Exploring the Potential for Tangible Social Technologies for Childhood Cancer Patients within the Hospital

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ABSTRACT
Through a multi-phased mixed method study with childhood cancer patients (8-12 years old) and their team of caregivers within US and Canadian hospitals we will explore (1) the ways the cancer experience impacts patient's social/emotional well-being, (2) how existing technologies fail to provide feelings of connectedness to friends/peers, and (3) how novel tangible technology could improve connectedness. We aim to (1) empower children with cancer by allowing 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 social tangible technologies intended for use in a real world pediatric hospitals.

Author Keywords
child-computer interaction; design research; childhood cancer; social health; in-situ hospital studies; children.

THE IMPACT OF CHILDHOOD CANCER & NEED FOR DESIGN-RESEARCH IN CHILDHOOD CANCER CARE
While leaps have been made to increase childhood cancer survivorship, the reality is that childhood cancer patients face many challenges on their way to recovery – outside of the obvious impacts on their physical bodies. During cancer treatment children's lives and the lives of their family members are upended. Treatment often leaves children isolated from friends and peers within a hospital environment and lacking the physical capabilities or energy to play 'normally'. From decades of child development and psychology research we understand that play is an essential part of how children come to understand their own bodies, sense of self, and the 'workings' of the world around them (e.g. social/cultural norms, physics and dynamics between different physical properties, emotion recognition and regulation, etc.). Research positioned within the tangible and embodied computing paradigm has focused on the embodied and social nature of play and opportunities to support or augment such play. Child-computer interaction research under this umbrella relies on assumptions about how physical interaction in and with the world underlies both internal and external ways of 'knowing'. Research focused on promoting normal and healthy child development point to the need for play, in particular for children with illness that are confined to hospital environments (e.g. [1, 5, 9, 13, 15]). For example, play is now widely recognized in the medical field as a way to reduce fear and anxiety (among other things) produced by medical procedures and the hospital itself [16, 20]. Many hospitals have explicitly created play environments for children that range from purely physical spaces (e.g. Vancouver Canucks-themed playroom at B.C. Children's Hospital [8]) to immersive environments (e.g. Infusionarium at Children's Hospital of Orange County [17]), and have also employed staff – play specialists, play therapists, etc. – who specialize in using play to meet the myriad needs of hospitalized children (e.g. [1, 9, 15, 16]). Yet there is little research that focuses on how social tangible technologies might support playful social interactions for children who are hospitalized and are isolated from friends.

Designing 'play' artifacts and spaces that promote social interaction and/or aid physical development can be extremely challenging as children enter *middle childhood* – a period of key developmental, social and contextual changes between the ages of 6-12 years old [28]. At this stage of life children seek increased autonomy and independence as they transition into adolescence by spending a large portion of time outside of the home by attending school, engaging in extracurricular activities, and playing/socializing with friends more independently, etc. [28]. However, children in middle childhood with cancer are robbed of time they would normally dedicate to these everyday activities – activities that provide opportunities for personal interest development, increased autonomy and independent decision-making, deep friendship building, exploration of peer connectedness, and maintaining physical health and a positive body image [28]. Despite efforts to provide opportunities to play and socialize – both in-person as well as through digital or virtual channels – children with cancer still report "feelings of loneliness and

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isolation" and "loss of a normal childhood" [26]. These reports are especially interesting in a world where so many 'socially-focused' technologies exist (e.g. mobile social games, social media, video enabled call services, internet enabled gaming platforms, etc.) that can connect people regardless of time and location. While I do not believe there will be a way to fully alleviate feelings of isolation, this leaves me with many questions about the efficacy of play spaces and readily available technologies intended to support meaningful play and social interaction for children within a hospital environment. Thus far efforts to explore existing and novel technologies that can help reduce these feelings by improving social connectedness and enhanced opportunities for play have been limited.

Few design research studies explore how technology can support childhood cancer patients, especially in dealing with feelings of loneliness, isolation and loss of normal childhood. For example, searching "cancer" within Association for Computing Machinery (ACM) Conference Proceedings reveals only 6 articles discussing childhood cancer patients. In 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 ([22, 30]). The ACM Journals database had 0 articles. Despite the gap in literature, 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" [18], including play (e.g. [2, 7, 25]), and to design meaningful technology for health/well-being [27]. Furthermore, Freed argued that play in middle childhood is essential to normal emotional and social development and exploring novel ways that "tangible" technologies can be created to produce meaningful play experiences is important especially for children who cannot play face-to-face [12]. It is within this context that I hope to explore the potential for socially-focused tangible technologies that can help children feel more like children despite the constraints imposed by childhood cancer, their treatment and their environment. My overarching research questions are as follows:

1. *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? In what ways do existing technologies help support/constrain social interaction?*
2. *In what ways does the hospital environment and/or treatment impact the use of interactive socially-focused technology within the hospital for children with cancer who report these feelings?*
3. *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?*
4. *What design considerations are necessary for social tangible technology aimed at alleviating these issues for child patients in the hospital environment?*

DESIGN SPACE: EXPANDING TANGIBLE SOCIAL PLAY INTO THE HOSPITAL

Decades of research across many fields has explored play as an integral part of not only normal child development, but also as a means to help children 'heal' within a hospital environment. As we've come to conceptualize play as the 'work of children', child research has expanded to examine the role play objects and environments have on children's development, relationships and health/well-being. This includes inquiries into computational, interactive technology that harness both the physical and digital world to promote play. Many researchers trace the origins of pervasive, augmented, and mixed reality games back to Ubicomp. Many of these explored ways to support play (e.g. [3, 4, 6, 7, 14, 19, 23]) and the authors in [23] pointed out that pervasive gaming encompasses many different areas that show potential for providing play opportunities for social interaction and improving feelings of connectedness to others: (1) smart toys, (2) affective gaming, (3) augmented tabletop games, (4) location-aware games, and (5) augmented reality games. This large landscape also overlaps with tangible computing and embodied interaction, where researchers work from "an understanding that you cannot separate the individual from the world in which that individual lives and acts" [11] because of the innate inseparability between the mind, body and environment. Research positioned within the tangible and embodied umbrella have focused heavily on children since there are assumptions about the 'naturalness' of physical interaction that capitalizes on children's intertwined motor and cognitive capacities. Dourish [11] pointed out that the field of tangible computing encompasses many different activities, which include: (1) creating smart environments that may include proximity based computational qualities, (2) augmenting everyday objects with computational faculties, and (3) capitalizing on physical manipulation of representational objects to directly interact with an interface. Shaer and Hornecker [29] discussed the breadth of tangible user interfaces, which can include: *tangible augmented reality* (combine tangible input with AR output), *tangible tabletop interaction* (includes tangible objects and interactive multi-touch surfaces), *ambient displays* (inspired by Ishii's Tangible Bits, now focuses on monitors and wall display), and *embodied user interfaces* (considers how technology can take advantage of or enhance bodily knowing). They pointed out that understanding the perspectives associated with tangible interaction requires that we unify or at least acknowledge different conceptualizations of computing, which include *tangible computing*, *tangible interaction*, and *reality-based interaction* (a broad area that includes studies involving VR, AR, UbiComp/Pervasive computing, handheld interaction, and tangible interaction).

Given existing inquiries in human and child-computer interaction using these computing/design paradigms one can envision ways to augment physical spaces and artifacts to encourage both active and passive social interaction for children (with cancer) isolated within a hospital. It seems that many existing technologies implemented in hospitals that fall under this computing paradigm, like CHOC's Infusionarium and Immersive Healing Experiences ([31]), take users 'elsewhere' as opposed to providing ways to re-imagine or re-purpose the physical spaces children already occupy through 'layers' of computation. One can imagine that changing the narrative experience around the space one occupies by embedding within it meaningful ways to maintain and build relationships through play can have positive impacts on children required to be in the space for long periods at a time – especially if these spaces are normally associated with fear, anxiety and/or pain. While the 'distraction' method is an effective best practice for children actively undergoing treatment that require them to remain stationary (e.g. chemotherapy), it seems that there are many opportunities to integrate novel technologies to increase feelings of *connectedness* as well as promote feelings of *autonomy* and *active participation* in their journey to healing. Technology has the potential to capitalize on these needs sought out by children during middle childhood – needs normally satisfied by spending increased time away from their direct family and home life via school and other activities. In order to ethically design technology to meet these needs first requires that we understand more about children's preferences for and access to interactive technologies within the hospital environment, particularly as it has to do with promoting and maintaining meaningful social interaction and connectedness to friends and peers. Furthermore, while we assume children in developed countries now have a fluency and an overall positive outlook on everyday technology use as 'digital natives', we also understand there may be many barriers in this design space, including issues like parental concerns/rules regarding 'social' technology use, hospital spaces, and hospital rules.

METHODOLOGY

Using a mixed methods in-situ design research approach with a vulnerable population we plan to triangulate data from observation of pediatric hospital spaces and conduct in-depth semi-structured interviews with multiple stakeholders (child patients, caregivers, parents) in both Vancouver, Canada and the US to answer our exploratory research questions. Overall, the exploratory study will be made up of several phases (See Figure 1). All interviews will be audio recorded and be administered with an interview guide. 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 a follow up with each child about data from parent and caregiver interviews will be done to better understand differences in point of view between participant groups. Throughout Phases 2-4 we 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. All participants will be recruited in person from B.C. Children's Hospital and from the Children's Hospital of Orange County in the United States. Data analysis will be as follows: (1) Transcribe interviews; (2) Open coding of transcribed interviews to produce primary themes [24], rigor ensured through statistical methods for intercoder reliability [10]; (3) Comparison of themes across ages of children; (4) Axial coding and comparison of themes between children and parents and caregivers to produce design considerations.

Child participants are included for the following reasons, which also motivate my first goal/contribution below: (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. [21]), and (2) adults and children have different points of view on the necessity, expectations and relevance of technology intended for social purposes.

GOALS & CONTRIBUTION

We aim to (1) empower children with cancer by allowing 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, by integrating them as a primary data source for our study, (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 social tangible technologies intended for use in a real world pediatric hospital environment.

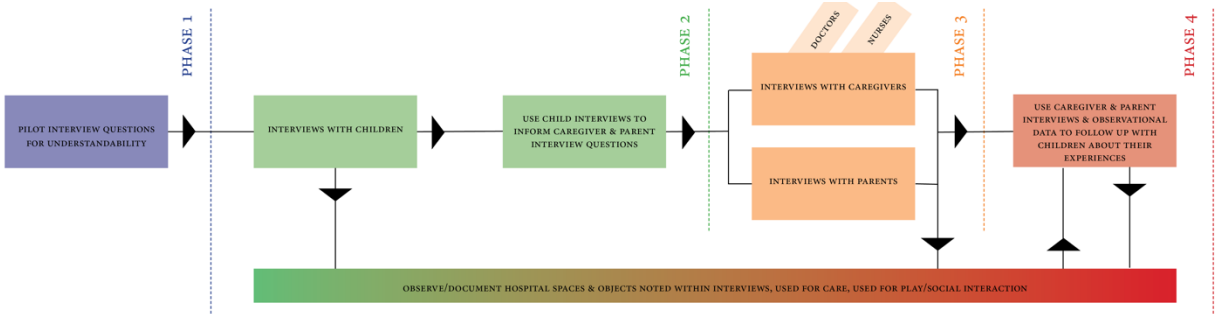

Figure 1. Proposed Study Process for Data Collection

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