De Verhalenhoek:

End of Life care in patient rooms of Erasmus MC

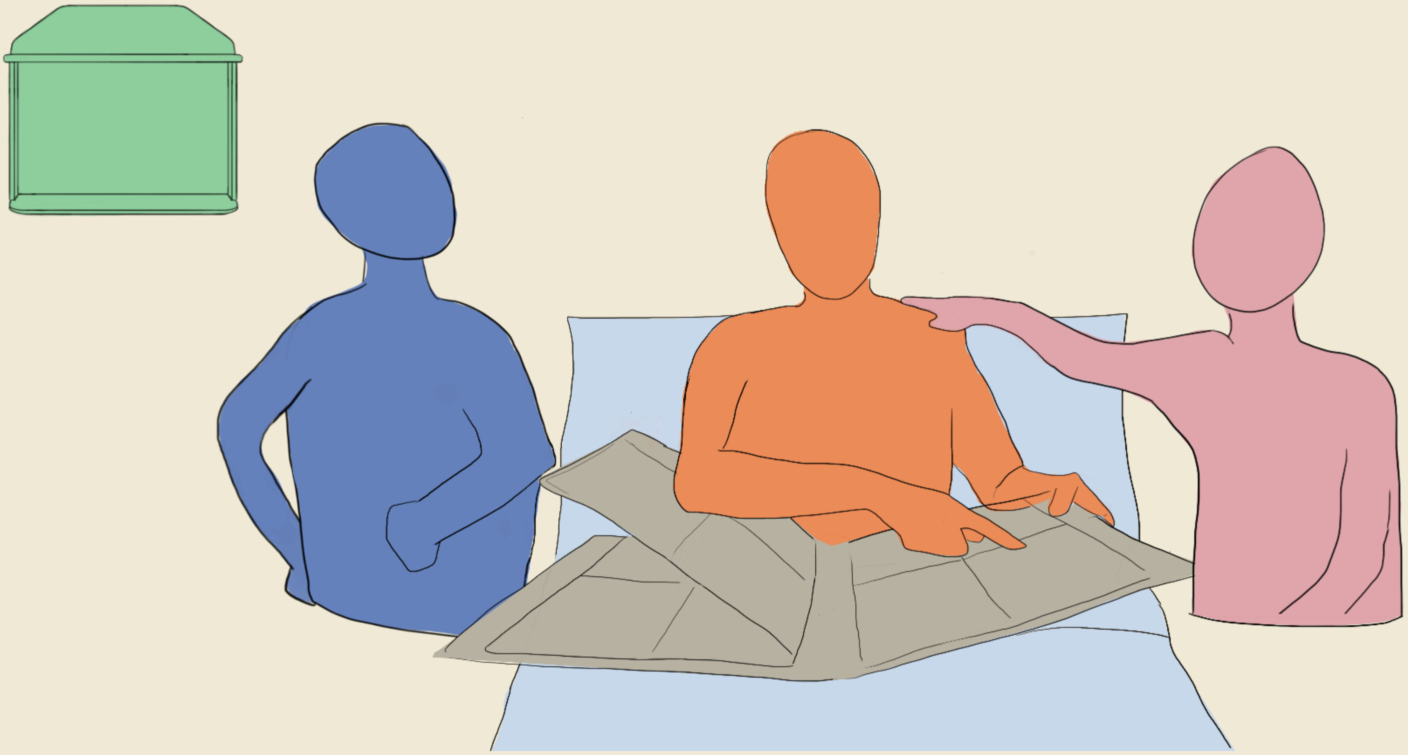
Thesis report

02-07-2024

Mathilde Claesen

MSc Design for Interaction

Industrial Design Engineering, TU Delft



Colophon

Author: Mathilde Claesen

Title: De Verhalenhoek: End of Life care in patient rooms of Erasmus MC

Submission Date: 02-07-2024

Program: Master Design for Interaction

Faculty: Industrial Design Engineering, TU Delft

Supervisors: Marieke van Sonneveld, Joost Alferink and Rozemarijn van Bruchem-Visser

The layout was designed by Mathilde Claesen and all drawings in the report are created by Mathilde Claesen.

Abstract

Palliative care is becoming increasingly important at Erasmus Medical Center (Erasmus MC) as the hospital sees around a thousand annual deaths due to various conditions. However, the hospital environment has not adequately addressed the psychological, spiritual, and social needs of patients and their loved ones during the end-of-life phase. This TU Delft graduation project, in collaboration with Erasmus MC, aims to explore the unique needs of patients, their families, medical staff and the patient environment in the final days of life. The goal is to develop a sustainable, design-driven concept that illustrates enhanced end-of-life care across different hospital departments.

This research employed a multi-phase design approach using the Double Diamond framework. The Discover phase involved extensive research, including literature reviews, visits to care facilities, patient room analyses and interviews with healthcare professionals. The Define phase synthesized these insights into a framework for the End of Life journey, analyzing the needs and responsibilities of key stakeholders. This analysis led to a future vision, outlining three design directions for improved palliative care. In the Develop phase, a concept was iteratively created and evaluated to align with this vision. The design process focused on the design goal: “To create a patient room that supports stakeholders in the End of Life process in facilitating a dignified end of life experience for all involved.” Finally, the Deliver phase presented a proof of concept to illustrate the possibilities of this research, with recommendations for future implementations at Erasmus MC.

The research identified several key findings, categorized into three main design opportunities: improving communication and expectations, enhancing the autonomy of actors involved and balancing the wishes of patients with the resources of the medical team.

“De Verhalenhoek" emerged from this process: a cabinet where patients can store meaningful items, facilitating conversations about values and interests between patients, loved ones and medical staff. The concept invites users to personalize the room and serves as a starting point for conversations about the End of Life process. De Verhalenhoek aligns with the goals by creating a welcoming space that encourages discussions about patients' values and the meaning of death, enhancing communication and quality of care. This helps to reveal individual, cultural and religious preferences, allowing medical staff to tailor treatments to patients' whishes and ensuring patients and loved ones feel seen and heard.

The research concludes that integrating thoughtful design into patient rooms can improve communication in end-of-life phases and enhance the sense of autonomy for stakeholders involved. Key recommendations include evaluating the interactions through a pilot study to assess the impact in the intended setting. This pilot aims to help patients feel more in control and supported in their final days and to better prepare the loved ones for the grieving process. Future research should focus on implementing these design solutions across various hospital departments to broadly enhance the quality of palliative care at Erasmus MC.

This project demonstrates the potential of design to improve End of Life care in patient rooms, making a contribution to the field of palliative care.

Preface

Dear reader,

This thesis project started in September 2024 with a search to the ‘fitting’ topic for my graduation project. Along the way, I got to know more about the End of Life-Lab at the IDE faculty and I met Marieke, Joost and Rozemarijn. The End of Life topic immediately felt like a beautiful challenge to me. Thank you to Marieke and Joost for trusting me with this topic. Thank you for allowing me to explore the context and guiding me through the process when necessary.

Rozemarijn, who initiated the project at Erasmus MC, shared what this project meant to her and the hospital, which only fueled my drive to take on this challenge. Her boundless energy and dedication to enhancing palliative care at Erasmus MC have been immensely helpful throughout this process. Rozemarijn has opened many doors for me, both figuratively and literally, whenever I found myself lost in the vast Erasmus MC building. Thank you!

I am grateful that I got the chance to dive in this sensitive topic, that allowed me to look at the process of death differently than before. Hearing personal stories of healthcare professionals, patients and loved ones has made me realize that the concept of death and dying is truly different for everybody. That is exactly what made this project so beautiful, yet difficult at the same time.

As I’m sure every graduation student had their ups and downs in the process, so did I. I have had to zoom in and zoom out multiple times, sometimes losing my way and finding it back in another place. Luckily I had a great support team of friends that provided me with a bit of realism, to put it all into perspective. A special thank you to Zep and Lies for taking the time to be there and hear me out, even during your own graduation struggles. Thank you to my Dad and brother, that ensured me their door is always open for good food and a good mood. And a big thank you to my Mom, for brainstorming with me about scenario, giving me feedback on my work and always accepting my calls – even when you’re in the middle of a game of golf.

This project focuses on a small part of the big subject of End of Life care in hospitals. Although I am satisfied with the research and design I delivered, there is much more progress to make in human-centered design in Dutch healthcare. Thus, I hope that more (student) research will devoted to this topic, so that design can really be implemented in the healthcare context and the balance in care and cure can be designed to fit the individual patient.

Enjoy reading!

Mathilde

Glossary

This glossary provides definitions and explanations for key terms and concepts used throughout this report.

Palliative care
Palliative care is a holistic approach to treating patients with serious illnesses, focusing on providing relief from symptoms, pain and stress. It involves a multidisciplinary team that addresses the physical, emotional, social, and spiritual needs of patients and their families. There are four phases within palliative care.

End of Life journey
The End of Life Journey is a framework used in this report. It summarizes the process patients, loved ones and healthcare professionals go through during palliative care in the hospital.

Curative care
Curative care refers to treatments aimed at curing the patient's illness, as opposed to palliative care which focuses on comfort and quality of life.

Palliative care phase
The palliative care phase refers to the second phase of palliative care in a hospital setting, where curative care is stopped and only palliative treatments are ongoing to enhance comfort and quality of life.

End of Life care
End of life care is the phase between palliative care and the death of a patient. This phase, also known as the terminal care phase, will be referred to as the End of Life (EOL) care or EOL phase in this report. It typically involves the last 1-4 days of a patient's life in the hospital.

Bereavement care
Bereavement care is the support provided to families or friends grieving the death of a loved one, helping them cope with their loss and navigate the grieving process.

Hospice care
Hospice care is a type of End of Life care provided in hospices, focusing on comfort and quality of life. This term is used in a hospice setting.

Health care professionals
Healthcare professionals are individuals educated to provide medical care and perform care activities in healthcare settings. When referring to healthcare professionals in a hospital, they are referred to as medical staff.

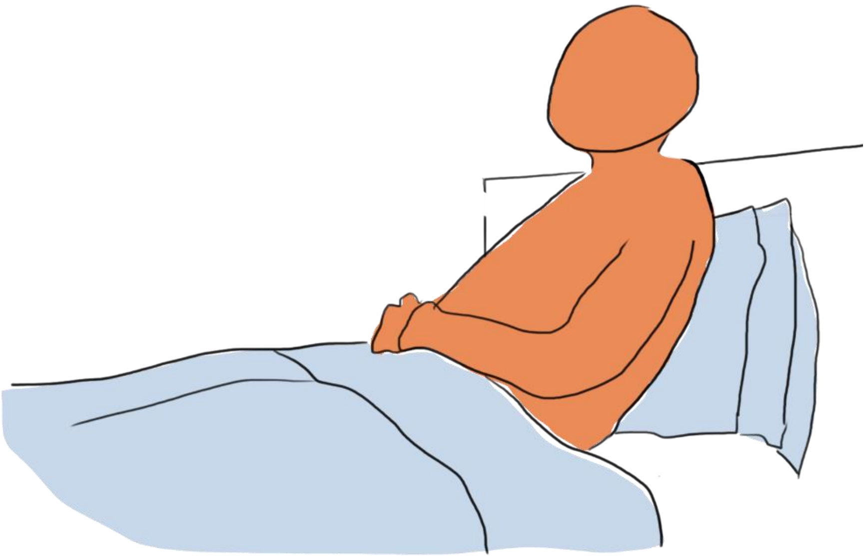
Informal caregivers
Informal caregivers are loved ones, family members or volunteers who provide care to the patient.

Patient room
The patient room is the room where patients sleep and stay during their stay in the hospital.

TABLE OF CONTENTS

1. INTRODUCTION

This chapter gives an introduction to the context of palliative care at Erasmus MC, the goal and scope of this thesis and the challenges this assignment brings along. Furthermore, the use of the Double Diamond method is explained in more detail and the research questions for the project are proposed.



1.1 Background and context

Awareness about palliative care

In recent years, Erasmus Medical Center (Erasmus MC) has noted that approximately a thousand individuals pass away in the hospital annually due to various conditions and illnesses (Erasmus MC, confidential data, 2024). Although it is not intended for patients to die in the hospital, unexpected circumstances can sometimes leave no other option for their final moments. Despite this unfortunate occurrence, the attention within the hospital's environment given to the diverse needs of the involved actors in the final stage of life was limited. However, there has been a shift in attention towards palliative care over the past decade, emphasizing the importance of delivering quality end-of-life support (Swami & Case, 2018). Health care professionals recognize the importance of providing emotional, psychological and spiritual support alongside physical care.

Patient room

It is crucial that the importance of palliative care is evident throughout the entire hospital, specifically in environments where patients spend the majority of their time: the patient rooms. The design of these rooms often lack explicit consideration for end-of-life processes, revealing gaps in meeting the emotional, psychological and spiritual needs of patients and their loved ones, since there is a predominant focus on medical care.

1.2 Goal and scope of thesis

This TU Delft graduation project dives into the unique needs of patients, their loved ones, medical staff and the patient environment during the final phase of life in the patient rooms at Erasmus MC in Rotterdam. Initiated by Erasmus MC, the project is aiming to identify patterns and opportunities for improvements in facilitating a peaceful passing in the patient rooms at Erasmus MC.

This project focuses on the last days of the 'unexpected deaths' at Erasmus MC. Specifically, the project focuses on the needs in the final 1-4 days of a patient's life and developing a feasible intervention to meet these needs. This intervention is created from a design perspective, to explore the value that design can bring in such a complex system.

This thesis is targeted at the focused on the department of Erasmus MC, due to its high passing rate and prolonged patient stays (Erasmus MC, confidential data, 2024). The bigger vision is to develop a sustainable solution adaptable for implementation across various hospital departments, thus positively impacting end-of-life care on a broader scale.

1.3 Design challenges

This project operates within a complex system, which requires thorough consideration of hospital regulations throughout the design process. The goal is to seamlessly integrate more focus on the end-of-life process into the patients environment without interrupting the vital work of hospital staff.

This project will involve various parties, including medical staff interacting with patients, personnel across hierarchical levels, vulnerable patients, their loved ones and the patient environment. Thereby it is acknowledged that variations in individual needs and wishes will occur, influenced by e.g. cultural backgrounds, age, or lifestyle.

In navigating this topic, it is vital to remain aware of the vulnerable setting and the sensitive conversations that will occur during the research in this context. Understanding and respecting the sensitivity of these interactions is crucial in providing comprehensive designs for the end-of-life phase for the individuals involved.

1.4 Project Approach

Design phases

This thesis follows the framework of the Double Diamond (Design Council, n.d.). This framework consists of two diamonds (figure 1), each representing a distinct phase in the design process to diverge and converge. The process is divided into four phases, which will be detailed in this report.

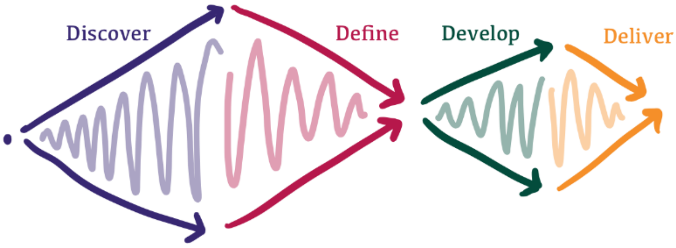


Figure 1: A visualization of the Double Diamon method

Discover

During the Discover phase, extensive research is conducted about the palliative care and the process of patients passing away at Erasmus MC, particularly within the patient room. Various research activities are undertaken to answer the research questions. These research questions are chosen to get a complete understanding of the last few days of a patient's life before passing away in a patient room at Erasmus MC.

Palliative care

- How is the palliative care structured at Erasmus MC?
- How is the palliative care structured in care facilities outside of Erasmus MC?

End of Life (EOL) journey at Erasmus MC

- What phases do individuals go through in the EOL journey at Erasmus MC?
- Who are key actors involved in the EOL journey and what roles do they play in the different phases?
- What are the needs of the individuals during these the phases of the EOL journey?

Patient environment

- How is palliative care currently facilitated within patient rooms at Erasmus MC and how does this meet the needs of the involved individuals?
- How are cultural, spiritual, and individual preferences considered and integrated into Erasmus MC's patient rooms during palliative care?

Building upon insights gained from the qualitative research, the Discover phase presents a current state analysis of the End of Life journey at Erasmus MC as a conclusion of the research. This framework demonstrates what different roles and needs the patient, loved ones, health care professionals and patient environment can take on during the End of Life journey. This analysis also shows the different outcomes such an End of Life journey can have in a hospital.

Define

In the Define phase a Future Vision is created in order to demonstrate what 3 design ingredients could be focused on in the future, to improve the palliative care in the patient rooms at Erasmus MC.

Additionally, a design goal is established, along with interaction qualities that fit with the intervention's place within the patient journey.

Develop

As an illustration of how the future vision would work, the Develop phase will show the design of a concept for the patient rooms at Erasmus MC that is in line with this future vision.

The Develop phase focuses on the ideation, where diverse activities are used to achieve the design goal. Through iterative processes and evaluation of the concept, design choices are made in order to design a concept that fits with the identified needs and in the context of Erasmus MC.

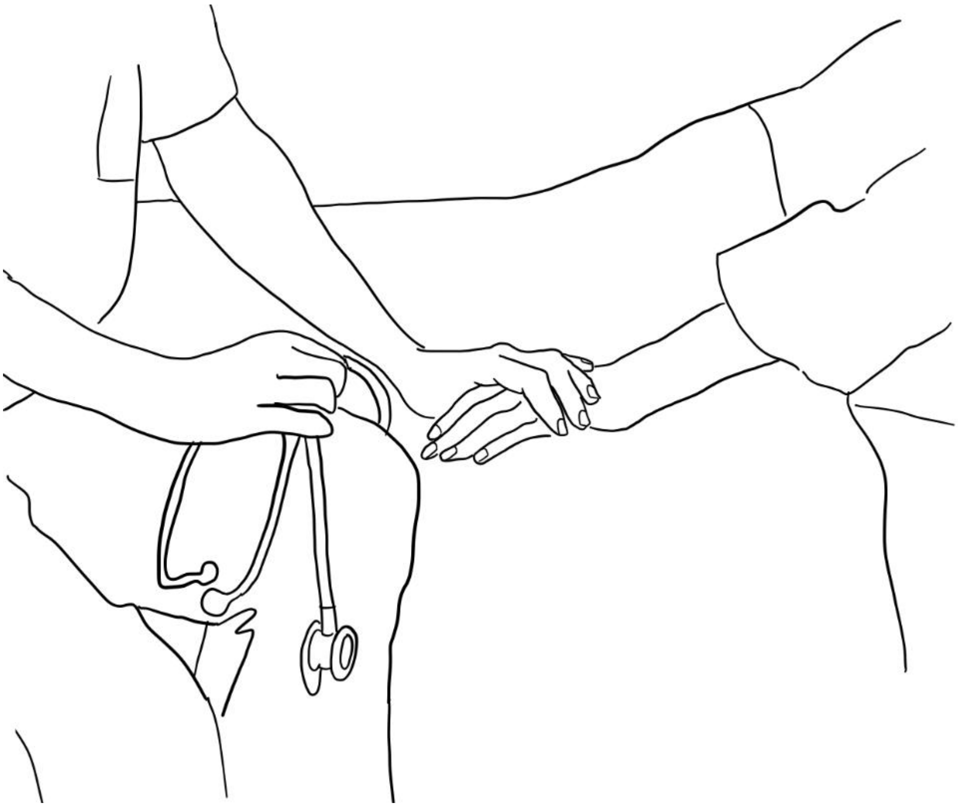
Deliver

The Deliver phase shows the finalization of the proof of concept for Erasmus MC. This phase results in the presentation of a potential implementation of the envisioned future in Erasmus MC's patient rooms. Recommendations are provided for future development and utilization of the concept, accompanied by reflections on the design process and personal insights gained throughout the thesis project.

The chapters of this report will follow the Double Diamond framework, to methodically explore, define, develop and ultimately deliver an innovative concept to enhance end-of-life care in the patient environment at Erasmus MC.

2. DISCOVER

The discover phase focuses on the current palliative care at Erasmus MC and how this care differs from other care facilities in the Netherlands. It shows the results of qualitative research and provides an overview of the End of Life journey at ERASMUS MC and zooms in on how this journey is experienced in the hospital patient rooms by the different individuals involved.



2.1 Method

The method section will present the research questions proposed for the Discover phase and explain with what research methods these questions will be answered.

2.1.1 Research questions

Research Questions:	**Research Methods used:**
Palliative care	
1. How is the palliative care structured at Erasmus MC?	1. Literature review and Interviews
2. How is the palliative care structured in care facilities outside of Erasmus MC?	2. Literature review, visits to hospices and Interviews
End of Life (EOL) journey at Erasmus MC	
3. What phases do individuals go through in the EOL journey at Erasmus MC?	3. Interviews
4. Who are key actors involved in the EOL journey and what roles do they play in the different phases?	4. Literature review and Interviews
5. What are the needs of the individuals during these the phases of the EOL journey?	5. Interviews, use of persona's and Visits
Patient environment	
6. How is palliative care currently facilitated within patient rooms at Erasmus MC and how does this meet the needs of the involved individuals?	6. Visits, Interviews and Patient room analysis
7. How are cultural, spiritual, and individual preferences considered and integrated into Erasmus MC's patient rooms during palliative care?	7. Interviews and Visits

2.1.2 Research methods

The following research methods are used in this project.

Literature review
A comprehensive literature review was conducted to gain an in-depth understanding of the context of palliative care and End of Life (EoL) processes in care facilities. This review primarily involved online research to explore the definition and scope of palliative care, as well as its role and implementation within hospital settings. The literature search was conducted using Google Scholar with search terms such as "Palliative care," "End-of-life care," "actors in end-of-life process," and "patient room architecture." Additionally, grey literature was used when published articles were not available or when specific organizational descriptions were required. The literature review also aimed to gather inspiration and insights regarding the impact of the patient environment on the well-being of patients and loved ones.

Visits to care facilities
Visits to Erasmus MC were conducted to understand the hospital environment and the patient rooms, as well as to gain valuable insights into the operational workflows and practices within the facility. These visits were instrumental in understanding the contextual factors that influence patient care in a hospital setting. Additionally, visits to two hospices in Rotterdam were done: Laurens Cadenza and Vier Vogels. These hospice visits provided a broader perspective on palliative care practices and the nuances of providing comfort and support to patients and their families during the final stages of life. This comparative approach allowed for a more comprehensive analysis of palliative care environments, informing the subsequent design and recommendations for improving patient rooms and care processes in the context of Erasmus MC.

Patient room analysis
An analysis of the rooms at Erasmus MC was conducted by creating rough 2D and 3D models of the room using Miro for 2D models and the software Blender for 3D models (figure 2). This approach provided a general understanding of the room's dimensions and layout, offering a visual aid that was particularly useful during (online) interviews. These models gave an overall picture and feeling of how the patient rooms are currently set up and helped in analyzing the elements present in the room for their relevance in palliative care. Besides, it helped to see what role the furniture offered for the patients, loved ones or medical staff. Using Blender for the 3D analysis made it easier to visualize potential improvements and modifications. This process provided valuable insights for the design phase and facilitated meaningful discussions.

Figure 2: Overview of a patient room at Erasmus MC, created in the software Blender

Persona's
Based on insights from literature and qualitative research, personas were created. This report uses scenarios reflecting different patient experiences, grounded in STEM research, to develop five distinct personas (Stichting STEM, n.d.).

Interviews with healthcare professionals
Interviews with healthcare professionals were conducted using a semi-structured format, both at Erasmus MC and at two hospices: Laurens Cadenza and Vier Vogels. With the help of Erasmus MC supervisor Rozemarijn van Bruchem-Visser, various employees of Erasmus MC were contacted through email to see if they would be willing to share their experiences and observations related to palliative care in the Erasmus MC patient rooms. The interviewed employees at Erasmus MC occupied various hierarchical positions, including medical students, nurses and doctors. This diverse selection was intended to provide a comprehensive understanding of how different healthcare professionals contribute to the patient room environment and their experiences with patient and family interactions.

Each interview lasted about 30 minutes up to one hour. Since one healthcare professional was not available for an in-person interview, that interview was conducted via an online video call.

The interviews were organized around a set of predetermined open-ended questions, with other questions emerging from the dialogue between interviewer and interviewee(s). The specific interview questions can be found in appendix B. In total, eight interviews were conducted with healthcare professionals. To protect their privacy, the names of the interviewees are semi-anonymized, by using fake names in this report.

The topic list for the interviews included:

- The role of the healthcare worker
- Wishes and needs of patients and loved ones
- Practical details of the room
- Transition from life to terminal care
- Different levels of family and friends
- Best practices in palliative care at Erasmus MC
- Brainstorming about future room possibilities

2.1.3 Project participants

To gain a comprehensive understanding of the vulnerable context in which this project is situated, individuals actively engaged within this setting were invited to share their insights. Engaging participants directly involved in the EOL-context ensured alignment between the future design's attributes and the dynamics of end-of-life care in hospital environments. A total of eight participants, each with a different connection to palliative care, contributed to this study through semi-structured interviews. All participants were women, with diverse religious and cultural backgrounds that contributed to the insights. All participants were between the age of 25 and 50 years old.

Their diverse roles and experiences provided a multifaceted perspective on the challenges and considerations specific to this sensitive area of healthcare. To comply with privacy regulations, all participant names have been semi-anonymized, faces have been blurred and personal information is not included in this report.

The research included visits to two hospices in Rotterdam, where staff members shared their professional experiences and insights:

- Participant 1: Monica, a volunteer at a hospice
- Participant 2: Lisa, a hospice nurse and coordinator

Additionally, interviews were conducted with four medical staff members at Erasmus MC, offering a broader view of the palliative care journey and the patient room. Together with these healthcare professionals, the patient room was analyzed with their experiences.

- Participant 3: Madelief, a resident physician geriatrics department
- Participant 4: Iris, a coordinator of the nurses and a geriatric nurse
- Participant 5: Anneke, an internist-oncologist with a focus on pain and palliative care management at the palliative care unit
- Participant 6: Rosalie, a geriatric nurse in training

The study also included perspectives from two medical Erasmus students closely associated with the field:

- Participant 7: Zoe, a medical student and nurse assistant at Erasmus MC
- Participant 8: Lana, a medical and philosophy student

Each participant's contribution provided depth and nuance to the understanding of the end-of-life care environment at Erasmus MC. To accommodate the varied schedules and locations of participants, some interviews were conducted in person, while others took place online through video calls.

Figure 3: Screenshot of an interview with participant 7, Zoe, discussing the current patient room at Erasmus MC

2.2 Results

2.2.1 Introduction

This chapter presents the findings from the research activities through primary and secondary sources to provide a comprehensive understanding of the subject. Primary sources include interviews, while secondary sources comprise literature reviews and other research activities. Key insights were gained from interviews with healthcare professionals in palliative care settings, highlighting their experiences, challenges, work environment and patient interactions. Visits to healthcare facilities further enriched these insights by offering a firsthand view of the context. Room analysis and persona creation added depth to the analysis of the individuals involved. The literature review provided broader context and validated these insights. This multifaceted approach ensures the conclusions are grounded in real-world experiences and supported by established research.

2.2.2 Understanding Palliative care

Definition

Palliative care is defined by the WHO as care that “relieves suffering and improves quality of life for patients and families dealing with any type of life-threatening disease” (World Health Organization: WHO, 2020). Palliative care extends beyond physical support to encompass emotional, spiritual, and social needs of patients (Galekop et al., 2019).

In addressing these needs of patients, it is essential to consider the framework of psychological human needs, which includes 13 fundamental needs and 52 sub-needs. These fundamental needs encompass the emotional, spiritual, and social aspects of well-being (Desmet & Fokkinga, 2020). Recognizing that palliative care addresses these fundamental needs is crucial not only for patients but also for their loved ones and medical staff, as it underscores the holistic nature of care required for overall well-being.

Importance in the Netherlands

The global need for palliative care will continue to grow as a result of the ageing of populations (World Health Organization: WHO, 2020). In the Netherlands, more than 105,000 people annually pass away from conditions often requiring palliative care, these are known as ‘expected deaths’ (Palliaweb, 2022). In 2020, of those ‘expected deaths’ requiring palliative care, 41% occurred at home, 33% in nursing or care homes, 18% in hospitals, and 8% in various other locations.

Palliative care phases

Figure 4 shows the different phases of palliative care proposed by the World Health Organization (WHO) in 1990. Since then, there has been a shift in healthcare approaches, recognizing that when curative treatments stop, it does not mean the palliative care phase stops and the patient is transferred to hospice care.

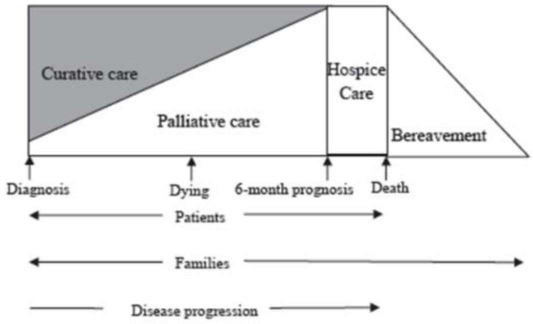


Figure 4: Model of palliative care adapted from ‘the integrated model of care’ proposed by World Health Organization (WHO), 1990

Nowadays, palliative care continues up until the patient’s condition declines significantly and the medical team transitions the focus entirely to comfort care. This project follows a current model of the palliative care (figure 5), where the palliative care phase focuses more on the quality of life of a patient and psychological, spiritual and social care.

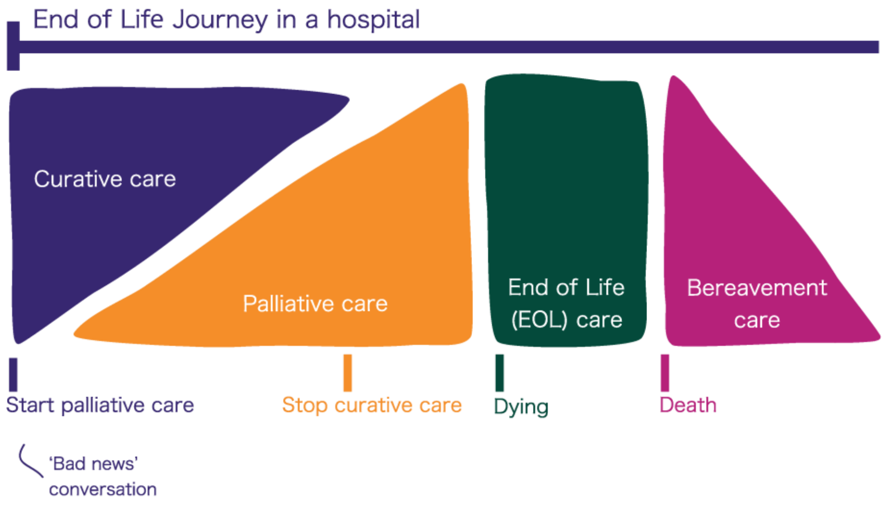


Figure 5: Schematic overview of four palliative care phases in the End of Life journey, based on 'the integrated model of care' proposed by World Health Organization (WHO), 1990

The 'palliative care phase' commences when it becomes apparent that full recovery from the illness is no longer feasible. This is often formalized in hospitals through a 'bad news conversation' with healthcare professionals, the patient and often loved ones (personal communication, March 11th, 2024; see Appendix B).

The palliative care phase culminates in terminal care, marking the patient's progression into the 'End of Life care phase', at which point all attempts at curative treatment are discontinued (Rome et al., 2011). The duration of the palliative phase varies widely due to differences in the illness, patient condition, possible treatments and external factors, extending from several years to a few hours (personal communication, March 22nd, 2024; see Appendix E).

This phase involves a critical point where a decision is made whether patients are able to be moved to another care facility for their final moments. The last phase, the 'bereavement care phase,' provides support and closure for the deceased's loved ones.

> **"For family and friends, the bad news conversation can also be a significant turning point in their lives; this experience stays with them forever."**
>
> **(Iris, personal communication, March 11th, 2024; see Appendix B)**

Unexpected deaths

Unfortunately, not all patients get the choice of where they want to spend their last moments. Patients in the hospital who pass away suddenly, referred to as 'unexpected deaths', often do not have the choice, due to limited time, physical strength or resources to be moved to a different location for their passing. This can be caused by various reasons, such as complications during treatment, lack of physical strength for transportation, or insufficient time left to ensure that the move does not decrease the quality of life.

Additionally, the desired care facility might not have a free bed available at that time, or there may be no caregiver at home, making the move back home impractical for ensuring quality of life and death (personal communication, March 22nd, 2024; see Appendix E). This project focuses on these 'unexpected deaths', that unfortunately pass away in the hospital environment.

2.2.3 Coping with death and dying

The quality of death and the surrounding environment play a vital role in this project, influencing the quality of life for both patients and family caregivers. For the bereaved, memories of a loved one are closely tied to the environment in which they spent their final moments. A positive experience in this setting can significantly aid the bereavement process (Design Council, n.d.). “Worse quality of death predicts a worse quality of life for the family caregiver and a higher occurrence of bereavement regret” (Garrido & Prigerson, 2013).

The quality of death can also vary depending on the type of patient. ‘Stichting STEM’ is dedicated to the mission to navigate the end of life processes, that involves coping with death and dying. They have developed comprehensive models and segmentation based on archetypes. Stichting STEM offers personalized and effective support tailored to the diverse needs and coping mechanisms of individuals in the end of life process. The archetype model identifies five distinct types of people, each with a unique approach to coping with the end of life: the proactive, the unguarded, the social, the trusting, and the rational patient (Stichting STEM, n.d.).

This variation underscores the importance of communicating with patients to understand how they cope with the bad news, a practice that is often overlooked in hospitals.

"The conversation about what really matters to this specific patient at the end of their life, apart from the medical discussion, is often not addressed." (Anneke, personal communication, March 22nd, 2024; see Appendix E).

This project draws on the STEM archetypes (see figure 6) as a source of inspiration and knowledge to understand the varied experiences of patients throughout their end-of-life journey. By exploring these different coping mechanisms, deeper insights are gained into how individuals might experience the end-of-life process at Erasmus MC. Understanding the different ways of coping with death and dying is essential to grasp the role of the quality of death.
The next section will go into more detail about the behaviour of these five archetypes.

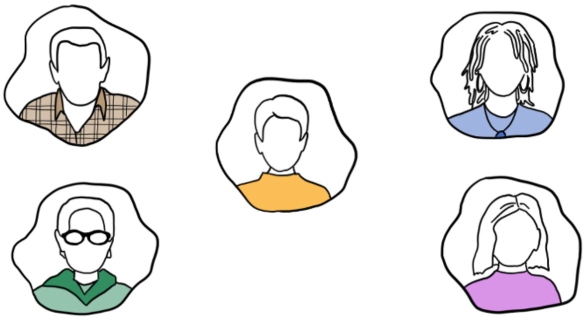


Figure 6: Illustration of 5 persona's for 5 archetypes of patients coping with the news of death

Proactive patients

Characteristics about the patients:

- Highly socially engaged and wish to remain useful until the end.
- Desire to make their own decisions about the end of life, maintaining dignity, independence, and control.
- Have the most arrangements in place, such as wills, medical declarations and insurance.

Insights:

- Patients might want to bring personal items from home, such as a blanket or pillow, to feel more comfortable.
- Communication with healthcare providers becomes more intimate and essential to make the patient feel useful in the process.

Unguarded Patients

Characteristics about the patients:

- Love to enjoy life, explore boundaries, and have distinct personal ideas.
- Relatively little experience with death.
- Prefer to keep death and its discomforts out of their awareness.
- Want to put their own spin on the final phase if they become aware of it.

Insights:

- The transition from life to death can be hard for them, but it is crucial to discuss in order to give them the opportunity to give it a personal touch.
- The presence and support of loved ones are critical for a dignified end-of-life experience.
- Personalized and flexible approaches to care are appreciated.

Rational Patients

Characteristics about the patients:

- Work hard, value appearance and status, follow trends, and believe in shaping life.
- Focus on friendship and family.
- Struggle with showing vulnerability and prefer a rational approach.
- Prioritize medical care, privacy, and objective information.

Insights:

- Preparation and clear communication from medical staff with patient and family about expectations are crucial for this kind of patient.
- Creating expectations for the dying phase is important to prepare the loved ones.

"Cognitively sound elderly can often come to terms with the dying process. Others can initially deny it, but when the topic is revisited, they can become emotional." (Madelief, personal communication, March 11th, 2024; see Appendix C).

Trusting Patients

Characteristics about the patients:

- Value rules and are conscientious.
- Rarely discuss death, considering it a natural part of life.
- Have less fear of the final phase of life.

Insights:

- Emphasis on the opportunity to say goodbye and have mourning rituals.
- These kind of patients often rely on healthcare providers for guidance and support.
- The presence of a supportive family environment is essential for a peaceful end.
- Clear, compassionate communication helps alleviate fears and anxieties.

Social Patients

Characteristics about the patients:

- They live carefree within established frameworks.
- Enjoy the company of friends and family.
- Strongly deny death but envision a ‘grand and majestic’ farewell.

Insights:

- Personal touches in care, such as bringing personal items and creating a home-like environment, are appreciated.
- Ensuring the family feels heard and supported by healthcare providers is crucial for a positive experience.
- Allowing the patients to give their personal touch on the last phase of live gives them appreciation.

2.2.4 Dutch care facilities

Patients typically prefer to spend their final moments in a place where they feel at home, which is often not the hospital (Anneke, personal communication, March 22nd, 2024; see Appendix E). If this is not possible due to various unfortunate factors, they have no choice but to remain in the hospital room. However, when there is a possibility to move a patient from the hospital to another care facility for their final moments, the Netherlands offers various options. Patients can be transferred to care units within elderly care homes, private hospices, or specialized clinics, among other facilities. When adequate care is available at the patient's home, they have the option to return home as well. This section zooms in on the environment of two hospices, in order to gather inspiration about creating an environment that allows patients to pass away in a dignified way.

2.2.4.1 Hospice environment

Two visits are made to hospices in Rotterdam, Vier Vogels hospice and Laurens Cadenza Zuid hospice, both designed to support patients towards passing away when this is not possible at home anymore. Hospices are known for their compassionate guidance of patients through their final life stages, when a cure is no longer possible, or the burdens of treatment outweigh the benefits (CaringInfo, 2023).
Specifically, hospice care prioritizes comfort, support and quality of death for both patients and their families at life's end, facilitated by a comprehensive team comprising volunteers and nursing staff (Clinic, 2024). The hospice environments that were visited present a marked contrast from the hospital setting, but also from each other.

> **“Most patients would rather not die in a hospital, but at home. If they had the choice.”**
>
> (Anneke, personal communication, March 22nd, 2024; see Appendix E)

Home-like hospice

Vier Vogels, a home-like hospice ('bijna-thuis-huis'), offers a very homely ambiance with a living room furnished with sofas and chairs, plants, a rug, and decorative throws. Here, residents can light a candle, read a book, or enjoy a cup of coffee. The interior features warm colors, such as light yellow and green walls. There is also an outdoor garden where residents and visitors can sit at various tables. The entire setting is reminiscent of visiting a beloved grandmother's home. There is enough room for family and friends to have a private moment of peace in the living room, meditation area, or garden. This creates a feeling of home, allowing freedom to walk and sit in multiple places.
The hospice accommodates four individuals, each in a private room named after a different bird, hence the name “Four Birds” Hospice. Each room is equipped with a bed for the patient and a visitor's bed. Additionally, there is seating space and room for personal items. The walls have space to hang art or photos or it can be placed on shelves or a table next to the bed. Each room features atmospheric lighting. The four rooms have distinct interiors, with different wall colors and designs. Despite the presence of a hospital bed, the rooms maintain a calm and spacious appearance, incorporating all the elements visitors might need.

The hallways downstairs, next to the rooms, are decorated with art pieces, calming lighting, a bouquet of flowers and a guestbook at the entrance. Overall, the hospice creates a serene ambiance.
The volunteers and nurses work hard to coordinate and communicate about the patients' conditions and wishes while maintaining this homely feeling. They document their observations after every shift to inform their colleagues. They strive to meet individual wishes regarding end-of-life rituals based on cultural background, religion, or other personal preferences (personal communication, March 20th, 2024; see Appendix I).

"I find 'hospice' an unpleasant name. I rather call this the comfort house." Resident Mien (80) about the Vier Vogels hospice (Eijgenraam, 2011).

High-end hospice
Laurens Cadenza is a larger hospice with medical staff on-site, enhancing its capability to provide comprehensive medical care. This high-end hospice offers a wide range of therapies, a garden, a music room, and an on-call doctor, ensuring that all psychological, social and medical needs can be met efficiently within the facility (personal communication, March 5th, 2024; see Appendix J).
Downstairs, there are areas for patients to engage in activities or sit and eat together. Besides the cafeteria, there are also multiple seating possibilities in the calming garden outside.
Upstairs, there are various patient rooms and spacious rooms are for families to gather.
The hallways are wide and filled with natural light due to the many windows.
The rooms feature a blend of medical devices and home-like comforts, including warm red colors and wooden details.
Instead of the typical white hospital beds, wooden bedframes are used, although the same medical tools are available.
The floors in the rooms are wooden and there are multiple seating options in the room, including blue and wooden chairs. The details are colorful, such as the brown curtains and wooden nightstand next to the bed. A TV is mounted opposite the bed for the patient's entertainment.
In this hospice, volunteers and medical specialists work together in shifts to provide the best possible support to patients. The hospice has room for 20 patients.
Overall, there is a feeling of welcome throughout the facility. The high ceilings and numerous windows in the building contribute to a sense of openness.

2.2.4.2 Hospital environment

This section focuses on the hospital environment and explains how the different palliative care phases are experienced in this pro. The four palliative care phases can be seen in ***Figure 5: Schematic overview of four palliative care phases in the End of Life journey, based on 'the integrated model of care' proposed by World Health Organization (WHO), 1990****Figure 5*.

1. Curative care phase

The 'bad news conversation' is seen as the beginning of the palliative care journey that patients undergo in the hospital. After the bad news conversation, it becomes clear that the patient will not fully recover from the illness. As seen in figure 5, palliative care will start in this phase and will gradually take over curative care. This can be a big adjustment for patients and their close circle, as it significantly impacts the rest of their lives (personal communication, March 11th, 2024; see Appendix B).
How patients and their loved ones deal with end-of-life news can vary significantly.

Coping with the bad news

For unguarded patients, the bad news can be extremely challenging. They may initially deny the reality of death and prefer to avoid discussing it. However, it is crucial to gently introduce and discuss this sensitive topic to help them process it.
These patients might need more time and guidance to come to terms with the situation.

Trusting patients are more likely to share their emotions with healthcare professionals and follow their instructions closely. For these individuals, professional guidance and nudges toward coping actions can be very beneficial.
Social patients have the need to share the news with important people in their lives, as their support network is crucial for them. These patients value being seen and heard, and might draw strength from personal connections and interactions during this difficult time.
Proactive patients more likely want to feel useful and in control. They seek to engage actively in the process, finding comfort in having tasks to manage.
While rational patients might struggle with vulnerability and showing emotional reactions, they prefer a logical approach and privacy. They might want to focus on practical tasks, such as exploring possible treatments or arranging affairs for the future. For them, addressing the situation rationally is essential.
By understanding these varied responses, healthcare professionals can tailor their approach to meet the unique needs of each patient, ensuring compassionate and effective support during the end-of-life phase.

At this stage, exploring life-prolonging treatments is an option, which will determine the duration of this phase.
The decision for future treatments is guided by the medical team, who aim to take the personal situation of the patient into account. However, the wishes and intrinsic motivations of patients and their loved ones are not always communicated effectively. This can make patients feel like they are losing autonomy over the situation, as they are not in control of the decisions.
Nurse Rosalie noted that "patients and their families will share their wishes when asked, but there are no formal agreements documented in the hospital.
Since the documentation of their whishes is not an official step in the initial phases, it is often not addressed properly." (personal communication, March 11th, 2024; see Appendix B).
As a result, the medical team might not know exactly what the patient's motivation for the upcoming phases is and what they would want or need. This could result in the patient feeling unseen and having different

expectations from the medical team regarding the next phases.

2. Palliative care phase

When curative care fades out, it is decided by a team of various doctors to estimate the progression of the patient’s quality of life. When determining the course of action for this phase, palliative care specialist Anneke underscores the importance of considering both curative and palliative treatments. Currently, the focus remains too heavily on treating the condition rather than the person. Anneke emphasizes that the priority should be the patient's quality of life following treatment, rather than pursuing curative options simply because they are available (personal communication, March 22nd, 2024; see Appendix E). At this stage, the wishes and motivations of patients should be taken into account. However, if the motivations of the patient or their family remain unclear, it becomes challenging for doctors to consider these factors in their decision-making and tensions can arise within the medical team.

"During consultation rounds, it is valuable to have a palliative specialist present in the room. When multiple doctors assess multiple issues of a single patient, this should involve the palliative perspective as well.” (Anneke, personal communication, March 22nd, 2024; see Appendix B)

The switch from curative to solely palliative care can significantly impact both patients and their loved ones. Some loved ones may experience a sense of uselessness, knowing that the patient can no longer be cured or helped with treatments. This transition might affect their sense of independence and making it feel like they have lost a sense of autonomy (personal communication, March 11th, 2024; see Appendix C).

“Some loved ones need to be involved and feel useful; otherwise, they become restless." (Madelief, personal communication, March 11th, 2024; see Appendix C)

According to Madelief, nurses have an important role in the shift from palliative care to terminal care: “By acknowledging the shift towards the last phase of life with patient and loved ones, we can bring the subject of passing away to the surface and hope to have a conversation about their expectations and needs.” (personal communication, March 11th, 2024; see Appendix C). Unfortunately, it does not always happen that these expectations are aligned well enough between the stakeholders in this phase, due to the lack of conversations and formal documentation.

“We see some patients slowly prepare themselves to pass away, while others hold on until they have seen a specific family member or witnessed a special event. After that, they can let go” (Madelief, personal communication, March 11th, 2024; see Appendix C)

3. Terminal care phase

The last 1-4 days of a patient's life are known as the terminal care phase, recognized by the medical team as the end of the patient's life approaches. During this time, information is formally documented in the "Zorgpad Stervensfase," an instrument used in the final 72 hours to record the detailed wishes of the patient and their loved ones regarding the manner of passing (personal communication, March 11, 2024; see Appendix B). Documenting this information earlier might allow the medical team to better shape the terminal care phase to align with the patient's and loved ones' wishes and needs. During these last 1-4 days, it may be too late, as most patients are not conscious throughout this stage (personal communication, March 22nd, 2024; see Appendix E).

"The way a patient copes with the transition from life to death is highly personal and can vary significantly between families and patients."
(Rosalie, personal communication, March 21st, 2024; see Appendix D)

Healthcare professionals observe a significant shift in the role of loved ones during this phase. Nurse Iris explains that communication between healthcare professionals and loved ones becomes more important and informal, focusing on the current state instead of the future: "Our focus is on ensuring the family has a beautiful ending and cherishes the final memories. This is crucial for the grieving process" (Iris, personal communication, March 11, 2024; see Appendix B). However, if the terminal phase is not recognized in time due to unforeseen factors where the patient's condition suddenly deteriorates, and a conversation about treatment options has not yet taken place, it becomes difficult to meet the expectations of the patient and their loved ones. "This is very tough for loved ones, who suddenly have to adapt and deal with a lot of grief" (Iris, personal communication, March 11, 2024; see Appendix B). This highlights the importance of setting clear expectations between patients, loved ones and healthcare professionals in case such situations arise. Unfortunately, communication in hospitals sometimes lack this crucial element according to Iris and Rosalie.

In this terminal care phase, Erasmus MC observes differences in how individuals cope with death in the terminal care phase in their patient rooms. These differences, varying across cultures, religious rituals or generational variations, underscore that no two patients or their loved ones are alike. These cultural aspects can for example influence the number of family members visiting in the room and wanting to sleep next to the patient, in the patient room. The current patient room at Erasmus MC is not very flexible for these different needs, unfortunately, making it not a welcoming space for multiple visitors to communicate about the End of Life process.

"To have a peaceful end of life, it would be nice to have a bit more space to add an extra bed or chairs. The sofa bed is extremely large and very difficult to move. It would be helpful to have some elements on the ward to improve this last phase."
(Iris, personal communication, March 21st, 2024; see Appendix B)

In the last moments before a patient passes away, common behaviors are seen in the patient rooms that enhance the quality of death: “Loved ones automatically dim the lights, draw the curtains, and begin to speak more softly as a universal sign.” (Madelief, personal communication, March 11th, 2024; see Appendix C).
However, not all visitors want to witness the dying process of a loved one. Anneke noticed that the expectations of loved ones about the last phase of life can often lie far from reality. (Anneke, personal communication, March 22nd, 2024; see Appendix E).

> **"Some do not really know what a deathbed looks like, or they do not accept it. Loved ones often do not want to see the suffering. They can have a romanticized view of dying and do not accept that it takes longer than expected."** (Anneke, personal communication, March 22nd, 2024; see Appendix E).

These differing reactions highlight the complex emotions and misunderstandings individuals can have surrounding the end-of-life process. This emphasizes the need for better communication and support for families during this critical time.

4. Bereavement care phase

After the death of the patient, the bereavement care phase begins. During this phase, goodbye rituals are offered and the final physical care is given to the patient. Healthcare professionals are expected to support the loved ones of the patient. According to Madelief, this support can be incredibly helpful for the family. “Feeling heard and supported by hospital staff leads to immense gratitude from their [family and friends] side" (personal communication, March 11th, 2024; see Appendix C).

However, this support typically lasts only a day or two, until the loved ones leave the room. The follow-up support after they have left the hospital varies between departments. There is no formal agreement about sending a support letter or reaching out to family members. If this occurs, it is usually initiated by the lead doctor, who must be informed that the patient has passed away. The primary care physician is informed, but there are no established protocols for offering condolences or scheduling a follow-up conversation. Most doctors do this, but it is at their discretion. For instance, in the oncology department, a letter is sent to the bereaved on own initiative, whereas other departments may not do this (personal communication, March 22nd, 2024; see Appendix E). This post-passing support can sometimes fail if the specific doctor is unavailable or not informed, such as during a vacation period. The hospital lacks a formal protocol to ensure consistent support and closure for the loved ones of deceased patients.

2.2.5 Quality of Death

The quality of death and the environment play a vital role in this project as it influences the quality of life of the patient and family caregivers. For the bereaved, the memories they have of a loved one are inextricably linked to the environment in which they last spent time with them. A positive experience of this environment is likely to help them in the bereavement process (Design Council, n.d.). “Worse quality of death predicts a worse quality of life for the family caregiver and a higher occurrence of bereavement regret” (Garrido & Prigerson, 2013).

The next section presents the impact of the patient room on the quality of death, to understand the role and impact environment can have in the lives of different patients.

Impact of the patient room

When patients are receiving palliative care, it is shown that they and their loved ones are likely to experience heightened awareness of their surroundings. These, in turn, are likely to affect their perceptions of the care they are receiving (Design Council, n.d.). This highlights the importance of the patient rooms during the experience of the End of Life journey for all individuals involved.

Among the most important considerations when designing accommodation for patients nearing the end of their lives are links to:

- Nature
- Private relaxation space
- Personal control over the environment
- Home comforts
- Artwork

(Design Council, n.d.)

Madelief confirms this need for personal control: “Especially if patients stay in the room for a longer period, they tend to take personal items with them to make them feel at home.” (personal communication, March 11th, 2024; see Appendix C.

Figure 7: The design of the patient rooms at Erasmus MC by EGM architects, photo by Rob van Esch

2.2.6 Patient rooms at Erasmus MC

At Erasmus MC, all patients have a single bedroom for themselves to stay in, see figure 7. During visits to Erasmus MC‘s departments and interviews with healthcare professionals, it was observed that the rooms are designed with a primary focus on medical equipment and operational space for medical staff, often at the expense of space for personal belongings of patients and visitors.

“Patients become restless in busy rooms, for example filled with lots of visitors or heavy lights."
(Madelief, personal communication, March 11th, 2024; see Appendix C).

Although each room is uniformly furnished, the layout can vary, with some rooms featuring mirrored furniture arrangements. Patients are accommodated in personal rooms equipped with basic amenities such as a bathroom, a bed, two large windows, and a convertible bed/couch (figure 8). Despite these provisions, the rooms lack room for personalization and storage space, according to nurse Rosalie (personal communication, March 21st, 2024; see Appendix D).
“Privacy and dignity for those who are dying and their relatives and friends is difficult to achieve in the midst of a busy hospital ward." (Building Better Healthcare, 2011).
This sentiment is evident at Erasmus MC, where the hospital's busy environment struggles to meet the social and psychological needs of patients and visitors. According to Madelief, it is preferable to create a low-sensory patient room (personal communication, March 11th, 2024; see Appendix C).

“We see patients bringing along a few personal items, like a blanket from home or their own pillow—things they are attached to." (Iris, personal communication, March 11th, 2024; see Appendix B)

Figure 8: The design of the convertible bed in the patient rooms at Erasmus MC, photo by Rob van Esch

2.2.7 End of Life journey at Erasmus MC

This section will present the details of the End of Life journey at Erasmus MC. This journey illustrates four individuals involved trough the four palliative care phases in a hospital. In order to create this framework, persona's of the stakeholders are used based on insights of interviews, visits and literature review. The use of persona's helps to gain a better understanding of the experiences, needs and responsibilities of this group of people. Furthermore, 'Whirlwind' moments are introduced. These are life-changing moments that can have impact on the experience one has in a hospital. These moments are symbolized with an icon of a whirlwind.

2.2.7.1 Whirlwind moments

To thoroughly understand the end-of-life care for patients at Erasmus MC, it is critical to map out the entire journey the individuals undergo within the hospital.
This was achieved through the qualitative research, leading to the creation of the End of Life-journey, illustrated in figure 11.
After analyzing the interactions between the involved individuals, the patient journey is marked by four 'whirlwind moments' that significantly influence the course of the journey and impact the actors involved.
These moments are detailed as 'whirlwind' moments, with a whirlwind icon in figure 9.

The first whirlwind occurs with the initiation of the palliative phase during the 'bad news' conversation, which makes it evident that the patient's time is limited. Although there might still be a considerable amount of time before the patient's passing, this news profoundly affects the mindset and well-being of both the patient and their surroundings.

The second whirlwind moment occurs when curative treatments are discontinued and the patient's condition deteriorates. Often, there is a brief period during which the patient feels better and gains more energy, but this improvement is short-lived (personal communication, March 22nd, 2024; see Appendix E). From this point forward, only palliative care is administered to enhance the patient's comfort and quality of life.

The third critical moment is noted when the doctors observe a significant decline in the patient's condition, indicating the nearing EOL-phase. The patient is estimated to have about a week to a few days left.

The fourth and final whirlwind occurs with the patient's passing and the start of the bereavement care for loved ones. This phase marks a significant transition from active caregiving to mourning and memory.

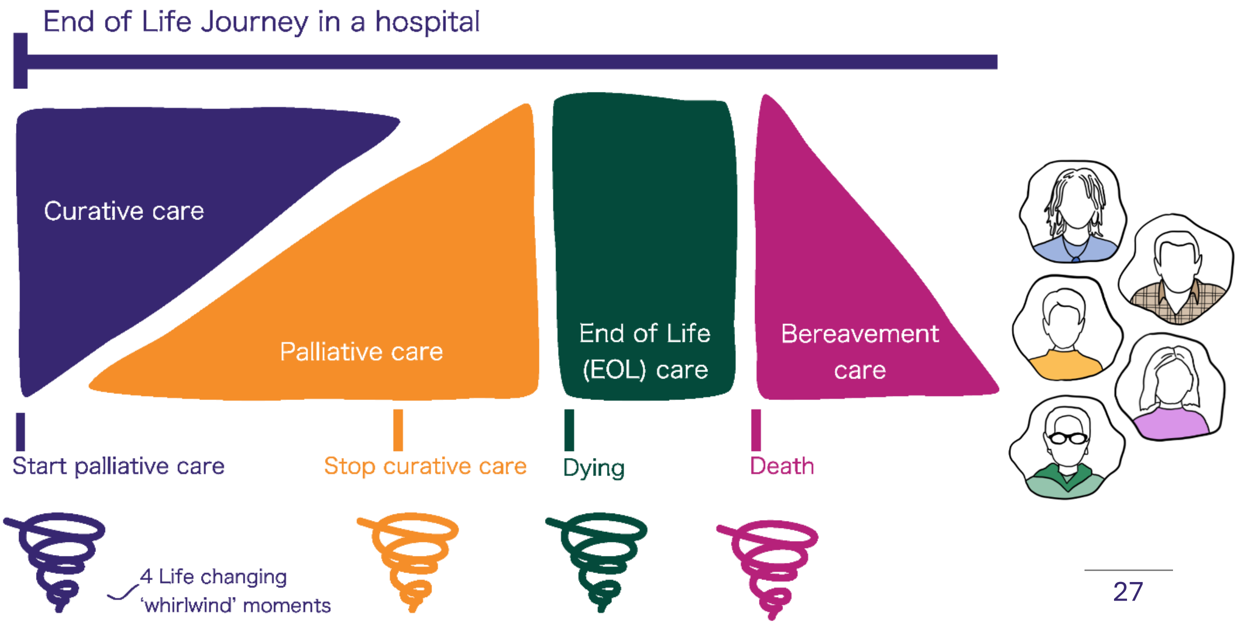


Figure 9: four whirlwind moments analyzed in the palliative care journey at Erasmus MC

2.2.7.2 EOL Framework with needs and responsibilities

A narrative approach is used to create a comprehensive End of Life (EOL) journey for the four key stakeholders involved, shown in figure 10.

As described in 2.2.3 Coping with death and dying, the coping mechanisms of patients can vary greatly. The STEM archetypes described in this chapter demonstrate that there are significant differences between patients and how they may respond to the end-of-life process. The differences in coping with death and dying requires a personalized response from medical professionals and their environment to each individual patient. For future implementations in end of life care, these differences in coping must be recognized.

The framework of the End of Life journey presents an analysis of all stakeholders and their needs. Here, all patients are summarized as a single stakeholder of ‘the’ patient, but this encompasses different archetypes. The needs and responsibilities have been chosen in such a way that the different types of patients can be included under this umbrella.

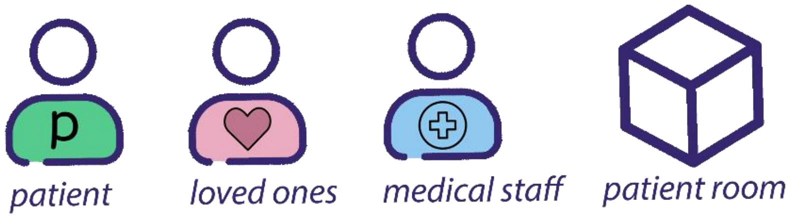
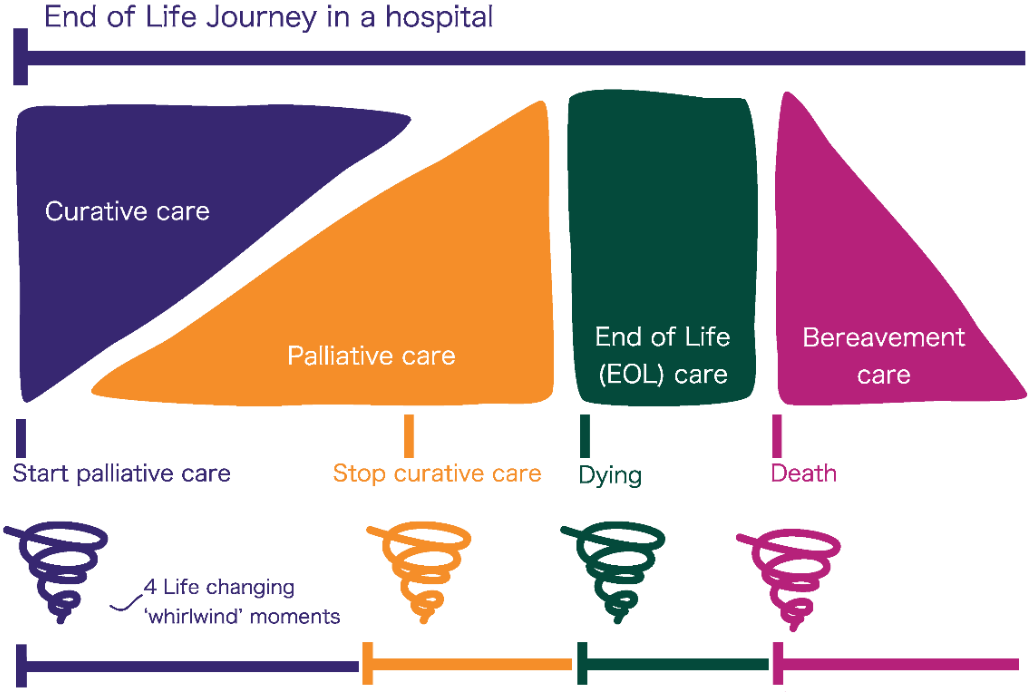


Figure 10: Four key stakeholder in the End of Life Journey: patient, loved ones, medical staff and the patient room

The framework is following the phases of palliative care and analyzing the interactions that reveal their needs and responsibilities. This narrative highlights the experiences of patients, loved ones, medical staff and the patient room at each stage, from diagnosis to post-passing support. By illustrating these interactions, the narrative identifies the emotional and practical needs and responsibilities of each stakeholder. Figure 11 provides a schematic overview of these needs and responsibilities, showing how they differ for each stakeholder as they navigate the EOL journey at Erasmus MC.

End of Life Journey in a hospital



Curative care

Palliative care

End of Life (EOL) care

Bereavement care

Start palliative care

Stop curative care

Dying

Death

4 Life changing 'whirlwind' moments

patient

Needs:

through all phases:
Physical, psychological and social care
Feeling heard and seen by medical staff
Having loved ones around for support

Coping with big changes of whirlwind moments
Feeling at ease to share personal needs and whishes about End of Life process

Having final whishes fulfilled
Passing away in a dignified way

Experience (cultural or religious) farewell rituals if desired

Responsibilities: Indicating personal needs and whishes about End of Life process

loved ones

Needs:

through all phases:
Knowing that patient is heard and seen as an individual
Feeling heard and seen themselves
Being 'there' and coping with whirlwind moments

Fight for patients'care
Feeling at ease to communicate about personal needs and whishes of patient

Express sadness and mourn
Fulfill last whishes of patient

Fight for patient's comfort
Perform (cultural or religious) farewell rituals if desired by patient

Responsibilities:

Giving psychological and social support to patient
Being the representative for patient when this is no longer possible for them

Arranging funeral and last care

medical staff

Needs:

through all phases:
Knowing and documenting patient's personal needs and whishes
Having tools to facilitate conversations about sensitive topics
Providing suitable care and cure for the patient

Feeling at ease to communicate about needs and whishes of patient and loved ones

Creating a dignified End of Life for the patient

Responsibilities:

Finding balance in care and cure
Monitoring and recognizing whirlwind moments for patient and loved ones
Preparing and supporting patient and loved ones for difficult journey ahead

Administrative tasks
Final physical care for patient
Offering support to loved ones

patient room

Needs:

through all phases:
Being a sustainable environment for future use
Contributing to a dignified End of Life, by enhancing quality of death
Enabling visitors and medical staff to be at ease during their time in the room

Responsibilities:

Facilitator of patients staying (for a longer period) in the hospital
Facilitator of medical staff providing physical care
Facilitator of visitors staying over and providing support

Facilitating a calming space
Facilitator of (cultural or religious) farewell rituals

Figure 11: The End of Life journey with needs and responsibilities

2.2.7.3 End of Life Journey for different stakeholders

This section will focus on the different stakeholders going through the whole EOL journey. It explains how they can experience the different palliative care and what key moments are important to consider in future palliative care.

Patient

In the first palliative phase, a patient may exhibit a strong personal drive to hold on to life, driven by desires such as recovery or significant life events (e.g., seeing a grandchild or reconnecting with an old friend). Alternatively, some patients may avoid confronting their mortality, either by ignoring it or placing complete trust in healthcare professionals. As shown by Stichting STEM, different archetypes can have different coping mechanisms. The emotions involved at this stage are profound and significantly influence how patients manage their care. As patients move closer to the end of life, they might become less aware or involved in their surroundings. However, there is often a moment before death when patients experience a surge of energy and seem more present. This phenomenon, sometimes referred to as ‘terminal lucidity’, can be a time when patients become more communicative and alert. In the final phase, the focus of patients usually shifts from prolonging life to seeking comfort and rest. The presence of family and friends becomes a high priority, although this varies by individual and cultural background. For instance, Eastern cultures may prefer having a larger family presence in the patient's room during the last moments, while Western cultures might opt for a more private and intimate setting.

For example, Lana stated that “in Islamic culture, suffering is seen as an inherent part of life, and being present during a patient's final moments is considered a significant act of compassion and respect” (Lana, personal communication, March 20th, 2024; see Appendix G)

How patients wish to spend their last days can vary greatly as well as their willingness to share these wishes with healthcare professionals also differs. If patients do share their wishes, farewell rituals can be organized in the room according to their cultural, religious, or personal preferences. If they do not communicate these wishes, loved ones often take charge in estimating what the patient would have wanted for their last moments.

Loved ones

For the loved ones, such as family and close friends, the EOL journey is centered around being present for the patient, which also provides them with a sense of purpose. As curative care gives way to palliative care, their dedication shifts to ensuring the patient's comfort and respecting their evolving wishes. In the EOL phase, loved ones often engage in more intimate contact, such as staying overnight in the patient's room ("rooming in").

Rituals of farewell and varying levels of hope and acceptance are observed. Moments of increased energy of patients can bring back hope to loved ones, but they must also cope with the reality that passing is approaching. This can be a difficult realisation. After the patient's passing, a final goodbye takes place, marked by profound sadness, bereavement and hopefully room for grief. There are also administrative duties to be handled, such as organizing the funeral and managing the patient's belongings. The responsibility for these tasks varies by culture, with different family members taking charge depending on cultural norms. Healthcare professionals provide assistance in the final physical care of the patient's body. Cultural differences play a significant role in these interactions. For example, in some cultures, the involvement of extended family members is crucial, while others might prioritize privacy.

“In Afghan culture, family members take a more active role in the patient's care, reflecting a deep sense of duty and connection.”

(Zoe, personal communication, see Appendix F).

Medical staff at Erasmus MC

In the initial stages, medical teams at Erasmus MC implement a two-track policy, balancing curative efforts with palliative care. This involves crucial decisions about continuing or ceasing treatments. Medical staff aim to support patients and their families by discussing sensitive topics, although there is no formal format for these discussions after the initial ‘bad news’ conversation.

As the patient's condition deteriorates, the focus shifts to comfort and quality of life. Medical staff monitor the patient and aim to prepare loved ones for the EOL phase. The formal step of documenting the patient's final wishes, known as "Zorgpad stervensfase," is undertaken in the estimated last 72 hours of the patient’s life. Staff continue to prioritize the patient's comfort and support loved ones. After the patient's death, the doctor confirms the death, and nurses provide final physical care before the patient is taken to the mortuary. This is a difficult time for loved ones, so the staff aims to support them in creating a calm environment where they are free to grieve.

Cultural sensitivity is essential in this process. According to Lana, healthcare providers must always be aware of and respect different religious rituals and family dynamics (Lana, personal communication, March 20th, 2024; see Appendix G).

Most doctors send a letter offering a conversation for closure with the hospital, a few months later. This is a way the medical staff reaches out to loved ones to give them a chance to talk about the grief period they have been having. Unfortunately, this differs per department and it is often the responsibility of the head doctor of the patient. Thus, this support cannot be guaranteed to happen every time.

Patient room

By addressing the patient room as an actor in the End of Life journey, its role and the design opportunities become clear. This is why it is seen as a stakeholder in the process, to ensure that design considerations can effectively meet the diverse needs and interactions observed during this critical time.
The patient environment, including the patient room and adjacent spaces for families and friends, plays a crucial role in the EOL journey. In the first palliative phase, the patient room supports medical care, comfort, and relaxation. It provides space for medical procedures and personal activities such as watching TV or reading.

In the second phase, as more visitors arrive, the room's function evolves to accommodate flexible visiting hours with additional seating and a sofa bed. Although medical devices may still be present, their use diminishes.

During the EOL phase, the environment supports intimate contact and farewell rituals, with guidelines available for different religious practices.
Healthcare professionals emphasized that enhancements to the patient room, such as providing more space for visitors and ensuring a home-like atmosphere, are essential to meet the diverse needs of patients and their families.

> **“The ideal patient room should be bright, with a nice view, and designed to accommodate multiple family members. It should also include a space for reflection and prayer.”** (Zoe, personal communication, see Appendix F).

2.3 Conclusion

2.3.1 Introduction

This section will present a conclusion of the research into the End of Life care at Erasmus MC and its patient rooms. This conclusion is illustrated by a schematic overview of the current state of the End of Life journey at Erasmus MC, which is divided into three design opportunities that could improve this current state:

- Communication and expectations
- Autonomy of Actors involved
- Balance in whishes of all involved and resources of the medical team

Figure 12 provides a schematic overview of the findings and the next section explains this visualization per design opportunity.

2.3.2 Current state analysis of palliative care in the End of Life journey at Erasmus MC

The analysis of the EOL journey unveiled where the needs of the different stakeholders are currently not met and where tensions could appear. The schematic overview, shown in Figure 12 and detailed in Appendix K, is a combination of the needs along the timeline of the four palliative care phases in the hospital and the four whirlwind moments. All design opportunities are illustrated in this figure.

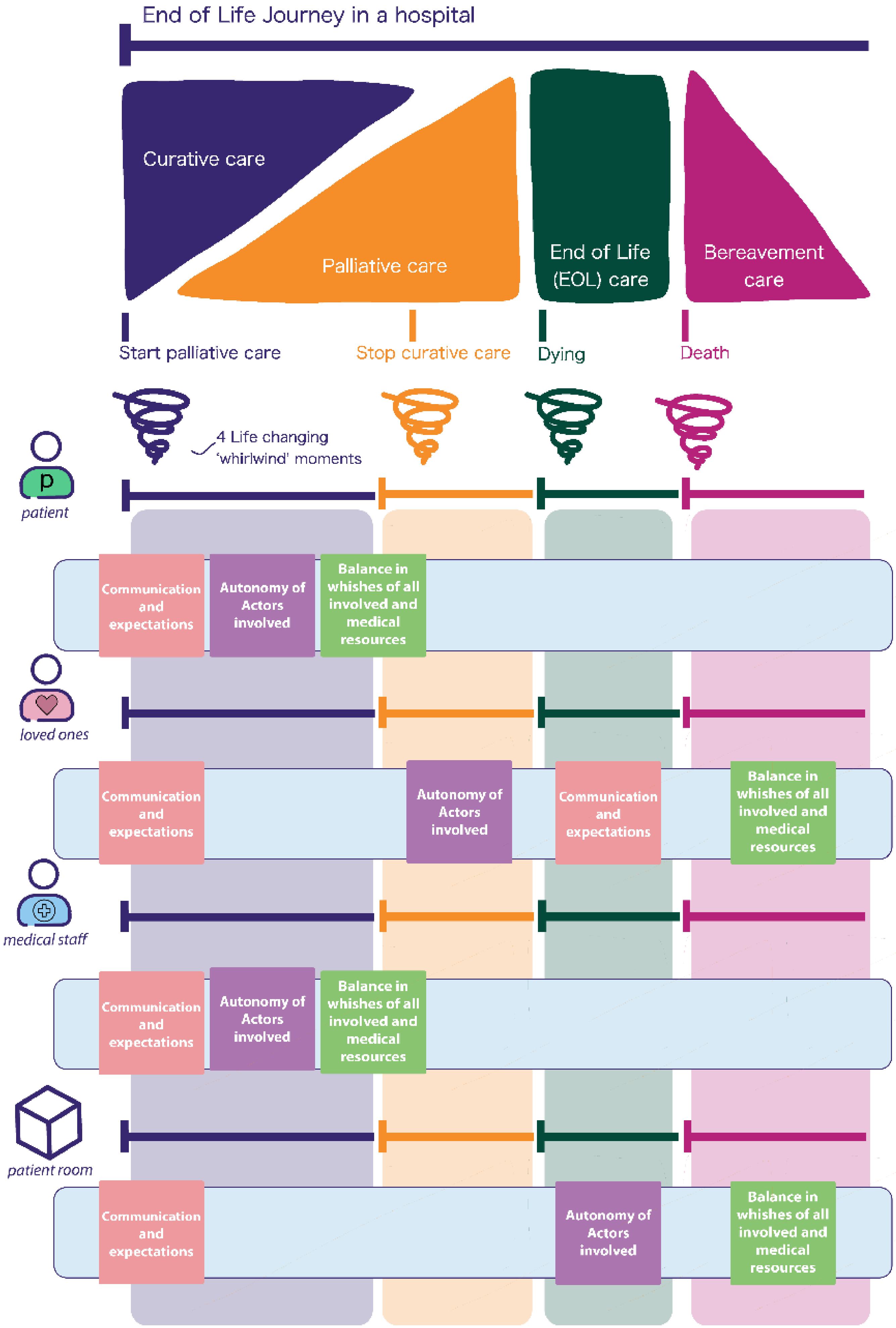


Figure 12: An overview of three design opportunities, found in the four palliative care phases

2.3.2.1 Communication and expectations

a. Inefficient communication leaves patients feel unseen
In the first phase of palliative care, poor communication between patients and medical professionals often results in patients not sharing their intrinsic motivations about the end of life with the medical staff. The intrinsic motivation of a patient includes understanding what drives them to continue treatments or what makes them content with the life they have had. These details are crucial for patients to feel seen and heard as individuals. Patients want to know that their personal perspectives are taken into account by the medical staff, but the formal conversation about what death and dying mean to a patient is still missing.

b. Unaligned expectations at the start of the End of Life journey between all stakeholders
The lack of communication can lead to misunderstandings and emotional distress for all throughout the process. Besides the lack of communication about what to expect, there is also insufficient guidance on dealing with uncertainty. Often in palliative care, it is unclear how the end-of-life journey will unfold, and even healthcare professionals cannot predict the outcome with certainty. This is a frightening but necessary reality for patients and loved ones to accept, yet there is not enough communication on how to cope with these uncertainties.

c. Unaligned expectations between loved ones and medical staff about the dying process
Unaligned expectations about the dying process can cause tensions in the end-of-life phase. Loved ones may become scared or angry when the patient experiences pain or discomfort if they are not prepared for the physical impact this can have on the patient. Although it is a difficult topic to discuss, medical staff are not currently communicating well enough with loved ones about what kind of experience the passing away can be for them.

d. Insufficient communication leaves intrinsic motivations unknown to the medical staff.
In the first phase of palliative care, insufficient communication between patients and medical staff can result in doctors being unaware of patients' intrinsic motivations. The intrinsic motivation of a patient includes understanding what drives them to continue treatments or what makes them content with the life they have had. These details are essential when balancing care and cure. If a patient does not want another treatment for personal reasons, continuing to recommend treatment will not improve their quality of life. On the other hand, a formal discussion about death and dying would give medical staff insight into how each patient views these matters, informing future care decisions. Without this communication, it is difficult to estimate how to improve their quality of life.

e. Patient rooms lack a sense of welcome and ease
The patient room plays a significant role in setting expectations and providing comfort from the beginning of the end-of-life journey. However, it often fails to provide a calming space that communicates a sense of welcome and ease. Patients spend a considerable amount of time in their rooms, making it essential for these spaces to feel personalized and comforting. When the room lacks personalization, it can contribute to a sense of unease and alienation for patients. This lack of a calming, personalized environment can exacerbate feelings of anxiety and distress, as patients may feel that their individual needs and preferences are not being acknowledged. Effective communication about the importance of the patient's environment, and ensuring that it meets their personal needs and expectations, is crucial for improving their overall experience and quality of life.

2.3.2.2 Autonomy of Actors

a. Patients lack a sense of autonomy
Patients currently feel less in control since they are not always treated or seen as individuals in the hospital. When patients are excluded from the decision-making process, they may feel helpless and small, while others may become angry or frustrated. This lack of recognition makes patients feel dependent on medical staff, leading to anxiety and tensions between them and the medical staff. The feeling of having control is universally important for psychological wellbeing and is especially crucial for patients in this critical phase of their lives.

b. Loved ones experience a loss of autonomy in the EOL process
When curative care ceases loved ones may feel that their responsibility to care for the patient has ended, especially as the patient starts to weaken. This sense of uselessness is difficult for loved ones and can affect their independence. As they begin to stay in the hospital more frequently, maintaining a sense of autonomy becomes crucial for them to feel at ease during this challenging process. Currently, loved ones are not adequately prepared for this period, leading to feelings of being unseen and uncomfortable, which can cause tensions during the second and third phases of palliative care.

c. Medical staff experience a lack of autonomy.
Although they are 'in control' of medical care, the connection between medical staff, patients, and loved ones impacts their experience in feeling autonomous as well. As professional caregivers, their ability to provide care is influenced by the dynamics of these relationships. The sense of autonomy for medical staff is crucial for maintaining a supportive and effective caregiving environment. A shift of focus to the autonomy of others is needed to maintain their own, ensuring that patients and loved ones feel empowered and respected in their roles, which in turn can foster a more positive and collaborative atmosphere for everyone involved.

d. **Patient rooms lack to facilitate the needs of comfort and privacy**
As loved ones begin to stay more often, it becomes apparent that patient rooms lack to facilitate the needs of comfort and privacy, particularly noticeable in the end-of-life phase. The current lack of accommodation for multiple visitors and privacy needs undermines the respect and flexibility necessary for a supportive end-of-life process. In this phase, the patient room is not contributing to the desired autonomy of the stakeholders. The patient rooms facilitate the 'rooming in' process, allowing visitors to stay overnight with their loved ones. However, the existing setup, including an uncomfortable sleeping couch, insufficient storage space for personal belongings of the patient and visitors, and limited seating, fails to create an inviting space for multiple loved ones to feel at ease and comfortable.

2.3.2.3 Balance in whishes and resources

a. Insufficient shared decision making between patients and medical staff
Discussions among medical staff frequently arise regarding differing perspectives on the importance of palliative care, often resulting in a disproportionate focus on curative measures. From the patient's perspective, this can lead to insufficient shared decision-making and a lack of involvement of the palliative care perspective. Medical decisions that do not fully consider the patient's wishes or motivations undermine patient autonomy and dignity, leaving patients feeling disempowered and inadequately prepared for the EOL) journey.

b. The lack of focus on intrinsic motivation impacts loved ones.
When medical decisions are made without sufficient shared decision-making and involvement of the palliative care perspective, loved ones may feel excluded and unprepared for critical moments, such as unexpected in the palliative care process. This can lead to emotional distress and a sense of helplessness during the process, as they are not adequately involved in discussions about life, death, and the patient's personal values, which are crucial for navigating the EOL journey.

c. Decision-making lacks palliative care aspects
From the medical staff's perspective, tensions escalate when there is insufficient shared decision-making and involvement of the palliative care perspective. Differing views on the importance of palliative care often result in a disproportionate focus on curative measures. Due to the lack of well-documented discussions about the intrinsic motivations of patients, doctors who want to advocate for palliative care often lack the necessary arguments. This oversight makes it harder to provide holistic care and support the needs of both patients and their loved ones, especially during critical moments such as shifts between the palliative care phases.

d. Formal post-passing support is absent in the patient rooms
Despite bereavement care being an integral part of comprehensive palliative care, formal post-passing support is absent in the patient rooms of Erasmus MC. This oversight in the EOL process underscores a crucial gap in addressing the holistic needs of loved ones beyond the patient's passing. The inclusion of post-passing support in patient rooms is essential to provide a space for loved ones to grieve and receive support immediately after their loss. This can help in managing the initial shock and emotions, ensuring they do not feel abandoned during such a vulnerable time. Integrating post-passing support can facilitate a smoother transition through the grieving process, offering immediate access to resources such as counseling, emotional support, and guidance on next steps. Ultimately, addressing this gap will reinforce the commitment to holistic care, recognizing that the well-being of loved ones is a fundamental component of palliative care.

These insights highlight critical areas for improvement in communication, autonomy and balance between the stakeholders' needs and the medical resources. Addressing these gaps will be crucial in shaping a future vision for comprehensive and suitable palliative care in the End of Life journey at Erasmus MC. Moving forward, these findings will guide the development of a future vision to enhance the quality of End of Life care at Erasmus MC.

3. DEFINE

The Define phase will provide a detailed future vision created for the palliative care at Erasmus MC, based on the research insights gained from the Discover phase. An infographic about this Future vision is created in order to communicate with stakeholders at Erasmus MC. The future vision aims to lay a foundation with design directions that fulfill the needs of the stakeholders involved in the EOL journey. Based on the current state analysis and the future vision, a Design Goal is created to illustrate future design directions.

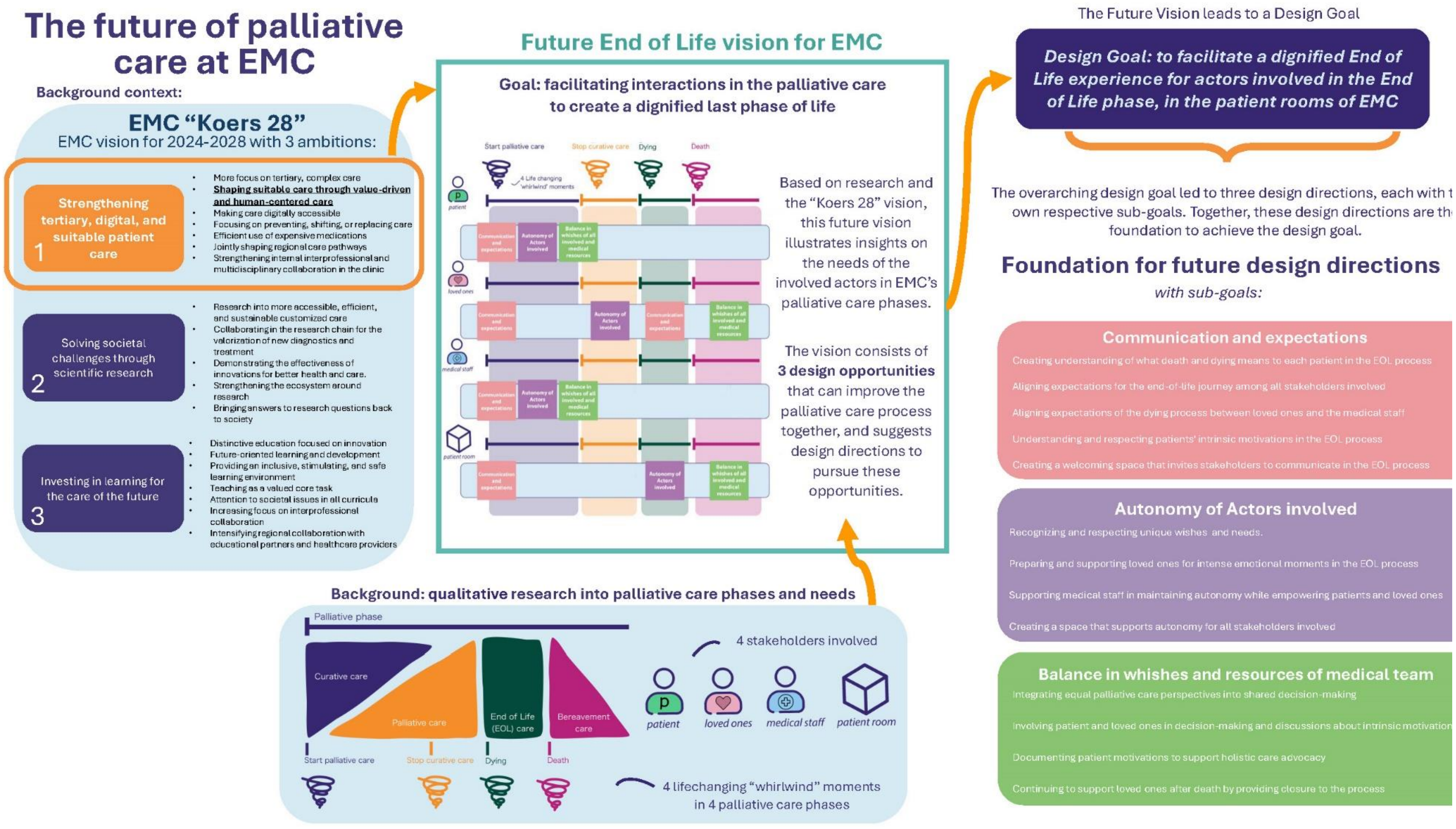
3.1 A Future vision: the future of palliative care at Erasmus MC

A vision statement for the future of palliative care at Erasmus MC was created to align with the hospital’s future vision, the “Koers 28” plan for 2024-2028. This project focuses on the first of three ambitions described in Koers 28: “Strengthening tertiary, digital, and suitable patient care”. This future vision specifically focuses on the following sub-goal: “Creating suitable care through value-driven and human-centered care”.

The long-term goals of Erasmus MC, the current state analysis, and the future vision are summarized in an infographic. To ensure that the future vision was well-received and understood by healthcare professionals, the infographic was created in Dutch as well. Through two feedback sessions, the elements of the vision were critically examined with Dutch healthcare professionals and members of the patient council, and valuable insights were gathered.

The infographic (seen in Figure 13) presents the outcomes of the research and provides a foundation for future design directions. It serves as a visual aid to explain the basis for future design directions. It can be used to communicate with stakeholders, such as other hospitals or care facilities, to highlight the importance of this research project and present its outcomes effectively. The infographic can also be found in full size in Appendix L.

3.1.1 Infographic: Future End of Life care at Erasmus MC



The future of palliative care at EMC

Background context:

EMC "Koers 28"
EMC vision for 2024-2028 with 3 ambitions:

1 Strengthening tertiary, digital, and suitable patient care

- More focus on tertiary, complex care
- **Shaping suitable care through value-driven and human-centered care**
- Making care digitally accessible
- Focusing on preventing, shifting, or replacing care
- Efficient use of expensive medications
- Jointly shaping regional care pathways
- Strengthening internal interprofessional and multidisciplinary collaboration in the clinic

2 Solving societal challenges through scientific research

- Research into more accessible, efficient, and sustainable customized care
- Collaborating in the research chain for the valorization of new diagnostics and treatment
- Demonstrating the effectiveness of innovations for better health and care.
- Strengthening the ecosystem around research
- Bringing answers to research questions back to society

3 Investing in learning for the care of the future

- Distinctive education focused on innovation
- Future-oriented learning and development
- Providing an inclusive, stimulating, and safe learning environment
- Teaching as a valued core task
- Attention to societal issues in all curricula
- Increasing focus on interprofessional collaboration
- Intensifying regional collaboration with educational partners and healthcare providers

Future End of Life vision for EMC

Goal: facilitating interactions in the palliative care to create a dignified last phase of life

Based on research and the "Koers 28" vision, this future vision illustrates insights on the needs of the involved actors in EMC's palliative care phases.

The vision consists of **3 design opportunities** that can improve the palliative care process together, and suggests design directions to pursue these opportunities.

Background: qualitative research into palliative care phases and needs

The Future Vision leads to a Design Goal

Design Goal: to facilitate a dignified End of Life experience for actors involved in the End of Life phase, in the patient rooms of EMC

The overarching design goal led to three design directions, each with t own respective sub-goals. Together, these design directions are th foundation to achieve the design goal.

Foundation for future design directions

with sub-goals:

Communication and expectations

Creating understanding of what death and dying means to each patient in the EOL process

Aligning expectations for the end-of-life journey among all stakeholders involved

Aligning expectations of the dying process between loved ones and the medical staff

Understanding and respecting patients' intrinsic motivations in the EOL process

Creating a welcoming space that invites stakeholders to communicate in the EOL process

Autonomy of Actors involved

Recognizing and respecting unique wishes and needs.

Preparing and supporting loved ones for intense emotional moments in the EOL process

Supporting medical staff in maintaining autonomy while empowering patients and loved ones

Creating a space that supports autonomy for all stakeholders involved

Balance in whishes and resources of medical team

Integrating equal palliative care perspectives into shared decision-making

Involving patient and loved ones in decision-making and discussions about intrinsic motivation

Documenting patient motivations to support holistic care advocacy

Continuing to support loved ones after death by providing closure to the process

Figure 13: Infographic: the future of palliative care at Erasmus MC

3.1.2 Design opportunities

The future vision presents three categories that show design opportunities, that are translated into design directions for the future of the palliative care at Erasmus MC. Each direction has their respective sub-goals (figure 14) and together these sub-goals lay the foundation the hospital should strive to in the future.

Foundation for future design directions

with sub-goals:

Communication and expectations

Creating understanding of what death and dying means to each patient in the EOL process

Aligning expectations for the end-of-life journey among all stakeholders involved

Aligning expectations of the dying process between loved ones and the medical staff

Understanding and respecting patients' intrinsic motivations in the EOL process

Creating a welcoming space that invites stakeholders to communicate in the EOL process

Autonomy of Actors involved

Recognizing and respecting unique wishes and needs.

Preparing and supporting loved ones for intense emotional moments in the EOL process

Supporting medical staff in maintaining autonomy while empowering patients and loved ones

Creating a space that supports autonomy for all stakeholders involved

Balance in whishes and resources of medical team

Integrating equal palliative care perspectives into shared decision-making

Involving patient and loved ones in decision-making and discussions about intrinsic motivations

Documenting patient motivations to support holistic care advocacy

Continuing to support loved ones after death by providing closure to the process

Figure 14: The three design directions as the foundation for future design processes

3.1.2.1 Design Direction: Communication and expectations

Sub-goals

a. Creating understanding of what dying means to each patient in the EOL process, by communicating about the intrinsic motivation of the patient.

By creating better communication between patients, loved ones and medical staff a deeper understanding of what death and dying means to them will develop. These topics and conversations will shed light on the intrinsic motivation of the patients and loved ones, such as their norms and values in life and their expectations for this EOL process.

b. Aligning expectations for the end-of-life journey among all stakeholders involved.

By improving early and ongoing communication between patients, loved ones and medical staff, expectations will align and misunderstandings and emotional distress will be reduced. Providing clear guidance on dealing with uncertainties in the palliative care process will help patients and loved ones cope better with the unpredictable nature of the journey. This approach ensures that everyone is better prepared and more comfortable with the realities of the end-of-life process.

c. Aligning expectations of the dying process between loved ones and the medical staff.

By improving communication between medical staff and loved ones about the dying process, loved ones will be better prepared for the physical and emotional experiences of the patient passing. This includes discussing potential pain and discomfort and what can be done to manage it. Ensuring that loved ones understand the process will reduce fear and anger, fostering a more supportive and peaceful end-of-life experience for everyone involved.

d. Understanding and respecting intrinsic motivations of patients in the EOL process.

By implementing formal discussions about death and dying, early in the palliative care process, medical staff will gain a deeper understanding of each patient's intrinsic motivations and personal preferences. Documenting these insights will help balance care and cure, ensuring that medical decisions align with the patient's wishes and improve their quality of life. This approach will enable more personalized and respectful care from medical staff throughout the end-of-life journey.

e. Creating a welcoming space that invites stakeholders to communicate in the EOL process.

By redesigning patient rooms to invite stakeholders for open dialogues about their preferences and needs in the EOL process, effective communication can start within the patient room. This approach not only improves the overall experience and quality of life for patients and their loved ones, but also helps reduce anxiety and distress. Ensuring that the room feels comfortable and inviting, with elements that resonate with the patient’s identity, fosters a sense of familiarity and peace.

3.1.2.2 Design Direction: Autonomy of Actors

Sub-goals

a. Recognizing and respecting unique wishes and needs.

By ensuring that patients are treated as individuals in the EOL process, their sense of autonomy and control will be restored. This approach will acknowledge the unique wishes and needs of each patient, improving their psychological wellbeing and reducing anxiety and tensions between patients and medical staff. It is crucial to support patients in this critical phase of their lives by making them feel seen and heard.

b. Preparing and supporting loved ones for intense emotional moments during the EOL process.

By providing loved ones with the necessary information, resources, and emotional support they will maintain a sense of autonomy and purpose during the palliative care process. Preparing them for the challenges ahead and ensuring they feel seen and supported will reduce feelings of uselessness and discomfort, leading to a more positive and collaborative atmosphere during the second and third phases of palliative care.

c. Supporting medical staff in maintaining autonomy while empowering patients and loved ones.

By fostering a collaborative environment where the autonomy of patients and loved ones is prioritized, medical staff can also maintain their sense of autonomy. This shift in focus will enhance the caregiving environment, ensuring that all parties feel empowered and respected. Medical staff will be better able to provide effective care when the dynamics of their relationships with patients and loved ones are supportive and respectful.

d. Creating a space that supports autonomy for all stakeholders involved.

By redesigning patient rooms to accommodate the needs of autonomy in flexibility and privacy, a personalized environment can be created for stakeholders. This for example includes providing comfortable sleeping arrangements, sufficient storage space for personal belongings, and adequate seating. Ensuring that patient rooms are adaptable and supportive of the 'rooming in' process, invites patients to bring their own items and create a space that feels uniquely theirs. This personalization gives patients and their families a sense of control and ownership over their environment, enhancing their autonomy and comfort during the EOL process. Being able to tailor their surroundings more to their own preferences helps patients maintain dignity and independence, which are crucial for their psychological well-being.

3.1.2.3 Design Direction: Balance in whishes and resources

Sub-goals:

a. Integrating equal palliative care perspectives into shared decision-making.

By fostering an environment where palliative care perspectives are equally considered alongside curative measures, medical staff will ensure that patients' wishes and motivations are fully integrated into their care plans. This approach will ensure Erasmus MC that discussions among doctors reflect a harmonized understanding of their equal importance.

b. Involving patient and loved ones in shared decision-making and discussions about intrinsic motivations.

By including patient and loved ones in discussions about the patient's intrinsic motivations and personal values, they will be better prepared for critical moments in the EOL journey. This will reduce feelings of exclusion and helplessness for the loved ones. This approach will support patients and loved ones emotionally and provide them with the necessary context to navigate the EOL journey effectively.

c. Documenting patient motivations to support holistic care advocacy.

By ensuring that discussions about patients' intrinsic motivations are well-documented and integrated into their care plans, medical staff can better advocate for palliative care. This documentation will provide the necessary arguments about the patients motivation and needs to balance curative and palliative measures. This will support a holistic approach that meets the needs of patients and their loved ones during critical transitions in the palliative care process.

d. Continuing to support loved ones after death by providing closure to the process.

By extending support to loved ones beyond the patient's passing, medical staff can offer help to navigate the bereavement process more effectively. Providing resources such as counseling, support groups, and follow-up communication ensures that loved ones do not feel abandoned and can achieve a sense of closure. This comprehensive approach to palliative care recognizes the ongoing needs of loved ones and supports their emotional wellbeing through the grieving process.

The design directions suggest critical areas for improvement in communication, autonomy, and balance between stakeholders' needs and medical resources. The next section will focus on illustrating what design can achieve with such opportunities, by creating an concept for Erasmus MC that aligns with one of the sub-goals. Moving forward, these findings will be the foundation of the intervention to enhance the quality of End of Life care at Erasmus MC.

3.2 Design goal

3.2.1 Introduction

To illustrate how the design directions could be translated into the hospital and to show what impact design could have on End of Life care at Erasmus MC, a concept will be developed. The concept will be created following the design goals formulated for the future of palliative care at Erasmus MC.

This research began with a specific design goal for this thesis: 'to identify patterns and opportunities for improvements in facilitating a peaceful passing in the patient rooms at Erasmus MC.'

Through learning from all the research insights and design directions, an overarching design goal has now emerged with more refined and fitting words to describe it. The Design Goal is:

"To create a patient room that supports stakeholders in the End of Life process in facilitating a dignified end of life experience for all involved."

The Design Goal involves the following key stakeholders, seen in figure 15:

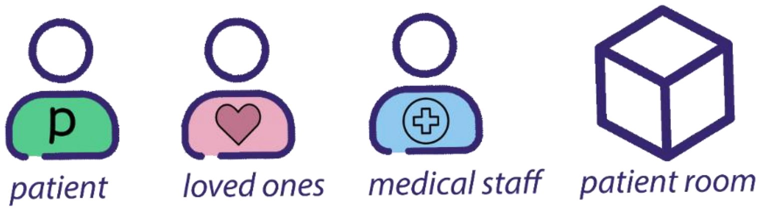


Figure 15: Key stakeholders for the Design process

3.2.2 Analogy

To get a feeling of underlying interaction qualities, an analogy is created and used as a source of inspiration for the Design process.

The interaction with the patient room should feel like dancing together; tuning into each other rhythms while maintaining their own pace and being in control. The analogy is illustrated in figure 16.

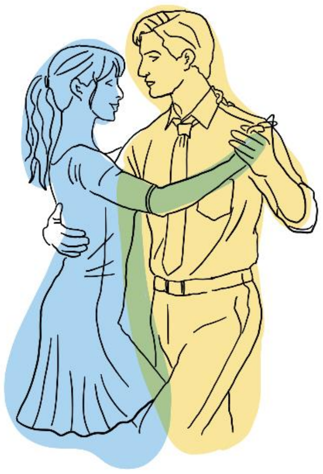


Figure 16: Analogy of two people dancing together

3.2.3 Interaction qualities

This analogy involves the following interaction qualities:

- Empowering
- Feeling in control
- Open / flexible
- Intimacy
- Personal
- Feeling seen
- Coordination

4. DEVELOP

The develop phase will focus on developing and evaluating a concept, to illustrate what design can do for the future of palliative care in Erasmus MC's patient rooms.

The concept will be guided by the following design goal:

"To create a patient room that supports stakeholders in the End of Life process in facilitating a dignified end of life experience for all involved."

4.1 Design Focus

4.1.1 Introduction

Through extensive research and interviews with various stakeholders and healthcare professionals, a future vision and several design (sub-)goals have emerged. The aim of the Develop phase is to demonstrate the importance of this research with a tangible concept, illustrating the power of design within the End of life context. This concept will serve as an example of how the future vision for Erasmus MC and the design goals can be realized, but it must be emphasized that this is not the only possible intervention. The concept focuses only on a small part of the design opportunities identified in the research. Therefore, the concept is not intended to serve as an overall solution, but merely as an illustration.

The design process for this concept will focus on two specific sub-goals, which will be detailed in the next section. Consultations with healthcare professionals have identified these sub-goals as both promising and feasible directions for the project. These discussions have provided a strong foundation for selecting them as the focal points of the design process.

This chapter will further delve into the rationale behind the selection of these sub-goals, it will focus on the iterative process of a designing a concept and ultimately presenting the evaluation of the concept.

4.1.2 Motivation

The focus will be on the following sub-goals:

Creating understanding of what aspects of death mean to each patient in the EOL process

- This goal is chosen for its crucial role in the end-of-life process. Often, there is a lack of communication at the beginning of the palliative phase, where the meaning of death and the patient's values are not adequately addressed. By focusing on meaningful conversations about the patient's values or providing a way for them to reflect on their own path of life and death, the other stakeholders can better understand their wishes and intrinsic motivations. There are many ways to create understanding about aspects of dying and death, which can also reveal cultural and religious differences. Addressing these differences provides a relevant opportunity to break barriers and learn from other stakeholders. When done effectively, this approach allows the medical staff to tailor treatments to align more with the patient's desires and values. Simultaneously, patients will feel more respected and valued as individuals, as their views on quality of life and death are given the attention they deserve.

Creating a welcoming space that invites stakeholders to communicate in the EOL process

- This goal is chosen due to its feasibility and importance. Often, the patient rooms do not adequately support open and meaningful dialogue among patients, loved ones, and medical staff. By redesigning the space to be more inviting and comfortable, the room can encourage conversations about the patient's needs, wishes, and values. This approach helps reduce anxiety and distress by providing a setting that feels safe and personal. Additionally, this approach is testable with medical staff to determine if the concept developed indeed fosters more communication. This makes it a feasible goal for this project, as its effectiveness can be measured and validated through practical application and feedback.

4.2 Ideation to concept

With the use of different design methods, the ideation process focuses on the development of a concept. Detailed explanation of the methods used for ideation can be found in Appendix O.

To initiate the process, an analogy was created to serve as a source of inspiration, along with specific interaction qualities. This foundational step helped guide the creative thinking and set the stage for generating innovative ideas.

In a short span of time, 30 ideas were generated that aligned with one of the two sub-goals. These initial ideas were then tested for the EOL setting at Erasmus MC. The testing involved evaluating the practicality and impact of each idea in the actual patient room environment, considering the unique constraints and requirements of palliative care. Afterwards, a selection of 13 ideas emerged as feasible ideas for concepts. Next, these 13 ideas were combined into 3 comprehensive concepts, which were then evaluated with stakeholders at Erasmus MC.

Following this evaluation, one concept was designed that was evaluated as innovative and feasible within the time span of this project. This concept not only fulfills the criteria set in the design goals but could also be integrated seamlessly into the patient room, aiming to improve communication for all stakeholders and create a welcoming, personalized environment for patients in their final days. In the following sections, this concept will be presented, showcasing the iterative design process in which it was created and prototyped into a tangible product. This product was then tested and evaluated, and recommendations were made. Based on the feedback received, a subsequent iteration was designed.

4.3 The concept: De Verhalenhoek

The foundation of the concept

The goal of designing the concept is to show what design can do in the End of Life context, when design opportunities arise. This section lays the foundation of the concept. Iterations will be conducted on this foundation to enhance the design.

The concept focuses on creating elements of strength to have close with you during the whole palliative care process in the hospital. These elements can be a source of strength, motivation or a sense of home for the patient when staying in the hospital room.

De Verhalenhoek

De Verhalenhoek is a small cabinet where patients can store elements or belongings that mean something to them. These elements can be different for every patient and it is up to them how and if they want to fill the cabinet with personal items, or if they rather choose items from the hospital's toolkit. When a patient does not have interest in placing elements in the cabinet it will serve as a regular cabinet as part of the interior. The concept aims to invite patients and loved ones to have a look at De Verhalenhoek, by making it an interesting object in the room. But at the end of the day, it is up to the patients if they are comfortable in using it.

By creating a place where patients can place objects that are valuable to them, it gives them a feeling of autonomy and being in control of the space. It also allows patients to personalize the room a bit more. This can make them feel more comfortable and maybe even feel at home in the room, by filling the space with elements they recognize and have special meaning for them.

Besides the autonomy it gives patients, the concept also facilitates valuable conversations with loved ones and healthcare professionals. The concept gives healthcare professionals an insight into who this patient is and what they stand for, which lowers the threshold for making a connection with the people in the room. De Verhalenhoek and its elements give healthcare professionals a point of reference to start a conversation, even for more sensitive discussions as the upcoming End of Life process. Referring to items in the cabinet lowers the barrier to initiate a conversation about difficult topics.

Toolkit

A hospital toolkit will be part of the concept and consists of a visualization of topics that could be valuable to the patients. The visual elements could inspire them or loved ones to communicate about these topics. The toolkit will be designed around seven topics that patients often seek meaning or support from:

- Family
- Loved ones
- Religion
- Hobbies
- Pets
- Art
- Nature

Prototyping

The first prototype for the concept was first designed in SolidWorks (Figure 17) and prototyped using laser-cut 5mm wood at the IDE faculty (Figure 18). This prototype aimed to determine appropriate dimensions. Symbols were crafted from clay and painted to symbolize items patients might place in the cabinet (Figure 19). The dimensions of the first prototype are 40 x 40 x 15 centimeters.

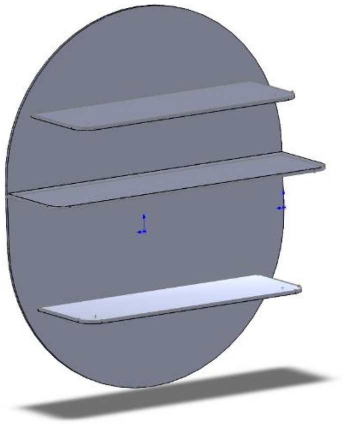


Figure 18: Solidworks model for the first prototype

Figure 17: First prototype of the concept, made out of plywood

Figure 19: Prototype for the symbols, made out of clay

Testing through feedback sessions

The first prototype of De Verhalenhoek was tested in three separate sessions with non-medical individuals, including friends and family. The testing method involved observing interactions between users and the concept and asking questions to assess the perceived value and understanding of the concept by users.

The feedback from the first feedback sessions included the following points for improvement:

- **Symbol Clarity:**

The symbols worked well in expressing different topics to address, but they were considered a bit small.

- **Look and feel**:

The neutral color of the prototype was effective in creating a calm look, but a warmer color was suggested to fit the circumstances better.

- **Size adjustments**
  - The shelves were too deep, making the cabinet less efficient for the space.
  - The overall height and width could be reduced as the current size was larger than necessary.

4.4 Iteration 1 on concept: second prototype

Based on the feedback, a new iteration of the concept was designed. This iteration addressed the size, color and shape to better embody the message of the concept and meet the needs of the future users.

For the second prototype, the design of the cabinet has been modified from standalone shelves to shelves that are surrounded by the sides, top, and bottom of the cabinet. Additionally, a front panel with various holes has been added, which can differentiate the different places to store elements in the cabinet. Round shapes were added to create a soft look, avoiding hard edges.

This new shape aims to create a more cohesive visual appearance and provides a 'protected' feeling for the elements that users place inside the cabinet, which is desirable in this context. By using top and side panels, an LED light strip can be discreetly added inside the cabinet. This adds an extra special dimension of attention to the valuable elements in the cabinet. Moreover, it adds functionality to the room; even if users are not interested in using the cabinet for 'special' elements, it can still function as a regular cabinet with additional lighting for the evenings.

Figure 20 and 21 show the new shape used for the second prototype, which was again designed in SolidWorks and laser-cut at the IDE faculty out of 5 mm plywood.

In the SolidWorks files, provisions have been made for holes to hide the wiring of the LED strip and for mounting screws, allowing the cabinet to be directly attached to the wall.

Figure 20: The assembling of the second prototype

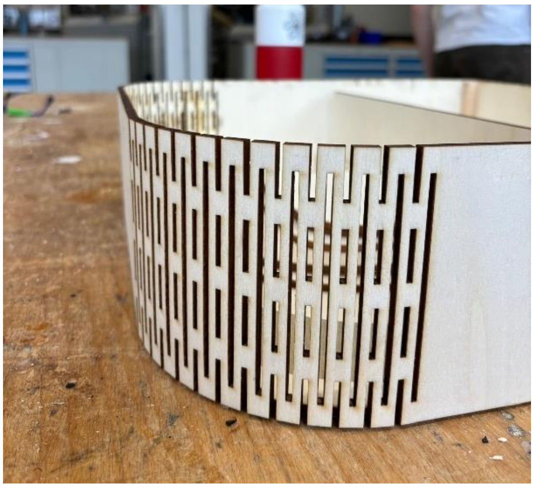


Figure 21: Close up of the bended wood, designed for the second prototype

After assembling the prototype, the cabinet was painted in a blue color as seen in figure 22. This color was chosen to create a positive effect, but still remain neutral in the interior of the hospital. Figures 23 and 24 show the features and different sides of the prototype.

Look and feel of second prototype

Figure 23: The front sides of the second prototype

Figure 24: The second prototype in the dark, showing its light functionality

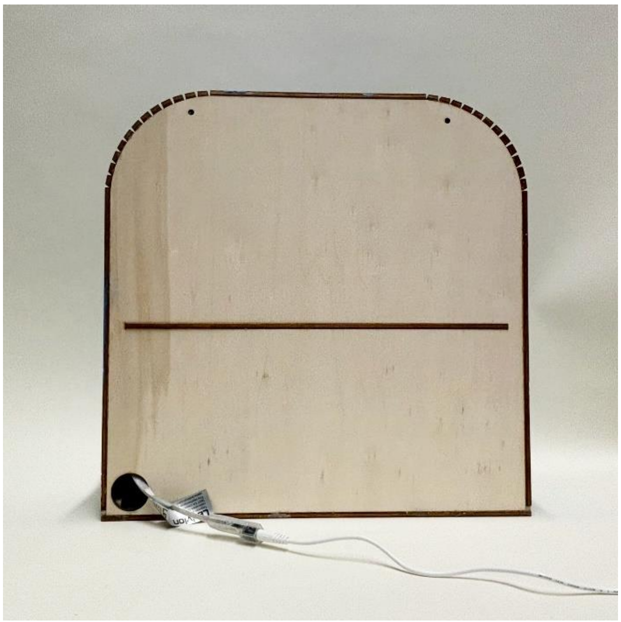


Figure 22: The back of the second prototype

Testing through feedback sessions

The revised concept shown in figures 23, 24 and 25 was tested, this time in a creative session with healthcare professionals at Erasmus MC. The testing involved evaluating the practicality and impact of the new design in the actual patient room environment. The feedback was used to further refine the concept, ensuring it effectively met both design goals and provided a valuable addition to the palliative care process. The feedback sampling was done in two feedback sessions. One session was done with 6 doctors from the geriatric department, after their consultation rounds at Erasmus MC. Another session was done with 10 nurses in training, in the break of one of their classes.

In the feedback session, the research project was explained and the physical prototype was shown to the group. They were given the opportunity to ask questions about the functionality of the concept, the use and the look and feel. In return, they were asked to give feedback on these three points and give any additional comments that they found important.

Overall the feedback was positive and the healthcare workers offered practical feedback about the usability in the patient room. Furthermore, they expressed enthusiasm about enhancing the patient-medical staff relation and making the patients feel more at home with this concept. The full notes of the feedback sessions can be found in Appendix P.

The feedback from the sessions included the following points for improvement:

Accessibility and usability:

- The size should accommodate a book, such as religious texts, as these can be very important and are used widely in the patient rooms
- The visibility of the concept should be taken into account when placing the concept in the patient room: the patient should be able to see the elements from their bed.

Aesthetic and integration:

- Including a name tag next to the concept, that all staff is aware that this cabinet is used to store patient's elements – not medical equipment.

Hygiene and safety:

- The design should be easy to clean, avoiding multiple levels in the shelves and using a single, straight surface.

Cultural Sensitivity:

- The toolkit of elements to lend out should ensure it includes all possible (religious) symbols, avoiding a limited selection that might not cater to everyone's needs.

Further suggestions:

- For certain departments (e.g. Medical Psychiatric Unit), considering a concept on wheels would be appropriate to enhance portability.
- Considering removing the plug and lamp to avoid dependence on a plug or battery, enhancing sustainability of the concept.

With these insights in mind, a third prototype is designed and developed to refine and enhance the design of De Verhalenhoek. This new iteration will incorporate feedback and suggestions gathered and will be presented in the next chapter.

4.5 Iteration 2 on concept: third prototype

Based on the feedback of the feedback sessions, a new iteration of the concept was designed. This iteration primarily addressed several points: the shape and dimensions of the prototype, the cultural sensitivity of the toolkit, and the interaction with users. These changes were evaluated again to test if they achieved the desired interaction between the stakeholders and the concept.

For the third prototype, the design of the cabinet was modified to a simpler model, without sides or a front. This change was made to lower the barrier for users to access items from the cabinet and place their personal elements inside. Symmetry was enhanced to create a calmer, more appealing model compared to the previous version. These details contribute to a new shape that aims to create a cohesive visual appearance and provide a welcoming feeling for patients when they see the prototype in a patient room.

In this iteration, the icons were replaced with postcards to evaluate whether this change aligned with the hypothesis that postcards offer a greater variety of feelings and emotions for patients. The postcards were selected to fit the same seven categories, as research indicated that these categories are often mentioned as important by patients:

1. Religion
2. Family
3. Loved ones
4. Hobbies
5. Pets
6. Art
7. Nature

The postcards aim to provide ambiguous meanings for different patients. For example, one patient might draw strength from an image of a flower, while another might think of their gardening hobbies and yet another might recall the smell of flowers that reminds them of home. This ambiguity improves the cultural sensitivity of the concept, reaching a wider range of people by offering many options for interpretation. Most importantly, it allows patients to control their own stories through cards or elements.

Prototyping Process

Another alteration made was by increasing the distance between the shelves of the cabinet. This change provides patients with more options for what to place in the cabinet, whether it's a book, a photo, or another valuable item—it should fit in the cabinet. This size difference aims to make the prototype more inviting, allowing both larger and smaller elements to fit on one of the two shelves. The LED functionality is left out of this concept, to focus on the main goal of the concept and avoid dependence on a plug or battery.

Figures 25 and 26 show the new design used for the second prototype, which was designed in SolidWorks and laser-cut at the IDE faculty from 9 mm plywood. Thicker wood was chosen to provide more sturdiness and stability in the prototype.

Figure 25: The SolidWorks model for the third prototype

Figure 26: Prototyping of the third prototype at IDE faculty

Testing through feedback sessions

The revised concept was tested again in two sessions with non-healthcare workers to gain a fresh perspective on the initial interaction between new users and the concept. First, the goal and context of the project were explained. Then, feedback was requested on the look and feel of the prototype, even though the users were not fully informed about its exact use.

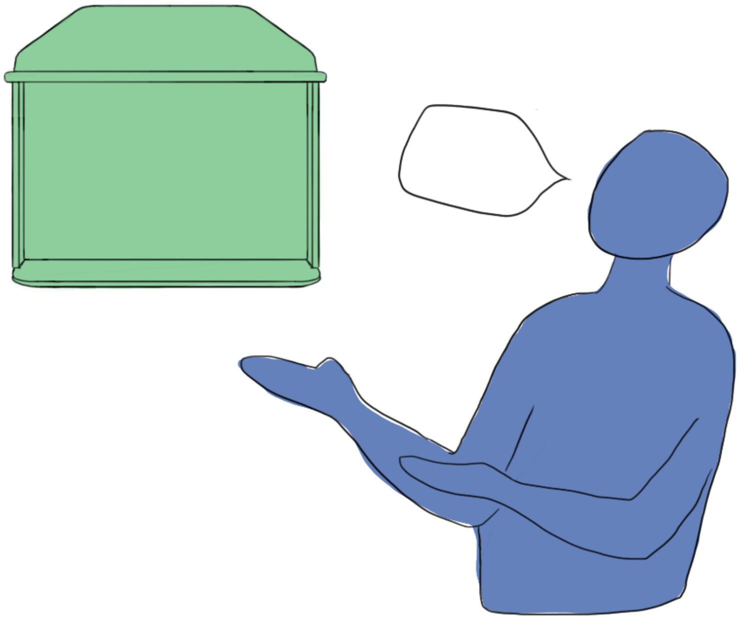
Next, the complete concept, including the postcards and the cabinet, was explained. As an example, two frames with postcards from the collection were displayed in the cabinet to give users an idea of how it would look in practice. Participants had the opportunity to ask questions about the functionality, use, and appearance of the concept. In return, they were encouraged to provide any additional comments they deemed important.

This feedback has been incorporated into the recommendations and presentation of the final proof of concept, which will be discussed in the next chapter. The goal is to create a suitable and user-friendly proof of concept that meets the diverse needs of the stakeholders at Erasmus MC, ensuring that De Verhalenhoek can be implemented and evaluated across various hospital departments in the future.

5. DELIVER

The Deliver phase will present a final proof of concept to illustrate the use of the future vision for End of Life care at Erasmus MC's patient rooms.

This chapter will present the proof of concept and explain its use, key aspects and limitations. Furthermore, it will focus on recommendations for further implementations and opportunities of the concept.



5.1 Introduction

The final design in this report is a proof of concept for De Verhalenhoek. This means that multiple iterations have been carried out on the original concept and different prototypes have been tested with a small target group. Based on several feedback sessions, improvements were made to the design. All of the feedback sessions led to the design of this proof of concept for De Verhalenhoek. It is important to emphasize that this proof of concept is not a finished product ready for market launch. It is a concept with a defined purpose and functionality, but the physical prototype can still be further refined with input from stakeholders at the relevant healthcare facilities.

This chapter will dive deeper into the functionality of De Verhalenhoek and show how it can contribute to improving End of Life care in Erasmus MC's patient rooms.

5.2 Proof of concept

Foundation of the design

De Verhalenhoek is a small cabinet in the patient room designed for patients to store personal or meaningful items, with the goal of providing patients with a sense of autonomy and the possibility for personalization of the patient room.

De Verhalenhoek features a designed guidebook for the staff of Erasmus MC to facilitate conversations using the elements placed in the cabinet by patients or loved ones. By using these elements as a foundation, the aim is that healthcare professionals can more easily initiate and navigate communication on difficult and sensitive topics with patients and their loved ones within the comfort of patient rooms.

The concept includes a toolkit to provide visual elements for patients unable to bring items from home, in the form of a card set. This is designed to make the use of "De Verhalenhoek" have a lower threshold and to offer alternatives for patients and loved ones who cannot retrieve valuable items from home. Both the design and use of the guidebook and card book are explained in more detail in the next sections.

Physical prototype

Figure 27 shows the prototype of the concept and it shows the proof of concept equipped with a combination of different cards.

Figure 27: A visualization of the plain prototype and the prototype equipped with photo frames

Figure 28 shows the versatility of the personalization of De Verhalenhoek.

Figure 28: The prototype for De Verhalenhoek with a variation of elements placed in it

Digital interface

In order to make the concept applicable to more departments and facilities, a digital interface has also been designed to suit the current possibilities in the room. The design is adapted to work on the iPad that is already present in the room, which hangs next to the bed. The iPad is currently used by patients to order food, view their documents, control the lights in the room and make service calls (see Figure 29).

Figure 29: The iPad hanging in patient rooms of Erasmus MC

The interface is designed so that patients can also view cards on their iPad without the physical prototype. An interface has been created with various cards, from which users can save three in their 'own' Verhalenhoek. This allows the concept to reach a larger audience, in departments or facilities where there is no space for the physical cabinet or where this is not possible due to stricter rules about for example infectious diseases.

In departments at Erasmus MC where patients have to stay for longer periods, like hepatology, this solution can be very comforting, providing a form of support in the form of a beautiful image. Here too, the same conversation can be facilitated, this time by medical staff looking at the digital Verhalenhoek op the iPad together with the patient and their loved ones.

Figures 30 show a new home screen designed for the Erasmus MC iPad, that includes De Verhalenhoek as one of the features.


WELKOM

Kamernummer: Rg-1009

Behandelaar:

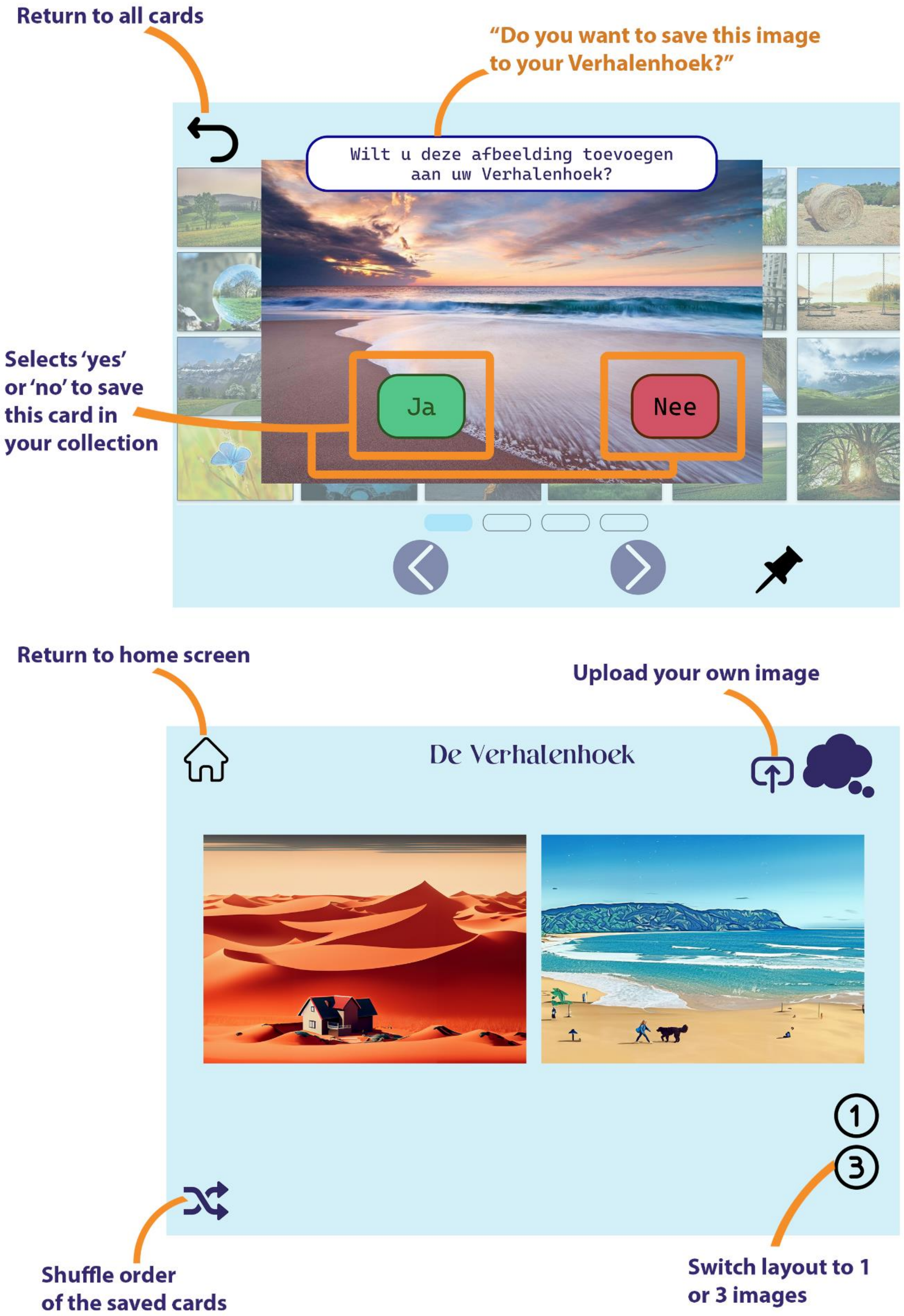
Voorlopige ontslagdatum:

Figure 30: Home screen for the iPad, including the feature of De Verhalenhoek

The following section present screens for the digital version of De Verhalenhoek, the full screens can be found in Appendix Q.

Figure 31 shows the digital version of the card set, to browse through and pick your favorite. Figure 32 shows the interaction of how to select cards to place in your virtual Verhalenhoek.

Figure 31: A digital version of the card set, designed for the iPad in patient rooms



Wilt u deze afbeelding toevoegen aan uw Verhalenhoek?

Return to all cards

"Do you want to save this image to your Verhalenhoek?"

Selects 'yes' or 'no' to save this card in your collection

Return to home screen

Upload your own image

Shuffle order of the saved cards

Switch layout to 1 or 3 images

Figure 32: Digital screen of placing images in your virtual Verhalenhoek

Conversation guidebook

The conversation guidebook is designed for the medical staff of Erasmus MC to learn about the use and goals of De Verhalenhoek. Additionally, it serves to explain De Verhalenhoek to patients and their loved ones, and to assist them in using it.

The guidebook includes guidelines for initiating conversations about the meaning of the elements placed in De Verhalenhoek. These guidelines are intended to start the conversation, though it can naturally lead in many directions. The direction depends on the individuals involved, such as how much a patient wishes to share with a specific healthcare professional or if the patient and their loved ones are comfortable discussing the end-of-life process. While these guidelines are meant to help uncover the personal wishes and motivations of the patient, this outcome cannot be guaranteed.

Therefore, the conversation can be held multiple times, as long as the patient is comfortable sharing. The guidebook is written in Dutch to align with the stakeholders of the Dutch hospital, and in English to communicate with other stakeholders. The full versions of the English and Dutch guidebook can be found in appendix Q, figure 33 and 34 give an example of the pages.

This guidebook is designed for the medical staff of Erasmus MC. It explains the use and goals of De Verhalenhoek—a concept for the patient room. Additionally, this guide can be used to explain De Verhalenhoek and to assist patients and their loved ones in using it.

Introduction

De Verhalenhoek is a concept designed to give a place in the hospital room for personal stories and memories of a patient. Through cards and personal elements, we aim to offer strength and comfort to patients and their loved ones, thereby lowering the threshold to start a conversation about aspects of the final phase of life and this intense period. Because there are many differences between patients, their needs and their responses to support, De Verhalenhoek is designed to invite them in personal customization.

With the help of De Verhalenhoek, animations on the iPad, and various images, a conversation is facilitated between medical staff, the patient, and possibly their loved ones.

De Verhalenhoek

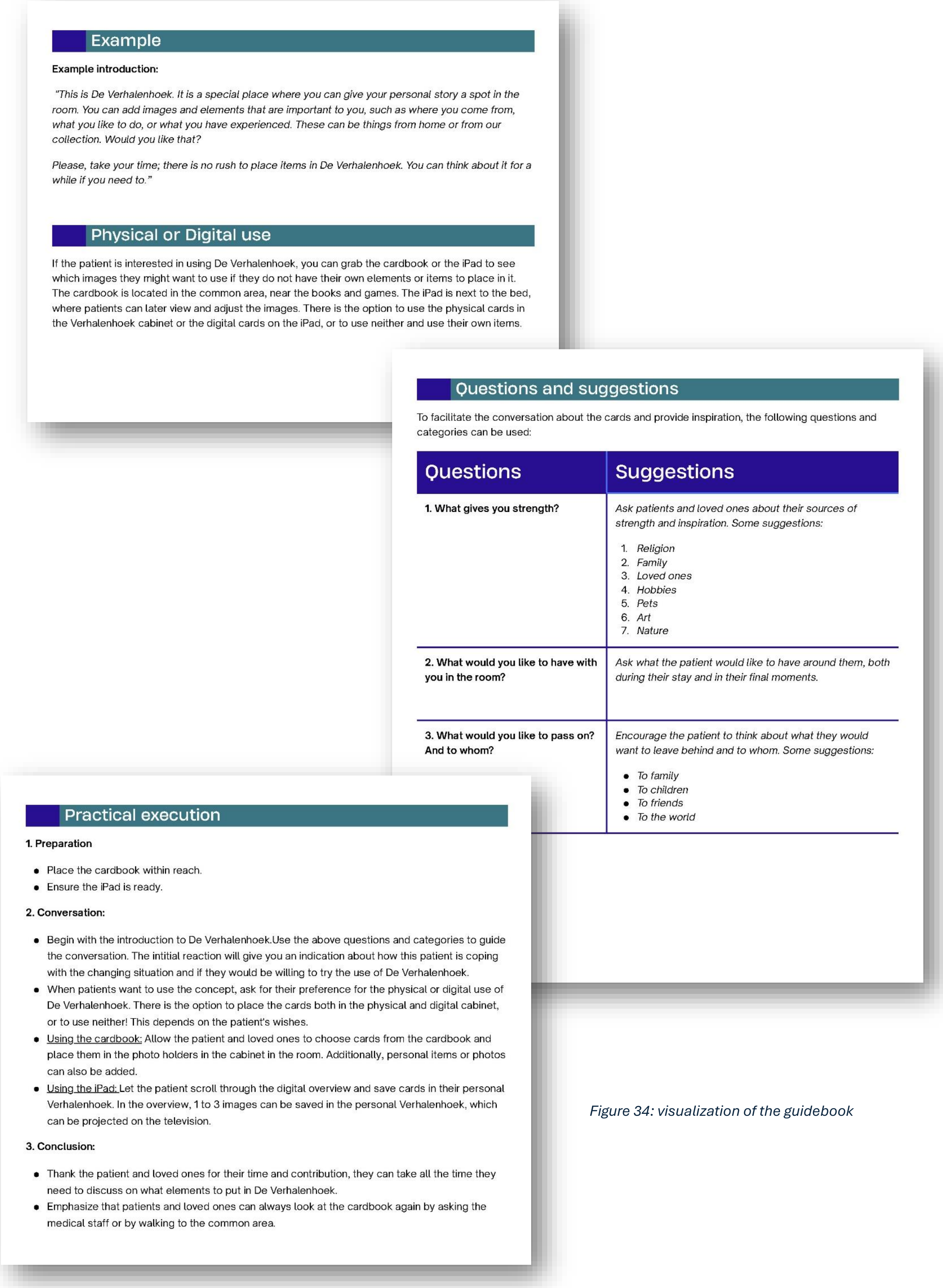
De Verhalenhoek hangs in the corner of the patient's room and will stand out as soon as patients enter the room. Here, medical staff can already give a brief explanation about the purpose and benefits of the cabinet, so that the patient and loved ones feel invited to bring items from home and place them inside.

Initiating the conversation

After delivering bad news to a patient, De Verhalenhoek can be valuable in initiating a difficult conversation and further supporting the patient and their loved ones. After the bad news conversation, is the moment to start this conversation. Start with an introduction to the concept. Medical staff can invite the patient and loved ones to add personal elements to De Verhalenhoek.

Everyone cope differently with the final phase of life . Patients will also respond very differently to the questions you ask and to De Verhalenhoek. For example, one patient might be eager to talk about their final moments, while another might reject the topic or need more time. It is important to give patients the time and space they need in your approach.

Figure 33: Visualization of the guidebook



Example

Example introduction:

"This is De Verhalenhoek. It is a special place where you can give your personal story a spot in the room. You can add images and elements that are important to you, such as where you come from, what you like to do, or what you have experienced. These can be things from home or from our collection. Would you like that?

Please, take your time; there is no rush to place items in De Verhalenhoek. You can think about it for a while if you need to."

Physical or Digital use

If the patient is interested in using De Verhalenhoek, you can grab the cardbook or the iPad to see which images they might want to use if they do not have their own elements or items to place in it. The cardbook is located in the common area, near the books and games. The iPad is next to the bed, where patients can later view and adjust the images. There is the option to use the physical cards in the Verhalenhoek cabinet or the digital cards on the iPad, or to use neither and use their own items.

Questions and suggestions

To facilitate the conversation about the cards and provide inspiration, the following questions and categories can be used:

Questions	Suggestions
1. What gives you strength?	*Ask patients and loved ones about their sources of strength and inspiration. Some suggestions:* 1. *Religion* 2. *Family* 3. *Loved ones* 4. *Hobbies* 5. *Pets* 6. *Art* 7. *Nature*
2. What would you like to have with you in the room?	*Ask what the patient would like to have around them, both during their stay and in their final moments.*
3. What would you like to pass on? And to whom?	*Encourage the patient to think about what they would want to leave behind and to whom. Some suggestions:* ● *To family* ● *To children* ● *To friends* ● *To the world*

Practical execution

1. Preparation

- Place the cardbook within reach.
- Ensure the iPad is ready.

2. Conversation:

- Begin with the introduction to De Verhalenhoek.Use the above questions and categories to guide the conversation. The intitial reaction will give you an indication about how this patient is coping with the changing situation and if they would be willing to try the use of De Verhalenhoek.
- When patients want to use the concept, ask for their preference for the physical or digital use of De Verhalenhoek. There is the option to place the cards both in the physical and digital cabinet, or to use neither! This depends on the patient's wishes.
- Using the cardbook: Allow the patient and loved ones to choose cards from the cardbook and place them in the photo holders in the cabinet in the room. Additionally, personal items or photos can also be added.
- Using the iPad: Let the patient scroll through the digital overview and save cards in their personal Verhalenhoek. In the overview, 1 to 3 images can be saved in the personal Verhalenhoek, which can be projected on the television.

3. Conclusion:

- Thank the patient and loved ones for their time and contribution, they can take all the time they need to discuss on what elements to put in De Verhalenhoek.
- Emphasize that patients and loved ones can always look at the cardbook again by asking the medical staff or by walking to the common area.

Figure 34: visualization of the guidebook

Card set

The card set is designed to inspire patients and their loved ones about elements or things that hold value for them, to place in De Verhalenhoek. The transition from symbols to postcards has the advantage that cards can have multiple meanings for individuals, making them more versatile. A picture is worth a thousand words. The card set is used when patients are unable or unwilling to place their own items in the cabinet but still want to personalize their room. In that case, Erasmus MC could still offer cards to patients to use.

By implementing the card set with the ambiguous visualizations, users can decide for themselves what each card stands for and what kind of value it holds in their own Verhalenhoek. Additionally, the card set makes the use of De Verhalenhoek more feasible for patients who cannot retrieve items from home.

The card set is designed to offer a diverse variety of visual images. The cards are collected from various bookshops and range from nature images, bicycles, animals, religious pictures, art and other hobbies (see figure 36). The goal is to initiate communication about (one of) the seven categories of topics, creating a link between the card and what it might mean for the patient.

The categories are:

- Family
- Loved ones
- Religion
- Hobbies
- Pets
- Art
- Nature

Transparent frames are placed in De Verhalenhoek, both horizontal and vertical, which allow easy insertion of postcards from Erasmus MC as well as personal photos or cards of patients. This keeps the cards clean and undamaged and provides an accessible way to interact with the elements. By using the frames, they can be taken out of the cabinet and brought closer to the patient. Another advantage is that the cards can be changed at any time. The combination of different postcards can mean something unique for each patient, highlighting the power of artistic images: it can show who this person is.

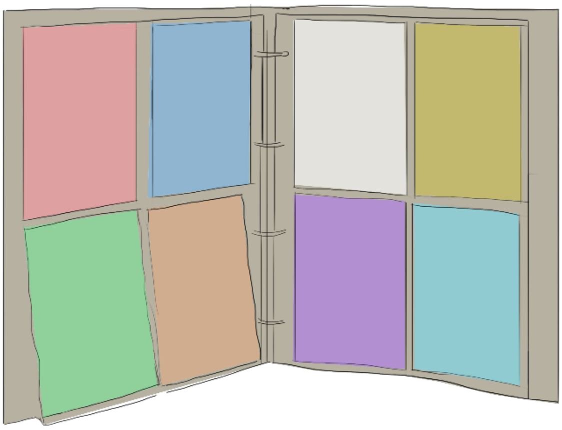


Figure 35: A drawing of the card set

Figure 36: The card set filled with a selection of postcards

Figure 37 presents some of the postcards that are used in the card set.

Figure 37: Selection of postcards in the card set

Placement in the room

Since there is limited room in the patient room, the concept should not take in too much valuable place nor should it stand in the way of the healthcare professionals while doing their work. By mounting the concept on the wall - next to the TV - it does not occupy crucial space needed by healthcare professionals, while still remaining accessible for patients and their loved ones to view and interact with. The design ensures a respectable distance between the concept and the patient, allowing every patient to see the elements clearly and up close.

Figure 38 shows the floor plan of a regular patient room at Erasmus MC, with in green the concept placed against the wall.

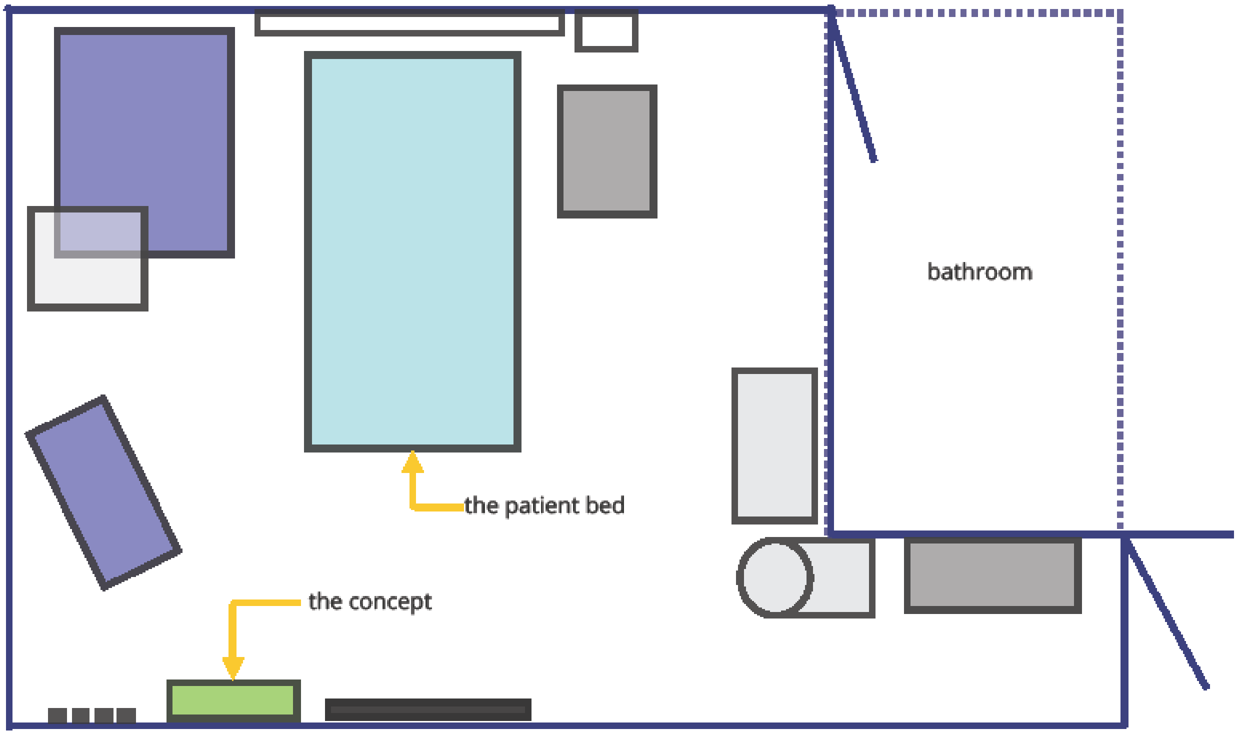
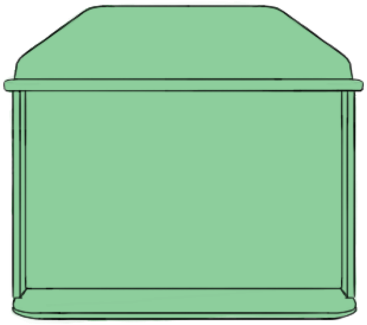


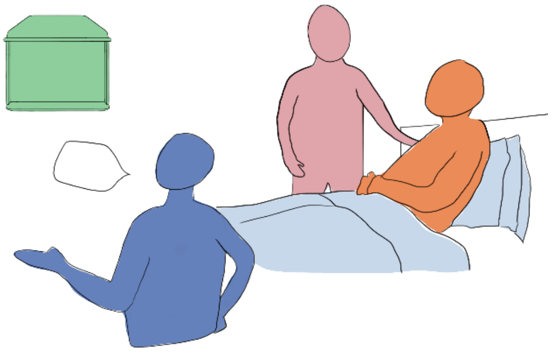
Figure 38: Floor plan of the patient room with De Verhalenhoek in it

5.3 User scenario

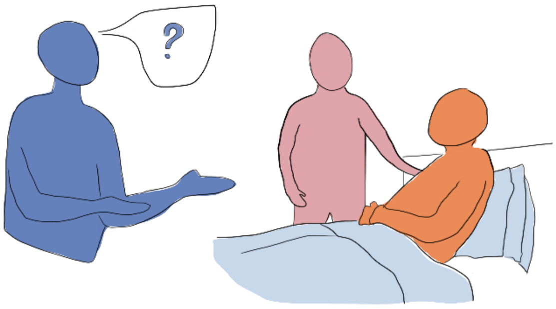
This section explains the use of De Verhalenhoek in a user scenario, which contains multiple steps of interaction. The scenario contains multiple outcomes, depending on what choices are made by the Patient, loved ones and medical staff.



1. The first contact with Verhalenhoek happens when entering the patient room. A patient or loved ones can notice the cabinet on the wall. De Verhalenhoek enables them to have a closer look.

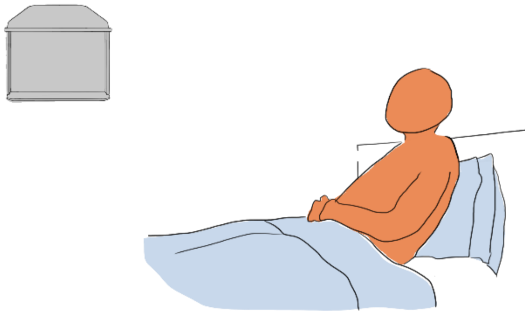


2. When medical staff comes by the room, they bring attention to De verhalenhoek to new patients through explaining its purpose and use. This explanation is supported by a guidebook that is accessible for all staff members prior.

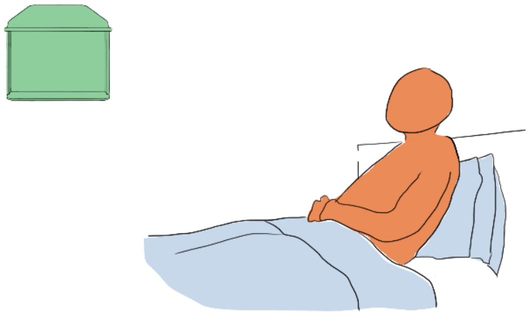


3. Medical staff asks if patient or loved ones are interested to place items in De Verhalenhoek, that have some special meaning to them. This choice does not need to be made right now, they can think about it for as long as they want.

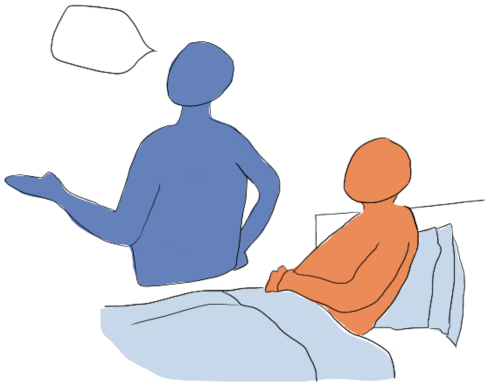
Medical staff emphasizes that if they are not able to retrieve items from home, the patient can loan elements from Erasmus MC.



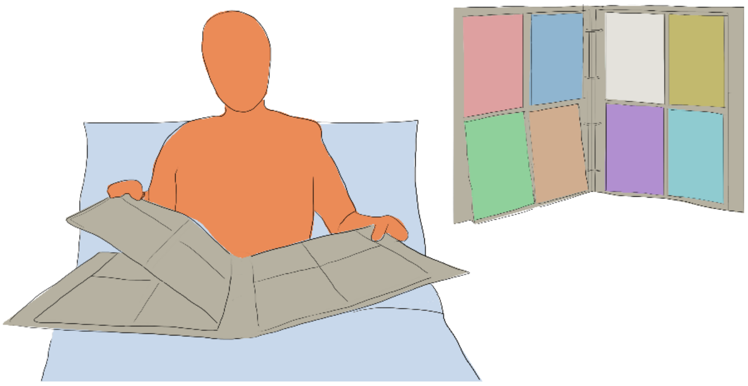
4. If patients and/or loved ones are not interested, that is no problem. The cabinet will remain in the room, with the functionality of a regular cabinet for the patient.



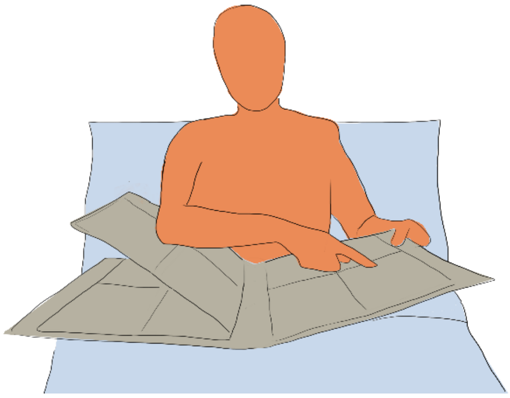
5. If patients are interested, medical staff starts a conversation where they ask about the personal interests and needs of this patient. This conversation is supported by designed questions, to find out what elements give strength to this patient and make them feel seen and heard. Of course, loved ones are always welcome to join and participate in these conversations.



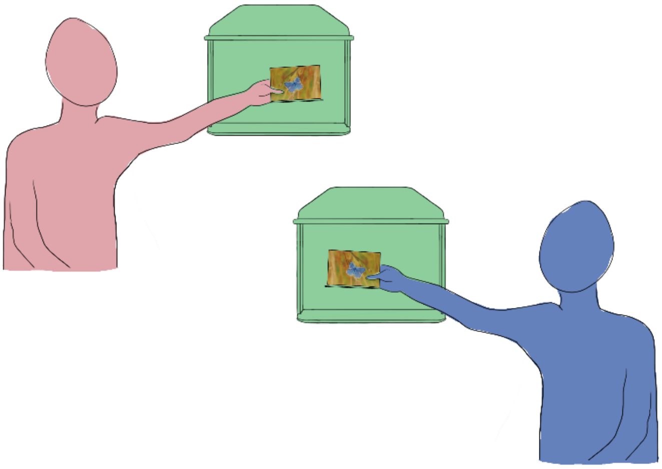
6. The conversation can inspire patients what items to place in De Verhalenhoek. This can be all types of small items, such as pictures of loved ones or decorations from home. At the same time, this first conversation gives medical staff insights into who this patient really is and what preferences they have.



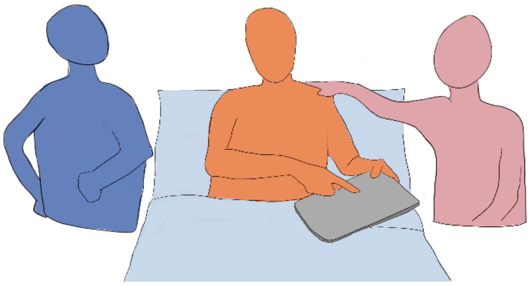
7. If loved ones are not able to retrieve items from home or the patient does not want to do this, medical staff can present the hospital's card collection. This is a booklet that is available in the general area on the ward, with all kinds of postcards in it.



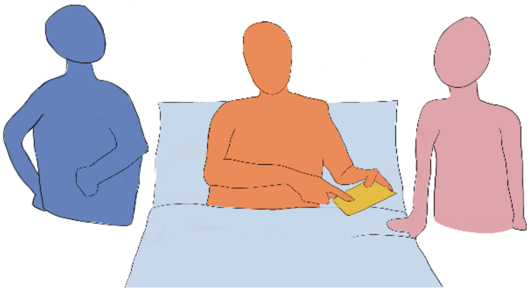
8. Patients can browse through the booklet to find suitable cards that support them or suit them. Medical staff can encourage them to take their time and choose whatever they would like to place in De Verhalenhoek. If they found a card they want, they can pick it out of the booklet.



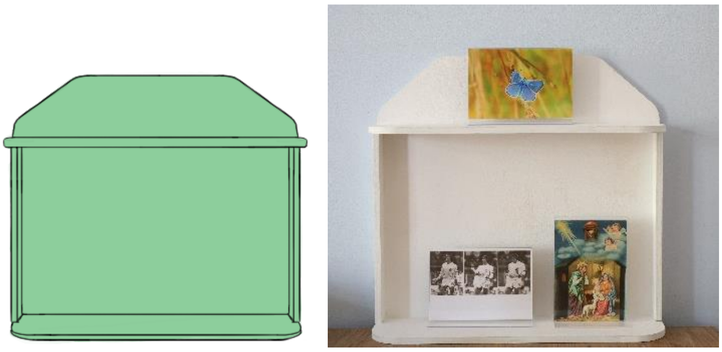
9. De Verhalenhoek is equipped with transparent photo frames, to invite patients to place cards or photos in the cabinet. When a patients chooses a specific card or item, medical staff or loved ones can help to place it in De Verhalenhoek.



10. If the physical cabinet of De Verhalenhoek cannot be implemented at a certain ward due to hygiene regulations, a digital personalization of the room is recommended. This can be done on the ipad in the room, instead of the cabinet. This ipad is equipped with the digital images of the cardbook to browse through, to create a virtual Verhalenhoek.



11. After personalizing their own Verhalenhoek, a conversation is initiated by medical staff about the specific elements. By talking about what they mean for this patient, it gives the patient a chance to be seen and heard. It gives the medical staff and loved ones a chance to better understand the needs and whishes of this patient.



12. A possible outcome of De Verhalenhoek: a patient room that is filled with a small personal touch of the patient. To make patients and loved ones feel more at home, in control and to create a lower barrier for difficult personal conversations between the medical staff and patients and loved ones.

5.4 Key aspects

Personalization and Autonomy

De Verhalenhoek allows patients to store personal items or belongings that hold special meaning for them. Patients can choose how and if they want to fill the cabinet, using either their personal items or selections from the Verhalen-toolkit. This can provide patients with a sense of autonomy and control over their space, which can enhance their comfort and make the environment feel more like home.

Invitation to Engage

The cabinet is designed to be an interesting and inviting object in the room, which can encourage patients and their loved ones to interact with it. It can offer a subtle invitation without pressure, respecting the patient's comfort level with using the cabinet.

Enhanced Comfort and Homeliness

By allowing patients to personalize their room, the concept can create a more comfortable and homely environment. Filling the space with familiar and meaningful elements can help patients feel more at ease.

Facilitating Conversations

De Verhalenhoek can serve as a conversation starter between patients, loved ones, and healthcare professionals. It can provide healthcare professionals with insights into the patient's identity and values, making it easier to connect on a personal level. The cabinet and its contents can be used to initiate sensitive discussions, such as the upcoming end-of-life process, by providing a reference point.

Emotional and Psychological

The concept can help reduce the emotional and psychological barriers that patients and their families might face during end-of-life phases. It can foster a supportive environment where meaningful interactions can take place, supporting in emotional well-being.

In conclusion, De Verhalenhoek has the aim to create a welcoming space by encouraging patients and their loved ones to place meaningful elements in the cabinet. Not only can this personalize the room, it can put stakeholders more at ease in the environment and it can facilitate meaningful conversations about sensitive topics between patients, loved ones and medical professionals.

5.5 Recommendations

User Interface Development

The current look and feel of the digital application have been designed for testing purposes, but the user interface is not yet fully functional for complete implementation on the iPad. It is recommended to collaborate with the Erasmus MC IT department to ensure the user interface is properly developed and integrated.

Integration with TV systems

Another recommendation is to implement a seamless connection between the application and the TV in patient rooms. This integration would allow chosen images to be projected onto the TV whenever the patient desires. The system could include a scheduling feature to automatically display images at set times and turn off when the patient wants to sleep.

Testing with a larger group of participants

It is crucial to test the card set and physical prototype with a larger group of participants, ideally real patients staying at Erasmus MC. For the card set, it is important to include participants of different ages, cultural backgrounds, and religious beliefs to ensure the images are inclusive and cater to different archetypes.

Exploring LED functionality

The second prototype included an LED light, enhancing the concept's functionality to improve personalization and ambiance in the patient room. Although this feature was not included in the final proof of concept, it has the potential to significantly enhance the patient's experience. Further research and design steps are recommended to explore the viability of incorporating LED lighting into this concept.

Accessibility and usability

The concept should be easy to detach or move from the wall for safety reasons, possibly allowing it to be placed in another spot in the patient room to have it closer to the patient.

Aesthetic and integration

The colors of the prototype should match the interior scheme, in Erasmus MC this could be a warm brown (as the door) or the green color of their patient room walls.

Hygiene and safety

Ensuring compliance with hygiene rules of the hospital is critical. Fire safety should be considered in the materials used in the design.

Durability

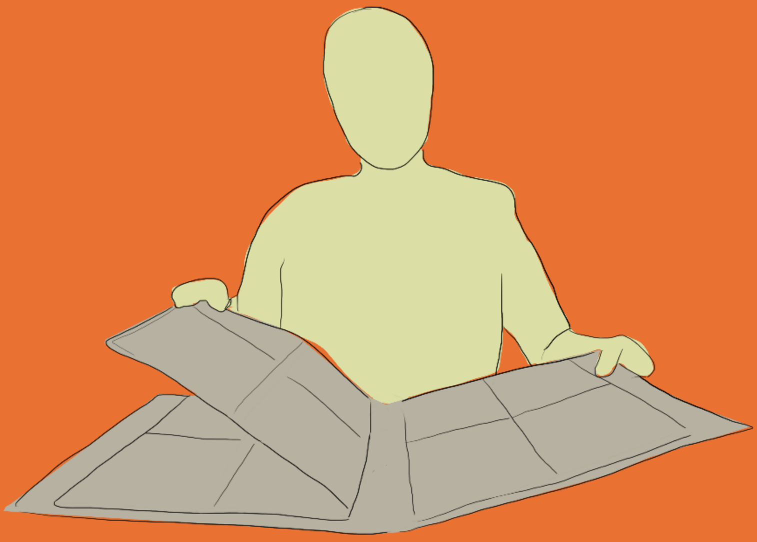
The cabinet should be able to withstand impact. It is recommended to implement a sturdy material choice that aligns with the design of the model.

Cultural Sensitivity

The card set and guidebook should be tested to ensure they can be used by users from different cultures and include cultural sensitivity, such as in the choice of the postcards. This should contain a wide range of religious and cultural symbols and images, avoiding a limited selection that might not cater to everyone's needs.

6. DISCUSSION

This chapter will provide a discussion on the thesis project as a whole. It will focus on the contribution of the research, the limitations of the research and design steps, future recommendations and lastly it will present a personal reflection on the project.



6.1 Contribution

This thesis project makes a contribution to the field of palliative care by introducing and refining the concept of De Verhalenhoek, a small cabinet designed to be placed in patient rooms at Erasmus Medical Center (Erasmus MC). This project, initiated as part of a collaborative effort between Erasmus MC and TU Delft, focused on improving the quality of end-of-life (EOL) care through design.

6.1.1 Importance of the Research

Raising Awareness and Attention

Palliative care is a critical but often under-discussed aspect of healthcare, particularly concerning the emotional and psychological needs of patients and their families during the EOL phase. By focusing on these aspects, this research brings much-needed attention to the importance of creating supportive environments that facilitate meaningful conversations about death and dying. It highlights the necessity of addressing not just the physical but also the emotional and psychological well-being of patients in their final days.

Encouraging Open Discussions

One of the design goals that followed out of the research was to encourage open discussions about death and dying. By providing a tangible tool like De Verhalenhoek, the concept offers healthcare professionals a way to initiate and navigate these sensitive conversations. This can help demystify the process of dying and reduce the stigma and discomfort often associated with discussing death. Such open communication is crucial for ensuring that patients' wishes are understood and respected, and that their final days are as comfortable and dignified as possible.

Inspiration for Future Research

This project serves as a foundation for further exploration into palliative care processes. It demonstrates the potential of design to improve EOL care and provides a framework for other students and researchers to build upon. By identifying key areas for improvement and proposing practical solutions, this research opens doors for future studies to continue enhancing the quality of palliative care. It encourages a multidisciplinary approach, combining design, healthcare, and psychology to create holistic solutions that address the complex needs of EOL patients and their families.

Contributions to Design and Healthcare Integration

The integration of design into healthcare settings is a relatively new but growing field. This research exemplifies how thoughtful design can make a substantial impact on patient care. De Verhalenhoek not only personalizes the patient room but also facilitates meaningful interactions between patients, loved ones and medical staff. This approach aligns with the broader goals of human-centered care, emphasizing the importance of considering the patient's psychological, spiritual and social needs alongside their physical health.

6.1.2 Foundation for Future Research

This research has laid a robust foundation for future studies by analyzing the needs and responsibilities of all stakeholders involved in the four palliative care phases. It has created a future vision with three design directions for enhancing EOL care:

- Improving communication and expectations
- Enhancing the autonomy of all actors involved
- Balancing the wishes of patients and resources of the medical team

De Verhalenhoek is an illustration of these directions, showcasing the potential impact of thoughtful design in palliative care. Future research could delve deeper into these specific sub-goals, exploring innovative solutions and further refining the concept.

Conclusion

De Verhalenhoek aims to create a welcoming space by encouraging patients and their loved ones to place meaningful elements in the cabinet. This personalization of the room helps stakeholders feel more at ease and facilitates meaningful conversations about sensitive topics between patients, loved ones, and medical professionals. This project highlights the potential of design to improve the emotional and psychological well-being of patients in their final days, making a significant contribution to the field of palliative care. It also serves as a foundation for other students and researchers to build upon, continuing to explore and enhance end-of-life care through innovative design solutions. By raising awareness and providing practical tools, this research has the potential to inspire further advancements in the compassionate care of patients at the end of their lives.

6.2 Limitations

This section will dive into several limitations that should be acknowledged within this research project. These limitations span various aspects of the research process, including participant demographics, participant scope, cultural representation, concept development and practical constraints. Addressing these limitations in future research will be crucial for obtaining a more comprehensive and representative understanding of the issues at hand and improving the applicability and effectiveness of the proposed concepts in the healthcare context.

6.2.1 Method

Participant Demographics

Interviews were exclusively conducted with women, which introduces a gender bias in the outcomes. The reason only women were interviewed is that they were the ones who responded to the call for participants willing contribute to this project. Furthermore, a significant proportion of nurses are women, which increased the likelihood of the respondents being women. This introduces another bias, as the findings might be more representative of female nurses' experiences. The women interviewed were all between the ages of 25 and 50 years old, which also limits the age diversity of the participants.

The limitation of gender means that the perspectives and experiences shared are solely reflective of women, potentially overlooking how men or non-binary individuals might experience or perceive the same issues. Consequently, the findings may not be fully generalizable across all genders. Additionally, the quantity of interviewed participants was quite limited, since only eight participants were formally interviewed.

Participant Scope

The interviews were limited to healthcare professionals and did not include patients or their loved ones, due to privacy regulations within the hospital setting. Applying for a student research permit to interview real patients and their loved ones on the ward could take months of administrative processing and would require approval from the Erasmus MC board. Given that this project only spans 20 weeks, the decision was made to focus on participants that could be interviewed without ethics committee approval: the healthcare professionals at Erasmus MC. This exclusion can lead to a significant gap in the collected data, as it does not take into account the firsthand experiences and insights of those directly receiving care or supporting those who do. The resulting data might lack a comprehensive view of the healthcare dynamics and the personal impact of healthcare practices.

Cultural Representation

The cultural representation of the interviewees was predominantly homogenous, with six out of eight participants being white women with a Western background. Only two participants openly identified as Muslim, while the other six did not share their religious background. This lack of cultural diversity may result in findings that do not fully capture the varied cultural perspectives and practices, potentially skewing the results towards the experiences and viewpoints of Western, white citizens. This limitation is particularly significant given that the project focuses on a hospital in Rotterdam, a multicultural city with a diverse population. The hospital's patients and their loved ones represent a wide range of cultural backgrounds, not just Western, white women.

6.2.2 Concept Development

Material Constraints

The development of the prototype for the designed concept was limited to woodworking in flat panels, with no possibilities for solid plastic fabrication, except for minor 3D printing capabilities. Additionally, the woodworking was done at the IDE campus at TU Delft, with a maximum thickness of the wood being 15mm. This restriction influenced the prototyping phase and functional aspects of the concept, potentially limiting its application or effectiveness in environments where other materials might be more suitable or necessary.

Concept as prototype

The concept was created primarily as a prototype to illustrate how the interaction and dimensions would function. As a result, it may not fully represent a finalized product or system, and additional considerations or modifications may be needed for a complete and operational version. The prototype serves more as a proof of concept rather than an end product. For example, the digital application is designed with a functional front-end interface, but the back-end technology has not yet been developed. Consequently, tests can be conducted to observe user interactions with the prototype, but it cannot be fully implemented without the necessary back-end programming. Similarly, the physical prototype is designed to demonstrate interactions, but alterations can be made to ensure it fits the specific healthcare facility.

Limited testing and prototyping time

The testing and prototyping phase for the concept was notably short, as the primary focus lay on the research aspect of the project. This limited time for testing and iteration may have resulted in a less robust or thoroughly evaluated prototype, where testing with the user group was not performed in the limited time.

Context visibility

The placement of the concept within the patient room was not tested yet, which is an important consideration in terms of visibility. The placement of the concept on the wall is crucial; if it is too far from the patient's bed, the elements inside the cabinet may not be visible to patients and therefore lose the intended purpose.

Hygiene Considerations

Hospitals have strict hygiene rules, and introducing new items into patient rooms is often met with resistance. This limitation constrained the design process, making it more challenging to design freely and creatively. This constraint is evident in the prototypes, where the focus is mainly on the physical aspects. This might not be the best approach given the strict hygiene regulations.

Human factors

Human judgment is a crucial requirement for this concept. In interactions that involve asking about personal aspects of a patient's life, medical personnel need to have the ability to gauge whether to probe further, assess the patient's emotional capacity to handle the conversation or determine if the patient has no interest in such questions. Additionally, they must be sensitive to the possibility that certain questions could evoke negative emotions.

These judgments are beyond the scope of what can be designed, as they depend on the interaction between two human beings. Each conversation between a healthcare professional and a patient can vary significantly, influenced by the unique perspectives and approaches of the individuals involved. This reliance on the emotional intelligence of medical personnel and the willingness of patients to engage with new approaches is a limitation of the design.

Sustainability Factors

Although the prototype does not use electronics, the materials used in the prototypes are not very sustainable. The environmental footprint was not considered in the material selection process, which is a limitation. Future iterations should focus on incorporating sustainable materials to minimize the ecological impact of the design.

6.3 Recommendations

To address the limitations identified in this research and to enhance the comprehensiveness and applicability of future research, several recommendations are proposed in this section.

6.3.1 Participant Demographics and Scope

Diverse participant pool

Future studies should involve a larger and more diverse participant pool, including men and non-binary individuals, to capture a broader range of experiences and perspectives. Expanding the age range of participants beyond 25 to 50 years old will also enhance diversity.

Inclusion of patients and relatives

Future research should include interviews with patients and their loved ones to gain firsthand insights and experiences. This will require navigating privacy regulations and obtaining necessary approvals, but it will provide a more comprehensive view of healthcare dynamics and personal impacts.

Cultural representation

Ensuring that the sample includes participants from various cultural backgrounds will help capture a wider range of perspectives and experiences. Engaging in conversations with the relatives of deceased patients and integrating the PATIO system at Erasmus MC, a space for cancer patients and their loved ones to share experiences, can enhance cultural diversity.

6.3.2 Concept Development and Implementation

Material Constraints

Future iterations of the prototype should explore the use of various materials beyond wood, such as plastics or other suitable materials, to enhance functionality and applicability. Developing a manufacturing plan to determine production quantity, suitable materials, and production location is essential for implementing the real concept.

Back-End Development

Future studies should develop the back-end technology for the digital application to enable full implementation and testing of the prototype. Alterations to the physical prototype should be made to fit specific healthcare facilities, ensuring the design meets practical requirements.

Extended Testing

Allocating more time for testing and development with a larger number of users will result in a more robust and thoroughly evaluated prototype. Future iterations should benefit from extended testing phases to address unforeseen issues and improve overall functionality and usability.

Context Visibility

Evaluating the optimal placement of the concept within patient rooms is crucial for ensuring maximum visibility and effectiveness. This should be done in the exact room where the concept will be implemented, considering appropriate dimensions. Tests should involve users from various age groups, particularly elderly patients with poorer eyesight.

Hygiene Considerations

Emphasizing digital solutions can help comply with stringent hospital hygiene standards. Digital prototypes can present fewer challenges and align better with cleanliness regulations, ensuring new designs can be implemented without compromising hygiene.

6.3.3 Implementation of the design

Material Choice

Carefully selecting materials for the concept's implementation is crucial to meet the practical needs and constraints of the healthcare environment. The following considerations should guide the selection process:

Durability and Longevity

Choose high-quality materials that are durable and can withstand rigorous cleaning and frequent use. Materials should resist damage to maintain the design's aesthetics and functionality.

Hygiene and Cleanability

Using non-porous materials that can withstand hospital-grade disinfectants without degrading, in order to easily clean and disinfect them.

Safety

Using non-toxic and hypoallergenic materials that are safe and unlikely to cause allergic reactions. Besides that, materials should meet fire safety regulations.

Aesthetic and Comfort

Materials and colors should be chosen that create a warm, inviting environment for patient and loved ones.

Sustainability

Eco-friendly options should be selected to reduce the ecological footprint and to promote sustainability within the hospital rooms.

Cost-effectiveness

Materials should be ensured to be cost-effective and fit within budget limits of Erasmus MC and readily available to adhere to timelines of a possible pilot implementation.

Pilot Study

Conducting a pilot study in a department at Erasmus MC will help evaluate the functionality and effectiveness of the concept. This can be especially beneficial in departments where patients have longer stays, such as hepatology, or in departments with a high number of patient deaths, to assess the concept's short-term impact. To execute this pilot study effectively, the following steps are recommended:

1. **Selection of Departments**

Long-Stay Departments: Departments such as hepatology, where patients typically have longer stays, can provide a comprehensive view of how the concept impacts patient well-being over an extended period.

High-Mortality Departments: Departments with a higher number of patient deaths such as oncology can help assess the emotional and psychological impact of the concept in more sensitive settings.

2. **Pilot Study Design**

The average ward at Erasmus MC has 16 patient rooms. For the pilot study, it is suggested that 8 of these rooms be designed with De Verhalenhoek concept. The remaining 8 rooms will serve as a control group, maintaining the standard room design without the concept.

3. **Evaluation and Measurement**

The pilot study should focus on testing the impact and interactions with the design. This involves observing how patients, loved ones and healthcare professionals interact with De Verhalenhoek and assessing any changes in patient well-being, engagement and end-of-life experience.

By comparing patient rooms with and without the design, differences in patient experiences can be measured. Metrics for comparison might include patient mood, levels of engagement, emotional responses, and overall satisfaction with the hospital stay.

Qualitative feedback should be collected from patients, loved ones and healthcare professionals to understand their experiences with the concept and gather suggestions for improvements. This feedback can provide valuable insights into how the concept can be refined and optimized for broader implementation.

4. **Longitudinal Assessment**

Conduct follow-up assessments to determine the long-term impact of the design on patient well-being. This can include periodic check-ins with patients who stayed in the rooms with De Verhalenhoek to gauge lasting effects on their mental and emotional health.

Based on the findings from this pilot study, a plan should be developed for scaling the concept to other departments and hospitals. This plan should address potential challenges and outline steps for training medical staff, managing logistical aspects and ensuring consistency in implementation. By conducting a thorough pilot study in a controlled environment, future research can gather essential data to refine the concept and ensure it meets the needs of diverse patient populations effectively. This approach will provide a robust foundation for expanding De Verhalenhoek across multiple healthcare settings, ultimately enhancing patient care and well-being in the End of Life phase.

6.4 Personal reflection

Throughout this thesis project, I have learned a lot about myself as a student and as a person. In this reflection, I would like to look back at the past 20 weeks and reflect on how I will leave my student time behind me.

Project Management

One of the most important lessons I learned was the value of zooming out and moving away from a strictly methods-driven, structured, and goal-oriented approach. Since I like a bit of structure and knowing what’s next, this was hard to let go of at times. Not knowing what’s next comes with insecurities about whether the outcome will be good enough. However, this project taught me that there is power in 'just' trying something based on intuition or a feeling. This flexibility allowed me to explore new ideas and approaches that I might have otherwise overlooked.

Lessons in conducting research with users

I learned to see participants as individuals rather than merely users. This shift in perspective helped me to better understand their unique needs, experiences, and emotions, enriching the depth and quality of my research.

Working in a professional setting and persuading busy healthcare professionals to participate in interviews was sometimes challenging. Especially in a healthcare setting, employees are busy and have more pressing matters than talking with a student. I learned that approaching people professionally takes time and patience, so once contact is made, all resources should be explored. The interviews I conducted with professionals led to valuable and insightful conversations that I would not want to have missed.

This experience brought me to my next insight: the joy I receive from collaborating with others. I hope to do more of this in the future because the passion of healthcare professionals for enhancing (palliative) care inspired me and gave me a new set of motivations to work with.

Communication

I learned that receiving unexpected feedback can be difficult to cope with, but it taught me the importance of adaptability. Learning to adjust my work based on feedback improved the overall quality of my project. Feedback is given with the right intentions, so I have learned to assess it and decide whether to incorporate it or set it aside.

Additionally, I learned that communication in larger projects is key. I have seen the advantages of planning meetings weeks ahead and aligning stakeholders with a plan for the upcoming weeks. I also learned that communicating your struggles is important. Throughout this project, there were moments when I doubted my design abilities, when in fact, I was just stuck. Communicating this with my coaches helped me realize that being stuck didn't mean I couldn't do it; it just meant I needed to find answers in a different direction. This was an important lesson for me.

Interest in Social Design

This project has solidified my interest in social design. Working on a project with such a meaningful social impact has been incredibly fulfilling, and it has inspired me to continue pursuing opportunities that have a societal impact. I am happy to have found an area in Industrial Design Engineering where I feel passionate and proud. When I started my Bachelor's at IDE seven years ago, I had no idea this field would captivate me so deeply.

I am grateful for the opportunity to work on a project that aims to make a meaningful difference in palliative care and I look forward to applying these lessons in my future endeavors.

7. CONCLUSION

This conclusion aims to present an overview of the thesis project, by answering research questions proposed in the Discover phase and present the outcomes of the design phase.

Conclusion

This TU Delft thesis project investigated the current state of palliative care in patient rooms at Erasmus MC and its effects on the people involved, specifically focusing on the End of Life (EOL) phase, 1-4 days before patients pass away in the patient room. The research followed the four phases of the Double Diamond method: Discover, Define, Develop, and Deliver. To structure the research, the following questions were proposed during the Discover phase:

Palliative care

1. *How is the palliative care structured at Erasmus MC?*
2. *How is the palliative care structured in care facilities outside of Erasmus MC?*

End of Life (EOL) journey at Erasmus MC

3. *What phases do individuals go through in the EOL journey at Erasmus MC?*
4. *Who are key actors involved in the EOL journey and what roles do they play in the different phases?*
5. *What are the needs of the individuals during these the phases of the EOL journey?*

Patient environment

6. *How is palliative care currently facilitated within patient rooms at Erasmus MC and how does this meet the needs of the involved individuals?*
7. *How are cultural, spiritual, and individual preferences considered and integrated into Erasmus MC's patient rooms during palliative care?*

In this conclusion, the research questions will be taken as a foundation on to where the design process is based. First, is explained how the research are answered and what insights it brought.

The Discover phase answered questions 1 and 2, providing insights into the structure of palliative care both inside and outside Erasmus MC. Palliative care in hospitals follows the four palliative care phases, where most patients have the option to be transferred to home, a care home, or hospice to spend their final moments. However, a significant number of 'unexpected' deaths still occur, making such transfers unfeasible due to time constraints or the patient's deteriorating condition.

Questions 3 to 7 were addressed through various research activities that analyzed the roles of stakeholders throughout the EOL journey in the hospital. It was found that each patient and loved one copes differently with the concept of death or dying. It is crucial for medical professionals to consider these different archetypes to provide tailored support.

A feeling of autonomy, clear expectations and communication are essential for patients and their loved ones. Healthcare professionals need to effectively communicate about the final phases of life and balance palliative care with curative treatments.

Combining insights from questions 3 to 7, a framework for the EOL journey was created, analyzing four stakeholders through four palliative care phases in Erasmus MC patient rooms. The framework outlines the needs and responsibilities of patients, loved ones, medical professionals, and the patient room. It emphasizes the diverse ways patients and their loved ones experience the EOL journey.

The framework presents the complexity of four palliative care phases:

1) the curative phase
2) the palliative care phase
3) the End of Life phase
4) the bereavement phase

After answering the research questions, the current state analysis led to the development of a future vision presented in the Define phase. This vision focused on three main design directions, each with respective sub-goals, and was visualized in an infographic to highlight future palliative care design opportunities at Erasmus MC.

The Develop phase involved creating a prototype to illustrate the use of design for future directions in patient rooms at Erasmus MC. Iterative design sprints and various design methods were used to create and evaluate the concept through different prototypes and creative feedback sessions.

The design and layout of patient rooms do not always reflect patient diversity or spiritual preferences, leading to unmet needs for personalization and better communication about these preferences during the EOL phase. More personalization possibilities that respect and honor individual backgrounds are necessary.

The Deliver phase presented a proof of concept: De Verhalenhoek. This concept aims to enhance end-of-life (EOL) care by providing patients with a personalized and comforting space in the patient rooms. De Verhalenhoek addresses the personal differences of patients and loved ones by inviting them to place meaningful elements in the cabinet. If this is not possible, a card set is provided for selecting personal, meaningful items to include in the cabinet. These items facilitate conversations between patients, loved ones, and medical staff about the values behind the items and preferences for the upcoming EOL phase.

In conclusion, the final proof of concept aims to accommodate elements of the design goal and the interaction qualities: providing a possibility for patients to personalize their room with meaningful elements, creating a more inviting environment where stakeholders can feel at ease. At the same time, these elements lower the threshold for medical staff to initiate conversations about personal aspects of the patient’s life. This can lead to meaningful discussions between patients, loved ones, and medical staff about their views on the EOL journey and the concept of death.

8. References

Building Better Healthcare. (2011, September). *The importance of design in the creation of end-of-life hospital environments*. https://www.buildingbetterhealthcare.com/news/article_page/The_importance_of_design_in_the_creation_of_end-of-life_hospital_environments/71234

CaringInfo. (2023, July 28). *Palliative Care vs. Hospice: Which to Choose - CaringInfo*. https://caringinfo.org/types-of-care/what-is-the-difference-between-palliative-care-and-hospice-care/#:~:text=Palliative%20care%20focuses%20on%20easing,receive%20this%20type%20of%20care%3F

Clark, D., & Centeno, C. (2006). Palliative care in Europe: an emerging approach to comparative analysis. *Clinical Medicine*, *6*(2), 197–201. https://doi.org/10.7861/clinmedicine.6-2-197

Clinic, C. (2024, March 19). *What's the difference between hospice and palliative care?* Cleveland Clinic. https://health.clevelandclinic.org/whats-the-difference-between-hospice-and-palliative-care

Design Council. (n.d.). *The Double Diamond - Design Council*. Retrieved March 27, 2024, from https://www.designcouncil.org.uk/our-resources/the-double-diamond/

Desmet, P., & Fokkinga, S. (2020). Beyond Maslow's Pyramid: Introducing a typology of thirteen fundamental needs for Human-Centered Design. *Multimodal Technologies and Interaction*, *4*(3), 38. https://doi.org/10.3390/mti4030038

Eijgenraam, S. (2011, November 2). *'Het draait om het leven'*. AD.nl. Retrieved May 8, 2024, from https://www.ad.nl/binnenland/het-draait-om-het-leven~ac34d306/?referrer=https%3A%2F%2Fwww.google.com%2F

Erasmus MC. (n.d.). *Over Erasmus MC - Erasmus MC*. https://www.erasmusmc.nl/nl-nl/pages/over-erasmusmc#aa34e9ff-54a5-42f8-a7f6-b1a63c99ca1a

Francké, A. L., & Kerkstra, A. (2000). Palliative care services in The Netherlands: a descriptive study. *Patient Education and Counseling*, *41*(1), 23–33. https://doi.org/10.1016/s0738-3991(00)00112-9

Galekop, M. M. J., Van Dijk, H. M., Van Exel, J., & Cramm, J. M. (2019). Views of professionals and volunteers in palliative care on patient-centred care: a Q-methodology study in the Netherlands. *BMC Palliative Care (Online)*, *18*(1). https://doi.org/10.1186/s12904-019-0479-5

Garrido, M. M., & Prigerson, H. G. (2013). The End-of-life experience: Modifiable predictors of caregivers' bereavement adjustment. *Cancer*, *120*(6), 918–925. https://doi.org/10.1002/cncr.28495

Keegan, L. (2017). The Golden Room: an innovative choice for end of life care (or) Changing the culture to allow for more end of life care options. *Nursing and Palliative Care*, *2*(1). https://doi.org/10.15761/npc.1000139

Lo, B., Quill, T. E., & Tulsky, J. A. (1999). Discussing Palliative Care with Patients. *Annals of Internal Medicine*, *130*(9), 744. https://doi.org/10.7326/0003-4819-130-9-199905040-00015

Ministerie van Volksgezondheid, Welzijn en Sport. (2020, December 18). *Monitor Palliatieve zorg 2020*. NZa-Magazines. https://magazines.nza.nl/nza-magazines/2020/03/monitor-pz-2020

Ministerie van Volksgezondheid, Welzijn en Sport. (2024, February 13). *Hospice*. Ongeneeslijk Ziek En Overlijden | Regelhulp - Ministerie Van VWS. https://www.regelhulp.nl/onderwerpen/zorg-in-laatste-levensfase/hospice

Palliaweb. (2022, February). *Behoefte aan palliatieve zorg nu per regio inzichtelijk*. https://palliaweb.nl/nieuws/2022/behoefte-aan-palliatieve-zorg-per-regio-inzicht#:~:text=Elk%20jaar%20sterven%20meer%20dan,zorg%2C%20de%20zogenaamde%20verwachte%20overlijdens.

Pollock, K. (2015). Is home always the best and preferred place of death? *The BMJ*, h4855. https://doi.org/10.1136/bmj.h4855

Stichting STEM. (n.d.). Retrieved May 15, 2024, from https://doodgewoonbespreekbaar.nl/ook-van-stem

Swami, M., & Case, A. A. (2018). Effective palliative care: what is involved? *ONCOLOGY (08909091)*. https://web.p.ebscohost.com/ehost/detail/detail?vid=0&sid=f12be58d-b810-4416-abc4-5c61e35cb662%40redis&bdata=JnNpdGU9ZWhvc3QtbGl2ZQ%3d%3d#AN=129092837&db=rzh

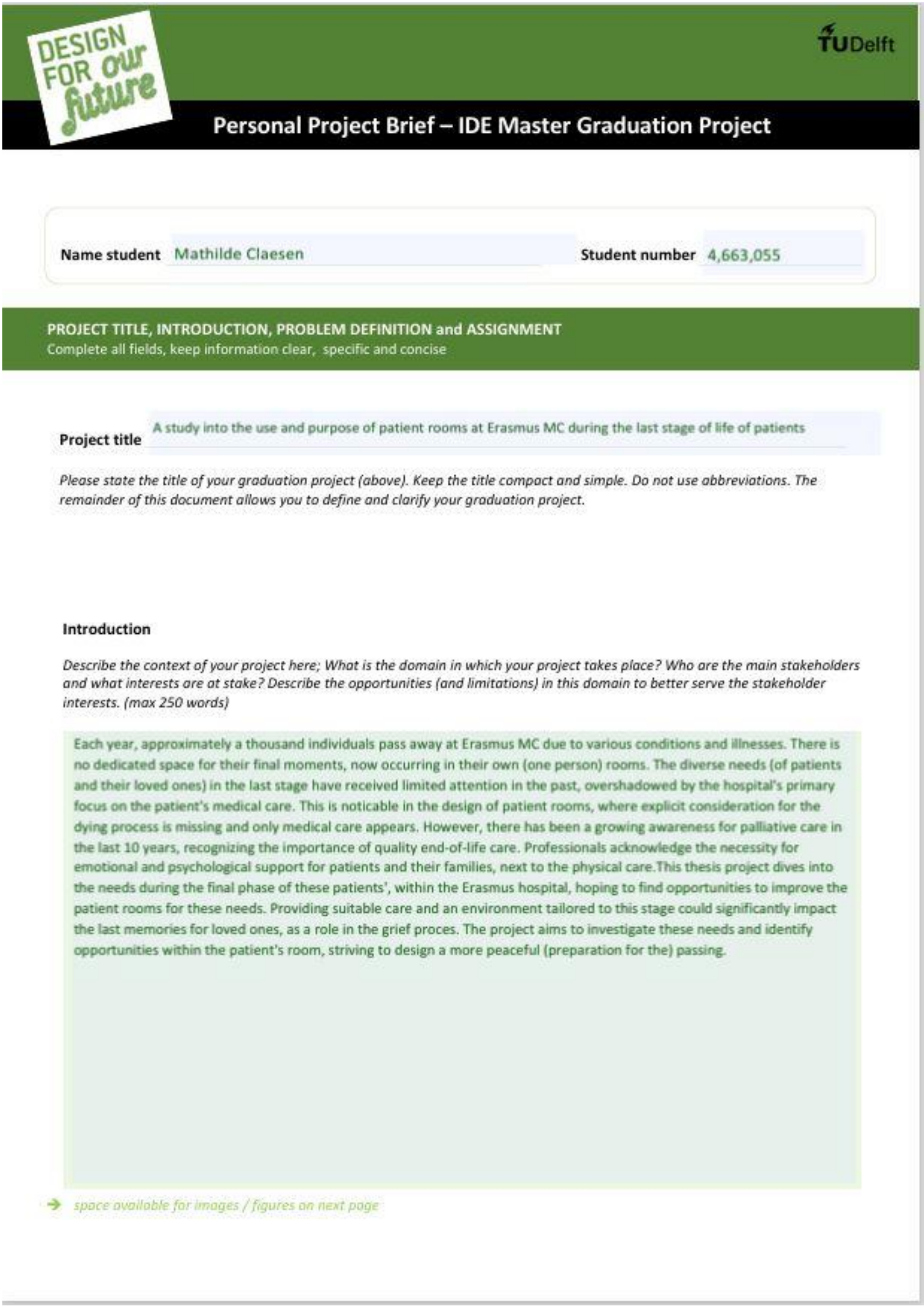
World Health Organization. (n.d.). *Palliative care* (pp. 3–9). https://cdn.who.int/media/docs/default-source/integrated-health-services-(ihs)/palliative-care/palliative-care-essential-facts.pdf?sfvrsn=c5fed6dc_1

World Health Organization: WHO. (2020, August 5). *Palliative care*. https://www.who.int/news-room/fact-sheets/detail/palliative-care

APPENDIX

A. Assignment Project Brief
B. Interview 1: Iris
C. Interview 2: Madelief
D. Interview 3: Rosalie
E. Interview 4: Anneke
F. Interview 5: Zoe
G. Interview 6: Lana
H. Interview questions hospices
I. Interview 7: Hospice Laurens Cadenza
J. Interview 8: Hospice Vier Vogels
K. Framework with needs and responsibilities
L. Infographic in full size
M. Infographic in full size in Dutch
N. Future vision explanation in Dutch
O. Design Goal and sub-goals in Dutch
P. Ideation phase
Q. Feedback session at Erasmus MC
R. Proof of concept
    a. Conversation guidebook in English
    b. Conversation guidebook in Dutch
    c. Card set, physical and digital
    d. Images of the final proof of concept

Appendix A: Assignment



DESIGN FOR our future

TUDelft

Personal Project Brief – IDE Master Graduation Project

Name student Mathilde Claesen **Student number** 4,663,055

PROJECT TITLE, INTRODUCTION, PROBLEM DEFINITION and ASSIGNMENT
Complete all fields, keep information clear, specific and concise

Project title A study into the use and purpose of patient rooms at Erasmus MC during the last stage of life of patients

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

Introduction

Describe the context of your project here; What is the domain in which your project takes place? Who are the main stakeholders and what interests are at stake? Describe the opportunities (and limitations) in this domain to better serve the stakeholder interests. (max 250 words)

Each year, approximately a thousand individuals pass away at Erasmus MC due to various conditions and illnesses. There is no dedicated space for their final moments, now occurring in their own (one person) rooms. The diverse needs (of patients and their loved ones) in the last stage have received limited attention in the past, overshadowed by the hospital's primary focus on the patient's medical care. This is noticable in the design of patient rooms, where explicit consideration for the dying process is missing and only medical care appears. However, there has been a growing awareness for palliative care in the last 10 years, recognizing the importance of quality end-of-life care. Professionals acknowledge the necessity for emotional and psychological support for patients and their families, next to the physical care.This thesis project dives into the needs during the final phase of these patients', within the Erasmus hospital, hoping to find opportunities to improve the patient rooms for these needs. Providing suitable care and an environment tailored to this stage could significantly impact the last memories for loved ones, as a role in the grief proces. The project aims to investigate these needs and identify opportunities within the patient's room, striving to design a more peaceful (preparation for the) passing.

→ *space available for images / figures on next page* *introduction (continued): space for images*

image / figure 1 The current one person patient rooms in Erasmus Medical Center

image / figure 2 Room to sit outside the patient room

Problem Definition

What problem do you want to solve in the context described in the introduction, and within the available time frame of 100 working days? (= Master Graduation Project of 30 EC). What opportunities do you see to create added value for the described stakeholders? Substantiate your choice.
(max 200 words)

Currently there is a gap in understanding what patients and their loved ones may feel lacking in the hospital/ patient room during the final stages of the patient's life or what specific needs they may have.

One of the hurdles in these understandings is the setting of a hospital, that comes with a set of regulations that need to be considered in the design process. To support the patients and loved ones with palliative care, involves consideration of the medical equipment in the patient room and adressing ethical and difficult questions. The challege is to seamlessly integrate more palliative care into the patients environment without interrupting the vital work of nurses, doctors and hospital staff. Which is why I see the hospital staff as an important stakeholder, next to the patients and their loved ones, to talk with to enhance the overall experience for all parties involved with the patient.
The primary focus of this project is to identify the common needs and turn them into opportunities. The interventions will be designed in the Erasmus Medical Center at the geriatric department, but should be also adaptable for implementation in other hospitals or departments, making it a sustainable solution that positively impacts end-of-life care across different healthcare settings.

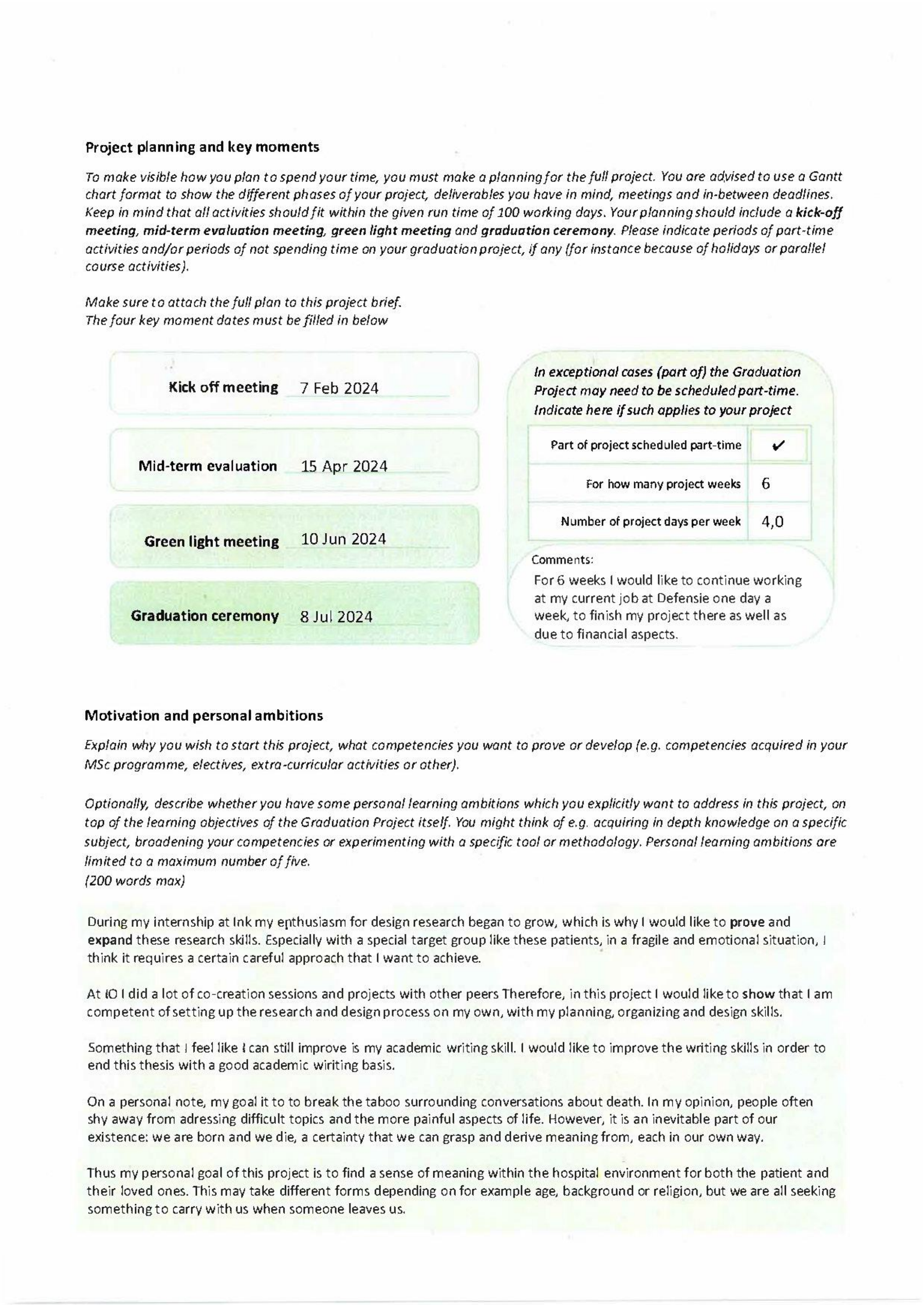
Assignment

This is the most important part of the project brief because it will give a clear direction of what you are heading for. Formulate an assignment to yourself regarding what you expect to deliver as result at the end of your project. (1 sentence)
As you graduate as an industrial design engineer, your assignment will start with a verb (Design/Investigate/Validate/Create), and you may use the **green text format***:*

Investigate the needs of patients on the geriatric ward in their last 1-4 days and the needs of their loved ones, and develop a vision in how patients can pass away peacefully in the patient rooms of the Erasmus Medical Center, and design an intervention to illustrate this vision to improve the experiences for patients and their loved ones.

Then explain your project approach to carrying out your graduation project and what research and design methods you plan to use to generate your design solution (max 150 words)

My project approach consists of 5 phases.
1: Determine the specific target group, followed by seeking approval from ethical comittee for research. Consists of:
desk research, literature review and conversations with medical experts to determine to which department/patients should (n't) be involved.
2.1 Research on the rules, restrictions and ethical dilemma's within EMC by desk research and interviews with medical staff.
2.2 Qualitative research on needs of patients and loved ones, to identify overlapping needs/struggles. Done through:
- Interviews with patients on the ward
- Interviews with their loved ones of patients and deceased patients
- Focus groups with nurses and medical staff from this ward, as well as experts of 'Pijn en palliatieve zorg' and patient panel. The interviews focus on the needs between families, as well as the purpose and structure of the current patient rooms.
3: Collect insights, cluster and find struggles and opportunities to design for the research questions.
4: Brainstorm and design phase of the vision, can be done in co-creation with medical staff or patients or by myself.
5: Validating phase, must be done within the hospital context.



Project planning and key moments

*To make visible how you plan to spend your time, you must make a planning for the full project. You are advised to use a Gantt chart format to show the different phases of your project, deliverables you have in mind, meetings and in-between deadlines. Keep in mind that all activities should fit within the given run time of 100 working days. Your planning should include a **kick-off meeting, mid-term evaluation meeting, green light meeting** and **graduation ceremony**. Please indicate periods of part-time activities and/or periods of not spending time on your graduation project, if any (for instance because of holidays or parallel course activities).*

Make sure to attach the full plan to this project brief.
The four key moment dates must be filled in below

Kick off meeting 7 Feb 2024

Mid-term evaluation 15 Apr 2024

Green light meeting 10 Jun 2024

Graduation ceremony 8 Jul 2024

In exceptional cases (part of) the Graduation Project may need to be scheduled part-time. Indicate here if such applies to your project

Part of project scheduled part-time	✓
For how many project weeks	6
Number of project days per week	4,0

Comments:
For 6 weeks I would like to continue working at my current job at Defensie one day a week, to finish my project there as well as due to financial aspects.

Motivation and personal ambitions

Explain why you wish to start this project, what competencies you want to prove or develop (e.g. competencies acquired in your MSc programme, electives, extra-curricular activities or other).

Optionally, describe whether you have some personal learning ambitions which you explicitly want to address in this project, on top of the learning objectives of the Graduation Project itself. You might think of e.g. acquiring in depth knowledge on a specific subject, broadening your competencies or experimenting with a specific tool or methodology. Personal learning ambitions are limited to a maximum number of five.
(200 words max)

During my internship at Ink my enthusiasm for design research began to grow, which is why I would like to **prove** and **expand** these research skills. Especially with a special target group like these patients, in a fragile and emotional situation, I think it requires a certain careful approach that I want to achieve.

At IO I did a lot of co-creation sessions and projects with other peers Therefore, in this project I would like to **show** that I am competent of setting up the research and design process on my own, with my planning, organizing and design skills.

Something that I feel like I can still improve is my academic writing skill. I would like to improve the writing skills in order to end this thesis with a good academic wiriting basis.

On a personal note, my goal it to to break the taboo surrounding conversations about death. In my opinion, people often shy away from adressing difficult topics and the more painful aspects of life. However, it is an inevitable part of our existence: we are born and we die, a certainty that we can grasp and derive meaning from, each in our own way.

Thus my personal goal of this project is to find a sense of meaning within the hospital environment for both the patient and their loved ones. This may take different forms depending on for example age, background or religion, but we are all seeking something to carry with us when someone leaves us.

Appendix B: Interview Iris

Datum: 11-03-2024
Onderwerp: "Patiëntenkamer sterfvriendelijk maken" – Masteronderzoek Mathilde Claesen
Interviewer: Mathilde Claesen
Geïnterviewde: Iris, verpleegkundige geriatrie in het ERASMUS MC

Rol van de Zorgmedewerker

Welke rol speel jij nu in de laatste dagen van het leven van een patiënt?

- Stervensbegeleiding zowel patiënt en familie, comfortabel maken en ervoor zorgen dat iedereen op de hoogte is van wat er gaat komen.
- In veel gevallen is er geen contact meer met de patiënt, dus dan is de familie aanspreekbaar. Ik vind het heel belangrijk dat zij weten wat er aan komt.
- Ademhaling gaat achteruit en is wel pijnlijk om te zien, het ziet eruit als lijden. Sommigen kiezen om dat 'lijden' niet te zien, en zijn dus niet bij het laatste stukje.

Welke rol heeft de familie?

- Aan het begin kunnen we vaak nog met patiënten praten, maar dat kan snel achteruit gaan, dan is de familie verantwoordelijk. Vaak hopen we dat ze weten wat de wensen van de patiënt zijn, zoals religie en hoeveel zorg we nog moeten verlenen.

Welke rol heeft de patiënt zelf hierin?

- Het is vaak te laat om dit soort dingen nog te bespreken, dus een erg kleine rol.

Wensen en Behoeften

Wat krijg je mee van wensen en behoeftes van patiënten in de laatste 1-4 dagen?

Wat vinden patiënten belangrijk? Wat vindt familie belangrijk?

- Bezoektijden aangepast, je kan 24/7 langskomen, blijven slapen gebeurt wel veel (50%). Ze wisselen elkaar vaak af.
- Familie wil ook in de ruimte ernaast zitten, zodat ze met elkaar kunnen opvangen. Veel overlap van bezoek, zo kunnen ze elkaar nog even zien en napraten. Niet te veel mensen in de kamer.
- De kamer iets aanpassen vindt familie fijn, nu kunnen we bijvoorbeeld een aparte stalamp neerzetten – maar dat is ook alles.
- Soms komt de hele familie en zijn ze het liefst er de hele tijd bij. Nederlandse families blijven niet tot het eind met zijn allen, iets afstandelijker.

Welke behoeften (van patiënten/naasten) zijn meer aanwezig in de laatste fase dan in het begin?

- Weinig patiënten die echt nog bij bewustzijn zijn, maar als je ze ervoor spreekt, is het vooral fijn als familie er vaak kan zijn. Ze vinden het fijn als er iets meer maatwerk wordt gegeven.
- Geen onnodige poespas in de terminale fase, zoals 'je moet je nu wassen of nu eten', regels worden iets losser gelaten. Comfortbeleid op alle facetten.

Praktische Details Kamer

Welke apparatuur/handelingen worden er nog gebruikt laatste 1-4 dagen?

- Pijnstilling, infuuspomp.
- Controlepaal wordt eruit gehaald. Voor de rest blijft alles zoals het is.

Richten familie/vrienden de kamer nu anders in, in de laatste momenten?

- Vaak zie je dat ze wat dingetjes meenemen, zoals een dekentje van thuis, eigen kussen. Dingen waar ze aan gewend zijn.
- Geen verschil naar deze fase: als het al in het ziekenhuis is, dan wordt het meegenomen.
- Familie neemt eigen spullen mee, bedbanken liggen niet echt fijn.

Omslagpunt tussen Leven en Sterven

Hoe ben jij betrokken bij het omslagpunt tussen de zorg om te leven en palliatieve zorg, om klaar te maken voor het sterven?

- Soms zie je – als we zelf de aanloop voelen – verpleegkundigen zien dit sneller dan artsen.
- Vanaf het moment van comfort, alles inzetten op het comfort en pijn verzachten, zie je dat de familie daar 100% op wil inzetten.
- Vanaf het omslagpunt vecht de familie dat het zo snel mogelijk gebeurt en comfortabel is.
- Het kan ook een opluchting zijn, als familie er zelf naar toe werkt. Dan zijn zij al verder in de fase.
- Bij de patiënt zelf: heel angstig, besloten om sedatie in te zetten. Die vrouw wilde zelf niet meer.

Verandert de houding van patiënt naar het personeel na het omslagpunt? En de houding van familie?

- Communicatie verandert; we gaan zelf meer het gesprek aan met familie, je hebt hun expertise dan echt gewoon nodig. In principe hoop je dat de patiënt weinig mee maakt van de stervensfase. Je bent bezig met dat de familie een mooi einde krijgt en mooie laatste herinnering heeft.
- Voor rouwverwerking heel belangrijk. Onze eigen attitude is daar heel belangrijk in. Familie uit dit heel erg.
- Voor familie en vrienden is dit ook een enorm omslagpunt in hun leven, dit blijft voor altijd bij ze.

Best Practices

Wat is de mooiste End of Life ervaring die je hebt meegemaakt?

- We hebben nog een koppelbed kunnen regelen, dezelfde dag overlijden. Hij was ook helemaal op. Heel fijn dat we dat hebben kunnen doen. Het was het idee vanuit hier, ze waren allebei op leeftijd en toen was het zo fijn dat we dit nog konden doen.
- Heel erg voelbaar dat ze elkaar misten, "dat gaat mijn vrouw verschrikkelijk vinden" zei hij. Ze moeten elkaar nog even kunnen vasthouden, anders dan vanuit rolstoel en bed. Zo'n bed moet je aanvragen, Daniel afdeling wel.

Heb je ook een minder fijne End of Life ervaring meegemaakt?

- Wanneer de stervensfase niet op tijd wordt opgemerkt, dan is iemand heel oncomfortabel komen te overlijden. De patiënt weigerde medicatie en er was geen goed plan. Er was geen familie bij, als mensen alleen moeten sterven.
- Het tijdig herkennen van de stervensfase en erkennen dat iemand niet meer kan genezen. Ook al heb je behandelopties, het gesprek van “wat als dit gebeurt” moet gevoerd worden, dat gebeurt niet altijd.
- Als de stervensfase niet op tijd erkend wordt en een gesprek over behandelopties nog niet is gevoerd, is het lastig om de verwachtingen van patiënt en naasten nog na te komen. Dit is heel pittig voor naasten, die ineens moeten schakelen en met veel verdriet zitten.
- In laatste 72 uur wordt het zorgpad stervensfase opgestart. Alles wat is besproken tot nu toe wordt daarin gezet zodat iedereen daarbij kan.

Brainstorm

Wat is volgens jou de ideale situatie voor een patiënt om zijn laatste dagen door te brengen?

- Iets meer ruimte om eventueel te schuiven, extra bed, stoelen erbij zetten. Slaapbank is gigantisch groot, heel lastig te verschuiven. Je moet echt verbouwen om iets te veranderen. Spulletjes op de afdeling hebben om het beter te maken.

Appendix C: Interview 2 Madelief

Datum: 11-03-2024
Onderwerp: "Patientenkamer sterfvriendelijk maken" – Masteronderzoek Mathilde Claesen
Interview met: Madelief, AIOS geriatrie

Rol van de Zorgmedewerker

Welke rol speel jij nu in de laatste dagen van het leven van een patiënt?

- Als AIOS: betrokken bij de zorg als dienstdoende (hiervoor word je gebeld) dokter of zaaldokter (doordeweeks dezelfde patiënten die onder jouw zorg vallen), zowel overdag als 's nachts.
- Verpleegkundigen staan het meest aan het bed, gevolgd door de dokters.
- Verpleegkundigen zien de patiënt het meest in de stervensfase.
- Zorgpad stervensfase: vastgelegd hoe vaak verpleegkundigen zaken moeten controleren. Wij streven naar drie keer per dag dat een dokter langsloopt. Je moet beschikbaar zijn als arts om langs te lopen als verpleegkundigen bellen.
- Verpleegkundigen hebben minder patiënten (2-3) terwijl artsen er 10-15 hebben, en tijdens een dienst 100 patiënten onder hun hoede.
- Mijn rol als verpleegkundige is om de patiënt te zien, het comfort te beoordelen en soms met de patiënt te praten – als dit nog kan.
- Wij hebben ook een belangrijke rol in het omslagpunt tussen zorg en sterven; door dit te benoemen en te bespreken met de familie. Dit houdt in het herkennen van symptomen, het maken van beleidsafspraken (stoppen van andere medicatie, fysiotherapie) en uitleg geven aan familie over wat ze kunnen verwachten.
- De meeste mensen maken dit niet vaak mee, dus het is fijn dat de familie weet waar ze aan toe zijn, zoals terminale onrust en de laatste ademhaling.

Welke rol heeft de familie?

- Sommige mensen zijn alleen, ik wil hen niet een te grote rol geven of iets opdringen. Voor de familie is dit de grootste overgang in het leven (het stervensproces). Sommige naasten vinden het juist heel fijn om betrokken te zijn en een rol te hebben, dus die geef ik een helpende, signalerende rol. Je merkt dat ze zich graag nuttig willen voelen en anders onrustig worden.
- Aanwezigheid voor de patiënt is belangrijk; soms weet je niet wat de patiënt nog meekrijgt. Het kan heel belangrijk zijn voor het rouwproces van de familie.
- Soms is de familie erg claimend naar de verpleegkundigen (altijd zorg vragen) of hebben ze nog nooit zoiets meegemaakt.

Welke rol heeft de patiënt zelf hierin?

- Meestal nihil. Voor het omslagpunt zijn er mensen die alles over zich heen laten komen, en anderen willen juist de regie pakken.
- Sommige mensen bereiden zich voor op de stervensfase, duidelijk wachtend op iets zoals de terugkomst van een familielid of een belangrijke gebeurtenis, waarna ze snel overlijden.
- Bij cognitief goede ouderen merk je dat ze naar het sterven toe kunnen leven. Sommigen ontkennen het (struisvogelpolitiek), maar als je het daarna aankaart breken ze nog harder.
- Ik ben een hele eerlijke dokter, dus ik probeer het toch aan te kaarten: "Ik denk dat u hieraan kunt overlijden. Hou daar rekening mee."
- Het herkennen van de dood is moeilijk en er zit veel spreiding in. Soms gebeurt er iets onverwachts, zoals dat een patiënt weer opleeft en de familie weer hoop krijgt.

Wensen en Behoeften

Wat krijg je mee van wensen en behoeftes van patiënten in de laatste 1-4 dagen?

- Veel mensen denken dat ze nog moeten eten en drinken, "maar dan heeft hij straks dorst". Ik begrijp dat dit binnen bepaalde culturen belangrijk is, zoals het vochtig houden van de mond.
- Er kan veel verschil zitten in hoe families omgaan met het sterven van een dierbare, dit verschilt ook per cultuur. Vaak zie je dat menselijk gedrag automatisch wordt aangepast: we dimmen het licht, de gordijnen gaan dicht en we praten zachter.
- Prikkelarme plekken zijn fijner omdat patiënten onrustig worden in drukke kamers.
- Weinig patiënten die echt nog bij bewustzijn zijn, maar als je ze spreekt is het vooral fijn als familie er vaak kan zijn. Ze waarderen ook maatwerk in de zorg.
- Geen onnodige poespas in de terminale fase, niet meer "je moet je nu wassen of nu eten", regels worden losser gelaten. Comfortbeleid op alle facetten.

Praktische Details Kamer

Welke apparatuur/handelingen worden er nog gebruikt in de laatste 1-4 dagen?

- Gordijnen dicht, verschillende vormen van verlichting kunnen worden aangepast. Medische apparatuur kan storend zijn.
- In mijn vorige ziekenhuis hadden we decoratieve items zoals planten en lampjes.
- Familie richt de kamer soms anders in met kaarten, knuffels, enz. De bedbank kan storend zijn.
- Familie blijft soms slapen. Eten en drinken mag op de kamer, maar roken en kaarsjes zijn niet toegestaan.
- Muziek kan worden afgespeeld via een JBL-boxje of televisie met radiofunctie, maar eigen muziek afspelen kan niet.

Omslagpunt tussen Leven en Sterven

Verandert de houding van patiënt naar jou na het omslagpunt? Verandert de houding van familie/vrienden naar jou na het omslagpunt?

- Zeker, de houding van loved ones verandert zichtbaar richting de laatste fase. Het contact wordt intiemer en zachter, een universeel teken is zachter gaan praten.

Verschillende Lagen Familie en Vrienden

Zie je verschillen in de houding tussen familie en goede vrienden?

- Partners en kinderen blijven het meeste, soms broers en zussen. Vrienden komen vaak langs om gedag te zeggen maar waken zelden.
- Cultuur afhankelijk: soms komt de hele familie langs. Bij Hindoestanen is iedereen welkom. Bij Turkse mensen zorgt vooral de directe familie, vrouwen doen veel zorgtaken.
- Generatieverschillen: steeds individualistischer. Vrienden worden zelf gekozen, familie betekent minder of heeft een andere rol.

Best Practices

Wat is de mooiste End of Life ervaring die je hebt meegemaakt?

- Als het goed gaat kan het enorm helpen voor de familie. Gehoord en gesteund voelen door zorgpersoneel, enorme dankbaarheid vanuit hun kant.
- Voor de patiënt: als het comfortabel is, is het gelukt.

Heb je ook een minder fijne End of Life ervaring meegemaakt?

- Soms lukt het niet om iemand comfortabel te krijgen, vooral bij verwarring of onrust. Veel pijnstilling kan mensen suf maken. COVID-patiënten die met slaapmiddel niet rustig werden, wat leidde tot verwarring en zuurstoftekort.
- Afwijkende ademhaling en reutelen zijn naar voor de familie om te zien.
- Familie heeft soms onrealistische verwachtingen die je niet kunt waarmaken, wat kan leiden tot frustratie en ruzie.

<u>Brainstorm</u>

Wat is volgens jou de ideale situatie voor een patiënt om zijn laatste dagen door te brengen?

- De patiënt mag prominent in de kamer zijn, maar hoeft niet opgebaard te liggen.
- Meer persoonlijke invulling mogelijk maken, zoals eigen dekbed meenemen.
- Koppelbed, maar niet elke afdeling is daarvoor geschikt.
- Verminderen van de ziekenhuissfeer, meer huiselijke en vertrouwde omgeving.
- Verbeteringen zoals dekbed en gordijnen, maar ook persoonlijke items kunnen toevoegen.
- Kamers zonder licht met groot foto behang, TV's met foto in lijst.
- Deur: moet transparanter zijn, zodat je kan zien wat er gebeurt.
- Badkamer met sloten voor veiligheid, maar met indicatielampje.
- Keukentje wordt door verpleegkundigen gebruikt voor opslag.

Appendix D: Interview 3: Rosalie (online via Microsoft Teams)

Datum: 21-03-2024

Onderwerp: "Patientenkamer sterfvriendelijk maken" – Masteronderzoek Mathilde Claesen

Interviewer: Mathilde Claesen

Geïnterviewde: Rosalie, verpleegkundige geriatrie Erasmus MC

Rol van de Zorgmedewerker

Welke rol speel jij nu in de laatste dagen van het leven van een patiënt?

- Ik ben verpleegkundige geriatrie bij het Erasmus MC
- Terminale patiënt heb ik in het verleden wel gedaan, nu niet altijd meer.
- Wij doen veel aan de lichamelijke verzorging
- We observeren of iemand comfortabel is, diegene pijn heeft of een droge mond.
- Bij onrustige patiënten zijn we alert en je zou dan stappen kunnen ondernemen voor sedatie.
- Tijdens avonden en nachten komen we ook langs, uitleg blijven geven aan de familie.

Welke rol heeft de familie?

- Interactiemomenten tussen verplegers en patiënten verschillen tussen palliatieve en terminale zorg, en ook tussen alle patiënten weer.

Omslagpunt tussen Leven en Sterven

Hoe ben jij betrokken bij het omslagpunt tussen de zorg om te leven en palliatieve zorg, om klaar te maken voor het sterven?

- Er is een andere interpretatie van het contact tussen arts en patiënt. Arts ziet de patiënt tijdens visite, maar hij/zij is er niet altijd tijdens het worstelen. Dat zien wij dan weer wel.
- Omslagpunt is heel persoonsafhankelijk en verschilt per familie en scenario.

Verandert de houding van familie/vrienden naar jou na het omslagpunt?

- Vaak is er door de familie gesproken met patiënten over hun wensen, dus dat communiceren zij dan weer naar ons.

Wensen en Behoeften

Wat krijg je mee van wensen en behoeftes van patiënten in de laatste 1-4 dagen?

- Patiënten en familie delen hun wensen als je er naar vraagt, maar er zijn geen formele afspraken die worden vastgelegd. Aangezien dit geen officiële stap is in de eerste fases, wordt het vaak niet goed behandeld.
- Verschillen per cultuur zijn ook groot hierin.

Appendix E: Interview 4: Anneke

Datum: 22-03-2024
Onderwerp: "Patientenkamer sterfvriendelijk maken" – Masteronderzoek Mathilde Claesen TU Delft
Interview met: Anneke Internist – Oncoloog Erasmus MC

Rol van de Zorgmedewerker

Welke rol speel jij nu in het ziekenhuis?

- Ik ben internist-oncoloog en werk wekelijks met oncologiepatiënten, waarbij ik betrokken ben bij de zorg van patiënten in de palliatieve fase.
- Ik ben betrokken bij de palliatieve zorgunit op de afdeling, waar we palliatieve zorgbedden hebben voor de meest complexe oncologiepatiënten. Eerder deed ik daar supervisie.
- Ik stuur het Pijn en Palliatie Team aan, een consultatieteam dat klinische consulten binnen het huis doet op het gebied van palliatieve zorg.
- Ik begeleid verpleegkundig specialisten in palliatieve zorg, die ook de poliklinische organisatie zien.
- Daarnaast ben ik betrokken bij de Netwerkgroep Palliatieve Zorg Embrace, waar we binnen het hele netwerk de palliatieve zorg proberen te verbeteren, vooral op het gebied van oncologie.

Welke rol speel jij nu in de laatste dagen van het leven van een patiënt?

- Ik werk binnen de tumor aandachtsgebied groep, waarin alle patiënten zich in de palliatieve fase bevinden.
- Als ik supervisie op de afdeling doe, zie ik de patiënten zelf ook.

Welke rol speelt familie in de laatste dagen van een patiënt?

- Tijdens de stervensfase mag de familie 24/7 aanwezig zijn, wat "rooming in" genoemd wordt. Dit geeft een andere betrokkenheid en dynamiek.
- Er zijn regels over hoeveel familieleden er op de kamer mogen zijn, maar daar wordt soms mee gesjoemeld, wat kan schuren met de verpleegkundigen die de ruimte nodig hebben om hun werk te doen.
- Sinds kort is er een koppelbed beschikbaar, dat aangevraagd moet worden met eigen financiering. Dat ligt dus aan de afdeling of ze dit aanvragen.

Betrokkenheid van de familie?

- De betrokkenheid verschilt heel erg per familie. Sommige familieleden maken zich enorme zorgen of zijn bang dat hun naasten ergens aan lijden. Meestal zijn dit familieleden die zich voor de stervensfase ook al zorgen maakten.

Patiëntreis: Wanneer begint de palliatieve fase?

- Volgens Erik Geijteman en het British Medical Journal zijn er verschillende trajecten voor ziekten en wanneer die palliatieve fase dan ook echt begint.
- De palliatieve fase begint eigenlijk bij het moment dat een ongeneeslijke ziekte is vastgesteld. Deze fase kan heel lang duren en het verloop is heel wisselend.

- Veel patiënten hebben ergens anders al gehoord dat ze kanker hebben, dan komen ze bij ons op spreekuur om palliatieve behandeling te krijgen met als doel: levensverlengend, behoud van comfort of verzachten van pijnklachten.
- Een klein deel van de patiënten wordt curatief behandeld bij ons, maar soms blijkt dat er uitzaaiingen zijn of dat curatieve behandeling niet meer mogelijk is.
- In Nederland vinden we dat palliatieve zorg een deel is van de generieke zorg, dus alleen bij complexe gevallen wordt echt de palliatief arts bijgehaald.

Verschillende Lagen (Patiëntreis)

Welke lagen personeel hebben we allemaal in het Erasmus MC voor patiënten in de palliatieve fase?

- Supervisie door fellow of staflid.
- Zaalarts; arts-assistenten (anios of aios).
    - Vaak jonge dokters die zich met name focussen op het medische stuk en vinden het vaak moeilijk om naar het hele plaatje te kijken.
    - Dokters zijn enorm opgeleid om te behandelen, maar palliatieve zorg moet breder zijn dan dat. Je hoopt dat artsen betrokken zijn met een bredere palliatieve kijk erop.
- Idealiter ook poliklinisch hoofdbehandelaar betrokken.
- Verpleegkundigen die patiënten zorgen op de afdeling.
- Supervisie: coördinerend verpleegkundigen palliatieve zorg.
    - Betrokken bij ernstig zieke patiënten die binnenkort komen te overlijden en worden ingeschakeld om mee te denken over coördinatie zorg.
    - Ook uitgebreide gesprekken met patiënt en naasten.
- Op aanvraag kan een geestelijk verzorger betrokken worden voor zingevingsvraagstukken of duidelijke geloofsovertuigingen die een rol spelen op het sterfbed.
- Medisch maatschappelijk werker voor ondersteuning in het systeem van de patiënt, als er ook ondersteuning nodig is voor naasten, familieleden of praktische vraagstukken op het gebied van werk, huisvesting, financiën.
- Fysiotherapeut, psychiater.

Omslagpunt tussen Leven en Sterven

Wanneer begint de terminale fase?

- De terminale fase is vaak heel kort. Zo'n 72 uur van tevoren.
- Het zorgpad stervensfase is een instrument waarmee je puntsgewijs stappen doorneemt die bespreekbaar moeten worden gemaakt in die laatste fase. Het is geen leidraad om het gesprek te voeren.

Wat gebeurt er nadat een patiënt is overleden?

- Het lichaam moet gekoeld worden en naar het mortuarium.
- De dokter wordt gebeld om te komen schouwen.
- Er is veel administratie, zoals overlijdenspapieren invullen.
- Obductie en donatie kunnen besproken worden.
- Nabestaanden condoleren.
- Het lichaam wordt verzorgd en daarna opgehaald naar het mortuarium.
- Verpleegkundigen weten deze regels beter, zoals na hoe veel uur dit moet gebeuren.

Terugkoppeling na de dood

- Nazorggesprek is in principe met verpleegkundigen, en als er wens is, met de hoofdbehandelaar/behandelend dokter.
- Hoofdbehandelaar/behandelend dokter wordt geïnformeerd, maar er zijn verder geen regels over condoleren of een gesprek aanbieden.
- De meeste artsen doen dit wel, maar de regie ligt bij de behandelend dokter.
- Op de oncologieafdeling sturen we een brief naar de nabestaanden op eigen initiatief. Andere afdelingen doen dit soms niet.
- Dit kan soms misgaan als je er niet bent of het je niet wordt verteld, bijvoorbeeld tijdens vakantie.

Twee Sporen Beleid

- Sommige artsen zijn bang dat zodra palliatieve zorg in beeld komt, dat ze het medische spoor willen stoppen.
- Er is een spanningsveld tussen artsen hierover, wat ik jammer vind.
- Dit leidt er vaak toe dat er te laat met patiënten wordt gesproken en nagedacht over "wat nu" als de patiënt er slecht aan toe is. Dan kun je het gesprek over wat er nu toe doet voor de patiënt bijna niet meer voeren omdat het te laat is.
- Bij grote visites is het waardevol dat palliatieve artsen erbij zijn. Artsen kijken naar meerdere problemen van één patiënt en bedenken hoe we per probleem kunnen helpen.
- Wat is het doel? Waar hoopt deze patiënt op? Mensen met uitgezaaide kanker die er slecht aan toe zijn na een chemokuur. Dan denk ik: zitten we nog op het goede spoor?

Slecht Nieuws Gesprek

- Na een slechte scan of klachten, of wanneer iemand onverwacht met complicaties komt.
- Het gesprek over “Wat doet er echt toe voor deze patient?”, los van het medische gesprek of medische details, wordt vaak niet behandeld. Dat is zonde.
- Vaak zetten we patiënten op het chemotraject, een keihard rijdende trein waar je bijna niet meer uit kunt stappen.
- Soms moet je stoppen en kijken of de trein nog de goede kant op gaat. Als het antwoord ja is, gaan we door. Maar die checkmomenten missen soms, waardoor we te ver doorgaan.
- Als de kwaliteit van leven achteruit holt, en iemand vraagt zich af of hij dit nog echt wil. Dan moet je je afvragen of de trein niet even moet stoppen. Dat gesprek moet meer gevoerd worden.
- Vragen worden te laat gesteld, of niet gedocumenteerd, wat een probleem is.

Advanced Care Planning – Proactieve Zorgplanning

- Is voor alle zorgverleners toegankelijk en veel overzichtelijker dan een lang dossier.
- Het is een manier om gestructureerd relevante informatie vast te leggen.
- Veel zorgverleners halen relevante informatie op die er echt toe doet, maar als we dat niet opslaan, kunnen we het niet terugvinden.
- In de proactieve zorgmodule kan je dit wel terugvinden, zodat je meteen ziet wat belangrijk is voor de patiënt. Wat zijn de wensen, doelen, waar hoopt deze persoon op?
- Als iemand goed kan verwoorden waarom hij/zij een bepaalde zorgaanpak wil, is dat belangrijk om te weten. Het helpt om keuzes te maken.
- Toestemming van de patiënt is onduidelijk, wel netjes.

- Documentatie is lastig omdat veel artsen maar een beetje meeschrijven en dit in het dossier zetten, wat weinig helpt op de spoedeisende hulp.
- Proactieve zorgplanning moet breder uitgerold worden, en we zijn bezig om dit te verbeteren.

Maakbare Maatschappij

- Het is toegenomen hoe mensen op de dood kijken vanuit een maakbare maatschappij. Mensen zeggen sneller: "Wat duurt het lang, kunnen jullie niet een spuitje geven, je laat je hond nog niet eens zo lijden."
- Het stervensproces wordt steeds meer gemedicaliseerd. Dat zie je ook aan de toename van palliatieve sedatie.
- Mensen weten niet goed hoe een sterfbed eruit ziet, of ze accepteren het niet. Ze willen het lijden niet zien.
- Sedatie mogen wij inzetten tegen het ondraagbare lijden, het moet een refractair symptoom zijn. Het is bedoeld als een laatste redmiddel, maar naasten willen het toch graag inzetten.
- Naasten zien het stervensproces vaak meer dan de patiënt zelf. Ze hebben een geromantiseerd beeld van overlijden en accepteren niet dat het langer duurt.
- Er is een tweestrijd tussen vechten om iemand beter te krijgen en niet het laatste beetje lijden willen zien.

Brainstorm

Wat is volgens jou de ideale situatie voor een patiënt om zijn laatste dagen door te brengen?

- Meer publieke bewustwording over het stervensproces, zodat mensen weten wat te verwachten.
- Mensen moeten kunnen overlijden waar ze willen, dat is meestal niet in het ziekenhuis, maar liever thuis of ergens anders.
- Passende zorg betekent dat je al met de patiënt bespreekt wat hij/zij wil; waar, wie wil je om je heen, wat voor zorg wil je, zodat dit tijdig kan worden toegepast.

Appendix F: Interview 5: Zoe

Datum: 15-03-2024
Onderwerp: "Patientenkamer sterfvriendelijk maken" – Masteronderzoek Mathilde Claesen
Interview met: Zoe

Rol van de Zorgmedewerker

Welke rol heb jij nu in het ziekenhuis?

- Ik zit in het 4e jaar van geneeskunde en doe mijn PDPC masteronderzoek.
- Ik werk op de HPB-afdeling, waar veel patiënten overlijden door leverziekten.

Heb jij een rol in de laatste dagen van het leven van een patiënt?

- Ik ondersteun de verpleging door bijvoorbeeld bloedsuiker te prikken.
- Ik heb patiëntencontact en help in de keuken met het rondbrengen van eten en drinken.

Culturele Achtergrond

Wat is jouw culturele achtergrond en hoe zou je omschrijven wat jij over de dood hebt meegekregen daaruit?

- Ik kom uit Afghanistan en mijn religie is de Islam. In onze cultuur geloven we in een hiernamaals.

Zie je verschillen in jouw familie en patiënten met een andere culturele achtergrond, in hoe zij kijken naar sterven in het ziekenhuis?

- In mijn familie en bij patiënten met een andere culturele achtergrond zie ik dat de wensen en behoeftes in de laatste 1-4 dagen variëren. Patiënten willen vaak zelf kiezen wat ze willen eten (wens dieet) en er is een voorzichtigere houding naar binnen, waarbij ik extra mijn best doe. Er is meer rust.

Zie jij een verschil in houding tegenover medisch personeel vanuit een andere cultuur?

- Ja, de houding is nauw verbonden met het geloof. Geloof is het belangrijkste.
- Ouders hebben een hele andere rol; ouders hebben voor ons gezorgd ons hele leven, dus zorgen wij ook voor hen. Bejaardentehuizen hebben een hele andere insteek, dat zouden wij niet doen.

Is er een verschil achter gesloten deuren (zonder staff)?

- Ja, er zijn verhalen van mijn opa waaruit blijkt dat de vader het gesprek met de arts voert en dat de regie bij de gezonden ligt. Zijn vader wilde dan niet dat mijn opa wist dat hij ziek was of misschien dood zou gaan.

Wat kan je me vertellen over rituelen bij de stervensfase?

- Sterven wordt gezien als een overgang naar een andere fase, niet als een einde.
- De Koran wordt gereciteerd.

Zijn er rituelen in het Erasmus MC die je kent?

- Soms komt er een priester langs en wordt er een bordje op de deur geplaatst. Verpleging weet dan dat de patiënt heel ziek is en er wordt extra zorg en aandacht aan de familie gegeven. Het is belangrijk dat iedereen dat weet.

Omslagpunt tussen Leven en Sterven

Heeft de patiënt regie of ligt de verantwoordelijkheid meer bij familie/naasten?

- De verantwoordelijkheid ligt vaak meer bij de familie en naasten.

Best Practices

Ben jij wel eens betrokken bij de laatste 1-4 dagen in iemands leven?

- Ja, ik ben betrokken bij de laatste dagen van patiënten.

Wat zou je nu willen veranderen aan de patiëntenkamer? Of denk je dat die goed functioneert?

- Als de deur dicht is, voelt het alsof je alleen bent. Alleen op de kamer hebben biedt privacy, maar aan de andere kant is er geen connectie met anderen zodra je de deur dicht doet.
- In Nederland is men meer individualistisch en houdt men afstand, het is een praktische benadering.
- In onze cultuur wil je mensen om je heen hebben, meer warmte om je heen. De deur zorgt voor een tweestrijd.

Welke onderdelen zijn volgens jou nog nodig in de laatste fase, als we kijken naar dit plaatje?

- Er moet iemand kunnen blijven slapen.
- Er moet ruimte zijn voor naasten en familie.

Aan welke 3 woorden moet een ‘sterfvriendelijke kamer’ volgens jou voldoen?

1. Raam/licht: zicht op het uitzicht.
2. Ruimte voor anderen op de kamer: niet willen kiezen tussen familieleden.
3. Gevoel: een bezinningsruimte om te bidden, rustgevend.

Wat zou er volgens jou veranderd moeten worden aan de kamer?

- De kamer is best wel saai, met witte muren, behalve als je zelf kaartjes krijgt.

Wat is volgens jou de ideale situatie voor een patiënt om zijn laatste dagen door te brengen?

- De ideale situatie voor een patiënt om zijn laatste dagen door te brengen, is omringd te zijn door familie. Dat is de laatste zegen. Het mentaal helder meemaken is een cruciaal moment aan het einde van het leven. Mens zijn betekent dat je verstand hebt.

Appendix G: Interview 6: Lana

Datum: 20-03-2024
Onderwerp: "Patientenkamer sterfvriendelijk maken" – Masteronderzoek Mathilde Claesen TU Delft
Interview met: Lana, medische studente ERASMUS MC

Rol van de Zorgmedewerker

Welke rol heb jij nu in het ziekenhuis?

- Ik heb geen klinische ervaringen. Ik studeer geneeskunde en filosofie.

Culturele Achtergrond

Wat is jouw culturele achtergrond en hoe zou je omschrijven wat jij over de dood hebt meegekregen daaruit?

- Ik heb een achtergrond in filosofie en geneeskunde, en ik kom uit een islamitische achtergrond.

Zie je verschillen in jouw familie en patiënten met een andere culturele achtergrond, hoe zij kijken naar sterven in het ziekenhuis?

- Ja, er zijn objectieve patiënten en gelovige patiënten. Er zit altijd een betekenis achter, ook als het niet als religie benoemd wordt. Iedereen heeft een geloof over wat er na de dood is, iedereen heeft wel een beeld hiervan. Nu is er een hele zwart-witte indeling in de zorg. Inclusievere zorg zou beter zijn.

Wat krijg je mee van wensen en behoeftes van patiënten in de laatste 1-4 dagen? Zie je verschillen per cultuur hierin?

- Het uitspreken van wensen helpt enorm. Stereotypes kunnen soms ook praktisch zijn. Als je dingen niet uitspreekt, is het voor een zorgverlener lastiger en zijn er meer blinde vlekken.
- "Je neemt altijd je persoonlijke identiteit mee naar je werk."

Praktische Details Kamer

Is er een verschil achter gesloten deuren (zonder personeel)?

- Er is een verschil in hoe graag mensen erbij willen zijn. Lijden is geen taboe in de islam; er is erkenning dat lijden inherent is aan het leven en dat er een beloning achter zit. Door zin te geven aan het lijden, is er meer acceptatie omdat je gelooft dat er nog iets na het leven komt.
- In Nederland is er veel maakbaarheid; mensen willen de touwtjes zelf in handen houden.

Omslagpunt tussen Leven en Sterven

Heeft de patiënt regie of ligt de verantwoordelijkheid meer bij familie/naasten?

- Het levenseinde is geromantiseerd. Het raakt mensen en kan mooi zijn, net als een bevalling. Het is heel belangrijk dat het einde wordt voorbereid door artsen.

Hoe kijk je naar de laatste fase?

- Als er medisch niets meer gedaan kan worden, vinden sommigen het niet meer nuttig om erbij te blijven. "Je kan toch niets meer doen."
- In de islamitische cultuur is er een holistische aanpak waarbij je nog veel kan betekenen, daarom blijven we erbij. Het laatste stukje 'glans' toevoegen is belangrijk. Je hele leven draait om die kern, waar het op het laatste moment op aankomt. Het is je laatste eindsprint met een beloning.
- In Nederland vragen mensen zich af waarom je nog een stap zou zetten als je toch niet meer beter wordt.

Brainstorm over de kamer

Aan welke 3 woorden moet een ‘sterfvriendelijke kamer’ volgens jou voldoen?

1. Privacy.
2. Huiselijke sfeer: een thuisgevoel, een setting die niet kil of steriel is.
3. Ingericht op meerdere mensen, zodat samen zijn gefaciliteerd wordt.

- De huidige kamers nodigen niet uit vanwege de hoogte en breedte; nu is het ongemakkelijk.
- Eerder genoemd: schoon geweten, tevredenheid, rust.

Wat is volgens jou de ideale situatie voor een patiënt om zijn laatste dagen door te brengen?

- Als je omringd kan zijn door familie, is dat je laatste zegen. Het mentaal helder meemaken is zo'n cruciaal moment aan het einde van je leven. Mens zijn betekent dat je verstand hebt.

Appendix H: Interview set-up for care facilities

Rol van de hospicemedewerker

- Welke functie heb je binnen het hospice?
- Kan je vertellen wat die rol inhield?
    - Hoe vaak was je in contact met patiënten?
    - Hoe zou je dit contact omschrijven? Formeel/informeel/
- Kan je me meenemen in het proces van als een patiënt gaat overlijden?
    - De aanloop; hoe worden wensen geuit?
    - Het overlijden; wie zijn er betrokken
    - Daarna?
- Welke rol speelde jij in de laatste dagen van het leven van een patient?
- Welke rol speelt de familie?
- Welke rol heeft de patiënt zelf hierin?

Praktische details

- Hoe lang liggen patienten gemiddeld in het hospice?
- Wat krijg je mee van de verplaatsing van ziekenhuis/huis naar hospice?

Wensen en behoeften

- Wat krijg je mee van wensen en behoeftes van patienten in de laatste 1-4 dagen?
    - Wat vinden patiënten belangrijk?
    - Wat vindt familie belangrijk?
    - Krijg je bepaalde concrete vragen of belangen mee?
    - Zie je verschillen per cultuur hierin?

Praktische details kamer

- Als ik het goed begrijp heeft elke patient zijn eigen kamer zonder medische apparatuur? hoe gaat de indeling van de kamer in proces? (is het vooral familie?)
    - Waar wordt rekening mee gehouden?
- [Welke apparatuur/handelingen worden er nog gebruikt laatste 1-4 dagen?]
- Richten familie/vrienden de kamer anders in, in laatste momenten?
    - Kaarten, knuffels, wat zie je voorbij komen?
    - Verschilt dit erg per cultuur, hoe zou je het samenvatten?

Omslagpunt tussen leven en sterven

Alhoewel het hospice is ingericht om te sterven, vraag ik me toch af of alle bewoners dit bewust meemaken. Hoe kijk jij daar tegenaan?

- Is er een bewust zijn of is er soms nog een omslagpunt tijdens het wonen in het hospice?

- Hoe was jij betrokken bij het klaar te maken voor het sterven)?
    - Verandert de houding van patient naar jou na het omslagpunt?
    - Verandert de houding van familie/vrienden naar jou na het omslagpunt?

Verschillende lagen familie vrienden

- Zie je verschillen in de houding tussen familie en goede vrienden?
    - Wie blijven er de hele tijd bij en wie komen (op een punt) afscheid nemen?
    - Verandert deze verhouding nog over de tijd?

Best practices

- Wat is de mooiste End of Life ervaring die je hebt meegemaakt?
    - (best practices, waar lag dit dan aan?)
- Heb je ook een minder fijne End of Life ervaring meegemaakt?
    - Waar lag dit aan? Wat ging er mis?

Brainstorm

- Wat is volgens jou het grootste verschil tussen in een zkhuis en hospice sterven?
- Wat zou met jouw ervaring de ideale situatie voor een patiënt om zijn laatste dagen door te brengen?

Appendix I: Interview7 with Laurens Cadenza

Datum: 06-03-2024
Onderwerp: Masteronderzoek Mathilde Claesen palliatieve zorg in Hospices

Welke functie heeft u binnen het hospice?

Ik ben in opleiding tot verpleegkundig specialist

Ik houd me bezig met het bieden van medische zorg aan de bewoners en ik ben verantwoordelijk voor het opstellen, uitvoeren en bijstellen van het zorgplan.

Hoe vaak ben je in contact met bewoners?

Dagelijks zie ik wel wat patiënten of ben ik in overleg over hun zorg. Ik ben verantwoordelijk voor de medische zorg en daarnaast probeer ik tijd door te brengen met de bewoners om te zien hoe het met ze gaat en wat hun behoeften zijn.

Hoe zou je dit contact met bewoners omschrijven?

Over het algemeen kan je het contact als laagdrempelig omschrijven. Ik probeer iedereen gelijk te behandelen en de zorg te geven die nodig is en waar behoefte aan is.

Met sommige bewoners heb ik een formele relatie vanwege de medische aspecten van mijn rol, maar met anderen bouw ik een informele band op door gesprekken en persoonlijke aandacht.

Kan je me meenemen in het proces van als een patiënt gaat overlijden?

- **De aanloop; hoe worden wensen geuit?**

Sommige bewoners zijn al bezig met het uiten van hun wensen, terwijl anderen minder proactief zijn en minder specifieke wensen kenbaar maken. Als bewoners bij het hospice komen verblijven, is er altijd een gesprek aan het begin van hun verblijf met zorgverleners en naasten. Hierin worden wensen en verwachtingen rondom het overlijden besproken.

Hier kan het personeel dan ook inspelen op de geuite behoeftes, door naar andere disciplines te kijken. Op het moment kunnen we bijvoorbeeld onder andere een muziek therapeut, maatschappelijk werker, geestelijk verzorger en fysiotherapeut ter beschikking stellen als dit gewenst is voor de patiënt.

- **Het overlijden; wie zijn er betrokken?**

Het verschilt wie er betrokken zijn, soms is er geen familie aanwezig en soms wel. Als iemand overleden is zorgen we ervoor dat iemand er netjes bij ligt. We doen niet de laatste zorg. Wel zorgen we voor een rustige sfeer op de kamer door deze wat op te ruimen en overbodige elementen weg te halen. Ook leggen we een mooi patchwork kleed op het bed. Verder steken we een kaarsje aan.

- **Wat gebeurt er na het overlijden?**

In principe wordt de overledene zo snel mogelijk opgehaald (ook zodat het lichaam goed gekoeld kan worden). De kamer moet in principe binnen 24 uur leeg zijn.

Welke rol heeft de patiënt zelf in de laatste 1-4 dagen?

Het uiten van wensen gebeurt vaak door de patiënt zelf, soms in overleg met de begrafenisondernemer of door het regelen van praktische zaken. Dit verschilt echter per persoon of ze hier mee bezig zijn of dat ze het overlijden ontkennen en er niet mee bezig willen zijn.

Hoe lang liggen patiënten gemiddeld in het hospice?

In sommige gevallen wordt het verblijf met 3 maanden verlengd. De gemiddelde duur dat mensen bij ons zijn is ongeveer 3 weken.

Wat krijg je mee van de verplaatsing van ziekenhuis/huis naar hospice?

Het verschilt heel erg hoe patiënten en naasten hierop reageren. Soms zie je dat naasten het gevoel hebben dat wanneer de patiënt bij ons is, hij of zij binnen een paar dagen overleden zal zijn. En anderen zien het juist als een opluchting, dat de patiënt nu in een rustige omgeving kan verblijven. Soms wachten mensen te lang met de overplaatsing, dat ze er dan eigenlijk weinig meer aan hebben. Zo'n overplaatsing is inspannend, dus als je daarmee wacht tot het laatst is dit ook heel vermoeiend voor de patiënt.

<u>Wensen en behoeften</u>

Wat krijg je mee van wensen en behoeftes van patiënten in de laatste 1-4 dagen?

- **Wat vinden patiënten belangrijk?**

Dit zijn dingen die meestal in het traject voor de laatste 1-4 dagen aan de orde komen. In de allerlaatste dagen is hier vaak geen energie meer voor.

- **Zie je verschillen per cultuur hierin?**

Ja zeker, er komen hier ook bewoners van meerdere culturen en je ziet dat families en vrienden ook anders naar de dood kijken. In bepaalde culturen zie je wel dat het gebruikelijker is om voor je naasten te zorgen.

<u>Praktische details kamer (inzichten opgedaan tijdens rondleiding)</u>

Notities:

Laurens Cadenza is een groter hospice met medisch personeel ter plekke, waardoor het in staat is uitgebreide medische zorg te bieden. Dit high-care hospice biedt een breed scala aan therapieën, een tuin, een grote eet-ruimte, een stilteruimte en artsen en verpleegkundig specialisten op locatie, in verschillende specialismes voor ondersteuning van patienten en naasten.

Het hospice heeft plek voor 20 bewoners en zit momenteel vaak vol.

Boven zijn er ruime kamers voor families om samen te komen, los van de eenpersoons patiëntenkamers. De gangen zijn breed en gevuld met veel natuurlijk licht. De kamers geven huiselijke comfort, met warme kleuren en houten details. In plaats van de typische witte ziekenhuisbedden worden er houten bedden gebruikt. De hoge plafonds en talrijke ramen dragen bij aan een gevoel van openheid, door het hele hospice heen. Over het algemeen heerst er een gevoel van welkom in de faciliteit, door de open ruimtes en kalme uitstraling.

Figure 2: Patient room in Hospice Laurens Cadenza Zuid (Laurens, 2024)

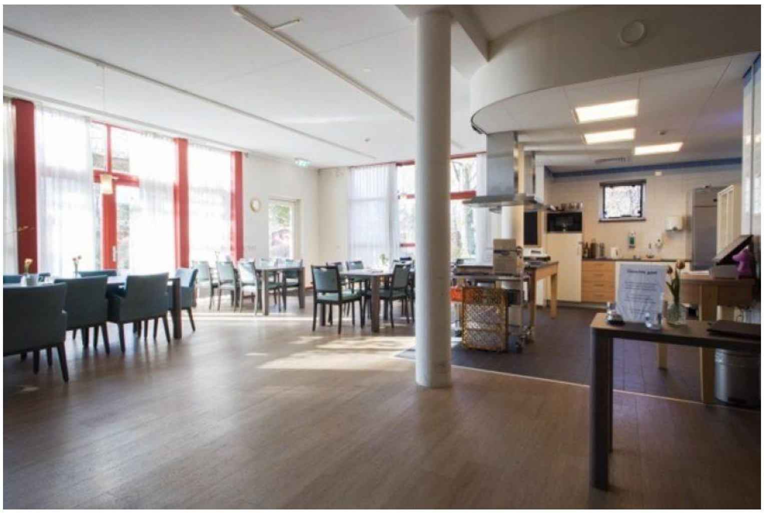


Figure 3: Dining area in hospice Laurens Cadenza Zuid (Laurens, 2024)

Appendix J: Quotes from Interview 8 at Vier Vogels hospice

Datum: 28-02-2024
Onderwerp: Masteronderzoek Mathilde Claesen palliatieve zorg in Hospices

Quotes interview 8 Vier Vogels

Contact met bewoners:

- Het verschilt heel erg per bewoner waar diegene behoefte aan heeft en of ze de hulp kunnen accepteren
- Het contact met verpleegkundigen is gebaseerd op vertrouwen, omdat zij echt de pijn verzachten. Veel gesprekken met de bewoners gaan ook over wat nog komen gaat qua pijn en afscheid.

Wensen en behoeftes bewoners:

- Bewoners zijn soms zelf al bezig met het inrichten of bedenken wat ze willen, maar er zijn ook bewoners die hier minder proactief in zijn, dan krijg je minder wensen mee.
- Het personeel is veel bezig met het waarmaken van bepaalde wensen qua inrichting van de kamer of elementen die de bewoner bij zich wil hebben.
- Er is een grote range tussen bewoners die veel zorg vragen, en bewoners die niet om hulp durven te vragen. de laatste groep heeft vaak aanmoediging nodig.

Cultureel aspect:

- In de Islamitische cultuur wordt iemand vrijwel meteen na het overlijden overgebracht naar de moskee. Andere culturele verschillen gaan over eten (naasten nemen hun eigen eten voor de bewoners mee) en wennen aan de regels in het hospice.

Inrichting kamer:

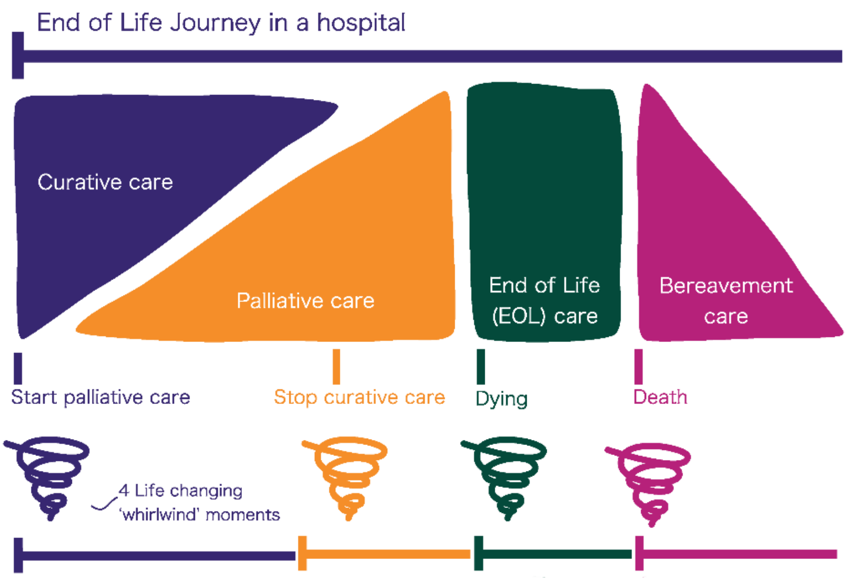
- De bewoner mag veel zelf bepalen wat betreft de opstelling van de meubels in de kamer. Vaak komen er foto's en kunst vanuit de familie mee de kamer in, dit is vaak geen hele nieuwe inrichting.

Ervaringen:

Sommige bewoners moeten wennen aan het aantal medewerkers die zij op een dag zien.

- Het is fijn als we alle wensen van de bewoner kunnen waarmaken zodat ze in rust kunnen gaan. Op een fijne, vriendelijke, geaccepteerde manier.

Appendix K: Framework needs and responsibilities End of Life journey



Needs:

through all phases: Physical, psychological and social care
Feeling heard and seen by medical staff
Having loved ones around for support

Coping with big changes of whirlwind moments
Feeling at ease to share personal needs and whishes about End of Life process

Having final whishes fulfilled
Passing away in a dignified way

Experience (cultural or religious) farewell rituals if desired

Responsibilities: Indicating personal needs and whishes about End of Life process

loved ones

Needs:

through all phases: Knowing that patient is heard and seen as an individual
Feeling heard and seen themselves
Being 'there' and coping with whirlwind moments

Fight for patients'care
Feeling at ease to communicate about personal needs and whishes of patient

Express sadness and mourn
Fulfill last whishes of patient

Fight for patient's comfort
Perform (cultural or religious) farewell rituals if desired by patient

Responsibilities: Giving psychological and social support to patient
Being the representative for patient when this is no longer possible for them

Arranging funeral and last care

medical staff

Needs:

through all phases: Knowing and documenting patient's personal needs and whishes
Having tools to facilitate conversations about sensitive topics
Providing suitable care and cure for the patient

Feeling at ease to communicate about needs and whishes of patient and loved ones

Creating a dignified End of Life for the patient

Responsibilities: Finding balance in care and cure
Monitoring and recognizing whirlwind moments for patient and loved ones
Preparing and supporting patient and loved ones for difficult journey ahead

Administrative tasks
Final physical care for patient
Offering support to loved ones

patient room

Needs:

through all phases: Being a sustainable environment for future use
Contributing to a dignified End of Life, by enhancing quality of death
Enabling visitors and medical staff to be at ease during their time in the room

Responsibilities: Facilitator of patients staying (for a longer period) in the hospital
Facilitator of medical staff providing physical care
Facilitator of visitors staying over and providing support

Facilitating a calming space
Facilitator of (cultural or religious) farewell rituals

Appendix L: Infographic in full size

The future of palliative care at EMC

Background context:

EMC "Koers 28"

EMC vision for 2024-2028 with 3 ambitions:

1 Strengthening tertiary, digital, and suitable patient care

- More focus on tertiary, complex care
- **Shaping suitable care through value-driven and human-centered care**
- Making care digitally accessible
- Focusing on preventing, shifting, or replacing care
- Efficient use of expensive medications
- Jointly shaping regional care pathways
- Strengthening internal interprofessional and multidisciplinary collaboration in the clinic

2 Solving societal challenges through scientific research

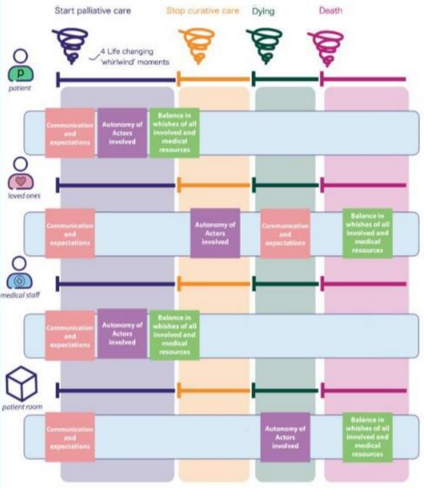
- Research into more accessible, efficient, and sustainable customized care
- Collaborating in the research chain for the valorization of new diagnostics and treatment
- Demonstrating the effectiveness of innovations for better health and care.
- Strengthening the ecosystem around research
- Bringing answers to research questions back to society

3 Investing in learning for the care of the future

- Distinctive education focused on innovation
- Future-oriented learning and development
- Providing an inclusive, stimulating, and safe learning environment
- Teaching as a valued core task
- Attention to societal issues in all curricula
- Increasing focus on interprofessional collaboration
- Intensifying regional collaboration with educational partners and healthcare providers

Future End of Life vision for EMC

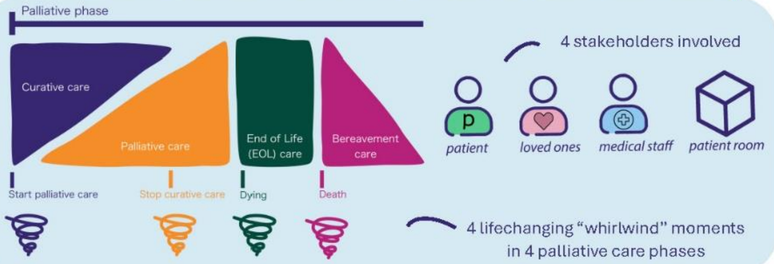
Goal: facilitating interactions in the palliative care to create a dignified last phase of life



Based on research and the "Koers 28" vision, this future vision illustrates insights on the needs of the involved actors in EMC's palliative care phases.

The vision consists of **3 design opportunities** that can improve the palliative care process together, and suggests design directions to pursue these opportunities.

Background: qualitative research into palliative care phases and needs



The Future Vision leads to a Design Goal

Design Goal: to facilitate a dignified End of Life experience for actors involved in the End of Life phase, in the patient rooms of EMC

The overarching design goal led to three design directions, each with their own respective sub-goals. Together, these design directions are the foundation to achieve the design goal.

Foundation for future design directions

with sub-goals:

Communication and expectations

Creating understanding of what death and dying means to each patient in the EOL process

Aligning expectations for the end-of-life journey among all stakeholders involved

Aligning expectations of the dying process between loved ones and the medical staff

Understanding and respecting patients' intrinsic motivations in the EOL process

Creating a welcoming space that invites stakeholders to communicate in the EOL process

Autonomy of Actors involved

Recognizing and respecting unique wishes and needs.

Preparing and supporting loved ones for intense emotional moments in the EOL process

Supporting medical staff in maintaining autonomy while empowering patients and loved ones

Creating a space that supports autonomy for all stakeholders involved

Balance in whishes and resources of medical team

Integrating equal palliative care perspectives into shared decision-making

Involving patient and loved ones in decision-making and discussions about intrinsic motivations

Documenting patient motivations to support holistic care advocacy

Continuing to support loved ones after death by providing closure to the process

Infographic in Dutch in full size

Toekomstvisie over palliatieve zorg in EMC

Achtergrond:

EMC "Koers 28"

EMC visie voor 2024-2028 in 3 ambities:

1 Versterken tertiaire, digitale en passende patiëntenzorg

- Meer focus op tertiaire, complexe zorg
- **Passende zorg vormgeven door waardegedreven en persoonsgerichte zorg**
- Digitaal toegankelijk maken van alle zorg
- Inzetten op voorkomen, verplaatsen of vervangen van zorg
- Doelmatig gebruik van dure geneesmiddelen
- Gezamenlijk vormgeven van regionale zorgpaden
- Verstevigen interne interprofessionele en multidisciplinaire samenwerking in de kliniek

2 Oplossen van maatschappelijke uitdagingen door wetenschappelijk onderzoek

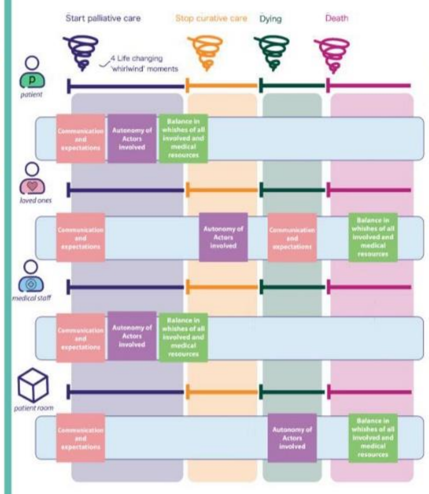
- Onderzoek naar meer toegankelijke, doelmatige en duurzame zorg op maat
- Samenwerken in de onderzoeksketen voor valorisatie van nieuwe diagnostiek en behandeling
- Effectiviteit aantonen van innovaties voor betere gezondheid en zorg
- Versterken ecosysteem rond onderzoek
- Antwoorden op onderzoeksvragen terugbrengen naar de maatschappij

3 Investeren in leren voor de zorg van de toekomst

- Onderscheidend onderwijs gericht op innovatie
- Toekomstgericht leren en ontwikkelen
- Een inclusieve, stimulerende en veilige leeromgeving bieden
- Docentschap als gewaardeerde kerntaak
- Aandacht voor maatschappelijke vraagstukken in alle curricula
- Vergroten van aandacht voor interprofessionele samenwerking
- Intensiveren regionale samenwerking met onderwijspartners en zorgaanbieders

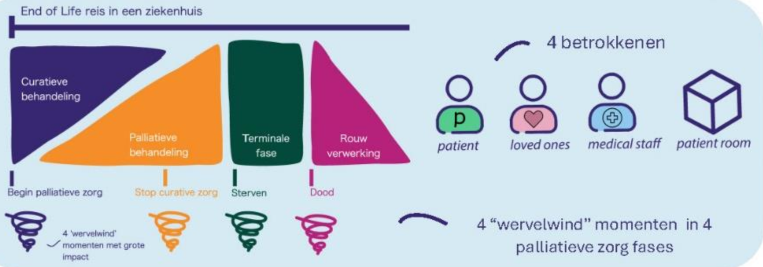
Toekomstvisie laatste levensfase in EMC

Doel: het faciliteren van interacties in de palliatieve zorg om een waardige laatste levensfase te creëren



Gebaseerd op de "Koers 28"-visie en onderzoek, geeft deze toekomst visie inzicht in de behoeften van de betrokkenen in de palliatieve zorgfases van EMC. De visie bestaat uit 3 elementen, die samen het palliatieve zorgproces kunnen verbeteren, en stelt ontwerprichtingen voor om deze kansen na te streven.

achtergrond: kwalitatief onderzoek naar palliatieve zorg fases en behoeftes



De toekomstvisie lijdt tot een ontwerp doel:

Ontwerpdoel: het faciliteren van een waardige End of Life-ervaring voor betrokkenen in de End of Life-fase, in de patiëntkamers van EMC.

Het overkoepelende ontwerpdoel leidde tot drie ontwerprichtingen, elk met hun eigen respectieve subdoelen. Samen vormen deze ontwerprichtingen de basis om het ontwerpdoel te bereiken.

De basis voor de ontwerp richtingen

met doelen:

Communicatie en verwachtingen

Inzicht creëren in wat sterven betekent voor elke patiënt in het End of Life-proces.

Verwachtingen afstemmen voor de End of Life-reis onder alle betrokken stakeholders.

Verwachtingen afstemmen van het stervensproces tussen dierbaren en het medisch personeel.

Begrip en respect voor de intrinsieke motivaties van patiënten in het End of Life-proces.

Een ruimte creëren die stakeholders uitnodigt om te communiceren in het End of Life-proces.

Autonomie van de betrokkenen

Unieke wensen en behoeften erkennen en respecteren.

Dierbaren voorbereiden en ondersteunen voor intense momenten in het End of Life-proces.

Het medisch personeel ondersteunen in het behouden van autonomie tijdens zorgprocessen.

Een ruimte creëren die autonomie ondersteunt voor alle betrokken stakeholders.

Evenwicht in wensen en middelen van het medisch team

Gelijke palliatieve zorgperspectieven integreren in gezamenlijke besluitvorming.

Patiënten en dierbaren betrekken bij besluitvorming en discussies over intrinsieke motivaties.

Patiëntmotivaties documenteren ter ondersteuning voor holistische zorg.

Dierbaren blijven ondersteunen na overlijden door afsluiting van het proces te bieden.

Appendix M: Future vision explanation in Dutch

Toekomstvisie over de Palliatieve Zorg in het Erasmus MC in de laatste levensfase, ontworpen om te bespreken met toekomstige stakeholders.

“Waar veel onzekerheden bestaan, zijn ook altijd kansen.” (Erasmus MC, n.d.)

In de toekomstvisie voor 2024-2028 "Koers28", laat het Erasmus MC zien hoe ze in de aankomende vijf jaar om wil gaan met verschillende maatschappelijke uitdagingen binnen de zorg. Binnen de Koers staan drie ambities centraal, waarvan één het versterken van tertiaire, digitale en passende patiëntenzorg. Het Erasmus MC wil naar een toekomst in de zorg waarbij behandelingen in samenspraak met de patiënt worden overlegd en waar wederkerige communicatie centraal staat, gericht op het verbeteren van zowel de fysieke als emotionele welzijn van patiënten.

De integratie van deze genoemde benaderingen is cruciaal om een creatief veld te openen over hoe deze interacties ontworpen kunnen worden, aangezien dit tot op heden nog niet is geuit in tastbare concepten. Hierop gaat de onderstaande toekomstvisie voor de palliatieve zorg in het Erasmus MC op door, door de principes van passende zorg te omarmen en uiteenzetten.

Deze toekomstvisie illustreert dan ook potentiële handvaten voor de innovatie binnen de zorg die bij de huidige visie van het Erasmus MC passen en inspelen op behoeften van de betrokkenen in de laatste levensfase van een patiënt in het Erasmus MC.

De visie is gebaseerd op vier fundamentele pilaren: balans tussen curatieve en palliatieve zorg, communicatie, besluitvorming en het kijken naar de betrokkenen als individu’s, geanalyseerd in het thesis-onderzoek over de palliatieve zorg binnen het Erasmus MC.

Het onderzoek heeft de palliatieve zorg in vier fasen verdeeld. Elk van deze fasen heeft zijn eigen specifieke behoeften en uitdagingen, die een gerichte aanpak vereist voor het leveren van passende zorg per betrokkenen. Door deze fasen te identificeren, kunnen gerichtere zorgstrategieën worden ontwikkeld die zijn afgestemd op de persoonlijke behoeften en wensen van de betrokkenen in elke fase.

1. Balans tussen Curatieve en Palliatieve Zorg:

a. Het ERASMUS MC streeft naar een geïntegreerde aanpak waarbij curatieve en palliatieve zorg in evenwicht zijn, zodat discussies tussen medisch professionals de gelijke prioriteit van beide behandelsporen weerspiegelen, waarbij rekening gehouden wordt met emotioneel welzijn en kwaliteit van leven.

b. De focus op intrinsieke motivatie tijdens ziekenhuisverblijven wordt versterkt, waardoor medische professionals effectiever kunnen pleiten voor palliatieve zorg, vooral tijdens kritieke overgangen zoals overgangen naar de intensive care of in andere noodgevallen. Door betere documentatie van deze behoeften en wensen is er meer ruimte voor betekenisvolle gesprekken over leven, dood en persoonlijke waarden, tussen medisch professionals, patiënten en naasten. Hierdoor kunnen patiënten in hun kracht worden gezet en beter worden voorbereid op het proces van levenseinde (EOL).

c. Het Erasmus MC biedt ondersteuning aan naasten na het overlijden van een patiënt als kernonderdeel van de palliatieve diensten, om te voldoen aan de holistische behoeften van geliefden na het overlijden van de patiënt en dit deel van de zorg goed af te sluiten.

2. Communicatie:

a. Communicatiestrategieën zijn nodig om een diepgaand begrip tussen patiënten en medische professionals mogelijk te maken over wat de dood voor elke betrokkenen betekent, waarbij hun intrinsieke motivaties worden benadrukt.

b. Verwachtingen tussen naasten en medisch personeel met betrekking tot het stervensproces worden afgestemd om spanningen en emoties als angst en woede te verminderen in het laatste deel van het leven, wat een begrip voor de natuurlijke aspecten van sterven kan bevorderen.

c. Het Erasmus MC streeft ernaar de verwachtingen voor de End Of Life-reis tussen patiënten, hun naasten en medisch personeel te synchroniseren, door betere communicatie kunnen misverstanden worden geminimaliseerd en emotionele stress over niet weten wat iemand kan verwachten worden verminderd.

d. De Patiëntomgevingen streeft ernaar om stimulatie tot communicatie uitstralen om de algemene communicatie te ondersteunen, waarbij patiënten kamers ingericht worden om patiënten en hun families op hun gemak stellen gedurende hun verblijf.

3. Besluitvorming:

a. Het Erasmus MC zet zich in om de processen van ‘shared decision making’ te verbeteren, waarbij wordt gewaarborgd dat alle beslissingen de wensen van de patiënt weerspiegelen en medisch professionals zijn geïnformeerd door een grondig begrip van hun motivaties. Deze aanpak zal de timing en relevantie van beslissingen verbeteren, waardoor de autonomie en waardigheid van de patiënt behouden blijven.

4. Autonomie van Actoren / Kijken naar het Individu

a. Het erkennen en respecteren van de unieke voorkeuren en behoeften van elk individu kan de huidige spanningen aanpakken die voortkomen uit gevoelens van afhankelijkheid en gebrek aan controle. Bij patiënten en naasten kan deze focus leiden tot een gevoel van autonomie en kracht.

b. Ook geliefden zullen worden erkend als cruciale individuen tijdens het zorgproces, waarbij ondersteuning wordt geboden die hen helpt zich voor te bereiden op intense emotionele momenten.. Deze ondersteuning om hen gewaardeerd en comfortabel te laten voelen strekt zich uit tot en met de rouwperiode, waardoor de spanningen tijdens en na het EOL-proces worden verminderd.

c. Het ontwerp van patiëntenkamers bij Erasmus MC legt meer nadruk op comfort en privacy om te voldoen aan de behoeften van de patiënten en naasten. Het ontvangen van meerdere bezoekers en het versterken van privacy is een ondersteunend onderdeel van de zorg waar veel betrokkenen respect en rust door kunnen ervaren in het levenseinde.

Appendix N: Design Goal and Sub-goals in Dutch

Ontwerpdoelen en sub-doelen in het Nederlands

De basis voor de ontwerp richtingen

met doelen:

Communicatie en verwachtingen

Inzicht creëren in wat sterven betekent voor elke patiënt in het End of Life-proces.

Verwachtingen afstemmen voor de End of Life-reis onder alle betrokken stakeholders.

Verwachtingen afstemmen van het stervensproces tussen dierbaren en het medisch personeel.

Begrip en respect voor de intrinsieke motivaties van patiënten in het End of Life-proces.

Een ruimte creëren die stakeholders uitnodigt om te communiceren in het End of Life-proces.

Autonomie van de betrokkenen

Unieke wensen en behoeften erkennen en respecteren.

Dierbaren voorbereiden en ondersteunen voor intense momenten in het End of Life-proces.

Het medisch personeel ondersteunen in het behouden van autonomie tijdens zorgprocessen.

Een ruimte creëren die autonomie ondersteunt voor alle betrokken stakeholders.

Evenwicht in wensen en middelen van het medisch team

Gelijke palliatieve zorgperspectieven integreren in gezamenlijke besluitvorming.

Patiënten en dierbaren betrekken bij besluitvorming en discussies over intrinsieke motivaties.

Patiëntmotivaties documenteren ter ondersteuning voor holistische zorg.

Dierbaren blijven ondersteunen na overlijden door afsluiting van het proces te bieden.

Appendix O: Ideation phase

The ideation phase started with the design goal:

"To create a patient room that supports actors in the End of Life process in facilitating a dignified end of life experience"

And two sub-goals:

- Creating a welcoming space that puts patients and their families at ease
- Creating understanding of what death means to each patient in the EOL process

Various methods are used in the ideation process. To start, an analogy was created as a source of inspiration, together with interaction qualities.

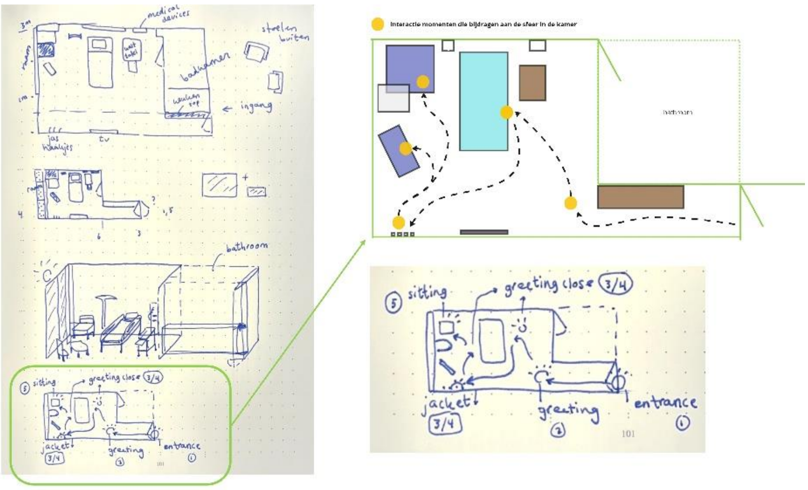
Ideation methods

The How To method was used to brainstorm about different possibilities within the design goals.

- "How To's"
    - 1 How to: feel welcome
        - offer privacy
        - offer flexibility
    - 2. How to: express expectations about death
        - Express feelings
        - Draw expectations
        - When in the timeline

Patient room analysis

The interior of the patient room was analyzed based on the current support it gives in privacy and being flexible. This was done my creating a map of the room, with all furniture in it. Then four categories were taken from the design goals and evaluated in the room: privacy, flexibility, comfort and autonomy. Different furniture was rated if it contributed to this category or not. By using this analysis, it became clear that autonomy and flexibility were the most lacking in the patient room, for the patient as stakeholder. Different interactions were analyzed in the patient room, checking to see if they had impact on the rate of flexibility, privacy, autonomy and comfort.



Creating ideas

The ideation process led to a total of 30 ideas for concepts that could show what Design can do in such a vulnerable time and setting.

How the 30 ideas led up to 1 concept:

30 ideas > 13 ideas

How: talking/discussing with family members and coaches, testing if it fits the design goal. By imagining the interactions in the context of the patient room and evaluating the impact on the stakeholders. This is how could be tested if the ideas could have the desired impact.

13 ideas were chosen to be innovative and in line with the design goals for this project to continue with.

13 ideas > 9 ideas

How: All 13 ideas were put on a Matrix of Impact, created with the knowledge gathered from the conversations I had during the whole research period with healthcare professionals, medical students and insights from experiences from friends and family.

After this Matrix, 9 ideas were rated innovative and impactful to continue with

9 ideas > 3 concepts

How: SCAMPER

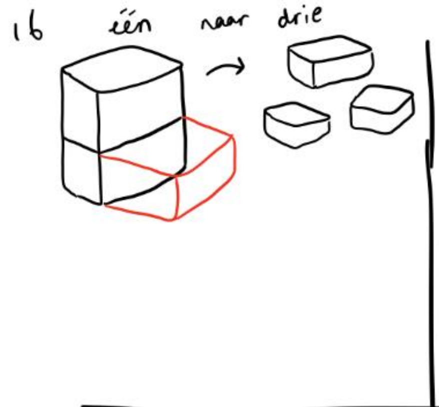
With the SCAMPER method, the ideas were substituted, combined, adapted, modified, eliminated, given a different purpose and reversed. This helped to see the valuable and less valuable aspects of each concepts and to determine which concepts were innovative, impactful and feasible enough for this project.

3 concepts > 1 concept

After discussing the concepts with the coaches and stakeholder at ERASMUS MC, the concept was chosen to be the most fitting with the design goal and context of the patient room at ERASMUS MC.

The next section will show detailed drawing of the ideation from 30 ideas to a concept.

Ideation of 30 ideas:

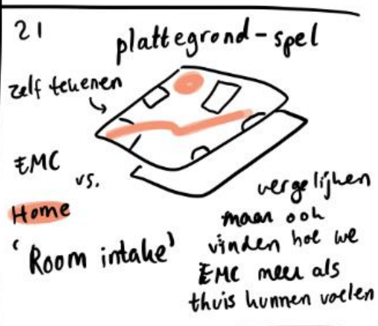

16
één naar drie

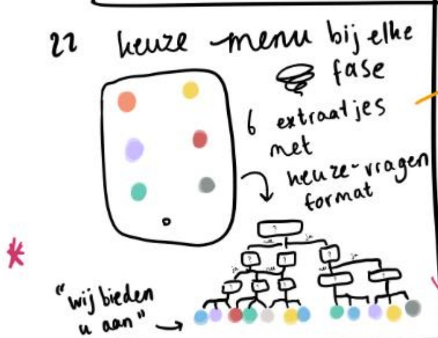

17
extra opslag
&
houten plankje er in
zodat bankje
→ tafeltje wordt
bloemen
spelletje
schrijven
rituelen
of
tafel op bed
of aan bed vast

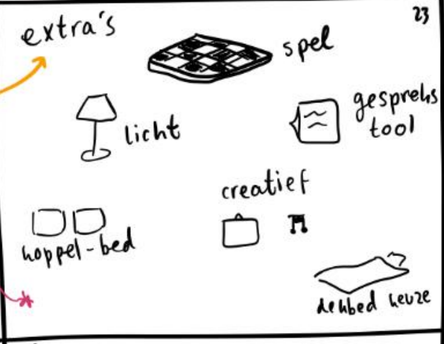

18
zitje met extra (lees) lamp erin voor bezoekers


19
process mindmap als gespreks-tool


20
alle 3
of
2
gespreks kaarten
"welke plaatjes passen nu bij jou?"
& vroeger
& toekomst


21
plattegrond-spel
zelf tekenen
EMC
vs.
Home
'Room intake'
vergelijken
maar ook
vinden hoe we
EMC meer als
thuis kunnen voelen


22
keuze menu bij elke fase
6 extraatjes met keuze-vragen format
"wij bieden u aan"

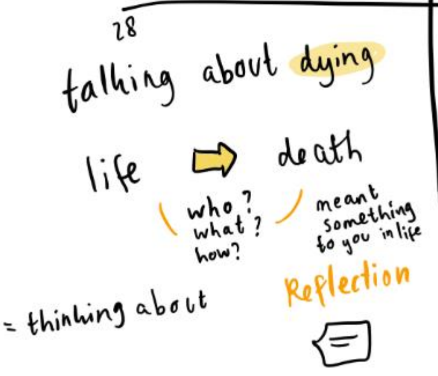

23
extra's
spel
licht
gespreks tool
creatief
koppel-bed
dekbed keuze


24
foto's verzamelen van levensloop
ophangen in kamer

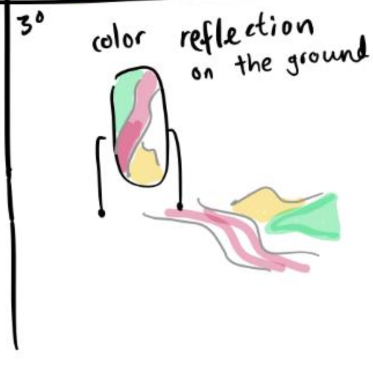

25
origami van fijne herinnering
leads to


26
blokkenspel
"letting go"
vind ik fijn
vind ik minder

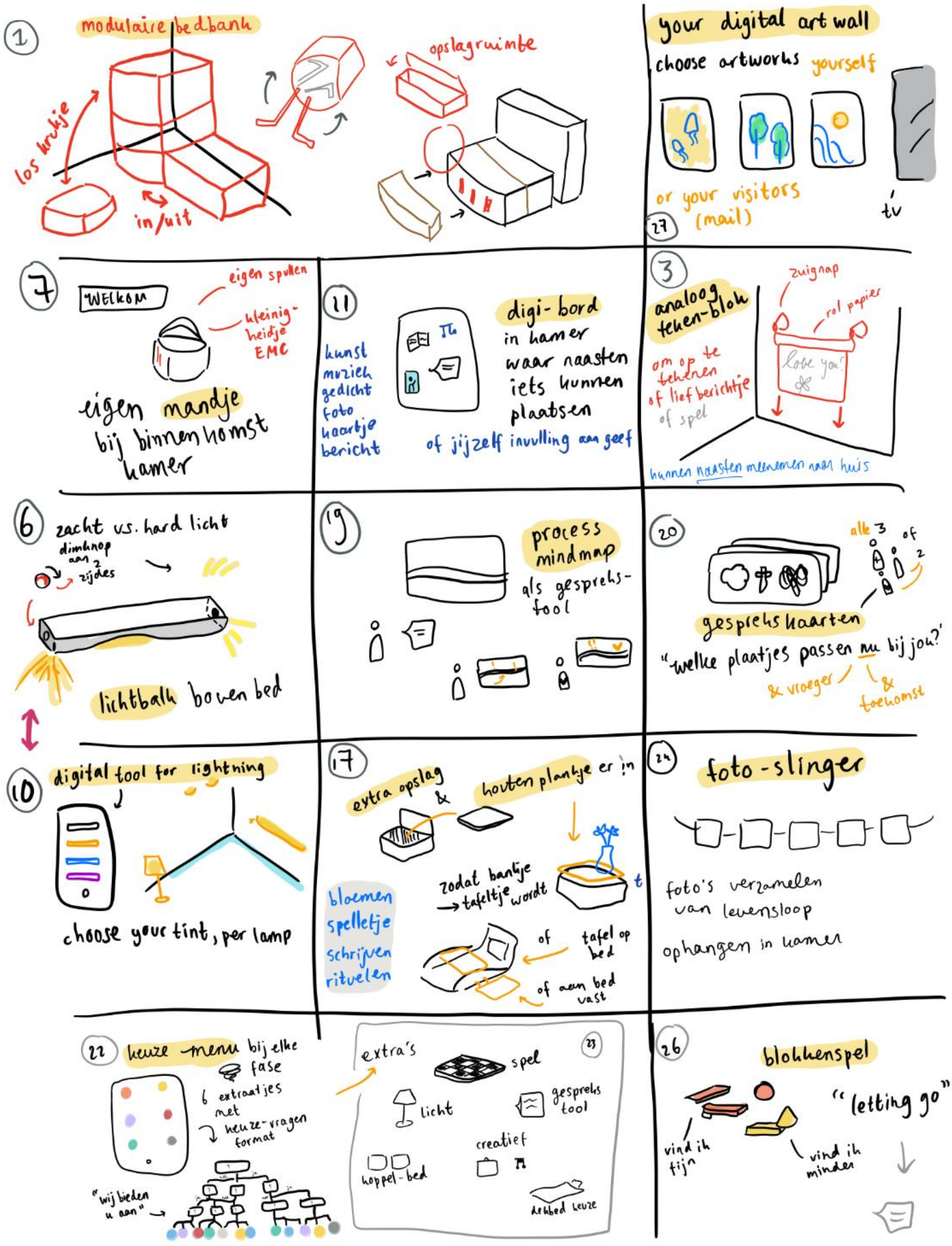

choose artworks yourself
or your visitors
(mail)
tv
27

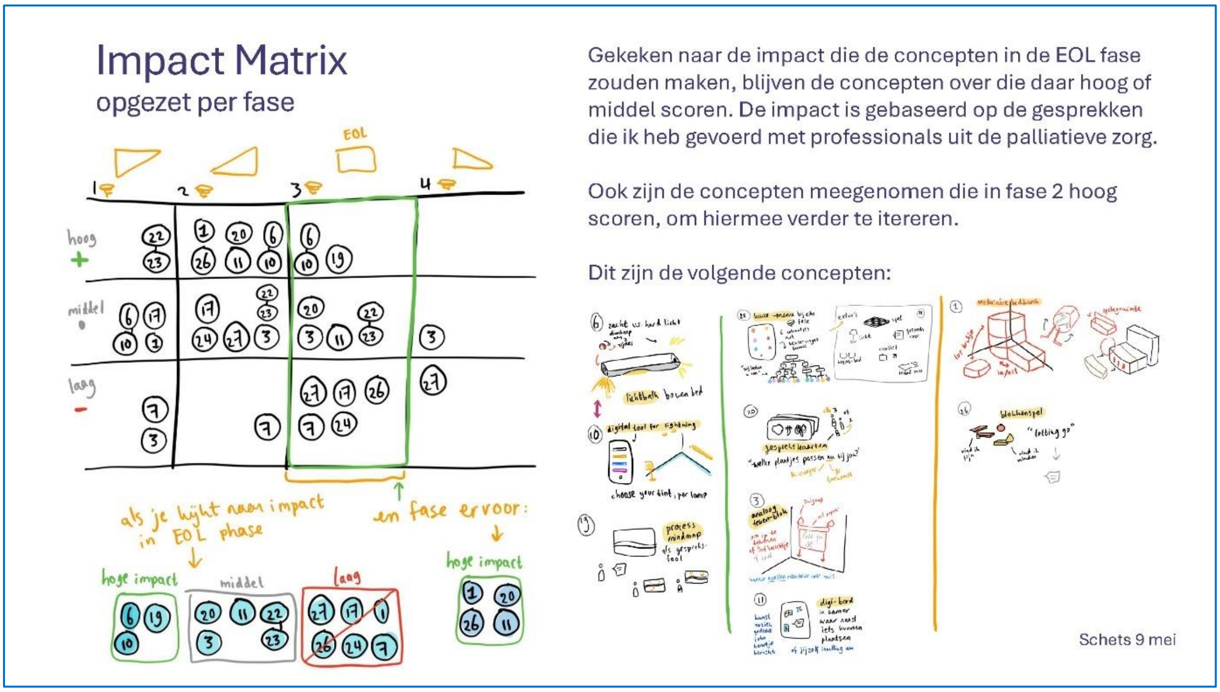

28
talking about dying
life
death
who?
what?
how?
meant something to you in life
Reflection
= thinking about


29
tovertafel
op de muur


30
color reflection
on the ground

Selection of 13 promising ideas





Impact Matrix

opgezet per fase

	1	2	3 EOL	4
hoog +	22, 23	1, 20, 6, 26, 11, 10	6, 10, 19	
middel ●	6, 17, 10, 1	17, 22, 23, 24, 27, 3	20, 22, 3, 11, 23	3
laag −	7, 3	7	27, 17, 26, 7, 24	27

als je kijkt naar impact in EOL phase

hoge impact: 6, 19, 10

middel: 20, 11, 22, 3, 23

laag: ~~27, 17, 1, 26, 24, 7~~

en fase ervoor:

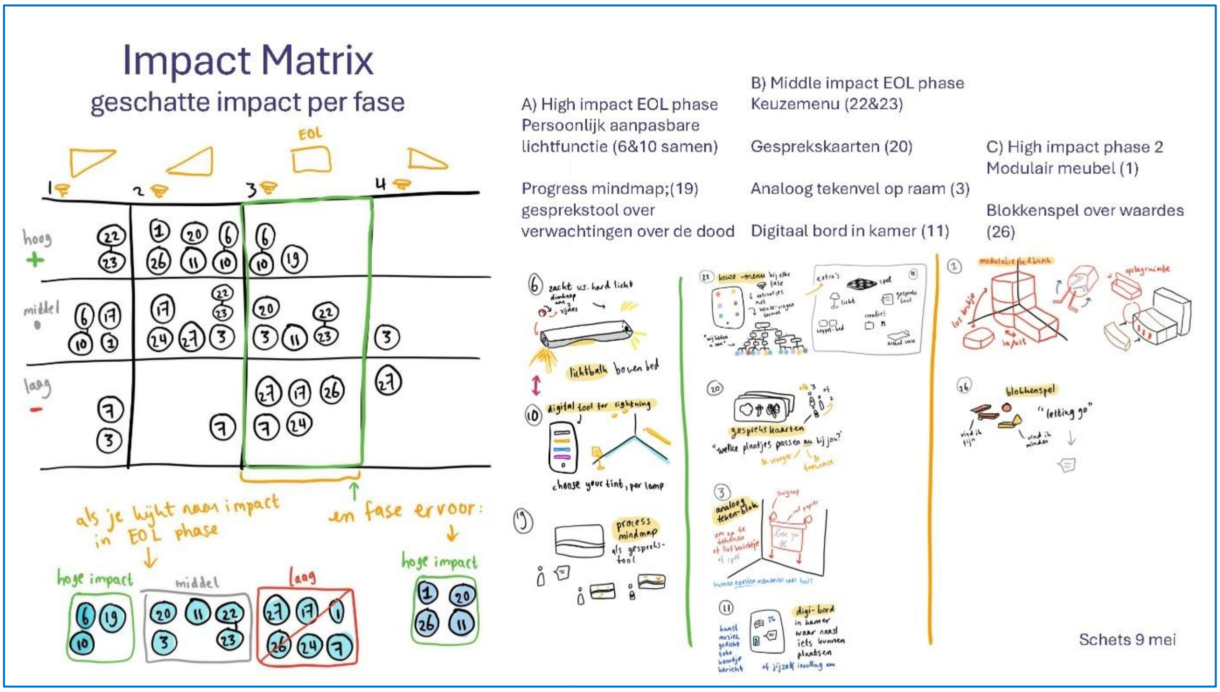
hoge impact: 1, 20, 26, 11

Gekeken naar de impact die de concepten in de EOL fase zouden maken, blijven de concepten over die daar hoog of middel scoren. De impact is gebaseerd op de gesprekken die ik heb gevoerd met professionals uit de palliatieve zorg.

Ook zijn de concepten meegenomen die in fase 2 hoog scoren, om hiermee verder te itereren.

Dit zijn de volgende concepten:

Schets 9 mei



Impact Matrix

geschatte impact per fase

	1	2	3 EOL	4
hoog +	22, 23	1, 20, 6, 26, 11, 10	6, 10, 19	
middel ●	6, 17, 10, 1	17, 22, 23, 24, 27, 3	20, 22, 3, 11, 23	3
laag −	7, 3	7	27, 17, 26, 7, 24	27

als je kijkt naar impact in EOL phase

hoge impact: 6, 19, 10

middel: 20, 11, 22, 3, 23

laag: ~~27, 17, 1, 26, 24, 7~~

en fase ervoor:

hoge impact: 1, 20, 26, 11

A) High impact EOL phase
Persoonlijk aanpasbare lichtfunctie (6&10 samen)

Progress mindmap;(19) gesprekstool over verwachtingen over de dood

B) Middle impact EOL phase
Keuzemenu (22&23)

Gesprekskaarten (20)

Analoog tekenvel op raam (3)

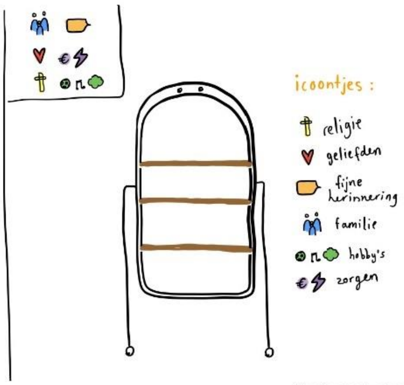
Digitaal bord in kamer (11)

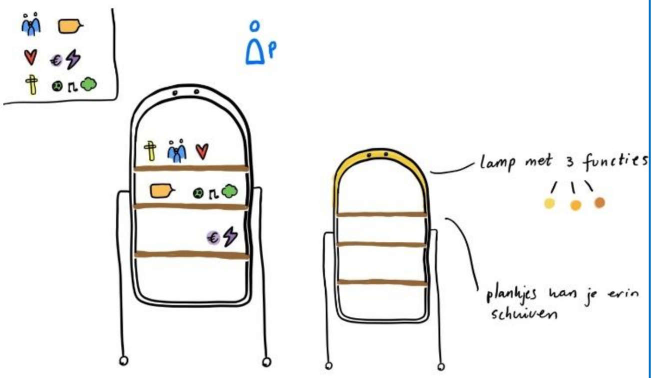
C) High impact phase 2
Modulair meubel (1)

Blokkenspel over waardes (26)

Schets 9 mei

Concept 1: persoonlijk museum / *personal museum*



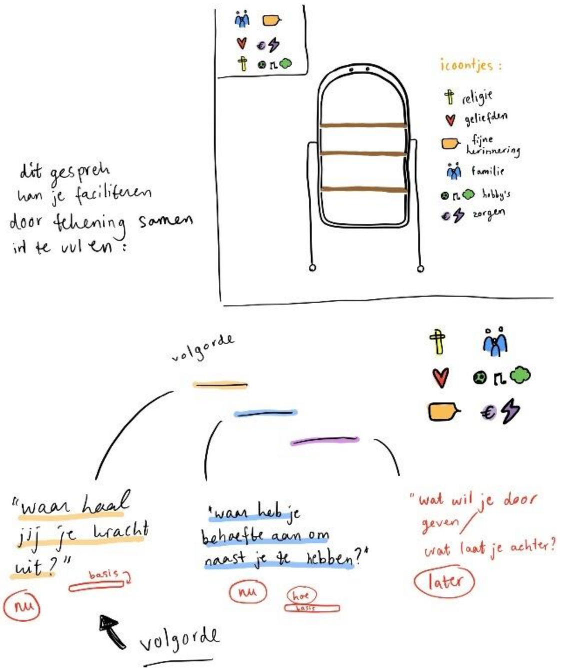


Nu:
1) geen toegewezen plek voor dierbare elementen die de patiënt kracht geven bij het sterven.
2) weinig inzicht door personeel in waardes patiënt door gebrek aan communicatie

Toekomst: **gesprekstool**
1) Het museum faciliteert een gesprek over de waardes van de patiënt (in het algemeen en richting het stervensproces).
Zo voelt de patiënt zich gezien en heeft het personeel meer inzicht in wat belangrijk is voor hen

Toekomst**: persoonlijk museum**
2) Het museum geeft die waardes meteen een plek in het museum, hier kunnen ze **elementen in zetten die hen kracht geven** of het simpelweg gebruiken als **bedlamp** met zachtere lichtfuncties.
3) Neer te zetten in de ruimte waar iemand wil, door de wieltjes is het makkelijk te verplaatsen

Schets 9 mei



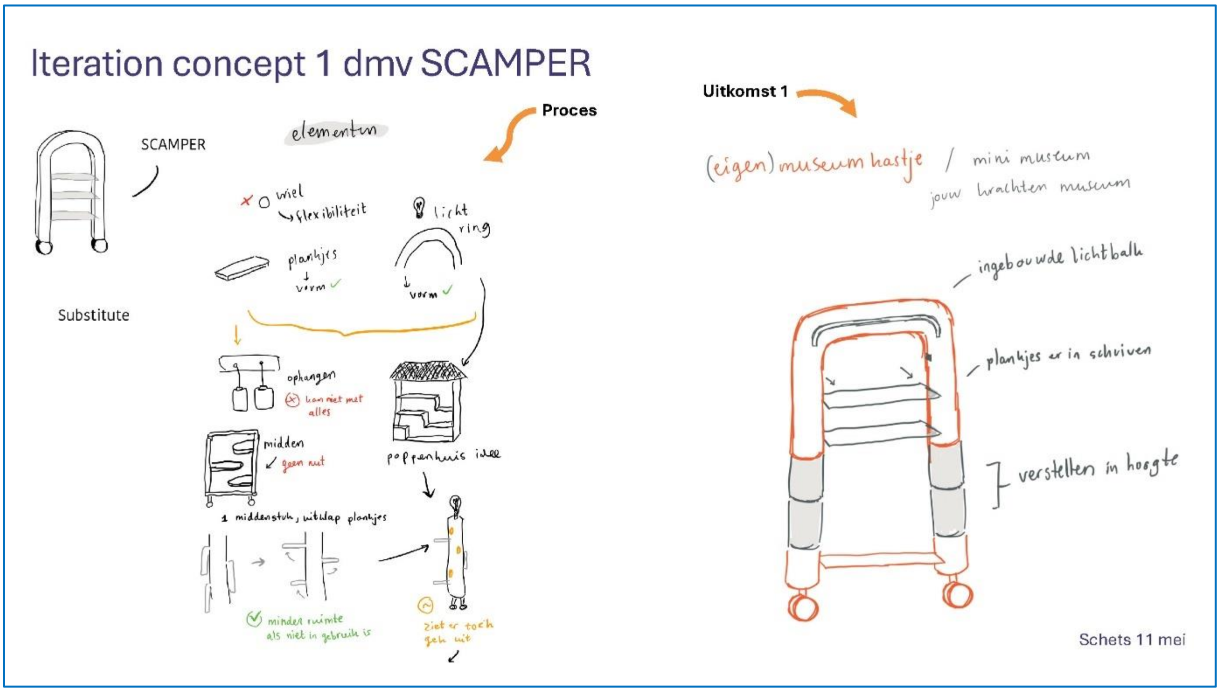
Werking: **gesprekstool**
Door middel van een tekening van het museum en 6 elementen.

De elementen mogen patiënten op volgorde zetten van het meest belangrijk voor hen (bovenste rij) naar het minste belangrijk nu (onderste rij)

Het gesprek kan verder gefaciliteerd worden door 3 vragen te stellen over de elementen:

- Waar haal jij je kracht uit?
- Waar heb je behoefte aan om naast je te hebben?
- Wat zou je willen doorgeven?

De gesprekstool kan getest worden met een magnetisch bord en 6 icoontjes die gebruikers kunnen verplaatsen over het bord



Iteration concept 1 dmv SCAMPER

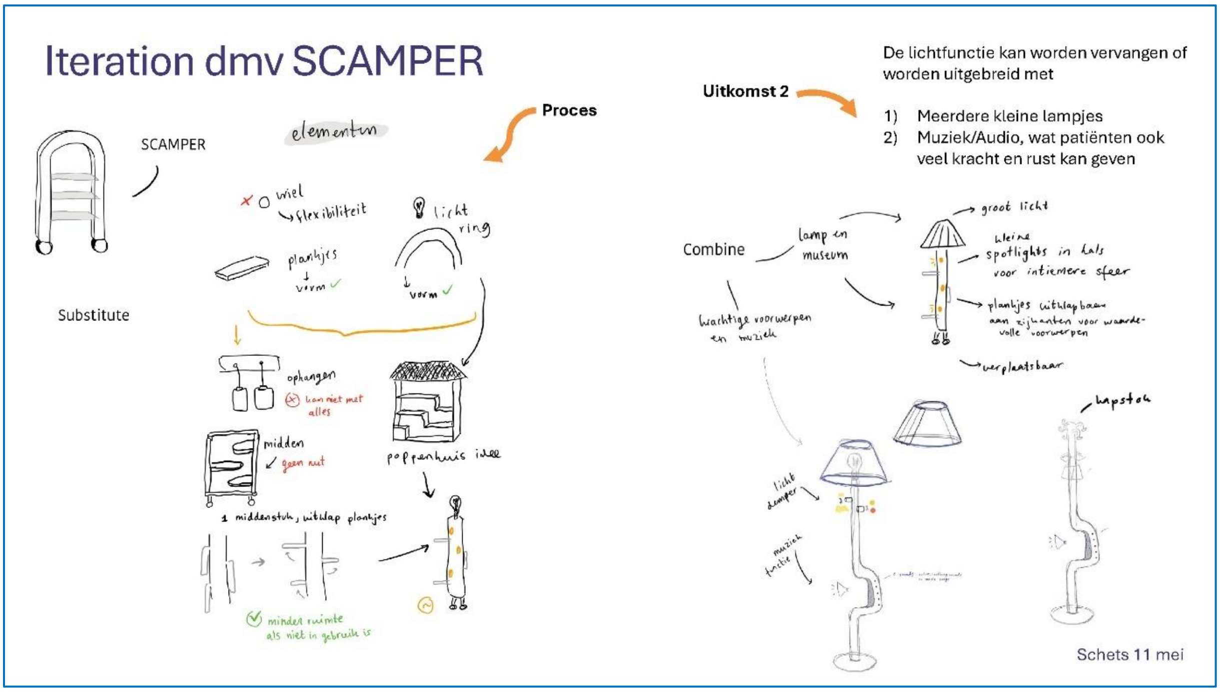
SCAMPER

Substitute

Proces

Uitkomst 1

Schets 11 mei



Iteration dmv SCAMPER

SCAMPER

Substitute

Proces

Uitkomst 2

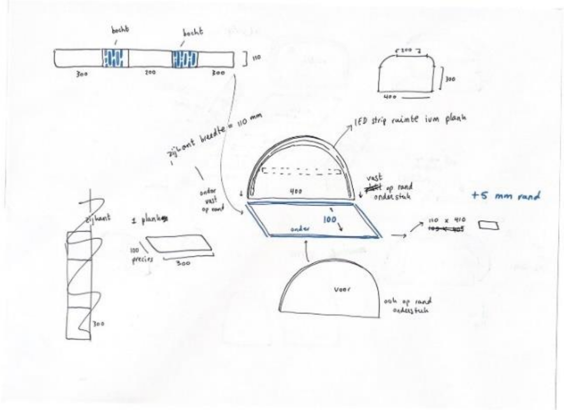
De lichtfunctie kan worden vervangen of worden uitgebreid met

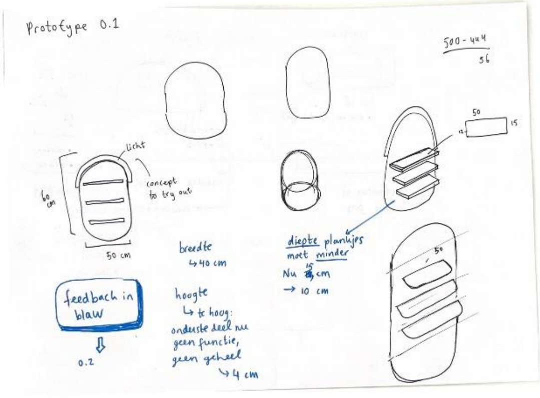
1) Meerdere kleine lampjes
2) Muziek/Audio, wat patiënten ook veel kracht en rust kan geven

Combine

Schets 11 mei

Prototyping phase





Appendix P: Notes of the feedback sessions at Erasmus MC

Session with doctors:

First Impressions:

- Positive point: This concept lowers barriers to use if all resources are readily available.
- It's a great goal to personalize the room and make it feel more like home.
- It's exciting to pilot this on one department!
- A digital version would be useful for departments with stricter rules, like hepatology, where patients stay for long periods.
- “This is great for patients. They can bring things now, but often don’t because they’re unsure what’s allowed in the room. A concept like this helps communicate what’s permissible.”
- The toolkit is a valuable addition; it can facilitate conversation by asking, "Is there something here that appeals to you?"
- It can enhance the relationship between doctor and patient.
- It might be less understood or desired in different cultural backgrounds, but initiating a conversation can bridge that gap.

Suggestions for Redesign:

- Check compliance with hygiene rules.
- It should be detachable or movable for safety; consider a design that allows it to hang at the foot of the bed for easier access.
- The color should match the interior scheme, likely the same wood color as the door, for a neutral, warm tone.
- It must be easy to clean; avoid multiple levels in the shelves and have a single, straight surface.
- It needs to be sturdy and able to withstand impact.
- Maximize robustness; avoid unnecessary holes (e.g., for bending).
- Consider fire safety.
- The plug and lamp might need to be removed for sustainability, avoiding dependence on a plug or battery.
- Be cautious with the toolkit to ensure it includes all possible (religious) symbols, not just a selected few.

Session with Nurses:

- This is very accessible if it’s already installed in the room, which is nice!
- They find it quite small; it should fit a book, especially religious texts, which can be very important.
- For certain departments (MPU), a version on wheels would be necessary; it might not work everywhere.
- It might need some explanation (about its purpose and benefits) in the room, perhaps with text beside it, to encourage use.

- The nice thing is that it can prompt immediate conversation if the nurse sees something in the cabinet. It makes starting a conversation less intimidating.
- Ensure it doesn’t get in the way.
- It shouldn’t be too far from the patient, as this can be challenging for older patients.
- A digital version would be useful for departments where a physical version isn't feasible.

Appendix Q: Proof of concept elements - Conversation Guidebook

English version

This guidebook is designed for the medical staff of Erasmus MC. It explains the use and goals of De Verhalenhoek—a concept for the patient room. Additionally, this guide can be used to explain De Verhalenhoek and to assist patients and their loved ones in using it.

Introduction

De Verhalenhoek is a concept designed to give a place in the hospital room for personal stories and memories of a patient. Through cards and personal elements, we aim to offer strength and comfort to patients and their loved ones, thereby lowering the threshold to start a conversation about aspects of the final phase of life and this intense period. Because there are many differences between patients, their needs and their responses to support, De Verhalenhoek is designed to invite them in personal customization.

With the help of De Verhalenhoek, animations on the iPad, and various images, a conversation is facilitated between medical staff, the patient, and possibly their loved ones.

De Verhalenhoek

De Verhalenhoek hangs in the corner of the patient's room and will stand out as soon as patients enter the room. Here, medical staff can already give a brief explanation about the purpose and benefits of the cabinet, so that the patient and loved ones feel invited to bring items from home and place them inside.

Initiating the conversation

After delivering bad news to a patient, De Verhalenhoek can be valuable in initiating a difficult conversation and further supporting the patient and their loved ones. After the bad news conversation, is the moment to start this conversation. Start with an introduction to the concept. Medical staff can invite the patient and loved ones to add personal elements to De Verhalenhoek.

Everyone cope differently with the final phase of life . Patients will also respond very differently to the questions you ask and to De Verhalenhoek. For example, one patient might be eager to talk about their final moments, while another might reject the topic or need more time. It is important to give patients the time and space they need in your approach.

Example

Example introduction:

"This is De Verhalenhoek. It is a special place where you can give your personal story a spot in the room. You can add images and elements that are important to you, such as where you come from, what you like to do, or what you have experienced. These can be things from home or from our collection. Would you like that?

Please, take your time; there is no rush to place items in De Verhalenhoek. You can think about it for a while if you need to."

Physical or Digital use

If the patient is interested in using De Verhalenhoek, you can grab the cardbook or the iPad to see which images they might want to use if they do not have their own elements or items to place in it. The cardbook is located in the common area, near the books and games. The iPad is next to the bed, where patients can later view and adjust the images. There is the option to use the physical cards in the Verhalenhoek cabinet or the digital cards on the iPad, or to use neither and use their own items.

Questions and suggestions

To facilitate the conversation about the cards and provide inspiration, the following questions and categories can be used:

Questions	Suggestions
1. What gives you strength?	*Ask patients and loved ones about their sources of strength and inspiration. Some suggestions:* 1. *Religion* 2. *Family* 3. *Loved ones* 4. *Hobbies* 5. *Pets* 6. *Art* 7. *Nature*
2. What would you like to have with you in the room?	*Ask what the patient would like to have around them, both during their stay and in their final moments.*
3. What would you like to pass on? And to whom?	*Encourage the patient to think about what they would want to leave behind and to whom. Some suggestions:* ● *To family* ● *To children* ● *To friends* ● *To the world*

Practical execution

1. Preparation

- Place the cardbook within reach.
- Ensure the iPad is ready.

2. Conversation:

- Begin with the introduction to De Verhalenhoek.Use the above questions and categories to guide the conversation. The intitial reaction will give you an indication about how this patient is coping with the changing situation and if they would be willing to try the use of De Verhalenhoek.
- When patients want to use the concept, ask for their preference for the physical or digital use of De Verhalenhoek. There is the option to place the cards both in the physical and digital cabinet, or to use neither! This depends on the patient's wishes.
- Using the cardbook: Allow the patient and loved ones to choose cards from the cardbook and place them in the photo holders in the cabinet in the room. Additionally, personal items or photos can also be added.
- Using the iPad: Let the patient scroll through the digital overview and save cards in their personal Verhalenhoek. In the overview, 1 to 3 images can be saved in the personal Verhalenhoek, which can be projected on the television.

3. Conclusion:

- Thank the patient and loved ones for their time and contribution, they can take all the time they need to discuss on what elements to put in De Verhalenhoek.
- Emphasize that patients and loved ones can always look at the cardbook again by asking the medical staff or by walking to the common area.

Deze handleiding is opgesteld voor medisch personeel van het Erasmus MC. Het beschrijft het gebruik en de doelen van De Verhalenhoek - een concept voor in de patientenkamer. Daarnaast kan deze handleiding gebruikt worden om uitleg te geven over De Verhalenhoek en patiënten en naasten hierin te begeleiden.

Inleiding

De Verhalenhoek een concept dat is ontworpen om persoonlijke verhalen en herinneringen van een patiënt een plek te geven in de ziekenhuiskamer. Door middel van kaarten en persoonlijke elementen willen we kracht en troost bieden aan patiënten en hun naasten, en zo de drempel verlagen om een gesprek aan te gaan over aspecten van de laatste levensfase en deze intensieve periode. Omdat er veel verschillen bestaan tussen patiwnten, hun behoeftes en hun reacties op ondersteuning is de Verhelanhoek zo ontworpen dat er veel vrijheid is voor persoonlijke invulling.

Met behulp van de Verhalenhoek, de animaties op de iPad en diverse afbeeldingen wordt een gesprek gefaciliteerd tussen medisch personeel, patiënt en mogelijk naasten.

De Verhalenhoek

De verhalenhoek hangt in de hoek van de patiëntenkamer en zal dus opvallen op zodra patiënten de kamer binnen komen. Hier kan medisch personeel al een korte uitleg geven over het doel en nut van het kastje, zodat de patiënt en naasten zich uitgenodigd voelen om elementen van thuis mee te nemen en hierin te zetten.

Start van het gesprek

Na het slecht nieuws gesprek kan de Verhalenhoek van waarde zijn om een lastig gesprek te moeten voeren en de patiënt en naasten verder te kunnen steunen. Dit is dus het moment om dit gesprek te initiëren. Start met een inleiding over het concept. Medisch personeel kan de patiënt en naasten zo uitnodigen om persoonlijke elementen toe te voegen aan De Verhalenhoek.

Iedereen gaat anders om met de laatste levensfase. Patiënten zullen dan ook heel verschillend reageren op de vragen die u hen stelt en ook op de Verhalenhoek. Zo zal de ene patiënt graag willen praten over de laatste momenten, terwijl de ander dit misschien afwijst of meer tijd nodig heeft. Het is belangrijk patiënten hierin de tijd en ruimte te geven in je voorstel.

Voorbeeld

Voorbeeldinleiding:

"Dit is De Verhalenhoek. Het is een plek waar u uw persoonlijke verhaal een plekje kunt geven in de kamer. U kunt hier afbeeldingen en elementen toevoegen die belangrijk voor u zijn, zoals waar u vandaan komt, wat u graag doet of wat u heeft meegemaakt. Dit kunnen objecten van thuis of vroeger zijn of spullen uit onze collectie. Zou u dat graag willen?

Neem vooral de tijd, het vullen van de Verhalenhoek kan altijd nog. U kunt hier ook nog even over nadenken."

Fysiek of digitaal

Als patiënt geïnteresseerd is in het gebruik van de Verhalenhoek, kunt u het kaartenboek of de ipad erbij pakken om te kijken welke afbeeldingen ze zouden kunnen gebruiken, wanneer ze zelf geen elementen of voorwerpen hebben om hierin te zetten. Het kaartenboek ligt in de algemene ruimte, bij de boeken en spelletjes. De ipad hangt naast het bed, hier kunnen patiënten later de afbeeldingen ook nog bekijken en aanpassen. Er is de mogelijkheid om gebruik te maken van de fysieke kaarten in het Verhalenhoek-kastje of de digitale kaarten te gebruiken op de ipad, of om geen van beiden te gebruiken en een eigen invulling hieraan te geven.

Vragen en suggesties

Om het gesprek over de kaarten te faciliteren en inspiratie te bieden, kunnen de volgende vragen en categorieën worden gebruikt:

Vragen	Suggesties
1. Waar haalt u kracht uit?	*Vraag patiënten en naasten naar de bronnen van hun kracht en inspiratie. Enkele suggesties:* 1. *Religie* 2. *Familie* 3. *Geliefden* 4. *Hobby's* 5. *Huisdieren* 6. *Kunst* 7. *Natuur*
2. Wat zou u graag bij u in de kamer hebben?	*Vraag naar wat de patiënt graag om zich heen zou willen hebben, zowel tijdens hun verblijf nu als in hun laatste momenten.*
3. Wat zou u willen doorgeven? **En aan wie?**	*Stimuleer de patiënt om na te denken over wat ze willen nalaten en aan wie. Enkele suggesties:* ● *Aan familie* ● *Aan kinderen* ● *Aan vrienden* ● *Aan de wereld*

Praktische uitvoering

1. Voorbereiding:

- Leg het Kaartenboek binnen handbereik.
- Zorg dat de iPad klaar staat.

2. Gesprek:

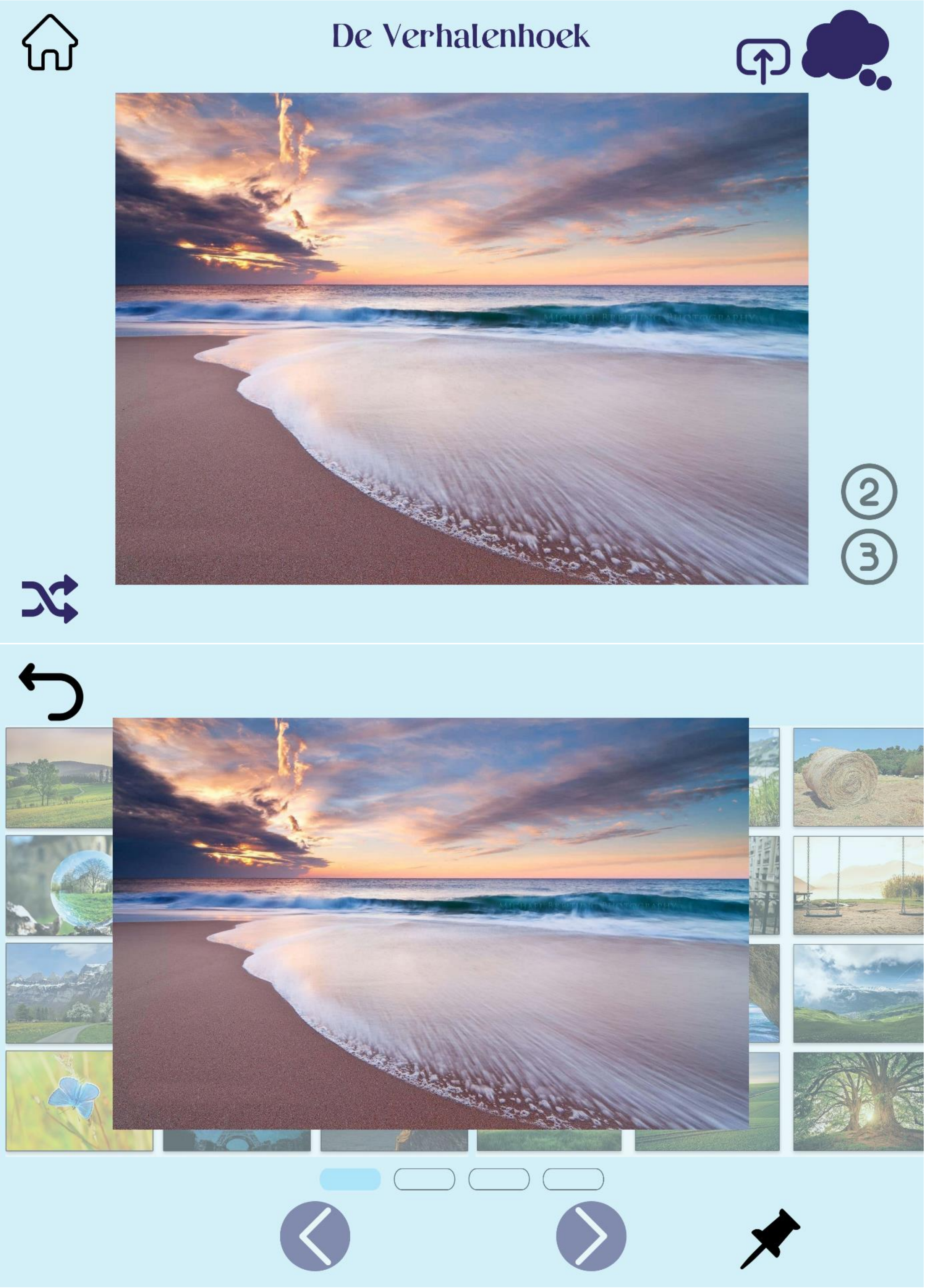
- Begin met de inleiding over De Verhalenhoek.
- Gebruik de bovenstaande vragen en categorieën om het gesprek te leiden. De eerste reactie zal een indicatie geven over hoe deze patiënt omgaat met de veranderende situatie en of zij bereid zijn om De Verhalenhoek te proberen.
- Wanneer patiënten het concept willen gebruiken, vraag je naar voorkeur voor fysiek of digitaal gebruik van de Verhalenhoek. Er is een mogelijkheid om de kaarten zowel in de fysieke als digitale kast te plaatsen, of om van geen van beiden gebruik te maken! Dit is afhankelijk van de wensen van de patiënt.
- Gebruik van het kaartenboek: Laat de patiënt en naasten kaarten uitzoeken uit het Kaartenboek en plaatsen in de fotohouders in het kastje in de kamer. Daarnaast kunnen eigen voorwerpen of foto's hier ook aan toe worden gevoegd.
- Gebruik van de ipad: Laat de patiënt door het digitale overzicht scrollen en kaarten opslaan in zijn persoonlijke Verhalenhoek. Bij het overzicht kunnen 1 tot 3 afbeeldingen worden opgeslagen in de persoonlijke Verhalenhoek, die op de televisie kunnen worden geprojecteerd.

3. Afsluiting:

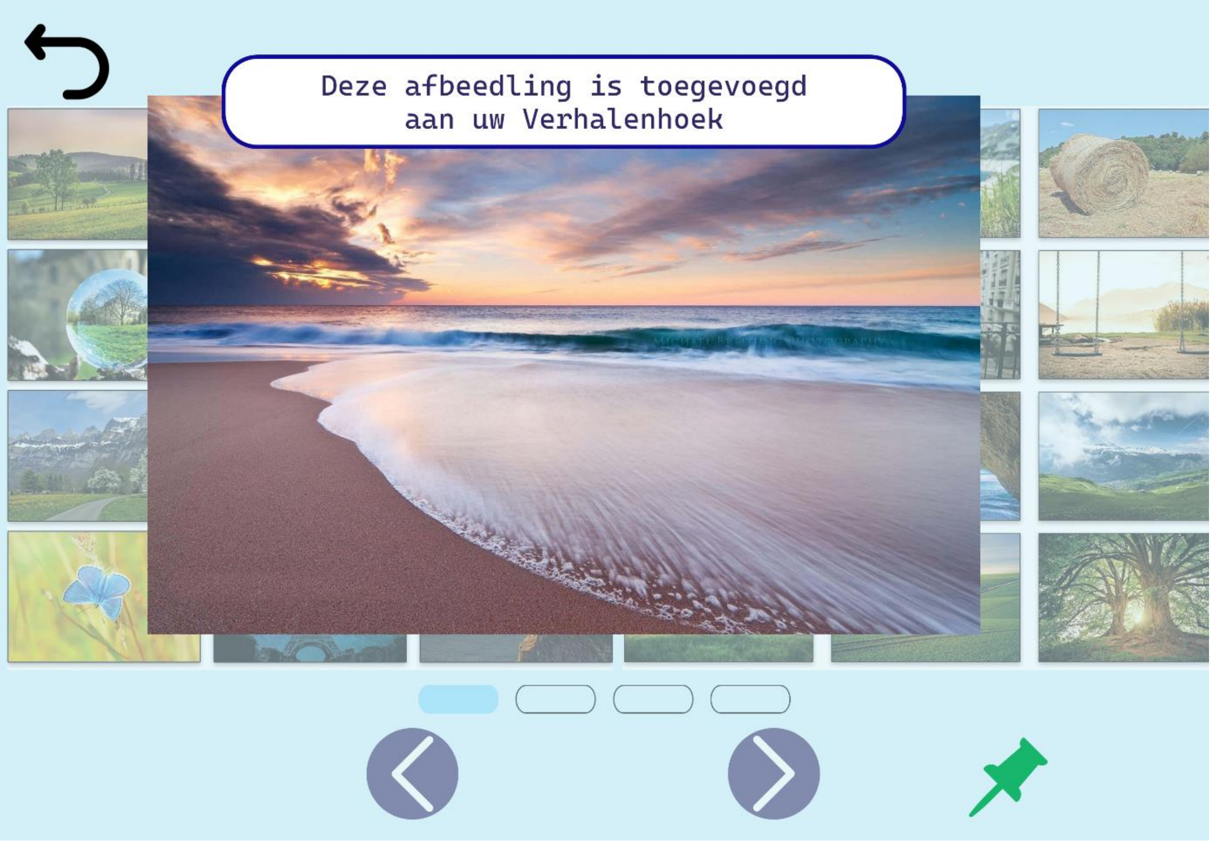
- Bedank de patiënt en hun naasten voor hun tijd en bijdrage. Laat de betrokkenen weten dat ze alle tijd kunnen nemen die ze nodig hebben om te bespreken welke elementen ze in De Verhalenhoek willen plaatsen.
- Benadruk dat de patiënten en naasten altijd nog een keer naar het kaartenboek mogen kijken, door dit aan medisch personeel te vragen of langs de gemeenschappelijke ruimte te lopen

Card set

Digital prototype of De Verhalenhoek for iPad screens



Wilt u deze afbeelding toevoegen aan uw Verhalenhoek?



Deze afbeedling is toegevoegd aan uw Verhalenhoek


De Verhalenhoek

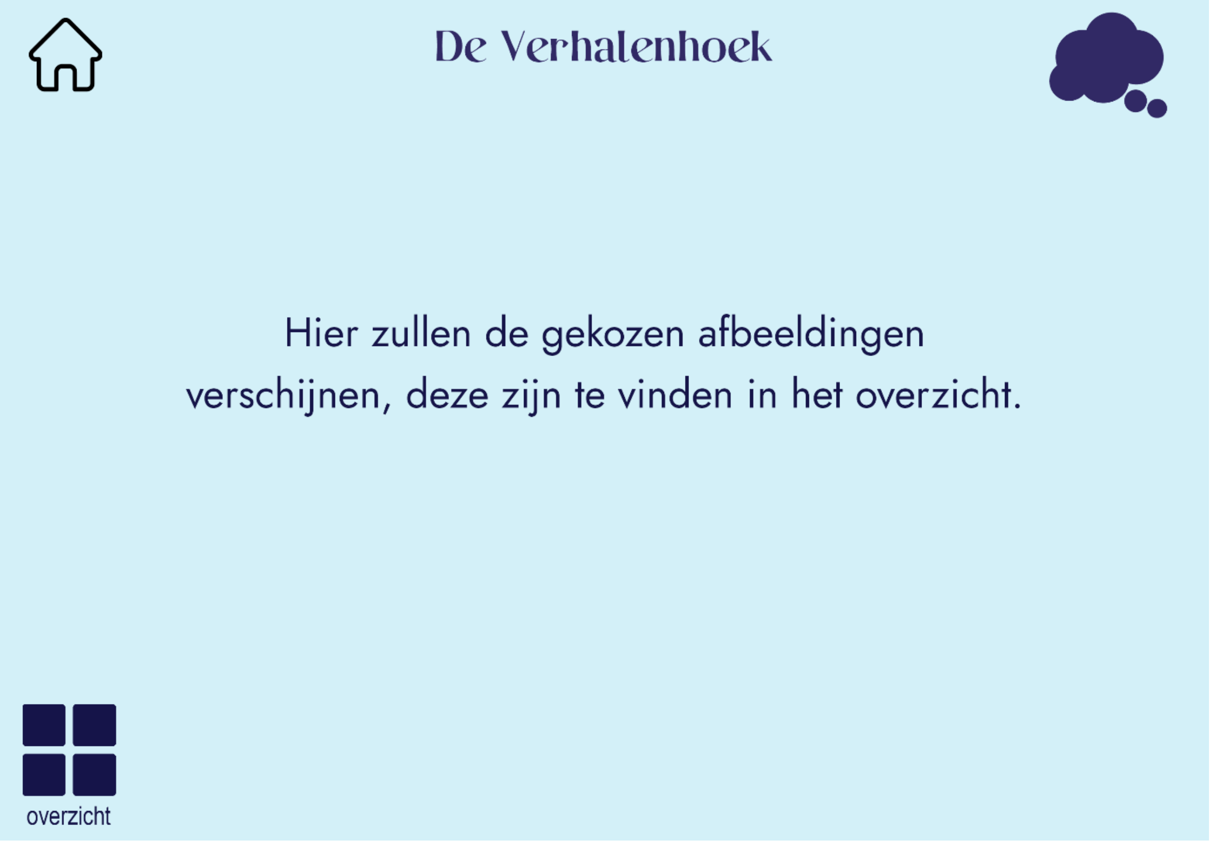

De Verhalenhoek

WELKOM

Kamernummer: Rg-1009

Behandelaar:

Voorlopige ontslagdatum:



De Verhalenhoek

Hier zullen de gekozen afbeeldingen verschijnen, deze zijn te vinden in het overzicht.


De Verhalenhoek
①
③


De Verhalenhoek
①
②

De Verhalenhoek

② ③

De Verhalenhoek

② ③

De Verhalenhoek

①

③

De Verhalenhoek

①

③


De Verhalenhoek
1
2


De Verhalenhoek
1
2

Final proof of concept