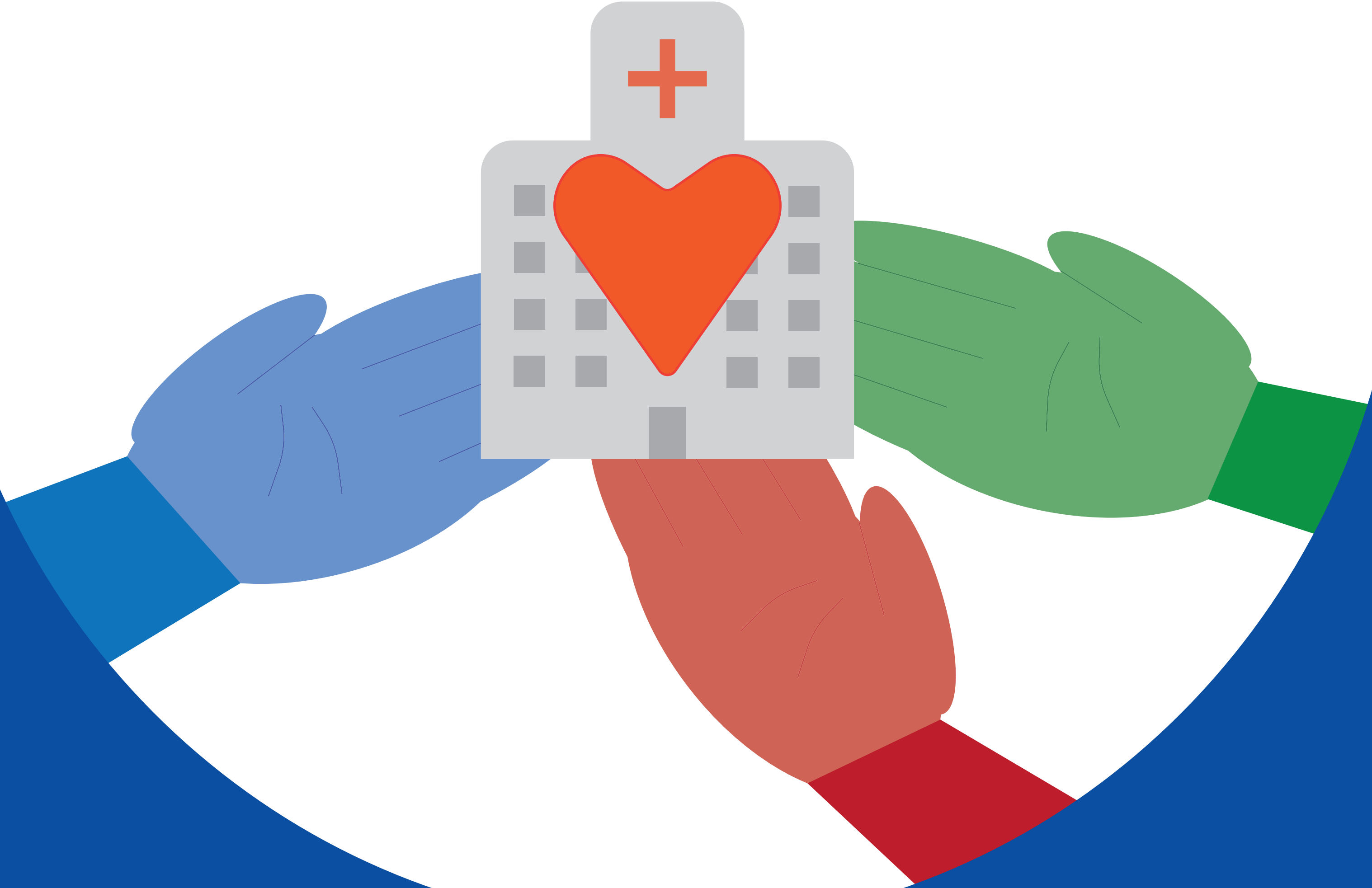
Prepared Care for Discharge

Designing the First Steps to Improve the Hospital Discharge Process for Oncology Patients and Their Close Loved ones



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Master thesis

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Preface

This project marks the final step in my Industrial Design master study program. It takes place in a context I find interesting, compelling but also challenging. During my entire study program, I always liked the projects with a sensitive target group. One which you cannot just approach without more preparations compared to more common target groups. This extra layer is something I always like to add to projects, as I feel it allows a designer to truly shine in a situation they have studied for. Onolcogy patients provide that extra layer, each with their own experiences to share that can contribute something insightful to the project.

The project takes place in the Reinier de Graaf Gasthuis in Delft in the oncology department. Due to the nature of the illness present in that department and the sensitive information often present, no images, names or detailed personal stories are presented in this report. This is out of respect for the patients and their close loved ones (partners, children, family etc.) who rather not publicaly share their illness and tough time they are going through. Any figures used in the project that reference the patients or a location in the oncology department are recreated using drawings to remove any identification. Personal stories are told at a surface level, mentioning the main subjects while not going into detail that might reveal who are present in the stories. This goes for scenarios that might happen as well, making them more generalised while still providing relevant insights for the project. The report also contains some medical terms but are mostly kept to a minimum. Terms that are present, are always explained during their first mention. The project is divided into four phases that are explained in the second chapter of this report. Each phase is marked by a distinct color to show where I was during the project and what has been gathered per phase. This is done to provide a clear structure but also a small look into how a design project is set up.

Before continuing, I want to thank everyone who has been a part of this project and helped in shaping it to what it has become. A personal thank you to everyone are given in the final chapter of this report.

The Hidden Side of the Hospital Discharge Process

Patients staying in the oncology department have to deal with fears and worries about their treatment, diagnosis and the effects it brings on their life and those around them. These fears and worries remain often hidden, due to patients needing time to open up about them and healthcare providers not immediately noticing these. They take these fears and worries with them when leaving the hospital, creating a negative discharge experience that provides a lot of stress in a setting where they can familiarize themselves again. The current discharge takes a clinical approach that favors time efficiency with a focus on the direct patient's needs while missing out on discussing hidden fears and worries of the patients, and no new knowledge is provided on how to effectively do this. This asks for new approaches and tools that can make these hidden fears and worries noticed by healthcare providers, being able to talk about them and prepare the patients and their close loved ones to leave the hospital with a confident feeling of being able to take care of themselves and provide the care necessary.

This project aims at finding such new approaches and providing tools that can help turn the discharge experience more positive. A mixed method approach is used where in four phases the context of the oncology department is explored, analysed and designed for. This is supported by an empathy framework, discharge journey map and other models in order to provide a human soft touch to the discharge process. A good understanding of the current discharge process is formed and insights are gathered that influence the discharge experience. Concepts are created that incorporate the insights to evaluate the effects on the discharge process.

The hidden fears and worries of patients and their close loved ones are the care not being of the same quality outside the hospital as within, their home turning into a second care home and them not being able to take care or provide the care. Healthcare providers hold on to their existing working methods due to their attitude of it working for some time without any form of self-reflective feedback. Six factors have an influence on the discharge experience that determine how everyone involved interacts with each other, of which confidence and expectations can be improved.

A concept goal and direction are formulated that focus on the two factors and additionally raise awareness, allow everyone to share their fears and worries and give confidence to be able to take or provide care. This has given two concepts which in a total of six tests have been evaluated on their influence and changes to the discharge process. A final concept proposal is given with an implementation plan for future design that expands on the first steps created in this project.

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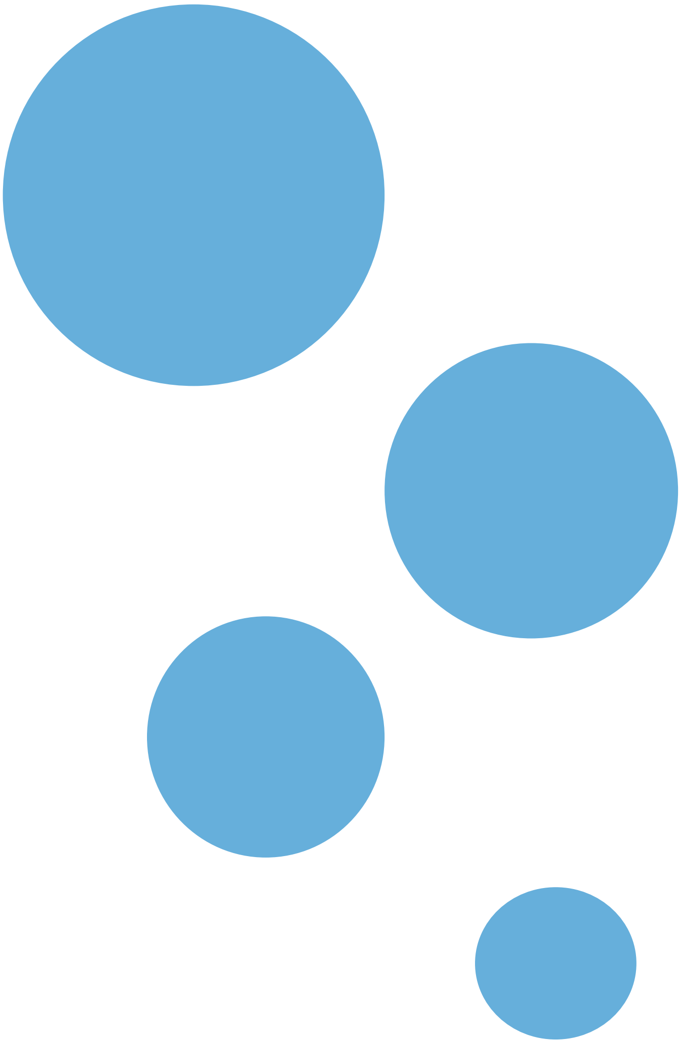

1 Introduction

Patients with a (long-term) stay or following a periodic procedure at the hospital can have an impact on their wellbeing. This is mainly due to stress from being in a different environment for an uncertain amount of time with limited communication with close loved ones and being surrounded by machines and unfamiliar hospital staff (Keirse, 2022). Healthcare providers in turn have to deal with an increasing workload and their working field demanding more and more of them, mainly to adapt a more human centered approach in their work (Bitkina et al., 2020). Healthcare consumption will increase exponentially in the next few years, resulting in a growing shortage of (human) resources and increasing costs. All this combined creates a challenge for patients and healthcare providers to form a connection to better understand their concerns, needs and questions. This can have an effect on the discharge of the patient as once the treatment in the hospital has finished, it is expected of the patient to take care of themselves in the aftercare phase, with or without assistance. If a patient leaves with concerns, needs and worries that are not addressed or taken care of, they will have a lot of stress in a setting where they can familiarize themselves again (Hesselink et al., 2013).

Patients going away from the oncology department carry a heavy weight of recovering from an often deadly disease. Even when recovered, and deemed cured, the lingering fear remains that can have a major change on their daily lives. Those who are less scared of the disease, still have to undergo heavy medication that follows them home (Lithner et al., 2015). The idea of a prepared discharge can get disrupted by this, and when the moment is missed to better talk about the fears and needs of patients, creating a warm coming home gets even more difficult. At the personal patient-doctor level, healthcare providers have limited time, availability, and knowledge about the possibilities for new working methods to approach and interact differently with patients. The existing solutions do not always fit into the healthcare processes resulting in potential resistance to use these tools in daily practice (Drejeris & Drejeriene, 2022). It therefore is necessary for a critical look at the current hospital discharge process and analyze its current state, in order to find a fitting alternative that can improve the discharge experience and create a prepared discharge for a warm coming home that every patient deserves.

1.1 Aim & Scope

The current system of the hospital discharge takes a clinical approach that favors time efficiency with a focus on the direct patient's needs while missing out on discussing hidden concerns and worries of the patient (Harrison et al., 2011). These hidden concerns and needs are difficult for the patient to express and might not be immediately noticed by the healthcare providers, due to the tight schedule of the healthcare providers and the patients needing time to open up to the healthcare providers (Centraal Bureau voor de Statistiek, 2022). This however comes from both sides as healthcare providers want what is best for the patient but also encounter barriers that do not allow them to provide what they want to provide.

A new approach and tools are suggested that help in better connecting the healthcare provider with the patient, in a way that they can talk about their concerns and needs with the same amount of limited time they have. This started by first exploring the oncology department to get a good understanding of the current discharge process and the interactions and emotions within that form the experience. Based on observations and interviews, a discharge journey map is created. This map shows a timeline with the various steps in the discharge process including the experience of those involved. The map identifies problem areas in the discharge process which can be improved. The discharge journey map helped in analysing the oncology department and find a concept direction in order to reshape the discharge process. Various concepts are created based on the concept direction which are tested and explored in the concept exploration to find out what the effects of the concepts were on the discharge process experience. Iterations of the concepts are made based on feedback from everyone involved in discharge process. This project concluded with a final look at the effects on the discharge process to propose a future implementation plan in order to continue the first steps made.

1.1.1 Project Focus

The following question is formulated in order to have a clear goal with this project and which can lead to a good implementation plan for the oncology department. This is based on the graduation project brief problem definition and assignment (see appendix A). The project will take place in the oncology department of the RdGG.

What is needed for healthcare providers, patients and their close loved ones for a good discharge process that leads to a warm homecoming?

Several sub-questions are formulated to help find answers to the main question.

1. *What does the current oncology discharge process look like?*
2. *How do the healthcare providers, patients and their close loved ones experience the discharge?*
3. *What are the unmet needs and hidden fears and worries that might influence the discharge process experience?*

1.1.2 The RdGG Oncology Department

Figure 1 shows an overview of all the stakeholders involved in the hospital discharge process. The rings represent the importance of the stakeholders, determined by their role during the discharge and how much presence they have. The first ring shows the main stakeholders of the project which are the patients, their close loved ones, doctors, and nurses. They are the ones who stand in the center and who this project is aimed at. Every ring after that shows various degrees of relevance or influence on the discharge process. The influence is measured based on the kind of communication with the first ring stakeholders, the amount of communication and how much the communication impacts the experience of the discharge process. These people are not the focus but are present in order to discover more about the discharge process and identify problems, challenges and opportunities.

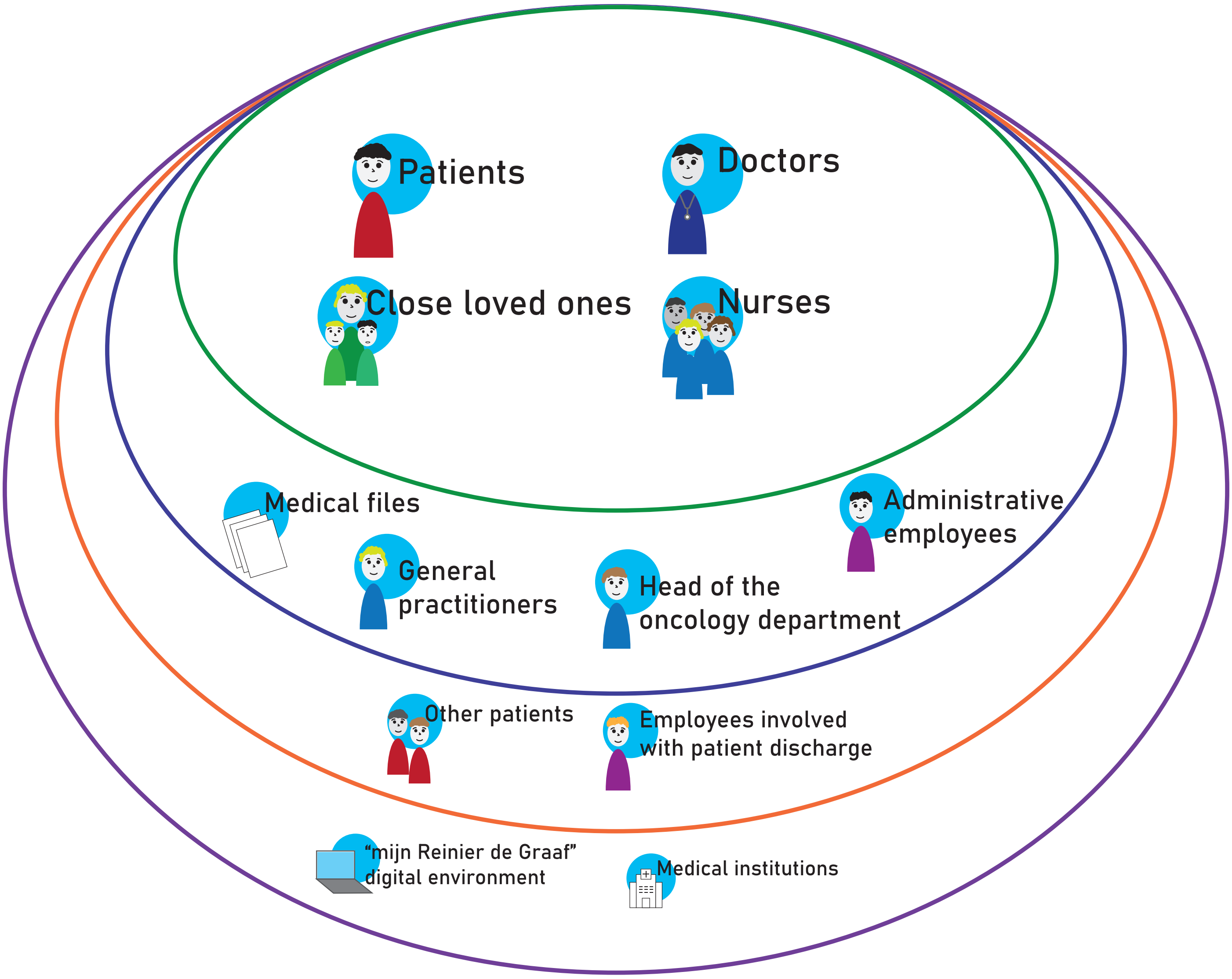

Figure 1: Stakeholder overview with the top ring containing the central stakeholders of the project, and each subsequent having less influence on the discharge process experience

1.2 Personal Motivation

The reason for choosing this context and specifically the oncology department, stems from personal experience. Having lost a father due to cancer after a two year long battle involving different treatments and constantly going from cured to needing treatment, provides a harsh reality check into the world of the oncology hospital discharge process. Fear, anger, sadness, curiosity, to name a few, all swirl around inside your head when experiencing this. This experience has shown the best intention of healthcare providers to help the patient and those close to them. Always lending a helping hand and even willing to listen but within the time that is allowed and to a certain level that both can quickly move on with their life. This shows an experience which can quickly sway towards a negative one and can therefore be improved. One where it is noticeable how little the emotions are taken into account.

Even though playing the role as a close loved one comes with many distractions that will not allow one to think about how they feel, there still are concerns and needs that linger throughout the whole discharge process. Mainly about what is going to change for the patient, the father, when they get home and how to deal with the chaos. It was not about getting the direct answers but about knowing there is room to talk about it, to know there is a voice on the other end that can guide you in this chaotic moment. From the healthcare provider side, other family members show a lack of trust or almost resentment towards them, which is unfair knowing that, in the end, they tried everything to help. This project is an extension of that experience which lays the groundwork for a motivation to provide something to others that experience or have experienced something similar. A way for both sides to understand each other and work together to reach a conclusion they can all accept and move on from.

2 Project Approach

The project centers on a large context exploration in which the interactions and actions are observed to get a better understanding of the oncology department. A co-creative approach is used to create multiple iterations of concepts to find the effect and changes to the experience of those involved in the discharge process. The discharge journey map is leading in formulating a concept direction. The journey map changed through communication and sessions with the stakeholders who shared their thoughts and ideas about their experience in the discharge process.

Figure 2 shows the timeline for the project. The first phase is the context exploration in which insights are gathered about the current experiences of those involved in the discharge process. The second phase analyses the insights gathered during the exploration. This leads to a concept direction with which concepts are created to measure the effects on the discharge process experience, and forms the start of phase three. Multiple iterations of the concepts are made based on feedback from the involved stakeholders. The project concludes in the final phase with an implementation plan for future design and use in the RdGG oncology department. At the end, some closing words are given for the project.

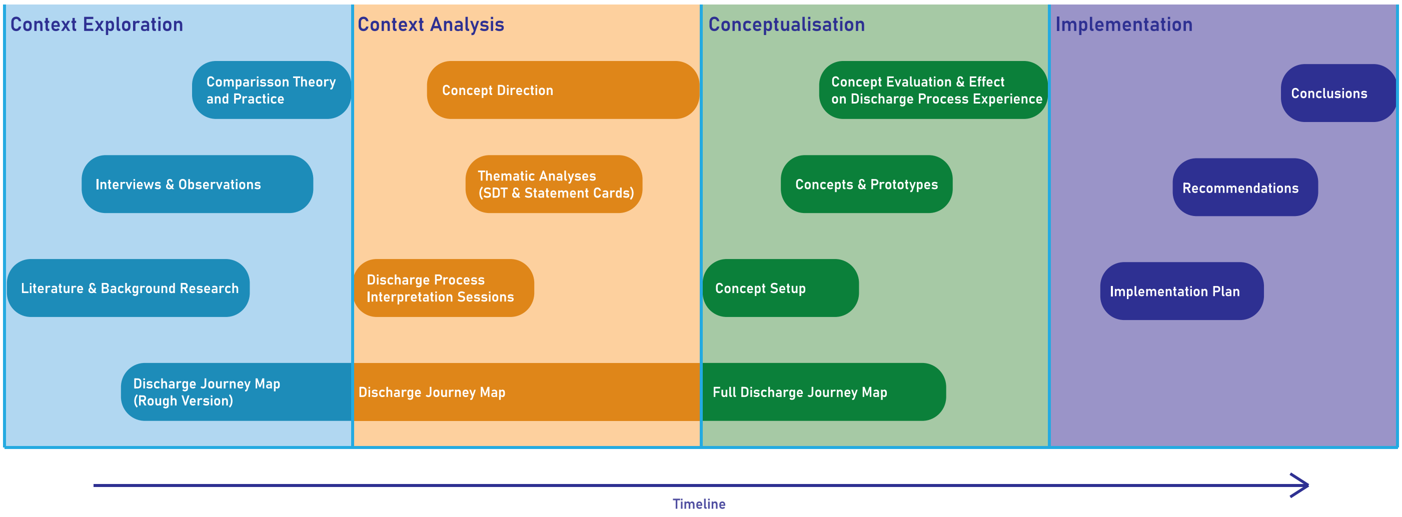

Figure 2: Project approach having four phases each with their own methods used to explore and design for the oncology discharge process

Context Exploration

This phase of the project explored the current discharge process experience and the RdGG oncology department. In chapter 3, literature and background research is done to get a good understanding of the current situation. This is compared to the oncology department RdGG through observation and interviews in chapter 4. The goal was to find how the theory was present in practice and what differences there were.

Discover
Enter the oncology department and be curious about the experiences within

3 Literature on the Discharge Experience

This chapter contains a literature review about the subjects introduced in the introduction. The goal of this chapter is to get a basic understanding of the current healthcare system, in particular the discharge process, and what the current experiences are of healthcare providers, patients and close loved ones of the patient. A look at existing solutions is taken to find out what these provide and what their strong and weak points are.

Methods used: For searching, the platforms Google scholar and regular Google searches were used. Keywords used are the following: current, healthcare system, discharge process, healthcare provider discharge experience, patient discharge experience, discharge process tools and methods.

3.1 Current State of the Healthcare System and the Discharge Process

It is no surprise that healthcare in the Netherlands for the past couple of years has been under a lot of pressure. An increasing workload and a society that gets older and older, more than ever is demanded from the field (Centraal Bureau voor de Statistiek, 2022). This is paired with a society that has an increasing general need for care (Poon, 2022). A response to keeping up with the increasing demands, is finding new approaches to performing healthcare. These approaches look at new working methods and implementation of tools to help tackle the workload but also improve the overall care provided to those who need it. A good example is the use of artificial intelligence (a.i.) in assisting healthcare providers during their daily practices, with the goal of increasing working efficiency (Kraus et al., 2020). During consultancy with a doctor, a.i. is used in transcribing and forming a summary of the entire conversation without the need for the doctor to remember every single detail to update the patient file.

A human centered approach is used daily in healthcare practices. This approach puts the real people at the center and designs the services to their needs (landry, 2020). It follows four steps to design the product/service that fits the target audience. The first step, clarify which looks at the problems that can be fixed, is the most interesting as it has two layers. Explicit are the immediate problems and latent are the hidden ones. In the context of healthcare, it are the latent ones that dominate the experience, and understanding these helps in finding the right options for the patient's needs (Spek, 2024). The current discharge is very clinical, involving steps which follow standard guidelines and checklists healthcare providers follow to send the patient home correctly. The main goal of these guidelines and checklists is to provide the necessary information for the patient about for example medication and follow up appointments (Bilgin et al., 2023). This leaves little room for talking about the emotions and feelings of the patients. Empathy is something that contributes greatly to the communication during the discharge process. It shows that employing empathy by healthcare providers, placing them into the shoes of the patients, helps them understand what the patients are going through and talk about their fears and worries (Ministerie van Volksgezondheid, Welzijn en Sport et al., 2017). Negative factors like the number of patients, lack of education on deploying empathy and a general lack of time contribute to not using empathy during consultations or discussions (Moudatsou et al., 2020).

The four phases of empathy, a framework by Kouprie & Visser (2009), show what needs to happen for empathy to take place to gather valuable insights about each other. Figure 3 shows the four phases, adepted to the oncology department. It starts with curiosity to enter the world of the other person and discover what they experience. Following this is immersion to learn more about the other which leads to a connection based on sharing and understanding each experience. Detachment can be seen as taking a step back to think about what has been shared while maintaining a connection with the other. Each step comes from both sides at the same time, as both healthcare providers and patients need to take the effort to understand each other. Attitude is an important factor for healthcare providers as it determines how they approach patients and the treatment. Knowing and understanding by having an open attitude without any unreliable or unrealistic expectations makes immersion easier and creates a valuable connection between healthcare provider and patient (Steinmair et al., 2022).

Expectation management has two sides in the oncology discharge process. The first focuses on the expectations of what is to come next after discharge. It allows all parties to be prepared for the future and provides a form of confidence to be able to tackle the next step. The second looks at the expectations of participation, which allows each party involved to have their word in the discharge process. This can also mean that for example patients have the expectations for no need to bring in their ideas and let the healthcare providers form the entire discharge process (Lithner et al., 2015). The study by Lithner et al. (2015) shows a lack of patients employing empathy towards healthcare providers, having little to no curiosity to discovery the world of the healthcare providers. The knowledge of the patient on what is happening during treatment or more specifically the workload of a healthcare provider can help them understand why certain steps in the treatment go as they go or why certain pieces of information are shared the way they are. It is often the healthcare providers who need to change their approach when it comes to providing healthcare but the patient can also contribute a lot by placing themselves into the shoes of the healthcare providers.

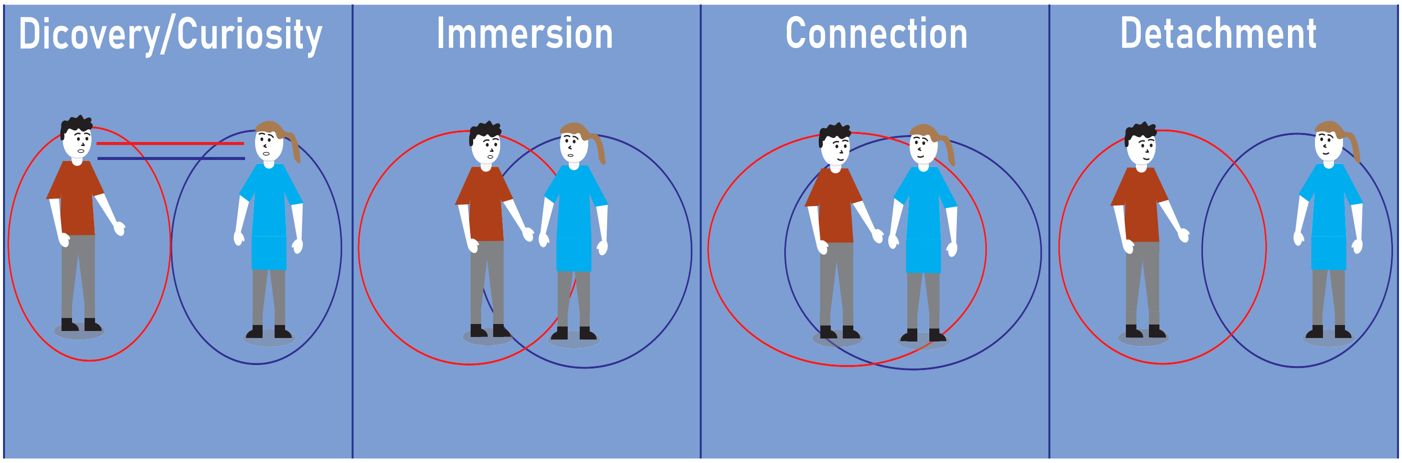

Figure 3: Four phases of empathy where both healthcare providers and patients follow the same steps

Patient participation is important in the discharge process, as it helps in them asking the questions and addressing their needs and worries. The value of building a relationship between the different parties involved (not only patients - healthcare providers but also close loved ones of the patient) improves the overall healthcare process for everyone (Beach & Inui, 2006). This starts with the patient participating on an equal ground as the healthcare providers in the discharge process, and by forming a connection, share their needs for discharge.

3.2 Current Discharge Experiences

The current discharge process show several factors present that influence the experience of those involved. Results from a study by Krook et al. (2020) show five key elements that contribute to the patient hospital discharge process for both patients and healthcare providers.

These elements are:
1. Accessibility
2. Information
3. Communication
4. Confidence
5. Participation

Communication and information are often sufficient as the channels used and explaining the information are usually clear. If not, these are written down to provide further explanation. With participation, the patients want to be actively a part of how the discharge is going to be. It is important to note that they want to participate and not take over control. The healthcare provider is the one that provides the information, where the patient decides what to do with this information. Confidence has to do with the skills of the healthcare providers and the feeling of the patients that they can leave the hospital correctly. This factor has to do with with what the patient is feeling. It shows the emotional side of the discharge process which is not always mentioned or talked about between the healthcare providers and the patients. Accessibility is how easily the patient can approach the healthcare providers for any questions they have. This is heavily influenced by the attitude of the healthcare providers and their available time. The quote underneath from a patient from the study summarizes this:

“If I could only talk as a patient to the doctor and nurse... and not a whole ward full of other patients and people running here and there... You need to understand, one is not given a chance, no chance to ask questions and wait for answers... What will I do...? I am thinking, I can do absolutely nothing.”

On the other hand, the patient can also have a different attitude that allows for the wrong kind of expected accessibility. The lack of the patient’s role in the empathy factor during healthcare is visible in figure 4. The knowledge of the patient on what is happening during treatment or more specifically the workload of a healthcare provider can help them understand why certain steps in the treatment go as they go or why certain pieces of information are shared the way they are. It is often expected that the healthcare providers need to change their approach when it comes to providing healthcare but the patient can also contribute a lot by placing themselves into the shoes of the healthcare providers.

The patient discharge experience has many differences between the individual patients as to how they experience it. Factors include the specific type of cancer, the treatment plan and length of stay. Harrison et al. (2012) found during their study in France, with over 1200 patients over the course of five to sixteen years, that the overall discharge experience is satisfactory but that there is still room for improvement. The overall management of the discharge was satisfactory, that being information shared and the communication with healthcare providers. The improvements that are suggested in the study are similar to the key elements of the previous study, which include accessibility and confidence. Specifically the accessibility and confidence to share the emotions during the discharge process.


Quote: plebpleb schreef op zondag 14 okt 2012, 14:18: De hele avond en nacht werd ik aan mijn lot overgelaten...einde Quote Wat een onzin. Je ligt in een ziekenhuis met artsen en verpleegkundigen. Je hebt een alarmbel, heb je iemand nodig, alarmeer je en komen ze naar je toe. Wat moeten ze dan doen? Elk kwartier even komen kijken? Je ligt daar voor een operatie niet voor de gezelligheid.

Reactie door plebpleb op 16-10-2012 15:07

Er zijn gewoon geen discussies op mijn ervaring in 't ziekenhuis...Alleen JA-knikkers kunnen zo negatief reageren...Ziekenhuisopname is geen pretje en 't wordt alleen maar erger in de zorg en verpleging doordat ze meer vrijwilligers inzetten om nog meer te bezuinigen...'t Verplegend personeel wil alleen maar prikken en spuitjes geven zonder overleg.... Patiënten worden monddood gemaakt en men mag totaal geen kritiek geven...Daarom worden de meesten binnen 1 á 2 dagen al ontslagen...

Figure 4: Blogpost of a discussion about a patient's experience in the hospital (in Dutch, from BNNVARA, 2012)

This shows again the need for emotion management, a connection between the healthcare providers and the patients which would allow them to talk about their emotions in a safe environment they create with each other.

A short study of nurses in hospitals across Bahrain by Abdullah et al. (2022) shows that self confidence and opinions on patients contribute to the patient experience. Two noticeable elements were the lack of self confidence the nurses felt when approaching patients and engaging in conversation, and an overall negative attitude towards patients which stems from the idea of a lack of knowledge patients have about their treatment. This later element could also result due to the high workload which results in stress and quick annoyance in the workspace.

Looking at the four phases of empathy framework, the current state of the discharge process and earlier recorded experiences show that healthcare providers and patients sometimes skip the first two steps to form their connection. Their curiosity often stops at knowing the information needed to start the treatment process but does not go further to truly get to know what is going on with the other person. Healthcare providers and patients do not get to understand each other, meaning that their immersion into each other experience is not there.

3.3 Existing Solutions and Their Effectiveness

Several existing services are currently being used that try to help in improving the previously mentioned factors. One of these is a patient confidant, someone that takes time to listen to the worries and needs of the patient for which the healthcare providers often lack time to do. This solution helps in someone being present to listen to the patient's fears and worries, as room is created for someone to open up about what they are dealing with. The main issue is that the patient confidant is a volunteer who has limited available time which quickly gets completely filled (see figure 5). Another issue is the fact that patients who use this service are already ready to talk with soemone about their thoughts but not for those who are not ready. The idea of another person being present in a difficult situation in which a patient is vulnerable and struggling with their own emotions does not invite room for more people to be included in this difficult space (Steinmair et al., 2022). As the patients themselves need to make the decision for a confident to visit them, there are many hurdles which prevent someone from choosing this option, and therefore makes it a non universal solution for many patients. The patients that do use it however notice a positive influence for their wellbeing by sharing their feelings and in their opinion allow emotions to find a place in their mind. This shows that curiosity and immersion are present that leads to a connection in which the patient feels safe to share what they want to share.

Another service is the use of online digital platforms which help in communication and monitoring results. These platforms have a chat where patients can ask their questions directly to their healthcare providers without the need for scheduling an appointment at the hospital. There is also the option for video chat use, which helps patients who have trouble going to the hospital. RdGG has the "mijn Reinier de Graaf" platform which offers the same functions. This service helps a lot in terms of communication. accessibility and participation. Patients can now more easily contact their healthcare providers, and viewing their results means that they can also better understand what is happening during the treatment (Patient Journey App, 2024). Information is also more easily shared through the platform in a way that it is understandable for the patients. One important note is that such services are meant for use back home, not while being inside the hospital. This causes a gap in the benefits such a service provides that are only present the moment the patients opt for using the service. If used inside the hospital, patients could benefit greatly from improved accessibility, communication, participation and information, which can sometimes lack during the stay and the discharge (Lin et al., 2017).

Reinier de Graaf

Een vrijwilliger met een luisterend oor

Als u behoefte heeft aan een gesprek

Reinier de Graaf

Als u te horen heeft gekregen dat u ziek bent, roept dat allerlei gevoelens en vragen op. Daarover praten kan opluchten en steun geven.

Als u behoefte heeft aan een luisterend oor kunt u een beroep doen op vrijwilligers van inloophuizen die twee dagen in de week in het Reinier de Graaf beschikbaar zijn voor een gesprek.

Deze vrijwilligers zijn getraind en zijn in sommige gevallen ervaringsdeskundigen, zij kunnen u goed bijstaan.

Op de volgende momenten zijn de vrijwilligers aanwezig:
Dinsdag van 10.00 tot 14.00 uur
Donderdag van 10.00 tot 14.00 uur

Wij werken samen met inloophuis Carma en inloophuis Debora. Deze inloophuizen zijn ontmoetingsplekken waar mensen een luisterend oor, lotgenotencontact, informatie of ontspannende of creatieve activiteiten kunnen vinden.

Heeft u behoefte aan een gesprek dan kunt u dat aangeven bij de verpleegkundige op de dagbehandeling, uw casemanager of uw behandelend specialist.

Carma

InloopHUIS Debora | Delft

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www.inloophuiscarma.nl
www.inloophuisdebora.nl

Figure 5: Folder on the oncology department in RdGG where patients can get into contact with volunteers to talk about their feelings and worries

3.4 Takeaways

The literature research shows several interesting takeaways which are listed underneath:

- In the empathy phases framework, discovery/curiosity and immersion are sometimes skipped which results in a connection that does not include a good enough understanding of the other's experience.
- The current healthcare system is under a lot of pressure, resulting in healthcare providers being overworked and having little time and patience in order to implement new methods.
- There currently is not a solution that helps in improving the six factors and allows for more room to open up about emotions in the discharge experience.
- There are six important factors that influence the discharge experience of patients, their close loved ones and healthcare providers:

  Communication, the way patients, their close loved ones and healthcare providers talk with each other.

  Information, what is being shared between patients, their close loved ones and healthcare providers.

  Confidence, to what extent healthcare providers securely perform their work, how confident patients are in getting the care they need to get better and how competent close loved ones can assist the patient during their treatment.

  Accessibility, to what extent patients, their close loved ones and healthcare providers feel they can interact and communicate with each other.

  Participation, how much patients, their close loved ones and healthcare providers are involved during the discharge process.

  Expectations, what patients, their close loved ones and healthcare providers think will happen during the discharge process and what they think the other party will do or say.

- Figure 6 shows which factors can be improved and which are often sufficient, according to the literature found in this chapter. The attitude of patients, their close loved ones and healthcare providers is an element that affects the six factors.

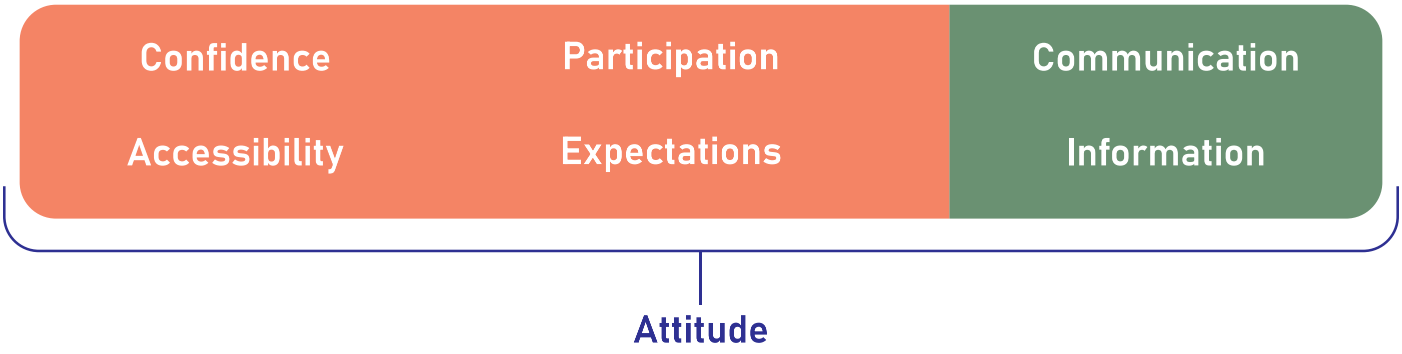


Figure 6: Overview of the six factors that influence the discharge experience which can be improved and which are sufficient according to literature

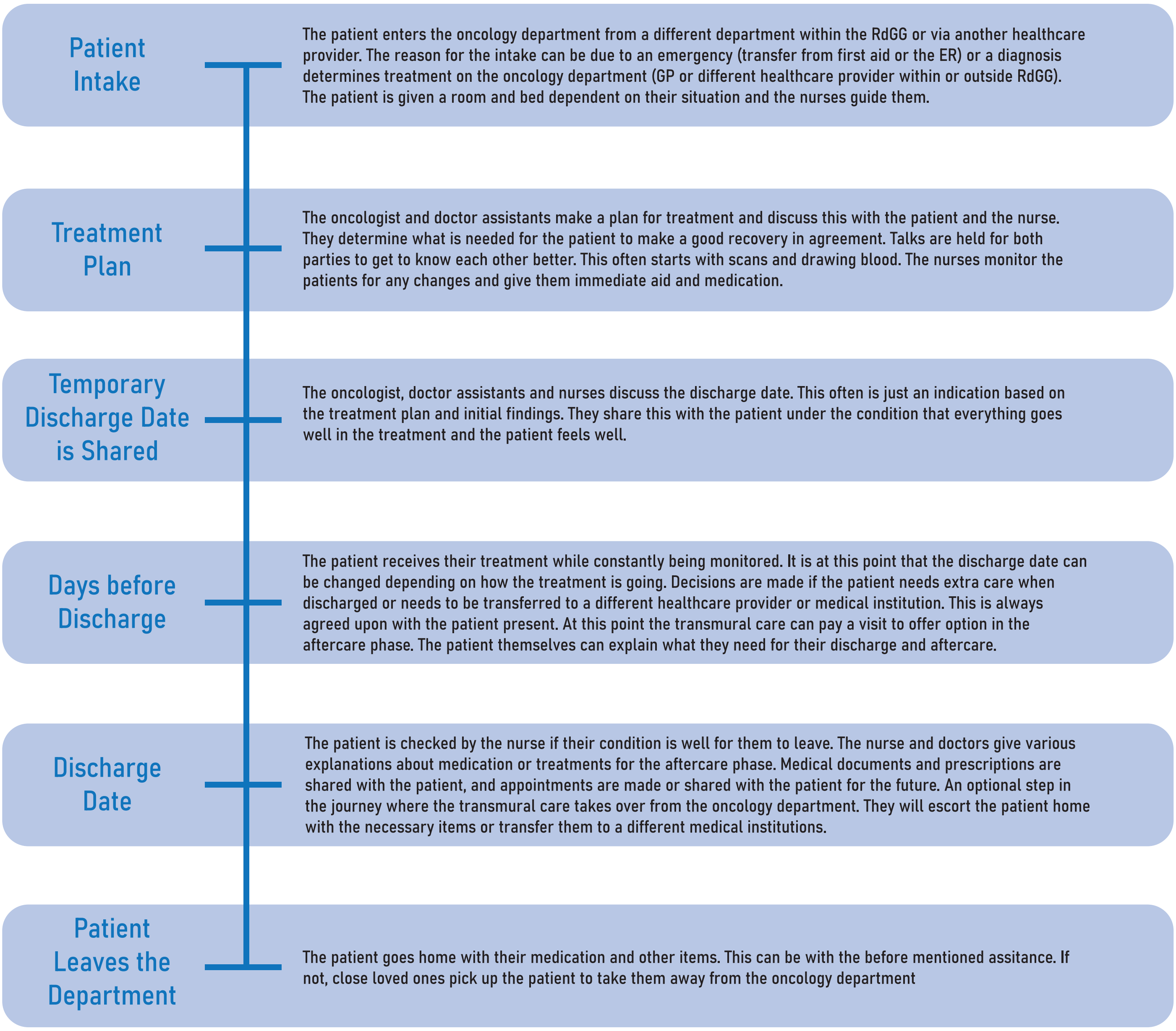
4 5 Days Inside the Oncology Department

This chapter presents the exploration of the oncology department inside of the RdGG The first goal is to get a better understanding of the context and how the discharge process goes in practice. This is done through observations and interviews with various stakeholders of the oncology department.

Methods used: Observations done by following healthcare providers like doctors, nurses and administrative employees and asking questions about their tasks. Interviews were done structured and semi-structured on appointment physically, or during the orientation days by asking on the spot if they had time and using the patient room or a different room away from noise.

4.1 Observations

A total of five days were used to observe the oncology department and how the stakeholders interacted with each other, and performed their work and/or filled their day with tasks/ activities. Of the five days, four were full days of observations and one day was only the morning. In figure 7 the discharge process is presented with a short explanation of each step. The results of the observations are summarized in figure 8.



Patient Intake

The patient enters the oncology department from a different department within the RdGG or via another healthcare provider. The reason for the intake can be due to an emergency (transfer from first aid or the ER) or a diagnosis determines treatment on the oncology department (GP or different healthcare provider within or outside RdGG). The patient is given a room and bed dependent on their situation and the nurses guide them.

Treatment Plan

The oncologist and doctor assistants make a plan for treatment and discuss this with the patient and the nurse. They determine what is needed for the patient to make a good recovery in agreement. Talks are held for both parties to get to know each other better. This often starts with scans and drawing blood. The nurses monitor the patients for any changes and give them immediate aid and medication.

Temporary Discharge Date is Shared

The oncologist, doctor assistants and nurses discuss the discharge date. This often is just an indication based on the treatment plan and initial findings. They share this with the patient under the condition that everything goes well in the treatment and the patient feels well.

Days before Discharge

The patient receives their treatment while constantly being monitored. It is at this point that the discharge date can be changed depending on how the treatment is going. Decisions are made if the patient needs extra care when discharged or needs to be transferred to a different healthcare provider or medical institution. This is always agreed upon with the patient present. At this point the transmural care can pay a visit to offer option in the aftercare phase. The patient themselves can explain what they need for their discharge and aftercare.

Discharge Date

The patient is checked by the nurse if their condition is well for them to leave. The nurse and doctors give various explanations about medication or treatments for the aftercare phase. Medical documents and prescriptions are shared with the patient, and appointments are made or shared with the patient for the future. An optional step in the journey where the transmural care takes over from the oncology department. They will escort the patient home with the necessary items or transfer them to a different medical institutions.

Patient Leaves the Department

The patient goes home with their medication and other items. This can be with the before mentioned assitance. If not, close loved ones pick up the patient to take them away from the oncology department

Figure 7: Discharge process consisting of six steps with a short explanation what happens in each step

There is a lot of movement in the oncology department, also from visits of different departments, that almost no one sits still.

The healthcare providers know the patients quite well and are aware of their personal life.

The healthcare providers have a digital system which provides a good overview of what the patient needs for their discharge.

The workload of the healthcare providers is high that they cannot always respond immediatly to patients or adjust to a new working method/ working schedule.

Patients and their close loved ones have hidden reasons, that healthcare providers don't notice, which makes them scared and/or worried to leave the hospital.

Figure 8: Observation of the orientation days

4.2 Interviews

Several interviews were taken during the orientation days, making agreements with the stakeholders when they were available for them.

4.2.1 Head of the Oncology Department

Structured interview: Set number of questions asked in order.

Amount of people: One.

Time: One hour.

Location: Backoffice of the oncology department in the RdGG.

Topics: Their experience and opinion on the current discharge process (see appendix B for the complete interview setup).

- A score of 6 (out of 10) was given for the current discharge process. While the baseline is sufficient, meaning patients are sent away medically ready, improvements can be made in how the nurses handle and interact with the patients.
- Communication and information are often clear.
- Confidence, accessibility and participation have big differences between the individual nurses. This can come from their background, years of experience and/or working method.
- There is not a shared working method between the nurses. While the same tools (like medical checklists and digital environment for notes) are provided, their way of following these tools is different. Some tend to follow the steps strictly while others follow the steps in a random order to get the same result.

4.2.2 Nurses and Nurse Specialists

Semi structured interview: Set number of questions are prepared but direction of interview is fluent.

Amount of people: Six.
Working experience ranging from 4 years to 20 years.

Time: 30 minutes to one hour.

Location: Oncology department in the RdGG.

Topics: Their experience and role in the current discharge process, and which methods and tools they use.

- The overall experience during the discharge is a positive one, due to the process going smoothly and the patients leaving the oncology department in good health for their next step in the treatment.
- They use a discharge checklist, a list of steps that need to be taken care of before the patient leaves the department. The checklist starts the moment a patient is taken in, having a template ready that can be applied for every patient. Every medical aspect is listed in the checklist which makes it a useful tool for nurses to use and easy to remember what needs to be done, what is being processed, and what has been completed.
- The nurses notice that from their perspective the patients leave the department satisfied with the care they have been given, which in turn gives them a good feeling about how the process went.
- The main role of the nurse is the day to day care of the patients leading up to discharge. The interaction is often done on auto pilot, where the nurses, using their working experience, communicate and perform their task in their own way which “works because it has so for some time”.
- The bond between the nurses and patients is oftentimes positive and well kept during the discharge. Some nurses mentioned how a silent introverted patient compared to a loud extroverted one, can give two completely different working experiences

4.2.3 Doctors and Doctors Assistants

Structured interview: Set number of questions asked in order.

Amount of people: Three.

Time: 20 to 30 minutes.

Location: Doctors room of the oncology department in the RdGG.

Topics: Their experience and role in the current discharge process.

- The role of the doctor and doctor assistants in the discharge process is large but their influence on the patient experience is a minor one.
- This is due to the contact moments being on a much lower frequency compared to nurses, resulting in them being less noticable during the process. Their role is behind the scenes where they discuss the treatment, medication and make decisions on when the patient gets to return home. They share this with the patient in a single to rarely two relatively short interaction(s) whereafter the doctors are mostly absent until the next day.
- They actively play a part in the treatment but less in the daily lives of the patient in the hospital.

4.2.4 Patients and their Close Loved Ones

Semi structured interview: Set number of questions are prepared but direction of interview is fluent.

Amount of people: Five.
Amount of discharge experiences range from 1 to 8.

Time: 30 minutes to one hour.

Location: Patient rooms in the oncology department in the RdGG.

Topics: Their experiences with discharge processes and interactions with healthcare providers (see appendix C for the complete interview setup).

- The patients experience the discharge process more negatively. This comes from the diagnosis of cancer and the accompanying fears and worries it brings with it, dominating most of the process.
- They carry the fears and worries with them when returning home, where in their eyes it is even more difficult to ask questions they might not have during their hospital stay.
- These worries and fears are often about how much this impacts their daily life, those around them and how they will recover.
- The specific reasons are difficult to find. Patients give the impression of underlying thoughts that are the root cause for their negative experience but are not keen on sharing these, which gives a gap in understanding the experience.
- Communication with the healthcare providers and the information received from them is always clear. The patients also find the healthcare providers are friendly to them and feel they are in good hands, and feel they can, despite their own reasons, approach them with questions.
- Close loved ones experience the discharge more neutral. They feel themselves as passengers along the ride but with a large question on their mind about what is expected of them and how much time and energy it will take.
- With the focus being on the patient, they feel that they are sometimes slightly less involved in the process which hinders their supportive role.

4.3 Reflecting the Literature on the RdGG Oncology Department

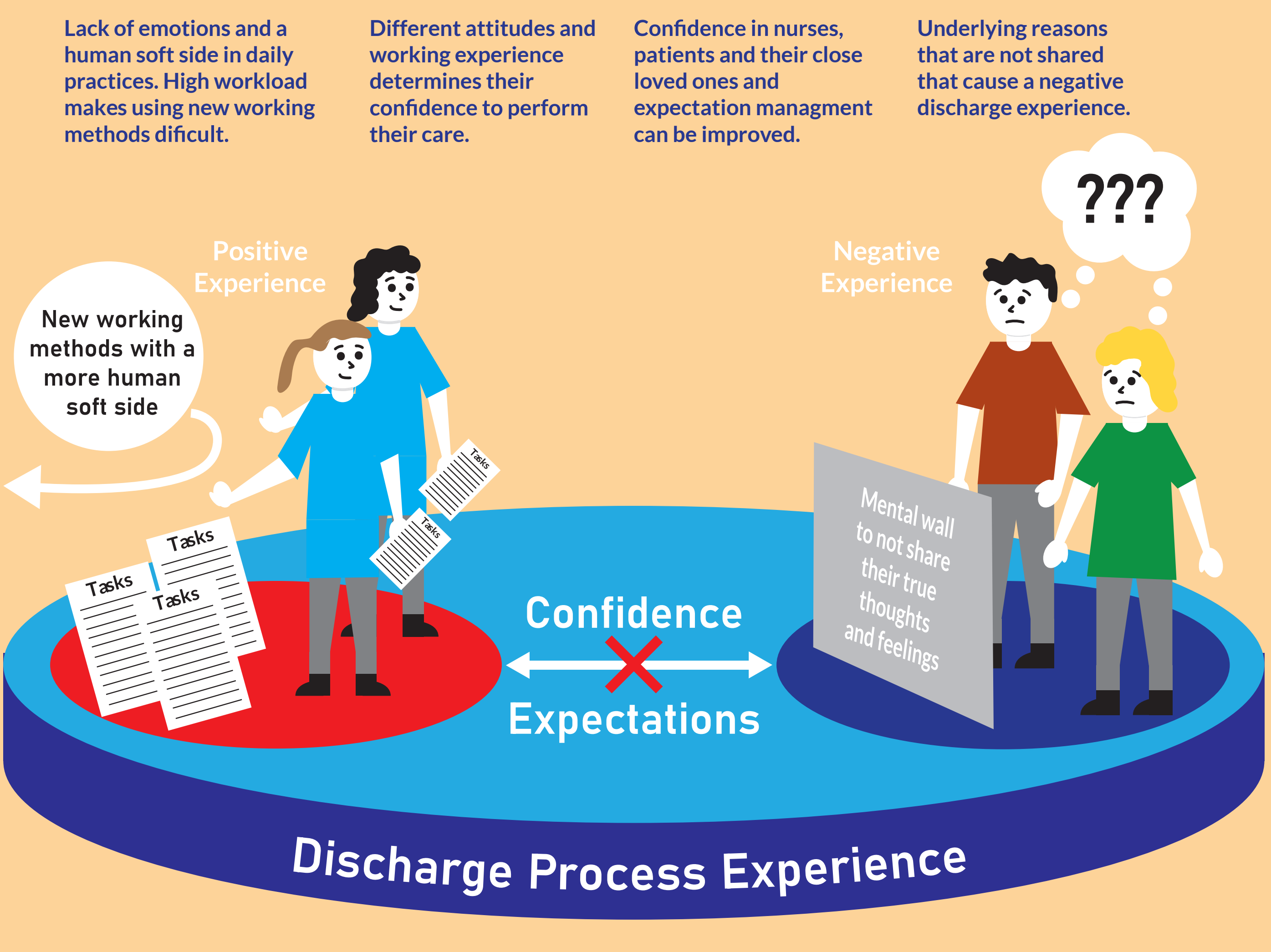
There are several differences comparing the findings of exploring the oncology department to the literature research. The first is that the bond between patients and healthcare providers is oftentimes well established in the RdGG oncology department, and healthcare providers know what is happening with the patients. The home situation or familial relationships are known and brought up when discussing the discharge of the patients. The second is that the factor accessibility is sufficient, as patients feel they can go to healthcare providers and ask their questions or request additional help. Third, participation is sufficient for the patients as they are always involved in decision making. Every step is focused on them and makes sure that the patients are aware of which stage they are in of the discharge process.

Healthcare providers do not implement an existing tool or method that improves the six discharge factors. The discharge checklist helps in making the process run smooth but lacks in assisting for example expectations patients might have outside of what is listed. It also does not help in addressing worries from both patients and healthcare providers. Participation for the patients is sufficient but a mixed bag for close loved ones. They sometimes feel completely involved while at other points less so. The workload of the healthcare providers is high which causes them to hold on to their working methods and has an effect on their attitude which is very clinical.

4.4 Takeaways

The main takeaway from this chapter can be seen in figure 9. Doctors will be removed from the scope of the project as of this point. Their influence on the discharge experience is minor which leaves more room to focus on the patients, their close loved ones, and the nurses.

Summarising the takeaways show the need for a thorough context analysis to find out what the underlying reasons are for the negative patient discharge experience. This analysis leads to a concept direction in which the sense of understanding each other’s feelings is achieved, as this is currently lacking in the discharge. This concept direction is formulated in a way that fits within the working method of healthcare providers and allows everyone involved in the discharge process to be on equal ground when talking about the discharge and their experiences.



Lack of emotions and a human soft side in daily practices. High workload makes using new working methods dificult.

Different attitudes and working experience determines their confidence to perform their care.

Confidence in nurses, patients and their close loved ones and expectation managment can be improved.

Underlying reasons that are not shared that cause a negative discharge experience.

Figure 9: Main takeaways from observations and interviews in the oncology department

Context Analysis

The context that has been explored is analysed using various methods to create a design goal for conceptualisation. In chapter 5, the discharge journey map is presented, and different theories and methods to find the underlying reasons for the current discharge experience. These are the discharge process interpretation sessions, Self Determination Theory and statement cards thematic analysis.

Immersion
Learn about the experiences and gain knowlegde to understand them

5 Insights on the Discharge Experience

In this chapter, the context that has been explored in the previous chapter will be analysed using various methods in order to formulate a clear concept direction. The previous takeaways are used as a basis for the analysis where the first step is in understanding what the reasons are for the different discharge experiences. Methods used in this chapter are a discharge journey map (to provide a timeline for the findings of the previous two chapters), interpretation sessions and a thematic analysis (statement cards and self determination theory). Each subchapter will explain how each method is applied.

5.1 Discharge Journey Map

Figure 10 shows a discharge journey map. This map functions as a summary of the findings from the previous two chapters, and places these on a timeline to find out where the discharge experience in the journey is the most negative (Albayrak, 2023). The journey map is divided in the discharge steps at the top. On the side are the following points: what happens per step in the form of a short explanation, what they do, what they are thinking, what they are feeling and how this changes, and what is on their mind. What is on their mind and what they think sound similar but the main difference is that the latter is a response to what they do while the first are inner thoughts they do not communicate directly. What is on their mind is an important part of the discharge journey as it reveals what the everyone is truly thinking about the situation and interactions they have.

As seen in chapter 4.4, there is a large difference between the experiences of the patients and nurses. This starts from the beginning, where patients have a mixture of positive and negative emotions and thoughts while nurses have a positive mindset. The main turning point is upon hearing what the discharge date is (TOD), where the negative thoughts and emotion take over. This happens mainly with the patients and their close loved ones but the nurses also experience a more negative experience compared to the steps before.

The difference is also visible in the what is on their mind section. Nurses think more about their work and tasks, and hope this goes as smooth as possible. Patients meanwhile have many more thoughts about their own health, how everything will be when they leave the hospital and how those around them respond.

It shows that something happens from this point that the entire experience becomes negative and remains negative (with some deviation) until the end of the process. As the starting point is found for when this happens, it is now finding what the true underlying reasons are that this turning point comes to be.

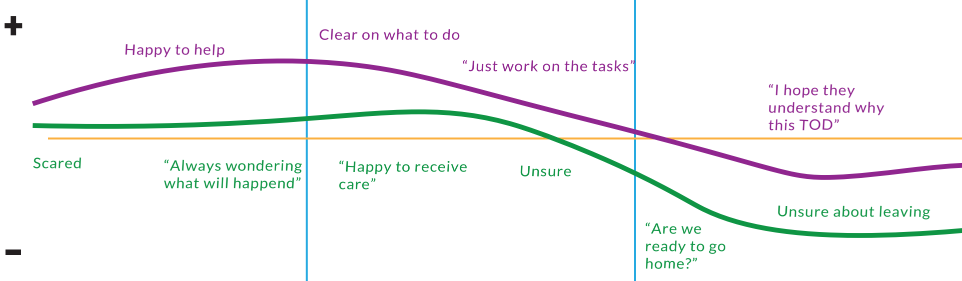
Legend

🟩 Patients and their close loved ones

🟪 Nurses

	Patient Intake	Treatment Plan	TOD is Shared
What is happening?	The patient enters the oncology department from a different department within the RdGG or via another healthcare provider. The reason for the intake can be due to an emergency (transfer from first aid or the ER) or a diagnosis determines treatment on the oncology department (GP or different healthcare provider within or outside RdGG). The patient is given a room and bed dependent on their situation and the nurses guide them.	The oncologist and doctor assistants make a plan for treatment and discuss this with the patient and the nurse. They determine what is needed for the patient to make a good recovery in agreement. Talks are held for both parties to get to know each other better. This often starts with scans and drawing blood. The nurses monitor the patients for any changes and give them immediate aid and medication.	The oncologist, doctor assistants and nurses discuss the discharge date. This often is just an indication based on the treatment plan and initial findings. They share this with the patient under the condition that everything goes well in the treatment and the patient feels well.
What are they doing?	Prepare for intake or adjust to oncology department. Assist the patient, prepare for treatment and prepare the patient file.	Try to make a list of questions and expres needs and expectations of the threatment. Hear what is going to happen. Getting to know the patient and get a task overview of what needs to be done during the treatment.	Talk to close loved ones when they will return home and what will change for the patient and for them. Prepare the discharge checklist, continue with tasks and discuss with patient and doctor what the next steps will be.
What are they thinking?	Wondering what will happen and how the disease will effect their health and life. Try to provide the best care and work under increasing pressure.	Hope that the doctors and nurses understand their needs. Often get a positive impression from them. Going into workmode to do the task while talking with the patient to shape a bond with them.	How will the close loved ones respond to them returning home and hoping that eveyrthing back home will be alright when they return. Try their best to remind the patient it is a TOD, and start with the discharge checklist.

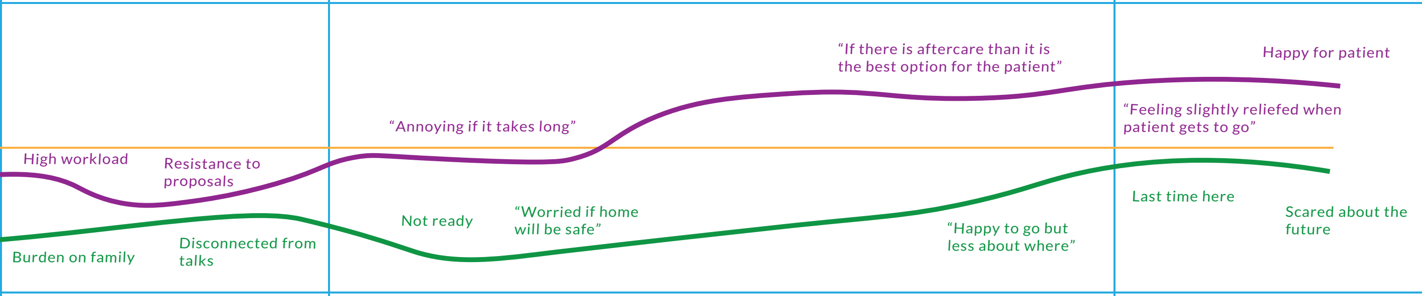
What are they feeling?



	Patient Intake	Treatment Plan	TOD is Shared
What is on their mind?	• I understand why I am here. • I want to go home quickly. • I hope this does not affect my daily life too much.. • Another patient to care of. • I hope they are easy to take care of. • What do they expect of me?	• Get through the treatment. • Getting to know if the doctors and nurses are alright. • I want my close loved ones to agree on the treatment. • Focus on doing the tasks. • Balanse the different patients and there needs. • Try to get to know the patient.	• I am unsure about going home. • I worry about the future. • What can I expect from everyone? • Work towards the TOD and hope it becomes the actual disharge date. • I want to offer the best care possible. • Making sure the close loved ones of the patient are up to date.

Figure 10: Discharge journey map, summarising the previous findings into a timeline

Days before Discharge	Discharge Date			Patient Leaves Oncology
	Check State of the Patient	Explanations for Discharge	Transfer to Transmural Care	
The patient receives their treatment while constantly being monitored. It is at this point that the discharge date can be changed depending on how the treatment is going. Decisions are made if the patient needs extra care when discharged or needs to be transferred to a different healthcare provider or medical institution. This is always agreed upon with the patient present. At this point the transmural care can pay a visit to offer option in the aftercare phase. The patient themselves can explain what they need for their discharge and aftercare.	The patient is checked, often the evening/night before, if they are well enough to go home.	The nurses and doctor assitents explain to the patient what need to do in the aftercare phase after discharge. This is mostly explaining the medication. Relevant files and prescriptions are shared with the patient. Appointments are made or shared with the patient for the future.	An optional step in the journey where the transmural care takes over from the oncology department. They will escort the patient home with the necessary items or transfer them to a different medical institutions.	The patient goes home with their medication and other items. This can be with the before mentioned assitance. If not, family or friends pick up the patient to take them home.
Go through treatment and discuss with nurses, doctors and close loved ones how the aftercare will be and what everyone's responsibility will be. Listen to option of aftercare and decide on visit from transumral care alone or with close loved ones. Inform the contactperson of the patient and go through the discharge checklist. Inform the patient if they need help from transmural care and agree on a visit.	Get ready to go home and listen to explanations of the nurses and doctors. Receive documents and prescriptions. Explain some of the medication and other medical items, and share necessary documents and prescriptions.		Leave the hospital with transmural care to go back home or to a different medical institute. Agreements on patient leave and hand over to care of transmural care.	Leave the oncology department and visit the pharmacy for any medication or go straight home. Final administrative tasks and wishing the patient the best.
Worrying about their health and how this will affect those around them. Not ready to go home. Aftercare provides options and assistance but difficult to talk about with close loved ones. Constant monitoring and maintain a good relation with the patient and their close loved ones. Hope that the TOD stays the same. Receive word from transmural care about next aftercare steps.	Hope everything will be okay when back home and that the information can be remembered correctly. Work as quickly as possible to explain everything, hoping the patient and their close loved ones understand, and send them home quickly.		Tried their best to provide the best care possible and let the patient go. Quickly move on to the next patient.	Unsure of they are happy to leave and how they will pick up their life. Tried their best to provide the best care possible and hope they will not return quickly. Quickly move on to the next patient.



- I rather not ask close loved ones for help. - I want to know what to expect when I am home. - Grateful for extra help from transmural care. - I worry how this affects my home. - I hope they think about the proposals for aftercare. - Quickly go through these days towards discharge. - Everything and everyone needs to get ready for the discharge.	- Scared I am not ready to go yet. - I wonder how everyone feels about me and the diagnosis going home. - What can I do to feel more ready? - Send the patient away as quick as possible so they do not have to be here unnecessary. - I hope they manage back home. - I often expect to see them again due to the nature of the illness.		- I wish them good luck. - It is out of our hands now.	- I do rather go home than stay here. - I want to feel safe leaving the hospital. - I want to share my final worries and needs with the healthcare providers. - I hope we do not see each other again or not too soon. - Hope they are ready to go home and recover well.

Figure 10: Discharge journey map, summarising the previous findings into a timeline

5.2 Discharge Process Interpretation Sessions

There are two goals with this interpretation session. The first goal is to find out what patients, their close loved ones and nurses focus on with each scenario. This reveals why there is a difference in the experience of patients and nurses and what they find most important during the discharge. Do they look at the emotions of everyone or only of a single person? Do they view the entire scene or only a part of it? Do they only look at the scenario or think beyond the scenario? The second goal is to find the underlying reason for what they feel when viewing the scenarios. While this question is mainly for the patients, it can also reveal reasons for the attitude of the nurses.

The interpretation sessions feature eight scenarios taken from the orientation days which feature common situations of the discharge process. Every scenario contains a short explanation of how the scene came to be, who is present and where it takes place. Figure 11 shows a scenario that is being shown to the participants.

Participants will see the eight scenarios and are asked per scenario the following questions:

- *What do you see and how do you interpret this?*
- *Which emotions do you feel when viewing the scenario?*

A total of eight people participated in this session, with three patients, three nurses and two close loved ones (both partners of the patient). Appendix D shows the entire interpretation session setup.

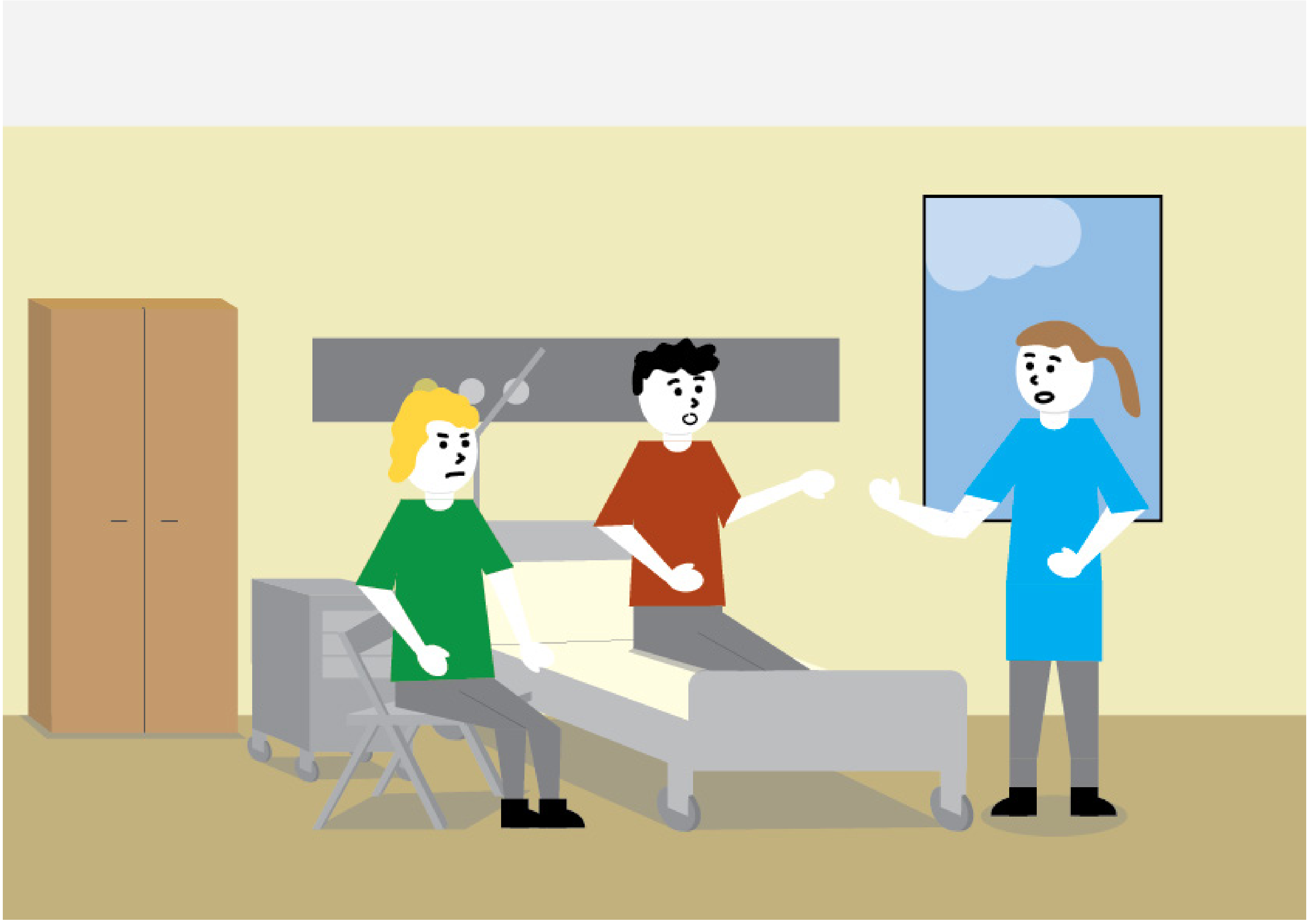


Figure 11: Discharge process interpretation session scenario which participants interpret and share their emotions about

5.2.1 Results

- Every participant interpreted from the character that resembles themselves. The close loved ones choose the perspective of the patient if no close loved ones were present in the scenario.
- The phases in the empathy framework are shown by each participant always interpreting the entire scene and everyone in it. They discover but do not fully immerse themselves in the other people, not thinking about what they might feel about what is happening in the scenario.
- Patients and their close loved ones interpreted with a mixture of feeling happy to go but alo worrying about the changes that it will bring them.
- They mentioned that in the scenarios they can imagine the characters not feeling they can perform the tasks required in order to care for themselves or provide the care needed. This is paired with their feelings of home becoming a place for care rather than a place for family or rest, essentially transforming it into a care home.
- Nurses showed an attitude of knowing it better during their interpretations. This is not only in performing their work but also in how the patient should go about recovering outside the hospital. While this can be helpful, as patients and their close loved ones lack the medical knowledge, this can cause them to quickly take over the discharge in which the patients and close loved ones should find ways in which they themselves can take and provide care.
- Their lack of emotional sharing comes from their focus on working and making sure “the patient leaves the bed in time for the next one”.
- Them being unaware of what is going on outside of a patient needing to undergo treatment and leave the hospital when they are deemed able, and not focusing on patients and their close loved ones worrying about the changes home and their worry for not being able to provide the care they must, makes them discharge patients unprepared.
- The participants interpreting from the character that represents them helped in understanding what emotions they feel during the steps of the discharge. Figure 12 shows some quotes the participants shared during the sessions, divided per group of people. These quotes provide a good indication what the underlying reasons are but they do not show what exactly the participants are thinking or feeling, as this is something impossible to find in a short period of time (Steinmair et al., 2022). It is therefore good to remember that these provide a good indication and basis for further analysis but are not the final answers to the question.

“Ik durf niet tegen mijn kinderen te zeggen wat er allemaal gaat veranderen.”

“Begrijp heel goed dat iemand met onzekerheid naar huis gaat omdat je niet weet wat er gaat gebeuren”

“Als je bepaalde verwachtingen hebt van een gesprek, bijvoorbeeld ik denk wel eens, nou nu mag ik naar huis of krijg hetzelfde te horen, en dan komt er iets anders wat je even verwarring geeft.”

“De focus is op de patient, wat ik heel goed begrijp, maar het zou fijn zijn om er net wat meer bij betrokken te zijn waardoor ik ook beter kan verwachten wat er gaat gebeuren.”

“De lijn tussen kind en verzorger begint steeds vager en vager te worden wat echt een enorm frustrerend gevoel geeft.”

“Sommige patienten blijven hier het liefst de hele tijd uit angst om het zelf niet te kunnen doen maar dat kan niet omdat we hierdoor geen zorg aan andere kunnen leveren.”

“Als je de checklist volgt en alles afvinkt dan lijkt het allemaal positief, al helemaal als je er snel doorheen gaat, maar werkelijkheid kan soms anders zijn waarin de patient het somber in ziet.”

“Ik denk dat veel verpleegkundigen onderschatten wat voor een impact dit allemaal heeft op de patienten.”

Figure 12: Quotes of patients (green), their close loved ones (dark green) and nurses (magenta) gathered from the interpretation sessions (in Dutch)

5.3 Thematic Analysis

As the underlying reasons have been found, the next step is to find patterns in these reasons in order to formulate a good conclusion that can help in formulating the design goal. A thematic analysis is used for this, a method that helps in finding such patterns by categorising findings in a comprehensible overview that leads to bigger themes for which a design goal can be more easily formulated (Finlay, 2021). One theory, the Self Determination Theory, and one method, statement cards analysis, are used for finding the themes. Each subchapter explains how the theory and method works and how these were applied.

5.3.1 Self Determination Theory

The Self Determination Theory (SDT) is a theory that delves into the understanding of the basic psychological needs of people to a high quality of life. It does this by looking at the personality and social behavior of the people and the context they are in. As patients, their close loved ones and nurses have their needs, the first two wanting a good healthy life while the latter wants a good working environment where this can be achieved. This theory can help in understanding what is needed in order to achieve this. The basic psychological need consists of three parts (Ryan & Deci, 2023):

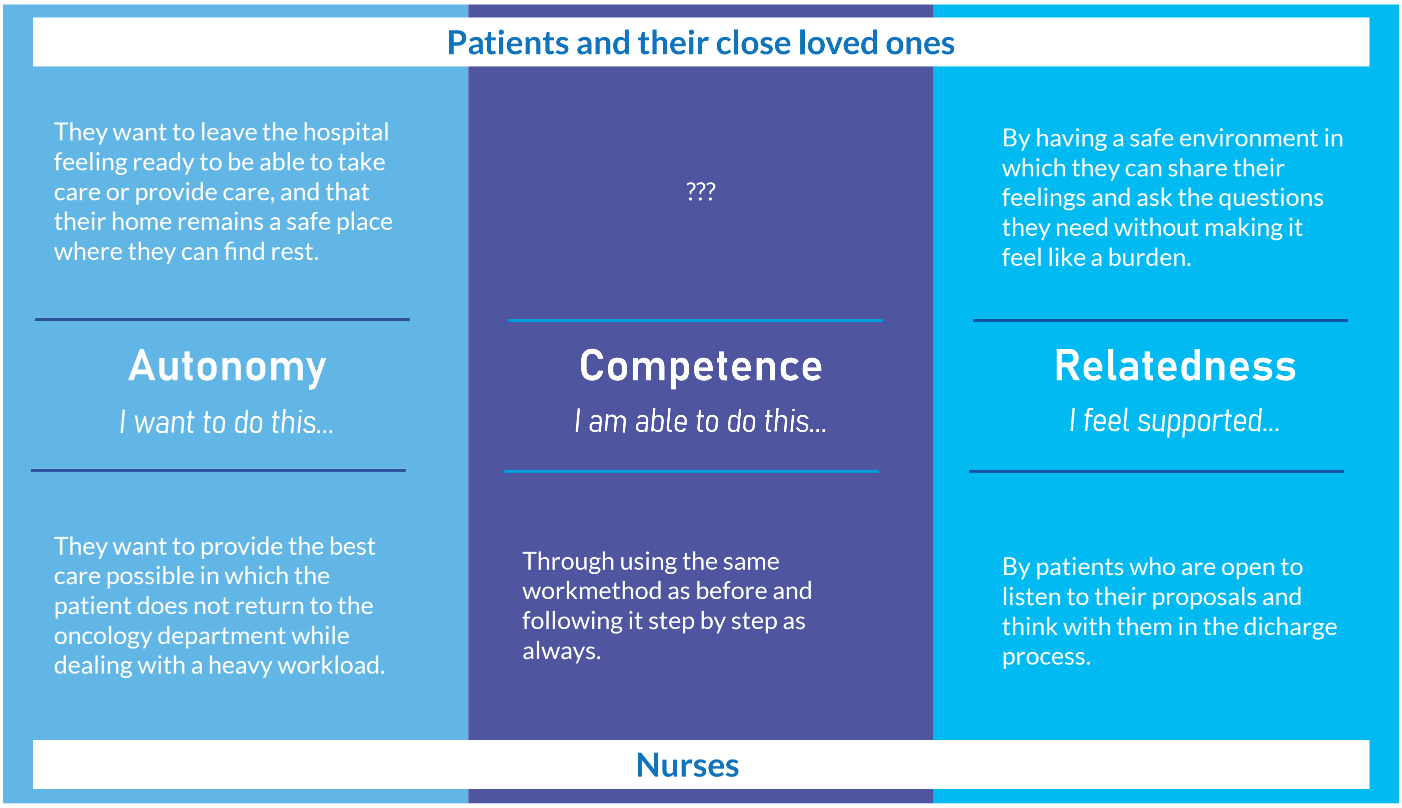
- Autonomy: having the feeling that one's action is one's own choice to reach a goal

- Competence: feeling that one is capable of achieving their goal

- Relatedness: feeling supported by important others to achieve their goal

These three parts can be seen as a timeline where autonomy represents the idea of wanting something or to achieve something, competence is having the skills, time, knowledge etc. to get what they want and relatedness is feeling supported in this and getting positive reinforcement during the process.

This timeline fits well within the context of the oncology discharge process, and what the patients, their close loved ones and nurses want to achieve. Figure 13 takes the SDT and places the patients, their close loved ones and nurses in each step to determine what they need per step. The figure shows what everyone wants to achieve during the discharge process and how they want to be supported in this. It is the competence, the feeling and knowing what they need to achieve this, where unknowns are present at the patients and their close loved ones. The interpretation sessions showed many times that participants mentioned how a scenario can be improved but not sure how to do that. Nurses hold on to their exisitng working methods that do not always contribute to a positive discharge experience for the others. Finding out what needs to be added or changed in the competence, can help in achieving a more positive discharge experience for everyone. Similar to the discharge factor confidence, it is about feeling they are ready to go through the discharge process. Changing confidence is something however that cannot be achieved on such a short notice. More time is needed for someone to adjust and change their current method and attitude of achieving their goal (Kermavnar, 2023). The first steps however can be taken to get an understanding of what is needed.



	Autonomy *I want to do this...*	**Competence** *I am able to do this...*	**Relatedness** *I feel supported...*
Patients and their close loved ones	They want to leave the hospital feeling ready to be able to take care or provide care, and that their home remains a safe place where they can find rest.	???	By having a safe environment in which they can share their feelings and ask the questions they need without making it feel like a burden.
Nurses	They want to provide the best care possible in which the patient does not return to the oncology department while dealing with a heavy workload.	Through using the same workmethod as before and following it step by step as always.	By patients who are open to listen to their proposals and think with them in the dicharge process.

Figure 13: The SDT placed in the RdGG oncology department with the patients, their close loved ones and nurses experessing their needs per step of the theory.

5.3.2 Statement Cards Analysis

The statement card analysis can help in finding what is needed for changing the competence in the SDT. Mainly, what do patients and their close loved ones need in order to achieve their goals and how do nurse need to change their work approach in to better support the patient in this.

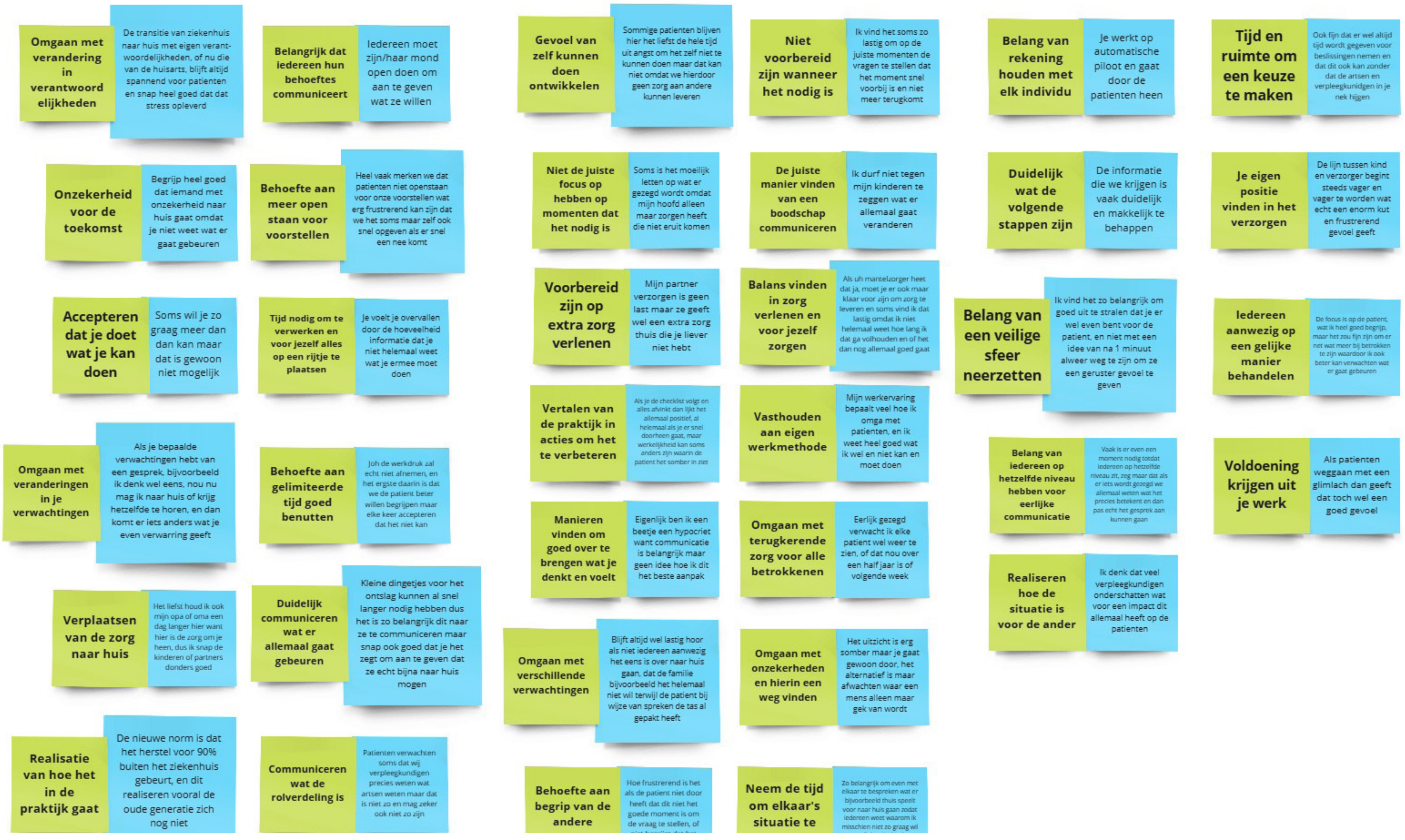
The quotes gathered during the interpretation session are used for this analysis. A paraphrase is added to each quote, a personel interpretation which essentially summarizes the importance and relevance of the quote. When each quote has been paraphrased, categorizing starts where interpretations are connected by a theme (Stappers, 2021). These themes help in formulating what patients, their close loved ones and nurses need to achieve their needs and create a more positive discharge experience for everyone involved.

Figure 14 shows the first step of adding paraphrasis to the qoutes gathered. Figure 15 shows the clustering of the paraphrases that leads to the themes that form the first setup to a concept direction.

Figure 15 consists of two layers. The outer layer has needs, empathy, communication and confidence. These can be seen as what is important to everyone in the discharge process. The inner layer shows insights as to what influences these.

- Changes in their life
- Preparedness for the treatment
- Fears and worries
- Taking/receiving/providing care

The four insights have an affect on the experience of patients, their close loved ones and nurses during the discharge process. They determine how everyone goes through the process. Changes in their life and fears and worries are happening throughout the discharge and patients and their close loved ones take these with them when they leave the hospital. Preparedness for the treatment is for nurses finding the right approach to take care of the patients and the patients and their close loved ones to take over this care after leaving the hospital. Everyone therefore could be prepared differently for these changes and how to deal with their fears and worries. This starts by knowing how to take care of themselves, receive care from others and those other providing care. An awareness needs to be raised with nurses that these four insights are constantly present in the discharge process to various degrees in order for them to offer the right treatment that can help the patients and their close loved ones.



Omgaan met verandering in verantwoordelijkheden

De transitie van ziekenhuis naar huis met eigen verantwoordelijkheden, of nu die van de huisarts, blijft altijd spannend voor patienten en snap heel goed dat dat stress opleverd

Belangrijk dat iedereen hun behoeftes communiceert

Iedereen moet zijn/haar mond open doen om aan te geven wat ze willen

Onzekerheid voor de toekomst

Begrijp heel goed dat iemand met onzekerheid naar huis gaat omdat je niet weet wat er gaat gebeuren

Behoefte aan meer open staan voor voorstellen

Heel vaak merken we dat patienten niet openstaan voor onze voorstellen wat erg frustrerend kan zijn dat we het soms maar zelf ook snel opgeven als er snel een nee komt

Accepteren dat je doet wat je kan doen

Soms wil je zo graag meer dan dan kan maar dat is gewoon niet mogelijk

Tijd nodig om te verwerken en voor jezelf alles op een rijtje te plaatsen

Je voelt je overvallen door de hoeveelheid informatie dat je niet helemaal weet wat je ermee moet doen

Omgaan met veranderingen in je verwachtingen

Als je bepaalde verwachtingen hebt van een gesprek, bijvoorbeeld ik denk wel eens, nou nu mag ik naar huis of krijg hetzelfde te horen, en dan komt er iets anders wat je even verwarring geeft

Behoefte aan gelimiteerde tijd goed benutten

Joh de werkdruk zal echt niet afnemen, en het ergste daarin is dat we de patient beter willen begrijpen maar elke keer accepteren dat het niet kan

Verplaatsen van de zorg naar huis

Het liefst houd ik ook mijn opa of oma een dag langer hier want hier is de zorg om je heen, dus ik snap de kinderen of partners donders goed

Duidelijk communiceren wat er allemaal gaat gebeuren

Kleine dingetjes voor het ontslag kunnen al snel langer nodig hebben dus het is zo belangrijk dit naar ze te communiceren maar snap ook goed dat je het zegt om aan te geven dat ze echt bijna naar huis mogen

Realisatie van hoe het in de praktijk gaat

De nieuwe norm is dat het herstel voor 90% buiten het ziekenhuis gebeurt, en dit realiseren vooral de oude generatie zich nog niet

Communiceren wat de rolverdeling is

Patienten verwachten soms dat wij verpleegkundigen precies weten wat artsen weten maar dat is niet zo en mag zeker ook niet zo zijn

Gevoel van zelf kunnen doen ontwikkelen

Sommige patienten blijven hier het liefst de hele tijd uit angst om het zelf niet te kunnen doen maar dat kan niet omdat we hierdoor geen zorg aan andere kunnen leveren

Niet voorbereid zijn wanneer het nodig is

Ik vind het soms zo lastig om op de juiste momenten de vragen te stellen dat het moment snel voorbij is en niet meer terugkomt

Niet de juiste focus op hebben op momenten dat het nodig is

Soms is het moeilijk letten op wat er gezegd wordt omdat mijn hoofd alleen maar zorgen heeft die niet eruit komen

De juiste manier vinden van een boodschap communiceren

Ik durf niet tegen mijn kinderen te zeggen wat er allemaal gaat veranderen

Voorbereid zijn op extra zorg verlenen

Mijn partner verzorgen is geen last maar ze geeft wel een extra zorg thuis die je liever niet hebt

Balans vinden in zorg verlenen en voor jezelf zorgen

Als uh mantelzorger heet dat ja, moet je er ook maar klaar voor zijn om zorg te leveren en soms vind ik dat lastig omdat ik niet helemaal weet hoe lang ik dat ga volhouden en of het dan nog allemaal goed gaat

Vertalen van de praktijk in acties om het te verbeteren

Als je de checklist volgt en alles afvinkt dan lijkt het allemaal positief, al helemaal als je er snel doorheen gaat, maar werkelijkheid kan soms anders zijn waarin de patient het somber in ziet

Vasthouden aan eigen werkmethode

Mijn werkervaring bepaalt veel hoe ik omga met patienten, en ik weet heel goed wat ik wel en niet kan en moet doen

Manieren vinden om goed over te brengen wat je denkt en voelt

Eigenlijk ben ik een beetje een hypocriet want communicatie is belangrijk maar geen idee hoe ik dit het beste aanpak

Omgaan met terugkerende zorg voor alle betrokkenen

Eerlijk gezegd verwacht ik elke patient wel weer te zien, of dat nou over een half jaar is of volgende week

Omgaan met verschillende verwachtingen

Blijft altijd wel lastig hoor als niet iedereen aanwezig het eens is over naar huis gaan, dat de familie bijvoorbeeld het helemaal niet wil terwijl de patient bij wijze van spreken de tas al gepakt heeft

Omgaan met onzekerheden en hierin een weg vinden

Het uitzicht is erg somber maar je gaat gewoon door, het alternatief is maar afwachten waar een mens alleen maar gek van wordt

Behoefte aan begrip van de andere

Hoe frustrerend is het als de patient niet door heeft dat dit niet het goede moment is om de vraag te stellen, of

Neem de tijd om elkaar's situatie te

Zo belangrijk om even met elkaar te bespreken wat er bijvoorbeeld thuis speelt voor naar huis gaan zodat iedereen weet waarom ik misschien niet zo graag wil

Belang van rekening houden met elk individu

Je werkt op automatische piloot en gaat door de patienten heen

Tijd en ruimte om een keuze te maken

Ook fijn dat er wel altijd tijd wordt gegeven voor beslissingen nemen en dat dit ook kan zonder dat de artsen en verpleegkunidgen in je nek hijgen

Duidelijk wat de volgende stappen zijn

De informatie die we krijgen is vaak duidelijk en makkelijk te behappen

Je eigen positie vinden in het verzorgen

De lijn tussen kind en verzorger begint steeds vager en vager te worden wat echt een enorm kut en frustrerend gevoel geeft

Belang van een veilige sfeer neerzetten

Ik vind het zo belangrijk om goed uit te stralen dat je er wel even bent voor de patient, en niet met een idee van na 1 minuut alweer weg te zijn om ze een geruster gevoel te geven

Iedereen aanwezig op een gelijke manier behandelen

De focus is op de patient, wat ik heel goed begrijp, maar het zou fijn zijn om er net wat meer bij betrokken te zijn waardoor ik ook beter kan verwachten wat er gaat gebeuren

Belang van iedereen op hetzelfde niveau hebben voor eerlijke communicatie

Vaak is er even een moment nodig totdat iedereen op hetzelfde niveau zit, zeg maar dat als er iets wordt gezegd we allemaal weten wat het precies betekent en dan pas echt het gesprek aan kunnen gaan

Voldoening krijgen uit je werk

Als patienten weggaan met een glimlach dan geeft dat toch wel een goed gevoel

Realiseren hoe de situatie is voor de ander

Ik denk dat veel verpleegkundigen onderschatten wat voor een impact dit allemaal heeft op de patienten

Figure 14: Quotes gathered from the interpretation sessions with added paraphrases

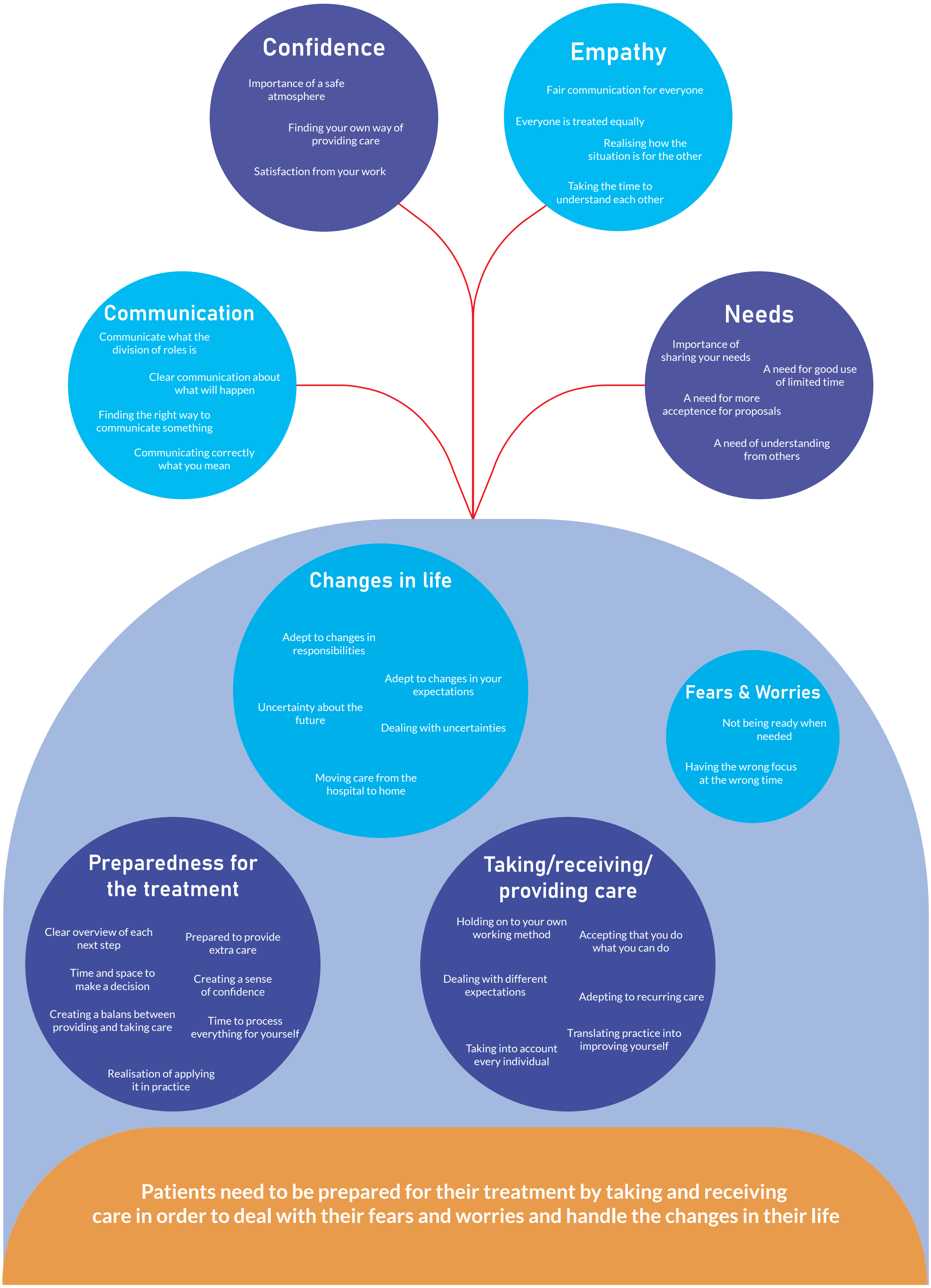


Figure 15: Statement card analysis leading to four selected insights for what influences the competence in the SDT for patients, their close loved ones and nurses

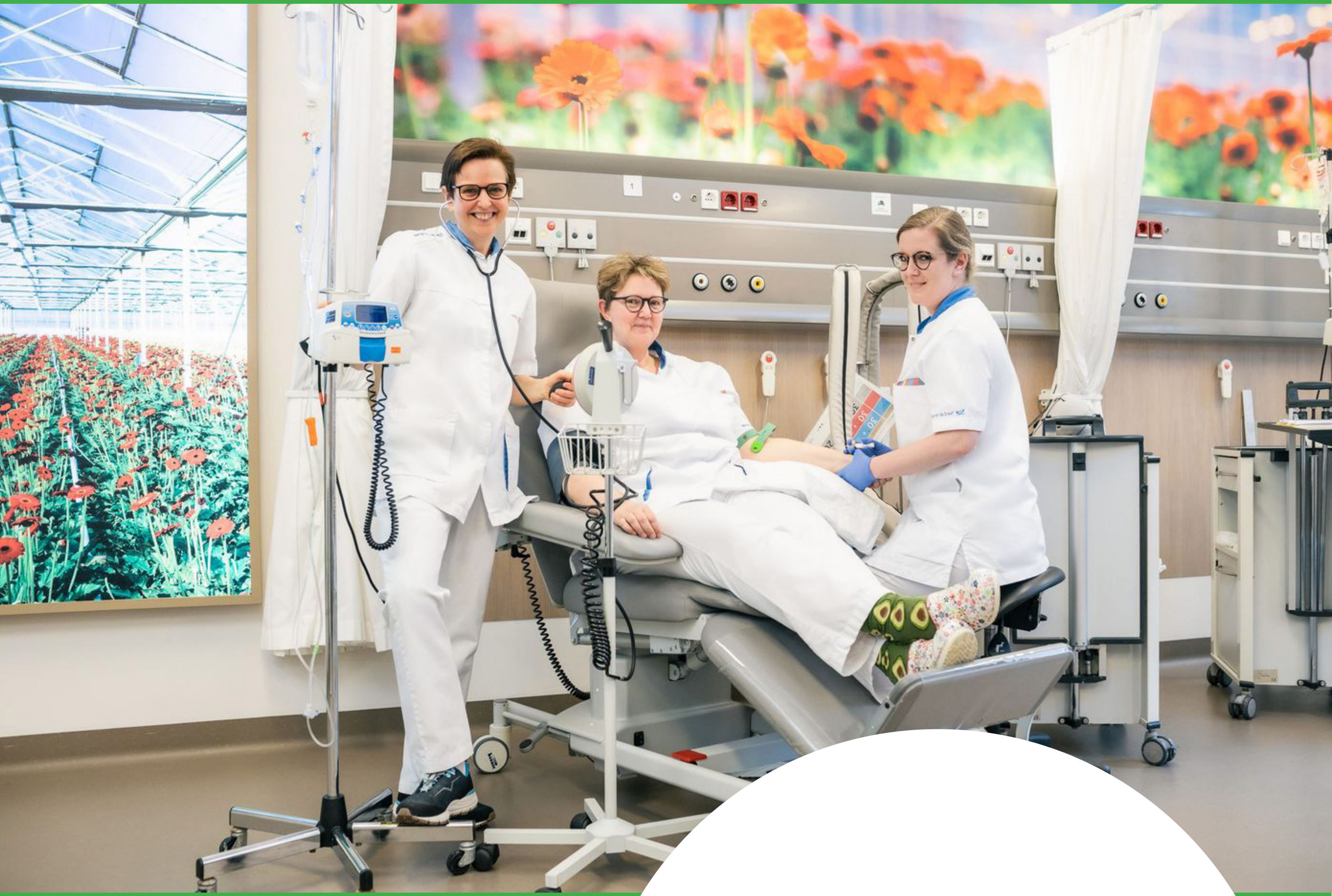
5.4 Design Goal

The moment patients hear about the discharge date, they worry about if the quality of the care outside of the hospital will be of the same quality as inside the hospital, and combined with a feeling of general unpreparedness, if they and their close loved ones have the competence to take over the care and carry it out correctly. Close loved ones are stuck with questions of what is expected of them and how this effects their own wellbeing. Nurses not only need to care for patients for them to leave the hospital but also making them prepared to properly take care of themselves or receive proper care from close loved ones. With the main insights, a design goal is created which is the following:

Patients need to feel prepared for their treatment during and after their hospital stay, in order to adapt to the changes in their life by taking care of themselves, receiving care from others and those others providing care through ways in which the patient and their close loved ones feel confident, and emotions are shared between them and the nurses, who are more aware of these emotions, that help in talking about their fears and worries.

This design goal forms the basis for conceptualisation, and allows for creating and testing concepts with patients, their close loved ones and nurses. This is explored in the next phase.

Conceptualisation



This phase presents the setup for the concept (taking inspiration from existing concepts, methods and theories from literature), and exploring the concepts in the oncology department to see the effects on the discharge process for everyone involved. This leads to a final concept proposal, suggesting design guidelines that takes the insights gathered from the other concepts and tests.

Connection
Resonate with the experiences and find interventions for them

6 Concept Direction

The design goal shows a clear path to take with the conceptualisation. Before the concepts are made, a direction is formulated to get a better understanding on how to implement the four insights from the statement card analysis. This is done through **a short literature research that provides the necessary knowlegde, models and methods that can be used to create concepts that fit the various needs of everyone in the oncology department.**

6.1 Literature Inspiration for the Concepts

A paper by Kwame & Petrucka (2021) suggests the use of a communication model, a tool that can help nurses in how they approach the patient but also what they want to get out of every visit. The PC4 model consists of three parts which can constantly be switched between (see figure 16). These parts are task-centered, process-centered and human-centered. Each part indicates what the purpose is of the patient visit, and what the nurse should focus on and get out of the visit. It can be seen as the working mode they use. Communicating through the use of the model what the nurse will do, helps the patients understand what they can ask themselves but also know how much time there is for this. If for example the nurse comes in task-centered mode, then the nurse should also communicate that a different moment is better suited for questions or longer talks. It provides both the patients, their close loved ones and the nurses more time to prepare for that moment. This could help with the expectation of each visit but also helps in finding a moment when certain topics can better be addressed.

Patients can share when a moment is right for discussing certain topics or when not. Awareness is raised through the use of the model as the nurse makes the active decision to take a moment to listen to the patient and their close loved ones about what is going on. Using this model throughout the discharge process helps in time management and not provide extra stress in daily practices. This also asks for a way the outcomes of the model can be written down somewhere. Mainly what comes out of talks, which can provide new information about the patient that helps in providing the right care that can cater to the worries or needs they share (El-Haddad et al., 2020).

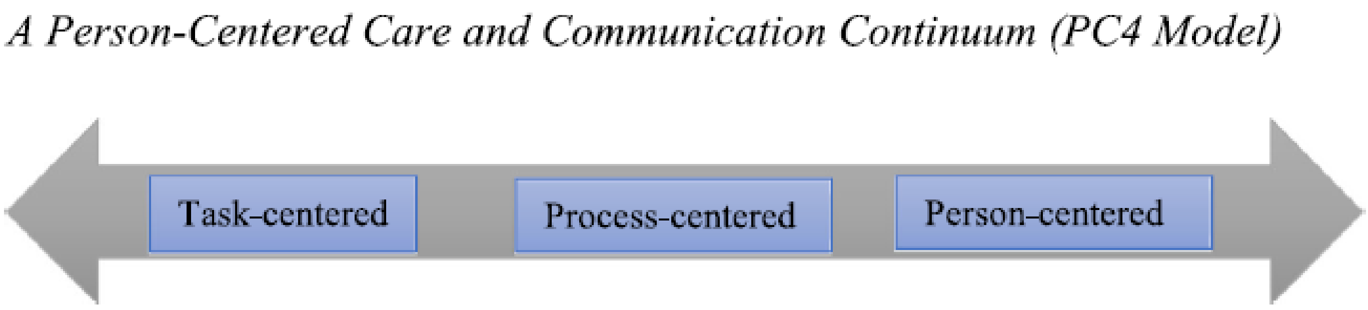


Figure 16: The PC4 model for communication between nurse and patient

The PC4 model can help in providing a more human side to the interactions with patients. By raising awareness, giving the nurses the idea to think about what might be going on with the patients that a person-centered mode can be used and making them curious to immersive themselves in the mind of the patients with their fears and worries, a stronger connection can be formed in the empathy framework. It is about taking the step to discover the other's experience and finding the right methods to immerse yourself that provides a valuable connection to learn about and improve the experiences.

A study by Keyworth et al. (2019) shows that changing confidence in patients is not impossible but something difficult, as it takes a long time before this can be achieved. What helps in getting to this point faster is asking what patients would like to learn or know about the care they themselves have to provide or the care close loved ones have to provide to the patient. The first step is in removing barriers that can stop this like expectations of what healthcare providers share about this (often believing they share nothing more than needed about the disease and treatment) and how much time there is for sharing this.

It still is not an easy task to change the behavior completely of the patients and their close loved ones. This is a starting point to push them into the right direction, as their knowledge gap or skill gap could be overcome with the help of nurses. This in turn promotes self management of their treatment and care (Dineen-Griffin et al., 2019). Looking at the behavior of the nurses in how they interact with the patients and their close loved ones, a form of self-monitored feedback can provide an overview of how tasks were performed or conversations were held and can be a sign that their approach needs adjusting. It sparks the idea of how an adjusted approach can benefit the discharge process by focussing on other points like talking more about fears and worries which could bring something positive to the interactions with patients and their close loved ones (Smith, 2004).

6.2 The Concept

Using the PC4 model can help nurses prepare how they interact with the patient and their close loved ones, and make effective use of their time and communication with the patient and close loved ones. Having a clear goal on what they can get out of the interaction helps with the expectations of everyone involved. There should be enough room for the patient to share his preferences and time schedule when they want to address certain topics. Making a schedule with each other when to address something helps in managing the fears and worries of the patient and not increase the workload of the nurses. An overview is needed to note down what has been discussed and what still needs to be addressed. This helps nurses reflect on their own work approach and helps patients and their close loved ones to . When the patient mentions needing an explanation for something, this can be prepared by writing it down, sharing it with the team and checking days after if the explanation is sufficient and the patient understands. The patient gets the feeling they have more room to adress what they need for the discharge while the nurse remains open about how to fulfill these needs.

Figure 17 shows an adjusted PC4 model. The main differences are the second and third parts which have been changed to treatment-centered and conversation-centered. Human-centered has been changed completely as the entire approach of a nurse during their interaction with the patient and their close loved ones should be human-centered. Treatment-centered is still about the process but now more clearly labeled and focused more on what the patient and their close loved ones are going through while in the hospital. Conversation-centered still touches the emotional side of the interaction. It is however placed more in the treatment perspective, and how patients and their close loved ones feel about undergoing/experiencing the treatment and the discharge process. A good balance is needed where both the patient and their close loved ones, and the nurses are on equal ground when discussing when to target specific subjects.

The literature has given inspiration that several concepts can be created and explored in the oncology department. The different concepts can be seen in the following chapter, with their effect on the discharge process experience.

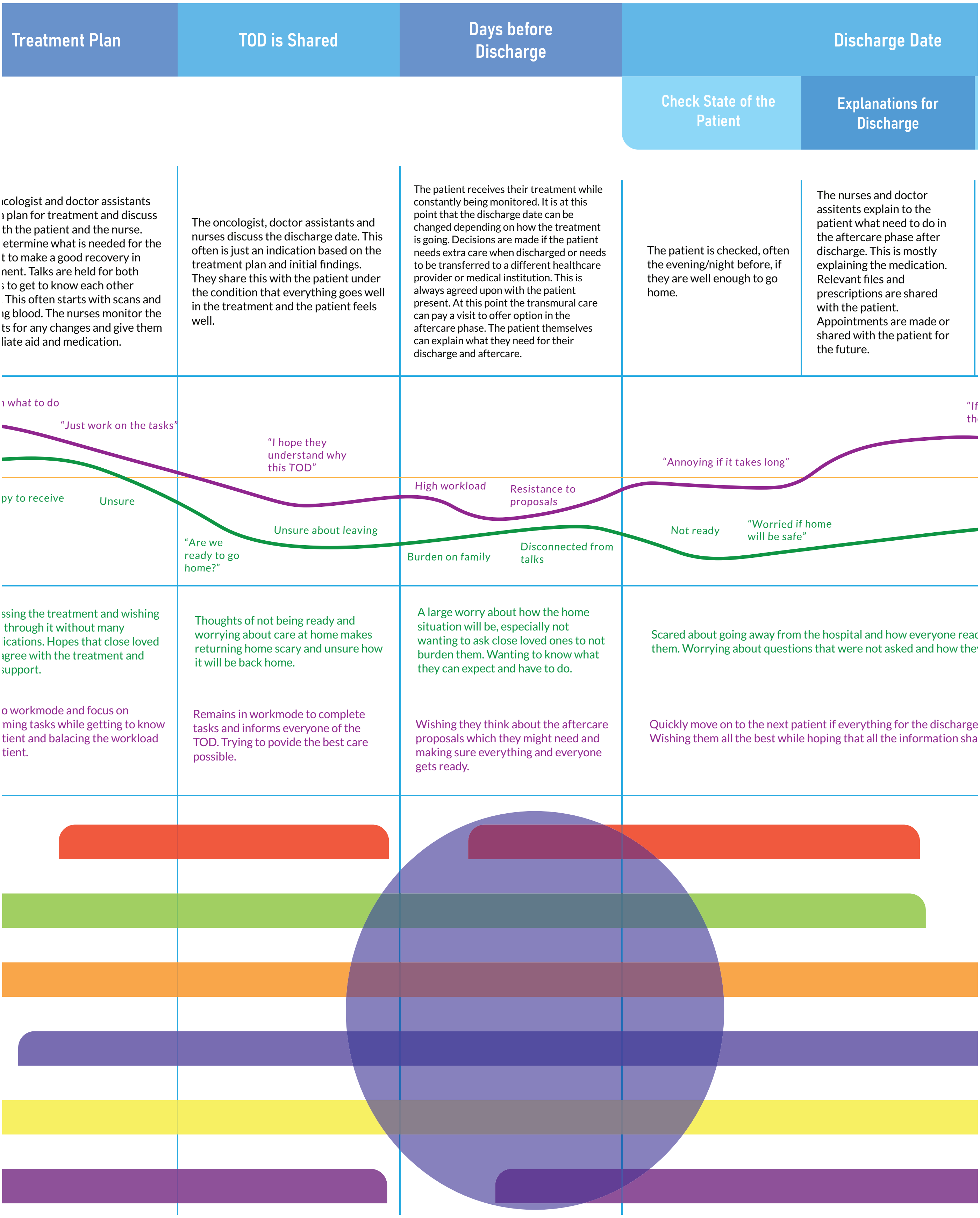
Figure 17: Adjusted PC4 model for the context of the oncology department in the RdGG

7 Concept Exploration & Evaluation

This chapter uses the concept in various forms to measure the influence it has on the interactions between the patient, their close loved ones and nurses, and the discharge experience. This first starts with a full discharge journey map, showing where the concepts are present in the discharge process. This is followed by presenting the concepts and to what extend they achieve the design goal. The prototypes, test plans and the results are shown per concept. A final concept is presented for future use, with the tips for implementation being addressed in the next and final phase.

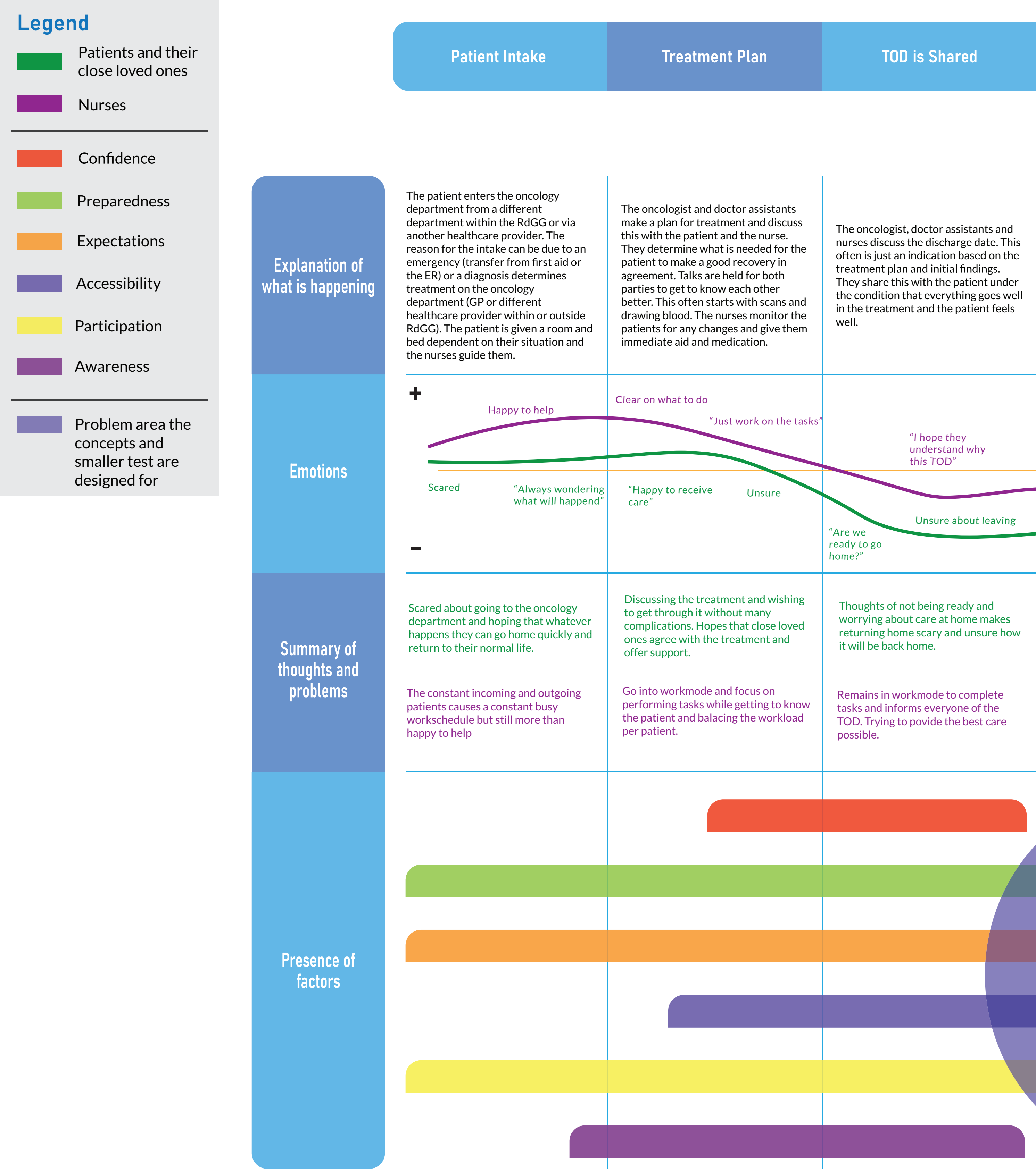
7.1 Full Discharge Journey Map

The full discharge journey map takes the previous discharge journey map of chapter 5.1 and adds the factors of chapter 3 and other relevant insights of previous chapters to get a good overview when something comes into play during the discharge journey, what the frequency of appearance is and where this applies in each specific step. Figure 18 zooms in on the area where the concepts are designed for in the discharge process, that being hearing about the discharge date, all teh days leading up to discharge and the beginning of the discharge date. Figure 19 shows the full discharge journey map.



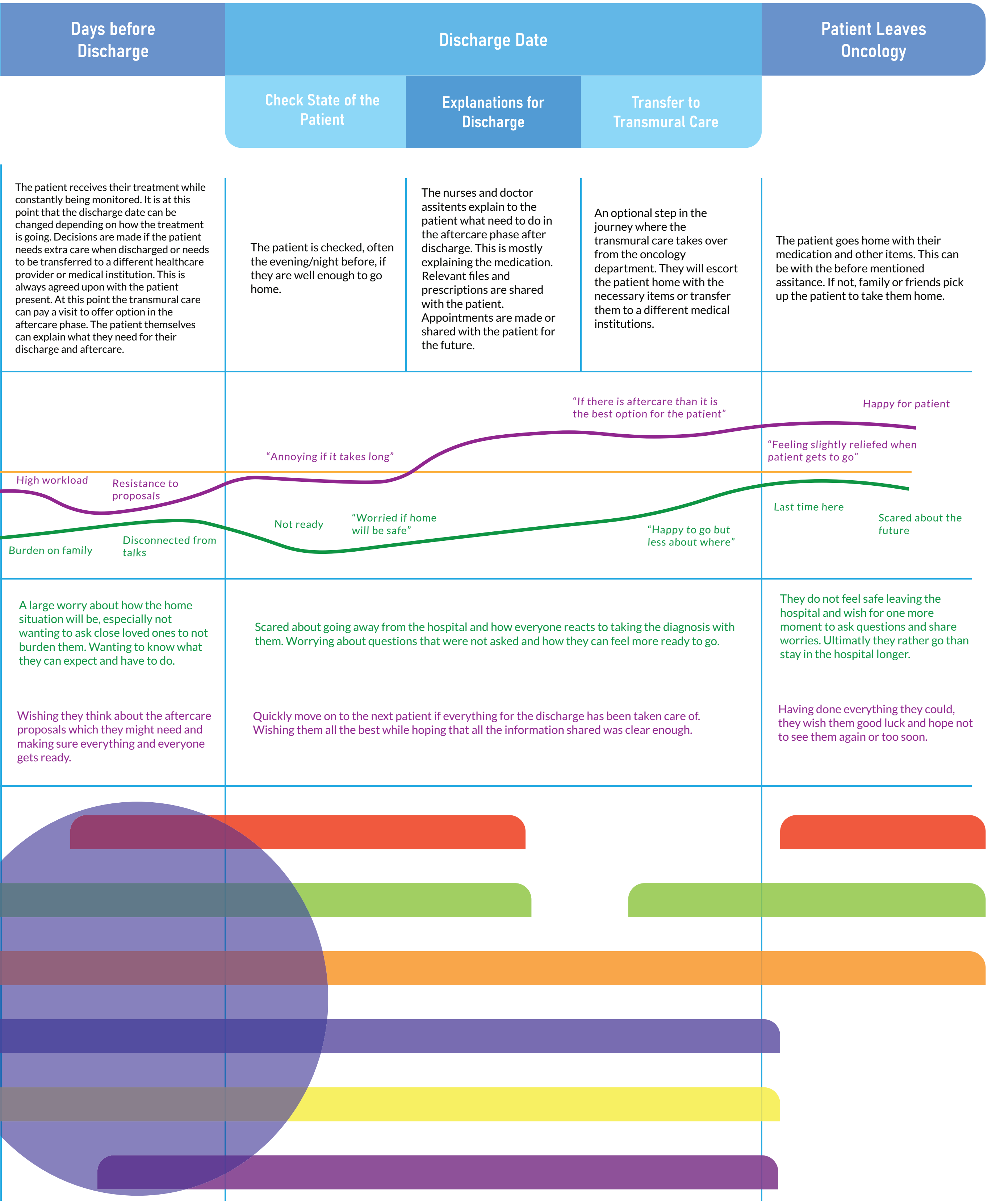
Treatment Plan	TOD is Shared	Days before Discharge	Discharge Date	
			Check State of the Patient	Explanations for Discharge
ıcologist and doctor assistants ı plan for treatment and discuss th the patient and the nurse. etermine what is needed for the t to make a good recovery in nent. Talks are held for both ; to get to know each other This often starts with scans and ıg blood. The nurses monitor the ts for any changes and give them liate aid and medication.	The oncologist, doctor assistants and nurses discuss the discharge date. This often is just an indication based on the treatment plan and initial findings. They share this with the patient under the condition that everything goes well in the treatment and the patient feels well.	The patient receives their treatment while constantly being monitored. It is at this point that the discharge date can be changed depending on how the treatment is going. Decisions are made if the patient needs extra care when discharged or needs to be transferred to a different healthcare provider or medical institution. This is always agreed upon with the patient present. At this point the transmural care can pay a visit to offer option in the aftercare phase. The patient themselves can explain what they need for their discharge and aftercare.	The patient is checked, often the evening/night before, if they are well enough to go home.	The nurses and doctor assitents explain to the patient what need to do in the aftercare phase after discharge. This is mostly explaining the medication. Relevant files and prescriptions are shared with the patient. Appointments are made or shared with the patient for the future.
ssing the treatment and wishing through it without many ications. Hopes that close loved ıgree with the treatment and support.	Thoughts of not being ready and worrying about care at home makes returning home scary and unsure how it will be back home.	A large worry about how the home situation will be, especially not wanting to ask close loved ones to not burden them. Wanting to know what they can expect and have to do.	Scared about going away from the hospital and how everyone reac them. Worrying about questions that were not asked and how the	
o workmode and focus on ming tasks while getting to know tient and balacing the workload tient.	Remains in workmode to complete tasks and informs everyone of the TOD. Trying to povide the best care possible.	Wishing they think about the aftercare proposals which they might need and making sure everything and everyone gets ready.	Quickly move on to the next patient if everything for the discharge Wishing them all the best while hoping that all the information sha	

Figure 18: Area in the discharge process for which the concepts are designed



	Patient Intake	Treatment Plan	TOD is Shared
Explanation of what is happening	The patient enters the oncology department from a different department within the RdGG or via another healthcare provider. The reason for the intake can be due to an emergency (transfer from first aid or the ER) or a diagnosis determines treatment on the oncology department (GP or different healthcare provider within or outside RdGG). The patient is given a room and bed dependent on their situation and the nurses guide them.	The oncologist and doctor assistants make a plan for treatment and discuss this with the patient and the nurse. They determine what is needed for the patient to make a good recovery in agreement. Talks are held for both parties to get to know each other better. This often starts with scans and drawing blood. The nurses monitor the patients for any changes and give them immediate aid and medication.	The oncologist, doctor assistants and nurses discuss the discharge date. This often is just an indication based on the treatment plan and initial findings. They share this with the patient under the condition that everything goes well in the treatment and the patient feels well.
Summary of thoughts and problems	Scared about going to the oncology department and hoping that whatever happens they can go home quickly and return to their normal life. The constant incoming and outgoing patients causes a constant busy workschedule but still more than happy to help	Discussing the treatment and wishing to get through it without many complications. Hopes that close loved ones agree with the treatment and offer support. Go into workmode and focus on performing tasks while getting to know the patient and balacing the workload per patient.	Thoughts of not being ready and worrying about care at home makes returning home scary and unsure how it will be back home. Remains in workmode to complete tasks and informs everyone of the TOD. Trying to povide the best care possible.

Figure 19: Full discharge journey map with added factors on the discharge process



Days before Discharge	Discharge Date Check State of the Patient	Explanations for Discharge	Transfer to Transmural Care	Patient Leaves Oncology
The patient receives their treatment while constantly being monitored. It is at this point that the discharge date can be changed depending on how the treatment is going. Decisions are made if the patient needs extra care when discharged or needs to be transferred to a different healthcare provider or medical institution. This is always agreed upon with the patient present. At this point the transmural care can pay a visit to offer option in the aftercare phase. The patient themselves can explain what they need for their discharge and aftercare.	The patient is checked, often the evening/night before, if they are well enough to go home.	The nurses and doctor assitents explain to the patient what need to do in the aftercare phase after discharge. This is mostly explaining the medication. Relevant files and prescriptions are shared with the patient. Appointments are made or shared with the patient for the future.	An optional step in the journey where the transmural care takes over from the oncology department. They will escort the patient home with the necessary items or transfer them to a different medical institutions.	The patient goes home with their medication and other items. This can be with the before mentioned assitance. If not, family or friends pick up the patient to take them home.
A large worry about how the home situation will be, especially not wanting to ask close loved ones to not burden them. Wanting to know what they can expect and have to do.	Scared about going away from the hospital and how everyone reacts to taking the diagnosis with them. Worrying about questions that were not asked and how they can feel more ready to go.			They do not feel safe leaving the hospital and wish for one more moment to ask questions and share worries. Ultimatly they rather go than stay in the hospital longer.
Wishing they think about the aftercare proposals which they might need and making sure everything and everyone gets ready.	Quickly move on to the next patient if everything for the discharge has been taken care of. Wishing them all the best while hoping that all the information shared was clear enough.			Having done everything they could, they wish them good luck and hope not to see them again or too soon.

Figure 19: Full discharge journey map with added factors and their influence on the discharge process

7.2 Concepts Explorations

Two concepts were designed with six tests total over a course of one week, each test having a different length of time. Each subchapter lists for how long each concept is used, and provide a short explanation of what the concept is, how it is tested and what the results are from the test.

7.2.1 Concept 1: Awareness Calender

Amount of participants: Five.
Two nurses and three patients.

Length of test time: One day to five days.

Location: Oncology department in the RdGG.

Figure 20 shows an user secnario of the Awarness Calender. The concept takes the function of a tear-off calendar, with various individual papers that the nurses can tear off and take with them. This paper is used for preparing their visit to the patient. Each paper contains a short sentence about what patients might go through in terms of fears and feelings that makes the nurses aware of the state they are in. Underneath, the nurses can write their approach from the adjusted PC4 model, what they want to get out of the patient visit and what they learned from the patient visit. What their approach is to the visit, must be shared with the patient. The papers have a specific shape which can be placed next to each other like a puzzle, and show a timeline of the day which approaches were used and what has come out of the patient visits. This can be shared with the team but also functions as a reflection of the working approach of the nurses. It is this final step of reflecting that can cause a intervention in the current discharge process, where the nurses learn how changing their approach could provide a more positive experience for the patients.

7.2.1.1 Test plan

A nurse takes one paper with them to the patient. Before they enter, they write down their approach and any questions, points or tasks they must do. During the first time they are supervised for assistance and direct observations. After the first one has been filled in, it is handed in and they take the next paper when they visit the patient again. The following visits will be done without supervision. This can be done for a total of five times, after which a final conversation is held about using the concept and concluding questions are asked. The prototype of Awareness Calender can be seen in figure 21. See appendix E for the complete test plan.

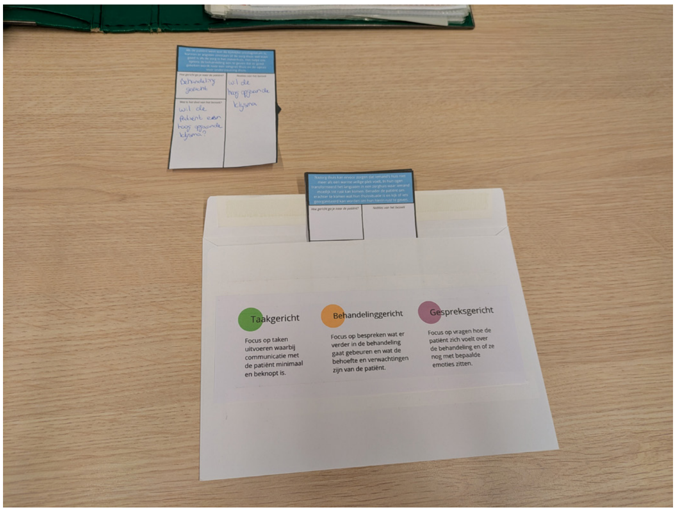
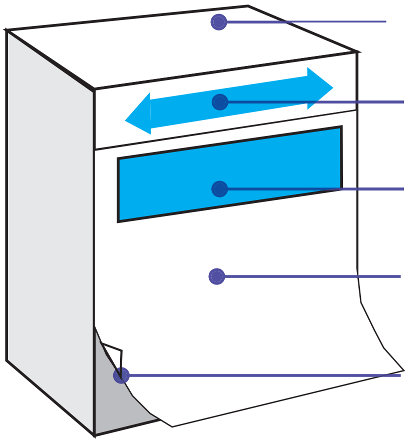


Figure 21: Prototype Awareness Calender, using an envelope as the calender in which the papers are taken out of one by one



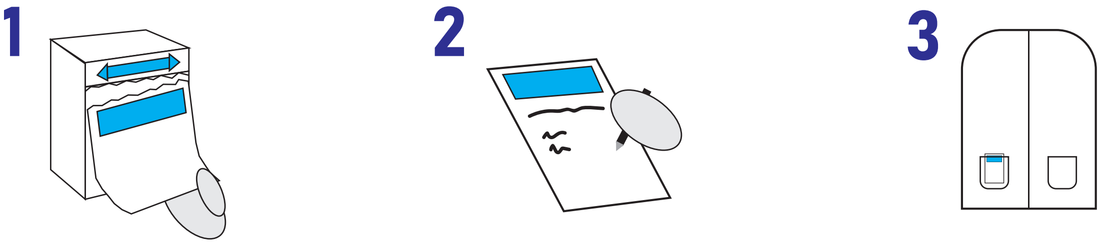
A tear-off calendar of which has multiple pieces of paper which nurses can use to prepare their visit to the patient.

This part descibes the PC4 model, and shows which approach the nurses can use based on their schedule and what they want to get out of the visit.

Each piece of paper has a sentence with what a patient might be going through as inspiration and awareness tool for nurses to start a conversation.

Underneath the sentence, nurses can write their approach, what their goal is with the patient visit and notes made during and after the patient visit.

Every paper has a mark to place the pieces in correct order and provide an overview how the visits were approached and what can be shared with the nursing team.



1

The nurse goes to the nurse station and rips of a single piece of paper from the tear-off calendar before they visit the patient.

2

They write down their approach for the visit and their goal of the visit. In this case it is treatment-centered and they want to know how they respond to the medication.

3

They bring the piece of paper with them which fits neatly in the pocket of their nursing jacket.

4

The nurse visits the patient and shares their intention with this visit. They talk about the topic the nurse wrote down and schedule another moment to talk about the patient's wellbeing.

5

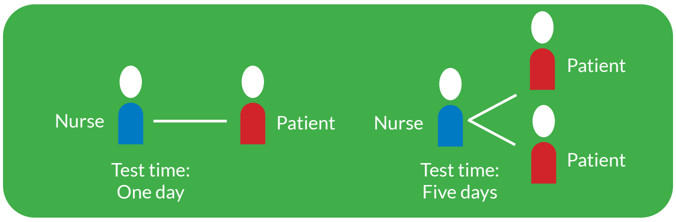
The nurse writes down important notes shared during the talk and places it in their pocket to keep. They pick up a new piece of paper for their next patient visit.

6

At the end of their shift, they go over what has been gathered and share this with the nursing team. The nurses see what appraoches they could take or what to prepare for their own patient visit.

Figure 20: Awareness Calender overview with a general explanation and a short user scenario

7.2.1.2 Results



- The nurse who used it one entire day mentioned that thinking about the approach and goal of the visit made them think more carefully about the communication with the patient. The awareness of what the patient might go through but also when to schedule a specific conversation was something the concept helped with. This nurse was more aware of the difficulties patients might face which they do not share.
- The concept helped them in finding the right approach to talk about these difficulties and make sure they are aware of the worries the patients had.
- The nurse who used it for five days agrees with this, and even noticed more structure in their approach and making a schedule when to target specific topics. The nurse also noticed that the patient opened up more to talk about other worries they had.
- Both nurses agreed that the sentences listed at the top helped in reminding them to keep in mind that more plays than they knew.
- One element of the concept they had difficulty with was sticking to an approach.
- They noticed that with task-centered the chance for having a conversation about several topics is high. There also was not a clear difference between treatment-centered and conversation-centered, as the nurse found these very similar.
- There was a clear awkwardness in the beginning of using the concept which made using it more difficult. Around the second time of taking a piece of paper, they got more used to it and the idea of what to focus on was more appriciated.
- The patients got the feeling they were listened to more. One patient mentioned that they were feeling down and having someone else addressing potential worries helped them a lot to open up about it and feel a bit better.
- Both the nurses and patients felt their expectation management improved due to knowing what the nurse wants and both scheduling when to talk about specific topics. One patient felt they could better predict how to start certain conversations and avoid others.

7.2.2 Concept 2: Interaction Evaluator

Amount of participants: Four.
Two patients and two nurses.

Length of test 30 minutes.

Location: Patient rooms in the oncology department in the RdGG.

Figure 22 shows an user secnario of the Interaction Evaluator. The concept consists of a paper on which a maximum of three topics can be written down by the patient. Next to the topics are scales that indicate to what extent the patient is satisfied with what has been discussed. Next to that is room for the patient to write comments like important info or questions for next time when they continue this conversation. Before the nurse arrives, the patient will write down topics they wish to talk about. These can be short questions about their treatment, requests for medication or anything else. When the nurse is present, they go over the topics one after another. After the conversations have ended, the patient gives a number to each topic on a scale on how satisfied the patient is talking about it. This scale is up to them how to interpret it. The most common one would be rating it to what extent the topic has been discussed and how satisfying the outcome is. Comments can be written down by the patient during and after the interaction with the nurse.

7.2.2.1 Test plan

The patient gets the paper about 10 minutes before the nurse arrives, giving them time to think about the topics they want to talk about. After 10 minutes, or when a maximum of three topics have been written down, the nurse enters the patient room and they go over each topic. They are observed while this is happening. After the final topic, the patient gets some time to give scores and write down any notes. A final conversation starts talking about their use of the concept and concluding questions are asked. The prototype of Interaction Evaluator can be seen in figure 23. See appendix F for the complete test plan.

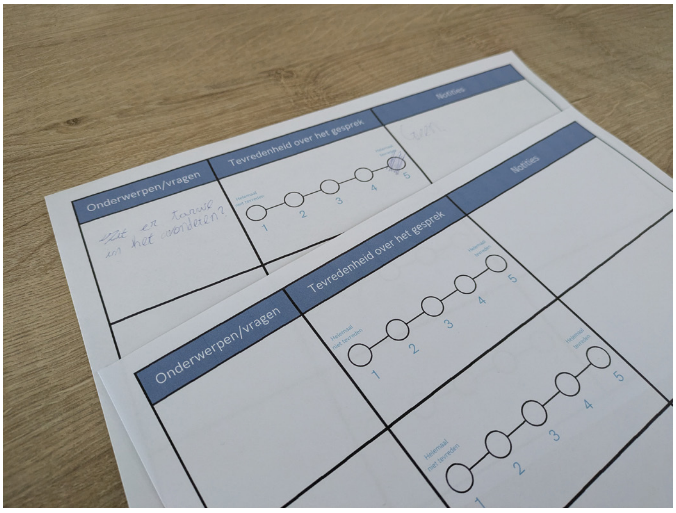
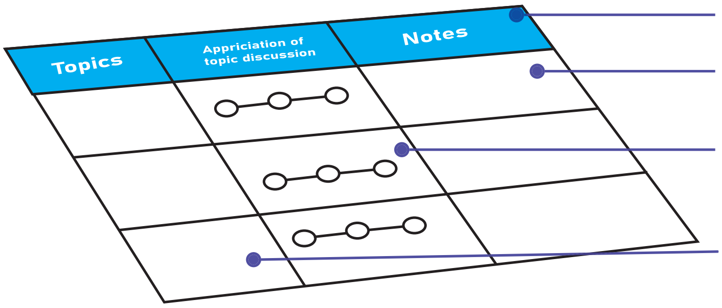


Figure 23: Prototype of Interaction Evaluator, a large piece of paper on which the patients can write down their topics, rate the coversation and notes to share with the nurse



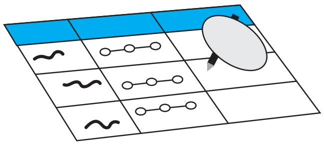
A large board with which the patient can write down the topics they wish to talk about with the nurse and rate how each topic discussion conclusion is.

Room for the patient to take notes during and after the conversation which the patient can use to prepare the next conversations with the nurse

The patient can rate how the a topic conversation went and how satisfied the conclusion is. Can be used to close or continue a topic next time.

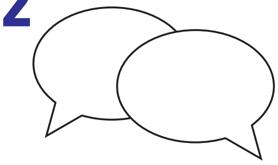
Topics can be about anything related to their treatment and hospital stay. For example it can be a question about an upcoming scan.

1



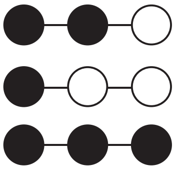
The patient writes down what they want to talk about with the nurse, having full control over what the conversations are going to be about.

2



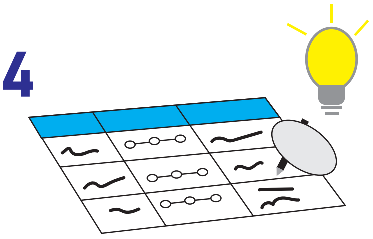
They go over each topic one by one. The patient can make notes in the meantime.

3



After each topic has been talked about, the patient rates each topic. This gives an indication what topic needs more attention and what can be close off.

4



Depending on how each topic has been rated and the notes taken, the patient can prepare new topics for the next time the nurse visits them.

Figure 22: Interaction Evaluator overview with a general explanation and a short user scenario

7.2.2.2 Results

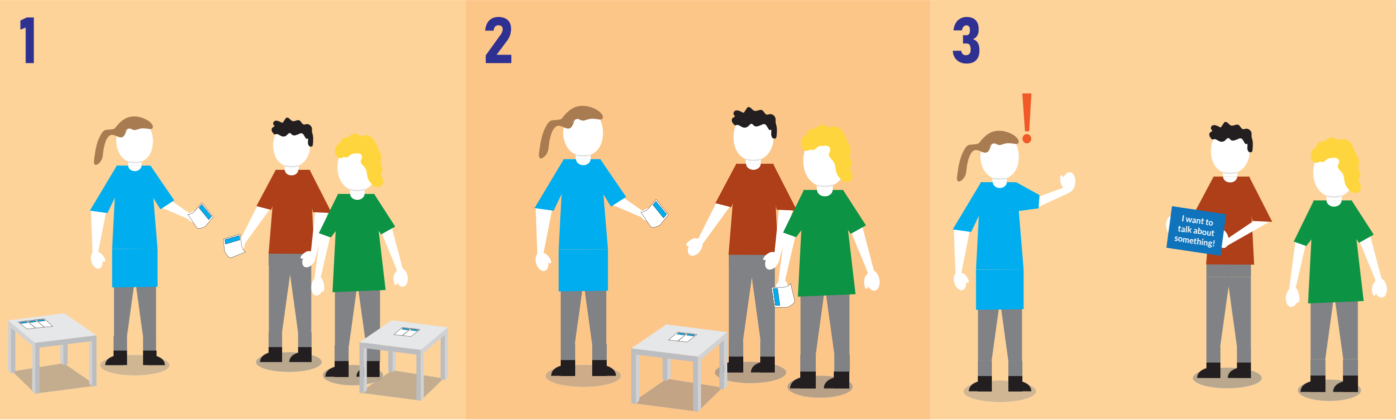
- Both patients had some difficulty coming up with topics to talk about. One of the patients only wrote down one question, about their gluten intolerance for the evening meal round, and was going to be discharged in about two days. The other patient managed to write down more topics about the treatment and was going to be discharged on the day of the test. The specific topics will not be mentioned as per the request of the patient.
- Talking about the topic went just as smooth as it would normally. The leading role of the patients was not necessary during the use of the concept as it did not add anything to the conversations. This was the case specifically for these two patients.
- The element of giving a score to a topic was on the other hand very much appreciated.
- They noticed, especially the patient with more topics, that it helps with questioning themselves if they truly understood everything and might want to continue the conversation.
- The visual aid which can be shared with the nurse helps both with knowing what the other wants for the next visit. The patients mentioned that their fears and worries (in this case being rather small ones) were eased and did feel more relieved talking about them.
- What was important in this is the nurse expressing they have time to talk. The small gesture of grabbing a chair and sitting down gives the feeling of being on an equal level (figuratively and literally).
- Their preparedness was also improved. This was with the gluten intolerance patient that they can safely have dinner tonight. The other patient mentioned that having the knowledge written down did make them more prepared to go home.

7.2.3 Three Smaller Tests

In total three small tests were held. Two of these small tests were variations on Awareness Calender and the third was a small original test. The first two tests took about 30 minutes each. The third test took about three hours. The setup of the small tests with the participants can be seen in figure 24.

7.2.3.1 Results

- Starting with the first two tests, the results were very similar to Awareness Calender. The awareness of everyone increased and they started to think more about the situation of the other person.
- The addition of the partner with test 1 provided an oppertunity for longer conversations between the partner and the nurse, talking about what they want from each other. This in turn helped with the expectation management for which the partner mentioned they better knew when to be present and when to ask certain questions.
- The second test brought some confusion as to when someone starts with their card, and when someone is supposed to respond and when to continue. The patient did not like this dynamic of responding to a card, and preferred having them all out in the open.
- The third test provided direct feedback when the patient and their partner needed something. This was appreciated as it communicated quickly what they wanted.
- One downside is the lack of privacy. This test was held in a four patient room which resulted in having everyone see what they were dealing with. The nurse and the partner of the patient thought that having different buttons to call the nurse that indicate what the patient needs, could be a good solution to this.
- Having a single patient room already solves this issue but not everyone has that luxury, as said by the patient.



A variation on concept 1 where the patient and their close loved ones also has a set of papers with which they choose an approach, set a goal and form a timeline to see how the interactions go that day.

A variation on concept 1 with which the nurse, patient and their close loved one share one set of papers to take turns picking a card and respond to each others cards. The timeline shows how they interact with each other.

The patient and their close loved ones hold a sign on which they can write what they need or wish to talk about. The nurse can see this and respond to it to discuss the topic or schedule it for a different moment.

Figure 24: Overview of the three smaller tests/ideas with a small explanation of the setup

7.3 Evaluation of Concepts

Each concept and smaller test contributes something to the interaction between the nurse, patient and their close loved ones, and the discharge experience. Figure 25 shows a timeline with each concept and smaller test to what extent it contributes to achieving the four points of the solution direction. One axis combines confidence and preparedness while the other combines talking about fears and worries and awareness. These are scored based on the answers the nurses, patients and their close loved ones gave to the closing questions of each test, mainly the score for to what extent the points of the solution direction have improvement.

The figure shows that the longer a concept is used, especially in the case of concept 1, that it effects the four insights of the desgin goal more. Confidence and preparedness are the two points improved the least with each concept and smaller test. As mentioned earlier, these are points which are difficult to improve in such a short time. One important influence of the concept is that it affects everyone involved. Never is, for example, only the nurse or the close loved one who has a positive or negative effect. This helped in analysing the changes to the experience of everyone. Each concept and test adds something to the experience, and lessons can be taken from them on what can be added to the discharge process and what direction should not be taken.

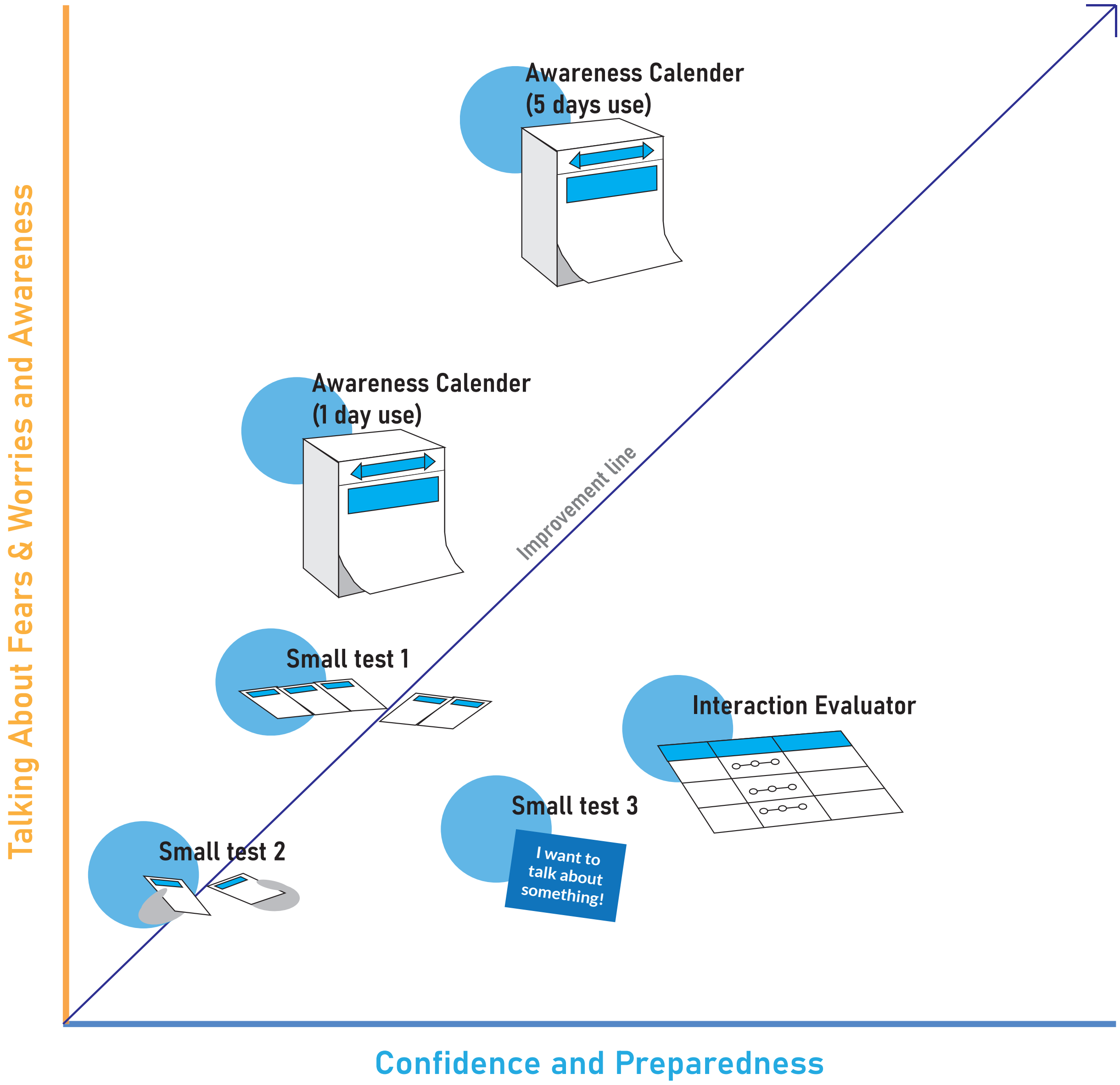


Figure 25: Evaluation of the concept tests and smaller tests based on the score given by nurses, patients and their close loved ones how each scores in terms of improving the points on the axes

8 Final Concept Proposal

The goal of this project is to find early signs of which future direction can be taken in order to truly improve the discharge process and provide a positive experience for everyone involved. A final concept is therefore given, taking the insights of the concepts and each test to combine these in a proposal that fits within the RdGG Oncology department.

8.1 Benefits of the Concept Direction

The concept direction, which aims at improving four aspects (preparedness, confidence, awareness and talking about fears and worries), provided a wake up call for the oncology department. While some nurses took some time to accept they lacked certain knowlegde, they are willing to learn about what they can do to improve the discharge process. The same can be said for patients and their close loved ones who are usually too eager to accept that the process is what it is. They close themselves off from having the opportunity to talk about their fears and worries, and to share what they need to leave the hospital correctly. Their biggest fear of care being worse outside the hospital, not having the means to pick up the care and their home changing into a nursing home is something that can be addressed during the entire discharge process. The concept Interaction Evaluator showed that patient felt comfortable writing down their questions and needs, while the concept Awareness Calender gave nurses a good idea how to act upon these questions and needs, and also think about what could be done or asked for the next visit to the patient.

Patients and their close loved ones need to be prepared and have the confidence to provide the care or take care when they leave the hospital. This starts with talking about their fears and worries, and sharing what they need in order to leave the hospital. Nurses need awareness that more plays than what they see or hear, and need to prepare themselves to talk about these fears and worries. Patients need to be aware that nurses try their best within the limited time they have and nurses need the confidence to address these potential difficult talks at the right time. The concept exploration has shown that these points can be improved, or in some cases be a focus point in the discharge process. Nurses, patients and their close loved ones started thinking about how the interactions and process during the discharge can be different after using the concepts. They actively wondered what more they might not see or how differently they can approach those involved in the discharge process to learn more about balancing everyone’s needs, and actively think about what fears and worries might play.

8.2 Design Guidelines for the Final Concept

Figure 26 provides an overview on how the concept is used and what the effects are on the discharge process. It follows the steps from the empathy phases framework. This is a general overview of what a final concept can add to the discharge process. Some design guidelines are provided for a future concept.

- The concept must be designed around the busy schedule of the nurses and combined with their regular work methods and tools. Making it digital to implement it in the discharge checklist makes it part of an exisitng system the nurses are familiar with.
- The concept benefits everyone involved and must be designed where everyone is on equal ground to have a say in the matter, initiated by nurses to guide the discharge process.
- Nurses need to increase their awareness. At some point this awareness is reached after which raising it is no longer necessary as they apply it in their daily work.
- Patients need an overview of what has been talked about to prepared themselves. They can have a similar discharge checklist present in the patient room on which they can take notes and check what they want to discuss and need for discharge. It can be placed next to standard medical equipment. If it is digital, it can be made small to take up less space and adepted to various age groups compared to a single rigid form/shape.

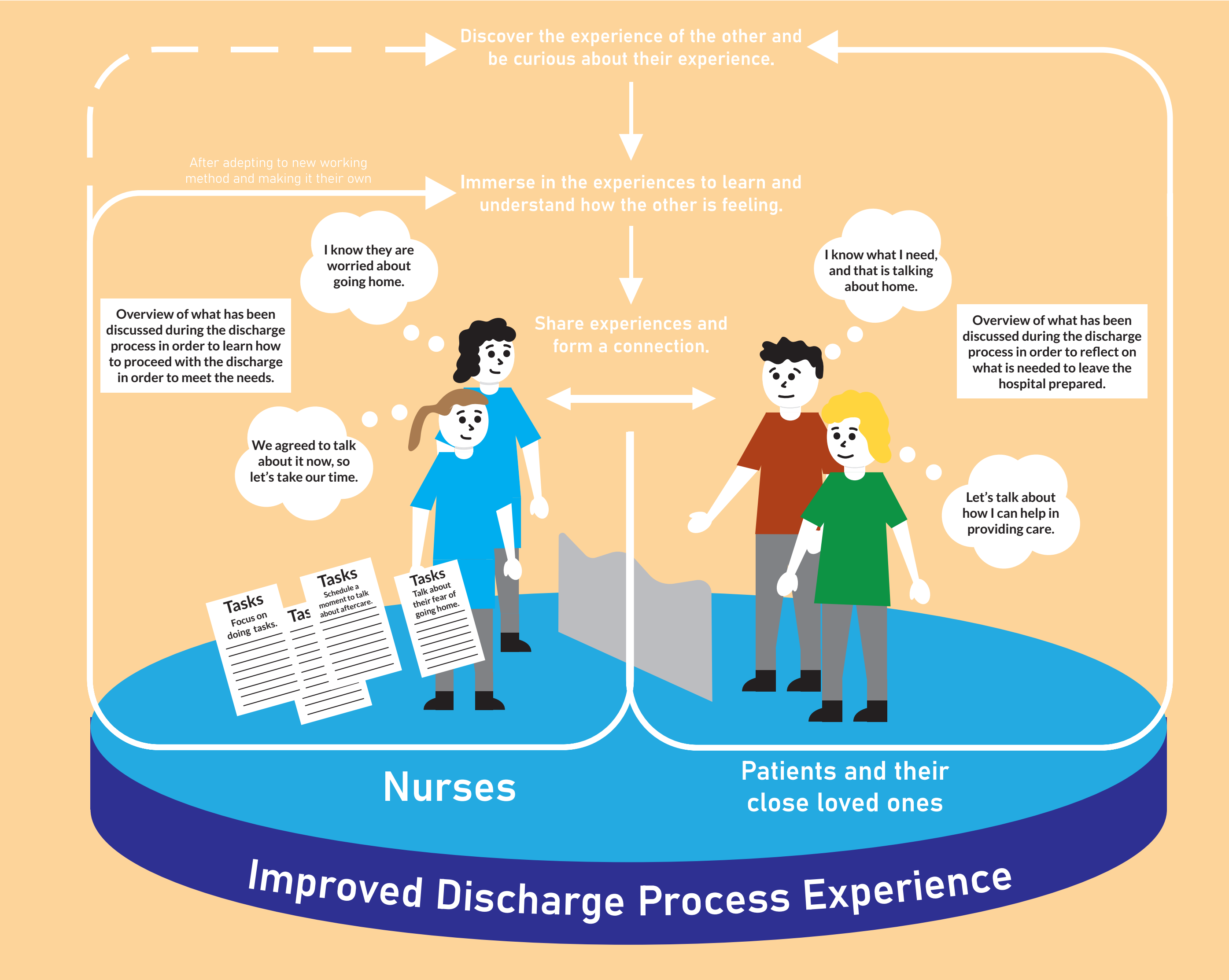


Figure 26: Final concept proposal showing the effect on the discharge process experience by following the phases of the empathy framework

Implementation

The final phase presents an implementation plan for future exploration of the final concept proposal design. Some additional general recommendations are given for designing for the oncology department and this specific target group. Finally, a conclusion is given which looks back at the project and the results achieved.

Detachment
Take a step back to reflect on the insights and plan for the future

9 Future Implementation

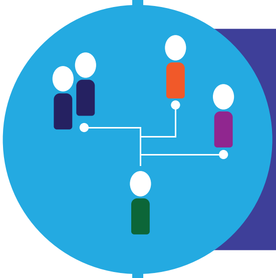
This chapter present an implementation plan, a step by step plan on how to utilise the approach and methods used in this project for future design. In addition, some final general recommendations are given for exploring the oncology department in RdGG, and designing for this specific target group.

9.1 Implementation Plan

The future implementation contains a practical step by step guide on how to best utilise the first steps set by this project. It can be seen as a continuation to expand what has been found, and place it on a larger scale. It will follow many of the steps in this project but also adding additional methods and a timeline to make good use of when steps need to be performed. Figure 27 shows the steps on a timeline. These steps are inspired by some methods and examples given in the Convivial toolbox by Stappers (2021).

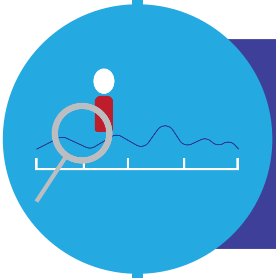
1. Set the scope and aim

Like with this project, the first step is to decide the scope and aim of what to achieve. This can the oncology department with the same people, or inlude additional people like doctors or the transmural care. Important to note is that the larger the scope and aim, the longer it will take to end with something valuable for everyone involved.



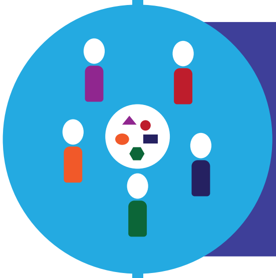
2. Get in touch with (additional) experts for further knowledge

Getting in touch with other experts can greatly contribute to the knowledge needed for a greater positive change of the discharge experience. Experts and other healthcare providers like psychologists and transmural care can add their knowledge to the discharge process. For example, psychologists can assist in understanding the reasons for patients to not communicate or help formulate mental and conversation models for behavior of each individual involved.



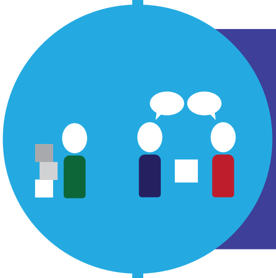
3. Expand the context exploration and the discharge journey maps

The effects of the discharge follow for longer than at the moment of leaving the hospital to go home or to a different healthcare institute. It is valuable to follow patients and their close loved ones outside the hospital. This complete journey can zoom in on what has already been found and add to the insights by seeing the effects on the negative experience in a different environment.



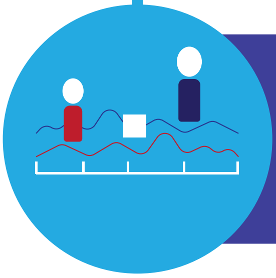
4. Schedule co-creation sessions with the target group

Co-creative sessions can give interesting insights and provides more feedback from the target group on the their discharge experience. With the help of (additional) experts and expanded journey maps, certain topics can be brought up during these sessions. A good approach is to invite the same patients, their close loved ones and nurses over the course of their discharge and some time after to gain a better understanding of their experience during different stages of the discharge and what the reasons might be behind them. This can be done with only one group (only patients, nurses etc.) or a mixed group to start a conversation about the influences of those involved on the experience of the other. Visual methods that capture what the stakeholders feel and say like context mapping can be a good method to use for a clear overview.



5. Design and iterate on concepts with the target group

Various concepts can be created based on the final concept proposal, and fit within the expanded discharge journey for selected steps or for the entire journey. This starts in the form of low fidelity prototypes and slowly turn into higher fidelity prototypes to test. Having them use the concepts for a longer period of time or during a specific step in the discharge process will provide the right feedback needed to iterate on the concepts. Ideation can be done with the target group to keep their needs in mind and how it fits for example in a home setting or how it can transition from various location during the journey.



6. Refine the final concept and measure the effect on the discharge experience

The final step involves refining the final concept and measuring the effect on the discharge experience of everyone involved thoroughly. The best case would be to measure this for a long time with multiple people involved, following them during the discharge and after the discharge. Having different people means that a good substantiated evaluation on their experience can be formulated. The final concept can then be turned into a final design and placed into production for practical use.

Figure 22: Implementation guide for future positive impact in the discharge process experience which follows a set of steps based on this project and expanding on them

9.2 General Recommendations

In addition to the future implementation recommendation step by step guide, some general recommendations are given for future research and design.

- Take the time to get a good understanding of the context and explore every inch, nook and cranny of it. As there are many elements and people present that form the discharge process experience, it requires thorough research to understand this process and everyone's role within it. Dare to ask questions to everyone involved and follow them around to see and hear what you normally would not. It is important to be proactive in this context due to it being a busy one that never sits still.
- Look outside the context as well. For example other healthcare institutes to which ex-clinical patients are sent to or general practitioners which will play a role when the patients and their close loved ones leave the hospital to go home. This can make refining the project and which direction to take even stronger, as it adds to the discharge journey and more is learned about the effect on the daily lives of everyone involved.
- Keep in mind that this is a sensitive context and group of people that are involved. Cancer is a serious illness with diagnoses that often have a large negative impact on people's lives. Researching and designing for this context means that everyone involved will share personal stories that might fall heavy for some. It is important to get the right support to talk with someone about topics or shared stories that hit deep, or take a step back from the project to take your mind off everything.

10 Project Conclusion

The final chapter of this project takes a look back at what has been done, what has been achieved and how the questions listed in the project focus have been answered. Some final closing words are given to conclude this project.

10.1 Conclusions

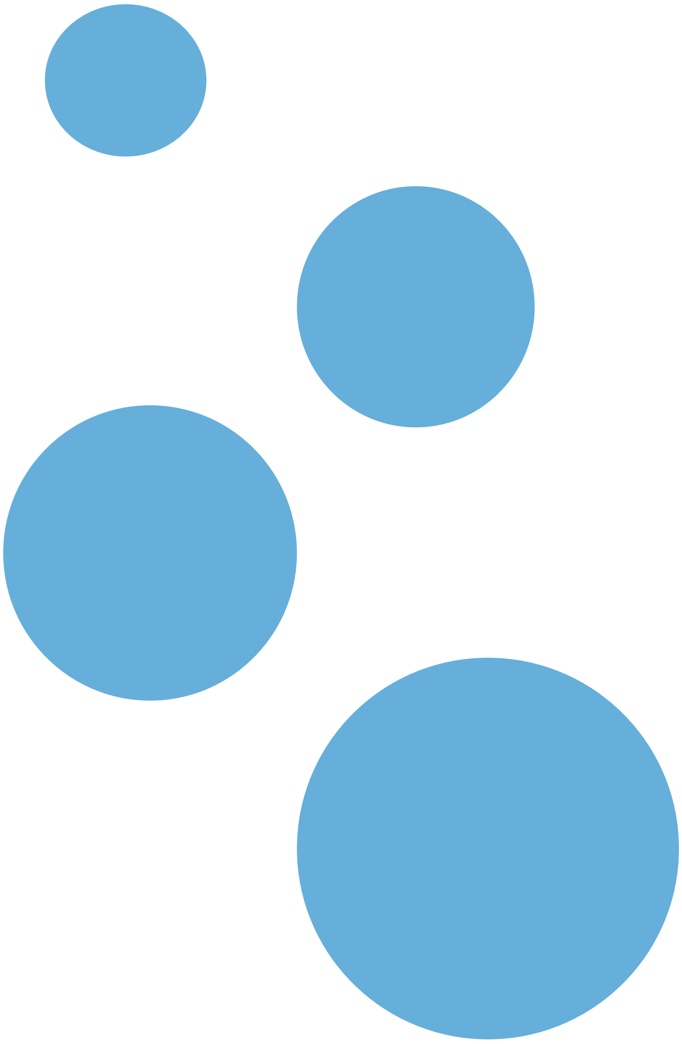
This project researched the discharge process experience of patients, their close loved ones and nurses in the oncology department of the RdGG. The current discharge experience has a large difference between on one side the nurses and on the other the patients and their close loved ones, the former having a more positive experience compared to the latter. Nurses often go into a work mode that makes the discharge clinical with little room for a human soft sided approach where emotions and specific needs are shared. This has the consequence of missing crucial information about what is going on with the patient and leads to a positive perspective on the experience. With a high workload and little to no knowledge on applying new working methods, this issue only increases. Patients and their close loved ones have underlying reasons, those being a fear of lower quality care outside of the hospital, uncertainty about their competence to take or provide care and worries of their home becoming a care home instead of a place to relax and recharge, they do not share when the moment is there for it to be discussed and find solutions that might lessen these fears and worries.

Opportunities arise for nurses, patients and their close loved ones to find the right moments during the discharge process, mainly after hearing the TOD, to approach each other and create a safe and trusting environment where they can solve these issues together. This first starts with raising awareness for both sides, knowing there plays more than what one sees and hears. Everyone's expectations can be managed better by being open about what is happening and what someone is thinking. Keeping notes and track on how these talks go and what conclusions come out of them helps in finding the right approach to help each other better understand what is needed for a good discharge and make someone ready to leave the hospital. This must be done on an equal level where everyone has an equal voice for their needs and questions to be heard, while not creating a conflicting method that forms a hurdle on the day to day working activities. Setting these first steps while keeping in mind how sensitive the context is with the many individuals, each with their own needs and worries, can provide a valuable intervention in the discharge process experience and could make it a more positive one.

10.2 Closing words

As the conclusion has been reached of this project, I want to take a short personal moment to look back on what I have learned. The personal motivation has been my reason for choosing this specific context and project aim. While challenging at certain moments due to seeing similar moments I have experienced during my father's illness, it was also a constant reminder how important it is to help these people when they are very vulnerable. A perfect solution cannot be created with this project while wishing that such a thing is possible, but hearing the feedback from everyone involved and seeing the first signs of positive change does give a gratifying feeling.

I want to thank everyone that has been a part of this project for their cooperation, guidance and feedback. Starting with my TU Delft supervisors. I want to thank Froukje Sleeswijk Visser for her guidance and sharing her personal experiences that helped in shaping the directions to take and getting a good feeling on the impact on someone's life, and Armagan Albayrak for helping create the discharge journey map and approaching the context due to her experience with similar projects in a healthcare setting. Then comes everyone from RdGG. I want to thank my hospital supervisor Petra Kok for her caring attitude and making sure that I find the right people within the hospital to make good progress, the head and nurses of the oncology department to always be ready and trying to help with the project and the patients for their participation in the project even while undergoing heavy treatment and having to deal with their diagnosis.



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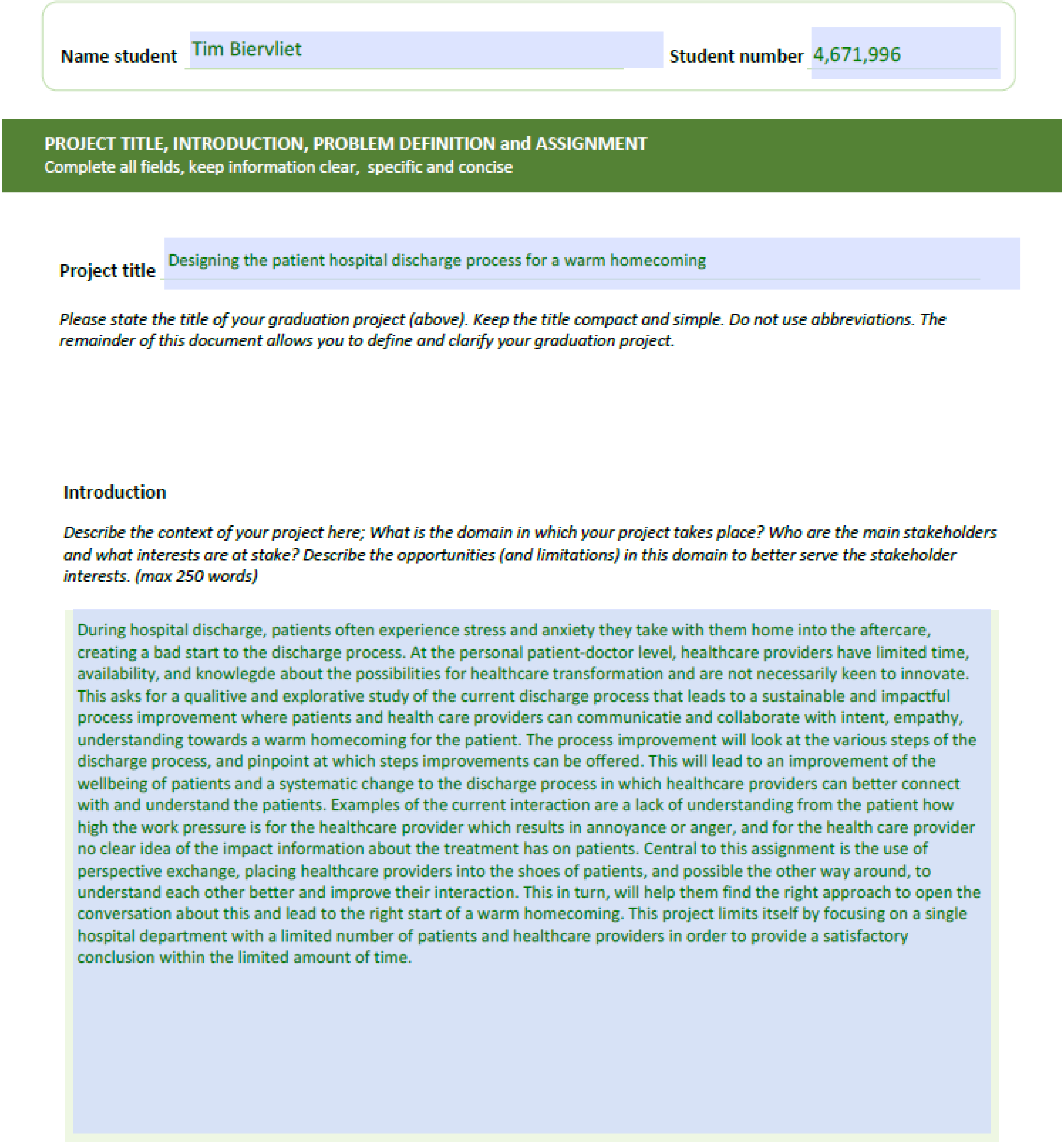
Appendix

A: Project Brief



Name student Tim Biervliet **Student number** 4,671,996

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

Project title Designing the patient hospital discharge process for a warm homecoming

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

Introduction

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

During hospital discharge, patients often experience stress and anxiety they take with them home into the aftercare, creating a bad start to the discharge process. At the personal patient-doctor level, healthcare providers have limited time, availability, and knowlegde about the possibilities for healthcare transformation and are not necessarily keen to innovate. This asks for a qualitive and explorative study of the current discharge process that leads to a sustainable and impactful process improvement where patients and health care providers can communicatie and collaborate with intent, empathy, understanding towards a warm homecoming for the patient. The process improvement will look at the various steps of the discharge process, and pinpoint at which steps improvements can be offered. This will lead to an improvement of the wellbeing of patients and a systematic change to the discharge process in which healthcare providers can better connect with and understand the patients. Examples of the current interaction are a lack of understanding from the patient how high the work pressure is for the healthcare provider which results in annoyance or anger, and for the health care provider no clear idea of the impact information about the treatment has on patients. Central to this assignment is the use of perspective exchange, placing healthcare providers into the shoes of patients, and possible the other way around, to understand each other better and improve their interaction. This in turn, will help them find the right approach to open the conversation about this and lead to the right start of a warm homecoming. This project limits itself by focusing on a single hospital department with a limited number of patients and healthcare providers in order to provide a satisfactory conclusion within the limited amount of time.

Problem Definition

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

When a patient is receiving treatment, many changes are happening regarding the wellbeing of the patient. One such important change is the hopsital discharge during which the patient experiences uncertainties and fears, causing them to not properly go home for the aftercare process. This is mainly caused by the amount of information a patient receives regarding their treatment and their aftercare. There isn't always enough time and space for a healthcare provider and the patient to talk about this information or to explain it in a empathetic way. This is also the case for other (healthcare) parties involved like healthcare institutions or physiotherapy. The high work pressure combined with the limited time of healthcare providers plays a huge role in this. On the other hand, patienten often have difficulty formulating their questions at the right moments which causes for unanswered questions to be more difficult to ask at later moments. All this causes the discharge process to not go well, leaving all parties involved to not receive the smooth and satisfactory process they deserve.

Assignment

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

Create a concept to improve the discharge journey for patients and provide the right start for the aftercare process.

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

The first step, which for some part has already been performed, is desk research to gain a basic understanding of the discharge journey of patients. This will be followed by interviews with patients and healthcare providers to understand their perspective on the discharge journey, and help with interlinking these perspective where oppertunities and risks can be found. Patients will be interviewed on specific dates within their discharge journey (before, day of discharge and after). After this, context mapping is used to acquire an overview of what the patients and healthcare providers feel in the given context. During the context mapping session, initial ideas formulated and information from the interviews will be shared with the participants. A patient discharge journey map will be created to identify specific points in the journey that can be improved. Further research on these improvements will result in a concept. The project will conclude with a final validation of the concept, in which low fidelity prototypes can be tested, and further improvements/recommendations are formulated.

Project planning and key moments

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

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

Kick off meeting: 25 Sep 2024

Mid-term evaluation: 5 Dec 2024

Green light meeting: 6 Feb 2025

Graduation ceremony: 6 Mar 2025

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

Part of project scheduled part-time	
For how many project weeks	
Number of project days per week	

Comments:

Motivation and personal ambitions

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

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

The subject of this graduation project falls perfectly in the domain I like to design for. Something that tackles societal issues but at a human centered level. I look at the individuals and together work towards something that can tackle multiple people within society. Co Creation and context mapping are skills I would like to develop further. In order to better these skills, I will implement the experience learned from my internship and truly make these my own. This includes project planning, communication and translating content into concepts. Another competence I would like to prove, is working with a sensitive target group. My Exploring Interaction course project had the target group of students with ASD, and I noticed that I like working with such target groups that require more effort to work with compared to non-sensitive target groups. As the target group of this project also includes a sensitive topic, I want to find out if my interests truly lie in this direction. Finally, one personal learning objective I set for myself is finding out if I like working in the medical sector, and learn to motivate myself to devote myself to this field. Throughout my masters program, I often tackled courses and/or projects that fit in the medical field. With this final project, I want to find out if it something for me to pursue in my future career path.

B: Interview Head of the Oncology Department

Thank you for doing this interview. Today I'm going to interview you about the discharge process of oncology patients. This will be questions about your own experience, those of fellow healthcare employees and patients currently in treatment or close to treatment conclusion. These experiences will be from your perspective.

First, a small introduction. My name is Tim Biervliet, a student from TU Delft and currently doing my master graduation project. In this project, I analyze the current discharge process to create an overview of needs and worries of the patient and healthcare providers. This in turn will lead to a patient journey map, a timeline which shows the steps both the patients and healthcare providers take in the discharge process. The timeline includes the emotions which indicate which step provides an overall negative or positive experience. The steps with a negative experience can then be selected to be improved.

The interview will take about half an hour and will consist of nine questions. This interview is entirely voluntarily, and you may at any point refuse to answer any question or decide to stop this interview.

Questions

1. Could you give a small introduction about yourself (function, years of experience etc.)?
2. How many patients enter the outpatient clinic and how many leave on a weekly basis? If on a weekly basis is too short, what about on a monthly basis?
3. On a scale from 1 - 10 how smooth would you rate the current patient discharge process?
    Why?
4. What are all the parties involved in the patient discharge process?
    What are the amount of contact moments with these parties?
5. What do you experience yourself during the patient discharge process (if not mentioned in the previous question)?
6. To what extent is the difference in the patient discharge process depending on the specific treatment, type of cancer etc.?
7. To what extent is/are the partner, family, friends etc. of the patient involved?
8. What kind of feedback do you get from fellow colleagues, patients and close loved ones of the patients, and how do you receive this?
    If you don't receive any feedback, why is that?
9. Do you have any worries or want to see anything changed about the current patient discharge process or for any potential future developments?

We have now reached the end of this interview. Do you have any questions about this interview or the subject?

I want to thank you again for participating in this interview. If at any point you wish to be updated on the use of the answers of this interview, or general progression of this project, I can share this via the same contact information previously provided.

C: Interview Oncology Patient

Bedankt voor het meedoen met dit interview! Mijn naam is Tim Biervliet, student aan de TU Delft, en ik doe onderzoek naar de ervaring van patiënten op de oncologieafdeling. Hierbij wordt gekeken naar wat u meemaakt tijdens het ontslag, wat u goed vond gaan en wat beter kon, om dit mee te nemen voor de verbetering van de zorg. U wordt geïnterviewd omdat u bent opgenomen en wordt behandeld op de oncologieafdeling en binnenkort met ontslag gaat. Tijdens dit interview, dat ongeveer 30 minuten duurt, worden 6 vragen gesteld. Dit interview is vrijwillig, en op elk punt kunt u weigeren een vraag te beantwoorden en/of u deelname aan dit interview te beëindigen.

Ten eerste wil ik u vragen of u het oké vindt als dit interview wordt opgenomen via deze laptop/recorder? In deze opname, wordt u geanonimiseerd en geen persoonlijke informatie zal worden verzameld of gedeeld. Na dit interview zal de opname binnen 24 uur worden verwijderd.

Vragen

1. Hoe lang ligt u opgenomen op de afdeling oncologie?
2. Hoe ervaart u het krijgen van informatie tijdens het zorgproces?
3. Hoe ervaart u de communicatie met de zorgverleners?
   Zit hier een verschil tussen de verpleegkundigen, arts-assistenten, oncologen enz.?
4. Hoe belangrijk vind u het betrekken van naasten (partner, familie, vrienden enz.) tijdens uw opname?
   Zijn er specifieke momenten waarbij u naasten er liever bij betrekt? En momenten waar u ze liever niet bij betrekt?
5. Hoe ervaart u of er rekening met u en uw naasten wordt gehouden tijdens de opname en ontslag?
   In hoeverre betrekt u uw naasten hierbij?
6. Er volgen nu een aantal vragen over hoe u zich voelde/voelt tijdens verschillende momenten in de opname. Voelen heeft hier betrekking op welke emoties u voelde/voelt tijdens de momenten. Hoe voelde u zich…
   …bij binnenkomst voor het begin van de opname?
   …na het eerste gesprek met een zorgverlener?
   …twee a drie dagen na de opname?
   …bij het eerste gesprek over uw ontslag?
   …op dit moment tijdens de opname?

Ik wil je nogmaals bedanken voor het delnemen aan dit interview. Mocht u interesse hebben in het verloop van dit project of graag willen dat de opname niet wordt gebruikt voor het onderzoek, kunt u een bericht sturen naar het emailadres.

D: Discharge Process Interpretation Sessions

Introduction
Bedankt voor het meedoen met deze sessie! Mijn naam is Tim Biervliet, student aan de TU Delft, en ik doe onderzoek naar de ervaring van patiënten en verpleegkundigen op de oncologieafdeling. Het onderzoek kijkt specifiek naar de ervaring van patiënten, naasten van patiënten en zorgverleners tijdens het ontslag. Wat maakt iemand mee en wat voelt degene per stap van het ontslag? Dit zijn een paar voorbeeldvragen die mee worden genomen tijdens het onderzoek. Deze sessie is de volgende stap in het onderzoek na meegelopen te hebben op deze afdeling, en na observaties en interviews te hebben afgenomen. Nu kort wat uitleg over deze sessie. Tijdens de sessie zult u wat scenario's zien die te maken hebben met het ontslag uit het ziekenhuis. Deze scenario's zijn gebaseerd op de stappen die worden genomen in het ontslagproces. Dit zijn de meest voorkomende stappen die worden genomen. Hierbij ben ik benieuwd hoe u naar de scenario's kijkt en hoe u deze interpreteert.

Bij elk scenario staat een afbeelding wat een scene presenteert. Aan de linkerkant staat hoe deze scene tot stand is gekomen, wie erbij aanwezig is en waar dit plaatsvindt. Op de afbeelding kan soms ook wat tekst staan in de vorm van wat de personen denken. Een voor een zal ik in totaal 8 scenario's laten zien. Hierbij krijgt u eerst 30 seconden de tijd om in stilte de afbeelding te bekijken en alle informatie te lezen. Hierna zal ik aan u vragen wat u ziet en waarom. Tot slot vraag ik aan u hoe u zich voelt over het scenario wat u ziet. Belangrijk om te weten dat de scenario's los van elkaar staan en elkaar niet opvolgen. Hierom is het belangrijk dat u elk scenario op zichzelf bekijkt en interpreteert.

Deze sessie zal in totaal 20 minuten duren. Er zijn geen goede of foute interpretaties/antwoorden, het gaat erom wat u ziet en wat u voelt. De sessie is vrijwillig, en op elk punt kunt u weigeren een vraag te beantwoorden en/of u deelname aan de sessie te beëindigen. Heeft u nog vragen over de sessie?

Voordat we verder gaan, wil ik u vragen of u het oké vindt als deze sessie wordt opgenomen via deze laptop/recorder? In deze opname, wordt u geanonimiseerd en geen persoonlijke informatie zal worden verzameld of gedeeld. Het is vooral om alle informatie van deze sessie goed te verzamelen. Na de sessie zal de opname binnen 24 uur worden verwijderd.

Start recording if permission is given

The session
Voordat ik het eerste scenario laat zien, wil ik u vragen om eerst een minuut na te denken over vorige ziekenhuisontslag ervaringen. Dit kan een ontslag van uzelf zijn of een ontslag waar u bij was voor bijvoorbeeld een familielid. Probeer goed na te denken hoe u zich voelde tijdens dit ontslag, wat er goed ging en wat er fout ging. U kunt hiervoor uw ogen dicht doen en/of ook hardop uw vorige ervaring(en) delen, als dat helpt. Mocht u geen eerdere ervaring hebben, kan ik wat anonieme ervaringen delen om voor u een beeld te vormen van het ontslag.

1 minute of silence

Nu gaan we beginnen met de scenario's bekijken.

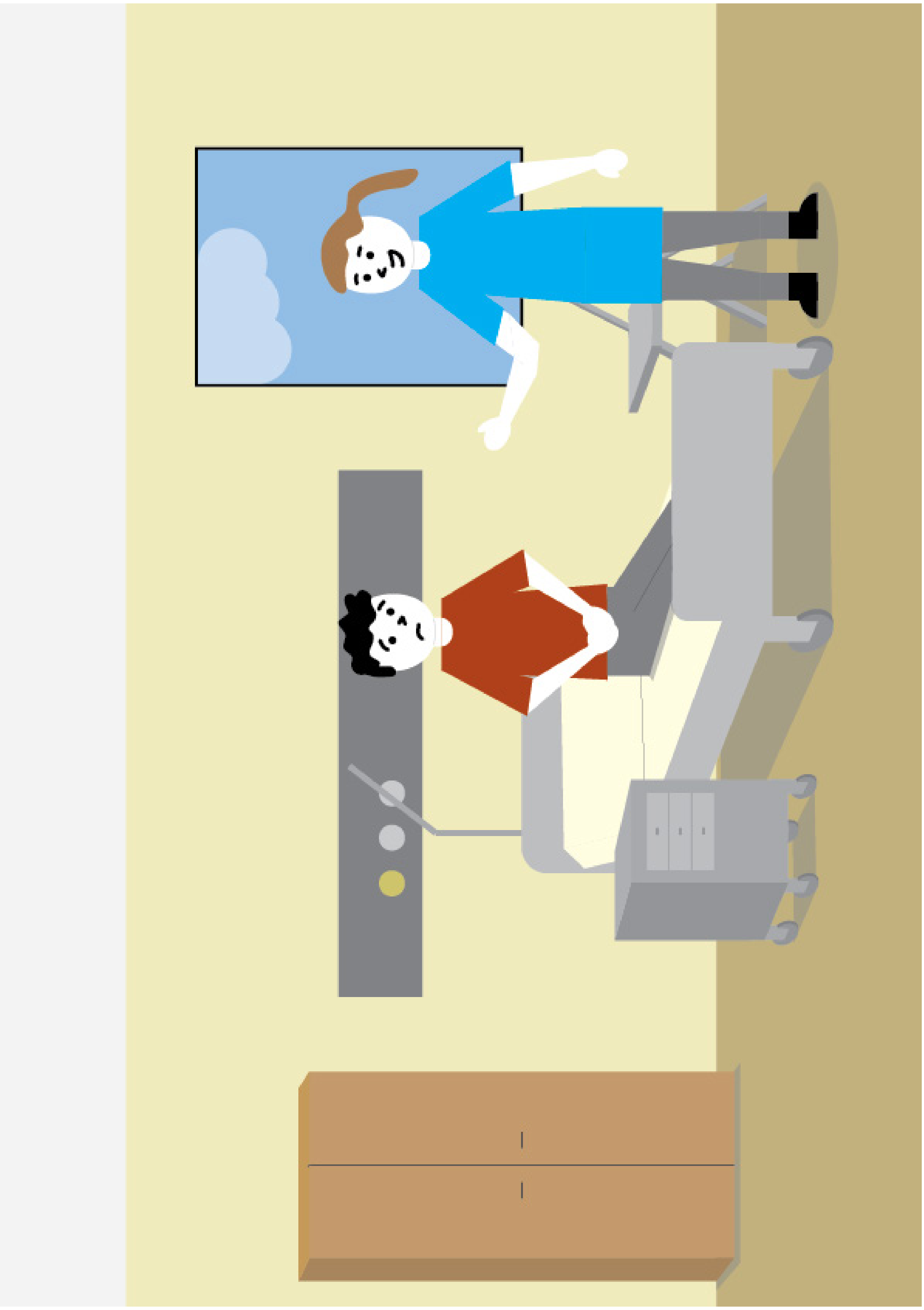
Open the presentation with the scenarios and take max 2 minutes per slide (except the first slide)
Keep time for 30 seconds for looking and afterwards ask their interpretation and feelings

End of the session
We zijn aan het einde gekomen van deze sessie. Hoe vond u het, en heeft u nog vragen?

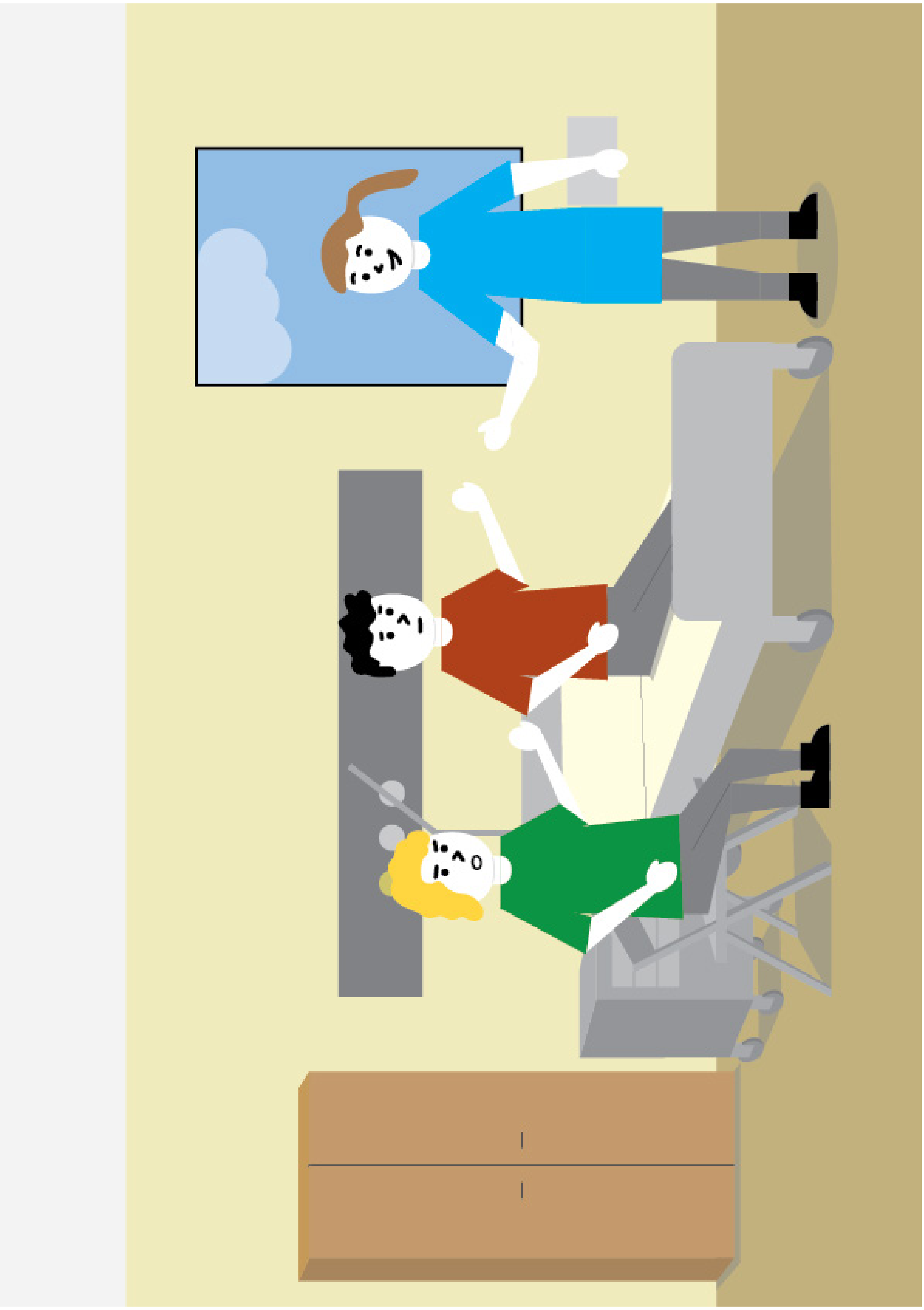
Stop recording if permission was given previously

Ik wil u nogmaals bedanken voor het deelnemen aan deze sessie en wens u een prettige dag!

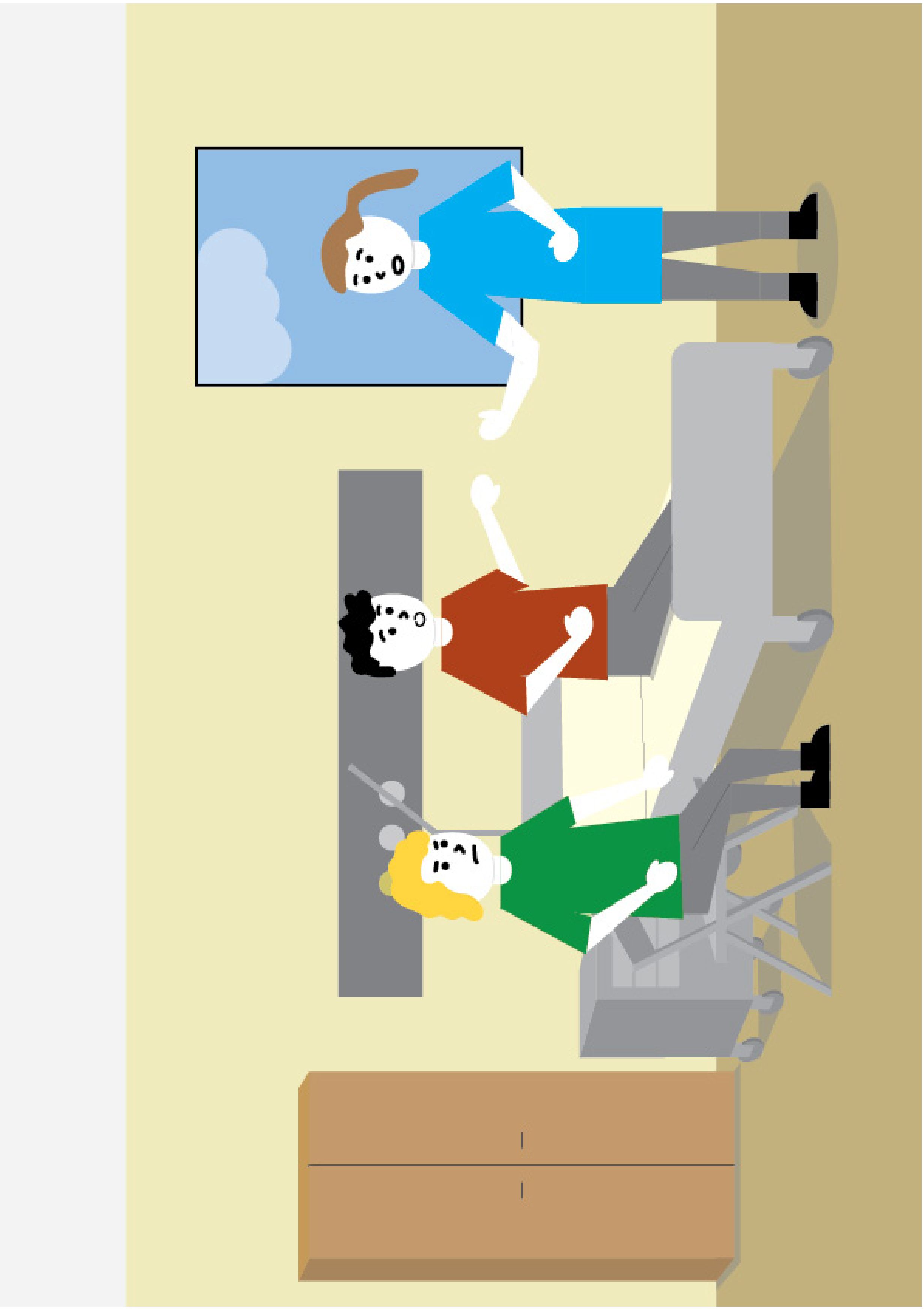
Sessions scenario 1



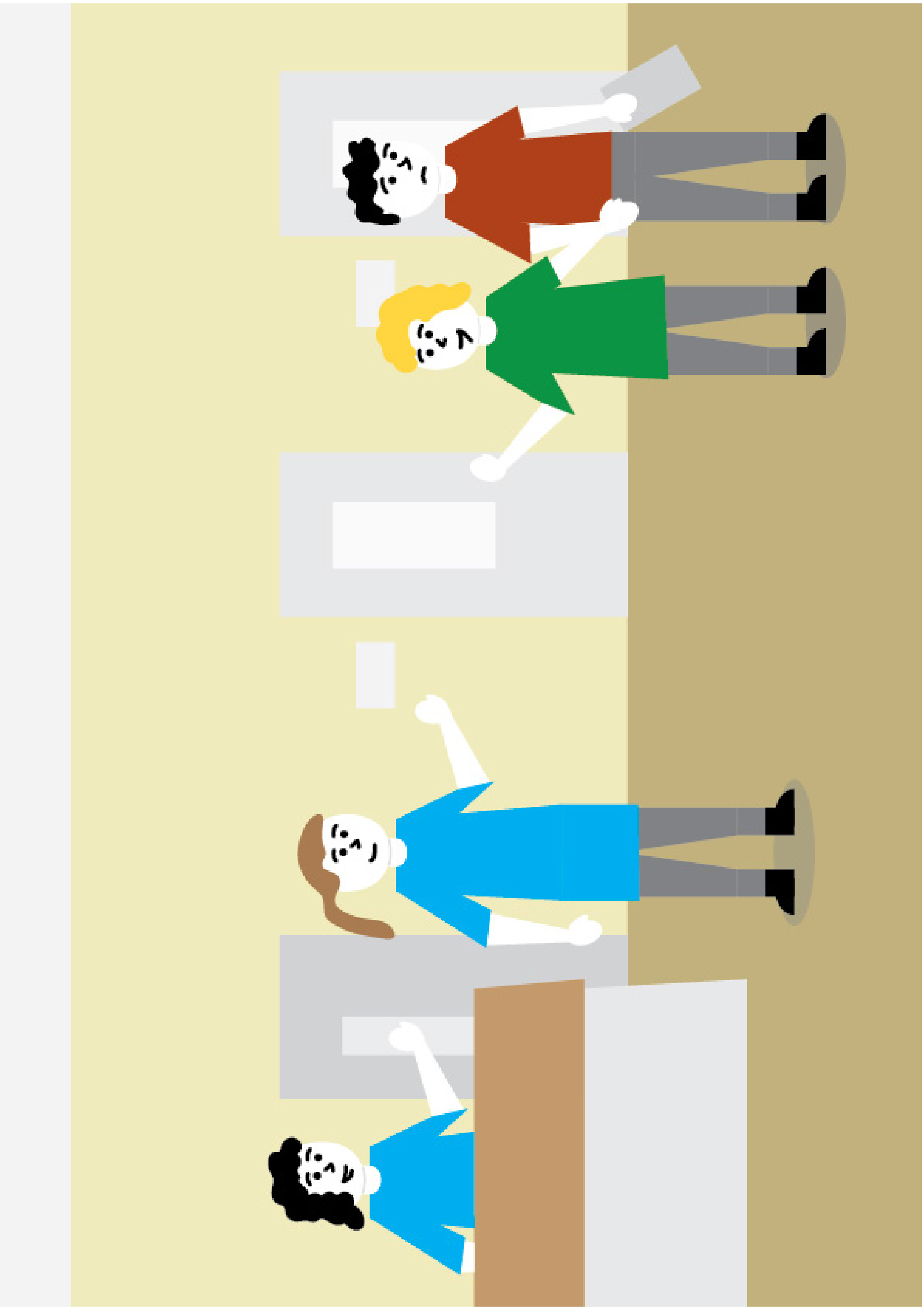
Sessions scenario 2



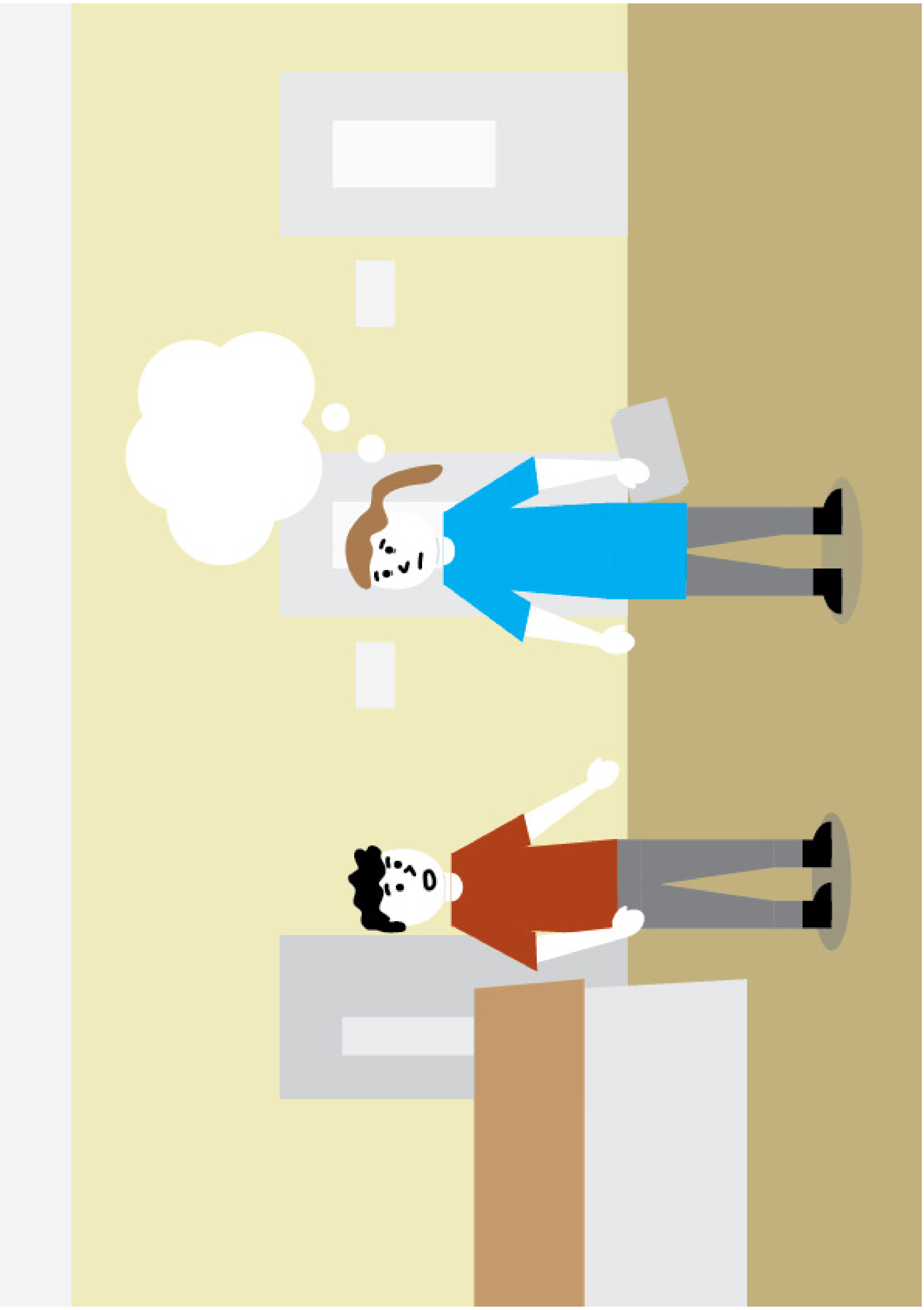
Sessions scenario 3



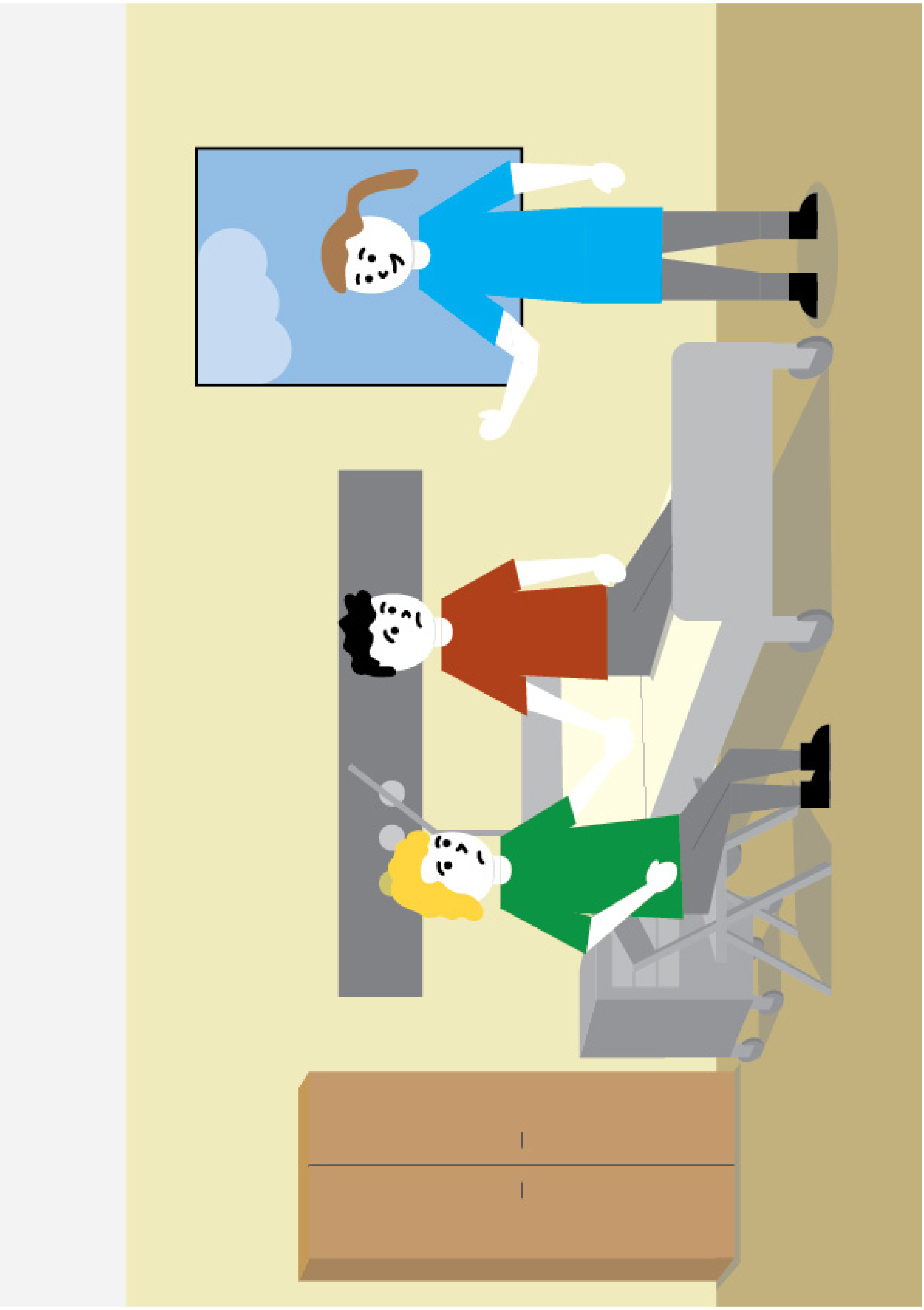
Sessions scenario 4



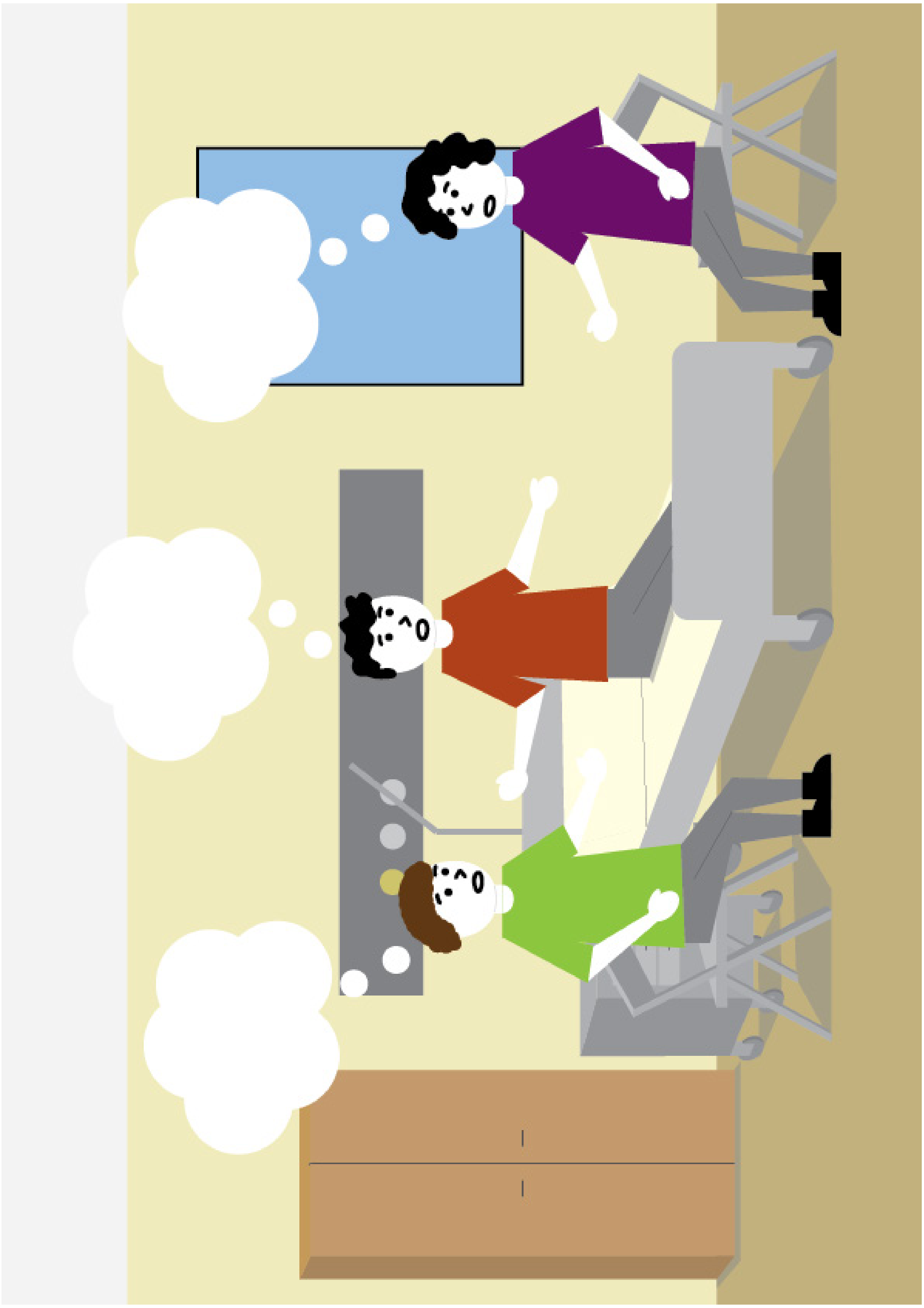
Sessions scenario 5



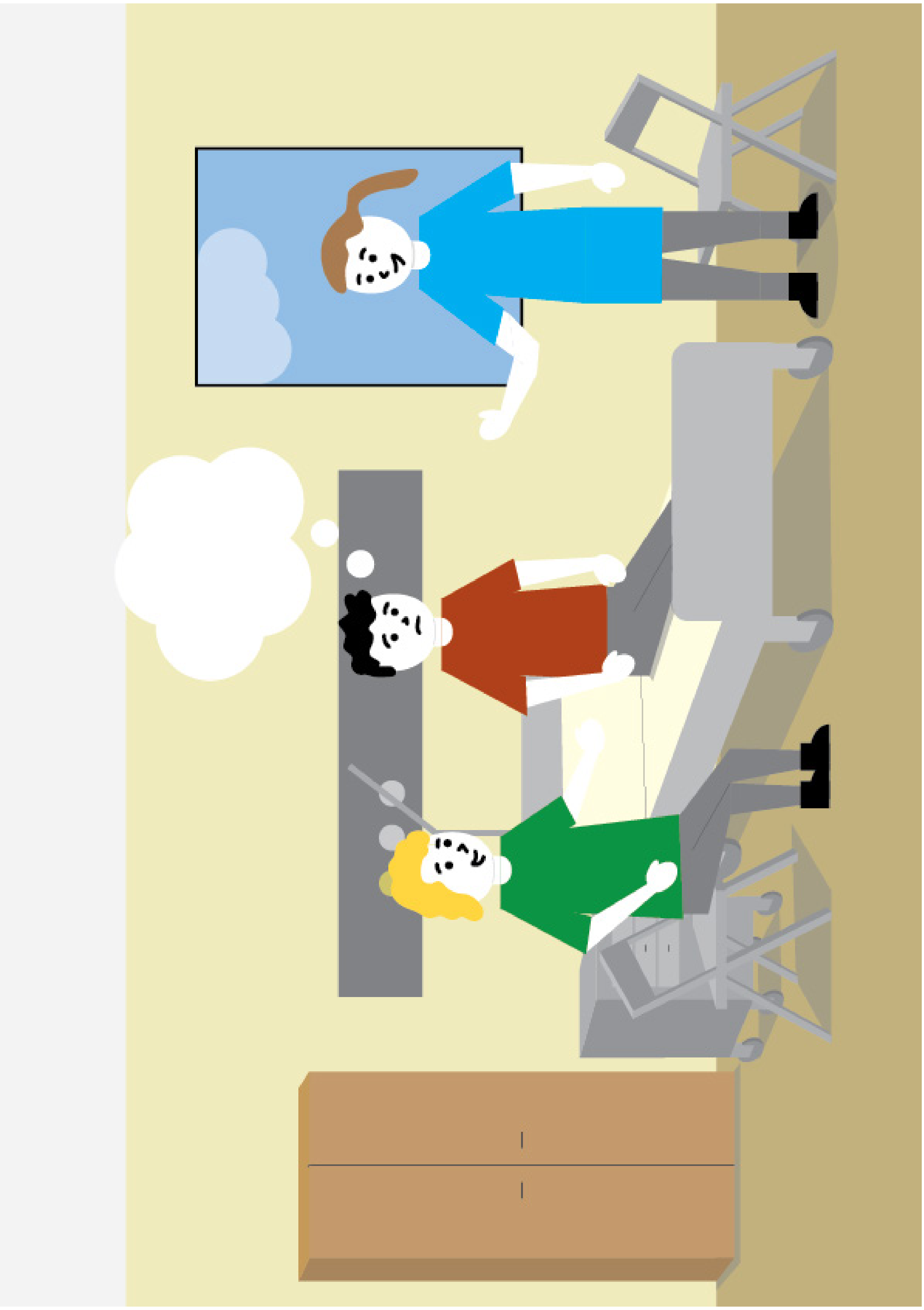
Sessions scenario 6



Sessions scenario 7



Sessions scenario 8



E: Concept 1 Test Setup

The goal of the test is to find out if the concept helps in reaching the points of the solution direction. These points are the following:

- Raising awareness in nurses that patients and their close loved ones carry fears and worries about moving the care away from the hospital.
- Dealing with expectations of yourself and from others, and how to manage these in a hospital oncology department context.
- Instilling confidence into patients and their close loved ones to make them ready to take care of themselves and provide care to the patient.

This can also be seen as to what extent the influence the concept has on the discharge process and to what extent it reaches the points of the solution direction. The opinion of the nurses, patients and their close loved ones are key here to get immediate feedback on their experience, and how this compares to a previous experience without the use of the concept. It is not about testing whether the concept itself works. Ultimately, the goal is to make the experience of everyone better, and getting closer to the warm home coming patients and their close loved ones deserve, through the use of a concept.

Test plan

The test starts by first picking one to two nurses for them to use the concept. They will receive an introductory explanation (in Dutch) of how to use the concept and what to expect.

Introduction

Bedankt voor het meedoen met het testen van het concept! Mijn naam is Tim Biervliet en ik ben nu al enige tijd bezig op de oncologieafdeling met onderzoek naar de ontslag ervaring van patiënten, hun naasten (partners, familie enz.) en verpleegkundigen. Na observaties, interviews en meelopen is gevonden dat patiënten en hun naasten vaak bang zijn voor de zorg verplaatsen van het ziekenhuis naar huis of ergens anders. Dit komt vaak door angst voor hun diagnose en wat voor veranderingen dit met zich meebrengt. Verpleegkundigen, wat jullie zijn, hebben een hoge werkdruk en zijn gewend aan een bepaalde werkhouding en methode waarmee deze angsten over het hoofd gezien kunnen worden. Verwachtingen zijn hier een belangrijk aspect die een grote invloed hebben op de ervaring tijdens het ontslag.

Dit concept is een oplossing hiervoor om deze angsten bespreekbaarder te maken, patiënten en hun naasten voor te bereiden om naar huis te gaan en om te gaan met verschillende verwachtingen van iedereen aanwezig tijdens het ontslag. Nu een korte uitleg over het concept en hoe deze gebruikt wordt.

Concept explanation

Het doel van het concept is om bewustwording te creëren voor jullie dat er vaak meer omgaat met een patiënt, onderliggende redenen ook wel, waardoor ze zich angstig of zorgen maken om het ziekenhuis te verlaten. Ook is het een hulpmiddel om patiënten op een efficiënte manier te benaderen door vooraf na te denken hoe je de visite wil invullen. Het concept functioneert als een soort scheurkalender. Er zijn in totaal vijf papieren waarvan je voor een bezoek aan de patiënt je er altijd een meeneemt. Het papier is een voorbereiding op het bezoek waar je het volgende op staat en wat geschreven kan worden: een korte zin die aangeeft wat de patiënt mogelijk kan voelen of meezit, welke richting je kiest voor het bezoek (hier meer later over), wat je zelf uit het bezoek wil halen en wat je hebt geleerd van het bezoek. Na het bezoek kan je het papier aan mij geven en leg ik het apart. Aan het einde kunnen we de papieren naast elkaar leggen als een soort tijdlijn en zien hoe je vandaag de patiënt hebt benaderd en wat je geleerd hebt. Nu nog kort over de richting. Voor het bezoek mag je zelf bepalen hoe je de patiënt gaat benaderen. Hier zijn drie mogelijkheden voor waarvan je er per bezoek elke keer eentje kiest:

- Taakgericht: je focust op taken uitvoeren waarbij communicatie met de patiënt minimaal en beknopt is.
- Behandeling gericht: je gaat met de patiënt bespreken wat er verder in de behandeling gaat gebeuren en wat hun behoefte en verwachtingen zijn.
- Gespreks gericht: hier ligt de focus op vragen hoe de patiënt zich voelt over de behandeling en het ontslagproces en of ze nog met bepaalde emoties of onzekerheden zitten.

Test progression

In het begin van het concept testen zal ik met jullie meelopen om te zien hoe dit gaat en jullie te helpen mocht dit nodig zijn. Hierna laat ik jullie zelf het concept gebruiken. Ik zal op de afdeling zitten waar jullie naartoe kunnen gaan als jullie nog vragen hebben. Dit zal doorgaan totdat jullie vijf papieren hebben verzameld of tot een bepaald punt. Dit kunnen we samen bekijken en bespreken. Hierna volgt er nog een afsluitend gesprek over hoe jullie het gebruik vonden gaan en zal ik nog wat vragen stellen. Hebben jullie nog vragen voordat we verder gaan? In dat geval geef ik jullie beide een concept en loop ik met jullie mee.

After following them to the first patient and taking notes, I will immediately ask the patient or the nurse how they thought the conversation went (and record this). The nurses will be left alone with the concept after this. After they went through enough papers, we will discuss their experience and have them answer some final questions.

Questions

1. What did you think of the concept, and using it in your daily work?
2. To what extent did your interaction with the patient change using the concept?
3. To what extent did you find the concept useful during your interaction with the patient?
    To what extent would you say it added something to the discharge process?
4. Was it difficult adjusting to the new working method using the concept?
    If yes, what specifically?
    If not, what made it easy to adjust/use?
5. To what extent are you more aware of what the patient and their close loved ones are experiencing?
6. To what extent did the concept help with managing expectations during your visit to the patient?
    Was this only the case for your expectations, the expectations of the patient and their close loved ones, or both?
7. Did you notice any differences in the patient's demeanor or emotion after the use of the concept?
    If yes, did you notice this quickly?
    Also if yes, did this change during the use of the concept?
8. Do you have any other feedback or points you like to share?

End of the test

Dit is het einde van de test. Mocht je later nog vragen hebben, kun je me bereiken via het emailadres.

Ik wil je nogmaals bedanken voor het meedoen en je feedback!

F: Concept 2 Test Setup

The same goals remain from the first test but more detail is given to the points of the goals that are either not tested as well or have not been given enough feedback on. These are mainly from the patient side, as the first concept focuses a lot on the nurses. The initial feedback from their side was relatively positive and shows good potential for the solution direction formulated. It is now up to the patients to see their response to the influence on their experience. It is mainly about their role in expressing what they need for a good discharge. Interesting to look at providing something that allows the patient to dictate what they want and how to use it.

Test plan
The test starts by first picking one nurse and one patient who are going to interact with each other. They will receive an introductory explanation (in Dutch) of how to use the concept and what to expect.

Introduction
Bedankt voor het meedoen met het testen van het concept! Mijn naam is Tim Biervliet en ik ben nu al enige tijd bezig op de oncologieafdeling met onderzoek naar de ontslag ervaring van patiënten, hun naasten (partners, familie enz.) en verpleegkundigen. Na observaties, interviews en meelopen is gevonden dat patiënten en hun naasten vaak bang zijn voor de zorg verplaatsen van het ziekenhuis naar huis of ergens anders. Dit komt vaak door angst voor hun diagnose en wat voor veranderingen dit met zich meebrengt. Patiënten vinden het moeilijk deze angsten te delen met zorgverleners. Verpleegkundigen hebben een hoge werkdruk en zijn gewend aan een bepaalde werkhouding en methode waarmee deze angsten over het hoofd gezien kunnen worden. Verwachtingen zijn hier een belangrijk aspect die een grote invloed hebben op de ervaring tijdens het ontslag.

Dit concept is een oplossing hiervoor om deze angsten bespreekbaarder te maken, patiënten en hun naasten voor te bereiden om naar huis te gaan en om te gaan met verschillende verwachtingen van iedereen aanwezig tijdens het ontslag. Nu een korte uitleg over het concept en hoe deze gebruikt wordt.

Concept explanation
Het doel van het concept is om de patiënt meer controle te geven over de gesprekken die gevoerd gaan worden en de onderwerpen die besproken worden. Voor jullie zien jullie een papier met hierop drie gedeeltes staan. Het eerste gedeelte is om de onderwerpen op te schrijven die de patiënt graag wil bespreken. Deze onderwerpen kunnen van alles zijn zoals vragen over de behandeling, een verzoek voor iets enz. Er kunnen maximaal drie onderwerpen op geschreven worden. De patiënt hoeft er niet drie op te schrijven maar zoveel als dat de patiënt wil. Hiernaast staan drie schalen. De schalen zijn voor de patiënt om aan te geven hoe tevreden ze zijn met het bespreken van het onderwerp en het resultaat wat er uit het gesprek is gekomen. Hierbij geeft 1 aan helemaal niet tevreden en 5 helemaal tevreden. Als alle onderwerpen besproken zijn, mag de patiënt de cijfers noteren op de schaal per onderwerp. Tot slot is het laatste gedeelte ruimte voor notities die gemaakt kunnen worden tijdens en na het bespreken van onderwerpen. Een voorbeeld is dat jullie een onderwerp hebben besproken en deze de volgende keer verder willen bespreken. Bij de notities kan de patiënt opschrijven wat er al besproken is (informatie die de verpleegkundige heeft gedeeld) en vragen opschrijven om te stellen voor de volgende keer.

Test progression
Bij de test zal ik erbij zitten om vragen te beantwoorden en te helpen bij het invullen, mocht dit nodig zijn. Verder is het gesprek helemaal tussen jullie twee en zit ik op de achtergrond. Als alle onderwerpen zijn besproken, geven we de patiënt wat tijd om nog de laatste notities op te schrijven en een cijfer te geven achter elk onderwerp. Hierna volgt er nog een afsluitend gesprek over hoe jullie het gebruik vonden gaan en zal ik nog wat vragen stellen. Hebben jullie nog vragen voordat we verder gaan? In dat geval geven we de patiënt heel even om wat onderwerpen op te schrijven en gaan we beginnen.

Questions
1. What did you think of the concept, and using it?
2. How did the interaction feel with the patient being in charge and dictating what is talked about?
    For the patient, did you like this balance in terms of saying power?
    For the nurse, to what extent did you have to adjust to this balance?
3. For the patient, to what extent did it help in writing down what you want to talk about and knowing everything can be discussed?
    To what extent does it help giving a number as to how satisfied you were talking about a topic?
4. For the nurse, to what extent does it help that the patient themselves introduces a topic they wish to talk about?
    To what extent did you miss not discussing your own topics?
5. To what extent were you satisfied with the topic discussion and the conclusion reached of each topic?
6. Does such a concept add something to your daily interactions with each other?
7. Do you have any other comments, remarks or questions?

End of the test
Dit is het einde van de test.

Ik wil je nogmaals bedanken voor het meedoen en je feedback!