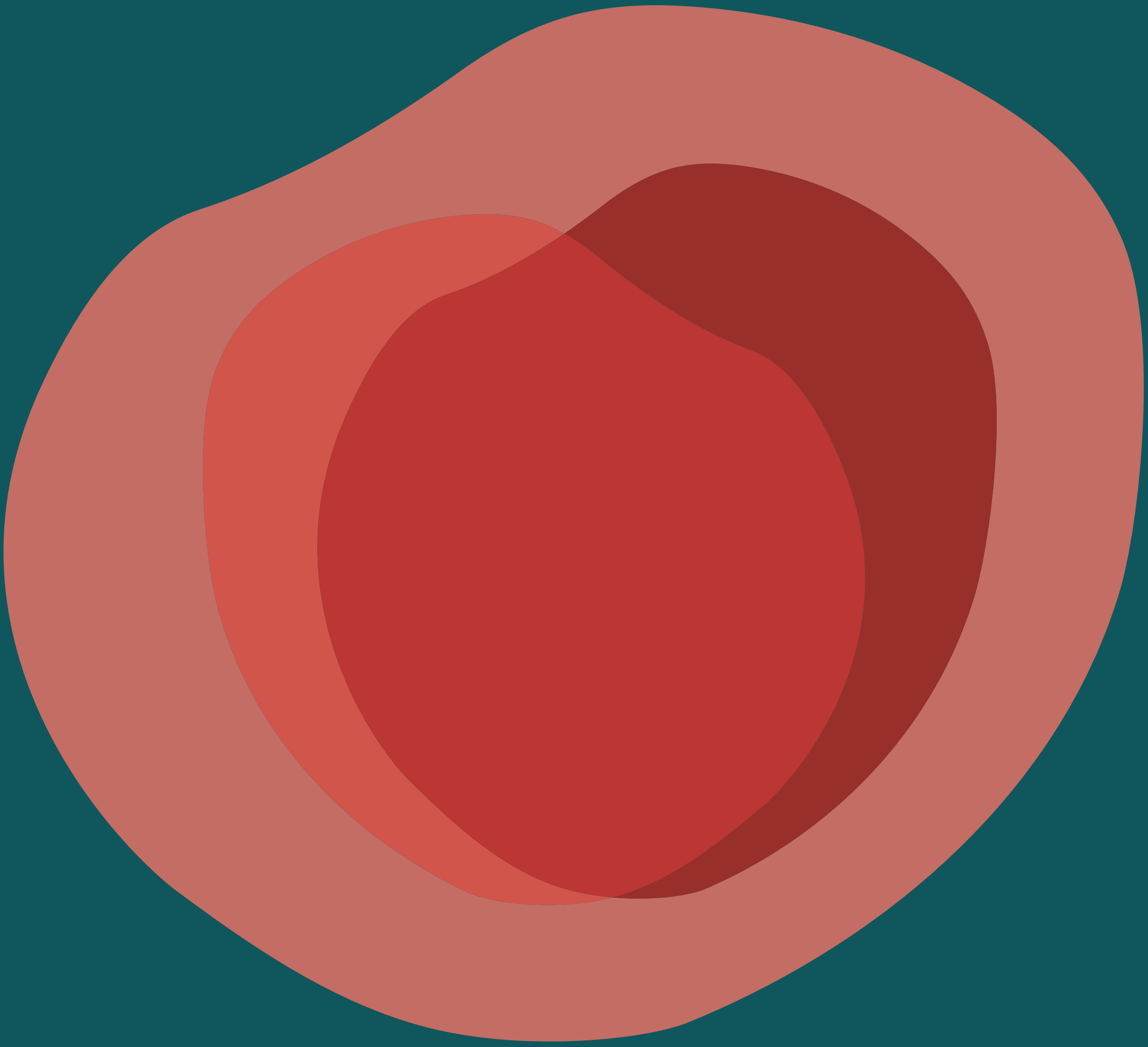

Deciding with heart

Supporting shared decision making process about life-prolonging treatments in patients with advanced heart failure

Martina Pozzoni

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Author
Martina Pozzoni

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

Supervisory team
Chair
Marieke Sonneveld
Faculty of Industrial Design Engineering
Delft University of Technology

Mentor
Renée Schuffelers
Faculty of Industrial Design Engineering
Delft University of Technology

Mentor
Irene Jongerden
Department of Public Health
Amsterdam UMC, Location Vumc

Mentor
Maureen Thodé
Department of Public Health
Amsterdam UMC, Location Vumc

8 November, 2019

Aknowledgements

This graduation thesis is the final milestones of an inspiring journey as a student of the Master Design for Interaction in TU Delft.

I would like to thank my supervisory team for coaching me and supporting me throughout the project.
Marieke, for believing in this project and in my skills from the beginning. Thank you for sharing the enthusiasm and the passion behind this project, and for keeping me down to earth at the same time. I appreciated your feedback style: honest and critical, but necessary to improve my skills.
Renee, for always providing inspiration and guidance. Thank you for kindness and for always checking up on me and my work. During the project I valued your point of view, which has a special feeling for emotions, which the project needed. I am grateful for your infinte sources of design methods and inspirations.

A special acknowledgement to my supervisory team at the Department of Public Health at the Amsterdam UMC, location VUmc.
Irene, for making this project happen. I am grateful for your precious guidance and moral support. I appreciated all the times you dropped around my desk with a piece of literature or an interesting source for my project, and for showing genuine enthusiasm for my design.
Maureen, thank you for guiding me through research about shared decision making in practice, in particular during the first phase of the project. Tank you for always having encouraging words and a cup of coffee for me, good luck with your project.

Thanks to the whole Department of Public Health, in particular to Martine, Mireille, Bernadette, Bo and Judith for the inspiring talks and for making writing more entertaining.
A special thanks to Inge, who was so kind to help me in my Dutch pilot interview.

I would like to thank the people that made this research possible by participating in my interviews and observations.
Thank you to the nurses and the ward physicians of the Department of Cardiology of the Amsterdam UMC, location VUmc, for their time and kindness.
In particular, I would like to thank Corine for helping me from the start, allowing me to carry out observations and in recruiting participants.
In addition, I would like to thank the heart failure nurses at the outpatient clinic for their time and their valuable insights.
You are all doing incredible work; it is inspiring to see healthcare providers who love their work and want to improve the system.

I would like to thank the three patients' representatives that I interviewed, I won't mention your name, but your contribution made the difference in this project. I want to thank you for taking the time and reflect on such sensitive and confronting topic and make me part of your experience. The gentle words you had for my design were worth every struggle. Your stories are an inspiration, and I wish you the best.

Many thanks to my friend and colleague, Judith. You are a great designer and a great friend. Thank you for the continuous exchange of advice, laughs, coffee and positive reassurance. Thank you for sharing this journey of highs and lows with me, this experience would not have been the same without your company.

A special thanking to Ruben, for his loving support and encouragement.
Thank you for being always by my side. I am happy you share my passion for improving healthcare, and I am grateful for your continuous review of my work.

To my family, for sending me love from Italy and Sweden.
Mamma, Papà, grazie di cuore for making my dreams come true and for always believing in me. This could not have been possible without you.

To the Duijm family, thank you for making me feel home away from home.

And last but not least, many thanks to my friends, for sharing the highs and the lows in these two years.
Thanks to Emanuele, who shared with me late working evenings.
To my roommates: Tirza, Samantha, Shriya and Eduardo for cheering me up after a long day of work.
And thank you, Alberto, Andrea, Carlos, Chiara, Emiel, Erica, Evy, Ilgaz, Liz, Merijn, Nazli, Nilesh, Salvo and my friends and fellow Infuse members: Albert, Carlijn, Emil, Emanuele, Bingyan, Eva, Federico, Laura for making this journey a pleasure.

Thank you,

Martina

Executive summary

Shared decision making is a process in which healthcare professionals and patients decide together on the course of the treatment. Shared decision making enables evidence and patients' preferences to be taken into account. It improves the patient's knowledge, understanding and patient-healthcare providers communication. However, various barriers for implementing shared decision making for patients with advanced heart failure were found, which consist of unclarity, uncertainty, lack of training, and lack of time. This thesis focuses on improving the shared decision making process at the Cardiology department at the Amsterdam UMC, location VUmc.

Observations and interviews were conducted in the Cardiology department at the VUmc. In order to find similarities and differences between literature research and the current context.

Interviews show that shared decision making partly applies to the current decision making process: although healthcare providers share plenty of information with the patient and family, they share it mostly verbally. Treatment options are explained to the patient multiple times, but no information is given in the written form.

The booklet "Deciding with heart" was created to support the communication between healthcare providers and patients in the shared decision making process. It provides information about life-prolonging treatments for patients with advanced heart failure and sensitise them in individuating their values and preferences tackling two of the barriers found in the research: limited understanding amongst people with heart failure and unclarity of the roles in the care team.

The booklet can be used to explain the patients' prognosis and their treatment options in order to support them in the decision making process. The booklet helps to start a conversation between nurses and patients about making the best choice.

The booklet was positively evaluated with nurses from the department of Cardiology in the VUmc and the outpatient clinic, and with patient representatives.

Patients should receive the booklet during the consultation with a cardiologist, a nurse or a heart failure nurse. The shared decision making process can be improved when physicians decide to stop curative treatments; the booklet should be handed to the patient before in order to empower the patient in making a treatment choice using shared decision making principles.

The booklet can help improve the shared decision making process at the Cardiology department at the Amsterdam UMC, location VUmc.

Further research and development are needed to implement the booklet in the Amsterdam UMC effectively, location VUmc to improve the shared decision making process.

Glossary

VUmc
Vrije Universitateit medisch centrum, it is used to indicate the hospital Amsterdam UMC, location Vumc.

Heart failure
Chronic cardiac disease in which the heart does not pump enough blood through the body. (American Heart Association, 2017)

Advanced heart failure
Stage D of heart failure, the patient is not expected to survive in the following 12 months. In this stage, conventional heart therapies and symptom management strategies are no longer working. (American Heart Association, 2017)

Shared decision making
Approach defined by the Amsterdam UMC project “Appropriate care in the last phase of life” as the “process in which patients, relatives, physicians and nurses are encouraged to share thoughts and decisions upon treatment options”.

Life-prolonging treatments
Any medical procedure, treatment, or intervention which uses mechanical or other artificial means to sustain, restore, or supplant a spontaneous vital function, or which affords no reasonable expectation of recovery from a terminal condition. When applied to a patient with a terminal condition, they prolong the dying process. (Segen’s Medical Dictionary, 2011)

End-of-life care
Healthcare services provided to people with a terminal illness that is considered advanced, progressive and incurable.
In this report it is referred to life- prolonging treatments and palliative care options offered to patients with worsening advanced heart failure.

Quality of life

The Quality of life Research Unit of the University of Toronto defines quality of life as "the degree to which a person enjoys the important possibilities of his or her life."(Quality of life Research Unit, 2019)
In healthcare this term is used to define how a certain condition or treatment may benefit a patient on an individual level.

Decision aids

Often referred to them as "patient decision aids" or "patient decision tools", they are tools designed to help people participate in decision making about health care options. They provide information on the options and help patients clarify and communicate the personal value they associate with different features of the options. (IPDAS, 2017)

Healthcare providers

Professionals that are responsible for the care of the patient.
In this graduation project the term refers in particular to physicians, cardiologists and nurses.

CCU

Cardiac Care Unit: It is the department of cardiac intensive care in the hospital VUmc.

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1 Introduction to the project

This chapter is an introduction to the scope, the research questions, and the design process of this graduation project.

This chapter consists of:
- 1.1 Introduction
- 1.2 Aim
- 1.3 Method

1.1 Introduction

In The Netherlands, 120,000 persons suffer from heart failure. (Leening et al., 2018) The illness is long and complicated, and it progressively deteriorates. In particular, the advanced stage is described as the phase in which “conventional heart therapies and symptom management strategies are no longer working.” (American Heart Association, 2017)

As the condition worsens, patients must face several choices of withholding or withdrawing life-prolonging treatments. To make a choice, the patient must consider their goals, their preferences, and the impact of treatments on their quality of life. Patients with advanced heart failure are not always fully aware of the choices and consequences of treatment and care. It can be attributed partly to poor communication from healthcare providers, and partly to their emotional state and illness. Healthcare providers find it challenging to initiate discussions about palliative care, as they are uncertain of the right timing, their role in the discussion, the effect on patients, and they lack the communication skills and comfort to carry out the conversation about treatments for the end of life. (Schallmo, Dudley-Brown & Davidson 2019) (Ahluwalia et al., 2013)

Decision making and treatment planning are significant aspects of care for patients and their families during an illness, especially in the advanced stage. (Price et al., 2019) Heyland et al. (2003) show that most patients and their families are open to discuss life-prolonging treatment options because they want to know what to expect.

The American Heart Association recommends healthcare providers to approach treatments decision using the shared decision making approach. (American Heart Association, 2017)

Shared decision making is a “process in which patients, relatives, physicians, and nurses are encouraged to share thoughts and decisions upon treatment options[1]”. This approach establishes a partnership between the patient, the family, and the healthcare providers to make the best decision considering the desires of the patient. In this partnership, healthcare providers offer medical evidence and support while the patient and the family provide personal goals and preferences.

1. Definition of shared decision making in the Amsterdam UMC project “Appropriate care in the last phase of life”

This graduation project focus on how shared decision moments among healthcare providers, the patient and family can be supported on life-prolonging treatments in advanced heart failure in the hospital ward through design.

1.2 Aim

Scope

With the support of the VUmc and the Delft Design End of life Lab, this project explores how design can contribute to offer appropriate care to improve the shared decision making process of life-prolonging treatments of hospitalized patients with advanced heart failure condition at the end-life stage.
The aim of this graduation project is to design an aid for patients with advanced heart failure, in hospital, to be part of the shared decision making process about their treatment and care, by giving them a voice in the process.

Research questions

This present graduation project focuses on answering the following research questions:

- *How are patients with advanced heart failure in hospital currently supported during the decision making moments for life-prolonging treatments by healthcare providers?*

- *What could help patients with advanced heart failure in taking part to shared decision making with healthcare providers for life-prolonging treatment decisions?*

1.3 Method

The project follows the double diamond model constructed by the Design The project follows the double diamond model constructed by the Design Council UK. (Design Council UK, 2019) This model divides the design process into four distinct phases. Discover, Define, Develop and Deliver. The phases have a diverging or converging objective, to enable the designer to explore the issue widely or deeply and then to narrow down the scope of action. This process is illustrated in Figure 1.
The double diamond approach divides this thesis in the chapters of the four phases.

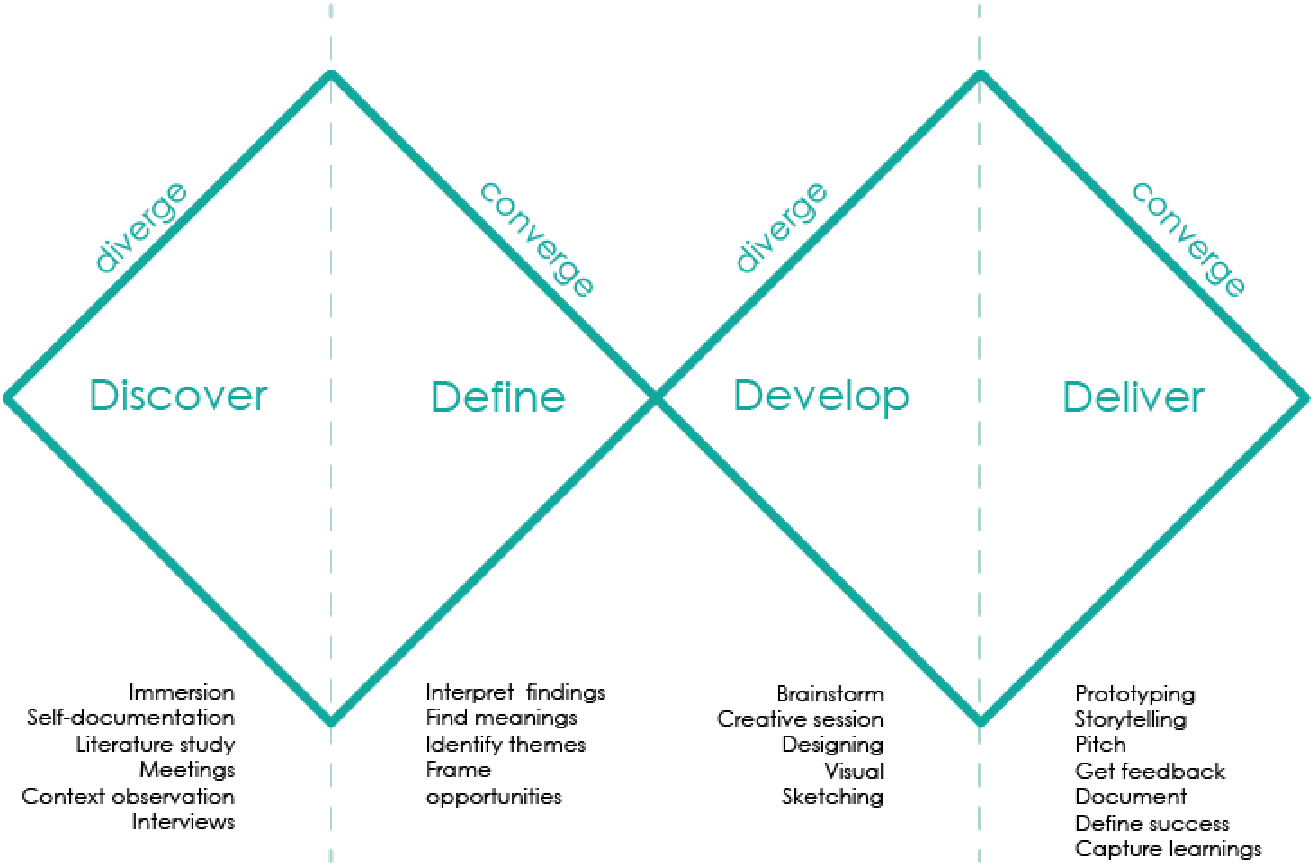

Figure 1
Double diamond design process visualization

Discover

The aim of the first phase is to explore the context and understanding what the problem is.
In this phase literature research, observations and interviews with healthcare providers were carried out.
This phase is described in Part 1: Research, in the chapters:
"2 Advanced heart failure"
"3 Shared decision making"
"4 Observation in Cardiology"
"5 The decision making process in Cardiology."

Define

The second phase, Define, focuses on analysing the results gathered in the Discover phase and define the brief for the following steps.
Ideas are visualised in a shared decision making map, which serves to highlight insights and to create a clear brief that frames the design challenge.
This process can be found in Part 1: Research, in the chapter "5 The decision making process in Cardiology", and in Part 2: Design Brief.

Develop

The second diamond focuses on exploring different solutions to the design brief formulated in the previous phase.
In this step, the project focuses on facilitating creative sessions and developing and prototyping different concepts to answer the requirements of the design brief.
The process is described in Part 3: Design, in the chapter "7 Design iterations."

Deliver

The last phase, Deliver, the design concept is validated through interviews.
Next to that, the research questions are answered and the project limitations and recommendations are discussed.
This phase is included in Part 3: Design in the chapter "8 Design: Booklet Deciding with heart" and Part 4: Conclusion.

It should be noted that, the design process is not a linear process.Designing is an iterative action that always moves back and forth through the different stages of design.

Part 1

Research

After defining the aim and the method, the following section focuses on investigating the experience of shared decision making about life-prolonging treatments with patients with advanced heart failure in literature and in context. The following chapters include findings from the literature research, observation and interviews.

This section includes:
Chapter 2: Advanced heart failure
Chapter 3: Shared decision making
Chapter 4: Observation in Cardiology
Chapter 5: The decision making process in Cardiology.

2 Advanced heart failure

The following chapter describes the context of patients with advanced heart failure. The chapter will describe the signs, symptoms, causes and care trajectory for these patients. After, life-prolonging treatments and palliative care options will be explored as well as the context in which these decisions are usually made.

This chapter consists of:

2.1 Advanced heart failure
2.2 Life-prolonging treatment choices in advanced heart failure
2.3 Palliative care in patients with advanced heart failure
2.4 Context and involvement in life-prolonging decision making with advanced heart failure patients
2.5 Conclusion

2.1 Advanced heart failure

Heart failure is a cardiac condition in which the heart is unable to pump sufficiently to maintain blood flow to meet the body's needs. (Oberg & Guarneri, 2018) Signs and symptoms of heart failure commonly include shortness of breath, excessive tiredness, and leg swelling as shown in Figure 2. (National Clinical Guideline Centre, 2010)

The causes of heart failure can be congenital or due to a coronary artery disease including a previous myocardial infarction (heart attack), high blood pressure, atrial fibrillation, valvular heart disease, excess alcohol use, infection, and cardiomyopathy of an unknown cause. (National Clinical Guideline Centre, 2010) (McMurray JJ, 2005) These conditions cause heart failure by changing either the structure or the functioning of the heart. (National Clinical Guideline Centre, 2010)

Heart failure is typically diagnosed based on the history of the symptoms and a physical examination, with confirmation by echocardiography. (National Clinical Guideline Centre, 2010) Heart failure affects women and men in the same percentage, although women tend to be older when diagnosed with heart failure. (Strömberg & Mårtensson, 2003) Taylor et al. (2019) show that in the UK, between the year 2000 and 2017, the average age at diagnosis was 77.1 overall (standard deviation 10.6). This study shows that when women were diagnosed on average almost five years older than men: women were 79.6 and men were 74.8 years old when diagnosed.

The New York Heart Association (NYHA) defines four different stages of heart failure based on the functional classification of symptoms, as Table 1 shows. (American Heart Association, 2017)

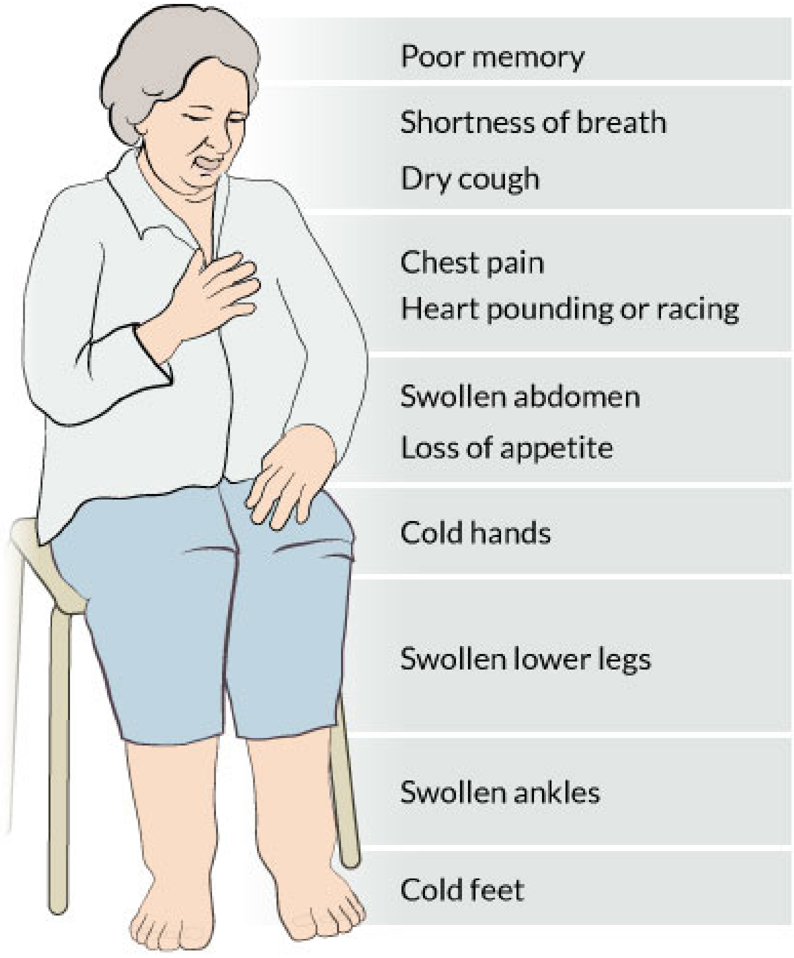

Figure 2
Symptoms of heart failure (Ted Rogers Centre for Heart Research, 2019)

Table 1
The New York Heart Association (NYHA) Functional Classification

NYHA Class	Description of Heart Failure Related Symptoms
I	Patients with cardiac disease but without resulting in limitation of physical activity. Ordinary physical activity does not cause undue fatigue, palpitation (rapid or pounding heart beat), dyspnoea (shortness of breath), or anginal pain (chest pain).
II	Patients with cardiac disease with slight limitation of physical activity. They are comfortable at rest. Ordinary physical activity results in fatigue, palpitation, dyspnoea, or anginal pain.
III	Patients with cardiac disease resulting in marked limitation of physical activity. They are comfortable at rest. Less than ordinary activity causes fatigue, palpitation, dyspnoea, or anginal pain.
IV	Patients with cardiac disease resulting in the inability to carry on any physical activity without discomfort. Symptoms of heart failure or the anginal syndrome may be present even at rest. If any physical activity is undertaken, discomfort is increased.

The second classification is the ACC/AHA classification, developed by the American College of Cardiology Foundation and the American Heart Association in 2001, which is based on risk factors as a classification model, as shown in Table 2 (American Heart Association, 2017).

Table 2
The ACC/AHA Classification

ACC/AHA Class	Objective assessment
A	No objective evidence of cardiovascular disease. No symptoms and no limitation in ordinary physical activity.
B	Objective evidence of minimal cardiovascular disease. Mild symptoms and slight limitation during ordinary activity. Comfortable at rest.
C	Objective evidence of moderately severe cardiovascular disease. Marked limitation in activity due to symptoms, even during less-than-ordinary activity. Comfortable only at rest.
D	Objective evidence of severe cardiovascular disease. Severe limitations. Experiences symptoms even while at rest.

In the ACC/AHA classification, progression occurs only in one direction and it can be complemented by the NYHA classification as shown in Figure 3. (Heartfailure.org, 2019)

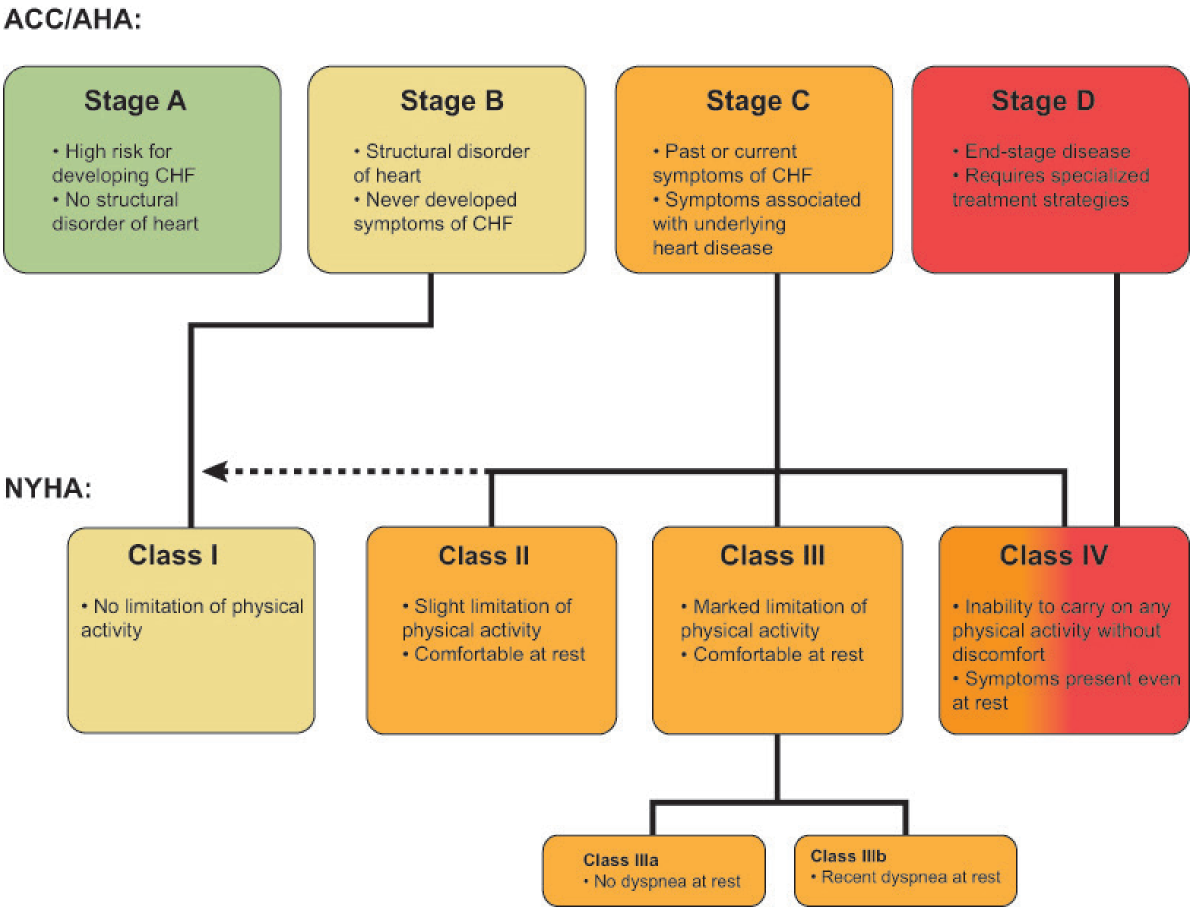

Figure 3
Classification methods crossover (Heartfailure.org, 2019)

Due to the chronic identity of the illness, the patient can find themselves in one of the stages for a long time, often several years. As the illness progresses, the exacerbations of their symptoms become more frequent and more intense, leaving them with declining health and decreasing functional status. (Lowey et al., 2013)
Figure 4a shows the progression of heart failure, and figure 4b shows the effect the illness has on the physical, social, psychological, and spiritual well-being of the patient. Death due to heart failure is usually preceded by severe signs and symptoms, frequent hospitalizations, and deterioration. (Wingate & Wiegand, 2008)

In this report, we will refer to patients with stage D-IV heart failure, defined as advanced heart failure, with a life expectancy shorter than 12 months and not eligible for a heart transplant or implantable devices (such as Implantable Cardioverter Defibrillator Left Ventricular Assist Device).
Patients with advanced heart failure, who have been admitted to the hospital, the patients are weak and bedridden. They experience tiredness, shortage of breath, swollen limbs and anxiety. They require constant care, and their life is dependent on medication to support the heart pumping function and the drainage of the liquids from their body. Patients can often suffer from comorbidities together with heart failure such as diabetes, COPD, cancer, dementia, which makes the trajectory of the illness more complex and difficult to predict.

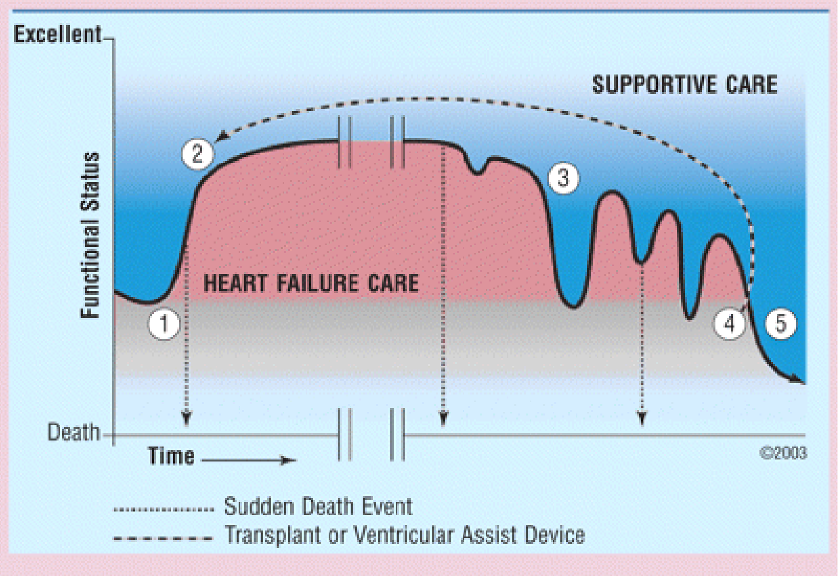

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Figure 4a
Trajectory of heart failure. (Wingate, 2008)

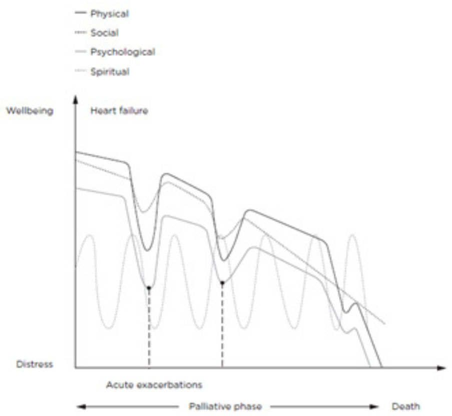


Figure 4b
Heart failure: physical, social, psychological, and spiritual well-being in the last year of life. (Murray, 2007)

2.2 Life-prolonging treatment choices in advanced heart failure

Depending on the stage of the disease, the patient faces different treatment choices. “Pumping Marvellous Foundation”, a British heart failure charity association which supports heart failure patients (Pumping Marvellous Foundation, 2019), visualises the illness trajectory and possible treatment choices as metro lines (see Figure 5, the back of the flyer can be found in Appendix B) (Pumping Marvellous Foundation, 2019). This model shows the care path of a patient from prevention to palliative care, although it does not consider the end-stage phase of the illness and the end of their life.

At a certain point, usually in the part visualised as “zone 6”, the patient must face the choice of life-prolonging treatment decisions: no active treatments can help to improve the heart conditions, and from then on, patients face the decline of their health. Some treatments pose a dilemma between quantity and quality of life, as certain treatments introduce risks that have to be taken into account as well.

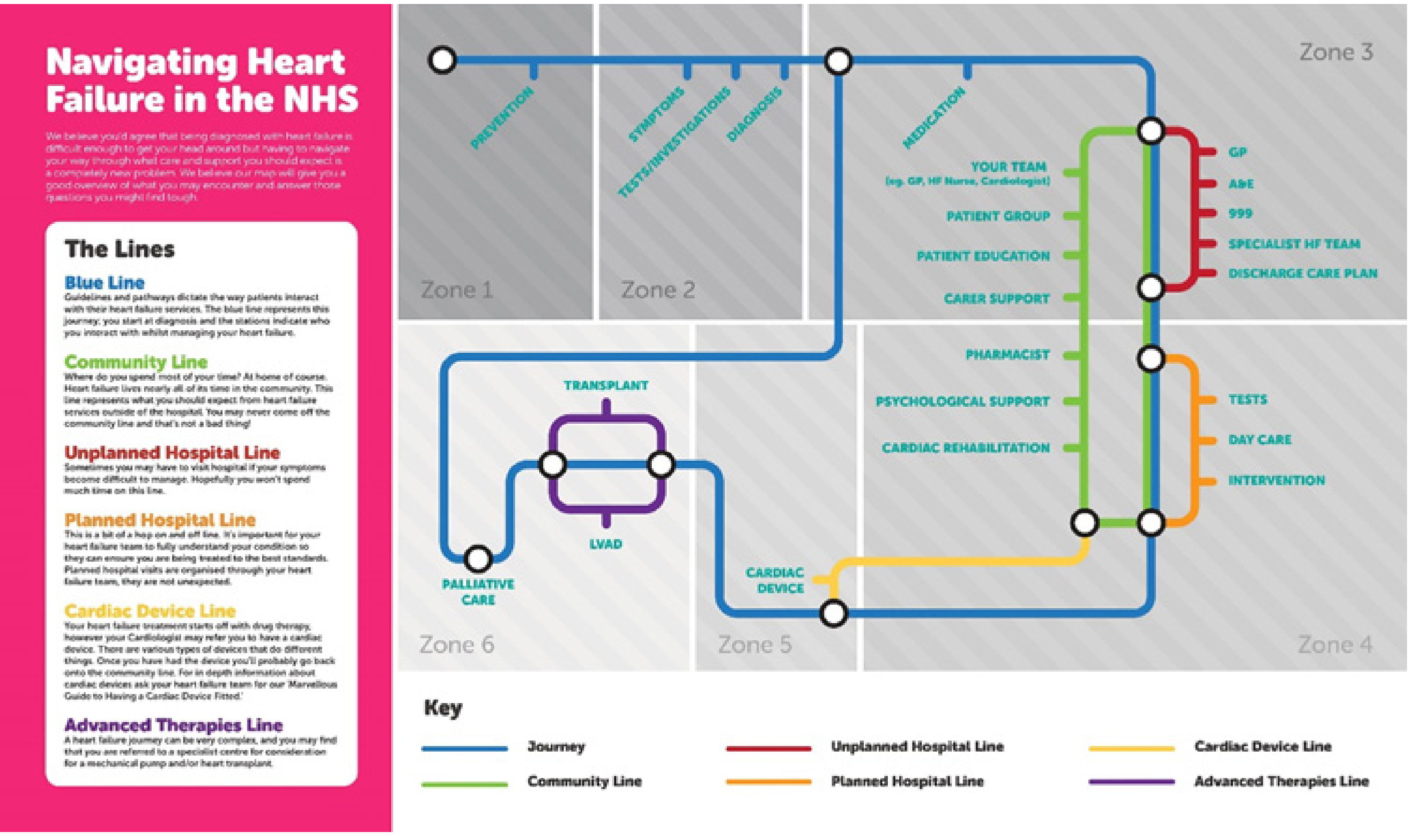
The patients face choices related to life-prolonging treatments that are defined by the following treatment restrictions protocols (Medisch Centrum Leeuwarden,2019):

- **Code A**: No treatment restriction. The patient does not pose limitations for treatments. This option can include continuity of therapies, artificial ventilation and artificial feeding with the scope of prolonging patient’s life.

- **Code B**: Treatment restrictions. The patient can choose to restrict some treatments while allowing others. For example, allowing antibiotics in case of infection but not allowing mechanical ventilation.

- **Code C**: No more treatments. The patient refuses any life-prolonging treatment, receiving only treatments that focus on comfort, such as pain relief, prevention of thirst, anxiety and shortness of breath. This is usually referred to as the palliative trajectory.

The treatment chosen should be the result of an agreement between the healthcare providers and the patient. These treatment decisions can be reversed and, if taken in advance, they should be re-evaluated with healthcare providers periodically to make sure that they are still in line with the patient’s desires. (Caswell J., 2016)



Navigating Heart Failure in the NHS

We believe you'd agree that being diagnosed with heart failure is difficult enough to get your head around but having to navigate your way through what care and support you should expect is a completely new problem. We believe our map will give you a good overview of what you may encounter and answer those questions you might find tough.

The Lines

Blue Line
Guidelines and pathways dictate the way patients interact with their heart failure services. The blue line represents this journey; you start at diagnosis and the stations indicate who you interact with whilst managing your heart failure.

Community Line
Where do you spend most of your time? At home of course. Heart failure lives nearly all of its time in the community. This line represents what you should expect from heart failure services outside of the hospital. You may never come off the community line and that's not a bad thing!

Unplanned Hospital Line
Sometimes you may have to visit hospital if your symptoms become difficult to manage. Hopefully you won't spend much time on this line.

Planned Hospital Line
This is a bit of a hop on and off line. It's important for your heart failure team to fully understand your condition so they can ensure you are being treated to the best standards. Planned hospital visits are organised through your heart failure team, they are not unexpected.

Cardiac Device Line
Your heart failure treatment starts off with drug therapy, however your Cardiologist may refer you to have a cardiac device. There are various types of devices that do different things. Once you have had the device you'll probably go back onto the community line. For in depth information about cardiac devices ask your heart failure team for our 'Marvellous Guide to Having a Cardiac Device Fitted.'

Advanced Therapies Line
A heart failure journey can be very complex, and you may find that you are referred to a specialist centre for consideration for a mechanical pump and/or heart transplant.

Figure 5
Pumping marvellous flyer: heart failure illness metro lines. Zone 6 is highlighted in red and shows the advanced stage of heart failure in which the patient can receive palliative treatments, although the map does not show the eventual end of the heart failure journey.

2.3 Palliative care in patients with advanced heart failure

The following paragraphs describe what palliative care is and, in particular, what kind of implications it has for patients with advanced heart failure.

The World Health Organization defines palliative care as an interdisciplinary approach that improves the quality of life of patients and their families in life-threatening illnesses. Palliative care addresses the patient's physical, psychological, and spiritual needs.

In particular, palliative care(WHO, 2012):

- provides relief from pain and distressing symptoms;
- approaches dying as a normal process;
- does not rush or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients' illness and in their bereavement;
- uses a team approach to address the needs of patients and their families, including grief counselling, if necessary;
- will enhance the quality of life, and may also positively influence the course of illness;
- can be provided as the primary treatment or along with curative treatment and, it can be introduced at any stage of the illness.

Palliative care is administered by a team of physicians, nurses, or other health professionals who work together with primary care professionals to provide additional support. In the hospital, the term palliative care often is used by healthcare providers to designate therapies with no curative intent for terminally ill patients.

Palliative care is well known for its benefits in oncologic patients, and it has been proven that it can offer benefits to patients with heart failure as well. (Kavalieratos et al., 2016) A Canadian study (Wiskar, Toma & Rush, 2013) reports how in the current practice palliative care is not often presented to patients with heart failure, due to the unpredictable trajectory of the illness and the misperception of palliative care from the patient and the physicians, despite cardiovascular societies guidelines recommend this approach throughout the illness trajectory. (Yancy et al., 2013) Figure 6 illustrates the benefits of the introduction of palliative care through the whole heart failure trajectory.

Wiskar, Toma and Rush (2013) encourage the collaboration between Cardiology and palliative care to make palliative care more accessible to patients with advanced heart failure. This project acknowledges the importance of offering palliative care during the entire illness trajectory, although in this thesis palliative care would be considered as a primary care option when curative treatments are no longer possible.

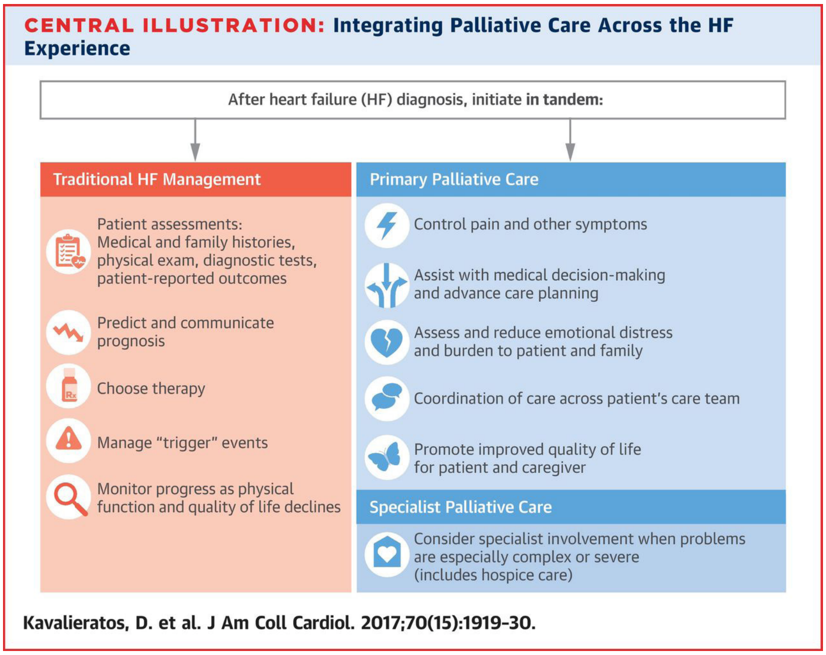


Figure 6

Integration of palliative care for heart failure patients across the whole heart failure trajectory (Kavalieratos et al., 2017)

2.4 Context and involvement in life-prolonging decisions with advanced heart failure patients

Context

Heart failure patients are often hospitalized following an acute episode of their illness. Depending on the gravity of their condition, they can be admitted to the Cardiac Care Unit (CCU) or in the Cardiology department. The length of stay varies depending on the case. Usually, the length of stay at the cardiology department varies between one night up to a month. It is mostly during the recovery in the Cardiology department that the healthcare providers communicate to the advanced heart failure patient about the termination of treatments and arrange an adequate aftercare plan. Therefore, the project focuses on the hospitalization of advanced heart failure patients in Cardiology.

Professionals involved

Team-based care for heart failure patients in Cardiology involves several different professionals, as: (Cooper & Hernandez, 2016)

- Primary care providers: cardiologists, physicians and nurses
- Heart failure nurses
- Clinical pharmacists
- Dieticians
- Physical therapists
- Social workers
- Psychologists

In different degrees, they have a direct influence to support the patient in the treatment decision making. Figure 7 illustrates the people in Cardiology connected to the care of advanced heart failure patients. In the inner circle, we can find the people with direct influence in the decision making process about life-prolonging treatments, while people and factors in the outer circles have a more indirect role in influencing the decision making process.

2.5 Conclusion

Heart failure is a progressive life-threatening illness. Palliative or life-prolonging decisions have to be made at the advanced stage of this disease. Numerous healthcare professionals and family members are involved in providing care for patients with advanced heart failure. These stakeholders have various levels of influence on the decision making process, which makes it a complex endeavour. Therefore, the next chapter will analyse models, uses and implications of shared decision making for patients with advanced heart failure.

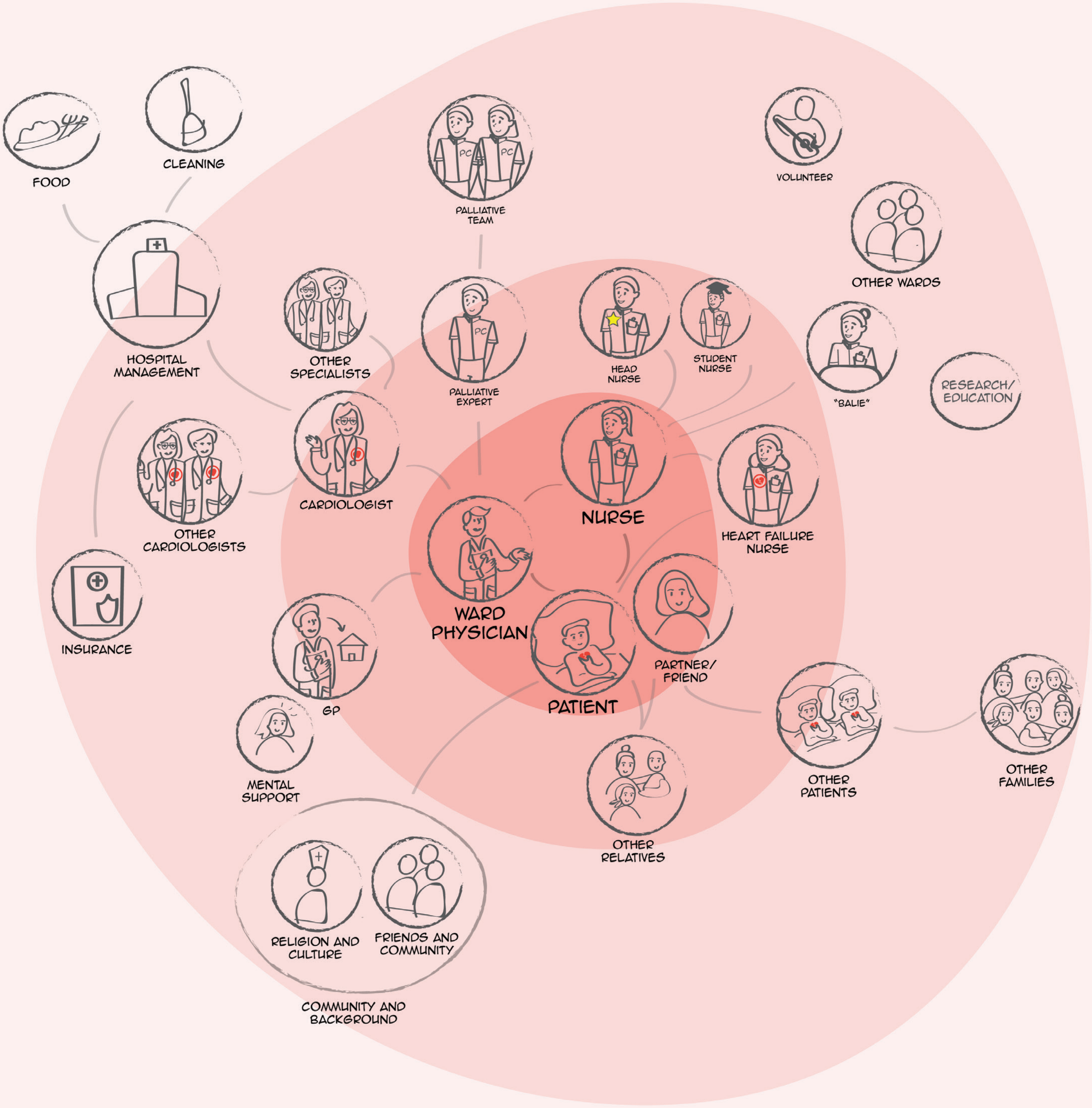


Figure 7
People involved in the life of a heart failure patient in the Cardiology department.

3 Shared decision making

The following chapter describes the theory of shared decision making, the model to implement it in clinical practice and what the current practice is with advanced heart failure patients who are facing palliative or life-prolonging care decisions.

This chapter consists of:

- 3.1 Method
- 3.2 Shared decision making in theory
- 3.3 Shared decision making in practice for advanced heart failure patients
- 3.4 Conclusion

3.1 Method

To find the appropriate literature, a manual research was conducted on papers in the databases PubMed and Scopus. The research keywords were: Advanced care planning, end-of-life, heart failure and shared decision making. The results were filtered by including only literature in English and Dutch about humans and adults. While searching the databases, suggestions from the databases or recommended by the supervisory team that were pertinent to the research topic were included. The papers included were 52 in English and one in Dutch. Included papers, were highlighted, the most significant findings were summarized and compared to find significant patterns.

3.2 Shared decision making in theory

The approach

Shared decision making is defined by the Amsterdam UMC project "Appropriate care in the last phase of life" as a "process in which patients, relatives, physicians and nurses are encouraged to share thoughts and decisions upon treatment options". Shared decision making happens when the patient is required to make a treatment choice. (Godolphin, 2003) A physician (or other healthcare professional) has to inform patients and engage them in shared decision making (Makoul & Clayman, 2006); (Towle et al., 1999).
Meyers & Goodlin (2016) explain how "shared decision making entails the following elements: involvement of the patient and the healthcare providers, sharing of information between parties, expression of treatment preferences on both sides (what is desired and what is medically feasible) and consensus about

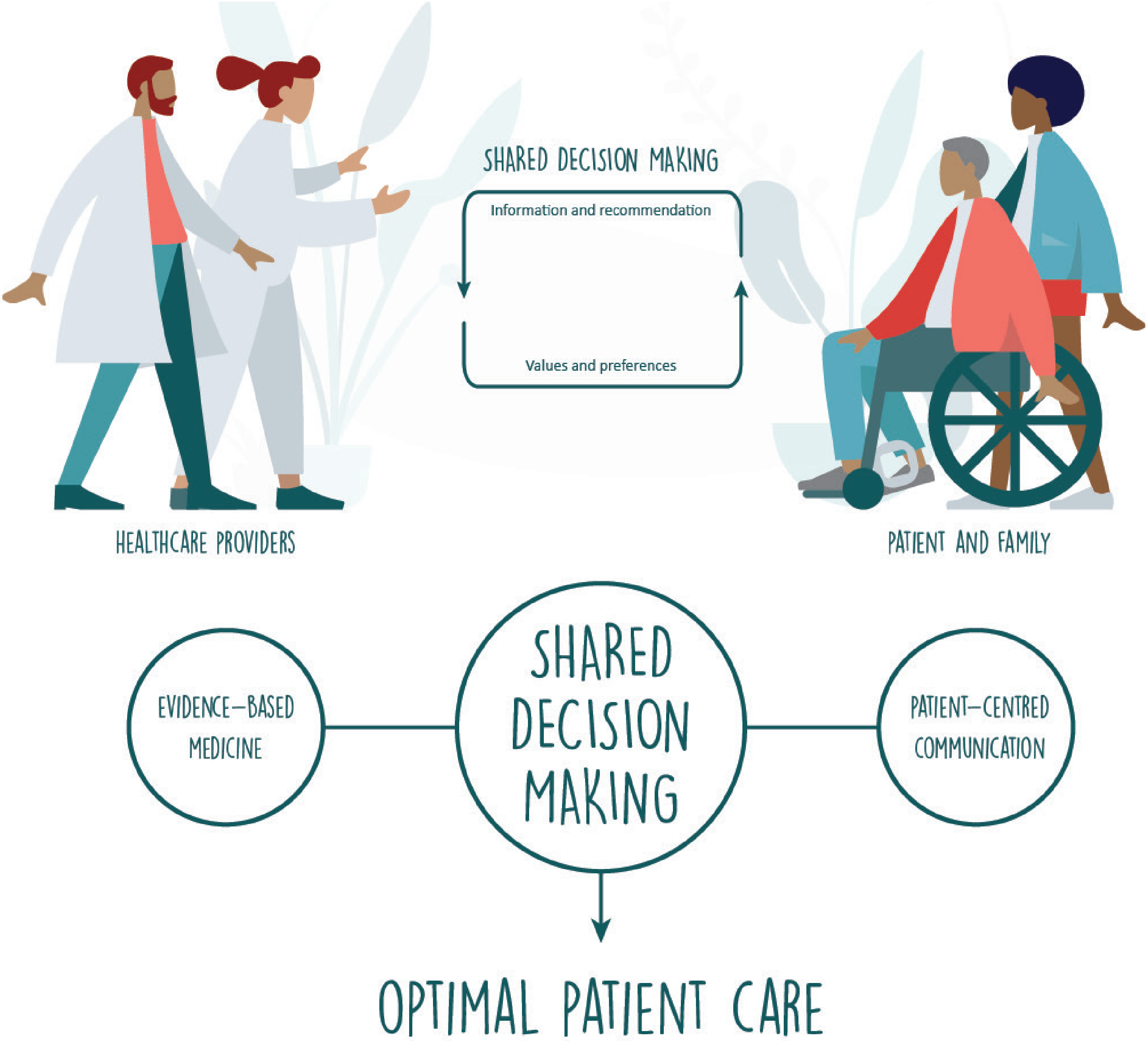


Figure 8
Illustration of the shared decision making approach between healthcare providers, patients and family.

a treatment plan.” Figure 8 illustrates the elements involved in shared decision making.
Approaching a treatment decision using shared decision making leads to patients and relatives being more confident in the treatments decisions and being more satisfied with the care received. (Elwyn et al., 2012)

Making a partnership during the shared decision making process is vital for the engagement of the patient. Towle et al. (1999) define the following competencies that physicians must have:

1. Build a trustful relationship with a patient
2. Determine the patient’s preferences for information (e.g., “How much do you want to know? How would you like to receive this information?”)
3. Determine the patient’s preferences for their role in decision making and individuate any uncertainty about the actions to take
4. Initiate a dialogue, welcome patient’s ideas, concerns and expectations
5. Identify choices (including ideas and information the patient may have) and evaluate the research evidence concerning the individual patient
6. Show evidence and help the patient to reflect and evaluate the impact of the options on the base of their values and lifestyles. Take into account the patient’s preferences for information and decision role, and how the framing may influence decision making (e.g. how to present the options)
7. Make or negotiate a decision together. In case conflicts arise, solve them in partnership.
8. Agree upon an action plan, document it and complete arrangements for follow-ups.

Culture, social behaviour and age are factors that should be taken into account when involving patients during the informed shared decision making process.

Inter-professional shared decision making

Shared decision making, as defined by the Amsterdam UMC, also involves a team of health professionals and significant others, such as partners and family. This team-based approach is called inter-professional shared decision making. It offers the benefit of the traditional patient-physician shared decision making while employing the skills of each member of the team. (Sieck, Johansen & Stewart, 2015)
Inter-professional shared decision making includes the patient as an active participant in a team of different professionals. The decisions do not involve only the medical team, but they are a joint effort among patient, family, physicians and other healthcare providers.

Inter-professional shared decision making contributes to meet the requisites of Towle et al., (1999) in different encounters, allowing team members to help the patient in processing the decision and increase the efficiency of care. (Sieck, Johansen & Stewart, 2015) In order to be effective, inter-professional shared decision making requires the alignment of roles, respect for other roles and consistency of information. (Sieck, Johansen & Stewart, 2015) Every profession should be actively participating as a team member, capitalizing the strength of their profession. For example, nurses may be the best person to discuss treatment options with the patient because they tend to spend more time with the patients. (Sieck, Johansen & Stewart, 2015)

As mentioned in the previous chapter[2], there are several professionals involved in the care of advanced heart failure patients. Of these professionals, physicians and nurses in the Cardiology department are the ones who are primarily involved in the shared decision making process about life-prolonging treatments. Therefore, the term shared decision making process in this project will refer to the interaction between family, physicians (in particular ward physicians) and nurses in the department of Cardiology in the VUmc hospital. (see Figure 9)

[2] See paragraph 2.4 Context and involvement in life-prolonging decision making with advanced heart failure patients.

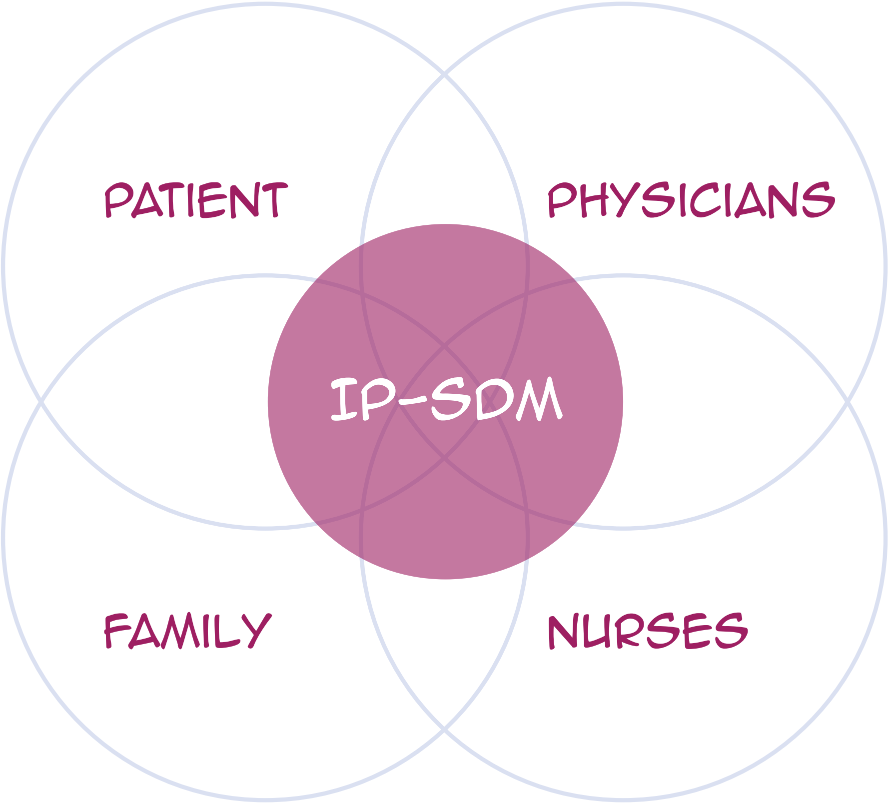


Figure 9
Inter-professional shared decision making model used for the project: it involves the active participation of the patients, family, physicians and nurses.

Shared decision making model for clinical practice

The project will use Elwyn et al.'s (2017) shared decision making model (see Figure 10) for clinical practice based on team, option and decision talk. This model has three steps: first introducing choice, describing options, often by integrating the use of decision aids, and helping patients explore preferences and make decisions. This model supports a process of deliberation, in which "what matters most" to patients should be explored and how this could influence the decision.

The model suggests a step-wise process, although the process is a cycle of fluid interactions, as the shape of the model in Figure 10 suggests.
Firstly, the care team and the patient should engage in a so-called "Team talk". Team talk refers to engaging in a partnership with the patient. Both parties must agree in working together, and healthcare providers should offer support, introduce reasonable choices and ask about personal goals (Elwyn et al., 2017). Then, the team can proceed to the "Option talk". In this step, healthcare providers give more detailed information about the possible options.
In the end, in the "Decision talk" the team considers informed preferences and

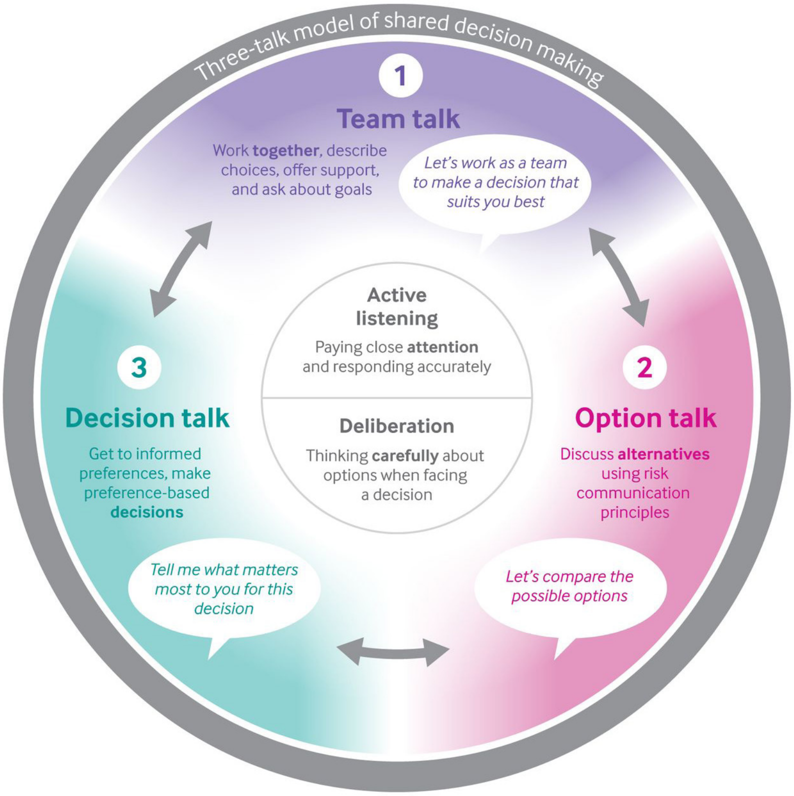


Figure 10
Shared decision making model for clinical practice (Elwyn G., 2017)

delivers preference-based decisions.
In this process, the team of healthcare providers must support the patient during deliberation. The term deliberation (see Figure 10) represents a process of considering information about the pros and cons of their options, considering their implications, and thinking about possible futures, on a practical and an emotional level (Elwyn et al., 2012). Deliberation starts as soon as the patient is informed about having options, and the process is iterative and recursive (Elwyn et al., 2012). In this phase, healthcare providers should explore the patient's reactions to information and avoid that the patient takes decisions when not sufficiently informed (Elwyn et al., 2012).
Deliberation may, in part, be done outside the appointment with healthcare providers, although often patients wish to confirm their preferences with a trusted professional. (Elwyn et al., 2012)

The model also includes the use of decision support interventions, to summarize information in ways that are accessible to patients, using current evidence to explain harms and benefits. (Elwyn et al., 2012) Decision aids can offer crucial support to the patient in the deliberation process.

3.3 Shared decision making in practice for advanced heart failure patients

Research has been conducted to assess the use of shared decision making with heart failure patients regarding their life-prolonging treatments in practice. This section focus in particular on the communication between healthcare providers and patients, which is the basis for shared decision making.

Findings

The research shows that patients with advanced heart failure and their family have a need for better communication with healthcare providers about the advanced stage treatment decisions. Effective and clear communication between healthcare providers and patients is the fundament of shared decision making. Moreover, proper communication, if done in time and with the right approach, can encourage self-management of medication, alleviate physical and psychological conditions, prevent unplanned admissions, lead to informed decision making and ultimately provide a good death. (Harding et al., 2008)
Usually, patients receive life-prolonging or palliative options too late. (Quill, 2000) The timing of the conversation is essential to ensure the best end-of-life care. Healthcare providers face a dilemma in introducing the topic early enough to organize a timely care strategy. They need to choose between having the conversation early, when death is unlikely to happen, or when death appears more likely. (Glogowska et al., 2016)

In one Canadian study (Caldwell, Arthur, & Demers, 2007), patients expressed the need for being able to make end-of-life plans before they were too ill to do so. The patient and their family must fully understand all their options to align the treatments with their specific goals, preferences, and values, considering the quality of life. (Hupcey, Kitko & Alonso, 2016)

Despite these findings show a need for patients and families to have timely conversations, healthcare providers still face barriers initiating conversations about life-prolonging treatments and palliative care.

The following paragraphs describe these barriers in detail.

Barriers for healthcare providers in initiating conversations about life-prolonging treatments and palliative care.

An honest conversation about a bad prognosis can be beneficial for the patients, and if conducted appropriately the stress on patients can be minimal. Still, discussions about the end-of-life are often avoided or delayed by healthcare providers.

The following paragraphs show the current barriers that prevent healthcare providers in initiating conversations with advanced heart failure patients in end of life treatment decisions.

The barriers are:

1. Uncertainty of the illness trajectory
2. Unclarity of the roles in the care team
3. Fear that conversation will bring distress and take away hope
4. Limited time
5. Lack of training and education for of communication skills in end-of-life talks
6. Focus on active treatment by physicians
7. Limited understanding amongst people with heart failure

1. Uncertainty of the illness trajectory

Heart failure is characterized by uncertain and variable clinical trajectory, which makes life expectancy estimation harder. This concern was expressed frequently in multiple studies (Schallmo, Dudley-Brown & Davidson 2019) (Selman et al., 2007) (Lowey et al., 2013) (Green et al., 2011) (Adler et al., 2009) The unpredictability of the disease causes healthcare providers to disagree on patient prognosis or delay the end-of-life conversation. Heart failure is also perceived as relatively benign in comparison with cancer, and it is not associated with the dying phase because “you can live with it for so long”.(Selman et al., 2007)

2. Unclarity of the roles in the care team

End-of-life care involves different professionals that work together as a multidisciplinary team. Although their role in care is defined, their role in starting a conversation about life-prolonging treatmetns is still not clear. The unclear communication structure in the hospital environment can lead to miscommunication between healthcare providers and unclarity on the responsible role in initiating the conversation about palliative care. (Schallmo, Dudley-Brown & Davidson 2019) The question among healthcare providers is which profession in the team is the most suitable to discuss palliative care with the patient and family.

Some physicians, in fact, hesitate to initiate palliative care conversations because they are concerned, they may invade another healthcare providers responsibility. In English study (Green et al., 2011) it is suggested that cardiologist specialists may be the best candidates to initiate conversations, as they have more expertise and they have a longer relationship with the patient.

Nurses were also indicated as good candidates to talk about sensitive topics due to the amount of daily contact they have with patients. Although, despite their great contribution, studies have also shown that nurses face further impediments in initiating the conversation.

In Canada, a study (Plaisance et al., 2018) reports that nurses are reluctant to discuss death with patients due to a social taboo, even when aware of official directives and patient's values. Moreover, Sussman et al. (2019) report that healthcare assistants feel disempowered to communicate their observations. (Sussman et al., 2019)

In the US, when nurses want to initiate conversation, Schallmo, Dudley-Brown & Davidson (2019) highlight that "nurses feel sometimes in direct conflict with physicians, especially when nurses want to promote palliative care earlier in the heart failure disease trajectory and physicians want to continue aggressive treatment".

On the other side, interestingly, Hupcey, Kitko and Alonso (2016) show that one of the main reasons for the lack of dialogue between the healthcare provider and the patient is that both are waiting for the other to start the conversation. This study also reports that "nurses typically believe that it is the physician's responsibility to begin these conversations, so they do not either initiate the conversations themselves nor encourage patients". (Hupcey, Kitko and Alonso, 2016)

3. Fear that conversation will bring distress and take away hope

Healthcare providers, in initiating end-of-life conversation, face the dilemma of scaring patients and taking away their hope versus providing some warning that death may occur. (Glogowska et al., 2016) Many physicians are uncertain if they are helping or harming patients when honestly discussing negative prognosis. (Davidson, 2007) Physicians feel that conversations about life-prolonging treatments and palliative care may bring distress and increase anxiety. They are concerned that patients may feel abandoned or give up hope if they initiated a conversation about palliative care.

4. Limited time

The American study by Schallmo, Dudley-Brown and Davidson, (2019) shows that the lack of time in healthcare providers' schedules is a significant barrier in initiating conversations about life-prolonging treatments and palliative care with patients. When there is not adequate staff in the hospital, it is difficult to make time to build a relationship with the patient, which is necessary to talk about complex matters, such as end-of-life conversations. The perception of the limited time available also affects the family's ability to ask questions and contributes to their poor understanding.

5. Lack of training and education for of communication skills in end-of-life talks

In the US, many healthcare providers cited inexperience in communication skills, a lack of confidence, or a lack of education, as a barrier to initiating the conversation with patients and their family. (Schallmo, Dudley-Brown & Davidson, 2019) In fact, palliative care and end-of-life care are not universally taught in university or residency programs. (Schallmo, Dudley-Brown & Davidson 2019)

6. Focus on active treatment by physicians

The cardiac care context is mainly oriented in optimizing medical management, treat symptoms and prolong life. The curative approach in care may be a barrier for physicians in approaching a difficult and time-consuming conversation with patients about the quality of life. (Howlett et al., 2010)

An English study (Green et al., 2011) highlights how cardiologists tend to focus on active treatments and dismiss the palliative trajectory until there are no more therapeutic options available. As a matter of fact, this study underlines that "Some physicians suggested that the cardiologists are resistant to initiate the transition to palliative care because they perceive it as a failure."

7. Limited understanding amongst people with heart failure

Another barrier in initiating end-of-life conversation with patients with advanced heart failure is their limited awareness of the disease. Misinformed patients may not understand the importance of end-of-life treatment choices so they may want to avoid talking about them. (Strachan, 2009)

Patients with advanced heart failure have been documented to possess a poor understanding of their condition, and they are not always involved in their care decisions.

In an English study (Gibbs et al., 2011) it is highlighted that half of the patients had been unable to get adequate information about their condition, and in Canada Howlett et al. (2010) show how "patients did not recall receiving material about their condition nor did they feel involved in the decision making process about their illness".

At times, either patients don't receive the information about the importance of end-of-life issues, or they receive the message but do not hear it. Even when the prognosis is routinely discussed, there is a concern about how the patients interpret such information. (Green et al., 2011)

> Communication is only effective if the patient fully understands what is being discussed.
> Sometimes, the acute nature of the illness in the end-stage decreases the cognitive function and stress may interfere with information processing and comprehension, making discussions ineffective. (Strachan, 2009)

To overcome some of these barriers and to give clear information to the patients it could be beneficial to introduce communication tools. Sussman et al. (2019) suggest using condition-specific pamphlets to engage the patient in early reflections and conversations about end-of-life care. Pamphlets are useful to establish a basic common understanding of illness-related end-of-life trajectories that can prepare patients and families for more detailed discussions with the staff.

These tools provide opportunities for all staff to play a role in discussions with patients and family and be appropriate means of transmitting information and supporting dialogue. (Sussman et al., 2019)

Moreover, Oczkowski et al. (2016) researched the effect of structured communication tool to help with decision making in Canada, concluding that the available evidence suggests that structured communication tools designed to assist in end-of-life decision making may improve the communication process.

Conversation approach

Initiating the conversation about life-prolonging treatment decisions is not the only concern. It is also important to focus on the communication approach and phrasing used in discussion with the patient. Back and Arnold (2006) propose a guideline of the words to use during discussions about bad prognosis. Their studies (Back & Arnold, 2006a) (Back & Arnold, 2006b) suggest asking patients how much they want to know first, to facilitate an explicit discussion and understand the patient’s needs. (Back & Arnold, 2006a)

Physicians often rely on their impressions to evaluate if their approach during a conversation with the patient is effective, although studies indicate that their self-evaluation is not always accurate. A more effective way is to check-in with the patient during the conversation. (Back & Arnold, 2006a) It is important to let the patient understand their situation, progressively including more information suitable for their evolving needs and communicate it in a way that the patient can understand. (Back & Arnold, 2006a)

Back and Arnold (2006a) invite physicians to ask patients questions like: “How much do you want to know about the likely course of this illness?” or “Some people want lots of details, some want the big picture, and others prefer that I talk to their family. What would be best for you?” to elicit an open response.

Moreover, Kelemen, Ruiz & Groninger (2016) suggest paying attention to that the language and phrasing used in communicating with patients since it “may significantly impact patient’s experiences, decisional outcomes, and family bereavement”.

As an example, focusing on the disease instead on the person, using the phrase

"your heart failure is worse" instead of "you are worse", it would help the patient avoiding potential negative emotions and may help the patient to engage more objectively with the physician.
Interestingly, after explaining the patient's prognosis Fine et al. (2010) suggest to focus on prioritizing emotional and quality of life issues in the conversation with the patient, listen more and speak less and offer support and emotional validation. Fine et al. study highlights how "patient and family satisfaction were higher when physicians used supportive statements to acknowledge patients' and families' feelings". The study suggests using statements like "We respect your decision" to support their decision, or "Whatever you choose we will not stop taking care of you," to avoid them to feel abandoned depending on the choice outcome. (Fine et al., 2010)

3.4 Conclusion

The shared decision making approach is beneficial in life-prolonging decisions in heart failure patients because it brings together values and preferences of patient and evidence-based medicine. However, seven barriers were found on the use of shared decision making in practice. The barriers consist of unclarity, uncertainty, lack of training, and lack of time. The next chapter explains the observations and interviews that were carried out to find the implications of shared decision making in the VUmc.

4 Observation in Cardiology

Literature shows that shared decision making proves to be valuable for the treatments decisions for advanced heart failure patients.
Observations were conducted to gain insight regarding the working dynamics at the Cardiology department at the VUmc.

This chapter consists of:

4.1 Method

Observations were conducted by following a nurse during a day-shift, from 8 to 12 and from 14 to 15, in the Cardiology 5B ward in the hospital Amsterdam UMC, location VUmc. During the observation, the researcher was wearing a nurse's uniform to be immersed in the context and to not alarm the patients by standing out as a stranger.
During the observation the researcher shadowed a nurse and a student nurse during the morning handover, the routine check-ups, meeting with the physician and a multidisciplinary consultation, in Dutch "MultiDisciplinair Overleg" (MDO). It was not possible to observe specifically a consultation with a patient with advanced heart failure regarding the communication of end-of-life and the choice of palliative care or life-prolonging treatments.
Notes were taken during the observation. The conversations were mostly in Dutch.

Figure 11
Amsterdam UMC nurses during their daily activities: checking prescription on the computer

4.2 Findings

Observation was valuable to explore the healthcare providers' routine and their atmosphere. In the following paragraph, the following themes are described:

- The nurses have more personal contact with patients than other healthcare providers.
- Information sharing system
- Patients' room
- Nurses are often interrupted

The nurses have more personal contact with patients than other healthcare providers.

At the beginning of the shift, nurses are assigned to specific patients. Usually, the same nurses are assigned to the same patients for a certain time, in order to establish a relationship.
Nurses are the ones that see patients more often, and they establish a connection with the patient that goes beyond medical check-ups. Nurses are always informed about the conditions of the patients and their appointments with physicians. They note medical status but also social and mental status, trying to improve the patient's stay.
They are usually cheerful and try to have a conversation with the patient.
Here an example of the conversation in a patient's room, in which a nurse tries to understand the patient's situation and offers to improve it:

> *"How are you doing?"*
> *"Ok, just bored"*
> *"I see... Is there something that I can do to make you less bored?"*
> *"Mmmh… not really"*

Nurses reserve attention also for the family visiting, trying to make sure that they are also comfortable by, for example, offering something to drink:

> *"Can I offer you a coffee or a tea...?"*
> *"No, thank you"*

Nurses leave time for the family to conversate with the patients, remaining available for questions.

Figure 12
An Amsterdam UMC nurse during her shift. Nurses at the Cardiology department attend to the needs of the patients and engage in conversation with the patients.

Information sharing system

Observations about the condition of the patient are shared with other medical professionals working in the same department in different ways.
The following paragraphs explain in detail the different moments of information sharing:

1. Handover
2. Meeting with the physician
3. MultiDisciplinair Overleg (MDO)
4. "Mijn notitiw" in Epic

1. Handover

At the beginning of every shift, nurses gather together for a meeting called handover. In this meeting, nurses are assigned to care for specific patients during the day.
During the meeting, the head nurse explains the schedule, and she communicates relevant news or changes in the department to the rest of the nurses. The head nurse assigns each nurse to specific patients.
Each nurse receives a sheet of paper which shows all the rooms and the patients admitted in the department. Then, the nurses of the previous shift share information about the specific patient's conditions and appointments to the nurses of the new shift. On the backside, each nurse writes down more information about the specific patients they will take care of during the day. They note their name, the age if they do not speak Dutch, their condition, and possible appointments with the physician.
At the end of their shift, they will repeat the handover with the nurses of the following shift.
The atmosphere of this meeting is relaxed, and the nurses drink coffee together.

2. Meeting with the physician

After a round of check-ups, the nurses share observations with the ward physician, in their office. The office is shared with another physician who is having a similar meeting with other nurses. Sharing the space can be confusing and distracting at times, because of the noise of different conversations. Moreover, the nurses can be often interrupted by the beeping sound of their devices or by a call, a sign that they may assist a patient. Sometimes it is difficult to focus, and this improves the chances of miscommunication.
During the meeting, the physician and the nurses go over the patients' conditions, one at time. Together they discuss the patient's medical conditions, their morale and any appointments that they or the family may have requested. If, for example, the patient expresses the need to go home, then nurses and physicians discuss together their opinions.
If necessary, the physician will approach the patient in their room after the meeting.

Figure 13a
Drawing of the handover among nurses at the beginning of their shift

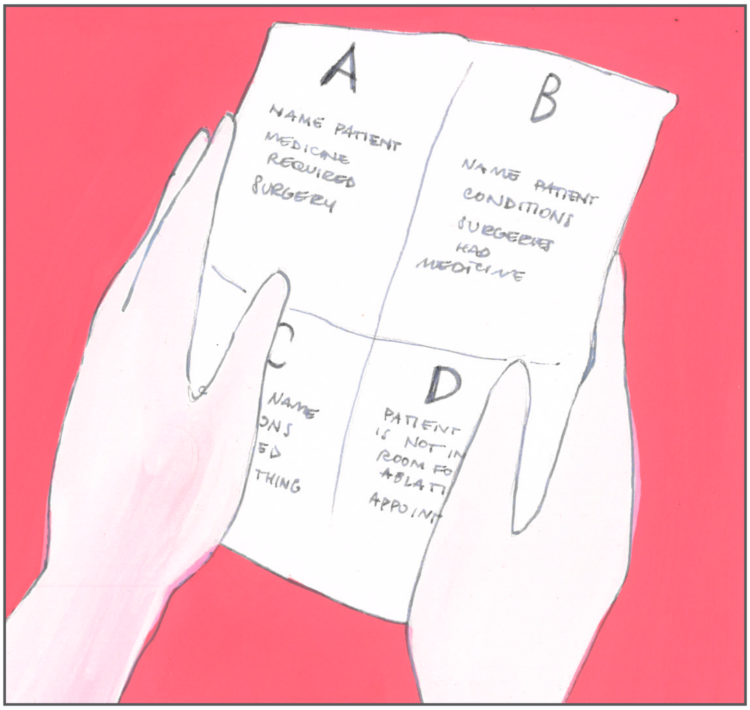


Figure 13b
Drawing of the paper given during the handover, with patients overview

3. MultiDisciplinair Overleg (MDO)

During a multidisciplinary meeting, different professionals meet together to discuss specific patients.

In the meeting observed, the participants were: a heart failure nurse from the outpatient clinic (in Dutch polikliniek), a managing-nurse working in Cardiology, a cardiologist, an internist and an assistant cardiologist.

In the meeting observed, the assistant cardiologist introduced each case presenting its conditions with the record of hospitalization in the previous years, and the treatments received. For every case, the healthcare providers discussed their medical conditions, the situation at home if known, the responsible person and the possibilities of care or treatment available for the person. During the discussion, every health care provider provides additional information if needed. On average, the conversation about the single patient lasts about 5-10 minutes.

In the meeting observed, they discussed a patient with heart failure and dementia with no possible further active treatments. The assistant cardiologist and the heart failure nurse had a "bad news" conversation a few days earlier with the patient's relative (in this case, due to dementia, the patient was considered not mentally capable of deciding on their care). In the MDO, they discussed the possibility of recommending a hospice or care at home. After the MDO, the assistant cardiologist is going to speak to the patient's relative. He will explain the different possibilities, and he will suggest the preferred option from the outcome of the MDO discussion.

4. "Mijn notitie" in Epic

Every healthcare provider in the Cardiology ward uses the software Epic. They have to write a summary of his observations in the "Mijn notitie" section of the software. Healthcare providers have access to all the written information, which allows everybody to be aware of the patient's situation.

At the end of their shift, nurses note the condition of the patient's circulatory, respiratory, digestive, and urologic system, skin, and psychological status (such as mood, morale, expressed thoughts or needs).

Finding specific information can be complicated because the notes are catalogued by date and by author.

Nurses are often interrupted

During their shift, nurses can be reached at any time by a cordless phone or by a "beeping device" they carry in their pocket. These devices alert them for possible emergencies situations.
During their meetings with the physicians and their break, they would be often interrupted by a call or a beeping sound. Often the alarm was not an emergency (for example in the case that a patient removed a sensor while in the shower) but the beeping sound did not provide any indication on the cause of the alarm. Nurses are obliged to go to the patient and verify the nature of the alarm.
The continuous beeping can become very distracting during a meeting or can cause distress during the whole shift and especially in a break.

Patient's room

The Cardiology department consists of the following rooms:

- four single rooms;
- four rooms hosting two patients;
- one room hosting three patients;
- four rooms hosting four patients;
- one room for particular observations (unused at the time of the study due to the scarcity of personnel).

The room observed hosted four patients, of which one was in surgery. The room is spacious, with a big window on the opposite side of the door and it faces a green area. The door always stays open. The bathrooms are just outside the room.
Space is divided into four sections, which can be separated by a curtain. Each section hosts a bed, a bedside table, a cabinet, occasionally machines for the check-ups and a table with a chair in front of the bed. Two of the patients were male, and the other was female. The patients were sitting or lying in bed.

4.3 Conclusion

Observations in the Cardiology department in the VUmc was valuable to understand the professionals' roles and schedule in the department. Healthcare providers pay attention to the physical and mental wellbeing of the patient recovered in Cardiology. Nurses spend more time with the patients, and they develop a personal relationship with them. They refer their observations to the physicians, functioning as the link between patients and physicians. Much information is shared between nurses and physicians, although it is often verbal. In this observation, it was not possible to observe a conversation between patient and healthcare providers about life-prolonging or palliative treatments. Additional insight is needed on the (shared) decision making process at this department.

5 The decision making process in Cardiology

Literature shows that shared decision making proves to be valuable for the treatments decisions for advanced heart failure patients. Observations did not show the decision making process. Therefore, interviews were conducted in order to gain insight in the decision making process at the Cardiology department at the VUmc.

This chapter consists of:

1. Method
2. Shared decision making journey
3. Phases of the shared decision making journey
4. Roles in the shared decision making journey
5. Life-prolonging treatment choices visualization
6. Validation with heart failure nurses
7. Conclusion

5.1 Method

After conducting literature research and observation in context, it was necessary to explore the personal experience of the healthcare providers involved in Cardiology. Interviews with patients with advanced heart failure were not conducted due to limited time and resources.

Semi-structured interviews were conducted with a total of six healthcare providers, specifically: three nurses, one managing-nurse and two ward physicians. The sample was chosen through an opportunity sampling, including Cardiology healthcare providers that were available at the time of the interviews. Two interviews with nurses were conducted in Dutch, while the rest was conducted in English. The interviews lasted from 20 to 30 minutes each and were audio-recorded. They were later transcribed, and every data that could refer to the person was omitted. The topic list is reported in Appendix D.

Quotes from the transcript were highlighted and analysed using analysis cards (see Table 3). The cards were divided on a matrix of stakeholders involved and moments of the decision making process and then clustered in common themes. The results of the interviews were visualised in the shared decision making journey (Figure 14 and 15), which is explained in the following sub-chapters.

Table 3
Example of an analysis card

Number of the interview	6
Title/summary of the quote	**It's a joint conclusion**
Quote highlighted	"Most of the time the patient, and the family and us, as a medical team come to a joint conclusion and then we decide as a team well, we include the patient and the family as well, that we cease the treatment."

5.2 Shared decision making journey

After analysing the data gathered in the interviews, the findings have been visualised as a journey map (see Figure 14). A journey map is a design tool meant to visualise the process of a person wanting to reach a goal. In this case, the tool has been used to document the involvement of different stakeholders in the shared decision making process for life-prolonging treatments decisions in patients with advanced heart failure.
The map focuses on the moments of conversation and decision that the patient, family, physicians and nurses have together during the (last) admission. These moments have been defined by the actions and the involvement of the stakeholders. The moments' duration can vary, depending on the patient's situation.

In the following pages:

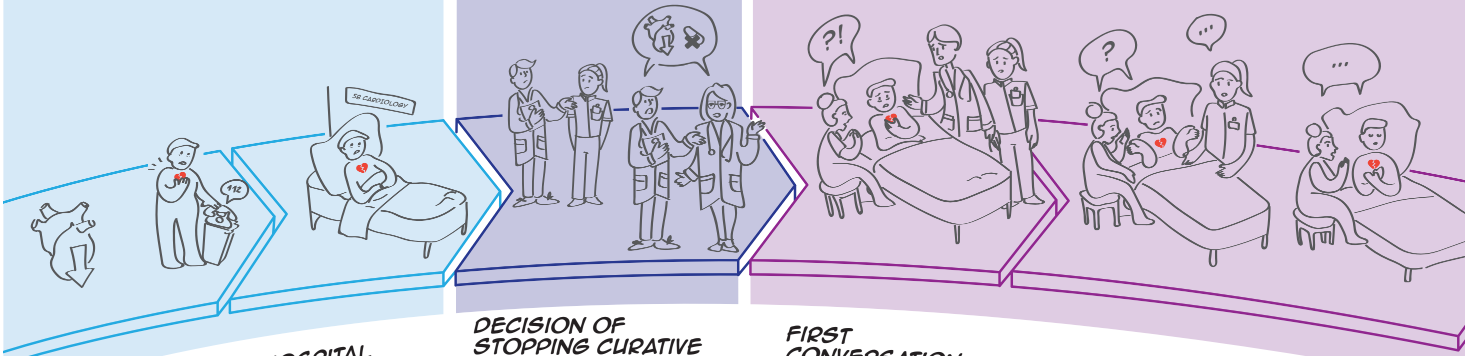
Figure 14
The shared decision making journey illustrates the moments and the involvement of an advanced heart failure patient in having to decide on life-prolonging treatments.

Figure 15
TThe second shared decision making journey illustrates the roles of the stakeholders in the journey of an advanced heart failure patient in having to decide on life-prolonging treatments.

TREATMENTS

MEDICAL DECISON

CONVERSATIONS



TREATMENTS PRE-ADMISSION

Heart failure is a long sickness, and during its course, the patient is admitted in the hospital multiple times, and they have frequent check-ups at the outpatient clinic. This phase is characterized by a cycle of periods with relatively good health and periods of exacerbation of the symptoms and progressive worsening of his conditions.

HOSPITAL ADMISSION

The patient is admitted to the department 5B Cardiology.
The patient comes either from the outpatient clinic or the coronary-care-unit (CCU). They are treated for the exacerbation of the symptoms. The doctor prescribes the treatments that could be a continuation of the treatments received in CCU or new necessary treatments. Then the nurse can administer the treatment to the patients.

DECISION OF STOPPING CURATIVE TREATMENTS

At a certain point, despite the administration of several treatments, the patient's conditions cannot get better: the heart is weak, and there are no other active treatments that can improve its functionality.
Therefore, the doctor consults with colleagues and other cardiologists in a meeting, and together they decide to stop active treatments.

FIRST CONVERSATION

The healthcare providers communicate to the patient, and the family, the decision to stop active treatments.
This conversation is held in the patient's room if they have a single room, or, if the person is mobile enough, they discuss it in a private office.
The patient can request the opinion of another specialist from another hospital, they usually share the same opinion, but otherwise, the VUmc team will follow the treatments the external doctor suggested.

TEAM TALK
OPTION TALK

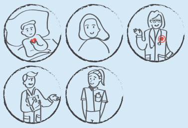
POST CONVERSATION

The patient is given time to take the information in and decide. In this phase, the nurse accompanies the patient back to their room and takes the time to explain once again what was said in the conversation. They explain what has been discussed to the patient in simpler terms.

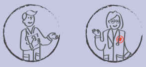
DELIBERATION

STAKEHOLDERS INVOLVED

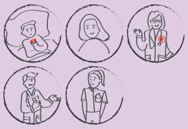
Patient, family, heart failure nurse at the outpatient clinic, cardiologist.



Patient, family, ward physician, cardiologist and nurse.



Ward physician and cardiologist.

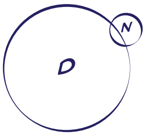


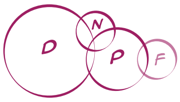
Patient, family, ward physician, cardiologist and nurses.

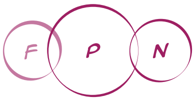
Patient, family and nurse.

DECISION-MAKING INVOLVEMENT

D: DOCTOR
N: NURSE
P: PATIENT
F: FAMILY OR PARTNER







DECISION MOMENT

AFTERCARE

MULTIPLE CONVERSATIONS

Many conversations are needed to let the patient accept their condition and to provide more information. These conversations can be informal moments with the nurse or the family, or more structured appointments with the ward physicians and/or the cardiologist. In the interviews, great importance was given to the fact that the patient must accept their condition, and they have to face the decline of their health.

DECISION

The patient is called to decide how they want to proceed to end-of-life care. They need to decide what kind of treatments they want to withhold or withdraw. When they make a choice, usually in agreement with the family, they communicate it to the nurse who refers it to the doctor. The doctor confirms the decision with the patient, and they create a policy.

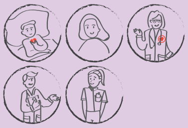
PLANNING AFTERCARE

After the decision, the healthcare providers gather to arrange aftercare. Depending on the choice of the patient, the physician involves the palliative team and the general practitioner. The patient situation is discussed in an MDO involving: the ward physicians, the cardiologist, the managing-nurse, the physiotherapist and sometimes a specialist in geriatric care, the palliative team and the heart failure nurse from the outpatient clinic.

AFTERCARE

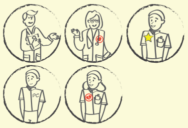
If the patient chooses for a palliative trajectory, they can be transferred at home with at-home care or at a hospice or care home, where they would spend their last moments.

DECISION TALK



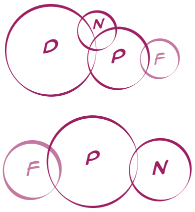
Patient, family, ward physician(s), (cardiologist) and nurse. In these conversations the stakeholders are not always all together in the same conversation.

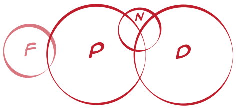
Patient, family, ward physician, cardiologist and nurse.

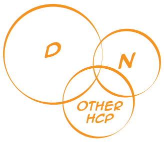


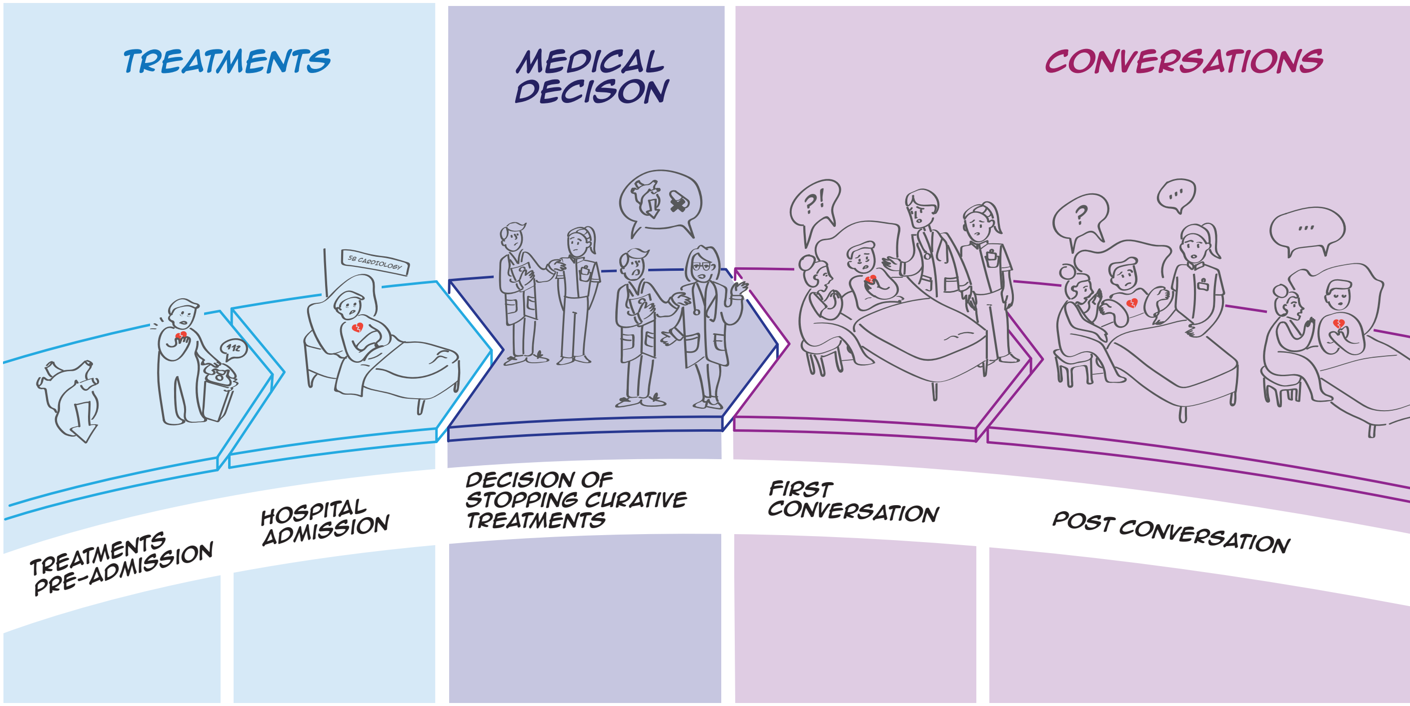
Ward physician, cardiologist and managing-nurse, palliative team and in some cases, the heart failure nurse.

Patient and family.







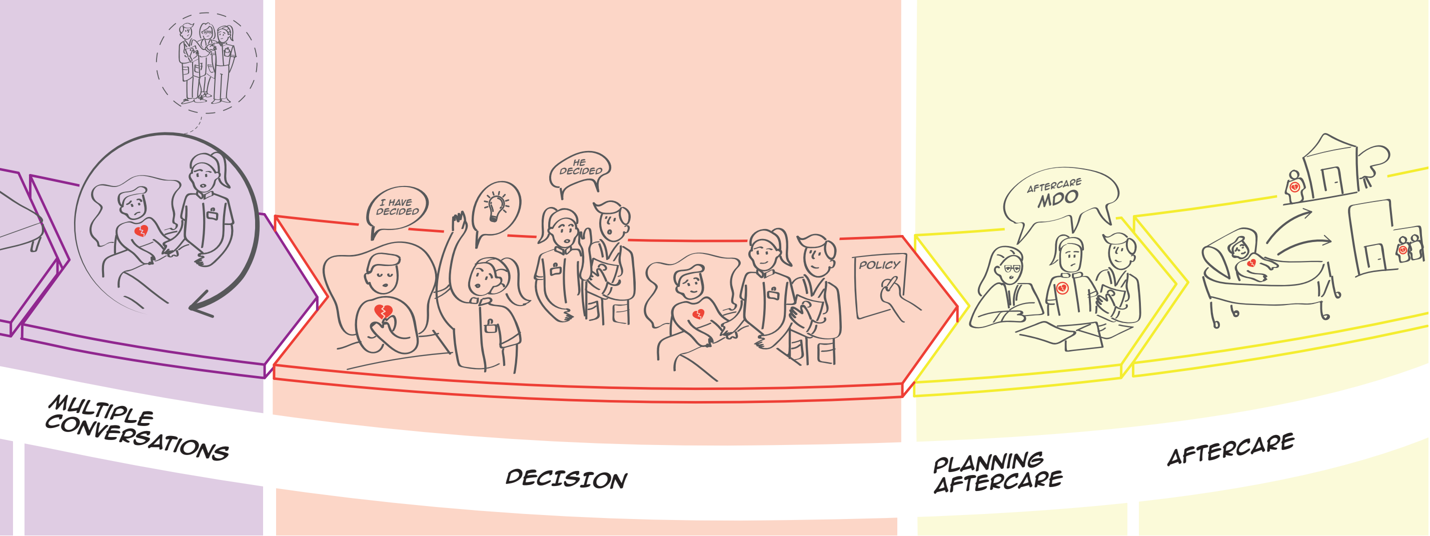


STAKEHOLDERS INVOLVED

	TREATMENTS PRE-ADMISSION	HOSPITAL ADMISSION	DECISION OF STOPPING CURATIVE TREATMENTS	FIRST CONVERSATION	POST CONVERSATION
Patient	In the last phase of heart failure, the patient's symptoms exacerbations become more frequent, resulting in more admissions and check-ups.	The patient is admitted again to the hospital. They are shocked and scared. They hope to get better with another treatment.		Although the patient knows he's getting progressively worse, he's shocked at the news. It is difficult to accept his condition.	The patient has to take in a lot of information. He talks to the nurse to have more information and to the family to have advice.
Ward physician		The ward physician is responsible for the patient. They prescribe the treatments and check the outcomes.	The ward physician sees that despite the previous treatments the patient's health deteriorates. They then propose to their colleagues and specialists the case suggesting to stop treatments. The ward physician listens to the nurses concerns, but stopping treatments is a medical decision.	The ward physician talks personally with the patient. They explain to the patient that they are not going to get better and their suggestion is to stop curative treatments. The ward physician gives the choice to the patient to choose withholding or withdrawing of life-prolonging treatments.	
Cardiologist	The cardiologist is a reference point for the patient. They see the patient during different stages of the disease.	The cardiologist has a saying in the treatments.	The cardiologist is involved in a meeting to discussed the patient case and decide with the ward physician if they should stopping treatments.	The cardiologist participates to the conversation.	
Nurse		The nurse follows the orders of the doctor. They administer the treatments.		The nurse participates to the conversation and supports the patient.	The nurse asks to the patient if everything is clear and if he has any questions. Sometimes they have to explain medical terms and repeat what has been discussed in the conversation.
Heart failure nurse	The heart failure nurse from the outpatient clinic does patient's check-ups, keeps contacts with them and can refer them to the hospital. At every appointment, they provide more information.				
Palliative team					
Family and friends	The family accompanies the patient to the visits and supports them when the patient is admitted.			If the patient wants to, the family is included in the conversation, and they support them in the decision.	The family supports and advice the patient in the decision.

DECISION MOMENT

AFTERCARE



The attitude towards the choice is different among people. Some actively study all the options, some already know the choice.	The patient is responsible for the decision. He communicates his wish about life-prolonging treatments.		The patient is transferred home or to a care facility where they can live their last days.
The ward physician talks with the patient alone or together with family, nurses, or rmanaging-nurse, family, cardiologist. The ward physician involves the palliative team if the patient is thinking of going in the palliative direction.	The ward physician is responsible to take the patient and family's wish and make it a medical decision.	The ward physician presents the situation of the patient to the other professionals. Together they look for the best aftercare setting for the patient.	
The cardiologist can be involved but usually the ward physician has more contact with the patient.			
The nurses are always at the patient's bed and they help them in his routine. The nurses have more conversations with the patients and they seem more approachable.	The nurse is a mediator between the patient and the doctor. When the patient takes the decision, they communicate it to the doctor.	The nurse is usually not involved in the meeting (the managing-nurse is). They communicate the patient's situation.	
		The heart failure nurse is involved in the after care plan of heart failure patients because they know very well the patient and their home situation.	If the patient is transferred at home, a heart failure nurse assists them.
		The palliative team is involved in the conversation after the patient decides to follow the palliative trajectory. The team advises the doctors in treatments.	
If there are any doubts, the family is welcome to make an appointment with the cardiologist and/or the ward physician to ask for more information.	The decision is a patient's responsibility. If the family and the patient's decisions are not aligned, the doctor will consider only the patient's opinion.		

5.3 Phases of the shared decision making journey

The map shows with colours the five crucial phases of the shared decision making journey.

Pre-admission care

Heart failure is a long sickness, and during its course, the patient is admitted in the hospital multiple times, and they have frequent check-ups at the outpatient clinic. This phase is characterized by a cycle of periods with relatively good health and periods of exacerbation of the symptoms and progressive worsening of his conditions.

Stakeholders involved: Patient, family, heart failure nurse at the outpatient clinic, cardiologist

Admission

The patient is admitted to the department 5B Cardiology. The patient comes either from the outpatient clinic or the coronary-care-unit (CCU). They are treated for the exacerbation of the symptoms. The ward physician prescribes the treatments that could be a continuation of the treatments received in CCU or new necessary treatments. Then the nurse can administer the treatment to the patients.

Stakeholders involved: Patient, family, ward physician, cardiologist and nurse

The decision to stop curative treatments

At a certain point, despite the administration of several treatments, the patient's conditions cannot get better: the heart is weak, and there are no other active treatments that can improve its functionality. Therefore, the ward physician consults with colleagues and other cardiologists in a meeting, and together they decide to stop active treatments. This moment is not part of shared decision making. However, this medical decision is the start of the shared decision making moment regarding life-prolonging treatments in patients with advanced heart failure.

Stakeholders involved: Ward physician and cardiologist

First conversation

The healthcare providers communicate to the patient, and the family, the decision to stop active treatments. This conversation is held in the patient's room if they have a single room, or, if the person is mobile enough, they discuss it in a private office.
The patient can request the opinion of another specialist from another hospital.

The specialist usually shares the same opinion with the VUmc physicians, but otherwise, the VUmc team will follow the treatments the external specialist suggested.
This moment is the first moment of shared decision making found in research. In accordance with Elwyn et al.'s model cited in chapter 3, this phase corresponds to the Team and Options talks (Elwyn et al., 2017).

Stakeholders involved: Patient, family, ward physician, cardiologist and nurses

Post-conversation

The patient has time to take the information in and decide. The nurse accompanies the patient back to his room and explains again what was discussed with the physician. The nurse explains it to the patient in simpler terms.
This moment corresponds to the deliberation phase in Elwyn et al.'s model (2017).

Stakeholders involved: Patient, family and nurse

Further conversations

It is necessary to have many conversations to let the patient accept his condition and to provide more information. These conversations can be informal moments with the nurse or the family or more structured appointments with the ward physician or the cardiologist. In the interviews, great importance was given to the fact that the patient must accept their condition and face the decline of their health.
This moment corresponds to the deliberation phase in Elwyn et al.'s model (2017).

Stakeholders involved: Patient, family, ward physician(s), (cardiologist) and nurse. In these conversations, the stakeholders are not always all together in the same conversation.

Decision

The patient needs to decide what kind of treatments they want to withhold or withdraw. When they make a choice, usually in agreement with the family, they communicate it to the nurse who refers it to the ward physician. The doctor confirms the decision with the patient, and they create a policy. In accordance with Elwyn et al.'s model, this phase corresponds to the Decision talk (Elwyn et al., 2017).

Stakeholders involved: Patient, family, ward physician, cardiologist and nurse.

Planning aftercare

After the decision, the healthcare providers gather to arrange aftercare. Depending on the choice of the patient, the ward physician can involve the palliative team and the general practitioner. The patient situation is discussed in and MDO which involves the ward physician, the cardiologist, the managing-nurse, the physiotherapist and sometimes a specialist in geriatric care, the palliative team and the heart failure nurse from the outpatient clinic.

Stakeholders involved: Ward physician, cardiologist and managing-nurse, palliative team and in some cases heart failure nurse.

Aftercare

If the patient chooses for a palliative trajectory, they can be transferred at home with at-home care or at a hospice or care home, where they would spend their last moments.

Stakeholders involved: Patient and family.

5.4 Roles in the shared decision making journey

Ward physician

The ward physician, or "zaalarts" in Dutch, are physicians that are assigned to the department for a determined period. They are sometimes referred to as "doctors" or "doctor assistants" by the patients and nurses.
In the Cardiology department in the VUmc, they are usually young physicians who are specializing in Cardiology, and they are supervised by a cardiologist. There are several physicians and they usually have a one-week shift in the department. A patient that is recovered for more than a week will speak to different ward physicians during his recovery. The ward physician usually visits the patient every day, they check on them and they are the ones responsible to prescribe treatments.
If despite several treatments, the patient's conditions don't improve and health keeps deteriorating, the ward physician decides between continuing or stopping active treatments. During a meeting with their colleagues and his supervisors, the ward physician discusses the patient's case, and they decide together if there is a solution. If there are no indications that the patient's heart may improve with active treatment, they decide to withdraw treatments and have a conversation about end-of-life. In the decision of stopping treatment, they listen to the nurses' opinions but in the end, it is a medical decision.
Compared to other specialists, the ward physician is the most involved in the conversation with the patient, as they are the physician with the most contact with the patient. The ward physician talks personally with the patient. They explain to the patient that they are not going to get better and their suggestion is to stop curative treatments. The ward physician gives the choice to the patient to choose withholding or withdrawing of life-prolonging treatments. After the first conversation, the ward physician has more conversations with the patient, alone or with family, nurses, or managing-nurses, family, a cardiologist and

the palliative team if the patient is thinking of going in the palliative direction. The patient must understand what it has been said in the conversation, and if they are conscious of what choices they have to make. The ward physician is responsible to take the patient and family's wish and make it a medical decision. The ward physician is responsible for arranging care after the hospitalization. He organizes an MDO with other professionals including the cardiologist, another specialist such as a geriatric care specialist, the managing-nurse, the palliative team and the physiotherapist. Together they look for the best aftercare setting for the patient.

Nurse

The nurse care for the patient daily since their admission. They are part of a team of nurses and together with a colleague they are usually assigned to the same patient for most of their shifts. They are always on the call for the patient. The nurse follows the orders of the ward physician, and administers the treatments prescribed. They have a crucial role in the communication between the patient and the physician. In fact, they have more contact with the patient and they seem more approachable than the physicians.

After the first conversation, the nurse asks to the patient if everything is clear and if they have any questions. Sometimes they have to explain medical terms and repeat what has been discussed in the conversation. The nurse is always helping the patient in his routine thus, they share more conversations. The nurse is a mediator between the patient and the physician. In fact, they are usually the first who hear the wish of the patient and communicate it to the physician, who will take action.

Sometimes the role of the nurse is not really clear. During the decision making process they are involved in the communication but it is not clear if they have a saying in the decision. This can be confusing: a nurse could decide to share her opinion while another would restrain to do so to avoid stepping boundaries. Their boundaries are not clear and their role in the decision making is not acknowledged.

The "common" nurse is usually not involved in the aftercare planning meeting, only the managing-nurse is. The nurse communicates the home situation to the managing-nurses and they will discuss it in the meeting.

Managing-nurse

The managing-nurse has a further training and is responsible to talk with the patient about their home situation, their wishes and plan their aftercare.

Family

A support network for the patient is really important. During the various consultations the patient brings their partner or a relative or a friend to their appointment. The role of this person is important to support the patient during difficult moments and during his decisions. They can record the information that the patient might forget and participate to the discussion.

Palliative team

The palliative team in Cardiology typically consists of an anaesthesiologist and a specialized nurse. In Cardiology, they are usually involved only when a patient chose to follow a palliative trajectory. They are consulted by ward physicians and cardiologist to have advice, particularly about sedation and pain relief.

Heart failure nurses from the outpatient clinic

Heart failure nurses are nurses with a specialization in the care of heart failure. They take care of the patient during the years, from the diagnosis of heart failure until the aftercare. They are involved in MDO meetings with the healthcare providers to give more information about the patient's situation and give advice since they know the patient for a longer time.

5.5 Life-prolonging treatment choices

Patients with advanced heart failure face three different possible treatment trajectories for end-of-life heart failure patients:

- Code A: Life-prolonging treatments
- Code B: Partial treatments
- Code C: Palliative care

The previous versions of the visualisation can be found in the Appendix D.

As an outcome of the research, the trajectories are visualised in Figure 16. The choice is reversible at any time and can involve only part of the treatment path.

Code A – Life-prolonging treatments

This trajectory involves trying to maintaining the status quo by administering heart-strengthening medicines to the patient, continuing with the liquid drainage and if necessary, involving artificial feeding and artificial ventilation to keep the patient alive as long as possible. This type of trajectory focuses on keeping the patient alive more than its quality of life, as some interventions can be quite aggressive.

Code B– Partial treatments

This trajectory involves being treated only for some conditions, for example, treating an infection with antibiotics but declining life-prolonging measures such as artificial feeding and artificial ventilation.

Code C- Symptoms care

This trajectory involves treating the symptoms of the ongoing conditions to ensure comfort and prevent pain. This type of trajectory is usually referred to as "palliative care", and its aim is not prolonging life but ensuring the quality of life in the last phase of life. The treatments that are usually prescribed are morphine and midazolam (also known as dormicum) for pain management and sedation. If the patient has an implantable cardioverter-defibrillator (ICD), which is an electric device to support the heart, they could request to turn it off. All three trajectories usually involve the use of diuretics and the drainage of the liquids to avoid the accumulation of the liquids in the patient's lungs or extremities.

It is important that all the people involved in shared decision making about life-prolonging treatments are aware of the treatments that the patient could face, to make an informed decision. There is not a better trajectory than the other, but there is a better choice fitting the patient's needs and values.

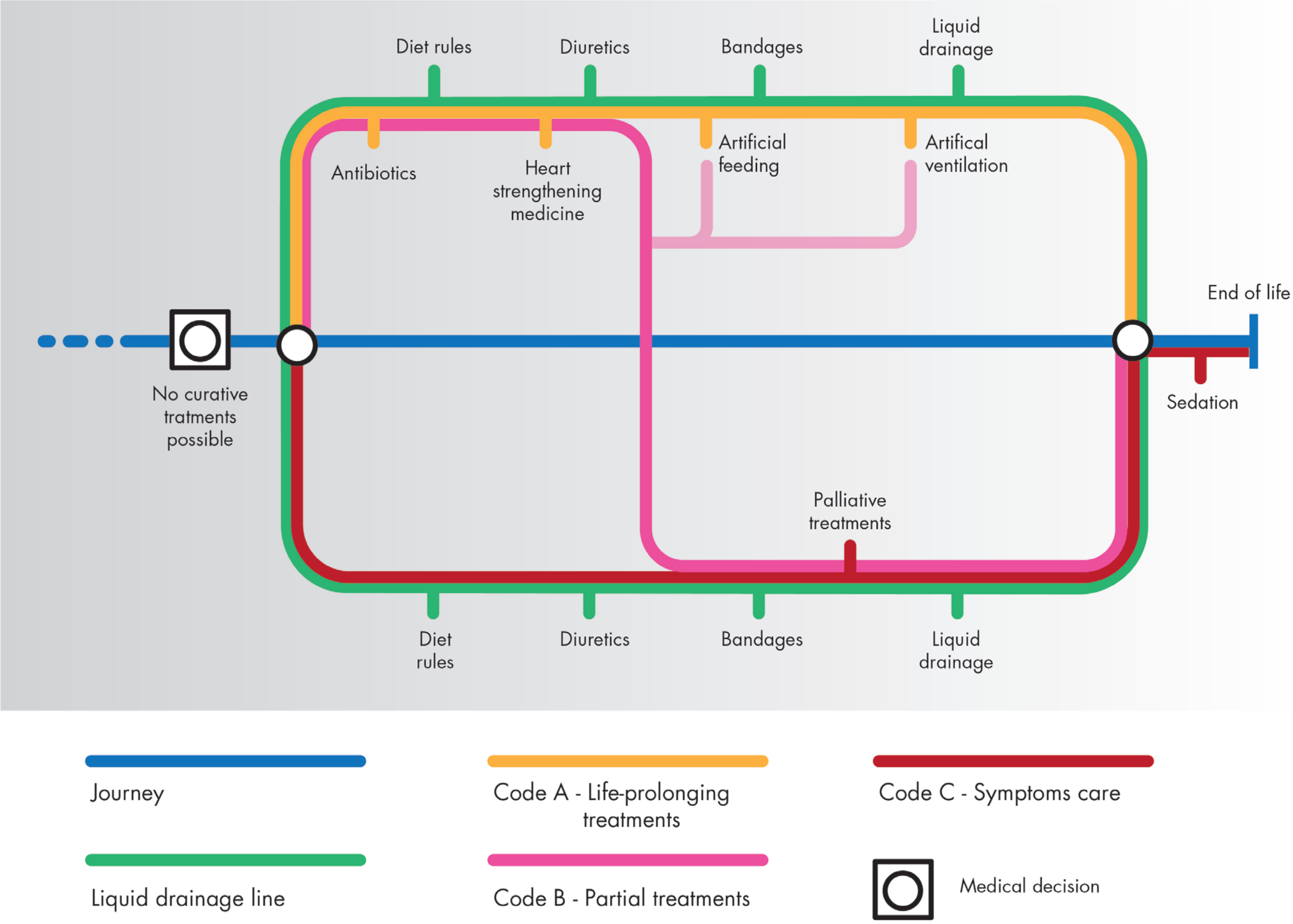


Figure 16
Life-prolonging treatment choices visualised as metro lines, developed as a design outcome after interviews with nurses and ward physicians in Cardiology.

5.6 Validation with heart failure nurses

An interview with two heart failure nurses was conducted in the outpatient clinic in the VUmc.

The interview aimed to understand the work of heart failure nurses, compare the information from the previous in Cardiology, check the validity of the shared decision making maps and the life-prolonging treatments map, and explore a possible design direction with them. The interview topic list can be found in Appendix E.

During the interview, the nurses evaluated the designed maps positively, contributing to information on the treatments involved before the decision of stopping active treatments. Their opinion was valuable and insightful on what the patient goes through before reaching Cardiology and the end-stage.

During the interview, they expressed the need for improvements in the communication between healthcare providers and the patient and family, including working as a team and implementing a decision aid to support the patient's decision. Additionally, they expressed that the palliative team should be involved earlier in the process, which is currently involved only if the patient has already chosen a palliative trajectory.

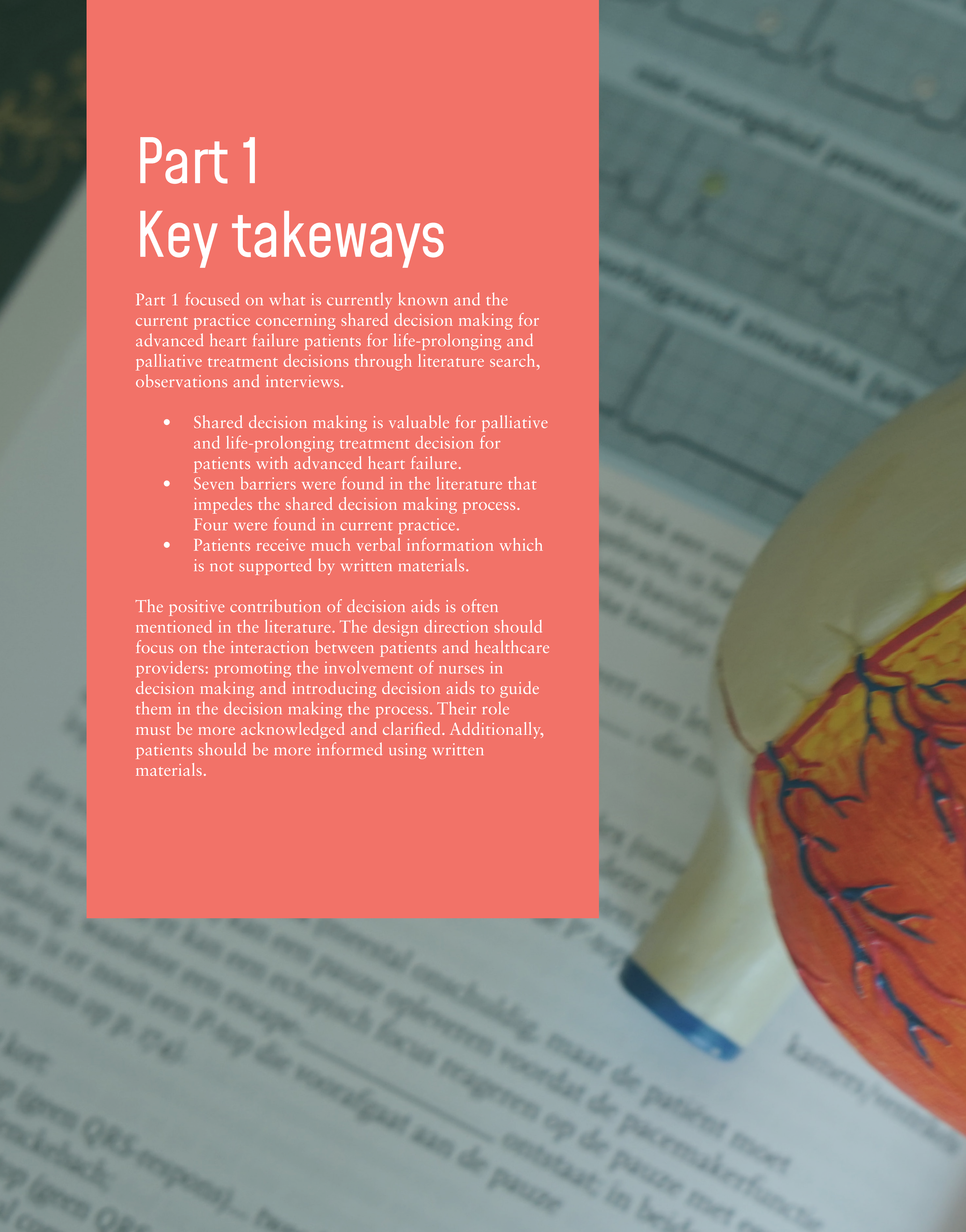
5.7 Conclusion

he interviews show that two decision making moments are present for patients with advanced heart failure. Firstly, the healthcare professionals decide on the discontinuation of curative treatment. Secondly, the patient and family are involved in the decision of life-prolonging or palliative treatments. Therefore, the interviews show that shared decision making principles partly apply to the second decision making moment whereas the first decision is made solely by healthcare professionals.

Healthcare providers are responsible for the introduction and promotion of shared decision making to support heart failure patients whereas nurses are a crucial mediator in the shared decision making process: they ensure clear communication between physicians and patients. Nurses’ role is especially valuable during the deliberation phase when the patient values their options and must come to a decision. During this time, nurses offer patient information and moral support.

Although healthcare providers share plenty of information with the patient and family, they share it mostly verbally. Treatment options are explained to the patient multiple times but no information is given in written form.

In the literature search in chapter 3, seven barriers of shared decision making for advanced heart failure patients for life-prolonging or palliative treatments were found. Four of these barriers were found during the interviews as well: 1) uncertainty of the illness trajectory, 2) unclarity of the roles in the care team, 3) limited time, and 4) limited understanding amongst people with heart failure. In the interviews, no new barriers were found.

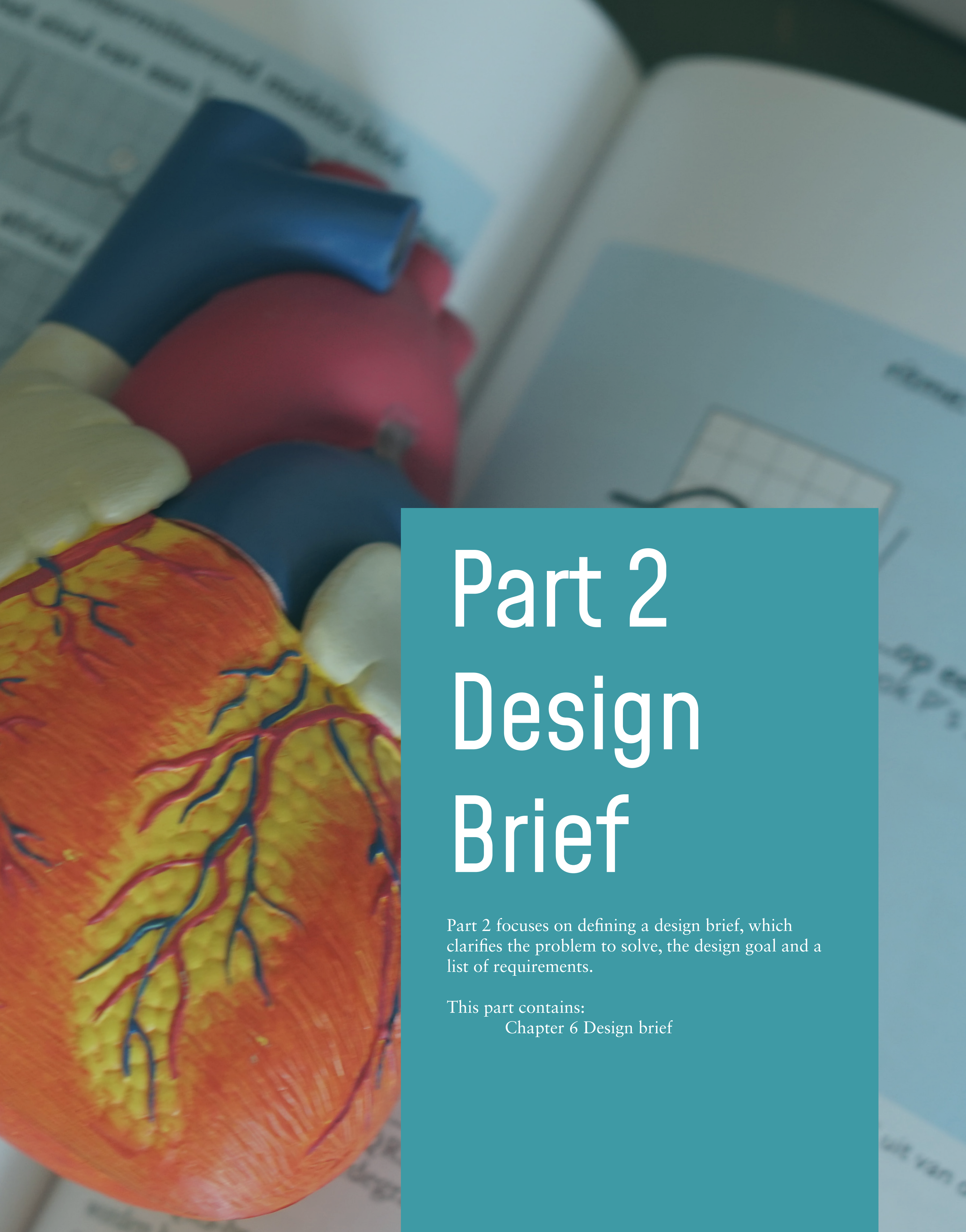


Part 1
Key takeways

Part 1 focused on what is currently known and the current practice concerning shared decision making for advanced heart failure patients for life-prolonging and palliative treatment decisions through literature search, observations and interviews.

- Shared decision making is valuable for palliative and life-prolonging treatment decision for patients with advanced heart failure.
- Seven barriers were found in the literature that impedes the shared decision making process. Four were found in current practice.
- Patients receive much verbal information which is not supported by written materials.

The positive contribution of decision aids is often mentioned in the literature. The design direction should focus on the interaction between patients and healthcare providers: promoting the involvement of nurses in decision making and introducing decision aids to guide them in the decision making the process. Their role must be more acknowledged and clarified. Additionally, patients should be more informed using written materials.



Part 2

Design Brief

Part 2 focuses on defining a design brief, which clarifies the problem to solve, the design goal and a list of requirements.

This part contains:
    Chapter 6 Design brief

6 Design brief

This chapter defines the design challenge by establishing the current problem found in context, setting a clear goal and a list of requirements and exploring the current solutions available.

This chapter consists in:

6.1 Problem

Currently, the communication with patients with advanced heart failure recovered in Cardiology, about life-prolonging treatments is overwhelming. Patients receive much information from their healthcare providers verbally, and they do not have written information. Due to their illness and their emotional state, patients are not able to process all that has been discussed. Significantly, some patients are not aware of their preferences and values, and they require time to establish them before taking a decision.

In the deliberation phase, in particular, patients need to process the emotions the information and make a decision for their future. In this phase, nurses have an essential role: they are the ones who spend more time in contact with the patients, and they are the link between the patients and the physician. Currently, nurses' role is limited to repeat information to the patient or report their observation to the physician.

6.2 Design goal

The project should focus on creating a conversation opportunity for patients and healthcare providers in order to support the patient in understating their values and their options.

The design goal is:

"I want to support the patient and healthcare provider communication during the deliberation phase of the shared decision making process for life-prolonging treatments by making the patient informed and aware of their preferences."

6.3 Interaction vision

To envision the desired situation, an interaction vision was developed.
An interaction vision is a metaphor that represents a situation with characteristics that are similar to the wanted situation. This tool helps to shape the desired interaction and consequently, the concepts and prototypes.
The interaction vision of this project is “I want the interaction between nurses and patients to be like an alpine guide and a climber linked together on an alpine climbing” (See Figure 17).
In this sport, when someone is struggling, they put their trust in the guide’s hands. The alpine guide always checks how the other climber feels and cannot go forward without them. They go in the same direction.
The image chosen shows a friendly interaction between two women climbing towards the top of a mountain, linked together by a safety rope. The interaction is friendly trustful, caring and safe. Taking inspiration by the elements of the images, the qualities of the desired interaction should be: tailored, focused, soft and reliable.

Figure 17
Interaction vision: “I want the interaction between nurses and patients to be like an alpine guide and a climber linked together on an alpine climbing”

Character of Interaction	**Design properties**	**Interaction qualities**
Friendly	Personal contact, warmth of the smile	Taylored
Trustful	Tightness of the ropes	Focused
Caring	Looking in the same direction	Soft
Safe	Reliability of the helmets	Reliable

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6.4 Requirements

After defining the scope and the characteristics that the envisioned solution should have, I proceeded with defining the practical requirements that my design should have.

The design should:

- Be accessible to patients
- Provide written information
- Compliant with the requirements of the VUmc Cardiology department
- Engage patients and healthcare providers in conversation

The requirements are further explained in the following paragraphs:

Accessible to patients

The targets of the design are mentally-able end-stage heart failure patients and nurses in the Cardiology department, during the deliberation phase of shared decision making in life-prolonging treatments. As patients at this stage are usually elderly (> 65 years old), the design should be accessible to this population. Therefore, the design should preferably be analogic and be easily understandable. Visual design should pay attention to the legibility of the fonts chosen and colour contrast, to ensure that the information is easily accessible to patients. Patients would likely use the solution while lying in bed or while being seated; accordingly, the concept should be of appropriate dimension.

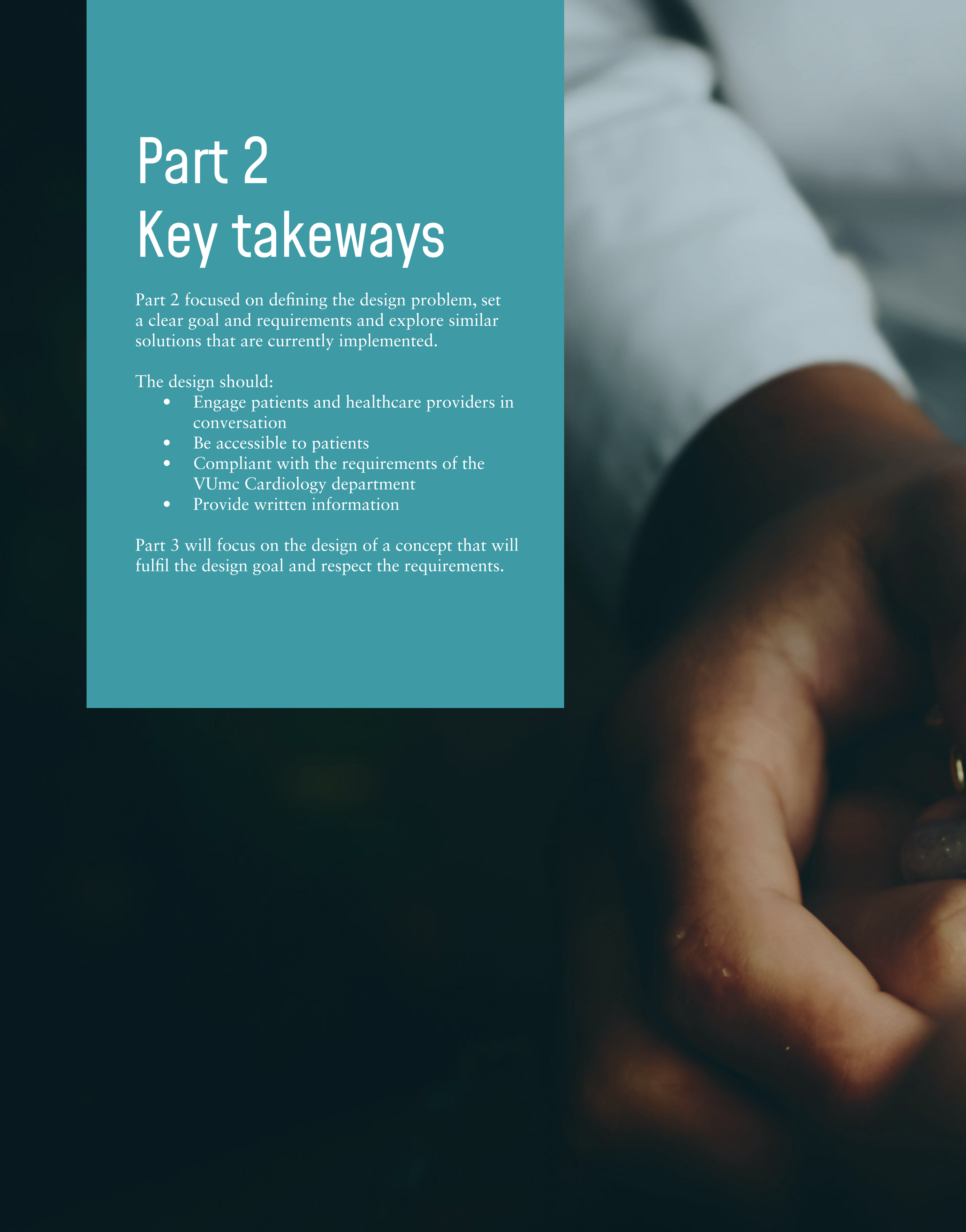
Compliance to the Cardiology requirements

The concept should comply with the rules of the department, including meeting the budget limitations of the Cardiology department. The solution should not involve the hiring of personnel or the introduction of new technologies, as it will not be feasible for the context. Also, the solution should fit the busy schedule of the nurses.
It is important to respect the privacy of the patients, complying with the privacy regulations in vigour in the hospital. In particular, sensitive data should not leave the hospital without authorisation.

Provide written information

The research highlights a lack of written information available to the patient during conversations with healthcare providers. The design should inform and offer emotional support to elicit the patient's preferences.

Patients might not be aware of their preferences: the design should sensitize and guide them into discovering what they value.



Part 2
Key takeaways

Part 2 focused on defining the design problem, set a clear goal and requirements and explore similar solutions that are currently implemented.

The design should:
- Engage patients and healthcare providers in conversation
- Be accessible to patients
- Compliant with the requirements of the VUmc Cardiology department
- Provide written information

Part 3 will focus on the design of a concept that will fulfil the design goal and respect the requirements.

Part 3
Design

Part 3 aims to solve the current problem through the design of concepts, respecting the requirements established in Part 2. The designed concept is the result of the iteration from creative sessions, three different concepts and evaluation with nurses and patients' representatives.

This part includes:

7 Design iterations

This chapter describes the ideation phase, including the creative sessions and the first three concept directions.

This chapter consists in:

7.1 Ideation

For the ideation phase, three creative sessions have been organized: one in the VUmc (see Figure 18) and two in collaboration with the course “Creative Facilitation” with TU Delft students (see Figure 19). More information about the sessions can be found in the Appendix F.

The creative sessions served as an inspiration. In the end some ideas that could be developed as concepts (see Appendix F).

Figure 18
Ideation session at the VUmc.

Figure 19
Ideation session with TU Delft students.

7.2 Three concept directions

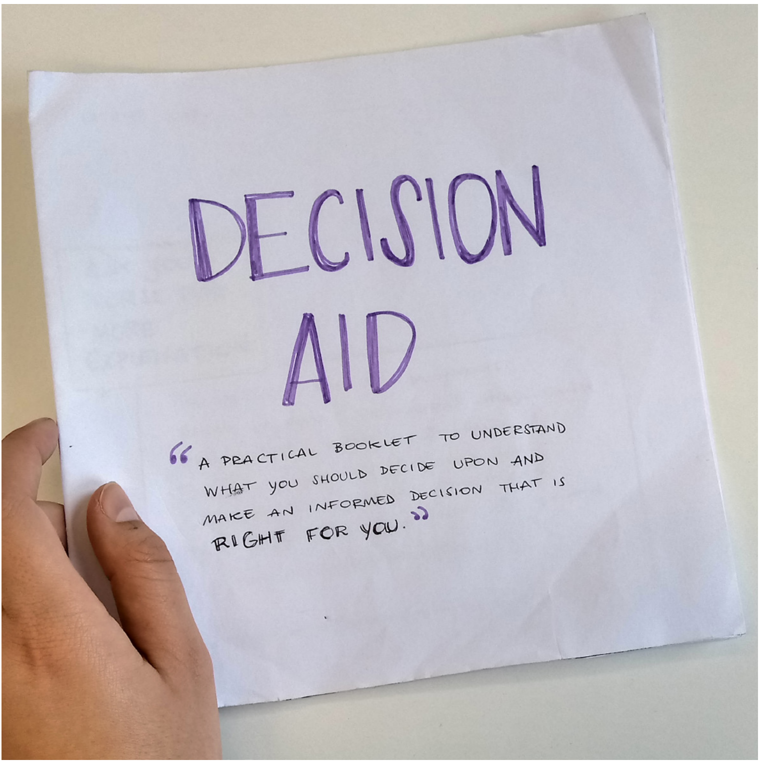
After the creative sessions, I created three direction concepts. These concepts were evaluated, taking in consideration the limitations set in the design brief.

Decision aid booklet

Patients need to be informed to make the correct decision. Having a booklet with all the necessary information about the treatments is beneficial to take an informed decision. Therefore, I made a quick prototype on how I could organize the information., which is shown in Figure 21. This booklet could be used by nurses to first explain the prognosis to the patient and the possible life-prolonging choices after the conversation with the physician.
On the first page the physician will write (or paste) the current prognosis, explaining why the patient cannot receive active treatments to cure their heart. Then, the physician will suggest that the nurse will give them a booklet and explain the treatments more in detail. The nurse accompanies the patient in the room and with the help of the booklet check if the patient understood all what have been said and has questions.

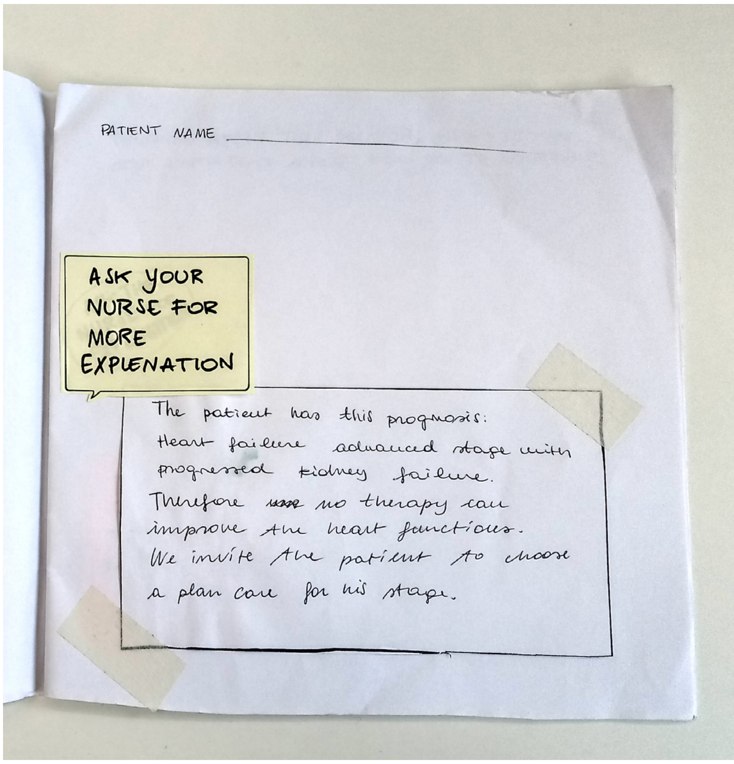
Strengths and limitations: The booklet is useful as it informs the patient about the treatments they may face, although it does not explore the values of the patient. It should include a part to increase emotional value.
To be appreciated, it should be aesthetically pleasant and inviting. The risk is for that to feel like other many booklets and flyers in Cardiology which are very informative but not used in daily practice.

In the next page:
Figure 20
Concept 1: Decision aid booklet prototype



DECISION AID

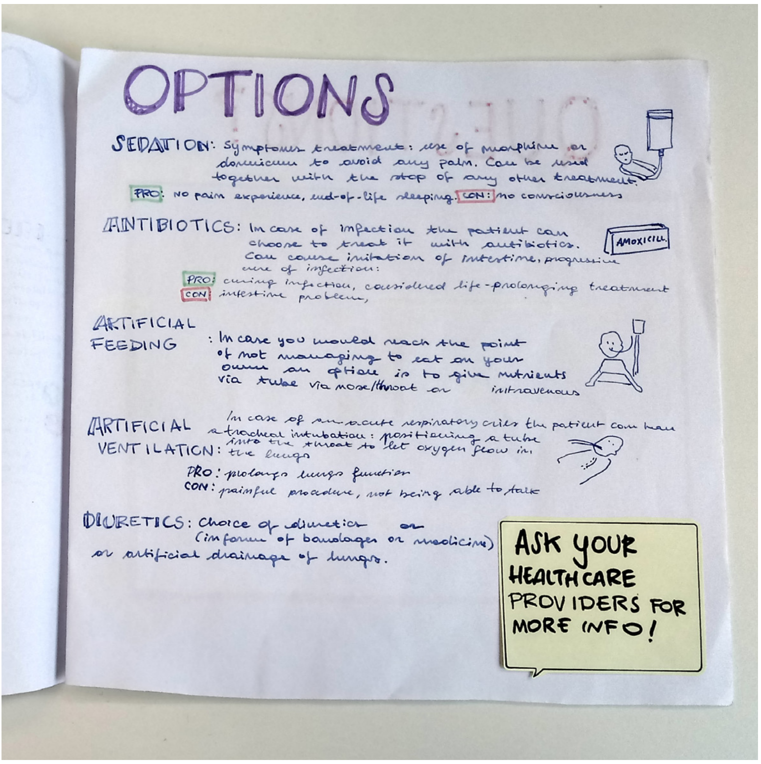
"A PRACTICAL BOOKLET TO UNDERSTAND WHAT YOU SHOULD DECIDE UPON AND MAKE AN INFORMED DECISION THAT IS RIGHT FOR YOU."



PATIENT NAME ______________________

ASK YOUR NURSE FOR MORE EXPLENATION

The patient has this prognosis:
Heart failure advanced stage with progressed kidney failure.
Therefore ~~was~~ no therapy can improve the heart functions.
We invite the patient to choose a plan care for his stage.



OPTIONS

SEDATION: symptoms treatment: use of morphine or dormicum to avoid any pain. Can be used together with the stop of any other treatment.
PRO: no pain experience, end-of-life sleeping. CON: no consciousness

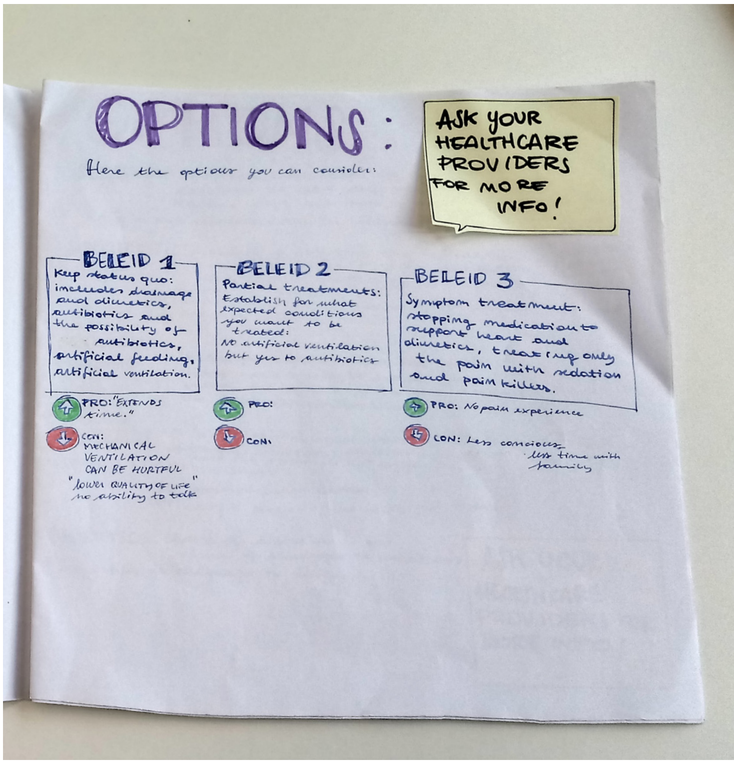
ANTIBIOTICS: In case of infection the patient can choose to treat it with antibiotics. Can cause irritation of intestine, progressive cure of infection:
PRO: curing infection, considered life-prolonging treatment
CON: intestine problem,

ARTIFICIAL FEEDING: In case you would reach the point of not managing to eat on your own an option is to give nutrients via tube via nose/throat or intravenous

ARTIFICIAL VENTILATION: In case of an acute respiratory crisis the patient can have a tracheal intubation: positioning a tube into the throat to let oxygen flow in the lungs
PRO: prolongs lungs function
CON: painful procedure, not being able to talk

DIURETICS: Choice of diuretics or (in form of bandages or medicine) or artificial drainage of lungs.

ASK YOUR HEALTHCARE PROVIDERS FOR MORE INFO!



OPTIONS:

Here the options you can consider:

ASK YOUR HEALTHCARE PROVIDERS FOR MORE INFO!

BELEID 1
Keep status quo: includes drainage and diuretics, antibiotics and the possibility of antibiotics, artificial feeding, artificial ventilation.
PRO: "EXTENDS time."
CON: MECHANICAL VENTILATION CAN BE HURTFUL "lower QUALITY OF LIFE" no ability to talk

BELEID 2
Partial treatments: Establish for what expected conditions you want to be treated: No artificial ventilation but yes to antibiotics
PRO:
CON:

BELEID 3
Symptom treatment: stopping medication to support heart and diuretics, treating only the pain with sedation and pain killers.
PRO: No pain experience
CON: Less conscious, less time with family

Tarot deck

Some patients don't know what their preference is regarding life-prolonging treatment choices. Statement cards could help the patient and the nurse engage in a conversation about important themes. The concept designed is a set of 15 tarot cards exploring positive and negatives themes related to the future of the patient. The themes are:

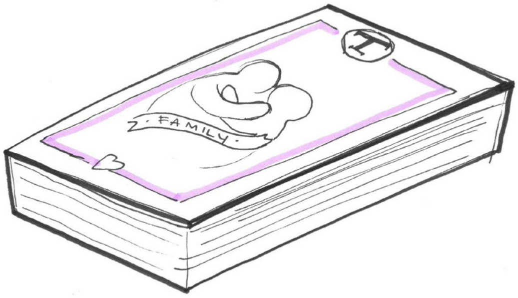
Positive:
- Love
- Comfort
- Personal space
- Friendship
- Family
- Food
- Desire
- Joy
- Fun

Negative:
- Fear
- Dependence
- Sickness
- Loneliness
- Pain
- Future

The cards include an illustration of the theme on the back of the card and questions to elicit discussions on the front.
The deck of tarot would be used positioning three random cards next to each other. The patient, together with the nurse and family, can start answering the questions on the front and discuss their values, worries and doubts for the future choices. The illustrations can serve as a stimulus for sensitising the people involved in the discussion to the topic described.

Strengths and limitations: The tarot cards have a high emotional value since they investigate emotions and values crucial for the patient's choice. The cards can be a tool to open up about topics that are difficult to mention to the patient. Having loose cards may be impractical in hospital, especially if the patient is lying down, and the solution does not offer a space in which to write a personal reflection if needed. The solution can clarify doubts only if used together with a trained nurse, if the deck of cards it is used alone or with an unprepared nurse the solution could be destabilizing for the patient.

In the next page:
Figure 21
Concept 2: Tarot deck card for eliciting values discussion.

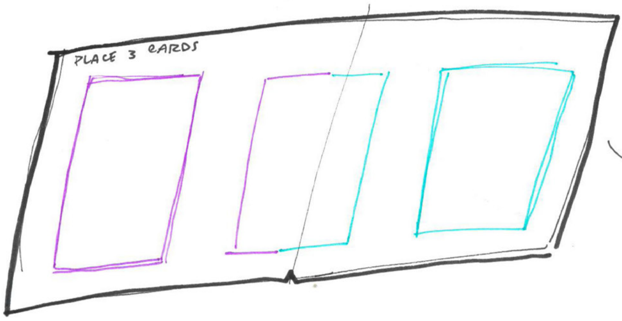


the cards can trigger conversations to understand what is important for the patient.

POSITIVE	NEGATIVE
LOVE	DEPENDING
COMFORT	FEAR
PERSONAL	SICKNESS
FRIENDSHIP	LONELINESS
FAMILY	PAIN
FOOD	FUTURE
DESIRE	
JOY	
FUN	

ON ONE SIDE THE CARD HAS AN EVOCATIVE ILLUSTRATION. THE COLOR INDICATES THE TYPE of the CARD. ON THE OTHER SIDE A PROMPT QUESTION.

ALL THE TOPIC CARDS with POSITIVE/NEGATIVE THEMES.



BOARD TO LAY 3 CARDS DOWN AND START TALKING HOW THE TOPICS OVERLAY

Digital app

The third concept is an app that explain all the different treatment choices. The user can click on the treatment choice and open a more detailed explanation. The app offers a quiz to verify if the patient has understood the options in detail.
In the "first conversation" the nurse present in the appointment is assigned to the patient as the first person to be contacted to clarify doubts and get more information. The patient in fact, can use a chat integrated in the app.

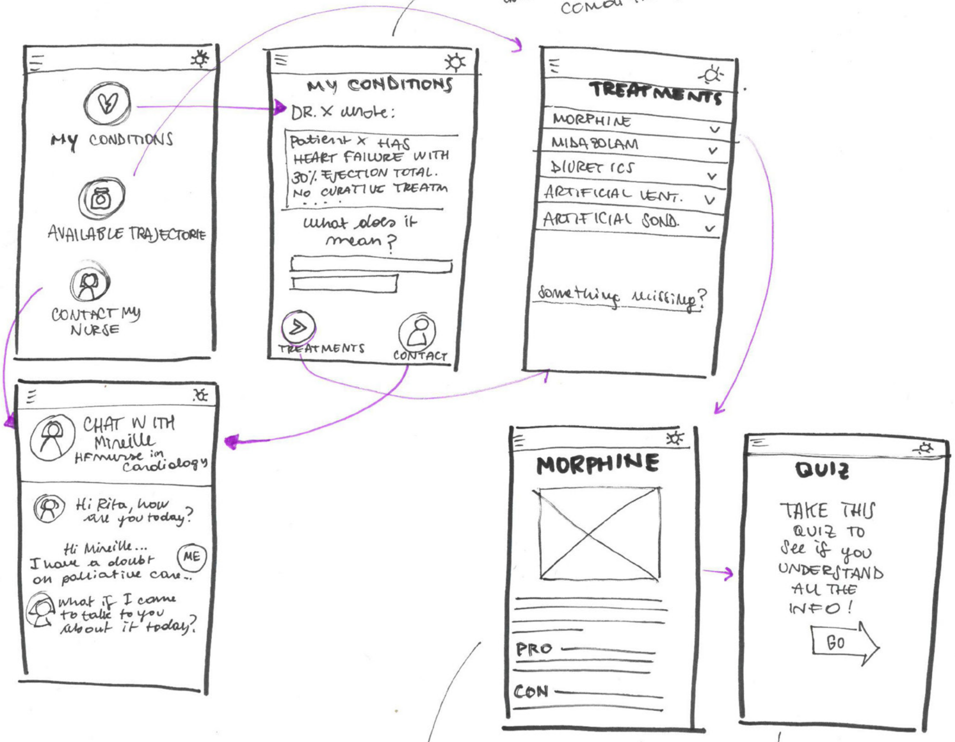
Strengths and limitations: the app offers information, verification of the understanding and a personal contact with the nurse although developing an app is costly and not appropriate for elderly people at the end of their life.

7.3 Conclusion

After considering the outcome of the creative sessions, three design options were defined.
The final design should inform and bring emotional value to help the patient understanding their preferences.
The most valuable elements of all three concepts were taken into consideration and combined in a single concept: the booklet "Deciding with heart", which is described in the following chapter.

In the next page:
Figure 22
Concept 3: Digital app.

THE CARDIOLOGY
OR WARD PHYSICIAN
writes the patient
condition / prognosis



THE NURSE THAT
WAS TOGETHER
WITH THE PATIENT
IN THE CONVERSATION
BECOMES A "PERSONAL
MENTOR" THAT
CAN BE CONTACTED
IN THE APP.

THE APP SHOWS FIRST
AN OVERVIEW OF the
TREATMENTS AND
THEN THE PATIENT
CAN VIEW THE SPECIFICS
OF EACH CASE.

TAKE THE
QUIZ to VALIDATE
YOUR UNDERSTANDI

8 Design: Booklet “Deciding with heart”

The patient must be informed about the treatment choices; at the moment it is done solely verbally. The patient could forget all the information received during the appointment, due to their emotional state or side effects of the illness or medication. Therefore, nurses and physicians must repeat the information often before the patient can understand it. The design should help the patient reflect on their conditions, consider what treatment options are possible, and make an informed choice.

Therefore, the designed concept is a booklet that can be used to explain the patients’ prognosis and their treatment options in order to support them in the decision making process. The booklet can help to start a conversation between nurses and patients about making a choice.

This chapter consists in:

Figure 23
Visualization of the booklet "Deciding with heart" in context.

8.1 Scenario

The booklet “Deciding with heart” has been designed to improve the communication between healthcare providers and patients in the deliberation phase of the shared decision making process (See Figure 24).
Figure 25 shows how the booklet would be used in practice. The physician should include the prognosis of the patient on the page “Your condition” before the first conversation with the patient and family, when the medical decision of not continuing treatments has been made. At the end of the first conversation with the patient, the physician will tell them that they will receive the booklet from the nurse. After the patient is back in their room, the nurse can introduce to them the booklet, using it to explain again what they discussed in the physician’s appointment and what options are available. The booklet will then stay with the patient: they can use it to discover what is important for them and what choice they can make.
The booklet has the function of the decision aid and sensitising booklet. During the daily care, the booklet can become a tool for initiating a conversation between nurses and patients. Both parties can ask about it, in particular, the patient can have tangible material to ask clarification.
The design is tangible and it can be personalized as a diary. The patient can use it as they please, following the correct order or not. The whole booklet is personally illustrated to give it a friendly and pleasing appearance.

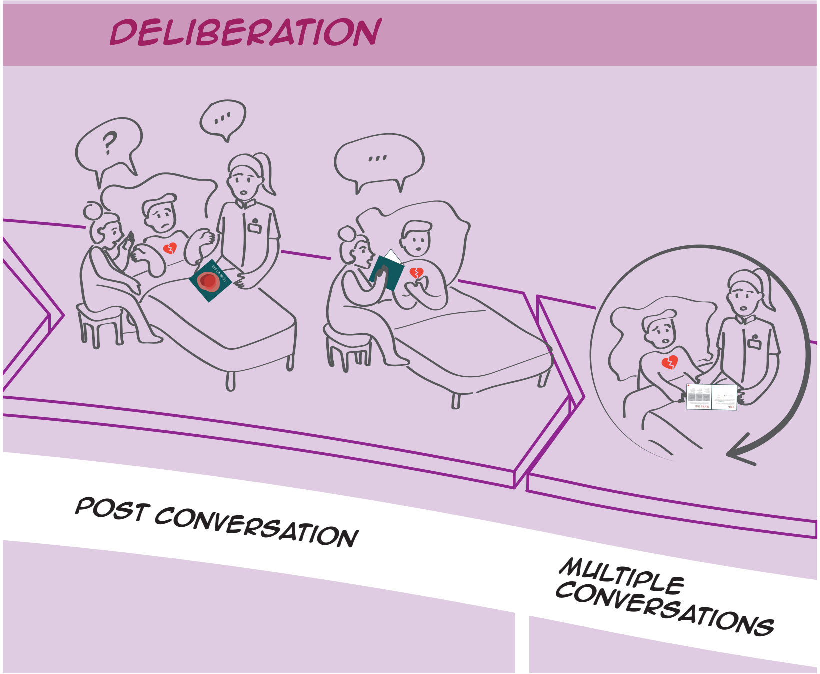
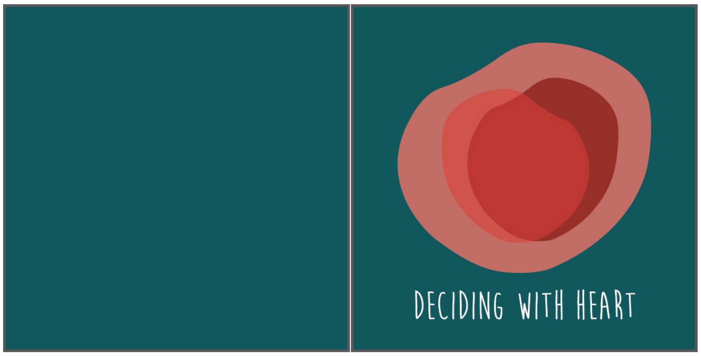
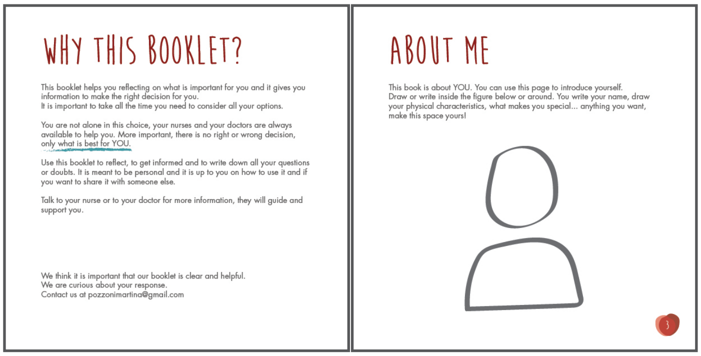


Figure 24
Visualization of the booklet in the deliberation phase of the shared decision making journey (from Figure 14)

Figure 25
Storyboard of envisioned use of the booklet "Deciding with heart"



DECIDING WITH HEART



WHY THIS BOOKLET?

This booklet helps you reflecting on what is important for you and it gives you information to make the right decision for you.
It is important to take all the time you need to consider all your options.

You are not alone in this choice, your nurses and your doctors are always available to help you. More important, there is no right or wrong decision, only what is best for YOU.

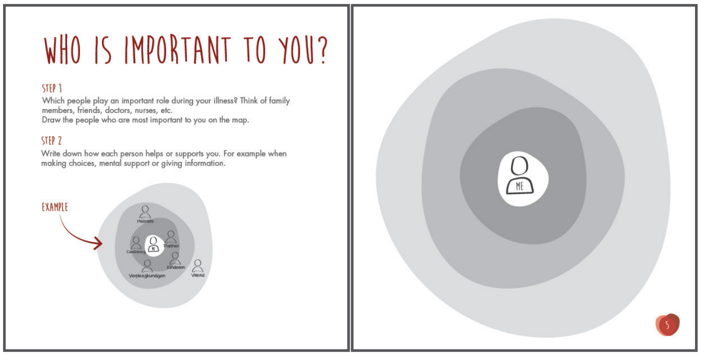
Use this booklet to reflect, to get informed and to write down all your questions or doubts. It is meant to be personal and it is up to you on how to use it and if you want to share it with someone else.

Talk to your nurse or to your doctor for more information, they will guide and support you.

We think it is important that our booklet is clear and helpful.
We are curious about your response.
Contact us at pozzonimartina@gmail.com

ABOUT ME

This book is about YOU. You can use this page to introduce yourself.
Draw or write inside the figure below or around. You write your name, draw your physical characteristics, what makes you special... anything you want, make this space yours!

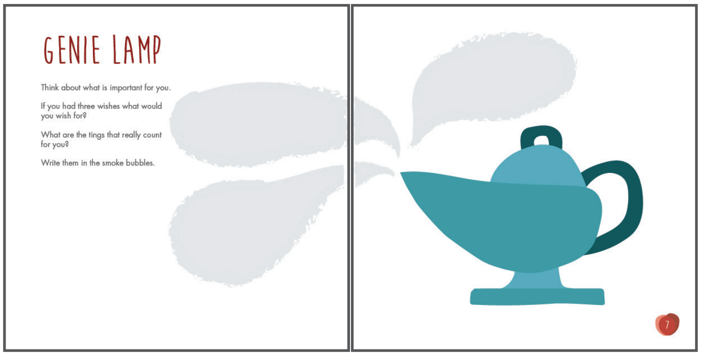


WHO IS IMPORTANT TO YOU?

STEP 1
Which people play an important role during your illness? Think of family members, friends, doctors, nurses, etc.
Draw the people who are most important to you on the map.

STEP 2
Write down how each person helps or supports you. For example when making choices, mental support or giving information.

EXAMPLE



GENIE LAMP

Think about what is important for you.

If you had three wishes what would you wish for?

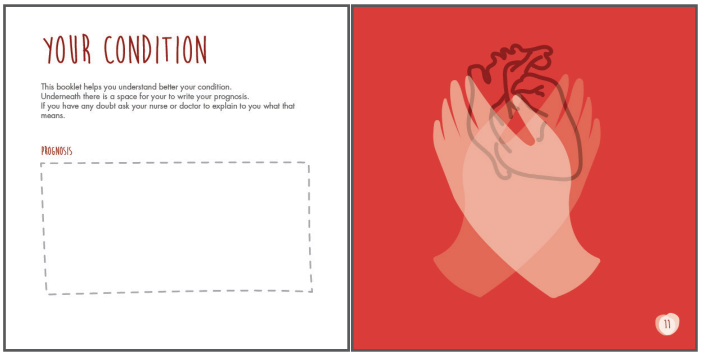
What are the tings that really count for you?

Write them in the smoke bubbles.

WHAT WORRIES YOU?

STEP 1
Thinking about your future and your future treatment decisions, what are you worried about? What makes you uncomfortable?
Write in the space below.

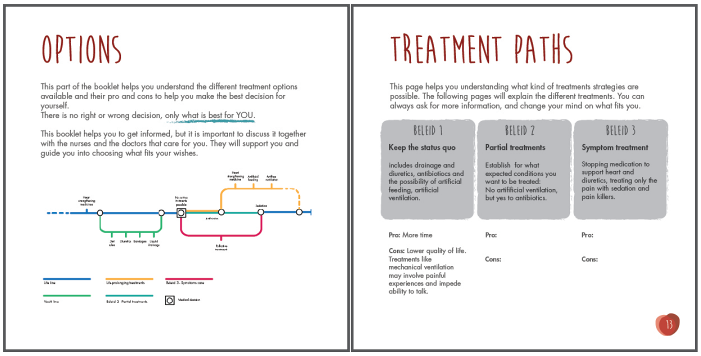
STEP 2
Talk to your nurse about it, she will advice you on how to best handle the situation.



YOUR CONDITION

This booklet helps you understand better your condition.
Underneath there is a space for your to write your prognosis.
If you have any doubt ask your nurse or doctor to explain to you what that means.

PROGNOSIS



OPTIONS

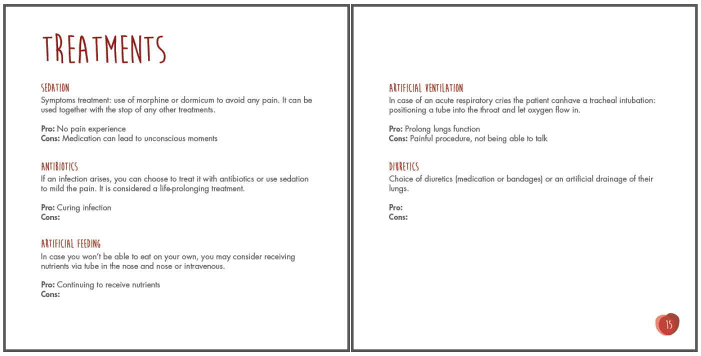
This part of the booklet helps you understand the different treatment options available and their pro and cons to help you make the best decision for yourself.
There is no right or wrong decision, only what is best for YOU.

This booklet helps you to get informed, but it is important to discuss it together with the nurses and the doctors that care for you. They will support you and guide you into choosing what fits your wishes.

TREATMENT PATHS

This page helps you understanding what kind of treatments strategies are possible. The following pages will explain the different treatments. You can always ask for more information, and change your mind on what fits you.

BELEID 1	BELEID 2	BELEID 3
Keep the status quo	**Partial treatments**	**Symptom treatment**
includes drainage and diuretics, antibiotiocs and the possibility of artificial feeding, artificial ventilation.	Establish for what expected conditions you want to be treated: No artifificial ventilation, but yes to antibiotics.	Stopping medication to support heart and diuretics, treating only the pain with sedation and pain killers.
Pro: More time	**Pro:**	**Pro:**
Cons: Lower quality of life. Treatments like mechanical ventilation may involve painful experiences and impede ability to talk.	**Cons:**	**Cons:**



TREATMENTS

SEDATION
Symptoms treatment: use of morphine or dormicum to avoid any pain. It can be used together with the stop of any other treatments.

Pro: No pain experience
Cons: Medication can lead to unconscious moments

ANTIBIOTICS
If an infection arises, you can choose to treat it with antibiotics or use sedation to mild the pain. It is considered a life-prolonging treatment.

Pro: Curing infection
Cons:

ARTIFICIAL FEEDING
In case you won't be able to eat on your own, you may consider receiving nutrients via tube in the nose and nose or intravenous.

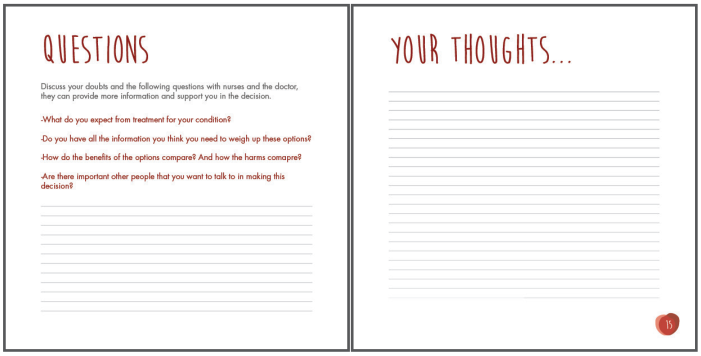
Pro: Continuing to receive nutrients
Cons:

ARTIFICIAL VENTILATION
In case of an acute respiratory cries the patient canhave a tracheal intubation: positioning a tube into the throat and let oxygen flow in.

Pro: Prolong lungs function
Cons: Painful procedure, not being able to talk

DIURETICS
Choice of diuretics (medication or bandages) or an artificial drainage of their lungs.

Pro:
Cons:



QUESTIONS

Discuss your doubts and the following questions with nurses and the doctor, they can provide more information and support you in the decision.

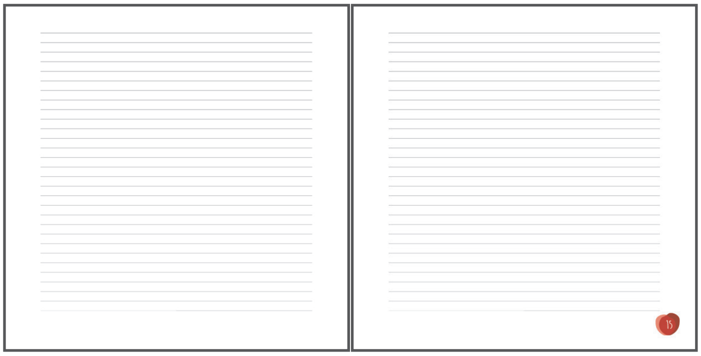
-What do you expect from treatment for your condition?

-Do you have all the information you think you need to weigh up these options?

-How do the benefits of the options compare? And how the harms comapre?

-Are there important other people that you want to talk to in making this decision?

YOUR THOUGHTS...



8.2 Content

Figure 26 shows an overview of the content of the booklet. The complete version can be found in Appendix J.

Cover

The cover (see Figure 27) shows an abstract figure that can be interpreted as a stylized heart or a blossoming flower and the title "Deciding with heart".

"Why this booklet?" page

The second page, "Why this booklet?" explains the how this booklet can be used, emphasizing on the personal scope of the booklet: the patient can read it, write or draw on it, can share it with family or nurses or, eventually, they can also ignore it. It also clarifies that there is no right or wrong choice, just the best for the patient. This page also includes an email to allow patients and family to give feedback on the clarity and usefulness of the booklet.
Although not visually divided, the design includes two conceptual parts: sensitising and informing.

In the previous page:
Figure 26
Content of the booklet Deciding with heart.

In this page:
Figure 27
Booklet Deciding with heart

Sensitising

The first part of this booklet is about sensitising and understanding what is important for the patient and what he is worried about. This part includes the pages:

- About me
- Who is important to you?
- Genie lamp
- What worries you?

These pages are meant to get closer to the patient, and discover what really counts for him. The pages include visualizations and spaces to write or draw. This part is at the beginning to ease the person in thinking about themselves as a person and not just about their condition.

About me

In the “About me” page the patient is free to disclose his personal information. Like in a diary, it is not required to sign a name or disclose age, but the patient can draw in or around the stylized person and make the space about him. Completing this page allows the patient to develop ownership over the booklet.

Who is important to you?

The “Who is important to you?” pages (Figure 28) ask the patient to show on a circle diagrams the most important people during his illness and describe how they were useful. This page helps understanding who are the people around the patient and should be involved in the conversation about his choice.

Genie Lamp

The “Genie lamp” pages asks the patient to think about what is important for them in life and make three wishes for their life. Often, these questions surface aspects that really count for the patients. Therefore, these pages are helpful to understand what the important aspects for the patients are. The question “What is important for you?” is crucial in shared decision making.

What worries you?

The page “What worries you?” (Figure 29) invites the patient to write down their fears. They could be related to his choice, his progressive illness or his death. It is important to address one’s worries because they can highly impact the decision.

After writing those down, the booklet invites the patient to talk to a nurse about them, to understand how to proceed. Many heart failure patients suffer the accumulation of liquids in their lungs and they experience shortness of breath. Some patient may fear death by suffocating or a similar painful experience. It is important for the healthcare provider to pay attention to these fears and address how such experiences could be avoided in the last phase of life.

WHO IS IMPORTANT TO YOU?

STEP 1
Which people play an important role during your illness? Think of family members, friends, doctors, nurses, etc.
Draw the people who are most important to you on the map.

STEP 2
Write down how each person helps or supports you. For example when making choices, mental support or giving information.

Figure 28
Content of the booklet Deciding with heart: "Who is important to you?" pages.

WHAT WORRIES YOU?

STEP 1
Thinking about your future and your future treatment decisions, what are you worried about? What makes you uncomfortable?
Write in the space below.

STEP 2
Talk to your nurse about it, she will advice you on how to best handle the situation.

Figure 29
Content of the booklet Deciding with heart: "What worries you?" pages.

Informing

The second part of the booklet shows the patient's prognosis and lays out different treatment options. The last pages invite the patient to reflect and write down their thoughts. On several pages, patients are invited to reach out to the nurses or physicians for additional information. It is important to use the booklet just as a tool and reach out for the experts' opinion.

This part includes the pages:

- Your condition
- Options
- Treatment paths
- Treatments
- Questions
- Your thoughts…

Your condition

The "Your condition" pages (Figure 30) have a blank space in which the doctor can paste a summary of the current prognosis and why further treatments are not possible. This information is not different than the one explained during the appointment together with the patient, family, the physician and nurse.

Options

The "Options" (Figure 31) page visualises the treatment paths and introduces what will be explained in the next pages.

Treatments paths and treatments

The "Treatment paths" page shows three treatment strategies that the patient could choose as three blocks with the explanations and pros and cons. Then, in the pages "Treatments", the booklet explains all the single treatments and their specific treatments.

Questions and Your thoughts…

The last pages are dedicated to the questions that could be discussed with the healthcare providers and space where to write one's thoughts.

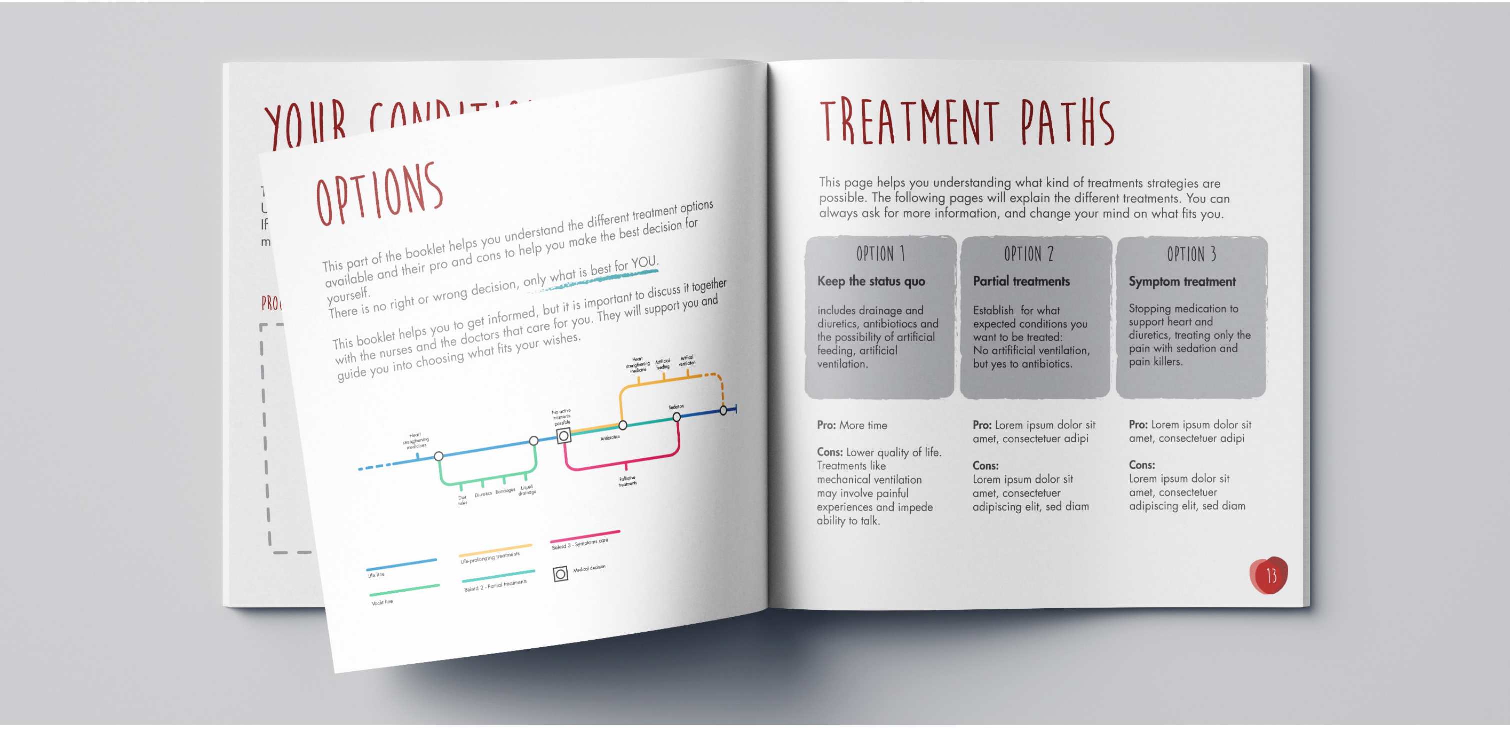
YOUR CONDITION

This booklet helps you understand better your condition.
Underneath there is a space for your to write your prognosis.
If you have any doubt ask your nurse or doctor to explain to you what that means.

PROGNOSIS

11

Figure 30
Content of the booklet Deciding with heart: "Your condition" pages.



OPTIONS

This part of the booklet helps you understand the different treatment options available and their pro and cons to help you make the best decision for yourself.
There is no right or wrong decision, only what is best for YOU.

This booklet helps you to get informed, but it is important to discuss it together with the nurses and the doctors that care for you. They will support you and guide you into choosing what fits your wishes.

TREATMENT PATHS

This page helps you understanding what kind of treatments strategies are possible. The following pages will explain the different treatments. You can always ask for more information, and change your mind on what fits you.

OPTION 1	OPTION 2	OPTION 3
Keep the status quo	**Partial treatments**	**Symptom treatment**
includes drainage and diuretics, antibiotiocs and the possibility of artificial feeding, artificial ventilation.	Establish for what expected conditions you want to be treated: No artifificial ventilation, but yes to antibiotics.	Stopping medication to support heart and diuretics, treating only the pain with sedation and pain killers.
Pro: More time	**Pro:** Lorem ipsum dolor sit amet, consectetuer adipi	**Pro:** Lorem ipsum dolor sit amet, consectetuer adipi
Cons: Lower quality of life. Treatments like mechanical ventilation may involve painful experiences and impede ability to talk.	**Cons:** Lorem ipsum dolor sit amet, consectetuer adipiscing elit, sed diam	**Cons:** Lorem ipsum dolor sit amet, consectetuer adipiscing elit, sed diam

13

Figure 31
Content of the booklet Deciding with heart: Option and Treatments paths pages.
The picture shows an older version of the life-prolonging visualization: this was the evaluated version.

8.3 Comparison with current decision aids in context

Patients with advanced heart failure are not new to booklets and communication tools. To introduce the booklet “Deciding with heart” is essential to investigate the current tools used in practice.
In the VUmc, the following communication tools are available to healthcare providers and patients with advanced heart failure:

- **Brochure: “Hartfalen wat is dat?”:**
  A detailed booklet providing information about heart failure. It describes the characteristics of the illness, the symptoms, the medicines and treatments that are available for a patient with heart failure.
- **Knmg checklist:**
  A series of questions for the patients to reflect on the issues about the end-of-life.
- **Doodgewoonbespreekbaar checklist:**
  A series of questions focused on the last stage of life. The checklist questions the current condition of the patient, their quality of life, and their wishes about dying.
- **Doodgewoonbespreekbaar wish book:**
  A detailed questionnaire to understand what is important for the patient, in life and the end-of-life phase, with space to reflect.

More information on each tool can be found in Appendix H.

Compared to the existing communication tools, the booklet “Deciding with heart” combines the purpose of informing with eliciting activities.
The booklet is appealing and concise.
It contains small portions of text, and the font is accessible to patients.
Figure 32, shows a benchmark of comparison between the booklet designed and the other communication tools used with advanced heart failure patients, regarding legibility and eliciting preferences criteria.

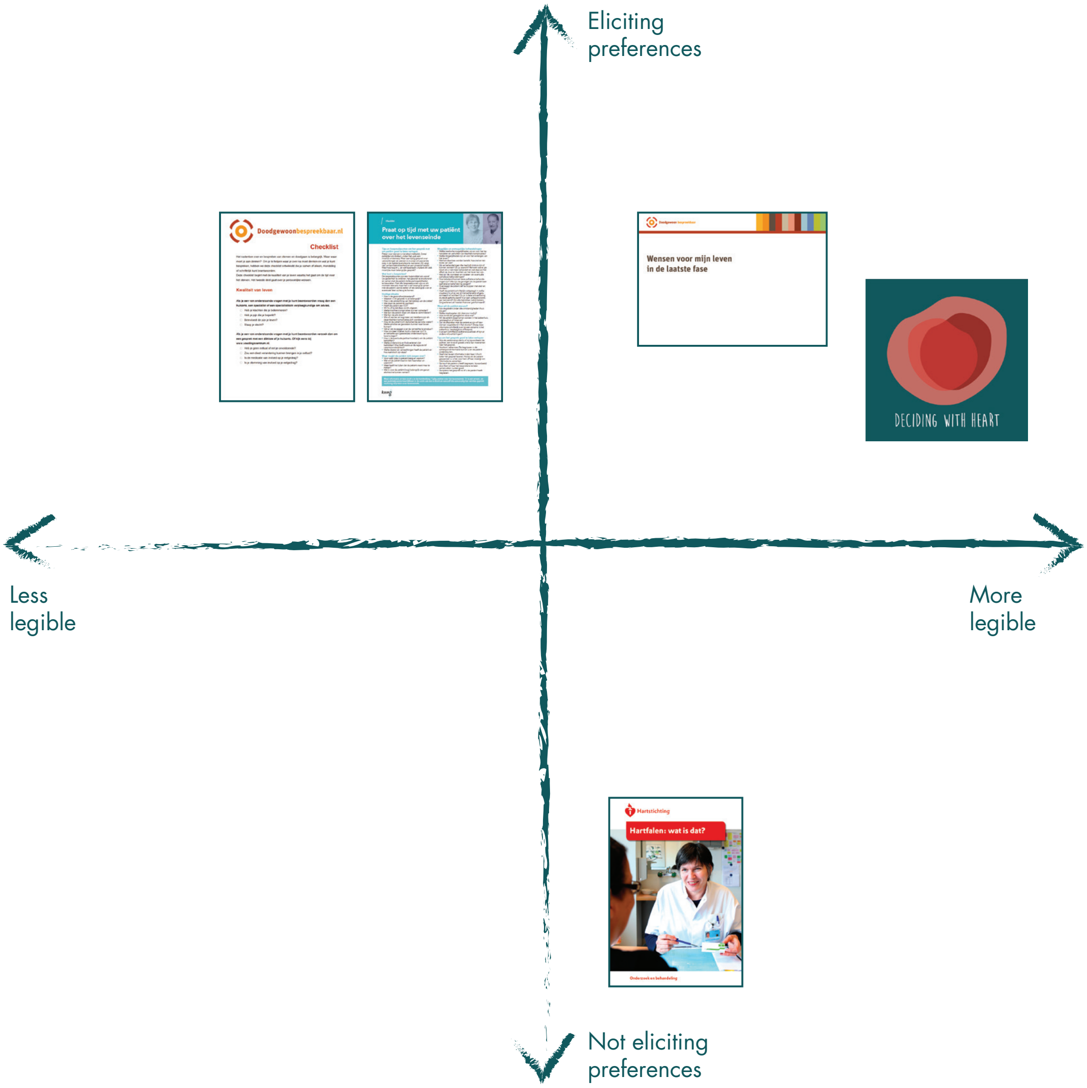


Figure 32
Benchmark of decision aids compared to booklet “Deciding with heart”

8.4 Evaluation of the booklet with nurses

The concept has been evaluated with nurses in Cardiology and heart failure nurses to understand if it could work in context and how it could be improved.

Method

Semi-structured interviews have been conducted with three nurses from Cardiology and two heart failure nurses from the outpatient clinic. In the interviews, the researcher showed the booklet to the nurses and asked for their impressions, following the topic list reported in Appendix G.

Results

The nurses interviewed reacted very positively to the booklet. They appreciated the visuals and the colours but also the size and the layout of the information. The size of the booklet and the font is big enough to be accessible to patients. One nurse appreciated the small amount of text because patients will not read lengthy paragraphs. On the contrary, they might find this solution fast to read and easy to understand. It was appreciated that the booklet does not lay out the sickness and treatments in the first pages but first focus on the values of the patient. One nurse thought that activities such as writing and drawing looked pleasant and inviting, without resulting childish or too much. The nurses agreed that the booklet would help patients to understand their situation better, although it should be available in Dutch.

Handing the booklet to the patient should be a department effort: although one nurse expressed enthusiasm for using the tool in practice, they express concern over other nurses as they might feel that it requires too much time in their shift. One nurse underlined the struggle to find a moment together with the patient alone, when talking about important issues, without being interrupted by the beeping machines or by their duties. Therefore, they suggest it should not be the responsibility of one, but rather a joint effort, organized together with the managing nurses and the head nurse of the department. Moreover, heart failure nurses, ward physicians and cardiologist may also benefit from the tool, allowing them to have a more productive conversation with the patient.

Patients come to the hospital following different trajectories: some are admitted firstly in Cardiology, some in CCU and some through the outpatient clinic. Nurses pointed out that this solution might be useful for patients with advanced heart failure in all three departments. If the patient comes to their department with the booklet, then they may mention it and engage in a conversation, while if they have not received it from other departments, they can provide it to them. One of the things that came up was that after having the end-of-life conversation the decision is rather quick, it usually takes less than a week, so it would be valuable to introduce the tool during the conversation or even before, as the patient is deteriorating and reaching an advanced stage of the illness. Since heart failure nurses expressed that the booklet could be useful to bridge a conversation about end-of-life with a patient that may not be ready talk about it yet, they should judge the most suitable moment to introduce it, depending by the patient.

Specific questions were asked about the “Treatment paths” and “Treatments” pages to validate the information. One nurse appreciated the shortlist of treatments and thought it was enough because patients should not be overwhelmed with information. On this matter, heart failure nurses were concerned that healthcare providers with less knowledge may be limited in suggesting only the options on the booklet or that more explanations would be required, hindering the efficacy. Therefore, one suggested that there should be space to add more treatments or to refer the patients to a website link for more information. The information provided should be complete and in line with the current evidence-based practice.

One nurse appreciated that the patient is called to write their thoughts and not just their questions. It is different from current practice, in which healthcare providers usually encourage patients only to write down questions.

8.5 Evaluation of the booklet with patients' representatives

Since the booklet is meant to support patients with heart failure in the shared decision making about life-prolonging treatments, it was relevant for the project to evaluate the booklet with patients' representatives, after interviewing healthcare providers.

Method

A semi-structured interview was conducted with three patients' representatives. The patients have been diagnosed with heart failure or a cronic heart condition, although they were not at the advanced stage when interviewed. Although they were not the specific target of this project, they were able to give feedback from their perspective as a patients.
The interviews were carried out by showing the booklet and ask for their feedback. The interviews were carried out in English.

Results

The patients' representatives reacted positively to the design of the booklet. One patient said: "I am super happy that something like this is being made because it is something that is absolutely missing in a lot of hospitals and not only for cardiac patients but for many other patients too."

One patient defined it confronting. In their opinion, it depends just on the subject that the booklet addresses. On the other hand, another patient mentioned that at the moment, the booklet is not clearly stating that the treatments described would be for the last stage of heart failure before dying. Therefore, the booklet should include words or expressions that refer to death and dying in the introduction, since some patients might think that the treatment could go on still for a long time, and get better in the end.

The patients appreciated the design of the booklet. One said: "it is like you [the researcher] know what it means to be a heart failure patient". One patient defined the layout as playful and mentioned that "it makes you think in a very gentle way".
One patient mentioned the "Who is important for you" page as a good way to visualise who is involved in the process. The patient can ask questions and involve not only family members but also other healthcare providers such as the general practitioner, the psychotherapist and professionals outside the hospital. In the page, the patient is in the centre, surrounded by others who are involved in their care.
One patient representative found that it was valuable to have a space about free-thinking like in the "genie lamp" page since it communicates that everything that the patient writes is important.

Regarding the implementation of the booklet in the Cardiology department in the hospital or the outpatient clinic, they suggested an organic approach rather than a fixed guideline, since it is new and it should not be imposed on patients that are not open for information yet. They also expressed that in their experience, cardiologists often have a taboo regarding the conversation about death and dying.

During the interviews, the emphasis was given on the way the patients' representatives expected to receive the booklet. Patients have different relationships and affinity with different healthcare providers. One patient would like to receive it from the cardiologist and have the opportunity to ask questions to them or the heart failure nurse, using the booklet as an aid. Another patient would prefer to receive it from the nurse in Cardiology, with a clear explanation of why this booklet is important and with the possibility to fill it together. The patients perceived nurses as more open to talking about options about the last stage of the illness and the possibility of dying.

Two of the patients suggested that the booklet should be available to every heart failure patient that wants to have information. One suggested to position a poster in the waiting room of the outpatient clinic with a short description, to allow the patients who want the information about choosing for life-prolonging treatments to reach out to nurses and receive the booklet, without troubling patients that are not open to that possibility yet. "Patients are hungry for information," they said and "for me, I want to know everything. […] So how can you give tools until the day they die... I think it is very important". Although confronting the booklet was defined as "something that the Cardiology department needs" and that although "we all know that we have a heart problem, so we all know that healthy or not we are going to die. So, yes, it is confronting, but it gives a bit of hope that when the day arrives that there is no treatment anymore, then there is this [the booklet]".

8.6 Conclusion

The designed booklet “Deciding with heart” provides information about life-prolonging treatments for patients with advanced heart failure and sensitise them in individuating their values and preferences.
The design respects the requirements set in chapter 6:

- Be accessible to patients
- Provide written information
- Compliant with the requirements of the VUmc Cardiology department
- Engage patients and healthcare providers in conversation

The interviews confirmed that the design is accessible to the patients. The fonts are legible, and the information is easy to read, short and straightforward. Both nurses and patient representatives defined the booklet useful to communicate to the patient their situation and help them understand better.
The booklet should be available in different departments: at the Cardiology department, the CCU and the outpatient clinic, and it should be available in Dutch. Patients should be able to receive the booklet during the consultation with a cardiologist, a nurse or a heart failure nurse even if they are not at an advanced stage. Healthcare providers could judge the opportune moment to handle it to the patient.

Figure 33
A physician introducing the booklet to a patient

9 Further developments

The design was received positively by nurses and cardiac patients. Although, as seen in Chapter 8, for the implementation in the VUmc there is the need for future developments.

The designer individuated the following steps for the future:
9.1 Content
9.2 Further tests with advanced heart failure patients
9.3 Implementation

They are explained in detail in the following paragraphs.

9.1 Content

The content should be updated and slightly edited. In particular:

- Translation in Dutch
- Make the scope clear
- A link to additional information
- Keep it up to date

Translation in Dutch

To be accessible to most patients recovered in the VUmc, the booklet should be available also in Dutch. The title of the booklet would be “Beslissen met uw hart”. Figure 34 and 35 show the Dutch version of the booklet.

Clear purpose

The booklet should clarify that the treatments mentioned are related to the last stage of the illness, before death. The message should be clear to avoid misunderstandings, although the words should be calibrated and sensitive.

A link to additional information

In pages 14 and 15 of the booklet, titled “Treatments”, should have a link to additional information such as to the website: https://www.heartfailurematters.org/nl_NL/

Keep it up to date

The booklet is a document that is meant to inform the patient with advanced heart failure. The information regarding the treatments must be periodically controlled and eventually updated. The information should be evidence-based and in line with the current practice.

Figure 34
The booklet "Deciding with heart" translated in Dutch

VRAGEN

Bespreek uw twijfels en de volgende vragen met verpleegkundigen en de arts, zij kunnen u meer informatie geven en u ondersteunen bij de beslissing.

Wat verwacht u van de behandeling van uw aandoening?

Hebt u alle informatie die u denkt nodig te hebben om deze opties af te wegen?

Hoe vergelijken de voordelen van de opties zich? En hoe de schade zich verhoudt?

Zijn er belangrijke andere mensen waarmee je wilt praten bij het nemen van deze beslissing?

UW GEDACHTEN...

15

Figure 35
The booklet "Deciding with heart" translated in Dutch

9.2 Further evaluations in practice

The booklet should be further evaluated with healthcare providers and patients with advanced heart failure in practice. Interviews should be conducted with cardiologists and with stage IV heart failure patients. A study should be conducted to verify the improved satisfaction of patients in making a life-prolonging or palliative treatment decision.

9.3 Implementation

The booklet should be available to the patients in the departments of Cardiology, CCU and at the outpatient clinic. The booklet could be requested, or a healthcare provider could give it.

The following paragraphs describe the implementation in particular in:

- The conversation with healthcare providers
- The waiting room
- Other departments

In the conversation with healthcare providers

When the physician is considering to stop curative treatments, as seen in the "Medical decision" step in the"Shared decision making journey" (see figure 14), healthcare providers should provide the booklet to the patient. Since the topic is rather confronting, the right moment and the healthcare provider responsible for delivering the booklet should be evaluated in an MDO, depending by case. It is crucial to identify a responsible professional for each case so that they could ask follow-up questions about their preferences and the treatments. Once the other healthcare professionals are aware of the decision of handling the booklet, they could use the opportunity to open a conversation about it during their appointment.

In the waiting room

While the patient and the family are waiting in the waiting room, a poster with a short description of the booklet should be visible to them. Therefore, if they want to, they can request the booklet to their cardiologist or nurse. The tool should be available to patients who are not in the advanced stage, but they are looking for more information about the last stage.

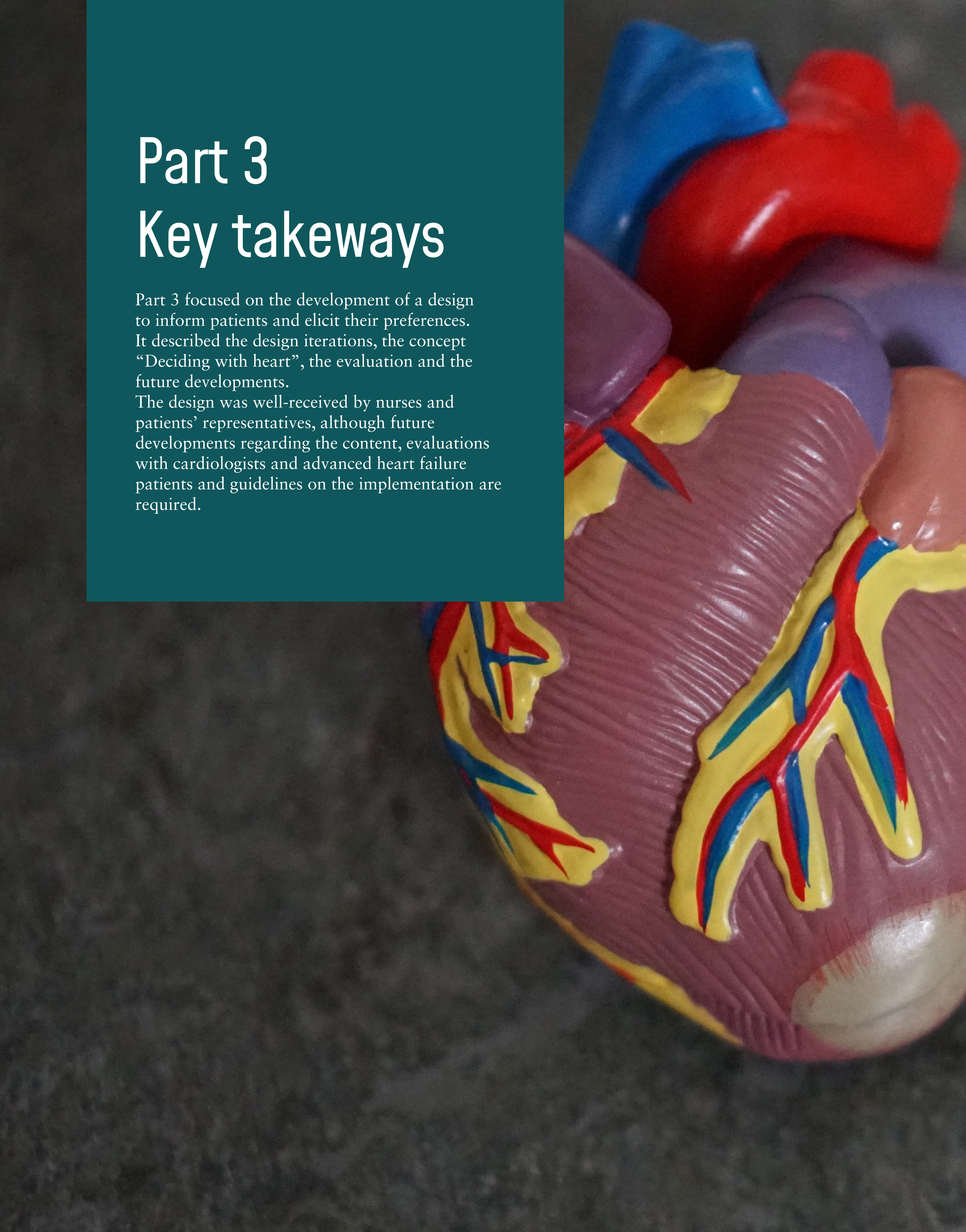
Other departments

After the implementation of the booklet for the patients with heart failure, the booklet could be developed for other departments. Patients from oncology in particular, could benefit from the being sensitized and informed about their treatments in the last stage of their illness, although more research should be conducted.

Figure 36
As suggested by a patient, a poster could be positioned in the waiting room in Cardiology, so that evn patient with early stages of heart failure could access to the booklet "Deciding with heart"

9.4 Conclusion

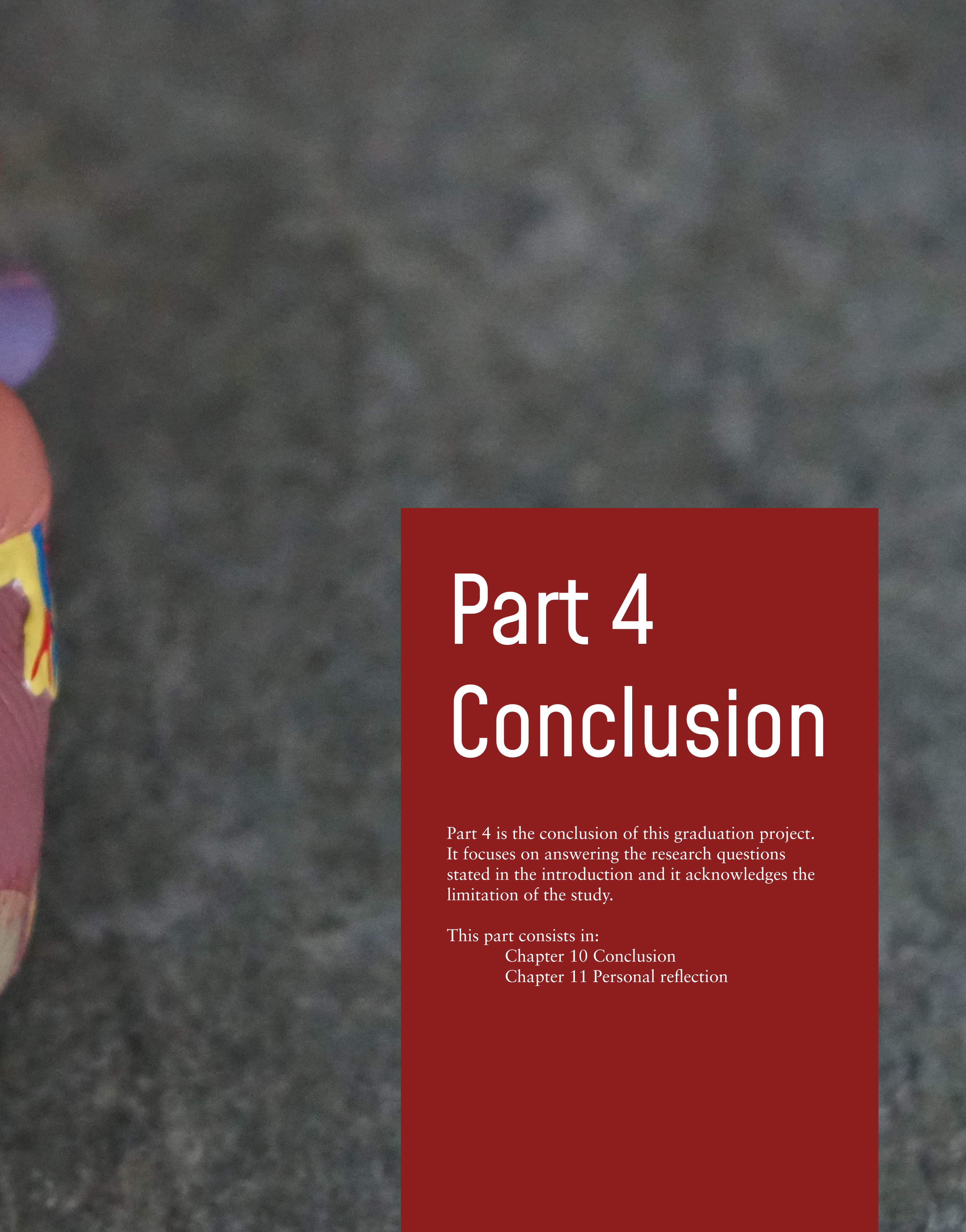
Further developments are needed to efficiently implement the booklet in the departments of Cardiology, CCU and the outpatient clinic. The developments include: editing and updating the content, further evaluations with patients with advanced heart failure and cardiologists, and testing the guidelines for implementations.



Part 3
Key takeaways

Part 3 focused on the development of a design to inform patients and elicit their preferences. It described the design iterations, the concept "Deciding with heart", the evaluation and the future developments.

The design was well-received by nurses and patients' representatives, although future developments regarding the content, evaluations with cardiologists and advanced heart failure patients and guidelines on the implementation are required.



Part 4
Conclusion

Part 4 is the conclusion of this graduation project. It focuses on answering the research questions stated in the introduction and it acknowledges the limitation of the study.

This part consists in:
Chapter 10 Conclusion
Chapter 11 Personal reflection

10 Conclusion

This project focused on supporting shared decision making for life-prolonging treatments with patients with advanced heart failure.
After defining advanced heart failure, the life-prolonging treatment decisions and the context of the project explored how shared decision making is applied in theory and practice in the relevant context.
To understand how patients with advanced heart failure in the hospital are currently supported during the decision making moments for life-prolonging treatments by healthcare providers, literature research, observation and interviews were conducted.

Shared decision making is valuable for patients with advanced heart failure to decide upon their best care, depending on their values and preferences.
In literature, barriers to initiating conversation between healthcare providers and patients were found. The barriers can be summarized as unclarity, uncertainty, lack of training and lack of time. Observations in Cardiology and interviews with the nurses and ward physicians were conducted to understand how the insights from the literature were comparable to the context.
As seen in the “shared decision making journey” (Figure 14), shared decision making is partly applied in Cardiology. After the physician decides to stop curative treatments, they engage with the patient in shared decision making between life-prolonging treatments, treatments restrictions or palliative care.

Four barriers of the barriers found in literature were also found in context, namely:

- Uncertainty of the illness trajectory
- Unclarity of the roles in the care team
- Limited time
- Limited understanding amongst people with heart failure.

In the interviews, no new barriers were found.

Moreover, in Cardiology, healthcare providers share plenty of information, although mostly verbally, and the use of decision aids or communication tools was not mentioned. The research showed a need for informing the patient through written material, which could be the opportunity to empower other professional figures who are less prominent in the shared decision making process, such as the nurses.

The project investigates what tool could help patients with advanced heart failure in taking part in shared decision making with healthcare providers for life-prolonging treatment decisions. For that, after setting a clear design brief, the booklet “Deciding with heart” was designed. The booklet tackles two of the barriers found in the research: limited understanding amongst people with heart failure and unclarity of the roles in the care team.

The booklet was evaluated with nurses and patients’ representatives. It was well-received, and it was evaluated as a useful tool for promoting shared decision making for life-prolonging treatments. The patients expressed the need for receiving it earlier in their illness trajectory when heart failure has not reached an advanced stage yet.
Making the booklet accessible to patients in the early stages of the disease will impact the shared decision making process about life-prolonging treatments: patients will be informed, and they could engage in a conversation before it is an imminent decision.

More research should be conducted for the implementation of the booklet in practice.
Moreover, to address the shared decision making approach with heart failure patients, more research should be conducted throughout the whole illness trajectory. It may include informing patients from the early stage, and it might include a different approach to the organisation and the training of healthcare providers.

10.1 Strengths

The following paragraphs address the strengths of the project.

Methods

The data was collected through a plurality of methods: literature research, observations and interviews. The use of different methods was valuable to investigate the problem from different angles. The qualitative methods used allowed the project to provide detailed information regarding the sensitive and complex issue.

The plurality of methods made it possible to compare the different data collected. The findings showed a correlation between the barriers found in the literature, and the ones found in the interviews.

Plurality of perspective

The project considered the point of view of different stakeholder, interviewing nurses, managing-nurses, ward physicians, heart failure nurses and patients' representatives. Considering a plurality of perspective gave strength to the validity of the data collected. The data collected was compared and found consistent.

Context

The solution designed was the consequence of the findings collected from the research of the context. The solution was designed to fit the socio-cultural aspects of the department of Cardiology department in the VUmc.

10.2 Limitations

The following paragraphs address the limitations of the project.

Language

The study was conducted mostly in English, which is the second language both for the researcher and the interviewees. Although the researcher is proficient in English, sometimes, the interviewees had struggles finding the right words or showed hesitation.

Some of the research has been conducted in Dutch, although the level of the researcher is intermediate.

The use of non-native languages could have influenced the findings, since some nuances may have been lost in translation. The result may have been more detailed in the mother tongue of both researcher and interviewee.

Recruitment

The subjects that were interviewed were recruited through personal connections. The sample was rather small, and they may not represent the whole population. The results of the research cannot be generalised.

During the research part, it was not possible to recruit patients with advanced heart failure hospitalised in Cardiology, due to time and language limitations.

Methods

Literature research

The literature research may present a case of report bias, in which the findings collected to support the assumptions of the researcher.

Observations

The researcher may have interpreted the activities observed in a biased way, influenced by her culture and familiarity with the hospital setting.

Interviews

In the interviews, the interviewees might have consciously, or subconsciously, answered in a way to please the researcher. During the evaluation of the design, the researcher also had the role of the designer, which may have influenced the answers of the interviewees.

Analysis of the data

The analysis of the data was carried out by a single researcher. Therefore the analysis may be subject to the unconscious biases of the researcher.

Time

The project was conducted in 100 days of work. The time limitation influenced the length of research and design activities.

11 Personal reflection

This graduation project was a personal valuable learning experience. The project presented a complex challenge that I tackled with enthusiasm and hard work.

At the end of this project, I, most of all, feel proud that my research and design received appreciation from the healthcare providers and the patients I interviewed. Having a patient telling me that I design like I "know what is to be a heart failure patient" was the best compliment I could have received.

The project allowed me to grow personally and professionally. Managing a project on my own was challenging and satisfying at the same time. Researching healthcare on such a sensitive topic was humbling and inspiring: even in the difficult moments of the project, it motivated me to work hard.
On this note, I think that collaborating with the hospital made me a better researcher. I dealt with different challenges, such as stricter ethical guidelines regarding the collection and privacy of the data, a mostly Dutch-speaking environment, and learning how to approach healthcare providers for the interviews. Through trial and error, I discovered the effective to approach subjects to interview, to schedule and plan research activities.
The project also allowed me to prove my Dutch proficiency in the field, interviewing healthcare providers in Dutch, with good results.

In the aftermath of this project, I would do some things differently.
At the beginning of the project, I would have worked more in refining the definitions and my focus, to feel more self-confident and have more focused interviews.
Interviews with the target patients could not be carried out due to time limitation and language barriers. Therefore, I would have liked to focus more on having extensive interviews with healthcare providers instead of preparing for the patients' ones. I personally believe that interviewing the target patients that early in the project would have been risky. I am happy that I had the opportunity to talk with the patients' representatives at the end of the project when I had more information about the experience of a patient with heart failure.
If the time could have allowed it, I would have like to focus more on the implementation of the booklet in practice, although there might be a possibility to do it in the future.

I believe that wanting to do things differently is a positive sentiment at the end of a graduation project since it connotates the goal of such experience: learning. I learnt by doing, and I am satisfied with my work.

In the future, I wish I could further develop this project to implement it in practice, and I hope to work as a designer in healthcare.

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