Designing Communication Technologies for Children with a Chronic Illness

Leslie S. Liu
Biomedical & Health Informatics
University of Washington
lслиu@uw.edu

ABSTRACT
Children with a chronic illness who must frequent the hospital for various treatments and procedures are removed from familiar environments, such as their home or school, to stay close to the hospital. Their temporary removal from familiarity can cause feelings of isolation. Social connectedness with their friends and classmates may help alleviate their feelings of isolation and help make them feel more “normal” like their healthy counterparts. However, current communication technologies are not designed specifically for chronically ill patients. By understanding how patients use current technologies to stay connected with their friends, I propose to develop and carry out a participatory design methodology to produce technologies that assist the chronically ill pediatric population.

Categories and Subject Descriptors
J.3 Life and Medical Sciences (Health)

General Terms
Human Factors.

Keywords
Children; chronic illness; participatory design; communication technologies.

1. INTRODUCTION
For children diagnosed with a chronic illness, growing up can be harder than their healthy peers. These patients face challenges in staying connected with their social circle. They may feel isolated because of their temporary removal from familiarity. Patients may also feel as if they are no longer who they use to be because of the changes in their physical appearance. Nowadays, patients, particularly teenagers, are likely to use some communication technology to keep in touch with friends while they are in the hospital or at home. Studies have focused on healthy children and the ways they communicate such as teenagers and video chat [2]. Few studies have examined how younger children with chronic illnesses communicate with healthy peers.

My research aims to not only inform the actual design of communication technologies for children with a chronic illness, but also to inform potential design methodologies specific to such children.

2. RELATED WORK
Children with a chronic illness may not be able to attend school or certain events due to procedures or a compromised immune system. Cancer survivors feel greater isolation [9], play less than healthy peers [10], and are teased [11]. However, being seen as “normal” by peers was helpful for patients [13]. Social support from peers may help alleviate their feelings of isolation and increase their social connectedness. Increasing positive peer relationships is associated with prosocial behavior, academic achievement, and also the ability to withstand stress [12]. Support from peers was found to be important [6] for reminding patients to stay optimistic [13].

Work on children and HCI has mostly focused on communication technologies for healthy children [1, 4]. Studies that have examined how to design for and with children with health conditions tend to emphasize solutions that allow children to communicate their needs to specialists [8] rather than friends.

3. STUDY DESIGN
To understand how to design communication technologies for chronically ill pediatric patients, I have broken my research into two steps: (1) understanding current communication practices of how patients stay connected with their friends; (2) informing the design of technologies and design methodologies through participatory design sessions.

3.1 Communication Practices and Challenges for Patients
To understand how to design communication technologies for chronically ill pediatric patients, I first examined how patients remain connected to their peers [5]. I conducted semi-structured interviews with 22 participants. Fifteen participants were healthcare professionals (e.g., physicians, social workers) working at a large children’s hospitals. Six were parents of children with cancer and one had a child with a blood disorder. Patients ranged from 5 to 17 years old.

I coded transcribed interviews looking for emergent themes using a grounded theory approach [10]. I interviewed healthcare professionals because they interact daily with a large number of patients and can give a broad perspective across many patients. I interviewed parents because they are able to reflect upon their child’s experiences more easily than young children. Due to the sensitive nature of these illnesses, I felt it was important to gain
an understanding of the key issues before interacting directly with the children.

My findings revealed that a major concern of pediatric patients was that their illness affected their feelings of normalcy. Due to this life-changing disruption, patients used various technologies to try and maintain normalcy in their lives. While striving for normalcy, patients knew that they could not continue to have the same lives as their healthy peers. Patients used various methods to "create a new normal", such as using Facebook postings to mediate classmates’ reactions to their different appearance (e.g., baldness).

3.2 Design by Play

Based off of my previous study, the next step is to understand how the design of technologies can support normalcy and how to help patients stay connected to friends. Design by play is a potential design methodology for these sensitive populations.

Inspired by Druin’s approach to participatory design (PD) from her cooperative inquiry framework [3], I plan to hold weekly PD sessions over 3 months. PD studies involve the end-user in activities that lead to design and products [7]. My PD sessions will be held at the Seattle Children’s Hospital near outpatient clinics. Long-term PD sessions can foster community building within Seattle Children’s Hospital.

I will target patients who are between the ages of 7-12 years old. The benefits are threefold. First, Druin [3] suggests that children between the ages of 7-10 can often make good design partners because they are able to discuss what they are thinking but are not influenced by pre-conceived notions. Second, many technologies such as Facebook and Twitter require users to be at least 13 years old. Therefore, pre-teen patients may not have as many resources to stay in touch with friends. Third, children have been found to be able to lead co-design sessions [14].

Because patients often come in and out of the hospital, the PD sessions will be designed to not require prior knowledge or involvement in order to participate. Each PD session will follow the below structure [14]:

1. **Hangout Time.** After introducing themselves and how many times they’ve participated in the sessions, patients will get to know each other without pressure to conduct design activities.

2. **Play Design Activity.** Activities will vary weekly to ensure that patients who have participated previously will still be engaged. Activities informed by my first study will revolve around a “Story of the Week” (e.g., Jo isn’t able to play or see her friend, Bob, for a few weeks. Can we think of ways to help Jo play with Bob?). Using low-fidelity materials (e.g., Play-Doh, Legos, markers) [3] in small teams, I will ask patients to come up with ideas on how to answer the Story of the Week.

3. **Sharing Time.** Teams will then share what they have come up with other teams.

4. **CHALLENGES**

PD literature on healthy children do not address the challenges of having pediatric patients as participants. Patients may feel more comfortable having siblings, friends, or parents with them, but they may become too overprotective of the patient and hinder the patient’s participation. Patients may also have varying levels of physical and cognitive limitations. When using different low-fidelity design materials, I will need to consider all levels of limitations to ensure that patients are not isolated from participation.

5. **CONCLUSION**

Children with a chronic illness lead very different lives than their healthy friends. Communication technologies can support patients in feeling connected with peers. However, many current communication technologies are not designed for younger children who are not well. My research will provide a deep understanding of how patients currently use technologies to stay in touch with friends as well as the design of these technologies. I also expect to contribute design methodologies specifically for children with chronic health conditions.

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7. **REFERENCES**


