Thinking beyond the Cure
A constructive design research investigation into the patient experience of radiotherapy

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Abstract
This constructive design research dissertation aims to understand how design can be used as part of a composite research approach to generate knowledge about how complex phenomena are composed through their interactions and relationships with various actors, both human and non-human. It has done this by investigating a single phenomenon, the patient experience of radiotherapy.

Through the purposeful selection and application of methods, theories, and existing research from design, nursing, and STS, this thesis utilizes a mixed-method approach comprised of qualitative, quantitative methods, and design experimentation, across multiple research sites and patient populations, in three research projects – PERT, DUMBO, and POIS – to generate rich and layered knowledge of the patient experience. Experience prototypes are used to challenge, through intervention or provocation, the relationships between the various radiotherapy actors identified through the empirical methods. Together, the research generated in PERT, DUMBO, and POIS construct a map of the networked, interdependent actors which shape the patient’s emotional experience of radiotherapy: the staff, technology, information, environment, and institutions. It also calls attention to the problematic relationship between radiotherapy patients and the technologies used to treat them, which can lead to anxiety, worry, and fear.

This thesis offers contributions related to both improving patient experience and designing for complex social issues. First, this research suggests that individuals, other than primary users, need to be acknowledged in the design of medical technologies. It proposes calling attention to patients by naming them as interactors in their relationships with the aforementioned technologies, removing them from the role of implicated actor. Second, this thesis problematizes treating the actors within a network as independent entities, which medical research and user-centered design often does, and calls for a new type of design practice which attends to these networked relationships. Third, this thesis suggests two ways in which design research practice should be shifted methodologically if it wants to engage with and design for complex social issues like patient experience; widening the researcher’s perspective on the issue through the use of a composite methodology, and having the researcher maintain this scope by remaining closely connected to their research context. The implications of this work concern how design research, design education, and design practice might shift their approaches to fully acknowledge and attend to the complexity of systems like healthcare.

Keywords
constructive design research, patient experience of radiotherapy, actor networks, design experiments, composite methodology, mixed-methods, prototyping, design research, research through design.