

Designing Digital Psychosocial Follow-up of Survivors of Childhood Critical Illness

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Figure 1: An illustration of a child in the target group positively impacted by digital psychosocial follow-up at home.

ABSTRACT

Hospitalization and intensive treatment procedures in childhood can increase the risk of long-term negative psychosocial consequences for survivors of childhood critical illness. This risk applies especially to the two congenital colorectal defects: Hirschsprung’s disease and Anorectal malformations, identified as the target group. Based on research indicating that information technology could provide beneficial psychosocial outcomes to survivors of critical illness, this PhD project aims to explore designing solutions for digital psychosocial follow-up of survivors of childhood critical illness. The PhD project uses a design science research approach to investigate existing solutions and needs to design a specific solution for the target group. Furthermore, the findings from testing this solution will be used to create design principles regarding digital psychosocial follow-up of survivors of childhood critical illness in general.

CCS CONCEPTS

• **Human-centered computing** → **User centered design**; • **Social and professional topics** → **Children**; • **Applied computing** → **Health informatics**.

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IDC ’22, June 27–30, 2022, Braga, Portugal

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ACM ISBN 978-1-4503-9197-9/22/06.

<https://doi.org/10.1145/3501712.3538824>

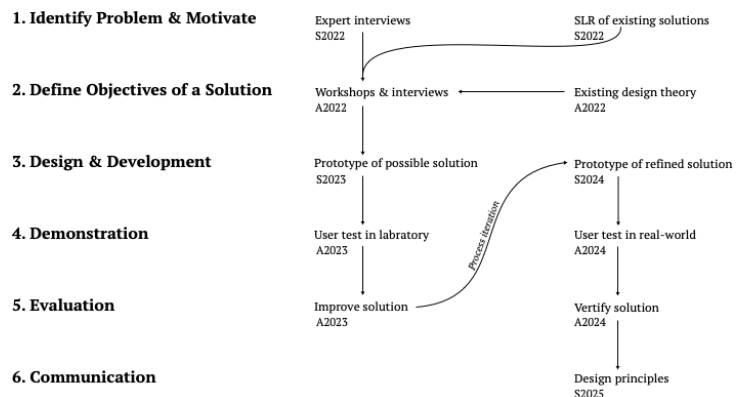


Figure 2: Overview of the steps and associated activities in the PhD project.

KEYWORDS

Design Science Research; Digital Psychosocial Follow-up; Survivors of Childhood Critical Illness

ACM Reference Format:

Marte Hoff Hagen. 2022. Designing Digital Psychosocial Follow-up of Survivors of Childhood Critical Illness. In *Interaction Design and Children (IDC ’22)*, June 27–30, 2022, Braga, Portugal. ACM, New York, NY, USA, 4 pages. <https://doi.org/10.1145/3501712.3538824>

1 RESEARCH TOPIC AND QUESTIONS

Hospitalization and intensive treatment procedures at Pediatric Intensive Care Unit (PICU) in childhood can have a traumatic impact on the person’s development, recently known as the new disorder Post-Intensive Care Syndrome in Children [10]. PICU mortality has decreased in the last decades, leading to increased survivors with disabilities [31]. A literature review from 2014 concluded that childhood critical illness could give the survivors long-term negative psychosocial consequences [28]. Besides, critical illness in childhood more than doubled the risk for social, familiar, and psychological issues [8]. This term, *childhood critical illness*, can be defined as any disease that requires treatment in a PICU [6, 33]. Many diseases can cause critical illnesses in children, e.g., lung injury, neurological diseases, infections, and complications of cancer treatment [19, 44]. Hirschsprung disease and Anorectal malformation are the most common congenital colorectal defects in newborns requiring surgery and treatment in a PICU, often followed by years of treatment, surgery, and hospital stays [9, 35]. In this way, Hirschsprung disease and Anorectal malformation are examples of childhood critical illnesses that increase the risk of psychosocial

problems [7, 12, 30, 35]. Many of these children continue to suffer disturbances in bowel function through life, reducing their life quality [35].

Information technology (IT) solutions have become increasingly usual, also in the health area in child-computer interaction (CCI). Examples include healthcare games improving nebulizer treatment for children by following proposed design principles [14], computational storytelling environments helping children cope with cardiac illness [2], and mobile applications assisting children manage diabetes [38]. IT solutions could also give beneficial psychosocial outcomes to hospitalized children in the form of support from digital plays [15] and anxiety-reducing from virtual reality applications and interactive technologies [21, 24]. Moreover, applications can assess children with intellectual disabilities' mental health [3], and robots and applications can socially support children with Neurodevelopmental Disorders and child cancer survivors [11, 23]. Besides, the community has developed a method to create child personas tailored to develop health-promoting services for survivors of childhood critical illness [43]. Because of these promising indications of IT solutions for psychosocial follow-up for survivors of childhood critical illness, this PhD project will explore how to design digital psychosocial follow-up for this group. The following research questions (RQs) will investigate this objective:

- **RQ1:** How to design digital psychosocial follow-up for survivors of childhood critical illness?
 - **RQ1.1:** What is the current psychosocial follow-up for these children?
 - **RQ1.2:** Which existing IT solutions do help these children psychosocially?
 - **RQ1.3:** What are the needs of psychosocial follow-up for these children?
 - **RQ1.4:** Which existing theories and methods could help designers gain an understanding of the need of these children?
 - **RQ1.5:** Which design principles are necessary to design IT solutions for these children?

2 CONDUCTED WORK

2.1 Preparation of Implementation

Yet, most of the conducted work in this PhD project has been regarding preparing the implementation of the research. Cooperation with a pediatric ward at a Norwegian hospital has been established to be able to recruit relevant stakeholders. It was discovered that the most feasible target group for this PhD project is children treated for Hirschsprung's disease or Anorectal malformations at this pediatric ward. To be able to recruit this vulnerable target group, ethical applications for the PhD project were sent to the following institutions:

- The pediatric ward at the hospital
- The Regional Committees for Medical and Health Research Ethics
- The Norwegian Centre for Research Data

All data from the participants in this PhD project will be handled legally and ethically following these institutions.

2.2 Expert Interviews

During February and March 2022, expert interviews were performed with six employees at the pediatric ward, recruited through phone numbers or mail addresses given by contacts at the pediatric ward. The interviewees had different roles; a child psychologist, a child psychiatrist, a pediatrician, a special pediatric nurse, and two PICU nurses, and comprised two males and four females working in three different units at the pediatric ward. Expert interviews are an efficient way to get specific knowledge of a theme in the exploratory phase of a research project [29] used in relevant CCI research [42]. In this case, the aim of the expert interviews was to answer RQ1.1 by finding the opportunities and limitations of the current psychosocial follow-up for survivors of childhood critical illness.

The interviews were held in Norwegian and lasted between 24 and 45 minutes. Because of the COVID-19 pandemic, the interviews were conducted digitally on the video communication platform Zoom. The interviewees needed to give informed consent to participate in the audio-recorded interview. For practical reasons, the two PICU nurses were interviewed together in a group interview. The interview was semi-structured to keep a general structure and allow the interviewees to discuss not considered aspects [25]. The interview guide was based on three topics: the current psychosocial follow-up, the patient groups, and the technological experiences.

A total of 2 hours, 50 minutes, and 55 seconds of audio recordings of the interviews were transcribed and anonymized. The qualitative data was analyzed through an inductive approach with thematic analysis, extracting data by systematically coding, organizing, and interpreting it into patterns and models [4] with the qualitative data analysis software NVivo. The sample size was decided to be six interviewees because it is the lower limit recommended by Braun and Clarke [5] for small research projects using thematic analysis. Previous qualitative health research has also demonstrated that six interviewees could be enough to reach saturation in thematic analysis [16, 17], especially for expert interviews [13, 20]. Based on the findings' indications of the current psychosocial follow-up, designing digital psychosocial follow-up for survivors of childhood critical illness should work towards *neutrality in gender, culture, and residence*. These three preliminary design principles of neutralities are justified in Table 1.

Neutrality	Justification
Gender	The current psychosocial follow-up tends to be less customized for boys compared to girls.
Culture	Immigrant families tend to use the psychosocial follow-up less than non-immigrant families.
Residence	People living far from the hospital tend to have less psychosocial follow-up than people living close to the hospital. The digitalization with video meetings during the Covid-19 pandemic was positive for this group.

Table 1: Overview of the PhD project's preliminary design principles.

3 PLANNED NEXT STEPS

To achieve RQ1, the approach design science research (DSR) was chosen. DSR is a relevant approach because it aims to solve a problem by generating knowledge of how an innovative artifact should be designed according to the applicable knowledge and the environment's needs [41]. In this case, the psychosocial follow-up of survivors of childhood critical illness is *the problem*, the IT solution is *the innovative artifact*, and different stakeholders are *the environment*. Figure 2 presents how the PhD project will follow the DSR approach's six steps with various interactions with the stakeholders to design a possible new IT solution to gain new design knowledge of the problem [41]. Since the process is agile, it could be iterations within each step.

The first step, *Identify Problem & Motivate*, consists of the expert interviews described in the previous section. Moreover, a systematic literature review based on the interview findings and Kitchenham's original guidelines for software engineering [18] will be conducted to develop a theoretical understanding of the applicable knowledge in the research topic, as other researchers in the CCI community recently have completed [1, 34, 37, 39, 40]. This literature analysis of existing IT solutions psychosocially helping children who have survived critical illness will answer RQ1.2 and identify relevant psychosocial theories for the PhD project.

The next step, *Define the Objectives of a Solution*, will conduct workshops with children in the target group and their custodians. Running workshops is a suitable method to answer RQ1.3 by identifying the target group's psychosocial needs. Because designing for children is about how to involve them [32], workshops can be used to generate ideas of possible solutions effectively [26]. Workshops are widely used in the CCI community to include survivors of childhood critical illnesses in the design process [22, 26, 27]. Since a workshop could contain different activities, it could be fun, creative, and interactive for children [36]. This workshop's activities will be drawing ideas, writing ideas and stories, testing various possible IT solutions in the form of interactive games, and discussion regarding hospital treatment, psychosocial follow-up, and technologies. The workshop will take place in connection with a hospital appointment and be customized to each child. A research nurse at the pediatric ward will help design the workshop to ensure the target group's needs. Moreover, semi-structured one-to-one interviews of designers and developers in companies and NGOs developing relevant IT solutions will be conducted to answer RQ1.4 by investigating if this existing design theory could help them understand the target group's needs.

The three steps *Design & Development*, *Demonstration*, and *Evaluation* will be combined in two iterations of designing, testing, and evaluating a prototype of a possible solution to investigate RQ1.5 regarding necessary design principles for IT solutions for psychosocial follow-up of survivors of childhood critical illness. The first prototype of the IT solution will be evaluated with user testing, including observations of children and custodians in a user experience laboratory setting. Further, the IT solution will be refined based on the first evaluation and empirically verified by the second user testing, including observations and one-to-one semi-structured interviews of children's applications in an appropriate real-world environment. Finally, the last step, *Communication*, will be reached

where the findings of this PhD project will answer RQ1 by adding information to the knowledge base in the form of design principles for digital psychosocial of survivors of childhood critical illness in general.

ACKNOWLEDGMENTS

I want to thank my supervisors, professor Maria Letizia Jaccheri and associate professor Sofia Papavlasopoulou, at Norwegian University of Science and Technology (NTNU) for their guidance and support in this PhD project. I am also grateful for NTNU founding this PhD project. Last but not least, I appreciate colleagues, friends, and family discussing my PhD project.

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