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Opinion Article

A Mobile Application for Childhood Cancer Survivorship Care: A Cross Sectional Survey Study

Eleanor Plaunt[1-3], Svatava Merkle[1,2], Jill Lee[2,3], Susan Flesch[2,3], Char Napurski[2,3], Bradley Benson[1], Karim Thomas Sadak[1-3]*

[1]University of Minnesota Medical School, Minneapolis, Minnesota, USA

[2]University of Minnesota Masonic Children's Hospital, Minneapolis, Minnesota, USA

[3]Masonic Cancer Center, University of Minnesota, Minneapolis, Minnesota, USA

***Corresponding author:** Karim Thomas Sadak, University of Minnesota Medical School, Minneapolis, Minnesota, USA

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Abstract

The population of childhood cancer survivors (CCS) is growing, along with the number of CCS who will experience physiological and psychosocial late effects from their prior cancer treatments. Educational interventions need to be developed to increase engagement, ownership of health practices and knowledge to better prepare adolescent- and young adult-aged CCS for the transition to health care as adults. In a program evaluation effort, 140 childhood cancer survivors (or their parents) of all ages receiving care in a structured childhood cancer survivor program (CCSP) were surveyed about their preferences and expectations for a mobile application as part of their routine survivor-focused care. Respondents reported great willingness in using such an app and incorporating its use to receive educational messages related to several aspects of their care. Incorporated within a long-term follow-up program, apps have the potential to support CCS in their life-long educational journey. Benefits may include supporting coordination of their clinical care, continuous educational interventions, and connections among survivors, both with clinicians, researchers, and the broader cancer community.

Abbreviations: CCS: Childhood Cancer Survivors; LTFU: Long-Term Follow-Up; SCP: Survivorship Care Plan; AYA: Adolescent and Young Adult; mHealth: Mobile Health; Apps: Mobile Applications; CCSP: Childhood Cancer Survivor Program; BMT: Bone Marrow Transplant

Introduction to Mobile Applications in Survivorship Care

The population of childhood cancer survivors (CCS) is growing, along with the number of CCS who will experience physiological and psychosocial late effects because of their cancer diagnosis and treatment. CCS require long-term follow-up (LTFU) care, often with multiple providers at multiple locations. CCS and their families have reported preferring an electronic or web-based delivery of their survivorship care plan (SCP), which helps to facilitate care among key stakeholders and deliver key educational messages [1].

Educational interventions need to be developed to increase engagement, ownership of health practices and knowledge to better prepare adolescent- and young adult-aged (AYA) CCS for the transition to health care as adults. Mobile health (mHealth) interventions provide such a system including the use of mobile applications (apps) to improve patient education, care coordination, communication, and access to resources [2-5].

Rationale for the Use of a Survivorship App

Technology-based interventions have already been used successfully in adult and childhood cancer survivorship care. Web-based or application-based interventions have sought to improve cancer knowledge among CCS, as many survivors are unaware of their risks for late effects [6]. The following provides a focused review of the existing literature on this topic highlighted by several key studies.

Educational interventions to improve LTFU care for CCS (including AYAs) have demonstrated acceptability and feasibility in the past, including those delivered digitally [2,5,7]. In a prospective randomized controlled trial by Casillas, et al., among 71 AYA, a text-messaging educational intervention showed significant increases in survivorship care knowledge among those who received individualized text messages over eight weeks. A second group randomized to peer navigation also had significant increases in health insurance related self-efficacy skills [2]. Another intervention by King-Dowling et al. that paired digital SCPs with a mobile app demonstrated improved perceived knowledge, health awareness, and motivation to improve health among its users [5].

Mobile apps that manage health care is not a new concept, but it has not yet been rigorously evaluated among CCS, especially considering efficacy. Most tools to support self-management have been geared towards populations with a cancer diagnosis in adulthood [8]. Robust data exist for the use of modern technology in management of breast cancer survivors [9], especially related to health issues such as weight loss [10,11], fitness [12], and mental health [13,14]. SCPs that are offered online or through an app have many benefits. They are accessible at any time and any place, as internet is available. They provide continuity as patients transition to new providers and can be easily and remotely updated. They also can be used to disseminate the most recent research findings and patient resources ensuring survivors have access to this information [7].

Opportunities and Barriers for App Integration into Survivorship Care

Although apps have the potential to improve knowledge among CCS, past studies have identified multiple barriers in their successful development and use in practice, such as feasibility (including incorporating data from the app into an electronic health record), usability, satisfaction, readability, compliance, impact, cost and re-imbursement, inequitable access to technology, and long-term effects [4,14]. A systematic approach in app development keeping these barriers in mind should include the following: identifying needs through engagement of all key stakeholders and multi-level testing of the app's effectiveness with selected population [4]. Significant advances in app development and their clinical use have been achieved in heart disease and diabetes, especially in preventative care. Personalized, motivational communication and feedback are strategies used to improve app compliance, health outcomes, and overall satisfaction among app users. Additionally, several large health systems are testing the direct incorporation of information collected through an app into the electronic health record, to improve patient satisfaction and streamline the collection of patient-reported information [16,17]. Robust literature on these topics will help raise awareness of the benefits of such interventions to all key stakeholders, including payers/insurers, public health officials, information technology communities and health systems.

While research has been conducted on the acceptance of mobile apps in survivorship care, additional research needs to be conducted evaluating the safety and efficacy of these interventions [3,4,15]. As apps are relatively new to the childhood cancer survivorship care environment, past research cannot yet validate and inform their role in larger-scale health care delivery [8]. To fully understand the role of apps in survivorship care, longitudinal studies will need to be conducted moving forward to examine the challenges in data entry/input, wide scale implementation and ongoing information technology support and maintenance.

User Preferences from the Childhood Cancer Survivor Program

When developing a new app for CCS, the opportunities must be weighed with the challenges specific to the patient population and the institution where care is delivered [8]. In a program evaluation effort, 140 childhood cancer survivors (or their parents) of all ages (3 to 48 years) receiving care in a structured Childhood Cancer Survivor Program (CCSP) at the University of Minnesota [18] were surveyed about their preferences and expectations for a mobile application that would aid their routine survivor-focused care. Participants were given iPads upon arrival to clinic which they used to complete an electronic online survey. This practice for program evaluation and quality improvement efforts has been previously integrated into the routine clinical care delivered to CCS at their yearly CCSP appointments. The survey was administered from October 2019 to March 2020. The survey included 9 items focusing on psycho-social care and care coordination describing their preferences and expectations for a mobile app specific to their survivor-focused care and related educational messaging. Most participants (86%, 120/140) reported being very willing or willing to use an app on their phone that was specifically designed for childhood cancer survivors. Survivors selected the most useful psychosocial aspects of an app from an extensive list of features created by review of the relevant CCS and mHealth literature (Table I).

Table I: App User Preferences	**% (n=140)**
Select three things from the list below that you would find most useful in an app for childhood cancer/BMT survivors that's on your phone:	
The app can be used to connect online with other survivors	53
The app can give you a list of online and in-person resources in the survivor community	53
The app can send your updates on the latest survivorship research and findings	52
The app can help you increase your knowledge about your (your child's) cancer history and future health needs	50
The app stored all you (your child's) treatment history and summarized what tests you (your child) needed in the future	50
The app can connect you right away with someone from our Childhood Cancer Survivor Program that can help answer your questions	49
The app can help you get your medical questions answered	46
The app can help you make doctors' appointments	45
The app can send your reminders for your (your child's) upcoming doctor's appointments	43
The app can help you get involved in survivorship research	37
The app can help with your (your child's) mental health	28
The app can help you (your child) stay active and fit	21
The app can give you driving directions to the location of your (your child's) doctor's appointments	16
The app has games and fun things to do on it	16
If you had a survivor app on your phone what would be the best way to contact you (check all that apply)?	
Text message	69
Email	38
Chat through the app	31
Pushed message to your phone	22

Table I: App User Preferences.

Incorporated within a LTFU program, apps have the potential to support CCS in coordinating their clinical care, provide a medium for continuous education, and connecting survivors with researchers and the broader cancer community. Apps can help coordinate care for CCS by providing appointment reminders, geolocation tools for routine well care and pharmacy needs, and store essential resources like medication lists, information on how to access care teams and psychosocial resources, and links to health system patient portals.

Apps could also help with facilitating the transition of care to adult-centered models. As CCS grow older, the transition to adult health care can be tumultuous and cause survivors to be lost to follow-up [19,20]. Housing individualized survivorship care plans within an app and using it to deliver transition-focused educational messages could be a part of future intervention-based research to study facilitators of successful transitions to adult-centered care.

In fact, fully integrated apps could serve as a platform for patient recruitment and enrollment in multiple types of research, including administration of surveys and other quantitative and qualitative data collection. Most surveyed survivors receiving care through the CCSP reported being very willing or willing to complete surveys and participate in research through an app on their phone (Table I). Apps are also a platform that can allow health information to be shared regarding an individual's treatment history, common late effects risks, and other information that promotes health and wellness generally for the population of CCS. Survivors can update their preferences within an app to reflect their individualized informational needs as well as the mode of delivery of such messages (Table I). This would allow the care team to deliver educational messages that are truly personalized.

Finally, apps can support social connection among CCS, as well as connect survivors with psychosocial resources and

relevant community updates. Social support is an unmet need of young cancer survivors, and an app can be a tool to encourage peer-to-peer connection, either directly through the app or a linked social network [21]. Sponsoring institutions and organizations will need to moderate peer-to-peer social connection that is created directly within the app to ensure the social support is appropriate and aligned with the institution's values. The app can also provide recommended online social networks outside of the institution for CCS, as not all social networks for cancer survivors are created with the specific needs of CCS in mind. These resources can be vetted and then more easily complied in one central repository of information such as an app.

Conclusion

Incorporating mobile health interventions such as app-based SCPs into the health care delivery for CCS is not only feasible, but could impact engagement, ease the transition from childhood to adult models of care, improve survivor knowledge of late effects and skill building in self-management, as well as increase access to psychosocial resources and ultimately serve as a core clinical, educational and research tool. An app would allow for personalized educational messaging and when partnered with care team personnel having expertise in care coordination, could support the continuation of longitudinal care for CCS across the life span.

Challenges will include feasibility of a survivorship app being fully integrated into the electronic health record, optimizing end-user usability (and the related impact on satisfaction and compliance), and ultimately how to measure its impact including outcomes in the areas of implementation science, healthcare utilization and finance as well as equitable access to care. Systematic app development with inspiration and lessons-learned from other industries will result in an expanding body of literature on education-focused mHealth interventions for CCS and hopefully provide the evidence to inform future clinical trials that measure app effectiveness and ensure its contribution to delivering high-value survivor-focused care across the lifespan.

Author Contributions

All authors contributed to the study concept and design. Material preparation, data collection and analysis were performed by authors KTS, JL, SF, CN and BB. The manuscript was written by EP, SM and KTS. All authors read and approved the final manuscript.

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