Design Considerations for Family-Centered Health Management: Preliminary Findings with Pediatric BMT Patients

Ji Youn Shin

University of Michigan
Ann Arbor, MI 48109, USA
shin jy@umich.edu

Jacob Kedroske

University of Michigan
jkedrosk@umich.edu

Rebecca Vue

University of Michigan
rebvue@umich.edu

Roshun Sankaran

University of Michigan
roshuns@umich.edu

Dima Chaar

University of Michigan
dimac@umich.edu

Tracey Churay

University of Michigan
tchuray@med.umich.edu

Sung Won Choi

University of Michigan
sungchoi@med.umich.edu

Abstract

Blood and marrow transplantation (BMT) is an intensive therapy for patients with life-threatening hematologic cancer as well as non-cancer diagnoses. Children, adolescents and young adults undergoing BMT (“pediatric patients”) experience intensive medical procedures during their treatment and post-treatment recovery phases. We conducted a field study to identify common barriers that interfere with pediatric patient engagement in the management of their health and challenges that caregivers confront. Our study revealed four main factors. By exploring emerging themes, we suggest design opportunities for health technology to support patients and their caregivers over the course of long-term outpatient management.

Author Keywords

Interaction design; patient-centered care; pediatric BMT; health information technology (HIT)

ACM Classification Keywords

CCS → Human-centered computing → Human computer interaction (HCI) → HCI design and evaluation methods → Field studies

Permission to make digital or hard copies of all or part of this work for personal or classroom use is granted without fee provided that copies are not made or distributed for profit or commercial advantage and that copies bear this notice and the full citation on the first page. Copyrights for components of this work owned by others than ACM must be honored. Abstracting with credit is permitted. To copy otherwise, or republish, to post on servers or to redistribute to lists, requires prior specific permission and/or a fee. Request permissions from Permissions@acm.org.

IDC '18, June 19–22, 2018, Trondheim, Norway

© 2018 Association for Computing Machinery.

ACM ISBN 978-1-4503-5152-2/18/06...\$15.00

<https://doi.org/10.1145/3202185.3210781>

Study Setting:

We conducted a field study in pediatric BMT units of a major academic health system (Michigan Medicine). The pediatric BMT team at Michigan Medicine performs approximately 50 BMTs annually in patients with age ranging 0–25 years. BMT is an intense treatment for many hematologic cancer and non-cancer conditions, requiring long-term follow up of at least 5-years after the BMT procedure.

Code	Age	Gender	Caregiver
PT 01	2	M	Mother
PT 02	1<	F	Mother
PT 03	20	F	Mother
PT 04	17	M	Mother
PT 05	16	M	Mother
PT 06	4	M	Mother
PT 07	2	M	Mother/ Grandmother
PT 08	11	F	Grandmother
PT 09	15	M	Father
PT 10	18	M	Mother
PT 11	13	M	Brother
PT 12	2	M	Mother
PT 13	25	M	Wife
PT 14	21	M	Mother/Father
PT 15	6	M	Mother
PT 16	4	M	Mother
PT 17	16	M	Mother
PT 18	11	F	Grandmother
PT 19	14	M	Mother
PT 20	5	F	Mother
PT 21	8	M	Mother

Table 1: Characteristics of study participants (PT: patient)

Introduction

Diagnosis with a life-threatening, childhood hematologic condition is not only an overwhelming experience for patients, but also for their family members. In the pediatric context, the caregiver often takes primary responsibility for illness management rather than a shared responsibility with the patient [5]. Since parents usually take responsibility as a caregiver, parents of pediatric patients are required to take on new rhythms of their everyday life [4]. These adjustments often involve dealing with multi-faceted medical care, including management of activities of daily living (ADLs), medications, and central line care, or transportation on behalf of patients. Often, caregivers become overwhelmed by the complex medical treatment plan and their subsequent caregiving tasks, particularly in the BMT setting [4]. Nonetheless, very few studies have been conducted on family-centered interventions in pediatric BMT, particularly in the outpatient setting. To examine design opportunities from the view of pediatric patients and caregivers on family-centered health management, we conducted a field study. Our study focused on understanding perspectives of both the pediatric patient and their caregiver in managing patient healthcare in the outpatient setting.

Background and Related Work

As health technology continues to rapidly develop and adopt within healthcare systems, patient and caregiver uptake of technology is actively being examined in the clinical environment. Patients and caregivers can take charge of health information, including tracking symptoms or scheduling medical appointments with health technology [9]. Over the last several years, researchers have begun to study the needs of

supporting families of patients with chronic illness [2,6]. Although studies have demonstrated improved outcomes when families have a shared sense of responsibility [1,7], there remains paucity of data supporting interventions for pediatric patients and family caregivers in the outpatient setting. There is lack of research on delivering health information in an age-adjusted manner through interactive patient engagement systems. Existing interventions are mainly used by caregivers and infrequently used by children. Consequently, pediatric patients are not routinely provided with appropriate information, skills, and confidence to understand health information or their medical issues [3]. These limitations lead to passive participation of pediatric patients in their healthcare [8]. Appreciating the potential strength that technology plays in the chronic care context, approaches through a family-centered lens that alleviate caregiver burden and promote engagement by the pediatric patient are urgently needed.

Study*Data collection*

We conducted field observations and semi-structured qualitative interviews. The goal of these observations and interviews was to gather in-depth understanding of pediatric patient participation, and caregiver roles and experiences of the BMT treatment process in the outpatient setting. We observed patients and caregivers in outpatient clinic rooms. Although our primary focus was on outpatient management, we also conducted inpatient observations to gather BMT patient experiences of the initial hospitalization. We observed patients and caregivers communicating medical information with their healthcare team. In total, approximately 40 hours of observation were conducted.

Data analysis: Data were collected through handwritten notes during observations, and interviews were recorded and professionally transcribed verbatim. The study team met regularly to discuss preliminary findings and to define emerging issues from transcripts and field notes. Two members of the study team analyzed the collected data using affinity clustering. Each researcher independently identified significant concepts and removed discrepancies by re-evaluating findings. Identified themes from observations and interviews were repeatedly discussed among all study team members as insights continuously emerged from ongoing field study collection. After multiple iterations of affinity clustering and discussions, we narrowed our focus to four main themes. As the study is currently ongoing, we report preliminary findings of both observations and interviews resulting from our analyses and discussion.

Each observation session lasted approximately two to three hours. We observed 15 patients and 15 caregivers. We also conducted 6 semi-structured interviews with caregivers. Interview questions for caregivers were designed with the goal of examining caregiver perceptions and experiences in managing their children's illness as well as their own health. Ethical approval was obtained by the University of Michigan Institutional Review Board (IRB number HUM00115569).

Overall Findings

(1) Patient's lack of ownership of their health

We found that a majority of caregivers speak on behalf of the patients. When clinicians asked questions regarding the patient's status, they often faced the caregiver; in turn, the caregiver initiated all responses while patients continued with their own activity. Although clinicians directed questions to the patient, we frequently found that patients looked to the parent to answer the question on their behalf. At the end of the encounter, patients were routinely asked if they had questions regarding their healthcare, but very few patients asked questions or provided any additional information. This issue led us to consider providing information about clinical trials for which pediatric patients are currently enrolled in or other routine health maintenance (e.g., vaccination schedule post-BMT) in age-adjusted text and visual components to further engage them during clinic visits.

(2) Limited access of information in clinical settings for both patients and caregivers

Patients and caregivers spend approximately an hour during their outpatient BMT clinic appointment and are seen by a medical assistant, nurse, nurse practitioner,

and physician. With each interaction, patients and caregivers receive medical information (e.g., height/weight, vitals, laboratory results, medication instructions, treatment changes). In addition, patients and caregivers are asked to provide updated information of their clinical status since the last clinic visit. During the conversation, clinicians view updated medical information of the patient in the EMR (Electronic Medical Record) in real-time. However, patients do not have access to these informational resources other than verbal instructions provided by clinicians in the clinic room (Figure 2). While some caregivers had their own note-keeping system to track and monitor health information, many rarely reviewed their notes from the prior clinic visit. This issue allowed us to consider how to provide customizable ways for patients and caregivers to keep track of and address patients' needs (e.g., symptom tracker, graphs of laboratory results over time).

(3) Changes in family routine with new restrictions

The day-to-day lives of patients and caregivers who participated in this study were challenged by frequent changes in medication dose/schedule or side effects, nutrition or other ADLs. Thus, we were interested in understanding how the BMT process impacted family dynamics. During our interview, caregivers reported a drastic change in their lives from before- and after-BMT. For example, PT18's caregiver shared the challenge of keeping track of time-sensitive medications: "At one time she was on 60 some medicines, plus IVs. I had to manage all of that. I would never have known a long time ago that I could do it, but I do. I administer all that to her... after she got sick our whole life changed. Not only our home, because it was set up like a hospital room when she

Figure 1: Many patients were occupied with technology-mediated activities during clinic visits

Figure 2: Patients did not have access to informational resources

was home, finances were different. We didn't know what our house looked like, did we?" These reported challenges led us to consider design guidelines for family members to share caregiving information among one another and with patients and empowering patients to "self-manage."

(4) *Psychological burden*

Many caregivers reported feeling physical and mental burden, including difficulties of seeing their loved ones "suffer." Outwardly expressing any negative emotion was not considered acceptable because of its potential adverse impact on the patient's emotional status. PT17's caregiver shared how she carried her burden: "Try to be focused. When seeing your children go through something this traumatic, it's wear tear on you, just try to remember to be strong and to look for support of family, friends, church, whoever can be a support. Stay focused because your child, or children need you. If they see you fall apart then they'll fall apart, so you have to be strong. Put aside your feelings and emotions in front of them and be there for them." Caregivers put their own issues aside, and focus on providing appropriate care for their loved one, which may ultimately impact their own physical and mental health outcomes. Even though all caregivers reported psychological burden due to the overwhelming tasks, none of them were regularly engaged in mental wellness programs provided by the hospital or their regional community due to limitation of time and resources. This allowed us to consider novel ways to alleviate caregiver burden through use of technology-mediated self-care rather than face-to-face support sessions.

Design Considerations

(1) An overview of each clinic visit for patients

As noted in the "Overall Finding" section, patients were often engaged in non-health-related activities, rather than actively participating in discussions of their healthcare with caregivers and clinicians. Many patients were occupied with technology-mediated activities during clinic visits (e.g., watching videos, playing games on a tablet or smartphone). When conversations between clinicians and caregivers increased in length, patients would request digital devices from their caregivers. Indeed, many caregivers commented that their children frequently used technology-mediated devices. However, we discerned that technologies seem to function as a distraction, rather than a tool for educational engagement in clinical settings. Based on these factors, we suggest a module that provides an overview of each clinic visit with the use of cartoons and/or characters. When patients arrive at the outpatient clinic, they could launch the app and log into their account. At the beginning of the clinic visit, they could choose a character to reflect their current "mood" or clinical status. Clinicians could then inquire why he/she chose that particular character. On this app, patients could be informed of their upcoming treatment procedure or could have access to educational resources that describe a particular treatment.

(2) Tracking and sharing information

From our field study, it is apparent that verbal interactions were the primary means of communication. Patients verbally received health information from their healthcare team and also reported multiple status changes that occurred between clinic visits. Several caregivers asked to see a visual representation of the lab results. In response, the clinicians turned their

Design overview: We suggest design guidelines with an over-arching aim of engaging both pediatric patients and their caregivers as active participants in their healthcare. On the pediatric patient-side, we mainly focused on fostering communication with their healthcare team; meanwhile, on the caregiver-side, we focused on providing ways to relieve their burden, self-care, and to share responsibility among family members. In “Design Considerations” section, we highlight four particular themes (modules) in which we see opportunities to design a web-based application to better support these goals. Using their own digital devices, such as laptop, smartphone, or tablet, patients and caregivers could easily access their account on an app either at home or in the hospital, as needed.

respective computer monitors for them to see. However, other caregivers relied on verbal information from their care team. Undocumented information was difficult to recall for caregivers, especially since many patients were seen at different units within the hospital or even at other health institutions, as they likely required multiple consultations from various specialists. As a result, if a patient’s case was complex, caregivers were in charge of organizing and tracking each of these visits. With an app, users could track patient symptoms, consult visits, or medications. The app could provide a convenient way to store and exchange information, and at follow-up visits, caregivers could more accurately report updates to the healthcare team.

(3) Shared goal and caregiving information

A frequently reported concern from caregivers was how the family could efficiently adapt to newly-implemented routines for patient health and well-being. We suggest a design module that allows family members to log into an account and share caregiving information with other family members. On each day, a family member could set a significant health goal or requirement for the patient. To that end, a reminder could pop-up regularly before the task was completed. For example, primary caregivers could be reminded in a timely manner to give a specific medication to the patient. With notifications of certain medications that patients need to take, patients and caregivers would both be informed. This could also encourage effective communication between patients and caregivers. When patients are away from home, including when they are at school, patients could simply push icons to make sure they have taken certain medications. With this module, the burden of remembering all of the medical

requirements and when they would be conducted could be lifted off the primary caregiver.

(4) Wellness support

Most caregivers interviewed expressed interest in participating in mental wellness programs, but due to various reasons, could not attend these events at the hospital or in the local community. One of the commonly stated reasons was time constraint. Many families lived too far away and did not have enough time to visit the hospital and to also attend support programs. With this module, both caregivers and patients could input their current mood status into the app and receive recommendations of different quick, easy-to-do and stress-relieving activities. For example, with a positivity quote in the morning and night times, the day could begin with a reminder stating that better days are ahead. These quotes could have the potential to provide caregivers and patients strength to carry on.

Discussion and Future Work

Our study has limitations that should be noted. The work is currently in progress and the findings reported herein are based on a relatively small number of participants at a single-institution. Nonetheless, we focused on a highly intense disease setting (pediatric BMT). We expect to enroll additional participants in, which may enable us to generalize our findings to a broader population of those with chronic care conditions. We understand that patient and caregivers needs change across the course of illness (e.g., diagnosis, active treatment, post-treatment, survivorship). We hope to broaden the scope of our follow-up studies with focus on these varied time points across the disease trajectory. In this study, we

Figure 3: A module of different quick, easy-to-do and stress-relieving activities, such as coloring, origami, baking, and gardening

Figure 4: On this app, patients could be informed of their upcoming medical procedure or could have access to educational resources that describe a particular treatment

captured barriers faced by patients in actively participating in their healthcare, and factors that potentially contribute to caregiver burden in the pediatric BMT setting for which technology-mediated approaches may address. Our findings provide design considerations in the development of an app with a family-centered focus. For next steps, we plan to develop a low-fi prototype based on design considerations, and to conduct usability tests. As current design ideas are not tailored to specific ages, we expect to develop multiple levels of contents for our prototype. Understanding the potential strength that technology plays in the healthcare context, user-centered design approaches that alleviate caregiver burden and promote engagement by the pediatric patient remain imperative.

References

1. Kenneth Haggerty, Borchuluun Yadamsuren, Francis Kibaru, and Josipa Basic. 2013. Children's information needs of a patient engagement system in a hospital room: Insights from usability testing in a simulation laboratory. *Proceedings of the Association for Information Science and Technology* 50, 1: 1–5.
2. Matthew K. Hong, Clayton Feustel, Meeshu Agnihotri, Max Silverman, Stephen F. Simoneaux, and Lauren Wilcox. 2017. Supporting Families in Reviewing and Communicating about Radiology Imaging Studies. In *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems*, 5245–5256.
3. Matthew K. Hong, Lauren Wilcox, Daniel Machado, Thomas A. Olson, and Stephen F. Simoneaux. 2016. Care partnerships: Toward technology to support teens' participation in their health care. In *Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems*, 5337–5349.
4. Elizabeth Kaziunas, David A. Hanauer, Mark S. Ackerman, and Sung Won Choi. 2015. Identifying unmet informational needs in the inpatient setting to increase patient and caregiver engagement in the context of pediatric hematopoietic stem cell transplantation. *Journal of the American Medical Informatics Association* 23, 1: 94–104.
5. Laura MJ Kerr, Margaret B. Harrison, Jennifer Medves, Joan E. Tranmer, and Margaret I. Fitch. 2007. Understanding the supportive care needs of parents of children with cancer: An approach to local needs assessment. *Journal of Pediatric Oncology Nursing* 24, 5: 279–293.
6. Molly Maher, Elizabeth Kaziunas, Mark Ackerman, Holly Derry, Rachel Forringer, Kristen Miller, Dennis O'Reilly, Larry C. An, Muneesh Tewari, David A. Hanauer, and others. 2016. User-Centered Design Groups to Engage Patients and Caregivers with a Personalized Health Information Technology Tool. *Biology of Blood and Marrow Transplantation* 22, 2: 349–358.
7. Laura R. Pina, Sang-Wha Sien, Teresa Ward, Jason C. Yip, Sean A. Munson, James Fogarty, and Julie A. Kientz. 2017. From Personal Informatics to Family Informatics: Understanding Family Practices around Health Monitoring. In *CSCW*, 2300–2315.
8. Hyunsook Shin and Rosemary White-Traut. 2005. Nurse-child interaction on an inpatient paediatric unit. *Journal of advanced nursing* 52, 1: 56–62.
9. Meredith Skeels and Desney S. Tan. 2010. Identifying opportunities for inpatient-centric technology. In *Proceedings of the 1st ACM International Health Informatics Symposium*, 580–589.