Probing the Patient Experience

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ABSTRACT
This paper presents the design probe kit as a valuable tool to investigate patient experiences within healthcare systems. Providing journals and cameras to cancer patients, we ask them to document their interactions and emotions while receiving radiotherapy treatment. The data gathered through these materials gives insight into the key role of nurses within radiation therapy, mediating the ‘unexpected’ negative effects of the treatment technologies on the patient experience. This paper suggests that there are multiple opportunities for patient-centered design to create positive change and increase both patient and provider wellbeing within this environment.

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Patient experience, design probes, healthcare, wellbeing.

ACM Classification Keywords
J.3 Life and Medical Sciences: Health;

INTRODUCTION
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. Findings from a growing body of research on experiences of illness, treatment and care have shown that healthcare driven from a purely biomedical perspective is unable to generate satisfactory or even acceptable care from the patient perspective [2]. This research highlights the importance of taking into account the subjective experiences of the patient within healthcare. A patient-centered approach to care involves treating patients as individuals and thereby assessing and meeting their individual needs rather than solely meeting the needs of the staff [1]. This approach advocates using insights gained from the patient’s perspective to create a positive social environment in which patients can experience wellbeing.

This paper uses design probe kits to collect personal stories of patient experiences during radiotherapy, looking specifically at the impact of treatment technology on the patient’s perceptions of their care experience. The research presented in this paper has been conducted in collaboration with the Radiotherapy Department of the Norrlands University Hospital (NUS) in Umeå, Sweden with ethical approval from the NUS ethics board (Dnr 2010-371-31M).

METHOD
The research approach implemented in this study is based upon the design probe method developed by Tuuli Mattelmäki [3]. This method was created to help designers understand human phenomena and explore design opportunities in a space that allows for unexpected results to emerge. Design probes are now a commonly used research method in user-centered design, and this approach was chosen for this study because it emphasizes the active role of the patient in recording the material, and it allows for the inclusion of personal contexts and perceptions, which is of important when trying to understand the care experience.

The probe kits used for this study were comprised of a journal and a camera. The material was handed out to interested patients at the start of their treatment, and they were asked to document their experiences for the duration of their treatment cycle. The journal contained daily open-ended questions about the patient’s perceptions of the care environment, and their interactions with the staff and technology within this space. The patients were asked to verbally document their experiences in the journal, and the camera was provided as an additional tool to help them visually record the aspects that they liked and disliked in the care environment. This approach was chosen over other qualitative approaches for gathering information about patient experiences, such as interviews and observational studies, because the focus of this study was to capture insights about the experience 1. over the duration of treatment and 2. from the patient’s point of view.

Radiotherapy treatment with curative intention is usually delivered over a period of several weeks, with an average duration of five weeks of daily treatment. While interviewing is a comparable method for gathering patient stories about their experiences, interviews generally take place as single meetings. In contrast, the daily journal allows for continued documentation of experiences that occur throughout the duration of treatment. Additionally, while user observation could be used to provide detailed analytical data about the experience of radiotherapy from an objective viewpoint, the experiential details of what it is like to go through radiation treatment can only be gathered from someone directly undergoing treatment, which is why a first-person approach was chosen.

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FINDINGS
The self-reported material provided in the journals provided rich descriptions of patient radiotherapy experiences. Drawing on material gathered from 14 different patients, a comparative analysis was performed on the words and images recorded in the probe materials to highlight shared themes between patients.

The stories captured in the journals showed that the interactions between patients and the treatment technology can be problematic, triggering anxiety and interfering with the treatment process. One patient who suffered from claustrophobia, and has been categorized as a key informant within this research, conveyed her experience with face mask fixation in the following statement: “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 suggests that the care staff has formed 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. In this example, the nursing staff mediates the negative impact of the fixation device through physical intervention, softening its restraint and making it more tolerable for the patient.

In another example, the perceived expertise of the care staff is used as a coping mechanism to help patients maintain calm when interacting with the technology. In the response to the question “what do you think about in the treatment room,” one patient replied, “[I think] what if the “equipment” falls down on me? The next moment, I trust the staff. That the technology holds.” This sentiment is supported by another patient’s statement about their experience within the CT room: “[It was] the first time I saw one such room. [It] wasn’t funny, but I trust the staff.”

In this way, trust in the competence of the care staff is used by patients to mitigate their negative responses to the treatment technology.

In her book, The Logic of Care, ethnographer and philosopher, 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, such as triggering strong negative emotional responses in patients [4]. 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 shouldered 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, such as anxiety from restraint, and fear of what the technology looks like and how it functions.

CONCLUSION
Patient-centered care has been argued to be essential in ensuring patient wellbeing during their healthcare experiences. In order to provide this type of care, we must first be able to understand the factors that influence this experience from the patient’s perspective. The design probe approach taken in this research has shown that it is a valuable tool for gathering insight into healthcare experiences from the patients’ perspective, a critical aspect of generating a patient-centered approach to care. Furthermore, this material has shown how the care experience within the Radiotherapy Department at NUS is highly dependent upon the nurse-patient relationship to mediate the negative impact of the technology on the patient experience. We suggest that the care experience could be enriched and more supportive of both the patient and staff if the responsibility of providing a care-centered experience was more distributed throughout the whole healthcare system, not just the burden of the nurses.

It can be argued that medical technologies currently produce ‘unexpected’ negative effects in patients because they have been specifically designed for the care providers, but lack consideration for patient interactions. The experience of providing and receiving care could be very different if these technologies incorporated patient-centered perspectives into their design, which either eliminated these ‘unexpected’ effects or decreased their impact through embedded support structures.

While the probe materials have provided us with a strong baseline understanding of the factors that play into defining the care experience for radiotherapy patients, it is difficult to gain detailed follow-up information about specific topics, due to the reporting structure of the probe kit. Structured interviews would be a good next step in this research to allow us to dig deeper into the topics we have pulled out of the probe material, specifically because this method would allow for targeted questions that feed upon one another.

REFERENCES