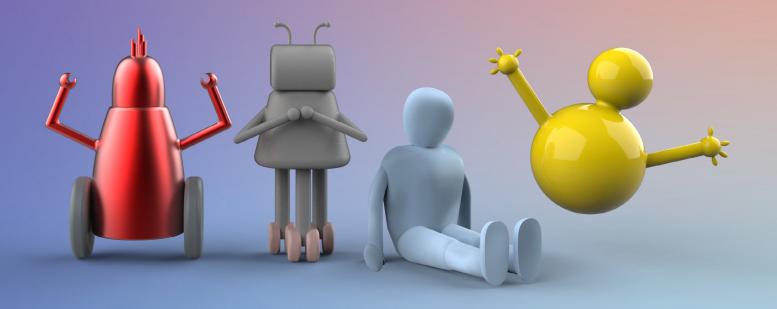


between children with cancer and their parents

Eda Karaosmanoğlu Master thesis • Integrated Product Design





A game that facilitates the emotional connection between children with cancer and their parents

MASTER THESIS

MSc. Integrated Product Design Faculty of Industrial Design Engineering Delft University of Technology July 2022

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PREFACE & ACKNOWLEDGEMENTS

This graduation project concludes my master's studies at TU Delft. As a person with an engineering background, studying design at TU Delft was a challenging journey. However, it broadened my vision, helped me to develop a new skillset, and brought me one step closer to the career that I want to pursue. This project showcases what I want to do for the future, tackling problems in people's lives by working with them, especially in the healthcare field.

Besides being the last step of my studies, this thesis has another meaning for me. I started it myself with an aim to help children with cancer and their families due to the tragic experience I had. I lost my best friend, Büşra, because of leukemia after her fight for three years. Therefore, I would like to dedicate this thesis to her.

Firstly, I would like to thank my graduation committee since they made this thesis possible. Mathieu, thank you for helping me to set up this project in the first place. Your extensive feedback challenged me to do my best and your expertise in play and co-designing with children guided and inspired me throughout the project. Iemkje, thank you for choosing to be a part of this project. Your expertise with ergonomics and user research taught me how to set up the interviews and user tests efficiently and your input inspired me to look at things from a different perspective. I am honored to work with both of you.

Secondly, I would like to thank Dr. Nicel Yıldız Silahlı, who enabled the communication and arrangements with the hospital in Turkey and helped with reaching out to the families and medical specialists.

Thirdly, to the families who participated in my studies, thank you for opening your heart to me, sharing your thoughts, and inspiring me. You are at the core of this project.

A special thanks to my family, without them, it would not have been possible in the first place to pursue a master's abroad. Mom, dad, and Ece, thank you for supporting my every decision, believing in me, and making my dreams come true.

I also want to thank all my friends here in Delft and Turkey. Especially GGs, MVE, and TSH gang, thank you for being there for me and making the past two years amazing.

Lastly, my boyfriend deserves a big thank-you. Sam, I am so grateful to have you with me during these two years. You always believed in me and encouraged me to do my best. Thank you for your love and support.

I hope that this thesis can make a contribution to improving the lives of children with cancer and their families.

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EXECUTIVE SUMMARY

In Turkey, roughly 3000 children and adolescents are diagnosed with cancer every year (Kebudi, 2012). Although there are different types of pediatric cancers, their trajectory is similar and filled with various physical and psychosocial challenges for the patients and their families. Moreover, cancer usually causes a drastic life change for the whole family. To adjust to the changes and cope better with the challenges, it is crucial that children understand cancer, its course, and the treatment (Eiser & Havermans, 1992; Scott, Prictor & Watt, 2003 as cited in Mant et al., 2018). However, in Turkey, parents often avoid sharing cancer-related information with their children, which hinders children's understanding, adjustment, and coping (Dr. N. Yıldız Silahlı (MD), personal communication, 2022). Therefore, this thesis aims to improve children's understanding, adjustment, and coping by nudging parents into changing their attitudes and encouraging children to express themselves. To do so, the project utilises the power of play.

The project starts by exploring the context of pediatric cancers, the factors that affect children's understanding, adjustment, and coping, and the strategies to utilise play in the pediatric cancer context through a literature review. Then, the project analyses families' current experiences, needs and wishes, and the barriers and opportunities in the context through generative interviews with the families and interviews with healthcare professionals, which

reveal the reasons behind parents' attitudes and another key problem: limited emotional sharing between children and parents. Based on the interview results, the project visualises the users' experiences, needs, and challenges through personas and a user journey map, which shows the need of focusing on the hospitalisation stage.

In the light of new findings, the project analyses and reframes the initial design problem and envisions the solution space by defining the design goal, vision and requirements. After generating various solutions that fit within the envisioned space through ideation and conceptualisation, the project introduces the final design: AstroMission, a space-themed role-playing game that aims to facilitate the emotional connection between children and parents.

AstroMission consists of several elements with different functions:

- **1. Storyline:** It is a metaphorical representation of cancer, treatments, and psychosocial challenges. Parents can use this storyline to give children cancer-related information.
- **2. Missions:** They are play opportunities that require the collaboration of children and parents. Their content nudges families into talking about cancer and sharing their emotions with each other in a fun way.
- **3. Emotion puppets:** They are a set of toys that represent four basic emotions of joy, anger, sadness, and fear. They help children to express

their feelings. Also, some missions require the family to play with them.

- **4.** Hospital room decorations and objects: They reframe the hospital room into a less scary, even fun environment for children. Also, some missions require the family use the objects in the room.
- **5. Mobile app:** It presents the missions and the story of the game to the family. Also, it has a social function of connecting the families going through the same experience.

Due to the project duration, the project iterates on and validates only the first three elements of the game with the users. However, user evaluations show that AstroMission is desirable and holds great potential to facilitate cancerrelated conversations and emotional sharing between parents and children throughout the cancer trajectory.

Lastly, the project shows how to put AstroMission into practice by proposing a material and production method and estimating implementation costs. Also, the project presents the recommendations for further development of AstroMission.

To conclude, the outcome of this project creates value for the users by improving children's understanding, adjustment, and coping, and alleviating parents' psycho-emotional burden. It also creates value for the hospitals by improving the user experience.

Executive Summary

READING GUIDE

This section guides the reader by explaining how to read this report.

Each chapter starts with an introduction that describes the content of the chapter and ends with key takeaways. Reading these introduction pages and takeaways (i.e., purple pages) provides a quick glance at the whole project in case there is limited time for reading.

Sometimes these key takeaways are translated into design opportunities or requirements. How the takeaways, opportunities, and requirements are represented in this report is shown on the right.

Each subchapter title is shown as:

X.X. SUBCHAPTER

Each subchapter also starts with a brief introduction shown in this format:

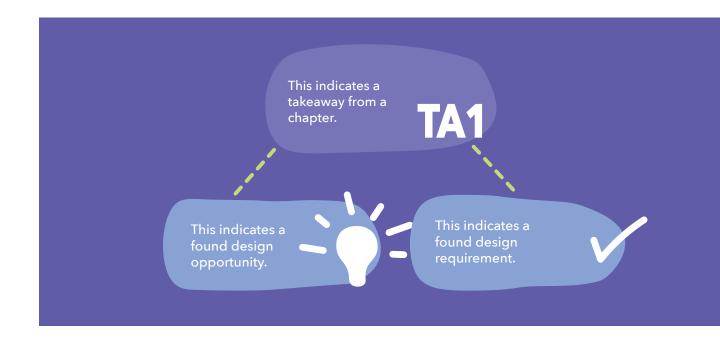
Subchapter introduction

Sub subchapters are formatted this way:

X.X.X. Sub subchapter

Quotes from the participants are formatted this way:

"Quotes"



Abbreviations

HP: Healthcare professional

ALL: Acute Lymphocytic Leukemia

OR: Operation room **IV:** Intravenous injection **LP:** Lumbar puncture

Reading Guide

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CHAPTER 1 INTRODUCTION

This chapter introduces the context of the project by providing information regarding the key statistics for pediatric cancers, their trajectory, and an overview of problems associated with pediatric cancers in Turkey. Moreover, the chapter presents the problem that caused the emergence of the project, the project scope, and the approach followed throughout the project.

1.1. BACKGROUND

This subchapter gives an overview of the project background.

Every year, more than 400.000 children and adolescents (0-19) are diagnosed with cancer globally (WHO, 2021). According to Kebudi (2012), this number is 2500-3000 in Turkey, and pediatric cancers are the 4th biggest cause of childhood mortality. Besides this life-threatening aspect, the trajectory of pediatric cancers is often lengthy, unpredictable, and traumatic for the patients and their families.

In general, the trajectory of pediatric cancers consists of several stages (see Figure 1). According to the Institute of Medicine (US) & National Research Council (US) & National Cancer Policy (2003), the trajectory starts with diagnosis during which physical examinations, imaging tests, and pathological and laboratory studies usually take place. They also indicate that an intensive treatment process is usually initiated in a short time after diagnosis to prevent the spread of fast-growing cancer cells. Although the specific treatment method depends on the characteristics of the cancer and the child, the most common methods are chemotherapy, radiotherapy, and surgery or the combinations of these modalities (Institute of Medicine (US) & National Research Council (US) & National Cancer Policy, 2003). Often, a long hospitalisation process that can disrupt families' daily life is a part of this stage (Prof. Dr. M. Elli (MD), personal communication, 2022). Following the treatment process, pediatric cancers can result in the survival or death of the patient. If death is expected, end-of-life or palliative care can also be a part of the trajectory (See Figure 1) (Institute of Medicine (US) & National Research Council (US) & National Cancer Policy, 2003). In the case of survival, the patients are regularly monitored for at least 3 years to check for recurrence (Institute of Medicine (US) & National Research Council (US) & National Cancer Policy, 2003).

As a result, pediatric cancers lead to various physical and psychological challenges and drastic life changes for the whole family. To cope with the challenges and adjust to the life changes effectively, it is crucial for the patient to understand their illness, its treatment, and its course (Eiser & Havermans, 1992; Scott, Prictor & Watt, 2003 as cited in Mant et al., 2018). However, in Turkey, especially children aged 0-12 obtain information regarding their illness through their parents, who usually leave them out of informational processes or discussions with the medical team (Dr. N. Yıldız Silahlı (MD), personal communication, 2022). Therefore, children's understanding, adjustment, and acceptance can be hindered by the communication and sharing dynamics between them and their parents.

Correspondingly, this project is initiated by the author with the aim of helping children to understand their illness for better adjustment and coping in the Turkish context. By providing consultancy and access to the patients, Istanbul Medipol University Hospital supported the project.

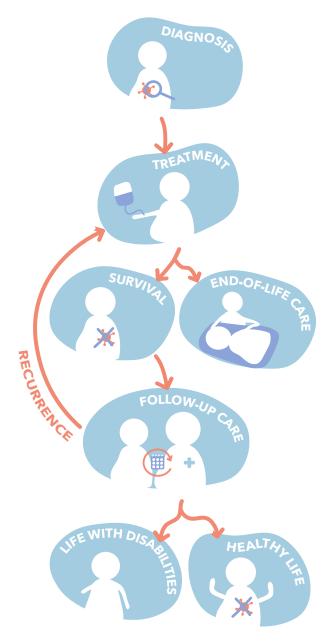


Figure 1: Trajectory of pediatric cancers

Chapter 1 • Background

1.2. PROJECT BRIEF

This subchapter explains the problem that the project aims to solve, for whom and how the solution will be generated, and the methodology followed throughout the project. For the complete brief, please see Appendix A.

1.2.1. Problem Statement

As mentioned in Chapter 1.1, if not sufficiently informed by their parents, younger pediatric cancer patients can experience various difficulties, such as understanding why certain treatments or procedures are necessary, complying with the treatment, adjusting to, or accepting a sudden life change. On the other hand, children are good at picking up cues in their environment (e.g., other ill children at the hospital), identifying their parents' emotions, and disguising their own emotions (Eiser & Havermans, 1992; Küreci & Büken, 2016). Thus, children can assume worse cases than their real condition, feel lonely due to not being able to share fears and concerns, and develop mistrust towards their parents (Eiser & Havermans, 1992; Küreci & Büken, 2016; Mant et al., 2018). Even in later stages of their lives, prolonged effects can be observed in the form of mental health, self-esteem, or confidence problems.

1.2.2. Project Scope

The initial project scope was to develop a product only for children. However, later, literature and user research revealed the need of developing a product that targets both children and their

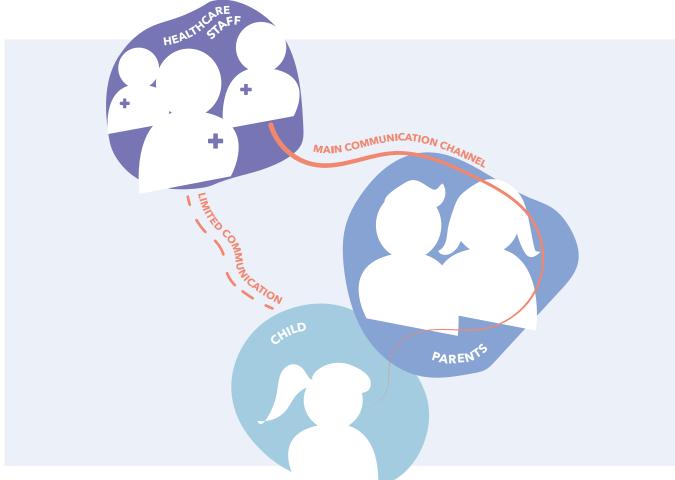


Figure 2: Stakeholders' relationship

parents (see Chapters 2.3 & 3.2).

Similarly, the project focus was initially on the diagnosis stage because it is when parents start hiding information from children. However, the user journey map in Chapter 4.1 showed the impact of hospitalisation period on the problem. Therefore, the scope was expanded to cover this period along with diagnosis.

Stakeholders

The project has three main stakeholders: children, their parents, and the healthcare professionals (or the hospital). While children and parents are the direct users of the product, healthcare professionals are the providers of the product. Figure 2 illustrates the relationship among the stakeholders in the problem context.

Target User Group

The project aims to generate solutions for children aged 8-9 and their parents. According to developmental psychology, children from this age group are in their middle childhood stage (i.e., school-age) (Slater & Bremner, 2017). At this stage, peer relationships are gaining importance, whereas children's dependency on their parents is decreasing (CDC, 2021). According to CDC (2021), this stage is also critical for children to develop confidence in life through friendships, schoolwork, or sports. Therefore, a lifethreatening illness can interrupt or slow down the development of the child while causing poor selfesteem, a sense of inadequacy, separation from peers, and limited physical activity (Armstrong-Dailey & Zarbock, 2001).

The Power of Play

According to Nijhof et al. (2018), play is essential for children's physical, emotional, cognitive, and social development. However, play behaviour is diminished in children with a life-threatening disease due to hospitalisation, pain and fatigue, social isolation, and intensive treatment procedures (Nijhof et al., 2018). As mentioned before, these children are at a greater risk of having mental health or social issues than their healthy peers later in their lives (Armstrong-Dailey & Zarbock, 2001; Patenaude and Kupst, 2005). However, several studies suggest that play has a great therapeutic potential to support these children cope with stress, anxiety, and depression, enhance social contact, adjust to the new living environment, and improve their selfesteem and confidence (Bettini et al., 2019; Lima

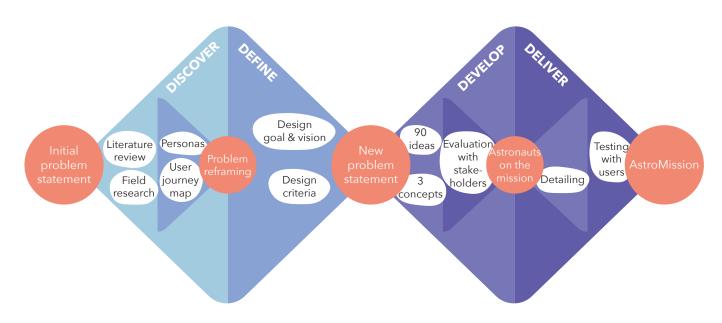


Figure 3: Approach & process of the project

& Santos, 2015; Nijhof et al., 2018). Therefore, this project aims to utilise the power of play to develop a product for children with cancer in their middle childhood stage and their parents.

1.2.3. Assignment & Approach

Based on the problem statement and the project scope, the assignment for the project was formulated as follows:

"Generate a proof-of-concept for a product that facilitates understanding, adjustment, and coping of pediatric oncology patients aged 8-9 throughout their cancer journey by utilizing the power of play." In order to realise the assignment, the double diamond approach by Design Council (2005) was followed.

While Figure 3 provides an overview of the design process, the following paragraphs describe the aim of each phase, the methods used, and the activities performed in each phase.

Discover

The Discover phase aims to explore the context around pediatric cancers in Turkey and analyse the initial problem (see Chapter 1.2.1) to identify the users' current experiences, needs and wishes. With this aim, a literature review (Chapter 2), interviews with HPs, and user research (Chapter

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3) were performed. For user research, simplified Contextmapping techniques (Sleeswijk Visser et al., 2005) and Draw & Write method (Pridmore & Bendelow 1995) were utilised. The outcomes of these studies were then combined into a context map, user journey map, and personas (van Boeijen et al., 2020) (see Chapters 3 and 4).

Define

The Define phase aims to reframe the initial problem and identify a design goal, vision, and design criteria based on the pain points, user needs, and the context identified in the Discover phase. In order to define the problem, the problem tree approach and WWWWWH questions (van Boeijen et al., 2020) were used (see Chapter 5.1). The design vision was created with the help of a metaphor that carries the same qualities as desired interaction (Pasman, Boess & Desmet, 2011) (see Chapter 5.2). Lastly, a list of requirements was created utilising Pugh's checklist (van Boeijen et al., 2020) (see Chapter 5.3).

Develop

The Develop phase aims to generate various creative solutions to the problem defined in the Define phase through ideas and concept iterations. For the first step, ideation, How-to questions, brainstorming, and brainwriting techniques (van Boeijen et al., 2020) were utilised (see Chapter 6). The strategies and mechanisms that the ideas embody were then combined and transformed into three design concepts by sketching (see Chapter 7.1). At the end of this phase, a concept was chosen as the final design

through evaluations with Harris profile, the users, and HPs (see Chapters 7.2 and 7.3).

Deliver

Lastly, the Deliver phase aims to propose a proof-of-concept that fulfils the design goal and is desirable, feasible, and viable. Throughout this phase, details of the final design proposal, such as the function, materials, and appearance, evolved through design iterations and testing with the users (see Chapters 8, 9, and 10). In Chapter 11, the implications of the final design proposal were discussed, and conclusions were drawn on its desirability, feasibility, and viability. As the final step, recommendations were given for further development of the design proposal.

On the right, key insights from the chapter are shown.

Pediatric cancers often cause various **physical** and **psychological challenges** and **drastic life changes**. In order to cope with the challenges and adjust to the changes, patients need to **understand** cancer, its trajectory, and treatments.

TA₁

In Turkey, especially **younger children's understanding** of their illness is **limited** to the information given by their **parents**.

TA2

Play has great therapeutic potential to support children with a life-threatening disease (Bettini et al., 2019; Lina & Santos, 2015; Nijhof et al., 2018).

TA3

This project aims to generate a proof-of-concept for a product that facilitates understanding, adjustment and coping of pediatric cancer patients aged 8-9 in Turkey throughout their cancer journey by utilising the power of play.

TA4

CHAPTER TAKEAN

Chapter 1 ● Project Brief

CHAPTER 2 LITERATURE REVIEW

This chapter presents the findings from the literature reviewed to analyse the context around the problem (see Chapter 1.2.1) and current patient experience. Under each research question that shaped the review, it provides information about pediatric cancer types and treatment methods, factors that affect children's coping and adjustment, the strategies for utilising play in the pediatric cancer context, and existing interventions. The chapter ends with a discussion of the implications of the key insights from the review for the prospective design.

2.1. WHAT ARE PEDIATRIC CANCERS?

This subchapter presents insights from literature about pediatric cancers and their statistics in Turkey.

Although specific causes of pediatric cancers are unknown, they occur as the result of a mutation in the embryonal tissues (National Cancer Institute, 2021; WHO, 2021). These abnormal cells start to divide uncontrollably and spread quickly throughout the body when they are untreated (WHO, 2021). With timely diagnosis and appropriate treatment, it is possible to remove or kill these cells, resulting in a cure (WHO, 2021). In Turkey, the percentage of patients who are alive at least 5 years after their diagnosis (i.e., survival rate) is 70.8% (Kutluk & Yeşilipek, 2019).

2.1.1. Types

According to ACCO (2022), American Cancer Society (2022), and WHO (2021), the most common pediatric cancer types are:

- Leukemia (blood cancers)
- Lymphoma
- Brain and other central nervous system (CNS) tumors
- Neuroblastomas (nerve cancers)
- Bone cancers
- Retinoblastomas (eye cancers)
- Wilms tumors (kidney tumors)
- Sarcomas (soft tissue tumors)

Based on the collected data in the years 2009-2018 by Kebudi (2012) and Kutluk & Yeşilipek (2019), the distribution of these cancer types in Turkey is presented in Figure 4.

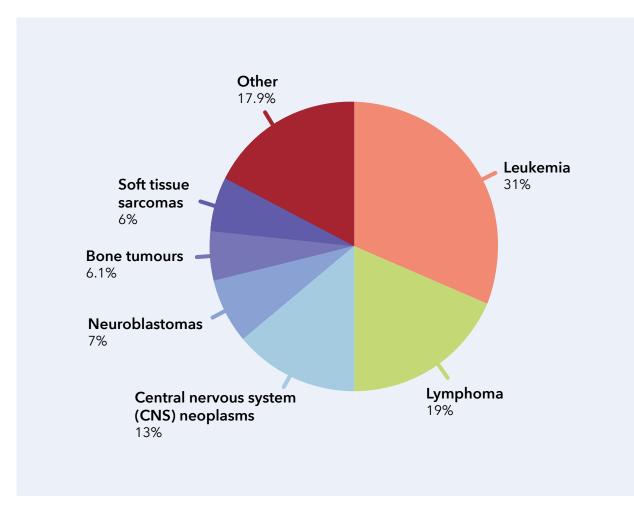


Figure 4: Distribution of pediatric cancer types in Turkey

2.2. HOW ARE PEDIATRIC CANCERS TREATED?

This subchapter presents insights from literature about common treatment methods for pediatric cancers and their effects.

As mentioned previously (see Chapter 1.1), treating cancer is often burdensome for children and their families. Firstly, treatment can last several months to 3 years, during which the child might need to stay at the hospital (Kuppenheimer & Brown, 2002). Moreover, it can involve invasive treatment methods and procedures such as

intravenous injections (IVs) or lumbar punctures (LPs), which could be distressing and painful for the child (Kuppenheimer & Brown, 2002).

The type of treatment depends on the characteristics of cancer (its type, site, stage, histology) and characteristics of the child (age, presence of symptoms, general health) (Institute of Medicine (US) & National Research Council (US) & National Cancer Policy, 2003). In general, chemotherapy is usually successful in the removal

of rapidly growing cells (Institute of Medicine (US) & National Research Council (US) & National Cancer Policy, 2003; WHO,2021). However, it is usually combined with other treatment options such as radiotherapy and/or surgery (Institute of Medicine (US) & National Research Council (US) & National Cancer Policy, 2003). Although these methods can yield promising results, they can cause many side and late effects. The methods, their side, and late effects are summarised in Figure 5.

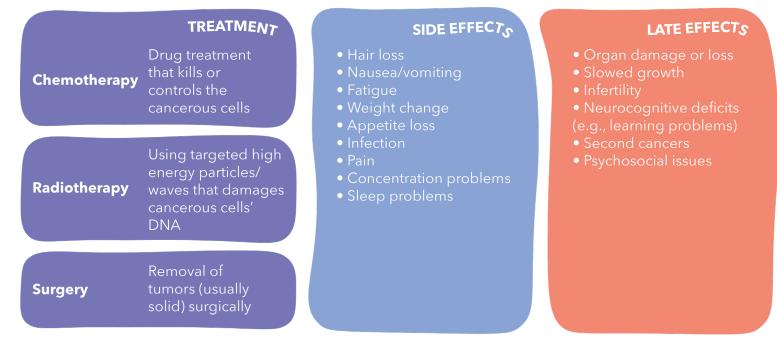


Figure 5: Treatment types of pediatric cancers (American Cancer Society, 2022; Institute of Medicine (US) & National Research Council (US) & National Cancer Policy, 2003; National Cancer Institute, 2021)

2.3. WHAT AFFECTS CHILDREN'S ADJUSTMENT AND COPING?

This subchapter presents insights from literature about the factors that affect children's adjustment to life changes and coping with cancer.

Besides physical challenges, cancer can cause the patients and their families to experience both short- and long-term psychosocial issues that affect their adjustment, coping, and consequently, their overall experience (Kuntz et al., 2019; Kurtz & Abrams, 2010). Moreover, the child's family is the main factor that shapes the medical, psychosocial, and developmental outcomes of their illness experience (Boles & Daniels, 2019). According to Kurtz & Abrams (2010), parents are the greatest potential source of support and strength for the child, but they might also be dealing with stress or anxiety themselves. Therefore, Koocher (1986) states that adjustment of children largely depends on social support available to parents and parental distress levels.

Although the cancer experience is challenging in general, some incidents have more negative psychosocial impacts on the children and their families. The following sections explain these incidents briefly.

2.3.1. Diagnosis

According to the parents who joined the study by Mant et al. (2018), the most challenging period of their child's journey is diagnosis. After a waiting period filled with uncertainties, tests, and procedures, diagnosis is usually first revealed to the parents (Prof. Dr. M. Elli (MD), personal communication, 2022; Taşkıran Tepe, 2019). Upon receiving this information, parents often go through the five stages of grief: shock, denial (as a defense/coping mechanism), anger, resentment, and acceptance (Er, 2006; Mant et al., 2018). When these feelings are combined with the urgency of the treatment, association of cancer with death, and lack of psychological support, parents might want to protect their children from this devastating information to maintain their hope and spirit (Coyne et al., 2016; Gray et al., 2014; Prof. Dr. M. Elli (MD), personal communication, 2022; Young et al., 2003). As a result, parents usually hide the diagnosis or give restricted information to their children about their illness and even try to control the information given by HPs to children in Turkey (Kebudi, Çakır & Büyükkapu, 2022; Mant et al., 2018; Taşkıran Tepe, 2019). However, the parents often underestimate their children's abilities to cope and understand while exhibiting such behaviour (Coyne et al., 2016; Küreci & Büken, 2016).

On the other hand, children are good at identifying adult emotions, picking up cues in their environment that might indicate the seriousness of their condition, and even shielding their knowledge from parents, who assume that they are unaware or not interested (Eiser &

Havermans, 1992). Therefore, parents' attitude of hiding or simplifying information can lead to confusion, anxiety, and loneliness in children since they cannot share their fears and concerns with anyone (Eiser & Havermans, 1992; Koocher, 1986; Küreci & Büken, 2016; Mant et al., 2018).

Although disclosure of diagnosis can evoke feelings such as shock, disbelief, or fear in children at first, early and honest information usually results in less anxiety and depression, higher self-esteem, increased coping ability, better compliance to the treatment, feeling prepared for the medical procedures, and feeling supported by the family (Eiser & Havermans, 1992; Mant et al., 2018; Ruhe et al., 2015; Scott, Prictor & Watt, 2003; Taşkıran Tepe, 2019). However, it should be noted that children can also have different coping strategies depending on their personality and developmental stage (Marcus, 2012). For example, children might choose not to be informed in detail or completely ignore the facts about their illness to protect themselves from fearful information (Coyne et al., 2016; Eiser & Havermans, 1992; Young et al., 2003).

2.3.2. Disruption of school life

Another impact that cancer creates on children's lives is the disruption in their school performance and peer relationships. School is an important factor that provides routine both to the child and their parents (Kuntz et al., 2019). Also, it

is a place to maintain social contact and gain skills needed for successful functioning later in life (Kuntz et al., 2019). However, especially hospitalisation period can cause the child to be separated from their peers and mentors (Kuntz et al., 2019). The impact of separation might be more burdensome for school-age children since peer relationships are gaining importance at this developmental stage (Kurtz & Abrams, 2010). In the study by Boles et al. (2017), children stated that they experienced loneliness, confusion, and the feeling of being different when separated from their school environment during treatment. Consequently, the importance of the relationship with the family can increase. Many patients expressed that cancer brought them closer to their families (Kuntz et al., 2019).

2.3.3. Limited physical activity

As a side effect of the treatments, patients can experience fatigue, loss of strength, and inability to participate in sports or activities (Kuntz et al., 2019). During the middle childhood stage, when rough-and-tumble play (i.e., play fighting) is common, limited physical activity can cause frustration and boredom in children (Angström-Brännström & Norberg, 2014; Slater & Bremner, 2017). Additionally, when children are hospitalised, and their infection risk is high, they are not even allowed to leave their room (oncology nurse, personal communication, 2022). Therefore, cancer treatment can be highly restrictive for the patient both in terms of physical activity and social contact with other patients.

2.3.4. Changes in physical appearance

Some unpleasant side effects, such as hair loss (see Figure 6) and weight change usually affect the body image of the patients or make them stand out in social settings such as school (Angström-Brännström & Norberg, 2014; Taşkıran Tepe, 2019). Although it is more important for adolescents and young adults, schoolage children can have concerns regarding the changes in physical appearance. According to the oncologist Prof. Dr. Elli, the question of "Am I going to lose my hair?" is frequently asked by especially female patients of this age group (Prof. Dr. M. Elli (MD), personal communication, 2022).



Figure 6: A patient experiencing hair loss (Branson, 1985)

2.4. HOW TO MAKE CHILDREN FEEL BETTER THROUGHOUT THE CANCER JOURNEY?

This subchapter presents insights from literature about the play strategies and existing interventions that are utilised to make children feel better throughout the cancer journey.

In general, children can be comforted in various ways: being touched, looking at or reading a book, listening to a story, playing, being close to and spending time with parents, and being held on their lap (Chang, 2001; Devereaux-Jordan, 1997; Haiat, Bar-Mor, & Shochat, 2003; Kankkunen, Vehviläinen-Julkunen, Pietilä, & Halonen, 2003; Pölkki, Pietilä, & Vehviläinen-Julkunen, 2003 as cited in Angström-Brännström & Norberg, 2014). For children with cancer, parents, visitors, friends, stuffed animals, entertainment, and play can be counted as sources of comfort (Angström-Brännström & Norberg, 2014).

In the context of childhood cancers, especially the potential of play is being explored and utilised by healthcare professionals, psychologists, and designers. Apart from providing entertainment in general, research shows that play is mainly used as a therapeutic tool that can improve the coping skills of children and their families or as an informative tool that can contribute to children's understanding of cancer-related topics (Huerga, Lade & Mueller, 2016; Marsac et al., 2012; Moreira-Dias & Silva, 2018). However, the research presents various strategies to benefit from play in a hospital setting, which are briefly

explained in the following sections.

2.4.1. Providing supportive care

The play interventions that use this strategy aim to improve the well-being of pediatric cancer patients and their families by identifying and discussing the psychosocial issues that they are experiencing, teaching them methods to cope with those issues, and allowing them to express their feelings. To exemplify, ShopTalk incorporates this strategy in the form of a board game. It allows patients to discuss issues with therapists and express their feelings, concerns, hopes, and fears in a playful way (Wiener et al., 2011). Similarly, Cellie Cancer Coping Kit in Figure 7 consists of cards with coping strategies on, a stuffed toy, and a caregiver book (Marsac et al., 2012). It helps children and their parents identify stressors, offers strategies to deal with them without the need for a therapist, and improves their communication around sensitive cancer-related topics (Marsac et al., 2012).

2.4.2. Providing distraction

The play interventions that use this strategy aim to provide distractions from the invasive procedures that can cause fear and pain in pediatric cancer patients and entertain them when hospitalised. To exemplify, Gershon et al. (2004) demonstrated that playing an immersive virtual reality game can reduce the pain and distress of children during port access procedures. Similarly, Aslan & Erci



Figure 7: Cellie Cancer Coping Kit (Marsac et al., 2012)

(2021) found that making toys out of medical materials (e.g., examination gloves, injectors, tongue depressors, and plaster) and playing with them during IV treatments caused distraction from the procedure and relieved the pain in children.

2.4.3. Providing information

Similar to serious games, the play interventions that use this strategy embody direct and honest information about cancer, treatments, their benefits, side effects, etc., while presenting them as a part of a storyline. An example is the ReMission computer game (see Figure 8) which aims to increase adolescent and young adult patients' adherence to treatment by engaging in positive self-care behaviours (Kato et al., 2008). In the game, the patients can destroy cancer cells by becoming a nanobot or manage adverse effects (e.g., nausea) by using treatments as ammunition (Kato et al., 2008). Another intervention is the Imaginary Friends Society by The Pediatric Brain Tumor Foundation (n.d.). A set of characters

inspired by children's drawings (i.e., imaginary friends) explain a wide range of complicated cancer topics in a way that kids can understand in short, animated movies (The Pediatric Brain Tumor Foundation, n.d.).

2.4.4. Reframing children's perspective

The play interventions that use this strategy aim to reduce negative feelings by reframing children's perspectives towards cancer, treatments, or experience with the hospital environment. For example, Medical Play Kit (see Figure 9) by American Childhood Cancer Association (2021) gives children a sense of control by taking the role of a doctor/nurse and prepares them for medical

procedures by desensitisation of commonly used medical materials. Doctor Giggles, a digital and interactive game by Huerga, Lade & Mueller (2016), changes children's perception of the hospital environment and medical tools by changing the meaning or function of these (e.g., the syringe is a magic wand that changes the color of the room's lighting). Another example is Beads of Courage (Children with Cancer UK, 2021) in Figure 10, which reframes the hospital as a place to collect memories and the child as a hero. The beads received for every stage of the cancer treatment form physical representations of children's recovery by keeping a record of every hospital trip and treatment on their courageous journey (Children with Cancer UK, 2021).



Figure 8: A screenshot from Re-Mission computer game (Tate, Haritatos & Cole, 2009)



Figure 9: Medical Play Kit (ACCO, 2021)



Figure 10: Beads of Courage® (Children with Cancer UK, 2021)

2.5. CONCLUSIONS & DISCUSSION

This subchapter concludes Chapter 2 by discussing the implications of findings from the literature for the prospective design.

The literature review helped to understand the context around pediatric cancers and the current experience of pediatric cancer patients and their families. It revealed the challenges and issues of the families throughout the trajectory of cancer, and the barriers and facilitators of children's understanding, adjustment, and coping.

Key insights from the review form the takeaways from this chapter. While some of these takeaways imply opportunities that show how to solve the problem described in Chapter 1.2.1, the others indicate requirements that the solution should comply with (on the right).

There are various types of pediatric cancers. Treatments differ according to the type of cancer and characteristics of the child and have serious physical and psychosocial side effects.

The prospective design should take the challenges and requirements of different cancer types into account (e.g.,

The communication dynamics between children and parents is the main factor that shapes children's understanding, adjustment, and coping. Open communication often yields better adjustment and coping.

Every child has **different** coping strategies. Some children want to be informed in detail, whereas other prefer to ignore the facts about their illness.

The prospective design should target the parent-child interaction rather than the child only. It can be an intervention that encourages open communication.



Most challenging incidents in the cancer experience of children in their middle childhood are diagnosis, disruption of school life, limitation of physical activity, and changes in physical appearance.

The prospective design should respect children's preferences of how much they want to be informed.

focus on at least one of these incidents while benefiting from the strategies of utilising play

The prospective design can_ at the hospital.

Play can facilitate children's adjustment and coping by changing their perspective of the illness and hospital, teaching methods for dealing with challenges and negative feelings, and providing information, distraction and entertainment.

CHAPTER TAKEAWA

CHAPTER 3 FIELD RESEARCH

This chapter presents the insights obtained from the field research conducted in Turkey. First, the chapter gives information about the interviews conducted with the healthcare professionals to understand their perspectives on the problem and specifics of the current context around pediatric cancers in Turkey. Then, it elaborates on the generative interviews conducted with the target users to understand their current experiences, needs, and wishes. The chapter ends with a discussion of the implications of the key insights gathered from field research for the prospective design.

3.1. INTERVIEWS WITH HPs

This subchapter describes the research questions, method, and outcomes of the interviews conducted with HPs in Turkey.

Although the healthcare professionals are not the end-users of the prospective design (see Chapter 1.2.2), they affect children's cancer experience by providing medical care. Along with the parents, they can also shape children's understanding by (not) providing information to them. Moreover, they are familiar with the problems, needs, and wishes of the patients and their families since they interact with them daily. Thus, interviews with a pediatric oncology specialist and a nurse were conducted to understand their perspective on the problems in patients' experiences throughout the cancer journey and their contribution to children's understanding of their illness in Turkey.

3.1.1. Research Questions

With the interviews, the following research questions were aimed to be answered:

- **1.** What are the most problematic aspects of the patients' current cancer experience, according to healthcare professionals?
- **2.** How and to what extent are school-age children informed about their illness?

3.1.2. Method

Two semi-structured interviews were performed with the pediatric oncology specialist Prof. Dr.

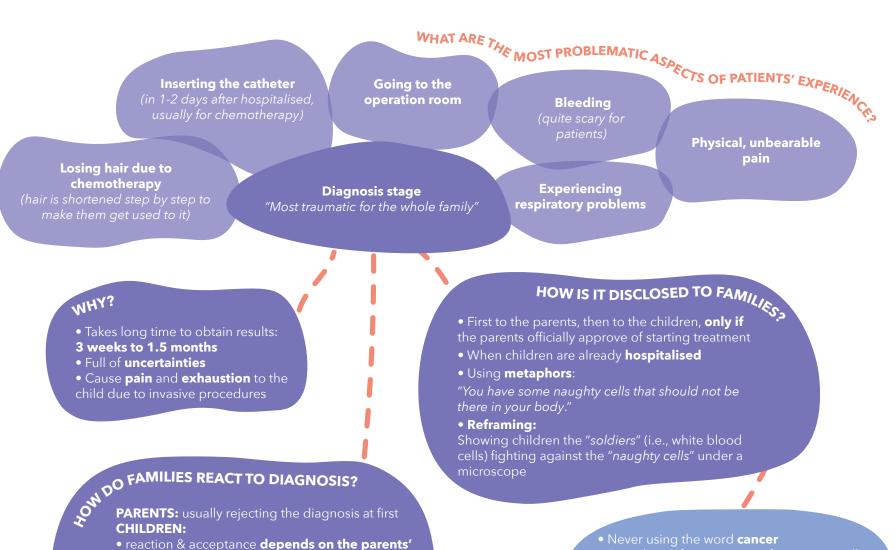
Murat Elli and the head nurse of the oncology ward separately. The interviews were not recorded, only notes were taken.

3.1.3. Results

The healthcare professionals indicated many pain points in patients' current cancer experience, including the impact of invasive procedures and side effects of the treatments. However, they named the diagnosis stage the most traumatic experience for the whole family, whose impact was highlighted in the literature review also (see Chapter 2.3). Moreover, they answered the second research question by indicating that they give patients limited or simplified information about cancer step by step, with the help of metaphors, and only if it is allowed by the parents. While Figure 11 on the next page gives an overview of these insights, their implications for the prospective design are discussed at the end of the chapter (see Chapter 3.3).

To see the complete list of questions and the transcripts of the interviews, please see Appendix B.

Chapter 3 ● Interviews with HPs 21



- acceptance, but often easier for them to accept
- cannot fully **comprehend** the concept of a life-threatening illness
- not asking questions at first, but common

"How long do we stay here?"

- "Am I going to lose my hair?"
- "Will I go to the operation room again?"

- Revealing information step by step, not all at
- "We tell them their hair will fall once we start

chemo"

NO TO WHAT EXTENT ARE THE PATIENTS INFORMED?

Figure 11: An overview of insights obtained from the interviews with HPs

3.2. USER RESEARCH

This subchapter presents the research questions, method, and outcomes of the generative research conducted with patients and their parents in Turkey.

During the literature review, no studies that explore the illness experiences of pediatric cancer patients aged below 12 from their own perspectives in Turkey were encountered. Therefore, user research was conducted with the patients in Medipol Mega University Hospital in Turkey upon approval of the hospital's ethical committee (see Appendix C). The research aimed to explore pediatric cancer patients' emotions, needs, wishes, and experiences from their own perspectives throughout their cancer journey. Throughout the research, the main focus was on the children and the diagnosis stage due to the initial project scope (see Chapter 1.2.2).

3.2.1. Research Questions

With the user research, the following research questions were aimed to be answered:

- **1.** How do school-age (8-9) children experience their cancer journey focusing especially on the diagnosis stage? How do they describe this journey?
- **2.** To what extent do they understand their diagnosis and trajectory of cancer treatment?
- **3.** What are the enablers and/or obstacles to help them understand their diagnosis?

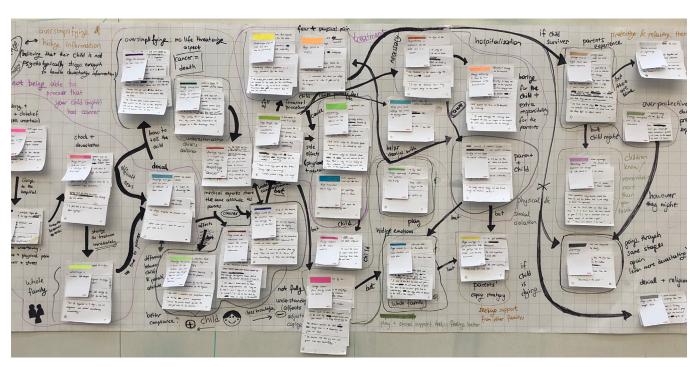


Figure 12: An illustration of clustering process of statement cards

4. What are the enablers and/or obstacles to help them accept their diagnosis?

3.2.2. Method

The research was conducted in the form of semi-structured interviews. During interviews, generative techniques (e.g., collaging) from Contextmapping (Sleeswijk Visser et al., 2005) and Draw and Write methods (Pridmore & Bendelow, 1995) were used. Figure 13 on the next page gives an overview of the whole procedure and the participant demographics. For a detailed description of the method and the interview guide, please see Appendix E.

3.2.3. Results

The interviews were analysed by using statement cards (Sanders & Stappers, 2013) and the Grounded Theory approach (Corbin and Strauss, 1990). Most interesting quotes were selected from the transcriptions (see Appendix F) and written down on separate cards with the researcher's interpretation above (see Appendix G for the complete set of the statement cards). Then by clustering and grouping these cards, themes, patterns, and connections in the data were explored. Figure 12 illustrates this process.

Chapter 3 ● User Research

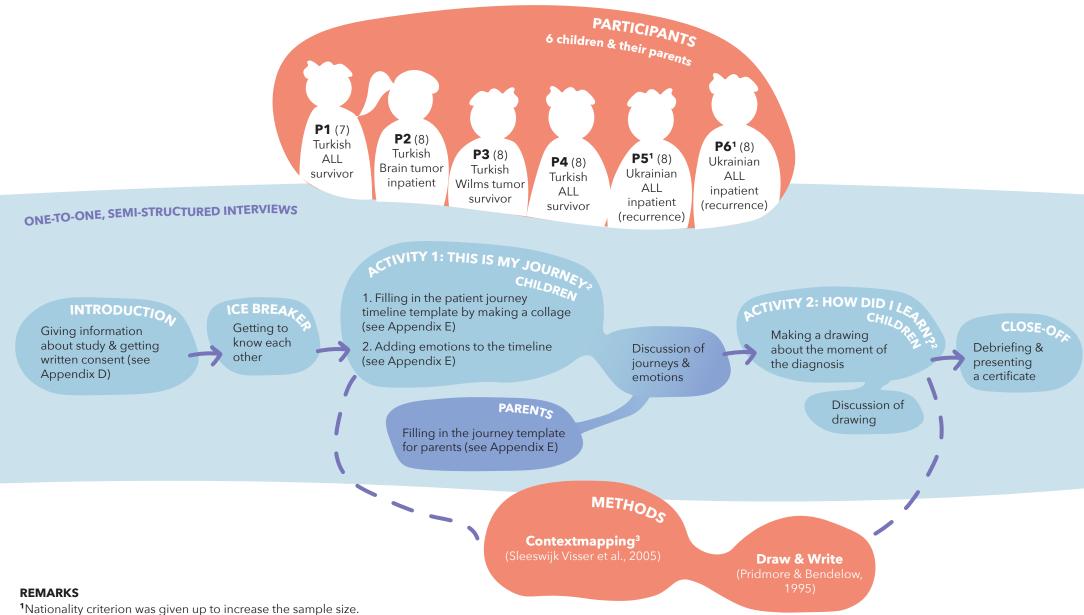


Figure 13: An overview of the research procedure & participant demographics

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²These activities were completely skipped in some cases:

⁻Child did not want to make a collage/drawing (children answered the questions directly)

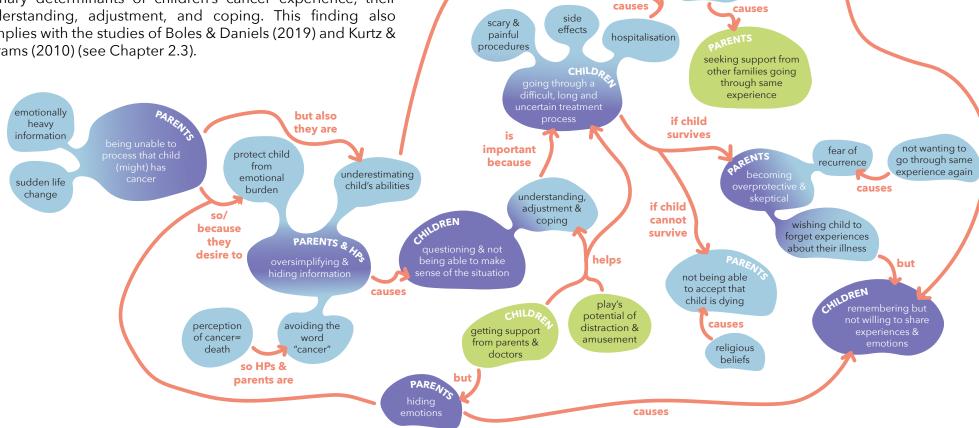
⁻Parents did not allow researcher to talk to children about their illness (only parents were interviewed)

³Sensitisation step was skipped due to time constraints.

Insights from the Analysis of Interviews

As a result of the statement card analysis, a map in Figure 14 was created. The map describes the current context around the cancer experience of children in Turkey by showing the problems (purple) and facilitators (green) in the context (i.e., themes), factors affecting them or they are affecting (i.e., subthemes) (blue), and their relationship with each other (orange arrows).

It is striking to see from the map that parents' mindsets, attitudes, beliefs, and psycho-emotional states are the primary determinants of children's cancer experience, their understanding, adjustment, and coping. This finding also complies with the studies of Boles & Daniels (2019) and Kurtz & Abrams (2010) (see Chapter 2.3).



but

difficulty of amusing

the child

social &

physical

isolation

Figure 14: A map explaining problems, facilitators, and their relationship in the context

Chapter 3 • User Research 25 The main themes (problems & facilitators) in the context are explained in the following paragraphs.

Problems

Theme 1: Being unable to process that child (might) has cancer

In line with the findings from the literature (see Chapter 2.3), parents often have difficulties processing that their child has cancer. Before receiving the diagnosis, some parents already suspect cancer due to their child's symptoms or the hospital's referral to the oncology ward. However, they refuse to believe that their child can have cancer. With this denial and disbelief. hearing that their child has cancer becomes shocking and devastating for them. Moreover, the hospital does not offer any psychological support to them while receiving the devastating news. Right after diagnosis, they experience a sudden and significant life change due to hospitalisation since the child needs urgent and intensive treatment. When this urgency is combined with the emotionally heavy nature of the diagnosis, the parents can find neither time nor resilience to process the fact that their child has cancer.

"When I heard that my child has cancer, I felt like I hit a wall, couldn't feel anything"

Mother of P6

Theme 2: Oversimplifying & hiding information

While still dealing with the fact that their child has cancer, parents assume that their child cannot also handle this information. They want to protect their child from the emotional burden that they are experiencing. However, they often underestimate their child's ability to understand and cope. As a result, they oversimplify or hide information about their illness from children.

"We never talked to him about his diagnosis. We only said to him that he is ill, and he needs to get treatment"

Mother of P5

In addition, the association of cancer with death makes it difficult for parents to be open and honest with the child and results in avoiding using the "cancer" word while communicating about the illness. Therefore, in many cases, they only tell their child that (s)he is ill and needs to stay at the hospital or present cancer as a "minor illness." Since the child does not know what their illness is or the details of it, parents feel threatened when someone else wants to communicate child about their experience and; they want to control the information given by others (e.g., the researcher, doctors).

Theme 3: Questioning and not being able to make sense of the situation

Because of their parents' attitude, children cannot understand or make sense of certain situations, such as why they need to stay at the hospital or why they are not going to school. Most of the time, parents weather these kinds of questions of children saying that because they "need" or "have to." Children are usually unsatisfied with their parents' answers, and; they keep asking such questions. Still, parents usually make them accept these sloppy answers in the end: by being persistent in their attitude.

On the other hand, parents do feel the need of giving information about procedures such as surgery or side effects, such as hair loss. In this case, the child can get confused and might not understand why they need to go through these procedures or treatments if they are "just ill." Even when they are given simplified information, they can come to the wrong conclusions. For example, a participant (P2) indicated that she had surgery because she had a "headache." In conclusion, this attitude of children emphasises that they experience difficulties understanding or adjusting to the changes in their lives (e.g., not going to school) due to their parents' attitude.

"Why am I not going to school?"

Р6

Theme 4: Going through a difficult, long, and uncertain treatment process

The long and uncertain treatment process is usually frustrating both for children and the parents since they usually experience social and physical isolation due to hospitalisation and side effects of treatments (e.g., weakening of the immune system). Children can be upset or scared because of the invasive procedures, side effects (e.g., hair loss, nausea), or restrictions (e.g., not being allowed to have visitors or eating certain foods) since they are not expecting to encounter these. As a result, children might want to know when this process will end, but it is often uncertain due to unexpected events such as having a fever or infection. These unexpected events, lack of social interaction, and seeing their child's agony often traumatise parents as well. While traumatised, they also feel the need of amusing their children, especially during hospitalisation since children feel boredom.

"Is it ever going to end?"

Ρ4

Theme 5: Hiding emotions

While the parents are still trying to process the diagnosis, they often go through a traumatising experience, as mentioned in the previous theme. On the other hand, they feel the need of entertaining their child, want to keep their morale up, and do not want to cause their child to worry about their illness. Therefore, parents hide their emotions from children with the desire

to protect them from the emotional burden. As indicated in the quote below, they often try not to break down in front of the child. However, they feel overwhelmed due to not being able to share it with someone.

"I am with him all the time. I need to keep him entertained but it is too hard sometimes, especially when you are feeling bad. I have to go out of the room, cry outside, come back and play with him again even if I feel bad."

Mother of P6

Theme 6: Becoming overprotective and sceptical

Even after the survival, the impact of cancer on parents lasts. The cancer experience usually makes parents overprotective and sceptical after survival with the fear of recurrence. Even the tiniest complaint of the child can alert them, and they can question every symptom.

In addition, they show overprotective and controlling behaviour by wanting their child to forget about the whole experience of their illness and feel psycho-emotionally unaffected. They also assume that their child has forgotten

everything.

"My child forgot about everything related to his illness and treatment process. That is why, I do not want you to remind him."

Father of P1

Theme 7: Remembering but not willing to share their experiences and emotions

As mentioned in the previous theme, parents desire their children to forget about the cancer experience completely and assume that they do. Although parents are underestimating children's abilities, children can actually remember many details; they just might not be willing to share, which is similar to parents' hiding behaviour. For example, a participant (P3) hinted that even after a year, he remembers who was in the room when his diagnosis was explained to him. However, he refused to give more details and express his emotions.

"Please don't ask me these familial questions"

Ρ:

(When he was asked if his family's presence gave him power while getting the diagnosis)

Facilitators

Theme 1: Getting support from parents & doctors Feeling the support of their parents and doctors makes children feel assured and more optimistic, which can lead to better coping. For example, a participant (P2) stated that she felt powerful and supported by her parents when she needed to have surgery.

"The doctors said my hair will grow back even more beautifully."

P2

Although parents often prefer to hide their emotions from children, they want to provide or show their support to their children just by being there for them, physically comforting them, or acting compassionately. For example, a father (P4) indicated that as parents, they wanted to show their support to their child by wearing face masks with him when they go out. With this act, they tried not to make him feel alone or "different" (before COVID-19).

Theme 2: Play's potential for distraction and amusement

As mentioned before, children can frequently experience boredom, fear, or sadness throughout the hospitalisation period. In these cases, play helps to uplift their mood, kill time, provide entertainment and strength, and distract them. Since the parents discovered this effect of play

on their children, they often seek opportunities for play at the hospital. For example, two mothers (P5 & P6) indicated that they found it hard to entertain their children due to the lack of social events, play areas, or opportunities at the hospital.

"It is really hard to keep children at the hospital during this process. There are no activities or a playing area here."

Mother of P6

Theme 3: Seeking support from other families going through the same experience

As a result of the social and physical isolation during hospitalisation and not being able to share emotions with the child, parents can find support from other parents of the patients staying at the hospital. They are more willing to share their feelings with the other parents since they think they can empathise with them. According to Gray et al. (2014), it is a common

coping strategy for parents in collectivistic

"Families going through same experience look for each other"

Father of P4

cultures, including Turkey.

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3.3. CONCLUSIONS & DISCUSSION

This subchapter answers the research questions and discusses the implications of the insights from the field research on the prospective design.

While the interviews with HPs revealed their perspectives of patients' cancer experience and the specifics of how cancer-related information is currently being communicated to children, user interviews put forward the enablers and obstacles in children's current cancer experience, their understanding, and adjustment. Together, they helped to understand the use context of the prospective design and identify design opportunities and requirements.

The following paragraphs answer the research questions.

1. How do school-age (8-9) children experience their cancer journey focusing especially on the diagnosis stage? How do they describe this journey?

Children usually experience pain or fear of pain due to invasive procedures and not being prepared for them, frustration or sadness due to side effects or restrictions, and boredom due to hospitalisation. Therefore, they describe this journey as scary and frustrating mainly due to physical pain, side effects, and unknowns.

2. To what extent do they understand their diagnosis and trajectory of cancer treatment?

In terms of diagnosis, they do not have much to say since they are usually not informed or given simplified information. This situation cause children to be more concerned about the hospitalisation period rather than the diagnosis itself since they do not know what to expect, therefore, are not prepared.

In light of this insight, prospective design should also target the hospitalisation period, although the project had started with a focus on the diagnosis stage (see Chapter 1.2.2). This decision will be further emphasised with the help of the User Journey Map in Chapter 4.1.

3 & 4. What are the enablers and/or obstacles to help them understand and accept their diagnosis?

As a recurring insight in both literature review and field research, the effect of parents on children's overall experience, particularly on their understanding and adjustment, is undeniable. Therefore, it can be said that parents are both the enablers and obstacles for children to understand and accept their diagnosis by hiding information and emotions and by being an important source of support.

In fact, it might not even be possible to facilitate children's understanding and adjustment without changing the parents' perspective first since they want to control cancer-related information given to their children by others as well. This insight emphasises that prospective design should target both parent and child rather than only the child, as indicated in Chapter 2.5.

On the next page, takeaways from the chapter and their implications for prospective design are shown.

APTER TAKEAWAYS

Parents hide illness-related information and their emotions from children to protect them from emotional burden because they are underestimating children's abilities and resilience.

Besides facilitating open communication for children and parents, prospective design can also facilitate expressing emotions to each other.



Although parents often prefer hiding their emotions from children, they want to provide or **show their support** to children with their **acts** or **physical contact.**

TA2

The prospective design can help parents to show support or express their emotions to children by offering an implicit and gentle way of doing so.



HPs in Turkey **never** use the word "cancer" and use **metaphors** to explain cancer to children.

TA3

The prospective design can also benefit from **metaphors** to facilitate communication with children about cancer and **make** it less threatening for parents.

The prospective design

should provide both children and parents a sense of being supported by each other.



Parents **feel threatened** when someone else wants to communicate their children about their illness, and they want to **control** the cancer-related information given to children by the others.

TA4

The prospective design should not present cancer-related information explicitly or force family to share emotions or show support (i.e., being intrusive) to be acceptable by the parents.

The prospective design should give parents a sense of being in control to be acceptable by them.



Parents are **aware** of play's potential. They want to utilise it to entertain their children but currently there are **no opportunities** at the hospital.

TA5

The prospective design can be easily acceptable or even desirable by the parents since play is at the core of the project.



Parents are more willing to share their feelings with the other parents going through the same experiences.

The prospective design can offer a way of bringing these parents together to alleviate the emotional burden of parents.



CHAPTER 4 RESEARCH SYNTHESIS

This chapter presents the user journey map and personas, which were created by synthesising field research insights. First, the chapter elaborates on the pain and delight points on the journey map. Then, it describes two parent and three children personas, which visualise different characteristics and needs of the target users. Finally, the chapter discusses the implications of the journey map and personas for the prospective design.

4.1. USER JOURNEY MAP

This subchapter presents the journey map (see Figure 15 on the next page) that was created out of the experiences, quotes, and emotions of the users from the field research (i.e., 6 patients & parents).

At the top, the map shows the steps that pediatric cancer patients and their parents go through in each stage of the cancer trajectory and their duration. Moreover, it provides insights into how the feelings and thoughts of the family change in each step. Therefore, it helps to identify the events or stages that create the most negative or positive impact on the parents and children.

At the bottom, the map shows the pain and delight points for the family throughout the journey. The pain points indicate the experiences that occur throughout certain events and create negative feelings. Therefore, they serve as an opportunity for improvements. On the other hand, delight points indicate the experiences that create positive feelings and can imply a way to improve the negative experiences.

When the map is examined, the impact of the hospitalisation period stands out since it embodies a considerable amount of pain points for both children and parents. Besides causing a sudden life change, the duration of hospitalisation and lack of social and cognitive stimulation throughout this period are common pain points for both children and parents. As discussed in Chapter 3.3, play, which will be at

the core of the prospective design, holds great potential to alleviate these pain points.

As also indicated in Chapter 3.3, children have a more negative experience during this period than their parents since they encounter invasive procedures, intensive treatments, side effects, and restrictions for which they are not prepared. As emphasized before, this situation is mainly caused by not being sufficiently informed by both parents and healthcare professionals. Consequently, children's confusion and distress transform into fear, anxiety, and sadness. As seen from the guotes and thoughts of children (red text in Figure 15) on the next page, children are more concerned about the procedure/treatmentrelated issues (e.g., pain) and the life change rather than the illness itself; because they are unaware of their illness's life-threatening nature.

On the other hand, parents experience the most negative feelings throughout the diagnosis stage, especially when the diagnosis is disclosed to them. Overall, the diagnosis stage is physically and psycho-emotionally tiring for parents since it can take time to obtain a certain result. Until they get the diagnosis, they experience mixed feelings of hope, doubt, and anxiety. Although they already have suspicions, hearing that their child has cancer is still shocking and difficult to accept for them. A pain point identified during this process is the lack of professional psychological support for the parents. As shown by the outcomes of user research (see Chapter

3.2), one of the reasons that parents hide or oversimplify information is not being able to process the diagnosis. Therefore, this pain point can be an opportunity for the prospective design to have a function that provides parents psychological support.

Despite the overall negative experience, there are some delight points, where both children and parents experience positive feelings as well. During the hospitalisation period, having social interaction, such as getting visitors or being allowed to have visitors, improves the parent and child's mood significantly. Naturally, having clear scans or blood test results creates relief. and being able to go home or back to their routine makes parents and children happy. The prospective design can benefit especially from the first delight point, having social interaction. In the previous chapter, a design opportunity, which brings the families of children with cancer together, was discovered. Besides this opportunity, the prospective design can have the function of facilitating contact with other family members, relatives, or friends.

In conclusion, the user journey map emphasises the insights discovered through field research and provides an overview of pediatric cancer patients and their parents' current experiences.

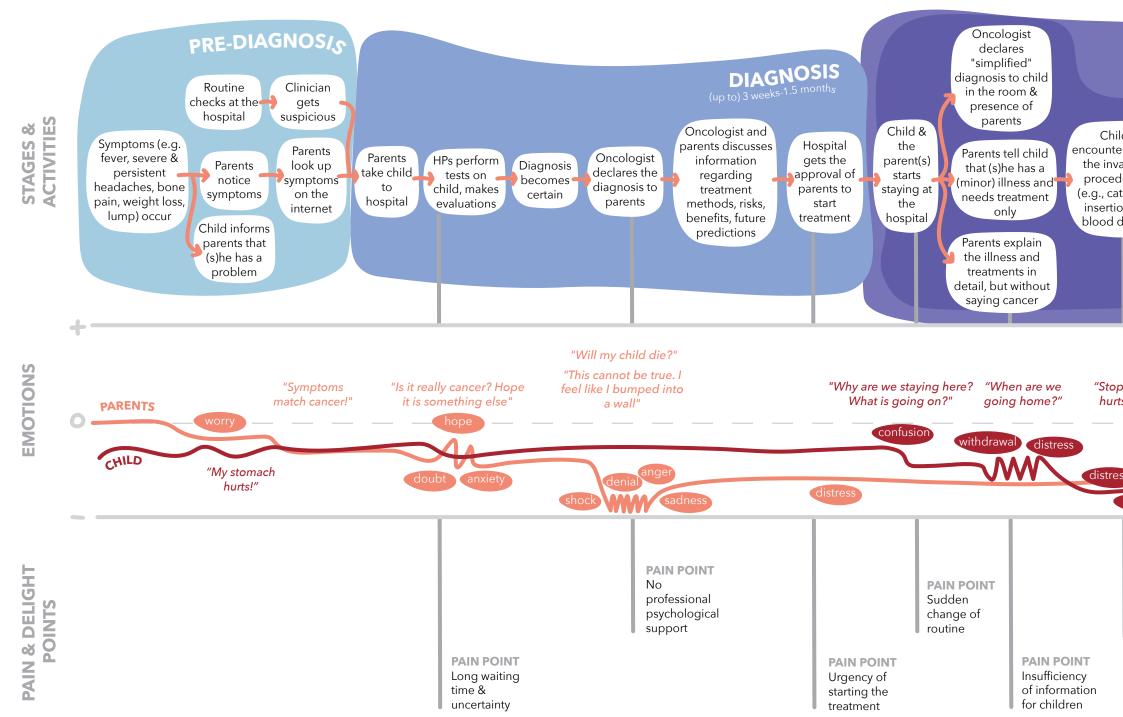
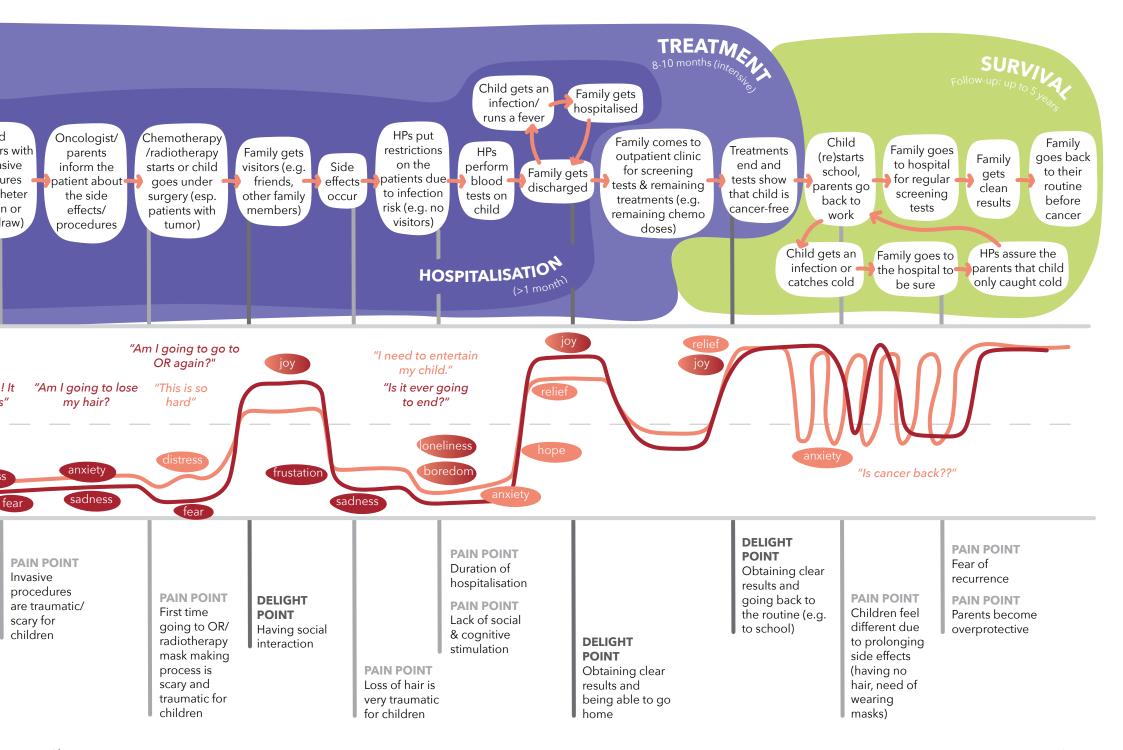


Figure 15: The cancer journey map of children & parents in Turkey

Chapter 4 ● User Journey Map



Chapter 4 ● User Journey Map

information & emotional sharing

In order to identify different types of prospective users in the target group and visualise their needs, attitudes, and goals, personas were created for children and parents. This subchapter presents these personas.

Based on the different attitudes of children and parents interviewed, three different patient types and two different parent types were identified. Each parent persona represents a different attitude in terms of information and emotionsharing characteristics with their children, whereas each child persona corresponds to different information and compliance level.

Figure 16 on the right illustrates the parent personas, whereas Figure 17 on the next page shows the child personas.

MEHMET (40

"You had a minor illness which I also have."
"I will do anything for my son."

Description:

Mehmet was told that his son has leukemia, which he already guessed because of child's symptoms. He was shocked and devastated. He started to worry about how to tell his son because he was too young and vulnerable. To protect and comfort him, he told his son that he had a minor illness which he also had. Throughout the treatment, he tried to be always by his son's side and show his support, even by having an IV drip himself. After his son was survived, he wanted him to forget about his illness experience. To make sure he forgot, he took him to play therapy.

Needs & Goals:

- Protect his child from possible trauma
- Show his son his support
- Control what other people say to his child
- Share how they feel as parents with other parents going through the same experience

Challenges:

- Thinks his child does not remember anything, because he does not talk about that period
- Feels failed when his child feels bad
- Is afraid of other people hurting his son reminding/telling something about his "real" condition
- Does not want professional help

"You are ill and need to stay at the hospital."
"We have to deal with this alone,
only me and my son. We have no one."

Description:

Aylin's son survived leukemia 2 years ago. She never told him that he had cancer because he was young. Recently, she received the bad news again: her son's cancer recurred. She got very depressed and could not accept it. She was questioning why it happened to them. She decided not to tell her son again. Even she herself could not handle the news, how could her son? But her son was questioning why they were staying at the hospital. She just told him he was ill and he needed to stay at the hospital. He was not convinced, he kept asking but she could not give him more details. She was dying inside, but she could not show him that because no one was allowed to be with them due to isolation. She needed to keep him entertained. That's why, she needed to go out of the room and cry without him seeing her.

Needs & Goals:

- Social support, cannot handle this experience alone
- Be strong for her child, she is his only support
- Entertainment options for her child while staying at the hospital
- Her child to accept the situation without questioning

Challenges:

- Cannot accept the situation
- Hides emotions from her child but has no one to share
- Hides information regarding cancer from the child completely



Figure 16: Parent personas

CEMRE (9

"My mom and dad gave me a lot of support"
"I know that my hair will grow even more
beautifully because my doctors said so"

Description:

One day, Cemre started to have headaches, which continued for a week. She told her mom and dad that she was having headaches. When they took her to the hospital, doctors told her she needed to have a surgery because of "her headaches". She was scared but when she got out of the surgery she was just feeling tired. Then she had to take chemotherapy 4 times and also radiotherapy. She got upset the most when she lost her hair. But her doctors assured her she would have her hair back and even more beautifully. Therefore, she was hopeful and grateful that her parents were always there for her.

Needs & Goals:

- •Support from her parents
- •Get better but she is hopeful that she will
- •Get rid of the side effects (e.g. hair loss, nausea)
- •Share her feelings & emotions with her parents

Challenges:

•Knows the name of the procedures but does not know the name of her illness, expresses it as "the headache"



"I don't remember, it has been a year"
"I have many things on mind but do
not feel like sharing them"

Description:

Can's family took him to the hospital because he was having stomach pain. He was scared that they would perform surgery on him. And his fears came true, he had to have a surgery. Actually he did not feel anything, because he was sleeping throughout. Afterwards, he went through a rough period with all the procedures like radiotherapy and chemotherapy. In the end, he was not sick anymore. He remembers many details from that period now but he does not like to talk about it, especially about how he felt back then.

Needs & Goals:

- •Forget about the experience he had
- Support from his family

Challenges:

- •Does not want to share his feelings & thoughts
- •Avoids situations that makes him uncomfortable



"Why am I here at the hospital?"
"Why can't I go to the school?"

Description:

Emre suddenly found himself in a hospital room. He asked his mom why he was there and his mom said he was ill and that's why they needed to stay there. Everyday nurses were coming in the room and pricking his skin with some needles, he could see his blood. He could not understand why they were doing this, it was very painful for him. Also, he was bored in the room. All he could do was drawing or playing with the toys but on his own. He was wondering why he could not go out and play with the other kids.

Needs & Goals:

- •Understand why some procedures or rules are necessary
- •Play & social interaction

Challenges:

- •Cannot realise the seriousness of his condition
- •Having difficulties with complying the treatment & procedures



4.3. CONCLUSIONS & DISCUSSION

This subchapter discusses the implications of the user journey map and personas for the prospective design.

Besides providing an overview of pediatric cancer patients and their parents' current cancer experience in Turkey, the user journey map helped to identify the change in the emotions of the users. Based on this change, the most impactful events and stages in their experience were determined. The design opportunities were further explored through the pain and delight points on the map. Additionally, personas helped to create representations of different types of target users. The individual needs, goals, and challenges of these users were later taken into consideration during defining design criteria and vision.

The most important insight from this chapter is the impact of the hospitalisation period, especially on children. The journey map showed that this period embodies various pain points both for children and parents. Moreover, it was discovered that children are affected more negatively from this period due to the treatments, side effects, restrictions, and ultimately, lack of sufficient information on their illness. On the other hand, parents have the most negative experience when the diagnosis is revealed to them. Therefore, the focus of the prospective design (see Chapter 1.2.2. Project Scope) should be expanded to cover the hospitalisation period besides the diagnosis stage.

On the right, chapter takeaways and their implications for the prospective design are shown.

There are **three** types of target users (children) in terms of their information and compliance level, and there are two types of target users (parents) in terms of information and emotion sharing characteristics.

should consider the **needs** and **challenges** of the different types of target users.

The prospective design

The user journey map pinpoints:

- 13 pain points (i.e., the most negative experiences), 7 of them during the hospitalisation period
- 3 delight points (i.e., the most positive experiences) in children and parents' cancer journey in Turkey.

The prospective design should **aim** to improve the experience during hospitalisation period ' besides the diagnosis



Important pain point:

The lack of professional psychological support at the hospital during disclosure of diagnosis contributes to the problem that parents cannot process the diagnosis.

The prospective design can have a function that provides parents psychological support.



Important delight point:

Having social interaction during hospitalisation period improves the experience and mood of the children and parents significantly.

CHAPTER TAKEAWA

The prospective design can have the function of facilitating contact with other family members, relatives, or friends **even** when the family is not allowed to have visitors.



CHAPTER 5 **DESIGN DIRECTION**

So far, the current context of pediatric cancer patients was discovered through literature review and field research. While the findings of these research activities helped to understand the target users' current experience, needs, and wishes, they also revealed a different dimension of the initial problem. With this new dimension and rich insights, characteristics of the solution space was envisioned. Hence, this chapter explains how the initial problem was reframed and how the qualities of future product experience were envisioned. In the end, the chapter presents a list of design requirements for the prospective solution.

5.1. PROBLEM REFRAMING

This subchapter explains how the initial problem (see Chapter 1.2.1) is analysed and reframed and; illustrates this analysis in Figure 18.

Based on the insights obtained from field research and the user journey map, the initial problem was reframed. The initial problem definition focused on the impact of information hiding attitudes of parents on children's understanding during the diagnosis stage. However, the user research showed that the problem lies not only in the communication of information but also: in expressing or sharing emotions throughout the whole trajectory. Therefore, the problem was analysed using WWWWWH questions (van Boeijen et al., 2020) and the problem tree approach.

In Figure 18, the core problem and underlying causes are shown in the middle with purple, contributing factors to the problem at the top with blue, and the effects of the problem at the bottom with green.

Obtaining information from other sources (e.g., internet) can create mistrust towads parents but they need parents' support

Children can feel lonely & isolated because there is no one to share concerns and fears

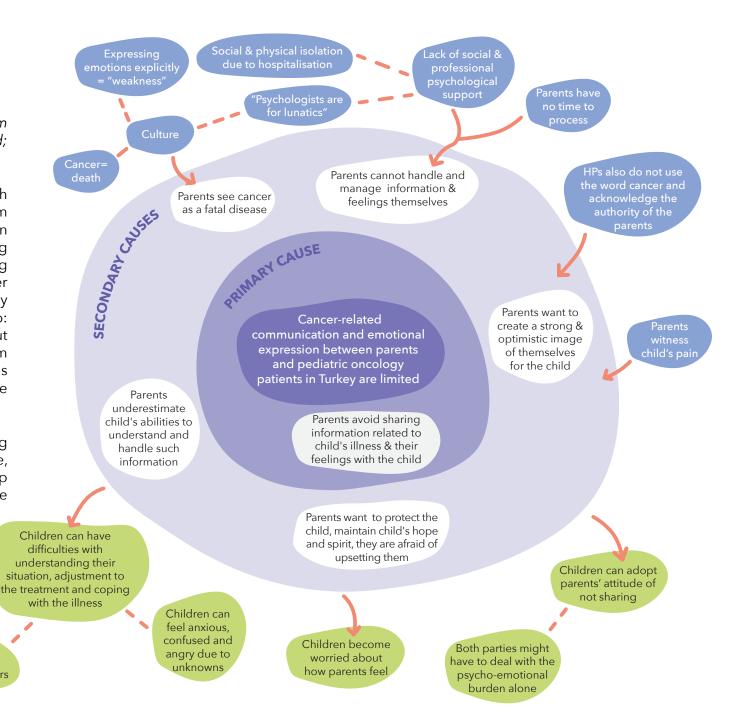


Figure 18: An overview of the problem analysis

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5.2. DESIGN GOAL & VISION

With the problem reframing, what the prospective design will be solving was clarified. The question "How will the prospective design solve this problem?" is answered in this subchapter through a definition of a design goal and a design vision.

5.2.1. Design Goal

Based on the new problem definition and the research insights (see Chapters 2, 3, and 4), a design goal was formulated. By indicating the desired characteristics of the prospective design, it provides a direction for the ideation phase. The goal statement is as follows:

"The prospective solution aims to facilitate information and emotional sharing between pediatric oncology patients and their parents throughout their cancer journey to alleviate the psycho-emotional burden of parents and improve adjustment and coping of children by using the power of play"

5.2.2. Design Vision

The design vision is the overarching goal that the designer is aiming for, the reason for creating the product (van Eijk, 2021). While showing the designer's way of envisioning the future experience of the user with the product, the vision describes the interaction qualities of the future product (van Boeijen et al., 2020). Therefore, it enables the designer to picture the

way the product is going to be viewed, used, understood, and experienced by the users, even before knowing what to design (van Boeijen et al., 2020). To facilitate envisioning the interaction qualities of a product early in the process, Pasman, Boess & Desmet (2011) point out the benefits of using metaphors or analogies that carry the same qualities as the desired interaction. To create a design vision for the project, this technique was utilised. The vision statement is as follows:

"I want to encourage pediatric oncology patients and their parents to have difficult conversations throughout their cancer journey by helping them take baby steps towards each other"

The Metaphor

The metaphor utilised in the vision statement is "baby steps" (see Figure 19). According to Cambridge Dictionary (2022), definition of baby steps is "an act that makes a very small amount of progress towards achieving something." Also, actual baby steps are usually not really sturdy; they are even a bit wobbly. So, they are not perfect. Therefore, it is desired that the product makes the users (i.e., parent & child) feel like they are allowed to take time, they are in charge, it is okay to go at their own pace, and the outcome does not have to be perfect. Moreover, the interaction with this product should show users that even a tiny bit of conversation is helpful, this conversation does not have to be explicit, and



Figure 19: Metaphor used in the vision statement (freepik, n.d.)

they are free to choose what and how they want to share. When these interaction qualities are translated into product qualities, the prospective product should be non-threatening, delicate, respectful, and nudging rather than confronting.

5.3. DESIGN CRITERIA

This subchapter presents the list of requirements that will be used to choose a concept and evaluate the final design.

Design criteria are the important characteristics that the design needs to meet to be successful (van Boeijen et al., 2020). As indicated at the end of Chapters 2 and 3, some of the key insights from the literature review and field research were translated into design requirements. While fulfilling these requirements can give an indication of the desirability and viability of the prospective design, feasibility should also be considered. Therefore, Pugh's checklist (van Boeijen et al., 2020) was utilised to have a complete list of requirements. Some criteria were added or refined after the conceptualisation stage.

On the list of requirements (right), the categories (in bold) indicate the important aspects that the prospective design should comply with. The criteria with (W) on the right indicate wishes, whereas others are the demands that the prospective design must satisfy. Moreover, the coloured dots () show what the category can be an indication of among desirability, viability, or feasibility, respectively.

Function





Does it facilitate sharing emotions & information regarding cancer with each other?

- 1. The design should facilitate giving cancer-related information to children without scaring them (i.e., being delicate).
- 2. The design should facilitate expressing the emotions of children and parents to each other.

Design Goal



Does it fulfil the design goal?

3. The design should encourage open communication about cancer and emotions between children and parents without being intrusive (i.e., it should respect the preferences of children and parents, be more nudging than confronting).

Product Experience



Does it evoke the desired emotions/experience?

- **4.** The design should contribute to children's needs of autonomy, competence, and relatedness (W).
- 5. The design should give parents a sense of being in control (W).

- 6. The design should provide parents with trust that it will help them (W).
- 7. The design should provide children and parents a feeling of being supported by each other (W)

Playfulness

Is it fun to play with?

- 8. The design should offer multiple and different play opportunities to children and parents.
- 9. The design should be flexible: it should give children and parents freedom to choose what and how to play.
- 10. The design should cover a broad range of gamer motivations (refer to Quantic Foundry model by Yee & Ducheneaut, 2015).

Usability —





Is it easy, efficient and effective to use?

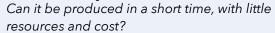
11. Learnability: The design should enable users to start playing as soon as possible such as by requiring little preparation time (e.g., no user manual, or should not take more than 15 minutes to learn how to play).

(continued)

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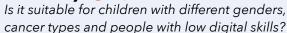
12. The elements of design should be easy to understand by children and parents (e.g., no complex language or terminology).

Ease of Implementation & Scalability



- 13. The production of design should not require hard-to-find resources and advanced technology to be implementable for public hospitals as well.
- **14.** The production time of the design should be as short as possible.
- 15. The production cost of the design should be as low as possible to be implementable for public hospitals as well.

Inclusivity (



- 16. The design should be suitable for the developmental level of school-age children aged 8-9.
- 17. The design should be suitable for children with different types of cancer (e.g.,

brain tumor, leukemia etc.).

- 18. The design should be desirable to children regardless of gender.
- 19. The design should be suitable for lowincome families and/or people with low digital skills (W).

Portability |



Can it be used in different environments?

20. The design should be able to be used in different environments & for different time spans (e.g. Hospital, home, school) (W).

Additional Requirements







- 21. The materials used in the design should be medical grade (i.e., complies with ISO 10993), and sterilisable (e.g. do not cause infections).
- 22. The design should provide cautious (e.g., avoids giving false hopes) and medically reliable information.

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CHAPTER TAKEAWAYS The problem in Chapter 1.2.1 is reframed due to the insights obtained in Chapters 2, 3, and 4. The problem is **not only the** limited communication about cancer-related topics but also: limited emotional sharing between parent & child throughout the cancer journey.

The design goal is: "facilitating **information** and emotional sharing between pediatric oncology patients and their parents throughout their cancer journey by utilising the power of play"



For parents: alleviate their psycho-emotional burden

For children: improve their understanding, adjustment, and, coping

The prospective product is **envisioned** to be:

- **nudging** families to share, not forcing them
- non-threatening for parents to accept it
- respectful to different user preferences
- Fun to use/play with it



CHAPTER 6

According to the Double Diamond Approach (Design Council, 2005), the ideation phase is the start of the second diamond, where the designer generates creative solutions based on the problem identified and in the direction of the design goal and vision. To generate such solutions, an individual and a group ideation session with fellow students were held with the help of How-Tos (van Boeijen et al., 2020) and Crazy 8 (Google, n.d.) techniques. The ideas that emerged as a result of these sessions were clustered to provide directions for the concept development later. Therefore, this chapter explains the details and the outcomes of these ideation sessions.

6.1. IDEATION PROCESS

This subchapter explains how the solutions were generated in the creative sessions to solve the design problem described in Chapter 5.1.

6.1.1. Individual Session

As a starting point, an individual brainstorming session was performed by utilising the How-To questions (van Boeijen et al., 2020). Six main questions were formulated based on the problem analysis in Chapter 5.1. The answers to these questions provided frames to ideate within.

Figure 20 shows these questions and the frames generated from them.

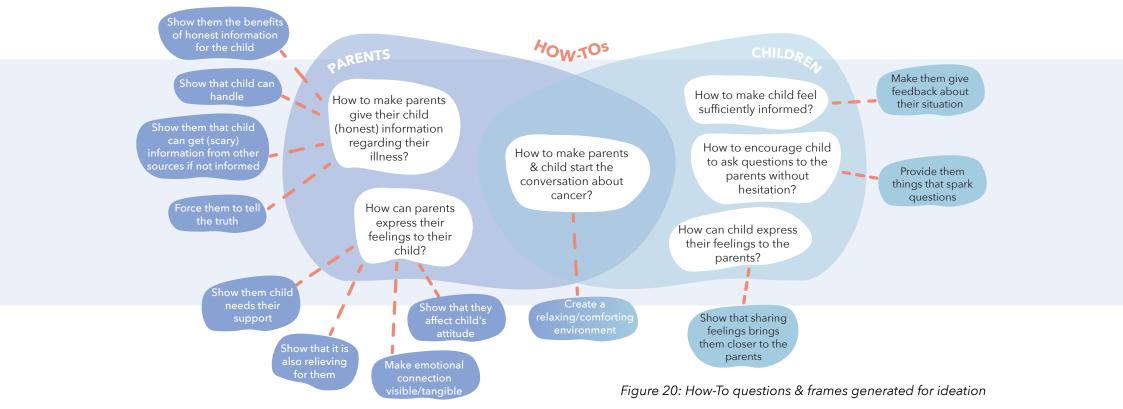
The ideas generated with this method were written down on post-it notes individually and visualised through rough sketches on the same post-its.

6.1.2. Group Session

The group ideation session was conducted to obtain fresh and different perspectives. With this

aim, a 1.5-hour session was performed with three fellow students from the other master track (i.e., Strategic Product Design). In this session, ideation was performed with the Crazy 8 method (Google Design Sprint Kit, n.d.).

The ideas were communicated through short explanations and rough sketches (see Appendix H). After the session, the ideas were written and drawn on individual post-its and combined with the other ideas from the individual session.



Chapter 6 • Ideation Process 45

6.2. RESULTS

This subchapter presents the categories that resulted from the two ideation sessions.

The individual and group sessions yielded roughly 90 different ideas (see Figure 21). However, they were grouped into 20 clusters according to the strategy/mechanism that they embody to solve the sub-problems reflected by How-to questions. These clusters were also combined into 6 categories that represent the overarching goal of the ideas in the categories. The following paragraphs explain these categories and the clusters they involve with examples of ideas from that category or cluster. For the complete list of ideas, please see Appendix I.

Category 1: Sharing Information

As understood from the name of the category, the ideas in the category are the solutions that help parents share information about cancer with their children or provide information to both parents and children. To do so, the ideas in the category incorporate different strategies/mechanisms:

Guiding parents and children by providing direct information through various channels: By means of handbooks, infographics, or a mobile application, open and honest information about cancer, treatments, and what to expect can be provided to parents and children to guide them throughout the trajectory.

Giving information through storytelling: Cancerrelated information can be presented to children



Figure 21: All ideas combined together

as a part of a fictional story to tone down its seriousness. Or specially designed muppets can be provided to parents and children for every stage of the treatment. By acting out scenarios, the parents and children can actually talk about cancer-related information via these puppets.

Giving information through play: Similar to the previous strategy, cancer-related information can be given to parents and children through play to make the information less threatening or scary.

Showing/representing drawbacks of not sharing information: Another strategy from this category is to show parents the drawbacks of not sharing information with children or provide them with an object/system that represents this situation. Although it is not quite realistic, an idea can be a magic globe that shows parents what can happen if they (do not) share information with their children.

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Category 2: Sharing feelings

Similar to the previous category, the ideas in this category focus on facilitating sharing of feelings for parents and children with each other. To do so, the ideas of this category suggest seven different strategies/mechanisms:

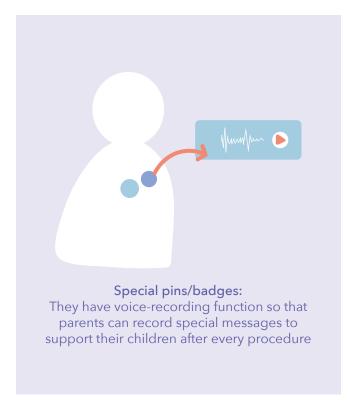


Figure 22: An idea that creates a small moment for parents to express their support to the child

Sharing feelings/showing support without words: As a found opportunity (see Chapter 3.3), if a design offers a more implicit way of

sharing feelings or showing support, it can be more acceptable, especially for parents. Besides, the parents are also currently exhibiting such behaviour. Therefore, the ideas in this cluster aim to amplify this behaviour of parents through different means such as music.

Small expression moments: Similar to the ideas in the previous cluster, these ideas create "small" moments in which parents and children do not have to be dragged into deep and emotion-loaded talks but gently and briefly show their support or feelings to each other. An example idea from this cluster is shown in Figure 22.

Rewarding sharing: To encourage parents and children to share their feelings with each other, the ideas in this cluster reward them when they do so.

Helping children express feelings: As indicated before, children also hide their emotions quite often throughout the cancer experience. When they express their feelings to their parents, their parents can comfort them or show their support. This way, they can see that they are not alone and feel supported. Moreover, it can help their parents to open up too. Therefore, the ideas in this cluster aim to facilitate expressing feelings for children, such as in the form of a plush toy that has different facial expressions on different sides of it. A similar toy is shown in Figure 23.

Identifying the right moment to share: As stated in Chapters 5.2.2 and 5.3, the prospective product should be nonintrusive while helping

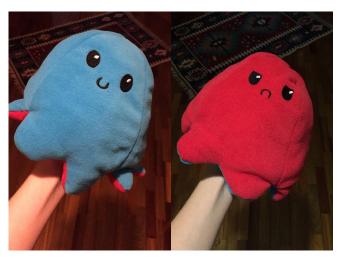


Figure 23: A plush toy that expresses different emotions when turned inside out

parents and children to share feelings. Therefore, the ideas in this cluster aim to detect the "right moment" to share feelings, which is the moment when parent and child are experiencing the same or similar emotions or the moment they decided together before.

Using a facilitator to share feelings/thoughts: Another implicit, non-threatening way of sharing feelings is to use a facilitator. An idea example is to create a physical object (e.g., doll, teddy bear, robot, etc.) that child can talk to.

Comfortable environment for sharing: Ideas in this cluster suggest creating designated private relaxation spaces in the hospital for children and parents. These spaces can be designed in a way that comforts them and ensures them it is relieving to share feelings.

Category 3: Sharing feelings & information

Apart from the first two categories, the ideas in this category aim to facilitate sharing of both emotions and information. All strategies/mechanisms under this category are as follows:

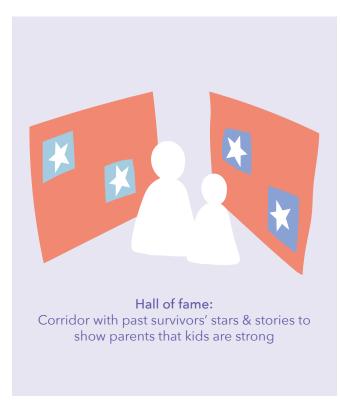


Figure 24: An idea that gives parents an indication of children's resilience

Forcing parents & children to share: As indicated in Chapter 5.3, the prospective solution should not force parents and children to share in order to be desirable. Although this strategy is not

desirable and the ideas using this strategy do not hold the potential to be realised, it helps to explore far out parts of the solution space. An idea example is to create a thought reader hat that shows children what is on their parents' minds.

Showing parents that children are strong: Since one of the reasons that parents do not share their emotions or cancer-related information with their children is underestimating their children's abilities, showing them how strong their children are can spark sharing. An idea example from this cluster is illustrated in Figure 24.

Empathy building: Since parents make assumptions about their children, it can be helpful to make parents empathise with their children to discover that their assumptions might be wrong. An example idea is designing a game in which parents and children can play the role of each other for a certain period.

Category 4: Conversation starters

Rather than focusing on a specific part of the problem, the ideas in this category explore the means to start a conversation about cancer between parents and children with a more generic approach. They utilise three different strategies/mechanisms to do so:

Starting a conversation through a board/card game: Talking about cancer, asking questions, or expressing feelings can be less threatening for parents and less scary for children when it is a part of a game. Board or card games usually



Figure 25: An example of a conversation starter product designed by Yaara Nusboim (Tuvie, 2019)

require collaboration or interaction between players. Thus, they hold a great potential to serve as a medium to start a conversation about cancer.

Starting a conversation through objects: Similar to board games, some (abstract) objects can also help to start a conversation between parent and child. A product exemplifying this function is shown in Figure 25. This product was designed for children to express their emotional problems in play therapy sessions (Tuvie, 2019). The "dolls" in this product subtly represent different emotions and are open for interpretation.



Figure 26: An idea that gamifies the treatment process

Starting a conversation through room/ hospital decor: As a found design opportunity mentioned in Chapter 3.3, certain areas at the hospital or the patient rooms can be redesigned in a way that sparks conversations between parents and children.

Category 5: Gamifying the whole journey

As understood by its name, this category also reflects the strategy itself and therefore,

incorporates only one strategy. Similar to the previous category, this strategy is also applicable to solve the main problem as a whole as well as its subparts. The ideas in this category aim to make children and parents cooperate and bring them closer by reframing the cancer experience as a game that they can play together.

Similar to live-action role-playing (LARP) games, children and parents can play the role of certain characters (e.g., superheroes), and together they can complete certain tasks to collect rewards throughout the treatment process. They can go through challenges that represent the actual challenges of cancer but are presented as a part of a story in the game. Moreover, sharing emotions or information can be encouraged by framing them as tasks. An example is shown in Figure 26.

Category 6: Building a community

This category focuses on the sub-problem of lack of external social support. Therefore, the ideas in this category aim to help children and/or their parents to get social support from other families, which was identified as a design opportunity before (see Chapter 3.3). These ideas utilise one strategy but target different parties:

Providing external support to the family: The ideas in this cluster bring families going through the same experiences together by means of social events at the hospital or help children interact with other children at the hospital through playing distant games (see Figure 27) to show them they are not alone or "different." This

way, both parents and children can cope better.

Providing external support to parents: As mentioned before, parents usually carry the psycho-emotional burden of the illness alone. To alleviate that burden, the ideas in this cluster suggest establishing psychological support programmes at the hospital. An example is to start a mentorship programme in which a survivor parent coaches a newly diagnosed parent.

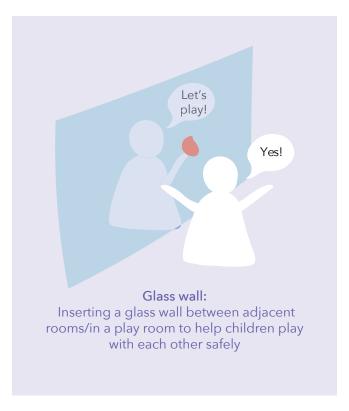


Figure 27: An idea that enables children to play together

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6.3. CONCLUSIONS & DISCUSSION

This subchapter discusses how the outcomes of the ideation process will be used.

As explained in the previous subchapters, the ideation process put forward various ways of solving the core problem or parts of it. In a typical design process, after generating a large number of ideas, usually the most promising ones are selected to form concepts. In this case, a selection was not made because all strategies (i.e., clusters) have the potential to form a promising concept on their own or when combined with others. Although no selection was made, there were some personal favourites due to their envisioned impact on solving the core problem. These favourite strategies were gamifying whole journey and conversation starters. As explained in the next chapter, these will serve as a starting point to generate concepts, but they will be combined with other strategies.

The takeaways from this chapter are presented on the right.

CHAPTER TAKEAWAYS vielded:

~90 ideas

20 clusters

6 categories

TA1

The ideas were grouped according to the strategy or mechanism they embody to solve the design problem. This way, 20 different clusters were identified.

20 clusters were grouped into 6 categories, which represent the overarching goal of the ideas in that category. These categories are:

- Sharing information
- Sharing feelings
- Sharing feelings & information
- Conversation starters
- Gamifying the whole journey
- Building a community

Unlike typical design process, no selection was made. All strategies (i.e., clusters) were kept for concept development.



CHAPTER 7 CONCEPTUALISATION

This chapter describes the concept development process, which was performed by utilising the strategies from the previous chapter and the resulting three concepts. Then, the chapter provides information about the evaluation of the three concepts through interviews with stakeholders and the Harris profile method (van Boeijen et al., 2020). In the end, it presents and discusses the outcome of the evaluation.

7.1. CONCEPT DEVELOPMENT

This subchapter provides an overview of the development of three concepts with Figures 28, 29 (on page 53), and 30 (on page 54), and describes these concepts. Providing information Reframing Providing children's PARC P TATENCIONS distraction perspective ASTRONAUTS ON THE MILE A space-themed role-playing, alternate reality game that reframes treatments and the hospital environment as a part of a story Parc d'atencions

Figure 28: An illustration of the development process of the first concept: Astronauts on the Mission

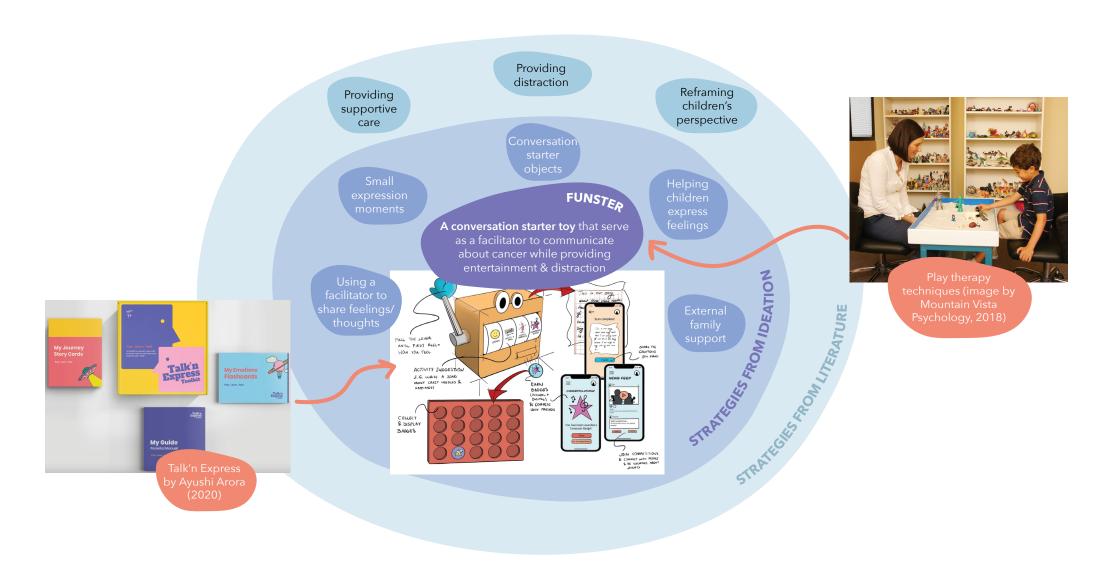


Figure 29: An illustration of the development process of the second concept: Funster

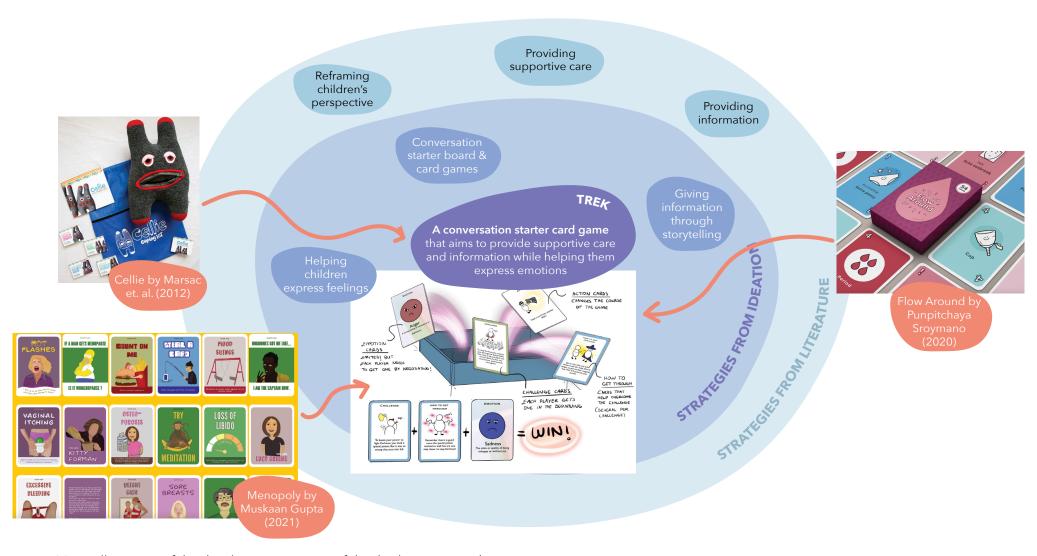


Figure 30: An illustration of the development process of the third concept: Trek

7.1.1. Concepts

As shown in Figures 28, 29, and 30, Astronauts on the mission, Funster, and Trek resulted from the concept development process. Each concept is designed to be provided to parents and children right after diagnosis, therefore at the beginning of the hospitalisation period to enhance their experience throughout, as discussed in Chapter 4.3. However, Funster and Trek are also suitable for home use, which is after the intensive treatment period (see User Journey Map in Chapter 4.1). The details of each concept are presented in the following paragraphs.

Concept 1: Astronauts on the mission Hospital room redesign & mobile app

The Astronauts on the mission concept is a roleplaying alternate reality game that consists of several elements: room decorations/objects, mobile application, emotion puppets, and storyline. As the theme, space is selected due to its potential of being attractive for all children.

As indicated in Chapters 3 and 4, there is usually a hospitalisation period right after diagnosis. Thus, in this concept, a different world is welcoming children and their parents into the hospital room right after diagnosis. In this different world, they can play the role of astronauts and space commanders. When they scan the QR code on the wall, they can access a mobile application in which an alien named Sanus (i.e., "healthy" in Latin) welcomes them to his planet and tells his story (see Figure 32 on the next page). Sanus asks the help of children (astronauts) and parents

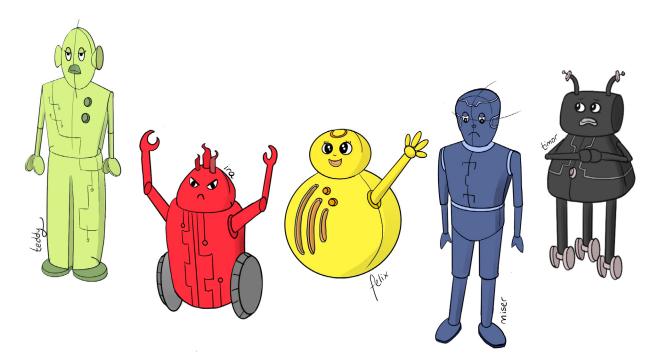


Figure 31: An illustration of the emotion puppets

(commanders) to save his planet Korpion (i.e., derived from the word korpio in Greek, translates as body in English) because his evil twin named Malus (i.e., "bad" in Latin) and his clones invaded his planet. Children and parents can help Sanus to save his planet by completing some "missions" together. These missions are actually the play activities that are suggested by the application based on children's physical tiredness level and mood (see Figure 32). Therefore, these missions can be performed by using the objects or décor in the room (for the ideation of these objects please see Appendix J). While the missions are presented as a part of the narrative, their content aims to facilitate having cancer-related conversations or expressing emotions for parents and children

while having fun. An example mission is sending each other encrypted messages by using the decoder wheel and pneumatic tube (see Figure 32) to help them express their support or emotions to each other in an unobtrusive way. On the other hand, parents and children do not have to perform these missions. They can also just play with the objects in the room for entertainment or distraction.

Another element of the game is the emotion puppets (see Figure 31). The emotion puppets are the Sanus' droid team consisting of Teddy (i.e., derived from the Latin word tedium that means boredom), Ira (i.e., anger in Latin), Felix (i.e., joy in Latin), Miser (i.e. miserable/unhappy in Latin) and

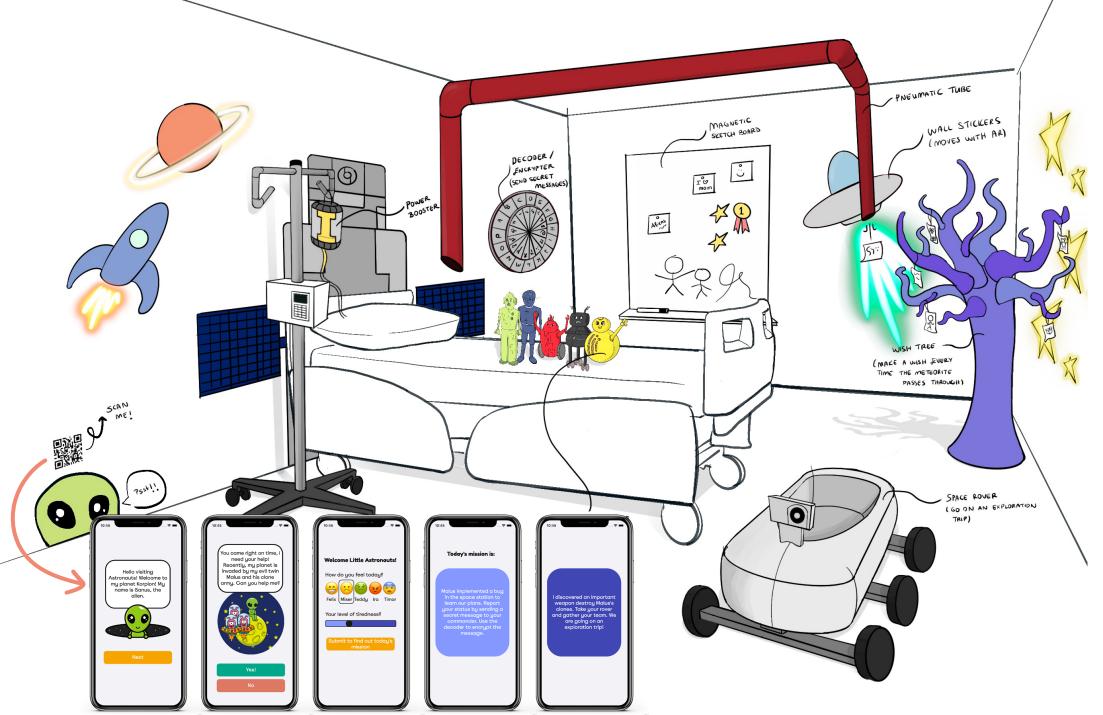


Figure 32: An illustration of Concept 1: Astronauts on the Mission

Timor (i.e., fear in Latin) to help children with the missions. By representing five basic emotions like the characters in the movie Inside Out (Docter, 2015), they aim to help children express their emotions to their parents.

The storyline of the game is a metaphorical representation of cancer: Sanus is the healthy cell, Malus and his clones are cancer cells, and the planet is the body. Other elements about cancer such as the treatments, procedures, or side effects are also incorporated into the narrative so that parents can inform their children about illness-related topics using these metaphors. A glossary of these metaphors and the explanation of the storyline is provided to parents in a separate parent interface of the mobile app. Also, parents can enter treatment data into the interface or make mission suggestions via their interface to get special missions aiming to prepare children for important procedures such as surgery.

In conclusion, the hospital environment is reframed into a less scary and boring place for children and parents by utilising the design opportunity discovered through field research (i.e., lack of play opportunities at the hospital). By being incorporated into a narrative, cancerrelated information is presented to parents and children in a subtle, less threatening way. Therefore, informing their children is only facilitated for the parents, not enforced, to give them a sense of control. Additionally, expressing emotions is encouraged through "small" moments and facilitator objects. Lastly, it is aimed to give children and parents a "We are in this together" feeling by making them collaborate on

the missions.

Concept 2: Funster An activity generator toy & mobile app

The Funster concept is a conversation-starting toy with a mobile application function. Again, the product is handed to the family by the hospital after the diagnosis so that they can use it throughout the hospitalisation process.

Designed in the form of a slot machine, the product offers the family a random activity to perform together when the lever is pulled. However, first, the lever should be pulled until the emoticon on the first reel matches the child's current feeling or the emoticon (s)he wants to have (see Figure 33 on the next page). Based on this action, a combination with the other reels occurs. While the second reel shows the suggested activity, the third reel provides a "random topic" for the activity. For example, it offers the parent and child to write a song about crazy needles (see Figure 33). As understood, these random topics are actually cancer-related topics but presented in a toned-down, nonthreatening way along with a funny illustration (see Appendix K for the complete list of topics). Additionally, the activities are based on play therapy techniques that help children and also adults to express themselves at their own pace, without feeling interrogated or threatened (The British Association of Play Therapists, 2014). Some examples of these activities are storytelling, roleplaying, creative visualisation, crafting, making music, and dancing.

The fourth reel shows what kind of a badge can be earned when the suggested activity is completed. The badge is dispensed from the product upon completion of the activity. Each time children and parents earn a badge, they can collect and showcase those on a board. Moreover, they can upload the results of the activities performed to a mobile social platform where other children at the hospital, family members, or friends are also in. Through this app, they can also get notified about the social events or competitions organised at the hospital and connect or meet with other families with similar experiences. Additionally, the badges can be collected and displayed digitally on the app. With this function, they can also compete with other children at the hospital.

As a side note, the set of emotions on the first reel is selected according to the frequently experienced emotions by children as discovered through the user journey map and by using the theories of Plutchik (1982), Cowen & Keltner (2017), and Gu et al. (2019). For the complete list, please see Appendix K.

In conclusion, the product aims to provide parents and children a starting point to talk about cancer-related topics and express their feelings to each other with the help of emoticons as facilitators without forcing them and to bring them closer by spending fun time together. Also, it utilises the design opportunity: the need for social interaction during hospitalisation. By providing external social support to the family, the product aims to facilitate their adjustment to the hospital and treatments and provide better coping.

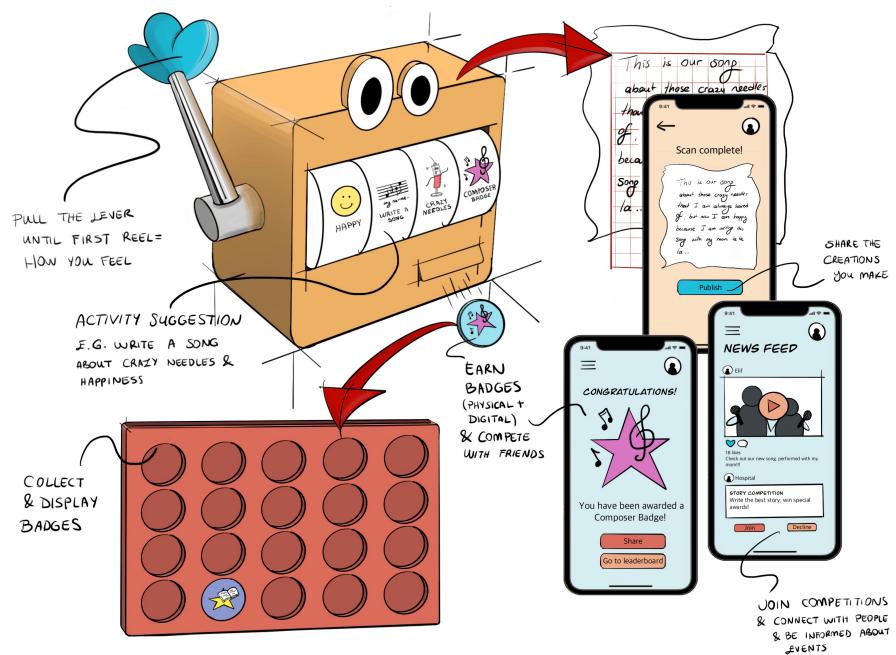


Figure 33: An illustration of Concept 2: Funster

Concept 3: Trek Card game

The Trek concept is a conversation-starting card game that is inspired by Cellie Cancer Coping Kit (Marsac et al., 2012). In the Cellie Cancer Coping Kit, there are cards with frequently experienced physical or psychosocial challenges throughout the cancer journey, such as fear of needles or missing school (Marsac et al., 2012). In the same cards, multiple coping strategies for the given challenge are offered to parents and children. In this concept, there are four types of cards: challenge, how to get through, action, and emotion cards. Similar to Cellie cards, challenge cards contain information about the physical and psychosocial challenges of cancer. For each challenge card, there are multiple how to get through cards that suggest different ways to cope with the corresponding challenge (see Figure 34 on the next page). Different from Cellie cards, these challenges and coping strategies are presented as a part of a storyline.

Similar to the first concept, children and parents become chevaliers or wizards that go through an expedition to prevent Lord Karkinos from occupying the kingdom. However, this expedition is filled with challenges, and the players need to learn how to deal with them. An example challenge is going through the scary "Spikey Valley," which represents fear of needles. A how to get through card that corresponds to this challenge is asking for the help of the wizard (parent) while passing through the valley. As in the second concept, emotion cards in this concept contain

frequently experienced emotions throughout the cancer journey, whereas the action cards are for changing the course of the game (see Figure 34).

The game can also be played with more than two players. In the beginning, each player is given a challenge card and two cards from the mixed deck of how to get through and action cards. The end goal of the game is to collect three cards: a challenge card, a how to get through card corresponding to that challenge (indicated with the same colour), and an emotion card (see Figure 34). However, to get an emotion card, the players need to negotiate. In each round, an emotion card is opened in the middle. To get the card, the player claiming the card needs to convince others that the emotion card in the middle fits their challenge the best. Also, action cards can change the course of the game, such as by exchanging the whole deck with a player or stealing a card from another player's deck. The first player who collects the three cards mentioned wins the game, thus, saves the kingdom from Karkinos by successfully overcoming the challenges (see Figure 34).

Similar to the second concept, the hospital provides the card game to the family after diagnosis.

Compared to the other two concepts, this concept is more direct or confronting in terms of discussing emotions or presenting the information. However, it can be still acceptable by the parents because it presents the information as a part of a story, and the expression of emotions

is for "game" purposes. Especially negotiation for emotion cards aims to spark discussions about real emotions. In conclusion, this concept can facilitate the exchange of information and emotions while providing children and parents guidance and supportive care without the need for a therapist. This function of the concept can be beneficial because parents sometimes refuse to get professional psychological support, as indicated in Chapter 5.1. Lastly, how to get through cards can inspire parents to find ways to show their support when challenges occur in real life.

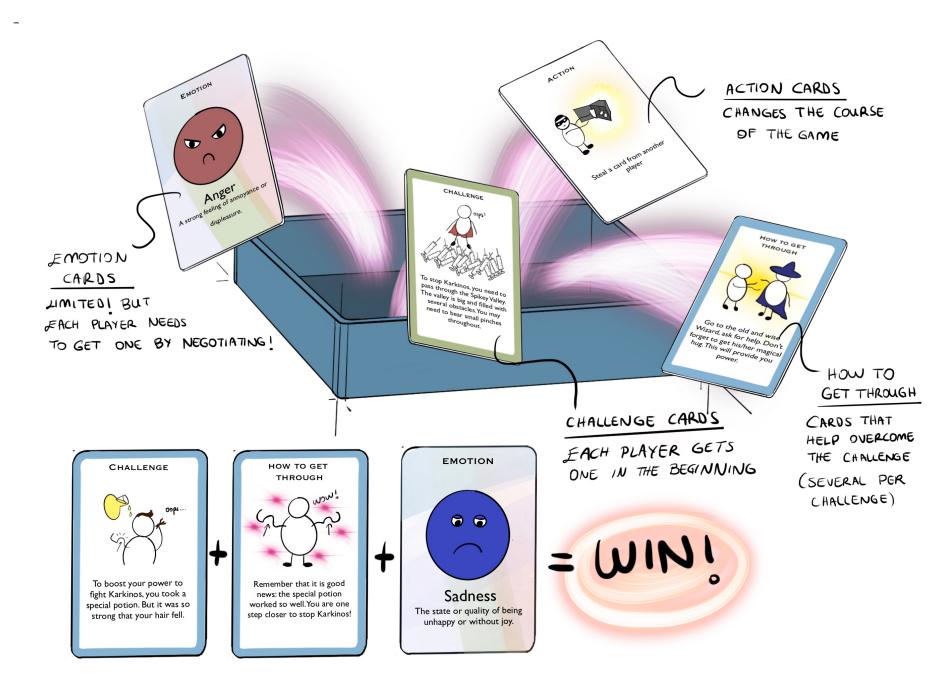


Figure 34: An illustration of Concept 3: Trek

7.2. CONCEPT EVALUATION

This subchapter presents the outcomes of the concept evaluations through the Harris profile and the interviews with the stakeholders.

To choose a concept to be developed as the final design, the concepts presented in the previous subchapter were evaluated through the Harris profile method (van Boeijen et al., 2020) and semi-structured interviews with the stakeholders. The Harris profile method helped to identify the extent that each concept satisfies the design requirements (see Chapter 5.3) whereas the interviews provided insights into the desirability, viability, and feasibility of each concept.

7.2.1. Evaluation through Harris Profile

Figure 35 shows the outcome of the evaluation with the Harris profile. It should be noted that the additional requirements on the list in Chapter 5.3 were excluded from the evaluation criteria since concepts are not fully developed yet at this stage. The reasoning behind these scores is explained in Appendix L.

As seen in Figure 35, Concept 1 fulfils the most important design criteria better, but in terms of ease of implementation, it scores lower than the other concepts. It can be said that Concept 2 satisfies all the requirements adequately except the wishes for desired product experience. Concept 3 scores quite low on the playfulness and usability requirements, whereas it is more

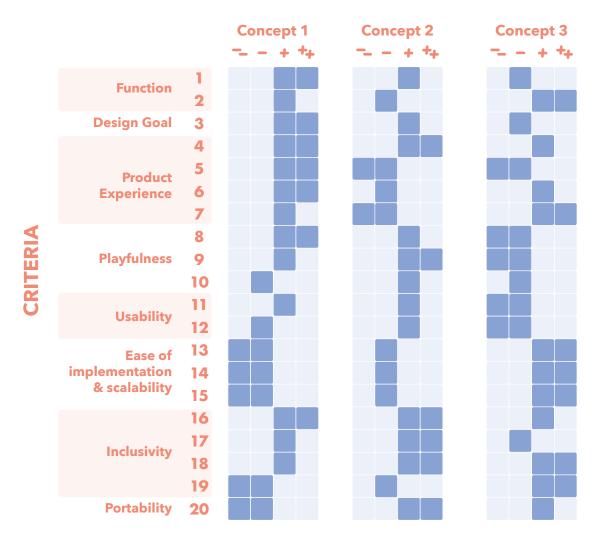


Figure 35: Harris profile

advantageous in terms of implementation and scalability. Based only on this evaluation, it is likely to choose Concept 1 due to its compliance with the most important requirements. However, the scores given on the Harris profile can reflect the

designer's perspective, bias, or tendency toward a concept. Therefore, semi-structured interviews were performed with the stakeholders to gauge the actual desirability, viability, and feasibility of each concept.

7.2.2. Evaluation through Interviews with Stakeholders

Method

In accordance with the previous ethical approval from the hospital (see Appendix C), five semi-structured online interviews were conducted with different stakeholders separately: parent-child couples (direct users), a specialist in pediatric oncology, and the head nurse of the oncology department (HPs). The demographics of direct users are presented in Figure 36. As seen from the figure, a healthy child was also included in the study due to the difficulty of reaching patients from the target age group. However, the child could still contribute to the study since play was at the core of each concept.

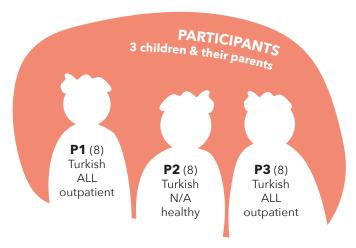


Figure 36: Participant demographics

During the interviews, each concept was presented to the participants as a combination of a sketch and a short explanation. After each concept was shown, the participant's opinion about the concept was asked. In the end, they were asked to state their preference and the reason why, as well as, their suggestions to improve concepts.

Results

The following paragraphs present the results from stakeholder evaluations. At the end of this section, Figure 37 gives an overview of each concept's strengths, weaknesses, and improvement opportunities based on the participants' remarks.

Concept 1: Astronauts on the Mission Perceived interaction qualities: Active, entertaining, motivating

All stakeholders combined, 4 out of 5 participants chose this concept. Especially, the children showed quite an excitement towards this concept. The main reasons behind this preference of the participants were the mobile app feature of the concept due to children's interests in digital games nowadays and its focus on the hospitalisation period. The oncology specialist did not prefer this concept due to its difficulty in implementation and higher cost.

A child (P2) indicated that he liked this concept because he thinks that this room can make children forget their thoughts about the illness.

Concept 2: Funster Perceived interaction qualities: interesting, social, fun

Funster was the least preferred concept by the participants, except by the oncology specialist. She found it the most interesting of all concepts. However, she also mentioned that the emotions and the random topics to be placed on the reels should be carefully selected to cover a broad range of personalities of children.

A parent (P3) stated that she liked the features of collecting and keeping the badges and being able to share the creations with other people since children like collecting/keeping memories and achieving things in general. Moreover, she indicated that this concept might help with the boredom experienced during hospitalisation and distract the child from illness and hospital environment. However, she was not sure whether this concept can facilitate communication about the illness.

The main reason the concept was the least preferred is the social aspect of being connected to others through the mobile app and the type of activity suggestions (i.e., creative). The parents indicated that some children are already or can become shy and withdrawn after having cancer. Therefore, they might be reluctant to socialise, join events or share their creations. Moreover, two children stated that the concept is "not for them" because they are not interested in doing creative activities.

Concept 3: Trek

Perceived interaction qualities: complex, exciting

The second-best option for the majority of participants was Concept 3: Trek. The parents and children indicated that they would like to play such a game. One mother (P3) indicated that the game can help her to explain to her child what he needs to deal with and how throughout his treatment.

The parents found the emotion card feature helpful for their children because they observed difficulties in children expressing their emotions after the diagnosis.

On the other hand, Trek was found a little bit complicated by a child participant (P2) because of its rules. Moreover, the nurse indicated that boys could be more interested in the game than girls due to its storyline and characters. She suggested giving a different character option for girls.

CONCEPT 1

CONCEPT 2

CONCEPT 3

OROS

- Mobile app: Attractive to children
- Helps with child's fears about invasive procedures and initial shock due to hospitalisation
- Helps parents to explain the illness to child
- All-in-one: child can play games, can be prepared for procedures, spend time with their parents and adapt to the new environment

- Nove
- Collecting and keeping badges
- Rewarding: feeling of achievement
- Sharing creations with others
- Helps with distracting child from the illness/hospital

- Easy to implement
- Helps children to express their emotions with the emotion cards
- Helps parents to explain their children what & how to deal with throughout the treatment

CONS

- Difficulty to implement:

 hospital rooms need to be changed completely
 high costs
- Offers only one kind of activities (creative)
- Social app
- Might not fulfil the design goal
- Complex: Can be difficult to be understood by children from the target age
- Might not be attractive for girls

SUGGESTIONS

- Activity suggestion: aim to change the negative feelings or amplify positive ones
- Parents' interface: Allow parents to talk to other parents to get advice, instead of giving direct information such as "how to tell your child"
- App function: Virtual visits to different parts of the hospital (e.g., OR)
- Add medical staff to the game as characters

- Blank emotion option for children that do not know how they feel/what to express
- Connecting two kids experiencing same illness, or bringing kids who recovered from same illness and kids are currently ill together through this game
- Receiving a reward after winning the game
- Adding cards related to hand hygiene, visitor restriction, fever
- Combination opportunity with the Concept 1: Concept 1 for hospital use & this concept for home use (can be given to the patients when they are discharged from the hospital)

Figure 37: The strengths, weaknesses and, improvement opportunities of each concept

Chapter 7 • Concept Evaluation

7.3. CONCLUSIONS & DISCUSSION

This subchapter discusses the implications of the concept evaluation results.

As emphasised in the previous subchapter, both the Harris profile and the interview results pointed out Concept 1: Astronauts on the Mission. The concept seems to satisfy the design requirements better than other concepts and is more desirable for the target users. However, the desirability of the space theme should be confirmed with girls as well.

Although putting Astronauts on the Mission into practice seems more difficult than the other concepts, it can be possible such as by refurbishing existing elements at the hospital room instead of redecorating the whole room.

Even though Trek and Funster were not chosen, some of their strengths can be useful to further develop Astronauts on the Mission. Also, some of the improvement suggestions of the participants can be incorporated into the concept. These can be summarised as:

- A social feature can be added to the parents' interface of the mobile app. This way, parents with similar experiences can contact each other.
- Upon completion of each mission, physical badges or rewards can be provided to children.

- The coping tips from the Trek concept can be incorporated into missions.
- Instead of the mobile app, card format can be utilised as a low-cost option for presenting missions.

With these improvements, the chosen concept will be further detailed and iterated for user testing. The detailing process and its outcomes are presented in the next chapter.

By using strategies (i.e., clusters) from ideation, strategies on implementing play from literature, and inspiration from existing products and movies, three design concepts were formed.

The first concept, Astronauts on the Mission, is a space-themed role-playing game that helps families share information and emotions by performing "missions" together and using puppets that represent five basic emotions.

TA2

The second concept, **Funster**, is a toy in the form of a slot machine, which **suggests** random activities that nudge families to talk about cancer and emotions.

The third concept, **Trek**, is a card game that helps families to share emotions and learn and talk about **cancer-related challenges** and **how to cope** with them.

Through Harris profile and interviews with the stakeholders, **Astronauts on the Mission** is selected for further development.

TA5

CHAPTER TAKEP

CHAPTER 8 **DESIGN DETAILING**

This chapter describes the detailing process of the chosen elements of the "Astronauts on the Mission" concept towards the final design proposal. First, the chapter investigates how emotion puppets can be more expressive of the emotions they represent and gives information about the mission types and contents. Then, it presents the outcomes of an evaluation of the improved elements with a developmental psychology expert. The chapter ends with introducing the prototypes developed for user testing.

8.1. DETAILING ON THE ELEMENTS

This subchapter presents the detailing process of the chosen game elements: emotion puppets and missions.

Towards creating the final design proposal, some design iterations on the chosen concept, Astronauts on the Mission, were made first. However, only core elements of the concept were chosen to be detailed further and tested due to time constraints and the complexity of the full-scale design. These elements are the missions and the emotion puppets which serve as the main function of the design: creating playful opportunities for parents and children to talk about cancer, explore and express their emotions at their own pace, as much as and in the way they want, and bring them closer while having fun.

8.1.1. Emotion Puppets

As the first improvement attempt, puppet names were changed upon discussions with the graduation committee. Since Felix and Teddy can also be children's names, children can get confused and identify themselves with these puppets instead of using them to express their emotions. Therefore, new names that are more straightforward and represent the "droid" characteristics of the puppets were created. Moreover, the puppet that represents boredom was discarded since it was decided that boredom is already one of the main reasons children want to play the game. As a result of these two

improvements, new names for the remaining puppets were selected as "Robojoy," "Sadbot," "Fearonic," and "Angroid."

For detailing the emotion puppets further, desktop research was performed. The research aimed to find ways to make puppets more expressive of the emotions they represent. Therefore, colours, body postures, facial expressions, materials, objects, and movements associated with each emotion were explored through the studies of Weerdesteijn, Desmet & Gielen (2005), Frijda (1986), Ekman & Friesen, (1971), Gohar (2008), Fugate & Franco (2019), and Sutton & Altarriba (2015). As a result of the research, the characteristics of each emotion puppet were defined and summarised in Figures 38 and 39 on the next pages.

Besides showing the characteristics, Figures 38 and 39 present further development options for each puppet. Although the current colours, facial expressions, and body postures of the puppets seem compatible with the characteristics on the figures, their expressiveness can be improved through materialisation and by adding a movement. However, these improvements could not be applied to the puppets that were prototyped for user testing due to time constraints (see Chapter 8.3). These improvement opportunities were later utilised as mentioned in Chapters 10 and 11.

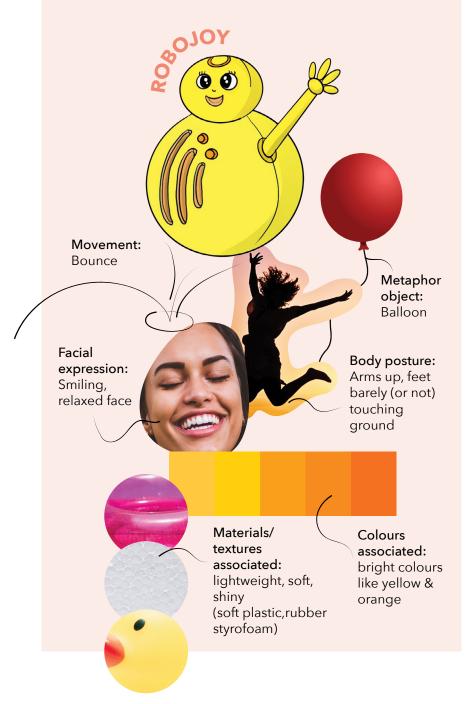
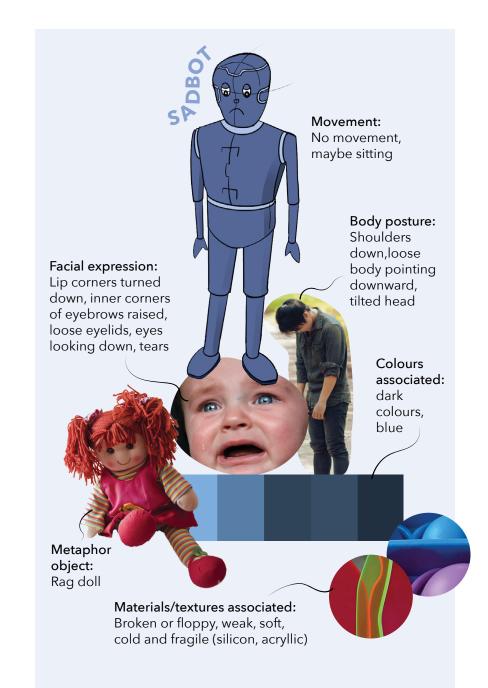


Figure 38: Characteristics of Robojoy & Sadbot



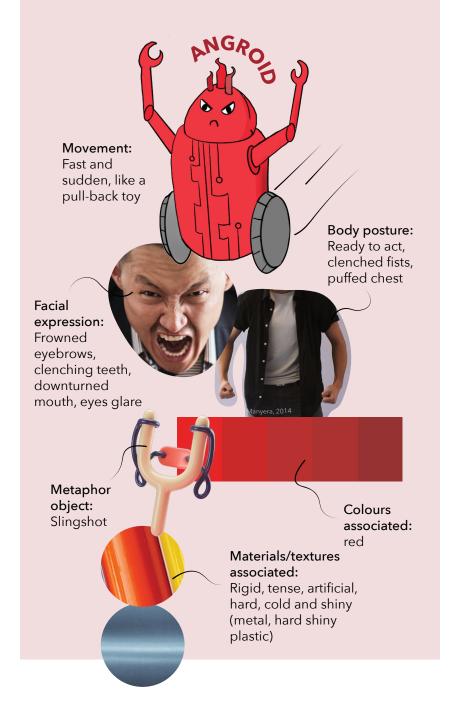
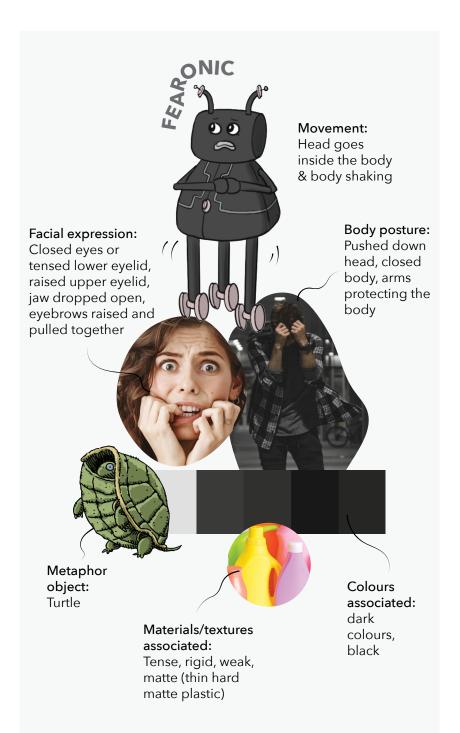


Figure 39: Characteristics of Angroid & Fearonic



8.1.2. Missions

As mentioned in Chapter 7.1, the "missions" are the collaborative play opportunities (i.e., activities) that Sanus offers via the mobile application. The types of activities offered to the family depend on the child's current physical tiredness level, as an indication of the child's physical ability due to side effects and isolation situation, and mood which is represented by the emotion puppets (see Figure 40). This way, parents can also understand how their children feel and have a chance to talk about it even when they do not perform the suggested activities. Moreover, it can encourage parents to open up their emotions to their children during the conversation as well.

The physical tiredness level is an important constraint because sometimes children cannot leave their beds due to exhaustion as a side effect of the treatments. Therefore, three levels were identified for the physical tiredness level:

- "1- I am super energetic today, have ants in the pants!"
- "2-I am a little bit tired, but feeling good enough to stand up!"
- "3- I am exhausted, do not feel like going out of bed."

For each physical tiredness level-mood combination, three categories of missions targeting the three aims of the overall design were defined:

 Missions (activities) that nudge the family to talk about or express their emotions

- Missions (activities) that are only for entertainment and distraction to reduce boredom at the hospital
- Missions (activities) that provide cancerrelated information (e.g., explaining procedures) or coping strategies

Since the first detailing process aimed to prepare the concept for user testing, activities that need to be performed with the room objects/decorations were left out. However, some missions require the family to use emotion puppets. For each category of the missions, three different options were defined to enable the family to choose the one that fits them more. Therefore, in total 36 different missions were created as the result of the detailing process. These missions were then rephrased as a narrative to make children and parents immerse into the theme. Therefore, each mission is presented by Sanus in the narrative (see Figure 41 on the next page).

Although missions involve ordinary activities or games (e.g., sketching, playing charades, etc.), these activities were manipulated in a way that encourages the family to talk about cancer, share/express emotions, learn how procedures work, or explore ways to cope with challenges (e.g., side effects). To do so, play therapy techniques and previously explored strategies (see Chapter 2.4) were used. Figure 41 presents examples of missions from different emotion-tiredness level-activity category combinations. For the complete list of missions, please see Appendix M.

As also mentioned in Chapter 7.1, cancer-related

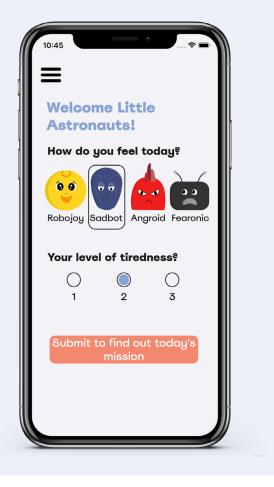


Figure 40: An illustration of the home page of the app

information in the missions is presented to the family as a part of the story to make the design more acceptable to the parents and less scary for children. Appendix N provides a glossary of terms/metaphors used in the missions.

As seen in Figure 41, the reward feature that was identified as a concept improvement opportunity

before (see Chapter 7.3) was added to the game. The children and parents can earn one to three stars for completing each mission. More stars were assigned to the missions that can be more confronting in terms of expressing emotions or sharing/getting cancer-related information.

Hence, families can be more willing to perform these missions with the goal of collecting more stars. As a part of the later iteration steps, these stars are planned to be collectible digitally in the app to unlock new levels as well as physically on a board in the hospital room. When the family gets out of the hospital, they can take the board with them as a memory that represents their journey similar to Beads of Courage (Children with Cancer UK, 2021).



finger) with the soap into the water.

4. Observe the pepper. It runs away, just like the



Missions for entertainment and distraction to reduce boredom at the hospital

Hi, my dear team! Today's mission is about training your senses to become superhumans! Grab something like a cloth that can be tied around the head. One of you blindfolds the other person with this cloth. Now, turn the blindfolded person 3 times around themselves. Anyone who is not blindfolded, run away, (s)he will try to catch you! The training will end when the blindfolded person catches someone. Then this person has to be blindfolded for the second round and so on.

Did you notice how good you are at wayfinding even without seeing it? Now you activated your hyper night vision feature!

Reward:



Missions that nudges the family to talk about or express their emotions

What's up defenders of Korpion? Today, I am very annoyed and cranky because I am tired of fighting against Malus. Anyway, let's grab pen and paper, we will design our new army robots! Sketch an angry robot. Then, if you feel like, tell the story about this robot to your commander: why is he/she angry? what is their power or function? how they will help us to fight against Malus' army?

If you are feeling too tired to tell the story, commanders can hang your sketch on somewhere. Maybe you will discuss these super secret army plans later on!

Reward:

Reward:

clones!

Figure 41: Mission examples

^{*}Experiment is adapted from Science Fun (n.d.).

8.2. EVALUATION OF DETAILS

While detailing the chosen elements of the design, a brief evaluation of the age suitability of the design under development was made with an expert on developmental psychology, Dr. Junko Kanero. This subchapter presents the outcomes of the evaluation briefly.

A short, informal interview was conducted with Dr. Kanero to get her expert opinion on the overall design before the user testing. After the design and the goal of the project were explained, a discussion about the design's age suitability and impact on solving the problem was carried out. The most important remarks from Dr. Kanero are presented on the right.

As understood from these remarks, the design was overall evaluated positively. Especially the remarks about giving children options and paying attention to logic and continuation of the story were implemented into the design as shown in the previous subchapter. The remark about the design's suitability for the target age was later evaluated through the user tests (see Chapter 9).

- 1. The design seems a bit more suitable for younger children since it has the characteristics of imaginative play, which is often a less preferred type of play by children through the end of ages 8-9.
- 2. Some missions, such as acting out the things that make children angry (see Appendix M), can be difficult for children from the target age since they involve abstract thinking. However, the involvement of the parent can solve this issue.
- 3. The school-age children do care about whether the story of the alien makes sense. Therefore, when incorporating the missions into the storyline, the logic and the continuation of the story should be considered.
- 4. As cognitive and social stimulation is a big issue for children with cancer, missions that are only for entertainment can be really helpful. However, every child has different preferences for the activities. While

- some children can really enjoy crafting an astronaut helmet, some can find it boring. Therefore, it is important to give them options.
- 5. In order to keep children engaged, it is crucial to give children feedback. The rewards given for completing the missions can provide engagement.
- 6. Using metaphors for cancer-related topics is beneficial for parents. However, the design might not create the desired impact in terms of making parents express their emotions. If their child is opening up parents can too, but it will probably take a long time. Therefore, it is possible that user testing does not yield desired results.
- 7. It is good that the design offers guided play to children instead of structured play. Guided play can be more engaging for these children since it gives them freedom and autonomy while providing a framework.

8.3. PROTOTYPING

As a result of the detailing process of chosen design elements, physical prototypes were created for user testing. This subchapter presents these prototypes.

As mentioned in the previous subchapters, due to time constraints, simple prototypes were created only for the missions and the emotion puppets.

Instead of presenting the missions on a mobile app, low-fidelity prototypes were created in a card format (see Figure 42). On one side of the card, the mission was presented with Sanus' narrative, whereas the emotion and the tiredness level were indicated on the other side of the card (see Figure 42). On the cards, the emotions are represented with circles in their colour. For user testing, the cards were grouped according to these emotions and put into transparent folders (see Figure 43 on the next page).

For the emotion puppets, clay models in Figure 44 (page 74) were created due to clay's convenience of creating organic shapes and details. Some details of the puppets, such as the wheels of Angroid and Fearonic and the elements on their heads, had to be eliminated or changed due to practical reasons (i.e., to make them stand still without support). Also, Sadbot's posture was changed into sitting to make the puppet stand without support and give it a sadder look (see Chapter 8.1.1). The colour and details (e.g., facial expressions) were given to the prototypes by painting them.

Greeting & Hello dear astronauts and space commanders! Hope you are feeling well. I have some good incorporating news: we discovered a way to get rid of some of the mission the clones of Malus. Apparently, these clones into story Tiredness level: do not like music. When they hear music, they run away! So your mission is to sing your family song super loud. Don't you have a family song yet? Gather family members (online/offline) and hold a meeting to pick a family song or make a Description family playlist together. You can even organise of the a karaoke night. Or if you picked several songs, activity listen them together whenever you need some "I am a little bit tired, but feeling P.S.: You can even write your own song! good enough to stand up!" The stars you can earn from the mission: Reward to be earned

Figure 42: An example mission card (front and back sides)

The size of the puppets was chosen in a way that fits into children's palms because of a father's remark during user research (see Chapter 3. 2. 3). The father indicated that his child had small toy cars that fit into his palm and he was carrying them around the hospital throughout his journey. He was also taking them with him to the operation room as if he was getting power from them. To create a similar effect, the puppets were given around 8 cm height and about 12 cm circumference* (DINED, 2020).

In addition to the prototypes of puppets and missions, an animated video was created to present Sanus' story and give instructions to the users for testing. To access the video, please visit https://youtu.be/54KtKaqm-u8 (in Turkish).

In conclusion, these prototypes served as the first step in the implementation of the final design proposal. Later, more iterations on these prototypes were made or suggested, as explained in Chapters 10 and 11.

Chapter 8 • Prototyping 72

^{*} grip circumference and hand length data from Dutch children population was used as a reference (DINED, 2020)



Figure 43: The mission cards prepared for user testing

Chapter 8 • Prototyping 73



Figure 44: Clay prototypes of the emotion puppets

Chapter 8 ● Prototyping 74

CHAPTER TAKEAWAYS

Due to the limited time allocated for the project, only **core elements** of the chosen concept, Astronauts on the Mission, were further developed. These elements are the **missions** and the **emotion puppets**.



Emotion puppets:

Boredom puppet (Teddy) was discarded and names of the puppets were changed as Robojoy, Sadbot, Angroid, and Fearonic.

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Missions:

On the mobile app, missions are **suggested** to the family based on the selected **mood** and **tiredness level combination**. For each combination, there are **three types of missions**:

- Missions that nudge the family to talk about or express their emotions
- Missions for entertainment and distraction to reduce boredom at the hospital
- Missions that provide cancer-related information or coping strategies

A developmental psychology expert evaluated the detailed concept and found it age-appropriate, but; she pointed out the importance of logic and continuity of the storyline for the target age group.



For user testing, **playing** cards were created instead of a mobile app to present missions to families. Also, clay prototypes were made for the emotion puppets.



CHAPTER 9 USER TESTING

This chapter presents the tests that were performed with the target users to evaluate the improvements made on the Astronauts on the Mission. The tests served as a final validation of the core elements' impact on the design problem before making a final design proposal. First, the chapter provides the aim, method, and results of these tests. Then, the chapter ends with a discussion of the conclusions derived from the tests and their implications for the final proposal.

9.1. RESEARCH AIM & QUESTIONS

This subchapter describes the aim of the user testing and presents the research questions formulated.

9.1.1. Research Aim

The tests aimed to understand how the actual users perceive and interact with the components of the design (i.e., mission cards, emotion puppets, and the storyline) and validate whether the design solves the problem (see Chapter 5.1) by creating the desired user experience (i.e., nudging families to share feelings and information about cancer in a playful way).

9.1.2. Research Questions

The research questions that were aimed to be answered with the testing are as follows:

For the overall design:

- **1.** What is the effect of the design on the interaction between the child and the parent regarding cancer?
 - **1.1.** Does the design facilitate having conversations about cancer?
 - **1.2.** Does the design help children and parents to express their emotions to each other?
- 2. How do families use the product?
 - **2.1.** Does the product encourage children-parents to play together?
 - 2.2. How do they use the puppets?
- 3. How do families experience the interaction

- with the product (e.g. confronting/pleasant/fun etc.)?
- **4.** What emotions does the interaction with the product evoke in the parent & child?
- **5.** Are the families willing to accept and use the new intervention?
- **6.** Is the story/theme clear and enjoyable for children and acceptable for parents?

For the emotion puppets:

- **7.** Are emotions represented by droid characters understood correctly by children?
- **8.** Are these emotions sufficient to express how they feel or do more emotions need to be added?
- **9.** Which features of the characters need to be changed (color, body posture, facial expression)?

9.2. METHOD

This subchapter provides an overview of participant demographics and the method of the testing via Figure 45. For a detailed description of the method and the interview questions, please see Appendix O.

P1¹(8) **P2**¹ (8) healthy P31(8) **P5**¹ (7) **P4**(7) extrovert ALL healthy Immuno-ALL outpatient deficiency extrovert outpatient introvert outpatient extrovert N/A^2

PROCEDURE



REMARKS

For the ethical approval, please see Appendix B.

As seen from participants, healthy children were also included in the study due to the insufficient number of patients from target age group.

- ¹ Other family members & younger siblings (aged 5-6) also joined in the testing.
- ² Family answered questions through an online questionnaire.
- ³ 1 other child (healthy, aged 8) was asked about the representativeness of the emotion puppets.
- ⁴ After each try-out session prototypes were taken back to hand it over to the next family.

Figure 45: An illustration of the method and participant demographics

9.3. RESULTS

During the interviews, predetermined questions were asked to the participants. To analyse the results, all participants' answers were gathered under each question (see Appendix P). From the answers, key insights were extracted and categorised. This subchapter presents these insights under the categories that reflect different aspects or components of the design.

9.3.1. The Impact of the Design

The parents who joined the study indicated that the game has the potential to facilitate talking about cancer-related topics with their children due to its storyline and metaphors. Some parents stated that they did not experience communication problems with their children regarding cancer, but they think the game might be helpful for the families who do.

"...it was hard to explain the illness to my child. You think a lot about how to explain, and also you are in a bad place. This game would make it easier for me to explain. I would not even have to think."

Mother of P4

About the game's impact on sharing emotions, almost all parents stated that the game can facilitate sharing or expressing emotions only if children want. It was also understood that parents will not be willing to share or express their emotions, if their child will not share, which is in line with Dr. Kanero's comments (see Chapter 8.2). Therefore, it can be said that the impact depends on children's personalities. However, the emotion puppets are useful, especially as an indicator of introverted children's emotions:

"I really think that it depends on the child. My child usually keeps his feelings to himself. The game or any method would work only if he wants to express his feelings. So, I am not sure. But the puppets can be an indicator."

Mother of P2

On the other hand, one parent mentioned that playing the game created a quite positive impact for them, both in terms of expressing emotions and reducing boredom:

"...Actually, we could not spend so much time together. This game connected us again. Brought an excitement to our lives. "

Mother of P4

9.3.2. User Experience

Naturally, the experiences of healthy and ill children with the game differed significantly. Overall, the game was more interesting and fun for ill children and younger siblings of healthy children. One mother (P4) indicated that performing activities like crafting made her child feel like going back to school, which he missed a lot during nine months of treatment. Therefore, playing the game evoked happiness and excitement in them.

For healthy children, the activities that are part of the missions were not interesting because they were time-consuming and ordinary. Moreover, the emotion puppets did not stand out among other toys that children have.

Lastly, the use context of the game affected families' experience. A mother (P5) indicated that their experience with the game was a bit boring because they tried it in the home environment.

During interviews, the families mentioned different use scenarios or interactions with the game (see Figure 46). In the first scenario, all family members joined the game. While a parent read the mission on the card, other parents and children acted out the characters from the game and performed the mission together. The game functioned as a fun experience. In the second scenario, the parent and child performed the missions together after the child read the missions from the cards. In this case, the interaction was more intimate; the game served as a parent-child bonding experience.

9.3.3. Emotion Puppets

Again, ill children found the puppets more interesting than healthy children. They even wanted to keep the prototypes after try-out sessions. On the other hand, some families did not really play with the puppet prototypes due to fear of harming them or receiving the prototypes broken. Therefore, it affected their experience negatively.

In terms of representativeness, joy and anger puppets performed very well due to their bright colours and clear facial expressions. Sadness and fear were harder to be recognised because their expressions were not obvious due to their dark colour. It was observed that children pay more attention to facial expressions (especially mouth) than posture. However, a participant (P3) mentioned the contribution of Robojoy's posture to its expressiveness by saying Robojoy does not have feet because it is super happy. The children also made the suggestions in Figure 47 on the next page to improve Angroid, Sadbot, and Fearonic. For Robojoy, they did not have any suggestions.

The number of emotions represented by the puppets was found sufficient. The families indicated that they did not feel the need for additional emotion while playing the game. Also, the size of the puppets was found ideal. As the last remark, one parent liked that all puppets had different appearances and characteristics:

"It is nice that all puppets are different and have unique characteristics; they are not standardised. It might support the feeling of being different from other kids in a positive way."

Mother of P1

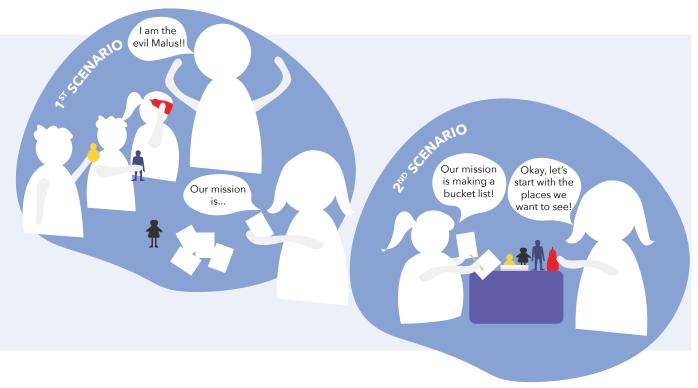
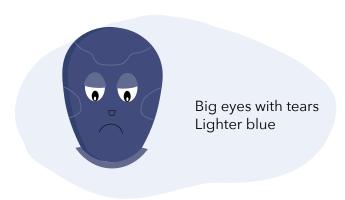


Figure 46: Illustrations of use scenarios of the game during try-out sessions





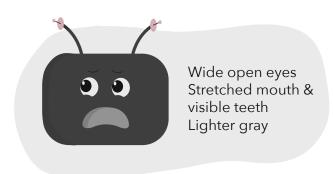


Figure 47: Improvement suggestions for puppets

9.3.4. Missions

Overall, the families liked the content of mission cards (i.e., activities) but had different opinions on the way missions were presented on the card. As mentioned in Chapter 8.3, a back story about the mission was given on the cards first, then the mission (i.e., activity) itself. However, it caused some children to lose interest halfway before getting to the activity itself. Also, one family (P3) indicated that they expected missions to be something concrete and quickly performed (e.g., find the orange box in the kitchen) because it was presented as a card game. As a result of this expectation, it was hard to keep the children's attention on the game.

Especially families of healthy children indicated that some activities presented as missions take a lot of time to perform and require preparation beforehand. Therefore, they did not want to perform these missions. Moreover, some missions were found unsuitable for hospitalised children because they might increase bleeding (e.g., the missions that require scissors use) or fall risk (e.g., pillow fight).

As Dr. Kanero indicated in Chapter 8.2, children do care about the logic and continuation of the story/theme:

"I liked the missions, but I didn't get how meditation and space are related!"

9.3.5. The Storyline of the Game

The narrative and theme of the game are liked by all parents and children regardless of gender. The storyline was found logical and suitable for children from the target age group. However, two children (P1 and P3) did not like that the bad character Malus was the good character Sanus's sibling. They indicated that they would like it more if the bad character was presented as the archenemy of Sanus instead of its sibling. A mother (P3) also indicated that it might be misleading for children since there is already a sibling rivalry around these ages.

9.3.6. Suggestions for Improvement

During the interviews, the families made some suggestions to improve the design. These are as follows:

- Adding a material kit so that they do not have to search for materials required for some missions (e.g., making astronaut helmets)
- Making mission cards more visual
- Presenting the mission first or highlighting it so that they can skip the narrative if they want
- A function to bring ill children together
- Adding movement to puppets
- Making more use of the emotion puppets while performing the missions

9.4. CONCLUSIONS & DISCUSSION

This subchapter discusses the limitations of the study and the implications of the results for the final proposal while answering the research questions.

First of all, there is a significant difference between the families of healthy and ill children's experiences with the game as understood from the results. Although the families of healthy children helped to evaluate the representativeness of the puppets, the game's age suitability, and appeal, the families of ill children were the key determinants to validate the user experience and the impact of the game.

The following paragraphs answer the research questions (see Chapter 9.1).

As an answer to the first and fifth research questions, the design is desirable and acceptable for the families of children with cancer (n=3) and; has the potential to facilitate cancer-related communication between children and parents. The storyline and metaphors incorporated into the narrative were the main factors that help with this potential and acceptance of the families. In terms of expressing emotions, the emotion puppets functioned well as an indicator of children's feelings regardless of their personality, although they might not start open discussions about emotions. However, the design still needs further testing with hospitalised and preferably

newly diagnosed families for a longer time to validate its impact on parents to share their emotions and on the actual target group.

As an answer to the second, third, fourth, and sixth questions, the experiences of the families were overall positive: they had fun, the game brought them closer as a family or parent-child couple, and evoked pleasant feelings such as joy. Therefore, it can be said that the game created the desired user experience, especially for the families of ill children, in which the parents and children immersed themselves in another world by becoming astronauts, got help from the emotion puppets, and performed the missions together. Also, all elements of the game were logical, age-appropriate, and clear.

On the other hand, it should be noted that the broken prototypes and the use context (i.e., home) resulted in a boring and frustrating experience for some families. Therefore, a more durable material needs to be selected for the puppets. Moreover, some families did not play with the prototypes freely since they knew that they need to give them back. For example, they did not take the cards out of the folders or try a lot of missions due to the fear of losing the cards, which affected their evaluation. Also, presenting missions in a card format with long descriptions caused confusion in some families. As mentioned in Chapter 8.1.2, the missions will be presented

to the family on a mobile app in the final design. Still, the way of presenting needs to be inviting for families to try out the missions.

In response to the questions about emotion puppets (7,8, and 9), the current puppets are sufficient for expressing children's emotions and represent the emotions well with their colours and body postures. However, Angroid, Fearonic, and Sadbot need to be improved as suggested by children.

To conclude, the tests validated that the design shows promising potential to fulfil the design goal (see Chapter 5.2) and solve the problem (see Chapter 5.1) when used in the actual context. Although no major changes are needed for the core elements and the function, small improvements will be made (see Chapter 10.1) or suggested for later (see Chapter 11.2) based on the results and participants' suggestions.

The impact, user experience, desirability, and clarity of the design and its core components were evaluated with user tests, in which users tried out the prototypes at home for 1-2 days.

Both healthy and ill children and their parents participated in the study. Ill children were almost at the end of their treatment period.

TA2

Tests showed that even with its core elements only, the design has the potential to help families communicate about cancer and help children express their feelings. However, this potential needs further testing with families with newly diagnosed children and for a longer period.

TA3

Families of ill and healthy children had different experiences with the game. The families of ill children had a **fun** and **joyous** experience. The game brought parents and children closer



CHAPTER 10 FINAL DESIGN PROPOSAL: ASTROMISSION

This chapter presents the final design proposal named AstroMission. First, the chapter gives information about the improvements made on the emotion puppets, missions, and the storyline based on the user feedback mentioned in the previous chapter. Moreover, it showcases the proposal for the mobile app interface. Lastly, the chapter looks into the implementation of the puppets and the mobile app in terms of materials, production methods, and costs.

10.1. FINAL DETAILS

This subchapter presents the improved emotion puppets and describes the changes made to the missions and storyline through the proposed mobile app interface.

10.1.1. Improved Emotion Puppets

The emotion puppets were improved based on the suggestions of the users. To visualise the changes, a new set of prototypes out of clay and styrofoam were created as in Figure 48. As seen in this figure, Robojoy was prototyped out of Styrofoam to make it more lightweight and therefore, more expressive of the emotion it represents (see Chapter 8.1.1). Moreover, the facial expressions of other characters were changed, and lighter colours were used for Sadbot and Fearonic.

In terms of final appearance and materialisation, the puppets were iterated once more. However, the expressions and colours were kept the same. The details of this iteration step are presented in the next chapter.

10.1.2. Mobile App

As indicated in Chapter 8.3, the mission cards and the video that presents Sanus's story were created only for testing purposes. Therefore, an interface for the mobile app was created to show how missions and Sanus's story are presented in the final design. While creating the app, the missions and the story were adjusted according to user feedback first. The following sections

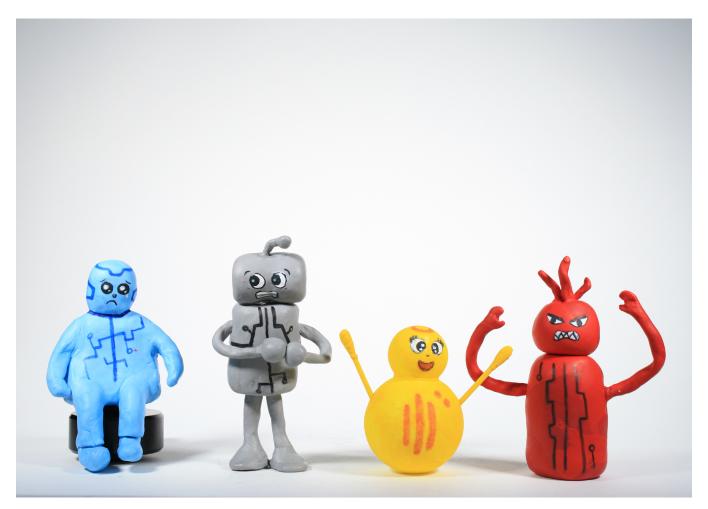


Figure 48: Improved emotion puppets

explain these adjustments and present the final appearance of the interface.

The Storyline

In the narrative, only Malus's role was changed from twin brother to an enemy, as suggested by children. With this change, the back story of Sanus is presented on the onboarding pages of the mobile app (see Figure 49 on the next page). Therefore, the users can read the story step by step or completely skip it. Later, they can also access a more elaborated version of the story from the menu.

Chapter 10 ● Final Details



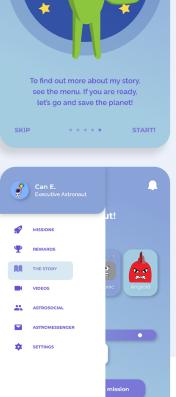
Figure 49: App onboarding pages that present Sanus's story

The Missions

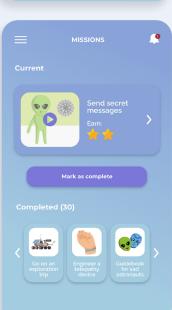
Upon the feedback of the parents (see Chapter 9.3.4), the missions that are not acceptable in the hospital setting (e.g., affecting end-oflife situations negatively) were removed (see Appendix Q).

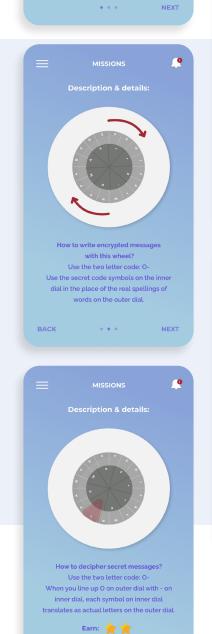
The way that missions are presented to families was also changed: families can watch a video of Sanus that explains the mission to them, or they can access the written descriptions of the missions on the app (see Figure 50 on the next page). The text is presented step by step, with visuals to avoid lengthy and hard-to-read descriptions.

As mentioned in Chapter 8.1.2, the app allows the family to earn stars when they complete a mission. For every five stars collected from similar kinds of missions, they can also earn a badge that allows them to unlock new levels and access new missions (see Figure 50). Moreover, a new social feature was added to the app by utilizing users' suggestions (see Chapter 9.3.6) and inspiration from the Funster concept (see Chapter 7. 1). This feature enables children to contact other children at the hospital, compete with each other by earning more stars, and share their achievements or mission outcomes if they want (see Figure 50).





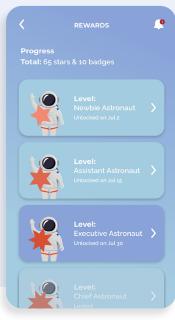




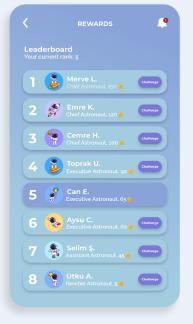
Ssshhh... We need to be quiet!! I learned that Malus implemented a bug in the space station to learn our planet-saving plans. Report your statuses to each other

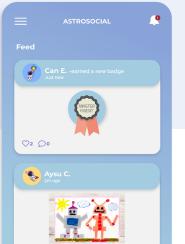
by writing secret messages with the decoder wheel in the space station.

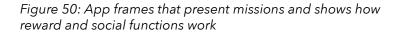














Hello, little astronaut!

Interface for the Parents

As mentioned in Chapter 7.1.1, a separate interface for parents was also a part of the design. The parents can access the interface from the same app by changing the login data. Both in the parents' and children's interface, the mission and rewards are the same since they play together. Also, the parents can utilise AstroSocial to connect with other parents at the hospital or survivors' parents. Additional features in parents' interface are a glossary of game metaphors that they can use for giving information to their children and a function that allows them to offer their children certain missions to prepare them for upcoming procedures. The app frames in Figure 51 illustrate these features.

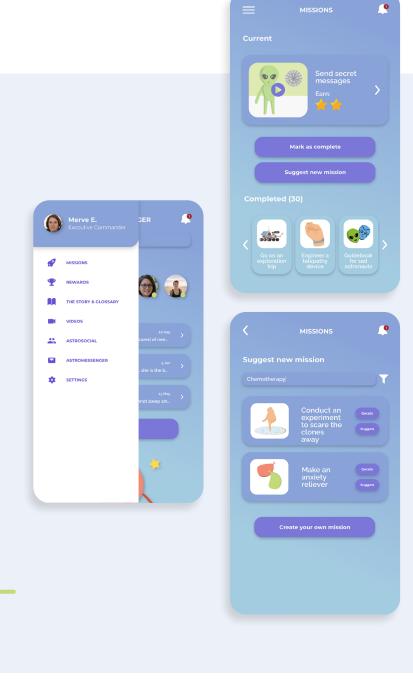


Figure 51: App pages that shows distinct functions of parents' interface





10.2. IMPLEMENTATION OF ASTROMISSION

The implementation of Astromission into practice was examined as the last step of the final proposal. This subchapter proposes a strategy to implement AstroMission in hospitals, and a material and method to produce emotion puppets. Also, it presents the cost estimation for the implementation of both the puppets and the mobile app.

10.2.1. Implementation Strategy

Although only the emotion puppets and app functions were iterated as a part of this project, when all elements of AstroMission are considered, it would be logical that hospitals offer AstroMission as a part of their services.

In Turkey, there are two types of hospitals in terms of the financing system: public and private (Özdeniz, 2011). Therefore, AstroMission needs to be feasible and viable for both types of hospitals. While private hospitals can allocate resources for this game, likely, that public hospitals cannot. However, there are several non-profit organisations, such as LÖSEV and KAÇUV, that work to enhance the care and living standards of children with cancer and their families and satisfy their needs. These organisations pursue similar projects, such as establishing play rooms for deprived hospitals (KAÇUV, 2021). Therefore, it is proposed to collaborate with such organisations to implement AstroMission in public hospitals.



10.2.2. Materialisation & Production

Although using different materials for each puppet (e.g., metal for anger and silicon for sadness-see Chapter 8.1.1) can accentuate its expressiveness, one type of material needs to be chosen for all puppets to keep the costs low and manufacturing as simple as possible. While using a single material, it is still possible to make puppets reflect the emotions they represent through texture, weight, colour, expression, and posture. To show that, several tryouts were made by 3D printing the puppets with the FDM method (see Figure 52). For each puppet, parameters

Figure 52: 3D printed tryouts of the emotion puppets

were tweaked to obtain desired qualities. For example, Angroid was printed with 0.06 mm layer thickness and 50% infill to obtain a rigid, tense body and smooth, shiny surface. For the printing settings for each puppet, please see Appendix R.

For choosing a suitable material and production method for the puppets, several factors need to be considered in addition to the design requirements in Chapter 5.3:

• The material should be medical grade, sterilisable & durable (e.g., impact-resistant).

- The production method should result in a near-net shape part, with little (or only light) post-processing required (e.g., no sharp edges and no chemical surface treatment).
- The production volume was estimated as 20-50 sets of puppets per hospital per year. Therefore, the production method should be feasible and viable for low volumes while able to provide distinct qualities for each puppet (e.g., posture, and texture).
- Repairing or replacing the puppets should be easy for the hospital. Rapid manufacturing methods can satisfy this requirement.

As the final material of puppets, plastic is proposed. Specifically, polyethylene, polypropylene, polyamide, ABS, and TPU are the best options since they have already been used widely in medical applications and toys and; are durable, safe, and suitable for low-volume production (Amery, 2021; Essentra Components, 2021).

For the production method, a preselection was made with an expert, Joris van Dam, based on the requirements mentioned and material choices. For example, injection moulding was eliminated due to being expensive and inefficient for small batches (Formlabs, 2022a). In the end, the three most suitable methods were selected and compared in Figure 53.

Even though in-house production of puppets is possible with the methods in the figure, it requires extra investment in tooling, skilled personnel, and resources. Therefore, it is proposed to outsource

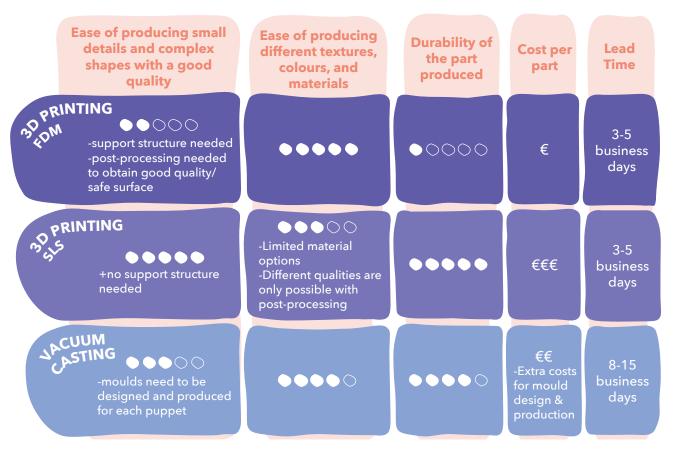


Figure 53: Comparison of selected production methods (Formlabs, 2022b; Luo, 2021; Materialise, 2022a)

the production to the companies that offer these applications.

As seen from the tryouts on the previous page (Figure 52) and Figure 53, FDM is a quick, cheap, and easy method in terms of obtaining different surface finishes. However, the major drawbacks of this method are the durability and post-processing (i.e., cleaning support structure) of produced parts. During tryouts, it was

observed that the parts break quite easily. Since children might drop or throw the puppets, this method might not be ideal. Also, when not well processed, an uncleaned support structure can be dangerous. Therefore, SLS is recommended among these three methods in Figure 53 since it leads to efficient manufacturing of high-quality, complex, and durable parts despite higher costs per part. When SLS is chosen, only polypropylene, polyamide, or TPU can be used from the

proposed materials. Although vacuum casting seems to be a comparable option to SLS due to obtaining desired qualities and more material options, the need for designing, manufacturing, and maintaining moulds for each puppet makes it less preferable. With any method, a post-

process like pad printing is needed to give facial expressions and other details to puppets.

10.2.3. Cost Estimation

As the last step of the implementation proposal, implementation costs were roughly estimated as

the sum of the costs for the proposed production method and mobile app development. Figure 54 shows the breakdown of the costs. For the details of calculation and manufacturer quotations, please see Appendix S.

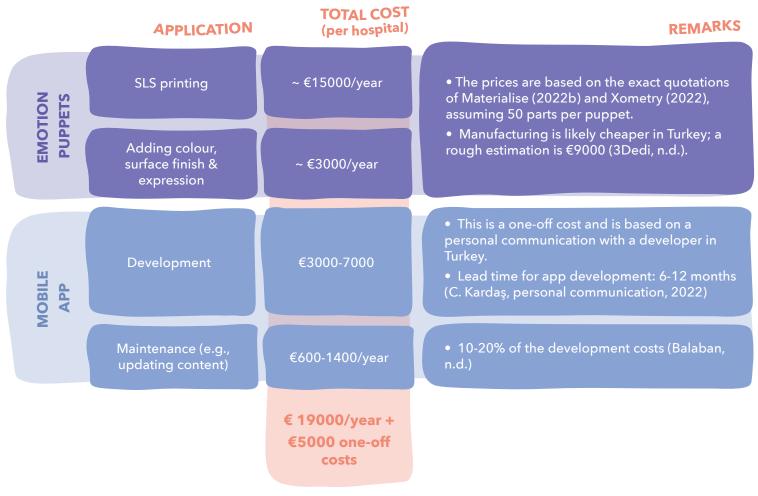


Figure 54: Breakdown of the implementation costs

CARTER TAKEAWAYS
Final design Final design proposal (i.e., the game) was named AstroMission. Emotion puppets, missions and the **storyline** of AstroMission were **improved** based on user feedback.



Emotion puppets:

- Facial expressions of Sadbot, Fearonic and Angroid were changed.
- Sadbot and Fearonic's colours were changed to a lighter shade.

Missions & storyline:

- Some missions were discarded (see Appendix Q).
- Mobile app interfaces were created for presenting missions and story of the game to families.

Production volume was estimated as 20-50 patients per hospital per year.



- To produce puppets, 3D printing with SLS method is recommended.
- As the material. polypropylene (PP), polyamide (PA), or TPU is recommended.



Total costs (emotion puppets + mobile app) were roughly estimated as:

€19000 per year per hospital plus €5000 one-off costs.



CHAPTER 11 DISCUSSION & CONCLUSION

This chapter concludes the project by discussing AstroMission's value proposition for different stakeholders, assessing its feasibility, desirability, and viability, highlighting the limitations of the project, and making recommendations for further research and development of the product. Lastly, the chapter reflects on the project process and personal earnings.

11.1. DISCUSSION & CONCLUSION OF THE PROJECT

This subchapter discusses AstroMission's and the project's impact in terms of fulfilling the design goal and solving the design problem. Moreover, the subchapter assesses AstroMission on the three lenses of innovation: Feasibility, Desirability, and Viability. Finally, it presents the limitations that may have affected the process and outcome of the project.

11.1.1. The Impact of Proposed Design & Project

The project started with an aim to help pediatric oncology patients in Turkey to understand their illness through play, so that they can adjust to the significant life change and cope better with cancer. The literature review and field research revealed that the parents are the main factor that affects children's understanding, adjustment, and coping by avoiding sharing cancer-related information and emotions. Moreover, this attitude of parents affects their own well-being negatively. These key insights caused the project focus to shift to developing a playful solution that facilitates the emotional connection between children and parents. However, the solution needed to be non-threatening and unobtrusive to be acceptable for the families.

Looking at the final outcome of the project, the user tests showed that AstroMission has the characteristics to help children and parents connect emotionally and have conversations about cancer:

- **1.** It is acceptable and useful since it facilitates the communication of cancer-related topics in a non-threatening way via metaphors and the story.
- 2. The emotion puppets help children express their emotions in a non-verbal way, which is suitable for both introverted and extroverted children. By showing parents how their children

feel, the puppets give parents a chance to talk to their children about it and share their own feelings.

3. The missions bring the family closer while creating a fun experience.

The final proposal of AstroMission and the graduation project create the following value propositions for different stakeholders:



Pediatric Oncology Patients

AstroMission contributes to children's understanding by nudging their parents to share cancer-related information with them. Moreover, it helps them to adjust to the hospital environment and treatments by reframing their cancer experience into a fun roleplaying game. Especially when children are isolated socially and physically, it creates opportunities for entertainment, safe social contact with other children, and physical activity. AstroMission also enables effective coping by helping children to express their emotions, strengthening their bonds with their parents through collaborations on missions, and giving them coping tips. While doing these, AstroMission provides freedom to children in terms of what and how they want to play and how much they want to share their feelings.



Parents

AstroMission guides the parents of especially newly-diagnosed children by facilitating sharing of cancer-related information with their children. Also, it alleviates the psychoemotional burden of parents by giving them opportunities to show their feelings and support to their children and to connect with other parents in a similar situation. Lastly, it helps parents to bond with their children while having fun together.



Hospitals & healthcare professionals

AstroMission can help hospitals improve their healthcare services and patient experience by providing families psycho-emotional support. The success rate of treatments can increase when the patients adjust and cope better. Moreover, the HPs can utilise metaphors and the story of AstroMission to communicate with their patients. This way, parents will be less likely to try to control or limit patient-HP interaction, which leads to a better understanding of patient needs by the HPs.



Other researchers, designers, and organisations who work in a similar context or want to develop AstroMission further

During the research, it was seen that design interventions in medical settings are not common in Turkey. Therefore, the project can be an exemplary work that shows how to design or develop such interventions by utilising co-design and play. Moreover, the project can help researchers, designers, or organisations examine the various aspects of the experiences of families of pediatric patients in Turkey with field research insights and the user journey map. Lastly, the project showcases how AstroMission can be implemented and developed further with the recommendations (see Chapter 11.2).

11.1.2. Conclusions on Feasibility, Desirability, Viability

Feasibility

Chapter 10.2 showed that the core elements of AstroMission can be put into practice within six months up to a year with the proposed materials and production methods. However, the acceptability of the implementation costs (i.e., whether the solution is feasible for them) needs to be discussed with the organisation that wants to implement AstroMission. On the other hand, as proposed, collaborating with non-profit organisations seems to be a promising option to finance the implementation of AstroMission through donations. Moreover, some changes can be made to the design to lower costs. These are mentioned in Chapter 11.2.

It should be noted that the emotion puppets might need certification (e.g., CE Mark) since the puppets will be used in a medical setting and by children. Therefore, the certification process might affect the implementation time.

Desirability

From the concept phase to the final proposal, the desirability of AstroMission was assessed with the target users several times. Despite the small sample size, the results of these assessments hint that regardless of gender, children with different diagnoses and their parents are willing to play AstroMission because it is useful, entertaining, and non-threatening. It gives them flexibility and freedom in terms of sharing information and emotions and playing. However, the latest

version of AstroMission with the mobile app and 3D printed emotion puppets was not tested. Therefore, the impact of these changes on the user experience and the app usability needs further testing.

Viability

In Turkey, the applications of design interventions like AstroMission are quite limited or non-existent. Therefore, as mentioned with the value propositions, AstroMission has the potential to improve the user experience at the hospital, which can return as profit to the private hospitals while increasing their publicity. Similarly, for public hospitals, AstroMission can help with improving the conditions in the hospital and receiving donations by attracting attention. However, a detailed implementation plan is needed to assess AstroMission's actual viability for the specific organisation that wants to implement it.

11.1.3. Limitations of the Project

Throughout the project process, several limitations encountered may have affected the outcome. First of all, time was the biggest constraint. All activities of the project, including travelling to Turkey, needed to be carefully planned and executed as sprints. Therefore, this situation might have caused missing out on some relevant literature or less extensive interview results. Due to the sensitivity of the topic, the children and the parents were hesitant to share their experiences with a stranger. With more time, the families' trust could have been earned, and more information could have been gathered. Moreover, the full-scale design could

not be fully developed and tested because of the time allocated for the project.

Lastly, the hospital did not know in advance which patients would be staying at the hospital since it depends on whether a child gets a diagnosis or have an emergency (e.g., fever). Although there were some hospitalised children for a long time, it was up to luck to find children of the target age among them. Therefore, the interviews and tests were difficult to plan beforehand. Additionally, concept evaluations and final tests could not be conducted with the exact target users and in the actual context of use. At least representative users participated in these studies, but the small sample size might also have influenced the results.

11.2. RECOMMENDATIONS

This subchapter presents the recommendations for further development of AstroMission.

11.2.1. Testing the full-scale design

As mentioned before, only the core elements of AstroMission were iterated and validated with the users. First, the hospital room decorations and objects need to be designed and developed. The mobile app needs to be adjusted accordingly, and the emotion puppets need to be SLS printed with their new facial expressions. With these developments, it is recommended to test the full-scale design with a larger sample of preferably newly diagnosed and hospitalised families for a few weeks up to a month. This way, AstroMission's actual impact on the design problem can be validated.

11.2.2. Developing the room décor and objects

While developing the room décor and objects, the initial concept, Astronauts on the Mission, can serve as a starting point. To make the implementation of the changes in the room feasible, repurposing the current room elements can be beneficial instead of redesigning the whole room and adding new objects. However, the board for collecting rewards (i.e., stars) needs to be designed since it is a part of the final proposal. Also, the wall stickers from the initial concept can be kept since they are easy to implement. They can even be placed in the other parts of the hospital, such as the radiotherapy room, to

expand the play opportunities that AstroMission offers and reframe children's perspectives of the hospital environment.

11.2.3. Improving the missions & story

It is recommended to conduct co-design sessions with children, parents, HPs, and play therapists. In these sessions, the current list of missions can be evaluated in detail, improvements can be made, and new missions can be added. These new missions can integrate the room décor and objects, and utilise the potential of the digital applications since the missions are presented on a mobile app. For example, the missions can integrate AR technology to collect surprise rewards or immerse children more into the story by catching Malus's clones like in Pokémon GO (Niantic, 2016).

Additionally, the storyline of the game needs to be detailed more. More procedures, treatments, and side effects can be incorporated into the game with new metaphors. Once a list of suitable missions is created and the story is elaborated, the mobile app can be fully developed based on the interfaces proposed in Chapter 10.1.2.

11.2.4. Improving the emotion puppets

For the implementation of the puppets, tryouts with the SLS method are recommended to confirm whether it is possible to obtain desired qualities

of the puppets (e.g., texture). When the method is confirmed, the puppets' geometries need to be optimised for SLS printing by considering tolerances and minimum wall thicknesses. While doing so, hygiene requirements should be considered as well. For example, hard-to-clean indents or features should be avoided.

Another recommendation is to add movements mentioned in Chapter 8.1.1 to the puppets to make them more expressive of the emotion they represent. For example, Fearonic's head can go inside its body, like a turtle goes into its shell, and it can start vibrating. In this case, the puppets need to be redesigned with electronics or compliant mechanisms.

11.2.5. Implementation options

The tested (see Chapter 8) and proposed designs (see Chapter 10) can be the two options for implementation. The implementation of the proposed design was presented in Chapter 10.2.

The tested design with only the cards and puppets can be a low-cost solution, especially for public hospitals or non-profit organisations. Moreover, the tested design can be further developed for different stages of the treatment and use contexts such as the home. In that case, as the user tests suggested (see Chapter 9), the design of the cards needs to be changed to a more visual layout that highlights the mission rather than the story.

11.3. PERSONAL REFLECTION

This subchapter reflects on the project process, lessons learned, and personal earnings from the project.

Eleven years ago, I had the worst experience of my life, lost my best friend to leukemia. After witnessing all the challenges that the illness brought, I was looking for ways to help cancer patients, their families, or friends. Finally, I found my chance to do so by initiating this project. Therefore, I must say that this project is more than a thesis to me. With this motivation, I tried to execute the project in the best way I could, and I hope the outcome can make an impact on the lives of children with cancer and their families.

Challenges

Looking back at the process, the most challenging part of the project was staying on track and following the project planning I made in the beginning. Obviously, not everything went according to plan due to external factors, and I faced many obstacles. The first obstacle was the parents' attitude when I wanted to interview their children and the difficulty of finding (enough) participants from the actual target group. On the first day of the interviews, I lost hope that I could gather enough data from the participants. However, this situation turned out to be the main problem, and it taught me to zoom out to see what the obstacles tell me and improvise based on the situation at hand. Therefore, I was prepared with my backup plans for the later interviews and

testing sessions.

The second obstacle was the difficulty of ending a design sprint and feeling satisfied. Since I am a perfectionist and due to the project's importance to me, I had a hard time deciding when to end a research or design phase. I must admit that it always felt like I was missing out on some crucial detail, or I could have done better. However, my graduation committee's input and the time pressure helped me to move forward.

The third obstacle was the time I spent on ideation and concept development. Throughout my master's studies, I experienced this problem often. During this project, I discovered the root cause of this problem: I am too critical of the ideas I come up with and eliminate them immediately if they are not innovative or feasible enough for my standards. As a result, I feel the need for spending more time than I plan to force myself to be more creative while dealing with the time pressure, which does not help with creativity. In this project, the co-creation session I conducted with my friends was quite useful for me, as I learned how to keep an open mindset. Moreover, my committee's feedback guided and inspired me, especially during concept development.

Another challenge for me was to share the interim results of my design sprints with my committee. Due to my perfectionism, I was afraid to show unfinished work, which may have resulted in me benefiting less from my mentors' expertise.

However, they made me become aware of this situation and nudged me into changing this attitude.

Lastly, the emotional load of the project was challenging. Especially interacting with children was really difficult in the beginning since they reminded me of my friend and the experience we had. Over time, the idea of helping children through my work motivated me to keep my focus on the work and overcome this challenge.

Gains

Besides the challenges I experienced throughout the project, I would like to mention what I earned from this project in the following paragraphs.

Being able to initiate and pursue a project on my own

Despite all the challenges, I managed to initiate my own graduation project and finished it on time. Throughout the project, I learned how to manage time, deal with various obstacles and keep myself motivated. I have a mechanical engineering background and that's why I was not always confident about my designer skills during my master's studies. With this project, I had a chance to improve my visualisation and 3D printing skills. Also, I gained experience with the tools and methods that I never used before, such as the user journey map and contextmapping. Therefore, I feel much more competent and ready to conclude my master's studies.

Gaining experience with designing for healthcare and interaction design

Since I want to pursue a career in social design in medical settings, I aimed to gain experience with designing for healthcare and explore the field of interaction design with this project. The project certainly challenged me to go out of my comfort zone by focusing on both children-parent and family-product interactions, and the families' experiences. Moreover, I had the opportunity to experience working with actual patients and healthcare professionals and learn how to design for sensitive settings.

Gaining experience with co-design with children

Throughout my master's studies, I worked on several projects during which I utilised codesign methodologies. However, this project was the first time I ever worked with children. It was challenging to communicate with them and estimate what they need and want. For example, I thought they would be interested in making a collage or drawing during the interviews; instead, they preferred to answer my questions directly. During the project, through frequent interactions and with the help of my mentor's expertise, I learned how to communicate with children, interpret their behaviour, and gained experience working with them.

AstroMission is a feasible and desirable game that has the characteristics to help children and parents connect emotionally and have conversations about cancer. However, a detailed implementation plan is needed to assess its viability.

TA1

the thesis creates value for different stakeholders:

improves their

understanding,

adjustment, and

coping

akeholders:

AstroMission and

For other researchers/designers:

provides know-how about designing and developing similar interventions in Turkey and ways to put AstroMission into practice and develop further

For parents:

facilitates cancer-related conversations with their children, alleviates their psycho-emotional burden For hospitals/HPs: improves patient experience, facilitates communication with patients

AstroMission can be **further developed** by adding room objects/decorations from the initial concept, adding movements to puppets, and improving/adding missions together with families and HPs.

TA3

GAPTER TAKEAWAYS

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