



# PROJECT DUMBO

## *FOLLOWUP APPLICATION*

### **Project Plan**

This funding application is an expansion of the ongoing multi-center study “Design and evaluation of technique and care environment in pediatric radiotherapy,” a.k.a. project DUMBO. The original study, which is a collaboration between the Umeå Institute of Design, the Departments of Nursing and Radiation Sciences at Umeå University, and the radiotherapy clinics at Karolinska, Akademiska and Umeå University Hospital, focuses on the development of new innovative methods to reduce anxiety and worry among parents and children undergoing radiotherapy.

To evaluate the design interventions in the radiotherapy environment we have set up a comprehensive set of measures (interviews, surveys and scales) with focus on both parents and children. We have also arranged a dedicated course focusing on improving the pediatric radiotherapy experience with design masters’ students in Umeå. In the ongoing project, these interviews, surveys, scales and interactions with the designers are all means to reach the goal of creating new innovative methods with proven benefit, but the outcome of the methods does in itself hold a scientific value. To our knowledge there are currently no published comprehensive investigations into how parents and children cope with radiotherapy, i.e. which tools and strategies that are most common and important. In addition, there is very limited descriptive literature on the integration of this knowledge into the design of healthcare environments, technologies, and support materials.

In the present project we want to make use of all the surrounding material from our



ongoing project to gather, translate, and disseminate knowledge about the tools and techniques currently used and needed for the alleviation of anxiety and discomfort in children and families during the radiotherapy process. The understanding of these aspects will be of fundamental importance for the development of the national care strategy for pediatric radiotherapy, within the Scandion Clinic.

### **Specific Aims**

1. Collect detailed descriptions of children's and parents experiences of going through the radiotherapy process.
2. Explore staff's experiences of helping children and families to manage the radiotherapy process.
3. Synthesize the gathered knowledge of children's' and families' needs during pediatric radiotherapy into key insights and opportunities for innovation using a human-centered design approach.

### **Background**

About 300 children every year are diagnosed with cancer in Sweden. Depending on their diagnosis, treatment can include chemotherapy, surgery, radiotherapy, or some combination of these. Research has shown that the whole family is affected when a child is diagnosed with cancer<sup>1</sup>. Parents describe their lived experience of going through the child's cancer treatment as "an everyday struggle" where the family's normal daily lives are disrupted and they have to focus only on the ill child. It is a taxing period and the entire family is in need of support to ease their burdens<sup>2</sup>.

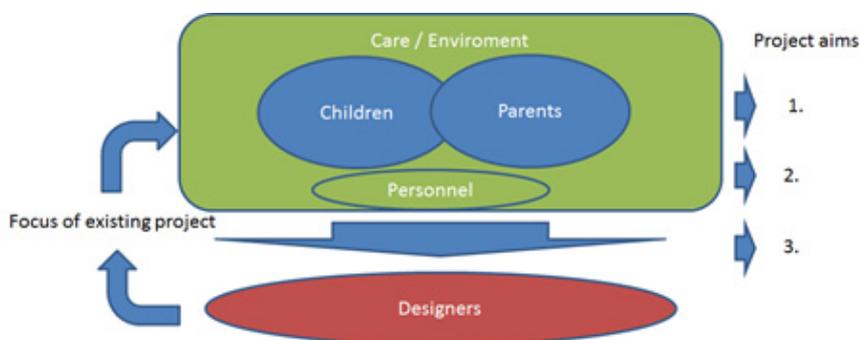
Children undergoing cancer treatment often experience pain, fear and worry from the disease, treatment related pain, and side effects of drugs<sup>3</sup>. They also experience stressors related to cancer treatment and side effects including pain, hair loss, needle sticks and they have to endure invasive and strenuous treatments<sup>4</sup>. Though radiotherapy per se is a non-invasive treatment, it can be both stressful and challenging for children. Children are exposed to a new, unknown, and highly technological environment with large radiation equipment, and the child can be threatened by requirement of remaining alone in a room during treatment, which can cause stress and anxiety<sup>5,6</sup>. For both parents and children, the difficulties of understanding how radiation works and as well as expected effects and side effects, can give birth to anxiety-ridden feelings. In particular, anxiety can increase when an immobilization device is required to ensure a fixed position for radiation<sup>5,7</sup>.

Anxiety can make it difficult or impossible for children to be left alone during treatment, and as a result, sedation and anesthesia are sometimes utilized to put the child to sleep for the procedure. However, there are several advantages to radiotherapy treatment without sedation or anesthesia<sup>7,6</sup>. The child experience decreased side effects, less disturbance in daily life, especially with sleep and nutrition, and radiotherapy without anesthesia is less expensive<sup>6</sup>. Psycho-educational programs<sup>8</sup>, audiovisual interventions<sup>9</sup>, and hypnosis<sup>10</sup> are interventions that have all been shown to reduce the need for anesthesia during radiotherapy for young childhood cancer patients.

Although the radiotherapy process is an encounter between the most advanced

technology in health care and a child, few studies have investigated the child's and the families' view of this specific procedure. We found one study where children with brain tumors undergoing radiotherapy in UK described it as "a drag": the boredom of waiting and the discomfort of treatment<sup>1</sup>. They suffered from fatigue, nausea, headaches and other symptoms. Play and school rooms, toys, and organized activities helped maintain normality and distraction during radiotherapy treatment. The children suggested improvements in the environment including specialized waiting areas, ward décor, and games, in addition to having a parent close by, which provided the children comfort, support and helped them sleep at night.

In the Swedish context there are, to our knowledge, no descriptive studies on children's and parents' experiences of going through radiotherapy, nor are there descriptions from the staffs' perspective. There is also a paucity of studies where mothers' and fathers' experiences of being with their child in the radiotherapy department are captured separately. In addition, while the treatment technologies have been proven to cause anxiety in children, the transfer of this knowledge into the designs of these technologies and environments, as well as the preparation and support materials provided to children and their parents, is also sparsely described within healthcare research. It is, however, being investigated by individuals from within other domains, such as human-centered design research<sup>11,12</sup>.



**Figure 1.** Diagram of the difference between the existing project and the aims of this extended project proposal.

In the proposed extended project aims, we want to use the gathered quantitative and qualitative information to analyze and describe pediatric radiotherapy both for the parents and children's, and from the personnel's perspective. To extend the impact of these findings into implementable designs within this environment, we will also look into how external actors, in our case the designers working with an ethnographic approach, will synthesize this knowledge into insights for actionable change within this environment, and thereby create new solutions to combat anxiety in children and their parents during radiotherapy.



## Methods

The study has a multi-method design where both qualitative data from semi structured interviews with families and staff and quantitative data from measurements of anxiety and health related quality of life (HRQoL) will be analyzed, merged together with ethnographic data from the human-centered design approach, and synthesized into design directions.

## Material

The majority of the material that will be used in the proposed study will be collected within the ongoing study. The additional data collection will be the interviews with the personnel and structured evaluation of the design process. Table 1 below summarizes the raw data.

**Table1.** Overview of the raw data used in the proposed project. The columns marked # gives the planned number of participants for each activity.

	Qualitative	#	Quantitative	#
Children	Interviews(1) Drawings (2)	36	Scales(3)), Ver- bal description of worry (4)	140
Parents	Interviews(1)	36x2	Scales(5), Sur- veys(6)	140x2
Personnel	Interviews(1)	15(*)		
Designers	Observation, Interviews			

(1) Semi-structured interviews by professional interviewers (end of treatment period)

(2) Child drawings during the interview

(3) FAS/VAS scales depending on age (4 times during treatment period)

(4) Verbal descriptions of the child's worry (4 times during treatment period)

(5) VAS scales (4 times during treatment period)

(6) PedsQL survey (3 times during treatment period)

(\*) Raw data collected within the proposed project

The families included in the interview part of the study are stratified based on gender, age of the child, and treatment site.

## Qualitative Analysis

The interviews will be recorded and transcribed verbatim for the research group, who will listen to the recordings and/or read the transcripts continuously during the data sampling period. Essential content from the interview text will be sorted out into categories and themes elucidating similarities and differences in important parts of the personal experiences described by the families, i.e. a content analysis will be performed<sup>13</sup>. During the interviews, children ages 5-11 years old will also be asked to draw a picture, and the drawing will be evaluated according to the Swedish version of the Child Drawing: Hospital Manual<sup>14</sup>.



### **Quantitative Analysis**

A self-report of perceived worry will be obtained for children ages 3-10 years old by the Facial Affective Scale (FAS)<sup>15</sup>. For adolescents and parents, the Visual analogue Scale-Anxiety (VAS-Anxiety) 0-10 cm will be used instead<sup>16</sup>. Verbal descriptions of current worry will also be obtained from the child at each FAS/VAS evaluation and categorized as either “no worry = 0, a little worry = 1, much worry = 2”<sup>17</sup>. The PedsQL™ Family Impact Module<sup>18</sup>, an instrument designed to measure the impact of pediatric chronic health conditions on parents and the family, will be given to and scored by both parents. It measures parent self-reported physical, emotional, social, and cognitive functioning, communication, and worry. The instrument is available in English, Spanish, Arabic and Swedish. The VAS/FAS ratings, HRQoL scores and verbal descriptions of worry for the control and intervention group will be compared. The need for general anesthesia or other sedatives for the child during RT will be recorded and compared between groups.

### **Mixed-Method Interpretation**

In using a combination of data collection methodologies that focus on children of different ages, developmental stages, and communication strengths -- talking during individual interviews, drawing a picture, describe their feelings in combination with pointing at a facial rating scale -- an overall picture or ‘mosaic’ of the child’s experience might be captured<sup>1</sup>. To describe different aspects of the phenomenon “safe children and families”, a mixed methods interpretation of data will be performed<sup>19</sup>. The quantitative measures will give information on perceived worry within the patient population and the qualitative data will highlight individual unique experiences of going through the radiotherapy process. Interview data expressing significant findings will be extrapolated and compared to quantitative ratings, i.e. significant distress or satisfaction in RT situations and experiences of the interventions implemented.

### **Human-Centered Design Approach**

Human-centered design (HCD) places emphasis upon understanding human needs and how design can respond to these needs. HCD processes focus on creating new solutions for the world, beginning with examining the needs, dreams, and behaviors of the people we want to affect with our solutions<sup>20</sup>. The collaborating design students from Umeå Institute of Design will employ a commonly utilized HCD research approach, ‘quick’ ethnographic methods, to understand and problematize pediatric radiotherapy for the children and their parents undergoing this experience. ‘Quick ethnography’ is a method for collecting and analyzing high-quality ethnographic data in a shorter timeframe than standard ethnography, i.e., 90 days or less, and it will enable the design students to gather rich data without direct interaction with the objects of study<sup>21</sup>.

Drawing from their own observations, as well as the wealth of information provided by the quantitative and qualitative measures listed above, the design students will implement HCD analytical methods to identify patterns within the data, codify the information into themes, create frameworks for this information, and identify key insights about the pediatric radiotherapy experience, for children, their parents, and the staff that interacts with them<sup>20</sup>. Finally, after aggregating, editing and condensing these insights, the students will identify opportunities for innovation within this clinical environment, and employ various HCD creative processes such as brainstorming, co-design



workshops, user prototypes, concept development and feedback with the radiotherapy staff, as well as the nursing and radiotherapy researchers involved in the project, to design interventions that will be installed within the participating radiotherapy clinics, and assessed for their positive impact on the patient experience.

### **Preliminary Interview Results**

Interviews were performed with the first included four children (one girl and three boys, aged 5, 9, 12 and 13 years) and their parents (five mothers and five fathers). The questions were open ended, focusing upon these individuals' experiences with radiotherapy. All interviews were voice-recorded, and analysis took place by listening to the recordings and categorizing the described experiences of radiotherapy into preliminary themes and subthemes, which were then discussed and reflected upon. Finally three themes and subthemes were formulated.

*From the children's and parents' perspectives: Radiotherapy affects the entire family and turns life upside down.* They describe being separated from family members, having a difficult time dealing with practical issues and problems, and being anxious for the child's health and survival.

*Preparation is significant and essential in order to be able to manage radiotherapy.* They describe that the staff is taking time and having time for preparing on what to expect during radiotherapy. They find radiotherapy strange and they experience "jittery". They describe that the staff prepares them for radiotherapy through stories/pictures, visiting, testing, and simulating, and having sufficient information and communication however, sometimes having lack of information and communication. Understanding the procedure allows them to feel calm and confidence.

*Radiotherapy includes experiences of emotional and physical distress, distraction, reassurance, support, guiding and comforting.* Children describe being alone and feeling some loneliness, but getting used to the process over time and the repeat nature of the experience helps them to get through radiotherapy. Parents share some of these same feelings as their children, but also describe feeling as if they have abandoned their child. In the children, physical distress includes experiencing pain, tensions, nausea and fatigue. They also notice physical sensations such as noises, lights and smells, and lying motionless a short or a long time. Sedation is sometimes necessary. They describe activities that distract them from the experience, such as music/stories, thinking of other things, self-talking and feelings of reassurance by parents' and/or staff's voices, cuddly toys, and familiar objects. Support is derived from parents and siblings, and the staff guides and comforts both parents and children. Below is an example of a drawing (made by one of the child respondents) to be evaluated according to Wennström et al,<sup>14</sup> and used as a complement to interviews and scales.





### **Significance for childhood cancer**

The aim of the interviews, the different scales, and the children's drawings is to help us understand children's, parents' and staffs' need of aid, information and routines to support them through the radiotherapy period. This knowledge, in a Swedish context, will be the base for creating unique and adapted tools and information materials, but will also have impact on the structure of routines and flows throughout the whole process, which includes both the pediatric oncology and the radiotherapy units at six different centers in Sweden after the start of the Scandion Clinic.

Our goal is to create calm and well informed children, parents and staff, and a safe environment, resulting in safer radiotherapy and less need of general anesthesia, which is a risk factor and also leads to discomfort in children already suffering distress from their cancer treatments. This knowledge will be important for the Swedish Working Group for Pediatric Radiotherapy when establishing structures and routines at the Scandion Clinic. Furthermore, the insights we gain through the translation of clinical and patient needs into creative design outcomes from our collaborative work with Umeå Institute of Design may trigger new directions for the development of medical tools and aids for alleviating anxiety in children undergoing radiotherapy, and medical care in general.



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