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Assessing Needs and Experiences of Preparing for Medical Emergencies Among Children with Cancer and Their Caregivers

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Abstract

BACKGROUND: Caregivers of children with cancer can experience stress when seeking care in the emergency department. We sought to assess how caregivers prepare for and manage a medical emergency that arises in the community setting.

PROCEDURE: A qualitative evaluation of emergency department (ED) visit preparations taken by children with cancer and their caregivers using self-reported interactive toolkits. Eligible participants included children with cancer (age 11 – 21) currently receiving therapy for a cancer diagnosis with an ED visit (besides initial diagnosis) within the previous 2 months and caregivers of same. Participants received a paper toolkit, which were structured as experience maps with several generative activities. Toolkits were transcribed, thematically coded, and iteratively analyzed using NVivo 12.0 software.

RESULTS: A total of 25 toolkits were received (7 children, 18 caregivers), with about three-quarters of participants living greater than 1 hour from the treating institution. Several important common themes and areas for improvement emerged. Themes included struggles with decision-making regarding when and where to seek ED care, preparing to go to the ED, waiting during the ED visit, repetition of information to multiple providers, accessing of ports, and provider-to-provider and provider-to-caregiver/patient communication.

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Conflict of Interest

The authors have no conflicts of interest to disclose.

CONCLUSION: The information gained from this study has the potential to inform a tool to support this population in planning for and managing emergent medical issues. This tool has the potential to improve patient and caregiver satisfaction, patient centered outcomes, and clinical outcomes.

Keywords

Emergency department; Healthcare utilization; Childhood cancer; Mobile health technology

BACKGROUND

Children with cancer have high emergency department (ED) utilization and require evaluation and management in the ED for a variety of reasons.^{1,2} Currently there is little medical literature that focuses on the full experience of children with cancer with medical emergencies in the community setting. This gap in the literature has been recognized by the National Cancer Institute (NCI) and the National Institutes of Health (NIH) Office of Emergency Care Research.³ This aspect of care is important because unexpected medical emergencies can be stressful and even traumatic for both patients and their caregivers.^{4,5}

Based on our clinical experience and recent study, we appreciate that children with cancer and their caregivers encounter many barriers to optimal care when preparing for and then seeking care in the ED.⁶ First, most newly-diagnosed pediatric cancer patients were previously healthy and unlikely to have experienced serious medical issues. Consequently, caregivers may be unfamiliar with navigating the healthcare system, especially when medical emergencies arise. Secondly, caregivers may not fully understand or know their childrens' current therapies, making it difficult for them to prepare for and relay this information to emergency care providers. Third, and perhaps most important, caregivers may not fully recognize the serious complications that can occur among children with cancer. For example, a fever that would be managed at home for a healthy child may—for a child with cancer—be a sign of a serious bacterial infection needing immediate medical evaluation and treatment.^{7,8,9} Our previous evaluation of important outcomes to children with cancer and their caregivers when they seek care in the ED revealed that they desired a way in which to improve their sense of preparedness.⁶

One way in which we believed we could support caregivers in their need to feel more prepared for when medical emergencies arise is through a mobile health (mHealth) technology tool. A mHealth tool could enable caregivers to become more efficient, effective, safer, and less stressed while managing their childrens' care.¹⁰ While patient portals¹¹ or care management plans have successfully allowed caregiver access to patient information,^{12,13} they were not designed to assist with planning for when medical emergencies arise in the community setting. We believe that the ideal mHealth tool will require input from all key stakeholders including children with cancer and their caregivers as well as the medical team. The purpose of this exploration was to engage specifically with children with cancer and their caregivers to reveal important elements of medical emergency preparedness. This information will be incorporated into the creation and refinement of a mHealth tool to improve preparedness for when medical emergencies arise in the community setting. This

tool has the potential to improve patient and caregiver experience,^{14, 15} patient centered outcomes, and clinical outcomes for children with cancer and their caregivers when seeking care in the ED for unexpected and emergent medical needs.

METHODS

Participants and Procedure

Study participants were recruited from Indiana University (IU) Riley Hospital for Children Hematology-Oncology clinic, which serves approximately 85–90% of Indiana children diagnosed with cancer. Eligible participants were identified through a daily clinical update list of children who had recently visited an ED. Our current institutional practice is for children to be evaluated for medical emergencies at an ED within 1 hour of their current location. Further eligibility was evaluated through a combination of medical chart review, discussion with the patient's primary oncology team, and verification of criteria with the participant. Demographic data was not collected from the child or caregiver participants, but we were able to obtain the child's age, gender, date of diagnosis, and home address from the medical record. The IU Institutional Review Board and IU Simon Cancer Center Scientific Review Committee reviewed and approved the study.

Participants were either caregivers of children with cancer or children with cancer between the ages of 11–21 with the following eligibility criteria: (1) participants had adequate English-language proficiency with grossly normal cognitive function, (2) the child was currently receiving cancer therapy at Riley Hospital for Children, and (3) the child had visited an ED within the last 2 months while on treatment for their cancer (i.e., not initial diagnosis visit). Those patients whose therapy was predominantly inpatient (e.g., Acute Myelogenous Leukemia or those undergoing Stem Cell Transplant) or those receiving hospice-directed care were excluded since the goals of care in the ED setting are different than those of therapies with curative intent. Potential participants were contacted by phone if they had been discharged from the ED or were approached on the inpatient unit if admitted. Recruitment was allowed for caregivers and children with cancer as dyads or as individuals.

We utilized a paper toolkit to explore the important elements of planning for medical emergencies and management for children with cancer and their caregivers. We chose the toolkit format because it allowed patients and caregivers from across Indiana to participate without traveling to Indianapolis. Consented participants received a paper toolkit, which included the activities described below (see Supplemental File). Participants were not required to work on the toolkits alone, although it was explained to caregiver/patient dyads that two separate viewpoints on the same experience was helpful. The toolkit was designed using methods grounded in human-centered design, which focuses on designing products and services through direct involvement with stakeholders.¹⁶ Completed toolkits were either mailed back using a self-addressed and stamped toolkit cover or collected by research staff.

Toolkit Contents

Experience Mapping for understanding “what is”—The first and largest part of the toolkit was an experience map with detailed prompts to help participants share their

planning for medical emergencies experiences step-by-step. An experience map is a visual tool traditionally used to represent the aggregate findings from research into peoples' experiences of a product or service going "from point A to point B as they attempt to achieve a goal or satisfy a need".^{17,18,19} Our experience map was anchored by six steps in the planning journey: 1) the patient experiencing symptoms at home, 2) preparing to leave for the ED, 3) deciding which ED to go to, 4) checking in, 5) waiting to be evaluated, and 6) evaluation and management by an ED provider. For each step, participants were asked about events that occur from their perspective, individuals they interact with, what tools were utilized, and the participants' thoughts/feelings. Within the experience map points, content was elicited using various methods, which are presented in Table 1.

Generative projective exercises for understanding "what could be"—The last section of the toolkit consisted of a series of activities based on projective generative research, which asks participants to engage in "expressive exercises" to articulate thoughts, feelings and desires that are difficult to communicate through more conventional means.²⁰ The first activity asked participants to reflect on their experiences in the ED, then respond to a series of questions about how they would improve them, including: "If you could change one thing about your experience in the ED, what would it be and why? What would help you be more prepared for the ED? What would help the ED be more prepared for you/your child?" Finally, in the Blue-Sky Drawing activity, participants were prompted to imagine they had unlimited resources to create a tool to improve the ED experience, then they were asked to draw the tool and describe it. This method allowed us to uncover additional, latent needs and desires that might not yet have been revealed previously as well as inspirational ideas and "rich information for concept development".²⁰

Data Analysis—Each toolkit was transcribed and analyzed using an iterative organizational style template as described by Crabtree and Miller.²¹ This style of interpretation involves: (1) creating a coding scheme, (2) hand or computer coding text, (3) sorting segments to group similar texts into themes, and (4) making connections within and between segments that are later corroborated with another researcher.²¹ Toolkits were transcribed and uploaded into NVivo 12 (QSR International). The initial codebook was developed iteratively by four members of the team (ELM, ARC, CMM, KBJ) using four toolkits with a high rate of activity completion. Initial themes were generated and then collapsed to form key themes in order to organize and understand the data as previously described.²² The initial codes were then added to NVivo and two team members (CMM and ARC) independently coded all 25 toolkits using this initial codebook. Codes were added, changed, and rearranged as needed to capture ideas not represented in the initial set of codes and further refined as new information and meanings emerged. These two coders then met to discuss their individual coding and decide on a final set of codes. Finally, the final set of codes were presented to the entire team for discussion, refinement, and final approval.

RESULTS

Study participants were recruited between April and May 2018. A total of 40 eligible participants agreed and were mailed toolkits, 25 of which were completed and returned (a 63% response rate). A total of 7 toolkits were completed by a child with cancer (range 13–

18 years, 4 female and 3 male). The remaining 18 toolkits were completed by a caregiver; eight by a caregiver of a child 10 or younger (range 1–9 years) and ten by a caregiver of a child 11 or older (range 11–18 years). A total of 6 dyads participated in the study. The children in this study population were primarily white, non-Hispanic, had Acute Lymphoblastic Leukemia, and lived more than an hour drive from their treating institution. Demographic statistics of child participants and caregiver participants' children are presented in Table 2. Respondents were from diverse locations throughout Indiana, with 18 respondents (72%) living an hour away or more from Riley Hospital for Children and 7 (28%) living within one hour.

Several important themes arose: decision-making surrounding when and where to seek ED care, preparing to go the ED, waiting during the ED visit, repetition of information to multiple providers, accessing of ports, and communication within and between providers and caregivers/patients. Representative quotes from caregivers and children with cancer for each theme are demonstrated in Table 3.

Decision-making surrounding when and where to seek ED care

Fever was the main symptom caregivers evaluated and monitored while deciding whether or not to visit the ED. Participants provided a variety of answers when asked what temperature would prompt a visit to the ED, but the mode was 101°F (range 100.4–103°F). Other symptoms of concern included lack of consciousness, unresponsiveness, or trouble breathing. Some participants mentioned specific written guidelines their oncology team had given them. Others reported that if they were unsure about whether or not to go to the ED right away, they would call the on-call number their oncology team had given them.

Participants lived between 30 minutes and 3 hours from their preferred ED and between 5 and 30 minutes from their local ED. Many caregivers and patients preferred to avoid the local ED and go instead to their treating institution whose staff they were familiar with and trusted. Many participants had encountered what they perceived as a lack of expertise and poor cancer care at their local ED. In particular, they expressed concern that the local ED did a poor job accessing ports and did not understand how important it was for cancer patients to be protected from infection exposure.

Preparing to go to the ED

Participants listed the steps they take and items they gather before beginning their journey to the ED. These are listed in Table 4. The most common task was to gather items and pack and the most common items brought were clothes and toiletries.

Caregivers commented about the need to contact others for help or coordination before leaving for the ED. They primarily identified contacting family members such as their spouses or the patients' grandparents. Some notified others in their community, such as a neighbor or the child's school. Caregivers often needed to arrange care for the patient's siblings. Sometimes this involved deciding which parent which would go to the ED and which would stay home with siblings. In other instances, siblings were taken to stay with grandparents. One caregiver mentioned arranging transportation to get a sibling home after school. Also, multiple participants mentioned needing to complete pet care tasks before

leaving for the ED. Participants also listed tasks related to securing their home, such as turning off the stove and locking their home before departure. Lastly, participants listed applying numbing cream to the patient's port and arm before leaving for the ED to ensure their child's comfort during forthcoming port access.

Waiting during the ED visit

There were several important concerns raised about waiting in the ED. Caregivers expressed concern about the potential for their immune-compromised children to contract infections from people in the waiting room. Many caregivers wrote about immediately notifying reception staff of the child's cancer diagnosis and asking for access to a private room. Participants noted that at some hospitals, the front desk staff had protocols for getting cancer patients into treatment rooms faster.

One caregiver reported refusing to allow her child to use the fingerprint scanning technology at check-in because of concerns of child picking up germs from touching the scanner. Many caregivers also ensured their child always wore a mask in the waiting room with preference for the "good green masks." Both caregivers and patients mentioned that waiting—whether in the waiting room or once in a private room—was unpleasant. It was often long and the chairs and beds are often uncomfortable. Caregivers commented that they were not comfortable leaving their child alone to step away and use the bathroom or get food. In the blue-sky drawing activity, two of the patients created tools that provided food.

Also, participants expressed that uncertainty and lack of distraction makes waiting difficult to tolerate. Two participants (one patient and one parent) sketched tools for helping patients track their progression through the ED and how much time was left. One participant envisioned an app that helps patients track their progress through the ED and provides entertainment during travel and wait times (see Figure 1).

Repetition of Information to Multiple Providers

Caregivers were asked to share their child's diagnosis, treatment, and symptoms repeatedly: during phone consultation with an oncology provider, during triage at the ED, when evaluated by nursing in the ED, and when they were seen by the ED provider. They expressed frustration at having to repeat themselves and perceived that staff were not communicating with each another.

When participants were asked to envision a tool that could improve their experience in the "Blue-sky Drawing" section, many participants included features to access medical history and track symptoms.

Accessing of Port

Port access was mentioned heavily in the toolkits. Participants were concerned about whether or not staff would be able to access the patient's port efficiently and effectively, with the proper needle, and with proper sterile preparation. Participants perceived that local ED's could not access ports and, for this reason, families would travel further to reach their treating institution. Some families even reported bringing their own port needle in the event

the local ED did not have the right size available. Even at their treating institution, some participants experienced port access issues with ED staff who were not oncology specialists.

Communication within and between providers and caregivers/patients

About half (N=12) of participants indicated contacting the on-call physician at their treating institution to alert them about the clinical situation and which ED they were planning to visit with the expectation that the on-call oncologist would contact the ED and provide medical guidance. Families appreciated the ability to do this because it provided them peace of mind and helped them navigate the ED setting more efficiently. The final functionality that was suggested for the “ideal tool” was the ability to check in prior to seeking care so that ED staff could prepare for their arrival.

DISCUSSION

In this qualitative inquiry, we explored the planning experience of children with cancer and their caregivers when a medical emergency arises in the community setting. We uncovered several important themes, including the initial decision-making aspects of planning and the multiple steps caregivers must take prior to seeking care in the ED. In addition, we uncovered perceived obstacles experienced upon arrival in the ED, including long wait times to receive information or be evaluated by the ED provider, the need to repeat information multiple times, the stress associated with port access, and inadequacies in provider-to-provider and provider-to-caregiver/patient communication. The information gathered in this study will be incorporated into our larger project to design and refine a mHealth technology tool to support caregivers in planning for when their child with cancer has a medical emergency arise in the community setting. By keeping stakeholders’ beliefs and needs at the forefront of this endeavor, this type of tool has the potential to improve the caregiver’s sense of preparedness, streamline the medical evaluation and treatment of children with cancer, and improve objective clinical outcomes.

One of the key components to planning for medical emergencies was decision-making around when and where to seek evaluation. We must remember that most pediatric oncology providers are trained in telephone triage and are aware of the potential pitfalls that come with the inability to physically assess the child. Yet, caregivers are thrust into this role with very little guidance and minimal practice. Therefore, they can experience uncertainty about whether medical evaluation is necessary. For those who live further away from their treating institution, they must also determine whether to be seen at a local ED,²³ which is less familiar with pediatric oncology,^{1-2, 24} or to take a longer drive to be seen at their treating institution. There can be significant risk in attempting to make it to a hospital farther away with a child whose condition can deteriorate quickly. Caregivers must weigh their own preferences, their fears about poor care in the local ED, their child’s current status, and the distance to each ED to make a decision. This is complicated further by variation both by institution and between providers as to whether they recommend evaluation locally or travel to the treating institution.²⁵ Many of the participants in this study utilized triage calls with oncology providers and most viewed these points of contact as helpful in the decision-making and management of their child’s emergent medical issue. Decision-making support

could be built into a mHealth tool through an algorithm that walks caregivers through the appropriate actions and steps for the most commonly experienced medical emergencies.

Another important but under-appreciated element of planning reported by caregivers is that preparing to seek care in the ED is a multi-step process. Caregivers in this study described a wide range of tasks they must complete and items they must gather and pack before they are ready to leave their home and seek care in the ED. The ability to quickly accomplish these tasks are likely dependent on the support structures available to them including the number of other dependents under their care, family and community support, and their access to reliable transportation. Based on our recent survey of caregivers, we know that the vast majority of caregivers of children with cancer use a smartphone and about 86% desired a mHealth tool to support them in the medical management of their child.²⁶ Therefore, a mHealth tool could aid them by providing a customizable checklist for items to bring and tasks to complete prior to leaving for the ED. The checklists could be pre-populated with the most commonly found items and tasks found during this investigation, but have the ability to be adjusted for each individual patient/caregiver needs. It could also aid in communicating the need for support to family members or friends through pre-planned text messaging or emails. Previous work has shown that a mHealth tool developed with the input of children with cancer and their caregivers can be well-received and useful part of emergency planning, thereby increasing the amount of control a family has over a situation.²⁷ It will be important to also ensure the app is created in a manner that is efficient for all caregivers and addresses the needs of those in all levels of health consciousness and health literacy.²⁸⁻³⁰

Participants expressed that once in the ED, they experienced concern and frustration about waiting, repeating information, and poor communication. Most caregivers are not medically trained but have been taught that timely evaluation and management are important; waiting for their child to be evaluated and to receive laboratory or imaging results can lead to increased stress. A concise summary of pertinent information about their child that they can present to medical providers throughout the journey might ease the burden of recalling and repeating consistent, accurate information each time. This medical summary and expectations for an ED encounter could be incorporated into a mHealth tool, providing caregivers with easy and reliable access to the information they need as they seek care for emergent medical needs. In order to ensure we are capturing the medical summary details that are most important to oncology and ED providers, the next step should be to engage with providers to assess key details to be incorporated into the mHealth tool.

As part of our overall plan to create a prototype for the planning for emergencies mHealth tool, we are currently engaging with oncology providers and emergency department providers and nurses to gather the medical team perspective. The input from all key stakeholders will then be incorporated into a prototype to be evaluated and refined through further interviews with caregivers of children with cancer.

Limitations

This study was performed at a single institution so may not represent the experience of all children with cancer and their caregivers. Also, the participants were mostly caregivers of patients with leukemia who were in maintenance therapy, therefore we may have missed key

features desired by caregivers of other disease processes or those who are earlier on in therapy. Also, there were only 7 patient participants in our study, therefore we did not attempt to separate the content of their responses as they tended to be shorter responses with less details than their caregivers. We only included English speaking participants, but it is important for future research to focus on non-English speaking caregivers since they may experience more barriers to seeking care than were identified in this study. Yet, we were able to capture participants who were located throughout the state, and therefore include those who are geographically near and some far from their treating institution. A toolkit approach does not allow for probing questions to clarify or understand more deeply the intent/motivation of a particular response; however, our toolkit elicited responses through multiple means to capture a well-rounded view. This is an opportunity for future research to build on the framework developed as part of this initial work.

Conclusion

We have identified key components of planning for medical emergencies that a mHealth tool could address to support caregivers of children with cancer when medical emergencies arise in the community setting. The mHealth tool must help with decision making, communication with the oncology team, preparations to leave to seek care, and communication within the ED. The creation of this tool will need to include input from a more diverse population of caregivers including those at other institutions and with a variety of types of cancer. This tool has the potential to improve caregiver and patient satisfaction as well as patient-centered and clinical outcomes for children with cancer when medical emergencies arise in the community setting.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Data Availability Statement

The data that support the findings of this study are available from the corresponding author upon reasonable request.

Abbreviations:

ED	Emergency department
mobile health	mHealth
NCI	National Cancer Institute

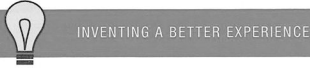
NIH

National Institutes of Health

References

1. Mueller EL, Sabbatini A, Gebremariam A, et al. Why pediatric patients with cancer visit the emergency department: United States, 2006–2010. *Pediatr Blood Cancer* 2015;62(3):490–495. 10.1002/pbc.25288 [PubMed: 25345994]
2. Mueller EL, Hall M, Shah SS, et al. Characteristics of Children With Cancer Discharged or Admitted From the Emergency Department. *Pediatr Blood Cancer* 2016;63(5):853–858. 10.1002/pbc.25872 [PubMed: 26713542]
3. Greene Jan. CONCERN for Cancer: New National Institutes of Health Network to Focus on Cancer Patients in the Emergency Department. *Annals of Emergency Medicine* 2015;66(1):A13–A15. 10.1016/j.annemergmed.2015.05.015
4. Rodriguez EM, Dunn MJ, Zuckerman T, et al. Cancer-related sources of stress for children with cancer and their parents. *J Pediatr Psychol* 2012;37(2):185–197. 10.1093/jpepsy/jsr054 [PubMed: 21841187]
5. Patino-Fernandez AM, Pai AL, Alderfer M, et al. Acute stress in parents of children newly diagnosed with cancer. *Pediatric blood & cancer* 2008;50(2):289–292. 10.1002/pbc.21262 [PubMed: 17514742]
6. Mueller EL, Cochrane AR, Lynch DO, Cockrum BP, Wiehe SE. Identifying patient-centered outcomes for children with cancer and their caregivers when they seek care in the emergency department. *Pediatr Blood Cancer* 2019 10;66(10):e27903. doi: 10.1002/pbc.27903. Epub 2019 Jul 16. [PubMed: 31309720]
7. Bodey GP, Buckley M, Sathe YS, et al. Quantitative relationships between circulating leukocytes and infection in patients with acute leukemia. *Ann Intern Med* 1966;64(2):328–340. 10.7326/0003-4819-64-2-328 [PubMed: 5216294]
8. Freifeld AG, Bow EJ, Sepkowitz KA, et al. Infectious diseases society of America: clinical practice guideline for the use of antimicrobial agents in neutropenic patients with cancer: 2010 update by the infectious diseases society of America. *Clin Infect Dis* 2011;52(4):e56–93. 10.1093/cid/cir073 [PubMed: 21258094]
9. Pizzo PA. Management of fever in patients with cancer and treatment-induced neutropenia. *N Engl J Med* 1993;328(18):1323–1332. 10.1056/NEJM199305063281808 [PubMed: 8469254]
10. National Alliance for Caregiving. e-Connected Family Caregiver: Bringing Caregiving into the 21st Century 2011. http://www.caregiving.org/data/FINAL_eConnected_Family_Caregiver_Study_Jan%202011.pdf. Accessed October 1, 2018.
11. Kruse CS, Bolton K, Freriks G. The effect of patient portals on quality outcomes and its implications to meaningful use: a systematic review. *Journal of medical Internet research* 2015;17(2):e44. 10.2196/jmir.3171 [PubMed: 25669240]
12. Zipkin R, Schragr SM, Nguyen E, et al. Association Between Pediatric Home Management Plan of Care Compliance and Asthma Readmission. *J Asthma* 2017;54(7):761–767. 10.1080/02770903.2016.1263651 [PubMed: 27929691]
13. Krishnamurti L, Smith-Packard B, Gupta A, et al. Impact of individualized pain plan on the emergency management of children with sickle cell disease. *Pediatric blood & cancer* 2014;61(10):1747–1753. 10.1002/pbc.25024 [PubMed: 24962217]
14. Heynsbergh N, Botti M, Heckel L, et al. Caring for the person with cancer and the role of digital technology in supporting carers. *Support Care Cancer* 2018;27(6):2203–220. 10.1007/s00520-018-4503-8 [PubMed: 30310987]
15. Nielsen AM, Welch WA, Gavin KL, et al. Preferences for mHealth physical activity interventions during chemotherapy for breast cancer: a qualitative evaluation. *Support Care Cancer* 2019;7 31 [Epub ahead of print] 10.1007/s00520-019-05002-w
16. Hassi L and Laakso M. Making sense of design thinking. IDBM papers Helsinki: IDBM Program, Aalto University. 2011;1:50–63. https://www.researchgate.net/publication/274066130_Making_sense_of_design_thinking. Accessed September 1, 2018

17. Adaptive Path's Guide to Experience Mapping. First ed. San Francisco and Austin: Adaptive Path 2013. <http://mappingexperiences.com/>. Accessed September 1, 2018.
18. McCarthy Stephen, O'Raghallaigh Paidi, Woodworth Simon, et al. An integrated patient journey mapping tool for embedding quality in healthcare service reform, *Journal of Decision Systems* 2016;25:sup1:354–368, 10.1080/12460125.2016.1187394
19. Haugstveit IM, Halvorsrud R, Karahasanovic A Supporting Redesign of C2C Services Through Customer Journey Mapping 2016. <http://www.ep.liu.se/ecp/125/018/ecp16125018.pdf>. Accessed August 2, 2018.
20. Hanington B, Martin B. *Universal Methods of Design* Beverly, MA: Rockport Publishers. 2012.
21. Crabtree BM, Miller WL., editors. *Doing qualitative research*. 2nd edition. Sage Publications; Thousand Oaks, CA. 1999.
22. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006;3(2):77–101. 10.1191/1478088706qp063oa
23. Walling EB, Fiala M, Connolly A, et al. Challenges Associated With Living Remotely From a Pediatric Cancer Center: A Qualitative Study. *Journal of Oncology Practice* 2019;15(3):e219–e229. 10.1200/JOP.18.00115 [PubMed: 30702962]
24. Pilkey D, Edwards C, Richards R, et al. Pediatric Readiness in Critical Access Hospital Emergency Departments. *J Rural Health* 2018;7 30 [Epub ahead of print] 10.1111/jrh.12317
25. Mueller EL, Walkovich KJ, Yanik GA, et al. Variation in Management of Fever and Neutropenia Among Pediatric Patients With Cancer: A Survey of Providers in Michigan. *Pediatr Hematol Oncol* 2015;32(5):331–340. 10.3109/08880018.2015.1036331 [PubMed: 26086779]
26. Mueller EL, Cochrane AR, Bennett WE, et al. A Survey of Mobile Technology Usage and Perceptions by Caregivers of Children with Cancer. *Pediatr Blood Cancer* 2018;65(11):e27359. doi: 10.1002/pbc.27359 . 10.1002/pbc.27359<http://www.ncbi.nlm.nih.gov/pubmed/30015371>. <http://www.ncbi.nlm.nih.gov/pubmed/30015371> [PubMed: 30015371]
27. Slater PJ, Fielden PE, Bradford NK. The Oncology Family App: Providing Information and Support for Families Caring for Their Child With Cancer. *Journal of Pediatric Oncology Nursing* 2018;35(2): 94–102. 10.1177/1043454217741874 [PubMed: 29161974]
28. Hyunmin K, Goldsmith JV, Sengupta S, et al. Mobile Health Application and e-Health Literacy: Opportunities and Concerns for Cancer Patients and Caregivers. *J Canc Educ* 2019;34(1):3–8. doi: 10.1007/s13187-017-1293-5
29. Kreps GL. The Relevance of Health Literacy to mHealth. *Stud Health Technol Inform* 2017;240:347–355. <https://www.ncbi.nlm.nih.gov/pubmed/28972527> [PubMed: 28972527]
30. Cho J, Park D, Lee HE. Cognitive factors of using health apps: systemic analysis of relationships among health consciousness, health information orientation, eHealth literacy, and health app use efficacy. *J Med Internet Res* 2014;16(5):e125. doi: 10.2196/jmir.3283 [PubMed: 24824062]



Imagine you have unlimited resources to create a tool that you could take to the ED with you to make the experience better. What would you create?

When going to the ED you are moving from one place to another quickly, and the rooms fill up with people quickly. Why add to the shuffle?
 I suggest
 An app that follows your progression.

A map quest kind of game that gives practical help along with entertainment.

DRAW AND DESCRIBE THIS TOOL

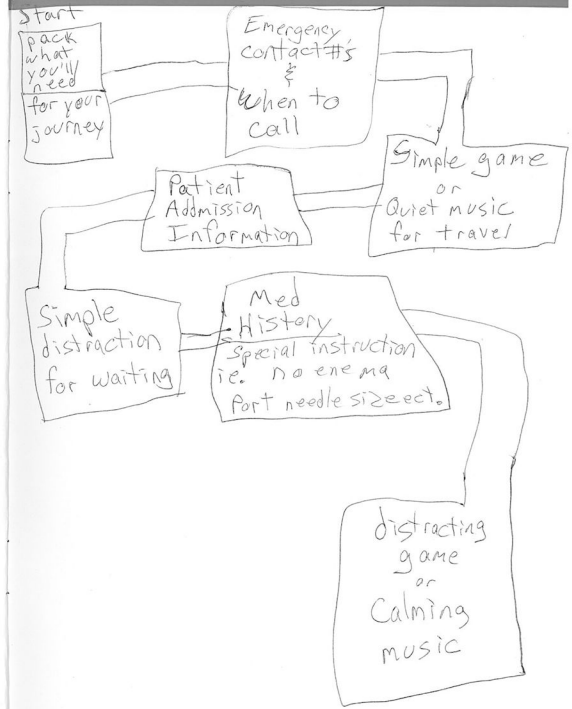


FIGURE 1. Blue-Sky drawing by child with cancer of emergency department visit tracking and entertainment app

TABLE 1.

Experience Mapping Methods

Method	Use
Check Boxes	Used when asking about which hospitals participants attended (the treating institution or a local hospital).
Open Ended Prompts	Used to elicit thoughts and feelings related to each step of the journey.
Fill in the Blank Prompts	Used to elicit specific pieces of information such as reasons for urgency when visiting the ED versus reasons to watch and wait.
Dialogue Writing	Used to elicit the kinds of conversations participants recall with various hospital staff such as the person at the check-in desk or the doctor.
List Making	Used to elicit selections within a category, such as what objects participants brought with them to the ED or to elicit steps in a process, such as what preparations participants took before leaving home for the ED.

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TABLE 2.

Demographics of Children with Cancer for Patient and Caregiver Participants

	Child with Cancer N=7	Caregiver's Child with Cancer N=18
	N (%)	
Age (years)		
Median	15	11
Range	13–18	1–18
Sex		
Male	3(42.9)	13(72.2)
Female	4(57.1)	5(27.8)
Race/Ethnicity		
White, Non-Hispanic	5(71.4)	15(83.3)
Black, Non-Hispanic	1(14.3)	0(0)
Hispanic	1(14.3)	3(16.7)
Type of Cancer		
Acute lymphoblastic leukemia	4(57.1)	9(50.0)
Central nervous system tumors	0(0)	2(11.1)
Solid tumors	0(0)	5(27.8)
Hodgkin lymphoma	1(14.3)	1(5.6)
Non-Hodgkin lymphoma	2(28.6)	1(5.6)
Time since diagnosis (months)		
Median	21	22
Range	0–27	1–108
Distance from treating institution		
Less than 1 hour	2(28.6)	7(38.9)
1 hour or more	5(71.4)	11(61.1)

TABLE 3.

Tasks to perform and items to bring when preparing to seek care in the ED

Tasks to Perform	Items to Bring
Gathering items	Clothes and toiletries
Packing	Medical supplies (medications, mask, etc)
Calling the oncology provider	Medical information (history, medication list, insurance card, etc)
Securing the home	Entertainment items
Finding caregivers for other children	Comfort items
Putting numbing cream on port	Food

* Listed by frequency of comments by participants

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TABLE 4.

Tasks to perform and items to bring when preparing to seek care in the ED

Tasks to Perform	Items to Bring
Gathering items	Clothes and toiletries
Packing	Medical supplies (medications, mask, etc)
Calling the oncology provider	Medical information (history, medication list, insurance card, etc)
Securing the home	Entertainment items
Finding caregivers for other children	Comfort items
Putting numbing cream on port	Food

* Listed by frequency of comments by participants

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