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# Exploring Socially-Focused Technologies that Can Help Children with Cancer Feel More Like Children Despite their Disease, Treatment and Environment

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## ABSTRACT

This describes the background and motivation for dedicating my PhD to the exploration of socially-focused technologies for childhood cancer patients. Very little work has been done, especially in the field of human and child computer interaction, to explore the ways in which the hospital context in conjunction with the cancer experience impact children's social and emotional well-being during middle childhood (ages 6-12), and in turn how technology could improve their experience. My research seeks to (1) empower children with cancer by providing a platform for them to voice their own experiences with isolation, loneliness, and loss of a normal childhood, as well as how technology may better support their needs, (2) contribute design knowledge about how to support meaningful social interaction and play that is age and 'ability' appropriate, and (3) provide insight for future design and evaluation studies by better understanding ...

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**CCS CONCEPTS**

- **Human-centered computing** ~ Human computer interaction (HCI)
- **Social and professional topics** ~ User characteristics

**KEYWORDS**

child-computer interaction; design research; childhood cancer; social health; in-situ hospital studies

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constraints/opportunities for socially-focused technologies intended for use in a real world pediatric hospital environment.

## 1 THE IMPACT OF CHILDHOOD CANCER & NEED FOR DESIGN-RESEARCH IN CHILDHOOD CANCER CARE

Each year childhood cancer threatens the lives of about 200,000 newly diagnosed children worldwide [8] and 800-900 children in Canada [4,9]. Though survival rates have increased to about 82% [7,10,20], cancer is still considered a chief disease-related cause of death in Canadian [4] and American children [20], taking more lives annually than “asthma, diabetes, cystic fibrosis and AIDS combined” [4]. Moreover, childhood cancers typically have short latency periods, grow more rapidly and invasively, and spread more frequently [4,5,7]. Aggressive treatment plans often combine chemotherapy, radiotherapy, and surgery as well as clinical trial protocols [10]. Many children with cancer report “feelings of loneliness and isolation” and “loss of a normal childhood” resulting from regimented and limited peer interaction often imposed by an aggressive treatment plan and its many side effects – like increased susceptibility to infection [17].

Cancer robs children of time that they would normally dedicate to everyday social childhood activities (e.g. school, extracurricular activities, playing with friends, etc.). While existing technologies and media can facilitate valuable social interaction among teens (e.g. Facebook), many barriers limit younger children’s access to these platforms (e.g. age restrictions on use). And studies of parents of healthy children reveal concerns about how social technology may impact their child’s wellbeing (e.g. bullying, etc.) [3], and point to skepticism for technology’s role in meaningful social interaction (e.g. screen time) [11]. But given the isolating nature of childhood cancer and the hospital environment, parents and caregivers encourage the use of technology to support social play and interaction. Interviews with medical staff to uncover how seriously ill children use technology for social purposes revealed drawbacks to existing technology capabilities related to a child’s (1) health limitations, (2) feelings of presence with friends, and (3) ability to integrate with friends and other peer patients [14]. They propose (1) investigating the topic from a child’s perspective and (2) exploring how age impacts a child’s use of technology for maintaining a normal childhood [14].

Furthermore, few design research studies explore how technology can support childhood cancer patients. Searching “cancer” within Association for Computing Machinery (ACM) proceedings from the premier conferences in my field reveals only 6 articles discussing childhood cancer patients and the ACM Journals database has 0. At the time of searching the proceedings the Interaction Design and Children (IDC) conference had 4 articles, the Conference on Human Factors in Computing Systems (CHI) had 2, and the Tangible and Embedded Interaction (TEI) conference had 0. Only two are for social support (e.g. [13][19]). But, there is a recent call to action within the field of human computer interaction to explore the “potential and value of technologies to augment our everyday social interactions” [11], including play (e.g. [1,2,16]), and to design meaningful technology for health/well-being [18]. This motivates me to explore the potential for

socially-focused technologies that can help children feel more like children despite the constraints imposed by childhood cancer, their treatment and their environment.

## 2 Research Questions & Methodology Summary

1. In what ways has the cancer journey impacted a child's social quality of life?
  - a. In what ways do children (aged 8-12) experience feelings of social isolation, loneliness and/or loss of a normal childhood due to hospitalization and cancer treatment?
  - b. What types of activities do children enjoy doing the most with peers and/or friends? How has this been impacted by cancer and hospitalization?
2. How are children currently interacting with peers and/or friends, especially for social purposes, within the hospital? And how does technology factor into this?
  - a. What technologies do children currently use for play and social interaction with peers/friends? In what ways do these technologies help support/constrain social interaction?
  - b. What spaces or events in the hospital do children currently use for play and social interaction with peers/friends? In what ways does the hospital environment support/constrain social interaction?
  - c. What types of concerns/rules do parents have in regard to their child with cancer's use of socially-focused technologies? Why? How does this compare to studies of parents of healthy children?
3. In what ways might the disease, treatment, and the hospital context impact the integration and/or adoption of technology applications for children with cancer?
4. What opportunities and challenges exist that can inform design considerations for technology aimed at alleviating these issues for child patients in the hospital environment?

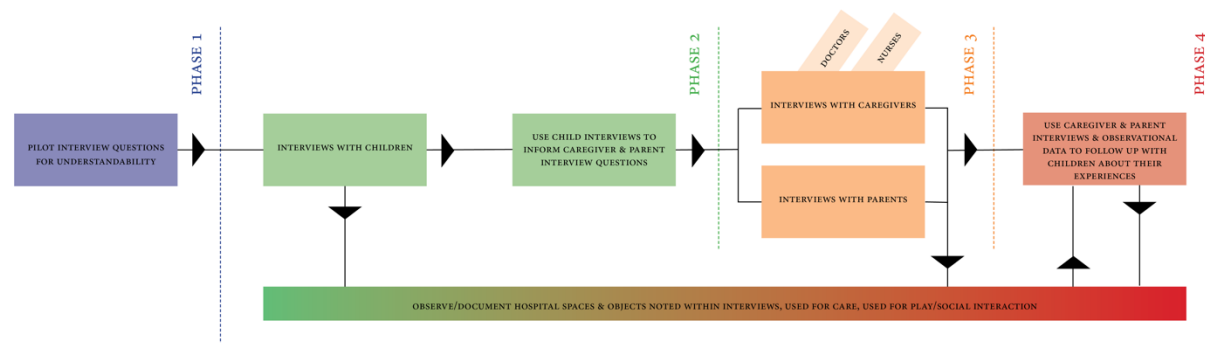


Figure 1. Study Process for Data Collection.

Building on my skills for mixed methods in-situ design research with vulnerable populations I plan to triangulate data from observation of pediatric hospital spaces and conduct interviews with multiple stakeholders (child patients, caregivers, parents) in both Vancouver, Canada and the US to answer my research questions. Overall, my exploratory study will be made up of several phases. See Figure 1. Phase 1 includes a pilot study to assess the understandability of child

interview questions. Phase 2 includes conducting interviews with children and then using the interview data to help inform interviews in Phase 3 with caregivers (e.g. doctors and nurses) and parents. In Phase 4 I will do a follow up with each child about data collected in parent and caregiver interviews to get a last round of feedback about the child's experience. Throughout Phases 2-4 I will collect observational data in the form of notes and photos that help document spaces, contexts and/or technologies discussed throughout the interviewing process. These may be used as independent data, but may also act as a means to better communicate questions or issues during the interviewing process.

I include child participants for the following reasons: (1) there is a gap in the literature providing child accounts of the cancer experience and studies point to discrepancies in how parents and their children with cancer report the child's 'quality' of life (e.g. [12]), and (2) adults and children have different points of view/wants/needs as to how socially-focused technology could improve a child's social experience.

### 3 Goals & Contribution

I aim to (1) empower children with cancer by providing a platform for them to voice their own experiences with isolation, loneliness, and loss of a normal childhood, as well as how technology may better support their needs, (2) contribute design knowledge about how to support meaningful social interaction and play that is age and 'ability' appropriate, and (3) provide insight for future design and evaluation studies by better understanding constraints/opportunities for socially-focused technologies intended for use in a real world pediatric hospital environment.

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