

**Wellbeing in Healthcare Environments:
A Human-Centered Design Research Approach to Improving the Cancer Patient Experience during
Radiation Therapy**

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Abstract

Healthcare and medical products are often designed with the singular focus of providing the best treatment available to patients. However, research has shown that this treatment-based approach does not result in quality care. There are many factors that play into making a healthcare experience patient-centered, and this paper explores the use of human-centered design research to understand this experience. This paper presents a case-study of a Radiotherapy Department at a University Hospital, where we used patient survey, observational, and narrative data to gain awareness into the patient experience during radiation therapy. Our research shows how the current radiotherapy environment is anxiety provoking to the patient, and how insights gained from the written and visual stories of the patients' experiences were used to develop a design solution that improves the patient view in the treatment room with the intent to make this space more patient-centered and inviting. In conclusion, this paper argues that designing for the patient experience and their emotional wellbeing is a crucial aspect of any healthcare service.

Introduction

In this paper we present a case-study of the Radiotherapy Department at Norrlands University Hospital (NUS), where we have taken a human-centered design research approach to researching the cancer patient's experience while undergoing radiation therapy. This approach is comprised of a variety of research methods, all focused around the following two questions: How do healthcare services, products, and spaces impact the emotional wellbeing of the patients that interact with them, and how can we understand and design for these emotional experiences?

This paper aims to show how human-centered design research can be used to mediate the treatment-focus of healthcare and medical technologies to understand and design for holistic patient experiences. We first look at the history of healthcare technological development and the importance of a person-centered care climate to set the stage for our research in the clinic. We then discuss the implementation of a patient-centered research approach within the clinic, involving surveys and journals, observational studies and cameras. We then go on to analyze the data we gained through these research methods to understand the patient experience, looking specifically at anxiety and the patient-centeredness of the environment. Taken together, we will attempt to show how these different research approaches can provide us with an increased awareness of the patient experience and how this insight can lead to designed change within the treatment room that considers both the patient's experience and point of view.

Background

Medical technologies are designed with the intention of improving patient health, with each new development aimed at improved detection and treatment offerings. However, patient well-being is rarely considered in this equation. The field of medicine has typically taken a very quantitative approach to healthcare, focusing on the immediate needs of treatment versus experience (Mah & Guenther, 2011). Healthcare facilities have been designed for the doctors' needs in identifying and treating the patient requiring medical attention. These spaces are dominated by various equipment and technologies which the doctors rely upon to diagnose the patient's condition and provide treatment. Unfortunately, the medical devices and technologies used to provide the most accurate and up to date diagnostics and treatments possible often unintentionally relegate the cares and experience of the patient as non-essential consideration. The best treatment option places emphasis on curing the patient to the exclusion of everything else, including the patient experience.

Findings from a growing body of research on experiences of illness, treatment and care have shown that healthcare care based purely on this biomedical perspective is unable to generate satisfactory or even

acceptable care from the patient perspective (Edvardsson et al, 2008; Edvardsson et al, 2006). This research highlights the importance of taking into account the subjective experience of the individual and how such a view constitutes a person-centered approach to care that can promote well-being. Person-centered care stands for the practice of valuing the person and those caring for them, treating people as individuals and thereby assessing and meeting individual needs of patients rather than meeting the needs of staff, using the perspective of the person and creating a positive social environment in which the person can experience wellbeing (Brooker, 2007).

Patients undergoing curative radiotherapy receive daily radiation treatments over a period of several weeks, for duration of up to two months. This means that these patients have a high level of exposure to the care environment, making it very important to understand what their experience is like and how it can be improved. This paper aims to show how human-centered design research can provide insight and understanding into patients' emotional experiences during their healthcare interactions, and show how the insights gained can be used to drive patient-centered design change within these environments.

Methodology

Three different research methods were used in our research to gather data about the patient experience. Quantitative methods were used to gather data about the radiotherapy patient population at NUS, while qualitative and design methods were used to get more detailed information about the patient experience within the clinic and while undergoing treatment. The rationale behind using this type of research approach was to gather data with differing perspectives in the attempt create a holistic understanding of what it is like to undergo radiation therapy.

Our quantitative survey, comprised of two previously validated surveys – the State-Trait Anxiety Inventory Form Y (STAI-Y) and the Person-centered Climate Questionnaire (PCQ) – in addition to demographic questions and treatment specific questions, was used to generate a baseline understanding of the patient population undergoing radiation therapy (Spielberger et al, 1970; Edvardsson et al, 2008).

For our qualitative studies, we conducted short-term ethnographic fieldwork at the clinic for a period of two months, comprised of in-depth observations of the patients and interviews with the staff (Hammersley & Atkinson, 2007). We documented our findings through extensive fieldnotes and used salience hierarchy to analyze the data recorded (Emerson et al, 1995; Wolfinger, 2002). This approach enabled us to create a detailed analytical account of the patients' experiences within the clinic, and gain insights into their physical and emotional experience of radiation therapy.

Thirdly, we used design probe kits to look at the patients' experience recorded through their own words and images (Mattelmäki, 2006). The design probe kit was comprised of a daily journal and a camera, and included open-ended questions about the treatment experience (See Figure 1). The stories gathered from the completed journals and cameras within our probe kit allow us to gain insight into the daily lives and personal experiences of the patients while they are undergoing radiation therapy, while minimizing our impact on these experiences.



Figure 1. Design Probe Kit

The research presented in this paper was conducted at the Radiotherapy Department of the Norrlands University Hospital (NUS), in Umeå, Sweden. Our research protocol was approved by the NUS ethics board (Dnr 2010-371-31M), and follows the ethical rules and guidelines set forth by the Swedish Research Council. All patients being treated with radiation therapy with curative intention at the NUS Radiotherapy Department were eligible for participation in our study, and interested patients were invited to document their experiences using our Design Probe kit.

Analysis

Looking first at patient responses to our questionnaire, we found that one out of every six patients undergoing treatment reported that they experienced some level of anxiety while in the treatment room. This finding was supported by STAI-Y scores (i.e. their state anxiety level) which were a mean of 10 points higher for patients who reported experiencing some anxiety during treatment than those who did not. In addition, patients who reported experiencing some anxiety also reported experiencing a less person-centered climate through the PCQ survey. However, while the survey data was able to numerically quantify the percentage of the patient population experiencing anxiety and tell us that they experienced a less person-centered climate, it was unable to tell us what was causing these feelings, when they were being experienced, or why.

This is where our ethnographic fieldwork within the clinic became very helpful. During our observational studies, we had the opportunity to view multiple patients being fitted with fixation devices for treatment (See Figure 2). These devices are used within radiotherapy to provide reproducible patient positioning from one treatment appointment to the next. Unfortunately, they also seem to trigger patient anxiety.



Figure 2: Patient fixated for treatment in a head mask

One patient was observed discussing with the nursing staff about how the mask had triggered feelings of anxiety and claustrophobia when it was being worn, despite this individual not normally having any problems with enclosed spaces. In a follow-up interview, the nurses explained to us that the patient had used breathing relaxation techniques to stay calm and avoid panicking. In this interview we also learned that these masks frequently cause feelings of anxiety in the patients, and that in order to alleviate some of these feelings, the nurses often need to alter the masks in different ways to make them tolerable to the patient. This can be through cutting eye openings in the masks to allow the patients the ability to observe what is going on around them and communicate, or adjusting the fit in other ways. Our observations led to the identification of the fixation device as one trigger of anxiety in patients undergoing radiation therapy.

Building upon these findings, the self-reported material collected from the Design Probe journals provided us with rich descriptions of patient radiotherapy experiences that were otherwise unattainable through the questionnaire and observational methods. Drawing on material gathered from 14 different patients, we looked for stories that would support our understanding of the role of the fixation device in causing anxiety.

In the journal of a patient who reported suffering from claustrophobia, we found a description of her experience with the face mask: *"I had a panic attack the first time. I could not handle being trapped in the mask. Then the staff modified the mask so that it didn't put pressure on the neck. The next day I asked to them to make eye holes for me, which they did. Now it's ok."* This statement, supported by our observational findings, suggests that the care staff form a tightly intertwined relationship with the treatment technology,

and the negative emotional impact of the equipment is often balanced out through the actions of the nurses. Through the example of the fixation device, we can see that the nursing staff mediates the anxiety provoking and claustrophobic nature of this technology through physical intervention, softening its restraint and making it more tolerable for the patient.

In her book, *The Logic of Care*, Annemarie Mol, discusses how the technologies involved in medical treatment are generally considered to be mere 'instruments' and a means to an end, but they also often have unexpected effects (Mol, 2008). Mol suggests that 'good care' involves the care provider's constant endeavor to adapt these technologies to their needs. From the examples provided in this paper, we can see that in the context of Radiotherapy, the nursing staff shoulders the burden of providing both treatment, and emotional and physical support to patients during radiotherapy in order to mediate the patients' 'unexpected' negative responses to the treatment technologies.

Design Solution

Taking our analysis a step further, we dug into the details provided in the patient journals about the radiotherapy experience to look for ways that we might begin to intervene in this environment and make it more person-centered. From the patient journals, we discovered that many patients emphasized in the design probe materials that there is a lack of visual stimuli during treatment. One patient wrote that she wished she had *"something in the ceiling to watch during treatment,"* while another patient wrote that she spends her time in the treatment room *"counting the tiles in the ceiling."* This finding was reinforced by images of the treatment room ceiling taken by the patients with the cameras that were part of the probe kit (See Figure 3).



Figure 3. Patient photographs of their view while lying on the treatment table

This insight pointed to a means for mediating the anxiety caused by the treatment technologies, and the concrete details provided by the patients in their journals and photographs provided a place to leap from research into design. Based upon the insights gathered through our patient-centered research, we chose address the issue of the bare ceiling in the treatment room and find a design solution that would engage and

distract patients from their immobilization-based anxiety within the treatment room. Since the patients reported the treatment room as being cold, uninviting, and a space predominated by technology, we decided to bring nature imagery into the room.

Previous research has shown that exposing patients to interesting and distracting environments through video and sound can have a beneficial impact on their hospital experience, especially if the imagery is nature imagery. It has long been known that views of natural landscapes provide a strong positive health effect in patients (Ulrich, 1984; Velarde and Tveit, 2007; Malenbaum et al, 2008). These health effects include short-term recovery from stress or mental fatigue, faster physical recovery from illness, and long-term overall improvement on people's health and well-being. In addition, Miller et al. (1992) found that burn patients exposed to scenic imagery through videos during dressing changes reported significant reductions in ratings of pain intensity, pain quality, and anxiety.

Working directly with the treatment room nursing staff to find a design that wouldn't interfere with their normal workflow, we arrived at a final solution using projection to screen video of clouds moving in the sky upon the ceiling of the treatment room (See Figure 4). The video provides visual stimulation for patients, and a place to focus their attention during treatment. The patient view is transformed from a static, unchanging landscape of ceiling tiles, to a dynamic colorful visual of nature.

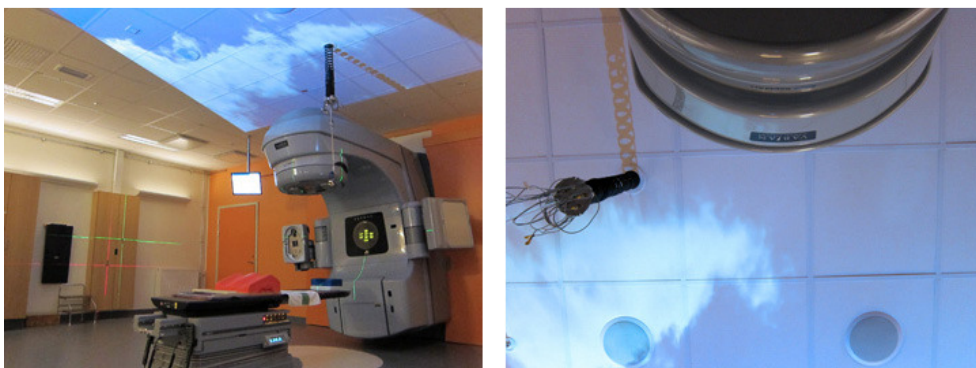


Figure 4. Ceiling Projection Intervention

Initial findings from the impact of the implemented design have shown that patients look for a focus point in the treatment room, to ground them during each visit and help them relax. The video intervention can be used as this focus point for some patients, and removal of the video imagery impacts these patients' ability to relax during treatment. However, more research needs to be done to assess whether this intervention actually decreases anxiety in this patient population.

Conclusions

Person-centered care has been argued to be essential in ensuring patient wellbeing during their healthcare experiences, but in order to provide this type of care we must first be able to understand the factors influencing this experience from the patient's perspective. Using three different methods to research patient experience in this paper, we looked for indicators to help us determine whether the radiotherapy experience is currently meeting patient's needs and providing a patient-centered environment.

The quantitative data gathered from the patient questionnaire provided data showing that anxiety is prevalent within a significant portion of this patient population. This information suggests that anxiety is something that needs to be addressed within radiotherapy treatment and one way to do this is to increase the person-centeredness of the clinic environment. However, the questionnaire data taken alone provided us with very little insight into the details of the patient experience, and this method is incapable of giving us any further information about where, when, how or why these patients experienced feelings of anxiety.

While the ethnographic fieldwork was helpful in identifying one cause of patient anxiety, the fixation device, it was the design probe material that was crucial in clarifying why this technology triggered anxiety. The probe kits were instrumental in constructing understanding around the role of anxiety in the patient experience because they gave us access to the patient voice, which showed that the fixation device triggered feelings of claustrophobia for many individuals.

The design probe kits have demonstrated that they are a highly valuable tool for gathering insight into healthcare experiences from the patients' perspective, a critical aspect of generating a patient-centered approach to care. Patient interviews is another technique that could be used for acquiring access to the patient voice, however the design probe kit is unique in that it provides multiple mediums for capturing experience, both verbal and visual. Regardless of the method implemented to capture the patients' perspectives, patients are our best tools in understanding the radiotherapy experience because only they can tell us what it is really like to go through the treatment process.

This paper demonstrates how medical technologies designed to treat disease can produce 'unexpected' negative effects in patients, such as anxiety. Furthermore, our research findings suggest that the care experience within the Radiotherapy Department at NUS is highly dependent upon the nursing staff to mediate the negative impact of the technology on patient experience. It can be argued that providing and receiving care within radiotherapy could be very different if these technologies incorporated patient-centered perspectives into their design, or if the environment was designed to be more person-centered and distract the patient from the technology.

The ceiling projection design intervention that arose out of this research is just one potential solution for diminishing the 'unexpected' effects of the fixation device and creating a more person-centered environment. While this paper focused upon the fixation device as a cause of anxiety for patients undergoing radiotherapy, the material gathered from the design probe kits shows that this is just one factor that plays into the creation of the patient experience. There are many other aspects that can influence patient anxiety and perceived patient-centeredness of the environment, and these factors work together to create a positive or negative patient experience. Design for patient wellbeing and care needs to go beyond providing the most advanced treatments to include consideration for the patient as an individual and their experiences. This paper demonstrates that human-centered design research can be a useful tool in providing insight into the patient experience as well as identifying areas where change can be implemented.