highlighted:

1. **Interaction:** A one on one interaction has the potential to not only let the elderly express themselves, but also offers possibilities for the other person to get to know them better. This way the conversation could contribute to the relationship of those involved. Note that in this intervention only socially frail elderly participated, since the former interventions questioned whether cognitive frail elderly were a suitable target group.

2. **Content:** The elderly find it easier to first explain their happiness and thereafter open up about their beliefs. Therefore a revised order of the desired quality of life themes and questions is proposed:

- Happiness: What matters to you?
- Beliefs: Who are you?
- Wishes: What do you desire?

3. **Tool:** Combining the poem and profile booklet results in a minimal viable product for the elderly. Reformulating the questions on the profile booklet could be interesting so in an indirect, more subtle manner the elderly thinks about their beliefs, happiness and desires.

To ensure a relation-centered design, it is also necessary to communicate the role of the listener to the person who has the conversation with the elderly visitor. This way they can also prepare themselves for the conversation and know how to approach the elderly.

4.5

Feedback session

Pieter van Foreest

Since only in the first intervention a meeting center employee was involved, a feedback session was held with two meeting center employees and an innovation expert from Pieter van Foreest.

The goal of this feedback session was to validate if the meeting center employees would be willing to have these conversations and if they consider the socially frail visitor a suitable target group. Finally a remaining question was posed: *When should this conversation (and potential follow ups) take place?*

During this session also the third prototype was presented and evaluated, see Appendix J for more information.

Socially frail visitors

Especially for the living room with socially frail visitors the tool is interesting, because they could find it hard to express themselves in a group setting.

“Juist in die groep [sociaal kwetsbare bezoekers] bereik je bepaalde mensen niet.”

Meeting center employee
(brainstorm)

Conversation with employee

The meeting center employees would like to have these individual conversations with the visitors to build a bond, outside of the usual group activities. They do mention that in the current situation, making individual time for a visitor could be troublesome.

“Het mooiste zou zijn als de begeleider van de groep het zelf zou doen.”

Meeting center employee
(brainstorm)

First conversation

The first conversation should take place, at the end of the visitor first month in the center, to get to know them better.

Follow up conversations

Follow up conversations could either be planned (every half year) or happen when the employee or elderly feel a need to talk again. For example when the elderly wants to share something or when the employee notices a change in the elderly's behaviour.

Necessary elements

The employees describe the conversation with the following keywords: quiet, familiar and intimate. They express the need for time and space to have the conversation. Furthermore they believe a tool should help them prepare for the conversation and it would be useful if it includes a conversation starter, such as the poem “Ook dat is toekomst”.

4.6

Conclusion

Interventions, ideation and co-creation

The design questions are answered below. To conclude this chapter all findings from the three interventions are combined in an infographic (Figure 30 on page 84). Furthermore the conversation elements presented in the storyboards are discussed.

1. **Interaction:** What is the right interaction for the conversation?

The first conversation should take place during the first month, when a socially frail visitor starts going to the center. It should be a one on one interaction between the employee and the visitor, which could be seen as a collaboration. Through personal contact the employee gives the elderly person the time and space to express themselves and their feelings. In this interaction the visitor is the narrator and the employee the listener. It is important that the visitor can freely speak their own truth, without feeling judged. The interaction could help to establish a better bond between the employee and the visitor.

2. **Content:** How to address the topic 'desired quality of life'?

The conversation should address desired quality of life in the following order: happiness, beliefs and wishes. The future is a sensitive topic for the elderly and they might feel like what is going to happen is inevitable (faith). It helps to make the now a central point in the conversation, to avoid that the conversation mainly evolves around memories. Through asking reflective questions the employee can help the visitor to keep expressing themselves, since the content of the conversation is layered:

- (in)ability to do something links the elderly to their feelings
- meaning and connection in the now, relates to both their past and future

3. **Tool:** How to design a tool for the conversation?

Letting the elderly read the poem "Ook dat is toekomst" at the start of the interaction, immediately clarifies the purpose of the conversation and sparks the visitor to tell their own story (Westerhof, 2018). Making the story tangible in a design evokes a feeling of ownership, so the visitor might share it with others. The themes happiness, beliefs and wishes should become the essential structure to keep the design simple.

Finally images should be used wisely, since photographs often bring back memories.

Conversation elements

In the storyboards of the interventions the five proposed conversation elements (*spark, reflect, collect, create, share*) are presented. These storyboards show that the conversation is a dynamic process, where some of the elements occur simultaneously and/or several times.

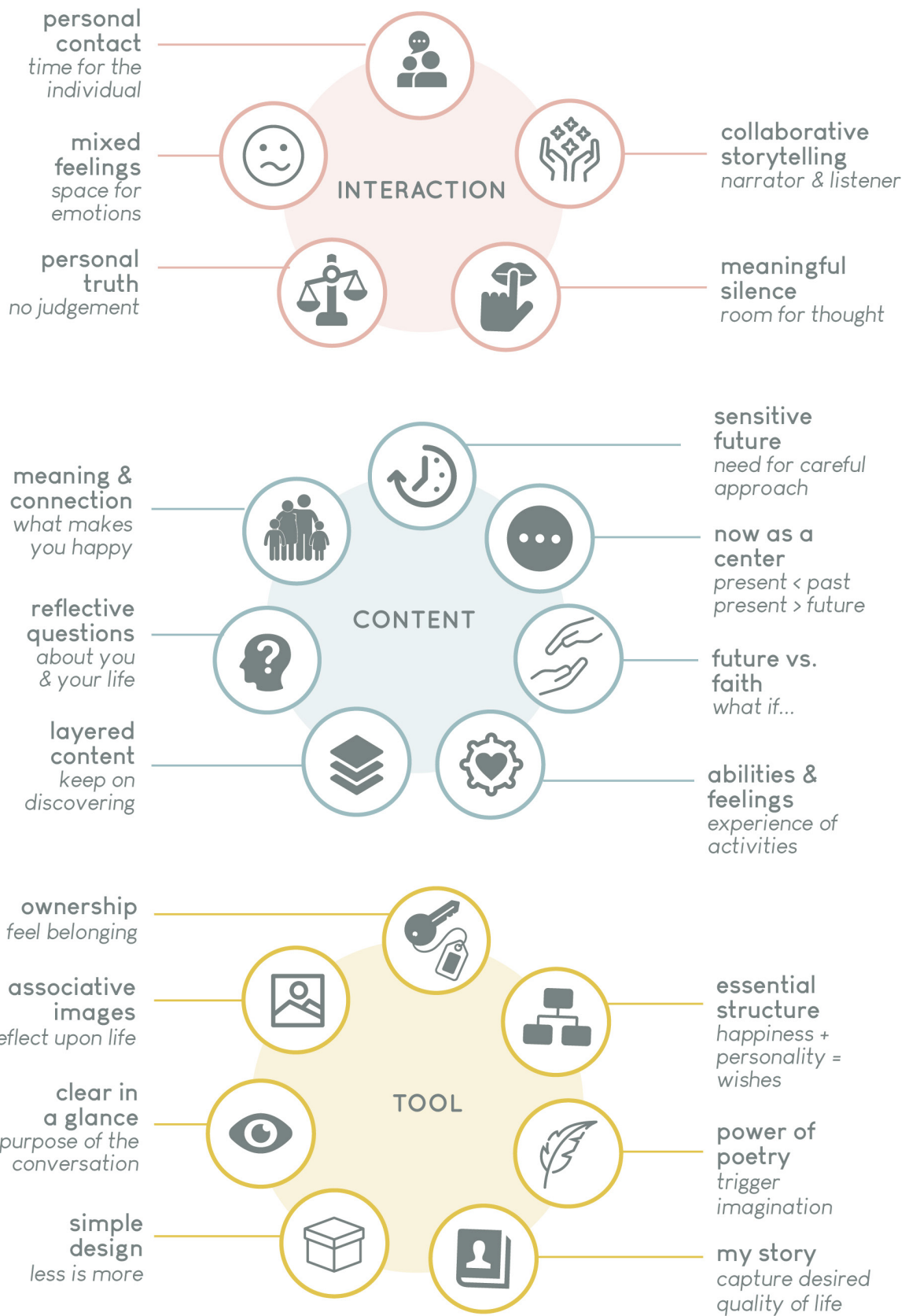


Figure 30. Findings of the three interventions combined.

5. DESIGN BRIEF

The brief explains how to design for a desired quality of life conversation between a socially frail elderly visitor and a meeting center employee in order to create a quality of life portrait. It presents a design goal, framework and desired interaction, which form the basis for the design in chapter 6.

5.1

Challenge & Design goal *framing the project*

Challenge

The current and ideal future situation in the meeting center are described to illustrate the opportunity for a conversation about the desired quality of life between a meeting center employee and socially frail visitor.

Now

The current focus in the center is on group interactions, leaving few opportunities for individual contact between an elderly visitor and an employee. Especially for the socially frail elderly it can be difficult to express themselves in a group setting.

Future

An opportunity lies in introducing a one on one interaction between a socially frail visitor and a meeting center employee in the visitor's first month.

This individual contact could give the elderly person the opportunity to express their desired quality of life and help the meeting center employee to get to know the visitor.

This meaningful interaction for both the visitor and employee promotes building a relationship between them and helps the elderly person to timely share their wishes in a timely way.

Design goal

The following design goal is formulated:

“**Spark** a socially frail visitor to **collect & create** their own **Quality of life Portrait** together with a meeting center employee, so the visitor can **reflect** upon their **desired quality of life & share** their **wishes** with others in order to treasure them together for the future.”



Interaction between meeting center employee and elderly during the first intervention.

5.2

Interaction

Metaphor, qualities and characteristics

A metaphor is formulated to describe the desired experience between the elderly person and meeting center employee, and with the design. This metaphor defines the interaction qualities and design characteristics.

Metaphor

The metaphor explains that it is not easy to define your desired quality of life, but also shows how and why it is valuable.

“Together finding the right path to unlock your treasure chest.”

In this metaphor the treasure symbolizes desired quality of life and the chest the elderly’s personal portrait. He or she already holds the key to open the treasure chest, but is uncertain how to find their way. Then the employee offers support. Together they start the treasure hunt. After conquering the bumps along the way they discover a chest. The elderly person opens it and feels reassured, when seeing their own reflection in the many sparkling treasures.

The moodboard in Figure 31 illustrates the interaction metaphor.

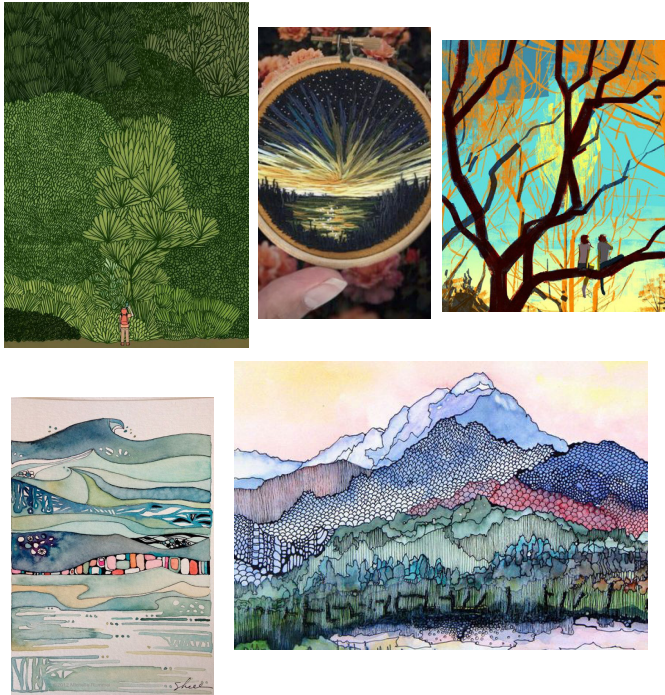


Figure 31. Moodboard to illustrate the interaction.

Interaction qualities

The metaphor describes the following interaction qualities:

Trustful

For the elderly person sharing their desired quality of life could be difficult, since it is a sensitive and personal topic. Therefore the treasure hunt calls for **trust** between the elderly person and meeting center employee.

Encouraging

The metaphor describes bumps on the way referring to how the elderly person might find it challenging to express their happiness, beliefs and wishes. The role of the tool and the employee is to **encourage** the elderly person to keep exploring.

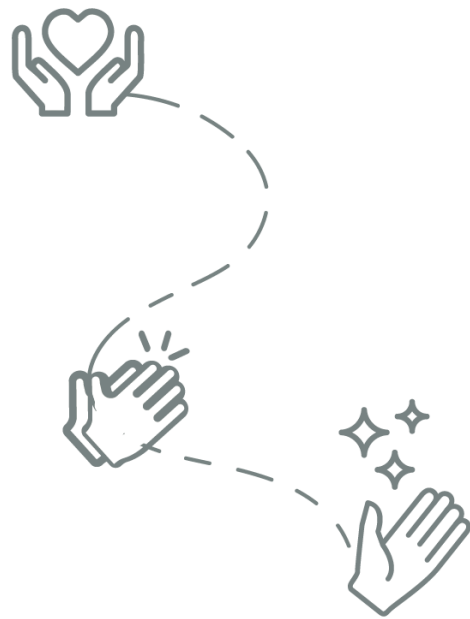
Invigorating

At the end the metaphor illustrates the experience of recognition and discovery. Whereas the elderly person's happiness and beliefs might seem familiar. Using these to view their future from a perspective and express their wishes should feel like an invigorating experience. This shows how desired quality of life is a layered portrait.

Design characteristics

The following characteristics for the tool are defined based upon the same order of the interaction qualities:

- > ***Inviting***
- > ***Guidance***
- > ***Tangibility and belonging***



5.3

Framework

Conversation elements and guidelines

The framework is an extension of the design goal, the interaction qualities and design characteristics. It presents five conversation elements and defines nine guidelines that describe how to design the interaction, topic and form of the conversation.

Conversation elements

The following five elements describe the conversation: spark, reflect, collect, create and share (Figure 32). The spark embodies the start and heart of the conversation: desired quality of life. The latter is defined by the elderly person's happiness, beliefs and wishes. These three themes are visualized as white circles in the remaining four elements. In the conversation the meeting center employee supports the elderly person to step by step reflect, collect, create and share their interpretation of the themes.

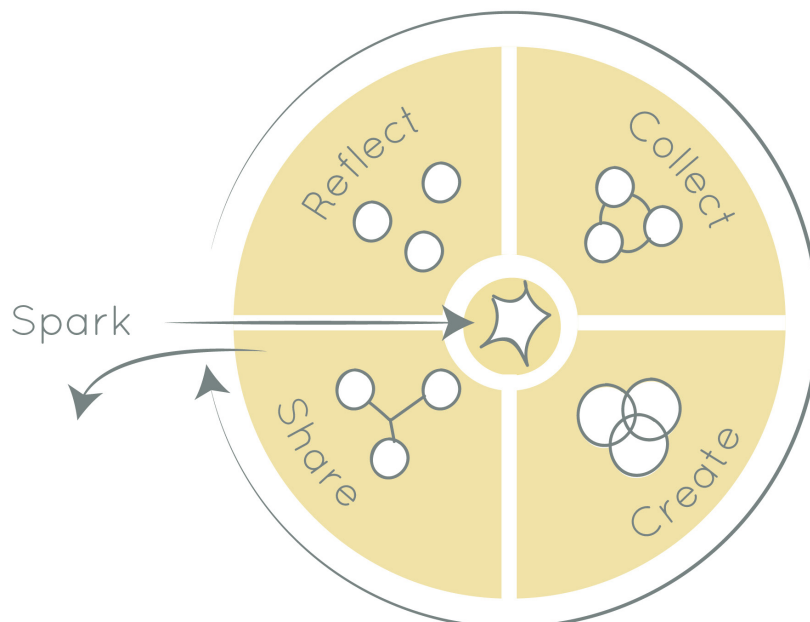


Figure 32. The 5 essential elements for a conversation about desired quality of life conversation: spark, reflect, collect, create and share.

Spark



Spark

The conversation should start with a meaningful interaction between the meeting center employee and the elderly in order to establish trust. The conversation starter clarifies the topic, desired quality of life, and introduces its themes:

After the spark the meeting center employee can help the elderly to step by step discover one of the themes:

Happiness //
meaning and connection

First discover how they currently perceive quality in their life; what do they enjoy in their daily life and which people or places are important.

Beliefs //
values and character traits

Secondly discover how the elderly's past and present shapes who they are today; how would the elderly describe themselves and what do they believe?

Wishes//
your desired future

Finally discover the elderly's wishes by taking a look at the earlier defined happiness and beliefs. How would they like to see those in the future?

See guidelines 1, 3 and 7 to learn more about designing the interaction and a conversation starter.

The other four elements describe the repeating flow in addressing these themes.



Reflect

The elderly need space to reflect upon the now, think about the past and imagine their future. Time brings perspective to their quality of life.

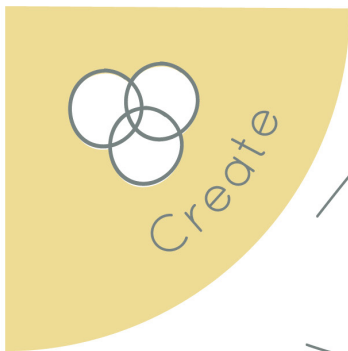
See guidelines 1,3 and 6 to learn more about ways to stimulate reflection.

Collect

Give the elderly the time to express their reflective thoughts and ask questions to encourage them. Their answers help to collect their desired quality.

See guidelines 1,2,3,4,5 and 8 to learn how to support this collection.





Create

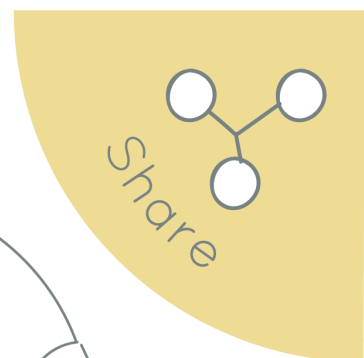
Stimulate (and if necessary help) the elderly to make their story tangible during the conversation. This way the outcome of the conversation becomes a personal representation of the elderly's desired quality of life.

See guidelines 3,5 and 9 as inspiration on how to create a tangible outcome.

Share

In this first conversation the elderly shares their desired quality of life with the meeting center employee. But when their conversation has a tangible outcome it can support the elderly to share it with others, or to reflect on it later.

See guidelines 1, 2, 3 and 9 to learn about sharing desired quality of life.



Design guidelines

The findings of both the exploration and analysis are used to define nine guidelines that describe how to design the interaction (1,2,3), the topic (4,5,6) and the tool (7,8,9). On page 95-97 the design guidelines are explained in detail.

1.

A safe haven
creating time and
space to share

2.

It's personal
everybody holds
their own truth

3.

Let me tell you
roles of listener
and narrator

4.

***More than
meets the eye***
really getting to
know someone

5.

***A multitude of
treasures***
collecting desired
quality of life

6.

***Painting my
future***
imagining how it
could be

7.

Power of art
an inviting
conversation
starter

8.

Follow the way
guidance

9.

This is my story
tangibility and
belonging

1. A safe haven

Creating time and space to share

The elderly should feel the time and space to share. The conversation should therefore be a one on one interaction in a private setting and take place when both the elderly person and the meeting center feel time to talk.



personal contact
(intervention 1)

“Ik bied ruimte om te delen, een vrijplaats.”

Spiritual caregiver
(interview)

2. No right or wrong

Everybody has their own truth

In the interaction the elderly should feel like they can share their personal truth without being judged or having to justify their feelings.



personal truth
(intervention 2)



mixed feelings
(intervention 1)

3. Let me tell you

Roles of narrator and listener

Help the elderly feel like the narrator of their desired quality of life story at the start of the conversation. Storytelling can help the elderly to reflect upon their current quality in their life, think about how it used to be and look forward to what is still to come. By balancing questions and meaningful silences the meeting center employee can become an interested listener.



collaborative storytelling
(intervention 3)



meaningful silence
(intervention 3)

“Ik kan twee boeken schrijven over m’n leven, ‘n goede en ‘n slechte.”

elderly woman (intervention 1)

4. *More than meets the eye*

Really getting to know someone

Keep asking the elderly reflective questions to help them dig deeper in their perception of quality of life, which also help the employee to better understand them. Some examples of these questions are:

- What does that mean for you?
- What is it like now?
- How does that make you feel?

5. *A multitude of treasures*

Collecting personal quality of life

Listening to who and what makes the elderly enjoy their daily lives is the key to finding their happiness; e.g. relatives, activities, hobbies. Furthermore talking about these topics teaches you more about their beliefs and how their in(abilities) to do certain things influence their happiness.

6. *Painting my future*

Imagining how it could be

The goal of the conversation is to help the elderly formulate their wishes. Their desires should embody a preferred future, and not focus on limitations. Do not directly ask them about their future, but try to use their current situation as a starting point. To help the elderly overcome the uncertainty and inevitabilities of aging, you can use their current beliefs and happiness to think about how they would imagine these in the future.



layered content
(intervention 2)



reflective questions
(intervention 1)

“Dat ik u nu in een hele korte periode...”

“Met andere ogen zie.”

conversation with elderly woman (intervention 3)



meaning and connection
(intervention 1)



abilities and feelings
(intervention 2)



now as a center
(intervention 3)



sensitive future
(intervention 1)



future vs. faith
(intervention 3)

“Om over de toekomst na te denken moet je eerst reflecteren op je huidige situatie.”

Psychologist (interview)

7. Power of art

An inviting conversation starter

Incorporating a form of art in the tool could help to communicate the goal of the conversation, as well as spark the elderly's imagination. Poetry and images have proven to speak to the imagination of the elderly, and evoke thoughts and feelings. Whereas photographs often make the elderly think about their past or present, words are open for interpretation, and, if chosen wisely, could help to address the future.



power of poetry
(intervention 3)



associative images
(intervention 1)



clear in a glance
(intervention 2)

“Een waarheid als een koe.” elderly man after reading the poem ‘Ook dat is toekomst’ at the start of the conversation (intervention 3)

8. Follow the way

Guidance

A tool with a logical structure helps to guide the conversation along the essential themes describing desired quality of life. It was learned that the best order to address these themes is as follows:

- happiness – what matters to you?
- beliefs – who are you?
- wishes – what do you desire?



essential structure
(intervention 3)



simple design
(intervention 2)

9. This is my story

Tangibility and belonging

A tool should help the elderly to create their story during the conversation and become the owner of it. This way the communication becomes tangible and a sense of belonging is established. This makes the tool valuable for the elderly and helps them to later on look back at their desired quality of life and share their wishes with others.



ownership
(intervention 1)



my story
(intervention 3)

“Dan wil ik graag deze aan u meegeven, want het is uw verhaal.”
“Ik ben daar heel blij mee. (...) Dan kan ik het nog eens opnieuw lezen.”

conversation with elderly woman (intervention 3)

6. DESIGN

The final design is a conversation package to start desired quality of life communication. The tool, it's content and use are presented.





DOOR MIJN OGEN

DOOR MIJN OGEN

Het verhaal van:



6.1

Door mijn ogen

Conversations about quality of Life

Everybody grows old. With age we become frail and our need for care increases. Care decisions are much more than just care choices alone. Who is the elderly person and what matters to him or her? How to discover on time which care can contribute to his or her quality of life?

For who and why?

As a care professional it is valuable to get to know the elderly person, but you can also encourage them to think about what is important in their life. The communication package "Door mijn ogen" helps meeting center employees to start a one on one conversation about quality of life with socially frail visitors. The conversation gives room to discuss both their present, past and future, to ensure that when the future becomes now, you can together with the elderly decide which care would contribute to their quality of life.

How does it work?

This package is a tool to help the frail elderly explore their quality of life. When the elderly reads the poem "Ook dat is toekomst" aloud the conversation starts, addressing:

> Quality: *How do you currently experience quality in your life?*

> Me: *How do you see yourself as a person?*

> My wishes: *What do you desire and how do we treasure your wishes together?*

During the conversation the personal story of the elderly develops step by step. Together you capture their desired quality of life in a booklet. While life continues for the elderly, their story also changes. After some time the meeting center employee can invite the visitor to continue the conversation.

Door mijn ogen

praatpakket voor een oudere en zorgverlener om in gesprek te gaan over kwaliteit van leven

Ouder worden we allemaal. Wanneer iemand ook kwetsbaarder wordt komt de zorgvraag om de hoek kijken. Die vraag gaat eigenlijk om veel meer dan zorgkeuzes alleen. Wie is die oudere eigenlijk en wat vindt hij of zij belangrijk? Hoe kom je er op tijd achter welke zorg kan bijdragen aan zijn of haar kwaliteit van leven?

Voor wie en waar

Naast dat het fijn is als zorgverlener en oudere beter te leren kennen, kan het ook belangrijk zijn om na te denken over wat belangrijk is voor hem of haar. Het praatpakket helpt zorgverleners en bezoekers te gaan over kwaliteit van leven. Het gaat erachter wie de oudere is en wat hij of zij belangrijk vindt. Hierbij zijn zaken als het later een onderwerp. Zo kan het later is, er samen met de oudere bespreken kan worden voor passende zorg.

Vergeet niet om...

- het boekje voor de verteller
- uitleg deel "4. Samen ontdekken"
- een pen en dit schrijfbord

mee te nemen naar het gesprek



Waarom?

Hoe gaat dat dan?

Dit pakket biedt handvaten om een gesprek te starten waarin de oudere, als persoon, centraal staat. Aan de hand van een gedicht, worden de drie thema's van het verhaal geïntroduceerd:

Kwaliteit: Wat is er nu belangrijk voor jou?
Ik: Hoe zie jij jezelf als persoon?
Mijn wil: Wat zijn jouw wensen en hoe zorgen wij daar samen voor nu en later?

Tijdens het gesprek vormt zich langzaam het persoonlijke verhaal van de oudere. Samen leggen jullie dit vast in een boekje. Het verhaal van de oudere verandert met hem of haar mee. Herhaal daarom het gesprek in verloop van tijd.

Het pakket

Het pakket bestaat uit een uitleg, boekje en schrijfbord. De uitleg bereidt de zorgverlener voor op zijn/haar rol als luisteraar. Het boekje stimuleert de oudere, als verteller zijn/haar verhaal over kwaliteit van leven vast te leggen. Het schrijfbord laat zien welke dingen je mee neemt naar het gesprek en zorgt ervoor dat je kan praten waar je wilt, ook als er geen tafel is om op te schrijven.

6.2

The package

Tools to facilitate the conversation

The conversation package consists of a wrapper, instructions for the employee, a booklet for the elderly person and a writing board. The booklet and instructions are further explained on page 104-107. For larger images of the whole package see Appendix L.



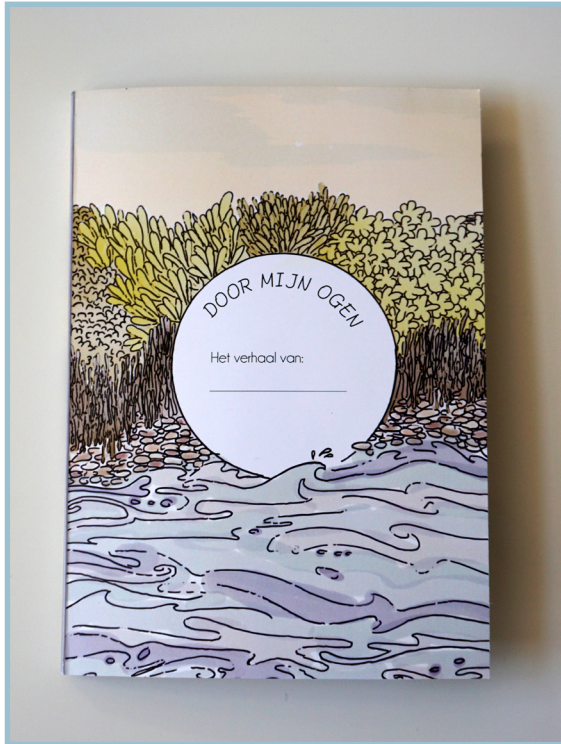
Wrapper (wikkel)

The conversation tool is packaged with a wrapper that gives the meeting center employee information about the purpose and contents of the package.



Instructions (uitleg)

The instructions are a preparation tool for the meeting center employee. It helps him or her to understand the purpose of the conversation, their role as interested listener, how to help the visitor express desired quality of life and finally it gives the employee tips on how to encourage the visitor to share their story.



Booklet (mijn verhaal)

The booklet is a personal gift for the visitor to help them become the narrator and writer of their own story about desired quality of life.

Writing board (schrijfbord)

The writing board:

- > offers a physical place to write, even if there is no table, and so supports the employee and the visitor in finding a quiet space.
- > a sticker to remind the employee what to take to the conversation: the writing board, a pencil, the booklet and the tips of the instructions.





Instructions (uitleg)

The instruction explains the meeting center employee the following things about the conversation:

1. the purpose
2. your role
3. their story
4. discover together

Ook dat is toekomst

(het gesprek door de ogen van de verteller)

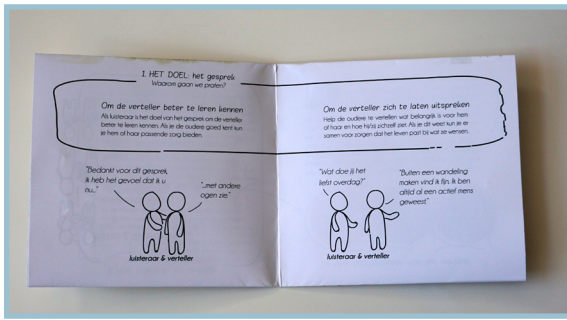
al zoveel geleefd
nu zal ik even
wachten op jou
jou de tijd geven

niet om te oordelen
maar om jou te laten
geef jou de ruimte
om met me te praten

wie jij bent
wat je voelt
goed te begrijpen
wat jij bedoelt

wat is belangrijk
voor jou in het leven
luister en verbind
mooiste wat je kan geven

om ervoor te zorgen
dat ik nimmer
vergeet wat je wil
jouw wil steeds herinner



1. The purpose: connect & share

The purpose of the conversation is twofold, to help:

- > the visitor to express their wishes
- > the meeting center employee to connect to the visitor and provide person-oriented care

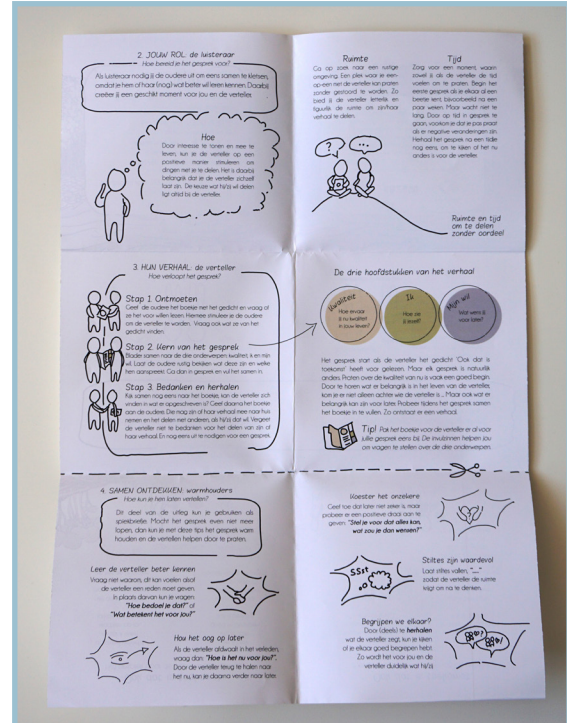


2. Your role: being a listener

Preparing and inviting the visitor.

- > **how:** be interested, stimulate in a positive manner and let the visitor decide what he/she wants to share
- > **space:** a quiet, peaceful place
- > **time:** start after a couple of weeks, but do not wait too long and make time for the conversation

Furthermore, the two versions of the poem “Ook dat is toekomst” are presented, to help the listener understand the different perspectives of the conversation.



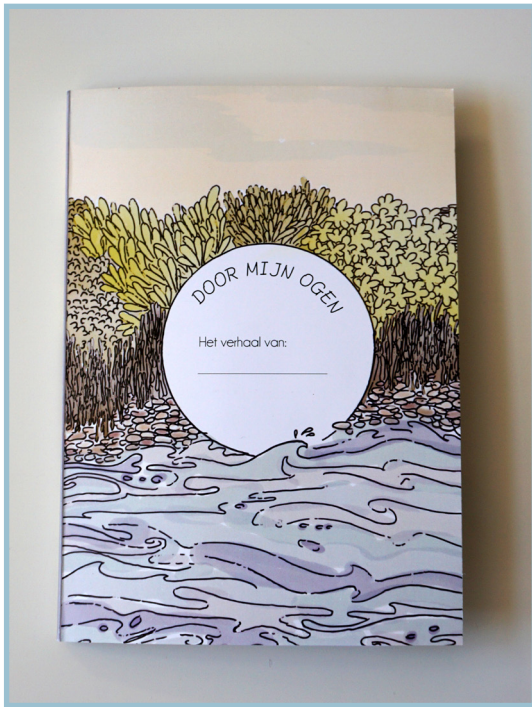
3. Their story: visitor as narrator

This part explains only about the flow and content of the conversation.

- > **Invite:** Give the visitor the booklet and ask them to read the poem in it as a conversation starter.
- > **Talk:** Use the poem, the example sentences in the booklet and the tips in part 4 to help the narrator share and capture their story.
- > **Thank:** Reflect upon the story written so far, thank the visitor for sharing it with you and be open for a next conversation.

4. Discover together: tips

- > Get to know the narrator ask about “you” and “your life”
- > Keep an eye on later use the present to get to the future
- > Cherish the uncertainty what if ...
- > Silences are meaningful (...) give the visitor time to think
- > Strive for mutual understanding repeat and check discussed content



Booklet (mijn verhaal)

The booklet consists of three chapters that guides the conversation along the themes of desired quality of life:

1. Quality (happiness)
2. Me (beliefs)
3. My will (wishes)

The idea is to use each chapter in the conversation; 'Quality' and 'Me' help to inspire the visitor to formulate wishes for later (My will). Each chapter consists of eight sets of four pages. The first page shows example sentences to spark thoughts about the theme. The second and third give the visitor the freedom to write, draw or paste photos. The fourth page is an invitation to continue the conversation. Here the visitor can suggest things to discuss the next time.

Ook dat is toekomst

(het gesprek door de ogen van de luisteraar)

zoveel geleefd
toch nu wel even
stilstaan bij alles
en het herleven

niet om te stoppen
maar om te ervaren
hoe kwaliteit er nu is
en die te bewaren

wie ik ben
wat ik voel
te delen met anderen
wat ik bedoel

wat is belangrijk
voor mij in het leven
luister en verbind
mooiste wat je kan geven

om ervoor te zorgen
dat jullie weten
wat ik graag wil
mijn wil niet vergeten

The first page of the booklet shows the poem "Ook dat is toekomst" (Figure XX). The conversation starts after the visitor has read the poem, and is asked to reflect upon what the poem means for him or her. Then the conversation continues with:



Quality
in my current life

Me
this is me

My will
wishes for later

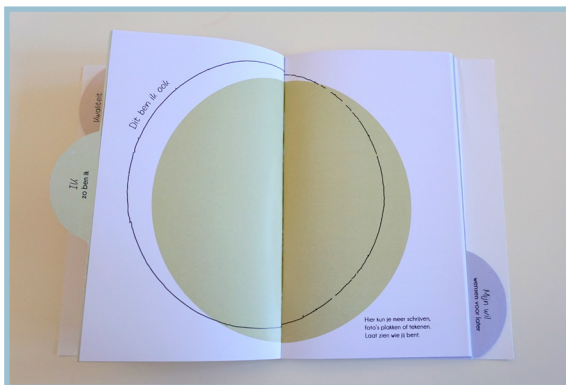


Page 1: example sentences

Quality:
> A good day is ...
> These people make my day ...
(...) when we are together

Me:
> I would describe myself as...
(...) this shows in...
> This is how I see my life ...
(...) I believe that...

My will:
> If I think about my current life,
I would like to later ...
(...) because this matters to me ...
> Together we can treasure my
wishes by ...



Page 2-3: open spread

Motivate the visitor to personalize the booklet through adding pictures, drawings or more text.



Page 4: invitation next time

Stimulate a follow up conversation by making room for topics that have not been discussed, but the visitor would like to talk about.

6.3

Use

Conversation with ‘Door mijn ogen’

On the pages 108-111 the use of the tool is illustrated in a storyboard (Figure 33). This gives an example of a possible conversation with the tool and shows how the interaction qualities, conversation elements and guidelines are present throughout its use.



The meeting center employee orders the conversation package “*Door mijn ogen*” to start communication about the visitor’s quality of life and to get to know them better in order to provide them appropriate care. She reads the information on the wrapper and uses the instructions to prepare herself for the conversation.

Figure 33. Storyboard of the use of the tool describing the following steps: prepare, invite, talk, thank & follow up.



Invite (Trustful)

The visitor has visited the meeting center for a little over a month. The employee feels it is the right moment to have a chat with her. The employee makes time, takes the necessary tools and invites the visitor for the conversation by giving her the booklet.



Invite (Trustful)

The employee takes the visitor to a private and quiet spot in the meeting center, then asks the visitor to read the poem "Ook dat is toekomst". - **Spark**



Invite (Trustful)

The employee asks the visitor how she feels about the poem and gives her the space to think and reflect. - **Reflect**



Talk (Encouraging)

The visitor and employee have a look at the content of the booklet: Quality, Me & My will. The example sentences help the visitor to reflect upon her happiness, thereafter upon her beliefs. The employee encourages her to share by asking “What does that mean to you?”.
- *reflect, collect, share*



Talk (Encouraging)

The employee encourages the visitor to write down her answers. The visitor could experience mixed emotions, so the employee gives her the space and time to express these if the visitor likes to.
- *create, share*



Talk (Encouraging)

The employee encourages the visitor to think about her wishes, whereby the content written in Quality and Me serve as a basis. If the visitor has difficulties with imagining her desired future, the employee can help her by first addressing the now and then asking *what if....?* Furthermore the employee should emphasize that she wants to support the visitor in treasuring her wishes and to encourage her to also share these with others.
- *reflect, collect, create, share*



Thank (Invigorating)

The visitor and employee reflect upon the content of the booklet to see if it covers the conversation and to note down if the visitor has things she would like to discuss in a follow up conversation.

- **reflect, collect, create, share**



Thank (Invigorating)

The employee thanks the visitor for sharing her desired quality of life story with her. The visitor can take the booklet home to share it with others and add a personal touch, e.g. a photograph. She can also use the booklet to later on reflect upon her desired quality of life and see if things have changed. Furthermore the booklet is a means to support the visitor in future care decisions. - **reflect, collect, create, share**



Follow up

Some time later the visitor and employee can meet again to pick up the conversation. This follow up could happen spontaneously, be planned or because the visitor might be facing a care decision.

- **spark, reflect**

mijn ogen

voor een oudere
ner om in gesprek
kwaliteit van leven

Ouder worden we allemaal. Wanneer iemand ook kwetsbaarder wordt komt de zorgvraag om de hoek kijken. Die vraag gaat eigenlijk om veel meer dan zorgkeuzes alleen. Wie is die oudere eigenlijk en wat vindt hij of zij belangrijk? Hoe kom je er op tijd achter welke zorg kan bijdragen aan zijn of haar kwaliteit van leven?

Voor wie en waarom?

Naast dat het fin is als zorgverlener een oudere beter te leren kennen, kun je diegene ook stimuleren om na te denken over wat belangrijk is voor hem of haar. Dit praatpakket helpt zorgverleners in gesprek te gaan over kwaliteit van leven. Zo kom je erachter wie de oudere is en wat hij of zij belangrijk vindt. Hierbij zijn zowel het nu, als het later een onderwerp. Zodat als het later is, er samen met de oudere gekozen kan worden voor passende zorg.

Hoe gaat dat dan?

Dit pakket biedt handvaten om een gesprek te starten waarin de oudere, als persoon, centraal staat. Aan de hand van een gedicht, worden de drie thema's van het verhaal geïntroduceerd.

Kwaliteit: Wat is er nu belangrijk voor jou?
Ik: Hoe zie jij jezelf als persoon?
Mijn wil: Wat zijn jouw wensen en hoe zorgen wij daar samen voor nu en later?

Tijdens het gesprek vormt zich langzaam het persoonlijke verhaal van de oudere. Samen leggen jullie dit vast in een boekje. Het verhaal van de oudere verandert met hem of haar mee. Herhaal daarom het gesprek in verloop van tijd.

Vergeet niet om...

- het boekje voor de verteller
- uitleg deel "4. Samen ontdekken"
- een pen en dit schijfboard
- mee te nemen naar het gesprek

DOOR MIJN OGEN - uitleg

Deze uitleg helpt jou, als luisteraar, op weg.
Leer meer over:

1. HET DOEL: het gesprek
Waarom gaan we praten?
2. JOUW ROL: de luisteraar
Hoe bereid je het gesprek voor?
3. HUN VERHAAL: de verteller
Hoe verloopt het gesprek?
4. SAMEN ONTDEKKEN: warmhouders
Hoe kun je hen laten vertellen?

DOOR MIJN OGEN

Het verhaal van:

7. Evaluation

The final design has been evaluated with the collaborating partners, Pieter van Foreest and Muzus. The goal is to discuss the tool 'Doormijn ogen' and formulate opportunities for future development and application of such a conversation package, beyond the scope of this project.

The following people were present: Ad Blom (Program manager innovation and expertise at Pieter van Foreest), Marijke van der Hoeven (Team manager meeting centers at Pieter van Foreest) and Helma van Rijn (Senior service designer at Muzus).

7.1

Discussion

The goal of the discussion with the collaborating partners is to evaluate the potential contribution and limitations of the design, the tool “Door mijn ogen”, in relation to Pieter van Foreest (Figure 34).

Vision Pieter van Foreest

The vision of Pieter van Foreest: “Samen jezelf, boven verwachting” is a kind of ‘one plus one’ makes three formula. It highlights their ideal of seeing elderly as individual people with their own desires, while also taking into account social network so they can together care for the elderly person.

The tool fits nicely with the vision of Pieter van Foreest stimulating the elderly to have a positive future perspective and share their wishes with care professionals. The social network of the elderly, however, are in this project only indirectly involved.

Person-oriented care

The conversation tool could be a means to the goal of Pieter van Foreest to offer person-oriented care. Because the tool helps care professionals to gain insight into the desired quality of life of an elderly person, so they can ensure this elderly person receives the kind of care that contributes to their personal quality of life.

“Door mijn ogen”

The content of the tool (*booklet, wrapper and instructions*) and its appearance are positively received by the collaborating partners.

The booklet is considered to be a way to create a representative document of an elderly person. Since it differs from the current official checklists and forms that often elderly themselves do not value or understand.

Ad Blom and Marijke van der Hoeven believe that the wrapper and instruction could speak to the intrinsic motivation of care professionals. They encapture the essence of why people became care professionals in the first place, illustrating the desire to connect to someone and care for them as a person.

“Dit snappen mensen, dit is waarom ze het vak gekozen hebben”

Marijke van der Hoeven
(evaluation)

The three experts involved perceive the appearance of the tool as an inviting and clear way to start the conversation.

Users and use

A more critical point of the discussion are the users and the use of the tool: frail elderly, meeting center employees and actually letting the conversation take place.

Frail elderly

In this project, socially frail elderly people were the focus group. Marijke van der Hoeven believes that the tool probably fits well with these elderly people and that this group is showing a growing interest in the meeting centers. However she also mentions that a large number of visitors suffer from dementia.

“Het nodigt uit (...) Door mijn ogen is ook een prachtige titel.”
Ad Blom (evaluation)

“Dit is het helemaal”
Marijke van der Hoeven (evaluation)



Figure 34. Evaluation of the tool with the collaborating partners.

Since this disease has several forms and stages, Marijke van der Hoeven believes that the elderly with a starting form of dementia could potentially also become a part of the target group, taking into account that some adjustments of the tool for this particular group might be necessary.

Meeting center employees

Some uncertainties also remain regarding the care professionals and their ability to have this conversation in an appropriate manner.

Firstly, the majority of care professionals, including the meeting center employees, are not educated for these kinds of conversations, the psychologist and the spiritual care giver being an exception. Whether the tool conveys the right skills to prepare them or whether they might need additional training is still open for discussion.

Secondly, every care professional has their own way of interacting with the elderly. Ad Blom mentioned that some might struggle with the fact that the tool is not a set checklist, whereas others might find it hard to focus on the positive rather than the negative potentials of the future.

Conversation

Finding the time to have this conversation still seems to be an issue in the current situation.

Ad Blom and Marijke van der Hoeven agree that time should not be the reason to miss the opportunity for this kind of communication. They believe that this conversation is meaningful for both the elderly as well as the care professional, since it not only contributes to the person-oriented care but also adds a bit of intimacy to their relationship.

“We moeten ergens tijd vandaan halen.”

Ad Blom (evaluation)

User testing

The final point of discussion is how the elderly and care professionals themselves experience the tool and conversation. The best way to see if this product-service is meaningful for them is to evaluate the tool through user testing with the target group. Within this project there was no time for such a test. The recommendation is perform several user tests with both the elderly and care professional to explore the potential target group and further develop the tool to their needs.

7.2

Future opportunities

Four opportunities for the future use of the tool were formulated during the evaluation session. These are presented in order of closest alignment to the current practices of Pieter van Foreest, with the fourth being the most difficult to implement for the organization.

***“Niet erbij,
maar in plaats van.”***
Marijke van der Hoeven
(evaluation)

***“Een visite kaartje voor
Pieter van Foreest.”***
Helma van Rijn
(evaluation)

1. Start today

The first four weeks when an elderly person starts visiting the meeting center an intake form about them should be completed. In order to complete this form a number of short conversations between the elderly person and the center’s program coordinator or their living room mentor are supposed to take place.

According to Marijke van der Hoeven this intake form is a required checklist, which does not necessarily help to get to know the desires of the elderly person, let alone support the relationship between the visitor and the care professional.

It would be interesting to look into the possibilities of integrating this required checklist into the tool, so the short intake conversations be replaced with one useful and meaningful interaction, in which not only the obligatory information is gathered, but the visitor and employee also have the opportunity to connect.

2. Welcome package

Next to the day care offered in the meeting centers, Pieter van Foreest also provides other services, such as home care.

This service is for many elderly people the first contact with the organization. For elderly who start making use of this service, the conversation package ‘Door mijn ogen’ could be a welcome gift, which presents how Pieter van Foreest and their employees strive to see the elderly as people, rather than clients.

Furthermore the package could serve as a trigger for those elderly people to start thinking about their desired quality of life, and possibly have a conversation with their relatives. By allowing these elderly to identify their desires in an early stage, this will also help Pieter van Foreest to later on offer them appropriate care, when they are in need of more support.

“Het kan best vroeger.”
“Beter zelfs.”

Marijke van der Hoeven and
Ad Blom (evaluation)

3. Young potentials

Another possibility for the tool is to find a way to a younger target group, who are not dependent on additional care, but indirectly might become acquainted with Pieter van Foreest.

‘De Vereniging’ is an example of such a service of Pieter van Foreest (Pieter van Foreest, n.d.-b). This is a meeting platform for seniors who are not considered to be frail elderly, but do like to meet up and undertake activities such as a trip to a nature area.

Furthermore Ad Blom, Marijke van der Hoeven and Helma van Rijn all agree that also for even younger people the use of the tool could be meaningful. For example by providing this package to people over sixty to stimulate them to give the future a thought before experiencing serious limitations in their well-being.

***“We kunnen de tool ook
gebruiken als een soort
breekijzer.”***

Ad Blom (evaluation)

4. Wake up call

The reason why the intake procedures of new clients at Pieter van Foreest currently includes a lot of administrative paper work is that this documentation is required by organizations outside of Pieter van Foreest, such as the council and health insurance companies.

Since Pieter van Foreest relies on their financial grants, they are currently not able to dismiss these procedures, even when these are considered to be bothersome for the care professionals and not directly meaningful for the elderly clients.

In the spirit of constructive progress Ad Blom suggested presenting the tool as a wake-up call to these organizations. The goal of the tool would be to show the local council and other institutions the need to go back to the essence of care, which is not registering the elderly as patients, but caring for them as people.



8. REFLECT

To conclude the project the contributions, its limitations and recommendation are discussed. Also a personal reflection upon the process and project is given.

Blue sticky notes at the top of the page, containing text that is mostly illegible due to blurring.

Light green sticky notes at the top right of the page, containing text that is mostly illegible due to blurring.

A grid of blue sticky notes on the left side of the page, arranged in approximately 5 rows and 3 columns. The text is illegible.

A grid of light green sticky notes on the right side of the page, arranged in approximately 5 rows and 3 columns. The text is illegible.

A grid of orange sticky notes in the middle section, with a person's hands visible as they peel one of the notes. The text is illegible.

A grid of yellow sticky notes on the right side of the middle section, arranged in approximately 4 rows and 2 columns. The text is illegible.



8.1

Project

Conclusion and contributions

The project outcome is discussed by concluding Part I, II & III of the report and reflecting upon its contributions in relation to the problem statement and aim.

Problem statement

At the start of the project the following problem statement was formulated:

Shared decision making has the potential to help the frail elderly acknowledge which care corresponds with their desired quality of life. However, for the frail elderly this process requires preparation and time. Currently the timing of such conversations is often too late and the approaches originate from a medical perspective, which defines the elderly as patients rather than people. Furthermore quality of life is a sensitive topic, because it is difficult to express desires for the future.

Aim

The problem statement resulted in the following aim.

“To design a tool to help frail elderly timely express their desired quality of life, so they receive care that contributes to their actual quality of life.”

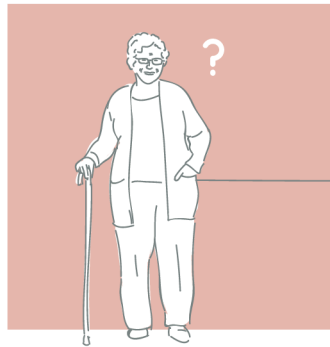
The aim of the project was to research and design an opportunity to enable elderly-centered communication about desired quality of life, which serves as a basis for shared decision making and results in person-oriented care.

PART I

2. ANALYSE

Research question

When and how should communication about quality of life with frail elderly take place to support future care decisions?



Vision

Stimulate the autonomous frail elderly to timely portray their desired quality of life in an exploratory conversation with a daycare professional. So the elderly are equipped to express themselves and their wishes to formal and informal caregivers, in order to make shared decisions about care that contributes to the elderly's quality of life.

3. DEFINE



→ **PART II** explore the possibilities to create the first portrait with frail elderly in the meeting center

Figure 35. Overview of Part I of the report.

Part I

Analyzing the current situation showed that a timely conversation should take place when frail elderly still have sufficient autonomy and are not yet facing care decisions related to the hospital or nursing home. A timely conversation results in the opportunity to communicate with the elderly about their desired quality of life first, before planning necessary care.

A tool should support the elderly in expressing their current happiness, beliefs, and wishes for the future. Their designated conversation partners are the daily care professionals, since they have the opportunity for personal contact with the elderly, while their professional incentive withholds them from getting too emotionally involved.

The conclusion of the analysis presents a journey of the current situation and a vision for the future (Figure 35).

This vision is summarized in a conceptual frame that proposes to focus on the first conversation in which a quality of life portrait is made with the frail elderly in the meeting center.

Part I defines the opportunity and moment to design a conversation tool that helps elderly express their desired quality of life. The vision proposes a change of mindset to improve the current situation from an elderly-centered perspective, and achieve timely communication with the frail elderly about a positive future perspective.

4. EXPLORE

Design question

How to design a conversation tool to capture the desired quality of life with frail elderly visitors at the meeting center?



Design goal

“Spark a socially frail visitor to collect & create their own Quality of life Portrait together with a meeting center employee, so the visitor can reflect upon their desired quality of life & share their wishes with others in order to treasure them together for the future.”

5. DESIGN BRIEF



—————> **PART III** Design to let elderly narrate and write their desired quality of life story together with a care professional

Figure 36. Overview of Part II of the report.

Part II

Design and research explorations with visitors and employees of the meeting center gave insights into the interaction, content and design of a desired quality of life conversation.

The conceptual frame and the exploration insights were combined into a design brief that describes how to design for the communication that helps socially frail elderly visitors to portray their desired quality of life (Figure 36).

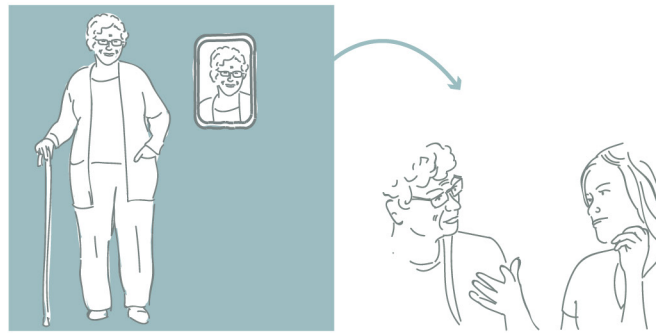
Besides a design goal, the design brief describes the desired interaction (*trustful, encouraging, invigorating*) and presents a framework that defines five conversation elements (*spark, reflect, collect, create, share*) with nine design guidelines to achieve these.

The design brief of Part II is meant to support and guide other designers in developing a product or service that helps the frail elderly communicate and express their desired quality of life.

6. DESIGN

Door mijn ogen

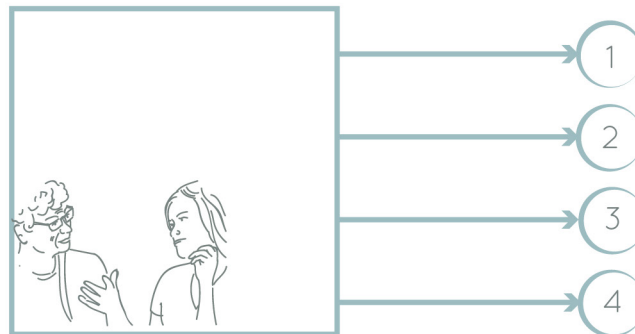
This conversation tool helps a socially frail visitor to capture their personal quality of life together with an employee, so future care decisions can be made according to the elderly's desires.



7. EVALUATE

What is next?

An evaluation with representatives of Pieter van Foreest and a service designer of Muzus resulted in four opportunities for the further development and potential use of the conversation package.



→ 8. REFLECT

Reflecting upon process and personal learnings of the project.

Figure 37. Overview of Part III of the report.

Part III

The tool designed for this project is “Door mijn ogen”. This conversation package includes a wrapper and instructions for care professionals, a booklet for the frail elderly and a writing board. These items support the care professional and elderly person to have a one on one conversation about the elderly person’s desired quality of life by making their happiness, beliefs and wishes tangible.

The goal of the conversation is not only to help the elderly to express themselves and timely share their wishes with a meeting center employee in a timely way, but also positively supports their relationship.

Furthermore insights in the elderly visitor’s desired quality of life helps Pieter van Foreest to provide person-oriented care. Finally in an evaluation session with Pieter van Foreest and Muzus four opportunities for the future development of the tool are defined (*start today, welcome package, young potentials, wake up call*) (Figure 37).

The tool 'Door mijn ogen' is meant as an inspiration for Pieter van Foreest, and others involved in the field of elderly care. It illustrates how enabling timely conversations about the elderly's desired quality of life contributes to providing appropriate care and establishes a better connection between the elderly and care professionals. .

8.2

Process

Limitations and recommendations

The outcome and the process of the project are inextricably linked. Critically reviewing the process helps to place the project's contributions in perspective. For this reason the limitations of the process and recommendations for future research and design are formulated.

Defining the frail elderly

The frail elderly are a target group that is difficult to define, not only since literature is not unanimous about the concept 'frailty', but also because frailty is a dynamic process and not a static state.

This project defines the frail elderly as people over 75 years of age, whose social, mental and/or physical limitations make them dependent on additional care. This helps to describe elderly, who have an increased risk to get involved with specialized elderly care, as well as (urgent) medical treatments. However no set checklist was made to exactly define, whether elderly belong to this target group or not.

It is recommended to critically review the definition of frailty and potentially make it measurable, objectively or subjectively, to make it easier to define whether elderly are considered frail or not.

Defining (desired) quality of life

At the start of this project quality of life is defined as the individual's perception of their desired and actual quality of life, and it is divided in four components: health, level of independence, happiness and beliefs. Eventually desired quality of life is defined as a combination of the beliefs, happiness and wishes based upon research activities with the target group. This project shows one way of looking at the concept quality of life and strives to make it a useful interpretation within the context of frail elderly and care decisions.

In reality, quality of life is a complex concept. Its definition might differ, when using a broader perspective or different angle, for example by involving more elderly, defining other components than the above mentioned, or by using both subjective and objective measurements.

Not only does this show how the definition described in this project should be used thoughtfully, but also how defining quality of life in a different manner might have resulted in another project outcome.

It is recommended to critically review the definition of quality of life and the defined components to evaluate how useful these are in relation to the frail elderly and care decisions.

Furthermore the division between actual quality of life and desired quality of life could be studied to learn to what extent happiness, beliefs, health and autonomy influence quality of life.

Explorative research, interpretation and results

The explorative research in this project includes interviews, observations, design interventions and feedback sessions. These activities made it possible to actively involve the target group, which included both the frail elderly and care professionals. It resulted in qualitative data, which was processed and interpreted by one designer.

The interpretation and gathering of the data was done individually. Since frequent

feedback sessions with other designers or researchers were considered to be too time intensive. This could have resulted in a misinterpretation and potential loss of data.

The care professionals and the elderly that participated in the research influenced the results of this project, which among others includes a persona, journey, formal care clusters and the framework. Since only a small number of care professionals and frail elderly were involved, the results of the project are probably not representative for the target group as a whole. Especially because these people were willing to participate, causing certain other groups to be excluded.

Furthermore the presence of the designer during the research, could also have biased the results of the interventions.

For future research and design it is recommended to critically evaluate the gathered data. It could also be useful when repeating the research and design activities to involve a larger and more diverse group of care professionals and elderly, and to involve more researchers and designers in gathering and processing the data. This way the results of the research a design could represent a larger target group.

Involvement of mentally frail elderly

This project resulted in a design brief and design that focusses on the socially frail elderly. However during all research and design activities before the third intervention, also mental frail elderly, who suffer from dementia were involved. This might have influenced the results and insights gathered during these activities, and thereby indirectly also the outcome of this project.

For future research it is recommended to either repeat these activities with frail elderly without cognitive issues, or in another way validate the results of these activities. The latter is especially interesting for the framework, which combines most of the knowledge of the research and design activities in a comprehensive manner.

Evaluating the design brief and design

The framework, design goal, interaction metaphor and qualities are a result of explorative research. This design brief eventually lead to the development of the tool "Door mijn ogen".

Due to time constraints the final design was not tested through a one on one conversation with a socially frail elderly visitor and meeting center employee. For this reason it is not possible to reflect upon the actual experience of the design or to explain if the desired interaction qualities are perceived during use.

Recommendations for future research are to evaluate the design brief and design itself by user testing the tool with the socially frail elderly and meeting center employees. In order to:

- 1. evaluate the use and experience of the tool with the target group*
- 2. see whether the framework, design goal and interaction qualities should be revised*
- 3. formulate recommendations for the further development of the tool*

Other conversation partners

Only during the observations were the relatives of the elderly directly involved. Therefore most of the information gathered about relatives is second-hand information, based upon the opinions of either the elderly or care professionals. It is still open for discussion if relatives are a potential conversation partner.

During this project the question whether meeting center employees are the right care professionals to have this conversation with the elderly was often a topic of discussion. It was proposed that maybe people with a spiritual or psychological background might be better able to have such conversations or even a complete stranger ('a pair of fresh eyes').

Furthermore the analysis phase presents the daily care professionals as the most suitable conversation partner. However not all professionals in this cluster have been interviewed, and their exact interaction with the elderly also differs in the duration and people present.

Finally the most important point is that it is always up to the elderly, if her or she opens up to the conversation partner.

It would be interesting to involve relatives and see whether they might be interested in and capable of having desired quality of life conversations with the elderly person they are related to.

Further research should show whether meeting center employees or other care professionals are the best fit for conversation partner.

Also it should be researched whether indeed other professionals of the daily care are able to have these conversations. All the above mentioned points potentially result in new opportunities to design a conversation about quality of life.

Timing the conversation

If after the vision it was decided to focus on a different moment within the journey, probably earlier when the elderly are not considered frail yet, this would have also resulted in another design brief and tool.

Exploring the possibilities to trigger people earlier to think about their quality of life could be an interesting opportunity for a future design.

Collaboration with other elderly care

The elderly clients and care professionals of Pieter van Foreest, in particular those in the meeting center, were closely involved in the process.

Even though this day care facility, the meeting center, and Pieter van Foreest as an organization provide similar services to other elderly care organizations in the Netherlands, it does not mean that the outcome of this project is representative for all.

For future research it would be interesting to involve other meeting centers and/or care institutions to see whether the results of this project are indeed also representative in another contexts.

Expressing desired quality of life to establish shared care decisions

Finally the aim of the project states that by helping the elderly timely express their desired quality of life this could contribute to shared care decisions that contribute to the elderly's actual quality of life.

This remains an assumption, because in the scope of this project it was not possible to actually prove this.

This kind of research reaches beyond the scope of this project and should involve various types of care professionals, elderly and actual care decisions. Furthermore it is recommended to design a more advanced prototype, than the final design outcome of this project, to use during testing.

8.3

Personal

Looking back at the project and process

Connecting to the target group

I dived right into this project with a lot of enthusiasm and an idealistic mindset, really wanting to change something for the elderly and help them express their desires regarding care.

Soon I discovered that as someone with no medical expertise, I was not in the position to give information about whether to undergo a potential treatment or not. The conversation with a geriatrician again made me realize that in fact these care decisions are not the goal, but merely a means to a greater good, supporting elderly and their personal quality of life.

This realization helped me to connect to the elderly during the interviews and interventions, and to listen to what really matters to them in their lives.

Letting go of the need to find solutions in the medical field helped me to relate to the target group and discover opportunities from their perspective, and eventually come up with a design that hopefully really supports the target group.

Time and space

Even though I am designing a conversation in which time and space to reflect are essential. I have to admit, ironically, that I believe that standing still for a moment is my personal biggest challenge as a designer and as a person.

My enthusiasm to learn, discover and design motivated me throughout the project, but also sometimes made me lose sight of its purpose. I was so busy going that I forgot to listen and understand.

The first time I realized the need to slow down was after the second intervention. I had a meeting with mentors in which they told me to take my time. During my small break I wrote the poem “Ook dat is toekomst”, trying to get back in touch with what this project is all about: the quality of life of frail elderly and how to help them treasure it for the future.

This was the first, but not the last moment during my graduation, when I was confronted by how difficult I find it to give myself some time. Especially, when the deadline for my report came close I experienced the same feeling. Now at the end of my project I realize more than ever that creating these moments of silence are the source of the best ideas. And that taking some time also helps me to listen to what really matters to me.

Doing it together

This project has always meant more to me than just a graduation. I believe this incentive motivated me to do well, but also made me sometimes feel alone in the process. Luckily, my tutors and other people involved supported me and helped me to see how I was still learning and to experience this project as a collaboration.

Quality of life

This graduation has taught me a lot about myself and my perception of the quality of life. It showed me the beauty of creating time and space for the stories of the elderly, myself and those around me. In the future I will try to keep reminding myself to every now and then slow down my pace, as time and space is something I wish to become more familiar with in my personal future and career as a designer.

Acknowledgements

Thanks Marieke and Jeske for supporting and stimulating me in my final academic learning experience. You both helped me in the moments when I lost the overview over my project and comforted me with the fact that I should take my time.

Thanks Marieke for teaching me about a sensitive and academic approach, and giving me guidance in how to structure my messy mind.

Thanks Jeske for your eye for detail and visual appearance, they helped me a lot during designing my products and report.

Thanks to Ad for giving me such a warm welcoming experience within Pieter van Foreest, and providing me with an opportunity to discover opportunities for innovation under your guidance.

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Thanks to all the employees and elderly of Pieter van Foreest who helped me throughout this project, in particular those of the meeting center de Vermeertoren. Without you this project would not have come to be.

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