

Keeping Calm: Supportive Radiotherapy Experiences for Children with Cancer



Introduction

Background

Approximately 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 cancer¹. Parents describe their lived experience of going through the child's cancer treatment as an "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 burdens². Children undergoing cancer treatment often experience pain, fear and worry from the disease, treatment related pain, and side effects of drugs³. 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 treatments⁴.

Though radiotherapy is considered 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 as a result^{5,6}. 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^{5,7}.

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^{6,7}. The child experience decreased side effects, less disturbance in daily life, especially with sleep and nutrition, and radiotherapy without anesthesia is less expensive⁶. Procedures reducing distress for both parents and children are important for the child's coping during radiotherapy.

1. Soanes L, Hargrave D, Smith L, Gibson F. What are the experiences of the child with a brain tumour and their parents? *Eur J Oncol Nurs*. Sep 2009;13(4):255-261.
2. Bjork M, Wiebe T, Hallstrom I. An everyday struggle-Swedish families' lived experiences during a child's cancer treatment. *J Pediatr Nurs*. Oct 2009;24(5):423-432.
3. Hildenbrand AK, Clawson KJ, Alderfer MA, Marsac ML. Coping with pediatric cancer: strategies employed by children and their parents to manage cancer-related stressors during treatment. *J Pediatr Oncol Nurs*. Nov-Dec 2011;28(6):344-354.
4. Griffiths M, Schweitzer R, Yates P. Childhood experiences of cancer: an interpretative phenomenological analysis approach. *J Pediatr Oncol Nurs*. Mar-Apr 2011;28(2):83-92.
5. Bucholtz JD. Comforting children during radiotherapy. *Oncol Nurs Forum*. Jul 1994;21(6):987-994.
6. Filin A, Treisman S, Peles Bortz A. Radiation therapy preparation by a multidisciplinary team for childhood cancer patients aged 3 1/2 to 6 years. *J Pediatr Oncol Nurs*. Mar-Apr 2009;26(2):81-85.
7. Scott L, Langton F, O'Donoghue J. Minimising the use of sedation/anaesthesia in young children receiving radiotherapy through an effective play preparation programme. *Eur J Oncol Nurs*. Mar 2002;6(1):15-22.

Course Aims

The aim of this course is to give students practical experience in designing a product or a system that addresses a broad user group. The project provides a platform to explore techniques and methods in the context of design ethnography and participatory design.

The second major project in the Master Programme in Interaction Design at Umeå Institute of Design focuses on Service Design, where students are tasked with discovering and thinking critically about design ethnography and participatory design through a combination of practical experience and others' experiences. Each phase of the project is supported by teachers, structured and unstructured activities and literature, and is dependent on students' engagement and discovery. Students work in groups throughout the project.

The final results may include software or hardware, service or organizational frameworks depending on the results of studies in design ethnography and participatory design. The results presented in the form of visualization of user observations, sketch models, interfaces, videos, reports and screen-based digital presentations.

Project Aims

The aim of this project, *Keeping Calm*, is for you to understand the healthcare services provided for children with cancer and their parents, looking specifically at radiation therapy treatment. We want you to learn how the service is currently provided, and from your fieldwork and insights you will develop new and scalable concepts of how the treatment experience could be reshaped to more fully support these families, and minimize their anxiety and worry.

During this project, you will have the opportunity to cooperate with the children's oncology and radiotherapy departments at three major hospitals within Sweden: Umeå University Hospital (Umeå), Karolinska Hospital (Stockholm), and Akademiska Children's Hospital (Uppsala). During this 10 week project, you will be given access to all of these facilities. Using the research skills you developed in your Design Ethnography course, you will be tasked with understanding how the oncology care chain works for all participants within this service, from the children undergoing treatment and their parents, to the staff involved with their care and wellbeing within these clinics. We want you to understand both the many different processes involved in providing treatment to the patients, as well as what the experience of having cancer and going through radiotherapy treatment is like.

You concepts should look closely at the way treatment services are currently provided, as well as other related services and the internal and external environments of the clinics. Your concept must take into account the needs of the children, their parents, and the staff. Think about ways to increase the level of understanding about radiation therapy, preparation for treatment, and minimizing anxiety during the treatment process for both the child and their parents. Your proposal should support and promote the health and wellbeing of all individuals involved in the service, and provide opportunities for these families to regain or maintain an active role in society, with a high degree of autonomy and quality of life. Furthermore, you must pay close attention to the age range of the children being treated with radiotherapy (from 3-17 years), and ensure that your concept is age appropriate and scalable.

The concepts generated in this project will be used to create designs that will be developed and installed within these sights, as part of a larger research project. This means that your concepts should be designed with consideration for what is feasible within today's technological environment. It also means that you will have access to a large collection of research materials that have already been generated within this study, such as interview transcripts, patient drawings, and information about children and parent anxiety.

Research Sites and Contacts:



VÄSTERBOTTENS
LÄNS LANDSTING

Norrlands University Hospital

Radiotherapy is given to approximately 160-170 patients every day. The department is equipped with six processing machines, CT and MRI, as well as a device for treatment planning. Physicians, oncology nurses, medical physicists, and engineers work together to provide the best possible radiotherapy.

<http://vll.se/default.aspx?id=22052&refid=23623&parid=1962>

Radiotherapy Clinic:

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Pediatric Oncology:

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Oncology Doctors:

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Karolinska Hospital

Sweden's largest cancer clinic treats oncological patients at special radiotherapy departments at Karolinska in Solna, and Stockholm South General Hospital.

<http://www.karolinska.se/AstridLindgrensBarnsjukhus>

Radiotherapy Clinic:

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AKADEMISKA BARNSJUKHUSET

Akademiska Children's Hospital

Akademiska is a hospital for children and adolescents, caring for children from all over our region. The goal is to provide the highest quality medicine in combination with good care, and we aim to provide support for the whole family. Cancer treatment with surgery, radiation, chemotherapy and cytokines is not easy for a child. Professional care with the child in the center is crucial for the whole family and also plays the role of the child's ability to heal. We aim to provide informed and honest information to the family and child for everything that is happening and why.

<http://www.akademiskabarnsjukhuset.se/>

Radiotherapy Clinic:

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Instructors



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Service & Interaction Designer, Designit Oslo.

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Collaboration with Utrecht School of the Arts

During the project, you will be collaborating with three students from the Utrecht School of the Arts, an art academy located in the Netherlands. They are 3rd-year bachelor students studying Image & Media Technology, which focuses on creating short videos with a broad use of techniques: Stopmotion, 2d animation, motion graphics, live action, special effects, 3d animation etc. They are experienced with filming, editing, visual effects and animation, and can cover the whole process, from the idea to the final video. More information about them and their work is available here: <http://www.oavsett.nl/>

These students will join in project presentations and workshops, in addition to brainstorming with you on your research insights and ideas. They will be joining us starting April 17th.

Project Structure

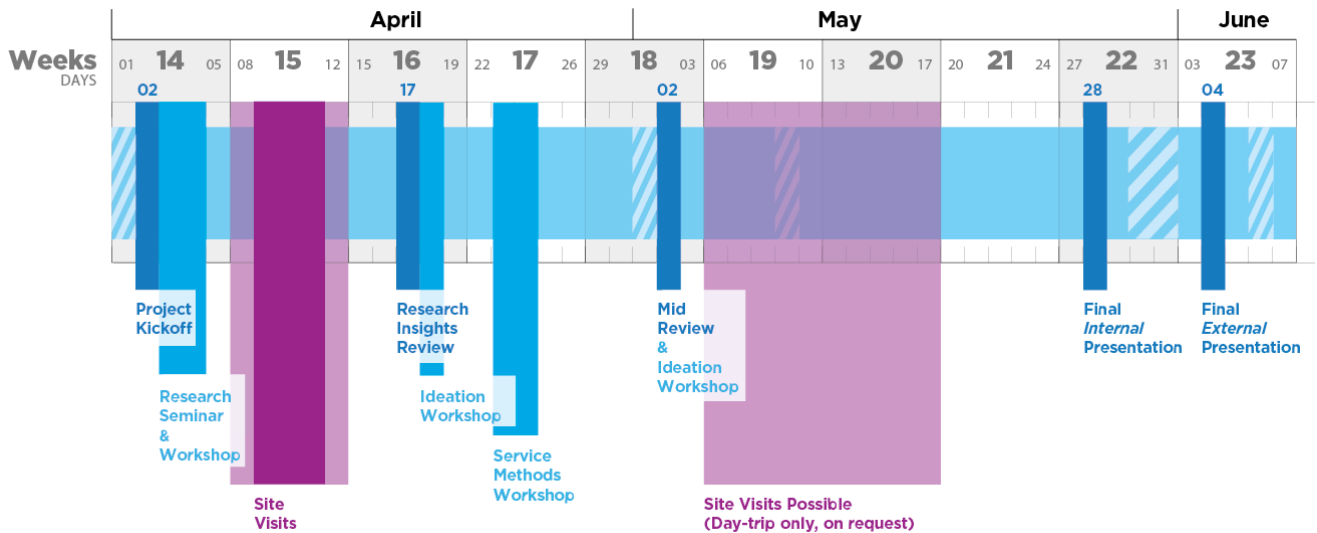
The project is divided in three phases:

Week 14-16: **Phase 1**, Initial research and analysis

Week 17-18: **Phase 2**, Ideation and initial concept development

Week 19 - 21: **Phase 3**, Concept finalization

Project Time Plan



PROJECT KICKOFF: April 2

PHASE 1: Research

Research conducted in 3 groups of 4 students, with each group responsible for being the primary informants about one of the three collaborating hospitals.

- April 3: Research Seminar with nurses on interviewing children and parents.
- April 4: Workshop on finding sources and delivery of research materials
- April 8-11: In-depth field work at sites
- April 17: Final Sharing of Research Material and Initial Insights presentation. Creation of new teams, 4 groups of 3 students (one from each research team), to be kept for the remainder of the project.

PHASE 2: Ideation

- April 18: Ideation Workshop to kick-off the next phase of the project and get the new teams working together.
- April 22-23: Service methods workshop with Ine from Designit Oslo.
- May 2: Mid Presentation in morning, and Ideation Workshops with the hospital staff in the afternoon

PHASE 3: Final Design Development

- Week 19-20: Site visits to test ideas with users (will be planned during the course)
- May 28: Internal Final Presentation
- June 4: External Final Presentation
- June 5: Individual Meetings

Project Deliverables

Research Phase Deliverables

to be delivered individually via email to Tara and Niklas by Wednesday, April 17, at 17.00:

1. Verbal and visual presentation (30 minutes/group)
2. A written report (8-12 pages) of your research results containing the following:
 - a 500 word abstract of your research results
 - a selection of illustrative short stories, images and accounts
 - a high level analysis of your field research with conclusions
 - a collection of design opportunities you have identified

Ideation Phase Deliverables

to be delivered individually at the mid-presentation on Thursday, May 2:

1. Verbal and visual presentation (30 minutes/group) with a clearly stated rationale for your concepts.
2. A written report on your findings and design directions (10 pages)

Final Design Deliverables

to be delivered individually via email to Tara and Niklas by Friday, June 7, at 17.00:

Group:

1. A blueprint of the final service concept (small, medium, and large)
2. A verbal and visual presentation of your concept with refined designs for at least two of your service touchpoints.
3. A short film that visualizes your concept (maximum 5 min.)
4. A written report (16 pages) of your process and final design.
5. Web content: three pictures (1024 x 768 px) with caption and a 500 words abstract of your project for publication on UID's website.

Individual:

1. An individual 3 page written report containing your reflections on the course highlighting:
 - Your individual contributions within the group work
 - What you learned about yourself as a designer and your way of working throughout the course.
 - Your critical feedback on the course: strengths, weaknesses, areas for improvement.

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