Title: A Survey of Mobile Technology Usage and Desires by Caregivers of Children with Cancer

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CAR	chimeric antigen receptor
GED	general education diploma
mHealth	mobile health
NIH	National Institute of Health

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Abstract

BACKGROUND: The use of mobile health (mHealth) has grown exponentially, even by caregivers of vulnerable populations. The study objective was to understand mobile technology usage, barriers, and desires by caregivers of children with cancer.

PROCEDURE: Paper surveys were mailed to caregivers of children diagnosed with cancer at Riley Hospital for Children between June 2015-June 2017. The survey contained 13 questions, both fixed and open-ended, and was sent in both English and Spanish up to three times.

RESULTS: Respondents (n=121) were primarily parents (93.2%), median age was 40.7 years (range 23-63), and most were white (78.5%) and non-Hispanic (87.1%). The majority made under $75,000 annual household income (59.3%) and had an education of at least high school or GED (76.2%). Nearly all owned a smart phone (99.2%) and most (61.2%) owned a tablet. Among operating systems, the majority used iOS (62.8%), while 49.6% used Android. About a third (35.5%) reported no barriers to mobile technology use, but 21.5% experienced "data limitations." Overall, 84.5% wanted at least one medical management website/app: medical knowledge (58.7%), symptom tracking/management (47.1%), and medication reminders (43%). Further, 59.5% wanted access to child's medical record and 56.2% wanted communication with medical providers. Lower education was significantly associated with experiencing phone/plan barriers (p-value=0.008).

CONCLUSION: The majority of caregivers of children with cancer use mobile technology with minimal barriers; future research should focus on designing an mHealth tool to address the medical management needs by caregivers of children with cancer.

Introduction

Although pediatric cancer is the 2nd leading cause of death in children (ages 5-14 years) in the United States[1], improved diagnosis and treatment options have translated into higher rates of cure and overall survival among children with cancer[2]. However, a diagnosis of cancer in a child is still a life-altering event not just for the child, but for the caregivers as well[3]. Caregivers play a significant role in coordinating complex healthcare services both inside and outside of the hospital setting. Children with cancer frequently require administration of oral chemotherapy or symptom management medications at home, which places a significant amount of pressure on caregivers[3].

The use of mobile health (mHealth), defined by the National Institute of Health (NIH) Consensus Group on mHealth as "the use of mobile and wireless devices to improve health outcomes, healthcare services, and health research"[4], has grown exponentially in recent years[5]. Importantly, mHealth tools have the potential to assist caregivers as they navigate the healthcare system and help direct the medical management of their child. mHealth has been successfully used among caregivers of the elderly with chronic conditions and dementia care to help with both medical management and to reduce stress through wellness programs[6,7]. However, none of these studies have specifically assessed the phenomenon among caregivers of children with cancer.

Prior to embarking on future research efforts, it is imperative to understand the mobile technology usage, barriers and desires of this unique population. We hypothesized that caregivers have adequate access to mobile technology and would desire new mHealth

tools specifically for aiding in the care of their child with cancer. The knowledge we gathered through this survey will inform future research endeavors to develop and implement an mHealth tool specifically designed for caregivers of children with cancer.

MATERIALS AND METHODS

Survey Design/Administration

We conducted a mailed cross-sectional paper survey of caregivers of all children who were newly diagnosed with cancer between June, 2015 and June, 2017 at Riley Hospital for Children. See Figure 1 for participant flow diagram. We mailed a total of three rounds of surveys over a 4-month period (July to October, 2017). The first survey mailing sent out contained a $1 incentive. Each round of mailing was about 1 month apart. Participants that had already responded were excluded from each subsequent mailing. After the first mailing, those surveys that were returned via the postal service for an incorrect address were excluded from repeat mailings. The study was approved by the Institutional Review Board of Indiana University.

Survey Sample

Patient names and addresses were extracted from the Clinical Trials Office research database. Deceased patients were excluded from our mailing using medical record data. Caregivers were instructed to complete the survey only if they met the following criteria: 1) age 18 years or older at the time of the survey, 2) a primary caregiver to a child (age 18 years or younger) who was diagnosed with cancer in the last 2 years, and 3) had a child who received chemotherapy and/or radiation in the last year.

Survey Instrument

The investigators developed and refined survey items that reflected the primary study aims, drawn from clinical experience and informal conversations with mobile technology experts (see Supplemental File). The survey introduction framed the focus of the survey on patients who were actively or recently received therapy for their cancer, as caregivers would be more likely to be currently using a form of mobile technology for caregiving and would be better able to express their mobile technology needs.

The 13-question survey included fixed-choice and open-ended questions in both English and Spanish. We also gathered the following demographic information for each caregiver participant: (1) relation to the child with cancer, (2) age, (3) ethnicity, (4) race, (5) income, and (6) highest level of education achieved. The age of the caregivers were combined into the following categories: 23-35 years, 36-45 years, and 46+ years. Race and ethnicity were combined into: White Non-Hispanic, Black Non-Hispanic, Hispanic, or Other/I prefer not to answer. Fixed-choice questions for personal mobile technology use included type of mobile technology used, which operating systems used, and what websites or applications they frequently used. Fixed-choice questions for caregiver mobile technology use included barriers experienced and the most helpful mobile-friendly website or application they used for themselves. An open-ended 'other' response option was available for barriers experienced. An open-ended question was also included asking for which website or application was most helpful for them with caregiving. Then

they were asked a close-ended question to rate their most used mobile-friendly website or application for caregiving on how it may have changed the care of their child.

Caregivers were then asked about which new mobile-friendly websites or applications they desired to help them care for their child with cancer. They were given fixed-choice options that were categorized as either 'Medical management' or 'Healthcare system.' The categories were chosen based on expert opinion and consensus among the investigators. The category of 'Medical management' included: 'medical knowledge', 'health symptom tracking or management', 'medication reminders', 'medical emergency preparedness', 'nutrition/dieting', 'physical activity tracking,' and 'calendar/organization.' The category of 'Healthcare system' included: 'access to child's medical record', and 'communicate with medical providers.'

Data Analysis/Key Variables

We calculated response frequencies for all multiple-choice and open-ended responses. We used the chi-square test to determine significance between demographic variables and response frequencies. We evaluated for associations between socioeconomic status variables (including age category, annual household income, and education) and both 1) barriers to usage of mobile technology categories and 2) desired mobile technology tools. We chose not evaluate by race/ethnicity categories or language of survey due to small categories (Hispanic n=4, completed in Spanish n=5). We included incomplete surveys, but left missing data out of our calculations. P-values were computed using Fisher's exact

test and considered significant if less than 0.05. Data were analyzed using SAS 9.4 (Carey, NC.)

Results

Demographics

A total of 121 caregivers responded to the survey, with a response rate of 30.8%. As presented in Table 1, survey respondents were primarily parents of children with cancer (93.2%) with a median age of 40.7 years (range: 23-63 years). They were primarily white, non-Hispanic 74.4%. The annual household income brackets included less than $25,000 to $49,999 (38.1%), $50,000 to $99,999 (34.8%), and $100,000 to $150,000 (19.5%). The majority had a college education: 52.5% had some college or were a college graduate and 22% had a graduate degree. 23.7% had a High School education or General Education Diploma (GED).

Phone/Operating System Use

Nearly all respondents owned a smart phone (99.2%, n=120), while 61.2% (n=74) owned a tablet, and 25.6% (n=31) owned a fitness tracker or smart watch. All respondents owned at least one type of mobile device and many owned more than one device. The majority of participants used an iOS operating system (62.8%, n=76), while 49.6% (n=60) reported use of a device with an Android operating system, 19.8% (n=19.8) used a Windows operating system, and 1.7% (n=2) used none of the above.

Personal Mobile Technology Use

All caregivers reported use of at least one mobile website/app regularly for their personal use. As shown in Table 2, all participants used some form of messaging on their mobile devices (i.e. email, text messaging) (100%). Other commonly used websites/apps included: social networking (i.e. Facebook, Instagram) (90.1%), multi-media tools (i.e. video, photos) (86.0%), map/directions (i.e. Google Maps, Waze) (81.8%), and calendar/organization (76.0%). Respondents were also asked about health mobile websites/apps for personal use and 71.1% reported use of at least one. The top health mobile website/app was physical activity tracking/exercises (40.5%), followed by medical knowledge (30.6%).

Barriers to Mobile Technology Use

Respondents were asked about barriers to their mobile technology use and could select more than one barrier. While 37.1% reported no barriers to mobile technology use, there were both phone/plan and website/app barriers experienced, see Table 3. Among phone/plan, the top barrier selected was 'data limitations' (22.4%). Also, participants had issues with inconsistent access to wireless internet connection (19.0%). Among website/app barriers, participants felt there were 'No good websites/apps that are helpful to me' (19.8%). Other barriers included that participants felt they could not trust the apps (19.0%). Only one respondent in our sample selected 'not having a smart phone or other internet capable device' and another selected 'no app for type of phone', while 8.6% selected they had 'other' barriers. Among the 10 respondents who wrote in "other" barrier responses, there were 3 who indicated that they felt a barrier was that they did not know of any useful websites/apps to help care for their child.

Mobile Technology Desires

Caregivers were asked to select what they would want in a mobile technology website/app to help them care for their child with cancer. Overall, 86.2% wanted at least one medical management website/app and 74.1% wanted at least one healthcare system website/app (Table 4). Among the options for medical management apps, participants were most interested in ones that addressed medical knowledge (61.2%), healthcare symptom tracking/management (49.1%), and medication reminders (44.8%). Participants also desired to have access to their child's healthcare system functions with 62.1% wanting access to their child's medical record and 58.6% wanting a website/app to facilitate better communication with medical providers. Among the 8 respondents who wrote in "other" desires responses, 2 mentioned features that would typically be part of a patient portal and 5 included features that would be within a medical management app.

Evaluation of Socioeconomic Status Impact

We evaluated the impact of socioeconomic status (including age, annual household income, and education categories) on the categories of barriers experienced and on which categories of websites/apps were desired by caregivers. The only significant finding for categories of barriers was that education level of caregivers significantly impacted participants experiencing phone/plan barriers with 61.5% of participants having less than high school to high school/GED experiencing barriers, as compared to participants with 32.8% with some college-college graduate and 20% with graduate degree (p-

value=0.008). There were no significant associations between socioeconomic status and whether the caregiver desired medical management or healthcare system websites/apps.

Open-ended response variables

Analysis of open-ended response variables such as which apps/websites were most helpful to the care of their child with cancer, caregivers wrote in that they used 'Google' (49.1%) and 'WebMD' (19.8%). Also, almost half (53.7%) felt their current mobile technology use did not change the quality of care they provided for their child.

Discussion

In this cross-sectional survey of mobile technology use and needs among caregivers of children with cancer, we found that caregivers frequently use mobile technology and want tools to help them care for their children with cancer. The vast majority of caregivers not only owned a smartphone and regularly used a mobile app/website for personal use, but also experienced few barriers. Most importantly, over four-fifths of caregivers desired a medical management mHealth tool to help with the care of their child with cancer. Among the most commonly desired medical management tools were medical knowledge, health symptom tracking/management, and medication reminders. Despite interest by caregivers, when provided with an open-ended question for which apps/websites they currently use to care for their child, they could only name a search engine (Google) and a generic medical reference site (WebMD). Due to the fact that healthcare system mHealth tools, such as access to a child's medical record and provider communication, are dependent on the medical system that the patient is in, we have

chosen to focus our discussion on the medical management tools desired by caregivers. The information gained in this survey provides key insight into the need for future research to develop and implement a mobile technology tool specifically to support caregivers in the medical management of their child with cancer.

The most highly desired medical management mobile technology tool among caregivers of children with cancer was one that would improve medical knowledge. It is imperative that caregivers have access to up-to-date medical knowledge pertaining to the supportive care and treatment of their child. Without adequate access and accurate information, caregivers may seek out information on their own and may make critical medical management decisions on the basis of incomplete or misunderstood information[8]. By including the pertinent medical knowledge within an mHealth tool, it can be easily and frequently updated as new treatment and supportive care therapies are utilized, such as Chimeric Antigen Receptor (CAR) T-cells or Blinatumomab for the treatment of relapsed or refractory acute lymphoblastic leukemia[9,10].

The second most desired medical management tool was for symptom tracking and management. Unfortunately, children with cancer experience a wide range of intense and bothersome symptoms during treatment,[11-13] which can impair their quality of life. Previous research has suggested that clinicians often underreport the severity and prevalence of the more common symptoms[14-17]. Therefore, the utilization of a symptom screening or tracking tool may lead to improvements in the discussion of these symptoms with healthcare providers in order to better address the patient's overall well-

being. An mHealth tool could be an ideal format for such a tracking system since smart phones or tablets are commonly in close proximity to the caregivers at most times. Luckily, there are currently available symptom screening tools, such as the SSPedi,[18] that could be incorporated into the medical management mHealth tool.

Lastly, caregivers requested an mHealth tool to provide medication reminders. This desire syncs well with their other preferences for medical knowledge and symptom tracking. Most treatment regimens for children with cancer include oral chemotherapy agents, antimicrobials for prophylaxis, and supportive care medications to manage side effects including chemotherapy-induced nausea or vomiting or pain. Previous research has found that medication reminders have the potential to improve adherence to prescribed regimens, especially among adolescents[19]. Specifically, improving adherence by incorporating the patient-centered reminders into a system that integrates well with the lifestyle of the patient or caregiver has shown promise[20,21]. Therefore, by incorporating medication reminders into the mHealth tool, caregivers of children with cancer will have a convenient way to ensure adherence to prescribed treatment regimens and evaluate the effectiveness of the symptom management plans.

Unfortunately, few mHealth applications are designed specifically for patient or caregiver use. In a 2016 study that evaluated 539 mobile applications related to oncology, only 21.7% were directed towards patients[22]. Importantly, many health apps have not been designed with input from health care or behavioral change professionals, have limited functionality, and may not have up-to-date information[23]. It is also not uncommon for

technology-focused health care interventions to be designed without any input from the targeted users[24-26]. Recently, federal funding agencies, such as the NIH and Patient Centered Outcomes Research Institute, have begun to recognize that the lack or only token level involvement of patients or caregivers has failed to result in interventions that are highly relevant to actual end users[27,28]. The inclusion of the intended user and a multi-disciplinary team in the development process increases the functionality and usability of the technology by keeping the focus on user's needs and increasing the likelihood it will be successfully used in the real-world setting. In a recent publication from Australia, a team of researchers engaged with oncologists, nurses, administrative staff, and caregivers to successfully design and implement the "Oncology Family App," which incorporated contact information, instruction on when to seek medical attention, and a laboratory examination tracking feature[29]. Previous research has also found that when intended users of mHealth technology are involved during the design process, development time is considerably reduced because usability problems are identified and resolved before launch[30]. Another important consideration would be to investigate the impact of health literacy and/or technology savviness on adoption and usage of mHealth tools by caregivers of children with cancer. Ultimately, we believe that it will be essential to utilize multi-disciplinary research teams, including providers and caregivers, for future research focusing on the development and implementation of mHealth tools.

Limitations

Our study has several important limitations. We performed a single institution survey, but our survey population spanned an entire state. Possibly due to responder bias, we found

higher rates of smart phone usage among our respondents than the general population, which may make the results of this survey less generalizable to all families of children with cancer[5]. Although, this finding may be related to the fact that those interested in mobile technology tools were more likely to complete our survey, they would also represent those most likely to use a mHealth tool. Additionally, since this was a cross-sectional survey among all caregivers of children diagnosed within the last 2 years at our institution, the respondents' child with cancer were likely in varying stages of treatment from recent diagnoses to off therapy monitoring. Yet, we still feel that the high usage of mobile technology and high interest in a new tool to provide medical management help among caregivers of children with cancer reassured us that this path of research should be pursued.

Conclusion

The vast majority of caregivers of children with cancer use mobile technology, with minimal barriers and desire a mobile technology tool to aid them in the medical management of their child with cancer. mHealth tools have the potential to provide support to caregivers across all aspects of healthcare from home management to organizing appointments to triaging acute medical needs, and could contribute greatly to providing higher quality of care and quality of life for caregivers and children with cancer. By supporting caregivers through a mobile technology tool that provides up-to-date medical knowledge, convenient patient symptom tracking, and medication reminders, we may be able to positively impact patient clinical outcomes through greater adherence to medications and treatment protocols. Future research should focus on

designing and implementing an mHealth tool to address the medical management needs

by caregivers of children with cancer.

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Figure Legend:

FIGURE 1. Participant flow diagram