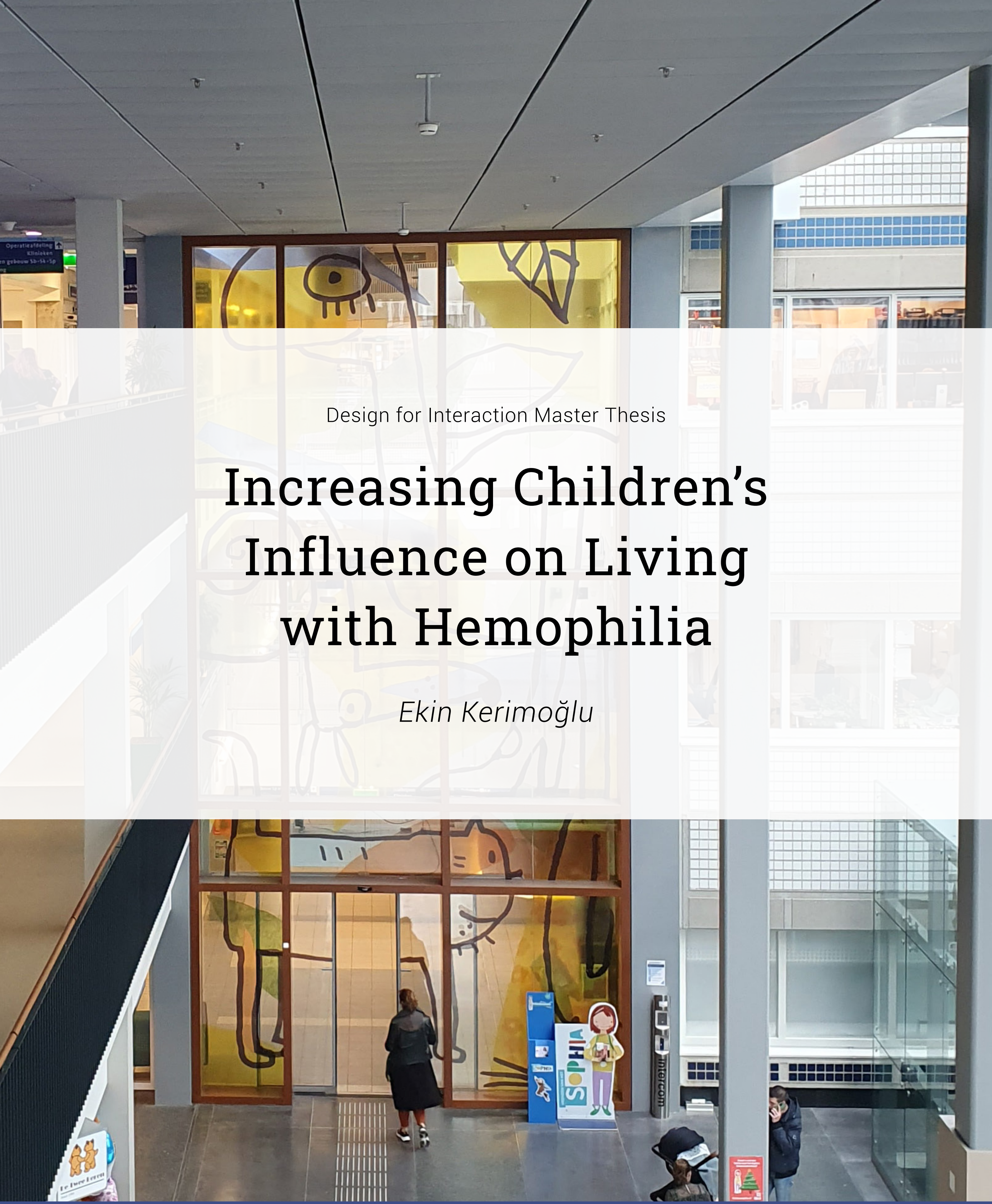

Design for Interaction Master Thesis

Increasing Children's Influence on Living with Hemophilia

Ekin Kerimoğlu

Master Thesis - Design for Interaction
Medisign Specialization
Faculty of Industrial Design Engineering
Delft University of Technology

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Design for Interaction Master Thesis

Increasing Children’s Influence on Living with Hemophilia

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This project has been a wonderful learning opportunity. My time at the Sophia Children's Hospital has taught me a lot and helped me gain perspective on what it means to create value for others. It was the best way to conclude my master, and I am so thankful for the journey. I was very lucky to work with and be supported by so many amazing people, without whom this project wouldn't have been possible.

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Glossary

The following are definitions of some important terms that will be used throughout the report, in alphabetical order.

Caregiver

The person who is responsible for providing the informal medical care of the patient (in the case of this project, often the parents).

Coagulation

(NL: Stolling)

Coagulation (or clotting) is the process of the blood turning into a thicker consistency, forming a blood clot and eventually stopping the flow of blood from a damaged vessel. Both words can be used interchangeably, but in this report the medical term, coagulation, will be used.

De Novo

Previously undetected. In the case of hemophilia, it refers to a patient who is the first in the family to carry the diseased chromosome as a result of a mutation.

Emergency Room

(NL: Spoedeisende Hulp/SEH)

Emergency Rooms (ER) is the department of the hospital for patients requiring immediate care.

Healthcare pathway

(NL: Zorgpad)

The visualization of the steps taken in the care of a certain medical condition from diagnosis to monitoring of the disease, with an emphasis on the actions and values of different stakeholders, from the perspective of a healthcare organization.

Healthcare Professionals

Healthcare professionals (HCPs) are doctors, nurses, physical therapists, home care and other individuals in/outside the hospital who offer medical care.

Hematology

(NL: Hematologie)

The study of blood and blood related disorders.

Hemophilia (Also spelled “haemophilia”)

(NL: Hemofilie)

An inherited bleeding disorder in which the blood does not clot properly, which can lead to spontaneous bleedings and/or severe bleedings after injury.

Home Care

(NL: Thuiszorg)

Home care is care and nursing that is delivered to patients at home, mostly from an external organization not within the hospital.

Intravenous Injection

(NL: Intraveneus injectie)

Intravenous (IV) injection is a technique where fluids, medication or nutrients are administered directly into the patient's blood vessel.

Specialist Nurse

(NL: Verpleegkundig specialist)

A nurse specialized in a certain medical condition or care domain who can work in various settings.

On-Demand Treatment

Treatment given at time of injury.

Pediatrics

The branch of medicine that involves the medical care of children, from infants to adolescents. The age range for pediatric care in the Netherlands is 0-18.

Patient

The person who is under medical care. In the case of this report, the child who is under medical care for hemophilia.

Patient Experience

(NL: Patiënt ervaring)

The range of interactions and feelings that patients have in various areas of their life in relation to their medical condition.

Patient Journey

(NL: Patiëntreis)

The visualization of the complete journey of the patient from first symptoms to the treatment and monitoring of the illness, with an emphasis on patient experience, from the perspective of the patient.

Port-A-Cath

A Port-a-Cath (PAC) is an IV method used to administer medication in the form of a small device with a flexible membrane and a tube that is surgically placed under the skin and is attached to a blood vessel.

Prophylaxis

(NL: Profylaxe)

Treatment given or action taken to prevent disease.

Regional Hospital

(NL: Regionale ziekenhuizen)

Regional hospitals treat patients with conditions that are common. The general hospitals are usually somewhat smaller and the patients are from within the region.

Subcutaneous Injection

(NL: Subcutaan injectie)

Subcutaneous (SC) injection is a technique where fluids, medication or nutrients are administered under the patient's skin with a small needle.

University Medical Center

(NL: Universitair Medisch Centrum)

A University Medical Center (UMC), also known as an academic hospital, is a hospital that is coupled with the medical faculty of a university. It provides the same care as a regional hospital, but also carries out the more rare and complex treatments, while also focusing on scientific research and medical innovations.

Venipuncture

The puncturing of a vein as part of a medical procedure.

Executive Summary

Project Assignment

For hemophilia patients, a simple fall or injury can cause excessive bleeding, which if not handled properly can cause major disabilities and in extreme situations even death. Due to the insufficient blood coagulation factors in their system, a fun day can easily end in the emergency room. Children, by nature, are still learning how to move and navigate the world. Where an adult may know the consequences of their actions, a child may not be able to see that, and therefore are an especially vulnerable group. With many challenges in their daily life, children with hemophilia have a complex experience with the disease. In collaboration with Partitura and the Sophia Childrens Hospital,

the goal of the project is to analyze the experience of severe hemophilia patients aged 0 to 8, visualize this in the form of a patient journey built from their perspective and find opportunities and patterns in the experience to eventually create a proposal for an intervention to improve quality of life.

Patient Journey

A patient journey was created, in order to visualize this complex experience. The journey showed that there were definitely opportunities for improvement, giving an overview of the different touchpoints the patient goes through in the 3 main phases, (1) diagnosis, (2) treatment and (3) living with hemophilia.

Research Outcomes

The patient journey, as well as various methods of research including a literature review, observations in the outpatient clinic and interviews with healthcare professionals, parents and patients showed that children want to feel more in control of their disease, and have more structure/predicability in their experience with hemophilia. Especially the 3 main contact areas of the patient, (1) home, (2) the outpatient clinic and (3) the emergency room, provided room for these needs to be met.

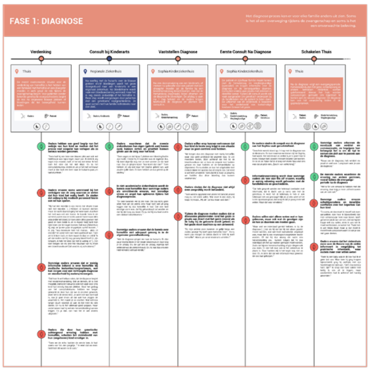
Design Goal

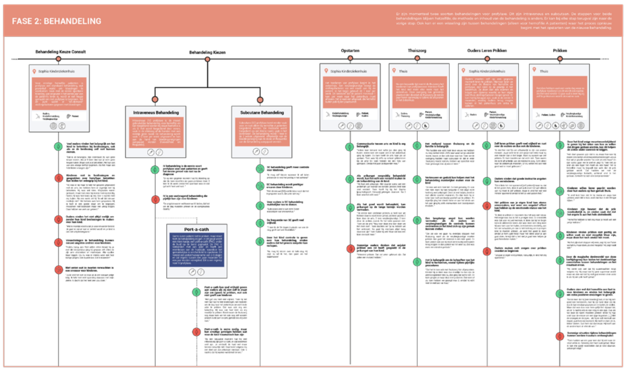
Based on the research outcomes, a design goal was formulated for the creation of an intervention:

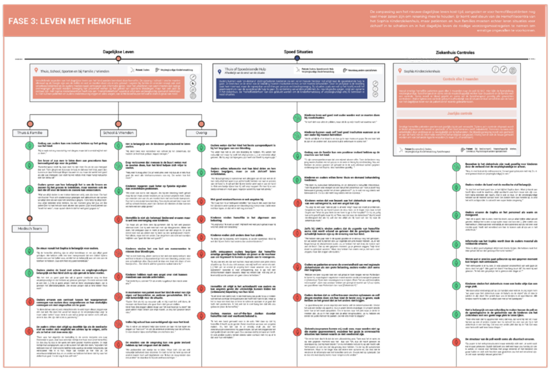
To design an intervention for children with severe hemophilia aged within the range of 0-8 years, that helps empower them and help them better comprehend their journey with the disease, by providing structure, consistency and control.

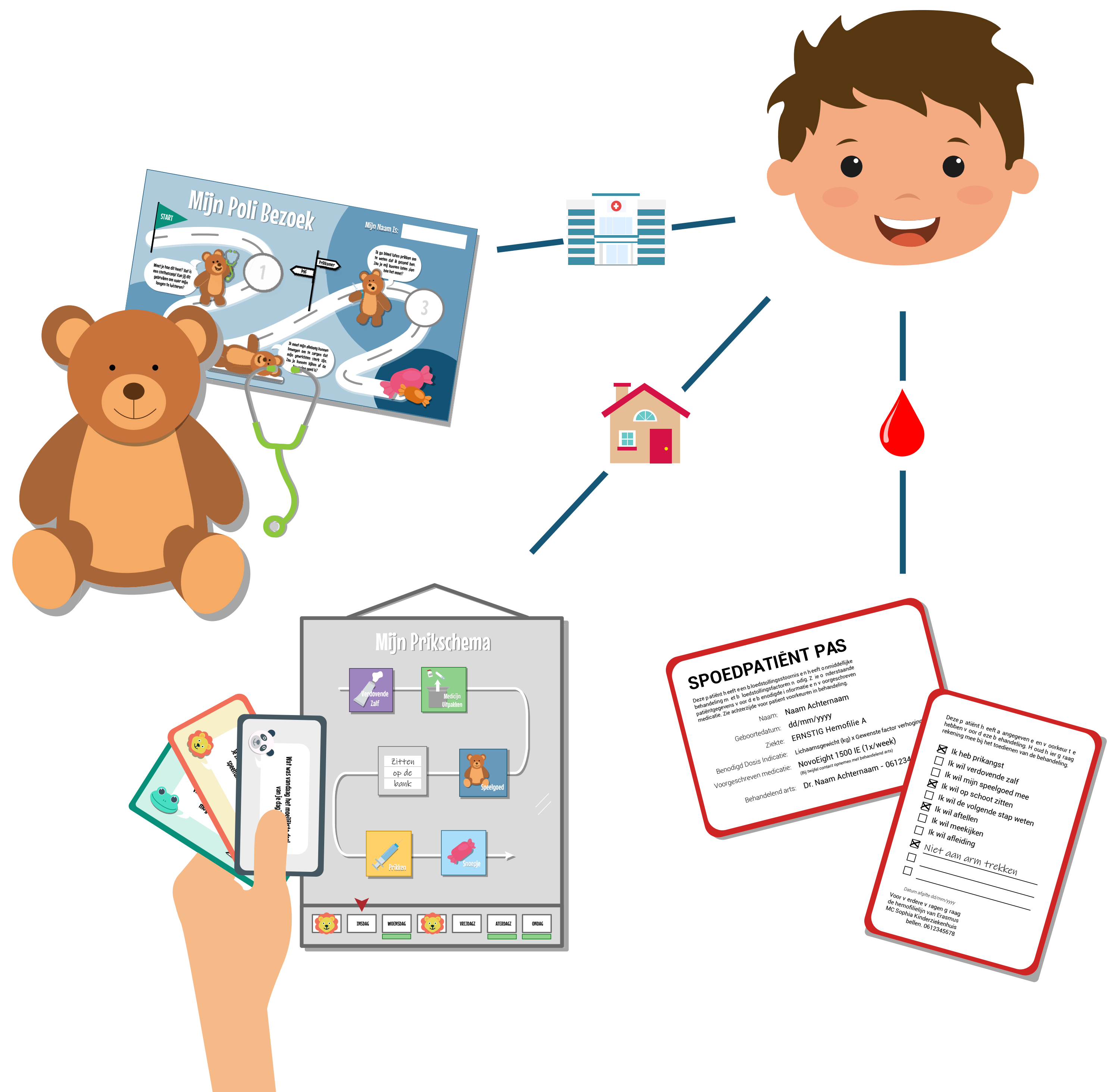
Intervention

3 concepts were created, all serving the different contact areas of the patient, with the overarching purpose of helping the child be more involved and active in his healthcare. The concepts were designed as seperate interventions, which can be combined and used together to strengthen each other by improving the patient experience in the different areas of the child's life. The evaluation sessions, carried out with parents and healthcare professionals showed that the concepts had a lot of potential, and was met with great enthousiasm. This project concludes with recommendations for the next steps, for the implementation of the interventions and also further research opportunities in the experience of children with hemophilia. The next steps for the project will be to prepare for implementation, with interest to implement nationally, and eventually to aid in improving the patient experience of children with severe hemophilia, not only in the context of the Sophia Children's Hospital but all patients of the Netherlands.









SPOEDPATIËNT PAS

Deze patiënt heeft een bloedstollingsstoornis en heeft onmiddellijke behandeling met bloedstollingsfactoren nodig. Zie onderstaande patiëntgegevens voor de benodigde informatie en voorgeschreven medicatie. Zie achterzijde voor patient voorkeuren in behandeling.

Naam: Naam Achternaam
Geboortedatum: dd/mm/yyyy
Ziekte: ERNSTIG Hemofilie A
Benodigd Dosis Indicatie: Lichaamsgewicht (kg) x Gewenste factor verhoging
Voorgeschreven medicatie: NovoEight 1500 IE (1x/week)
(Bij twijfel contact opnemen met behandelend arts)
Behandelend arts: Dr. Naam Achternaam - 061234

Deze patiënt heeft aangegeven een voorkeur te hebben voor deze behandeling. Houd hier graag rekening mee bij het toedienen van de behandeling.

- ☒ Ik heb prikangst
- ☐ Ik wil verdovende zalf
- ☐ Ik wil mijn speelgoed mee
- ☒ Ik wil op schoot zitten
- ☐ Ik wil de volgende stap weten
- ☒ Ik wil aftellen
- ☐ Ik wil meekijken
- ☐ Ik wil afleiding
- ☒ Niet aan arm trekken
- ☐
- ☐

Datum afgifte dd/mm/yyyy

Voor verdere vragen graag de hemofilielijn van Erasmus MC Sophia Kinderziekenhuis bellen. 0612345678

Table of Contents

01 Introduction 1
1.1 Introduction to the Project 2
1.2 Introduction to Hemophilia 6
1.3 Introduction Patient Journey Mapping 7

02 Literature Research 8
2.1 Study Purpose 9
2.2 Method 9
2.3 Research Outcomes 10
    2.3.1 The Clinical Presentation 11
    2.3.2 Understanding the Patient Group 14
    2.3.3 Patient (and Parent) Experience with Hemophilia 17
2.4 Conclusion & Discussion 20

03 Context Exploration 22
3.1 Study Purpose 23
3.2 Method 24
3.3 Research Outcomes 26
    3.3.1 Hemophilia at the Sophia 27
    3.3.2 Sources of Information 32
    3.3.3 Accommodating Fears 34
    3.3.4 Communication with the Patient 36
    3.3.5 Parental Stressors 38
3.4 Conclusion & Discussion 40

04 User Research 43
4.1 Study Purpose 44
4.2 Method 45
4.3 Research Outcomes 50
    4.3.1 Understanding the (needs of) a child 51
    4.3.2 Fears and Stressors 57
    4.3.3 Reflection of the Parents on the Child 59
    4.3.4 Reflection of External Factors on the Child 63
    4.3.5 Finding Information 66
4.4 Conclusion & Discussion 68
4.5 Concluding the Research Phase 71

05 The Patient Journey 73
5.1 Creating the Patient Journey 74
5.2 Exploring Weaknesses & Strengths 77
5.3 Finding Trends 79

06 The Design Space 81
6.1 Concept Directions 82
6.2 Requirements and Considerations 84
6.3 Choosing a Direction 84
6.4 Evaluation & Discussion 85

07 Conceptualization 86
7.1 Design Vision 87
7.2 Evaluation Criteria 89
7.3 Ideation 90

08 Concepts for Intervention 99
8.1 Concept 1 - At Home 101
8.2 Concept 2 - At the Clinic 106
8.3 Concept 3 - At the Emergency Room 109

09 Evaluation of the Concepts 111
9.1 Study Purpose 112
9.2 Method 112
9.3 Results 114
9.4 Conclusion & Discussion 127

10 Conclusion 130
10.1 General Conclusion 131
10.2 Final Recommendations 133
10.3 The Next Step 133

11 Bibliography 134

Appendix 138

01 Introduction

This graduation project focuses on the improvement of the patient experience of pediatric hemophilia patients aged 0-8. This chapter will introduce the assignment and the client (Partitura and Sophia Children's Hospital) will be introduced, followed by the chosen approach for the project. Then, an explanation will be given for a preliminary understanding of the physiology of hemophilia. This chapter will conclude with an introduction into patient journey mapping, which will be one of the main tools used within this project.

Entrance of the Sophia Children's Hospital

1.1 Introduction to the Project

Approximately 1000 people in the Netherlands are currently living with hemophilia, a very rare inherited bleeding disorder in which the blood does not clot properly (Sanquin, 2022). The disorder can present itself as unusual bruising, excessive bleeding after injuries and spontaneous internal bleeds, mainly in joints and muscles. In the past 25 years, treatments for hemophilia have seen drastic improvements. It is very clear that the patient quality of life is much better than it was back in the 1960s when the life expectancy was approximately 20 years, and physical disabilities due to joint bleeds were common (National Hemophilia Foundation, 2022). Nowadays, hemophilia patients can live long lives. New treatments are still being developed to improve the medical side of the disease, yet hemophilia remains a large consideration in the daily experience of patients, especially child patients, and there is room for improvement.

For hemophilia patients, a simple fall or injury can cause excessive bleeding, which if not handled properly can cause major disabilities and in extreme situations even death (Konkle and Fletcher, 2022). Children, by nature, are still learning how to move and navigate the world. Where it might be easier for an adult to see consequences and as a result avoid injuries, children do not yet have the comprehension level to do that. Therefore, children with hemophilia are more open to the dangers of failed coagulation (Kulkarni and Soucie, 2011). This awareness of danger can be detrimental to the development of a child, possibly making them become over-cautious and limit themselves in their daily lives. For severe hemophilia patients, preventive treatment and constant monitoring play a role in daily life, in which the parents have to be heavily involved (García-Dasí, 2016; Limperg, 2017; Von der Lippe, 2017). Since this is the case, the parents are the first line of contact regarding the health status of the child. This seems logical, a child is not yet capable of making their own decisions. However, due to this shift in contact, the experience of the parents seems to outweigh the experience of the actual patient, the child. The knowledge about the experience usually does not come from the patient themselves, but from those around them. Which in turn means that the care is not fully patient-centered.

1.1.1 Partitura

Sophia Children's Hospital (referred to in this report as "the Sophia", abbreviated as SKZ) is the pediatrics partner of the Erasmus Medical Center (referred to in this report as "Erasmus MC", abbreviated as EMC). Holding the title of the largest academic children's hospital, the Sophia is the pediatric hospital of the Erasmus MC and treats various complex pediatric diseases (Vrienden van het Sophia, 2022). Being a university medical center (UMC), the Erasmus MC plays a large role in the research of complex diseases and has specialized centers for the diagnosis and treatment of several conditions. The Sophia is a major player in most of these centers and handles the pediatric side of the conditions. The two hospitals share several treatment centers, one of them being the Hemophilia Treatment Center. The center combines specialisms like hematology, physiotherapy, clinical genetics, and others, with specific knowledge of blood coagulation disorders, specifically hemophilia. The pediatric side of the hemophilia treatment center will be the context of the project.

Within the Pediatric Hemophilia Treatment Center, there are multiple studies currently taking place, researching the intricacies of blood coagulation disorders and their treatments. One of these is the Symphony Consortium, a collaboration between all hemophilia treatment centers in the Netherlands, blood banks (Sanquin) and pharmaceutical companies. Symphony consists of several studies researching different aspects of bleeding disorders, ranging from pathophysiology to value-based healthcare (Symphony, 2022). A spinoff of Symphony, combining various studies related to value-based healthcare is Partitura, a collaboration between Erasmus MC, Erasmus University, TU Delft, and the company Roche. Partitura, specifically Partitura 1, aims to determine the patient journeys and healthcare pathways of children with inherited bleeding disorders between the ages of 0-8 (NVHP, 2022). The Sophia Children's Hospital, and in extension Partitura, are the clients of this project.

Erasmus MC
Sophia Children's Hospital

Partitura.

Pediatric Hematology Department

Sophia Children's Hospital Entrance
Olli the Elephant

Project Assignment

The experience of children may offer opportunities for improvement, but it is difficult to improve the experience when there are not any defined problems from the patient's perspective. How can an intervention be made for a population if it is not clear what it is they need? The approach until now has been to ask those who are directly involved in the process, the parents and medical professionals. It is only natural they then provide information from their own perspective, but seeing situations directly from the patient's perspective is necessary to improve their quality of life.

The goal of the project is to analyze the experience of severe hemophilia patients aged 0 to 8, visualize this in the form of a patient journey built from their perspective and find opportunities and patterns in the experience to eventually create a proposal for an intervention to improve quality of life.

The patient journey will aim to be a visualization of how a patient experiences their disease. The main audience of this patient journey will be healthcare professionals (HCPs), designers and other stakeholders who work behind the scenes in improving care for hemophilia; therefore, the visualization will aim to be clear and understandable by these stakeholders. The journey will also be modular to a certain extent, providing the space for it to be applicable even with new types of treatment and new information. The patient journey, in addition to the other findings of the research, will be used to identify opportunities, leading to recommendations for improving the patient experience of living with hemophilia. The main outcome of the project will be the intervention; feasible, desirable and viable concept(s) within the context of the Sophia Hemophilia Treatment Center or the home of the patients.

Project Approach

In this project, children with severe hemophilia aged 0-8 will be the main focus. Within the project, the following questions will be investigated:

1. What are the main factors influencing the experience of a child with hemophilia?
2. What does a child's journey with hemophilia look like? Who are the actors involved and which touchpoints do they come in contact with in each step of their journey?
3. Which areas of the journey offer opportunities for improving the experience of the child with hemophilia, what are these opportunities?

Multiple methods of research will be used to answer these main questions and subsequently to create a viable result. The approach to the project in general and the division of the various methods can be seen in Figure 1.1.

With the use of the Double Diamond Model, the project is split into 4 main phases: Discover, Define, Develop and Deliver. The Discover stage has been further divided into 3 substages.

Discover

I: Literature research is carried out for an initial understanding of existing information on the illness and the target group, and how hemophilia care is given in theory.

II: The context is further explored to understand the care given specifically at the Sophia, and how this care is perceived by the different actors within the hemophilia clinic, by carrying out informal interviews with HCPs and first-hand observations.

III: In-depth research is done outside of the context of the clinic, by carrying out semi-structured interviews with patients and their parents, to understand the full range of the experience as well as the intricacies of the disease which are not handled within a hospital clinic.

Define:

A patient journey is mapped with the analysis of the research done in the phase "discover" and will be used to identify weaknesses and opportunities in the disease.

Develop:

Within the opportunities, design directions are identified and ideated upon to reach a final concept that will be used as an intervention.

Deliver:

The final concept is worked out and evaluated, resulting in a feasible intervention concept and a list of recommendations for the improvement of experience.

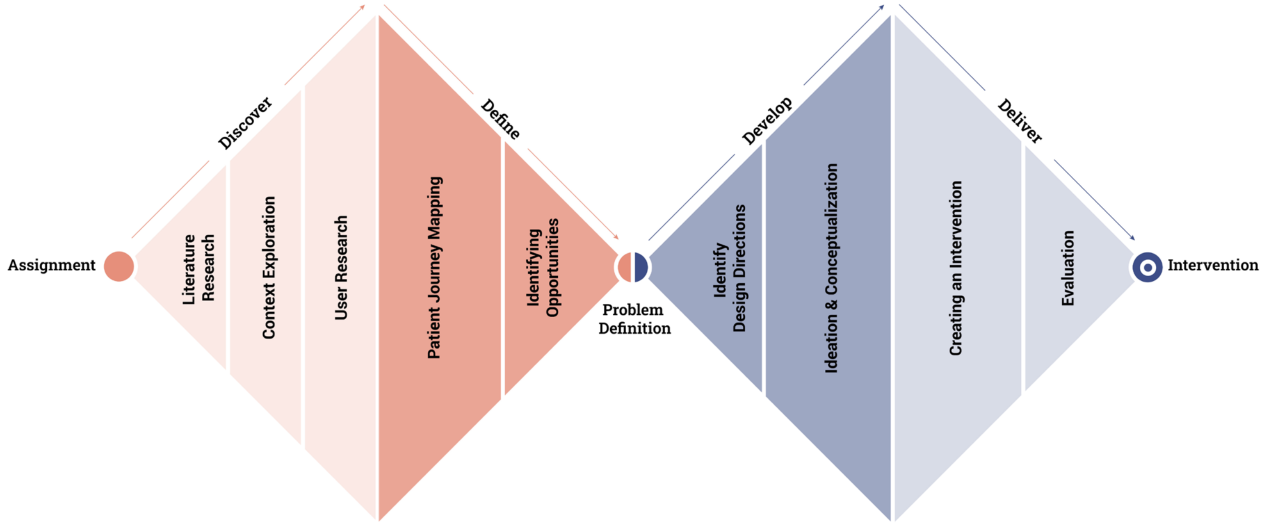


Figure 1.1 - The Double Diamond Model

1.2 Introduction to Hemophilia

Hemophilia is a genetic disease, which is inherited with the X chromosome, and mainly presents itself in males with carrier mothers. (Zimmerman, 2013).

The main attention point in hemophilia, whether it be in diagnosis or daily life, is injuries. In a healthy person, the blood vessels around the injured area will constrict and coagulation factors will be activated. With the help of these factors, a strong platelet plug will be formed followed by the formation of a strong fibrin mesh, which finally seals the damaged area and stops the bleeding. This process can be seen in Figure 1.2. In patients with hemophilia, there is a coagulation factor deficiency, meaning that the wound will not be able to form a strong clot, it will remain damaged and keep bleeding, until coagulation factors are introduced to the system.

There are several types of hemophilia, defined by type and severity. These types can be identified by taking a closer look at the coagulation process. The process of forming a clot after an injury is called the "coagulation cascade", as seen in Figure 1.3. All players in this system are vital and the dysfunction of any of the parts can cause delays in coagulation, which can be very dangerous. As mentioned before, the activation of the coagulation factors is what kicks off the process and without these, coagulation becomes basically impossible. Hemophilia A is defined by the deficiency of factor VIII, and Hemophilia B is defined by the deficiency of factor IX. Hemophilia A is the most common, comprising 85% of the patients. Both types usually present with the same symptoms. Once the deficiency is discovered, the function of the factor is tested and categorized into levels of severity. A healthy person has a function of 100%, a mild case of hemophilia means 5-40% function, moderate 1-5% and severe means less than 1% function. Mild and moderate hemophilia are usually not a daily burden, and in only cases of extreme injury will need treatment, whereas severe, will require frequent monitoring and treatment.

Hemophilia can cause spontaneous bleeds, commonly under the skin and in the joints and muscles too. It is also a disorder that has to be monitored carefully, especially for young children who are just learning to move around and are prone to falling. The "invisible bleeding" like brain bleeds and bleeding in the joints are the most difficult to notice, and when left untreated can be detrimental to the health of the patient. Uncontrolled bleeding can lead to disabilities or even death. This is why a multidisciplinary approach is necessary, to be able to treat and monitor the disorder from all sides and make sure the patient stays healthy and that nothing goes unnoticed.

Nowadays, hemophilia is a highly treatable (not curable) disease. Depending on the type and severity, different treatments are available. The main type of treatment is coagulation treatment, which is done by introducing the missing coagulation factors into the body and facilitating coagulation. This can be done on-demand at the moment of trauma, or preventatively depending on the severity of the disorder. For patients with severe hemophilia, prophylaxis (preventive treatment) is a standard. With this, there are more experiences that come into play compared to the other patients, which creates a complex and interesting narrative, with a lot to consider. For this project, this will be the population of focus.

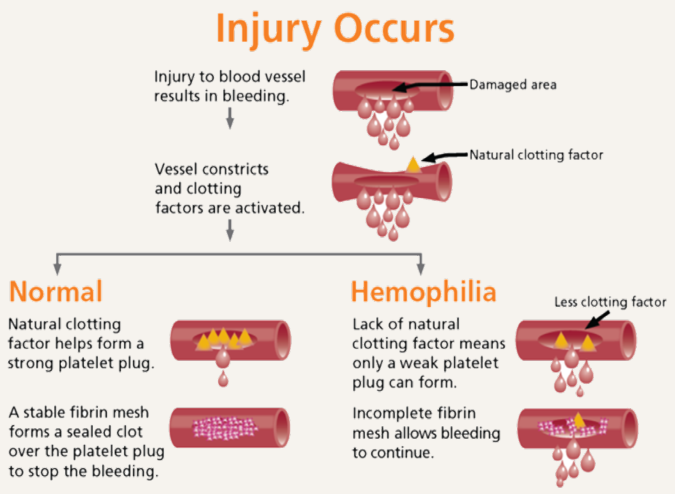


Figure 1.2 - Healthy vs. hemophilic coagulation (MetroHealth, 2019)

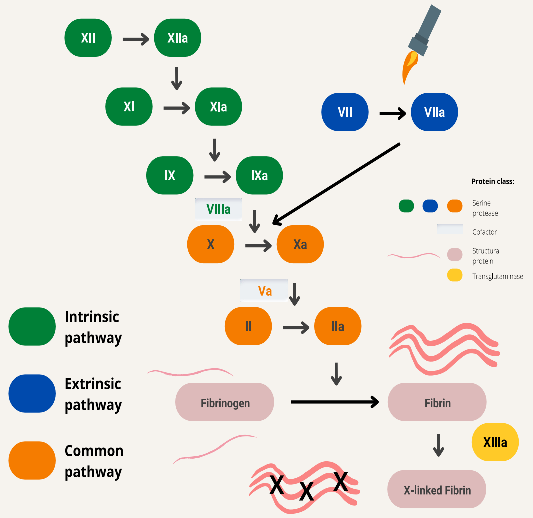


Figure 1.3 - The Coagulation Cascade (The Blood Project, 2022)

1.3 Introduction Patient Journey Mapping

Patient journey mapping will be a tool used in this project to visualize the experience of a child with hemophilia, finding weaknesses within this experience and identifying opportunities for design.

What is Patient Journey Mapping?

Patient journey mapping is a tool that can be used to map the trajectory a patient goes through when experiencing a medical situation and visualizes the interactions within the situation (Joseph, 2020). The journey shows the interactions with several actors and touchpoints involved in the process, creating a full overview of the healthcare system which can be used to identify design directions (Simonse, 2019).

Two important terms are patient journeys and care pathways. Most sources in literature use the two terms interchangeably, but within this project and in the context of the Partitura study, the client, there is a distinction between the terms. The patient journey is based on the experiences of the patient themselves. A care pathway is mainly based on the care carried out within a health system, mostly from the perspective of a medical professional. Care pathways usually describe procedures or other actions that are performed with or without the patient, where a patient journey highlights the experience of the patient and their interactions with the process.

Using Patient Journey Mapping as a Tool for Visualizing Complex Diseases

The main advantage of using a patient journey is seeing the process as a whole, instead of the individual interactions (Simonse, 2019). This is important when considering complex diseases, which have steps that are heavily influenced by each other. Especially for complex and/or chronic diseases, the journey is long and changes with time, which makes the overview all the more valuable (Joseph, 2020). In addition to this, complex diseases often present themselves differently in each patient, giving more importance to understanding the different steps and touchpoints of a health system and the possibilities that arise. Hemophilia is a disease with different trajectories for each patient, with various diagnosis experiences and multiple types of treatment. Therefore, a patient journey is a good way to visualize the whole process to be able to see the full picture but also zoom into certain situations if necessary.

02 Literature Research

This chapter starts with background information on the clinical presentation of hemophilia. This will lead into research about the current patient experience of the target group, children with hemophilia aged 0-8, and the important developmental factors that need to be considered in analysis and design. Then, the themes found in the literature research will be presented. The chapter will conclude with the trends found in the research, and the connections between the various elements.

2.1 Study Purpose

In order to explore the current context regarding children with hemophilia, a literary review was done. The aim of this exploration was to gain a broader understanding of (1) the clinical presentation of hemophilia, (2) the important considerations regarding the target population, (3) what the current experience with hemophilia looks like. The literature research aimed to answer the following research questions:

RQ1 - What does the clinical presentation of hemophilia look like? Which medical procedures, treatments and steps are involved in living with hemophilia, and which points contribute to the perception of the disease?

RQ2 - What considerations have to be taken into account when understanding the cognition and development of children aged 0-8? How do these affect a child's perception of his/her disease, and can these be used in design?

RQ3 - What are the main factors that affect the quality of life of a child with hemophilia? What does the current patient experience look like?

Stage	Age Group (years)
Infant	0 - 2
Toddler	2 - 4
Play Age	4 - 6
School Age	6 - 8

Figure 2.1 - Definition of Development Stages as referred to in this report. When referred to in text, the stages will be identified as defined in the figure, not as defined in the specific theory.

2.2 Method

The literature research was done through the electronic databases PubMed and Google Scholar, in addition to websites of organizations or hospitals. Due to the rarity of the disease and the relatively low amount of research done about the experience of the specific target population, the literature review included other age groups with hemophilia and relevant experiences in other pediatric chronic diseases. The articles used were not all about the target group but served in gaining a full understanding of the various parts of the experience of children with severe hemophilia aged 0-8. In addition to this, within the context of Dutch hospitals, there is not enough research about patient experience with the disease. Therefore the exploration of literature includes sources from all around the world, with patients from different backgrounds, to be able to draw viable conclusions on how the disease is experienced. These findings may not necessarily correlate with the reality of the Sophia, of which the context will be explored in the next chapters.

In addition to this, different theories (of development) are used within this chapter, each with its own focus. Each theory uses a different age group, as defined by their authors, which are different to the age groups defined for this project. Therefore, these theories will be used for understanding the situation and not to define age groups within the target group. The purpose is to understand the matters that have to be considered when researching, talking to and designing for a child. To keep the findings uniform, a separate split was made, as will be referred to in the interpretation of the findings during this project. These groups are defined as shown in Figure 2.1.

2.3 Research Outcomes

Figure 2.2 illustrates an overview of the main themes and relationships that resulted from the literature review. These relations have been numbered and used to identify trends in the patient experience, and color-coded depending on whom the trend prominently influences. The experiences have been placed according to which part of the process they are mostly present, under (1) diagnosis, (2) treatment, or (3) living with hemophilia. These are not ordered in level of importance, however, the findings about the effects on children were prioritized. These findings will be further explained in the following subchapters.

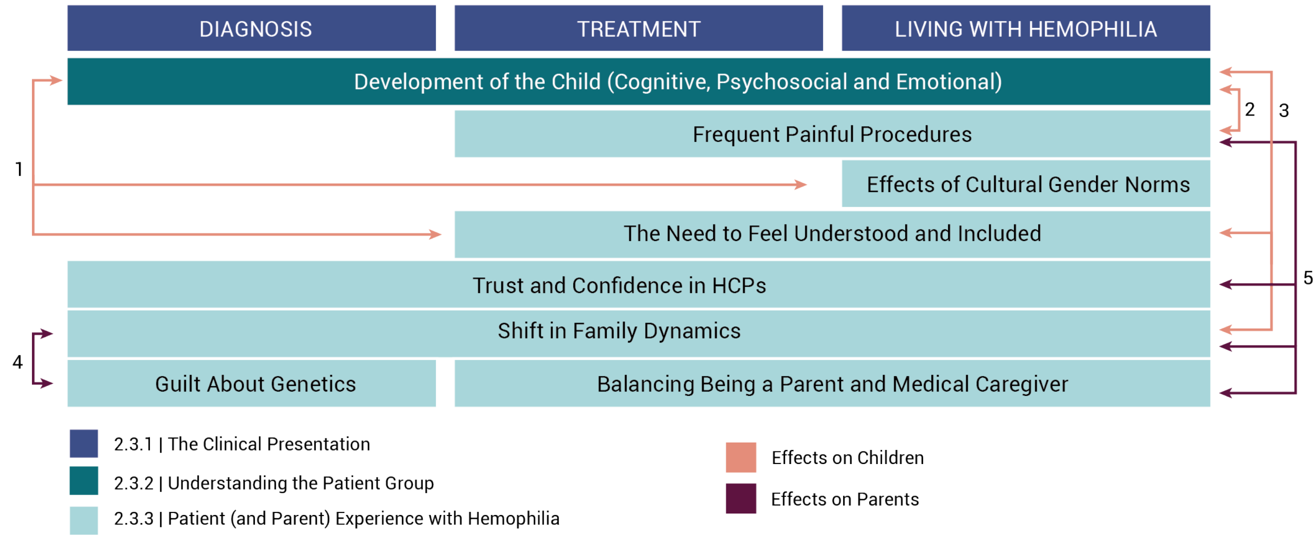


Figure 2.2 Overview of main themes in the literature research

1. Hemophilia has a prominent effect on social relationships. Due to the complexity of the disease, children cannot always express themselves and explain their condition, at times leading to exclusion and even bullying. This can cause issues in the psychosocial development of a young child.

2. The painful procedures (e.g. prophylaxis) that are a part of the children's daily lives can become stressors and possibly end up creating severe emotional and cognitive problems for the child.

3. The family dynamics are deeply affected in accommodating the new situation. The child may feel like they sometimes do not fit in, experience feelings of guilt and have problems expressing their feelings.

4. The parents, especially mothers, often have family histories with the disease. Having seen the way hemophilia used to be handled, there can sometimes be a misconception of what to expect with their child. They can harbor feelings of guilt and even fear, which often **affects their parenting style**, often manifesting in overprotectiveness, creating anxiety in the children, as well as developmental issues.

5. The parents become experts in the disease with time, and learn to do medical procedures, which often puts them in a difficult position with the healthcare professionals (HCPs). They often trust themselves more in giving their child the best care and are sometimes not on the same page with the HCPs. This role also brings the problem of balancing being a parent (the person who comforts) and a medical caregiver (the person inflicting pain).

2.3.1 The Clinical Presentation

RQ1 - What does the clinical presentation of hemophilia look like? Which medical procedures, treatments and steps are involved in living with hemophilia, and which points contribute to the perception of the disease?

Diagnosis

The most common diagnosis of hemophilia is by birth, due to hemophilia appearing in the family history, often with a carrier mother (Kulkarni & Soucie, 2011). Not all babies are tested for hemophilia at birth. Testing is done after birth for patients who either have a known family history of hemophilia or exhibit signs of abnormal bleeding during or right after birth (Kulkarni & Soucie, 2011). For those who show no signs or have no family members with hemophilia, testing will be done at a later age, once symptoms out themselves. Within the first 6-8 months, the baby will be less mobile and therefore might not immediately show signs of active bleeding. They may however have an unusual amount of bruises or immobility in joints due to spontaneous bleeding, which are typical symptoms in the diagnosis. After 6-8 months once the baby starts crawling around and eventually walking, they will start falling, causing unusual bleeding (Kulkarni & Soucie, 2011). The most common areas that will exhibit signs will be around mucous membranes like prolonged bleeding on the lips or nosebleeds (Chandy, 2005). The average maximum age for diagnosis is usually around 1.5-2 years, depending on the severity of the hemophilia. For children with severe hemophilia, bruising will be very excessive at a very young age, where with mild hemophilia most symptoms can go unnoticed (Peerlinck, & Jacquemin, 2010).

Treatment & Prophylaxis

Once the diagnosis is given, the question arises of how treatment will be administered. In the past, common methods of treatment included whole blood transfusions from healthy people and factor concentrate administration. Since these came from other people, this opened up the recipients to a wide variety of infections like hepatitis and HIV, which caused a lot of deaths among the patients of blood related disorders. Nowadays the standard treatment consists of synthetic factor products and the infection possibilities are virtually non-existent (National Hemophilia Foundation, 2022). Where in the 1960's life expectancy was less than 20 years, now hemophilia patients live well into their elderly years.

The standard now for all types of hemophilia is receiving on-demand coagulation factors at moments of injury, administered as soon as possible. For all hemophilia patients, it is advised to be vigilant about head and stomach injuries, which can cause severe internal bleeding, and treatment is always provided for these specific injuries. In special cases like operations or more commonly for dental extractions, a treatment plan will be made and coagulation factors will be supplied for the situation (Zaliuniene, 2014).
Severe hemophilia is another story. These patients are known for having spontaneous

bleeding in joints, muscles or mucous tissues and have to be treated more regularly (Coppola, 2010). A lot of the internal bleeding is invisible and is not comprehensible until it is too late. For example, a child may be sleeping and have a spontaneous bleed in the elbow joint. The child will not immediately notice what has happened and also not see anything that will arouse suspicion. After a while, the joint might start to swell up and cause immobility and this is when they will go to the emergency room. This can take up to days, meaning that there will be a certain amount of blood collecting in the joint, possibly damaging it beyond repair. In order to prevent events like this, patients of severe hemophilia undergo prophylaxis in addition to the on-demand factors given at the time of trauma (Berntorp, 2021). This entails receiving coagulation factors regularly, to allow the blood to clot regularly, if a trauma should occur.

Prophylaxis can be in the form of intravenous administration (IV), which is the most common, and also in the form of subcutaneous administration (SC), which is less invasive. SC is currently only available for severe hemophilia A, whereas IV is available for all kinds. IV is administered 1-3 times a week depending on age, severity and situation of the patient and SC is often administered around once per two weeks. SC treatment is a newer form of prophylaxis and is not the standard in treatment. Prophylaxis is a lifelong treatment and has to be done continuously for the rest of the patient's life (Kempton, 2014). The parents are the first administrators after the nurses, and after the child reaches a certain age, the children themselves take over the venipuncture and are responsible for injecting themselves. Prophylaxis has been proven to cause fewer spontaneous bleeding and research shows that this can be correlated with better quality of life (Kulkarni & Soucie, 2011).

IV treatment is typically administered with a wing needle (Figure 2.3) into the vein. The preparation is more laborious than SC treatment, where liquids have to be mixed the right amount before administering. SC treatment is typically administered with a smaller needle (Figure 2.4) under the skin. For this, a vial of liquid is also used, but mixing is often not necessary. This is done on skin which can be pulled and stretched, like the upper leg or abdomen.

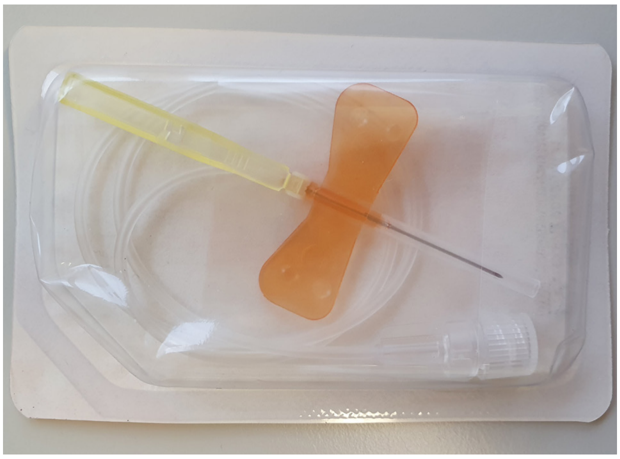


Figure 2.3 - Wing Needle

Figure 2.4- Subcutaneous Needle

Prophylaxis typically starts before 2 years of age, which is also called the primary prophylaxis, which is also usually the time where severe hemophilia patients exhibit their first joint bleed. Secondary prophylaxis is also an option, where treatment will commence after 2 or more joint bleeds, which is often before any permanent joint damage, although research does show that primary prophylaxis is more efficient (Oldenburg, 2015). There is research into how to optimize the treatment process, and analyzing bleeding tendencies is a major step into optimization (Oldenburg, 2015).

In all treatments, one problem seems to keep showing up: inhibitors. These are antibodies that work against the factors that are results of intensive exposure to factor concentrates (Ananyeva, 2004). This is mainly a problem for severe hemophilia patients and has to be monitored regularly, so the dosage of the treatment can be changed to counteract it. It is an important medical consideration, but also adds to the experience of the patient since it can mean extra trips to the hospital, or treatments that stop working (Garagiola, 2018). In the prevention of inhibitors early initiation of prophylaxis has shown promising results (Oldenburg, 2015).

New treatments are constantly being developed, with the most prominent one being gene therapy, which is now being researched for adult patients in the Netherlands, showing promising results (Cyberpoli, 2022). It will still take a while for it to be approved and be used on children, but it really is a testament to the fast pace of the medical innovations within blood disorders.

Daily Life with Hemophilia

Once the initial transition to the disease occurs, there are a lot of things the patient and their family have to consider daily. Physical activity is necessary for hemophilia patients, in order to strengthen muscles and joints, helping prevent spontaneous bleeds (Lane, 2015). This does seem counter-intuitive though, as other studies show that intensive sporting can actually cause bleeds in the first place and may lead to disabilities in hemophilia patients. Nowadays this is much less likely with a good prophylaxis regimen (Moretti, 2021). Therefore, in the daily life of patients the activities that for a healthy person may seem mundane, become moments of extensive monitoring. Patients are typically diagnosed at a young age, and go through a long learning process of what they can and cannot handle. Research shows that the patient gets to really learn their body, as they learn about the disorder, and patients become increasingly self-confident in the management of their disorder by learning how to administer the medication themselves (Saxena, 2013).

2.3.2 Understanding the Patient Group

RQ2 - What considerations have to be taken into account when understanding the comprehension and development of children aged 0-8? How do these affect a child's perception of his/her disease, and can these be used in design?

The target group for this project is between the ages of 0-8, as defined by the client, Partitura. This is the range that spans from birth and diagnosis to the "treatment maturation" of the child, where some children start treating themselves with prophylaxis. Within this age range, the phases of care are relatively similar, where after the age of 8, the trajectories tend to vary depending on whether the child wants to take over treatment.

A child with a chronic illness will carry their disease throughout their lives. For an illness like hemophilia, which is diagnosed very early, children will have to go through their development with their disease. As children grow up and develop, their needs and values change. Children at different ages can perceive the same situation differently. To understand a child and their needs within a given age group, this subchapter will focus on the cognitive, psychosocial and emotional development of children. This will be used in further chapters as strategies in designing for children, and also comprehending the intricacies of what they may be trying to express.

Cognitive Development

To understand a child's perception of their disease, it is important to look at cognition and development. For this section, Piaget's Theory of Cognitive Development (Piaget, 1929; Piaget, 1950) has been used to gain an understanding of what different stages mean within the child's life. Since a chronic illness moves along with the child throughout their lives, their understanding and approach toward the illness will change with time. Figure 2.5 shows the stages of development as identified by Jean Piaget. How does cognition theory relate to the approach to having hemophilia? Infants (0-2) are mostly oblivious to the disorder, and will not acknowledge it. For this stage, the pain and bleeding are isolated events, they have not yet made the connection between having a

Stage	Defined Age Group (years)	Cognitive Goal	Major Characteristics
Sensorimotor	0 - 2	Object permanence	Learning about the world through their senses and through their actions. Until 8 months, the assumption is that if he/she cannot see it, it does not exist.
Preoperational	2 - 7	Symbolic thought	Representation through language and mental imagery. Egocentric; assumption that other people see the world as he/she does.
Concrete operational	7 - 11	Logical thought	Realizing that people see the world in a different way than he/she does (decentring), begin thinking about how others think/feel.
Formal operational	12 +	Scientific reasoning	Understanding abstract concepts, solving hypothetical problems, can deal with "what if?"

Figure 2.5 Jean Piaget's Stages of Cognitive Development. Adapted from McLeod (2007).

disease and its consequences. Toddlers (2-4) do not yet understand the disorder, and due to the stage of their cognitive development are also in an egocentric stage, thus blame themselves for any and all symptoms. Play age (4-6) is when the children start developing coping systems, and depending on their environment these may result in careless behaviors. With school age (6-8) they will start to have a working understanding of what the disorder is, what symptoms they can expect and what consequences will follow (Mattsson, 1984).

Hemophilia does require a certain amount of comprehension from the child. Where in many cases a child may be too young to comprehend the situation, research shows that it is important to involve them early on in the process (García Dasí, 2016). Studies show that the toddler stage of a child's development is the best time to instill self-confidence which would also be an appropriate time to start helping them understand their condition (García Dasí, 2016). This way, the child could grow up with the confidence of knowing they can handle the disorder and also help them be more independent when the time comes for them to take over responsibilities from their parents regarding their care. Research shows the value in extra care taken when helping the child work through understanding their situation and how this relates to the children being more actively involved in their care. Studies find that considering cognitive development while explaining diseases to children can aid in a smoother transition and help with the psychological well-being of the child (Potter & Roberts, 1984). Education of children and families seems to be key, especially with an emphasis on cognitive development (Mattsson, 1984).

Psychosocial Development

The psychosocial development of a child is equally important as the cognitive development, and can pose various challenges for the child to face throughout their illness. For this section, Erikson's Theory of Psychosocial Development (Erikson, 1963; Erikson, 1968) has been used. Figure 2.6 shows the stages of development as identified by Erik Erikson.

Stage	Defined Age Group (years)	Radius of Significant Relations	Psychosocial Crises
Infancy	0 - 1.5	Maternal Figure	Basic Trust vs. Mistrust
Early Childhood	1.5 - 3	Parental Figure	Autonomy vs Shame and Doubt
Play age	3 - 6	Core Family	Initiative vs. Guilt
School Age	6- 12	Neighborhood and School	Industry vs. Inferiority

Figure 2.6 Erik Erikson's Stages of Psychosocial Development. Adapted from Batra (2013).

Psychosocial care has been proven to be vital for hemophilia patients (Mattsson, 1984). Infants need a good sense of trust. In most cases, this is when the diagnosis occurs and is followed by shifts in family routines which coincides with the mental development of the child. Creating a trusting bond is important in this period, which in some situations can be broken with painful procedures, which is common in hemophilia treatment. Given the lack of verbal communication, physical reassurance (e.g. cuddling) is valuable for this bond (Eiser, 1993). In addition to this, allowing the child to discover the world on their own and letting them do anything a healthy child would do, can aid in development too (García Dasí, 2016). Self-confidence is especially important to instill in the toddler age, where the autonomy of the child is important, and wrongly handled can lead to deep self-doubt (Eiser, 1993). The approach of the parent is important, an approach that is too restrictive can create problems in the social development of the child (Williams & Chapman, 2011). The play age is a critical time to give space for the expression of feelings, as if the child is not trusted enough to take care of themselves at this time, this can turn into feelings of guilt for inflicting difficulty on the family due to their disease and even turn into rage (Batra, 2013).

Schooling and education play a large part in any child's mental development. In the case of a child with hemophilia, it is a special consideration. At school, a child comes into contact with a variety of different people. Having a chronic illness in this stage can bring about feelings of 'being different' or 'being inferior' (Batra, 2013). Activities like (group) sports, which parents at times can find dangerous, have been proven to improve the psychosocial wellness of the child, especially during this stage, once again reiterating the importance of inclusion in activities (Cuesta-Barriuso, 2016). Research has also shown that frequent bleeding can affect academic success, as well as the development of social skills (Kulkarni, & Soucie, 2011). With injuries, children are often forced to miss school to a certain extent, and this is frequent for blood coagulation disorders. Having the school staff and students informed has been proven to help with the avoidance of excessive injuries (Bertamino, 2017). By keeping the injuries under control, children are less likely to miss out on school and therefore also their development, mental and social.

Emotional Development

Hemophilia can also take an emotional toll on children, especially since coming to terms with their disease happens simultaneously with their emotional development. Children with hemophilia have been found to have a higher tendency for psychological problems and there are multiple stressors that can contribute to this (Buckner, 2018). As children grow older, they also become more aware of their place in the family and start noticing the effect their disorder has on the family and daily routine. This can cause feelings of guilt, and feeling like a burden to the family. Studies show that certain coping strategies which are introduced with the diagnosis can be beneficial to alleviate these negative feelings as well as allow a smoother transition into living with the disease (Torres Ortuño, 2014). For chronic diseases in general, coping strategies that focus on the child, highlight self-acceptance and growth, encourage social support and reiterate a positive outlook on the disease has been successful (Wiedebusch, 2010). Within these strategies, a common link seems to be identifying the perceived stress of parents and family in general, as this also has a large effect on the child's perception of the situation and can offer opportunities in alleviating the child's stress too (Saviolo-Negrin, 2001; Wiedebusch, 2010). Allowing the child to express their emotions in an understanding and reassuring environment is also important for the child to grow up with a good amount of self-confidence (Eiser, 1993).

The approach of the family is important throughout the child's development. Children will copy all reactions and coping methods, and these can be detrimental to the emotional development of the child. Children soak up the stress and anxiety of their parents, giving them the same level of anxiety, albeit maybe subconsciously (Torres Ortuño, 2014). Therefore, the stressors for the parents are important as well, which will be further discussed in the next subchapter.

2.3.3 Patient (and Parent) Experience with Hemophilia

RQ3 - What are the main factors that affect the quality of life of a child with hemophilia? What does the current patient experience look like?

This part of the research aimed to gain a broader view of hemophilia and the factors that influence the children. It is also important to understand how the parents experience the disease, since established in the previous subchapter, children are deeply influenced by their parents and their reactions.

Frequent Painful Procedures

A main stressor for the children is the painful procedures that occur regularly. Most children with severe hemophilia will receive treatment at least once a week, typically increasing in frequency as they get older. The treatment regimens for severe hemophilia are quite intensive for a young child to handle (Gringeri, 2004). In some cases of severe and moderate hemophilia, children tended to show more aggression and rejection than those with mild hemophilia (Trzepacz, 2003). The psychological stress can lead to the rejection of treatment altogether (Mattsson, 1984). Pain also comes with the nature of hemophilia, where acute pain can also be felt in cases of bleeding in joints, also leading to chronic pain due to arthropathy (Stromer, 2021). Research shows that consistent treatment regimens, open communication and empathy can help with improving the experience surrounding the pain, even if the pain itself cannot be alleviated (Mattsson, 1984). Patients also have to go to the hospital quite often for monitoring, and for those receiving prophylaxis even more frequently, which can also become a stressor. Parents mention the practicality of learning venipuncture, since it clears up their schedule and gives the freedom to give the treatment how it best suits them. This also creates a feeling of normalization for the child since the hospital is not as frequently visited anymore (Von der Lippe, 2017).

This is also a consideration for parents when bringing activity restrictions. Studies prove time and time again that normalcy is one of the most important factors when dealing with a disorder like hemophilia (Williams & Chapman, 2011;

juxtaposition appears in this situation, with the children feeling normal where they are actually excluded from the "normal". Most children feel the normalcy disappears when they are around those who are different to them, who do not have the same disease. These camps provide a space where everyone is going through the same treatments, which removes the barrier of being different and makes the child feel included, even if the whole concept is technically based on exclusion.

Shift in Family Dynamics

Within the family dynamics, there can also be a lot of stressors for the child, like overbearing parenting and the general reflection of the parents' personal stress (Banis, 1999). In most activities, special considerations may be taken for the child, making them feel different to the siblings which increases the awareness of the position in the family (García Dasí, 2016). Research shows that a consistent empathetic approach can be beneficial to not only the stress of the child but also to the family dynamics in general (Mattsson, 1984). In addition to this, a lot of the emotional turmoil of the parents can lead to changes in parenting styles. Some parents become hypervigilant and overprotective, in the fear of something happening if they are not in control. Others seem to take a more relaxed approach, letting their child go and allowing them to discover consequences on their own. Research does show that as the severity of the disorder increases, the overprotection does too (Banis, 1999).

This can have a big impact on family functioning, especially if the child with hemophilia has siblings that are healthy. For the siblings of the patient, it could also cause feelings of guilt for being healthy, also known as the "healthy sibling syndrome" in exclusion, and even bullying. Bullying and teasing take a toll on any child, but children with hemophilia are more prone to this behavior since they might have restrictions and may be excluded from events (Williams & Chapman, 2011). Children will tend to make the connection between the bullying and the results of their disorder as they grow up causing additional frustrations. For young children, their peers may not understand or even take the disorder seriously and this has been found to be a frustrating aspect for children with a chronic disorder (Williams & Chapman, 2011). For other children it might be a case of not being able to comprehend the situation, but for the child with hemophilia it brings the need of understanding that is not being fulfilled (Williams & Chapman, 2011). On the other hand, some children may be facing the opposite, and not wanting to share since they want to avoid the teasing. In this case the fear of being bullied might overweigh the want of understanding (Williams & Chapman, 2011).

One activity that has been found to be beneficial in the psychosocial development of the children is hemophilia camps (Limperg, 2017). These are camps where children with hemophilia can go, meet others with their disorder, learn about their condition and do activities they otherwise would not be able to, due to around-the-clock medical care (Boutaugh & Patterson, 1977). This brings about a feeling of normalcy for children, allowing them to develop self-esteem and independence, as well as be more social by easily talking with others in their situation, fulfilling the need for understanding (Breakey, 2018). These camps are becoming more common nowadays, and the effects on the mental well-being of the children seem to be very positive (Limperg, 2017). A

Bertamino, 2014; Trzepacz, 2003). Research shows that this normalcy can be achieved by giving young children the space to do anything their peers do, and allowing them to discover their limits on their own (García Dasí, 2016). This does bring a dilemma in question, since being allowed to do activities will most likely also include injuries at times, again drawing unwanted attention from peers. However research does show that children who are given the same opportunities as others are happier and have a better quality of life (García Dasí, 2016).

Effects of Cultural Gender Norms

Hemophilia is a disorder that presents mainly in males, and in some cases brings challenges with cultural gender norms (Williams & Chapman, 2011). Boys are often expected to do sports, play fighting games and be generally more reckless in most cultures. For a child with hemophilia, this can be quite dangerous considering it opens the children up to more injuries. In many cases, the result of this is teasing or bullying by peers, causing a lot of social tension in groups (Williams & Chapman, 2011).

The Need to Feel Understood and Included

Missing out on school and therefore seeing their peers less can be detrimental in children developing strong relationships. Studies show that peer relationships are especially important for children with chronic health conditions, and can be a defining factor in emotional development (Williams & Chapman, 2011). In contrast, the interactions with friends can also be stressors for a child with hemophilia. Frequent bleeding may also attract unwanted attention. This can result which in turn also gets reflected onto the child with hemophilia, with an endless loop where the child can feel guilty for making their sibling feel that way (Bertamino, 2017). With the right adaptation system though, families do show easier transition into life with hemophilia, with strong emotional bonds within the family, which seems to be a vital part of the process (Torres Ortuño, 2014).

Guilt About Genetics

There are a lot of emotional factors involved when looking at the genetics of the disorder. Unless there is a very rare situation where the child is a de novo case, the disorder is passed down from the carrier mother. These mothers usually exhibit signs of guilt, mainly because they themselves do not have to deal with the disorder, yet passed it onto their child (Torres Ortuño, 2014). Even though this in most cases is inevitable and the mother has no control over it, they still may have an overwhelming feeling of guilt, knowing they are the reason their child has hemophilia. In addition to this, most mothers will also have a father with hemophilia. In many cases this means that they have seen the symptoms before and are aware of what the disorder entails. Yet it may sometimes also create a distorted view of what the disorder is today. As mentioned before, treatment for hemophilia has seen drastic changes, meaning that the mother may have seen her own father go through treatment that may have not been as effective, or even not received any therapy and as a result suffered from physical disabilities. As established in the explanations of the physiology of the disorder, this is definitely not the case today, but may leave the mother with a subconscious feeling of anxiety which can then be projected onto the decisions they make (García Dasí, 2016).

Balancing Being a Parent and Medical Caregiver

Even though this may seem like a practical problem at first glance, there are a lot of emotional factors that come into play when administering medication to your own child. Most parents report having trouble doing venipuncture, knowing they are hurting their child even though it will help them in the long term (Von der Lippe, 2017). Others mention that failing to insert the tube to give the medication makes their child cry and that is something they cannot handle, which creates a fear, increasing the number of failed attempts since the parent focuses on not getting it wrong, instead of getting it right (Von der Lippe, 2017). This also highlights the emotional significance of the act, and how it overweighs the practical. Parents are mostly open to treating their own child, until the emotions get involved. This is also seen in the changing role of the parent. Some parents have trouble solving the inner conflict of being a parent to their child versus being a medical caregiver (Von der Lippe, 2017). Where the parent usually has the role of soothing their child when in pain, the caregiver (though not purposefully) is the one who is inflicting the pain on the child by injecting them. This not only causes turmoil within the parent, but can also be reflected on the child. Research shows that children subconsciously pick up on their parents' stress, and can in turn develop anxieties of their own (Torres Ortuño, 2014).

Trust and Confidence in the HCPs

Parents of hemophilia patients tend to become medical experts, learning all the intricacies of their child's disorder and exactly what has to be done in any situation. There is definitely a learning curve but parents do gain self-confidence with time (Von der Lippe, 2017). This does bring some conflicts along, especially between the parents and medical professionals. Parents report problems in acute situations, where they do not want to step on doctors' toes but they still want to keep control as they know what is best for their child. Other parents recognize the complexity of the disorder and notice that not all emergency room doctors know about the disorder, yet still approach the situation egotistically, unwilling to admit not knowing. This in turn can cause the child to receive delayed treatment, or even the wrong treatment, which can be detrimental to the child and an extreme stressor for the parent (Von der Lippe, 2017). Some parents even test the attitude of doctors by asking a question they already know the answer to, just so they can know who they are dealing with, which reiterates the large gap in trust (Von der Lippe, 2017). Especially in an emergent situation, which children with hemophilia are unfortunately often in, trust and confidence in treatment is key. However, this does not seem to be the standard case.

2.4 Conclusion & Discussion

The first point to consider when reviewing the literature is that in the existing research, children's quality of life is usually measured by asking the parents so there is some bias involved (Cuesta-Barriuso, 2016). There is not a lot of research that focuses on the experience of the child, from the child's perspective, so this is an important consideration when looking at the whole picture. When looking at the approach of medical professionals as mentioned in the literature, it is clear to see that parents are the first contact and children tend to not be consulted as often, which also creates a bias (Potter & Roberts

1984). This poses an interesting opportunity in filling a gap of knowledge, which this project also aims to be a part of. The main phases of interaction with hemophilia seem to be diagnosis, treatment and daily life. Within these points there are several steps that take place, but this does seem to be the main timeline of the disease for most (if not all) patients. In general, families do seem to consider hemophilia a burden in their daily lives (Krasuska, 2012). There is a significant impact on the whole family's quality of life, most of which reflects on the child. Where emotional aspects play a role, like feelings of pain and anxiety; practical challenges like disruptions to routines and time commitments also take a toll on the members of the family unit (Torres Ortuño, 2014). It seems like the effects felt by all actors come around to directly or indirectly affect the patient, the child. There are already a lot of opportunities visible in areas like communication, perceptions and approach. For example, the medical professional's approach seems to be a player in many of the emotional challenges faced (Von der Lippe, 2017). As an extension of this, the self-confidence of the parent, and after a certain time of the child as well, becomes an important factor. The parents feel they should trust the communication enough to know they are getting the best care for their children, and in turn be able to reflect this on their child when the time comes. Once the parent feels confident in their knowledge and skill, daily life seems to become much smoother.

Adaptation periods after the diagnosis are also vital, since in most cases this time period seems to make or break the approach to the disorder in general, and later within treatment decisions. It is important to consider the child's cognition and development in the approach to the new normal, and research shows the importance of families receiving extensive education in these areas, being reminded of a constant empathetic approach (Mattsson, 1984). Children of different ages have different needs, which are especially important in recognizing the needs of a child with a chronic illness that they have to grow up with. Especially the needs of trust, autonomy and guilt (among others) seem to be highlighted within life with hemophilia, and are important points to consider in further research and conceptualization.

KEY TAKEAWAYS FROM THIS CHAPTER

- The main phases of hemophilia are DIAGNOSIS, TREATMENT and DAILY LIFE
- The most basic and recurring needs of children at all ages are trust and reassurance.
- Each child must be approached differently, considering their age, comprehension, wants and needs.
- Hemophilia is generally considered a burden and affects all areas of a child's life from a very young age, including their development.
- There are a number of discrepancies and biases in protocols and treatments in existing literature, a complete visual of the experience is not yet clear.
- Due to the complexity of the disease and the many actors with an effect on the child. a patient journey is necessary for the visualization of the experiences.

03 Context Exploration

This chapter will investigate the context of the project. First, the Hemophilia Treatment Center will be explored, understanding the purpose of the clinic and the practical effects it has on its visitors. This is followed by short informal interviews with the HCPs, aimed at understanding how hemophilia is seen and treated at the Sophia, as well as understanding the view of the HCPs regarding the current care. Observations of the interactions within the clinic are also made, to gain a deeper understanding of the current situation. These will then be analysed together to understand the themes among the different perspectives.


Reception Area of the Pediatric Hematology Department

3.1 Study Purpose

There are discrepancies in literature when it comes to the diagnostics and treatment of hemophilia. It is a rare and complex disorder which can present itself differently per person, depending on the background, which means the protocols on how to handle the disorder can vary not only by country, but even by hospitals in the same country. Most of the literature review looks at different sources from all around the world, so the situations that have been mentioned may not necessarily be a part of the protocol or experience within the Erasmus MC, but aid in understanding the bigger picture. The final results delivered at the end of this project though, will consider the Erasmus MC protocols as that is the context of intervention. Therefore, this subchapter will focus on understanding how hemophilia is handled in the Erasmus MC, specifically in the Sophia.

The methods followed for understanding the context of the hospital were informal interviews with the HCPs and observations in the hospital of how consultations and treatments are done. These methods aim to answer the following questions:

RQ1 - What does the patient experience look like in the Sophia Children's Hospital, how is the care handled and are there differences to the literature?

RQ2 - How do the HCPs perceive the care they provide?

RQ3 - What are the main points of care within the clinic which contribute to the experience of the patients?

RQ4 - How do the HCPs and patients/parents interact within the clinic?

RQ5 - What are the different channels of communication between the patient/parents and HCPs?

RQ6 - Which methods are used in providing information to the patient/parent?

3.2 Method

3.2.1 Study Setup

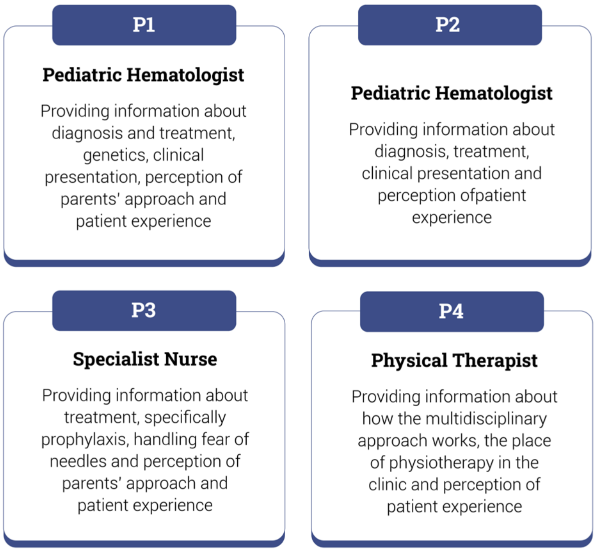
In order to understand the experience of patients, parents and HCPs within the context of the hospital, first-hand observations were made in the outpatient clinic in the pediatric hematology department of the Sophia. The clinic is held once every week, seeing patients of various blood coagulation disorders, including but not limited to hemophilia. The clinic accommodates checkup consults, prophylaxis treatments, physical examination and at times blood testing for children who are difficult to inject. The main two events are a consultation with the hematologist and treatments with the specialist nurse. These procedures were all observed, often following individual patients through their whole journey in the clinic that day, whether it be a consult, physical exam or treatment. There are approximately 7-8 patients every week of different backgrounds, and the consultations and/or treatments of these patients were observed for a time span of 10 weeks.

The HCPs in the Hemophilia Treatment center have a strong bond with their patients and a deep understanding on what hemophilia is, with most of them having worked in the field for at least a decade. In addition to observations, informal interviews were conducted with HCP's and insight was gained on how the theory relates to practice regarding the clinical presentation of the disease, how hemophilia is handled in the Sophia and how this care is perceived by the medical professionals providing it.

3.2.2 Participant Selection

Given the fact that hemophilia is a rare disorder to begin with, this was also considered in carrying out further research. Out of approximately 8 patients in a given day, on average 2-3 patients had a type of hemophilia (A or B; mild, moderate or severe). Ages 0-17 were observed, including patients from other comparable bleeding disorders (mainly Von Willebrand Disease, which has comparable procedures to that of hemophilia), to understand the full presentation of the disorder and be able to consider various backgrounds. This was done to have a larger reach of information. Both male and female patients were observed, since other blood coagulation disorders can also show up in females, however, the hemophilia patients observed were all males. Since some procedures happen simultaneously, not all patients who were in the clinic that day could be observed. In choosing which patient to observe, the priority was given to hemophilia first, then to patients aged between 0-8. Approximately 16 patients were observed in detail, most of whom had hemophilia, in addition to general observations of patients who were in the waiting room and the HCPs and parents, during and between consults and procedures.

The informal interviews were done with 4 HCPs, of whom the profiles can be seen in Figure 3.1. These HCPs were also shadowed throughout the clinic hours, and questions were asked during the shadowing or during morning meetings.



P1

Pediatric Hematologist

Providing information about diagnosis and treatment, genetics, clinical presentation, perception of parents' approach and patient experience

P2

Pediatric Hematologist

Providing information about diagnosis, treatment, clinical presentation and perception ofpatient experience

P3

Specialist Nurse

Providing information about treatment, specifically prophylaxis, handling fear of needles and perception of parents' approach and patient experience

P4

Physical Therapist

Providing information about how the multidisciplinary approach works, the place of physiotherapy in the clinic and perception of patient experience

Figure 3.1 Participants of the informal interviews

3.2.3 Analysis

An impression of the analysis of data can be seen in Figure 3.2. The findings were clustered into matching insights. The findings were separated in different ways:

With the color of post-it (white: during consult/ procedure, blue: in waiting rooms or general observations, green: information from the informal interviews with HCPs) Labels on the post-its (whether the patient was a hemophilia patient: red, and if the patient was in the 0-8 age range: black)

The clusters were then further divided to get a more compact overview of the interactions and considerations in the clinic and their relations to each other. These will be discussed further in the next subchapter.

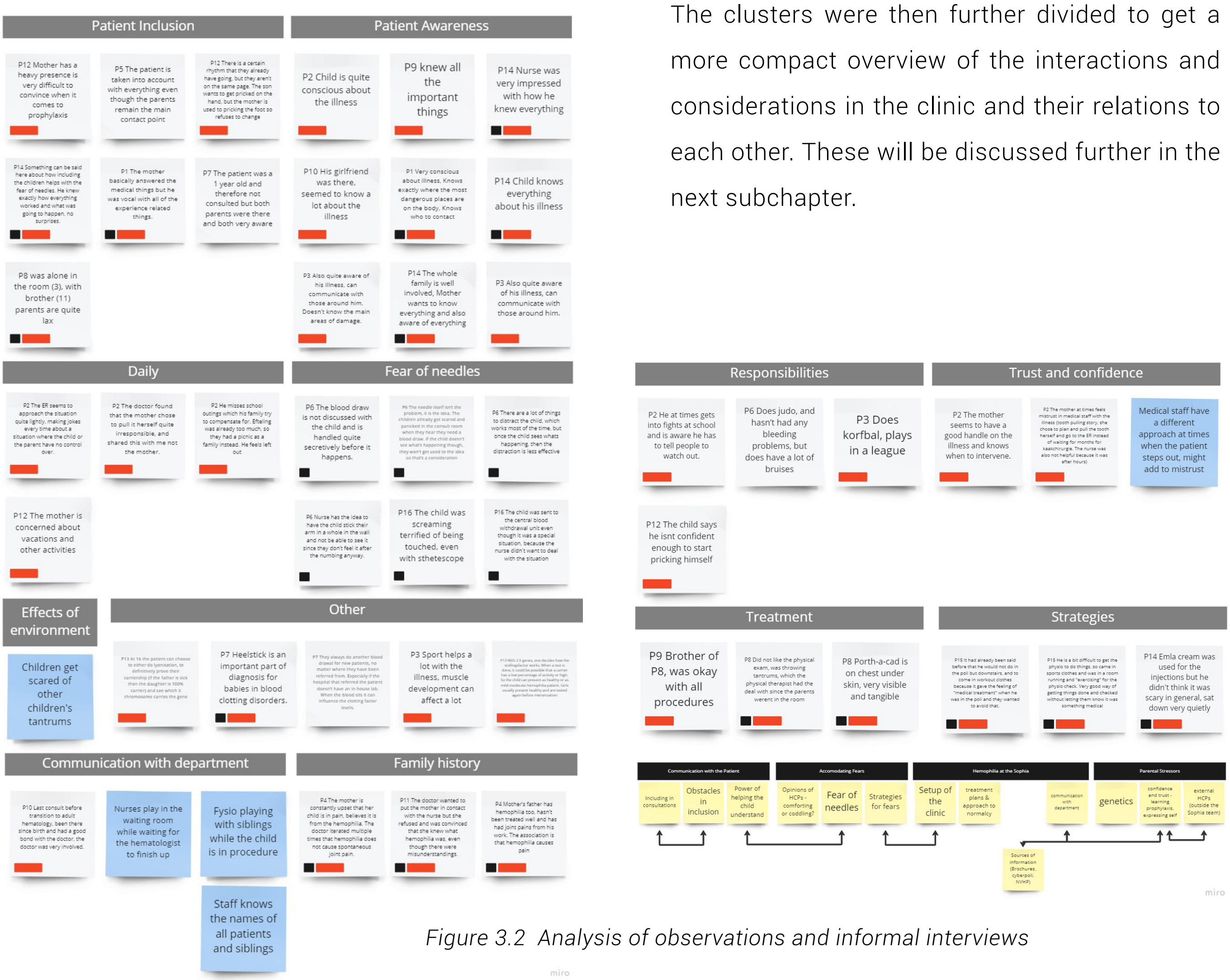


Figure 3.2 Analysis of observations and informal interviews

2.3 Research Outcomes

The following section presents the findings that resulted from this study. An overview of these findings can be found in Figure 3.3. The main trends found in the outcomes are explained below. These findings will be further explained in the following subchapters.

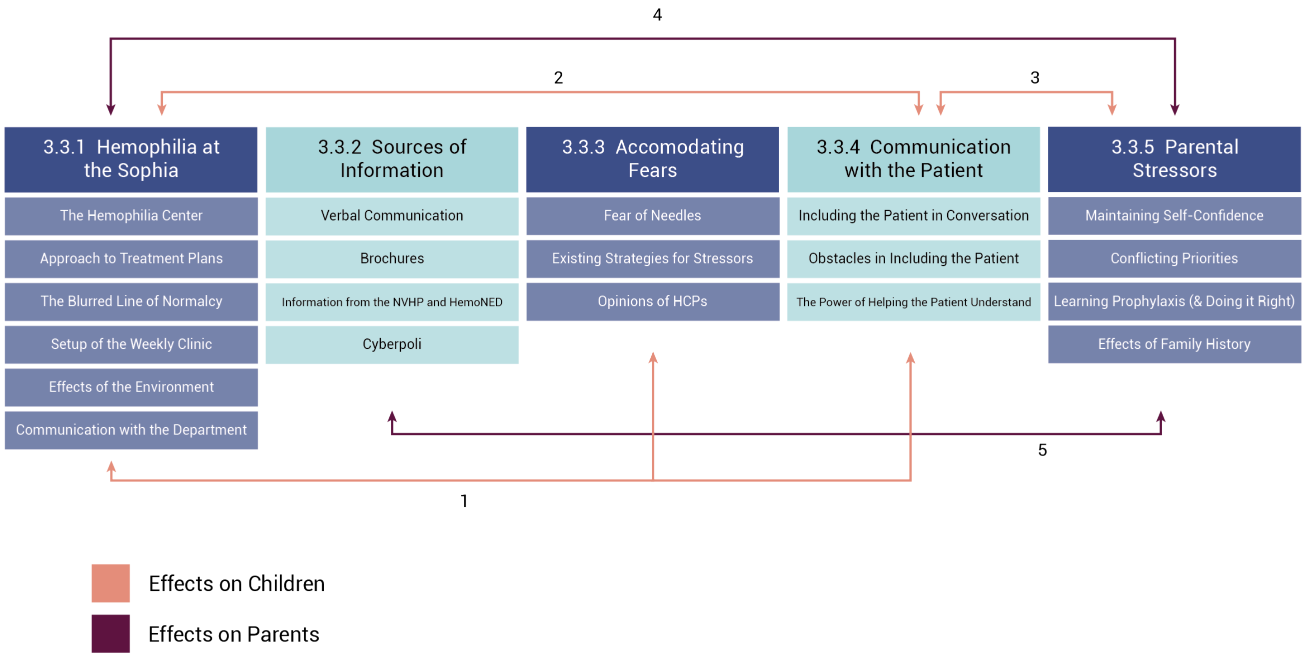


Figure 3.3 Overview of main themes in the context exploration.

1. There is a very present fear of needles/ procedures. The Sophia has implemented multiple strategies in order to alleviate these fears and make the patient feel comfortable, including toys and distractions. One of the most powerful strategies seems to be including the child in the process and helping them understand.

2. The inclusion of the children is also dependent on the treating HCP. Most HCPs have a very good bond with the child and ask them questions as well, where others do tend to prioritize the conversation with the parent. In the consultations, when asked, young children often know what to do at a moment of injury, but seem disinterested in the general conversation.

3. The experience of the parents seems to have an effect on the children. The different parenting styles are apparent in consultations, with some parents being more assertive and taking over the conversation. This can at times become an obstacle in including the child in conversation.

4. The parents at times have conflicting opinions with HCPs. The priorities of the family and the HCP aren't always aligned, and as the parent often has the final say, this disagreement can have a significant effect on the child. Most medical disagreements do seem to be solved, in favor of the well-being of the child.

5. Knowledge and information seem to have an effect on the self-confidence of the parents. The self-confidence seems to go up as the amount of knowledge increases and practical information like what to do when an injury happens is appreciated by the parents. As specific practical information is not always provided from the clinic, parents have to often rely on their own experience.

3.3.1 Hemophilia at the Sophia

RQ1 - What does the patient experience look like in the Sophia Children's Hospital, how is the care handled and are there differences to the literature?

RQ2 - How do the HCPs perceive the care they provide?

RQ3 - What are the main points of care within the clinic which contribute to the experience of the patients?

RQ5 - What are the different channels of communication between the patient/parents and HCPs?

The Hemophilia Center

The hemophilia center has two locations, the pediatric center in the pediatric hematology department in the Sophia and the adult center in the main hematology department of the Erasmus MC. An advantage of having a center like this is encouraging the collaboration of specialisms, not only those who are directly involved but also those who are less often contacted, like gynecology and even oral surgery, allowing a multidisciplinary approach to the condition. In the case of hemophilia, which is a lifelong disease, it also creates the advantage of a smooth transition for the patients around the age of 17-18, when they are transferred to the adult hemophilia center.

Each patient has a specific hematologist and specialist nurse with whom they are affiliated, the other departments are flexible and step in when necessary. Each patient is discussed thoroughly, with a multidisciplinary team, considering the different aspects of the condition. This team and their degrees of interaction with the patient can be seen in Figure 3.4.

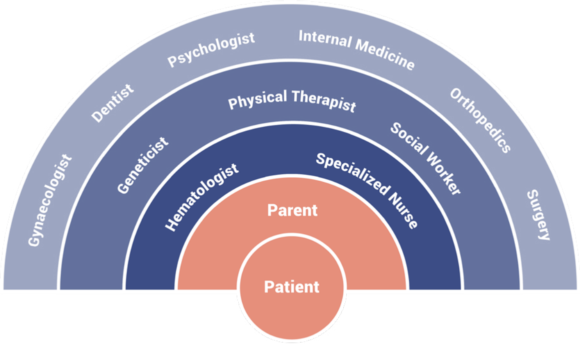


Figure 3.4 Degrees of interaction with the patient.

Approach to Treatment Plans

Treatment plans are an important part of hemophilia and even though there are protocols, there are at times variant ideas of how treatment should be approached. In existing literature, this also seemed to be a discrepancy. Upon asking the 2 hematologists and the specialist nurse, all had a different definition of what initiates prophylaxis treatment. One definition was that treatment started around 10-13 months old, another was that the initiation coincided with the first joint bleed, and the final one referred to bleeding tendencies and that a plan would be made according to whether it was manageable. Looking at the three definitions, they could all technically be referring to the same time of the child's life, and could be considered the same approach, but it shows that there is not a clear-cut definition of what initiates the treatment. This does not indicate a lack of knowledge on the disease, instead highlights the complexity of the disease.

The main approach from the Sophia is focused on bleeding tendencies, which is identified by creating a pharmacokinetic profile (PK-profile). This is done by measuring factor VIII or IX values from a given patient over a certain set time.

Depending on how high the patient's values rise due to the administration of the factors, how long and with what values these remain in the blood, the dosage of the treatment can be changed. Then each patient gets exactly what he needs. This is a method that is still in development, and is not done for each patient, but the HCPs at the Sophia see a lot of value in this, not only from the medical side but also for the experience of the patient, since it can affect the frequency of prophylaxis.

The Blurred Line of Normalcy

Hematologists refer to the desensitizing aspect of prophylaxis, reminding that it is an aid in helping the child return to a more "normal" routine, but can have downsides due to this very fact. Prophylaxis assures that the bleeding is relatively normal, and for patients that have this routine for years, they may become somewhat disconnected from their disorder. As the child gets older, and receives treatment, they may forget what happens in a situation where they bleed. In these cases, where toddlers know what to do in a situation of emergency, older patients (above 8 years old) have trouble identifying the important parts of the body to look out for, because they have simply forgotten and have not had to worry about it. T

he hematologist also mentioned the importance of the regular check ups in cases like these, as they serve as a reminder of what the patient has. This brings up the juxtaposition of the positive effect of allowing the child to live a relatively normal life (if the treatment is working well enough) but also the negative effect of not knowing what to do, should they be in a dangerous situation. Therefore the check-ups not only serve as an understanding of whether the child is fine, but also as a reminder to the child that he is still sick even if it does not seem that way. This brings up an interesting juxtaposition of trying to give the child normalcy through prophylaxis, but not wanting to make them feel too normal. This somewhat blurs the line of what "normal" actually is for a child with hemophilia.

Setup of the Weekly Clinics

Every Thursday morning from 9:30-13:00, there is an outpatient clinic within the hematology department for blood coagulation diseases. The floor plan of the department can be seen in Figure 3.5 (on page 29) to better understand the contact points the patients have within the clinic. The floor plan also shows point-of-view images to more easily orientate in the space. The clinic always starts with a multidisciplinary team in the meeting room of the department going through each patient and their needs. The main people who are always there are the leading hematologist, the specialist nurse and physical therapist. In these meetings anything from patient history to new treatment plans are discussed, with the opinion of everyone, and the final approval of the hematologist.

There are currently three different doctors who lead the consultations, switching every week. Each week is led by one specific hematologist. Within the Sophia, each patient is assigned one hematologist and one specialist nurse to their team who remain their first point of contact through their journey. However, this does not always mean that they always see their own hematologist during their consultation, this depends on the day they come to the hospital and

1

Hallway from the main hall to the pediatric hematology/oncology clinic

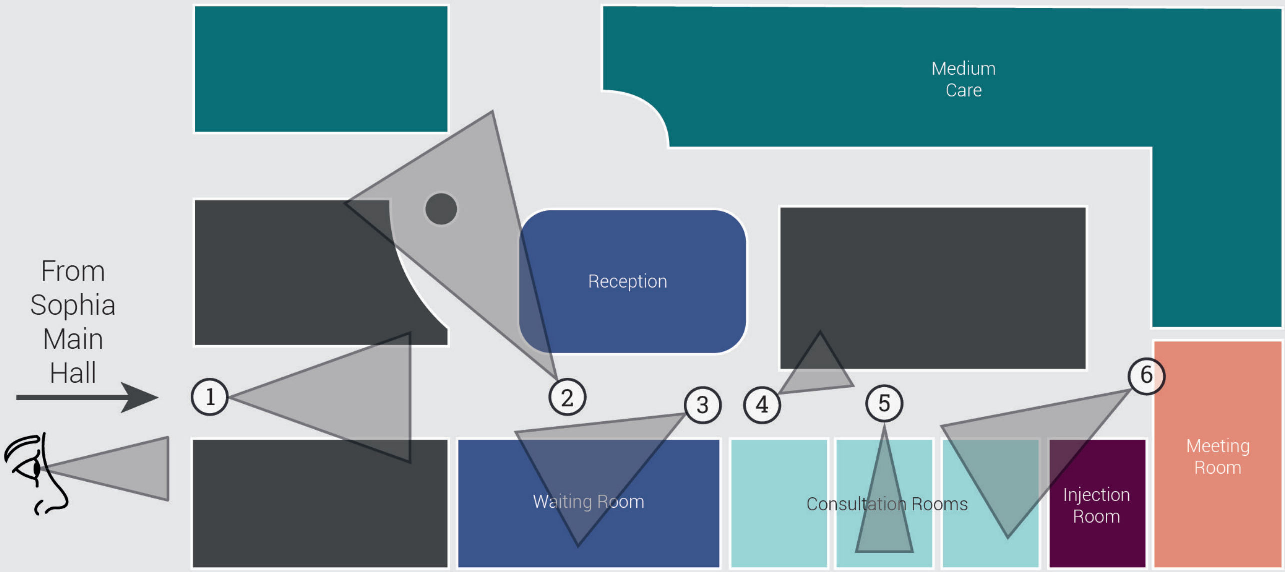
2

Hallway to the medium care

3

Waiting room of the pediatric hematology/oncology clinic

Pediatric Hematology Clinic Floor Plan



4

Brochure/information board

5

Preview of the consultation rooms

6

Toys in front of the injection room

Figure 3.5 Floor plan of the hematology/oncology department who is leading the clinic that day, meaning that the approach towards the patient is not always the same.

The weekly clinic accommodates checkup consults, prophylaxis treatments, physical examination and at times blood testing. Figure 3.6 (on page 31) shows the different rooms the patients come into contact with and their function within the weekly clinics. The norm for tests is to go to the central blood testing department, but for children who are difficult to inject, this is sometimes done at the clinic itself. The specialist nurses of the hemophilia team have received several trainings, with one of them being specially trained in dealing with children with a fear of needles. At times, even the hematologist will step in and help with the blood withdrawal, to make the situation as easy as possible for the patient. The clinic seems to be generally quite accommodating and prioritizes the children's needs.

Effects of the Environment

In certain cases, the fear of one child can affect another. Sometimes the fear at times manifests in crying, screaming or even tantrums, which is very visible to others. In that case the distraction for a child that may not necessarily be scared at that point becomes more difficult as the child is suddenly scared of what may be awaiting him. This is especially true for toddler and play age children, as they are more egocentric and assume everyone has the same reactions and experiences as they do, which could bring up the question "What did they do to him/her? I will also feel like that." This is not the case for everyone, but is observable in the more extreme situations. This is also the case in the worries of parents, which get reflected onto the child. In the consultations it is always reiterated that sports and activities are vital, especially at a young age, however some parents find this dangerous, but the physicians take the time to explain the benefits of developing joints and muscles on hemophilia. This does require vigilant monitoring though, both on the parent's and the patient's part. Most patients seem to be participating in some kind of sport, mostly on the "less aggressive" side.

Communication with the Department

The hematology department has an open line for communication about hemophilia. This is a telephone number parents can call at times of accidents, to get advice on what they should do in certain situations, and to update on anything the department should be aware of. They will get immediate answers for their questions, and these points will be further discussed in the consultation. When they are at the consultation, the hematologist will mainly ask about recent falls or injuries, about how they were handled, and also about treatments. The patients also have an impressive bond with the HCPs, especially with their assigned specialist nurse. This seems to stem from the fact that a lot of attention is given to each patient and their families, including the siblings. Each patient seems to be received positively within the clinic and at times the HCPs can even be seen in the waiting room between procedures playing with the patients or having a conversation with the parents. The parents frequently express their fondness of the HCPs and the convenience of how accessible the department is though the hemophilia line.

Reception and Waiting Room

The departments of pediatric hematology and pediatric oncology share a clinic, with the medium care department adjacent, but not visible from the waiting room. The reception has a ladder, which the child can use to step up to the desk.

The waiting room has a variety of toys and games, accommodating different ages. Especially toddlers and play age children appear to enjoy themselves before consultations or treatments. The HCPs often reiterate the importance of distraction. If the child is having fun and not feeling like they are there for a procedure, they are also less likely to push back when the time comes.

The HCPs can also often be seen playing with the children in the waiting room. Even with the distractions there seems to still be a significant amount of children who are scared (mostly of needles and treatment) which due to the open plan of the clinic, is visible even at a first glance into the waiting room.

Consultation Room

There are 3 consultation rooms, one of which is accomodated by the hematologist for consults, at times joined by the other staff if necessary (nurses, physical therapists, geneticists or at times social workers). The second room accomodates the specialist nurse and physical therapist, with the third room being reserved for external consults that are not a part of the clinic schedule.

The specialist nurse will switch between consultation rooms and the injection room to carry out consults and treatments. One of the staff members will come to pick up the family for the first appointment, this is usually the consultation with the hematologist. If the family is in for multiple procedures, this will be told and a plan for the day will be given during the first consultation.

The family is usually brought to the next procedure by the HCP. Usually patients will not be back at the waiting room between procedures, instead they have a chat with the HCP until they can move to the next appointment.

Injection Room

The setup of the injection room, seen above, aims to distract the child and make them feel comfortable. This room is full of toys and books, allowing for a more pleasant experience. With one of the specialist nurses having had training in managing fears (of needles), the room is equipped to adress these fears.

The room is used mainly for prophylaxis treatments. Blood testing is usually done at the blood withdrawal center located elsewhere, but for especially difficult patients, this room can be used as well.

Down to the tourniquet and wing needles, all medical equipment is playful, or the colour/shape is used to create a playful experience (eg. pretending the colourful wing needle is a butterfly).

Figure 3.6 Rooms that patients come into contact with at the outpatient clinic

3.3.2 Sources of Information

RQ5 - What are the different channels of communication between the patient/parents and HCPs?

RQ6 - Which methods are used in providing information to the patient/parent?

Verbal Communication

Within the verbal communication a number of different situations are discussed with the parent and the child, mainly about what to do when a bleed occurs and what the most important things are to look out for, namely injuries to the head and abdomen. Within the communication between the parent and HCP, it is clear that the parent often relies on their own experience dealing with practical situations. Specific practical information is not provided, and the information seems quite uniform for all patients, newly diagnosed and years into the experience.

Brochures

The brochures are given to the parents, with information on the diagnosis, numbers to call in case of emergency or general questions, including the hemophilia line which gives direct access to a specialist nurse and child hematologist at any given time. An impression of these brochures can be seen in Figure 3.7, and can be found on the wall next to the reception for easy access, visible in Figure 3.8.

Information from the NVHP and HemoNED

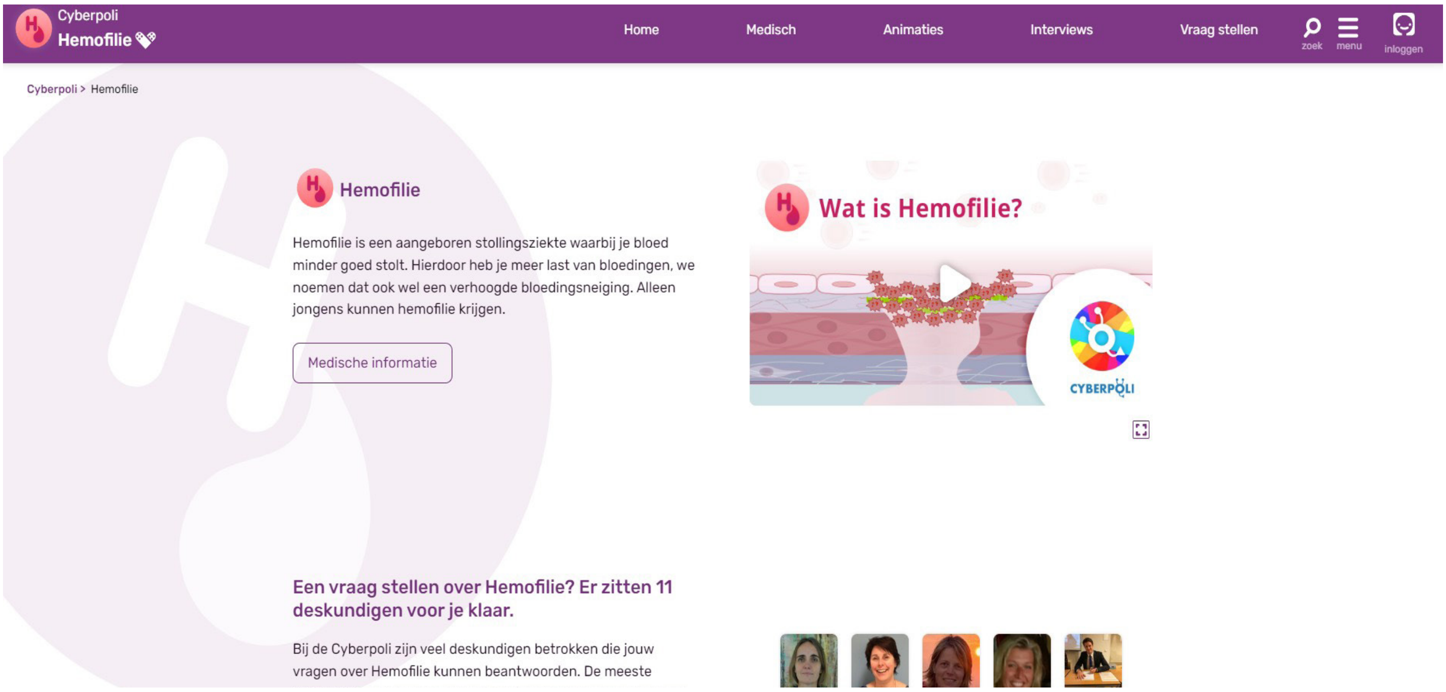
The Dutch Association of Hemophilia Patients (in Dutch: Nederlandse Vereniging van Hemofilie Patienten, abbreviated as NVHP) provides information for patients and parents too, with a comprehensive website, brochures (included in the brochures provided by the hospital, visible in figure 3.8) and magazines about blood coagulation, "Faktor", published twice a year. These magazines are available to subscribers but are usually also found at the clinic. The Dutch Hemophilia Registry (in Dutch: Nederlands Hemofilie Register, abbreviated as HemoNED) is an organization that also has a website as well as brochures provided in the clinic and products like apps that are offered to hemophilia patients. One of these is the "Vaste Prik" which gives the parents a way to track the injections and how many doses they have left before they need to order a new batch.

Cyberpoli

Another source of information is the Cyberpoli website, which contains detailed medical information, explained with text and videos, as well as interviews with parents. The website is meant for both parents and children and the HCPs express their pride in the website reiterating its usefulness. An impression of the website can be seen in Figure 3.9.

Figure 3.8 The brochure wall next to the reception

Figure 3.7 Impression of the brochures



Hemofilie

Hemofilie is een aangeboren stollingsziekte waarbij je bloed minder goed stolt. Hierdoor heb je meer last van bloedingen, we noemen dat ook wel een verhoogde bloedingsneiging. Alleen jongens kunnen hemofilie krijgen.

Een vraag stellen over Hemofilie? Er zitten 11 deskundigen voor je klaar.

Bij de Cyberpoli zijn veel deskundigen betrokken die jouw vragen over Hemofilie kunnen beantwoorden. De meeste

Figure 3.8 The brochure wall next to the reception

3.3.3 Accommodating Fears

RQ1 - What does the patient experience look like in the Sophia Children's Hospital, how is the care handled and are there differences to the literature?

RQ2 - How do the HCPs perceive the care they provide?

RQ3 - What are the main points of care within the clinic which contribute to the experience of the patients?

RQ4 - How do the HCPs and patients/parents interact within the clinic?

Fear of Needles

It is important to point out that there are a lot of children with a fear of needles, some of which are very visibly scared. Sometimes children are even scared of being touched, for example with a stethoscope, which makes the general hospital visit quite jarring. For all children up until age 7, regardless of fears, numbing cream is applied. Numbing cream does generally help, but in most cases the children are still terrified of the needles, and at times are even scared of the applying of the cream. Which supports the idea that it's not the needle that is the problem, but the idea surrounding the needle. Even though the clinic sees a lot of patients who are scared of needles, there is definitely a population of patients who can sit through venipuncture without being afraid. This does not mean they do not get impatient, but will not be visibly scared of the pain. With the observations made, it seems that one of the reasons for this is including the child in the care. For many children with a fear, the whole procedure is tiptoed around, with the child only realizing it going into the procedure room. For the children who are relaxed, there is usually an inclusive approach, the parent telling the child what to expect, letting them be a part of the process.

Existing Strategies for Stressors

There are several strategies that the clinic carries out to decrease the stress on the child:

- The children are often tested for mobility and flexibility to make sure nothing goes unnoticed in the case of a joint bleed. For this, patients are taken to "work-out" outside of the clinic in a large hall, so that the physical therapist can analyze the movements but the patient does not feel monitored. This is especially done for patients who find the clinic too "medical" and "scary".

- For children who come into the hospital and have severe fears, they will not be planned within the clinic hours which are mostly fast-paced. They will come in at a more relaxed time of the day and time will be taken to make them feel comfortable.

- Distraction is a key element in providing a calm treatment. One of the specialist nurses has had training in medical hypnosis and calming techniques and usually goes into conversation with children to distract them. In addition to this, mostly for smaller children who sit on a parent's lap during the procedure, they are put on the parents chest, facing one way where the parent uses a toy or book to distract. On the other side the venipuncture happens, where the child has had numbing cream so cannot feel the needle, but will feel some pulling on the arm, which most children do not have an issue with. This position makes it difficult for the child to turn his head and

Figure 3.10 “Injection prizes”

Figure 3.11 Books for patients, parents and siblings

Figure 3.12 Distraction material

see what's happening, and therefore has less of a problem with the procedure.

- A fully stocked injection room is also helpful in exciting the child to be there, and highlights the toys, instead of the injection itself. Patients who are scared of needles usually do blood tests here instead of the central blood withdrawal department as it is easier for patients. An impression of which can be seen in Figure 3.10-3.12.

Opinions of HCPs

One of the specialist nurses of the clinic has received special training in order to help children with a fear of needles, taking the fear very seriously. She mentions how important it is to distract the child during procedures and says that if the children were not allowed to see what happens during the venipuncture, they would not feel it anyway due to the numbing cream and would not be scared, expressing that the fear stems from the idea of pain, not the needle itself. This does bring up some ethical issues though, since the procedure would then be done without the knowledge and therefore also consent of the child. There are also a number of medical professionals that are against the numbing cream, and see it as coddling the children. The belief of some is that children should “just sit through it and learn to fight fears instead of running away from them”. The HCPs do still mention their respect for the child, and still express they do all they can in order to accommodate the child in the clinic, with the numbing cream being a standard for all children under the age of 7. An interesting juxtaposition to this is to avoid the word “injection” and instead to use words such as “medication”. The HCPs believe not using the word helps with the management of fears, however this effect was not observed and is open to further research.

3.3.4 Communication with the Patient

RQ1 - What does the patient experience look like in the Sophia Children's Hospital, how is the care handled and are there differences to the literature?

RQ3 - What are the main points of care within the clinic which contribute to the experience of the patients?

RQ4 - How do the HCPs and patients/parents interact within the clinic?

RQ5 - What are the different channels of communication between the patient/parents and HCPs?

Including the Patient in the Conversation

As the child is the best source of information when it comes to their own disease, the importance of teaching what to watch out for and how to handle situations becomes apparent. When talking to the children themselves, it is interesting to see how in touch most of them are with their disorder. Most older patients (above the age of 10) are already administering prophylaxis themselves and have the forethought to understand consequences. Younger patients, specifically toddler and play age, are also quite aware of the situation, when asked what parts of the body are the most important to look out for, most patients can correctly identify them. They understand they will need medication if they bleed and that they have to find someone who can call their parents if they are injured. This is the case for patients as young as three years old.

The patients have to develop a sense of responsibility around their disease. In consults, parents and patients also mention other daily difficulties, like children missing out on school outings which the family is left to compensate for. The children who are in these positions will mention being excluded and not being able to make friends. Some patients themselves also talk about classmates pushing them into fights, where they are supposed to take the responsibility to step out of the situation, and ultimately get teased for their decision, which puts an unusual amount of responsibility and stress on a young child. Helping the child take control of their disease and be active in their care seems to help with the development of this responsibility.

Obstacles in Including the Patient

During the consultation, the hematologist asks questions to either the parent or the patient to understand the daily activities of the patient. Some physicians tend to direct their question immediately to the parent, and others will mainly talk to the patient, whatever their age may be. It does seem that talking to the patient themselves is more common if the hematologist is the assigned physician, and less if it is another physician who is leading the clinic that day. This being said, sometimes this will be overpowered by a parent that takes over the conversation, however old the child may be, leaving the physician to fight to be able to talk to the child themselves, which at times can lead the physician to give up after several tries and directly converse with the parent. Parents are also left to divide their attention during consults in this case, since when the child is not involved in the conversation they will get bored and impatient. This can be difficult for a parent to manage while trying to have a serious conversation.

The Power of Helping the Patient Understand

In one specific case, a 4-year-old was in the injection room, with the parent administering prophylaxis. In this case, even the specialist nurse was impressed as to how involved and aware the child was. The child helped his mother prepare the medication, correctly identifying each part of the medication. The sister was also there, very aware of the brother's disorder and said she liked keeping her brother company. The prophylaxis procedure is shown in Figure 3.13. There was a moment the mother accidentally punctured the wrong vein and the child pulled away. The child was hesitant, until the mother explained the situation, apologized for causing pain, reminded him of the consequences of not continuing, and asked permission to continue. Everyone waited patiently while the child asked questions and understood the situation, then the procedure restarted. The child was then relaxed and continued playing with his toy, as seen in Figure 3.14. This was a very special case, but within the rest of the observations, it is still clear that including the child in decision making and helping them understand, can have a positive effect on the perception of the procedure.

Figure 3.13 The prophylaxis procedure

Figure 3.14 The prophylaxis procedure continued

3.3.5 Parental Stressors

RQ1 - What does the patient experience look like in the Sophia Children's Hospital, how is the care handled and are there differences to the literature?

RQ4 - How do the HCPs and patients/parents interact within the clinic?

Maintaining Self-Confidence and Trust

Most parents have a good handle on the situation and know when to intervene. The self-confidence here seems to increase as the child gets older. In some cases though, there seems to be an overconfidence in situations, where the parent chooses to take control. Typically, there is talk about recent events, most of them including a trip to the emergency room, and having a bad experience with it. In regional hospitals, all parents generally mention the lack of knowledge on the disorder and not getting the care they need, and having to call the hemophilia line of the Sophia to get help from them. At the emergency room of the Erasmus MC some patients report a lack of urgency, staff making jokes like "Could you not have fallen at another time?" which parents find to be concerning as this is where they come to feel safe and understood for their child's disorder. The parents see the situation being taken lightly, and mention they cannot give their full trust in these situations, especially when the child and parent do not have control over things. Situations like this force the parent to gain confidence in their skills and try to avoid emergency rooms in the first place.

Conflicting Priorities

Some parents also report that the HCPs may not always understand the priorities of the family. One mother mentions an incident where the child needed a tooth extraction, which is an event where coagulation factors have to be provided and plans have to be made. The plan was given to have the appointment in three months, which was when the mother, who is a dental assistant, decided to plan for extracting the tooth herself. After dinner they called the Erasmus MC emergency room saying they would be arriving shortly and she pulled the tooth out herself, having the confidence that she handled the situation in the most convenient way possible. The mother's reasoning was that her child was in pain and that waiting that long, letting her child suffer, was unnecessary. The hematologist gave a vague response to this in the consultation and moved on, but once the parent stepped out with the patient, mentioned that even if the frustration was understandable, it was "unbelievably irresponsible" on the parent's part.

Learning Prophylaxis and Doing it "Right"

Most parents will learn how to administer prophylaxis to their child themselves, as this allows for independence in treatment. Most cases go well and there is a new routine formed at home. There were also cases of parents learning to do venipuncture themselves, yet were struggling, either because their child was difficult with needles or they did not feel they had the skill to do so. This causes a lot of stress for the parent, as they feel they are hurting their child and also creates visible impatience from the child's side. There is also a surgical procedure that can be done to place a little device into the child's chest to allow for easier venous access. This is called a Port-a-Cath (PAC) and is used in cases where the child is not easy to puncture. This is for children that receive regular treatment and need constant access to a blood vessel. This not only helps the parents and HCPs while administering medication but also the child, as they do not have to sit through the many failed attempts that result from an inaccessible vein. Children who have the PAC device usually seem to have a better experience with the prophylaxis, since it makes the medication much easier to administer. But the device also opens the child up to infections as it is a surgical procedure, so it is not very common, and only used if medically necessary. It is not a device that is meant to be used for children who have a fear of needles and do not want to be injected.

Effects of Family History

Within the initial understanding of the diagnosis process, one of the HCPs mentioned that even though the assumption may be that parents with hemophilia in their family history would be more calm in the process knowing what to expect, this is generally not the case. Since hemophilia has changed significantly in its clinical presentation within the years, most parents, often a mother with a father with hemophilia, will be expecting something very different. The HCP went on to explain that given the age of the father in question, he probably did not receive synthetic prophylaxis at the time, which is a relatively new treatment. The HCP highlights that it is only natural for a mother to be scared of her child having hemophilia if the image she grew up with was a bedridden father and also mentions the importance of giving the parents information on the future of the child and reassuring them. The HCP also found that the genetic testing process was also crucial in the journey, in order to understand where the disease comes from, and also to manage expectations with other family members.

There are, albeit not many, parents who have a somewhat distorted understanding of the disorder due to their own family history. At times parents will come and report symptoms that are not related to hemophilia, getting angry that the treatment is not working and starting with the notion of stopping treatment. In these cases the child has no say in the matter, and the physician is left to convince the parent of the facts. In multiple cases, these parents have shown a disinterest in learning more about the disorder, claiming they know all there is to know. Physicians report this to be detrimental for the children's health as the parent has the final say if they are unable to convince them. In the consultations that were observed, these communications were all resolved relatively positively, but did give another view of how the approach of the parent can ultimately affect the child.

The Injection Room

3.4 Conclusion & Discussion

In line with the literature research, within the hospital there is definitely a presence of fear surrounding medical procedures. The Sophia does use a variety of methods to avoid stressors for the children and try to make their visit to the hospital a happy event. The protocols of the Sophia line up with the theory as well, with the addition of patient-specific care, which they are currently moving towards with the analysis of bleeding tendencies. The HCPs do frequently reiterate that hemophilia is a highly treatable disease in which the quality of life is relatively good. The practice does show a lot of parents and patients complaining about the negative aspects overweighting the positive, which the literature also tends to focus on. The literature also tends to highlight an overprotective parenting approach that arises with severe hemophilia, which does not seem to be the case in practice. There are definitely parents who bring certain limitations or who take over conversations during consults, but it is not the standard it seems to be in the literature.

Information and knowledge seem to have a great influence in the self-confidence of parents. As the parents know more about the disease, their confidence goes up as well. The information provided in the clinic seems to be quite uniform, with sources like brochures and verbal information being given to all patients new and old, in a practically identical way. It seems the parents gain the most knowledge from their own experience, mentioning examples of situations and how they handled them, at times asking whether it was correct as they could not find information about it. Verbal communication is very important, as parents often ask questions they cannot find answers to elsewhere, and this helps them to better care for their child. Practical information seems to be desired by the parents, yet the HCPs find it at times difficult to answer, as each situation differs greatly and they do not want to provide the wrong information. This is understandable, but is also important in the parents' sense of self-assurance.

Children with severe hemophilia are required to visit the hospital frequently, to the point where it becomes another normal aspect of their life, like school. Which means that their experience during their visit becomes vital and can have effects in the other parts of their lives. There are several points of interaction within the several locations of the hospital which can add to a child's experience during their visit, and can reflect onto their general experience with their disease. These points can be seen in figure 3.15.

There are also differences in how the HCPs perceive the care they provide and how it is in practice. In certain areas like genetic history, what a child can comprehend and the approach of parents in general, the HCPs seem to have preconceived notions which were formed with more than a decade of examples. This does, however, seem to play into how the parents and patients are viewed. One main reason for this can be that there is currently not a complete picture of what a patient's experience with the

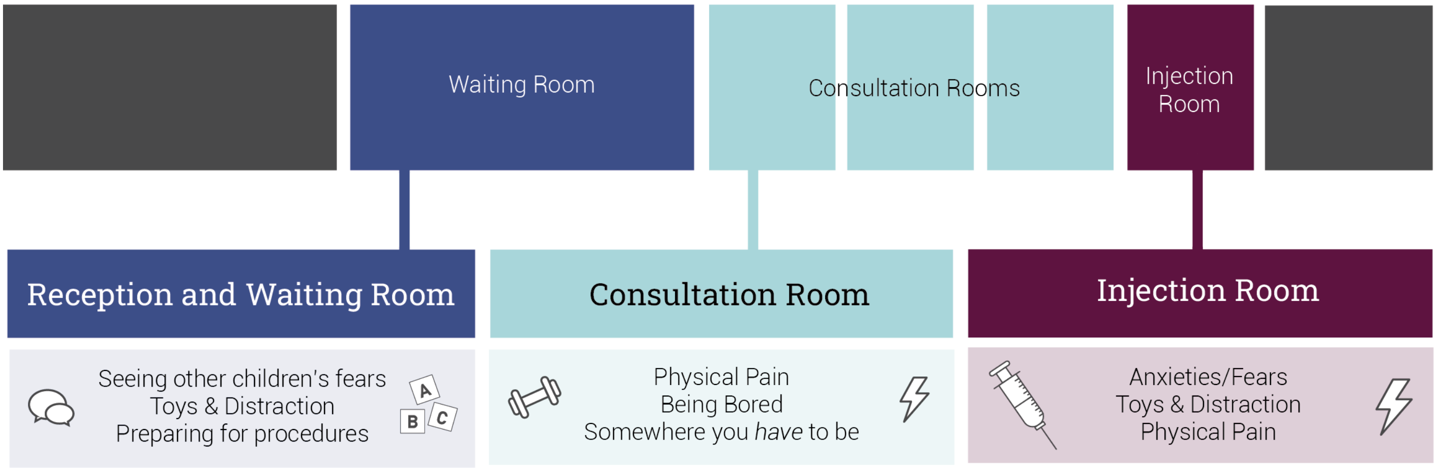


Figure 3.15   Found touchpoints in the outpatient clinic

The Consultation Room

disease looks like outside of the confines of the clinic, and what the parent (and at an older age, the patient) chooses to share with the HCPs. Within the hemophilia clinic all actors seem to have an open line of communication due to the belief that the more that is shared, the better the care that can be given. However, there are situations where the transparency between the HCPs and parents/patients decreases, with the HCPs expressing their problems with certain situations once the parent leaves the room. This is also a problem that is reflected in the parents, choosing to express their issues once the doctor leaves the room. Knowing that a person is not a medical professional is in some cases a trigger for parents to elaborate on problems in a way they do not towards the doctor. This shows that to some extent, the perception of communication is not as transparent as one might assume.

Most medical professionals will go out of their way to accommodate a child, but it is a fact that the patients are there for a reason and procedures have to be done on a schedule. So in some cases the experience of the child might be overpowered by either a schedule or the general approach of the medical professional. In most cases the child will already have numbing cream applied yet still will not allow venipuncture, in which case the parent and nurse (in some cases even the doctor) are left to hold down and pull on the child's arm and do the procedure through the screams. This is resorted to relatively quickly as at most times the parent and nurse will both know the child will be in the same state however long they wait. Fear of needles remains a significant concern in the experience. Even with the comprehensive distraction techniques within the clinic, the children are still scared of procedures and treatments. This brings up the question of whether numbing cream and toys are enough of a precaution to avoid the fear from developing in the first place, and whether there are other factors that play into experience with treatments, and with the disease in general, that are not always visible in a short visit to the clinic. The user research will be used to shed light on what information might be missing to understand the full image of the experience, as well as any additional interaction points that may have an impact on the experience outside of the hospital.

KEY TAKEAWAYS FROM THIS CHAPTER

- The approach of each HCP is different, creating an **inconsistent view of the given care**.
- The clinic is well equipped for children with a fear of needles, and the **fear is mostly taken seriously**.
- There are multiple touchpoints within the clinic that can create **negative experiences for the patient**.
- **Medical procedures are often perceived as 'scary'** by children.
- Even within the hospital, there are v**arying views on the definitions** regarding hemophilia.
- The **clinic is not a complete representation of the child's experience** as the parents (the main point of contact) could be providing the information they themselves perceive as important/what they think the HCP wants to hear.

04 User Research

In order to create a viable intervention, understanding the needs and experience of the user is necessary. In this chapter, user research is done through interviews. Firstly the interview setup will be explained, followed by the participant profiles and the materials used in carrying out the interviews. The findings of the interviews carried out with patients and their parents will be presented, followed by a general conclusion of the whole research phase, with links between the various insights gained.

4.1 Study Purpose

Within the context exploration, valuable insights were obtained about the care the Sophia provides for their patients and how the patients and their families perceive their visit in the clinic. Within this research, some insights also came up about the daily life of the children outside of the hospital, but remained incomplete due to the limited research opportunities during the clinic. Further information was necessary in understanding what a child's daily life with hemophilia looks like and what touchpoints the child comes across. This was done in an isolated situation, where the parents did not feel the presence of HCPs to censor their opinions and the child felt comfortable in a situation without the stressors a hospital clinic may create. Therefore, semi-structured interviews were carried out with children and their parents, in the comfort of their home (barring a few exceptions). The following research questions will be answered with this research.

RQ1 - What are the needs and wants of children regarding their care? Are these currently being met?

RQ2 - What are possible moments that can create negative experiences for the children, are there existing strategies to overcome them?

RQ3 - What are important touchpoints that a child comes into contact with, within/outside the hospital, and which of these have an impact on the experience with the disease?

RQ4 - How do parents and children experience living with hemophilia? Which experiences of the parents, if any, have an effect on the children?

RQ5 - How do external factors and actors affect the child's perception of the disease?

RQ6 - How is the provided information perceived by the parents and children, is it sufficient?

The "Walk-in" Aquarium at the entrance of the Sophia

4.2 Method

4.2.1 Interview Setup

Planning the interviews, some assumptions were made and the setup was done accordingly:
Not every child will be able to participate in the interview (e.g. too young to answer questions, parent might not want child to participate or the child themself might not want to participate.)
Not every family has the same experience, and are not in the same phase of the process, therefore not every family may give the same amount of information regarding the steps of the process.
In a situation where the parent is present, the child may not be able to answer as freely, or the parent may take over the conversation.

The interview structure allowed the whole family to join in on the conversation at the start of the interview, with questions mainly directed at the children. The child's portion of the interview mainly consists of going over the sensitizing cards previously filled in (explained further in the next subchapter) and asking questions about the drawings. With the explanations of the child, further questions came up and these were discussed with the child. The duration of this was set as 15-20, keeping the child's attention span in mind. For the parents, the questions were pre-set, according to their specific situation, and further questions came up as the discussion ensued. This portion of the interview was planned as 45-60 minutes. Within their answers, parents were encouraged to answer with their child's experience and perspective in mind, and this was considered in the formulation of the questions. The questions of the interviews were based on a preliminary protocol and edited per participant according to their situation. The preliminary interview protocol can be found in Appendix A, and the template for the consent forms can be found in Appendix B

The interviews took place mainly at participants' homes, this was to create a comfortable environment for the child, and also for the parent to be more comfortable in answering their own questions. Parents found the conversations in consultations difficult as they had to divide their attention between the doctor and entertaining their child, so there was also the added benefit of having the child go play once he was done. Within a total of 7 interviews, 2 participants were interviewed remotely, by phone or online and 1 participant was interviewed in a private consultation room of the clinic.

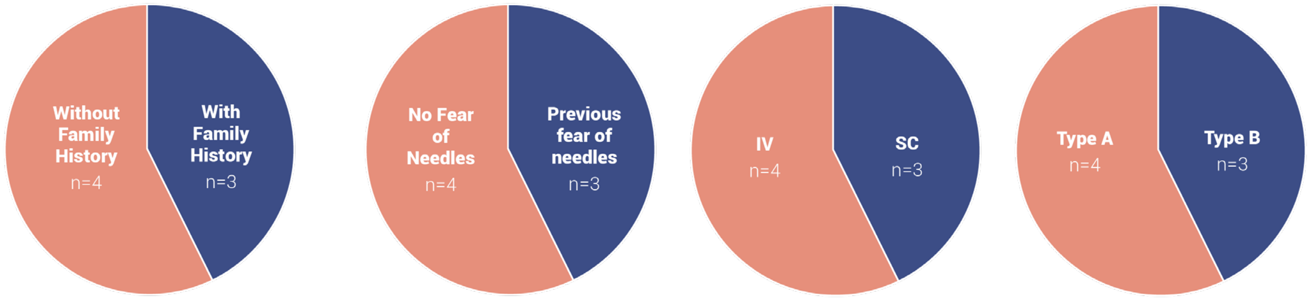
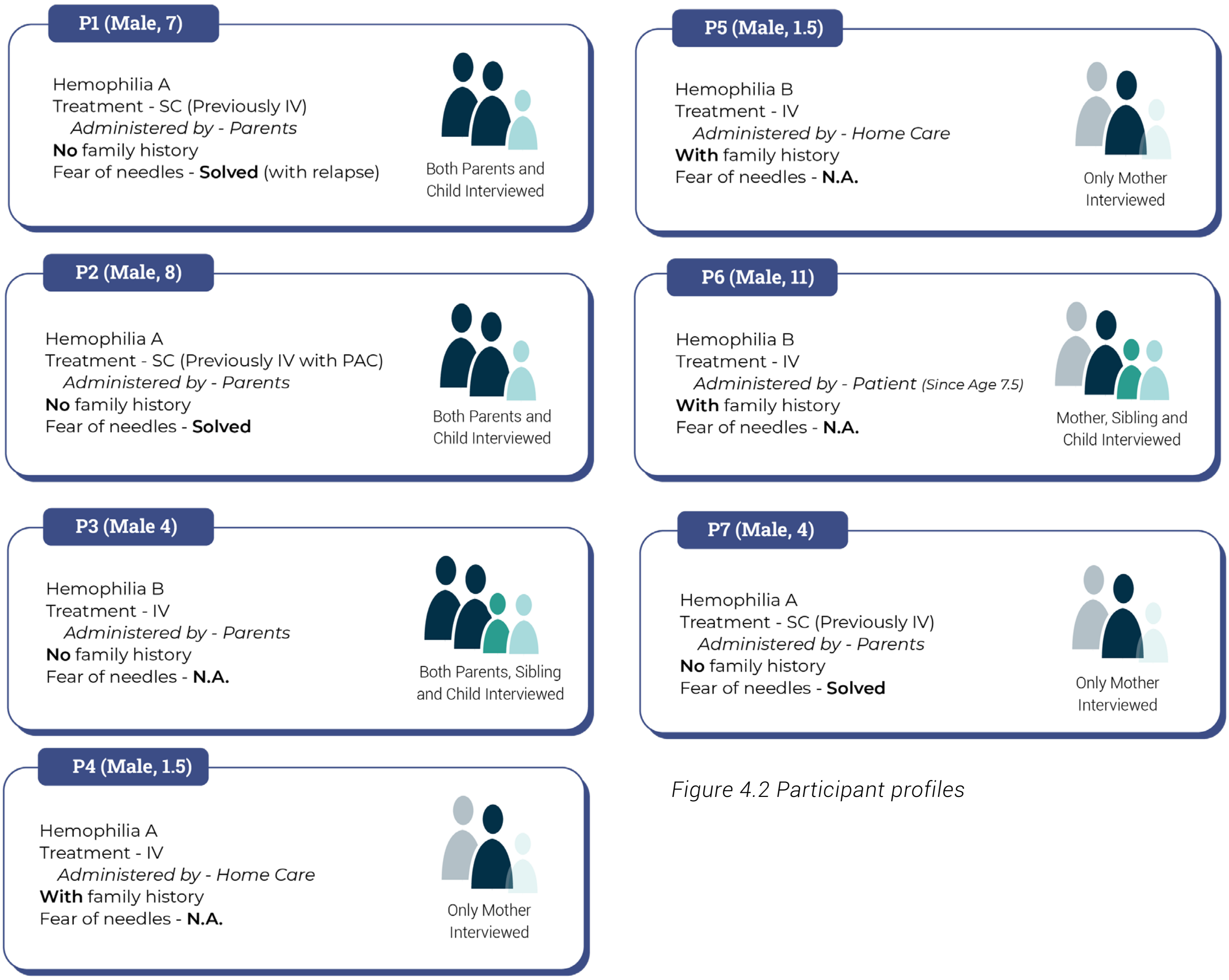


Figure 4.1 Distribution of interviewed participants

4.2.2 Selection of Participants

All participants who were interviewed were male patients of severe hemophilia either A or B, all getting prophylaxis treatment. The initial pool of patients was held between the ages of 0-8, but due to unforeseen circumstances, had to be expanded. As hemophilia is a rare disease the patient pool is relatively small, and the priority in the expansion was to have patients who could share their own experience as to not rely solely on the parents, so the range was expanded to 0-12. Some of the participants were also observed previously at the clinic, either during a consultation or during prophylaxis treatment.

The patients chosen had an even distribution of type of hemophilia, type of treatment, fear of needles and family history. The distribution can be seen in Figure 4.1. Special cases were also considered by for example, including a patient with experience having a Port-a-cath (PAC) and another with who started venipuncture at the age of 7.5, which falls within the project's target group. At the time of interviewing, none of the patients had a fear of needles but some did in the past, which were solved with a variety of methods. The profiles of the participants interviewed can be seen in Figure 4.2.



P1 (Male, 7)

Hemophilia A
Treatment - SC (Previously IV)
Administered by - Parents
No family history
Fear of needles - **Solved** (with relapse)
Both Parents and Child Interviewed

P2 (Male, 8)

Hemophilia A
Treatment - SC (Previously IV with PAC)
Administered by - Parents
No family history
Fear of needles - **Solved**
Both Parents and Child Interviewed

P3 (Male 4)

Hemophilia B
Treatment - IV
Administered by - Parents
No family history
Fear of needles - **N.A.**
Both Parents, Sibling and Child Interviewed

P4 (Male, 1.5)

Hemophilia A
Treatment - IV
Administered by - Home Care
With family history
Fear of needles - **N.A.**
Only Mother Interviewed

P5 (Male, 1.5)

Hemophilia B
Treatment - IV
Administered by - Home Care
With family history
Fear of needles - **N.A.**
Only Mother Interviewed

P6 (Male, 11)

Hemophilia B
Treatment - IV
Administered by - Patient (Since Age 7.5)
With family history
Fear of needles - **N.A.**
Mother, Sibling and Child Interviewed

P7 (Male, 4)

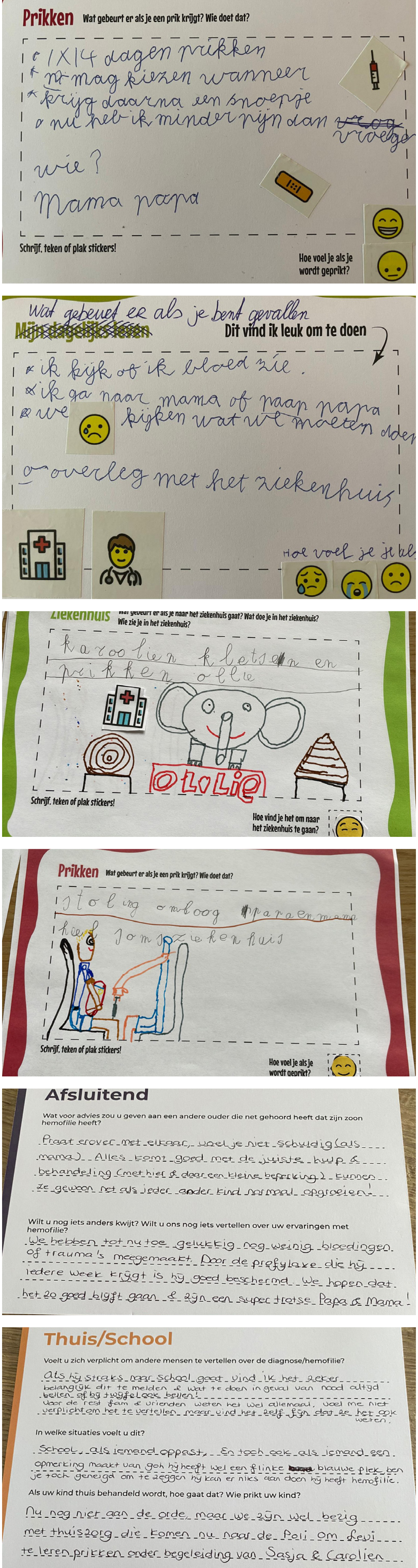
Hemophilia A
Treatment - SC (Previously IV)
Administered by - Parents
No family history
Fear of needles - **Solved**
Only Mother Interviewed

Figure 4.2 Participant profiles

4.2.3 Materials Used

Prior to the interviews, the families were sent sensitizing cards, one set for the parents and another for the children, in order to prepare them for the interviews. Both sets served a different purpose. For the parents' set, these were used to prepare the interview questions since the questions are very situation dependent. These also served the purpose of allowing the participants to think back to phases like diagnosis which was quite some time ago for many patients.

The set for the children was used as the base of the interview. By going over the cards together with the child, asking about details that they had drawn, the conversation was easily started, and the child felt more comfortable answering questions. The cards were designed in a way that there was limited input from the parents. The questions were asked in a way that the child would understand once it was read out and that the parent would not have to elaborate, and that the actual filling in of the cards could be done by the children without the parent's help as well. This was meant to avoid biases of the parents' own experiences. One unforeseen benefit of these cards was to be able to gain information even if the child was not feeling well during the interview time. The parents chose the right time for their child where they could comfortably fill in the cards at their own pace, so even if during the interview they were impatient or uncomfortable, their view was still considered. These cards were sent back a day before the interview to analyze. An impression of these cards can be seen in Figure 4.3. The templates of the cards as well as more filled examples and advice from parents, can be found in Appendix C.



Prikken Wat gebeurt er als je een prik krijgt? Wie doet dat?

° 1X14 dagen prikken
* ~~ni~~ mag kiezen wanneer
* krijg daarna een snoepje
° nu heb ik minder pijn dan ~~vroeg~~ vroeger

wie?

Mama papa

Schrijf, teken of plak stickers!

Hoe voel je als je wordt geprikt?

Wat gebeuet er als je bent gevallen

~~Mijn dagelijks leven~~

Dit vind ik leuk om te doen

* ik kijk of ik bloed zie.
* ik ga naar mama of naar papa
* we kijken wat we moeten doe

° overleg met het ziekenhuis

Hoe voel je je bl

Ziekenhuis Wat gebeurt er als je naar het ziekenhuis gaat? Wat doe je in het ziekenhuis? Wie zie je in het ziekenhuis?

karoolien kletsen en prikken ollie

OLLIE

Schrijf, teken of plak stickers!

Hoe vind je het om naar het ziekenhuis te gaan?

Prikken Wat gebeurt er als je een prik krijgt? Wie doet dat?

stoling omboog papa en mama heel som ziekenhuis

Schrijf, teken of plak stickers!

Hoe voel je als je wordt geprikt?

Afsluitend

Wat voor advies zou u geven aan een andere ouder die net gehoord heeft dat zijn zoon hemofilie heeft?

Praat erover met elkaar, voel je niet schuldig (als mama). Alles komt goed met de juiste hulp & behandeling (met hier & daar een kleine beperking) kunnen ze gewoon net als ieder ander kind normaal opgroeien!

Wilt u nog iets anders kwijt? Wilt u ons nog iets vertellen over uw ervaringen met hemofilie?

We hebben tot nu toe gelukkig nog weinig bloedingen of trauma's meegemaakt. Door de profylaxe die hij iedere week krijgt is hij goed beschermd. We hopen dat het zo goed blijft gaan & zijn een super trotse Papa & Mama!

Thuis/School

Voelt u zich verplicht om andere mensen te vertellen over de diagnose/hemofilie?

als hij straks naar school gaat vind ik het zeker belangrijk dit te melden & wat te doen in geval van nood altijd bellen of bij twijfel ook bellen! Voor de rest fam & vrienden weten het wel allemaal, voel me niet verplicht om het te vertellen maar vind het zelf fijn dat ze het ook weten.

In welke situaties voelt u dit?

School, als iemand oppast, En toch ook als iemand een opmerking maakt van goh hij heeft wel een flinke [illegible] blauwe plek ben je toch geneigd om te zeggen hij kan er niks aan doen hij heeft hemofilie.

Als uw kind thuis behandeld wordt, hoe gaat dat? Wie prikt uw kind?

Nu nog niet aan de orde, maar we zijn wel bezig met thuiszorg die komen nu naar de Poli om Levi te leren prikken onder begeleiding van Sasja & Carolien

Figure 4.3 Impression of the sensitizing cards

4.2.4 Analysis

To analyze the data collected from the interviews, Ackoff's DIKW (Data-Information-Knowledge-Wisdom) model was used (Sanders and Stappers, 2012). The model goes through 4 steps in which raw data is translated into insights.

DATA - Interviews

For each interview, the families were labeled with a participant number. In this context, the term "participant" was used for the interview, thus the whole family, instead of an individual. Each interview was recorded in order to fully transcribe, which due to the long recording times and the time constraints of the project, was not completed. Instead, the interviews were replayed multiple times, transcribing only (possibly) relevant quotes. For each quote, a label was set with which participant the quote came from, context was added where necessary and identifying features (e.g. names) were anonymized.

INFORMATION - Statement Cards

The quotes were then translated into statement cards, which are used to interpret the data and turn it into usable information. The statement cards were also labeled with from whom the quote came from and context, for easier clustering later on in the process. This was done for each interview, with various colors to identify the different participants. For each quote, an interpretation was done. In the initial statement card generation, a total of 367 statement cards, of which an impression can be seen in Figure 4.4.

KNOWLEDGE - Clustering

All of the statement cards were put into initial clusters by matching interpretations, to gain an overview of the larger themes at play. An impression of the initial clustering can be seen in Figure 4.5. The main clusters were the earlier defined phases of the disease: diagnosis, treatment and living with hemophilia, which were also used as labels in the generation of the cards. During the clustering, the cards which ultimately were not relevant in context were discarded. Within the clusters, there were themes affecting the parents, as well as the children. With this in mind, the themes that did not have an influence on the child, which were specifically about the perspective/experience of the parents, were also eliminated. In certain clusters, there were cards from the same participant which were very similar in context, of which the doubles were also (within reason) discarded. Initial links were then made between the themes, in order to understand the relation of each theme to the experience of the child.

This led to a second (more compact) clustering, highlighting the main themes derived from the interviews, which can be seen in Figure 4.6. These were then printed to re-cluster and/or eliminate where necessary, and add any extra explanation to communicate the insights of the research. These insights are explained in the next subchapter.

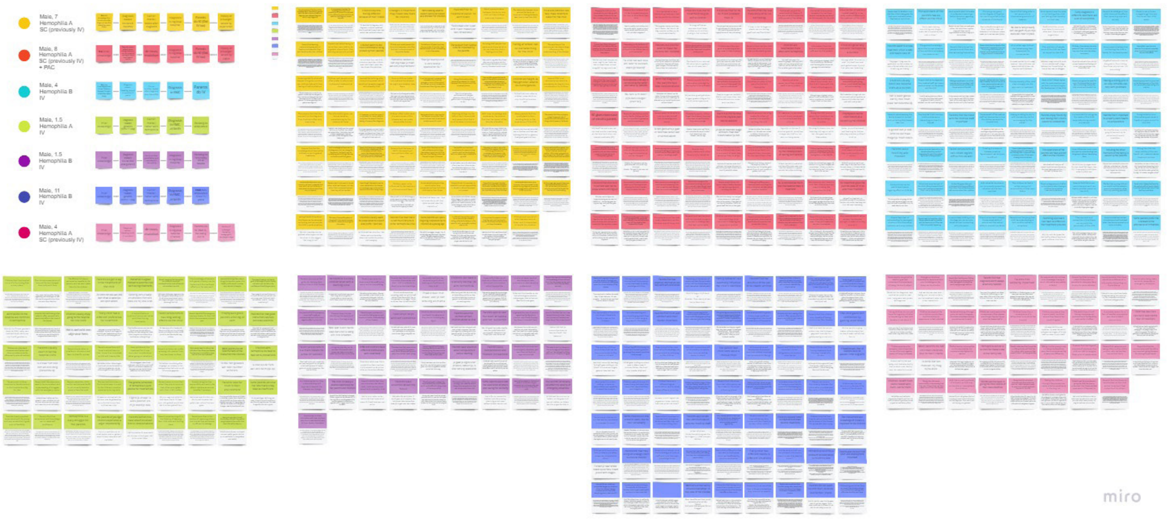


Figure 4.4 Statement card generation

Figure 4.5 Initial clustering

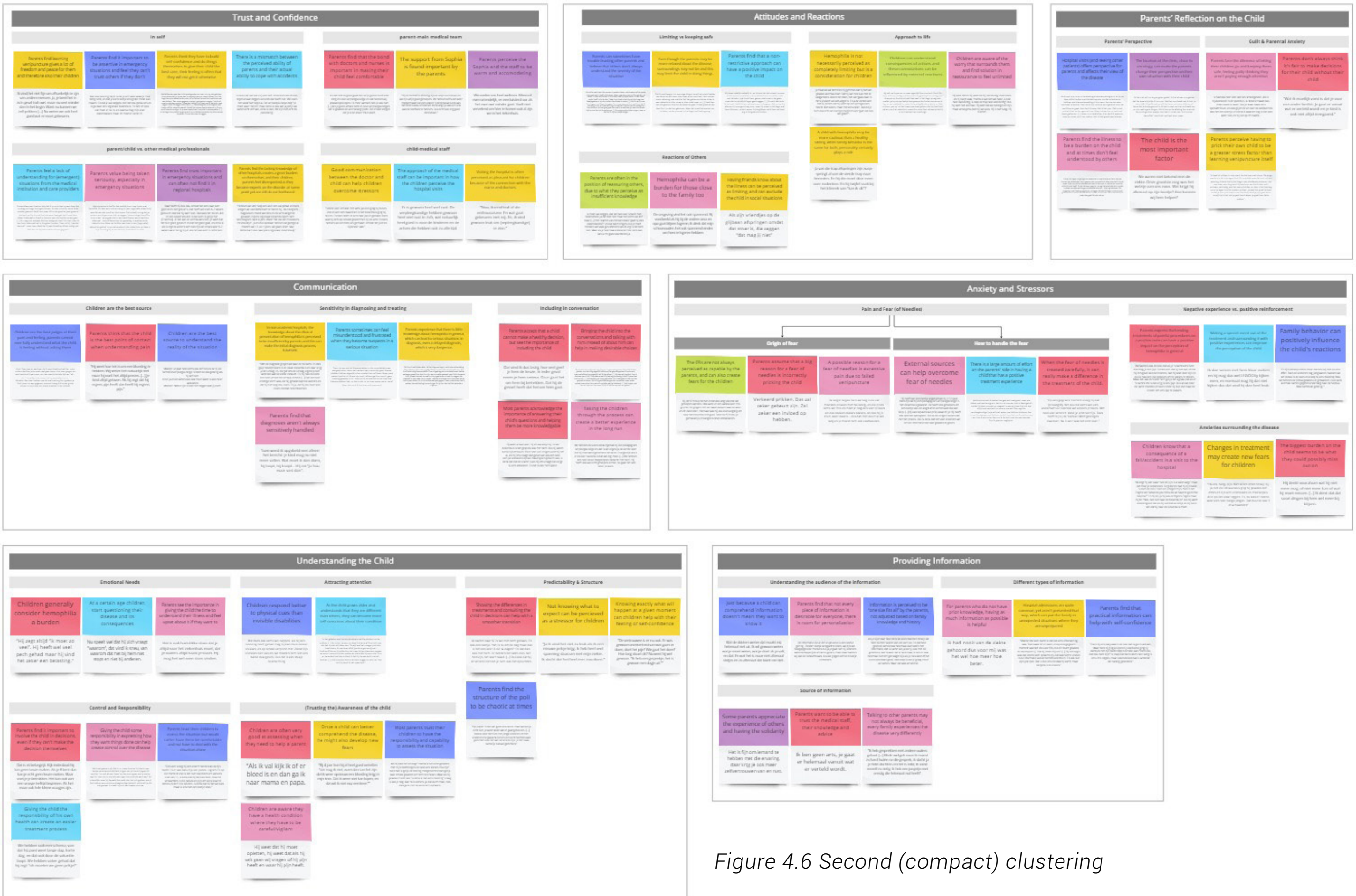


Figure 4.6 Second (compact) clustering

4.3 Research Outcomes

As a result of the interview study, some trends were found regarding the experience of the children and their parents. The outcomes and trends are divided under the research questions of this study. Figure 4.7 shows an overview of the trends that will be discussed in this section, with the relationships among the trends. The interviews were carried out in Dutch, therefore they were translated into English for this report. All quotes used in this section can be found in Appendix D, with the translation followed by the original. The main trends found in the outcomes are explained below. These findings will be further explained in the following subchapters.

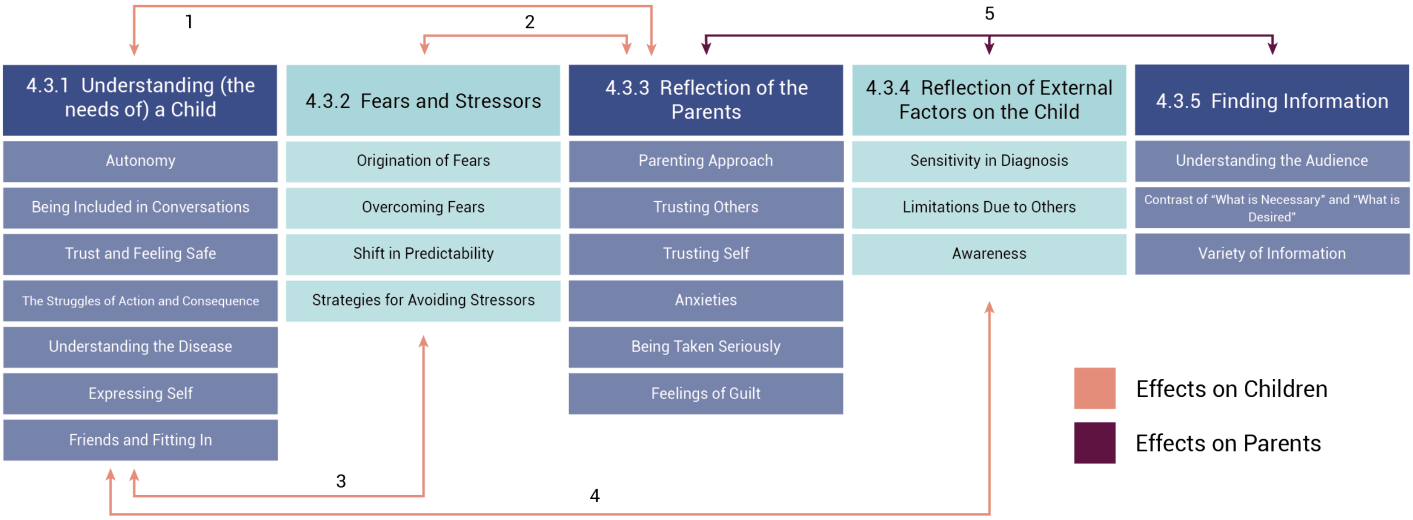


Figure 4.7 Overview of main themes in the interviews.

1. The parenting approach seems to be very relaxed, which has benefits for the child. **Most parents reiterate normalcy, and how important it is to let the child be a child, even with the consequences of hemophilia.** The children seem to be able to do whatever they like, barring some unexpected emergency situations.

2. The parents play a large role in the fears of the children, in helping overcome and pushing to avoid them in the first place. Most parents are vigilant about the care of their children, making sure they put a stop to procedures if they notice their child is in distress. Many also report that **including the child in procedures and explaining properly** has aided them in more comfortable procedures, and **closing off a negative moment with a positive experience** can aid in the reduction of the child's stress.

3. There are multiple forms of fears and anxieties. In addition to the well-known fear of needles, children also have **anxieties regarding the unknown and unexpected.** Due to their need for structure and predictability, children want to be aware of what is coming, which is not always possible with hemophilia. Due to their need for inclusion, missing out on events due to injuries also becomes an anxiety, affecting the child's approach to life, often **becoming overly cautious.**

4. The child has an intrinsic need to **feel socially included,** which due to the consequences of hemophilia isn't always the reality. Due to external factors, whether it be friends' parents who do not understand, the child's own parents not trusting others or the child himself feeling different, he can sometimes be left in positions where they are excluded from social events. The key points seem to be sensitivity, trust and awareness, which are external factors but have a significant effect on the children.

5. Parents are the main contact point, they are often in the position where they have to advocate for their child. Whether it be with other parents or other HCPs, the parent has to communicate with the different actors to get their child the care they need. There is a certain amount of **assertiveness and self-confidence** involved in this, which comes from building knowledge from a variety of information and experiences.

4.3.1 Understanding the (needs of) a child

RQ1 - What are the needs and wants of children regarding their care? Are these currently being met?

RQ3 - What are important touchpoints that a child comes into contact with, within/outside the hospital, and which of these have an impact on the experience with the disease?

Autonomy

Interviews showed the benefits of helping a child build their autonomy, by giving small responsibilities and choices, just so that the child knows he has contributed to his own care. This can be done in many ways, but an important factor to keep in mind is the child's comprehension level. One parent mentions the method they use, with comparing the procedure speed to the speed of different animals, and how it does not make a difference in how the administrator of the medication carries out the treatment, but makes a world of a difference for the child. As established before, children at a young age, mainly toddlers and play-age children, understand the world best by imagination, which seems to work well in medical situations as well. Giving this control and responsibility where the medical procedure itself is not affected can have benefits for the child and how he perceives his disease.

"It just hurts that's true, but how can he get a little bit of responsibility in that like how does he want to be injected, "as fast as a hare" and then sometimes we go too fast and he says "no not as fast as a tiger it has to be like a hare" it is the same but he determines with which animal the injection is done. We had come up with that with the nurse, in retrospect I think it's genius. That way he has a little bit of control." (Parent, P7)

Bearing this in mind, it is important to understand the limits of the child, asking the question "does capability of taking the responsibility mean that it is fair for the parent to hand it over?" The parent of an older patient who currently does prophylaxis by himself keeps mentioning how she has always trusted him from even a very young age, and mentions the deal she and her child have, that if something happens he will call immediately and they will assess the situation together, instead of the parent taking over and deciding what will be done. However, she recognizes that he is still a child, and that having to take certain responsibilities should not be an obligation.

"Once he got a really hard blow to the head. And of course there was a lot of panic. Logically. And at that moment I don't think it's realistic to expect an 11 year old child, I think he can do it, but in that panic and pain to get everything ready and inject himself… I think he can do it but I think it's a bit sad." (Parent, P6)

Most parents seem to give their child the freedom to discover the world on their own, but one parent does mention that even if her child does everything, he feels the need to reassure others that everything is okay too. This may be due to the child's understanding of the parents' worry, and wanting to avoid it, which the parent also confirms. In many cases children have difficulty detaching from their parents and fully discovering their own autonomy, without the need to reassure others.

"He knows he has to be careful, and he often yells "Mommy I can do it, I am careful, I will walk down the stairs very carefully" so he does it all. He knows we are concerned about him, but then he does everything. He is not afraid. He is active." (Parent, P7)

Being Included in Conversation

Usually a child with hemophilia will have a carrier mother and a healthy father, so the parents will not know what hemophilia feels like themselves, so they can assess the situation but in many situations it is merely a guess. This is where the child's inclusion becomes vital. That the child himself can explain what he feels and assess the situation. Parents see the value in including the child in the assessment and feel it is the most accurate identification of the issue. This is also an important part of treatment since the HCPs can also get more precise information and plan accordingly.

"He knows what it's like to have a bleed. We don't know, of course, but he always feels it exactly. [...] Always believe your child. If he says he has pain somewhere, then he has pain." (Parent, P2)

*"**Mother**: Sometimes you even call the hemophilia nurse yourself. They also like it when he calls himself. **Child**: Yes and they know more because I can sense more **Mother**: Of course! I can't say what you feel." (Parent and Patient, P6)*

One parent recalls the time that they made a decision without a child, resulting in the child becoming very sad and angry. These specific parents realized it relatively early and amended the situation, but for parents not as attentive, this issue could have manifested in feelings of rage. No matter what the age, parents see a lot of value in including the child, but also see that this is not always initiated by the medical professional. This reiterates the need to talk to the child instead of about him.

"Then I sat there for the explanation, we had the conversation, me and the doctor, but we didn't actually involve him. [...] He was still small, I think about 4-5 years old. Then after that he got very rebellious, crying, he was very angry with me. [...] We talked about him. He's very capable of having a conversation. Whether he can make good decisions, that's another story. But you can really tell him what it means." (Parent, P2)

Inclusion can also help in treatments, where treatments planned and set up with children shows the most benefits. This is not a standard in care currently, but can improve the experience of not only the children but also their parents significantly.

"We had a consultation with a pedagogical nurse and that is actually the first time that he was taken along with everything. And actually, when I think about it that way, it's really nice. [...] We came up with a very nice step-by-step plan with him. He actually helped make it, now the injections are much better." (Parent, P7)

All parents mention that it isn't realistic to give the child the deciding place in the decision making process, but that the child should have an opinion in all decisions made about him. The involvement of the child from a young age has shown benefits in acceptance and the feeling of control.

"That is so important. Look indeed, he can't make a choice. When you're 8, you really can't make a decision. But you feel involved. It can also start from an early age. Even if they are very small questions."

(Parent, P2)

Trust and Feeling Safe

There seems to be a power in managing expectations in creating trust with the child. Doing this at home is important, but also in a place which is practically the second home of the child, the clinic. One family mentions how the overall framing of "just a conversation", and knowing that tests will be done by a familiar face can help bring peace of mind for the child, which again alleviates the fear of the unknown.

"There is confidence now. There was just uncertainty of "what are they going to do, does it hurt? Who's going to do it? How long will this take?" Now he just knows. "I'm having a chat, it's just a day out."" (Parent, P1)

The interviews also highlight the importance of trusting the child and making them feel that they will be taken seriously. Not trusting the child's complaints and comments can have very severe consequences, and can make the child feel very unsafe. In some cases a complaint can be confused as trying to attract attention, as other children may also do. But in the case of hemophilia it is clear that parents and HCPs should err on the side of caution, and believe the child in his complaint. Some parents mention that they believe that even if he is faking, it is worth it to believe him rather than the alternative.

*"**Child**: Then there was one time when I had a bleed here, my parents thought yes you have to walk a lot, so then we went for a long walk and stuff, and then I was all the time 'ah... oh. .." they said don't put it like that and stuff like that. **Mother**: Once we did it very wrong, yes. **Child**: Yes and at one point I got a big tear in my muscle and had to be in a wheelchair for 4 weeks." (Parent and Patient, P6)*

"With the candies and the ice creams… if he ever abuses it, give him that moment. He just wants an ice cream, whatever. He must have taken advantage of it. Cool, ice cream. Then give him that. He is already burdened by the rest of it." (Parent, P2)

Parents and patients also highlight the importance of the trusting bond with the medical team at the hospital in making the child feel safe. All parents reiterate the welcoming nature of the team at the Sophia and know they can trust the team to make their child feel safe. The main point here is that both the parents and children feel important and taken care of, which they see in the approach of the medical team. The children are also happy with the care given, most of them mentioning their bond with their specialist nurse specifically. The bond is often so strong that parents mention the child being upset about going to other parts of the hospital for other departments, as they often define "going to the hospital" and "going to visit the specialist nurse", and feel disappointed if they do not get to see the nurse.

"If you have good doctors and nice nurses, that's just the most important thing. That ensures that your child feels at home. [...] We got that." (Parent, P1)

"We feel very welcome. All equally friendly, and a listening ear when things aren't going as well. It doesn't feel bad to come here even though we are in the hospital." (Parent, P5)

"Well, I like all the enthusiasm. And what will happen to me. And, I just like to see [nurse]." (Patient, P1)

"There is just a lot of peace. The nurses simply have a lot of peace in them, which is of course very good for the children and the doctors also have plenty of time." (Parent, P3)

The Struggles of Action and Consequence

When asked whether their child sees hemophilia as a burden, parents usually said no, however, prefaced it by saying that the fears of what may happen usually are more of a problem than what actually does happen. Parents mention the anxieties about the possibilities to be more heavy on the child than the things that happen daily, for example treatment. This also highlights the need for structure and predictability children have, as most fears are due trying to predict the unexpected. Many children are riddled with the burden of having to think, "what if". Many are afraid of what they might miss out on or what they will not be allowed to do anymore, which parents, and the children themselves, find the most visible burden that hemophilia creates. There seems to be a daily anxiety about consequences which may push the child to be more cautious, at times limiting himself.

"He mainly thinks about what he will no longer be allowed to do, or can no longer be able to do or what he has to miss. [...] I think things like that stick with him more." (Parent, P2)

"What is very irritating is, for example, you have a bleed just before a school trip or something. Or if you are going to do something fun with the class or have a party or something... I think that is the biggest disadvantage there is." (Patient, P7)

The parents say that even though they let their child do everything, it is very clear some become more careful. It seems that as children get older and see the consequences of their actions, most become more cautious. Going through certain situations does bring the understanding of action and consequence, and therefore at times the avoidance of that particular action in the future. Especially if they have had a prior negative experience, this can create a subconscious fear of the possibility that it will happen again.

"It's happened a few times that he fell very hard and had to go to the hospital, so perhaps unconsciously he does get affected by it." (Parent, P4)

"Yes, jumping down the stairs, his younger sister is already jumping down the fourth step of the stairs. And he has to think about that for a moment. And he often hesitates at the railing like "can I do this"?" (Parent, P1)

Depending on the severity of the prior experience, the awareness of the children can be heightened, where they will take extra measures to make sure that they do not have to relive it again. In many cases for a child, the fear of a negative experience takes precedence over being healthy. One parent recalls a recent event where the fear of the child was visible, and the awareness of "you need to be treated" was not there as much as the "you need to go to the hospital" was. Many parents also express their surprise in how aware a child can be of a situation and that it can bring a number of anxieties in the daily life of "what if?".

"Now he often says "no, the pain is already gone!" but you have to deny that. The day before yesterday he had his hand in the door, then I said to my husband in English "What do you think? Do we have to go to the hospital?" And he said, he really can't speak English but he said "No, no not to the hospital!" so he knows full well that if he falls hard he needs to go to the hospital." (Parent, P7)

Understanding the Disease

Most children are very aware of their disease. Even at a very young age, they are taught what to look out for and they are aware that the second something happens, they should go to their parents to assess the situation. Parents are also aware that the children know what to do, which helps in letting go, as they know the child will be there if something goes wrong. Children mostly know that they will need treatment if they have fallen, but also know their own limits in not doing certain things at all as they can see the consequence.

"If I fall, I look if there is blood and then I go to mom and dad." (Patient, P2)

"He knows he has to pay attention, he knows that if he falls we will ask if he is in pain and where he feels the pain." (Parent, P7)

"At 4 years old, he was already very good at saying "I'm not allowed to do that, because then I may have another bleeding in my knee. Then I can't walk again, and I don't want to do that again."" (Parent, P1)

Helping the children understand can have very positive effects on how the child feels about their disorder and can help them come to terms with their disease. Most patients above the age of 4, knew why they were receiving treatment and could explain that their disorder meant that their blood did not clot. The parents of these patients mention that it is important to explain things in a way the child can understand and not overwhelm them, but also that transparency is key.

"If he asks something, we also give a very honest answer, we don't make a secret of it. I think that's the power, if he asks something, he gets an answer. And that is good for him." (Parent, P2)

What a patient is able to understand is not always enough, as there is at times a discrepancy between what a child can understand and what they want to know. Some parents mention that their child will look up information sometimes online or ask questions, but others say their child is not interested in knowing any of it. Even the children themselves say that some information is unnecessary for them to know and that they are not interested.

"I don't care what the doctors know. I just want to know what you need to know, what to do if you fall, and that. And what it is, but not all substances and all that, I don't care." (Patient, P6)

Considering the child's comprehension is important in helping them understand not only the disease, but also their treatments and responsibilities. Planning with the children, setting up times to do the treatments but also to help them understand why prophylaxis is important, can help the children take control, going so far as reminding the parents to administer the medication. One family has created a family schedule, in a way that the child can understand. A 4-year-old will not know what day it is, but finding other ways to identify days will help in creating structure in when treatments will happen. For example a long or short school day will quickly help the child see if it is a prophylaxis day.

"We also have a schedule that he knows well, long day, short day, and that also runs through the holidays. We've often had him say "oh shouldn't we do the injection?"" (Parent, P3)

Expressing Self

Children with hemophilia grow up with their disease. The diagnosis takes place early on in the childhood, which means that the child will develop mentally and physically with the awareness that they have a chronic disease. As the child grows up he will start understanding cause and consequence and comprehend that their "bad luck" with falling, bleeding and having to go to the hospital is actually due to their hemophilia, and this can bring feelings of frustration and annoyance. This is also clearly visible in the patients interviewed. After the age of 4-5, most patients start questioning their situation and start to understand they are different from their peers. For many, the time when these questions came up, there wasn't a standard space for these feelings to be discussed, causing for a build-up of frustration.

"Now he asks himself "why", I think that's sad, why [the bleeding] doesn't stop with him and not with others." (Parent, P3)

For some, acceptance comes easy, these were mainly the patients with family history and examples of others with the illness. This draws attention to the loneliness the disease can bring to those who suddenly are different from their friends and even family. However, even those who do accept the situation, can find themselves in situations where they feel the burden of the illness and need a moment of venting. An example is an 8-year-old participant, who has been through various treatments and procedures, with some bad luck, but has grown to understand and accept his disease. He and his parents do still mention the occasional feeling of frustration and sadness.

"He always says "I have to do so much". He's had a lot of bad luck, but he definitely thinks it's a burden." (Parent, P2)

Most parents understand the need of the child, to vent and feel understood. Where some have a fully positive outlook on life and see the benefits of fully positive encouragement in words like "it will all be okay", other parents mention the need for full transparency and that dealing with the disease should not always be rose coloured, that the child needs the space to vent. This does become interesting when seeing that the children do not seem to know how to express their emotions, and the parents, however willing, do not know how to give this to them. A parent, who was coincidentally a child psychologist, says that her child was too young to understand now, but that she found it to be vital to give the space to share when the time came and he started grappling with the facts of his disease.

"It is also very frustrating that you always have to go to the hospital, that your parents are always next to you. He is allowed to feel frustrated about it." (Parent, P7)

Friends and Fitting in

Hemophilia is mainly an invisible disease, but at times the internal effect can be detrimental. If there has been a bleed, it is important to keep it in check for the few days that follow, which is difficult when it is not visible. However, it is difficult for other children to understand the situation if they cannot see it. Children respond to visual cues, like crutches or wheelchairs, otherwise there is no reminder and they will forget that something is wrong.It is only normal that children want to play with their friends, and it is difficult for that to suddenly change. One parent mentions the solution they found, where they use crutches even when it's not medically necessary, just so that others see that the child is injured. She mentions that they have a pair of crutches at home ready for these situations, and have seen the benefits in knowing her child will be protected at school.

"We also fake it sometimes. If he has had a bleed, he can walk around at home without crutches, and at school he has to walk with crutches. So that his friends see "oh, we shouldn't give him a hard shove". So it's a bit of protection." (Parent, P6)

The invisibility of the disease can also have the opposite effect, where other children may misunderstand the disease, and limit the child in the things he can do. Most parents and patients acknowledge that this is mostly done in kindness, with other children trying to be "protective", but can come off as a difficult limitation, excluding the child.

"If his friends jump off the slide because it's cool, they say 'you can't do that'." (Parent, P1)

Visible cues are not always in the child's benefit though, as one parent shares the unwanted attention that her son no longer enjoys. Prior to IV, the children will have numbing cream applied, even at home, which will stay on for about an hour. The fact that it is visible can open conversations that the child does not like taking part in, and also will again reiterate the difference of the child from others. Most children do not enjoy this extra attention and prefer to hide their visual cues.

"In the past it was like something cool with the plasters after the injections. [...] Now, after an hour he takes it off. So there's something he doesn't want to show. While it used to be something very tough. And we always do [numbing cream] with cling film, so he didn't want to go out with that. Sometimes we go out to play in the evening, and sometimes he doesn't want to. So something changed in that I think he doesn't want that attention. [...] People he doesn't know also say something about it. I don't think he likes that anymore." (Parent, P3)

4.3.2 Fears and Stressors

RQ2 - What are possible moments that can create negative experiences for the children, are there existing strategies to overcome them?

Origination of Fears

At the time of interviewing, none of the patients had a present fear of needles. There were some patients of whom the parents mentioned having a fear in the past, especially after a related trauma, but they were treated for the fear. Patients have had experiences at the emergency room of different hospitals, where the venipuncture was rushed, or poorly done. Parents mention that after this experience the children were scared of needles, and were very difficult to treat, with one of them (at 1.5 years old) not allowing anyone to touch him, let alone treat him. In the long run, the fear can cause rejection of treatment, which can be dangerous. Most parents mention their bad experience with the emergency rooms, with most of them criticizing the behavior and injection capability of emergency staff. Some preface this by saying they understand how busy an emergency room is and that they do the best they can, but that for them their own child is the priority and they want the best care, which in many cases they do not receive.

"At the ER it took forever before we were helped. He was also injected wrong a few times. They went to search for the vein with the needle and it hurt. He was also afraid to go to the hospital. You could easily develop a fear of needles from the emergency room." (Parent, P4)

"Wrong injection. That must have happened. Must have had an impact." (Parent, P2)

"The fear started when we still had to inject the vein with home care, and sometimes it didn't work and you had to puncture again and then search... [...] It takes a long time and you also have to hold him." (Parent, P7)

Overcoming Fears

Some parents of children with a fear of needles shared their approach in dealing with the situation. It seems the main point is including the child in the process. Giving the necessary information, and allowing them to identify their needs and wants seems to help with avoiding or even overcoming fears. This being said, the parents also highlighted that when necessary external help can be helpful, in which case they expect the HCPs to take initiative and refer them to the appropriate person who can help. When timely and properly handled, children seem to forget they had the fears in the first place. However relieved the parents are that their child does not remember the experiences, they repeatedly mention how horrible their child felt back in the day and wished it did not happen at all.

"He did have a bit of fear at 2.5-3 years, when we went to a pedagogical nurse in the hospital. It helped us to get rid of that fear a bit, which also helped. [...] He can determine who injects, where he sits. He also has special toys. So all those things do help with the process. So I think it's okay for children to just give the information anyway." (Parent, P7)

"At one point he got [a fear of needles]. It sometimes took an hour and a half before we could inject. With a lot of sadness. [He] really didn't like it. Then he got

EMDR about it at the Sophia. After 3 times it was really over." (Parent, P2)

The feeling of trust once again plays a role too, with the approach of the HCPs being an important factor in overcoming fears. Parents see importance in how the fears are handled by doctors and nurses, whom the parents look to for making their child feel safe. Flexibility and accommodation seem to be key factors.

"Every time he saw someone in a white coat, he cried. Every time he saw a needle in the hospital he cried. And then the doctor took off her coat. Then he even climbed onto the doctor's lap!" (Parent, P1)

Shift in Predictability

For all children, it seems like not knowing what to expect creates one of the biggest fears. One patient, 7 years old, recalls the recent change in treatment from IV to SC, saying that even though the new treatment is much less painful and easier, he was very scared when the switch was happening. The parents mention that he is a person of structure, and changes bring him panic. Having gotten used to IV, though much easier, SC treatment gave him months of stress. The parents mentioned hearing this from others as well, for children switching treatments.

"Crying, scared, pain. Not wanting to sit while he, with that IV he just sat himself and stretched out his arm and helped get all the stuff ready. And, suddenly there was a different, very scared boy. " (Parent, P1)

"I don't like it very much when I get a new shot. I have a lot of stress about that with my illness. I thought it would hurt really bad." (Patient, P1)

An interesting point to mention is the different approaches to the switch in treatment. It is very clear that the fear of the unknown plays a role in this situation, as other parents mention taking their child through the process and showing the options can help avoid the fears from originating in the first place. Creating predictability and showing what to expect can be a defining factor in how the decision is perceived. In the case of the participant with the fear, nothing was shown and he was only told that he would be getting new treatment after having another treatment for 6 years. When a child has only known one thing for his own life, it is difficult to change to something else, especially when the consistency is suddenly lost. Another family highlights the benefit of mentioning the positives of the new treatment and showing every detail of the new situation, which in turn manages the expectation of the child.

"The switch to SC is done with him. And also a bit of, "it's every other day now, but then it's once every 14 days!" And that with him. They showed it, the medicine, the kind of needle. [...] So also that he sees the difference, that you also see him relieved." (Parent, P2)

Strategies for Avoiding Stressors

Families have varying opinions on how the clinic is structured, some mentioning the chaotic nature of the clinic, and how not knowing what will happen that day can create panic. Some parents find that it does not make much of a difference if they know prior to the visit all the details of what will happen, but the approach of the parents and the personality of the child plays a role in what is expected of the predictability. Within the interviews, 5 of 7 participants said their child would prefer knowing the setup of the day before going there. With the observations done at the clinic prior to the interviews, it was clear that there was a chaotic atmosphere. As another parent also mentions, for someone who has not yet overcome their fears, the space can serve as a catalyst. All parents acknowledge that the clinic has low predictability where they are informed of any tests or treatments in the consultation room, which means most of the time the child does not have sufficient time to prepare themselves.

"On paper it is structured, but in reality it is not. You never know what will happen. [...] Especially for families with young children or with children who cry easily and are really attached to faces, it would be annoying. You often see new faces." (Parent, P6)

In treatment, parents see power in creating predictable positive experiences that follow the negative. Most parents have a structure with their child where the child can close off the painful treatment moment with a positive activity. Parents mention making these special moments, like letting the child eat something he normally wouldn't be allowed to. This seems to create a more positive perception of the otherwise painful event, and they are less likely to run away or reject treatment. This also serves as a good distraction from the painful event as the excitement about the positive activity afterwards often overshadows the negative start.

"First time he had [a bleed], or the first one he could remember well, he had his tooth through his lip so I had given an ice cream to cool, to clot. But that was the signal for him that, if there is something at night, I get an ice cream. So when we had to poke through the night, he quickly ran to the freezer to get an ice cream." (Parent, P2)

"I do the preparation together with him and he can watch LEGO City for a while, and normally he is not allowed to watch that so he really likes that." (Parent, P3)

4.3.3 Reflection of the Parents on the Child

RQ3 - What are important touchpoints that a child comes into contact with, within/outside the hospital, and which of these have an impact on the experience with the disease?

RQ4 - How do parents and children experience living with hemophilia? Which experiences of the parents, if any, have an effect on the children?

Parenting Approach

The parenting approach of participants were quite similar, all of them being very open and relaxed about the situation. All parents interviewed had the approach of not limiting their child, and letting them do whatever they want. Parents recognize that there is a very delicate balance of limiting their child and keeping them safe. Most parents who were interviewed mentioned that they had created that balance well with time, letting their child roam free, dealing with consequences if necessary. Parents do also express the need to keep watching their child, but to try to do that passively, not stopping their child but just keeping a safe eye.

"Just let him do that and who knows, it will go right 10 times and once wrong. Yes, that can happen. But that is the way of letting go, which people find very scary in the beginning." (Parent, P1)

"We are fairly easy-going, and I think that makes a difference. I think you have to pay extra attention, of course that is part of it, like with the helmet. Yes, you just keep an eye on him more, but that's not always about saying things." (Parent, P3)

Parents play a large role in the child's perception of the disease and the possible development of fears. Most parents interviewed mentioned that they did their best as a family to accommodate the child, especially because they know stories of other patients and what happens if they do not pay that extra attention. Parents obviously do not like seeing their child fearful and in pain, so they do their best to avoid it.

“It’s going really well, but we’re putting in a lot of energy. It’s not easy. It was partly successful because he reacts so well to it, but we always do it with extra attention, at least we try. Then the nurse says “yes you don’t want to know, we have children here in a headlock with left and right” well I couldn’t watch that. As a parent, I really wouldn’t be able to see that.” (Parent, P3)

Some parents also mention the importance of normalcy. Treating the situation like any other and just going on with their day as normal, seems to keep the child calm, and accept the consequences of the disease. The parents mention that this way, when the child looks back, he won’t remember the bleed but the time they played a special game or in one family’s case had pizzas in the car together. Which seems to also help with the feeling of guilt, where when the situation is handled with panic, the child feels that it is “his fault” for causing it and creating a burden on his family. When the situation is handled with normalcy, it just seems like it is just a part of the day for the child, and also for the rest of the family, not leaving space to place blame.

“When the kids were young, we had just put pizzas in the oven and he started bleeding. Well we just took out the pizzas and ate it all together in the car on the way to the Sophia. It was really nice.” (Parent, P6)

Trusting Others

Many parents find it difficult to trust other hospitals, mainly due to prior negative experience, and find solace in the trust they have in the team at the Sophia. Many parents mention that they find it is worth it to drive for hours, because they trust the care that will be given to their child. In many cases this is also a point that gives the feeling of safety for the child, seeing a familiar face and being less scared of a procedure.

“So he has also been there, because it was pricked a few times and it was not successful, that took 6-7 weeks before he could go again. [...] If there is an emergency situation, I will come here [Erasmus] right away. I do have the confidence here, you know that things are going well here and that things are going well, and I think if I go somewhere else then we will be back to square one in 6-7 weeks. I prefer to come here if I can.” (Parent, P5)

As hemophilia is a disease that has to be treated relatively quickly though, this is not always possible. In these cases the parents are very happy about the accessibility of the medical team, any time they need. This is also helpful in building trust as the parents mention the helpfulness of the HCPs even with the smallest questions that may be bothering the parent or child. This contact is mostly done by parents, but in one specific case an older patient, he mentioned calling the line a few times, for a question or at a moment of a fall. This accessibility makes the patients and parents feel important and taken seriously.

“They are always available at the hemophilia department and we have always received good help. We even once had a doctor call us while refueling because it was so important to have us on the phone. So it's really very easily accessible.” (Parent, P1)

Trusting Self

There is a learning curve in treating hemophilia, and many parents become experts at it with time. In the beginning parents report a lack of confidence, where with time they are sure they know how to assess and treat a situation. There is an interesting dynamic though, as parents become confident in their medical abilities and position as a caregiver, where the HCPs doesn't always agree. Parents mention that they don't always agree with the approach of the HCPs.

They feel like the perception of what the HCPs thinks the parents are capable of doing, does not match with reality. The balance of confidence and overconfidence comes into play, where the parents mention sometimes feeling undermined in what they are sure they know well.

"I don't like being dependent on other people. Yes, in this case you often are, but now much less than in the beginning. Because now we can do the injection ourselves. [...] Now we also know very well what needs to be done." (Parent, P1)

"I think we also quite often say to each other, maybe a little too much, 'oh, that's not necessary'. We've been doing it from the start. The nurse says "you should call more often" but I also think yeah [jeetje], we really know it ourselves, that's what I think at least..." (Parent, P3)

Parents also mention trusting themselves or their family at times more than the advice of the HCPs. Some parents have experienced moments with the HCPs whom they experienced to be "too cautious" about certain situations. Parents mention that they do follow medical advice, but do not always agree with the choice. In the case of one family, the medical advice kept them from going on vacation which the parent found unnecessary, which also ultimately limited the child from going on a family vacation.

"It was actually the intention in the first instance to go to Austria, my cousin was also there with her son [with hemopilia]. And then he would have to be injected once in that week. And my cousin had indicated, that all three of them can do it [the cousin, her husband and her son], "we will do it for you". I thought that was a great idea, because they know exactly how to do it, I have that confidence in them. But they didn't think so here [at the Sophia]. So with that responsibility, they said we'd rather he go to the hospital. And I didn't see that myself." (Parent, P5)

Anxieties

For parents, venipuncture can be an emotional struggle. Even parents who themselves come from the medical world and do venipuncture on a daily basis, express the difficulty of treating your own child. They mention that there comes a moment where you have to disconnect from your role as a parent and become the caregiver, doing the healthy thing for your child no matter how painful it may be. This also correlates with the findings in the literature review, with parents finding the balance in their new roles. It is also important to consider that for parents that cannot create the balance as easily, their fears and anxieties may reflect on the child and create deeper anxieties about treatment.

"I was already doing injections in my work so it wasn't new. So the only thing is it's your own child. And it was some getting used to for me, I think that at the beginning at the very first times, that was more of a thing because he was crying then, really extremely sad, shaking his head no, and then it is very sad to inject your own child. You know to do it because you're helping him but it feels like you're going to hurt him, when it's not that, you're going to help him, you're going to make him better." (Parent, P1)

Being Taken Seriously

Parents feel that due to their position as the

parent and not a medical caregiver, many medical prohfessionals do not take them seriously. In many cases a parent can be well aware if something is not going well and can assess their child's needs. When this is undermined or not taken seriously, it can make the parent feel like their child is unsafe and create mistrust in emergent situations. One parent mentions a situation she was in with her son before the diagnosis, where she had to fight to get her child the best care and still was left in a dangerous position. Parents want to feel like if they say something is necessary, that it will be taken seriously, so that in turn they can trust the medical advice they receive. In this case, the parent mentioned the mistrust she still had years later, due to this in combination with another event, constantly researching for more information herself, just in case the advice was wrong. In the bond between the family and HCPs, there should be a mutual trust, which for some is not the case.

"I was just a bit annoyed that I had to try so hard that Sunday to come by. And then it's nice I think that as a mother I just think "but this is not good" and just go there. And I also thought it was very strange that I had to go to the Sophia with him alone in the car completely covered in blood. [...] I also asked if it would be okay, because I have to drive and I can't keep an eye on him at all. Then he said "no, you can", but then it turned out that he needed a blood transfusion. What if he had gone completely cold?" (Parent, P3)

Specifically in the care for hemophilia in regional hospitals, parents do not think that the awareness is enough. In many cases the parents are turned away, or made to wait, which the parents are at times frustrated about, since they themselves know that treatment has to happen fast but cannot do it themselves. Parents mention feelings of helplessness and hopelessness especially when they are, as they refer to it, "belittled". They mention being well aware of their child's needs but that in certain cases they are made to feel like they are exaggerating and that they lose some self confidence. This puts the child in dangerous situations, making the experience more negative than it should be.

"Later we had another fall and then we were told by Rotterdam [the Sophia] that he had to be neurologically checked and [the pediatrician at the regional hospital] simply refused to check him neurologically. Because "it will be fine, little miss". Yes and so from then on we said even if we have to drive 1.5 hours, we would rather go to Rotterdam than to [a regional hospital]." (Parent, P1)

"That makes such a difference that you are taken seriously that they say 'okay severe hemophilia come on through' and you don't wait in a waiting room first. Hemophilia centers are great, in academic hospitals. But we went to a [regional] hospital once, to a non-academic hospital, and there my experience in the emergency room was... very bad I thought." (Parent, P7)

Many parents talk about the learning curve when it comes to gaining the confidence to speak up. The parents interviewed who are at the start of their journey mention that they understand that the emergency room staff is busy and are doing the best they can, and that they don't want to be a nuisance. The more experienced parents confirm this defense but also mentioned that with time they notice that they can achieve more by speaking up. Parents mention the importance of being well informed about your child's situation and having the courage to stand up and tell the HCPs what they need to do to give better care and take the situation more seriously. Most parents mention the emergency room staff undermining them, and that having this information can overcome that, as the HCPs will not have anything to object to.

"What really helps us is that you know what you're doing, and that you can have a bit of a big mouth. And that you can say, suppose it happened and I go to a regional hospital, "I have this stuff, it has to go in now, and then you can examine my child, but this has to go in first". (Parent, P6)

"In the beginning you are the waiting parent. Yes, they're busy, we'll be next. Then at some point, you're just going to say, "My child needs help now." But then they're like, yes, you can say that, but that's what all parents say. [...] Gradually you actually learn a bit about the hospital world yourself. Because it is also a bit of a profession. So you're getting more empowered. And you know better and better how to handle it. [...] Now we have the right people sooner. Dare to say something more." (Parent, P1)

Feelings of Guilt

Parents feel guilt in different situations regarding their child's disease. They feel like they have to constantly watch their child and make sure they are safe. However, if during the watching the child gets injured, the parent is likely to feel guilty about not being careful enough even though this may not be the case. At times this can manifest in the parent subconsciously being scared that they are not watching the child enough, and therefore limit the child from doing the "dangerous activity" completely.

"I also had a lot of guilt. For example, if I was on the playground, I was standing next to him, I would never sit. So you're standing next to the playground equipment, and then he slides over the grains of sand and I think why didn't I see that and he fell on his head..." (Parent, P7)

Parents do grapple with this guilt daily, some mentioning that they feel like they feel sometimes they cannot protect their child enough, and at times they let limiting words like "stop" or "watch out" slip out. Many mention feeling bad about this as well, with one mother saying that even though these are words any mother would say, it makes her feel guilty because she's specifically thinking about the consequences of hemophilia, and that she perceives it as the limitation of her child due to his disease. which she does not want to do. The internal struggles of parents seem to pass with time as they learn more about the disease and gain experience, but the effects on the child until that transition happens is not clear, and parents do mention that without willing to they might be reflecting limitations onto the child which they in turn internalize.

"I sometimes feel like a, well not a bad mother, but all the time I'm like 'watch out, watch what you're doing, watch where you're walking'. Then my mother said, "But other mothers also say that to children who are just starting to walk, it's not because he has hemophilia". But I do have that feeling sometimes. Sometimes I feel really bad about it." (Parent, P5)

Parents also feel guilt about deciding for their child, since they are not old enough to do so themselves. Medical advice is seen as a priority as the parents want what is best and most healthy for the child. The parents do feel the burden of the decision since they know it has to be made, and the children aren't always happy with the result, so a decision made by the parent can have long lasting negative results on the child.

"What I found difficult is that you decide for someone else. You assume what is being told is right and your child is not always happy about it." (Parent, P2)

4.3.4 Reflection of External Factors on the Child

RQ3 - What are important touchpoints that a child comes into contact with, within/outside the hospital, and which of these have an impact on the experience with the disease?

RQ5 - How do external factors and actors affect the child's perception of the disease?

Sensitivity in Diagnosis

For families with a genetic history, the diagnosis is usually expected, but not always handled the best way. One parent remembers having to wait for her child's diagnosis, even though she was sure that he had hemophilia. She mentions the frustration of not being able to get answers and having to wait for an official diagnosis, where with her older children she had immediately heard that they didn't have hemophilia. She mentions that getting the diagnosis should be a faster process, and that it should not be necessary to wait for a child hematologist to have time to explain the situation. For most parents with prior knowledge, they explain just hearing a yes or no is often already enough.

"They immediately came with my other son, a nurse, who said 'he doesn't have hemophilia'. And now the doctor won't come until tomorrow, I thought "ohh he has hemophilia". But it had to be the pediatrician who had to tell me." (Parent, P6)

For families without a genetic history, the diagnosis can be quite a shock, and is not always handled with the sensitivity it deserves. One of the families had a very traumatic situation, first hearing about their child's diagnosis from a doctor who they described as not knowing anything about hemophilia. They were told that their child would be disabled and would not live long, and referred them to the Erasmus MC. In most cases the parents are given a blunt diagnosis, at times a wrong one, which kicks off the journey with a very negative outlook.

"[Pediatrician at regional hospital] gave us the results, not really knowing what the disease is. And so he had told us a very wrong story. [...] That was the severe kind, that he would become handicapped and that he would not live long. And that he would very soon end up in a wheelchair." (Parent, P1)

"Then I was called with only the message: your child is no longer allowed to fall. What should I do then, he walks, he crawls... He said "Yes well, hold him then"." (Parent, P7)

Some parents mention being accused of child abuse due to the bruises on their baby, being told it could not happen for any other reason. 3 of the families interviewed had an experience with the suspicion of child abuse, with two of them being questioned about it but quickly being let go, and one of them experiencing a prolonged suspicion, ultimately delaying the diagnosis. They mention feeling helpless, and also feeling scared to go back to the doctor. In hindsight they say their child went 2 months without treatment, which they recognize as a problem that could have been avoided and that they did not know better than to trust the HCPs. This once again highlights the mistrust that can be caused by a lack of knowledge, going as far as delaying a diagnosis and putting the child in a dangerous position. Most families are then told at the Sophia that it is in fact a manageable disease, and this experience creates a bond between them and the Sophia, knowing that they can trust the staff there.

"Unfortunately, I often hear that the diagnosis starts with child abuse. That they think, this is not possible. It doesn't happen often, of course. Our child had severe bruising. Because of the behavior of the health center we waited longer and because of them we were so insecure, because it is the first child. You don't know what's normal, so you assume what they say is true. It makes you so insecure. Which means it takes longer that you call a doctor. And now it all went well, but in the meantime he could have had a brain bleed. And yes, then it would have all looked different." (Parent, P1)

For another family the diagnosis came from the Sophia, with initially a "wrong" diagnosis, leading to an injury that could have been avoided. The mother mentions how the tests were not enough and that her son was diagnosed as a moderate hemophilia patient whereas he was severe and should have been treated that way. The parent then went into the literature, finding evidence of disabilities and getting scared, then fought for new testing for her child. This "misdiagnosis" is explained by the hematologists as not a mistake, and that his levels must have dropped in between the two tests, but the mother still seems to have an underlying mistrust, wanting to be in control of all the information. Which is also seen in the behavior of other parents, where the trust is very fragile in the beginning, and has to be built properly.

"So we were diagnosed with moderate hemophilia, so no prophylaxis was given. [...] And now they did the extensive test and then it suddenly turned out to be severe. I found that very annoying. Then I thought, yes guys, so we could have prevented this bleed." (Parent, P3)

Limitations Due to Others

In some cases parents mention the limitations others can create for the children. Some mention the lack of trust they have in some other parents as they don't find their approach fitting for a child that has to be watched and cared for. This usually goes in two ways, (1) the parent will not allow the child to go to the event at all or (2) will have to take extra measures, mostly go to the event themselves and carefully watch their child. Most other parents seem to be too vigilant, limiting the child from doing activities because they don't know the consequences. However, there are also cases when children are not invited to parties at all if the parents organizing it do not feel like they want to take the responsibility, when dealing with a number of other children at the same time, once again creating limitations for the child due to his disease. Parents do mention the burden this creates on the children, feeling very upset that sometimes safety does have to take precedence.

"But I do find it irritating when my child goes to a party and there are parents who get stressed. [...] I'm not going to say "come home with me because I see that this isn't safe for you" but I'll make sure that I'm home for the rest of the afternoon that if something goes wrong then I have to I'll be there because the mother wasn't watching him, I think that's a shame. [...] Some parents don't look at anything, and I find that a little more difficult with him." (Parent, P6)

Awareness

Parents believe that there is a general lack of awareness about hemophilia, and do talk about that since it is an invisible disease, it is difficult to imagine the possible consequences. The parents realize how the diagnosis of "blood coagulation disorder" can bring a number of anxieties to others, and find themselves in the position of reassurance, letting others know that "it's not actually that bad". In many cases, due to this lack of awareness others can be anxious about taking the responsibility of a child with hemophilia, which can create unwanted limitations for the child.

"Others also find it exciting. For example, if he is going to stay with his other grandma and grandpa, I think my parents-in-law will also find it exciting to have him stay over." (Parent, P7)

"I must say that awareness makes a big difference. [...] With reactions from people such as "will he bleed to death?!" and things like that, so you often have to reassure people that it's not that bad. But if you're completely unfamiliar with it, I can imagine [you think that] yes." (Parent P4)

Most parents do acknowledge the burden that hemophilia creates for the children, but also mention the perspective change that seeing other, more burdening diseases can bring. Given the fact that the hematology department is next to the oncology department, a lot of the patients and parents come in contact with the oncology patients. This is mainly due to the fact that the two departments work closely together, but creates an unexpected effect that is reflected on the visitors of the departments. Due to the more visible effects that cancer can have, parents mention in multiple interviews that it is very easy to underestimate, forget even, the severity of hemophilia as they can see their child play around, where the other patients are visibly not able to. When asked if they see hemophilia as a burden many say yes, but preface it by saying it could be much worse so they are grateful for the treatment that is available. The invisibility of hemophilia does have an effect on how it is perceived. When the parents themselves can underestimate the severity at times, it is only logical for others to not understand how severe the disease can really be. The presence of visual cues are often key in creating awareness in medical situations, which hemophilia often does not have.

"When I'm in the pediatric hematology department with my son, I see all those kids with bald heads, because they have leukemia, with the tube feeding in their nose, too

tired to walk across the room. Then I see my son going through the waiting room, full of life, then I think what am I talking about. [...] Life is so fragile, then I think why do you have to make such a point of it. It is very manageable to live with." (Parent, P6)

"With the example I have, yes, of course I was disappointed, you would rather not [get the diagnosis] of course, you would rather have that your baby is healthy. I had so many examples of much worse things. When I'm here in the department with the oncology [next to it], you know, I'm like "it's just hemophilia". It sounds really stupid but..." (Parent, P5)

4.3.5 Finding Information

RQ1 - What are the needs and wants of children regarding their care? Are these currently being met?

RQ6 - How is the provided information perceived by the parents and children, is it sufficient?

Understanding the Audience

The key in providing desirable information seems to be understanding the audience. Parents come from very different backgrounds and use different languages in their daily lives. Some prefer more scientific information where others want simple, practical information. The current information is delivered in one specific method, which is not always fitting in the needs of the parent or the patient. Most parents have complaints about the way the information is presented, especially during the diagnosis. Some mention that information is delivered the same way for everyone, sometimes too detailed, given that many patients have a family history and already know a lot. Others prefer the overload of information, mostly those with no prior knowledge, to be able to cater to their child's needs as best as possible and sometimes find the information limited in its presentation, looking for external sources themselves. Most of the parents do mention that the Sophia provides sufficient information and they always have the space to get answers to their questions. Parents definitely see room for improvement in providing information, especially with considering the family history and background.

"That whole conversation we were completely overloaded with information, that I thought yes sorry, also with the geneticist, I already know, I didn't ask for this at all! If you don't know anything or it is a spontaneous case, I understand that you would like to know more. But that was annoying." (Parent, P6)

"I found the information you get a bit limited. Without being a bit arrogant, we are highly educated people, so yes, you are not going to give scientific articles to everyone, but we did have the need for that, so we went to investigate a bit ourselves." (Parent, P7)

"Everything is always well explained. Always with direct lines. We never felt that we didn't have enough information." (Parent, P2)

The HCPs often mention the Cyberpoli website and mention how useful the parents find the website. However this seems to not correlate with the interviews. Out of the 7 patients interviewed, 1 did not know about the website and 6 mentioned having looked at the website, finding it unnecessary/not interesting and since then not going back. These parents (n=6) stated that the audience of the site does not seem to be clear, with the parents finding it too childish and the children finding it too medical, filled with information they do not need. Parents mention trying to use the site in the beginning after the diagnosis, but not finding answers to their questions and therefore abandoning it completely. Parents also confirm the initial assumptions made about the website, finding it overwhelming and too theoretical when the expectation is that it would be full of practical information. The website seems to not be as useful as it is perceived and has room for improvement, reiterating the importance of considering the audience of the information. The parents find that it is a great initiative with lacking execution.

"Cyberpoli is really a bit too baby language for me. Too little information for me. I would have liked an adult version of it." (Parent, P7)

*"**Mother**: Have you ever looked at Cyberpoli, to see if anyone you know has been featured, yes, but have you ever done anything with it? **Child**: No. **Mother**: I didn't think so." (Parent and Patient, P6)*

Contrast of "What is Necessary" and "What is Desired"

There seems to be a contrast in what the HCPs sees as important information and what the parents want to know. Parents mention the importance of practical information, of how to handle certain situations, whereas they feel there is a "bombardment of theoretical information". Parents perceive the information provided to be based on medical information, and less on experience. Some situations, for example admittance to the hospital after a fall on a head, are not communicated to parents before it actually happens. Information like this, which the HCPs may not find pressing and therefore do not communicate, can be vital for some parents to know and have a peace of mind.

"When he was a baby in the playpen, it didn't bother me. But when he started to crawl, for example, he gently pressed his head against the table. "Ooh! Would that be hard?" I understand that falling hard is very difficult to explain, but afterwards I would have found examples useful." (Parent, P6)

"The first time I thought that was an exception. Then it happened again, and at one point it was like, "Oh, so this is just standard. That he should be admitted." [...] At the beginning it was every time admittance and that was not in the information from the hemophilia center. And not on Cyberpoli either. So that is something that comes with it, but is nowhere to be found." (Parent, P1)

Variety of Information

Every parent and every patient is different. The information and the source they want to receive that information from varies per person. The parents find the information they receive currently to be very one-size-fits-all, where they all get the same kind of information. The same source and same information can have very different effects, which reiterates the need for options. For example, contacting other parents of children with hemophilia seems to be a common wish, which the HCPs also supports. Most parents enjoy hearing other experiences, often finding it calming to know everything will be okay. Some, though, have an opposite reaction where they feel even more panic about their situation. Therefore the attention to the wishes and needs of the parents, and the patients themselves becomes even more vital. Not every source is the right outlet for everyone.

"It's nice to have someone with that experience, it also gives you more confidence and peace of mind." (Parent, P5)

"I've had conversations with other parents. [...] Sounds crazy but I cried so hard after that conversation, I thought yes you have daughters and it's mild, I thought I was so pathetic. I have a son with severe who has zero [percent]! [...] I thought if you are panicking then I must be panicking even more." (Parent, P7)

4.4 Conclusion & Discussion

The interviews reiterated the children's need for trust, control and inclusion. The interviews showed that the perception of the HCPs on how included the child is in the process did not correlate with how the parents and children perceive it. There were examples of good strategies that were found by parents to be beneficial, but the consensus is that these are currently exceptions and not the standard. These strategies included positive reinforcement, the power of structure and predictability, the need for encouragement and reassurance, and most importantly inclusion of the child in the different aspects of his illness. The findings showed that the biggest fear was in fact not a fear of needles, but the fear of the unknown. Most children create coping mechanisms or anxieties surrounding the consequences of their disease, which often causes them to miss out on events or detaches them from the feeling of "being normal". Normalcy came up in all forms of research, as being an important need of the child.

The information obtained from the interviews were similar to the findings in the literature, supporting most of it. The parenting approach seems to be one of the biggest differences, with the literature leaning towards overprotective parents and the interviews including more open approaches. The observation provided views from both sides making it clear that hemophilia does not have one set parenting approach that comes with it. There are a lot of different experiences in different phases, and obviously various personalities, so it is not possible to categorize parents within an approach, between "relaxed" and "overprotective". The approach seems to change with the experiences of the parents and their perception of their children's experience. Trust and understanding seem to play a large role in the approach of the parents, as well as how negative experiences are handled. Most parents try to be vigilant of their reactions, making sure they do not limit their child, yet this sometimes seeps through anyway. So this is a consideration when it comes to the perception of the child. Another difference between the literature and the interviews is the perception and knowledge of parents with the disorder in their family history. Where the literature usually refers to distorted views of the disease, the parents in the participant group who maybe had parents with hemophilia themselves, were very knowledgeable about the innovations in treatment and went into the diagnosis knowing that it was a treatable disorder.

The results obtained from the interview did not fully correlate with the observations. Where in the consultations, some negative aspects were mentioned, and treatments were difficult to administer, the interviews involved participants who had the disease under control and were all quite happy with how things were going. Within the observations it seemed like the majority of children had a fear of needles, whereas with the participants who were interviewed, this was not the case. There were participants who had a fear previously, but they were not the majority. The patients who did have a previous fear, went through multiple negative experiences in a short period of time, which may have strengthened the formation of the fear. The parents play a role in this, as their approach can also change the perception of the child, with open conversations and helping the child to understand the reasoning behind certain actions aiding in the reduction of stressors. Within the interviews, the results showed that the child's personality is also a factor, with most of the children who never developed a fear being calm and curious in nature.

Recommendations for Further Research

A few points that were mentioned quite often yet fall outside of the scope of the project were the parental anxiety, general awareness about the disease, and communication during diagnosis. These topics show a lot of value for the parents' experience, and therefore indirectly the child's experience, therefore will be used in the visualization of the patient journey, but will not be further researched in this project.

There were also some interesting unexpected findings, which did not come up in any of the other study outcomes. Firstly, the fact that the oncology and hematology departments share a clinic came up in 4 of the 7 interviews. This was not expressed by children, but the parents seemed to be influenced by it. This is not necessarily a negative effect, and for many parents results in a new perspective and a more relaxed approach to hemophilia. However, for some other parents, it can have other effects, so even though it is not feasible to change the location of the departments, it can be an important point of conversation as the parents expressed the need for adjustment in the placement of waiting rooms. This was brought up with the HCPs, and they also mentioned that it was brought up by parents, and they have taken steps in changing the clinic days of the departments so that they no longer coincide. An interesting point may be to analyze the effects of having 3 relatively "intense" departments like oncology, hematology and medium care in the same location can have on the visitors. As this was not expressed as having an effect on the children within the studies carried out in this project, this will not be further researched.

Secondly, the fact that patients had to be admitted to the hospital unexpectedly. This didn't come up at all in literature and in interviews with HCPs, yet seemed to be a large part of the negative experience faced by the patients. The parents mainly mentioned how regular of an event it was, and were surprised that it never was mentioned as a possibility. When asked after the interviews, the HCPs denied the frequency of the admittances due to bleeds, as the parents named them, and said that instead, it was national hospital protocol for concussions to admit patients for neurological check-ups. These admittances are done within the neurology department, completely for neurological reasons and most aren't even communicated to the hemophilia center. Once the child receives the coagulation factors, hemophilia is no longer a concern. The hemophilia department does not receive information on every admittance, therefore they may not understand the severity of the experience on the patients and their parents. The HCPs did recognize that the parents may be feeling uninformed, and therefore making correlations between the hospital stays and hemophilia and that they would be making an effort to better explain the reasoning behind decisions and procedures. The communication and transparency between the departments within the hemophilia center, and information provided to the parents may be an interesting part of the experience to look into, but will not be further researched within this project.

Study Limitations and Biases

A main point of this project was to try to obtain information from the child first-hand, however, this was not completely successful. In addition to this and other assumptions made before the interviews, there were also other limitations, such as (1) The child not wanting to talk or not knowing what to say, (2) Being too tired or impatient at the time of interview, so not participating and (3) Looking at the parent for approval when answering. The space was given for the child to answer freely, and the questions were asked in a way the child could understand. However, the parents sometimes took over the answers, not necessarily initiated by the parent themself, but more due to the child being quiet and looking to the parent. For future research, it could be a consideration to interview the child in another room, or to use other methods like gamification or focus groups to activate the child.

There is an indication of a certain level of selection bias. Considering that the patients were chosen by a HCPs from the Sophia, there is an understandable conflict of interest. All participants were those who have participated in other studies before and were described as "full of good information" by the HCPs, indicating a population who are more "active" in their child's care. Due to this, the population did miss those with difficulties that may have not been solved so easily. In addition to this, some patients seemed a bit scared to step on toes during the conversations with doctors, as also mentioned in the observations in the clinic. Even in the interviews, the participants thought that the research was conducted by the HCPs, and when contacted consequently and understood it was an independent study had an audible positive "Oh" moment. Which confirms the presence of a bias. This may not be relevant in the answers of all, if any, patients. However it is important to know that the general patient population is more than those who were interviewed.

KEY TAKEAWAYS FROM THIS CHAPTER

- Most children are very aware of their illness and are mainly scared of the consequences of their illness, the **"what if?",** which can create internal limitations.
- **Giving the child control, trust, understanding and autonomy** can have value in the experience with the disease.
- Children **value predictability and benefit from structure**. **Predictable positive reinforcement** is vital in receiving from negative experiences.
- Parents still have to stay as the main decision-maker, but including the children in the conversation from young age can help with **gaining self-confidence**.
- **Switches in treatment and emergency room visits create unexpected burden** on the children. Especially non-UMC emergency rooms are experienced negatively.
- Children currently do not have a **space to express opinions and feelings**, which can manifest in negative emotions.
- The perception of the medical staff on how included the child is in the process **did not fully correlate** with how the parents and children perceive it.
- There seems to be a discrepancy in what the medical staff sees a **important information and what the parent/patients want to actually know**.

4.5 Concluding the Research Phase

The various research studies: (1) literature research, (2) context exploration and (3) user research, have contributed valuable insights to the project. A broad understanding of the patient experience was gained as a result and an overview was created. Many of the findings in the various studies confirmed each other, with others creating interesting juxtapositions in experience. Once again confirming the complexity of the disease, the research provided important outcomes that will be taken into account during the design phase.

Figure 4.8 on the next page shows an overview of all of the outcomes of the research phase, with the corresponding relationships between the findings. In some relationships, a causation link is present, which is shown with an arrow. The types of findings can be seen in the key, in Figure 4.9. The findings in the overview represent the findings that came up most often within the research studies, and/or seemed to be priorities for improvement in the current patient experience.

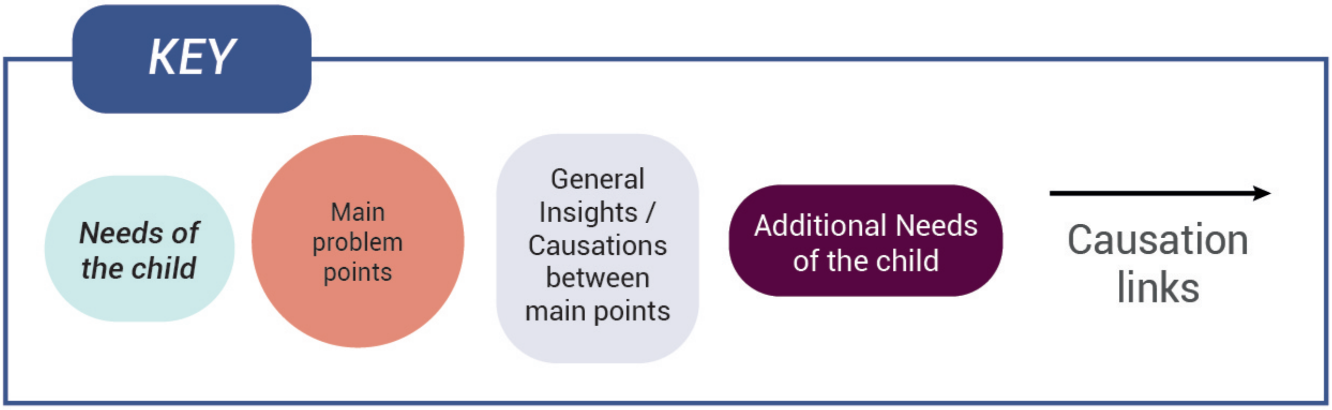


Figure 4.9 Key for the research phase overview


Medical materials in the injection room

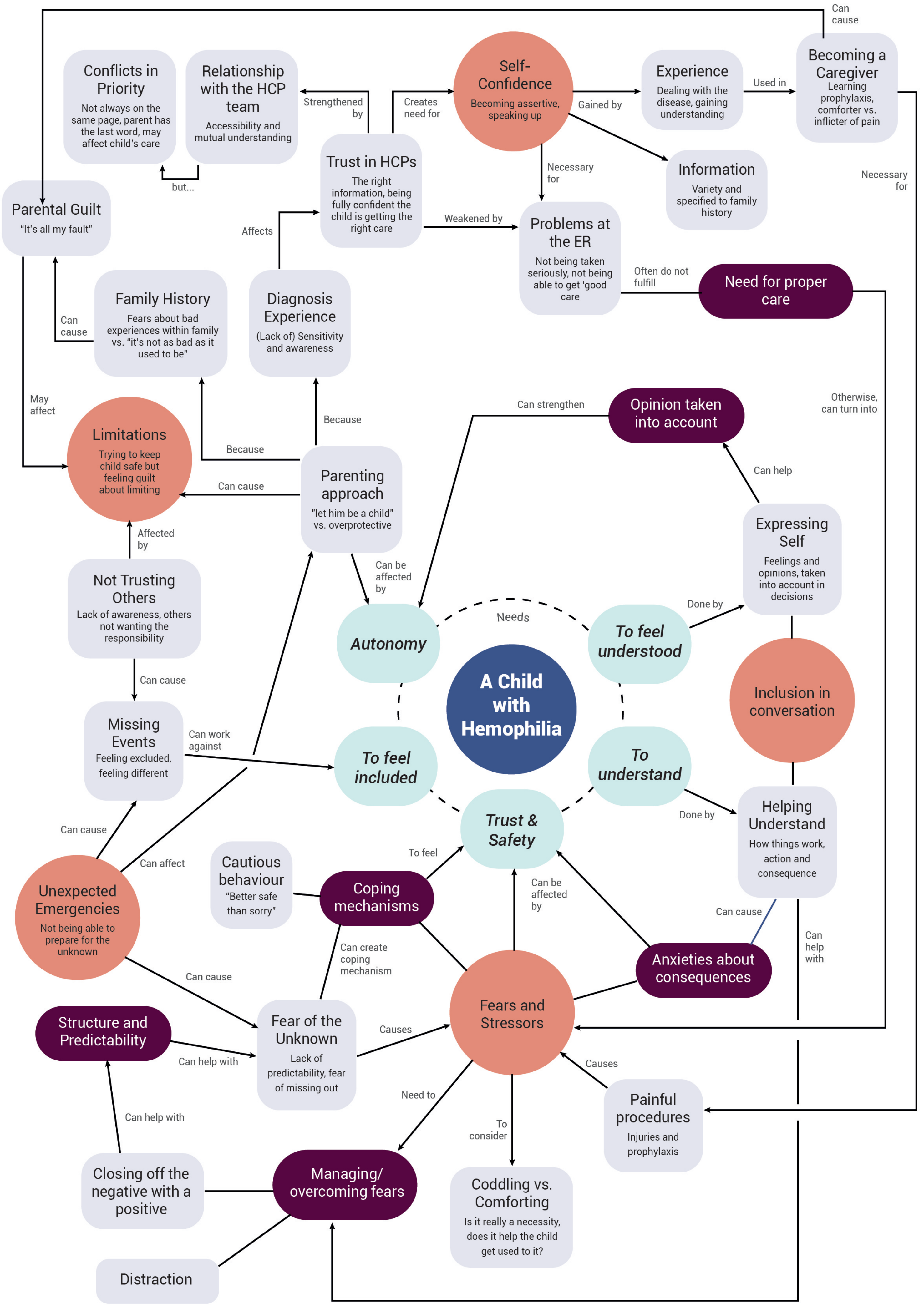


Figure 4.8 The research phase overview

05 The Patient Journey

This chapter will focus on the creation and analysis of the patient journey of a child aged 0-8 with severe hemophilia. First the purpose of the patient journey will be reiterated, and the key aspects will be defined. Then, the strengths and weaknesses of the patient journey will be pinpointed in order to find opportunities and trends. The chapter will conclude with the conclusions derived from the patient journey.

5.1 Creating the Patient Journey

The outcomes of the literature research, context exploration and user research have all been combined to create a coherent visual of the experience of a child aged 0-8 with severe hemophilia. With the results derived from the various studies, it is clear that hemophilia has a very complex presentation, with a lot of varying aspects for each patient, therefore the use of a patient journey as a method for this visualization will be beneficial.

The purpose of creating the patient journey is to be able to gain an overview of the experience and identify the areas of opportunity for improving patient experience. The audience of this patient journey is therefore the HCPs, designers and other stakeholders within Partitura, and in extension Symphony, who can use the information to strengthen the system of value-based healthcare and apply the findings to the patient experience where necessary. The patient journey was created in Dutch for the client's ease of use. The following research questions have been formulated for this section, which have also been used as evaluation criteria in the completion of the journey.

RQ1 - The main needs of a child have been defined in previous chapters; trust, control, autonomy and understanding. In which steps of the journey do/can these play a role?

RQ2 - What are important parts in a child's life showing weaknesses in experience?

RQ3 - Which areas of the journey show the most opportunity?

RQ4 - Which steps are connected and how do they influence each other? Can these connections be utilized in creating a large impact?

The outcomes of the studies have been placed into the form of a patient journey. An impression of the journey can be seen below in Figure 5.1, with the complete readable version in Appendix E. (The patient journey is designed to be viewed on a monitor. Therefore, some edits have been made to improve readability, these changes do not affect the content).

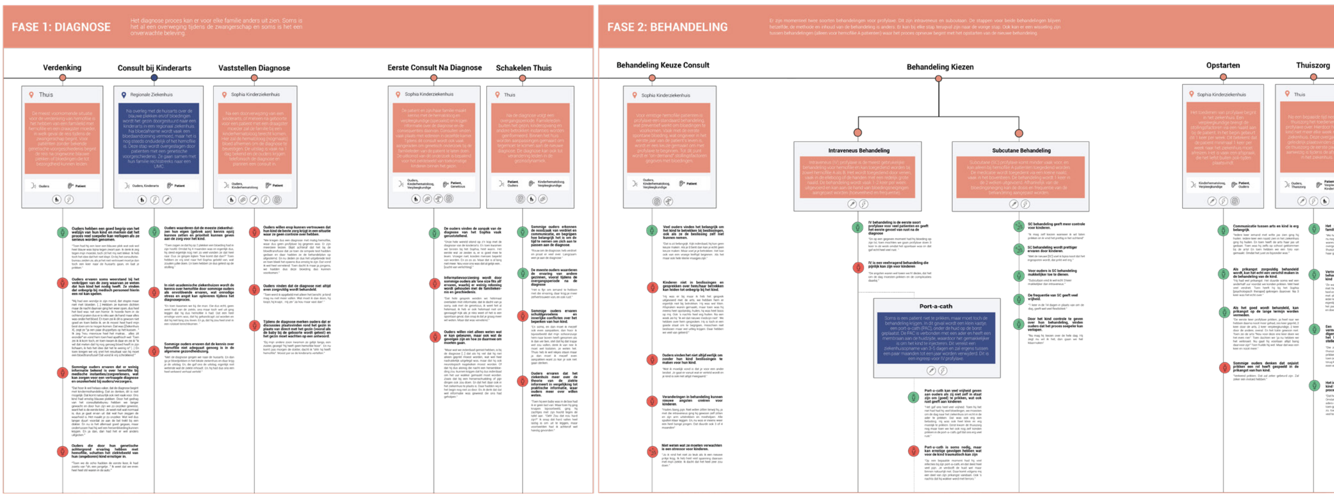


Figure 5.2 shows which parts of the research aided in the creation of the visual. The patient journey is made up of 4 layers, (1) the main phases of the journey that remain the same for everyone, (2) the steps within each phase which can vary per patient, and (3) the experiences of parents and patients presented in the form of quotes which then led to the creation of (4) Opportunities for improvement. The side goal of this patient journey was to be dynamic, in order to adjust itself to the new treatments and steps that may be added in the care of hemophilia. Due to the complexity and the size of the journey, this was done by creating a modular approach, with all steps on a main line, with separately movable steps. In the future of this patient journey, the expectation is for further research to be done, namely from the parent's side or of children in other age groups. In this case the relevant steps can be adjusted and replaced if necessary, with the main phases and steps staying the same.

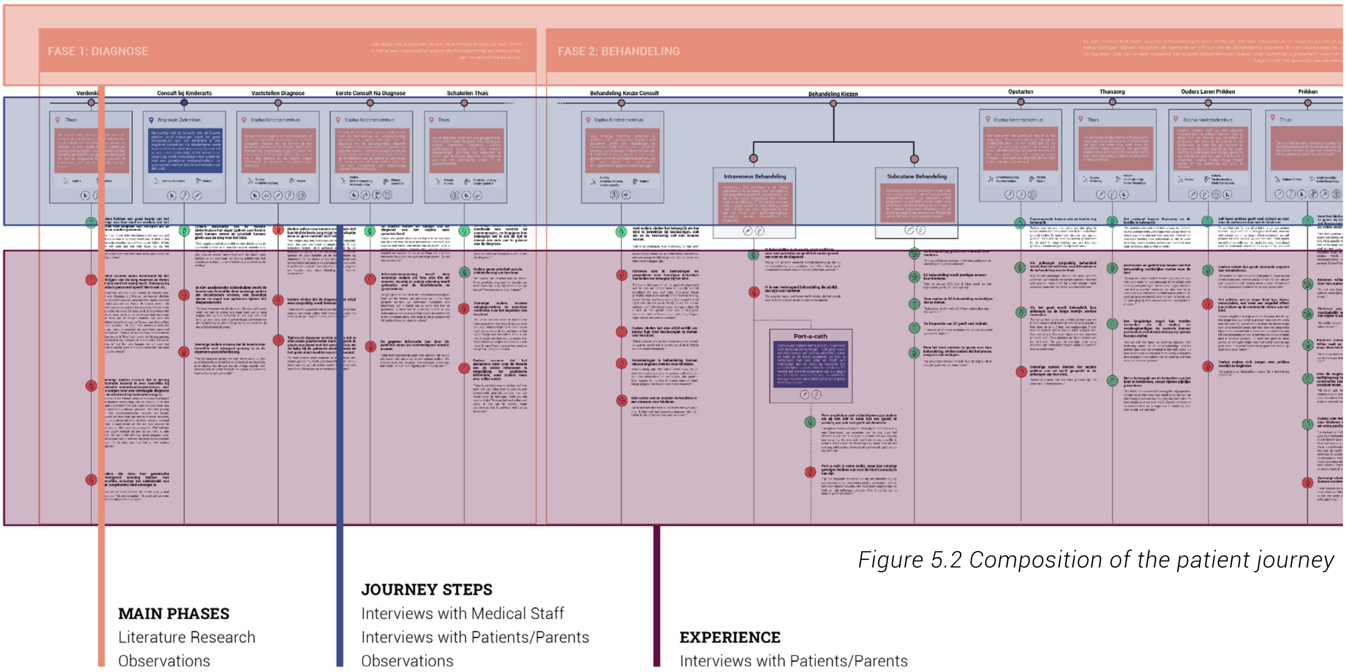


Figure 5.2 Composition of the patient journey

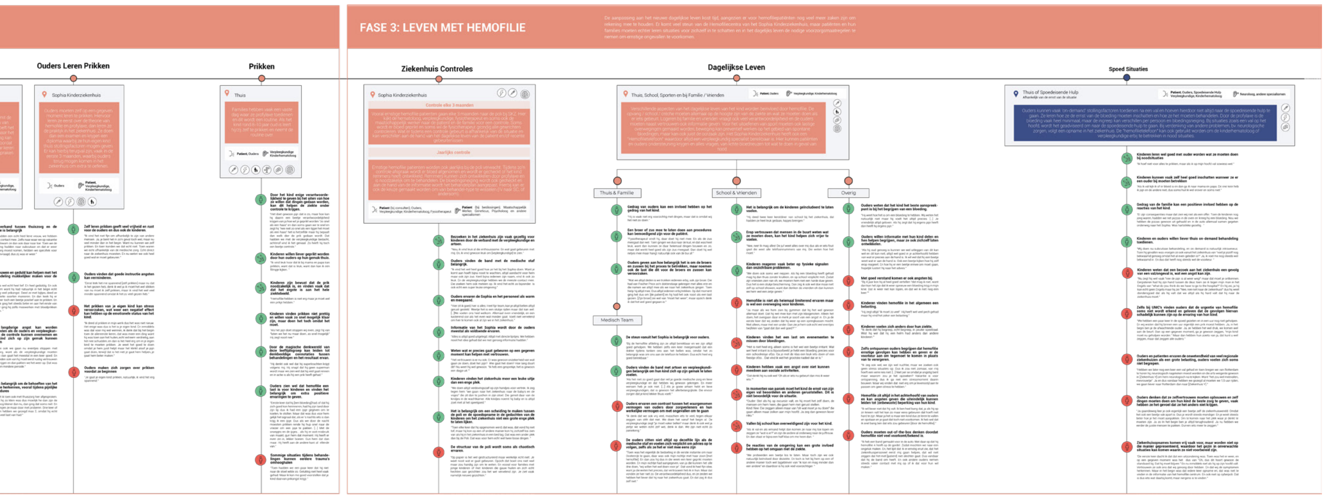
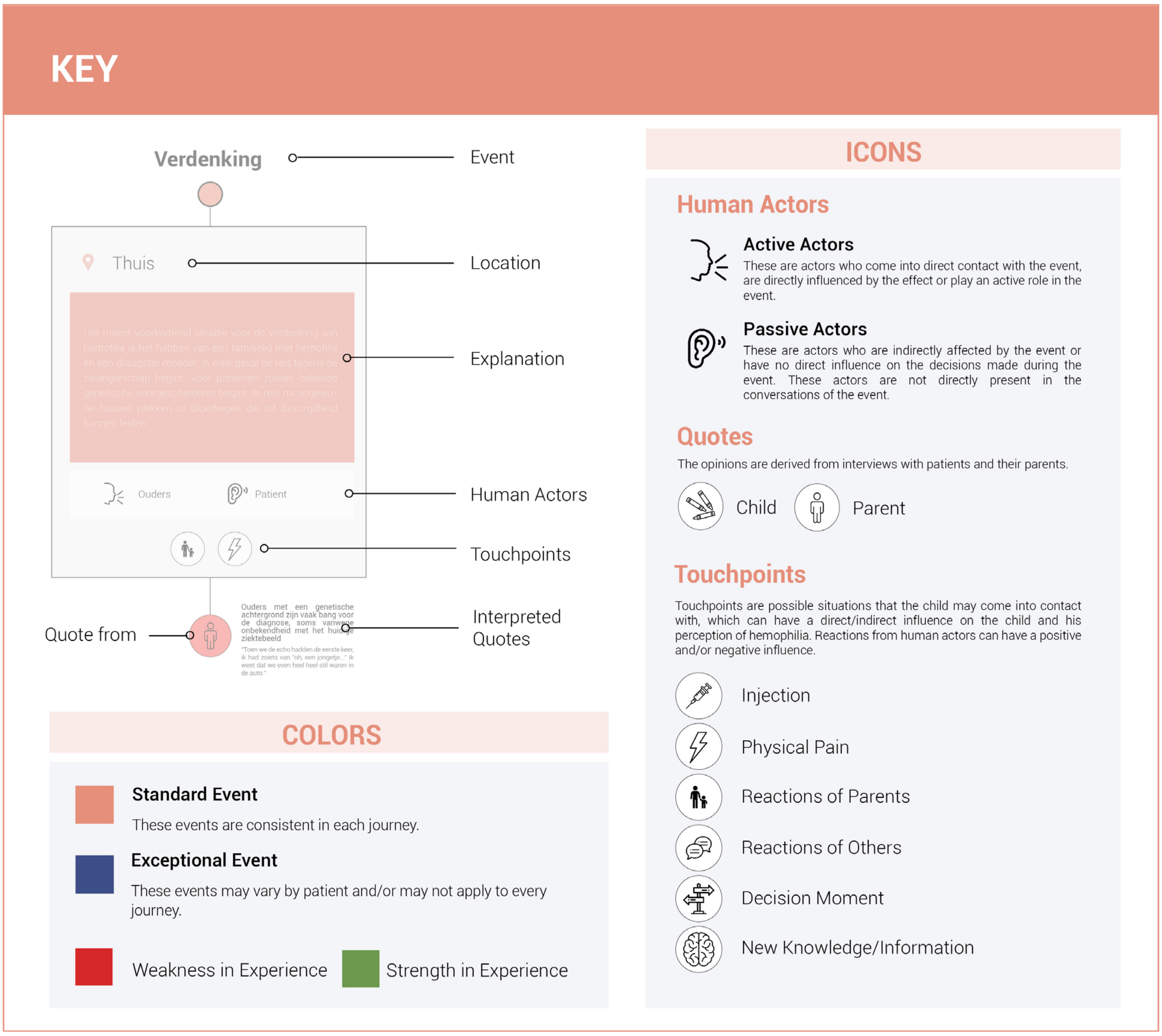


Figure 5.1 The Patient Journey

To be able to understand the visual, a key was made to identify the separate parts of the journey. This key can be seen in Figure 5.3 (The original version of this key is also in Dutch, which can also be found in Appendix E with the original patient journey). Each step includes a number of icons, each with a different meaning. Firstly the human actors in the step are split into passive and active actors. Then for each step we see touchpoints, which are moments that a child may come into contact with but does not necessarily have to be affected by it. The different quotes and experiences for each step are derived from different participants, as shown on the icon next to the quote. These are either from a parent or the child. Important to keep in mind is that the patient journey has been made with exactly that purpose, the journey of the patient, the child. There are more steps involved when looked at from a HCP or parent perspective, however these do not have an effect on the child and therefore have not been included. In addition to this, the diagnosis does involve a number of parent experiences but the studies done have shown that these experiences can have an effect on parenting approaches and parental anxieties, which ultimately can have an effect on the child, so these have been included as well.



Het meest voorkomend situatie voor de verdenking van hemofilie is het hebben van een familielid met hemofilie en een draagster moeder, in welk geval de reis tijdens de zwangerschap begint. Voor patiënten zonder bekende genetische voorgeschiedenis begint de reis na ongewone blauwe plekken of bloedingen die tot bezorgdheid kunnen leiden.

Ouders met een genetische achtergrond zijn vaak bang voor de diagnose, soms vanwege onbekendheid met het huidige ziektebeeld

"Toen we de echo hadden de eerste keer, ik had zoiets van "oh, een jongetje..." Ik weet dat we even heel heel stil waren in de auto."

COLORS

Standard Event

These events are consistent in each journey.

Exceptional Event

These events may vary by patient and/or may not apply to every journey.

🟥 Weakness in Experience 🟩 Strength in Experience

ICONS

Human Actors

Active Actors

These are actors who come into direct contact with the event, are directly influenced by the effect or play an active role in the event.

Passive Actors

These are actors who are indirectly affected by the event or have no direct influence on the decisions made during the event. These actors are not directly present in the conversations of the event.

Quotes

The opinions are derived from interviews with patients and their parents.

Child Parent

Touchpoints

Touchpoints are possible situations that the child may come into contact with, which can have a direct/indirect influence on the child and his perception of hemophilia. Reactions from human actors can have a positive and/or negative influence.

- Injection
- Physical Pain
- Reactions of Parents
- Reactions of Others
- Decision Moment
- New Knowledge/Information

Figure 5.3 The Patient Journey Key

5.2 Exploring Weaknesses & Strengths

Instead of the typical positive/negative experience approach, a weakness and strength approach was chosen. This was due to the fact that the research showed a number of positive and negative experiences, but also showed clear lines of how they affected each other. For example, in the case of a young patient with a fear of needles, this fear was treated with psychological therapy. The fear itself is a negative experience, which is not handled (as with many patients) can be a weakness in the journey. The therapy may be a positive (or negative) experience which leads to the overcoming of the fear, which is again positive. When combined these show a strength in the process, but also the fact that it is not a standard to treat these fears, as it is not a step in the process but merely an individual experience. With this in mind, the whole journey was analyzed to identify important strengths and weaknesses per phase.

Diagnosis

- The main actors here with the experience are the parents.
- Being referred to the Sophia serves as a calming effect for patients who were diagnosed at a regional hospital.
- There is a prominent weakness in delivering diagnoses, especially for parents without prior knowledge, specifically from regional hospitals.
- The parents seem to find that there is a general lack of awareness about the disease.
- Information seems quite "one-size-fits-all" where parents with and without prior knowledge are given the same information.

Treatment

- The expectation is for the child to be active in this phase, but the role is mainly passive through the steps.
- There seems to be a prominent weakness in decisions regarding treatments, mainly the change between treatments.
- SC treatment is generally more positively experienced than IV, showing strengths in giving parents self confidence and children control.

Living With

- The main weakness is the emergency rooms, being taken seriously, understanding the urgency and proper treatment seem to be missing in many hospitals, at times including the Sophia.
- Most of the negative experiences in areas like school, home and friends seem to stem from the fear of something happening, or missing out on something due to a fall, once again highlighting the weaknesses in emergency situations.
- There is no consistency or control in emergent situations.
- The Sophia clinic is generally experienced positively with strengths in bonds with children, treating fears and making the child feel at home, and weaknesses in predictability and structure.

5.3 Finding Trends

Based on these outcomes, trend lines were drawn between steps. These lines were drawn on the main patient journey as seen in Figure 5.4, but are also visualized in a more compact way in Figure 5.5. These trends were found by analyzing the similarities in experience, the effects the strengths and weaknesses have on other steps and which steps show the most promise.

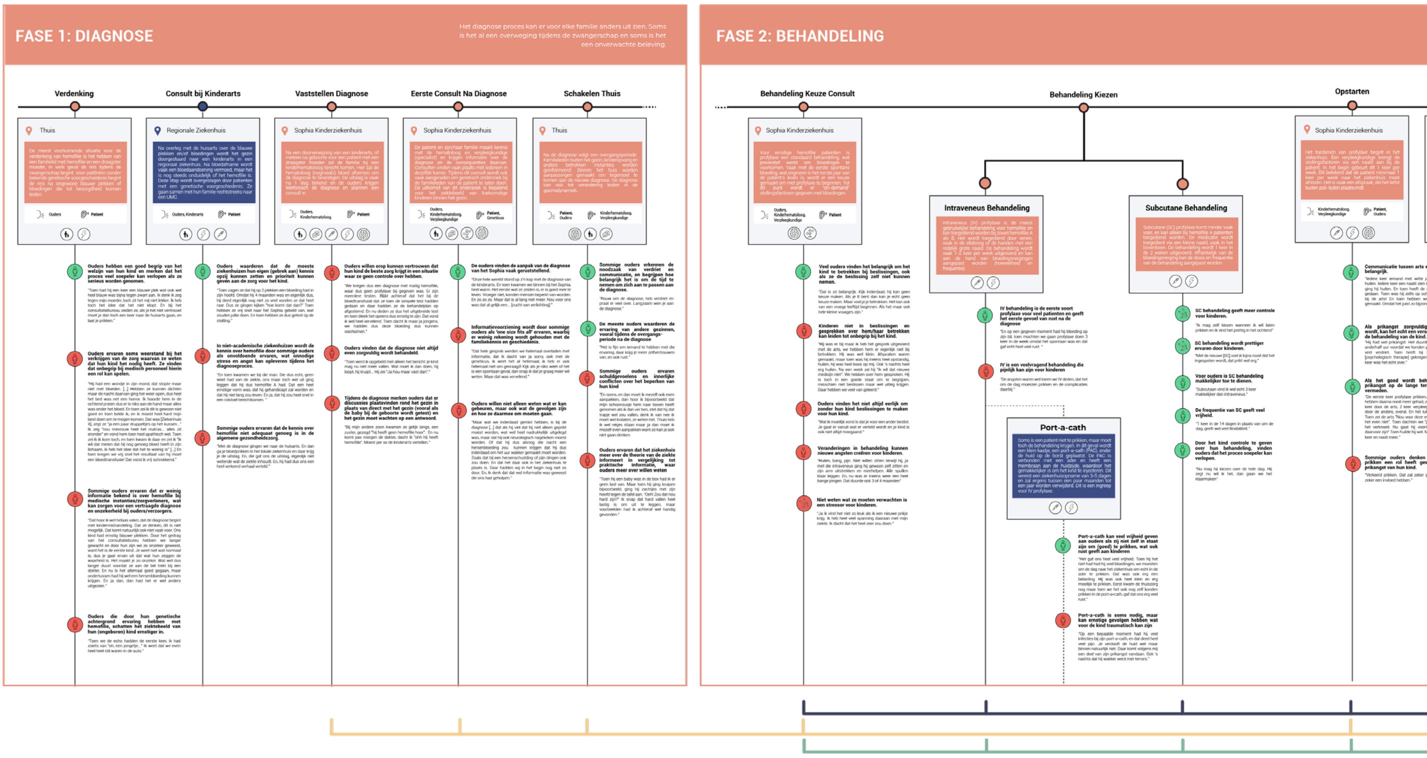


Figure 5.4 The Patient Journey with trend Lines

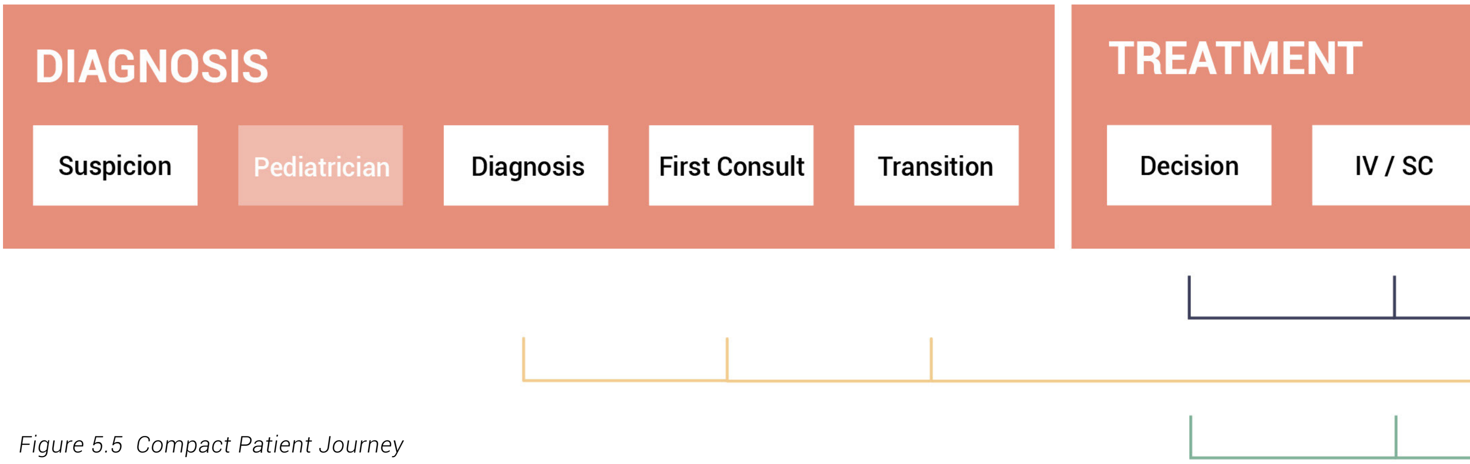
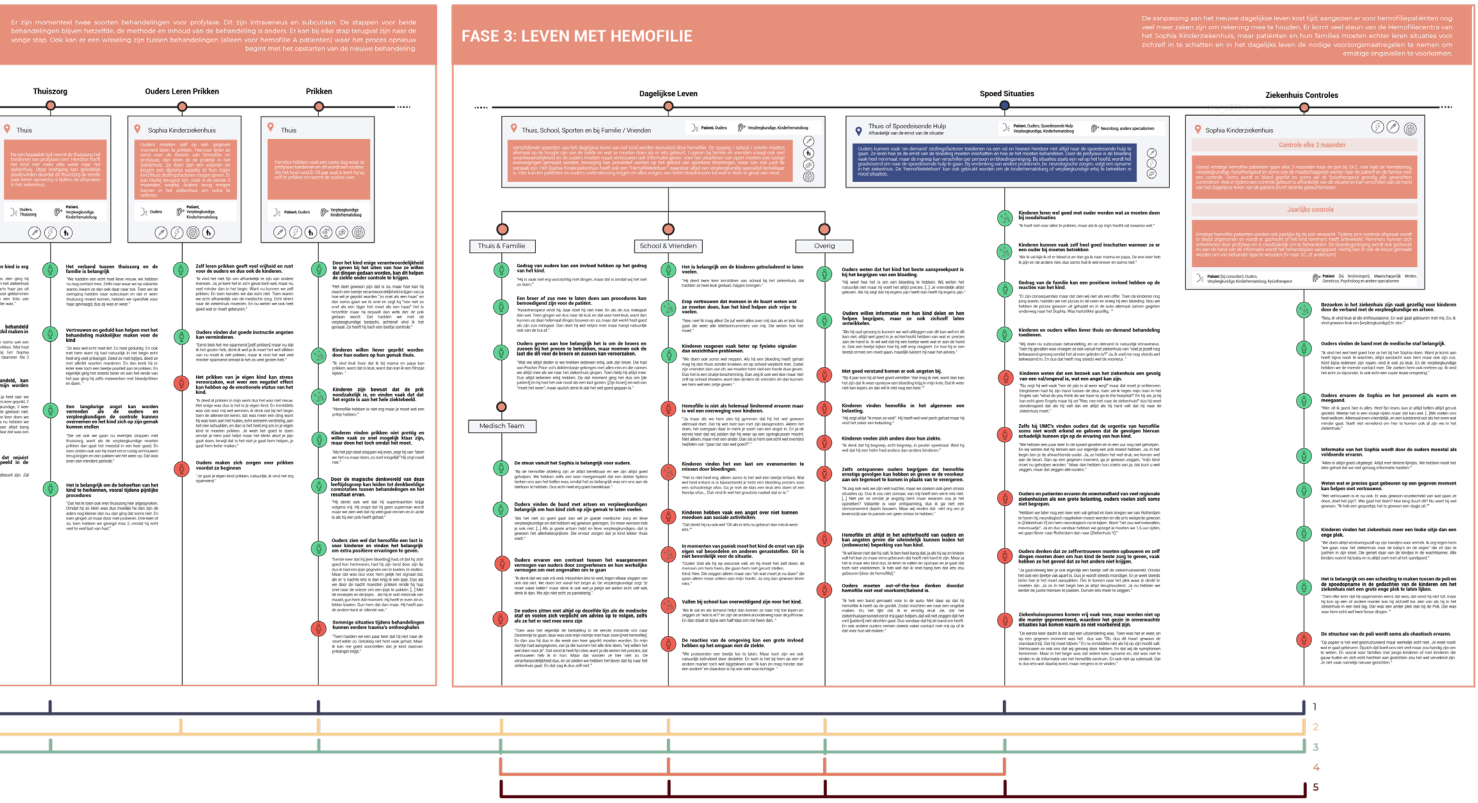
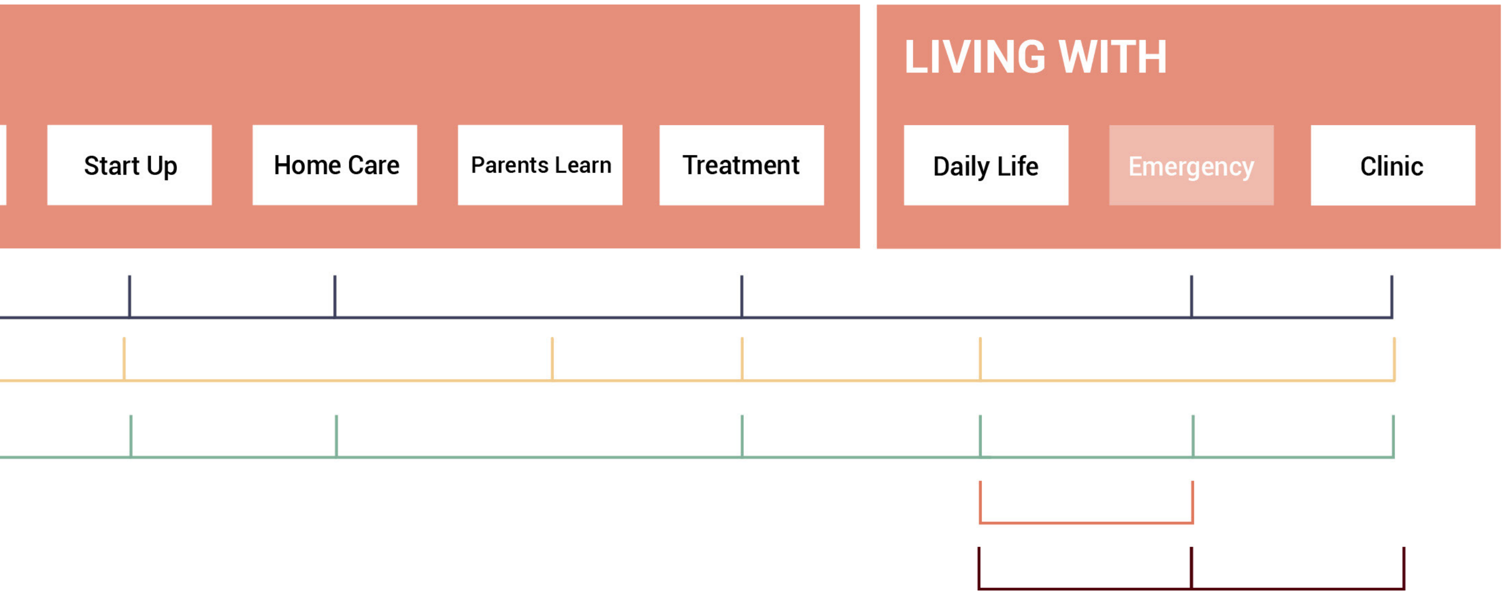


Figure 5.5 Compact Patient Journey


Er zijn momenteel twee soorten behandelingen voor profylaxe. Dit zijn intraveneus en subcutaan. De stappen voor beide behandelingen blijven hetzelfde, de methode en inhoud van de behandeling is anders. Er kan bij elke stap terugval zijn naar de vorige stap. Ook kan er een wisseling zijn tussen behandelingen (alleen voor hemofilie A patienten) waar het proces opnieuw begint met het opstarten van de nieuwe behandeling.
FASE 3: LEVEN MET HEMOFILIE
De aanpassing aan het nieuwe dagelijkse leven kost tijd, aangezien er voor hemofiliepatiënten nog veel meer zaken zijn om rekening mee te houden. Er komt veel steun van de Hemofiliecentra van het Sophia Kinderziekenhuis, maar patiënten en hun families moeten echter leren situaties voor zichzelf in te schatten en in het dagelijks leven de nodige voorzorgsmaatregelen te nemen om ernstige ongevallen te voorkomen.
Thuiszorg
Ouders Leren Prikken
Prikken
Dagelijkse Leven
Spoed Situaties
Ziekenhuis Controles
Thuis
Sophia Kinderziekenhuis
Thuis
Thuis, School, Sporten en bij Familie / Vrienden
Thuis of Spoedeisende Hulp
Afhankelijk van de ernst van de situatie
Sophia Kinderziekenhuis
Controle elke 3 maanden
Jaarlijks controle
Thuis & Familie
School & Vrienden
Overig
Medisch Team
1
2
3
4
5


LIVING WITH
Start Up
Home Care
Parents Learn
Treatment
Daily Life
Emergency
Clinic

Trust, control, autonomy and understanding were the most important needs defined in previous chapters, these also seem to be the common link in the trends, with the lines being connected with at least one of these needs in mind. These will be further described in the next chapter, the Design Space. The exploration of these trends can be seen in Figure 5.6.

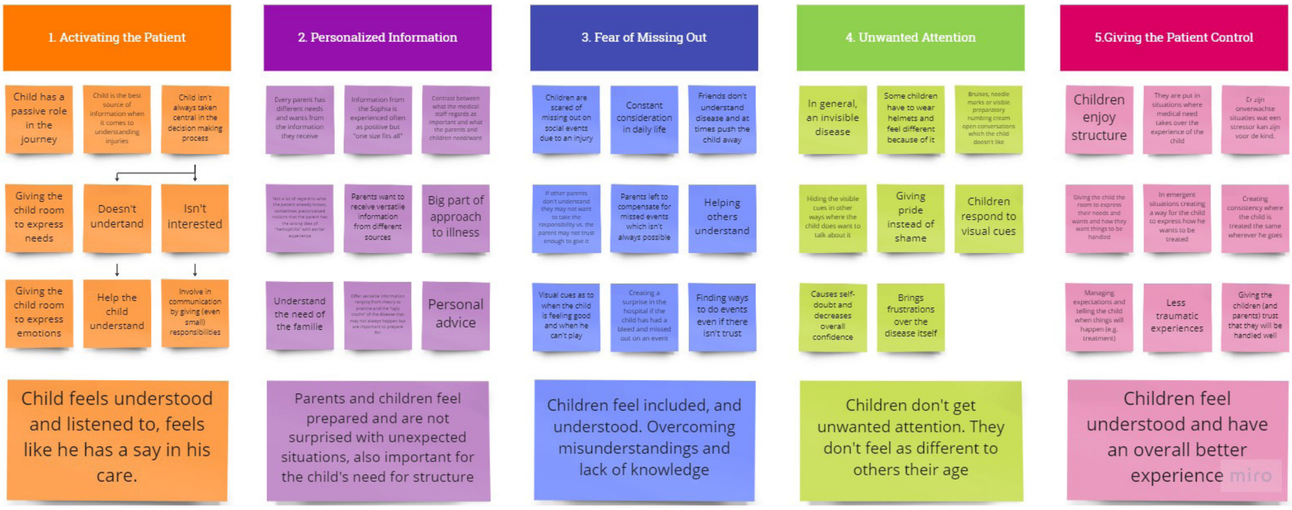


Figure 5.6 Exploration of trends

KEY TAKEAWAYS FROM THIS CHAPTER

- Children are often passive actors in their journey.
- The main weakness affecting all other steps seems to be emergent situations and emergency rooms.
- There are good strategies in place for overcoming fears, specifically of needles, but these are not the standard.
- There are a number of opportunities for improvement in the care of a child with severe hemophilia.

06 The Design Space

In this chapter the different design spaces within the project will be discussed. Firstly, the various directions which were derived from the patient journey are explained. This is followed by important requirements to consider in making a choice regarding the final direction. The requirements will then be used to find a final design space to ideate in.

6.1 Concept Directions

Giving the Patient the Feeling of Control

Children like structure, which is not always possible with hemophilia. There are often unexpected situations that can cause stress for the child. In these situations, medical necessity usually takes priority and the child's experiences come second. This creates an inconsistency in the handling of the child, which can cause distrust in the child and can lead to severe fears. All children have a specific preference in which they want to be treated, and giving them the space to express those wishes can bring peace, not only to the children, but also to the parents, knowing that they can rely on the child's needs being met.

Understand the child's needs and exactly how they want situations to be handled

Manage expectations and tell the child when and how things will happen, especially in a situation that is not pleasant for the child and outside of his/her wishes

Create consistency for the child

Personalized Information

Every family has a different preference in what information they want to know about the disease, and where the information comes from. The information from Sophia is often experienced positively, but can sometimes be seen as overwhelming. There also seems to be a contrast in what the health care providers consider important information in the explanation of the clinical picture, and what the parents themselves think they need. Good information provision is experienced by parents as an important point.

Ensure that the information is offered in a versatile way

Keep the history and existing knowledge of the family in mind

Understand what the specific family needs to understand the disease, the parents and the children themselves

Give as much personal advice and information as possible

Activating the Patient

Healthcare providers want to know exactly what is going on, and this information is best obtained from the child. It is common for children to be passive in their own illness journey. Many decisions seem to be made about the child, not always asking for the child's opinion. It may often be that the child does not understand the situation, but may have an opinion about its consequences. Children often feel out of control over their own illness and experience that what they want/need is not always considered.

Give the child the space to express his/her opinion

Explain the situation in such a way that the child can understand

Try to understand better what the child needs in different situations and try to actually do this as much as possible

Create a sense of responsibility in the child about his own illness

Fear of Missing Out

Children with hemophilia often face medical emergencies. Patients indicate that they are afraid that they will miss important events due to the consequences of their illness. Children are limited in their social contacts and limited in their participation in social events due to (prejudices about) hemophilia and its consequences. Parents of friends sometimes do not want to take responsibility for the sick child. Or it may also be that the parents of the child themselves do not want or dare to give up this responsibility. Peers of the same age can also exclude the child from social contacts due to (prejudices about) hemophilia. This can limit the child and his social development.

Help others understand

Give the child the space to express feelings about (disappointing) situations

Try to understand an fulfill the needs of the child in situations with unexpected consequences

Dealing with Unwanted Attention

In general, hemophilia is an invisible disease. In some cases, the consequences become visible and can attract unwanted attention from others. Some children have to wear helmets for a while to avoid serious injuries and feel different as a result. Bruising, needle marks or visible numbing cream (preparing for an upcoming treatment) can open conversations that can be perceived negatively by the child. They can feel left out of peers and can sometimes feel judged, which can eventually manifest in self-doubt and frustration with the disease.

Encourage the child to claim ownership of his disease

Help the child understand the reasoning behind the visible cues as well as their (positive) effects on the child

Provide the child with tools to communicate their thoughts, within the family and also to others

6.2 Requirements and Considerations

The aim of this project is to analyze the experience of severe hemophilia patients aged 0 to 8, visualize this in the form of a patient journey built from their perspective and find opportunities and patterns in the experience to eventually create a proposal for an intervention to improve quality of life. The goal was also to provide a viable and feasible intervention for the client. Keeping these goals in mind as well as the outcomes of the conducted research and patient journey, the following requirements were formulated to aid in the choice of a valuable design direction.

Direct Effect on the Child

There are many factors in how a child experiences their disease, and experiences of others can have an effect on the child's perception too. The chosen design space should be aimed directly at the child's experience, rather than the experience of others, creating a more direct effect on the situation.

Prevention Instead of Overcoming

The patient journey shows how different triggers can affect the several steps in the process. It is also visible that there are certain moments in the journey which happen to have more trigger points in which new fears and anxieties can be developed. With the interviews and observations, the conclusion was that once a child has a negative experience with a situation, they are more likely to fear it in the future. Therefore, there is clear value in preventive techniques.

Easy Implementation

The final intervention will be made for the Sophia to implement, which means that it must be (1) possible and (2) relatively easy to implement seamlessly into the existing situation.

Effect on the Whole Journey

The journey of a hemophilia patient is quite complex, where each step has an influence on another step in another phase. The design direction should serve an overarching purpose, looking into effects on as much of the journey as possible, and not necessarily aim to improve one specific step.

6.3 Choosing a Direction

With the requirements in mind, the direction of "Giving the Patient the Feeling of Control" seems to provide the most value. "Activating the Patient" follows close behind, with aspects that could be important as well. "Personalized Information" does have value, yet does not have a visible direct effect on the child, and is mostly aimed at the parents' experience which indirectly can affect the child at some point. In designing for parents, this area would provide the most value. "Fear of Missing Out" and "Dealing with Unwanted Attention" are still relevant for design opportunities, yet serve as space for further research instead of areas where concepts can be developed at this point in the process.

6.4 Evaluation & Discussion

This project will move forward with the direction of "Giving the Patient the Feeling of Control" with the addition of some relevant parts within "Activating the Patient". These areas will have the most direct effect on the child compared to the other directions. In the following chapter, these will be further investigated to understand the underlying purpose of each, to create a design vision combining both.

Recommendations for Further Research

An area that showed a lot of value but missed out on the key requirement of direct effect on the child, was personalized information. Some initial ideas for personalized information include the improvement of the Cyberpoli website, by adding a variety of new information, depending on the wants of the parents and or patients, as well as a filtering option which can allow the users to see what they need. Another opportunity is a "welcoming packet" which the parents can opt for in diagnosis by filling in a short questionnaire about what they want to know and the way they want to receive it. This can be in the form of quick-guides in handling situations, scientific articles or phone numbers of other parents willing to share their experience. The information can also be aimed at children, but the main audience still remains the parent, for which further research has to be done. The other areas also show benefits, but will not be further looked into within the scope of this project.

07 Conceptualization

In this chapter the design goal will be formulated based on the chosen design spaces and the desired interaction qualities. These will be followed by 3 ideation sessions (1) an individual ideation, (2) a creative facilitation session and (3) a final individual conceptualization session, concluded with the generation of 3 concepts.

7.1 Design Vision

With the results of the conducted research and the outcomes of the patient journey, the next step was to create a base for the design. Having understood the different factors at play within the patient experience, a design goal was formulated. This was done by analyzing the elements of the design direction chosen in the previous chapter, and translating these into the desired interaction qualities. These, in addition to the evaluation criteria which were defined, led to an ideation process, resulting in concepts.

7.1.1 Design Direction

As a result of the research done within the context of the hospital and the information from the patients, the following were found to be the most valuable in improving the child's experience:

Giving the Patient the Feeling of Control

Structure and predictability

Consistency and managing expectations

Understand the child's needs and exactly how they want situations to be handled

To be used within and outside of Erasmus MC, to create a consistent treatment for the child

Could play a part in the prevention of fears from originating

Patient activation

Allows space to express opinion/understand situations

Sense of responsibility

The feelings of being able to express opinion and feel that it is valued

Currently done at Erasmus MC, but not a standard for all patients

Could play a part in the treating existing fears

Both directions have the main aim of making the child understand and feel understood. The first direction does this by giving structure and letting the child know his needs have been understood and will be followed. In the second direction, the child is given a voice and a place in his care, where he gets a certain amount of responsibility, fitting the situation at hand.

7.1.2 Interaction Qualities

The essence of the directions can be identified with the following interaction qualities:

Gives the Feeling of Control

Understandable

Personal

Predictable/Consistent

7.1.3 Analogy

An analogy was chosen to give a better understanding of the feeling the chosen interaction qualities should give.

Chosen Analogy (MyRecipes, 2022)

The chosen analogy for these interaction qualities is “Cooking with a Cookbook”. Cooking with a cookbook guides the user through the necessary steps to create a delicious meal of his/her own choice.

It **Gives the Feeling of Control** - There are steps but you can edit the recipe as you like, adding or removing anything you want.

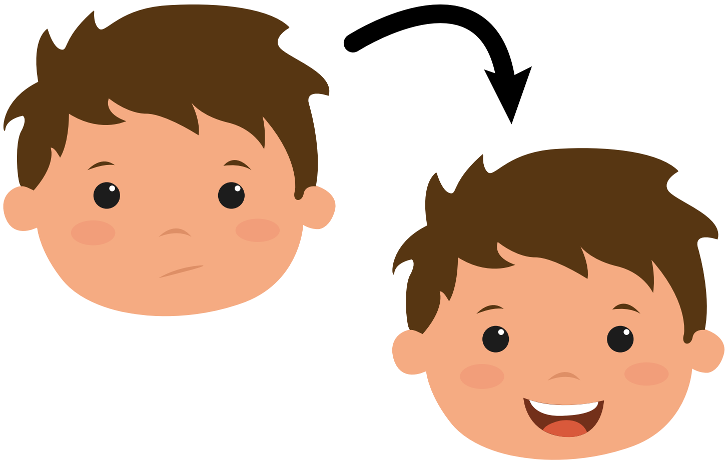
It is **Understandable** - With various forms of information like pictures and writing making sure you know you understand the step exactly.

It is **Personal** - You choose the book you want to cook from and you choose the recipe.

It is **Predictable/Consistent** - You know which step is coming up so you can prepare. Every time the steps are followed the results will be the same.

7.1.4 Design Goal

To design an intervention for children with severe hemophilia aged within the range of 0-8 years, that helps empower them and help them better comprehend their journey with the disease, by providing structure, consistency and control.



7.2 Evaluation Criteria

With the findings of the various research studies, the results of the patient journey and the design goal, the following criteria were created for evaluation. These are presented in order of importance.

1. Should give a feeling of control - the child can give their preferences and can see that their opinion has been listened to.

2. Should give a feeling of structure/predictability - consistent and predictable.

3. Should have a direct effect on the child - improves patient experience directly.

4. Should be desirable by the child (and parents) - the child (and parent) should want to use it.

5. Should be accessible by child - usable and accessible to the child without primarily needing the parents.

6. Should be understandable by the child - in a language the child understands and suitable for different ages.

7. Should give the space to understand the child - allowing the child to express opinions and ask questions where necessary.

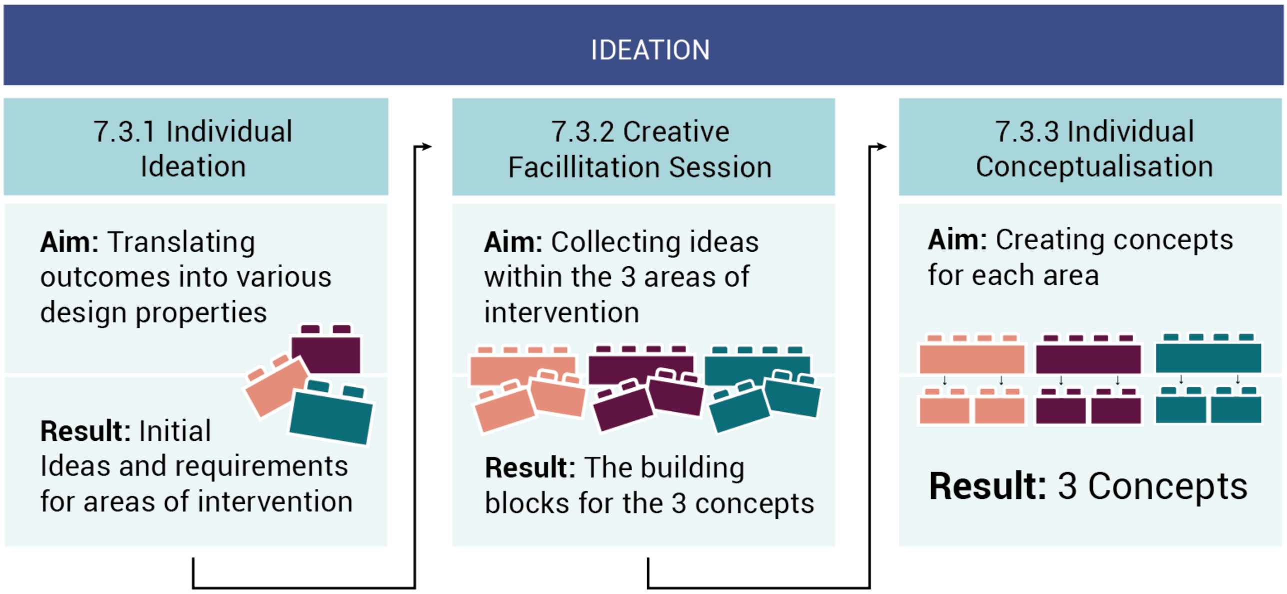
8. Should be implementable - feasible to produce and distribute, viable in use.

9. Should work preventively - working to avoid the formation of fears.

Waiting room of the hematology department

7.3 Ideation

The ideation was done in 3 separate sessions. All of these sessions served a different purpose and built on each other, resulting in the combination of ideas turning into concepts. A summary of this process can be seen in Figure 7.1.



IDEATION

7.3.1 Individual Ideation

Aim: Translating outcomes into various design properties

Result: Initial Ideas and requirements for areas of intervention

7.3.2 Creative Facillitation Session

Aim: Collecting ideas within the 3 areas of intervention

Result: The building blocks for the 3 concepts

7.3.3 Individual Conceptualisation

Aim: Creating concepts for each area

Result: 3 Concepts

Figure 7.1 Overview of ideation process

7.3.1 Individual Ideation

Purpose

The aim of the initial ideation was to take the outcomes of all the research and use them to identify the first ideas for the concepts.

Method

Based on the defined interaction qualities and the subsequent evaluation criteria, 3 individual brainstorm sessions were conducted: (1) What a child needs, and what design opportunities there are to address them, (2) How to integrate the defined interaction qualities into a design, and (3) Initial ideas for a possible intervention. The starting point for the brainstorms were the different research studies carried out previously and the results of the patient journey.

Outcomes

An impression of the mind maps that resulted from the brainstorm can be seen on pages 91-92.

WHAT DOES A CHILD NEED ? ? ? ? ?

important points !
1. structure
2. predictability
3. Trust
4. control
5. empowerment

SCHOOL AGE 6-8

- * New friends → new problems
  - ↳ school → SHAME !
- * wanting friends to understand / not limit.
- * inclusion control of what you can and can't do.
- * Trusting teachers are aware of situation and can intervene
- * missing out on events – unpredictable consequences.
- * almost time to take over treatment
  - ↳ feeling of control is vital !
- * wanting to be cool but also normal.
- * gain responsibility, understand situations, be able to gain control
- * express opinions, feel heard.

INFANT 0-2

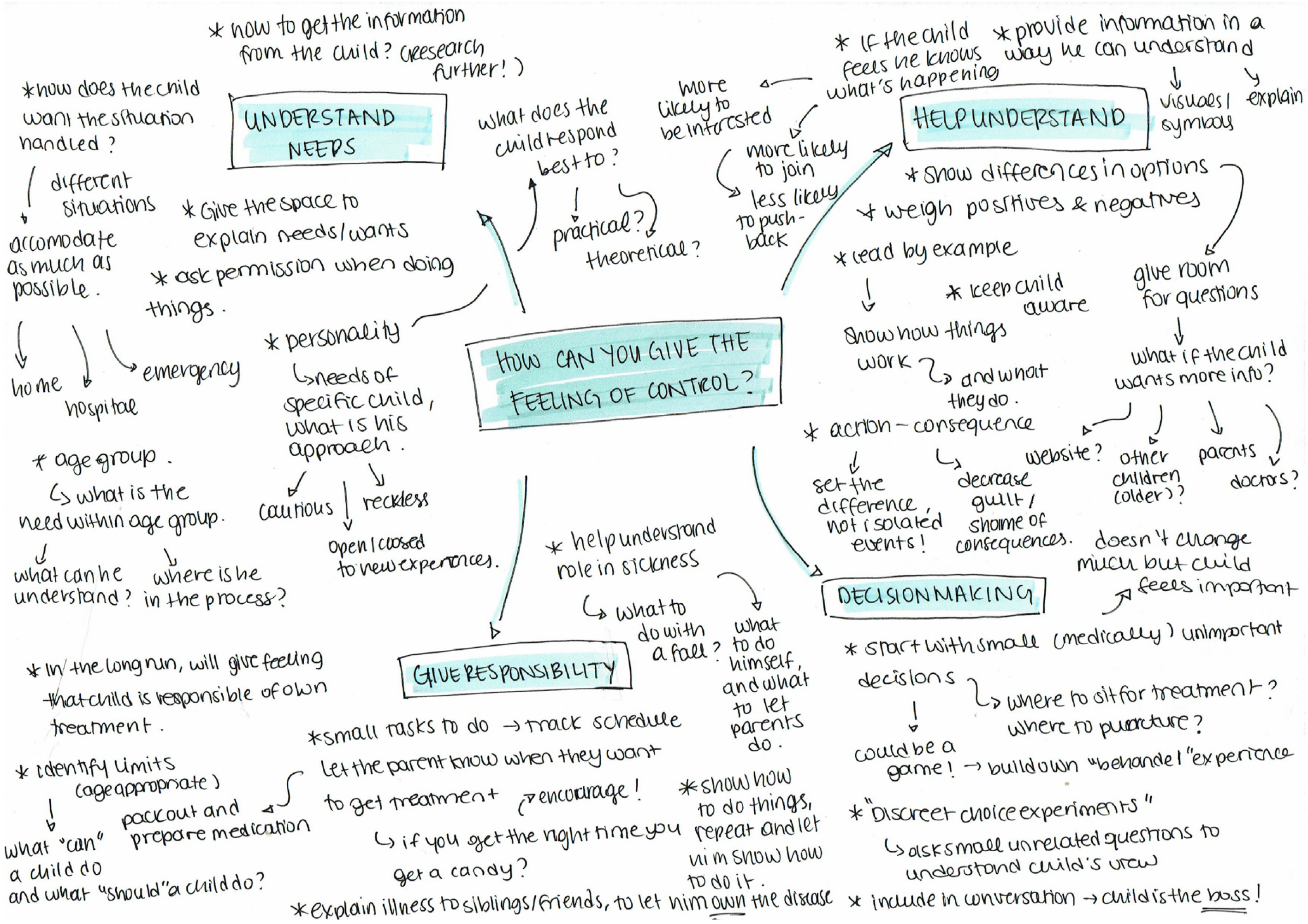
- * setting up structures
- * avoid physical pain → avoid the fear of the idea
- * Activate the senses → taste, smell, sight, sound, touch
- * creating a feeling of trust. → predictable
- * parental figure always close by can be seen / felt
- * Diagnosis time → trust and good bonds
- * always let the child see what you are doing!
  - ↳ * let the child see procedure "done" on a parent.
- * mother is important figure.

PLAY AGE 4-6

- * express feelings / gain control → handle anxieties !
- * physical reassurance ! - cuddling.
- * avoiding rage / frustration
- * verbal reassurance
  - → solving / treating fears immediately.
- * development of fears
- * starting to give responsibility & autonomy.
- * development of coping systems.
  - ↳ doable with imagination, symbols, characters & images.
- * feelings of guilt toward family
  - ↳ play with family dynamics / something whole family can do.
- * structures are important !

TODDLER 2-4

- * lack of communication
  - ↳ physical contact !
    - ↳ cuddles !
- empowerment ! w/ autonomy.
- * self-awareness / self doubt and shame
- * crucial to understand the child
  - ↳ he thinks everyone thinks the same way, will lose trust if something unexpected happens
- * let the child understand the bleeds are not isolated events
- * represent with images / symbols
- * strong imagination
- * asking permission ! child in charge !
- positive framing ← action - consequence
- * pain → fear !



HOW CAN YOU GIVE THE FEELING OF CONTROL ?

UNDERSTAND NEEDS

- * how to get the information from the child? (research further!)
- * how does the child want the situation handled ?
  - different situations → accomodate as much as possible.
    - home
    - hospital
    - emergency
- * Give the space to explain needs / wants
- * ask permission when doing things.
- * personality
  - ↳ needs of specific child, what is his approach.
    - cautious | reckless
    - open / closed to new experiences.
- * age group.
  - ↳ what is the need within age group.
    - what can he understand?
    - where is he in the process?
- what does the child respond best to?
  - practical?
  - theoretical?

HELP UNDERSTAND

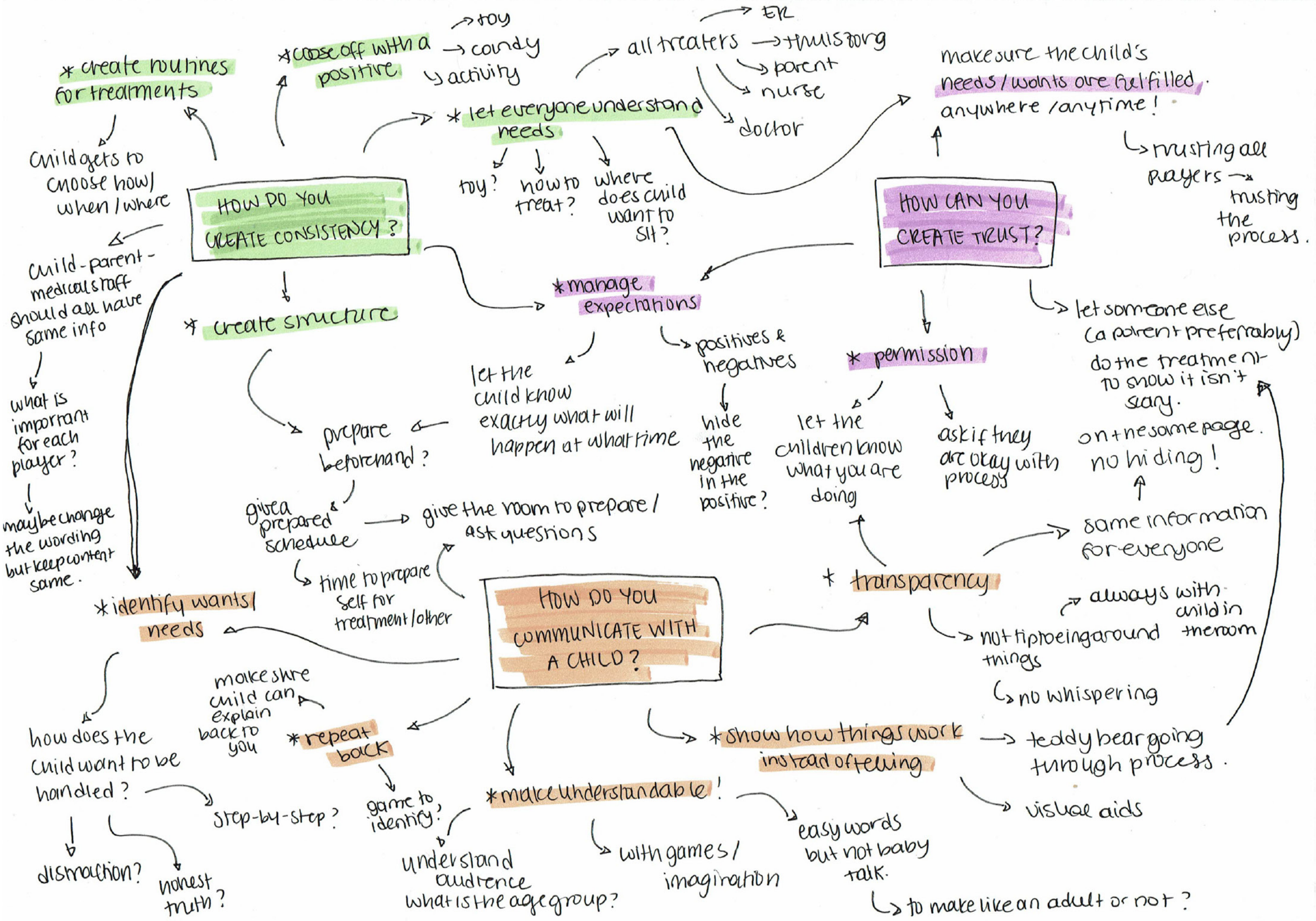
- * If the child feels he knows what's happening
  - more likely to be interested
  - more likely to join
  - less likely to push-back
- * provide information in a way he can understand
  - visuals / symbols
  - explain
- * show differences in options
- * weigh positives & negatives
  - give room for questions
    - what if the child wants more info?
      - website?
      - other children (older)?
      - parents
      - doctors?
- * lead by example
  - show how things work
    - ↳ and what they do.
- * keep child aware
- * action – consequence
  - set the difference, not isolated events!
  - decrease guilt / shame of consequences.

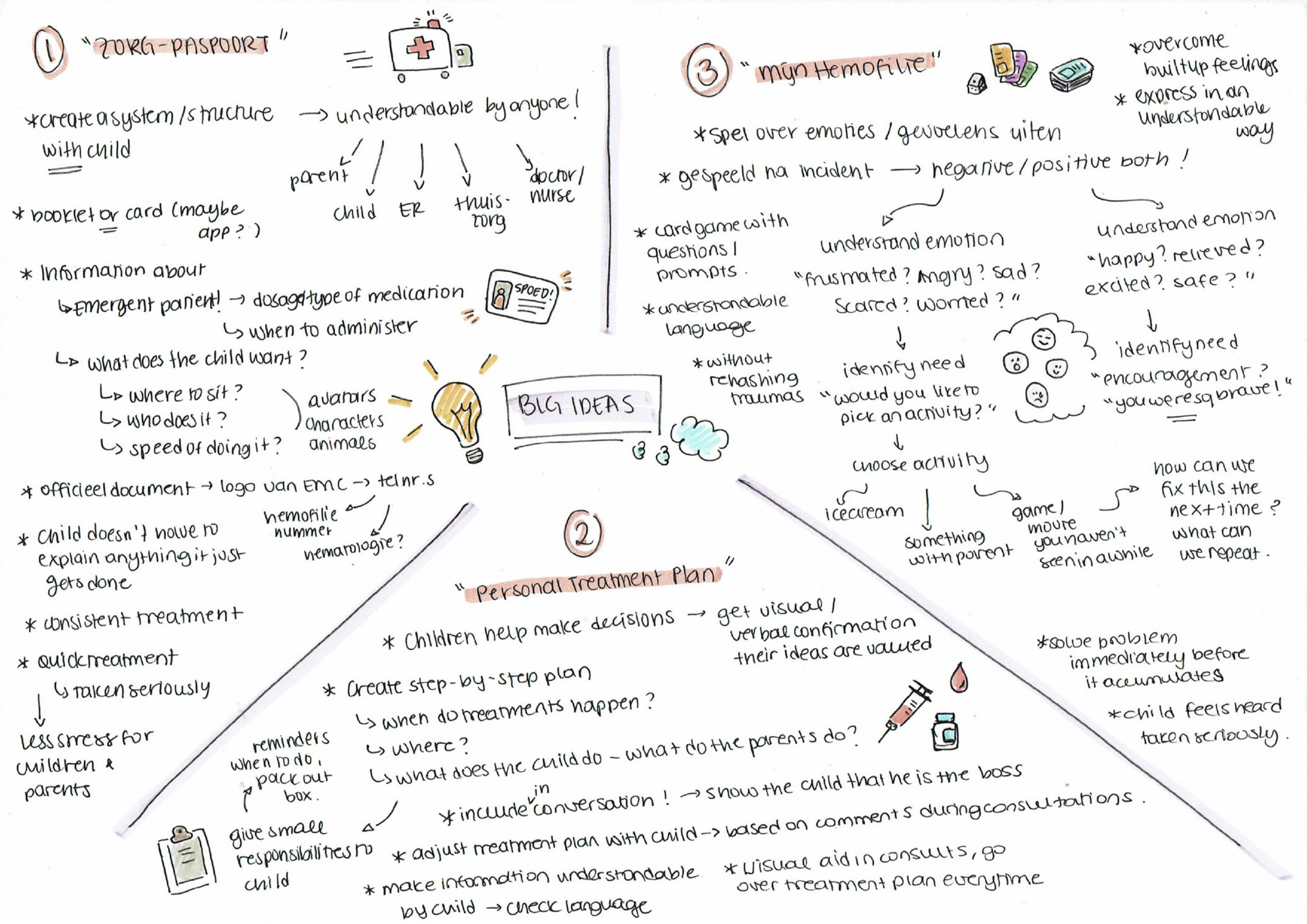
GIVE RESPONSIBILITY

- * help understand role in sickness
  - ↳ what to do with a fall?
  - what to do himself, and what to let parents do.
- * In the long run, will give feeling that child is responsible of own treatment.
- * identify limits (age appropriate)
  - what "can" a child do and what "should" a child do?
  - packout and prepare medication
- * small tasks to do → track schedule
- Let the parent know when they want to get treatment → encourage !
  - ↳ if you get the right time you get a candy?
- * show how to do things, repeat and let him show how to do it.
- * explain illness to siblings / friends, to let him own the disease

DECISION MAKING

- * start with small (medically) unimportant decisions
  - ↳ where to sit for treatment? where to puncture?
  - could be a game! → build own "behandel" experience
  - doesn't change much but child feels important
- * "Discreet choice experiments"
  - ↳ ask small unrelated questions to understand child's view
- * include in conversation → child is the boss !


HOW DO YOU CREATE CONSISTENCY?
* create routines for treatments
child gets to choose how/ when/ where
* close off with a positive
→ toy
→ candy
↳ activity
* let everyone understand needs
toy?
how to treat?
where does child want to sit?
all treaters
→ ER
→ thuiszorg
→ parent
→ nurse
doctor
child-parent-medical staff should all have same info
what is important for each player?
maybe change the wording but keep content same.
* create structure
prepare beforehand?
give a prepared schedule
→ give the room to prepare / ask questions
↳ time to prepare self for treatment/other
* manage expectations
let the child know exactly what will happen at what time
↳ positives & negatives
hide the negative in the positive?
HOW CAN YOU CREATE TRUST?
make sure the child's needs/wants are fulfilled anywhere/anytime!
↳ trusting all players → trusting the process.
↳ let someone else (a parent preferably) do the treatment to show it isn't scary.
* permission
let the children know what you are doing
ask if they are okay with process
on the same page. no hiding!
* transparency
same information for everyone
→ always with child in the room
↳ not tiptoeing around things
↳ no whispering
HOW DO YOU COMMUNICATE WITH A CHILD?
* identify wants/ needs
how does the child want to be handled?
distraction?
honest truth?
step-by-step?
make sure child can explain back to you
* repeat back
game to identify?
* make understandable!
understand audience what is the age group?
with games/ imagination
easy words but not baby talk.
↳ to make like an adult or not?
* show how things work instead of telling
→ teddy bear going through process.
visual aids


① "ZORG-PASPOORT"
* create a system/structure with child
→ understandable by anyone!
parent
child
ER
thuis-zorg
doctor/ nurse
* booklet or card (maybe app?)
* Information about
↳ Emergent patient! → dosage type of medication
↳ when to administer
↳ what does the child want?
↳ where to sit?
↳ who does it?
↳ speed of doing it?
avatars
characters
animals
SPOED!
* officieel document → logo van EMC → tel nr.s
hemofilie nummer
hematologie?
* child doesn't have to explain anything it just gets done
* consistent treatment
* quick treatment
↳ taken seriously
less stress for children & parents
BIG IDEAS
③ "mijn Hemofilie"
* overcome built up feelings
* express in an understandable way
* spel over emoties / gevoelens uiten
* gespeeld na incident → negative/positive both!
* card game with questions/ prompts.
* understandable language
* without rehashing traumas
understand emotion "frustrated? angry? sad? scared? worried?"
identify need "would you like to pick an activity?"
choose activity
icecream
something with parent
game/ movie you haven't seen in a while
how can we fix this the next time? what can we repeat.
understand emotion "happy? relieved? excited? safe?"
identify need "encouragement?" "you were so brave!"
② "Personal Treatment Plan"
* Children help make decisions → get visual/ verbal confirmation their ideas are valued
* Create step-by-step plan
↳ when do treatments happen?
↳ where?
↳ what does the child do - what do the parents do?
* include in conversation! → show the child that he is the boss
give small responsibilities to child
reminders when to do, pack out box.
* adjust treatment plan with child → based on comments during consultations.
* make information understandable by child → check language
* visual aid in consults, go over treatment plan everytime
* solve problem immediately before it accumulates
* child feels heard taken seriously.

Infants (0-2) need trust, they need to know what is happening and need transparency. For this, an interesting direction may be to **show instead of tell**. Seeing something done to someone else first may help, especially the mother, as she is a main figure in the child's life at this point. An idea to **activate the senses and create physical contact** may be beneficial too, as communication may be lacking at this age. **Setting up structures and consistency** might also be necessary at this age, for the child to develop trust.

Toddlers (2-4) have a **strong imagination** which can be utilized in giving an understanding of what is happening. **Using animals or symbols** can help toddlers to start comprehending what is happening, but can also help express themselves and what they need. At this point trust should be established of which a main part is permission. The child should be able to **see their opinion is considered and understand why not if it isn't.** Autonomy is also developing, therefore a game with an element of responsibility can be beneficial, like **doing a task or making a small decision**. Having a **step-by-step approach** can also help in managing expectations, so that the child knows what is happening at all times, which should be **as visual as possible**. The child should understand without having to ask the parent.

Play age (4-6) need reassurance, they have started to become aware of consequences and yet do not fully comprehend their feelings, which can manifest in negative emotions. Here **giving the space to express feelings** may be necessary, but it isn't easy since the child most likely doesn't understand his emotions. An idea would be to have a system where there is **constant reassurance, verbal or physical, through a game or even a stuffed animal.** Speaking in the child's language in a way he can understand, with **concrete examples** (e.g. previous situations or memories) may help in **grounding the conversation** and help get the necessary information without overwhelming the child.

School age (6-8) needs control, they **want to express their opinions and feel heard** and want to know their opinions are valued, they can also benefit from small responsibilities showing them that **they are in charge**. Repeating decisions back and showing evidence of effect may help with this. By using **understandable figures** like cartoon characters or animals in the explanations, or even letting the child choose from familiar figures may give this feeling. The child might see and immediately understand that it was his choice, as opposed to text he can't understand. Baby talk or "belittling" can have the opposite effect, so using **easier vocabulary with the same tone as spoken to with the parent can help the child feel important**.

There are multiple actors in the system, from the children and parents to home care professionals to the team at the Sophia. All actors should be using the **same information**, all stemming from the **child's preferences**. To ensure that the preferences/needs are understood by everyone, the same information can be **translated per actor**, starting with simple visuals for the child to medical terms for the HCPs. This can help with the **consistency** that is experienced by the child.

Initial Intervention Ideas

From these brainstorming sessions, 3 initial ideas were created.

"THE HEMOPHILIA-ID"

The Hemophilia-ID is a system (e.g. a card, an app or a booklet) that is understandable by anyone, presenting the needs of the child in a concise manner.

It is an official document that will be supplied by the Erasmus MC (or on a more national scale eg. by NVHP or HemoNED), which can be used in different hospitals, by different caregivers.

The product includes medical information about the child such as, their disease, their doctor and their medication but also the child's personal preferences, like where they like to sit during treatment and how they like getting their injection. Most importantly the product will show that the child is in need of urgent care and requires priority.

The aim is quick and consistent care in the way the child prefers.

The child will not have to explain anything in a moment of panic, yet still can see that his opinion was taken into account.

"PERSONAL TREATMENT PLAN"

Treatment plans are made yearly, mainly with the medical facts and what the medical team sees fit. The personal treatment plan takes the child as main contact and serves as a protocol for how to include the child in decisions and conversations.

There is a step-by-step plan included in how and when treatments are applied, in a way that the child can understand, made with the child himself, with the use of characters and symbols.

The plan also gives the child small responsibilities in the steps, giving some control in how things are done.

The treatment plan will be used in every visit instead of only yearly, and will include questions directed to the child to gain an understanding of how things are going and if anything needs to be adjusted. The child gets a copy of this, which they can look back to before every visit and can prepare questions if necessary.

Every visit repeats the decisions made the last time letting the child know that his opinions were taken into account.

Methods like "discreet decision making" (Angie, 2010; Fegert, 2014; Webb, 2019) can aid in understanding the wants of the child and let them be a part of the decision making process.

"CONVERSATION GAME"

The Conversation Game is a game about starting the conversation of expressing emotions and opinions in order to gain an understanding of feelings and claim ownership of the disease.

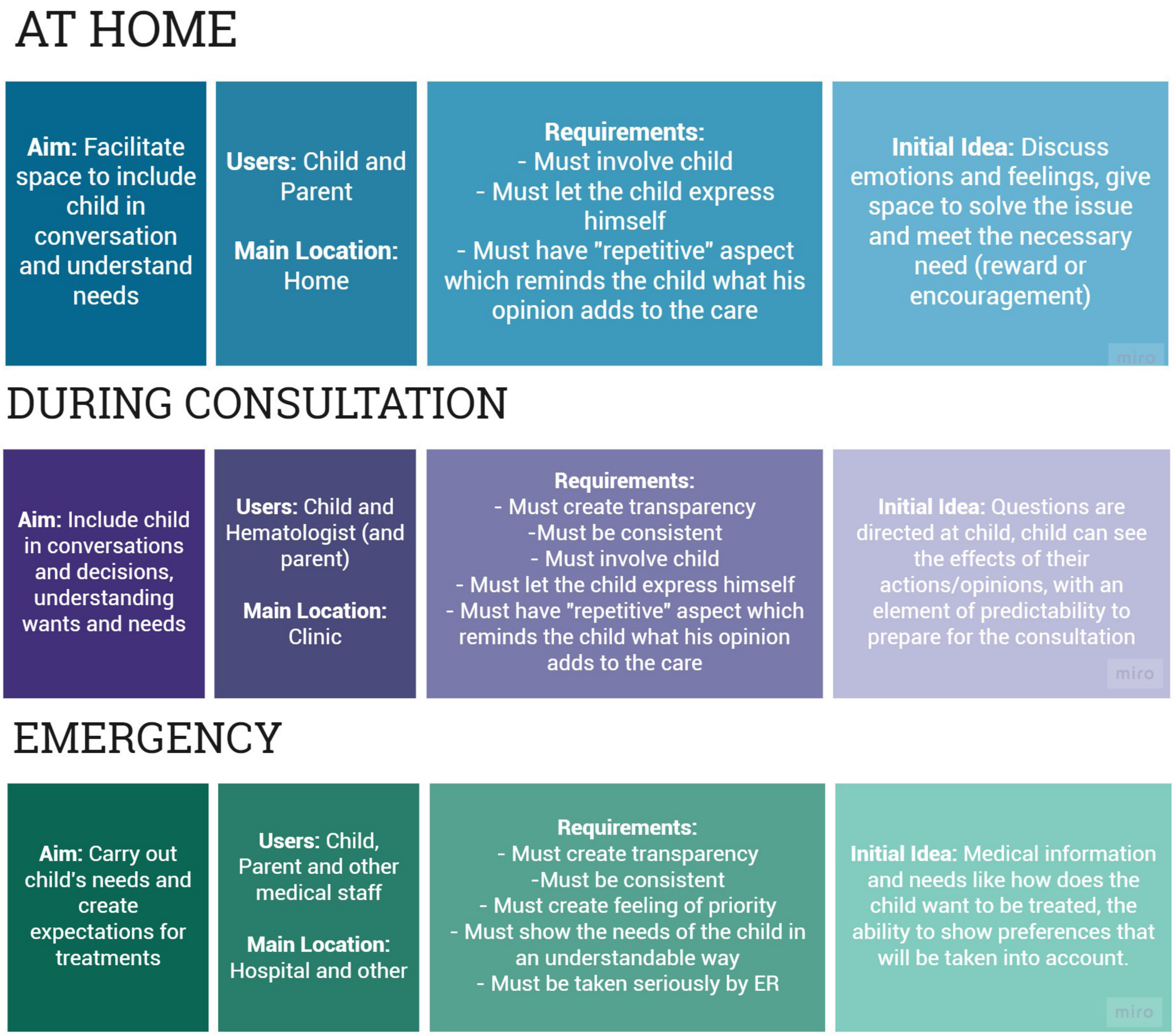
It is a card game played between a parent and child after an incident, for example a fall or a trip to the emergency room, to understand and solve problems without them building up.

This game aims to give the child the space to express their feelings and needs. This may not be autonomously done at first, so the initiative will be on the parent to take out the cards. With time if this is done enough, the cards will be transferred to the child, where they can themselves initiate the conversation, once they know it is okay to do so.

Firstly emotions are identified. Young children cannot easily identify emotions (Stifter, 1986) therefore small questions are asked which then lead to other cards to then narrow down to a specific emotion, negative (frustrated, angry, scared, sad, etc.) or positive (proud, happy, relieved, safe, etc.).

Then the problem is analyzed, “what can we do differently next time?” or “what did you like most about this?”. This can be for example in the context of an ER visit that went wrong, where the child wanted to hold his toy but wasn’t given the time to do so. The parent can then understand that this was a preference and can reiterate this in the next visit.
Next, the need is identified. For a negative emotion this can be reassurance or a reward, like watching a movie you haven’t seen in a while or having ice cream to close off the situation positively. For a positive emotion this can be encouragement like “you were so brave!”

Initially designed as 3 separate ideas, where the one with most value would be chosen for further analysis, it was apparent that the essence of the ideas addressed different areas of the experience, which were all equally important in the patient experience and could strengthen each other. These were therefore deconstructed into the main interaction points of each area, which served as a starting point for the creative facilitation session. These can be seen in Figure 7.2.



AT HOME

Aim: Facilitate space to include child in conversation and understand needs

Users: Child and Parent

Main Location: Home

Requirements:
- Must involve child
- Must let the child express himself
- Must have "repetitive" aspect which reminds the child what his opinion adds to the care

Initial Idea: Discuss emotions and feelings, give space to solve the issue and meet the necessary need (reward or encouragement)

DURING CONSULTATION

Aim: Include child in conversations and decisions, understanding wants and needs

Users: Child and Hematologist (and parent)

Main Location: Clinic

Requirements:
- Must create transparency
-Must be consistent
- Must involve child
- Must let the child express himself
- Must have "repetitive" aspect which reminds the child what his opinion adds to the care

Initial Idea: Questions are directed at child, child can see the effects of their actions/opinions, with an element of predictability to prepare for the consultation

EMERGENCY

Aim: Carry out child’s needs and create expectations for treatments

Users: Child, Parent and other medical staff

Main Location: Hospital and other

Requirements:
- Must create transparency
-Must be consistent
- Must create feeling of priority
- Must show the needs of the child in an understandable way
- Must be taken seriously by ER

Initial Idea: Medical information and needs like how does the child want to be treated, the ability to show preferences that will be taken into account.

Figure 7.2 Essential properties of the 3 areas

7.3.2 Creative Facilitation Session

Purpose

This session aimed to get a broader understanding of the possibilities within the three idea spaces, and to fully define the requirements of each area. The 3 main areas of brainstorming were in the home, clinic and ER contexts, as defined in the initial ideation phase.

Method

The creative facilitation session was done with the collaboration of 3 designers with experience in healthcare. The important elements of the initial ideas were also provided, not to give a preconceived notion of a possible idea, but merely to create a better understanding of what the mentioned requirements mean. This was helpful in understanding the situation without having to go through all the findings specifically. The patient journey was also quickly shown with the main lines, to understand which parts of the experience the areas fit into.

The method followed here was for each person to start in the middle of one of the areas, work on generating ideas for 10 minutes, and then switch to the next area to build on the ideas of the previous person. The ideas went from general (center) to more specific (outer sides) as ideation was done. These did not have to specifically meet the interaction requirements of the area, as the aim of this portion was to generate as many ideas as possible. This portion took 30 minutes in total, followed by a 30 minute collective brainstorm all together to identify the points that fit within the interaction requirements.

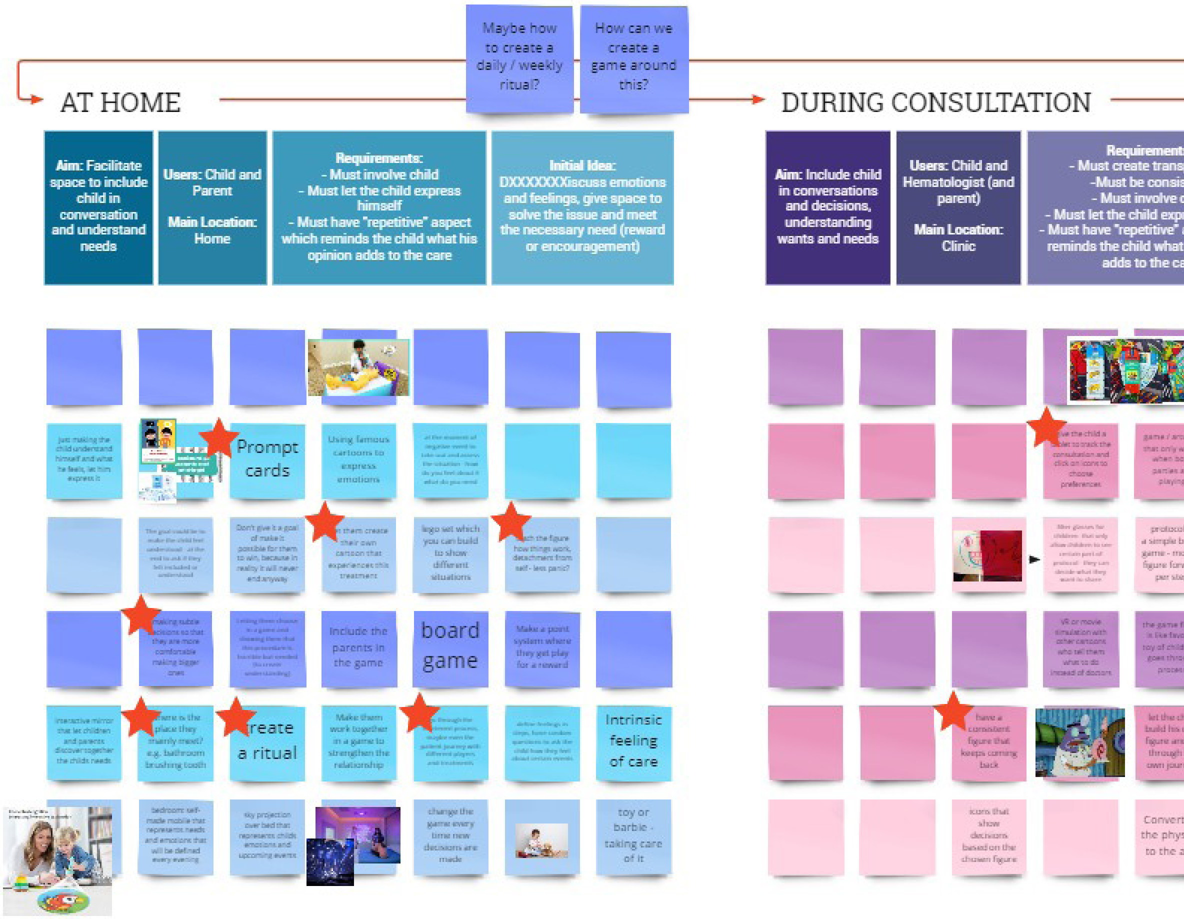


Figure 7.3 Outcomes of the creative facilitation session

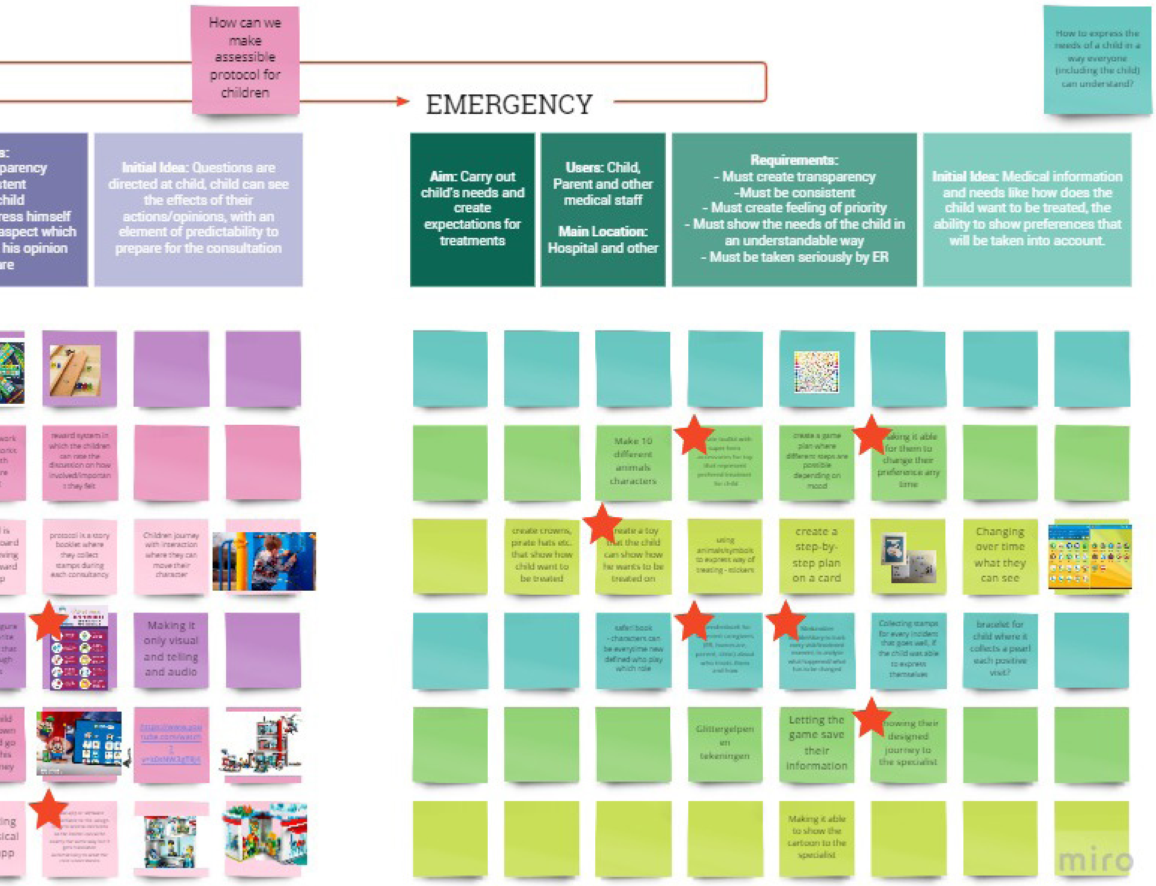
Outcomes

Figure 7.3 shows the outcomes of the session. The red stars indicate the ideas that fit or had a potential of fitting the interaction requirements.

All areas showed an element of consistency, whether it was a symbol that kept coming back, or a fixed structure for a process. Some ideas included a consistent figure that could be found throughout the process, binding the 3 areas together. This was eventually scrapped, due to the attachment that can happen between the child, and in the case of this example, a toy that would take him through the process. The attachment could work in the favor of the process, but could have dire consequences in the case of a broken or lost toy. The consistency element was chosen to be kept within the area, not throughout the whole system.

Another important point was accessibility. Due to the young age of the children, where apps and electronic games would be desirable for the child, it would create a significant barrier. As the children will be relying on their parents' devices, the parent would once again be in between. Therefore, the decision was made to take the essence of this, which were the colorful games, to integrate them into a concept that is more accessible to the child.

This session made it clear that all 3 areas had value, and therefore it was decided to create 3 concepts that addressed the different areas, with the overarching aim of giving the feeling of control and structure. With the results of the session, an individual session followed, with the analysis of the outcomes and combining the ideas to create 3 concepts.



7.3.3 Individual Conceptualization

Purpose

The final session aimed to identify the building blocks of the different areas and to combine them in viable concepts.

Method

The outcomes of the creative facilitation session were used in combining ideas. The ones that fit together were integrated into each other, and further research was done where necessary to identify the value and check feasibility.

Outcomes

The findings of this session can be seen in Figure 7.4. These findings were used in turning the ideas into concepts, as presented in the next chapter.

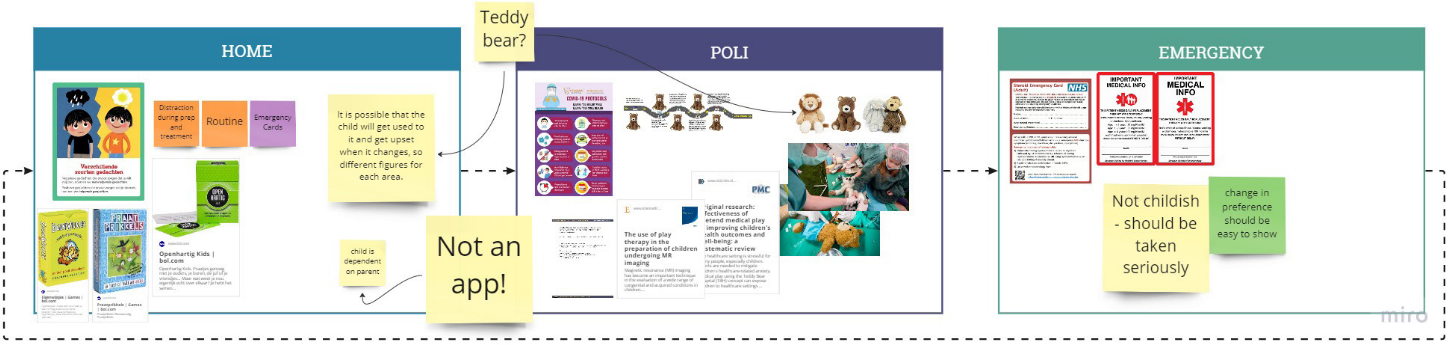


Figure 7.4 Outcomes of the individual conceptualization session

KEY TAKEAWAYS FROM THIS CHAPTER

3 areas of intervention were defined with new requirements for each area to fulfill, to serve the overarching aim of giving the child the feeling of control and structure.

- **HOME - Facilitate space to include child in conversation and understand needs,**

  Must ***involve*** child, must let the child ***express*** himself, must have "***repetitive***" aspect which reminds the child what his opinion adds to the care

- **CLINIC - Include child in conversations and decisions, understanding wants and needs**

  Must create ***transparency***, must be ***consistent***, must ***involve*** child, must let the child ***express*** himself, must have "***repetitive***" aspect which reminds the child what his opinion adds to the care

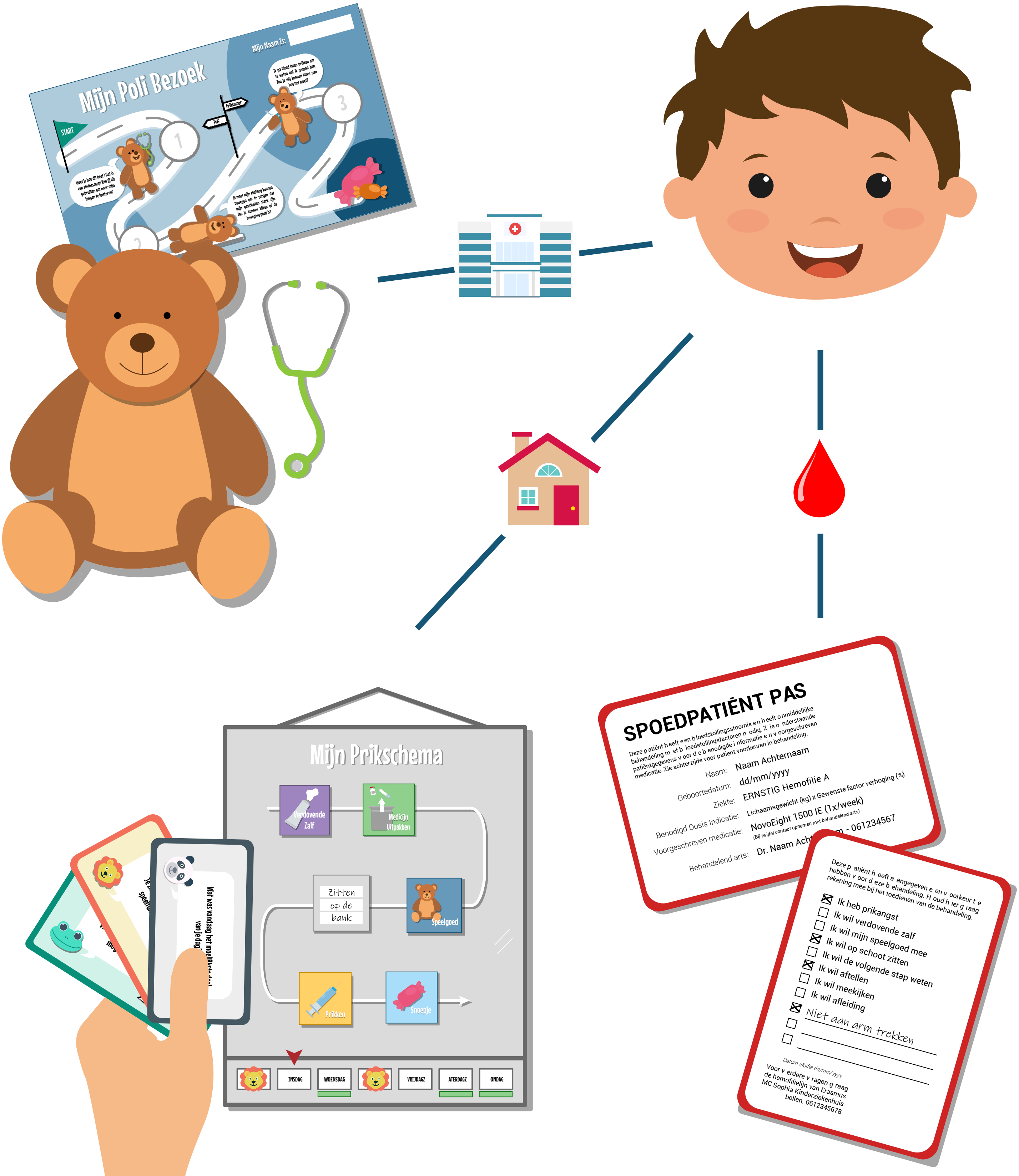
- EMERGENCY - Carry out child's needs and create expectations for treatments

  Must create ***transparency***, must be ***consistent***, must create feeling of ***priority***, must show the needs of the child in an ***understandable*** way, must be taken ***seriously*** by ER

08 Concepts for Intervention

In order to create an intervention of value, 3 important areas of the patient experience were addressed, within the home, at the clinic and at the emergency room. This chapter will explain the use of the concepts, as well as their value to the patient experience.

A first impression of the concepts is shown in Figure 8.1, The concepts can be used individually, but are designed to strengthen each other when used simultaneously.



SPOEDPATIËNT PAS

Deze patiënt heeft een bloedstollingsstoornis en heeft onmiddellijke behandeling met bloedstollingsfactoren nodig. Zie onderstaande patiëntgegevens voor de benodigde informatie en voorgeschreven medicatie. Zie achterzijde voor patient voorkeuren in behandeling.

Naam: Naam Achternaam
Geboortedatum: dd/mm/yyyy
Ziekte: ERNSTIG Hemofilie A
Benodigd Dosis Indicatie: Lichaamsgewicht (kg) x Gewenste factor verhoging (%)
Voorgeschreven medicatie: NovoEight 1500 IE (1x/week)
(Bij twijfel contact opnemen met behandelend arts)
Behandelend arts: Dr. Naam Ach m - 061234567

Deze patiënt heeft aangegeven een voorkeur te hebben voor deze behandeling. Houd hier graag rekening mee bij het toedienen van de behandeling.

- ☒ Ik heb prikangst
- ☐ Ik wil verdovende zalf
- ☐ Ik wil mijn speelgoed mee
- ☒ Ik wil op school zitten
- ☐ Ik wil de volgende stap weten
- ☒ Ik wil aftellen
- ☐ Ik wil meekijken
- ☐ Ik wil afleiding
- ☒ Niet aan arm trekken
- ☐
- ☐

Datum afgifte dd/mm/yyyy

Voor verdere vragen graag de hemofilielijn van Erasmus MC Sophia Kinderziekenhuis bellen. 0612345678

Figure 8.1 Impression of concepts

Concept 1 - Home

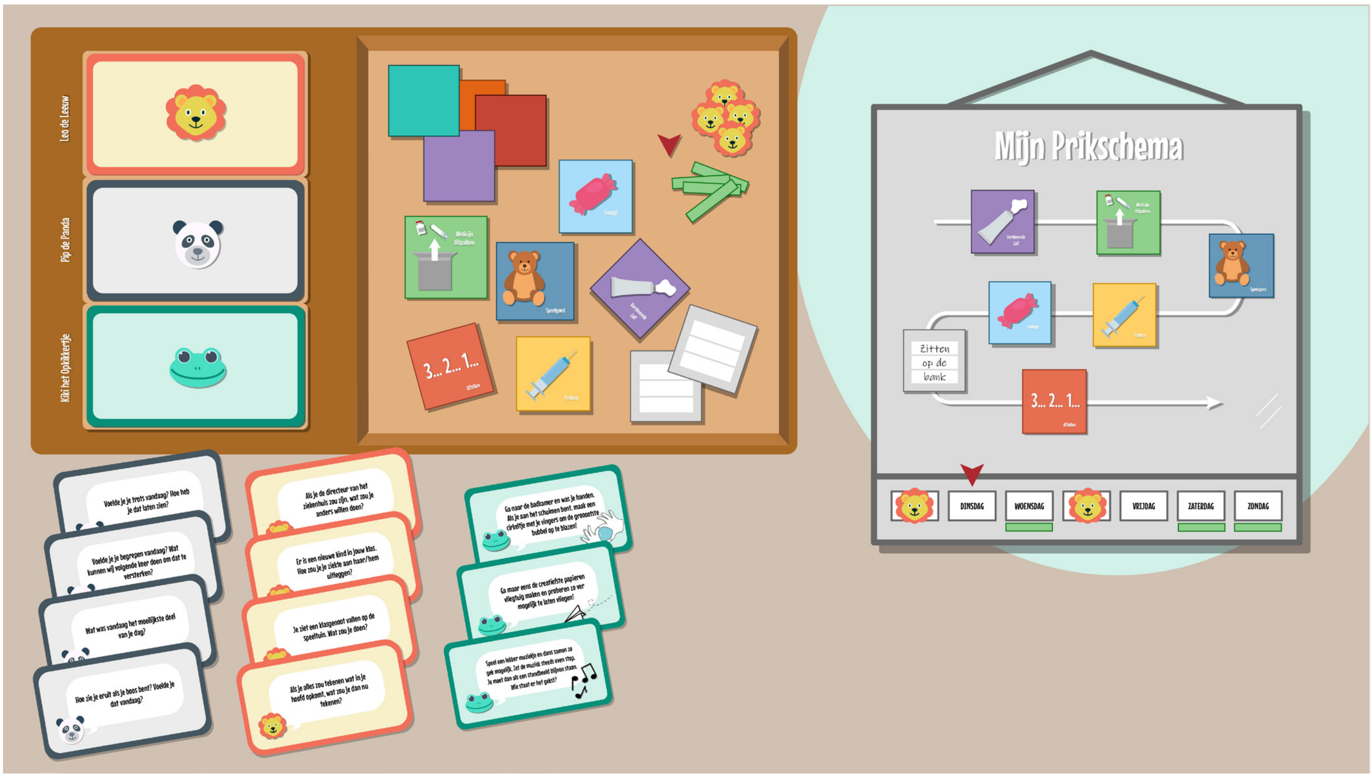
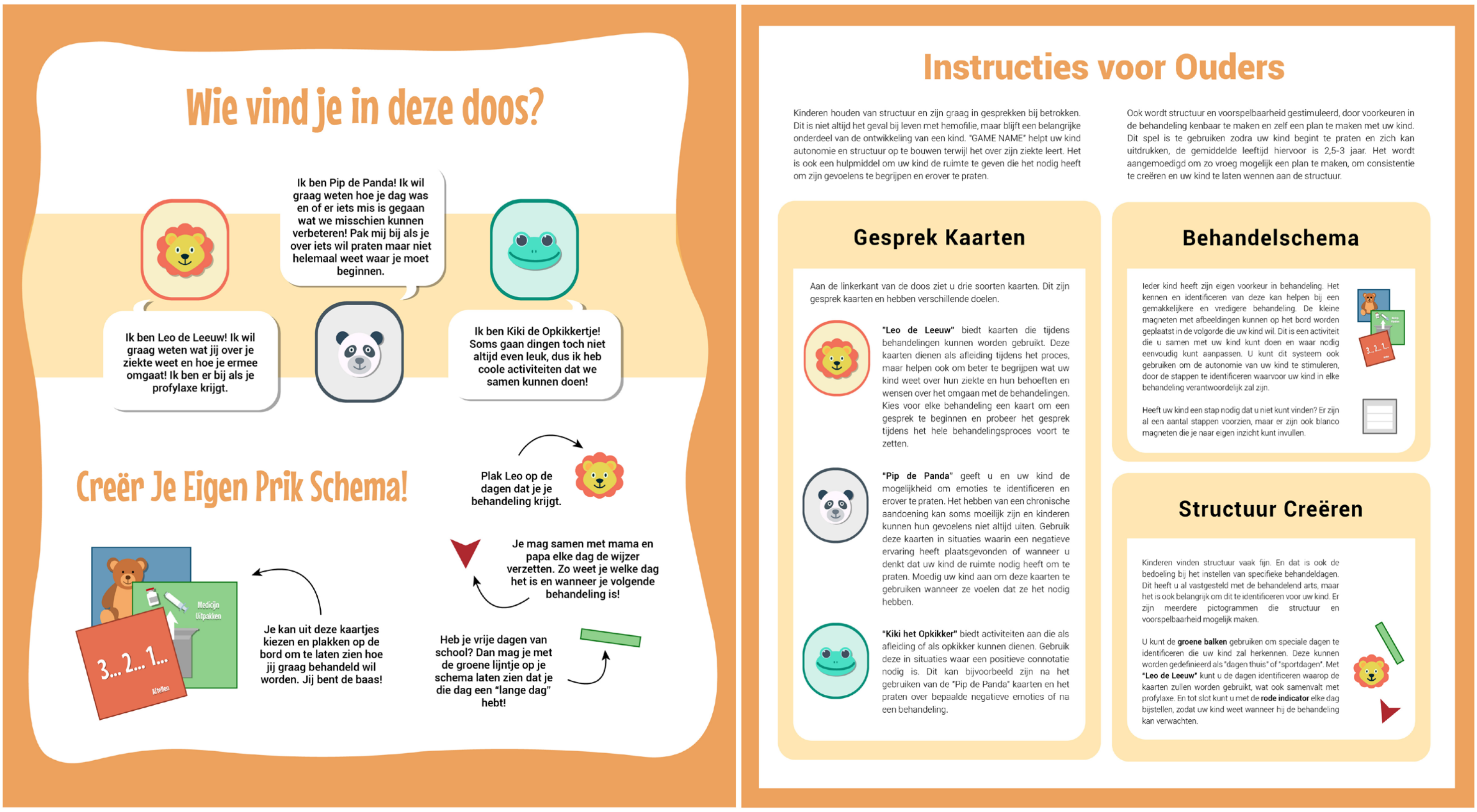


Figure 8.2 Concept 1 - Home

The first concept (Figure 8.2) is aimed for use at home. The research conducted in the previous chapters showed that the majority of hemophilia takes place at home, and that even though parents know the problems faced by the children and want to help, they do not always know how. These problems mainly include opening conversations to understand the child's needs and provide structure in a way that the child can comprehend. This concept aims to address these areas, and create concrete tools to help the children feel better understood and more in control. The concept is in the form of a tangible box, in which 3 sets of cards, a magnetic board and magnetic icons are provided. This concept consists of 2 parts, each with its own purpose. An instruction book is supplied as well, with one side explaining the concept to the parents and the other to the children, in a language they can understand, which the parents can read out to them. The instructions can be seen in Figure 8.3.



Wie vind je in deze doos?

Ik ben Pip de Panda! Ik wil graag weten hoe je dag was en of er iets mis is gegaan wat we misschien kunnen verbeteren! Pak mij bij als je over iets wil praten maar niet helemaal weet waar je moet beginnen.

Ik ben Leo de Leeuw! Ik wil graag weten wat jij over je ziekte weet en hoe je ermee omgaat! Ik ben er bij als je profylaxe krijgt.

Ik ben Kiki de Opkikkertje! Soms gaan dingen toch niet altijd even leuk, dus ik heb coole activiteiten dat we samen kunnen doen!

Creër Je Eigen Prik Schema!

Plak Leo op de dagen dat je je behandeling krijgt.

Je mag samen met mama en papa elke dag de wijzer verzetten. Zo weet je welke dag het is en wanneer je volgende behandeling is!

Je kan uit deze kaartjes kiezen en plakken op de bord om te laten zien hoe jij graag behandeld wil worden. Jij bent de baas!

Heb je vrije dagen van school? Dan mag je met de groene lijntje op je schema laten zien dat je die dag een "lange dag" hebt!

Instructies voor Ouders

Kinderen houden van structuur en zijn graag in gesprekken bij betrokken. Dit is niet altijd het geval bij leven met hemofilie, maar blijft een belangrijke onderdeel van de ontwikkeling van een kind. "GAME NAME" helpt uw kind autonomie en structuur op te bouwen terwijl het over zijn ziekte leert. Het is ook een hulpmiddel om uw kind de ruimte te geven die het nodig heeft om zijn gevoelens te begrijpen en erover te praten.

Ook wordt structuur en voorspelbaarheid gestimuleerd, door voorkeuren in de behandeling kenbaar te maken en zelf een plan te maken met uw kind. Dit spel is te gebruiken zodra uw kind begint te praten en zich kan uitdrukken, de gemiddelde leeftijd hiervoor is 2,5-3 jaar. Het wordt aangemoedigd om zo vroeg mogelijk een plan te maken, om consistentie te creëren en uw kind te laten wennen aan de structuur.

Gesprek Kaarten

Aan de linkerkant van de doos ziet u drie soorten kaarten. Dit zijn gesprek kaarten en hebben verschillende doelen.

"Leo de Leeuw" biedt kaarten die tijdens behandelingen kunnen worden gebruikt. Deze kaarten dienen als afleiding tijdens het proces, maar helpen ook om beter te begrijpen wat uw kind weet over hun ziekte en hun behoeften en wensen over het omgaan met de behandelingen. Kies voor elke behandeling een kaart om een gesprek te beginnen en probeer het gesprek tijdens het hele behandelingsproces voort te zetten.

"Pip de Panda" geeft u en uw kind de mogelijkheid om emoties te identificeren en erover te praten. Het hebben van een chronische aandoening kan soms moeilijk zijn en kinderen kunnen hun gevoelens niet altijd uiten. Gebruik deze kaarten in situaties waarin een negatieve ervaring heeft plaatsgevonden of wanneer u denkt dat uw kind de ruimte nodig heeft om te praten. Moedig uw kind aan om deze kaarten te gebruiken wanneer ze voelen dat ze het nodig hebben.

"Kiki het Opkikker" biedt activiteiten aan die als afleiding of als opkikker kunnen dienen. Gebruik deze in situaties waar een positieve connotatie nodig is. Dit kan bijvoorbeeld zijn na het gebruiken van de "Pip de Panda" kaarten en het praten over bepaalde negatieve emoties of na een behandeling.

Behandelschema

Ieder kind heeft zijn eigen voorkeur in behandeling. Het kennen en identificeren van deze kan helpen bij een gemakkelijkere en vredigere behandeling. De kleine magneten met afbeeldingen kunnen op het bord worden geplaatst in de volgorde die uw kind wil. Dit is een activiteit die u samen met uw kind kunt doen en waar nodig eenvoudig kunt aanpassen. U kunt dit systeem ook gebruiken om de autonomie van uw kind te stimuleren, door de stappen te identificeren waarvoor uw kind in elke behandeling verantwoordelijk zal zijn.

Heeft uw kind een stap nodig dat u niet kunt vinden? Er zijn al een aantal stappen voorzien, maar er zijn ook blanco magneten die je naar eigen inzicht kunt invullen.

Structuur Creëren

Kinderen vinden structuur vaak fijn. En dat is ook de bedoeling bij het instellen van specifieke behandeldagen. Dit heeft u al vastgesteld met de behandelend arts, maar het is ook belangrijk om dit te identificeren voor uw kind. Er zijn meerdere pictogrammen die structuur en voorspelbaarheid mogelijk maken.

U kunt de **groene balken** gebruiken om speciale dagen te identificeren die uw kind zal herkennen. Deze kunnen worden gedefinieerd als "dagen thuis" of "sportdagen". Met **"Leo de Leeuw"** kunt u de dagen identificeren waarop de kaarten zullen worden gebruikt, wat ook samenvalt met profylaxe. En tot slot kunt u met de **rode indicator** elke dag bijstellen, zodat uw kind weet wanneer hij de behandeling kan verwachten.

Figure 8.3 Instruction Book

The Injection Schedule

The first part of the concept is the injection schedule, which is a magnetic board that can be used to create personalized schedules. The top section of the board has a line, providing space for preferences to be set, and the bottom section shows days in which the prophylaxis days can be identified. Also included are small magnetic icons, with different steps/activities. These show the steps with icons, where the child can identify the step and choose the order that he would prefer.

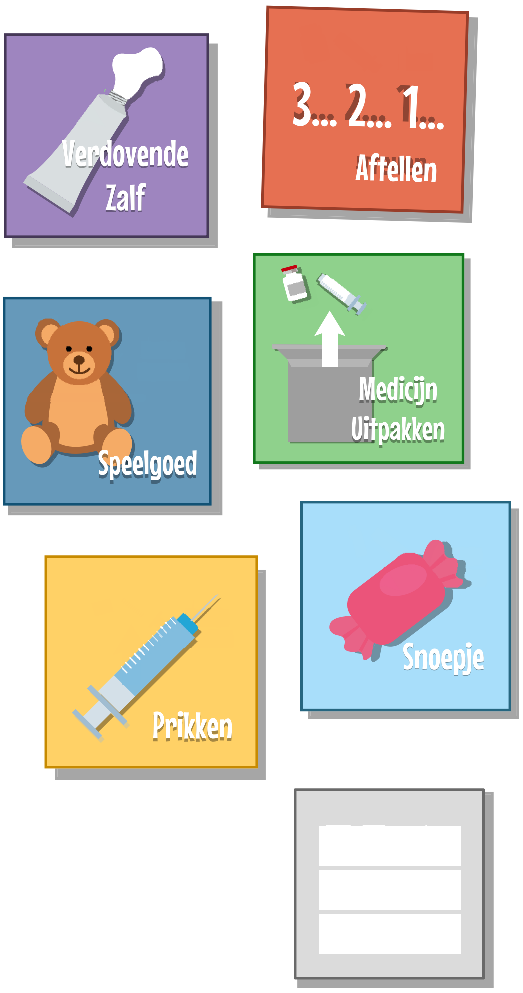
The aim is for this to be fully customizable, 7 examples of icons were illustrated, the intervention itself will be provided with 30-40 icon magnets, as well as blank ones so if the preference of the child is not included, this can also be catered to. These will have to be further researched to identify the specific needs of each child.

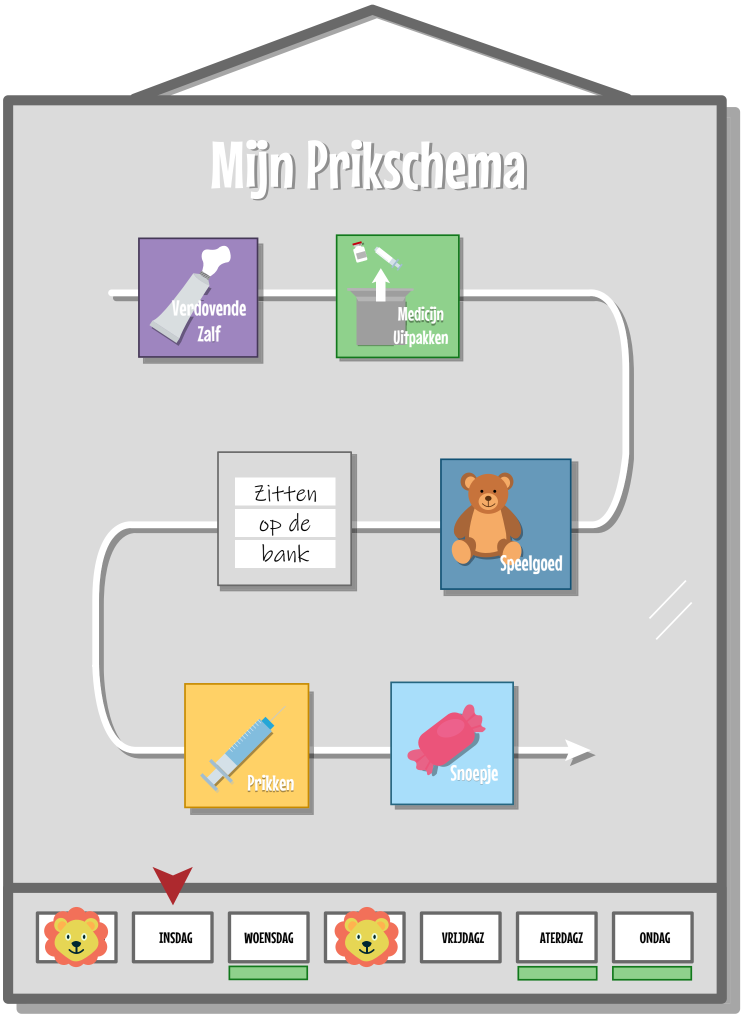
There are also icons to identify prophylaxis days (for this identification, lion icons were used, this will be further explained within the explanation of the conversation cards), a red arrow to show which day it is, and green lines to identify special days (for example days at home or at school). Within the interviews and observation, when talking about days of prophylaxis it was visible that children do not know how to identify days at a young age, which makes it difficult for them to understand when the prophylaxis will happen. Parents usually find other ways to explain, like "home day-school day" or "gym day" which are also applicable in placing the green lines. These tools help the child understand which day it is, and when to expect the prophylaxis.

The board is made of soft material, like silicone, so that it can be usable by the child as well. The metal board will be under a layer of plastic, making it safe for the children to use. Considering the age of the children, the icons will be of a larger size, and to be used with supervision until a certain age to avoid a choking hazard. This will have to be further researched before implementation.

The aim of this part is to create **consistency, predictability and control** for the child. The feeling of control is given by letting the child set up his own schedule, the predictability is done by letting him see what to expect at any time he wants and consistency by making sure that everyone is on the same page about the child's preferences. There are different actors treating the child, for example the parents and home care. This allows for everyone to follow the same schedule creating a consistent experience for the child. The icons also allow for small responsibilities to be given to the child. For example, the agreement can be made that the child will apply the numbing cream or pack out the medication box, which could give the child a feeling of importance in the process.

The main user of the product is the child, with some help from the parent. For infants and toddlers, the parent can fill out the board as they observe their child's preferences. From play age on, the child can sit with a parent, and as the icons are familiar, the child can independently decide which step he would like to take. This can be hung up on a wall or the fridge, which most families use for this sort of purpose, and be **accessible to the child whenever necessary.**





Conversation & Activity Cards

The second section consists of 3 sets of cards: "Leo the Lion" (NL: Leo de Leeuw), "Pip the Panda" (NL: Pip de Panda) and "Kiki the Frog" (NL: Kiki het Opkikkertje, where "kikker" means frog and "opkikkertje" means a pick-me-up). These cards each serve a separate purpose, with the overarching aim of helping understand the needs and feelings of the child.

"Leo the Lion''

These are general conversation cards. These provide questions to understand what the child knows about his disease and to give room for any questions from the child. These cards are meant to be used during the prophylaxis, with a card being picked before each session. By asking the question, the parent will start a conversation, which will serve as a distraction from the injection itself, but also create a ritual in how the process takes place. With time, the goal is for the child to start associating the (interesting) conversation with the parent as a part of the routine. Since the icon of the card is a lion, this was used as the icon for identifying prophylaxis days, allowing the child to see it as a day of conversation, instead of a day of injection. The example questions include (translated) "If you were the director of the hospital, what would you like to change?", "There is a new child in your class. How would you explain your condition to him/her?", "You see a classmate fall in the playground. What do you do?" and "If you could draw anything that comes in your head, what would you draw right now?".

"Pip the Panda"

These cards aim to help the child work through emotions, by asking short questions to start a conversation. The purpose of these is to be used after a negative experience, whether it be disappointment or frustration, to address the situation, before it builds up into bigger emotions, which the child doesn't know how to handle. In the beginning, the initiative lies with the parent, where they would bring up the conversation, but with time as the child grows with this routine, it may become easier for him to reach for the cards when he feels it's necessary. The questions are intentionally vague, as children may find it difficult to talk directly about the event that upset them, and the goal here is to address the situation but not build on a trauma. The example questions include (translated) "Did you feel proud today? How did you show this?", "Did you feel understood today? What can we do next time to strengthen this?", "What was the most difficult part of your day today?" and "What do you look like if you are angry? Did you feel like that today?".

"Kiki the Frog"

These cards serve as pick-me-ups, in Dutch "opkikkertjes", which are meant to be used in a situation where distraction is necessary. This may be after an injection that went wrong, or the child was not able to join the school trip due to a bleed. The cards have small, easy activities that the children can do alone or with a parent to get their mind off the situation. These also have icons which the child can also see to understand what they have to do. The activities are applicable to

Voelde je je trots vandaag? Hoe heb je dat laten zien?

Voelde je je begrepen vandaag? Wat kunnen wij volgende keer doen om dat te versterken?

Wat was vandaag het moeilijkste deel van je dag?

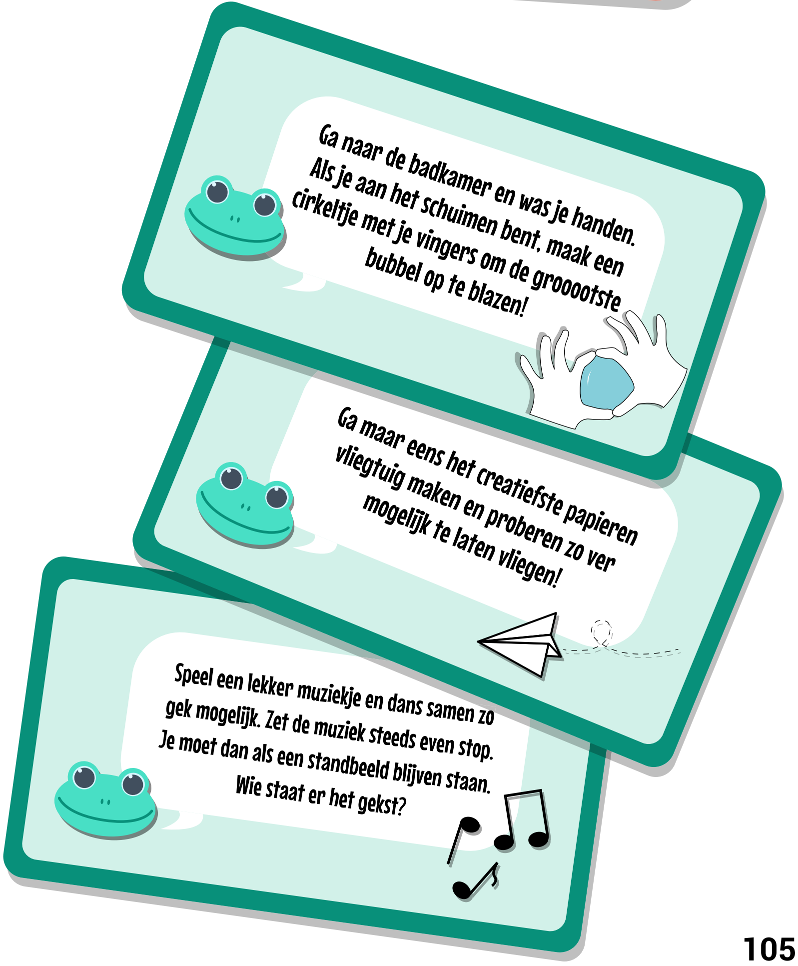
Hoe zie je eruit als je boos bent? Voelde je dat vandaag?

Als je de directeur van het ziekenhuis zou zijn, wat zou je anders willen doen?

Er is een nieuw kind in jouw klas. Hoe zou je je ziekte aan haar/hem uitleggen?

Als je alles zou tekenen wat in je hoofd opkomt, wat zou je dan nu tekenen?

Je ziet een klasgenoot vallen in de speeltuin. Wat zou je doen?



Ga naar de badkamer en was je handen. Als je aan het schuimen bent, maak een cirkeltje met je vingers om de grooootste bubbel op te blazen!

Ga maar eens het creatiefste papieren vliegtuig maken en proberen zo ver mogelijk te laten vliegen!

Speel een lekker muziekje en dans samen zo gek mogelijk. Zet de muziek steeds even stop. Je moet dan als een standbeeld blijven staan. Wie staat er het gekst?

children starting from toddlers, but there are some included that a parent can help a younger child with if necessary. Ideally, these are used with the panda cards, first identifying and addressing the feelings, and then closing off the situation with a positive experience. Example activities include (translated) "Go to the bathroom and wash your hands. While you are foaming, make a circle with your fingers to blow the biggest bubble!", "Try to make the most creative paper plane, and try to fly it as far as possible!" and "Play some music and dance as crazy as possible. Turn off the music every few minutes, when it stops you should be standing still like a statue. Who looks the craziest?"

Concept 2 - Clinic

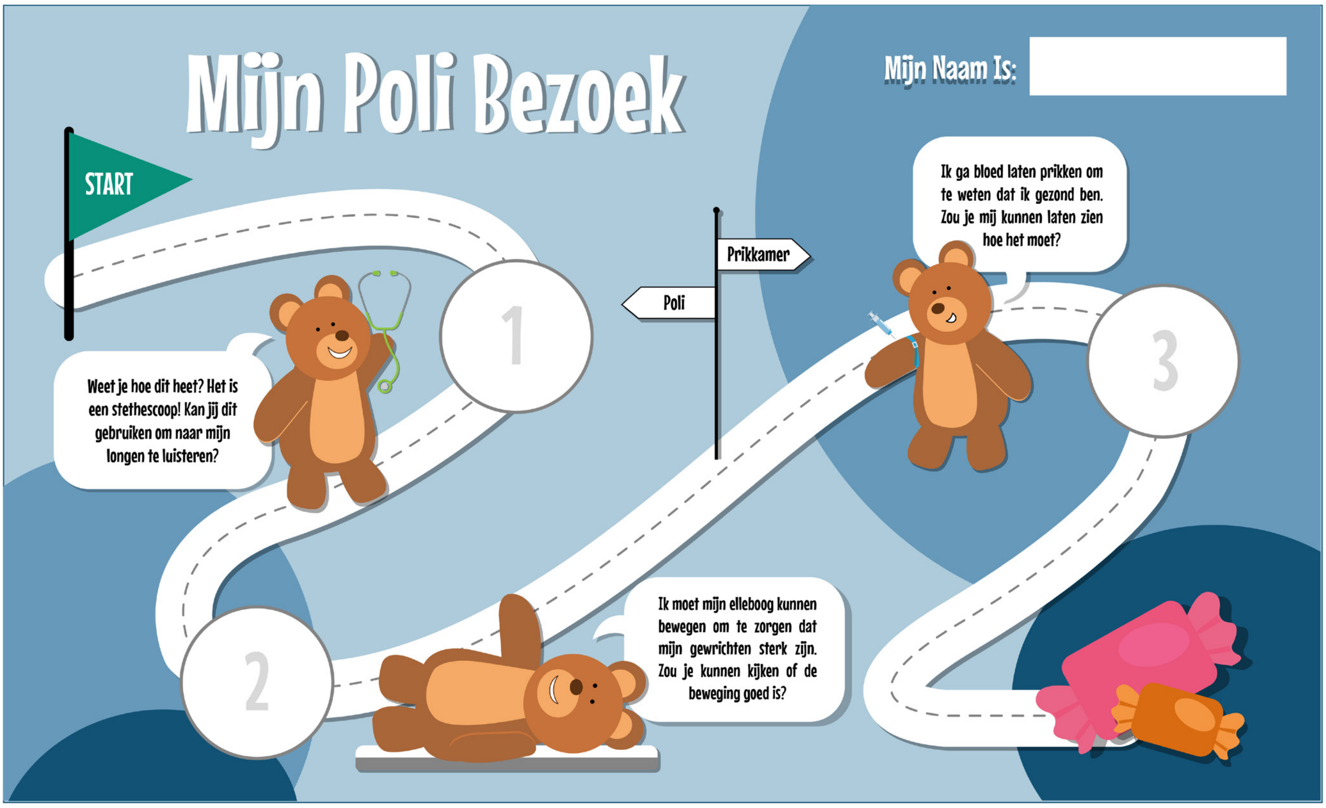
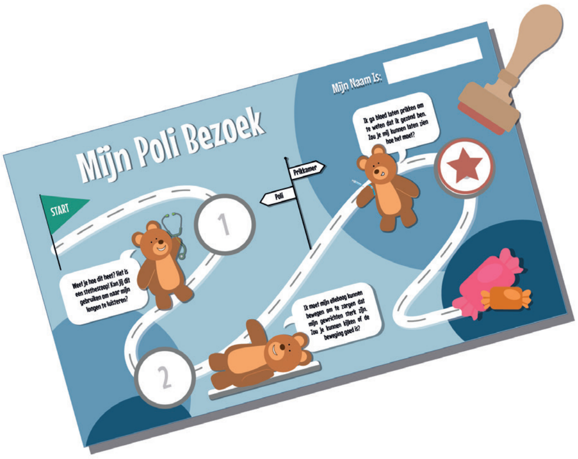


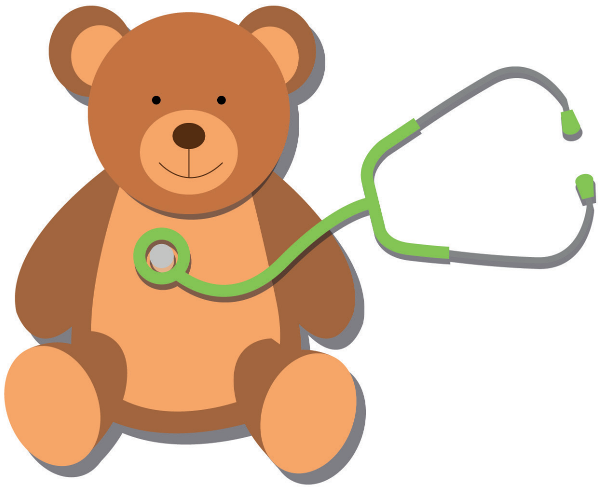
Figure 8.3 Concept 2 - Clinic

The second concept (Figure 8.3) is meant to be used during the clinic hours. The main findings of the clinic visits were inclusion in conversation, awakening interest and predictability of procedures. The observations showed that even though the patients prefer a certain amount of predictability, this was not possible in practice. As decisions are made the morning of the clinic, the earliest time the expectations can be shared is when the patient checks into the clinic. It is in the form of a game, in which the patient can carry out tasks, in order to get a prize in the end. This game is based on the decisions made in the morning about the procedures of the day which are translated into pre-made tasks, to be printed for the patient to pick up at the reception while checking in. Necessary explanations will be given to the patient and the parent to start off the game.

The tasks show the procedures that the patient will carry out on a teddy-bear, with replica toy set, for example a wing needle set without the actual needle, in order to avoid accidents with needles and other sharp objects. The HCPs will help in this, giving instructions where necessary. Once the child is done with his task, the same procedure will be done on him by the HCP. Every time a task is completed, a stamp will be placed on the sheet and once all stamps are collected, a prize will be given at the reception, while the parent is making the appointment for the next check-up. The prize has currently been defined as small pieces of candy, as this is given by parents currently at home after treatments. The content of the prize should be further researched, to understand whether candy is the best option, and also what other options may be available.

Research shows that if a child can detach from a situation and see it happening to someone or something else, they are more likely to be open for it to be done on themselves. This has often been tested with stuffed animals, where the patient can see how a procedure works, and can logically look at the situation without fearing the possible pain it may cause (Rashid, 2021; Pressdee, 1997; Jazrawy, 2021). This method is used in the game, by allowing the patient to carry out tasks with a teddy bear, present in the consultation/procedure room. The task will be accompanied by the procedure done on the patient, where the bear can then serve as a comfort tool. As the patient carries out his task, the parent can speak with the physician, without being interrupted or dividing attention.

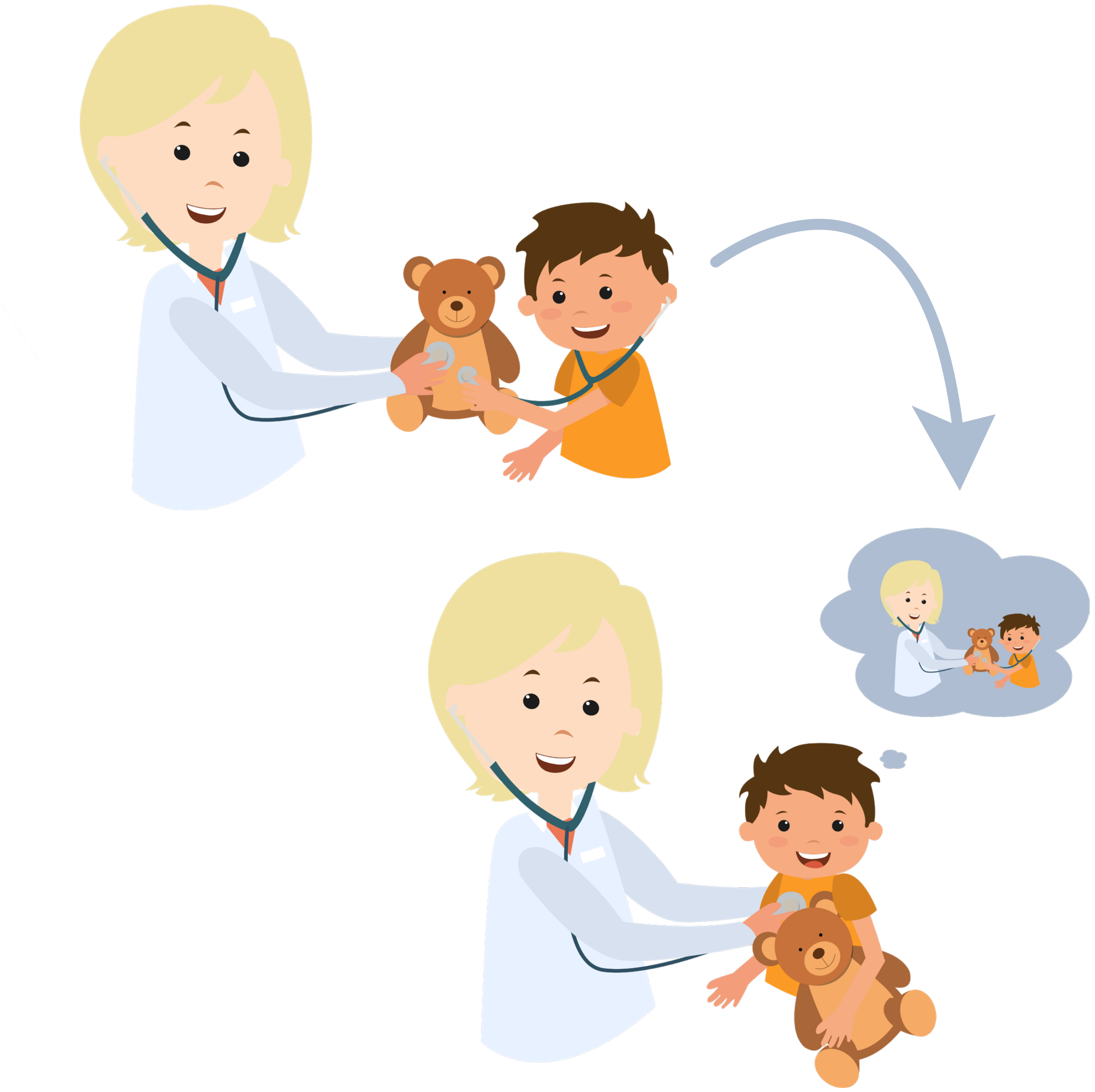




For the generation of tasks, a database will be created with multiple tasks for each procedure, so that the patient can have new tasks each time and not get bored. These procedures can be checking inhibitors (blood draw), checking joints or listening to the lungs.

The concept aims to provide a **feeling of control for the child, as well as predictability and elements of responsibility.** He can see what to expect on that specific day and prepare, and see exactly what will happen next. He can learn each situation with the bear first and know how it will turn out, which also allows him to understand procedures in a way that just explaining would not be able to achieve. As established before, children respond to visual cues, and this creates a concrete example of how a certain procedure looks like. This can also aid in decision making, for example in switching treatments, where the children can look as an external figure and be asked "which needle do you think bear would prefer?". As in this case the size of the needle will be the most apparent feature, the most likely answer will be the smaller one. This way, the child doesn't have the extra element of anxiety added and can make a relatively logical decision, making it somewhat easier to accept when the time comes to ask him what he himself prefers. The game is generally carried out with a replica toy kit. However, when decisions are being made, like which needle to use for prophylaxis, the actual needle will be shown to the child in a safe way. This will have to be further researched to understand if using toys will give the desired effect and also create a safe environment, as the child may be upset that it is not the exact same item.

The concept also adds the **element of inclusion in conversation**, as it may keep the patient interested in the situation, rather than having to sit next to the parent, and quickly feel bored. Having done the task (properly) there will also be a sense of accomplishment, which the prize at the end will strengthen. The concept can be used from approximately 3 years old, and for younger children it is a way to get used to the consultations with a fixed symbol (the bear), and hopefully later find it easier to participate in conversations. At the time that the child cannot read, the parent or the HCP will read out the task, and help where necessary. In some cases, for a new procedure, instructions may be necessary in which the HCP will show the procedure on the bear first, let the patient try and then work on the patient. There is some initiative necessary from the HCPs side here, where they will have to lead the task. This will be evaluated with HCPs, among other aspects in Chapter 9.



Concept 3 - Emergency Room

SPOEDPATIENT PAS

Deze patiënt heeft een bloedstollingsstoornis en heeft onmiddellijke behandeling met bloedstollingsfactoren nodig. Zie onderstaande patiëntengegevens voor de benodigde informatie en voorgeschreven medicatie. Zie achterzijde voor patient voorkeuren in behandeling.

Naam:	Naam Achternaam
Geboortedatum:	dd/mm/yyyy
Type Hemofilie:	ERNSTIG Hemofilie A
Benodigd Dosis Indicatie:	Lichaamsgewicht (kg) x Gewenste factor verhoging (%)
Voorgeschreven medicatie:	NovoEight 1500 IE (1x/week) *(Bij twijfel contact opnemen met behandelend arts)*
Behandelend arts:	Dr. Naam Achternaam - 061234567

Deze patiënt heeft aangegeven een voorkeur te hebben voor deze behandeling. Houd hier graag rekening mee bij het toedienen van de behandeling.

- ☐ Ik heb prikangst
- ☐ Ik wil verdovende zalf
- ☐ Ik wil mijn speelgoed mee
- ☐ Ik wil op schoot zitten
- ☐ Ik wil de volgende stap weten
- ☐ Ik wil aftellen
- ☐ Ik wil meekijken
- ☐ Ik wil afleiding
- ☐
- ☐ ______________
- ☐ ______________

Voor verder vragen graag de hemofilielijn van Erasmus MC Sophia Kinderziekenhuis bellen. 0612345678

Datum afgifte dd/mm/yyyy

Figure 8.4 Concept 3 - Emergency room (front and back)

The final concept (Figure 8.4) is for use in the emergency room. In many cases, research showed that parents had trouble feeling heard in the emergency room, reporting that they weren't taken seriously by the ER staff. The stress caused by this is also often reflected on the child, creating unnecessary panic. In many cases, due to rushed care, or simply lack of awareness about hemophilia, the child doesn't get the care that they should be getting. This concept aims to alleviate this stress on the parents, and allow for the treatment preferences of the child to be taken into account.

The "Emergency Patient Card" is an official document, which includes information about the patient. On the front, medical information is provided for the ER staff, so with one look it is clear that the patient has a blood coagulation disorder which has to be treated immediately, the information necessary to administer the medication and the contact information of the assigned physician. On the back, preferences of the patient are identified, which for infants parents can fill in with their observations and from toddler age the patient can choose what he prefers. These are simple preferences, intentionally so, as research showed that even with low amounts of effort, parents found that ER staff still did whatever was easier for them, often not taking the child's needs into account. These preferences were kept simple so that the pushback can be less once the HCP sees that it isn't that much effort to make the child feel comfortable. The parents mentioned in interviews that listing out preferences sometimes seemed to be perceived as undermining the ER staff, which caused even more push-back. This concept is an official document from the hospital, where this perception may be avoided.

The concept also aims to give the parent a tool to fall back on. In research it was clear that a certain level of assertiveness was necessary on the parent's part to get things done at the ER, and in cases where the parent does not yet have the confidence to do so, this card can serve as the assertiveness that is necessary. This can help bring a peace of mind to the parent, resulting in a calmer child.

This product mainly interacts with the parent and HCP, and only with the patient once they want/are able to speak up for their own care in the ER. The card can be given to the child, to carry in their bag once they start going to school, but this is often not necessary between the ages of 0-8 as the parents are always close by. From the age of 10-12 patients are often able to talk about their care, in this case the card will once again serve as a tool for the patient to more easily express himself in a moment of emergency.

09 Evaluation of the Concepts

In this chapter, the findings of the evaluation sessions with parents and HCPs are presented. These findings are presented per evaluation criterion, followed by general outcomes and discussions. The chapter concludes with recommendations from parents, and points for further research for the implementation of the concepts.

9.1 Study Purpose

The purpose of the evaluation of the concepts was to investigate whether the concepts explained in the previous chapter are desirable, feasible and viable. For this, parents and HCPs were interviewed. The evaluation criteria previously defined in Chapter 7, will be used to evaluate the concepts, as well as other general questions regarding the design, for example identifying any foreseeable pitfalls.

EC1 - Does it give a feeling of control?

EC2 - Does it give a feeling of structure/predictability?

EC3 - Does it have a direct effect on the child?

EC4 - Is it desirable by the child (and parents)?

EC5 - Is it accessible by the child?

EC6 - Is it understandable by the child?

EC7 - Does it give the space to understand the child?

EC8 - Is it implementable? (Feasible and Viable)

EC9 - Does it work preventively?

9.2 Method

9.2.1 Evaluation Setup

The concepts were evaluated with parents and HCPs. The evaluations with the parents were in the form of semi-structured interviews. Since the parents had been interviewed previously for the user research, the interviews were tailored to the participant, drawing back to their own experiences which were expressed earlier, and putting the concepts into the context of the participant. Due to the parents' limited availability, the interviews were carried out online with a duration of 45-60 minutes. These interviews also included recommendations from the parents, which led to short brainstorms throughout the interview. The parents were interviewed mainly to understand if the concepts were desirable and the willingness to use the products, as well as the feasibility in the different contexts of the families. Therefore, a certain amount of bias was considered in the analysis of the outcomes.

The evaluation of the HCPs was done with a focus group, with multiple HCPs present. This was in the form of a short semi-structured interview, followed by a brainstorm with recommendations. The total duration of the evaluation was 1-1.5 hours. The HCPs were interviewed for mainly the second and third concepts, which are meant to be used in a hospital context. Here, the purpose was to understand the desirability and feasibility, but also the viability of the concepts. The HCPs were also asked about possibilities of implementation, whether there was value in doing so and from which channels it could be provided.

The protocols for the evaluation interviews can be found in Appendix F. The patients themselves could not be interviewed in this study, so the desirability was tested with the parents and HCPs, asking whether the child would like the concept.

9.2.2 Participants

A total of 6 participants were involved in the evaluation, 3 parents and 3 HCPs. 2 of the parents were a couple, the parents of one patient and therefore interviewed together. Patients were not interviewed in this study, due to limited time availability. The participant profiles for this study can be seen in Figure 9.1.

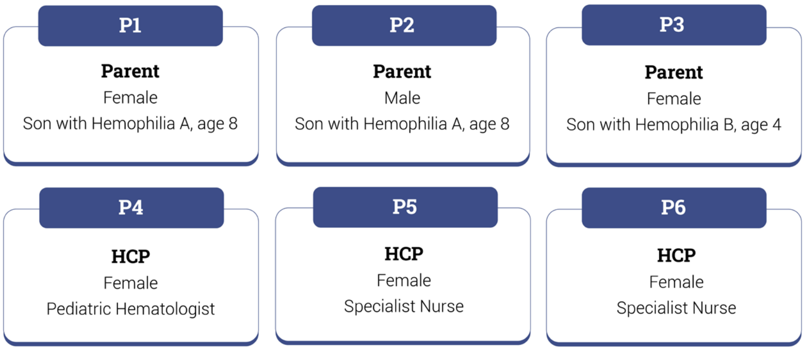


Figure 9.1 Participant profiles for evaluation

9.2.3 Analysis

For the analysis of the results, a streamlined version of the DIKW was used, as used previously in Chapter 4. For this process, the interviews were once again not transcribed but instead quoted, anonymized and color-coded per participant. The quotes were then divided per question, and lines were drawn between relevant findings. As most of the quotes were straight-forward answers to questions or recommendations, separate interpretations were not made per quote. First these were separated per question, and then the relevant quotes were divided according to the various evaluation criteria. An impression of the analysis can be seen in Figures 9.2 and 9.3.

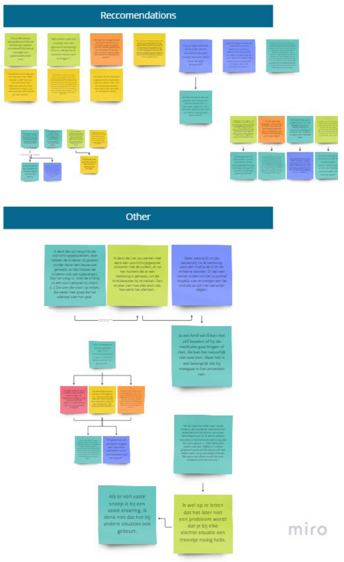


Figure 9.2 Analysis evaluation criteria

Figure 9.3 Analysis evaluation outcomes

9.3 Results

As a result of the evaluation sessions, questions regarding the value and implementability of the concepts were answered. These led to recommendations for changes to the concepts to strengthen their viability, desirability and feasibility. As was in the interviews, the evaluation sessions were carried out in Dutch, therefore they were translated into English for this report. All quotes used in this section can be found in Appendix G, with the translation followed by the original. The results are presented by evaluation criteria, followed by recommendations for each concept.

A summary of the results can be seen in Figure 9.4. This figure shows the various evaluation criteria that have been investigated in this study, and how well the concepts fulfill them. This measurement was done qualitatively, based on the answers of the participants regarding the various concepts. In many cases the words in the evaluation criteria were used by the participants themselves, as the questions were directed that way, but some are interpretations based on the collected data.

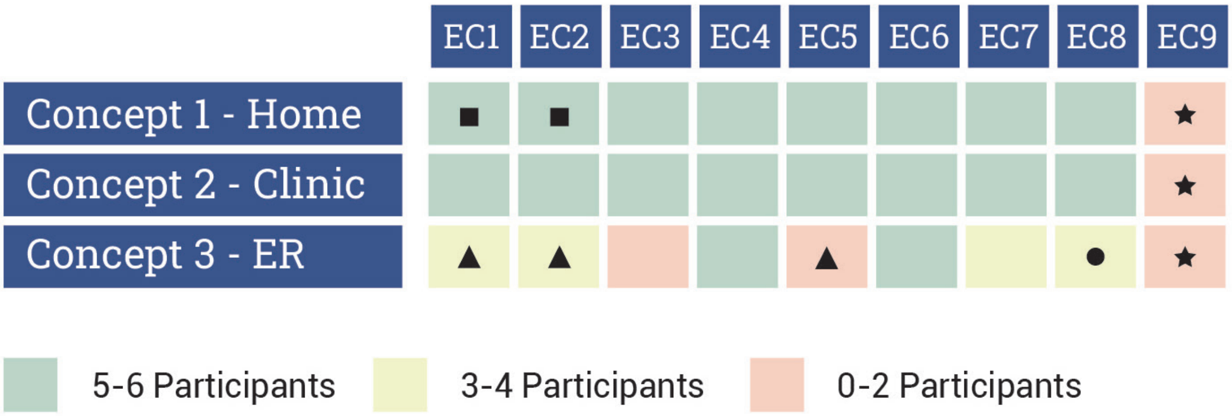


Figure 9.4 Summary evaluation outcomes

	EC1	EC2	EC3	EC4	EC5	EC6	EC7	EC8	EC9
Concept 1 - Home	🟩 ■	🟩 ■	🟩	🟩	🟩	🟩	🟩	🟩	🟥 ★
Concept 2 - Clinic	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟥 ★
Concept 3 - ER	🟨 ▲	🟨 ▲	🟥	🟩	🟥 ▲	🟩	🟨	🟨 ●	🟥 ★

🟩 5-6 Participants 🟨 3-4 Participants 🟥 0-2 Participants

■ The home concept in general did seem to meet the criteria, but as it had 2 parts, these were separately evaluated at times. Specifically for the feeling of control and structure, the injection schedule seemed to be stong, whereas the cards weren't as obvious in its effect.

▲ The ER concept was found to appeal more to parents rather than children, with the explanation that the children would be too young to understand the contents and see the effect. There is a clear dependency on the parent. The value for older children (above the age of around 6) was seen, once the child could read, and talk for themselves in the ER. In this case the card was found to give a sense of control and allow the child to see the link between using the card, and getting his preferred treatment.

● The implementability of the ER card seems to be dependent on how the ER staff receives it. Some HCPs made the point that the card can be given and not be taken seriously by the staff, but also that the card creates the potential for easier care, starting the conversation of how the child wants to be handled.

★ None of the concepts worked preventively, with the parents mentioning that the problem lies in the painful medical procedure and the experience with it, and also that each child is different and will have a different origin of fear. The participants found that this area was not solvable by the concepts and should be approached from the medical side.

9.3.1 Findings per Evaluation Criteria

EC1 - Does it give a feeling of control?

Concept 1

All participants found the home concept to bring a feeling of control, mentioning different aspects like self-control and responsibilities. Having the child involved in his own disease was found to be a priority, and the injection schedule was found to provide this. Having a personalizable schedule was found to give a feeling of importance to the child, with concretely visible decisions, letting him know that his preferences have been taken into account, and also allowing him to change preferences whenever he wants. Allowing the child to choose what he would like to do also gave a bigger sense of control, in that the child could take control of his disease, claiming it as their own. The cards were found to not provide an immediate feeling of control, but the parents could see that if they were used regularly, they could provide a sense of self-confidence for them with a better grip on dealing with his illness, which was interpreted as a feeling of control.

"The great thing is that you can involve the child, that he can adjust it himself, then you really keep it lively." (P3)

"I think involvement in your own illness is especially important. So what many parents do is just take care of it, but involving them in the "this is my medication, I'm going to get it ready" I think is very important for the perception in general. Even if it is something very small that he has to do himself, that really makes the difference, if there is also a ritual involved. Not like, oh I'm just going to sit and wait." (P5)

"It's really funny to see what a difference self-control makes. I inject the same way, with a short wait in between, but he has chosen to wait a while. You can see that he handles it better. You could easily show that here as well."(P5)

Concept 2

With the clinic, once again responsibilities were mentioned, which seems to often be used when referring to a feeling of control. Parents found the concept to give the child a better understanding of what is happening and that including them in conversation by letting them do tangible tasks would help in making the child feel in control of his decisions, by seeing what happens first before having it done on himself. The element of "permission" was appreciated, where parents mentioned that asking the child himself to do the procedure on the him after demonstrating on the bear, would most likely result in an answer of yes. This way, they mentioned the child would feel like he had the chance to give consent, however little, which they found to give the feeling of control.

"Involving them in actions indeed, you can get a stamp or this or that, I think that helps with young children." (P1)

"By showing on something else first, he also finds it less annoying on himself, I think you solve that with this. [...] That's very good, it's more for giving some kind of responsibility and you involve also inform him of what is happening with the child himself." (P3)

Concept 3

The ER concept was somewhat lacking in the direct feeling of control for younger patients (0-

6), where parents did recognize the eventual goal of making the child feel like they had an impact on the process. They found that the simplicity of preferences on the back of the card would aid in making sure they were properly done, but they did mention that a certain amount of external factors played a role in creating the feeling of control, mainly for the ER staff to keep interacting with the child instead of just receiving the card and then administering. As the preferences are not always possible to carry out, explaining why it was not possible was found to also play a role in making the child feel in control. The concept was found to help in the feeling of control for older patients (above the age of 6, after starting school) where the patients themselves could carry the card and use it when necessary. One parent mentioned that sometimes children want to speak up and explain their preferences, but cannot, and in this case the card would help give that self confidence.

"I certainly think it is nice for children to just say what they want and that they are also listened to, or at least explained to why it may not be possible, of course that is also the case sometimes. But something very simple like counting down, yes everyone can do that." (P1)

"As a parent you have to speak up. [...] If you are not very assertive as a parent, or find it difficult to just say 'hey, I want you to look at my child now' I think it would be very good. Or also older children, who would like to speak for themselves but find it exciting to say something, then I think it would be very helpful." (P3)

EC2 - Does it give a feeling of structure/predictability?

Concept 1

The schedule part of the home concept was aimed at providing structure and predictability, which it was found to definitely do. The parents were very excited by the visual aspect, clearly understandable by the children and reiterated the need for structure especially young children have. They mentioned that this concept would be a good grip on the process, and even somewhat get a feeling of control, as they would be able to see the schedule whenever they want, independently, without having to ask their parents which they do now. The parents were also happy about the fact that the child could see and prepare for their prophylaxis, instead of the parent having to feel like they have to be the ones upsetting their child the day of prophylaxis by saying it's time.

"Children have the order in their head quite quickly, but it helps hold on to the structure, it really suits small children very well. Because they really need that structure and to know what is happening now." (P3)

"Definitely! Then we don't have to say every time when the injection will come, he can see for himself whenever he wants, and he also knows immediately what will happen." (P2)

Concept 2

The parents also saw a strong sense of structure in the clinic concept, with the child being able to see exactly what will happen and how it will be done, in a playful, not scary way. Parents mentioned that it helped include the child in the process, instead of just taking them along, and that it was especially important for children with previous negative experiences to prepare for what is coming.

"We always say 'we're just going to chat, it's not an injection', because we usually don't have to do that at the outpatient clinic. And that is nice to prepare them, especially if they also have the experience of lying in the hospital with the necessary fuss around it." (P1)

"This is very strong with the involvement and with the steps that the child knows, what goes first what comes next." (P3)

Concept 3

The ER concept was found to provide a sense of structure and predictability for the parent, while currently they most often do not know what to expect. With the card, they can create the routine of calling the hospital, letting them contact the ER and once they arrive, hand the card. The parents mentioned expecting much less pushback with a routine like this, with HCPs confirming that it would work in creating consistency in the ER trips. The feeling of structure was found to be indirect on the child, as a result of the parent using the card, the child would be getting a similar treatment each time, which would create consistency for the child as well.

"I hear that very often that they [ER] do not listen to the parent. [...] We say every time "he is a very anxious boy" but it is important that you give the parent something to push under the nose of "look". (P5)

EC3 - Does it have a direct effect on the child?

Concept 1

The schedule was found to have the most direct effect on the child, in improving the overall experience with prophylaxis. The parents mentioned the difference the smallest detail can make, and appreciated that different choices were provided. In addition to this, the schedule also had the most direct interaction with the child, allowing mostly independent use. The cards were found to have a direct effect on the child as well, helping the child express himself better. However, it was found to not be an immediate effect, instead to be observed in the long term.

"These are nice details. I hadn't considered that the child would want to sit in a certain place for the shot, for example, because we didn't have that. But that's definitely something that can make a difference." (P1)

Concept 2

The clinic concept was also seen to have a direct effect, and successful in involving the child in the process. Seeing the various procedures and being more likely to have it done on themselves, parents mentioned that the children would have a more pleasant experience in the clinic. This being said, they did mention that fears and anxieties may not always be the problem, but more often than not, children did feel bored in consultations and procedures. This was found valuable in changing that.

"It is something that would help to involve them in the conversations at the outpatient clinic and give them something to do so that they don't find it boring. Because that's how it really goes, then they start pulling and "this is taking too long"." (P5)

Concept 3

The emergency card was found to have an indirect, yet valuable, effect on the child. Having an ER staff that takes the preferences seriously and at least tries to fulfill the needs, was found to have potential in improving patient experience. However, there is once again the human element involved, where for this effect to be realized, all actors should be prioritizing the needs of the child. The value the parents and HCPs saw in the concept is assuming that the parent presents the card and the ER staff reads it, otherwise the effect of the card itself is nullified. Most participants did believe that the ER staff would take the card seriously and accommodate the child's needs.

"Anesthetic cream is difficult, because you have to work quickly, but it also takes a while to get its effect. But giving a preference, that's fine, they're going to try there anyway." (P6)

EC4 - Is it desirable by the child (and parents)?

Concept 1

Most of the participants found the concept very desirable, and to mainly appeal to younger patients (3-5 years old). A comment, which may also explain a part of why the audience was identified as the younger patients, was that the design may be a bit juvenile, but that it was understandable given the target group. They mentioned that the design could be tweaked to make it desirable for other ages as well, seeing the value for all ages. One participant also mentioned the possible need for a "tougher" design as the target group mainly consists of boys. This was not expressed by other participants.

Most parents did enjoy the aspect of using the cards during injections, as they believed it would be an interesting conversation to have, that they otherwise wouldn't bring up, creating a positive connotation to the injection like a moment of the day to spend together. The pick-me-up cards were also appreciated, with the "playful images" appealing to children, and small activities that the parents would enjoy doing with their children. One parent mentioned appreciating it wasn't exactly a prize, but instead a distraction and that she would use them often, especially due to the fact that they could be done with household items and didn't require cleanup. The parents did mention the need for a concept like this, stating they would immediately buy it if they found it in a store.

"I think it's already possible from 3-4, and yes one child does have a grip on the conversation earlier than the other, so it could be introduced soon, see how it goes." (P5)

"It depends on the child but we would have already used it at 4-5 years old I think." (P1)

"From 0-12 this would be good, childish they don't mind, but maybe after 12 years something tougher could come, an adolescent version. On your phone or something. Because I think they could use this too." (P4)

"There are also girls with hemophilia, but more boys. They do need something tougher sometimes." (P2)

"I think it's [the schedule] really good, especially for younger kids. But it's good for any child to see. [...] I also really like the pick-me-ups, you can use that very easily if things don't go as expected with an injection." (P3)

"If I had seen this in a store, I would have bought it right away." (P1)

Concept 2

Within the clinic, all participants recognized the need to include the child, and were very excited about the use of the concept. The concept was found to work for all ages between 0-8, with most participants leaning towards above the age of 4. The parents mentioned really liking the game aspect, and that they would take the initiative to help their children, even at a younger age (2-3) as they saw the value in it for the child.

"I do recognize that you say that it is easy to talk over them, especially at that age. [...] Certainly from 5-6, or even 4, you can involve them a bit." (P5)

"This would definitely work for 0-8, they would be excited." (P4)

"I think 4-8 years old would really enjoy this, but could start much younger depending on the child." (P1)

Concept 3

The parents found that the ER card would be a necessary tool, especially for parents that may not be so assertive. Even for experienced parents, it seemed like a nice fallback in unexpected situations. For the children, it wasn't found to be too interesting, with initial recommendations of making the card more colorful and appealing to children, but quickly going back to the initial concept appearance due to the need to make it look official and serious. All parents mentioned that they would use the product at one time or another, as it gave a boost of self-confidence. They mentioned they would hand the card off to the children as they got to school age, and that it would be valuable in situations where the child may not know what to do in a panic situation.

"I think this is more useful for a parent or an ER doctor who is helping at that moment than for the child himself. Especially if you are 3 years old, for example, you cannot read, you want to see pictures. I think this is really more for parents, and also children from the moment they can read." (P2)

"The SOS card is also not really intended for this age category, it is very difficult for 0-8 to give something like this, it would mainly be with the parents." (P4)

EC5 - Is it accessible by the child?

Concept 1

The schedule was found to be fully accessible

for the child, with the preparation, adjustment and viewing. Parents mentioned that it was something that the child could do independently, with minimal supervision. They mention the icons are understandable, which once again adds to the independence as the parent does not have to read the contents each time.

"We used to write and draw on a large paper with pins. This is much more convenient, it gives him a lot of clarity too."(P1)

Concept 2

The clinic concept was found to have a level of dependency, as the parents would have to read out the tasks, and HCPs would have to instruct. Parents liked this, mentioning that they would love to have something like this to do with their child and would be more than happy to help. They did say that when it comes to doing the task itself, the parents felt comfortable not supervising and continuing their conversation, mentioning that it was nice they had something to do themselves.

"It's super fun, I think it really works because then the children also have something to do." (P3)

Concept 3

The ER concept was not found to be accessible by a young child (0-6), but had a level of accessibility from the school age. Parents felt comfortable giving the card to the child after they start school, let them mark their preferences and use the card themselves at the ER, in which case the use would become fully independent.

"Nice and clear! And he can tick what he wants!" (P1)

EC6 - Is it understandable by the child?

Concept 1

Especially due to the icons present on the schedule and the language of the questions, the concept was found understandable and clear. The parents mention that it would require little to no help for the child to use the schedule. The cards would require some help, like reading out the question, but the parents (and HCPs) found that the questions would be understood without the need for further explanation.

"I really like the way the questions are asked. A child psychologist should certainly check, but I think this can be understood by a child!" (P6)

"I really like the idea. I also use this myself, not so much the steps, but the schedule that he sees when he is injected. That is very good for children." (P3)

Concept 2

HCPs mentioned the need to help the child understand, and the ways that they explain situations at the hospital. They found playfulness to be an important factor in explaining different processes, and that the clinic game and the tasks with the bear seemed to fulfill this need. The participants also found instruction necessary at the reception to explain the goal of the game, and for the tasks to be read out if the child cannot do so himself, but that the child would know where the stamp would go and how to find the next step.

"We know that if you change the color of a wing needle with our hemophilia patients, they are already upset. So we might have been better off guessing "this is something really different". Now getting a shot in the leg instead of the elbow, we have to explain that properly, but that might be possible with such a bear. (P5)

"It really depends on how you bring it to a child, then he says yes or no I don't want it [decisions]. I think this gives room to explain it playfully." (P5)

Concept 3

Younger children were not seen as the audience of the ER card, and therefore the participants found it logical that it wasn't understandable. However, they did find it straightforward and easy to understand for the parents and the ER staff, which was also applicable to school age children, who have learned to read.

"I think this is more useful for a parent or an ER doctor who is helping at that moment than for the child himself. Especially if you are 3 years old, for example, you cannot read, you want to see pictures. I think this is really more for parents, and also children from the moment they can read." (P2)

EC7 - Does it give the space to understand the child?

Concept 1

The questions were found to be very helpful, with parents recognizing the need for help starting a conversation with their child. The different purposes of the cards were well received, with many participants expressing the value of talking about not just hemophilia, but a wider spectrum of things, which they found would help the child open up and be more likely to share. The schedule was also found to give the space for the child to express his needs, as the parents mentioned they would just let the child pick out all icons that he wanted and place them as he liked. One parent also mentioned that it could open up a conversation with home care, and that they would want to accommodate the child's needs as well, which would be made easy be the schedule.

"If you have a card, there is something to hold on to the conversation. It helps to start the conversation. [...] These are questions that we would otherwise not discuss, but are nevertheless important."(P1)

Concept 2

Especially in understanding the preferences of the child, the task aspect of the game was praised By doing the tasks and getting the instructions, the child would more easily ask questions and give opinions as he would see the space to do so. This was found to not be as easy in a regular consultation room setting, not because it was not encouraged, but because there was not anything holding the child's attention. This concept was found to be able to change that.

"Showing a lot, with the first needle and what we are using now with SC he thinks "hey, this needle is much

thinner and shorter!" Then you also see something forming in his head." (P2)

Concept 3

The ER card was also found to give the space to explain needs. By selecting the preferences on the back, the parents and HCPs found that the child could express their opinions and feel heard, without having to actually try to explain their needs in an emergency situation, which was found to often be ignored by the ER staff.

"It helps respect the opinion. Even if the preference is not possible, he still feels listened to." (P4)

EC8 - Is it implementable? (Feasible and Viable)

Concept 1

The home concept received a lot of praise and was

found valuable for the children. The HCPs were very enthusiastic about the implementation of the concept, and could see it be provided nationwide. They found it an important improvement in the patient experience.

"This will then be published nationwide. It is nice to see this on the website of the NVHP of "this is what we do in the Netherlands". (P6)

Concept 2

The clinic concept was also positively received, with the HCPs mentioning that it was not only feasible but also desirable to implement in the current structure in the clinic. There is a need for further testing, and to create a sustainable, functional system in which the concept can be easily used in the context, but the initial response was very positive.

"I can fill this in very easily in my preparation per patient, that we then put the name on it, and immediately inform the desk when registering that they can already have a look. Very handy!" (P5)

"I often also listen to the lungs of the parent before looking at the child, [...] taking the extra time to show first is not a lot of extra effort." (P4)

Concept 3

The ER card was also found to be implementable, especially considering the existing SOS pass. The pass would be adjusted to the contents of the ER card, and be produced in the same way. The viability of the card was a consideration, in that if the ER staff does not take the card seriously, the concept could not move forward. The response to this was positive as well, with most participants mentioning that they could see it be taken seriously, and even start a conversation in understanding the needs of the child. Due to the fact that the card is an official document, all participants mentioned it would have more backing than just the parent saying that it is important, making it more likely that the ER staff would read it. All in all, the concept was found implementable and while the viability would have to be tested in use, there was a high potential for a positive response.

"I think it's a good pass either way. And I do indeed think that the Erasmus logo helps, that you also feel that you have been taken seriously when you show this. That you can say 'Well, hey, this is it, look, otherwise call Erasmus.'" (P1)

"When you see this, I think you're also asking the parent, "Are there other things we should pay attention to?" And that conversation is important to start." (P4)
"And starting the conversation, I think, when you come to the ER you never know the people, and that is therefore fundamentally different than when you come to Erasmus. Sometimes it's new people, just give this [urgent pass] and say this is what we're sticking to. I always explain myself, I say "yes we come here, but we have to give that shot again at home. I don't want any resistance at home because we are stepping over certain points here." But we've done that before. [...] Such a card can start the conversation of 'hey, well we have a lot of experience in the hospital, would you please take this into account?', 'Oh! Yes, tell me..." you know?" (P1)

EC9 - Does it work preventively?

None of the concepts were found to work in the prevention of fears. All parents mentioned that the fears of needles came predominantly from the medical procedures and the physical pain. They mentioned that it was not likely that the fears could be prevented with anything, as injections do sometimes go wrong and it is not possible to prevent fears from originating unless the procedure itself becomes less painful.

“I don’t think everyone would ever not develop a fear of needles after so many shots, and so many experiences. But yes, one doesn’t have that many experiences, so it never gets to that point. And the other one has a lot in a very short time, so it also develops very quickly. [...] I don’t think you can just prevent those fears.” (P2)

“It’s a lot less bad now, but maybe that’s because he’s used to the needle that is worse. For other kids who aren’t used to it, maybe this [SC] is already very bad. It really stays with the medical things I think. ” (P1)

9.3.2 General Findings

During the evaluation sessions, two interesting points came up, (1) whether or not giving the child a prize may cause a kind of “addiction” or whether the prize should be candy, and (2) whether the word “injection” should be used around children.

The result of the candy/prize conversation was that a prize should be devised that is specific to the prophylaxis procedure, so that that is the only connotation. If the prize is only given at that moment, the child is more likely to not expect it in other situations. Candy was also brought up, with the fact that some parents may not appreciate it, and that it wasn’t healthy for a child to consume so much sugar. The argument was made that even adults like to have some chocolate after a bad day, and that sweets did serve as a comfort. The decision was made that small colorful candies (known as “tumtums” in Dutch) could be used and that it was a relatively ‘innocent’ prize to give a child in distress, if it was going to help comfort the child. Another discussion was about whether a repetitive prize would be better than a one-time prize. The point of collecting medals or puzzle pieces was brought up, where the child could collect pieces that formed a whole, which could be displayed at home. This also would create the want to come back, do the tasks and complete the display. This definitely seems like a promising adjustment and should be tested with users to evaluate the feasibility and desirability.

Another point is one on a larger scale, whether or not to use the word “injection” around children. The concepts all contained the word, and when asked the parents who evaluated all mention not tiptoeing around the word and that they preferred to use it. Not using it seemed to create disappointments with the child, as the result was still the same, and the child didn’t have time to prepare. This was also apparent in the interviews done in the research phase. Yet the HCPs have an opposite outlook, finding the word to have negative connotations. After having heard the research outcomes and the views of the parents, there seemed to be a change in the approach, where they also agreed that for this target group, it may be more beneficial to use the word directly. It was interesting to see that this realization hadn't come earlier, and could offer opportunities in testing more with parents before the application of practices, strengthening the concept of "shared decision-making". Quotes from these discussions can be seen in Figure 9.5.

Are candies/prizes the best way to go?

"Just make sure it **doesn't become a problem** later that you need comfort in every bad situation." (P4)

"If there's a **fixed candy with a fixed experience**, I don't think it will happen with other situations." (P5)

"Many parents do that too, apparently sweets are just comforting. If you don't feel well yourself, eat a piece of chocolate. **Who knows, maybe it really makes a difference for children.**" (P6)

"If we always have the same kind of candy, then that **indeed becomes part of the process**, a kind of reward ritual. I'm thinking maybe it's not so bad that it's a candy after all." (P5)

Is "needle/injection" a bad word?

"Fortunately, we have a child who is not afraid of it. [...] He is not afraid, but we also played a role in that with **naming it as it is**, however difficult it may be." (P3)

"The fear is really not in the word but a number of other things. The negative experiences. [...] Yes, **that word can have negative connotations, but the experience gives the fear of needles**." (P1)

"Could this [injection schedule] be changed to my 'medication schedule'? **Injection is a word we don't use.**" (P5)

"They're going to get the prophylaxis anyway, so **maybe it's better to get used to the word.**" (P6)

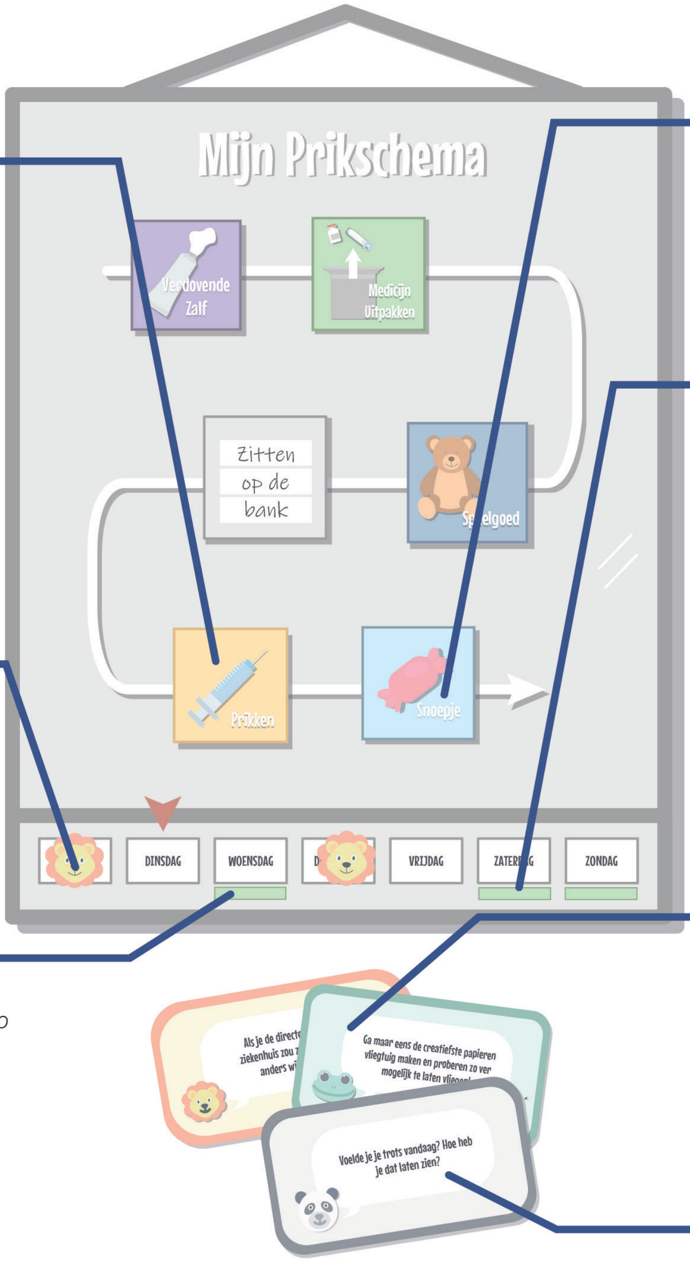
"Perhaps for this category of children, **who have to be injected all their lives, that it is simply called that.** It is of course a bit different for children who have to get an injection for a screening at some point, and children who have it every week as medication." (P5)

"We don't mind the word 'injection', it's really not about the word but everything around it. We say everything what it is. We really don't want to talk around it on purpose, because **it's only disappointing when we tell something nice, but it's still just an injection.**" (P2)

Figure 9.5 Quotes from general discussions

9.3.3 Recommendations for Improvement

For each concept, the participants gave recommendations as to what they would like to see added/changed in the concepts for what they considered would provide a better experience for the children. The input requires further research, for example in the form of focus groups of parents, patients and HCPs, separately and together. Therefore, these recommendations, among others, will be recommendations for further user testing, and adjustments will not be made within this project. The recommendations per concept can be seen in Figures 9.6 - 9.8.



P3, Parent

*"If the word injection is experienced [negatively], you could perhaps use other options in the concept, with other icons such as a train, which they sometimes call it, because it goes like a "train" in the line. **I would just use the injection, but maybe it would be nice to give other parents the choice as well.**"*

P3, Parent

*"**Instead of the lion I would just do a shot**, look those kids, it's such a part of their life that you don't have to hide it or anything."*

P2, Parent

*"We do injections [with SC] every 14 days, not weekly, so **maybe the green lines can give an indication of whether it's an injection week or not**, then he knows it's coming again next week and he can see when."*

P4, HCP

*"**Maybe also an icon of a general reward?** That they can choose what they get each time."*

P3, Parent

*"This could also be done for children who do not go to school, then it is difficult again [identifying days]. Long short days only have to do with school, of course. [...] Or when are you at home, when at grandma and grandpa, depending on the situation. **A green line may not be clear enough, but I don't know if it will be too complicated otherwise.**"*

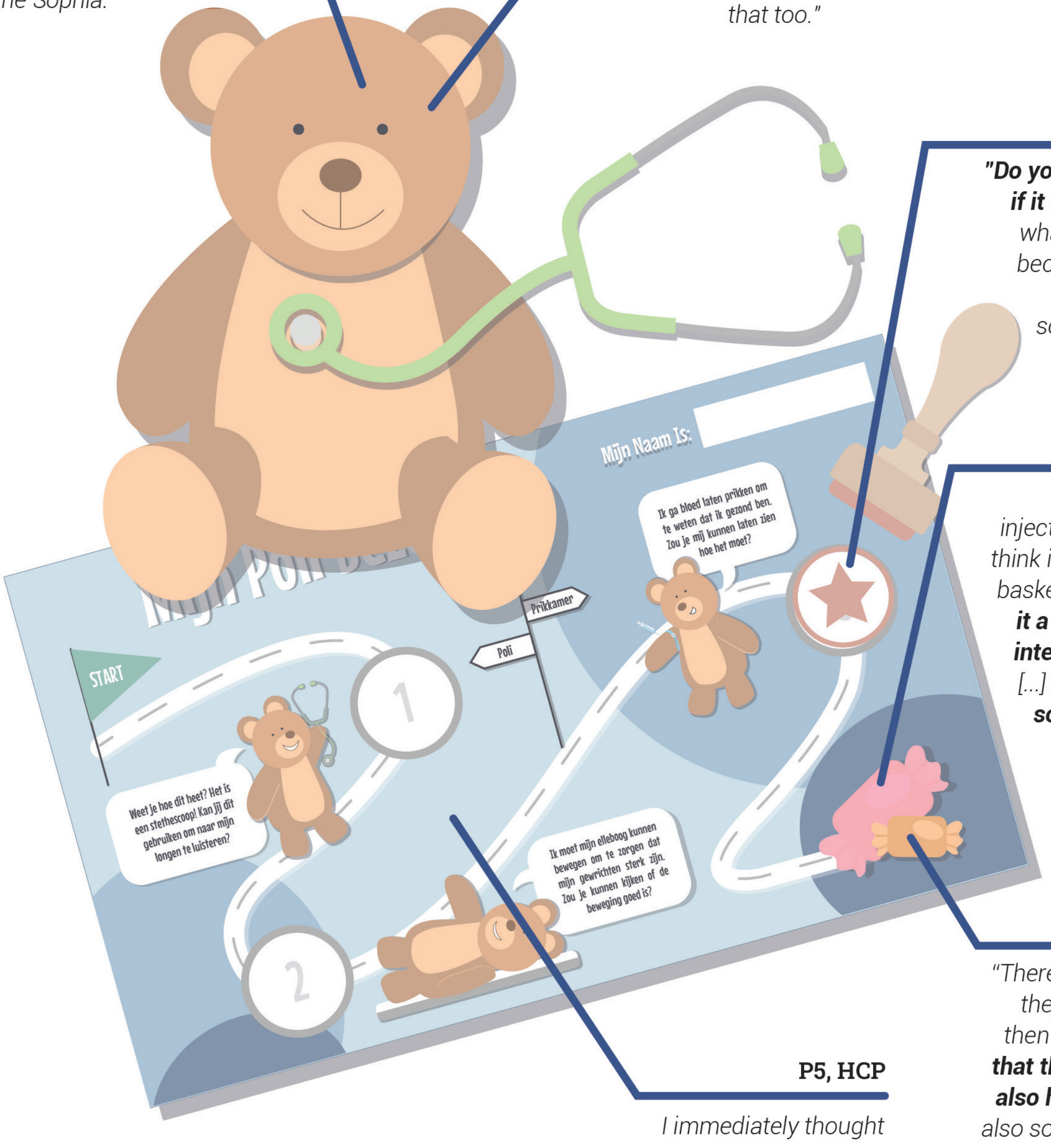
P3, Parent

*"I also think the cards are a very nice idea. But then **I wouldn't link them to an injection every time, then it might take too long.** [...] As a parent, you really have to have the time."*

P5, HCP

*"Could you personalize this? **That the cards change per patient?** Then you have truly personalized care."*

Figure 9.6 Recommendations for Concept 1 - Home



P4, HCP

*I'm also thinking, maybe **instead of a bear it could be a "Sophia Monkey"?** Or even several, that the child can choose himself, between a monkey and a Sophietje? Then it is tied to the Sophia.*

P3, Parent

*"**The Sophia monkey would be very nice,** because they all know that too."*

P5, HCP

*"**Do you also give something if it doesn't work out?** And what if it doesn't work out because of someone else, then maybe there is something of a negative feeling."*

P5, HCP

*"With us you also get a injection present. Some kids think it's stupid what's in that basket, **they've already seen it a hundred times, it's not interesting at all anymore.** [...] I'd rather do a medal or **something that they can save too.**"*

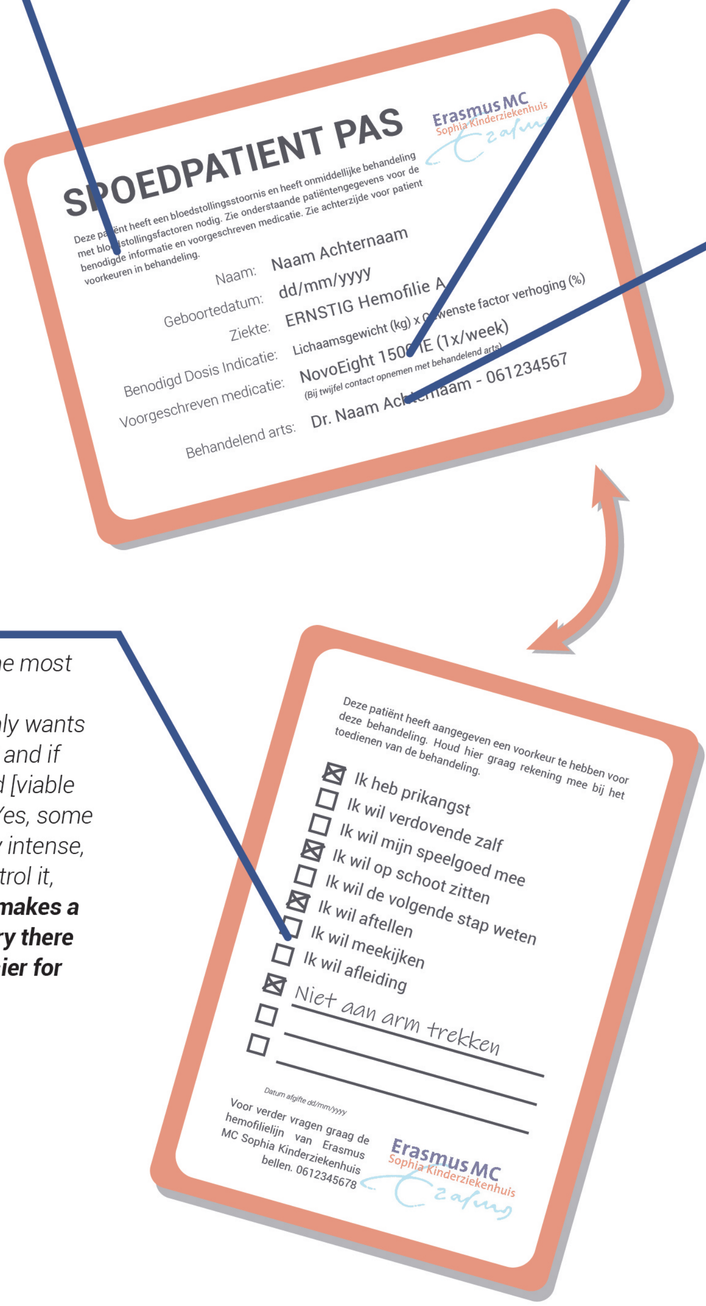
P6, HCP

*"There's also a DNA gift thing they can collect pieces for, then you build it up. **It's nice that they get something that also has a follow-up.** Maybe also something they can bring to the outpatient clinic that we say "Oh! Have you saved that much already??"*

P5, HCP

*I immediately thought maybe it could be thicker material and then used as an coaster at dinner that day, **starting a conversation of "what did you do today?"***

Figure 9.7 Recommendations for Concept 2 - Clinic



SPOEDPATIENT PAS

Erasmus MC
Sophia Kinderziekenhuis

Deze patiënt heeft een bloedstollingsstoornis en heeft onmiddellijke behandeling met bloedstollingsfactoren nodig. Zie onderstaande patiëntengegevens voor de benodigde informatie en voorgeschreven medicatie. Zie achterzijde voor patient voorkeuren in behandeling.

Naam: Naam Achternaam
Geboortedatum: dd/mm/yyyy
Ziekte: ERNSTIG Hemofilie A
Benodigd Dosis Indicatie: Lichaamsgewicht (kg) x gewenste factor verhoging (%)
Voorgeschreven medicatie: NovoEight 150[illegible] IE (1x/week)
(Bij twijfel contact opnemen met behandelend arts)
Behandelend arts: Dr. Naam Achternaam - 061234567

Deze patiënt heeft aangegeven een voorkeur te hebben voor deze behandeling. Houd hier graag rekening mee bij het toedienen van de behandeling.

☒ Ik heb prikangst
☐ Ik wil verdovende zalf
☐ Ik wil mijn speelgoed mee
☒ Ik wil op schoot zitten
☐ Ik wil de volgende stap weten
☒ Ik wil aftellen
☐ Ik wil meekijken
☐ Ik wil afleiding
☒ Niet aan arm trekken
☐
☐

Datum afgifte dd/mm/yyyy

Voor verder vragen graag de hemofilielijn van Erasmus MC Sophia Kinderziekenhuis bellen. 0612345678

Erasmus MC
Sophia Kinderziekenhuis

P5, HCP

"The amount of medicine is not necessary at all, that changes with time. If it changes then the card can still remain the same. It's a different amount for emergencies anyway. [...] ***Only the type of medication is important factor 8 or 9,*** *Novoeight or something else."*

P5, HCP

"I also had someone on the phone who said "Yes, but we're going to check the child first" then I said ***"No first the coagulation in and then the rest."*** *So it's important to have something like that on it."*

P5, HCP

*"**During office hours, our number, outside [business hours] another** number, if it says so on the card, they know who to find, so the name and number of the doctor is not necessary."*

P4, HCP

"So we also have existing passes, which can be adapted to this. ***Maybe with a QR code, then you use something that already exists.*** *Because the information on this, it also changes. It would be nice if it were timeless."*

P6, HCP

"We have to look at what the most important things are. The discussion is also of "he only wants to be injected in the elbow" and if there is nothing to be found [viable vein] there, it goes wrong. Yes, some children find that to be very intense, and even if you cannot control it, ***giving preference already makes a difference, then they will try there first instead of what is easier for them."***

P5, HCP

*"**The ER must be able to see immediately what they have to do, without effort**, so if they have to scan something, will it go well?"*

Figure 9.8 Recommendations for Concept 3 - Emergency Room

9.4 Conclusion & Discussion

The evaluation sessions showed that both the HCPs and parents saw great value in the concepts. The participants mentioned that the concepts addressed important needs that were previously unmet or required a lot of effort. As a result of the sessions, it was also clear that the intended interaction qualities were fulfilled, (1) Gives the Feeling of Control, (2) Understandable, (3) Personal and (4) Predictable/ Consistent. The qualities were actually found to work together, strengthening each other.

The home concept embodied all qualities in balance, with the parents and HCP especially praising the customization and clarity, which both aided in helping the child feel in control. It seemed to not fully serve the younger children who do not yet know how to read, as the cards would then require help from the parents. The parents did mention that they found it important to ask the questions by using the cards, as they wouldn't know how to bring it up otherwise. The schedule was also found to bring structure to the child, and also responsibility, through being able to identify tasks that the child himself would do in the process. The sessions reiterated that each family is very different, some of which are polar opposites. This shows the value in customization, to fully create a personalized care experience, which the parents found the concept to have, but may still offer room for improvement, especially with input of the children and understanding their preferences. The general reception was positive, and value was also seen in editing the appearance and content of the concept to cater to older children as well, as they have the need for expression as well, if not more.

The clinic concept was mainly found to give the child room to ask questions and better understand situations, which could aid in more comfortable procedures. It was mentioned that the children are often bored in consultations and that that was a bigger factor than any fears that the child may have, and the concept was found to 'solve this problem'. The parents enjoyed the fact that they could help their child, and the HCPs confirmed that letting the child see what will happen first, would most likely reduce pushback. In addition to this, helping the child understand the different procedures was found to improve the inclusion of the child in conversation, as not only would the space be given for the child to express himself and ask questions but also for these to be taken into account when making decisions..

The ER concept was found to be more for parents and HCPs, where it could serve as a fallback, and create a more predictable situation where the parent could hand over the card and get consistent care for their child. As it was created to have a more serious appearance, participants did not find that it would appeal to the children, but also questioned whether it should. The concept could help the child with a feeling of control and feeling like his opinions are taken seriously, but this may be too indirect for the child to make the connotation between the two. The value for the children was seen for above the age of 6 or 8, where some children want to speak up in ER's, but don't know how. In this case, and also in the case of a parent finding it difficult to be assertive, the card was found to be a good conversation starter as to how the child would like to be handled. All participants found that the ER staff would take the card seriously, but it is important to note that the parents who evaluated the concepts did not have any experience at the ER which they perceived as "traumatic", as other parents who were interviewed during the research phase did. The parents with known negative experiences were unavailable at the time of the evaluation, and therefore the findings here do not seem complete, as the opinions of someone with experience in other hospitals in other situations may have other insights. This should be considered in future research.

Unfortunately, none of the concepts served a preventive purpose in terms of fears. As the parents mentioned, the fears were mainly due to negative medical experience, like failed injections or other physical pain, and these could only be solved by either changing processes or medical equipment, which the parents understood was not possible at this point of time for hemophilia. Parents did mention that even though in general SC is better. easier and most of the time less painful than IV, the situation may have been different if the first interaction was SC. As their child had seen 'worse', they believe that this is what made the difference in experience. This of course also has to do with the child's personality and pain threshold and is not exactly a controlled factor for all patients. However, it is a comfort to parents to know that the medical care is also constantly improving, with new treatments being developed, which gives them the peace of mind that even if their own child will have gotten used to procedures by then, other children will be able to benefit from easier and painless procedures, hopefully soon.

Recommendations for Further Research

For the concepts to become products which can be implemented, further research and testing is necessary. In addition to the recommendations provided by the parents, the following points must be further investigated as well. These points were the result of the various studies for research as well as the evaluation sessions.

Concept 1

* Which questions should be asked to the child to achieve the desired effect of the cards? This should be discussed with a child psychologist for generation of cards.

* Which steps are involved in the prophylaxis procedure, which steps do most children do in their processes? This should be discussed with parents (Infants and toddlers) and children (play age and school age) to make sure the necessary steps are covered.

* Which materials and sizes should be used to make the product safe for young children?

* The product should also be tested in the long term, to see if the cards have the desired effect, and the schedule aids in the creation of a routine.

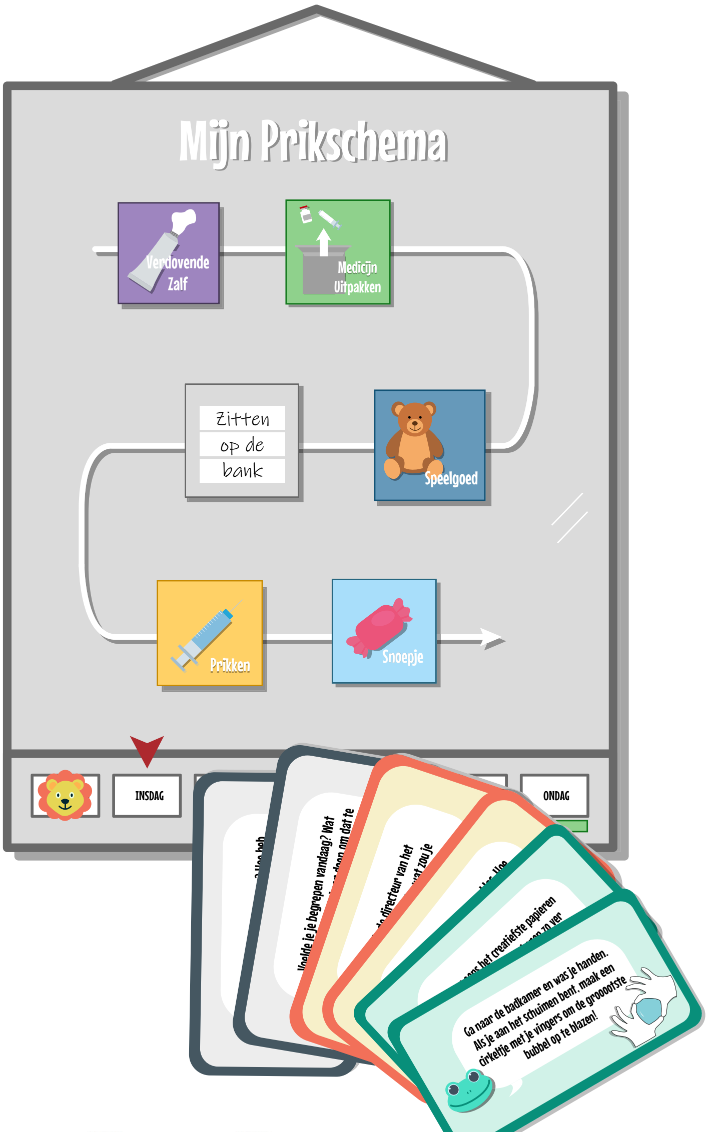
Concept 2

* Which tasks can be given to the child to help ease into the procedure? This should be discussed with HCPs for the generation of tasks, as well as a full list of procedures involved, and a child psychologist for the formation of the tasks, with emphasis on the language used.

* Not all parents want to give their child a prize, is the game itself enough to keep the child interested?

*Does showing the procedures on the bear give the desired effect for this group of patients? Would the same effect be reached with the use of toys instead of actual medical equipment? This should be tested with different ages of children in a long term study.

* For hygiene reasons, tests should be done with multiple bears per room or with sanitization between patients.



Concept 3

* What medical information is necessary on the card? This should be extensively discussed with HCPs.

* Are the preferences on the back of the card enough for the child to feel in control? This should be tested with children and their parents, with the addition of any extra preferences.

* Will these cards actually be used and/or taken seriously by the ER staff? This should be tested in a long term study, evaluating the patient experience when using this card. In this case the importance would be that the preferences were taken seriously and tried to be fulfilled even if it eventually did not work out.

SPOEDPATIENT PAS

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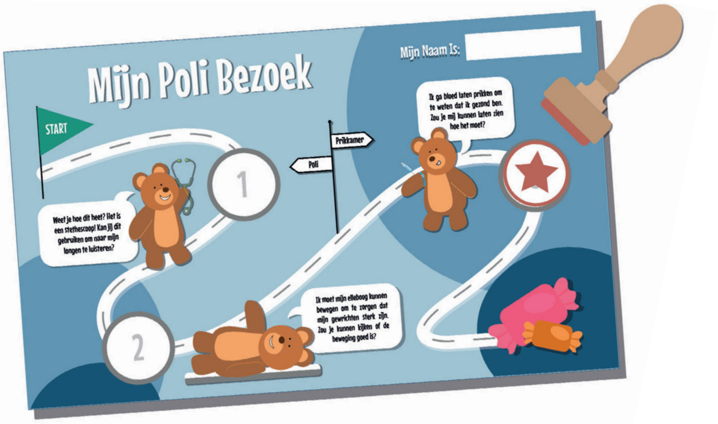
Naam:	Naam Achternaam
Geboortedatum:	dd/mm/yyyy
Type Hemofilie:	ERNSTIG Hemofilie A
Benodigd Dosis Indicatie:	Lichaamsgewicht (kg) x Gewenste factor verhoging (%)
Voorgeschreven medicatie:	NovoEight 1500 IE (1x/week) *(Bij twijfel contact opnemen met behandelend arts)*
Behandelend arts:	Dr. Naam Achternaam - 061234567



10 Conclusion

This chapter concludes the project. After a general conclusion, final recommendations are made for the future of patient experience research, and the next steps for this project are explained.

10.1 General Conclusion

The patient experience with severe hemophilia includes unique challenges, especially when considering the fact that the patient is a child. Due to the complexity of the disease and the scarcity of the patient group, viable conclusions about the daily experience were difficult to visualize, but it was clear that the experience could be improved. In order to create a better understanding of the journey of a patient with severe hemophilia and to contribute in the improvement the patient experience, the project started by asking the following questions:

What are the main factors influencing the experience of a child with hemophilia?

What does a child's journey with hemophilia look like? Who are the actors involved and which touchpoints do they come in contact with in each step of their journey?

Which areas of the journey offer opportunities for improving the experience of the child with hemophilia, what are these opportunities?

The various steps of research and design showed that these do not have straight forward answers. The findings of each step once again reiterated the complexity of the disease, and how each step could play a role in the patient's experience. Especially with a young child growing up with a disease complicated factors are involved, most of them external, which creates an even more difficult experience than of an adult hemophilia patient. The conducted research showed the various parts of a child's daily life which were affected by hemophilia, and offered room for improvement.

By creating a patient journey, an overview was created to understand what it meant to be a child with severe hemophilia and the experiences were visualized with the help of the parents and the patients themselves. The patient journey provided insight to the cause and effect of the various steps on each other, creating areas for opportunity where patient experience could be improved. This patient journey was delivered to the client, with


Leaving the hematology department


Leaving the Sophia

positive feedback and enthusiasm to take the next steps. In addition to providing insight about the current state of patient experience, concepts were created. These aimed to create a concrete understanding of the improvements that can be made and to provide the tools to take a step in the right direction.

The main needs of a child were found to be a feeling of control, wanting to understand, wanting to be understood and a feeling of structure. These all aid in the child feeling trust and safety, which all children should feel. Hemophilia does bring challenges in these areas and the aim of the concepts was to address these, by at the same time helping the child be more active in their own care process. The interventions were very positively received, by parents and HCPs, with a high potential for implementation. This being said, the concepts are currently not ready to be implemented, with multiple aspects that still need to be thoroughly researched. The recommendations of the evaluating participants were valuable, and will be used in the next step of design to create products ready for implementation. The aim of creating feasible, desirable and viable concepts was fulfilled, with all participants seeing the value of use. The findings of the project showed great potential for not only the target group of the project but others as well (e.g. parents and other age groups), and will be used in future research into patient experience. Overall, the final results of the project (the research, patient journey and the concepts) were all found to have great potential, and are expected to aid in improving the patient experience of children with severe hemophilia.

10.2 Final Recommendations

During both the research and design phases, a variety of insights were gained, which weren't always applicable to the confines of the project. For each chapter, the applicable recommendations were provided, and the following areas show value for taking the next step in improving (patient) experience.

This project covered the age range of 0-8, which showed a good variety of experiences to understand a large portion of the journey. However, the "patient experience" with hemophilia should consider other age groups as well. The interviews included an 11-year-old patient, who gave a peek into what happens after the age of 8. From new challenges like learning to do prophylaxis yourself, becoming somewhat independent from your family and eventually transitioning from a child to an adult patient can include drastically different experiences to that of a child between 0-8. Within the pediatric hemophilia center all patients between the ages of 0-18 are treated, meaning that the understanding of the "patient" experience is currently still not fully complete.

Within the research, interesting relationships between the outcomes were seen, some of which did not have a direct effect on the child (aged 0-8) but were nevertheless important. Many parents seemed to experience the diagnosis process negatively, which was also included in the patient journey. When reminiscing about the diagnosis process, many were still emotional and had a lot of opinions on what "shouldn't" have been done. As this was an aspect that wasn't reflected on the children (or this reflection wasn't observed) it wasn't further researched in this project. However, the experience of the parents not only during the diagnosis, but also learning to administer treatments, and the daily life of having a child with hemophilia shows a lot of opportunities for improvement and should be researched further. The general family dynamic and experiences of the siblings also offer room for investigation.

10.3 The Next Step

The next step to take for this project would be the testing of the concepts, through focus groups including the patients themselves to use and evaluate the concepts, creating desirable products. In the discussion with the HCPs, the possibilities of implementation were discussed. National distribution of the products were offered by the HCPs, seeing that the value would be best realized with a larger scale. Plans were made to further investigate the possibilities, by approaching the NVHP and other organizations that may be able to fund and/or distribute the products, to not only cater to the patients of the Sophia Children's Hospital but all patients of the Netherlands.

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Appendix

Appendix A - Preliminary Interview Protocol

Appendix B - Template of Interview Consent Forms

Appendix C - Sensitizing Cards

Appendix D - Interview Quotes | Original and Translation

Appendix E - Complete Patient Journey

Appendix F - Evaluation Interview Protocol

Appendix G - Evaluation Quotes | Original and Translation

Appendix H - Original Project Brief

Appendix A - Preliminary Interview Protocol

Gegevens deelnemer				
Naam deelnemer:				
Naam patient:				
Leeftijd patient:				
Type hemofilie:				
Behandeling:				
Kaarten ingevuld? (Ouder)		Kaarten ingevuld? (Kind)		

Interview met ouders

INTRODUCTIE

1. Kunt u iets vertellen over uw familie/gezinssamenstelling? Hoe centraal staat hemofilie in uw gezin?
2. Is er iemand in uw familie die gediagnosticeerd is met hemofilie, en wat is uw eigen ervaring ermee?

DIAGNOSE

1. Kunt u vertellen hoe u erachter gekomen bent dat uw kind hemofilie heeft?
2. Naar aanleiding van welke klachten/signalen van uw kind heeft u bijvoorbeeld medische hulp gezocht? En hoe heeft u dat proces ervaren?
3. Wat voor kennis had u over hemofilie voor de diagnose?
4. Hoe oud was uw kind tijdens de diagnose?
5. Kunt u vertellen hoe de diagnose is gesteld en hoe het proces naar de diagnose eruitzag?
6. Wat waren uw grootste zorgen nadat u te horen kreeg dat uw kind hemofilie heeft? Zijn deze nu veranderd?
7. Had u de mogelijkheid om met andere ouders te praten over de situatie? Had u dat gewild?

AFSPRAKEN

8. Wat vindt u van het poli/ziekenhuisbezoek? Wat doet u bij het ziekenhuis, is het vaak alleen een consult of is er altijd een prik bij?
9. Hoe vindt u dat u kind de ziekenhuisbezoeken ervaart?
10. Bereid u uw kind voor op het poli bezoek? Hoe bereid u uw kind voor op het poli bezoek?
11. Wat voor rol speelt het ziekenhuis in uw zelfvertrouwen over de ziekte? Krijgt u genoeg informatie en steun?
12. Vind u het moeilijk om medische hulp te zoeken?
    a. Welke bronnen gebruikt u om de informatie te vinden?
    b. Hoe vaak neemt u contact op met de verpleegkundige van de poli?
13. Hoe ervaren u en uw kind de consulten in het Sophia Kinderziekenhuis? Zijn er aspecten die u zou willen veranderen of misschien juist prettig vindt?

BEHANDELING

14. Wanneer was de profylaxe begonnen?
15. Kunt u vertellen over de keuze process?

16. Hoe was het proces van zelf leren prikken? Thuiszorg, ziekenhuis?
17. Hoe was het eerder?
18. En hoe verloopt het proces nu van medicijn(en) nemen/toedienen?

ERVARING KIND

19. Wat weet uw kind over hemofilie, en/of in het algemeen over zijn ziekte?
    a. Hoe heeft u dit gesprek aangepakt?
    b. Wanneer heeft u dit besproken met uw kind (of wanneer bent u van plan om het met uw kind hierover te hebben)?
20. Vindt u kind het heel erg om hemofilie te hebben?
21. Wat vindt uw kind ervan dat hij/zij hemofilie heeft?

LEVEN MET

22. In hoeverre beïnvloedt hemofilie uw leven en dat van uw kind?
23. Heeft u wel eens tegen uw kind moeten zeggen dat hij niet aan een bepaalde sport of spel mocht doen vanwege zijn hemofilie?
    a. Hoe heeft u dat aangepakt?
24. Mag u kind bij anderen logeren? Vrienden/familie?
    a. Hoe regelt u dat, zijn er extra dingen om op te letten hierbij
    b. Hoe bereid u uzelf en uw kind hierop voor?
25. Neemt u aanvullende maatregelen met school en vakanties?
26. Hoe bewust is de school van de diagnose?
    a. Wordt er meteen contact opgezocht als u kind op school valt?

- Waar denkt u dat de grootste pijnpunten liggen in het proces, voor de kinderen en voor de ouders?

Indien de ouder/verzorger zijn/haar kind meeneemt naar het interview

Indien de kaarten niet (volledig) ingevuld zijn

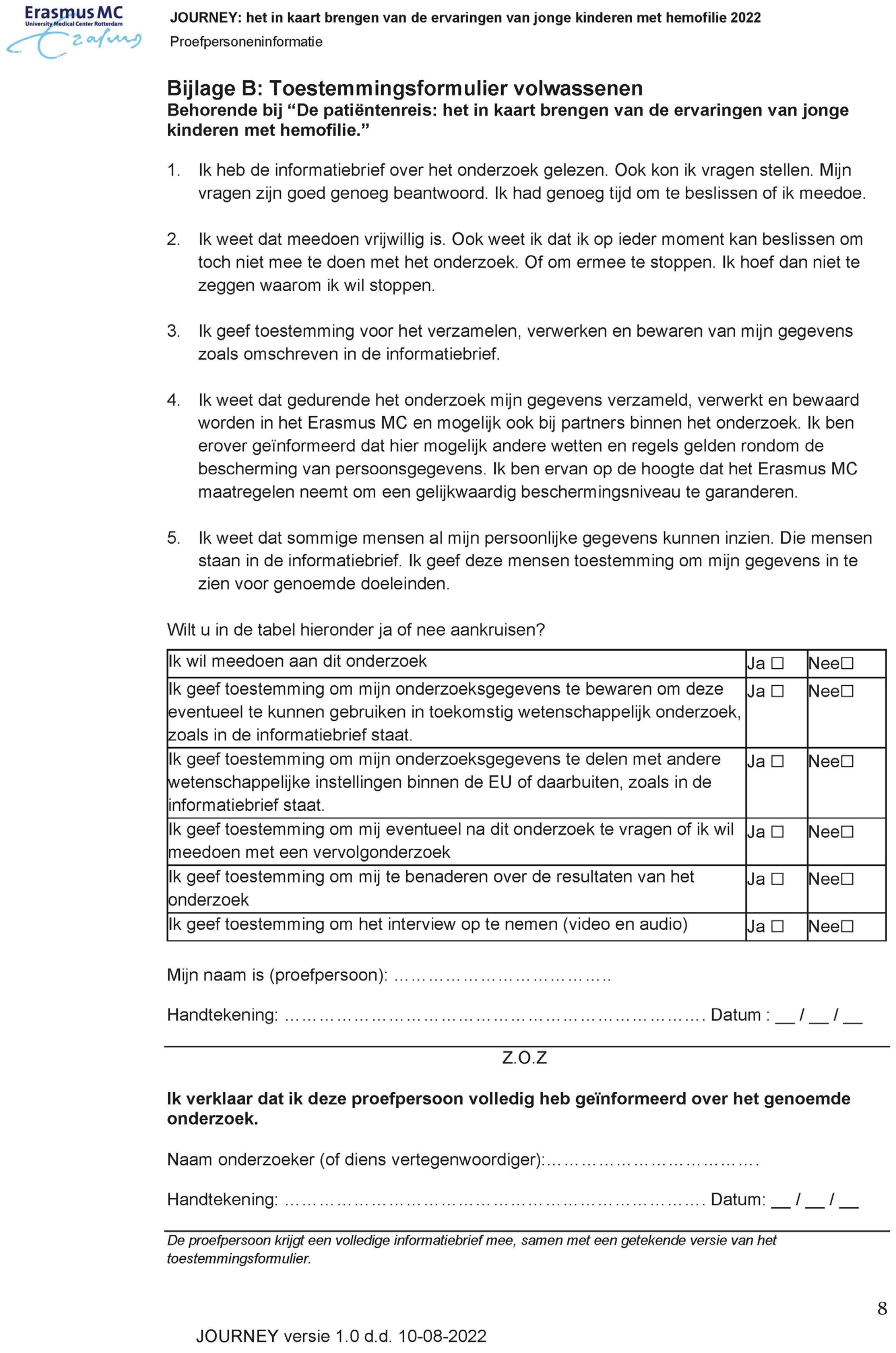
1. Weet je wat hemofilie is? Hoe vind je het om hemofilie te hebben?

Iemand geeft je om de zoveel tijd een prikje met medicijnen.

2. Weet je waarom je deze prikjes krijgt?
3. Wat vind je van de prikken?
4. Bereid je je hierop voor?
5. Zouden wij dit prettiger voor je kunnen maken?
6. Hoe vind je het om naar het ziekenhuis te gaan? Vind je dit leuk of vervelend?
7. Wat vind je dan niet leuk? Wat vind je wel leuk?

- Er is een jongetje/meisje zoals jij die ook moet oppassen met spelen, wat zou je tegen hen zeggen?
- Wat is iets dat je heel graag zou willen veranderen? Wat vind je de ergste aan hemofilie?

Appendix B - Template of the Interview Consent Forms



Erasmus MC
University Medical Center Rotterdam

JOURNEY: het in kaart brengen van de ervaringen van jonge kinderen met hemofilie 2022
Proefpersoneninformatie

Bijlage B: Toestemmingsformulier volwassenen

Behorende bij "De patiëntenreis: het in kaart brengen van de ervaringen van jonge kinderen met hemofilie."

1. Ik heb de informatiebrief over het onderzoek gelezen. Ook kon ik vragen stellen. Mijn vragen zijn goed genoeg beantwoord. Ik had genoeg tijd om te beslissen of ik meedoe.

2. Ik weet dat meedoen vrijwillig is. Ook weet ik dat ik op ieder moment kan beslissen om toch niet mee te doen met het onderzoek. Of om ermee te stoppen. Ik hoef dan niet te zeggen waarom ik wil stoppen.

3. Ik geef toestemming voor het verzamelen, verwerken en bewaren van mijn gegevens zoals omschreven in de informatiebrief.

4. Ik weet dat gedurende het onderzoek mijn gegevens verzameld, verwerkt en bewaard worden in het Erasmus MC en mogelijk ook bij partners binnen het onderzoek. Ik ben erover geïnformeerd dat hier mogelijk andere wetten en regels gelden rondom de bescherming van persoonsgegevens. Ik ben ervan op de hoogte dat het Erasmus MC maatregelen neemt om een gelijkwaardig beschermingsniveau te garanderen.

5. Ik weet dat sommige mensen al mijn persoonlijke gegevens kunnen inzien. Die mensen staan in de informatiebrief. Ik geef deze mensen toestemming om mijn gegevens in te zien voor genoemde doeleinden.

Wilt u in de tabel hieronder ja of nee aankruisen?

Ik wil meedoen aan dit onderzoek	Ja ☐	Nee☐
Ik geef toestemming om mijn onderzoeksgegevens te bewaren om deze eventueel te kunnen gebruiken in toekomstig wetenschappelijk onderzoek, zoals in de informatiebrief staat.	Ja ☐	Nee☐
Ik geef toestemming om mijn onderzoeksgegevens te delen met andere wetenschappelijke instellingen binnen de EU of daarbuiten, zoals in de informatiebrief staat.	Ja ☐	Nee☐
Ik geef toestemming om mij eventueel na dit onderzoek te vragen of ik wil meedoen met een vervolgonderzoek	Ja ☐	Nee☐
Ik geef toestemming om mij te benaderen over de resultaten van het onderzoek	Ja ☐	Nee☐
Ik geef toestemming om het interview op te nemen (video en audio)	Ja ☐	Nee☐

Mijn naam is (proefpersoon): …………………………………..

Handtekening: ………………………………………………………………….. Datum : __ / __ / __

Z.O.Z

Ik verklaar dat ik deze proefpersoon volledig heb geïnformeerd over het genoemde onderzoek.

Naam onderzoeker (of diens vertegenwoordiger):………………………………….

Handtekening: ………………………………………………………………….. Datum: __ / __ / __

De proefpersoon krijgt een volledige informatiebrief mee, samen met een getekende versie van het toestemmingsformulier.

8

JOURNEY versie 1.0 d.d. 10-08-2022

Bijlage D: Toestemmingsformulier ouders of voogd

Behorende bij "De patiëntenreis: het in kaart brengen van de ervaringen van jonge kinderen met hemofilie."

Ik ben gevraagd om toestemming te geven voor deelname van mijn kind aan dit medisch-wetenschappelijke onderzoek:

Naam proefpersoon (kind): ………………………………………….. Geboortedatum: __ / __ / __

1. Ik heb de informatiebrief voor de proefpersoon/ouders gelezen. Ook kon ik vragen stellen. Mijn vragen zijn goed genoeg beantwoord. Ik had genoeg tijd om te beslissen of ik wil dat mijn kind meedoet.

2. Ik weet dat meedoen vrijwillig is. Ook weet ik dat ik op ieder moment kan beslissen dat mijn kind toch niet meedoet. Ik hoef dan niet te zeggen waarom ik dat wil.

3. Ik geef toestemming voor het verzamelen, verwerken en bewaren van de gegevens van mijn kind zoals omschreven in de informatiebrief.

4. Ik weet dat gedurende het onderzoek de gegevens van mijn kind verzameld, verwerkt en bewaard worden in het Erasmus MC en mogelijk ook bij partners binnen het onderzoek. Ik ben erover geïnformeerd dat hier mogelijk andere wetten en regels gelden rondom de bescherming van persoonsgegevens. Ik ben ervan op de hoogte dat het Erasmus MC maatregelen neemt om een gelijkwaardig beschermingsniveau te garanderen.

5. Ik weet dat sommige mensen de persoonlijke gegevens van mijn kind kunnen inzien. Die mensen staan in de informatiebrief. Ik geef deze mensen toestemming om de gegevens van mijn kind in te zien voor genoemde doeleinden.

Wilt u in de tabel hieronder ja of nee aankruisen?

Ik geef toestemming dat mijn kind meedoet aan dit onderzoek	Ja ☐	Nee☐
Ik geef toestemming om de onderzoeksgegevens van mijn kind te bewaren om deze eventueel te kunnen gebruiken in toekomstig wetenschappelijk onderzoek, zoals in de informatiebrief staat.	Ja ☐	Nee☐
Ik geef toestemming om de onderzoeksgegevens van mijn kind te delen met andere wetenschappelijke instellingen binnen de EU of daarbuiten, zoals in de informatiebrief staat.	Ja ☐	Nee☐
Ik geef toestemming om mij en mijn kind eventueel na dit onderzoek te vragen of hij/zij wil meedoen met een vervolgonderzoek	Ja ☐	Nee☐
Ik geef toestemming om mij en mijn kind te benaderen over de resultaten van het onderzoek	Ja ☐	Nee☐
Ik geef toestemming om het interview op te nemen (video en audio)	Ja ☐	Nee☐

Naam ouder/voogd**: ………………………………

Handtekening: …………………………………………………………………. Datum: __ / __ / __

Naam andere ouder/voogd**: …………………….

Handtekening: …………………………………………………………………. Datum: __ / __ / __

Ik verklaar dat ik de persoon/personen hierboven volledig heb geïnformeerd over het genoemde onderzoek.

Naam onderzoeker (of diens vertegenwoordiger): …………………………

Handtekening: ……………………………………………………………………. Datum: __ / __ / __

De ouder/voogd krijgt een volledige informatiebrief mee, samen met een getekende versie van het toestemmingsformulier.

* Doorhalen wat niet van toepassing is.
** Als het kind jonger dan 16 jaar is, ondertekenen de ouders die het gezag uitoefenen of de voogd dit formulier. Kinderen van 12 t/m 15 jaar die zelfstandig beslissingen kunnen nemen (wilsbekwaam zijn), moeten daarnaast zelf een formulier ondertekenen

Appendix C - Sensitizing Cards

Patient/Child Cards


Partitura

Tekenboekje voor kinderen


Wie Ben Ik?

Mijn naam is ____________

Ik ben ______ jaar oud

Ik heb hemofilie type ____

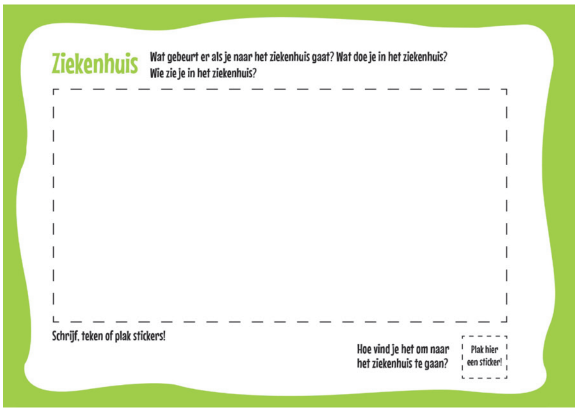
En dit ben ik!

Teken jezelf hier!


Mijn dagelijks leven

Dit vind ik leuk om te doen

Schrijf, teken of plak stickers!

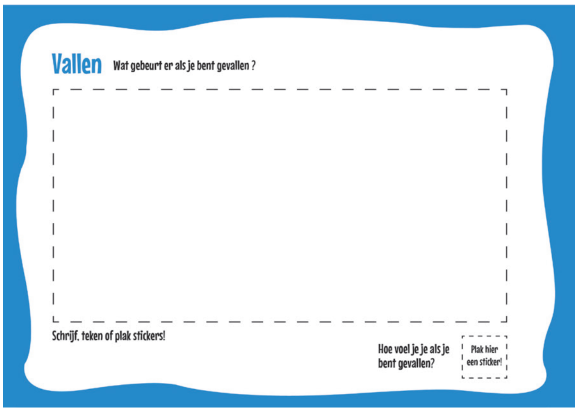

Ziekenhuis

Wat gebeurt er als je naar het ziekenhuis gaat? Wat doe je in het ziekenhuis? Wie zie je in het ziekenhuis?

Schrijf, teken of plak stickers!

Hoe vind je het om naar het ziekenhuis te gaan?

Plak hier een sticker!

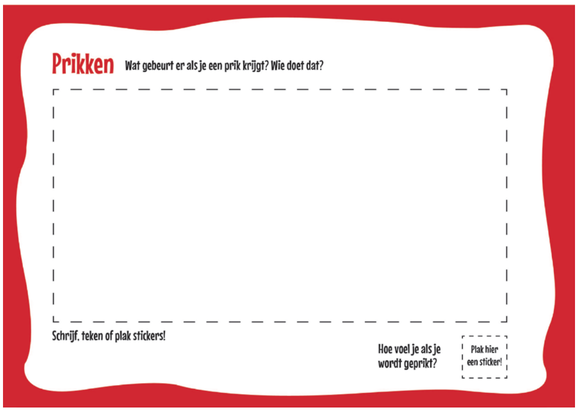

Vallen

Wat gebeurt er als je bent gevallen ?

Schrijf, teken of plak stickers!

Hoe voel je je als je bent gevallen?

Plak hier een sticker!


Prikken

Wat gebeurt er als je een prik krijgt? Wie doet dat?

Schrijf, teken of plak stickers!

Hoe voel je je als je wordt geprikt?

Plak hier een sticker!

Parent Cards

Partitura.

Invulboekje voor ouders

Introductie

Naam:

Leeftijd:

Geslacht:

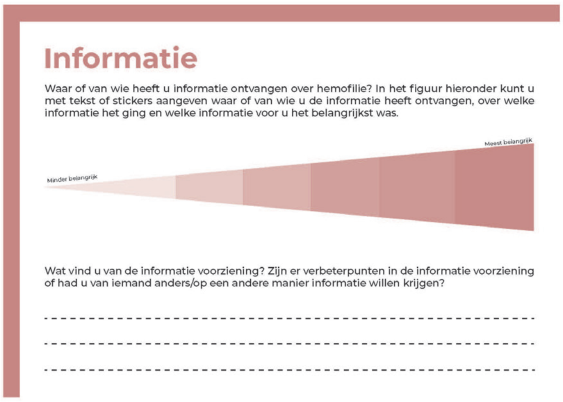
Ik ben de ouder / verzorger van:

Ik ben **draagster** / heb **geen hemofilie**

Behandeling & Keuze

Welke behandeling ontvangt uw zoon/dochter? Kon u meebeslissen over de behandeling? Waarom is er gekozen voor deze behandeling?

Wie heeft een rol gespeeld in deze keuze voor behandeling? In het figuur hieronder kunt u met tekst of stickers aangeven welke personen een rol speelde (bijv. familieleden, artsen, lotgenoten etc.) en hoe belangrijk zij waren in het keuzeproces.



Informatie

Waar of van wie heeft u informatie ontvangen over hemofilie? In het figuur hieronder kunt u met tekst of stickers aangeven waar of van wie u de informatie heeft ontvangen, over welke informatie het ging en welke informatie voor u het belangrijkst was.

Wat vind u van de informatie voorziening? Zijn er verbeterpunten in de informatie voorziening of had u van iemand anders/op een andere manier informatie willen krijgen?

Ziekenhuis

Hoe ziet een dag in het ziekenhuis eruit? Bereid u zich voor? Hoe bereid u zich voor?

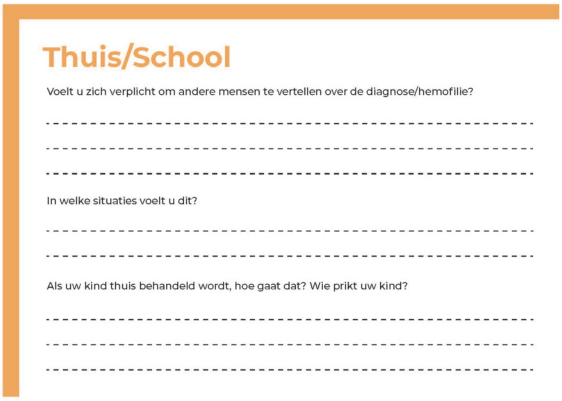
Hoe ervaart uw kind het om naar het ziekenhuis te gaan?

Is er iets dat u zou willen verbeteren aan het ziekenhuisbezoek?

Diagnose

Hoe lang duurde het voordat uw kind werd gediagnosticeerd met hemofilie? U kunt hieronder op de tijdlijn tekenen hoe de diagnose tot stand is gekomen, hoe lang het diagnostisch proces heeft geduurd en uw ervaringen/emoties tijdens het proces.

Was u al bekend met hemofilie? Wat waren/zijn uw grootste zorgen rondom de ziekte?



Thuis/School

Voelt u zich verplicht om andere mensen te vertellen over de diagnose/hemofilie?

In welke situaties voelt u dit?

Als uw kind thuis behandeld wordt, hoe gaat dat? Wie prikt uw kind?

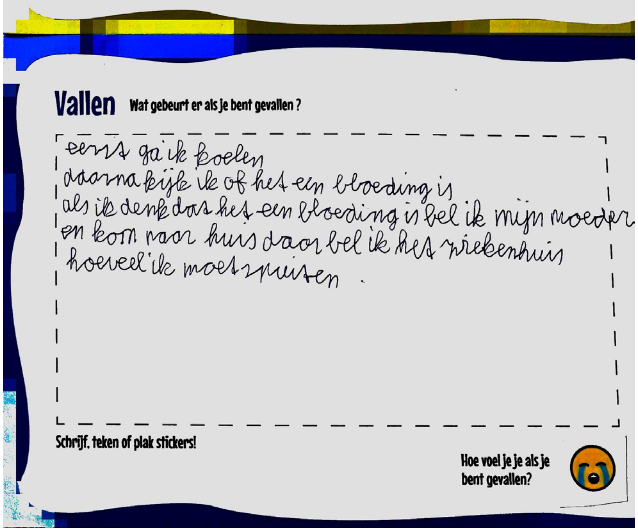
Afsluitend

Wat voor advies zou u geven aan een andere ouder die net gehoord heeft dat zijn zoon hemofilie heeft?

Wilt u nog iets anders kwijt? Wilt u ons nog iets vertellen over uw ervaringen met hemofilie?

A7

More Examples of Filled Cards



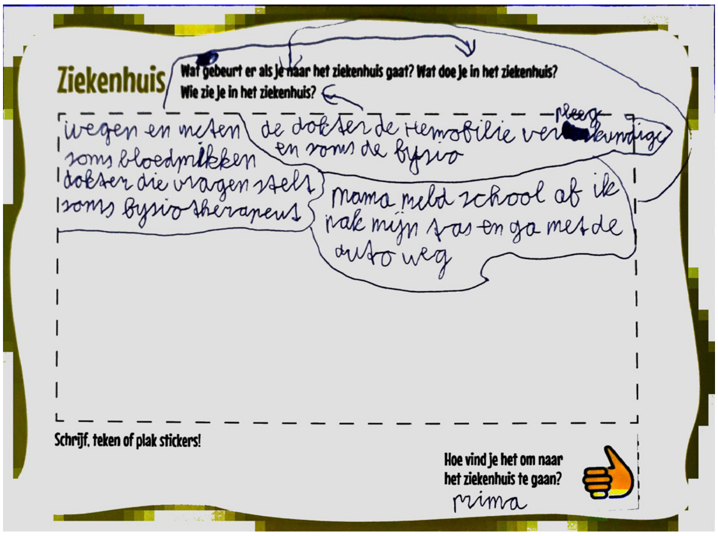
Vallen

Wat gebeurt er als je bent gevallen ?

eerst ga ik koelen
daarna kijk ik of het een bloeding is
als ik denk dat het een bloeding is bel ik mijn moeder
en kom naar huis daar bel ik het ziekenhuis
hoeveel ik moet spuiten .

Schrijf, teken of plak stickers!

Hoe voel je je als je bent gevallen?



Ziekenhuis

Wat gebeurt er als je naar het ziekenhuis gaat? Wat doe je in het ziekenhuis? Wie zie je in het ziekenhuis?

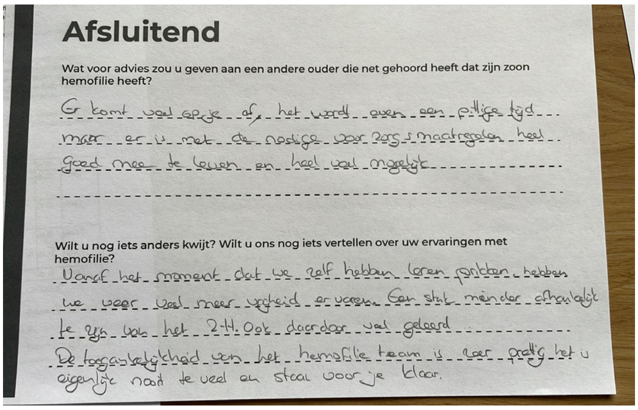
wegen en meten
soms bloedprikken
dokter die vragen stelt
soms fysiotherapeut

de dokter de hemofilie verpleegkundige
en soms de fysio

mama meld school af ik
pak mijn tas en ga met de
auto weg

Schrijf, teken of plak stickers!

Hoe vind je het om naar het ziekenhuis te gaan?
prima



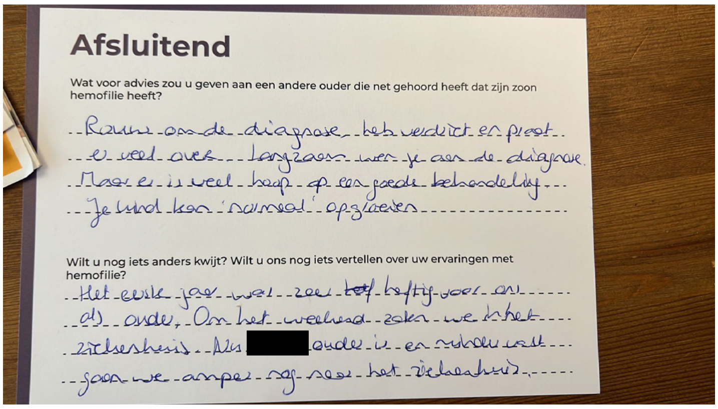
Afsluitend

Wat voor advies zou u geven aan een andere ouder die net gehoord heeft dat zijn zoon hemofilie heeft?

Er komt veel op je af, het wordt even een pittige tijd maar er is met de nodige voorzorgsmaatregelen heel goed mee te leven en heel veel mogelijk

Wilt u nog iets anders kwijt? Wilt u ons nog iets vertellen over uw ervaringen met hemofilie?

Vanaf het moment dat we zelf hebben leren prikken, hebben we weer veel meer vrijheid ervaren. Een stuk minder afhankelijk te zijn van het Z-H. Ook daardoor veel geleerd. De toegankelijkheid van het hemofilie team is zeer prettig het is eigenlijk nooit te veel en staat voor je klaar.



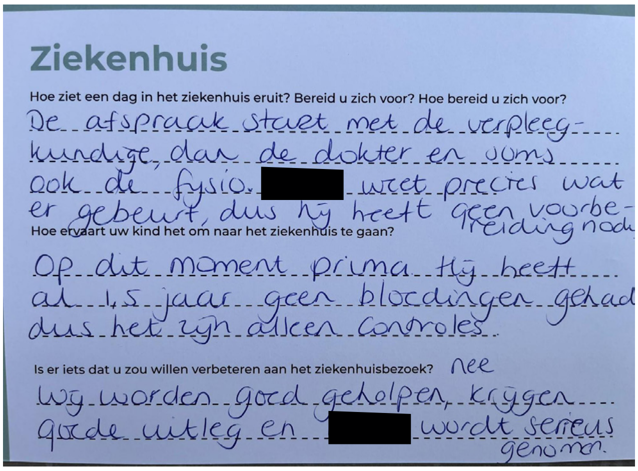
Afsluitend

Wat voor advies zou u geven aan een andere ouder die net gehoord heeft dat zijn zoon hemofilie heeft?

Rouw om de diagnose, het verdict en proces er veel over. Langzaam went je aan de diagnose. Maar er is veel hoop op een goede behandeling. Je kind kan 'normaal' opgroeien

Wilt u nog iets anders kwijt? Wilt u ons nog iets vertellen over uw ervaringen met hemofilie?

Het eerste jaar was zeer ~~tof~~ heftig voor ons als ouder. Om het weekend zaten we in het ziekenhuis. Als [redacted] ouder is en minder valt gaan we amper nog naar het ziekenhuis.



Ziekenhuis

Hoe ziet een dag in het ziekenhuis eruit? Bereid u zich voor? Hoe bereid u zich voor?

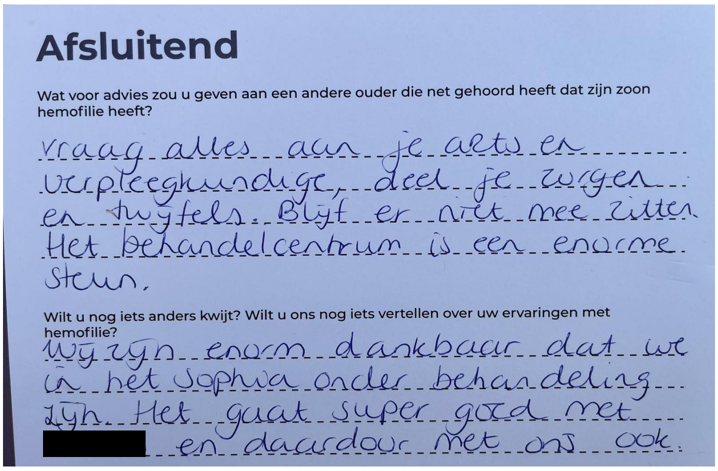
De afspraak staat met de verpleegkundige, dan de dokter en soms ook de fysio. [redacted] weet precies wat er gebeurt, dus hij heeft geen voorbereiding nodig

Hoe ervaart uw kind het om naar het ziekenhuis te gaan?

Op dit moment prima. Hij heeft al 1,5 jaar geen bloedingen gehad dus het zijn alleen controles.

Is er iets dat u zou willen verbeteren aan het ziekenhuisbezoek? nee

Wij worden goed geholpen, krijgen goede uitleg en [redacted] wordt serieus genomen.



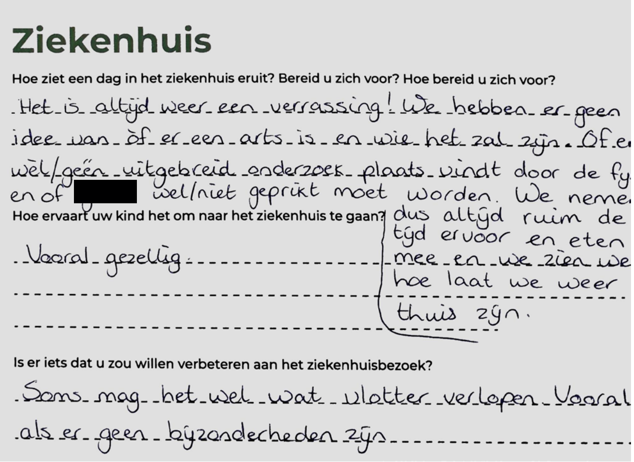
Afsluitend

Wat voor advies zou u geven aan een andere ouder die net gehoord heeft dat zijn zoon hemofilie heeft?

vraag alles aan je arts en verpleegkundige, deel je zorgen en twijfels. Blijf er niet mee zitten. Het behandelcentrum is een enorme steun.

Wilt u nog iets anders kwijt? Wilt u ons nog iets vertellen over uw ervaringen met hemofilie?

Wij zijn enorm dankbaar dat we in het Sophia onder behandeling zijn. Het gaat super goed met [redacted] en daardoor met ons ook.



Ziekenhuis

Hoe ziet een dag in het ziekenhuis eruit? Bereid u zich voor? Hoe bereid u zich voor?

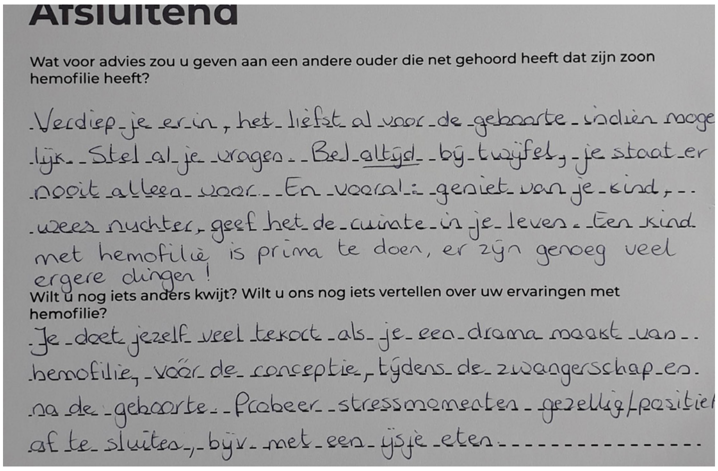
Het is altijd weer een verrassing! We hebben er geen idee van òf er een arts is en wie het zal zijn. Of e wèl/geen uitgebreid onderzoek plaats vindt door de fy en of [redacted] wel/niet geprikt moet worden. We neme dus altijd ruim de tijd ervoor en eten mee en we zien we hoe laat we weer thuis zijn.

Hoe ervaart uw kind het om naar het ziekenhuis te gaan?

Vooral gezellig.

Is er iets dat u zou willen verbeteren aan het ziekenhuisbezoek?

Soms mag het wel wat vlotter verlopen. Vooral als er geen bijzonderheden zijn



Afsluitend

Wat voor advies zou u geven aan een andere ouder die net gehoord heeft dat zijn zoon hemofilie heeft?

Verdiep je er in, het liefst al voor de geboorte indien mogelijk. Stel al je vragen. Bel altijd bij twijfel, je staat er nooit alleen voor. En vooral: geniet van je kind, wees nuchter, geef het de ruimte in je leven. Een kind met hemofilie is prima te doen, er zijn genoeg veel ergere dingen!

Wilt u nog iets anders kwijt? Wilt u ons nog iets vertellen over uw ervaringen met hemofilie?

Je doet jezelf veel tekort als je een drama maakt van hemofilie, vóór de conceptie, tijdens de zwangerschap en na de geboorte. Probeer stressmomenten gezellig/positie af te sluiten, bijv. met een ijsje eten.

Appendix D - Interview Quotes | Original and Translation

** Original Dutch quotes are presented in **RED**, translated English quotes are **BLACK**.

Understanding the (needs of) a child

Autonomy

"It just hurts that's true, but how can he get a little bit of responsibility in that like how does he want to be injected, "as fast as a hare" and then sometimes we go too fast and he says "no not as fast as a tiger it has to be like a hare" it is the same but he determines with which animal the injection is done. We had come up with that with the nurse, in retrospect I think it's genius. That way he has a little bit of control." (Parent, P7) "Het doet gewoon pijn dat is zo, maar hoe kan hij daarin een beetje verantwoordelijkheid krijgen van ja hoe wil je geprikt worden, "zo snel als een haas" en dan soms gaan we te snel en zegt hij "nee niet zo snel als een tijger het moet als een haas" het is dezelfde maar hij bepaald dan met welk dier het prik gedaan wordt. Dat hadden we met de verpleegkundige bedacht, achteraf vind ik het geniaal. Zo heeft hij toch een beetje controle." (Ouder, P7)

"Once he got a really hard blow to the head. And of course there was a lot of panic. Logically. And at that moment I don't think it's realistic to expect an 11 year old child, I think he can do it, but in that panic and pain to get everything ready and inject himself… I think he can do it but I think it's a bit sad." (Parent, P6) "Een keer kreeg hij een enorm harde klap op zijn hoofd. En er was natuurlijk veel paniek. Logisch. En op die moment vind ik het niet realistisch om van een kind van 11, ik denk dat hij het kan hoor, maar te verwachten in die paniek en pijn om alles klaar te zetten en zelf in te spuiten… Ik denk dat hij het wel kan maar ik vind het een beetje sneu." (Ouder, P6)

"He knows he has to be careful, and he often yells "Mommy I can do it, I am careful, I will walk down the stairs very carefully" so he does it all. He knows we are concerned about him, but then he does everything. He is not afraid. He is active." (Parent, P7) "Hij weet dat hij voorzichtig moet doen, en hij roept vaak "mama ik kan het wel hoor, ik doe heel voorzichtig, ik loop de trap heel voorzichtig" dus hij weet het allemaal. Hij weet dat we bezorgd om zijn, maar vervolgens doet hij wel alles. Hij is niet bang. Hij is actief." (Ouder, P7)

Being Included in Conversation

"He knows what it's like to have a bleed. We don't know, of course, but he always feels it exactly. [...] Always believe your child. If he says he has pain somewhere, then he has pain." (Parent, P2) "Hij weet hoe het is om een bloeding te hebben. Wij weten het natuurlijk niet maar hij voelt het altijd precies. [...] Je kind altijd geloven. Als hij zegt dat hij ergens pijn heeft dan heeft hij ergens pijn." (Ouder, P2)

"Mother: Sometimes you even call the hemophilia nurse yourself. They also like it when he calls himself. Child: Yes and they know more because I can sense more Mother: Of course! I can't say what you feel." (Parent and Patient, P6) "Moeder: Je gaat heel soms ook zelf bellen he bij de hemofilieverpleegkundige. Vinden ze ook gezellig als hij zelf belt. Kind: Ja en ze weten dan ook meer want ik kan meer aanvoelen Moeder: Natuurlijk! Ik kan niet zeggen wat jij voelt." (Ouder and Patient, P6)

“Then I sat there for the explanation, we had the conversation, me and the doctor, but we didn’t actually involve him. [...] He was still small, I think about 4-5 years old. Then after that he got very rebellious, crying, he was very angry with me. [...] We talked about him. He’s very capable of having a conversation. Whether he can make good decisions, that’s another story. But you can really tell him what it means.” (Parent, P2) “Toen heb ik daar gezeten voor de uitleg eigenlijk hebben wij het gesprek gevoerd ik en de arts, maar we hebben hem eigenlijk niet bij betrokken. [...] Hij was wel nog klein hoor ik denk een jaar of 4-5. Toen daarna werd hij heel erg opstandig, huilen, hij was heel boos op mij. [...] We hebben over hem gesproken. Hij is heel goed in staat om een gesprek te voeren, Kijk of hij goed beslissingen kan nemen dat is een ander verhaal. Maar je kan hem wel echt vertellen wat het betekend.” (Ouder, P2)

“We had a consultation with a pedagogical nurse and that is actually the first time that he was taken along with everything. And actually, when I think about it that way, it’s really nice. [...] We came up with a very nice step-by-step plan with him. He actually helped make it, now the injections are much better.” (Parent, P7) “We hebben dus een consult gehad bij die pedagogisch verpleegkundige en dat is wel eigenlijk de eerste keer dat hij mee werd genomen met alles. En eigenlijk als ik er zo over nadenk is dat wel erg mooi. [...] We hebben een heel leuke stappenplan bedacht met hem. Hij heeft ook wel echt geholpen ermee, nu gaat het veel beter prikken.” (Ouder, P7)

“That is so important. Look indeed, he can’t make a choice. When you’re 8, you really can’t make a decision. But you feel involved. It can also start from an early age. Even if they are very small questions.” (Parent, P2) “Dat is zó belangrijk. Kijk inderdaad, hij kan geen keuze maken. Als je 8 bent dan kan je echt geen keuze maken. Maar voel je je betrokken. Het kan ook van een vroege leeftijd beginnen. Als het maar ook hele kleine vraagjes zijn.” (Ouder, P2)

Trust and Feeling Safe

“There is confidence now. There was just uncertainty of “what are they going to do, does it hurt? Who’s going to do it? How long will this take?” Now he just knows. “I’m having a chat, it’s just a day out.”” (Parent, P1) “De vertrouwen is er nu ook. Er was gewoon onzekerheid van wat gaan ze doen, doet het pijn? Wie gaat het doen? Hoe lang duurt dit? Nu weet hij wel gewoon. “Ik heb een gesprekje, het is gewoon een dagje uit.”” (Ouder, P1)

“Child: Then there was one time when I had a bleed here, my parents thought yes you have to walk a lot, so then we went for a long walk and stuff, and then I was all the time ‘ah... oh. ..” they said don’t put it like that and stuff like that. Mother: Once we did it very wrong, yes. Child: Yes and at one point I got a big tear in my muscle and had to be in a wheelchair for 4 weeks.” (Parent and Patient, P6) “Kind: Toen was er een keer dat ik een bloeding had hier, mijn ouders dachten ja je moet veel gaan lopen, dus toen gingen we een heel eind lopen enzo, en toen was ik de hele tijd van “ah... oh...” ze zeiden doe maar niet zo aanstellen en zo. Moeder: Een keer hebben we het wel heel erg fout gedaan ja. Kind: Ja en op een gegeven moment kreeg ik dus een grote scheur in mijn spier en moest 4 weken in de rolstoel.“ (Ouder and Patient, P6)

“With the candies and the ice creams… if he ever abuses it, give him that moment. He just wants an ice cream, whatever. He must have taken advantage of it. Cool, ice cream. Then give him that. He is already burdened by the rest of it.” (Parent, P2) “Met de snoepjes en de ijsjes… als hij er ooit misbruik van maakt, gun hem dat moment. Hij heeft er even zin in, lekker boeiend. Hij heeft reus wel misbruik van gemaakt. Koelen, ijsje. Gun hem dat dan maar. Hij heeft aan de andere kan al ellende van.” (Ouder, P2)

“If you have good doctors and nice nurses, that's just the most important thing. That ensures that your child feels at home. [...] We got that.” (Parent, P1) “Als je goede artsen hebt en lieve verpleegkundigen, dat is gewoon de allerbelangrijkste. Die ervoor zorgen dat je kind lekker thuis voelt. [...] Dat hebben wij gewoon gekregen.” (Ouder, P1) “We feel very welcome. All equally friendly, and a listening ear when things aren’t going as well. It doesn’t feel bad to come here even though we are in the hospital.” (Parent, P5) “We voelen ons heel welkom. Allemaal even vriendelijk, en een luisterend oor als het even wat minder gaat. Voelt niet vervelend om hier te komen ook al zijn we in het ziekenhuis.” (Ouder, P5)

“Well, I like all the enthusiasm. And what will happen to me. And, I just like to see [nurse].” (Patient, P1) “Nou, ik vind leuk al die enthousiasme. En wat gaat gebeuren met mij. En, ik vind gewoon leuk om [vepleegkundige] te zien.” (Patient, P1)
“There is just a lot of peace. The nurses simply have a lot of peace in them, which is of course very good for the children and the doctors also have plenty of time.” (Parent, P3) “Er is gewoon heel veel rust. De verpleegkundigen hebben gewoon heel veel rust in zich, wat natuurlijk heel goed is voor de kinderen en de artsen die hebben ook zo alle tijd.” (Ouder, P3)

The struggles of action and consequence

“He mainly thinks about what he will no longer be allowed to do, or can no longer be able to do or what he has to miss. [...] I think things like that stick with him more.” (Parent, P2) “Hij denkt vooral van wat hij niet meer mag, of niet meer kan of wat hij moet missen. [...] Ik denk dat dat soort dingen bij hem wel meer bij blijven.” (Parent, P2)

“What is very irritating is, for example, you have a bleed just before a school trip or something. Or if you are going to do something fun with the class or have a party or something... I think that is the biggest disadvantage there is.” (Patient, P7) "Wat wel heel irritant is is bijvoorbeeld je hebt een bloeding precies voor een schoolreisje of zo. Ga je met de klas een leuk iets doen of een feestje of zo... Dat vind ik wel de grootste nadeel dat er is." (Patient, P7)

“It’s happened a few times that he fell very hard and had to go to the hospital, so perhaps unconsciously he does get affected by it.” (Parent, P4) “Het is een paar keer gebeurt dat hij heel hard viel en naar het ziekenhuis moest dus misschien onbewust dat hij er toch wel wat van mee krijgt.” (Parent, P4)

“Yes, jumping down the stairs, his younger sister is already jumping down the fourth step of the stairs. And he has to think about that for a moment. And he often hesitates at the railing like “can I do this”?” (Parent, P1) “Ja van de trap afspringen zijn zusje springt al van de vierde trap naar beneden. En hij die moet daar even over nadenken. En hij twijfel vaak bij het klimrek van “kan ik dit”?” (Parent, P1)

“Now he often says “no, the pain is already gone!” but you have to deny that. The day before yesterday he had his hand in the door, then I said to my husband in English “What do you think? Do we have to go to the hospital?” And he said, he really can’t speak English but he said “No, no not to the hospital!” so he knows full well that if he falls hard he needs to go to the hospital.” (Parent, P7) “Nu zegt hij wel vaak “nee de pijn is al weer weg!” maar dat moet je ontkennen. Eergisteren had hij zijn hand tussen de deur, toen zei ik tegen mijn man in het Engels van “what do you think do we have to go to the hospital?” En hij zei, ja hij kan echt geen Engels maar hij zei “Nee, nee niet naar de ziekenhuis!” dus hij weet dondersgoed dat als hij hard valt dat hij naar de ziekenhuis moet.” (Parent, P7)

Understanding the disease

“If I fall, I look if there is blood and then I go to mom and dad.” (Patient, P2) “Als ik val kijk ik of er bloed is en dan ga ik naar mama en papa.” (Patient, P2)

“He knows he has to pay attention, he knows that if he falls we will ask if he is in pain and where he feels the pain.” (Parent, P7) “Hij weet dat hij moet opletten, hij weet dat als hij valt gaan wij vragen of hij pijn heeft en waar hij pijn heeft.” (Ouder, P7)

“At 4 years old, he was already very good at saying “I’m not allowed to do that, because then I may have another bleeding in my knee. Then I can’t walk again, and I don’t want to do that again.”” (Parent, P1) “Bij 4 jaar kon hij al heel goed vertellen “dat mag ik niet, want dan kan het zijn dat ik weer opnieuw een bloeding krijg in mijn knie. Dat ik weer niet kan lopen, en dat wil ik niet nog een keer.”” (Ouder, P1)

"If he asks something, we also give a very honest answer, we don't make a secret of it. I think that's the power, if he asks something, he gets an answer. And that is good for him." (Parent, P2) "Als hij iets vraagt dan geven we ook een heel eerlijke antwoord op we maken geen geheim van. Ik denk dat dat de kracht is, als hij iets vraagt dan krijgt hij een antwoord. En dat is voor hem goed." (Ouder, P2)

"I don't care what the doctors know. I just want to know what you need to know, what to do if you fall, and that. And what it is, but not all substances and all that, I don't care." (Patient, P6) "Wat de dokters weten dat maakt mij helemaal niet uit. Ik wil gewoon weten wat je moet weten, wat je doet als je valt, en dat. En wat het is, maar niet allemaal stofjes en zo allemaal dat boeit me niet." (Patient, P6)

"We also have a schedule that he knows well, long day, short day, and that also runs through the holidays. We've often had him say "oh shouldn't we do the injection?"" (Parent, P3) "We hebben ook een schema, van dat hij goed weet lange dag, korte dag, en dat ook door de vakantie loopt. We hebben vaker gehad dat hij zegt "oh moeten we geen prikje?"" (Ouder, P3)

Expressing Self

"Now he asks himself "why", I think that's sad, why [the bleeding] doesn't stop with him and not with others." (Parent, P3) "Nu speelt wel dat hij zich vraagt "waarom", dat vind ik sneu, van waarom dat het bij hem niet stopt en niet bij anderen." (Ouder, P3)

"He always says "I have to do so much". He's had a lot of bad luck, but he definitely thinks it's a burden." (Parent, P2) "Hij zegt altijd "ik moet zo veel". Hij heeft wel veel pech gehad maar hij vind het zeker een belasting." (Ouder, P2)'

"It is also very frustrating that you always have to go to the hospital, that your parents are always next to you. He is allowed to feel frustrated about it." (Parent, P7) "Het is ook hartstikke stom dat je altijd naar het ziekenhuis moet, dat je ouders altijd naast je staan. Hij mag het wel even stom vinden." (Ouder, P7)

Friends and Fitting in

"We also fake it sometimes. If he has had a bleed, he can walk around at home without crutches, and at school he has to walk with crutches. So that his friends see "oh, we shouldn't give him a hard shove". So it's a bit of protection." (Parent, P6) "We doen ook soms wel neppen. Als hij een bloeding heeft gehad mag hij dan thuis zonder krukken, en op school verplicht met. Zodat zijn vrienden zien van oh, we moeten hem niet een harde duw geven. Dus het is een stukje bescherming." (Ouder, P6)

"In the past it was like something cool with the plasters after the injections. [...] Now, after an hour he takes it off. So there's something he doesn't want to show. While it used to be something very tough. And we always do [numbing cream] with cling film, so he didn't want to go out with that. Sometimes we go out to play in the evening, and sometimes he doesn't want to. So something changed in that I think he doesn't want that attention. [...] People he doesn't know also say something about it. I don't think he likes that anymore." (Parent, P3) "In het geleden was het als iets stoers met de pleisters na de prikken. [...] Nu is het, na een uur doet hij het eraf. Dus toch is er iets dat hij niet wilt laten zien. Terwijl was het vroeger juist iets heel stoers. En we doen altijd [verdovingscreme] met huishoudfolie, en hij wilde dus niet naar buiten daarmee. Ja gaan we soms 's avonds buiten spelen, en dat wilde hij soms niet. Dus er veranderd wel iets in denk ik dat hij die aandacht niet wil hebben. [...] Ook mensen die hij niet kent zeggen er iets van. Dat vind hij denk ik niet meer leuk." (Ouder, P3)

"If his friends jump off the slide because it's cool, they say 'you can't do that'." (Parent, P1) "Als zijn vriendjes op de glijbaan af springen omdat dat stoer is, die zeggen "dat mag jij niet"." (Ouder, P1)

Fears and Stressors

Origination of fears

“At the ER it took forever before we were helped. He was also injected wrong a few times. They went to search for the vein with the needle and it hurt. He was also afraid to go to the hospital. You could easily develop a fear of needles from the emergency room.” (Parent, P4) “Bij de SEH duurde het eindeloos lang voordat we geholpen werden. Ook werd er een aantal keer mis geprikt. Ze gingen met de naald zoeken naar de ader en dat deed zeer. Hiernaar was hij ook even angstig om naar het ziekenhuis te gaan. Door de SEH zou je gemakkelijk prikangst kunnen ontwikkelen.” (Ouder, P4)

“Wrong injection. That must have happened. Must have had an impact.” (Parent, P2) “Verkeerd prikken. Dat zal zeker gebeurt zijn. Zal zeker een invloed op hebben.” (Ouder, P2)

“The fear started when we still had to inject the vein with home care, and sometimes it didn’t work and you had to puncture again and then search… [...] It takes a long time and you also have to hold him.” (Parent, P7) “De angst begon toen we nog in de vat moesten prikken met thuiszorg, en die prikte soms wel mis en moet je nog een keer prikken en dan zoeken… [...] Het duurt al wel lang en je moest hem ook vasthouden.” (Ouder, P7)

Overcoming fears

“He did have a bit of fear at 2.5-3 years, when we went to a pedagogical nurse in the hospital. It helped us to get rid of that fear a bit, which also helped. [...] He can determine who injects, where he sits. He also has special toys. So all those things do help with the process. So I think it’s okay for children to just give the information anyway.” (Parent, P7) “Hij heeft wel een beetje angst gehad bij 2.5-3 jaar, toen zijn we bij een pedagogisch verpleegkundige in het ziekenhuis geweest. Die heeft ons geholpen om een beetje van die angst af te komen wat ook wel hielp. [...] Hij kan bepalen wie prikt, waar zit je. Hij heeft ook speciale speelgoed. Dus al die dingen helpen wel met het proces. Dus ik denk dat het voor kinderen wel om de informatie toch wel gewoon te geven.” (Ouder, P7)

“At one point he got [a fear of needles]. It sometimes took an hour and a half before we could inject. With a lot of sadness. [He] really didn’t like it. Then he got EMDR about it at the Sophia. After 3 times it was really over.” (Parent, P2) “Op een gegeven moment kreeg hij [prikangst]. Het duurde soms wel een anderhalf uur voordat we konden prikken. Met heel veel verdriet. Vond [hij] echt niet fijn. Toen heeft hij bij de Sophia EMDR gekregen daarover. Na 3 keer was het echt over.” (Ouder, P2)

“Every time he saw someone in a white coat, he cried. Every time he saw a needle in the hospital he cried. And then the doctor took off her coat. Then he even climbed onto the doctor’s lap!” (Parent, P1) “Iedere keer iemand met witte jas zien ging hij huilen. Iedere keer een naald zien in het ziekenhuis ging hij huilen. En toen heeft de arts haar jas uit gedaan. Toen was hij zelfs op schoot geklommen bij de arts!” (Ouder, P1)

Shift in Predictability

“Crying, scared, pain. Not wanting to sit while he, with that IV he just sat himself and stretched out his arm and helped get all the stuff ready. And, suddenly there was a different, very scared boy. ” (Parent, P1) “Huilen, bang, pijn. Niet willen zitten terwijl hij, ja met die intraveneus ging hij gewoon zelf zitten en zijn arm uitstrekken en meehelpen. Alle spullen klaar leggen. En, nu was er ineens weer een heel bange jongen.” (Ouder, P1)

“I don’t like it very much when I get a new shot. I have a lot of stress about that with my illness. I thought it would hurt really bad.” (Patient, P1) “Ik vind het niet zo leuk als ik een nieuwe prikje krijg. Ik heb heel veel spanning daaraan met mijn ziekte. Ik dacht dat het heel zeer zou doen.” (Patient, P1)

“The switch to SC is done with him. And also a bit of, “it’s every other day now, but then it’s once every 14 days!” And that with him. They showed it, the medicine, the kind of needle. [...] So also that he sees the difference, that you also see him relieved.” (Parent, P2) “De switch naar SC is wel met hem gedaan. En ook een beetje, “het is nu om de dag, maar dan is het een keer in de 14 dagen!” En dat dan ook met hem. Ze hebben het laten zien, het medicijn, het soort naald. [...] Dus ook dat hij de verschil ziet, dat je hem ook ziet opluchten.” (Ouder, P2)

“On paper it is structured, but in reality it is not. You never know what will happen. [...] Especially for families with young children or with children who cry easily and are really attached to faces, it would be annoying. You often see new faces.” (Parent, P6) “Op papier is het wel gestructureerd maar werkelijk echt niet. Je weet nooit wat er gaat gebeuren. [...] Vooral voor families met jonge kinderen of met kinderen die gauw huilen en zich echt hechten aan gezichten zou het wel vervelend zijn. Je ziet vaak namelijk nieuwe gezichten.” (Ouder, P6)

“First time he had [a bleed], or the first one he could remember well, he had his tooth through his lip so I had given an ice cream to cool, to clot. But that was the signal for him that, if there is something at night, I get an ice cream. So when we had to poke through the night, he quickly ran to the freezer to get an ice cream.” (Parent, P2) “Eerste keer dat hij [een bloeding] had, of dat hij zich goed kon herinneren, had hij zijn tand door zijn lip dus ik had een ijsje gegeven om te koelen, te stollen. Maar dat was dus voor hem gelijk het signaal dat, als er ‘s nachts iets is dan krijg ik een ijsje. Dus als we door de nacht moesten prikken rende hij hup snel naar de vriezer om een ijsje te pakken.” (Ouder, P2)

“I do the preparation together with him and he can watch LEGO City for a while, and normally he is not allowed to watch that so he really likes that.” (Parent, P3) “Ik doe samen met hem klaar maken en hij mag dus wel LEGO City kijken even, en normaal mag hij dat niet kijken dus dat vind hij dan heel leuk.” (Ouder, P3)

Reflection of Parents on the Child

Parenting approach

“Just let him do that and who knows, it will go right 10 times and once wrong. Yes, that can happen. But that is the way of letting go, which people find very scary in the beginning.” (Parent, P1) “Laat hem dat ook gewoon doen en wie weet het gaat 10 keer goed en een keer fout. Ja, dat kan gebeuren. Maar dat is wel het manier van loslaten, vinden mensen in het begin wel heel erg eng.” (Parent, 7)

“We are fairly easy-going, and I think that makes a difference. I think you have to pay extra attention, of course that is part of it, like with the helmet. Yes, you just keep an eye on him more, but that’s not always about saying things.” (Parent, P3) “Wij staan redelijk makkelijk in, en ik denk dat dat scheelt. Je moet vind ik wel extra opletten, natuurlijk dat hoort er wel bij, zoals met de helm. Ja je houdt hem gewoon wel meer in de gaten, maar dat is niet altijd dingen gaan zeggen.”(Parent, P3)

“It’s going really well, but we’re putting in a lot of energy. It’s not easy. It was partly successful because he reacts so well to it, but we always do it with extra attention, at least we try. Then the nurse says “yes you don’t want to know, we have children here in a headlock with left and right” well I couldn’t watch that. As a parent, I really wouldn’t be able to see that.” (Parent, P3) “Het gaat echt wel goed, maar we steken wel veel energie in. Het is niet zomaar. Het is deels gelukt omdat hij daar zo goed op reageert, maar wij doen het ook wel altijd met aandacht, proberen we wel. Dan zegt de verpleegkundige “ja je wilt niet weten, we hebben kinderen hier in een houdgreep met links en rechts” nou dat zou ik niet kunnen zien. Kan ik als ouder dan zou ik dat echt niet kunnen aanzien.” (Ouder, P3)

“When the kids were young, we had just put pizzas in the oven and he started bleeding. Well we just took out the pizzas and ate all together in the car on the way to the Sophia. It was really nice.” (Parent, P6) “Toen de kinderen nog jong waren, hadden we net pizzas in de oven en kreeg hij een bloeding. Nou we hebben de pizza’s gewoon uit gehaald en in de auto allemaal samen gegeten onderweg naar de Sophia. Was hartstikke gezellig.” (Ouder, P6)’

Trusting others

“So he has also been there, because it was pricked a few times and it was not successful, that took 6-7 weeks before he could go again. [...] If there is an emergency situation, I will come here [Erasmus] right away. I do have the confidence here, you know that things are going well here and that things are going well, and I think if I go somewhere else then we will be back to square one in 6-7 weeks. I prefer to come here if I can.” (Parent, P5) “Daar heeft hij dus ook, omdat het een paar keer geprikt en niet gelukt is, dat heeft wel even 6-7 weken geduurd voordat hij weer kon. [...] Als er een spoed situatie is dan kom ik gelijk hier [Erasmus]. Ik heb wel de vertrouwen hier, je weet dat het hier goed gebeurt en dat het goed gaat, en denk ik als ik ergens anders kom dan zijn we straks weer 6-7 weken weer terug bij af. Als het kan kom ik liefst hier.” (Parent, P5)

“They are always available at the hemophilia department and we have always received good help. We even once had a doctor call us while refueling because it was so important to have us on the phone. So it’s really very easily accessible.” (Parent, P1) “Bij de hemofilie afdeling zijn ze altijd bereikbaar en we zijn altijd goed geholpen. We hebben zelfs een keer meegemaakt dat een dokter tijdens tanken ons aan het bellen was, omdat het zo belangrijk was om ons aan de telefoon te hebben. Dus echt heel erg goed bereikbaar.” (Parent, P1)

Trusting Self

“I don’t like being dependent on other people. Yes, in this case you often are, but now much less than in the beginning. Because now we can do the injection ourselves. [...] Now we also know very well what needs to be done.” (Parent, P1) “Ik vind het niet fijn om afhankelijk te zijn van andere mensen. Ja, je bent het in zo’n geval toch wel, maar nu veel minder dan in het begin. Want nu kunnen we zelf prikken. [...] Nu weten we ook heel goed wat er moet gebeuren.” (Ouder, P1)

“I think we also quite often say to each other, maybe a little too much, ‘oh, that’s not necessary’. We’ve been doing it from the start. The nurse says “you should call more often” but I also think yeah [jeetje], we really know it ourselves, that’s what I think at least...” (Parent, P3) “Ik denk dat we ook vrij veel zelf, misschien iets te veel, tegen elkaar zeggen van “oh, dat hoeft niet”. We doen het vanaf het begin al. De verpleegkundige zegt “je moet vaker bellen” maar denk ik ook wel ja jeetje we weten echt zelf wel, denk ik dan...” (Ouder, P3)

“It was actually the intention in the first instance to go to Austria, my cousin was also there with her son [with hemophilia]. And then he would have to be injected once in that week. And my cousin had indicated, that all three of them can do it [the cousin, her husband and her son], “we will do it for you”. I thought that was a great idea, because they know exactly how to do it, I have that confidence in them. But they didn’t think so here [at the Sophia]. So with that responsibility, they said we’d rather he go to the hospital. And I didn’t see that myself.” (Parent, P5) “Toen was het eigenlijk de bedoeling in de eerste instantie om naar Oostenrijk te gaan, daar was ook mijn nichtje met haar zoon [met hemofilie]. En dan zou hij dus in die week een keer geprikt moeten worden. En mijn nichtje had aangegeven, van ja die kunnen het alle drie doen, “wij willen het wel doen voor je”. Dat vond ik heel fijn idee, want ja die weten het precies, dat vertrouwen heb ik in hun. Maar dat vonden ze hier niet zo. De verantwoordelijkheid dus, en ze zeiden we hebben het liever dat hij naar het ziekenhuis gaat. En dat zag ik dus zelf niet.” (Ouder, P5)

Anxieties

“I was already doing injections in my work so it wasn’t new. So the only thing is it’s your own child. And it was some getting used to for me, I think that at the beginning at the very first times, that was more of a thing because he was crying then, really extremely sad, shaking his head no, and then it is very sad to inject your own child. You know to do it because you’re helping him but it feels like you’re going to hurt him, when it’s not that, you’re going to help him, you’re going to make him better.” (Parent, P1) “Ik deed al prikken in mijn werk dus het was niet nieuw. De enige was dus is het is je eigen kind. En inmiddels was dat voor mij wel wenning, ik denk dat bij het begin toen de allereerste keren, dat was meer een ding want hij was toen aan het huilen, echt extreem verdrietig, aan het nee schudden, en dan is het heel erg om in je eigen kind te moeten prikken. Je weet het goed te doen omdat je hem juist helpt maar het klinkt alsof je pijn gaat doen, terwijl dat is het niet je gaat hem helpen, je gaat hem beter maken.” (Ouder, P1)

Being Taken Seriously

“I was just a bit annoyed that I had to try so hard that Sunday to come by. And then it’s nice I think that as a mother I just think “but this is not good” and just go there. And I also thought it was very strange that I had to go to the Sophia with him alone in the car completely covered in blood. [...] I also asked if it would be okay, because I have to drive and I can’t keep an eye on him at all. Then he said “no, you can”, but then it turned out that he needed a blood transfusion. What if he had gone completely cold?” (Parent, P3) “Ik was alleen een beetje nijdig dat ik zo mijn best moest doen die zondag om langs te mogen komen. En dan is het fijn denk ik dat ik als moeder gewoon denk van “maar dit is niet goed” en ga gewoon die kant op. En ik vond het ook weer heel gek dat ik met hem alleen helemaal in bloed in de auto naar de Sophia moest gaan. [...] Ik vroeg ook wel gaat dat dan wel goed, want ik moet rijden ik kan hem helemaal niet in de gaten houden. Toen zei hij “nee dat kan wel”, maar toen bleek dat hij een bloedtransfusie nodig had. Wat dan als hij helemaal koud was gegaan?” (Parent, P3)

“Later we had another fall and then we were told by Rotterdam [the Sophia] that he had to be neurologically checked and [the pediatrician at the regional hospital] simply refused to check him neurologically. Because “it will be fine, little miss”. Yes and so from then on we said even if we have to drive 1.5 hours, we would rather go to Rotterdam than to [a regional hospital].” (Parent, P1) “Hebben we later nog een keer een val gehad en toen kregen we van Rotterdam te horen hij, neurologisch nagekeken moest worden en die arts weigerde gewoon in [een regionale ziekenhuis] om hem neurologisch na te kijken. Want “het zal wel meevallen, mevrouwtje”. Ja en dus vandaar hebben we gezegd al moeten we 1,5 uur rijden, we gaan liever naar Rotterdam dan naar [een regionale ziekenhuis].” (Parent, P1)

“That makes such a difference that you are taken seriously that they say ‘okay severe hemophilia come on through’ and you don’t wait in a waiting room first. Hemophilia centers are great, in academic hospitals. But we went to a [regional] hospital once, to a non-academic hospital, and there my experience in the emergency room was… very bad I thought.” (Parent, P7) “Dat scheelt zo erg dat je serieus wordt genomen dat ze zeggen “oke ernstige hemofilie kom maar” en je gaat niet in een wachtkamer eerst wachten. Hemofiliecentras zijn geweldig, in academische ziekenhuizen. Maar we hebben een keer in een [regionale] ziekenhuis gehad, in een niet-academische ziekenhuis, en daar was mijn ervaring bij de eerste hulp… heel slecht vond ik.” (Parent, P7)

“What really helps us is that you know what you’re doing, and that you can have a bit of a big mouth. And that you can say, suppose it happened and I go to a regional hospital, “I have this stuff, it has to go in now, and then you can examine my child, but this has to go in first”. (Parent, P6) “Wat ons heel erg helpt is dat je zelf weet waar je mee bezig bent, en dat je klein beetje een grote mond kan maken. En dat je kan zeggen, stel het zou gebeuren en ik ga naar een regionale ziekenhuis, “ik heb dit spul, dat moet er nu in, en daarna mag je mijn kind onderzoeken, maar dit moet er eerst in”. (Parent, P6)

“In the beginning you are the waiting parent. Yes, they’re busy, we’ll be next. Then at some point, you’re just going to say, “My child needs help now.” But then they’re like, yes, you can say that, but that’s what all parents say. [...] Gradually you actually learn a bit about the hospital world yourself. Because it is also a bit of a profession. So you’re getting more empowered. And you know better and better how to handle it. [...] Now we have the right people sooner. Dare to say something more.” (Parent, P1) “In het begin ben je de afwachtende ouder. Ja, ze hebben het wel druk, we komen wel aan de beurt. Dan op een gegeven moment, ga je gewoon zeggen, "mijn kind moet nu geholpen worden." Maar dan hebben hun zoiets van ja, dat kunt u wel zeggen, maar dat zeggen alle ouders. [...] Gaandeweg leer je ook eigenlijk een beetje zelf het ziekenhuiswereld. Omdat het ook een beetje vak apart is. Dus je wordt steeds mondiger. En je weet steeds beter hoe je het moet aanpakken. [...] Nu hebben we eerder de juiste mensen te pakken. Durven iets meer te zeggen.” (Parent, P1)

Feelings of Guilt

“I also had a lot of guilt. For example, if I was on the playground, I was standing next to him, I would never sit. So you’re standing next to the playground equipment, and then he slides over the grains of sand and I think why didn’t I see that and he fell on his head…” (Parent, P7) “Ik had ook heel veel last van schuld gevoel. Als ik bijvoorbeeld in de speeltuin, ik stond ernaast dan, zitten deed ik nooit. Dus je staat naast zo’n speelattribuut, en dan glijdt die uit over zo zandkorrels was het een keertje, en denk ik waarom zag ik dat dan weer niet, en hij viel op z’n hoofd…” (Ouder, P7)

“I sometimes feel like a, well not a bad mother, but all the time I’m like ‘watch out, watch what you’re doing, watch where you’re walking’. Then my mother said, “But other mothers also say that to children who are just starting to walk, it’s not because he has hemophilia”. But I do have that feeling sometimes. Sometimes I feel really bad about it.” (Parent, P5) “Ik voel me soms wel een, nou niet slechte moeder maar, dat ik de hele tijd ben van “kijk uit, kijk wat je doet, kijk waar je loopt”. Toen zei mijn moeder van “Maar dat zeggen ook andere moeders tegen kindjes die net beginnen met lopen, het is niet omdat hij hemofilie heeft”. Maar dat gevoel heb ik soms wel. Dat ik me soms even heel rot erover voel.” (Ouder, P5)

“What I found difficult is that you decide for someone else. You assume what is being told is right and your child is not always happy about it.” (Parent, P2) “Wat ik moeilijk vond is dat je voor een ander beslist. Je gaat er vanuit wat er verteld wordt en je kind is ook niet altijd meegaand.” (Ouder, P2)

Reflection of External Factors on the Child

Sensitivity in Diagnosis

“They immediately came with my other son, a nurse, who said ‘he doesn’t have hemophilia’. And now the doctor won’t come until tomorrow, I thought “ohh he has hemophilia”. But it had to be the pediatrician who had to tell me.” (Parent, P6) “Bij mijn andere zoon kwamen ze gelijk langs, een zuster, gezegd “hij heeft geen hemofilie hoor”. En nu komt pas morgen de dokter, dacht ik “ohh hij heeft hemofilie”. Moest per se de kinderarts vertellen.” (Ouder, P6)

“[Pediatrician at regional hospital] gave us the results, not really knowing what the disease is. And so he had told us a very wrong story. [...] That was the severe kind, that he would become handicapped and that he would not live long. And that he would very soon end up in a wheelchair.” (Parent, P1) “[Kinderarts bij regionale ziekenhuis] gaf ons de uitslag, eigenlijk niet wetende wat de ziekte inhoudt. En, hij had dus ons een heel verkeerde verhaal verteld. [...] Dat een heel ernstige vorm was, dat hij gehandicapt zal worden en dat hij niet lang zou leven. En ja, dat hij zou heel snel in een rolstoel terechtkomen.” (Ouder, P1)

“Then I was called with only the message: your child is no longer allowed to fall. What should I do then, he walks, he crawls... He said “Yes well, hold him then”.” (Parent, P7) “Toen werd ik opgebeld met alleen het bericht: je kind mag nu niet meer vallen. Wat moet ik dan doen, hij loopt, hij kruipt... Hij zei “Ja hou maar vast dan”.” (Ouder, P7)

“Unfortunately, I often hear that the diagnosis starts with child abuse. That they think, this is not possible. It doesn’t happen often, of course. Our child had severe bruising. Because of the behavior of the health center we waited longer and because of them we were so insecure, because it is the first child. You don’t know what’s normal, so you assume what they say is true. It makes you so insecure. Which means it takes longer that you call a doctor. And now it all went well, but in the meantime he could have had a brain bleed. And yes, then it would have all looked different.” (Parent, P1) “Dat hoor ik wel helaas vaker, dat het diagnose begint met kindermishandeling. Dat ze denken, dit is niet mogelijk. Het komt natuurlijk ook niet vaak voor. Ons kind had ernstig blauwe plekken. Door de gedrag van consultatiebureau hebben we langer gewacht en door hun zijn we zo onzeker geweest, want het is de eerste kind. Je weet niet wat normaal is, dus je gaat ervan uit wat hun zeggen die waarheid is. Het maakt je zo onzeker. Wat wel dus langer duurt dat je aan de bel trekt bij een dokter. En nu is het allemaal goed gegaan, maar ondertussen had hij wel een hersenbloeding kunnen krijgen. En ja dan, dan had het wel anders uitgezien.” (Ouder, P1)

“So we were diagnosed with moderate hemophilia, so no prophylaxis was given. [...] And now they did the extensive test and then it suddenly turned out to be severe. I found that very annoying. Then I thought, yes guys, so we could have prevented this bleed.” (Parent, P3) “We kregen dus een diagnose met matig hemofilie, waar dus geen profylaxe bij gegeven was. [...] En nu deden ze dus de uitgebreide test en toen bleek het opeens dus ernstig te zijn. Dat vond ik wel heel vervelend. Toen dacht ik maar ja jongens, we hadden dus deze bloeding dus kunnen voorkomen.” (Ouder, P3)

Limitations due to Others

"But I do find it irritating when my child goes to a party and there are parents who get stressed. [...] I'm not going to say "come home with me because I see that this isn't safe for you" but I'll make sure that I'm home for the rest of the afternoon that if something goes wrong then I have to I'll be there because the mother wasn't watching him, I think that's a shame. [...] Some parents don't look at anything, and I find that a little more difficult with him." (Parent, P6) "Maar ik vind wel irritant als mijn kind naar een feestje gaat en er zijn dus ouders die schieten in stress. [...] Ik ga niet zeggen "kom maar mee naar huis want ik zie dat dit niet veilig is voor je" maar dan zorg ik er wel dat ik de rest van de middag thuis ben dat als er iets niet goed gaat dan moet ik er wel daar zijn want die moeder kijkt er niet dat vind ik wel jammer. [...] Sommige ouders kijken nergens naar, en dat vind ik bij hem ietsjes lastiger." (Parent, P6)

Awareness

"Others also find it exciting. For example, if he is going to stay with his other grandma and grandpa, I think my parents-in-law will also find it exciting to have him stay over." (Parent, P7) "De omgeving vind het ook spannend. Bij voorbeeld als hij bij de andere oma en opa gaat blijven logeren, ik denk dat mijn schoonouders het ook spannend vinden om hem te logeren hebben." (Parent, P7)

"I must say that awareness makes a big difference. [...] With reactions from people such as "will he bleed to death?!" and things like that, so you often have to reassure people that it's not that bad. But if you're completely unfamiliar with it, I can imagine [you think that] yes." (Parent P4) "Ik moet wel zeggen, dat het heel veel scheelt met bekendheid. [...] met reacties van mensen zoals "gaat hij dan doodbloeden?!" en dat soort dingen, dus je moet mensen wel vaak geruststellen van zo erg is het toch niet. Maar als je helemaal onbekend mee bent dan kan ik me goed voorstellen [dat je zo denkt] ja." (Ouder P4)

"When I'm in the pediatric hematology department with my son, I see all those kids with bald heads, because they have leukemia, with the tube feeding in their nose, too tired to walk across the room. Then I see my son going through the waiting room, full of life, then I think what am I talking about. [...] Life is so fragile, then I think why do you have to make such a point of it. It is very manageable to live with." (Parent, P6) "Als ik met mijn zoon in de afdeling kinderhematologie zit, en ik zie daar al die kindjes met de kale koppies, omdat ze leukemie hebben, met de sondevoeding in hun neus, te moe om naar overheen te komen. Dan zie ik mijn zoontje springlevend door de wachtkamer gaan, dan denk ik waar heb ik het over. [...] Leven is zo kwetsbaar, dan denk ik waarom moet je zo een punt van maken. Het is heel goed mee te leven." (Ouder, P6)

"With the example I have, yes, of course I was disappointed, you would rather not [get the diagnosis] of course, you would rather have that your baby is healthy. I had so many examples of much worse things. When I'm here in the department with the oncology [next to it], you know, I'm like "it's just hemophilia". It sounds really stupid but..." (Parent, P5) "Met het voorbeeld wat ik heb. Ja natuurlijk ik baalde wel, je wilt liever niet [het diagnose krijgen] natuurlijk, je wil liever dat je kindje gezond is. Ik had zo wel met de voorbeeld van er zijn veel ergere dingen. Als ik hier op de afdeling ben met ook de oncologie [hiernaast] dan weetje, dan heb ik zo iets van "het is maar hemofilie". Het klinkt wel heel stom maar..." (Ouder, P5)

Finding Information

Understanding the Audience

"That whole conversation we were completely overloaded with information, that I thought yes sorry, also with the geneticist, I already know, I didn't ask for this at all! If you don't know anything or it is a spontaneous case, I understand that you would like to know more. But that was annoying." (Parent, P6) "Dat hele gesprek werden we helemaal overladen met informatie, dat ik dacht van ja sorry, ook met de geneticus, van ik weet het al helemaal, ik heb er ook helemaal niet om gevraagd! Kijk als je niks weet of het is een spontaan geval, dan snap ik dat je graag meer wil weten. Maar dat was vervelend." (Ouder, P6)

“I found the information you get a bit limited. Without being a bit arrogant, we are highly educated people, so yes, you are not going to give scientific articles to everyone, but we did have the need for that, so we went to investigate a bit ourselves.” (Parent, P7) “De informatie dat je zelf krijgt vond ik een beetje gering. Zonder beetje arrogant te doen, we zijn wel hoogopgeleide mensen dus ja je gaat niet bij iedereen wetenschappelijke artikelen geven, maar daar hadden wij wel de behoefte aan, dus we gingen zelf een beetje uitzoeken.” (Ouder, P7)

“Everything is always well explained. Always with direct lines. We never felt that we didn’t have enough information.” (Parent, P2) “Alles is altijd goed uitgelegd. Altijd met directe lijntjes. We hebben nooit het idee gehad dat we niet genoeg informatie hadden.” (Ouder, P2)

“Cyberpoli is really a bit too baby language for me. Too little information for me. I would have liked an adult version of it.” (Parent, P7) “Cyberpoli is voor mij echt een beetje te babytaal. Weinig informatie voor mij. Een volwassene versie ervan had ik wel prettig gevonden.” (Ouder, P7)

“Mother: Have you ever looked at Cyberpoli, to see if anyone you know has been featured, yes, but have you ever done anything with it? Child: No. Mother: I didn’t think so.” (Parent and Patient, P6) “Moeder: Heb je ooit gekeken op cyberpoli, wel om te kijken of er bekenden op staat, maar heb je ooit ermee wat gedaan? Kind: Nee. Moeder: Dacht ik ook niet.” (Ouder en Patient, P6)

Contrast of “what is necessary” and “what is desired”

“When he was a baby in the playpen, it didn’t bother me. But when he started to crawl, for example, he gently pressed his head against the table. “Ooh! Would that be hard?” I understand that falling hard is very difficult to explain, but afterwards I would have found examples useful.” (Parent, P6)“Toen hij een baby was in de box had ik geen last van. Maar toen hij ging kruipen bij voorbeeld, ging hij zachtjes met zijn hoofd tegen de tafel aan. “Oeh! Zou dat nou hard zijn?” Ik snap dat hard vallen heel lastig is om uit te leggen, maar voorbeelden had ik achteraf wel handig gevonden.” (Ouder, P6)

“The first time I thought that was an exception. Then it happened again, and at one point it was like, “Oh, so this is just standard. That he should be admitted.” [...] At the beginning it was every time admittance and that was not in the information from the hemophilia center. And not on Cyberpoli either. So that is something that comes with it, but is nowhere to be found.” (Parent, P1) “Dat eerste keer dacht ik dat dat een uitzondering was. Toen was het er weer, en op een gegeven moment was het dus van “Oh, dus dit hoort gewoon de standaard bij. Dat hij moet blijven.” [...] Bij het begin was dat iedere keer opname en, dat was niet te vinden in de informatie van de hemofiliecentrum. En ook niet op Cyberpoli. Dat is dus iets die daarbij komt, maar nergens is te vinden.” (Ouder, P1)

Variety of Information

“It’s nice to have someone with that experience, it also gives you more confidence and peace of mind.” (Parent, P5) “Het is fijn om iemand te hebben met die ervaring, daar krijg je ook meer zelfvertrouwen van en rust.” (Parent, P5)

“I’ve had conversations with other parents. [...] Sounds crazy but I cried so hard after that conversation, I thought yes you have daughters and it’s mild, I thought I was so pathetic. I have a son with severe who has zero [percent]! [...] I thought if you are panicking then I must be panicking even more.” (Parent, P7) “Ik heb gesprekken met andere ouders gehad. [...] Klinkt wel gek maar ik moest zo hard huilen na die gesprek, ik dacht ja je hebt dochters en het is mild, ik vond mezelf zo zielig. Ik heb een jongetje met ernstig die helemaal nul [procent] heeft! [...] Dacht ik nou, als jullie zo aan het panikeren zijn dan moet ik helemaal aan het panikeren zijn.” (Parent, P7)

Appendix E - Complete Patient Journey

FASE 1: DIAGNOSE

Het diagnose proces kan er voor elke familie anders uit zien. Soms is het al een overweging tijdens de zwangerschap en soms is het een onverwachte beleving.

Verdenking

Thuis

De meest voorkomende situatie voor de verdenking van hemofilie is het hebben van een familielid met hemofilie en een draagster moeder, in welk geval de reis tijdens de zwangerschap begint. Voor patiënten zonder bekende genetische voorgeschiedenis begint de reis na ongewone blauwe plekken of bloedingen die tot bezorgdheid kunnen leiden.

Ouders — **Patient**

Consult bij Kinderarts

Regionale Ziekenhuis

Na overleg met de huisarts over de blauwe plekken en/of bloedingen wordt het gezin doorgestuurd naar een kinderarts in een regionaal ziekenhuis. Na bloedafname wordt vaak een bloedaandoening vermoed, maar het is nog steeds onduidelijk of het hemofilie is. Deze stap wordt overgeslagen door patienten met een genetische voorgeschiedenis. Ze gaan samen met hun familie rechtstreeks naar een UMC.

Ouders, Kinderarts — **Patient**

Vaststellen Diagnose

Sophia Kinderziekenhuis

Na een doorverwijzing van een kinderarts, of meteen na geboorte voor een patient met een draagster moeder zal de familie bij een kinderhematoloog terecht komen. Hier zal de hematoloog (nogmaals) bloed afnemen om de diagnose te bevestigen. De uitslag is vaak na 1 dag bekend en de ouders krijgen telefonisch de diagnose en plannen een consult in.

Ouders, Kinderhematoloog — **Patient**

Ouders hebben een goed begrip van het welzijn van hun kind en merken dat het proces veel soepeler kan verlopen als ze serieus worden genomen.

"Toen had hij een keer een blauwe plek wat ook wel heel blauw was bijna tegen zwart aan. Ik denk ik zeg tegen mijn moeder, toch zit het mij niet lekker. Ik heb toch het idee dat het niet klopt. En bij het consultatiebureau zeiden ze, als je het niet vertrouwt moet je dan toch een keer naar de huisarts gaan, en laat je prikken."

Ouders ervaren soms weerstand bij het verkrijgen van de zorg waarvan ze weten dat hun kind het nodig heeft. Ze vinden dat onbegrip bij medisch personeel hierin een rol kan spelen.

"Hij had een wondje in zijn mond, dat stopte maar niet met bloeden. [...] Hebben ze kunnen dichten maar de nacht daarvan ging het weer open, dus heel het bed was net een horror. Ik hoorde hem in de ochtend praten dus er is niks aan de hand maar alles was onder het bloed. En toen zei ik dit is gewoon niet goed en toen belde ik, en ik moest heel hard mijn best doen om te mogen komen. Dat was [Ziekenhuis X], zegt ze "ja een paar druppeltjes op het kussen..." Ik zeg "nou mevrouw heel het matras... alles zit eronder" en vond hem toen heel apathisch wel. Toen zei ik ik kom toch, en toen kwam ik daar en zei ik "ik wil dat meten dat hij nog genoeg bloed heeft in zijn lichaam, ik heb het idee dat het te weinig is" [...] En toen kregen we vrij snel het resultaat van hij moet een bloedtransfusie! Dat vond ik vrij schrokkend."

Sommige ouders ervaren dat er weinig informatie bekend is over hemofilie bij medische instanties/zorgverleners, wat kan zorgen voor een vertraagde diagnose en onzekerheid bij ouders/verzorgers.

"Dat hoor ik wel helaas vaker, dat de diagnose begint met kindermishandeling. Dat ze denken, dit is niet mogelijk. Dat komt natuurlijk ook niet vaak voor. Ons kind had ernstig blauwe plekken. Door het gedrag van het consultatiebureu hebben we langer gewacht en door hun zijn we zo onzeker geweest, want het is de eerste kind. Je weet niet wat normaal is, dus je gaat ervan uit dat wat hun zeggen de waarheid is. Het maakt je zo onzeker. Wat wel dus langer duurt voordat ze aan de bel trekt bij een dokter. En nu is het allemaal goed gegaan, maar ondertussen had hij wel een hersenbloeding kunnen krijgen. En ja dan, dan had het er wel anders uitgezien."

Ouders die door hun genetische achtergrond ervaring hebben met hemofilie, schatten het ziektebeeld van hun (ongeboren) kind ernstiger in.

"Toen we de echo hadden de eerste keer, ik had zoiets van "oh, een jongetje..." Ik weet dat we even heel heel stil waren in de auto."

Ouders waarderen dat de meeste ziekenhuizen hun eigen (gebrek aan) kennis opzij kunnen zetten en prioriteit kunnen geven aan de zorg voor het kind.

"Toen zagen ze dat hij op 2 plekken een bloeding had in zijn hoofd. Omdat hij 4 maanden was en eigenlijk dus, hij deed eigenlijk nog niet zo veel vonden ze dat heel raar. Dus ze gingen kijken "hoe komt dat dan?" Toen hebben ze vrij snel naar het Sophia gebeld van, wat zouden jullie doen. En toen hebben ze dus getest op de stolling."

In niet-academische ziekenhuizen wordt de kennis over hemofilie door sommige ouders als onvoldoende ervaren, wat onnodige stress en angst kan opleveren tijdens het diagnoseproces.

"En toen kwamen we bij die man. Die dus echt, geen weet had van de ziekte, ons maar toch wel uit ging leggen dat hij dus hemofilie A had. Dat een heel ernstige vorm was, dat hij gehandicapt zal worden en dat hij niet lang zou leven. En ja, dat hij zou heel snel in een rolstoel terechtkomen. "

Sommige ouders ervaren dat de kennis over hemofilie niet adequaat genoeg is in de algemene gezondheidszorg.

"Met de diagnose gingen we naar de huisarts. En dan ga je bloedprikken in het lokale ziekenhuis en daar krijg je de uitslag. En, die gaf ons de uitslag, eigenlijk niet wetende wat de ziekte inhoudt. En, hij had dus ons een heel verkeerd verhaal verteld."

Ouders willen erop kunnen vertrouwen dat hun kind de beste zorg krijgt in een situatie waar ze geen controle over hebben.

"We kregen dus een diagnose met matig hemofilie, waar dus geen profylaxe bij gegeven was. Er zijn meerdere testen. Blijkt achteraf dat het bij de bloedtransfusie dat ze toen de simpele test hadden gedaan en daar hadden ze de behandelplan op afgestemd. En nu deden ze dus het uitgebreide test en toen bleek het opeens dus ernstig te zijn. Dat vond ik wel heel vervelend. Toen dacht ik maar ja jongens, we hadden dus deze bloeding dus kunnen voorkomen."

Ouders vinden dat de diagnose niet altijd even zorgvuldig wordt behandeld.

"Toen werd ik opgebeld met alleen het bericht: je kind mag nu niet meer vallen. Wat moet ik dan doen, hij loopt, hij kruipt... Hij zei "Ja hou maar vast dan"."

Tijdens de diagnose merken ouders dat er discussies plaatsvinden rond het gezin in plaats van direct met het gezin (vooral als de baby bij de geboorte wordt getest) en het gezin moet wachten op een antwoord.

"Bij mijn andere zoon kwamen ze gelijk langs, een zuster, gezegd "hij heeft geen hemofilie hoor". En nu komt pas morgen de dokter, dacht ik "ohh hij heeft hemofilie". Moest per se de kinderarts vertellen."

Eerste Consult Na Diagnose

Sophia Kinderziekenhuis

De patient en zijn/haar familie maakt kennis met de hematoloog en verpleegkundige (specialist) en krijgen informatie over de diagnose en de consequenties daarvan. Consulten vinden vaak plaats met iedereen in dezelfde kamer. Tijdens dit consult wordt ook vaak aangeraden om genetisch onderzoek bij de familieleden van de patient te laten doen. De uitkomst van dit onderzoek is bepalend voor het ziektebeeld van toekomstige kinderen binnen het gezin.

Ouders,
Kinderhematoloog,
Verpleegkundige

Patient,
Geneticus

De ouders vinden de aanpak van de diagnose van het Sophia vaak geruststellend.

"Onze hele wereld stond op z'n kop met de diagnose van de kinderarts. En toen kwamen we binnen bij het Sophia, heel warm. Het eerste wat ze zeiden is, er is goed mee te leven. Vroeger niet, konden mensen beperkt van worden. En zo zo zo. Maar dat is al lang niet meer. Nou voor ons was dat al gelijk een... [zucht van verlichting]."

Informatievoorziening wordt door sommige ouders als 'one size fits all' ervaren, waarbij er weinig rekening wordt gehouden met de familiekennis en geschiedenis.

"Dat hele gesprek werden we helemaal overladen met informatie, dat ik dacht van ja sorry, ook met de geneticus, ik weet het al helemaal, ik heb er ook helemaal niet om gevraagd! Kijk als je niks weet of het is een spontaan geval, dan snap ik dat je graag meer wil weten. Maar dat was vervelend."

Ouders willen niet alleen weten wat er kan gebeuren, maar ook wat de gevolgen zijn en hoe ze daarmee om moeten gaan.

"Maar wat we inderdaad gemist hebben, is bij de diagnose [...] dat als hij viel dat hij niet alleen geprikt moest worden, wat wel heel nadrukkelijk uitgelegd was, maar dat hij ook neurologisch nagekeken moest worden. Of dat hij dus alsnog die nacht een hersenbloeding zou kunnen krijgen dat hij dus inderdaad om het uur wakker gemaakt moet worden. Zoals dat bij een hersenschudding of pijn dingen ook zou doen. En dat het daar ook in het ziekenhuis te plaats is. Daar hadden wij in het begin nog niet zo door. En, ik denk dat dat wel informatie was geweest die ons had geholpen."

Schakelen Thuis

Thuis

Na de diagnose volgt een overgangsperiode. Familieleden buiten het gezin, kinderopvang en andere betrokken instanties worden geinformeerd. Binnen het huis worden aanpassingen gemaakt om tegemoet te komen aan de nieuwe diagnose. De diagnose kan ook tot verandering leiden in de gezinsdynamiek.

Patient,
Ouders

Kinderhematoloog,
Verpleegkundige

Sommige ouders erkennen de noodzaak van verdriet en communicatie, en begrijpen hoe belangrijk het is om de tijd te nemen om zich aan te passen aan de diagnose.

"Rouw om de diagnose, heb verdriet en praat er veel over. Langzaam wen je aan de diagnose."

De meeste ouders waarderen de ervaring van andere gezinnen, vooral tijdens de overgangsperiode na de diagnose

"Het is fijn om iemand te hebben met die ervaring, daar krijg je meer zelfvertrouwen van, en ook rust."

Sommige ouders ervaren schuldgevoelens en innerlijke conflicten over het beperken van hun kind.

"En soms, en dan moet ik mezelf ook even aanpakken, dan hoor ik bijvoorbeeld dat mijn schoonzusje hem naar boven heeft genomen als ik dan ver ben, stel dat hij dat trapje wel zou vallen, denk ik van nee ik moet wel loslaten, ze weten het. Thuis heb ik wel rekjes staan maar ja dan moet ik mezelf even aanpakken want zo kan je ook niet gaan denken.

Ouders ervaren dat het ziekenhuis meer over de theorie van de ziekte informeert in vergelijking tot praktische informatie, waar ouders meer over willen weten.

"Toen hij een baby was in de box had ik er geen last van. Maar toen hij ging kruipen bijvoorbeeld, ging hij zachtjes met zijn hoofd tegen de tafel aan. "Oeh! Zou dat nou hard zijn?" Ik snap dat hard vallen heel lastig is om uit te leggen, maar voorbeelden had ik achteraf wel handig gevonden."

FASE 2: BEHANDELING

Behandeling Keuze Consult

Sophia Kinderziekenhuis

Voor ernstige hemofilie patienten is profylaxe een standaard behandeling, wat preventief werkt om bloedingen te voorkomen. Vaak met de eerste spontane bloeding, wat ongeveer in het eerste jaar van de patient's leven is, wordt er een keuze gemaakt om met profylaxe te beginnen. Tot dit punt wordt er "on-demand" stollingsfactoren gegeven met bloedingen.

Ouders,
Kinderhematoloog,
Verpleegkundige

Patient

Veel ouders vinden het belangrijk om het kind te betrekken bij beslissingen, ook als ze de beslissing zelf niet kunnen nemen.

"Dat is zó belangrijk. Kijk inderdaad, hij kan geen keuze maken. Als je 8 bent dan kan je echt geen keuze maken. Maar voel je je betrokken. Het kan ook van een vroege leeftijd beginnen. Als het maar ook hele kleine vraagjes zijn."

Kinderen niet in beslissingen en gesprekken over hem/haar betrekken kan leiden tot onbegrip bij het kind.

"Hij was er bij maar ik heb het gesprek uitgevoerd met de arts, we hebben hem er eigenlijk niet bij betrokken. Hij was wel klein. Afspraken waren gemaakt, maar toen was hij ineens heel opstandig, huilen, hij was heel boos op mij. Ook 's nachts heel erg huilen. Na een week zei hij "ik wil dat nieuwe medicijn niet". We hebben over hem gesproken. Hij is toch in een goede staat om te begrijpen, misschien niet beslissen maar wel uitleg krijgen. Daar hebben we veel van geleerd."

Ouders vinden het niet altijd eerlijk om zonder hun kind beslissingen te maken voor hun kind.

"Wat ik moeilijk vond is dat je voor een ander beslist. Je gaat er vanuit wat er verteld wordt en je kind is ook niet altijd meegaand."

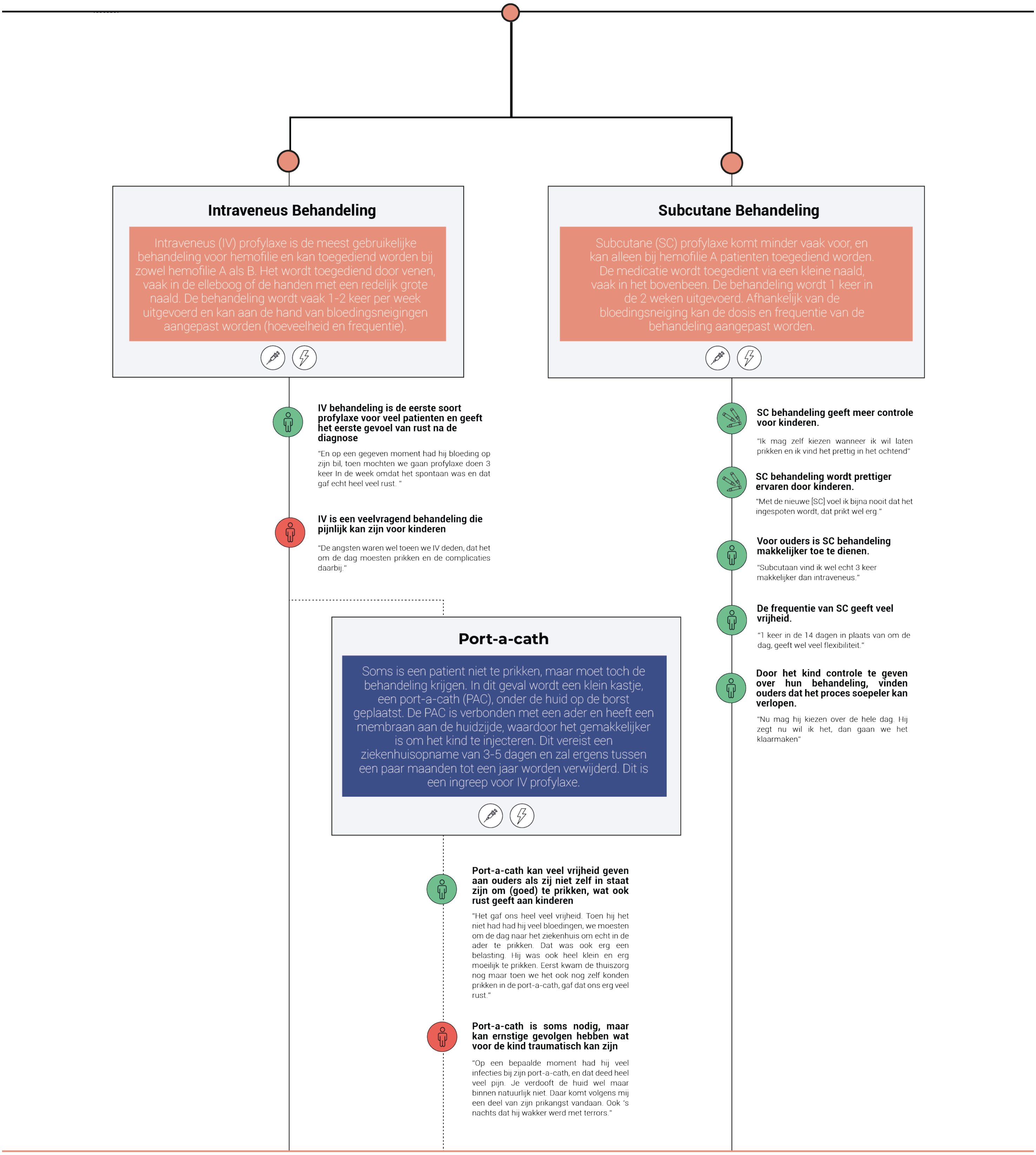
Veranderingen in behandeling kunnen nieuwe angsten creëren voor kinderen.

"Huilen, bang, pijn. Niet willen zitten terwijl hij, ja met die intraveneus ging hij gewoon zelf zitten en zijn arm uitstrekken en meehelpen. Alle spullen klaar leggen. En, nu was er ineens weer een heel bange jongen. Dat duurde ook 3 of 4 maanden"

Niet weten wat ze moeten verwachten is een stressor voor kinderen.

"Ja ik vind het niet zo leuk als ik een nieuwe prikje krijg. Ik heb heel veel spanning daaraan met mijn ziekte. Ik dacht dat het heel zeer zou doen."

Er zijn momenteel twee soorten behandelingen voor profylaxe. Dit zijn intraveneus en subcutaan. De stappen voor beide behandelingen blijven hetzelfde, de methode en inhoud van de behandeling is anders. Er kan bij elke stap terugval zijn naar de vorige stap. Ook kan er een wisseling zijn tussen behandelingen (alleen voor hemofilie A patienten) waar het proces opnieuw begint met het opstarten van de nieuwe behandeling.



Behandeling Kiezen

Intraveneus Behandeling

Intraveneus (IV) profylaxe is de meest gebruikelijke behandeling voor hemofilie en kan toegediend worden bij zowel hemofilie A als B. Het wordt toegediend door venen, vaak in de elleboog of de handen met een redelijk grote naald. De behandeling wordt vaak 1-2 keer per week uitgevoerd en kan aan de hand van bloedingsneigingen aangepast worden (hoeveelheid en frequentie).

IV behandeling is de eerste soort profylaxe voor veel patienten en geeft het eerste gevoel van rust na de diagnose

"En op een gegeven moment had hij bloeding op zijn bil, toen mochten we gaan profylaxe doen 3 keer In de week omdat het spontaan was en dat gaf echt heel veel rust. "

IV is een veelvragend behandeling die pijnlijk kan zijn voor kinderen

"De angsten waren wel toeen we IV deden, dat het om de dag moesten prikken en de complicaties daarbij."

Port-a-cath

Soms is een patient niet te prikken, maar moet toch de behandeling krijgen. In dit geval wordt een klein kastje, een port-a-cath (PAC), onder de huid op de borst geplaatst. De PAC is verbonden met een ader en heeft een membraan aan de huidzijde, waardoor het gemakkelijker is om het kind te injecteren. Dit vereist een ziekenhuisopname van 3-5 dagen en zal ergens tussen een paar maanden tot een jaar worden verwijderd. Dit is een ingreep voor IV profylaxe.

Port-a-cath kan veel vrijheid geven aan ouders als zij niet zelf in staat zijn om (goed) te prikken, wat ook rust geeft aan kinderen

"Het gaf ons heel veel vrijheid. Toen hij het niet had had hij veel bloedingen, we moesten om de dag naar het ziekenhuis om echt in de ader te prikken. Dat was ook erg een belasting. Hij was ook heel klein en erg moeilijk te prikken. Eerst kwam de thuiszorg nog maar toen we het ook nog zelf konden prikken in de port-a-cath, gaf dat ons erg veel rust."

Port-a-cath is soms nodig, maar kan ernstige gevolgen hebben wat voor de kind traumatisch kan zijn

"Op een bepaalde moment had hij veel infecties bij zijn port-a-cath, en dat deed heel veel pijn. Je verdooft de huid wel maar binnen natuurlijk niet. Daar komt volgens mij een deel van zijn prikangst vandaan. Ook 's nachts dat hij wakker werd met terrors."

Subcutane Behandeling

Subcutane (SC) profylaxe komt minder vaak voor, en kan alleen bij hemofilie A patienten toegediend worden. De medicatie wordt toegedient via een kleine naald, vaak in het bovenbeen. De behandeling wordt 1 keer in de 2 weken uitgevoerd. Afhankelijk van de bloedingsneiging kan de dosis en frequentie van de behandeling aangepast worden.

SC behandeling geeft meer controle voor kinderen.

"Ik mag zelf kiezen wanneer ik wil laten prikken en ik vind het prettig in het ochtend"

SC behandeling wordt prettiger ervaren door kinderen.

"Met de nieuwe [SC] voel ik bijna nooit dat het ingespoten wordt, dat prikt wel erg."

Voor ouders is SC behandeling makkelijker toe te dienen.

"Subcutaan vind ik wel echt 3 keer makkelijker dan intraveneus."

De frequentie van SC geeft veel vrijheid.

"1 keer in de 14 dagen in plaats van om de dag, geeft wel veel flexibiliteit."

Door het kind controle te geven over hun behandeling, vinden ouders dat het proces soepeler kan verlopen.

"Nu mag hij kiezen over de hele dag. Hij zegt nu wil ik het, dan gaan we het klaarmaken"

Opstarten

Sophia Kinderziekenhuis

Het toedienen van profylaxe begint in het ziekenhuis. Een verpleegkundige brengt de stollingsfactoren via een naald aan bij de patient. In het begin gebeurt dit 1 keer per week. Dit betekent dat de patient minimaal 1 keer per week naar het ziekenhuis moet afreizen. Het is vaak een afspraak, die het liefst buiten poli-tijden plaatsvindt.

Kinderhematoloog,
Verpleegkundige

Patient,
Ouders

Communicatie tussen arts en kind is erg belangrijk.

"Iedere keer iemand met witte jas zien ging hij huilen. Iedere keer een naald zien in het ziekenhuis ging hij huilen. En toen heeft de arts haar jas uit gedaan. Toen was hij zelfs op schoot geklommen bij de arts! En toen hebben we een foto van gemaakt. Omdat het juist zo bijzonder was."

Als prikangst zorgvuldig behandeld wordt, kan het echt een verschil maken in de behandeling van de kind.

"Hij had wel prikangst. Het duurde soms wel een anderhalf uur voordat we konden prikken. Met heel veel verdriet. Toen heeft hij bij het Sophia [psychologisch therapie] gekregen daarover. Na 3 keer was het echt over."

Als het goed wordt behandeld, kan prikangst op de lange termijn worden vermeden.

"De eerste keer profylaxe prikken, ja heel raar we hebben daarna nooit meer gehad, zes keer geprikt, 2 keer door de arts, 2 keer verpleegkundige, 2 keer door de andere, overal. En het lukte gewoon niet. Toen zei de arts "Nou voor deze ene keer doen we het even niet". Toen dachten we "ja nu hebben we het verknoeit. Nu gaat hij voortaan altijd bang daarvoor zijn" Toen huilde hij wel. Maar dat was een keer en nooit meer."

Sommige ouders denken dat onjuist prikken een rol heeft gespeeld in de prikangst van hun kind.

"Verkeerd prikken. Dat zal zeker gebeurd zijn. Zal zeker een invloed hebben."

Thuiszorg

Thuis

Na een bepaalde tijd neemt de thuiszorg het toedienen van profylaxe over. Hierdoor hoeft het kind niet meer elke week naar het ziekenhuis. Deze overgang kan geleidelijk plaatsvinden doordat de thuiszorg de eerste paar keren aanwezig is tijdens de afspraken in het ziekenhuis.

Ouders,
Thuiszorg

Patient,
Verpleegkundige,
Kinderhematoloog

Het verband tussen thuiszorg en de familie is belangrijk

"We hadden een echt heel lieve vrouw, we hebben nu nog contact mee. Zelfs naar waar we op vakantie waren, kwam ze dan ook daar naar toe. Toen we de overgang hadden naar subcutaan en dat er weer thuiszorg moest komen, hebben we specifiek voor haar gevraagd, dus zij was er weer."

Vertrouwen en geduld kan helpen met het behandeling makkelijker maken voor de kind

"Ze was wel echt heel lief. En heel geduldig. En ook met hem want hij had natuurlijk in het begin echt heel erg veel prikangst. Deed ze met bijtjes, deed ze met allerlei soorten manieren. En dan keek hij er ieder keer toch een beetje positief aan te prikken. En eigenlijk ging het steeds beter en aan het einde van het jaar ging hij zelfs meewerken met bloedprikken en doen. "

Een langdurige angst kan worden vermeden als de ouders en verpleegkundigen de controle kunnen overnemen en het kind zich op zijn gemak kunnen stellen

"Die zei ook we gaan nu eventjes stoppen met thuiszorg, want als de verpleegkundige moeten prikken dan gaat het meestal in een keer goed. En toen zeiden ook van hij moet eerst rustig vertrouwen terug krijgen en dan pakken we het weer op. Dat was even een mindere periode."

Het is belangrijk om de behoeften van het kind te herkennen, vooral tijdens pijnlijke procedures

"Dat het ik toen ook met thuiszorg hier afgesproken. Omdat hij zo klein was dus moeilijk he dan zijn de aders nog kleiner dan nu, dan ging dat soms niet. En toen gingen ze maar door met proberen. Drie keer of zo, toen hebben we gezegd max 2, omdat hij echt veel te veel last van had."

Ouders Leren Prikken

Sophia Kinderziekenhuis

Ouders moeten zelf op een gegeven moment leren te prikken. Hiervoor leren ze eerst over de theorie van hemofilie en profylaxe, dan leren ze de praktijk in het ziekenhuis. Ze doen dan een examen en krijgen een diploma waarbij ze hun eigen kind thuis stollingsfactoren mogen geven. Er kan hierbij terugval zijn, vaak in de eerste 3 maanden, waarbij ouders terug mogen komen in het ziekenhuis om extra te oefenen.

Ouders

Patient,
Verpleegkundige,
Kinderhematoloog

Zelf leren prikken geeft veel vrijheid en rust voor de ouders en dus ook de kinderen.

"Ik vind het niet fijn om afhankelijk te zijn van andere mensen. Ja, je bent het in zo'n geval toch wel, maar nu veel minder dan in het begin. Want nu kunnen we zelf prikken. En toen konden we dat echt niet. Toen waren we echt afhankelijk van de medische zorg. Echt direct naar de ziekenhuis moesten. En nu weten we ook heel goed wat er moet gebeuren."

Ouders vinden dat goede instructie angsten kan verminderen.

"Eerst leek het me spannend [zelf prikken] maar nu dat ik het gezien heb, denk ik wel ja ik moet het wel slikken van nu moet ik zelf prikken, maar ik vind het wel veel minder spannend omdat ik het zo veel gezien heb."

Het prikken van je eigen kind kan stress veroorzaken, wat weer een negatief effect kan hebben op de emotionele status van het kind.

"Ik deed al prikken in mijn werk dus het was niet nieuw. Het enige was dus is het is je eigen kind. En inmiddels was dat voor mij wel wennen, ik denk dat bij het begin toen de allereerste keren, dat was meer een ding want hij was toen aan het huilen, echt extreem verdrietig, aan het nee schudden, en dan is het heel erg om in je eigen kind te moeten prikken. Je weet het goed te doen omdat je hem juist helpt maar het klinkt alsof je pijn gaat doen, terwijl dat is het niet je gaat hem helpen, je gaat hem beter maken."

Ouders maken zich zorgen over prikken voordat ze beginnen

"Je gaat je eigen kind prikken, natuurlijk, ik vind het erg spannend."

FASE 3: LEVEN MET HEMOFILIE

Prikken

Thuis

Families hebben vaak een vaste dag waar ze profylaxe toedienen en dit wordt een routine. Als het kind rond 8-10 jaar oud is leert hij/zij zelf te prikken en neemt de routine over.

Patient, Ouders

Verpleegkundige Kinderhematoloog

Door het kind enige verantwoordelijkheid te geven bij het uiten van hoe ze willen dat dingen gedaan worden, kan dit helpen de ziekte onder controle te krijgen.

“Het doet gewoon pijn dat is zo, maar hoe kan hij daarin een beetje verantwoordelijkheid krijgen van ja hoe wil je geprikt worden ”zo snel als een haas” en dan soms gaan we te snel en zegt hij ”nee niet zo snel als een tijger het moet als een haas” het is hetzelfde maar hij bepaalt dan welk dier de prik gedaan wordt. Dat hadden we met de verpleegkundige bedacht, achteraf vind ik het geniaal. Zo heeft hij toch een beetje controle.”

Kinderen willen liever geprikt worden door hun ouders op hun gemak thuis.

“Ik vind leuk hoor dat ik bij mama en papa kan prikken, want dat is leuk, want dan kan ik een filmpje kijken. ”

Kinderen zijn bewust dat de prik noodzakelijk is, en vinden vaak dat dat het ergste is aan het hele ziektebeeld.

“Hemofilie hebben is niet erg maar je moet wel een prikje hebben.”

Kinderen vinden prikken niet prettig en willen vaak zo snel mogelijk klaar zijn, maar doen het toch omdat het moet.

“Als het pijn doet stoppen wij even, zegt hij van “laten we het nu maar doen, zo snel mogelijk” Hij zegt nooit nee.”

Door de magische denkwereld van deze leeftijdsgroep kan leiden tot denkbeeldige connotaties tussen behandelingen en het resultaat ervan.

“Hij denkt ook wel dat hij superkrachten krijgt volgens mij. Hij snapt dat hij geen superman wordt maar we zien wel dat hij veel gaat rennen en in actie is als hij een prik heeft gehad.”

Ouders zien wel dat hemofilie een last is voor kinderen en vinden het belangrijk om extra positieve ervaringen te geven.

“Eerste keer dat hij [een bloeding] had, of dat hij zich goed kon herinneren, had hij zijn tand door zijn lip dus ik had een ijsje gegeven om te koelen, te stollen. Maar dat was dus voor hem gelijk het signaal dat, als er 's nachts iets is dan krijg ik een ijsje. Dus als we door de nacht moesten prikken rende hij hup snel naar de vriezer om een ijsje te pakken. [...] Met de snoepjes en de ijsjes... als hij er ooit misbruik van maakt, gun hem dat moment. Hij heeft er even zin in, lekker boeien. Gun hem dat dan maar. Hij heeft aan de andere kant al ellende van.”

Sommige situaties tijdens behandelingen kunnen eerdere trauma's omhooghalen

“Toen hadden we een paar keer dat hij niet naar de stoel wilde zo. Gelukkig niet heel vaak gehad. Maar ik kan me goed voorstellen dat je kind daarvan prikangst krijgt.”

Ziekenhuis Controles

Sophia Kinderziekenhuis

Controle elke 3 maanden

Vooral ernstige hemofilie patienten gaan elke 3 maanden naar de poli bij SKZ. Hier kijkt de hematoloog, verpleegkundige, fysiotherapeut en soms ook de maatschappelijk werker naar de patient en de familie voor een controle. Soms wordt er bloed geprikt en soms wil de fysiotherapeut grondig alle gewrichten controleren. Wat er tijdens een controle gebeurt is afhankelijk van de situatie en kan verschillen aan de hand van het dagelijkse leven van de patient en/of recente gebeurtenissen.

Jaarlijks controle

Ernstige hemofilie patienten worden ook jaarlijks bij de poli verwacht. Tijdens zo'n controle afspraak wordt er bloed afgenomen en wordt er gecheckt of het kind remmers heeft ontwikkeld. Remmers kunnen zich ontwikkelen door profylaxe en is noodzakelijk om te behandelen. De bloedingsneiging wordt ook gecheckt en aan de hand van de informatie wordt het behandelplan aangepast. Hierbij kan er ook de keuze gemaakt worden om van behandel-type te wisselen (IV naar SC, of andersom).

Patient (bij consulten), Ouders, Verpleegkundige, Kinderhematoloog, Fysiotherapeut

Patient (bij beslissingen), Maatschappelijk Werker, Geneticus, Psycholoog en andere specialismen

Bezoeken in het ziekenhuis zijn vaak gezellig voor kinderen door de verband met de verpleegkundige en artsen.

“Nou, ik vind leuk al die enthousiasme. En wat gaat gebeuren met mij. En, ik vind gewoon leuk om [vepleegkundige] te zien.”

Ouders vinden de band met de medische staf belangrijk.

“Ik vind het wel heel goed hoe ze het bij het Sophia doen. Want je komt aan hoeft bijna nooit te wachten, altijd aandacht voor hem maar ook zijn zus. Kent bijna iedereen zijn naam, vind ik ook zo leuk. En de verpleegkundige hebben we de meeste contact mee. Die zoeken hem ook meteen op. Ik vind het echt zo bijzonder. Is ook echt een super leuke omgeving.”

Ouders ervaren de Sophia en het personeel als warm en meegaand.

“Hier zit ik goed, hier is alles. Heel fijn team, kan je altijd bellen altijd gerust gesteld. Weetje het is een stukje rijden maar dat kan wel. [...]We voelen ons heel welkom. Allemaal even vriendelijk, en een luisterend oor als het even wat minder gaat. Voelt niet vervelend om hier te komen ook al zijn we in het ziekenhuis.”

Informatie van het Sophia wordt door de ouders meestal als voldoende ervaren.

“Alles is altijd goed uitgelegd. Altijd met directe lijntjes. We hebben nooit het idee gehad dat we niet genoeg informatie hadden.”

Weten wat er precies gaat gebeuren op een gegeven moment kan helpen met vertrouwen.

“Het vertrouwen is er nu ook. Er was gewoon onzekerheid van wat gaan ze doen, doet het pijn? Wie gaat het doen? Hoe lang duurt dit? Nu weet hij wel gewoon. “Ik heb een gesprekje, het is gewoon een dagje uit.””

Kinderen vinden het ziekenhuis meer een leuke uitje dan een enge plek.

“We doen altijd verdovingszalf op zijn handjes voor vertrek. Ik zeg tegen hem “we gaan naar het ziekenhuis naar de baby's en de visjes” die zit dan te juichen in zijn stoel. Die geniet daar van de kindjes in de wachtkamer. Alle kindjes noemt hij baby en is altijd zoet met al het speelgoed.”

Het is belangrijk om een scheiding te maken tussen de poli en de spoedopname in de gedachten van de kinderen om het ziekenhuis niet een grote enge plek te laten lijken.

“Toen elke keer dat hij opgenomen werd, dat was, dat vond hij niet tof, maar hij kon op een of andere manier kon hij zichzelf los zien van als hij in het ziekenhuis in een bed lag. Dat was een ander plek dan bij de Poli. Dat was voor hem echt wel twee losse dingen. ”

De structuur van de poli wordt soms als chaotisch ervaren.

“Op papier is het wel gestructureerd maar werkelijk echt niet. Je weet nooit wat er gaat gebeuren. Opzich dat boeit ons niet veel maar zou handig zijn om te weten. En vooral voor families met jonge kinderen of met kinderen die gauw huilen en zich echt hechten aan gezichten zou het wel vervelend zijn. Je ziet vaak namelijk nieuwe gezichten.”

De aanpassing aan het nieuwe dagelijkse leven kost tijd, aangezien er voor hemofiliepatiënten nog veel meer zaken zijn om rekening mee te houden. Er komt veel steun van de Hemofiliecentra van het Sophia Kinderziekenhuis, maar patiënten en hun families moeten echter leren situaties voor zichzelf in te schatten en in het dagelijks leven de nodige voorzorgsmaatregelen te nemen om ernstige ongevallen te voorkomen.

Dagelijkse Leven

Thuis, School, Sporten en bij Familie / Vrienden

Patient, Ouders

Verpleegkundige, Kinderhematoloog

Verschillende aspecten van het dagelijkse leven van het kind worden beinvloed door hemofilie. De opvang / school / creche moeten allemaal op de hoogte zijn van de ziekte en wat ze moeten doen als er iets gebeurt. Logeren bij familie en vrienden vraagt ook veel verantwoordelijkheid en de ouders moeten naast vertrouwen ook informatie geven. Voor het uitoefenen van sport moeten ook lastige overwegingen gemaakt worden; beweging kan preventief werken op het gebied van spontane bloedingen, maar kan ook juist de oorzaak zijn. Het Sophia Kinderziekenhuis heeft ook een "Hemofilietelefoon" waardoor altijd een verpleegkundig specialist bereikbaar is. Hier kunnen patiënten en ouders ondersteuning krijgen en alles vragen, van lichte bloedneuzen tot wat te doen in geval van nood.

Thuis & Familie

🟩 **Gedrag van ouders kan een invloed hebben op het gedrag van het kind.**

"Hij is vaak niet erg voorzichtig met dingen, maar dat is omdat wij het niet zo doen."

🟩 **Een broer of zus mee te laten doen aan procedures kan bemoedigend zijn voor de patiënt.**

"Fysiotherapeut vindt hij, daar doet hij niet mee. En als de zus meegaat dan wel. Toen gingen we dus naar de kuil, en dat was heel leuk, want dan kunnen ze daar helemaal dingen bouwen en zo, maar dat werkt heel goed als zijn zus meegaat. Dan doet hij wel netjes mee maar hangt natuurlijk ook van de bui af."

🟩 **Ouders geven aan hoe belangrijk het is om de broers en zussen bij het proces te betrekken, maar noemen ook de last die dit voor de broers en zussen kan veroorzaken.**

"Wat we altijd deden is we trokken iedereen erbij, ook zijn broer. Die had van Fischer Price zo'n dokterstasje gekregen met alles erin en die namen we altijd mee als we naar het ziekenhuis gingen. Toen hielp hij altijd mee. Dus altijd iedereen erbij trekken. Op dat moment ging het dus om [de patient] en hij had het ook nooit als een last gezien. [Zijn broer] zei wel van "moet het weer", maar opzich denk ik dat het wel goed gegaan is."

Medisch Team

🟩 **De steun vanuit het Sophia is belangrijk voor ouders.**

"Bij de hemofilie afdeling zijn ze altijd bereikbaar en we zijn altijd goed geholpen. We hebben zelfs een keer meegemaakt dat een dokter tijdens tanken ons aan het bellen was, omdat het zo belangrijk was om ons aan de telefoon te hebben. Dus echt heel erg goed bereikbaar."

🟩 **Ouders vinden de band met artsen en verpleegkundigen belangrijk om hun kind zich op zijn gemak te laten voelen.**

"Als het niet zo goed gaat dan wil je goede medische zorg en lieve verpleegkundige en dat hebben wij gewoon gekregen. En meer wensen heb je ook niet. [...] Als je goeie artsen hebt en lieve verpleegkundigen, dat is gewoon het allerbelangrijkste. Die ervoor zorgen dat je kind lekker thuis voelt."

🟥 **Ouders ervaren een contrast tussen het waargenomen vermogen van ouders door zorgverleners en hun werkelijke vermogen om met ongevallen om te gaan**

"Ik denk dat we ook vrij veel, misschien iets te veel, tegen elkaar zeggen van ohh dat niet. We doen het vanaf het begin al. De verpleegkundige zegt "je moet vaker bellen" maar denk ik ook wel ja jeetje we weten echt zelf wel, denk ik dan. We zijn niet echt zo paniekerig."

🟥 **De ouders zitten niet altijd op dezelfde lijn als de medische staf en voelen zich verplicht om advies op te volgen, zelfs als ze het er niet mee eens zijn**

"Toen was het eigenlijk de bedoeling in de eerste instantie om naar Oostenrijk te gaan, daar was ook mijn nichtje met haar zoon [met hemofilie]. En dan zou hij dus in die week een keer geprikt moeten worden. En mijn nichtje had aangegeven, van ja die kunnen het alle drie doen, "wij willen het wel doen voor je". Dat vond ik heel fijn idee, want ja die weten het precies, dat vertrouwen heb ik in hun. Maar dat vonden ze hier niet zo. De verantwoordelijkheid dus, en ze zeiden we hebben het liever dat hij naar het ziekenhuis gaat. En dat zag ik dus zelf niet."

School & Vrienden

🟩 **Het is belangrijk om de kinderen geïncludeerd te laten voelen.**

"Hij deed twee keer kerstdiner van school bij het ziekenhuis, dat hadden ze heel leuk gedaan, hapjes brengen."

🟩 **Erop vertrouwen dat mensen in de buurt weten wat ze moeten doen, kan het kind helpen zich vrijer te voelen.**

"Nee, nee! Ik mag alles! De juf weet alles over mij dus als er iets fout gaat die weet alle telefoonnummers van mij. Die weten hoe het moet."

🟩 **Kinderen reageren vaak beter op fysieke signalen dan onzichtbare problemen.**

"We doen ook soms wel neppen. Als hij een bloeding heeft gehad mag hij dan thuis zonder krukken, en op school verplicht met. Zodat zijn vrienden zien van oh, we moeten hem niet een harde duw geven. Dus het is een stukje bescherming. Dan zeg ik ook wel doe maar niet zelf op school showen, want dan denken de vrienden oh dan kunnen we hem wel een zetje geven."

🟥 **Hemofilie is niet als helemaal limiterend ervaren maar is wel een overweging voor kinderen.**

"Ja maar als we hem zien bij gymmen dat hij het wel gewoon allemaal doet. Dat hij wel mee kan met zijn klasgenoten. Alleen het doen, het overgaan daar in merk je soort van een angst in. En ja de eerste keer dat wij zeiden dat hij weer op een springkussen mocht. Niet alleen, maar met een ander. Dan zie je hem ook echt wel eventjes twijfelen van "gaat dat dan wel goed?"."

🟥 **Kinderen vinden het een last om evenementen te missen door bloedingen.**

"Het is niet heel erg, alleen soms is het wel een beetje irritant. Wat wel heel irritant is is bijvoorbeeld je hebt een bloeding precies voor een schoolreisje ofzo. Ga je met de klas een leuk iets doen of een feestje ofzo... Dat vind ik wel het grootste nadeel dat er is."

🟥 **Kinderen hebben vaak een angst over niet kunnen meedoen aan sociale activiteiten.**

"Dat denkt hij nu ook wel "Oh als er iets nu gebeurt dan mis ik weer iets.""

🟥 **In momenten van paniek moet het kind de ernst van zijn eigen val beoordelen en anderen geruststellen. Dit is niet bevordelijk voor de situatie.**

"Ouder: Stel als hij op excursie valt, en hij moet het zelf doen, de mensen om hem heen, die gaan hem niet gerust stellen.
Kind: Nee. Die zeggen alleen maar van "oh wat moet je nu doen" die gaan alleen maar zeiken aan mijn hoofd. Ja zeg dan gewoon liever niks."

🟥 **Vallen bij school kan overweldigend zijn voor het kind.**

"Als ik val en als iemand helpt dan komen ze naar mij toe lopen en zeggen ze "wat is er?" en zijn de andere al onderweg naar de juffrouw. En dan staat er bijna een half klas om me heen dan. "

🟥 **De reacties van de omgeving kan een grote invloed hebben op het omgaan met de ziekte.**

"We probeerden een beetje los te laten. Maar toch zijn we ook natuurlijk beïnvloed door deziekte. En toch is het bij hem op een of andere manier toch wel bijgebleven van "ik kan en mag minder dan een andere" en daardoor is hij ook veel voorzichtiger. "

Overig

🟩 **Ouders weten dat het kind het beste aanspreekpunt is bij het begrijpen van een bloeding.**

"Hij weet hoe het is om een bloeding te hebben. Wij weten het natuurlijk niet maar hij voelt het altijd precies. [...] Je vriendelijk altijd geloven. Als hij zegt dat hij ergens pijn heeft dan heeft hij ergens pijn."

🟩 **Ouders willen informatie met hun kind delen en hen helpen begrijpen, maar ze ook zichzelf laten ontwikkelen.**

"Als hij oud genoeg is kunnen we wel uitleggen van dit kan wel en dit kan niet, altijd wel goed in je achterhoofd hebben van wat er precies aan de hand is. Ik wil wel dat hij een beetje weet wat er aan de hand is. Ook een beetje kijken hoe hij zelf erop reageert. En hoe hij er een beetje ermee om moet gaan, hopeljik luistert hij naar het advies."

🟥 **Met goed verstand komen er ook angsten bij.**

"Bij 4 jaar kon hij al heel goed vertellen "dat mag ik niet, want dan kan het zijn dat ik weer opnieuw een bloeding krijg in mijn knie. Dat ik weer niet kan lopen, en dat wil ik niet nog een keer.""

🟥 **Kinderen vinden hemofilie in het algemeen een belasting.**

"Hij zegt altijd "ik moet zo veel". Hij heeft wel veel pech gehad maar hij vind het zeker een belasting."

🟥 **Kinderen voelen zich anders door hun ziekte.**

"Ik denk dat hij begreep, echt begreep, in peuter speelzaal. Wist hij wel dat hij een helm had anders dan andere kinderen."

🟥 **Zelfs ontspannen ouders begrijpen dat hemofilie ernstige gevolgen kan hebben en geven er de voorkeur aan om tegemoet te komen in plaats van te verergeren.**

"Ik zeg ook wel, we zijn wel nuchter, maar we zoeken ook geen stress situaties op. Dus ik zou niet zomaar, van mij hoeft een verre reis niet. [...] Niet per se omdat je angstig bent maar waarom zou je het opzoeken? Vakantie is voor ontspanning, dus ik ga niet een stressmoment daarin bouwen. Maar wij vinden dat niet erg om je levensstijl aan te passen om geen stress te hebben."

🟥 **Hemofilie zit altijd in het achterhoofd van ouders en kan angsten geven die uiteindelijk kunnen leiden tot (onbewuste) beperking van hun kind.**

"Ik wil liever niet dat hij valt. Ik ben heel bang dat, ja als hij op zn knieen valt het kan zo maar eens gebeuren dat hoeft niet hard te zijn. Maar ja het is maar een kind dus ze leren te vallen en opstaan en je gaat dat toch niet voorkomen. Ik heb wel dat ik snel bang ben dat iets zou gebeuren [door de hemofilie]."

🟥 **Ouders moeten out-of-the-box denken doordat hemofilie niet veel voorkomt/bekend is.**

"Ik heb een band gemaakt voor in de auto. Met daar op dat hij hemofilie A heeft op de gordel. Zodat mochten we naar een ongeluk maken. En, het lijkt dat Ik er ernstig eruit zie, dat het ziekenhuispersoneel eerst mij gaan helpen, dat wil niet zeggen dat het met [patient] niet slechter gaat. Dus vandaar dat hij de band om heeft. En ook andere ouders nemen steeds vaker contact met mij op of ik dat voor hun wil maken."

Spoed Situaties

Thuis of Spoedeisende Hulp

Afhankelijk van de ernst van de situatie

Patient, Ouders, Spoedeisende Hulp Verpleegkundige, Kinderhematoloog

Neuroloog, andere specialismen

Ouders kunnen vaak 'on-demand' stollingsfactoren toedienen na een val en hoeven hierdoor niet altijd naar de spoedeisende hulp te gaan. Ze leren hoe ze de ernst van de bloeding moeten inschatten en hoe ze het moeten behandelen. Door de profylaxe is de bloeding vaak heel minimaal, maar de ingreep kan verschillen per persoon en bloedingsneiging. Bij situaties zoals een val op het hoofd, wordt het geadviseerd om naar de spoedeisende hulp te gaan. Bij verdenking van andere problemen, bv. neurologische zorgen, volgt een opname in het ziekenhuis. De "hemofilietelefoon" kan ook gebruikt worden om de kinderhematoloog of verpleegkundige erbij te betrekken in nood situaties.

Kinderen leren wel goed met ouder worden wat ze moeten doen bij noodsituaties

"Ik hoef niet voor alles te prikken, maar als ik op mijn hoofd val sowieso wel."

Kinderen kunnen vaak zelf heel goed inschatten wanneer ze er een ouder bij moeten betrekken

"Als ik val kijk ik of er bloed is en dan ga ik naar mama en papa. De ene keer heb ik pijn en de andere niet, dus soms huil ik wel erover en soms niet."

Gedrag van de familie kan een positieve invloed hebben op de reacties van het kind.

"Er zijn consequenties maar dat zien wij niet als een offer. Toen de kinderen nog jong waren, hadden we net pizzas in de oven en kreeg hij een bloeding. Nou we hebben de pizzas gewoon uit gehaald en in de auto allemaal samen gegeten onderweg naar het Sophia. Was hartstikke gezellig. "

Kinderen en ouders willen liever thuis on-demand behandeling toedienen.

"Wij doen nu subcutaan behandeling, en on demand is natuurlijk intraveneus. Toen hij gevallen was vroegen ze ook vanuit het ziekenhuis van "voel je jezelf nog bekwaamd genoeg omdat het al even geleden is?" Ja, ik voel me nog steeds wel bekwaamd in. En dus dat heeft nog steeds wel de voorkeur. "

Kinderen weten dat een bezoek aan het ziekenhuis een gevolg van een val/ongeval is, wat een angst kan zijn.

"Nu zegt hij wel vaak "nee de pijn is al weer weg!" maar dat moet je ontkennen. Eergisteren had hij zijn hand tussen de deur, toen zei ik tegen mijn man in het Engels van "what do you think do we have to go to the hospital?" En hij zei, ja hij kan echt geen Engels maar hij zei "Nee, nee niet naar de ziekenhuis!" dus hij weet dondersgoed dat als hij valt dat we altijd als hij hard valt dat hij naar de ziekenhuis moet."

Zelfs bij UMC's vinden ouders dat de urgentie van hemofilie soms niet wordt erkend en geloven dat de gevolgen hiervan schadelijk kunnen zijn op de ervaring van hun kind.

"We hebben een paar keer In de spoed gezeten en in een uur nog niet geholpen. En wij wisten dat hij binnen een uur eigenlijk een prik moest hebben. Ja, in het begin ben je de afwachtende ouder. Ja, ze hebben het wel druk, we komen wel aan de beurt. Dan op een gegeven moment, ga je gewoon zeggen, "mijn kind moet nu geholpen worden." Maar dan hebben hun zoiets van ja, dat kunt u wel zeggen, maar dat zeggen alle ouders."

Ouders en patienten ervaren de onwetendheid van veel regionale ziekenhuizen als een grote belasting, ouders voelen zich soms niet begrepen.

"Hebben we later nog een keer een val gehad en toen kregen we van Rotterdam te horen hij, neurologisch nagekeken moest worden en die arts weigerde gewoon in [Ziekenhuis Y] om hem neurologisch na te kijken. Want "het zou wel meevallen, mevrouwtje". Ja en dus vandaar hebben we gezegd al moeten we 1,5 uur rijden, we gaan liever naar Rotterdam dan naar [Ziekenhuis Y]."

Ouders denken dat ze zelfvertrouwen moeten opbouwen en zelf dingen moeten doen om hun kind de beste zorg te geven, vaak hebben ze het gevoel dat ze het anders niet krijgen.

"Ja gaandeweg leer je ook eigenlijk een beetje zelf de ziekenhuiswereld. Omdat het ook een beetje vak apart is. Dus je wordt steeds mondiger. En je weet steeds beter hoe je het moet aanpakken. Om te komen naar het plek waar je denkt te moeten zijn. Ja zo In het begin ben je altijd terughoudend. Ja nu hebben we eerder de juiste mensen te pakken. Durven iets meer te zeggen."

Ziekenhuisopnames komen vrij vaak voor, maar worden niet op die manier gepresenteerd, waardoor het gezin in onverwachte situaties kan komen waarin ze niet voorbereid zijn.

"De eerste keer dacht ik dat dat een uitzondering was. Toen was het er weer, en op een gegeven moment was het dus van "Oh, dus dit hoort gewoon de standaard bij. Dat hij moet blijven." En nu inmiddels niet als hij op zijn hoofd valt. Vertrouwen ze ook ons dat wij genoeg door hebben. En dat wij de symptomen herkennen. Maar in het begin was dat iedere keer opname en, dat was niet te vinden in de informatie van het hemofilie centrum. En ook niet op cyberpoli. Dat is dus iets wat daarbij komt, maar nergens is te vinden."

Appendix F - Evaluation Interview Protocol

Parents

CONCEPT 1 – Kaartspel

- Wat zijn uw initiële meningen over het concept?
- Vanaf welke leeftijd ziet u dit gebruikt worden?
- Zou u het initiatief nemen om de kaarten te gebruiken? (Leeuw, Panda en Kikker)
- Ziet u tot nu toe dat uw zoon negatieve ervaringen heeft gehad met zijn ziekte die hij niet zo goed kon duiden? Denkt u dat zo een spel zou kunnen helpen?
- Denkt u dat de kaarten nuttig zou zijn in het starten van een gesprek met uw kind?
- Denkt u dat het concept een gevoel van structuur zou kunnen brengen?
- Denkt u dat het concept het kind een gevoel van controle zou geven?
- Zou u hierin meer onderdelen willen zien? Zo ja, welke?

CONCEPT 2 – Poli Bezoek Print-out

- Wat zijn uw initiële meningen over het concept?
- Vanaf welke leeftijd ziet u dit gebruikt worden?
- Denkt u dat uw zoon geïnteresseerd zou zijn in het gebruik van dit product?
- Denkt u dat dit waarde zou toevoegen in de inclusie van de kind in de poli gesprekken/behandelingen?

CONCEPT 3 – Spoed Pas

- Wat zijn uw initiële meningen over het concept?
- Als u naar een SEH zou gaan, zou u eraan denken om dit te gebruiken? *(ervaring van patient van interviews benoemen)*
- Denkt u dat dit zou helpen met het serieus nemen van de ziekte en de ernst ervan?
- In uw ervaring met SEH's, zou dit werkelijk gebruikt kunnen worden om de wensen van uw zoon te voldoen?

COMBINATIE VAN CONCEPTEN

- Zou u/(denkt u dat uw zoon) een combinatie van deze concepten willen gebruiken?
- Ziet u waarde in deze concepten voor het preventie van angsten?
- Denkt u dat deze concepten in het algemeen een gevoel van controle en consistentie kunnen geven aan een kind?
- Wat vind u over het gebruik van de woord “prik” in de concepten?
- Heeft u nog vragen of opmerkingen?

HCP's

CONCEPT 1 – Kaartspel

- Wat zijn uw initiële meningen over het concept?
- Vanaf welke leeftijd ziet u dit gebruikt worden?
- Denkt u dat dit soort spel, die thuis het ruimte geeft voor gesprekken, ook zou reflecteren in de poli gesprekken?

CONCEPT 2 – Poli Bezoek Print-out

- Wat zijn uw initiële meningen over het concept?
- Vanaf welke leeftijd ziet u dit gebruikt worden?
- Denkt u dat dit haalbaar is met de huidige opzet van de poli? Wat zou er veranderd moeten worden om het haalbaar te maken?
- Denkt u dat dit zou helpen met interesse opwekken in kinderen?
- Denkt u dat dit zou helpen met soepeler behandelingen?
- Mist u hier iets in? Zo ja, wat?

CONCEPT 3 – Spoed Pas

- Wat zijn uw initiële meningen over het concept?
- Denkt u dat het haalbaar is om dit in SEH's te gebruiken?
- Ouders ervaren dat ze soms niet serieus genomen worden door SEH zorgverleners, en vinden dat de ernst van hemofilie vaak niet erkend wordt. Denkt u dat dit daarmee zou kunnen helpen?
- Wat voor (medische) informatie zou op deze kaart moeten staan?
- Patiënten hebben nu al vergelijkbare kettingen en kaarten. Wat voor informatie staat er precies op, worden die vernieuwd, hoe vaak?
- Zou het mogelijk zijn om dit soort kaart aan te bieden aan alle patiënten?
- De informatie op de kaart zou met de tijd kunnen verschillen. Is er een mogelijkheid om per patiënt elke jaar met een nieuwe behandelplan dit opnieuw aan te kunnen vragen?

COMBINATIE VAN CONCEPTEN

- Denkt u dat deze concepten haalbaar zijn? Wat zou er nodig zijn om dit te kunnen implementeren?
- Zou Erasmus MC deze producten kunnen aanbieden? Voor de kaart en spel zou het misschien met een groter schaal implementeert worden, bv. door NHVP?
- Ziet u waarde in deze concepten voor het preventie van angsten?
- Denkt u dat deze concepten in het algemeen een gevoel van controle en consistentie kunnen geven aan een kind?

Appendix G - Evaluation Quotes | Original and Translation

** Original Dutch quotes are presented in **RED**, translated English quotes are **BLACK**.

EC1 - Does it give a feeling of control?

“The great thing is that you can involve the child, that he can adjust it himself, then you really keep it lively.” (P3) “Het mooie is dat je het kind bij kan betrekken, dat hij zelf aan kan passen, dan hou je het ook echt levendig.” (P3)

“It’s really funny to see what a difference self-control makes. I poke the same way, with a short wait in between, but he has chosen to wait a while. You can see that he handles it better. You could easily show that here as well.”(P5) “Het is echt grappig om te zien wat een verschil de zelf-controle maakt. Ik prik opzicht hetzelfde, met eventjes wachten ertussen maar hij heeft zelf gekozen om even te wachten. Je ziet dat hij dan beter mee om gaat. Dat zou je hier ook makkelijk kunnen laten zien.” (P5)

“I think involvement in your own illness is especially important. So what many parents do is just take care of it, but involving them in the “this is my medication, I’m going to get it ready” I think is very important for the perception in general. Even if it is something very small that he has to do himself, that really makes the difference, if there is also a ritual involved. Not like, oh I’m just going to sit and wait.” (P5) “Vooral vind ik de betrokkenheid bij je eigen ziektebeeld belangrijk. Wat veel ouders doen is dus alleen voor zorgen, maar door ze juist bij te betrekken van “dit is mijn medicatie, ik ga het klaarzetten” vind ik dat heel belangrijk voor de perceptie in het algemeen. Ook als het iets heel kleins is, dat hij zelf moet doen, dat maakt echt het verschil, als er ook een ritueel is daarbij. Niet van oh ik ga alleen maar zitten wachten.” (P5)

“Involving them in actions indeed, you can get a stamp or this or that, I think that helps with young children.” (P1) “Ze zelf te betrekken met acties inderdaad, je kan een stempel halen of dit of dat, ik denk dat dat wel helpt met jonge kinderen.” (P1)

“By showing on something else first, he also finds it less annoying on himself, I think you solve that with this. [...] That’s very good, it’s more for giving some kind of responsibility and you involve also inform him of what is happening with the child himself.” (P3) “Door op iets anders te laten zien eerst dat hij ook minder vervelend vind op zichzelf, dat los je denk ik hiermee op. [...] Dat is wel heel goed, het is meer voor het geven van een soort verantwoordelijkheid en je betrekt hem ook bij wat er gebeurt bij de kind zelf.” (P3)

“I certainly think it is nice for children to just say what they want and that they are also listened to, or at least explained to why it may not be possible, of course that is also the case sometimes. But something very simple like counting down, yes everyone can do that.” (P1) “Ik denk zeker dat het fijn is voor kinderen om gewoon te zeggen wat zij willen en dat er ook naar geluisterd wordt, of dat er in ieder geval uitgelegd wordt waarom misschien ook niet kan, dat kan ook soms natuurlijk. Maar iets heel simpels zoals aftellen, ja dat kan iedereen.” (P1)

“As a parent you have to speak up. [...] If you are not very assertive as a parent, or find it difficult to just say ‘hey, I want you to look at my child now’ I think it would be very good. Or also older children, who would like to speak for themselves but find it exciting to say something, then I think it would be very helpful.” (P3) “Je moet je als ouder wel uitspreken. [...] Als je niet erg assertief bent als ouder, of het moeilijk vindt gewoon om te zeggen van “he, ik wil dat jullie nu kijken naar mijn kind” dat vind ik dan wel heel goed. Of ook oudere kinderen, die graag zelf het woord willen doen maar het spannend vinden om iets te zeggen, dan vind ik het wel erg handig.” (P3)

EC2 - Does it give a feeling of structure/predictability?

“Children have the order in their head quite quickly, but it helps hold on to the structure, it really suits small children very well. Because they really need that structure and to know what is happening now.” (P3) “Kinderen hebben wel best snel de volgorde in hun hoofd, maar het is wel een heel goed houvast, het past echt heel goed bij kleine kinderen. Want die hebben echt de behoefte aan die structuur en wat gebeurt er nu.” (P3)

“Definitely! Then we don’t have to say every time when the injection will come, he can see for himself whenever he wants, and he also knows immediately what will happen.” (P2) “Zeker! Dan hoeven wij niet elke keer te zeggen wanneer de prik komt, hij mag zelf kijken wanneer hij wil, en hij weet ook gelijk wat er gaat gebeuren.” (P2)

“We always say ‘we’re just going to chat, it’s not an injection’, because we usually don’t have to do that at the outpatient clinic. And that is nice to prepare them, especially if they also have the experience of lying in the hospital with the necessary fuss around it.” (P1) “Wij zeggen dan altijd “we gaan alleen kletsen, het is geen prik”, want meestal hoeven wij dat niet bij de poli. En dat is dan wel fijn om ze voor te bereiden, zeker als ze ook de ervaringen hebben van in het ziekenhuis liggen met de nodige gedoetjes eromheen.” (P1)

“This is very strong with the involvement and with the steps that the child knows, what goes first what comes next.” (P3) “Dit is heel sterk met het betrekken en met de stappen dat het kind weet, wat gaat eerst wat komt er nog.” (P3)

“I hear that very often that they [ER] do not listen to the parent. [...] We say every time “he is a very anxious boy” but it is important that you give the parent something to push under the nose of “look”. (P5) “Dat hoor ik ook echt vaak dat ze [SEH] niet luisteren naar de ouder. [...] Wij zeggen wel elke keer “het is een prik angstig jongetje” maar het is wel dan belangrijk is dat je de ouder iets geeft om daar onder de neus kunnen duwen van “kijk”.” (P5)

EC3 - Does it have a direct effect on the child?

“These are nice details. I hadn’t considered that the child would want to sit in a certain place for the shot, for example, because we didn’t have that. But that’s definitely something that can make a difference.” (P1) “Dit zijn leuke details. Ik had er niet bij stilgestaan dat het kind bijvoorbeeld op een bepaalde plek wil zitten voor de prik, want dat hadden we niet. Maar dat is zeker iets dat het verschil kan maken.” (P1)

“It is something that would help to involve them in the conversations at the outpatient clinic and give them something to do so that they don’t find it boring. Because that’s how it really goes, then they start pulling and “this is taking too long”.” (P5)“Het is wel iets dat ze bij de poli te betrekken bij de gesprekken en iets geven te doen zodat ze het niet saai vinden. Want zo gaat het ook echt dan gaan de trekken en “duurt ook lang”.” (P5)

“Anesthetic cream is difficult, because you have to work quickly, but it also takes a while to get its effect. But giving preference, that’s fine, they’re going to try there anyway.” (P6) “Verdovingscrème is wel moeilijk, want je moet snel werken, maar dat duurt ook even om zijn effect te krijgen. Maar de voorkeur geven, dat is prima, gaan ze toch proberen daar.” (P6)

EC4 - Is it desirable by the child (and parents)?

“I think it’s already possible from 3-4, and yes one child does have a grip on the conversation earlier than the other, so it could be introduced soon, see how it goes.” (P5) “Ik denk van 3-4 kan het al, en ja de ene kind heeft wel eerder een grip aan het gesprek dan de andere, dus het zou al snel geïntroduceerd kunnen worden, even kijken hoe het gaat.” (P5)

“It depends on the child but we would have already used it at 4-5 years old I think.” (P1) “Het hangt af van de kind maar wij hadden het al met 4-5 jaar gebruikt denk ik.” (P1)

“From 0-12 this would be good, childish they don't mind, but maybe after 12 years something tougher could come, an adolescent version. On your phone or something. Because I think they could use this too.” (P4) “Van 0-12 zou dit wel goed zijn, kinderlijk vinden zij niet erg, maar misschien dat er na 12 jaar iets stoerders zou kunnen komen, een adolescent versie. Op je telefoon of zo. Want ze zouden dit ook kunnen gebruiken denk ik.” (P4)

“There are also girls with hemophilia, but more boys. They do need something tougher sometimes.” (P2) “Er zijn ook meisjes met hemofilie maar meer jongens. Zij hebben dan wel wat stoerders nodig soms.” (P2)

“I think it's [the schedule] really good, especially for younger kids. But it's good for any child to see. [...] I also really like the pick-me-ups, you can use that very easily if things don't go as expected with an injection. “ (P3) “Ik denk dat het heel goed is vooral voor jongere kinderen. Maar het is wel goed voor elke kind om te zien. [...] De opkikkertjes vind ik heel leuk, dat kan je heel makkelijk gebruiken als het bij een prik net niet zo gaat als verwacht. “ (P3)

“If I had seen this in a store, I would have bought it right away.” (P1) “Als ik dit in een winkel had gezien, had ik het meteen gekocht.” (P1)

“I do recognize that you say that it is easy to talk over them, especially at that age. [...] Certainly from 5-6, or even 4, you can involve them a bit.” (P5) “Ik herken wel dat je zegt van dat het gauw, zeker bij die leeftijd, over ze heen gepraat wordt. [...] Zeker vanaf 5-6, of zelfs 4, kan je ze wel een beetje betrekken.” (P5)

“This would definitely work for 0-8, they would be excited.” (P4) “Dit zou zeker werken voor 0-8, zouden ze enthousiast van worden.” (P4)

“I think 4-8 years old would really enjoy this, but could start much younger depending on the child.” (P1) “Ik denk 4-8 jaar zou hiervan echt genieten, maar kan al veel jonger beginnen, afhankelijk van het kind.” (P1)

“I think this is more useful for a parent or an ER doctor who is helping at that moment than for the child himself. Especially if you are 3 years old, for example, you cannot read, you want to see pictures. I think this is really more for parents, and also children from the moment they can read.” (P2) “Dit is denk ik meer voor een ouder handig of een SEH arts die op dat moment helpt, dan voor de kind zelf. Zeker als je bijvoorbeeld 3 jaar oud bent kan je niet lezen, je wil plaatjes zien. Dit is denk ik echt meer voor ouders, en ook kinderen vanaf het moment dat ze kunnen lezen.” (P2)

“The SOS card is also not really intended for this age category, it is very difficult for 0-8 to give something like this, it would mainly be with the parents.” (P4) “De SOS pasje is ook niet echt bedoeld voor deze leeftijds-categorie, dat is wel heel moeilijk voor 0-8 om zo iets te geven, zou dan voornamelijk bij de ouders zijn.” (P4)

EC5 - Is it accessible by the child?

“We used to write and draw on a large paper with pins. This is much more convenient, it gives him a lot of clarity too.”(P1) “Wij deden vroeger schrijven en tekenen op een grote papier met prikken. Dit is dan wel veel handiger, geeft hem ook wel duidelijkheid.” (P1)

“It's super fun, I think it really works because then the children also have something to do.” (P3) “Het is super leuk, ik denk dat het ook wel echt werkt want dan hebben de kinderen ook iets te doen.” (P3)

“Nice and clear! And he can tick what he wants!” (P1) “Lekker duidelijk! En hij kan zelf aanvinken wat hij wil!” (P1)

EC6 - Is it understandable by the child?

“I really like the way the questions are asked. A child psychologist should certainly check, but I think this can be understood by a child!” (P6) "Wat leuk ook echt die manier dat de vragen gesteld zijn. Een kinderpsycholoog zou zeker moeten nakijken maar ik denk dat dit wel te begrijpen is door een kind!" (P6)

“I really like the idea. I also use this myself, not so much the steps, but the schedule that he sees when he is injected. That is very good for children.” (P3) “Ik vind het heel erg leuk bedacht. Ik hanteer dit ook zelf, niet zo zeer de stappen maar wel het schema dat hij ziet wanneer hij wordt geprikt. Dat is wel heel goed voor kinderen.” (P3)

“We know that if you change the color of a wing needle with our hemophilia patients, they are already upset. So we might have been better off guessing “this is something really different”. Now getting a shot in the leg instead of the elbow, we have to explain that properly, but that might be possible with such a bear. (P5) “Wij weten dat als je de kleur van een vlindernaaldje al veranderd bij onze hemofilie patienten, dat ze al van slag zijn. Dus we hadden misschien beter kunnen inschatten van “dit is wel iets echt heel anders”. Nu een prik in zijn been krijgen in plaats van de elleboog, dat moeten we even goed uitleggen, maar dat kan wel misschien met zo een beertje.” (P5)

“It really depends on how you bring it to a child, then he says yes or no I don’t want it [decisions]. I think this gives room to explain it playfully.” (P5) “Het ligt echt aan hoe je het bij een kind brengt, dat hij dan zegt ja of nee ik wil het niet [beslissingen]. Ik denk dat dit wel de ruimte geeft om het speels uit te leggen.” (P5)

“I think this is more useful for a parent or an ER doctor who is helping at that moment than for the child himself. Especially if you are 3 years old, for example, you cannot read, you want to see pictures. I think this is really more for parents, and also children from the moment they can read.” (P2) “Dit is denk ik meer voor een ouder handig of een SEH arts die op dat moment helpt, dan voor de kind zelf. Zeker als je bijvoorbeeld 3 jaar oud bent kan je niet lezen, je wil plaatjes zien. Dit is denk ik echt meer voor ouders, en ook kinderen vanaf het moment dat ze kunnen lezen.” (P2)

EC7 - Does it give the space to understand the child?

“If you have a card, there is something to hold on to the conversation. It helps to start the conversation. [...] These are questions that we would otherwise not discuss, but are nevertheless important.”(P1) “Als je een kaartje hebt dan is er houvast aan het gesprek. Helpt toch om de gesprek aan te gaan. [...]Het zijn vragen dat we anders niet zouden bespreken, maar toch belangrijk zijn.” (P1)

“Showing a lot, with the first needle and what we are using now with SC he thinks “hey, this needle is much thinner and shorter!” Then you also see something forming in his head.” (P2) “Veel laten zien, van eerste naald en wat we nu met SC gebruiken denkt hij van “hé, dit naald is veel dunner en korter!” Dan zie je ook iets in zijn kopje ontstaan.” (P2)

“It helps respect the opinion. Even if the preference is not possible, he still feels listened to.” (P4) “Het helpt de mening respecteren. Ook als de voorkeur niet kan, voelt hij toch wel geluisterd.” (P4)

EC8 - Is it implementable? (Feasible and Viable)

“This will then be published nationwide. It is nice to see this on the website of the NVHP of “this is what we do in the Netherlands”. (P6) “Dit zal dan wel echt landelijk uitgegeven worden. Het is dan wel leuk om dit op de website van de NVHP te zien van “dit doen we in Nederland”.” (P6)

“I can fill this in very easily in my preparation per patient, that we then put the name on it, and immediately inform the desk when registering that they can already have a look. Very handy!” (P5) “Dit kan ik heel makkelijk in mijn voorbereiding per patient invullen, dat we dan de naam erop zetten, en bij de balie bij het aanmelden gelijk meegeven dat ze al een beetje kunnen kijken. Heel handig!” (P5)

“I often also listen to the lungs of the parent before looking at the child, [...] taking the extra time to show first is not a lot of extra effort.” (P4) “Ik doe vaak ook bij de ouder naar de longen luisteren voor naar de kind kijken, [...] de extra tijd nemen om eerst te laten zien is weinig moeite.” (P4)

“I think it’s a good pass either way. And I do indeed think that the Erasmus logo helps, that you also feel that you have been taken seriously when you show this. That you can say ‘Well, hey, this is it, look, otherwise call Erasmus.’” (P1) “Ik denk dat het sowieso goed is zo’n pasje. En ik denk inderdaad dat de logo van de Erasmus dan ook helpt, dat je dan ook voelt dat je serieus bent genomen als je dit laat zien. Dat je kan zeggen ‘Nou ho maar, dit is het, kijk maar bel anders de Erasmus.’” (P1)

“When you see this, I think you’re also asking the parent, “Are there other things we should pay attention to?” And that conversation is important to start.” (P4) “Als je dit ziet denk ik dat je ook gelijk aan de ouder vraagt “Zijn er ook andere dingen waar we op moeten letten?” en dat gesprek is juist belangrijk om aan te gaan.” (P4)

“And starting the conversation, I think, when you come to the ER you never know the people, and that is therefore fundamentally different than when you come to Erasmus. Sometimes it’s new people, just give this [urgent pass] and say this is what we’re sticking to. I always explain myself, I say “yes we come here, but we have to give that shot again at home. I don’t want any resistance at home because we are stepping over certain points here.” But we’ve done that before. [...] Such a card can start the conversation of ‘hey, well we have a lot of experience in the hospital, would you please take this into account?’, ‘Oh! Yes, tell me...” you know?” (P1) “En het gesprek openen denk ik, als je op de spoed komt je kent de mensen nooit, en dat is dus wezenlijk anders dan als je bij het Erasmus komt. Soms zijn het nieuwe mensen, even dit [het spoed pas] geven en zeggen van dit is waar we ons aan houden. Ik leg zelf ook altijd uit, ik zeg “ja we komen hier, maar wij moeten thuis opnieuw die prik geven. Ik wil dan geen weerstand thuis omdat we hier over bepaalde heen stappen.” Maar dat hebben we vroeger wel laten gebeuren. [...] Zo’n kaartje kan wel het gesprek openen van ‘hé, nou wij hebben veel ervaring in het ziekenhuis, wil je alsjeblieft hier rekening mee houden?’, ‘Oh! Ja vertel eens...’ weet je wel?” (P1)

EC9 - Does it work preventively?

“I don’t think everyone would ever not develop a fear of needles after so many shots, and so many experiences. But yes, one doesn’t have that many experiences, so it never gets to that point. And the other one has a lot in a very short time, so it also develops it very quickly. [...] I don’t think you can just prevent those fears.” (P2) “Dan denk ik zou niet iedereen ooit een prikangst ontwikkelen na zo veel prikken, en zo veel ervaringen. Alleen ja de ene heeft niet zo veel ervaringen, dus die komt nooit bij die punt. En de andere heeft heel veel in een heel korte tijd dus die ontwikkelt het ook heel snel. [...] Die angsten kan je niet zomaar voorkomen denk ik.” (P2)

“It’s a lot less bad now, but maybe that’s because he’s used to the needle that is worse. For other kids who aren’t used to it, maybe this [SC] is already very bad. It really stays with the medical things I think. ” (P1) “Het is een stuk minder erg nu, maar dat komt misschien omdat hij gewend is aan de ergere prik. Voor andere kindjes die niet gewend zijn, is misschien dit [SC] al heel erg. Het blijft echt bij de medische dingen denk ik.” (P1)

Recommendations for Improvement

“If the word injection is experienced [negatively], you could perhaps use other options in the concept, with other icons such as a train, which they sometimes call it, because it goes like a “train” in the line. I would just use the injection, but maybe it would be nice to give other parents the choice as well.” (P3) “Als het woord prik toch zo ervaart wordt, zou je misschien toch andere opties in kunnen zetten in het concept, met ook andere icoontjes zoals een trein, dat benoemen ze het ook soms, omdat het als een “treintje” in de lijn gaat. Ik zou gewoon de prik gebruiken hoor, maar misschien is het toch leuk om andere ouders ook nog de keuze te geven.” (P3)

“Instead of the lion I would just do a shot, these children, it's such a part of their life that you don't have to hide it or anything.” (P3) “In plaats van de leeuw zou ik gewoon een prikje doen, kijk die kinderen, het is zo een onderdeel van hun leven dat je dat niet hoeft te verbloemen of zo.” (P3)

“We do injections [with SC] every 14 days, not weekly, so maybe the green lines can give an indication of whether it's a injection week or not, then he knows it's coming again next week and he can see when.” (P2) “We doen elke 14 dagen prikken [met SC] niet wekelijks, dus misschien kunnen de groene lijnen een indicatie geven of het een prik-week is of niet, dan weet hij dat het volgende week weer zal komen en kan hij zien wanneer.” (P2)

“Maybe also an icon of a general reward? That they can choose what they get at a time.” (P4) “Misschien ook een icoontje van een algemene beloning? Dat ze zelf per keer kunnen kiezen wat ze krijgen.”(P4)

“This could also be possible for children who do not go to school, then it is difficult again [identifying days]. Long short days only have to do with school, of course. [...] Or when are you at home, when at grandma and grandpa, depending on the situation. comic may not be clear enough, I don't know if it will be too complicated.” (P3) “Dit zou ook kunnen voor kinderen die niet naar school gaan dan is het weer moeilijk [dagen identificeren]. Lange korte dagen heeft alleen met school te maken natuurlijk. [...] Of wanneer ben je thuis, wanneer bij oma en opa, afhankelijk van de situatie. Groene strip is dan misschien net niet duidelijk genoeg, ik weet dan niet of het te ingewikkeld wordt zo.” (P3)

“I also think the cards are a very nice idea. But then I wouldn't link them to an injection every time, then it might take too long. [...] As a parent, you really have to have the time.” (P3) “De kaarten vind ik ook wel een erg leuke idee. Maar dan zou ik zelf niet elke keer aan een prikje koppelen, dan duurt het misschien te lang. [...] Je moet als ouder wel echt de tijd voor hebben.” (P3)

“Could you personalize this? That the cards change per patient? Then you have truly personalized care.” (P4) “Zou je dit kunnen personaliseren? Dat de kaarten per patient veranderd? Dan heb je namelijk echt gepersonaliseerde care.” (P4)

“I'm also thinking, maybe instead of a bear it can be a “Sophia Monkey”? Or even several types, that the child can choose himself, between a monkey and a “Sophietje”? Then it is tied to the Sophia.” (P4) “Ik zit ook te denken, misschien in plaats van een beer dat het een “Sophia Aapje” wordt? Of zelfs verschillende, dat de kind zelf kan kiezen, tussen een aapje een Sophietje? Dan is het gebonden aan het Sophia.” (P4)

“The Sophia monkey would be very nice, because they all know that too.” (P3) “Sophia aapje zou wel heel mooi zijn, dat kennen ze namelijk ook allemaal.” (P3)

“Do you also give something if it doesn't work out? And what if it doesn't work out because of someone else, then maybe there is something of a negative feeling.” (P3) “Geef je dan ook iets als het niet lukt? En wat als het door iemand anders niet lukt, dan is er toch iets van een negatieve gevoel bij misschien.” (P3)

“With us you also get a injection present. Some children think it's stupid what's in that basket, they've already seen it a hundred times, it's not interesting at all anymore.” (P5) “Bij ons krijg je ook wel een prikcadeautje. Sommige die vinden wel stom wat er allemaal in die prikmandje zit, ze hebben al honderd keer gezien, is helemaal niet interessant meer.” (P5)

“I'd rather do a medal or something like that so they can save too.” (P6) “Ik zou eerder zo een medaille of zo doen, dat ze ook kunnen sparen.” (P6)

“There is also a DNA gift thing, for which they can collect pieces, then you build it up. It's nice that they get something that also has a follow-up. Maybe also something they can bring to the clinic that we can say “Oh! Have you already saved that much??"" (P6) "Er is ook een DNA cadeau ding, dat ze stukken kunnen sparen, dan bouw je het op. Dat is dan leuk dat ze iets van krijgen wat ook een vervolg heeft. Misschien ook iets dat ze naar de poli kunnen brengen dat we zeggen "Oh! Heb je al zo veel gespaard??"" (P6)

"I immediately thought maybe it could be a thicker material and then used as a coaster at dinner that day, with a conversation of 'what did you do today?'" (P5) "Ik dacht gelijk aan dat het misschien dikkere materiaal kan zijn en dan als onderzetter gebruikt kan worden bij de avondeten die dag, dan opent een gesprek van "wat heb je vandaag gedaan?"" (P5)

"I also had someone on the phone who said "Yes, but we're going to check the child first" then I said "No, first the coagulation in and then the rest." So it's important to have something like that on it." (P5) "Ik heb ook iemand aan de lijn gehad die zei "Ja, maar we gaan eerst de kind checken" toen zei ik "Nee eerst de stolling erin en dan de rest." Dus het is belangrijk dat er zoiets op staat." (P5)

"We have to look at what the most important things are. The discussion is also of "he only wants to be injected in the elbow" and if there is nothing to be found [viable vein] there, it goes wrong. Yes, some children find that to be very intense, and even if you cannot control it, giving preference already makes a difference, then they will try there first instead of what is easier for them." (P6) "We moeten wel kijken naar wat de belangrijkste dingen zijn. De discussie is ook van "hij wil alleen in de elleboog geprikt worden" en als er daar niks te vinden is dat gaat het fout. Ja sommige kinderen vinden dat heel erg, en ook als je het niet kan controleren, de voorkeur geven maakt al een verschil, dan gaan ze toch eerst daar proberen in plaats van wat voor hen makkelijker is." (P6)

"The amount of medicine is not necessary at all, that changes with time. If it changes then the card can still remain the same. It's a different amount for emergencies anyway. [...] Only the type of medication is important factor 8 or 9, Novoeight or something else." (P5) "De hoeveelheid van medicijn hoeft ook helemaal niet, dat veranderd met de tijd. Als het dan veranderd mag het pasje toch hetzelfde blijven. Het gaat toch om een andere hoeveelheid voor spoed. [...] alleen de soort medicatie is belangrijk factor 8 of 9, Novoeight of iets anders." (P5)

"During office hours, our number, outside [business hours] another number, if it says so on the card, they know who to find, so the name and number of the doctor is not necessary." (P5) "Tijdens kantooruren ons nummer, buiten een andere, als dat erop staat weten ze wie te vinden, de naam en nummer van de arts hoeft dan ook niet." (P5)

"So we also have existing cards, which can be adapted to this. Maybe with a QR code, then you use something that already exists. Because the information on this, it also changes. It would be nice if it were timeless." (P4) "We hebben dus ook bestaande pasjes, die kunnen aangepast worden aan dit. Misschien met een QR code, dan maak je gebruik van iets die al bestaat. Want de informatie hierop, het veranderd ook. Zou toch leuk zijn als het een tijdloos is." (P4)

"The ER must be able to see immediately what they have to do, without effort, so if they have to scan something, will it go well?" (P5) "De SEH moet gelijk kunnen zien wat ze moeten doen, zonder moeite, dus als ze iets moeten scannen gaat dat dan wel goed?" (P5)

General Findings

"If we always have the same kind of candy, then that indeed becomes part of the process, a kind of reward ritual. I'm thinking maybe it's not so bad that it's a candy after all." (P5) "Als we altijd hetzelfde soort snoep hebben, dan wordt dat inderdaad een onderdeel van het proces, een soort beloningsritueel. Ik zit dan te denken misschien is het dan toch niet zo erg dat het een snoep is." (P5)

“Many people do that parents too, apparently sweets are just comforting. If you don’t feel well yourself, eat a piece of chocolate. Who knows, maybe it really makes the difference for children.” (P6) “Dat doen veel ouders ook wel, blijkbaar is snoep gewoon troostend. Dat doe je zelf niet lekker voelt, eet je een stukje chocola. Wie weet misschien maakt het voor kinderen echt het verschil.” (P5)

“Make sure that it does not become a problem later that you need comfort in every bad situation.” (P4) - “If there is a fixed candy in a fixed experience, I don’t think it happens in other situations.” (P5) “Is wel op te letten dat het later niet een probleem wordt dat je bij elke slechte situatie een troostje nodig hebt.” (P4) - “Als er een vaste snoep is bij een vaste ervaring, ik denk niet dat het bij andere situaties ook gebeurt.”(P5)

“Could this be adapted to my ‘medication schedule’? ‘Injection’ is a word we don’t use.” (P5) “Zou dit aangepast kunnen worden naar mijn ‘medicatieschema’? ‘Prikken’ is dus een woord dat we niet gebruiken.” (P5)

“We don’t mind the word ‘injection’, it’s really not about the word but everything around it. We say everything what it is. We really don’t want to talk around it on purpose, because it’s only disappointing when we tell something nice, but it’s still just an injection.” (P2) “De woord ‘prik’ vinden wij niet erg, het gaat echt niet om de woord maar alles eromheen. Wij zeggen alles wat het is. Wij willen ook echt expres niet omheen praten want het valt alleen maar tegen als we iets moois vertellen, het is nog steeds gewoon een prik.” (P2)

“The fear is really not in the word but a number of other things. The negative experiences. [...] Yes, that word can have negative sounds, but the experience gives the fear of needles.” (P1) “De angst staat echt niet in de woord maar een aantal andere dingen. De negatieve ervaringen. [...] Ja dat woord het kan negatieve klanken hebben, maar de ervaring geeft de prikangst.” (P1)

“Fortunately, we have a child who is not afraid of it. [...] Look, he is not afraid, but we also played a role in naming it, however difficult it may be.” (P3) “Wij hebben gelukkig een kind die er niet bang voor is. [...] Kijk hij is niet bang maar daar hebben wij ook een rol gespeeld in het juist wel te benoemen. Hoe moeilijk dat het dan ook is.” (P3)

“Perhaps for this category of children, who have to be injected all their lives, that it is simply called that. It is of course a bit different for children who have to get an injection for a screening at some point, and children who have it every week as medication.” (P5) “Misschien is het voor deze categorie kinderen, die zijn hele leven, gaan we ervan uit moeten prikken, dat het zo gewoon benoemd wordt. Het is natuurlijk wel wat anders voor kinderen die ooit voor een screening een prik moeten krijgen, en kinderen die het elke week als medicatie hebben.” (P5)

“They’re going to get the prophylaxis anyway, so maybe it’s better to let them get used to the word.” (P6) “Ze gaan toch de profylaxe krijgen dus misschien toch beter om te laten wennen aan het woord.” (P6)

Appendix H - Original Project Brief

Personal Project Brief - IDE Master Graduation

Improving the Quality of Life of Children with Hemophilia — project title

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

start date 17 - 05 - 2022

31 - 10 - 2022 end date

INTRODUCTION **

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

A child with hemophilia travels through a complex journey, facing many different situations in which many different people play a role. Currently, there seems to be little knowledge as to how children experience their journey and what their biggest challenges are. In this project, we will define the challenges the children may face in their care and aim to improve the experience of children with hemophilia aged 0-8 in the hospital and/or at home.

Hemophilia is a rare hereditary blood clotting disorder which can cause abnormal amounts of bleeding and bruising. See figure 1 for the explanation of the difference between regular clotting and hemophilic clotting. Inherited hemophilia is split into two types: A and B, A being the most common. The symptoms of each are very similar, the difference in each is the mutation of different clotting factors [1]. The illness is carried with the X-chromosome, meaning that the prevalency is higher in males (and consequently their children) [2]. See Figure 2 for the inheritance pattern of hemophilia in families. Hemophilia can be treated but not cured. Even though gene therapy is being used for curing the mutations, it isn't yet a common treatment [3]. This means the disease requires regular treatment and/or check ups.

Hemophilia is quite a difficult illness for a child to deal with, arguably more difficult than it is for an adult. Children want to play and discover, meaning that they fall and sometimes injure themselves. For a healthy child, this can be shaken off and the child will get up and keep playing. For a child with hemophilia, it can be what leads to bleeding out. This is a burden for the children, and also for the parents. Not only do hospital visits become regular, but growing up becomes a fragile task.

This is why Erasmus MC, specifically the Partitura study, is looking into ways how to improve the care of children with hemophilia. They want to understand the patient experience journey of children with hemophilia, putting the patient in the center of their care, and utilize the experiences of the medical staff to further improve care and communication. This is where my project steps in. First a patient journey will be developed to analyse the context and the current experiences of children with hemophilia and define opportunities for improvement. Starting from these insights, an intervention will be developed aimed at improving the child's experience with their disease.

1. Haider MZ, Anwer F. Acquired Hemophilia. 2021 Oct 1. In: StatPearls [Internet]. Treasure Island (FL): StatPearls Publishing; 2022 Jan–. PMID: 32809329.
2. Kulkarni R, Soucie JM. Pediatric hemophilia: a review. Semin Thromb Hemost. 2011 Oct;37(7):737-44. doi: 10.1055/s-0031-1297164. Epub 2011 Dec 20. PMID: 22187396.
3. Berntorp E, Fischer K, Hart DP, Mancuso ME, Stephensen D, Shapiro AD, Blanchette V. Haemophilia. Nat Rev Dis Primers. 2021 Jun 24;7(1):45. doi: 10.1038/s41572-021-00278-x. PMID: 34168126.

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Initials & Name E Kerimoglu Student number 4495675

Title of Project Improving the Quality of Life of Children with Hemophilia

introduction (continued): space for images

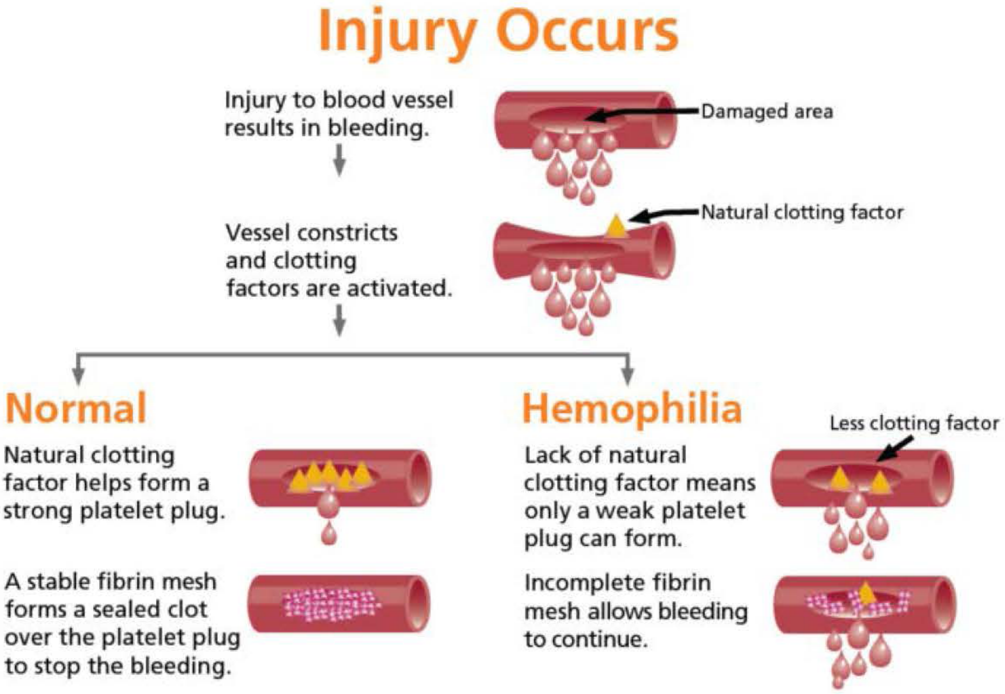


image / figure 1: Difference between normal/hemophilic clotting. (MetroHealth, 2019)

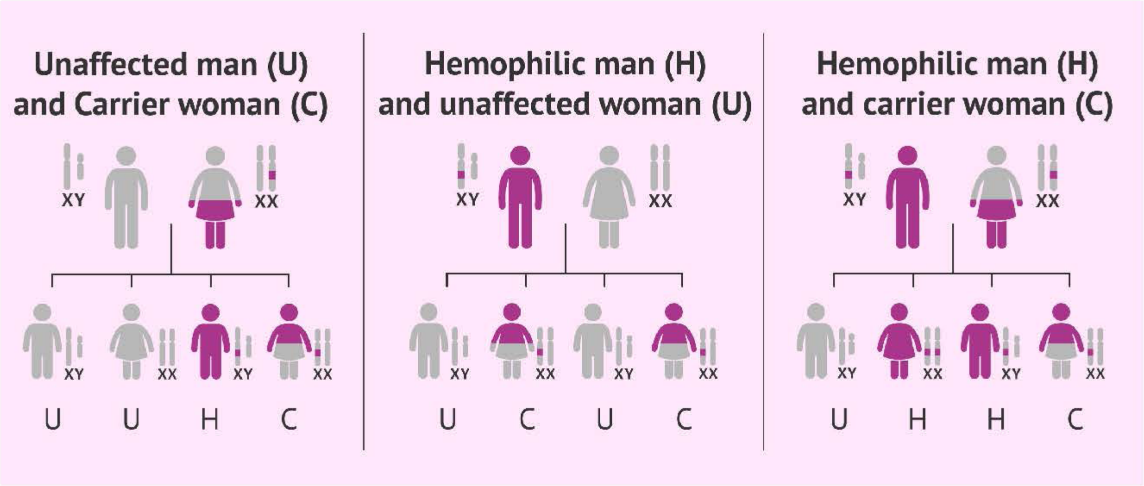


image / figure 2: Inheritance pattern of hemophilia. (InVitra, 2020)

PROBLEM DEFINITION **

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

The current knowledge about the daily life of a child with hemophilia is limited. Information about their daily experience and to what extent their hemophilia plays a role in their school life, home life and their hospital visits haven't yet been analyzed from the child's perspective. The information usually does not come from the patient themselves, but those around them. Which in turn means that the care becomes not fully patient-centered, and the experience is difficult to improve when there aren't any defined problems from the patient's perspective. In this project the (young) children will participate in the various studies (e.g. interviewing) which can be challenging and might need adapted research approaches.

In addition, hemophilia is a constantly changing disease. Even though treatments like gene therapy are are yet to be put into practice, it is important to consider when analyzing the journey of a child with hemophilia, as this journey will have to adapt to the future conditions. A certain amount of prediction is necessary for this project, as well as a good base to build those predictions upon.

One foreseeable limitation is the patient inclusion. My scope is children aged 0-8, but I am limited to the patient scope of the Erasmus MC. Meaning that I might not have access to a balanced age distribution. In addition to this, the patients who are accessible might not be able to participate, due to their age or their parents' permission. Regardless of their parents' permission, children aged 0-3 will be excluded from this part of the research, since the methods I will mostly be using, like interviewing, will not be applicable for the younger children. Some assumptions will probably have to be made (with the help of literature research) with the ages that have not been interviewed, or have not been tested with in person.

ASSIGNMENT **

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

With this project, I want to identify the experiences of children with hemophilia in their daily lives through a patient journey. With the insights gained from this journey, I will find painpoints and design an intervention (product or product-service combination) aimed at improving the child's experience with their disease.

Living with hemophilia can take a toll on a child's daily life and in some cases can lower the quality of life significantly. I believe that with the right intervention, the quality of life can be improved. When looking at a child's experience with hemophilia, there are many different phases and important factors. In this project, I want to analyze all parts of the children's journeys, whether it be giving blood at the hospital or playing at the park. I aim to investigate all aspects and co-create as much as possible with the children, understanding their needs and wants to come up with the best solutions possible. I hope to create an intervention for a key moment in the child's journey, that I will select at the end of my research. This intervention will have to seamlessly fit in the journey effectively improving the experience, as well as being a sustainable solution that fits in with future changes in the treatments and care.

Initials & Name E Kerimoglu Student number 4495675

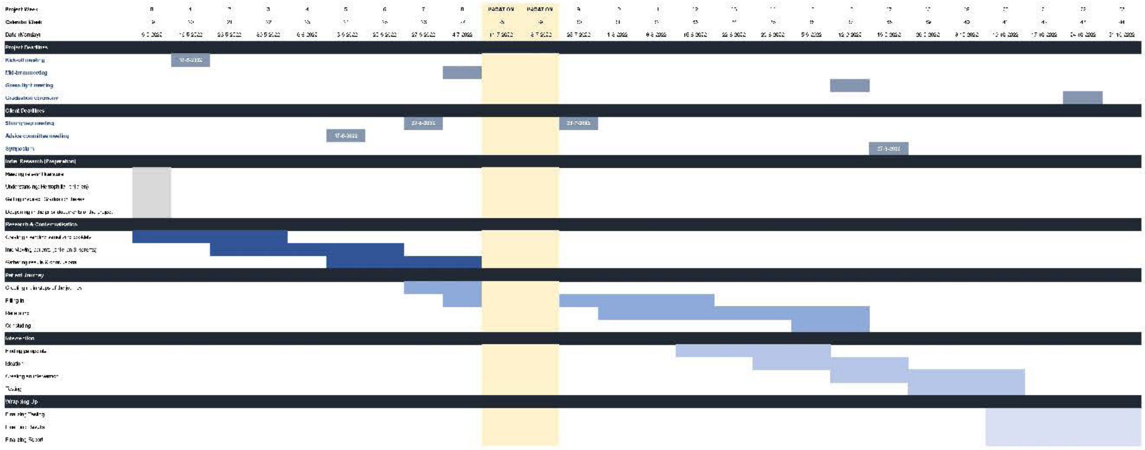
Title of Project Improving the Quality of Life of Children with Hemophilia

PLANNING AND APPROACH **

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

start date 17 - 5 - 2022

31 - 10 - 2022 end date



The schedule for my graduation project can be seen above. I am currently a student assistant for a course which has a time commitment of half a day per week this means that I will be giving 4.5 days of my week to my graduation project. This means that my total project time will be 23 weeks. Since I will be working with children, I recognize that most of them will be on vacation during the summer, as well as the employees of Erasmus MC, so during this time I will also take a vacation, and around my vacation work individually as much as possible.

I split the project into three main parts, that do overlap in order to give some flexibility, which is necessary when working with a hospital and patients. These are the approaches I'm hoping to carry out in each section:

1. Research – Interviews (with patients and parents), shadowing nurses at the clinic, analyzing previous research done in the study to understand other stakeholders, and doing new interviews if necessary.
2. Patient journey – Bringing together all information, co-creating with other researchers in Partitura and carrying out focus groups with children (and their parents)
3. Intervention – Analysis of pain points and possible places to create interventions, ideation (with cocreation sessions where necessary), testing in focus groups and working out the final concept.

My goal in finalizing the project is to improve patient experience with a final concept/prototype. The level of working out the final concept into a "ready to place in the hospital" solution will depend on the complexity of the chosen concept, as well as the protocols of the Erasmus MC.

Initials & Name E Kerimoglu Student number 4495675

Title of Project Improving the Quality of Life of Children with Hemophilia

MOTIVATION AND PERSONAL AMBITIONS

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

This project fits in well with my interests and capabilities as a designer. Having done the C&C course and the Context Mapping Skills elective, I have developed a fondness in using patient journeys in design. I have always been a person who likes to look at the whole picture before deepening into the individual needs of a user, and patient journeys allow me to see that very clearly. When looking into projects for my graduation, my first choice was to work with a hospital. Hospitals are always researching ways to improve patient care, and especially for people dealing with illnesses their whole lives, trying to improve patient experience and well being. Improving the daily experience of patients with chronic illnesses is quite close to my heart, and is a big part of my motivation for working in the Medisign field. In addition to this, hospitals have prime access to patients. They can make sure patients are on board with any decisions made along the way and can put any improvements into practice almost immediately. The best way to understand the needs of patients is to ask them directly, so this is an amazing opportunity for me to understand the context of their illness. This project does bring a few challenges, which I am excited to face.

Firstly, I have never worked with children before. I have designed for children during my bachelor, but I have never had the opportunity to actually come in contact with them. This contradicted my usual approach, which is to get the information from the user themselves, and I had to settle with information obtained from the parents. That said, I do know that children cannot be approached the same way adults can, the questions asked and tools provided are on a whole different level when it comes to children. So my main ambition with this project is to learn how to communicate effectively with children. I want to make sure I am doing things that are actually beneficial for them, not per se things that their parents think they need.

Secondly, within the methods of context mapping, I would like to put all that I have learned further into practice. I have learned how to, for example; create sensitizing booklets, carry out interviews or interpret statement cards, but I would like to learn how they are adaptable when communicating with different people. I will be in contact with children, their parents, doctors and nurses, and I want to learn how to adjust my methods in order to accomodate all of them.

Thirdly, I would like to improve my analysis techniques. So far I have had the most trouble when deciding which information is important to show in a patient journey, and what is unnecessary. I would like to be able to differentiate between those and make my point come across more efficiently.

Lastly, this project will require a "dynamic" patient journey. With new treatments and steps in the medical field, the journey will change. This means that the patient journey will need to adapt to the new circumstances. I have never done a patient journey like this before, and it is definitely something I would like to learn, since I think it will also be vital for me to know and use in my future career.

FINAL COMMENTS

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

Initials & Name E Kerimoglu Student number 4495675

Title of Project Improving the Quality of Life of Children with Hemophilia