

Internet-Based Survivorship Care Plans for Adult Survivors of Childhood Cancer: A Pilot Study

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Survivorship care plans (SCPs) provide health information to survivors and providers. An existing internet-based SCP generator was adapted to incorporate guidelines for adult survivors of pediatric leukemia and lymphoma. Survivors created an SCP online and completed a survey. Survivors ($N=30$) took an average of 10 minutes to complete the SCP. The majority (95%) found the platform easy to use, would recommend it to others (85%), and intended to share SCP with their healthcare team (90%). Thus, a patient-generated internet-based SCP for adult survivors of childhood cancer may be a feasible tool to improve consistency of information for survivors and their providers.

Keywords: survivorship, pediatric, care plans, internet

Background

WITH IMPROVEMENTS IN PEDIATRIC and adolescent cancer treatment, the number of childhood cancer survivors is growing rapidly. Adult survivors of childhood cancer have demonstrated a higher proportion of chronic health conditions than their peers, and disengagement with ongoing adult-oriented cancer-related follow-up care.¹⁻³ Even when engaged in the adult healthcare system, the providers they see (oncology, primary care, or subspecialty care) are often not familiar with the unique health vulnerabilities of survivors.^{4,5} Thus, survivors may not be receiving recommended risk-based survivorship care or understand their health vulnerabilities.⁶⁻¹⁰

Survivorship care plans (SCPs) have been cited as a means of providing survivors and providers with information and resources to engage in risk-based cancer-related follow-up care across multiple care settings.¹¹ In addition, recent accreditation standards for cancer centers include the provision of SCPs to survivors.¹² Creating SCPs can be timely, as ideally they are detailed and highly personalized. Free internet-based SCP generators exist for survivors of adult cancers.^{13,14} These care plans have been demonstrated to be valuable resources for the increasing number of survivors who self-seek information on the web.¹⁵ Although care plans for survivors

of childhood cancer are available through pediatric clinics, a free readily available SCP generator for adult survivors of childhood cancer and their adult providers that incorporates established long-term follow-up guidelines has not been available.^{16,17}

To improve the quality of survivorship care delivery for adult survivors of childhood cancer, the goal of this study was to adapt an existing internet-based SCP generator (OncoLife, housed at Penn Medicine) to include capacity to provide SCPs to adult survivors of pediatric cancer and to assess survivor-reported feasibility and acceptability.

Methods

Adaption

OncoLife SCPs have been described previously.¹³ In brief, the existing internet-based SCP generator utilizes demographic and diagnostic information (diagnosis, chemotherapy, radiation, and surgeries received) to create an individualized document. The resultant SCP contains content consistent with the Institute of Medicine (IOM) guidelines including risk for late effects and recommended screening guidelines, general health maintenance recommendations, and resources for survivorship. All guidelines provided are evidence or consensus based. Versions are available for patients and healthcare

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TABLE 1. DEMOGRAPHIC AND TREATMENT-RELATED INFORMATION (N=30)

<i>Demographics</i>	
Age (median, range)	32.4 (19–47)
Gender	
Female, n (%)	14 (46)
Race, n (%)	
Non-Hispanic Caucasian	22 (73)
African American	2 (7)
Mixed race/Other	1 (3)
Did not answer	7 (23)
Employment, n (%)	
Full time	15 (63)
Part time	4 (17)
Student	2 (6)
Unemployed	3 (1)
Insurance, n (%)	
Private	21 (84)
Public	2 (8)
Parents' plan	2 (8)
<i>Treatment related</i>	
Diagnosis, n (%)	
ALL	19 (63)
HL	11 (37)
Age at diagnosis, years, median (range)	9 (1–17)
Received chemotherapy, n (%)	30 (100)
Received radiation, n (%)	23 (76)
Underwent stem cell transplant, n (%)	7 (23)

Missing values excluded from percentage calculations.

ALL, acute lymphoblastic leukemia; HL, Hodgkin lymphoma.

providers. The SCP is available electronically and may be emailed or printed for later use by patients and/or providers.

OncoLife was adapted to create Smart Adult Living After Childhood Cancer (SmartALACC) plans for survivors of pediatric acute lymphoblastic leukemia (ALL) and Hodgkin lymphoma (HL). We adapted existing content or created new content by incorporating pediatric protocol information and Children's Oncology Group (COG) long-term follow-up guidelines into existing information technology logic. The content was vetted by a pediatric oncologist, radiation oncologist, pediatric psychologist, nurse educator, and young adult representatives. ALL and HL were targeted for the initial adaptations for this pilot study because of high cure rates of these disease processes and information about late effects for long-term survivors of these conditions.

Participants and procedures

The study was approved by the institutional review board at the University of Pennsylvania. A convenience sample of patients who were long-term survivors of pediatric ALL or HL who were registered to be seen at the Abramson Cancer Center Young Adult Survivorship Program or radiation oncology clinic were eligible to participate. Additional inclusion criteria included being English speaking, at least 16 years of age, and greater than 5 years from treatment.

Patients were approached either over the phone or in person before a clinic appointment and provided consent.

TABLE 2. FEASIBILITY AND ACCEPTABILITY MEASURES ASSESSED ON FOLLOW-UP SURVEY (N=20)

<i>Measure</i>	<i>n (%) in agreement</i>
Average time to completion	9min 46s
Website easy to use	19 (95)
Would recommend to another survivor	17 (85)
Satisfied with amount of information	16 (80)
Intend to discuss information with healthcare team	18 (90)

Participants navigated the SmartALACC SCP generator through their personal device (smart phone, tablet, or computer) at home or a tablet provided to them by the study team in the clinic waiting room. Patient demographics, including age, gender, race, employment, and insurance status, were self-reported with creation of the SCP. Participants self-reported their diagnosis (both type and age at diagnosis) and treatment (chemotherapy, radiation, surgery, and stem-cell transplant) using the built-in prompts based on the entered diagnosis and age. In many cases, participants have an existing treatment summary from prior clinic appointments to accomplish this. No treatment summaries were provided for the purpose of this study. The intention was to better understand the survivors' perspective of acceptability and feasibility of accessing the plan through the internet (and not necessarily in a clinical setting). Care plans were created in real time, and time to completion was recorded by the online system.

After participants reviewed their care plan, they were prompted to complete a short online survey. The survey assessed level of agreement to items including ease of website use, positive likelihood of recommending the site to another survivor, amount of SCP content, and intention to discuss the SCP with their healthcare team. Participants were also asked about their preferences for communication about survivorship care between clinic visits, including use of written plans, internet-based plans, phone calls, or additional in-person consultation. Finally, participants were asked to report their prior use of web-based health resources by items asking about use of the internet to search for survivorship-related information or general health information in the past.

Results

Eighty-six percent of patients contacted (30/35), consented, and completed an SCP and 57% (20/35) SCP also completed the online assessment survey. Of the participants who created a SCP (N=30), the median age was 31.4 years (19–47 years), 53% were female, and the majority were Caucasian (73%). Over half of survivors were employed full time (55%) and had private insurance (70%). There were more ALL (63%) than HL survivors (37%) represented. The median age at diagnosis was 9 years (range 1–17 years) and time since diagnosis was 22.4 years (range 8–40 years). Every survivor received chemotherapy, 76% received radiation (mediastinal, cranialspinal, or total body radiation) and 23% had a stem cell transplant (four allogenic and three autologous) (see Table 1).

Patient generation of SCPs was feasible, taking an average of 9 minutes and 46 seconds to complete. Of those who filled

out the follow-up survey ($N=20$), the majority (95%) found the SCP generator easy to use and would recommend it to another survivor (85%). Eighty percent of participants were satisfied with the amount of information received; those who were not satisfied were evenly split between wanting more information (10%) or a less lengthy plan (10%). Ninety percent stated they intended to discuss information from their plan with their healthcare provider (see Table 2).

Preferences for communication of survivorship information between clinic visits included 70% of survivors wanting a paper-based or online comprehensive care plan to reference. Half (50%) of those who wanted a written plan preferred the online format. Preferences for use of internet-based SCP included 70% wanting a treatment summary to complete their SCP and 50% wanting personal information to be saved for later use. About half (55%) endorsed using the internet for health-related information in the past and only about a third (35%) had specifically used the web to find information related to cancer survivorship.

Conclusions

SCPs have been cited as a mechanism to provide cancer survivors with tailored recommendations for follow-up and self-management.^{11,12} Adult survivors of childhood cancer pose a unique challenge as many of these survivors may have long moved on from their primary oncologist who could generate an individualized plan, yet may be seeking information themselves or require “just in time” information by a new provider based on their health-related risks and recommended follow-up.^{7,11} Internet-based SCPs may be a feasible way to deliver information to adult survivors of pediatric cancer and their healthcare teams.

This pilot project incorporated COG guidelines for long-term survivors of pediatric ALL and HL into an internet-based SCP generator. This website, which incorporates treatment algorithms to create an individualized SCP, was found to be highly feasible and acceptable by survivors. The majority of survivors report they would share information received with their healthcare teams. Thus, this patient facing tool may help to improve care coordination and shared decision making across multiple members of a healthcare team.

This is a pilot study meant to demonstrate feasibility and cannot yet be generalized to all survivors. Future work will focus on expanding the use of this SCP generator for adult survivors of other childhood cancers, providing this resource free on the web and testing the effect of this SCP on health behaviors and self-management. An SCP that is feasible for a survivor to generate and is freely available on the web will expand the reach of survivorship information to those who traditionally disengage with healthcare and improve health outcomes.¹⁸ Research into implementation of internet-based SCPs for adult survivors of childhood cancer in healthcare settings should continue to include integration into electronic medical records¹⁹ and primary care settings²⁰ to improve the quality and consistency of care received by survivors.

Author Disclosure Statement

No competing financial interests exist.

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