Title: The Children's Oncology Planning for Emergencies (COPE) Tool: Prototyping with Caregivers of Children with Cancer

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Abstract:

As part of a larger project to co-design and create a mHealth tool to support caregivers of children with cancer, we performed a pilot, qualitative study. For this portion of the project, we engaged with caregivers of children with cancer to co-create and refine a low-fidelity prototype of the Children's Oncology Planning for Emergencies mHealth tool. Testing was accomplished through recorded semi-structured interviews with each caregiver as they interacted with a low-fidelity wireframe using Adobe Xd. Through the engagement of our key stakeholders, we were able to refine the COPE tool to provide the key elements they desired including pertinent patient medical information, checklist for planning when seeking urgent care, and coordination of care with the medical team and other caregivers.

Introduction

Children with cancer and their caregivers encounter many barriers to optimal care when preparing for and then seeking care in the emergency department (ED). In our extensive clinical experience, we have seen these barriers first-hand. First, most newly-diagnosed children were previously healthy and unlikely to have experienced serious medical issues previously. Consequently, caregivers may be unfamiliar with navigating the healthcare system, especially in an urgent situation. Secondly, caregivers may not know or be able to accurately relay their child's current therapies, making it difficult for them to provide this information to emergency care providers.[1,2] Third, and perhaps most important, caregivers may not fully recognize how serious seemingly minor complications can be when they 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 that needs medical evaluation and treatment urgently.[3,4]

To address these issues, we are developing a mobile health (mHealth) tool for caregivers of children with cancer: the Children's Oncology Planning for Emergencies (COPE) tool. Research has shown the potential for caregiver-focused mHealth tools to enable caregivers to become more efficient, effective, safer, and less stressed while managing their child's care.[5] However, there are few such mHealth tools in use. Some supportive tools such as patient portals[6] or care management plans have successfully allowed caregiver access to patient information[7,8], but they were not designed to assist with the emergency planning experience for children with cancer and their caregivers.

In this paper, we describe the human-centered development and evaluation of an early-stage prototype of the COPE tool in collaboration with caregivers and healthcare professionals. We present the stakeholder-engaged design process, and the current prototype. We then present specific findings from two rounds of rapid prototyping interviews. This paper contributes key insight and understanding into both the processes taken by caregivers when preparing to seek care in the ED for their child with cancer and the aspects they desire within a mHealth tool to assist in this journey.

Related Work

Children with cancer require evaluation and management in the ED for a variety of reasons and often have extensive utilization.[9,10] There is currently little medical literature that focuses on the full experience of children with cancer who encounter medical emergencies in the community setting. The National Cancer Institute (NCI) and the National Institutes of Health (NIH) Office of Emergency Care Research have recently recognized that this information is lacking.[11] Unexpected medical emergencies can be stressful and even traumatic for patients and their caregivers; therefore, this aspect of care is an important area to explore.[12,13]

Human-Centered Design and Healthcare Technologies

In the past, the development of a tool such as COPE would have been designed with minimal patient or caregiver input. However, federal funding agencies such as the NIH and PCORI have recently begun to recognize that this traditional research approach featuring minimal end-user involvement has failed to result in research that is highly relevant to actual health decisions faced by users and has led to many interventions and tools not achieving outcomes desired by patients.[14] Consequently, these organizations have urged the inclusion of the patient perspective in all aspects of the research process. This study incorporates human centered design methods[15,16,17] with traditional qualitative research methods. Human-centered design uses various techniques to communicate, interact, empathize with, and stimulate the people involved. Its techniques allow research teams, which includes experts in design thinking, to obtain an understanding of people's needs, desires, and experiences in ways that often transcend what people themselves actually realize.[18,19]

User-centered design methods are not new,[20,21] however its application in healthcare is recent with early applications primarily seen in medical engineering, health information management, and safety-oriented analyses.[22] This approach is beginning to expand into more traditional areas of health research. Unlike traditional qualitative or quantitative research, user-centered design approaches allow stakeholders, especially patients and caregivers, to participate in multiple aspects of the research process (i.e., research design, planning, and implementation) in new and innovative ways. Design techniques such as rapid-prototyping,[23,24] which was used in this study, was able to elicit reactions to the prototype and provide feedback related to content, look and feel, and user interface.

Caregiver-focused Technology Research

Scholars in Health Informatics and Human-Computer Interaction have devoted increased attention to caregivers as users of health technology, but this research has yet to translate to pediatric cancer applications (apps). Researchers in Human-Computer Interaction have demonstrated the unique needs and priorities for cancer caregivers as they balance parenting and caregiving duties[25,26] and provided design implications for adolescents and parents to coordinate cancer care.[27,28] However, these findings have yet to be implemented in apps for cancer. A review of the literature found that most caregiver-focused technology interventions are developed for caregivers of adults with cancer rather than children, ignoring the unique needs of this population. A recent meta-analysis indicated that although these interventions had small to medium effects, they significantly reduced burden, improved the ability to cope, increased self-efficacy, and improved aspects of caregivers' quality of life.[29] Yet, several recent reviews highlighted a lack of interventions to provide practical skills for the day-to-day provision of care.[2,30] One app we found was developed to support caregivers of children with acute lymphoblastic leukemia in China, but is limited to Android users in the Chinese population as well as a specific type of cancer.[31] Another app also provided supportive care for caregivers of children with cancer, but is specific to the resources available in Australia.[32] Future research is needed to support the development of caregiver-focused technology in pediatric oncology that can assist a broader population of caregivers with provision of care.

Prior Work: Feasibility and Acceptability of Mobile Apps for Caregivers of Children with Cancer

Prior to the start of this current study, we had performed a survey to understand better mobile technology usage, barriers, and desired mHealth tools by caregivers of children with cancer.[33] In this mailed, cross-sectional survey, we found that the vast majority (99%) of respondents owned a smart phone and 37% reported no barriers to mobile technology use. We determined that the majority of caregivers (85%) desired a mHealth tool that would support them in the medical management of their child with cancer. Therefore, this suggests that caregivers of children with cancer would be receptive to and able to use a mobile app with minimal barriers.

Methods

Study Design

This is a pilot, qualitative research study that consisted of developing a prototype of a mHealth app using input from a variety of key stakeholders. In the first phase of this project, we engaged with caregivers of children with cancer and healthcare professionals involved in the management and triaging of children with cancer experiencing medical emergencies.

In the second phase, we performed two rounds of rapid prototyping interviews with the intended end user (i.e. the caregiver) using a semi-structured qualitative interview. The interviewer asked caregivers to freely explore the prototype and try to speak their thoughts aloud and ask questions. As caregivers commented, the interviewer would follow-up to probe deeper into the comment or to get clarification. The interviews were audio recorded and the screen was recorded so that during analysis, the reviewer could refer to which screen was being referenced by the participant. Between rounds, the prototype was refined based on caregiver feedback. The IU Institutional Review Board and IU Simon Cancer Center Scientific Review Committee reviewed and approved this study.

Study Population/Identification of Cases

Participants were caregivers of a child 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 year 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) and those who were receiving hospice-directed care were excluded since the goals of care in the ED setting are different than those of therapies with curative intent. Demographics and eligibility of the caregiver's child with cancer were obtained from the Clinical Trials Office and the medical record. We recruited participants through flyers posted throughout the inpatient and outpatient clinic. When this did not yield adequate number of participants, we contacted potential participants based on the clinical list of patients diagnosed with cancer at Riley Hospital for Children which is compiled and maintained by our Clinical Trials Office. Potential participants were contacted by phone to assess interest in recruitment. We then scheduled the in-person interviews, which were conducted either in the inpatient setting or in the outpatient clinic at Riley Hospital for Children. If the child had multiple primary caregivers, then we allowed for more than one primary caregiver to participate in a joint interview.

Table 1. Demographics of Caregiver Participant's Child with Cancer

	Caregiver's Child with Cancer N=12
	N (%)
Age (years)	
Median	6
Range	1-20
Sex	
Male	7(58.3)
Female	5(41.7)
Race/Ethnicity	
White, Non-Hispanic	12(100)
Black, Non-Hispanic	0(0)
Hispanic	0(0)
Type of Cancer	
Acute Lymphoblastic Leukemia	7(58.3)
Central Nervous System	1(8.3)
Solid Tumor	3(25.0)
Hodgkin Lymphoma	0(0)
Non-Hodgkin Lymphoma	1(8.3)
Time since diagnosis (months)	
Median	10
Range	2-34
Distance from treating institution	
Less than 1 hour	2(16.7)
1 hour or more	10(83.3)

Participants

In round one, a total of 10 caregivers in eight interviews were interviewed. In round two, five caregivers in four interviews were interviewed. In total, 15 caregivers of 12 children with cancer participated in the study. Interviews lasted about 30 minutes on average. Demographics of caregivers was not collected, but demographics of their child with cancer are presented in Table 1. The median age was 6 years with a range of 1-20 years. The majority was male (58.3%), white non-Hispanic (100%), diagnosed with Acute Lymphoblastic Leukemia (ALL) (58.3%), and lived more than 1 hour away from their treating institution (83.3%). The median monthly time since diagnosis was 10 months (range: 2-34 months).

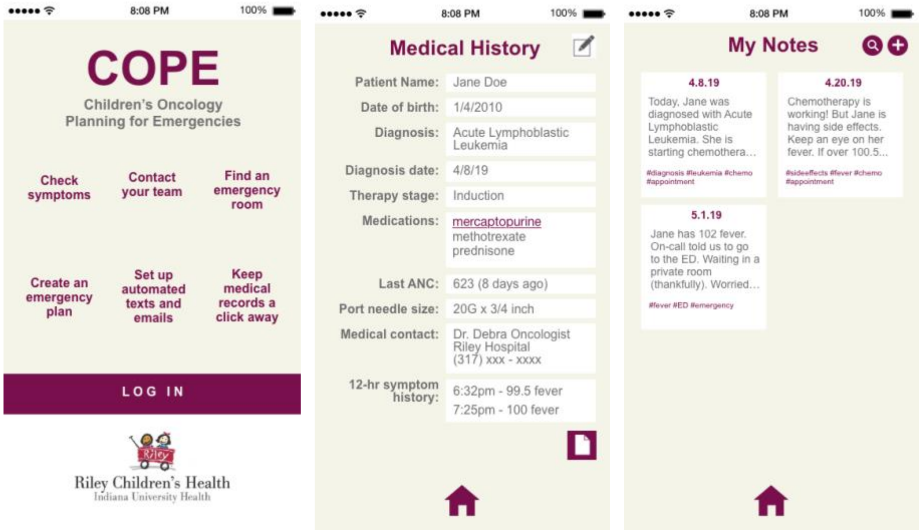
Analyses

Each interview was reviewed and transcribed with a mix of paraphrasing and direct quotes[34] to capture content from the audio. These transcriptions were then analyzed using NVivo 12 by a team member trained in human-centered design and qualitative analysis and who created the prototype app. Data from the transcriptions was grouped by similarity, allowing themes to emerge freely from the data[35]; no coding structure was imposed initially. In this way, overarching themes could emerge that would suggest wholistic edits across the app. Data that related to specific app sections was also coded in themes by section and then by Function and Content to allow for easy translation into more granular app edits. This same approach was taken for both rounds of interviews.

The COPE Tool

As part of a larger project investigating technology opportunities for pediatric cancer caregivers, we designed the Children's Oncology Planning for Emergencies (COPE) tool. The version evaluated in this study is minimally interactive low-fidelity prototype of a proposed mHealth smartphone app, utilizing Adobe Xd.

The COPE prototype has six main components. The first component is medical history, a place where caregivers could input details of their child's medical information that could be needed in an emergency situation. The second component is symptom checking, a place where common symptoms such as fever and pain could be documented and advice given based on the inputted information. Users can also contact their medical team; make an emergency plan that includes automated features such as texts/emails and a packing list; find a nearby emergency department; and access resources such as sanitation and port access videos. The final version of the prototype includes a section for caregiver to take notes.



Medical History

Patient Name: Jane Doe
Date of birth: 1/4/2010
Diagnosis: Acute Lymphoblastic Leukemia
Diagnosis date: 4/8/19
Therapy stage: Induction
Medications: mercaptopurine, methotrexate, prednisone
Last ANC: 623 (8 days ago)
Port needle size: 20G x 3/4 inch
Medical contact: Dr. Debra Oncologist, Riley Hospital, (317) xxx - xxxx
12-hr symptom history: 6:32pm - 99.5 fever; 7:25pm - 100 fever

My Notes

4.8.19
Today, Jane was diagnosed with Acute Lymphoblastic Leukemia. She is starting chemothera...
#diagnosis #leukemia #chemo #appointment

4.20.19
Chemotherapy is working! But Jane is having side effects. Keep an eye on her fever. If over 100.5...
#sideeffects #fever #chemo #appointment

5.1.19
Jane has 102 fever. On-call told us to go to the ED. Waiting in a private room (thankfully). Worried...
#fever #ED #emergency

Figure 1. Images of the final Children's Oncology Planning for Emergencies app

We developed the COPE prototype using a human-centered design process, iteratively gathering input from caregivers of children with cancer and healthcare providers. Prior to the current project, we sought to assess how caregivers prepare for and manage a medical emergency that arises in the community setting by performing a qualitative evaluation of 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 their caregivers. Participants received a paper toolkit, which was structured as experience maps with several generative activities. Toolkits were transcribed, thematically coded, and iteratively analyzed using NVivo 12.0 software. 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. 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. The goal of this study was to inform the tool to support this population in planning for and managing emergent medical issues as well as improving patient and caregiver satisfaction, patient centered outcomes, and clinical outcomes. This data was the basis of the initial prototype.

We utilized the information and ideas generated from the toolkits as the basis for a design research session that was conducted with healthcare providers to provide further input on the design of the tool. All of this information was then compiled and utilized to create the COPE tool with the goal of improving the patient and caregiver experience, patient centered outcomes, and clinical outcomes for children with cancer and their caregivers when seeking care in the ED for urgent medical needs. We hypothesize that prototyping this tool among caregivers will provide insightful feedback that would aid in the development and refinement of a mHealth tool that is best suited for their unique needs.

We tested the COPE prototype in two rounds. Adjustments for round two of the prototype incorporated feasible suggestions by caregivers as well as further refinements that we tested among a smaller segment of caregivers in round two. Key changes included: adding their treating institution's logo, a log-in screen, additional symptoms to the symptom tracking page, additional content to the medical history page, image upload feature to the medical history page, medication descriptions to the medical history page, and a 'my notes' section. We had initially included an 'entertainment' section and a red color theme to match the hospital's branding, but removed both based on feedback.

Results

Our findings suggest that caregivers are enthusiastic about the prospect of a mHealth tool such as COPE to support them when their child has a medical emergency, and that such tools can help caregivers feel calm and reassured while keeping them informed and connected. As one caregiver commented, *"As a parent I would love to see this happen. It would make decision-making a lot easier."* Our collaboration with caregiver stakeholders also revealed that caregivers of a child with cancer engage in a series of complex processes when a medical emergency arises in the community setting and they prepare to seek care in the ED. Our results show three key ways that mHealth tools such as COPE can support caregivers: access to a thorough patient medical history, ED-specific planning support, and communication with the medical team and their family support structure.

Emotional Response to Using the App: Calm and Reassurance

When asked about how caregivers wanted an app that supports planning for emergencies to make them feel, the most common responses were calming or reassurance: *"Calm comes to my mind. This would just be another thing to calm you and ease your mind. If you looked up a side effect, and went, 'Oh okay vomiting is a common side effect.' While you still may let your doctor know, it can kind of ease your mind."* Technologies that act as backup notetakers can be especially valuable during an emergency, when caregivers have a lot of competing demands on their attention: *"Calming, organization, knowing you have everything. Don't have to think about 'am I missing anything?' I'm not as organized so if you have everything written down..." "Sense of security. Having the information you need just in case you forget. Or if you can't think of it off the top of your head."*

Patient Medical Information Requirements: As Detailed as Possible

One way in which COPE provides reassurance is through access to a detailed patient medical history, which can be easily forgotten or lost in an emergency. Caregivers appreciated this feature, suggesting many additional types of information an app like COPE could provide. These suggestions included factors related to the patient such as: patient past medical history, appropriate port needle size, patient blood type, date of diagnosis, chemotherapy treatment timeline, laboratory data (specifically the absolute neutrophil count trends), medication allergies, vaccination history, and the ability to upload images of radiographic findings or other medical documents.

In regards to the patients' medications, caregivers desired to have these listed on the patient information page and also wanted there to be more information available regarding what the function of the medication is for and any potential medication side effects. Caregivers expressed that having these listed would improve their ability to relay them to the medical teams since they find it difficult to recall all of the names of the medications their child is receiving. One caregiver described her child's *"bucket of medications."* In addition, the names of the medications can be difficult to memorize and pronounce properly. The medication list avoids this problem, as one caregiver described: "*My wife's really good at knowing all the medical terms. I'm not as good at that. Especially medications that I have a hard time pronouncing. Better to show them than play guessing games".* Caregivers also suggested a feature in the medical history page that would provide descriptions of medications to help caregivers remember which medication is for which purpose. *"Medications definitely because I can't pronounce anything. Would they come with maybe where you could click on it and get a small description of them too? Because that would also be nice...What's that one do? Even just a brief little, 'This one is for nausea or aches and pains."* Medication tracking was a popular suggestion for helping to decrease caregiver burden. Caregivers wanted a place to track when medications were given and get reminders of the next doses. Some children are on multiple medications that can be difficult to keep track of. One caregiver suggested: *"One thing you could do is have a medication list and it has a timer that lets you know it's time [for meds]."*

Consolidated Information Retrieval and Planning: All in One Place

When children with cancer develop a medical emergency in the community setting, there are a series of communications that occur with the medical team in preparation to seek care and when they arrive at the ED. This information work begins before caregivers even know *which* ED to contact. While preparing for travel to the ED, we created a maps page that would show their local ED. Caregivers suggested that additional details about the specific ED would be helpful including if the hospital had pre-arrival check-in capabilities, whether or not the hospital staff has experience with port access, the size of the hospital and what its trauma level designation is, what health system the hospital belongs to and whether the family's insurance is accepted, whether or not the hospital has an oncology department, whether or not the hospital has a pediatric care specialist, and reviews from other families.

After arrival at the ED, the COPE tool was seen by caregivers as a way to decrease the burden of retrieving all necessary information. Caregivers mentioned how the app would make things easier for them by decreasing what they had to remember, keep track of, and decide. One caregiver, when asked if there were any other resources she thought would be helpful said, *"Anything that's less thinking."* Caregivers reported that it was a burden to try to find documents from previous clinical visits. Several expressed difficulty keeping track of their personal identification and medical insurance cards. Multiple caregivers described digging through purses or binders for paperwork and information and some suggested that the app could help with this burden by keeping everything in one place: *"I'm forever digging around in my purse for the cards."* "*As part of that admission process, you've got all this-your kid is sick and you're digging through your bag trying to find all the things they need. If you could just say, 'here it is.' Just so it's all right there."*

Care Coordination With the Oncology Team

In addition to coordinating with the medical team at the ED, caregivers of children with cancer must also loop in their oncology team. Caregivers envisioned that the app might help them get in contact with their treating institution faster during an emergency. They mentioned that they must use various phone numbers given to them by their children's' oncology teams; specifically the on-call numbers were frequently used and very valuable to them. They discussed having been given a different number for regular business hours and a number for nights and weekends: *"At least two main numbers. We have a number to get ahold of someone and the after hour's number. Sometimes you forget which you programmed [your phone] to."* Many caregivers wanted the app to automatically call the correct number based on the time of day or day of the week: *"That is nice! I like that a lot! Because when you are worried, upset, you're thinking 'who do I need to call' and going through your contacts. Just having that would be super good. I like that!"* Upon calling the number for regular business hours during a night or weekend, they are typically sent through an operator who contacts the on-call provider. Once the on-call providers reaches the operator, the operator then calls back the caregiver and connects the caregiver to the on-call provider. This was frustrating to some caregivers who wished they could get help faster: *"Right now you have to call someone and they have to call you back. Is it better to call someone on the phone versus thinking you know what you're doing on an app? If he's cramping for two hours and it's getting worse, what do I do?"* A few caregivers suggested other ways to contact their treating institution such as via text or video chat.

Caregivers believed the app might help with care coordination between their ED and Oncology medical teams. Many reported that their treating institution usually called their local ED to coordinate care. There were some, however, who had not had success in this area: *"Home ED told us it wasn't a perfect world and they didn't have to talk to [our treating institution]."* This care coordination was very important to caregivers. One caregiver suggested: *"I would change being able to text somebody [at our treating institution]...'Hey can you please call [the local ED] and let them know they're not supposed to do anything with him other than get him stable until [our treating institution] is in contact with them."* Specifically, caregivers hoped that the Resources Section, especially the 'Letter from the Oncologist' (as long as it was kept up-to-date), would help coordinate care between the treating institution and a local ED. The letter included recommendations for patient evaluation and treatment along with contact information for the treating institution oncology team. *"I really like the letter because if you have to go to a different hospital. I can kind of remember the medical language, but having that would be super helpful."* There was an education video about how to access a port-a-cath that caregivers thought might help local ED staff who are less familiar with port access: *"We've been concerned if we would ever have to have her accessed at a different hospital. I could see our local hospital pulling out a big manual and going step by step. You don't have a lot of confidence when they do that."* Caregivers wondered, however, how they might approach medical staff about watching the video: *"I would hope nurses would be open to reviewing it before accessing it."*

Other Requests: Multiple Caregivers, Note Taking, Symptom Tracking

Inclusion of Other Caregiver Members: Caregivers expressed that it was important for multiple caregivers to be able to manage the child's account on the app. This would allow for any of the potential caregivers to have access to the information and planning for when a medical emergency arises while they care for the child with cancer.

Incorporation of Note Taking: Multiple caregivers suggested the app could include a note-taking capability so caregivers could capture their own notes in the same place as the rest of their child's information. Caregivers felt that this note-taking feature would allow them to adapt the app to fit their existing practices. As one parent put it: *"We all have our own ways of doing things. Mine is writing it all down in a journal. You know just, the trip, how he did. Any hiccups we come across. I do it [in a physical journal]."* Caregivers' note-taking goals varied. Some were focused on the immediate use. For example, one caregiver wanted to take notes of what her child's oncologist said to review later: *"Somewhere to just write down pinpoints of what your doctor says or add a recorder in there to go back and listen to what they've said."* Other caregivers wanted to take notes for posterity. As one caregiver put it: *"I have all* *this information here that one day he's going to come back and ask me about. Right now he's still just processing cancer."*

Future Ability to Track Symptoms: Our initial intent with the COPE tool was to only focus on preparing for when a medical emergency arose, but many caregivers pointed out that in the event of an emergency they need to describe the symptoms the child is experiencing. Therefore, they recommended the inclusion of the ability to track the patient's symptoms. One specific request was the be able to track pain. In addition, many caregivers talked about the specific symptoms they were asked to monitor for their child's cancer type. As one caregiver mentioned: *"We had mouth sores, facial swelling, toe infection concerns."* Caregivers were interested in the ability to have additional symptoms included on the symptom tracking page based on the child's diagnosis.

App Security Concerns

Caregivers were asked about how to ensure their trust in the app. They suggested that their treating institution's branding and a login feature would help them feel safe using it. Many relayed that if it were recommended to them by their child's oncologist, or if it came from their treating institution, they would trust the app: *"Like if it said it was from [our treating institution]. Anything they've given us that says it's trusted. Just like the phone system. Maybe [our treating institution's] logo." "I trust in you guys I guess. [This is] where all of our faith is right now."* In addition, many suggested that a log-in process might help protect the data on the app: *"Something you read in the beginning when you first open it have some text about how your info is protected. Maybe a lock thing you have to login to get into the app."*

Discussion and Implications

Caregivers of children with cancer were optimistic that a mHealth tool could support them when a medical emergency arises in the community setting. The prototyping process outlined in this paper demonstrated continued refinements to the tool that aligned with the complex needs experienced by caregivers as they proceed through the typical steps to determine their child needs urgent evaluation, contact the oncology team, prepare and pack for an ED visit, and initiate the evaluation process upon arrival to the ED. We believe that involvement of caregiver stakeholders in the co-design process is imperative for success in future research utilization of a mHealth tool to support caregivers of children with cancer.

Our original prototype had included information gathered from caregivers and children with cancer via a qualitative, user-centered design toolkit that walked them through the process of experiencing an emergency through completing an ED encounter. We appreciated that through this prototyping process outlined in this paper, we were able to gather and incorporate practical recommendations after the caregivers were able to "work with" the low-fidelity app prototype. We believe that by viewing the prototype, caregivers were better able to consider the steps in the process of preparing for an emergency more concretely. This open the conversation to include more practical application use by the caregivers. Thus, this led to improvements in the both the necessary information that should be contained within the app, but also the function of the features desired by caregivers.

Our original focus had been only on the preparations for seeking emergency care, but caregiver's insight and expertise revealed a larger base of need including the inclusion of medications and a capacity to track their child's symptoms. When assessing the practical needs of actually engaging with the oncologist over the phone and discussing the medical situation that led to an ED visit, caregivers appropriately identified two areas that a mHealth tool could further support. The addition of the medication list, function of the medications, and possible side effects would be key for keeping track of any recent changes which could impact clinical complications. Similarly, many of the chemotherapy medications cause a wide range of side effects and therefore the incorporation of symptom tracking could potentially improve communication with the medical teams when seeking care in the ED. Future research focus should be placed on these components in order to design an optimal platform for managing medications and tracking symptoms.

Important insight was gathered from caregivers about their ability to trust an app that would include personal health information for their child within it. It was clear from their responses that they have a strong trust within their healthcare system and for the medical providers whom they interact with. We hope that the inclusion of the hospital logo and utilization of the affiliated academic institution color schema will provide necessary reassurance of trust from the caregivers. It will also be imperative for the entire oncology provider team to be aware of the security features of the app in order to ensure their encouragement of caregivers to utilize the app. If both the caregivers and oncologists trust the security and integrity of the app, this could improve utilization of the app and its incorporation into clinical care.

Our team is moving forward with the continued co-design, refinement, and testing of a mHealth tool to support caregivers in the overall medical management of their child with cancer. The key features and elements of the planning for emergency tool will be incorporated into this more comprehensive app. The decision to focus on medical management stemmed from our previously mentioned survey where the caregivers expressed that the most desired were medical knowledge, medication reminders, and symptom tracking[23]. Our experience of engaging with caregivers in the project outlined in this paper was instrumental in envisioning the scope of the broader mHealth tool. Their experience and concerns they wanted addressed aided in the ability to create a defined scope surrounding the focus of addressing supportive care for children with cancer through organized medication lists with reminders, specific medical information directly related to symptoms, and monitoring symptoms experienced by patients. It is our hope to continue to find innovative methods to include caregivers in the co-design and creation of this future app and evaluate the impact on specific patient and caregiver outcomes. In order to create the optimal tool for this population, our future endeavors will strive to include a diverse set of caregivers that are representative of the heterogeneity of our population of children with cancer.

Limitations

Our results highlight additional opportunities to support caregivers in the care of their child with cancer. However, we acknowledge some limitations. First, we had a small sample size of caregivers and healthcare providers, our results may not reflect all the viewpoints of caregivers and healthcare providers at Riley Hospital for Children. Second, our participants represent a homogenous population concerning race/ethnicity. Although our participants were from diverse locations in the state of Indiana, our results may not be generalizable to other institutions or geographic areas. We did not capture demographic data specific to the caregivers, thus missing the opportunity to ensure diversity in our sample. Future work should aim to explore these results among a larger and more diverse population.

Conclusion

The COPE tool was designed as part of a larger project that investigated technology opportunities for caregivers of children with cancer. The portion of the project evaluated in this study is a minimally interactive low-fidelity prototype of a proposed mHealth smartphone app utilizing Adobe Xd. An important next step is to continue to refine the app through engagement via alpha testing with both caregivers and healthcare providers. Future work should focus on evaluating the feasibility and efficacy of the app, including measuring its impact on both caregiver and patient health outcomes. We intend for this preliminary work to set the stage for a high-fidelity prototype that will be used in a real-world setting.

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References

1. Hentea C, Cheng ER, Bauer NS, Mueller EL. Parent-centered communication at time of pediatric cancer diagnosis: A systematic review. Pediatr Blood Cancer [Internet]. 2018 Aug;65(8):e27070. doi: 10.1002/pbc.27070. Epub 2018 Apr 18. Available from: https://doi.org/10.1002/pbc.27070
2. Applebaum AJ, Breitbart W. Care for the cancer caregiver: a systematic review. Palliat Support Care [Internet]. 2013;11(3):231-252. Available from: https://doi.org/10.1017/S1478951512000594
3. Bodey GP, Buckley M, Sathe YS, Freireich EJ. Quantitative Relationships between circulating leukocytes and infection in patients with acute leukemia. Ann Intern Med [Internet]. 1996 Feb;64(2):328-40. Available from: https://doi.org/10.7326/0003-4819-64-2-328
4. Mullen CA. Which children with fever and neutropenia can be safely treated as outpatients? Br J Haematol [Internet]. 2001 Mar;112(4):832-7. Available from: https://doi.org/10.1046/j.1365-2141.2001.02632.x
5. National Alliance for Caregiving. e-Connected family caregiver: bringing caregiving into the 21st century. 2011. Available from: http://www.caregiving.org/data/FINAL_eConnected_Family_Caregiver_Study_Jan%202011.pdf.
6. Kruse CS, Bolton K, Freriks G. The effect of patient portals on quality outcomes and its implications to meaningful use: a systematic review. J Med Internet Res. Feb 10 2015;17(2):e44.
7. Zipkin R, Schrager SM, Nguyen E, Mamey MR, Banuelos I, Wu S. Association Between pediatric home management plan of care compliance and asthma readmission. J Asthma. 2016 Dec 8:0.

8. Krishnamurti L, Smith-Packard B, Gupta A, Campbell M, Gunawardena S, Saladino R. Impact of individualized pain plan on the emergency management of children with sickle cell disease. Pediatr Blood Cancer. 2014 Oct;61(10):1747-53.
9. Mueller EL, Sabbatini A, Gebremariam A, Mody R, Sung L, Macy ML. Why pediatric patients with cancer visit the emergency department: United States, 2006-2010. Pediatr Blood Cancer [Internet]. 2015;62(3):490-95. Available from: https://doi.org/10.1002/pbc.25288
10. Mueller EL, Hall M, Shah SS, August KJ, Radhi MA, Macy ML. Characteristics of children with cancer discharged or admitted from the emergency department. Pediatr Blood Cancer [Internet]. 2016;63(5):853-58.
11. Greene, Jan. CONCERN for cancer: new national institutes of health network to focus on cancer patients in the emergency department. Ann Emerg Med [Internet]. 2015 Jul;66(1):A13-A15. Available from: https://doi.org/10.1016/j.annemergmed.2015.05.015
12. Rodriguez EM, Dunn MJ, Zuckerman T, Vannatta K, Gerhardt CA, Compas BE. Cancer-related sources of stress for children with cancer and their parents. J Pediatr Psychol [Internet]. 2012 Mar;37(2):185-97. Available from: https://doi.org/10.1093/jpepsy/jsr054
13. Patino-Fernandez AM, Pai AL, Alderfer M, Hwang WT, Reilly A, Kazak AE. Acute stress in parents of children newly diagnosed with cancer. Pediatr Blood Cancer [Internet]. Feb 2008;50(2):289-292. Available from: https://doi.org/10.1002/pbc.21262
14. Jani B, Bikker AP, Higgins M, Fitzpatrick B, Little P, Watt GC, et al. Patient centredness and the outcome of primary care consultations with patients with depression in areas of high and low socioeconomic deprivation. Br J Gen Pract [Internet]. 2012 Aug;62(601):e576-81. Available from: https://doi.org/10.3399/bjgp12X653633
15. Bennett A, Eglash R, Krishnamoorthy M, Rarieya M. Audience as co-designer: participatory design of HIV/AIDS awareness & prevention posters in Kenya. Design Studies. New York: Princeton Architectural Press; 2006:179-97.
16. IDEO Method Cards: 51 Ways to Inspire Design. Palo Alto: IDEO; 2003.
17. Sanders EB-N, Brandt E, Binder T. A framework for organizing the tools and techniques of participatory design. Proceedings of the 11th Biennial Participatory Design Conference; 2010; Sydney, Australia.
18. Sanematsu H, Wiehe S. Learning to look: design in health services research. Touchpoint. 2014; July:TP06-02P82.
19. Sanematsu H. 53. Fun with Facebook: the impact of focus groups on the development of awareness campaigns for adolescent health. Journal of Adolescent Health. 2011;48(2, Supplement):S44-S45.
20. Sanematsu H, Hong Y, Cole L, Zollinger T. Listening through seeing: using design methods to learn about the health perceptions of Garden on the Go customers. IUPUI Research Day 2014. 2014; Apr 11. Indianapolis, Indiana.
21. Bate P, Robert G. Experience-based design: from redesigning the system around the patient to co-designing services with the patient. Qual Saf Health Care [Internet]. 2006 Oct;15(5):307-310. Available from: http://dx.doi.org/10.1136/qshc.2005.016527
22. Hasso Plattner Institute of Design. bootcamp bootleg. Available from: http://dschool.stanford.edu/use-our-methods/the-bootcamp-bootleg/.
23. Schnall R, Rojas R, Bakken S, Brown W, Carballo-Dieguez A, Carry M, et al. A user-centered model for designing consumer mobile health (mHealth) applications (apps). Journal of Biomedical Informatics. 2016 Apr;60:243-251. DOI: 10.1016/j.jbi.2016.02.002.
24. Yen PY, Bakken S. Review of health information technology usability study methodologies. J Am Med Inform Assoc [Internet]. 2012 May-Jun;19(3):413-22. Available from: https://doi.org/10.1136/amiajnl-2010-000020
25. Yunan Chen, Victor Ngo, and Sun Young Park. 2013. Caring for caregivers: designing for integrality. In proceedings of the 2013 conference on computer supported cooperative work (CSCW ’13). Association for Computing Machinery, New York, NY, USA, 91–102. Available from: https://doi.org/10.1145/2441776.2441789
26. Seo W, Berry ABL, Bhagane P, Choi SW, Buyuktur AG, Park SY. Balancing tensions between caregiving and parenting responsibilities in pediatric patient care. Proc. ACM Hum.-Comput. Interact. 2019 Nov;153:24. Available from: https://doi.org/10.1145/3359255.
27. Ancker JS, Sharko M, Hong M, Mitchell H, Wilcox L. Should parents see their teen’s medical record? asking about the effect on adolescent–doctor communication changes attitudes. J Am Med Inform Assoc [Internet]. 2018 Dec;25(12):1593-99. Available from: https://doi.org/10.1093/jamia/ocy120

28. Hong MK, Wilcox L, Machado D, Olson TA, Simoneaux SF. Care partnerships: toward technology to support teens' participation in their health care. Proc SIGCHI Conf Hum Factor Comput Syst. 2016 May 7:5337–49. Available from: https://doi.org/10.1145/2858036.2858508.
29. Northouse LL, Katapodi MC, Song L, Zhang L, Mood DW. Interventions with family caregivers of cancer patients: meta-analysis of randomized trials. CA Cancer J Clin [Internet]. 2010;60(5):317-39. Available from: http://dx.doi.org/10.3322/caac.20081
30. Bee PE, Barnes P, Luker KA. A systematic review of informal caregivers' needs in providing home-based end-of-life care to people with cancer. J Clin Nurs. 2009;18(10):1379-93. Available from: https://doi.org/10.1111/j.1365-2702.2008.02405.x
31. Wang, J., Yao, N., Wang, Y., Zhou, F., Liu, Y., Geng, Z., & Yuan, C. Developing "Care Assistant": A smart-phone application to support caregivers of children with acute lymphoblastic leukaemia. J Telemed Telecare [Internet]. 2016 Apr;22(3):163-71. Available from: https://doi.org/10.1177/1357633X15594753
32. Slater PJ, Fielden PE, Bradford NK. The oncology family app: providing information and support for families caring for their child with cancer. J Pediatr Oncol Nurs. 2018;35(2): 94–102. Available from: https://doi.org/10.1177/1043454217741874.
33. Mueller EL, Cochrane AR, Bennett WE, Carroll AE. A survey of mobile technology usage and desires by caregivers of children with cancer. Pediatr Blood Cancer [Internet]. 2018 Nov;65(11):e27359. Available from: https://doi.org/10.1002/pbc.27359
34. Aronson, J. A pragmatic view of thematic analysis. The Qualitative Report.1995;2(1):1-3. Available from: https://nsuworks.nova.edu/tqr/vol2/iss1/3
35. Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol 2006;3(2):77-101.