Reducing Preoperational Anxiety in Children aged 8-12 through the Design of a Digital Paediatric Hospital Information System

Through co-design with children

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Prologue

Within this document, I (Tessa Aarts) will describe my research proposal for my Final Master Project (FMP) at the Eindhoven University of Technology at the Department of Industrial Design. This project is based within the Future Everyday (FE) research group and is executed within the Constructive Design Research (CDR) track. Within my Masters, I am going to concentrate on the expertise areas of 'User and Society' and 'Math, Data & Computing'.

Within this project, I will work together with dr. Lisa Aufegger. Dr. Lisa Aufegger previously completed a study [1] where she co-designed a digital hospital information system with children, parents and clinicians, in order to prepare children undergoing medical treatment. She has now applied for funding at the Eindhoven University of Technology to continue this research. In waiting to see if the application will be honored, I will start a collaboration with Dr. Lisa Aufegger on this project where Lisa will act as the client of my FMP, which we will finish whether the funding application will be approved or not. When the proposal will be approved, I will have the opportunity to work with the Utrecht University Medical Center as well.

During this project I will focus on designing a digital paediatric hospital information system for children aged 8-12, through co-design. Based on previous research, the use of such an information system has the ability to reduce preoperational anxiety for children as well as their parents.

About Me

Professional Identity & Expertise Areas

Professional identity

Topics I find interesting and am passionate about are multi-stakeholder projects which have a large societal relevance and (often) fall into the healthcare context. My interest lies within design for accessibility, self-awareness and behavior-change, which could be individual approaches or combines.

I believe that, in order to make a successful product or system, there needs to be a deep understanding of the user; understanding of their wishes, believes, difficulties and needs. At the start of a project I dive into the context by literature review and gain insights in practice from different stakeholders. This results in getting myself as familiar with the context as possible, to create empathy and understanding for the user(s). Through involving stakeholders from different angles, I aim to combine multiple perspectives to determine gaps and opportunities and formulate a design research challenge. This is particularly essential to me because the healthcare system is a complicated system with many responsibilities, tasks and people entangled or influencing one another.

In my design research process, I apply a user-centered approach with both a research *for* design and/or a research *through* design process. I involve the stakeholders and users in an active way throughout the whole process. Using interviewing techniques to familiarize with the context, co-designing and/or participatory design to create solutions, user testing the iterations that follow and deploying the final prototype in context, are typical examples of such user involvement.

I want to specialize in using co-design and participatory design methods to conduct design research. Hence, I have learned about this method and gained experience in my (previous) M1.2 research project (see Figure 1 & 2). In this research project, I focused on optimizing the data collection of sleep self-reporting for children aged 8-12, by means of an experience sampling chatbot, which was created through informant design. Within my FMP, I intend to build upon the expertise that I gained during my M1.2 and investigate further how co-design with children can lead to creative and meaningful solutions, optimally designed for the user.

I have an interest in doing academic research with a close connection to the industry and real-life application. I am comfortable with a leading role and am equipped of an entrepreneurial mindset that translates in actively seeking opportunities and contacting stakeholders. In the future, I would be interested in doing more longitudinal and large-scale studies, with socially high impact. I would like to work as a design researcher in multidisciplinary teams and/or collaborate with other design researchers, where sharing ideas and expertise is a fundamental part. Constant self-development is really important

Figure 1: Informed Design Session Tool Box

Figure 2: Informed Design Session Children 8-12

to me: there is a whole world to see and a lot of knowledge and skills to gain. I try to constantly broaden my view and keep learning and I am always eager to learn more.

I have a close connection to philosophies and ethics and pay attention to ethical considerations, which is especially important because I often work with vulnerable target groups. I like using my wide interest in design, psychology, ethics, technology, artificial intelligence and creative technologies to create the best possible solution. In a design process I work systematically and goal-orientated, but with creativity and out of the box thinking. I am structured, make a planning and document the steps I take, which is important for me to not get distracted. However, there should be some freedom for creativity or unexpected findings in order to avoid squandering any opportunities.

I am enthusiastic and positive, like to try out new things and take risks, but at the same time I am realistic and see what is actually possible. That's where structure and planning come in helpful, allowing me to stay on track and see what's achievable. I am critical and a perfectionist, which results in working hard, pushing myself, having an eye for detail and going for the best possible result. However, this can occasionally lead to pushing myself too far and testing my limits.

To conclude, a user-centered approach and a design-research focused process in a healthcare context are the core of my PI&V. By exploring different (co-design) research methods and data analyzing techniques, I challenge myself to keep discovering and developing within this core. My interest lies within design for accessibility, self-awareness and behavior-change as well as designing for children, which I could explore very well with this project.

Expertise areas

Within the Master program, I have decided to focus on the expertise areas 'User and Society' and 'Math, Data and Computing'. In agreement with my way of working as stated above, this choice was made due to the societal relevance, high user involvement and user-centered approach of my project as well as the research focus. In my FMP, I intend to build upon the expertise related to user involvement that I gained previously, but especially during my M1.2 research project.

I have challenged myself to explore new research approaches while also using those taught in earlier electives and the CDR track course. As I consider a future in research (possibly academic or corporate), I am very keen on getting as much knowledge and experience in design research during my studies, to be able to develop and profile myself.

I have collected a lot of data in past projects, both via user involvement and from extensive literature review. I have used a variety of different methods in qualitative data analysis. During the analysis of qualitative data from e.g. interviews, I found curiosity and joy in discovering patterns and interesting things. However, I have limited experience with quantitative data analysis, which is something I intend to explore more in my FMP. I do want to challenge myself more in this area by doing mixed method research and train my quantitative analysis skills.

During my M2.1 minor in Artificial Intelligence, I have gained a deeper understanding in intelligent technologies, their logic and reasoning, how they operate and are applied, what kind of impact they (can) make, as well as the societal and ethical implications. I will use this knowledge while scoping the design research challenge, ethical and societal implications and designing the digital information tool. In my FMP I will create a digital information tool, for which meaningful communication of data is very important. Last year I followed 'data-enabled design' and would like to combine my knowledge from this course in designing more with the data and communicate the meaning of data.

Theoretical Background

Introduction

Hospitalization is a frightening and stressful experience for children, and it can be emotionally and physically damaging [26, 36]. Several studies have found that hospitalizations, especially those involving surgery, have both immediate and long-term psychological and behavioral impacts for children [25]. For both children and their parents and caregivers, paediatric surgery is a very stressful event [13]. Current research shows that children often do not feel supported enough in their medical treatment [20].

Children undergoing treatment in the hospital face an unfamiliar environment because of the routine changes, (temporary) separation from friends and family members and unknown hospital professionals [10]. This can have a direct negative impact on their behavior and emotions [37, 53] as well as their recovery rate [26, 44]. Anger, uncertainty, anxiety, and emotions of powerlessness may occur as a result of this, of which anxiety is the most commonly reported [11, 37]. Children not receiving correct or enough information before their hospital stay, can result in increasing worries, fears and anxiety [13]. Anxiety can increase a child's pain and distress, and can be hazardous to a their physiological and psychological health [11, 37, 52]. In the long run, this can lead to a loss in their ability to cope with hospitalization and medical treatment, as well as an increase in their uncooperative conduct and negativity toward healthcare professionals and healthcare in general [15, 22, 39, 50].

Aufegger et al. [1] interviewed parents and clinicians to understand the perceptions and concerns of a virtual information system specifically designed for children, and found a strong need of information for both the parents and children, before the hospital admission. Accurate and complete preoperational information can contribute to the decrease in anxiety and creates a realistic representation and expectation of the hospital and medical procedure [13].

There has been a concerted attempt and emphasis at improving preoperative treatment in order to reduce anxiety about the surgical procedure [13]. Improving preoperative information is especially beneficial since information systems provided after admission are less flexible and more limited in time [37] and there are fewer opportunities for interaction with the health care professionals [13]. Educational preoperative information technologies can enable patients to gain control over their hospital environment and upcoming medical treatment [8], allowing them to develop a positive coping strategy and view the event as non-threatening, which has a positive impact on their mental and physical health [14, 37].

Existing information technologies to reduce anxiety include the use of videos [2, 13], videogames [13, 30, 43], hospital play interventions [21, 37, 50] and virtual reality [9–11, 42, 45–47]. Hospital play intervention studies showed the importance of playful elements for children in order to have fun, create understanding and approach the situation in a non-threatening way [21, 37, 50]. Virtual reality studies highlighted the significance of letting the children interactively experience the hospital environment and medical procedure to reduce preoperative anxiety. Additionally, the presence and involvement of the parents during the child's preoperational preparation was seen as crucial [1, 5, 42].

However, these information technologies are generally aimed at distracting the patients when they are already admitted and are frequently built without recognizing the age-appropriate understanding of health and illness [1]. Hence, a gap is revealed in research for using information systems as preparation for a medical procedure to reduce preoperational anxiety [1, 11]. Furthermore, in order for patient-centered health information systems to be truly effective, the user must be actively involved in the design process [1, 4].

Aufegger et al. [1] interviewed parents and clinicians and co-designed with children (8-10 years) to explore a virtual information system specifically designed for children. Their findings support the development of such a system, which should focus on information regarding roles and responsibilities of healthcare staff, hospital facilities and the patients' treatment, such as a timeline [1].

Research Aim

This motivates the development of a safe digital paediatric hospital information system for children aged 8-12 which educates and supports the children on their upcoming hospital stay, aiming to reduce preoperational anxiety. Consequently, the research question this design research project will focus on is:

"How can a digital paediatric hospital information tool be designed through co-design with children aged 8-12, aiming to reduce preoperational anxiety?"

Additionally this study focusses on the sub-questions:

- "How to make a digital paediatric hospital information tool communicate the preoperational information, while matching the age-appropriate understanding of health and illness of children aged 8-12?"
- "How can the digital paediatric hospital information tool support the parents and children to prepare for their hospital stay?"
- "How can the input data be structured in such a way that it matches the requirements of current preoperational information of medical experts?"

Literature Review

Current (digital) information systems

Aufegger et al. [1] explored the perceptions and concerns of a virtual information system specifically designed for children, to enable parents to prepare both their child and themselves for the hospital stay. They interviewed parents and clinicians and co-designed with children (8-10 years) to understand how the information system can be designed, presented and delivered in an engaging, age-appropriate manner. Their findings support the use of a virtual information systems for children to increase confidence and reduce anxiety in children. Particularly, this system should enable the child to explore and learn about information related to roles and responsibilities of healthcare staff, hospital facilities and basic medical information regarding patients' treatment [1].

Existing information systems include the use of videos [2, 13], hospital play interventions [21, 37, 50] and virtual reality [9–11, 42, 45–47], but are generally aimed at distracting the patients when they are already admitted. Additionally, these systems are frequently built without recognizing the age-appropriate understanding of health and illness [1]. Hence, a gap is revealed in research using age-appropriate information systems as preparation for a medical procedure to reduce preoperational anxiety [11].

Videos

Batuman et al. [2] developed an informative video, using role playing scenarios with doctors, nurses, an 11-year old actress and her mother that explained the procedure and the hospital. Using the Post Hospitalization Behavior Questionnaire (PHBQ) [25] to detect behavioral changes in children after surgery, they found that showing the video resulted in lower anxiety scores during the induction of anesthesia and less pain and postoperative maladaptive behavior (POMP) in the post-surgery period [2].

Fernandes and Arriaga [13] used both role-playing video's and games in their developed multimedia tool. They studied the efficacy of this tool on the cognitive and psychological responses of children undergoing surgery, including the parental anxiety. Participants (90 children) were randomly assigned to either the experimental group (multimedia tool intervention), the comparison group (video game intervention) or the control group. Their results show that the use of the multimedia tool was followed by the lowest level of stress and worries, and parental anxiety was lower in both the experimental- and comparison group compared to the control group [13]. These findings suggest that providing information (both video and multimedia) about the hospital regulations, routines and medical procedures to children, is important to alleviate preoperational anxiety in both children and their parents [2, 13].

Hospital Play Interventions

Hospital play interventions (also referred to as 'therapeutic play interventions') have been widely used to prepare children for invasive medical procedures and hospitalization [37]. Hospital play interventions are activities designed to prepare children psychologically for their hospitalization, matching their levels of psychosocial and cognitive development and their health-related issues [35]. Executing these play interventions can be done through, for example, medical dolls, music, books, (fake) medical equipment, arts and craft supplies, games or toys [37]. Playing with (fake) clinical equipment supports the children in expressing their feelings and thoughts about the hospital [12]. Preparing children for their hospital stay using hospital play interventions, has been shown to result in less upset and adverse behavior, less post-hospital adjustment problems and more cooperation with the medical specialists [51, 55].

Previous studies have been conducted that use hospital play interventions, aiming to support children in their preparation for a medical procedure. While William Li et al. [50] focused on children undergoing day surgery, He et al. [21] focused on children undergoing in-patient elective surgery. They both found that the children experiencing the hospital play interventions, experienced less anxiety and fewer negative emotions than the children receiving conventional information in the pre- and postoperative periods.

Li et al. [37] examined the effectiveness of hospital play interventions to help children cope with the general stress of hospitalization. The participants, who were all paediatric patients, were divided into two age groups: of 3-7 and 8-12 years old. The total control group (150 children) received usual care and the others (154 children) received play interventions. Their study also shows that hospital play interventions reduce negative emotions and levels of anxiety in both age groups of hospitalized children, compared to children who received 'usual' care [37].

Additionally, during the play interventions, the children were visibly having fun and encouraged to numb stressful situations which gave the children greater self-control over the new situation they found themselves in [37]. Li et al. [37] found that the play interventions gave the children the opportunity to practice and get used to new medical situations in a playful manner, which created understanding and allowed them to actively interact with the hospital environment in a safe and harmless way. Both the parents and the children stated that their perspectives on the hospital changed after the interventions and they felt more at ease in the hospital afterwards [37].

These findings point out the significance of the positive effect of hospital play interventions on the psychological burden of hospitalized children [21, 37, 50] and the parents [37]. The playful element is suggested to be important for children in order to have fun, create

understanding and approach the situation in a non-threatening way.

While promising in reducing anxiety in children, these hospital play interventions are resource intensive, costly and not always available [1]. The interventions have limited flexibility, especially since repeated sessions are advised (30 minutes a day) and healthcare professionals have limited manpower [37]. Implementing (part of) these playful intervention into a digital environment could create more flexibility for the children, parents and healthcare professionals, while still preparing the children for a medical procedure.

Virtual reality

Virtual reality is a technological intervention, used to 1) prepare children for medical procedures and 2) provide distraction to children during the procedures [11]. While the use of VR for distraction has limited efficacy [10], research on the use of VR for preparation is sparse [11]. Eijlers et al. [11] performed a meta-analysis, focused on the effectiveness of different applications of VR on reducing pain and anxiety in children undergoing medical procedures, where VR was defined as: "a fully immersive 3-dimensional environment displayed in surround stereoscopic vision on a head-mounted display (HMD)" [p.2].

Their meta-analysis, including 14 studies for pain and 7 for anxiety, reports VR as an effective tool to reduce patient-reported pain and anxiety for a range of different medical procedures, especially for children [11]. VR interventions can truly captivate and engage children as it sparks their magical thinking [11, 38] and imaginative play [38]. It can be even more efficacious for younger than for older children, as they tend to have higher levels of anxiety before medical procedures [6, 24].

With their meta-analysis, Eijlers et al. [11] reveal a gap in literature, of research focused on the use of VR as preparation for a medical procedure, to reduce pain and anxiety during the medical procedure, instead of using VR during the medical procedure itself for distraction. They invite researchers to pursue more studies such as Eijlers et al. [9, 10] and Ryu et al. [45–47], focusing on the application of VR for preparation.

Eijlers et al. [9, 10] created a Virtual reality Exposure Tool (VRE) that resembles the environment of the operating room and medical staff, to prepare children undergoing elective day surgery under general anesthesia. A total of 191 children were included in the analysis, where a modified Yale Preoperative Anxiety Scale [27] (mYPAS) was used to measure anxiety during the induction of anesthesia [9]. They did not find a significant different for the control group and children undergoing VR in levels of anxiety, pain, parental anxiety or emergence delirium [9]. However, the results did show that children in the VR group needed significantly less rescue analgesia (morphine), a drug for pain relief that is associated with many negative side effects [9]. While Eijlers et al. [9] did find a significant difference indicating the effectiveness of VR on anxiety and/or pain, measuring the anxiety of children on multiple moments during their hospital stay could provide a clearer image of the effects of VR on anxiety, as the induction of anesthesia is not the only moment of anxiety for children [29].

In a similar study, Ryu et al. [47] used virtual reality (VR) to provide a realistic operating room experience for children before surgery, aiming to reduce preoperative anxiety. While the control group (34 children) received conventional information regarding surgery and anesthesia, the VR group (35 children) watched a 4-minute video showing a penguin visiting and explaining the operating room [47]. Using the Yale Preoperative Anxiety Scale (m-YPAS) [27, 28], they found that the VR tour of the operating room was effective for children in reducing preoperative anxiety and increase compliance during the induction of anesthesia [45, 47].

In a later study, Ryu et al. [46] applied gamification to the VR tour and asked 34 children to play a 5-minute VR game to experience the preoperative procedure, while the control group (35 children) received the conventional information. While the parent/guardian satisfaction was comparable for the control- and VR group, they again found a reduction of preoperative anxiety and an increase in compliance during the induction of anesthesia in the VR group. Letting the children experience the preoperative procedure reduces preoperative anxiety, which suggests this is an effective way of preparing children for their hospital stay and surgery.

Going beyond Rye et al.'s [47] findings, Park et al. [42] studied if parental co-experience of such a VR experience, could further reduce preoperative anxiety. The results of their clinical trial with eighty children, indicate a lower rate of preoperative anxiety in both parents and children for the parental co-experience and a higher satisfaction for the parents. These results suggest the importance of the presence and involvement of the parents when the children prepare for their hospital stay.

Approach

Proposed Method & Expected outcome

The method of the design research project as proposed in this document, combines a research through design and research for design approach, where co-design will be used to inform the final prototype.

Co-design with children

Technology is playing a bigger and bigger role in today's society, especially those of children [16]. Children interact with technology when learning in school and in after-school play and it is thereby changing the way children live and learn [7]. Today it is most common to involve children in the process of designing new technologies for children and use their input to make sure the technology is meaningful for them, since they are the experts on their own everyday lives [23]. Children can show imagination, remind us of the obvious, consider the impossible and add cutting-edge, often visionary ideas [19].

Different roles have been outlined that children can play to empower them in the design process: a user, tester, informant or design partner [7, 54]. Numerous methods have been developed over the past years for the last two. As an informant, the children are seen as experts or consultants and brought in when they are needed, while as a design partner, the children work as an equal member of the design team through the whole process [19, 32]. Cooperative inquiry is an approach which involves intergenerational design partners including children and adults, iterative low-tech and high-tech prototyping and field research [7]. Informant (based) design is a mix of user-centered design and participatory design, carefully considering the involvement of children as an informant, while using the low-tech creative tools of participatory design [33].

Children aged 7-12 have considered to be suitable for cooperative inquiry and informant design, as they are good collaborators, verbal and self-reflective enough to discuss what they are thinking and are able to understand abstract ideas [7, 18]. Informant design has been suggested to be the best method to use when designing interactive software for non-typical users or users who cannot be design partners, such as children [33, 49]. Since this research focusses on designing an interactive virtual digital information system for children, an informant design session will be set up to gain more insights.

Design-research process

The design-research process will be similar to the Bluebells' method [32] and consists of three stages: 1) Before play; 2) During play; 3) After play.

1. **Before Play:** The Before play stage is done by the researcher and consists of literature review and semi-structured interview analysis with medical experts and possibly parents, to comprise initial facts and findings.

Although there is mostly research on reducing preoperational anxiety in children for cancer [17, 31, 36, 48] or burn treatments [3, 40, 41], but these treatments are long-term and this research needs to be done in 16 weeks. Thus, this phase will also be used to scope the medical treatment this project will focus on in order to make a suitable information system

2. **During Play:** During play is the stage where the children will be involved in design activities, using several techniques within the informant design session. The specific techniques that will be used, will be determined in phase 2 of the project (see project planning).

3. **After Play:** After play is the stage where the output from the design activities is analysed and used in producing initial prototypes, which will be the latest iteration of a virtual digital information system for children, educating and supporting children on their upcoming hospital stay.

Expected Outcome

This study aims to develop a safe digital paediatric hospital information system for children aged 8-12 which educates and supports the children on their upcoming hospital stay, aiming to reduce preoperational anxiety.

Semi-structured interviews with medical experts and co-design with children will be used to construct this system. The findings of this study will be presented in a research paper that will act as the project report deliverable. After the assessment, I would like to adapt the paper to submit it to an ACM conference. Based on the exact content, I will pick the conference that I find most suitable. Possibilities include (but are not limited to): CHI, DIS, TEI and IDC.

This research hereby aims to (partially) fill the gap for research focused on using information systems as preparation for a medical procedure to reduce preoperational anxiety, instead of distraction for the medical procedure after admission [1, 11].

With this research I also aim to invite future research to examine what the exact influence of the digital information interface is on the children's preoperative anxiety, which could for example be measured based on behavioral observations, self-reports, or questionnaires. Future studies can look into cultural (hospital) differences, where the application and implementation of such a digital information system might vary. For example Chinese parents and healthcare professionals are accustomed to advise hospitalized children to take more rest and not to engage in any energy-consuming activities, such as playing, as it would distract the child from healing [37].

Planning

I will be working on my FMP for five months, from September 2021 to January 2022, of which the project itself will be executed in 16 weeks and January will be used to conclude, reflect and prepare deliverables. To meet the objectives outlined in this paper, I devised a planning for accomplishing my Final master project (see Figure 3).

The project will essentially consist of four phases. The first phase consists of preparation, including literature research and context framing. The proposal is part of this phase. The second phase involves designing and running the co-design session and analyzing the data. In the third phase I will process the insights and translate them into an iteration of the digital paediatric hospital information system, validate it and prepare for demo-day. In the fourth phase, I will write the paper, reflect on the results and insights and prepare the paper, portfolio and presentation.

Phase 1: June - September 2021

A. Literature research & stakeholder involvement.
At the start of a project I dive into the context by literature review and gain insights in practice from different stakeholders, using semi-structured interviews. This results in getting myself as familiar with the context as possible, to create empathy and understanding for the user(s). I consider this phase very important, as it informs me on previous work in the field wherein I am researching and context information of the future use, allowing me to process that information to inform the design of the co-design workshop as well as the final prototype.

May	June	July & August	September
* Literature Review * Scoping	* Client meeting * Literature Review * Scoping **10/06 FMP proposal**	* Contact stakeholders-medical experts * Recruitment for co-design session	* Literature review * Stakeholder involvement * Paper writing
October	**November**	**December**	**January**
* Design co-design session *Research through Design* * Run co-design session	* Data analysation * Literature review * Paper writing * Start prototyping	* Prototyping *Research for Design* * Validating * Preparing Demo day **24/12 Demo Day**	* Paper writing * Prepare portfolio * Prepare presentation **13/01 Paper** **20/01 Portfolio** **24-28/01 Presentation**

Figure 3: Planning for Final Master Project

Phase 2: October – November 2021

A. Design co-design session
After the first phase, I will start designing the co-design session. To do so I will use the insights gained from the literature review, previous experience of co-designing with children and insights from the semi-structured interviews of stakeholders

B. Run co-design session
I will start recruiting participants for this session/ these sessions in July and August, due to the limited timeframe in which this FMP needs to take place.

C. Data analyzation & revising literature review
After the co-design session, I will go back to my literature research and adjust it according to my findings, in order to be able to better answer my research question and create a latest iteration of the digital paediatric hospital information system.

Phase 3: November 2021 – December 2021

A. Prototyping
Convert co-design data into useful insights and incorporate them into a latest iteration of the digital paediatric hospital information system.

B. Validating
Validate the latest iteration of the digital paediatric hospital information system, through either user testing with children (possibly the same participants as from the co-design session), or through a medical expert meeting. Based on the feasibility concerning the available timeframe, a choice will be made between those two options, or ideally both options. The user testing with children could possibly run after demo day as well.

C. Demo Day: 24th of December 2021
During this day I will present my demonstrator (final prototype) and material for the co-design session(s) on the Industrial Design Demoday.

Phase 4: January 2022

A. Write, reflect & prepare deliverables
I will write the paper, reflect on the results and insights and prepare the paper, portfolio and presentation.

After the assessment, I would like to adapt the paper to submit it to an ACM conference. Based on the exact content, I will pick the conference that I find most suitable. Possibilities include (but are not limited to): CHI, DIS, TEI and IDC.

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