Journal of Cancer Education (2019) 34:638–646
https://doi.org/10.1007/s13187-018-1349-1

After Childhood Cancer: a Qualitative Study of Family Physician, Parent/Guardian, and Survivor Information Needs and Perspectives on Long-Term Follow-up and Survivorship Care Plans

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Abstract

Despite support for the provision of a survivorship care plan (SCP) to every cancer survivor, there is a lack of understanding of the needs and preferences of key stakeholders. We examined perspectives of a novel personalized SCP for childhood cancer survivors (CCS), their family, and family physicians (FP). We conducted semi-structured telephone interviews with a purposefully selected sample of CCS, parents/guardians, and FPs. Data included responses to stakeholder cancer care information needs, concerns with or gaps in communication, the perceived role of the FP in the long-term management of CCS care, utility of the SCP, preferred format, and suggestions for improvement. A deductive content analysis was conducted. Twenty-four participants including 8 CCS, 10 parents/guardians, and 6 FPs completed an interview. Four main and several sub-categories emerged. Core categories were coded as (1) informative reference, (2) coordination of follow-up, (3) barriers to follow-up care, and (4) suggestions for improvement and future implementation. The majority of participants preferred an electronic- or web-based format. Overall, the SCP was seen as an informative and concise resource. The SCP was thought to be a valuable tool to foster communication and empower CCSs to become more fully engaged in their own cancer-related health care. FPs viewed the SCP as a useful resource to facilitate and guide the long-term management of the CCS. In addition to the treatment summary, a comprehensive follow-up timeline, personalized lifestyle information, and details on how to access additional psychosocial support were highlighted as important components.

Keywords Childhood cancer · Survivorship care plan · Surveillance · Needs

Many children diagnosed with cancer in high-income countries will become long-term survivors [1]. However, studies have shown that the damage caused by the treatments responsible for this success can lead to other adverse physical (e.g., secondary cancers, abnormal growth and development, organ dysfunction, activity limitation) and psychosocial health outcomes [2, 3]. Of note, according to Phillips et al. [3], 66% of childhood cancer survivors were found to have at least one chronic health condition 5 to 14 years post-diagnosis. Of these, more than 25% report a serious or life-threatening condition. Regrettably, this health burden appears to worsen over time with as many as 88% of survivors between the ages of 40–49 years reporting at least one adverse chronic condition and 48% presenting with a severe/life-threatening health event [3]. The cumulative incidence of any chronic health condition has been reported to be as high as 99.9% in survivors by 50 years of age [4]. With as many as 400,000 childhood cancer survivors in the USA alone, the health burden associated with a childhood cancer diagnosis in high-income countries is a significant and growing concern [5].

As many childhood cancer survivors (CCS) are at risk of developing health issues several years following the completion of their treatment, it is recommended that CCS receive risk-based follow-up care throughout their lives [2, 6]. Regrettably, several studies have shown that survivors are

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Portions of this manuscript were presented at the inaugural American Society of Clinical Oncology Survivorship Symposium (2016).

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often unaware of their previous diagnosis, treatments, and their risk for long-term side-effects and are consequently inadequately prepared to seek out or advocate for the medical care necessary to meet their ongoing health care needs [7–9]. Similarly, family physicians (FPs) caring for CCS often report having no record of their patients' past disease, treatment history, or need for follow-up [10, 11]. Singer et al. [11] have proposed that a FP-directed, shared-care model is a feasible and sustainable option for the long-term follow-up and care of the CCS. Notwithstanding, FP training, supported transition and clinical support from the oncology treatment center, and access to detailed and up-to-date surveillance guidelines, as well as detailed treatment summaries and follow-up care plans (i.e., survivorship care plan; SCP) are needed to ensure that both the survivor and their FP are adequately prepared for the transition to FP-directed care and that FPs are fully informed of the survivors' diagnosis, treatment, potential risk for late-effects, and need for long-term surveillance [11, 12]. While the SCP has been identified as a valuable tool to improve patient-provider communication and the coordination and transition of care [13], a recent review by LaGrandeur [14] found that despite positive feedback from FPs, patients/survivor outcomes were mixed—potentially a result of a lack of use. Consequently, the need to identify user preferences is paramount to the ultimate acceptance and implementation of the SCP. Despite support for the provision of a SCP to every cancer survivor, relatively few studies have explored the needs and opinions of the CCS, their family, and FP [15]. Accordingly, this qualitative study explored the individual needs, preferences, and perceived utility of a personalized, algorithm-driven, automatically generated SCP for CCS.

Methods

Design and Participants

This descriptive qualitative study invited CCS, parents of CCS, and FPs with a known CCS in their current practice to participate in a semi-structured interview. To ensure that a range of survivor experiences were considered, a purposive sample of CCS was selected to solicit representation from survivor sex, common childhood diagnoses, and current age (14–29 years). CCS were eligible if they were diagnosed before the age of 17 years, had received treatment/care at the participating long-term follow-up clinic, had completed active treatment, and were able to read and understand English. Parents/guardians of survivors meeting these same criteria were also sought to participate. While most CCS and parents/guardians were recruited from the same family, this was not a study requirement. All interviews were conducted individually by telephone and lasted between 12 and 62 min.

Interview questions and prompts were informed by a review of the literature and tailored to the specific stakeholder group. Interviews included both closed- and open-ended questions and were conducted by a facilitator experienced in working with CCS and their families (KS). Survivors and parents/guardians were asked about their cancer care information needs, concerns with or gaps in communication with their FP about their cancer care needs, their perceived role of the FP in the long-term management and surveillance of CCS, perceived utility of the SCP, preferred format, and suggestions for improvement. FPs were asked about their current practice and perceived role in the long-term management of CCS, cancer information needs, concerns with communication, perceived utility of the SCP, preferred format, and suggestions for improvement. The study protocol was reviewed and approved by the local institutional review board and informed consent/assent was obtained from all participants.

Participants were identified and recruited from a Canadian pediatric hematology-oncology long-term follow-up clinic. A random selection of eligible survivors and their parent/guardian were mailed a separate letter of study invitation outlining how they were identified and the purpose of the study. Those interested in learning more about the study were instructed to contact the research team directly. Consenting survivors and parents/guardians received a novel, personalized SCP prior to the scheduled interview date. Where parents participated without their child, survivors (+ 18 years) were asked to provide written consent prior to releasing the personalized SCP to their parent. Following the completion of the interview, participants were sent a $20 gift card in appreciation for their participation.

FPs were similarly identified from the long-term follow-up clinic and were mailed a letter of invitation. Participating physicians received a mock SCP prior to the scheduled interview date. Participant recruitment was closed upon the emergence of theoretical data saturation [16].

SCP

Data extracted from an administrative patient data source was used to auto-populate a personalized SCP [17]. SCPs included an introduction, a patient's cancer diagnosis and treatment history, summary of disease, a description of possible late-effects and management strategies, a follow-up care plan [18], healthy living and lifestyle recommendations, and frequently asked questions. The SCP averaged 10–12 pages in length.

Analysis

Demographic and medical information were summarized using descriptive statistics using IBM SPSS Statistics for Windows Version 23. Participant interviews were transcribed

Table 1 Representative survivor participant quotes supporting data grouping and categorization

Category	Sub-category	Quote
SCP as an informative resource	Enhanced understanding of treatment received, risk of late effects, and need for follow-up care	"…some of these things I didn't even know about beforehand and so I guess it is good to know exactly my drugs that I've taken and their possible side-effects, long-term effects." (male, age 29) "…it gave me some useful information and things I sort of forgot about over the years…" (Female, age 16)
	Identify and reinforce importance of lifestyle choices	"…and now I look at this document and the first thing it says is don't smoke, I'm like crap, I should, you know, really quit, so you know with regards to making you aware that I may have a slightly, a slight increase in certain illnesses and that I should take precautions for that…" (male, age 29)
Coordination of care	Improved communication	"…here on my own and like forced to talk to my new doctor where I moved after that about my history without any documentation or path, so yah I can definitely see that this would be a really useful tool to have with you when you're sort of discharged from the treatment center." (female, age 28) "…now I know about stuff that it recommends for me I can tell my doctor…" (Male, age 14)
	Empowered to manage care	"…because I don't have a long-lasting family physician, I now can approach a new one and with this document and say I would like us to look at having this test or that test done, and how often we should repeat it." (male, age 29) "…it would help me coordinate my medical care with my medical providers or physician to meet my healthcare needs…" (female, age 16)
Barriers to follow-up care	Lack of knowledge/confidence	"…the reaction that I've had from new doctors, and I've had a lot of new doctors, like it's in the past you know, take care of yourself the way that anybody else needs to take care of themselves." (female, age 28)
Suggestions for improvement and preferred format	Detailed surveillance timeline	"…I think what would really help…specific dates…when people get so far out from their end of treatment…you can't remember without some sort of prompt…" (female, age 22)
	Need for disease-specific lifestyle recommendations	"…information about like don't smoke, eat well, make sure you're a healthy weight…it's very generic." (female, age 27)
	Additional supportive care resources	"…maybe a general hotline or something, or like a number for a support group or link to a website or something…" (female, age 22)

verbatim and the resulting data was imported into NVivo software to facilitate the development and comparison of categories. In keeping with inductive content analysis, investigators (KS and MK) performed independent open coding of all interview transcripts and then met to discuss data grouping and generation of categories [19]. Representative quotes are presented in the text and in Tables 1, 2, and 3 to support the generated categories.

Results

Participant Characteristics

A total of 24 interviews were conducted with survivors, parents/guardians, and FPs. Seventy-four letters of invitation were sent to both survivors and their parents/guardians. Of these, 11 survivors and 15 parents/guardians consented to participate. Eight survivors and 10 parents/guardians ultimately completed the interview. Those who consented to participate but were not interviewed were unable to be reached for the interview during the study period (July 2015–February 2016). Survivors were diagnosed between the ages of 3–15 years (mean = 9; SD = 4.7) and ranged in age from 14 to 29 years (mean = 23; SD = 5.6) at the time of interview. The most common childhood diagnosis was acute lymphoblastic leukemia (5/8; 62.5%). Other diagnoses included osteosarcoma, lymphoma, nephroblastoma, germinoma, and embryonal rhabdomyosarcoma. Two survivors were currently attending high school and all others had either completed or were in the process of completing a university degree. Parents/guardians ranged in age from 44 to 63 years (mean = 52.2; SD = 6.2) at the time of interview. One parent reported having completed high school, seven had completed a university degree, and two had completed post-graduate training. The majority of parent participants reported working either full or part-time (70%). The others were either unemployed (20%) or retired (10%). Of the 100 FPs invited to participate, 6 consented and completed the interview. FPs reported practicing family medicine for an average of 26.3 (SD = 10.1) years (range 9–39 years) and had an average of 2.8 (SD = 1.5; range 1–5) CCS in their current practice.

Table 2 Representative parent/family participant quotes supporting data grouping and categorization

Category	Sub-category	Quote
SCP as an informative resource	Enhanced understanding of treatment received, risk of late effects, and need for follow-up care	"…it's a point of reference, I think that's where I see that document being beneficial for sure and in future years…"
	Identify and reinforce importance of lifestyle choices	"…reminds you of good, basic, common sense health practices that everybody should practice and especially cancer survivors, so it's like a reminder, or reinforcement I guess or encouragement."
Coordination of care	Improved communication	"It's good for the doctor to be aware and to have a guideline. Cause you get in there and you try and tell them things but it's hard to remember everything."
	Empowered to manage care	"...maybe let's say that a family doctor might say you know she doesn't need, like you don't need that, you're jumping the gun on this or you're I don't know, you're too anxious or any of those things, and I might say no this is what's in the plan…"
Barriers to follow-up care	No longer a dependent	"…she went a few years without doing anything which was very problematic for me, but you know, she was an adult, I couldn't do it for her."
	Transition of care	"…now that we have left the pediatrician and the (treatment center) I'm just worried about the information being transferred over properly and understanding what she went through properly, all the medications and what not."
Suggestions for improvement and preferred format	Detailed surveillance timeline	"…the follow-up care, like the visits, how often they're going to be seen by the [treating hospital], how often they will be seen by a family doctor, physician and what tests are going to be done during those times."
	Need for disease-specific lifestyle recommendations	"…like that whole section, healthy living…I just find that's very generic to anybody. I don't see anything there that is particular to a cancer survivor."
	Need for an evolving document	"I wonder though whether some of this changes with time. In that, like sort of long-term effects of some of these drugs maybe is an evolving thing, and one would presume as new information becomes available it would be made available."
	Additional supportive care resources	"…one thing that they never, that they don't talk about is the emotional toll this takes on the child…There was no care plan on how to deal with the mental effects of this."

Participant Perspectives

Survivors were initially asked to comment on their current relationship with their FP with respect to their cancer care. Of the seven survivors who reported having a FP, three indicated that their FP had advised for or requested specific follow-up care. Two of these participants indicated that their FP had previously received a treatment summary from the participants' oncologist. The third participant whose physician had requested additional follow-up and who noted *not* having previously received a SCP perceived the care to be "pretty mild" and seemingly lacking any "pattern of regularity." When asked about cancer-specific health concerns, four survivors stated that they did not have any significant concerns, while the others expressed some uncertainty with respect to issues of fertility, cancer recurrence, and treatment-related late-effects.

Six of the 10 participating parents/guardians reported having received documentation outlining their child's diagnosis and treatment history at the time that their child was discharged from the long-term follow-up clinic. Others noted that while they did not recall having received a written summary, they felt well informed of their child's cancer history upon their child's discharge from the treatment center. Although some parents indicated that the SCP provided little or no new information, they all noted that it was a useful and concise summary of their child's cancer history and an important reminder for the need for long-term surveillance. With respect to follow-up care provided by their child's current FP, several parents/guardians found it difficult to comment as their child has reached adulthood and is no longer under their direct care. Parents/guardians of dependent survivors reported mixed findings with respect to the involvement of their FP in their child's cancer-related health care needs. Some reported that their child's FP was an active participant (i.e., providing disease specific follow-up surveillance and screening recommendations) their child's cancer follow-up care, while others stated that very little or no cancer-specific discussions or follow-up recommendations have been initiated by the FP.

Of the six FPs interviewed, two recalled having received a discharge summary from the oncology clinic with follow-up

Table 3 Representative family physician quotes supporting data grouping and categorization

Category	Sub-category	Quote
SCP as an informative resource	Enhanced understanding of treatment received, risk of late effects, and need for follow-up care	"…I really wasn't aware of these late effects from cancer treatment, so I guess as a family physician, your awareness needs to be increased, that this is how survivors need to be followed."
Coordination of care	Improved communication	"I think that it is just a good vehicle for talking."
	Empowered to manage care	"As GPs we are seeing 50-60 people a day, all with different kinds, you know some are acute, some are follow-up, some are chronic, so it's very important to have some direction as to what we do with each particular patient."
Barriers to follow-up care	Lack of knowledge/confidence	"I guess the biggest barrier would be a lack of knowledge as to what we should be looking at."
	Patient communication and compliance	"If there is a loss of communication between physician and patient that's the big one. But that's no different than any disease. If I tell you that you have diabetes and never seen you again, you and I can't manage your condition together."
Suggestions for improvement and preferred format	Detailed surveillance timeline	"I just thought yearly as just being a generic kind of frequency…"
	Risk appraisal	"…I think the key is to normalize it for folks and say this has happened, here are the actual odds, because some of these people get very exaggerated ideas of their risks. Or alternatively, they go too far the other way and minimize their risks."
	Additional supportive care resources	"…in the document you talk about a physical check-up, but I think it is also important that patient and doctor both realize that you need a psychological check-up."

recommendations, but none reported having received a detailed SCP. With respect to follow-up care, the majority (5/6) noted a lack of information and/or sufficient knowledge with respect to pediatric cancer treatments, potential late-effects, and recommended guidelines for surveillance and follow-up testing. Despite not having received a detailed SCP, most reported having initiated some type of cancer-related health care discussions with their CCS patients. The two participating physicians who reported receiving a surveillance plan for their patients indicated that they have used these documents to guide patient care.

Participant Assessment of the SCP

When asked about the personalized SCP, four main categories and several sub-categories emerged. The main categories were grouped as (1) SCP as an informative resource, (2) coordination of care, (3) barriers to follow-up care, and (4) suggestions for improvement and preferred format. While there was an overlap of sub-categories, sub-categories unique to each stakeholder group also emerged (Tables 1, 2, and 3).

Category 1: SCP as an Informative Resource

Participants found the SCP to be an informative and concise resource which provided an enhanced understanding of the cancer diagnosis, treatment(s) received, potential for late-effects, significance of a healthy lifestyle, and need for long-term follow-up. Several stakeholders noted that they were not aware of the late effects and need for long-term follow-up. For example, as one survivor noted, "some of these things I didn't even know about beforehand and so I guess it is good to know exactly my drugs that I've taken and their possible side effects, long-term side effects." (female CCS, age 29). A family physician similarly stated, "I wasn't aware of their increased risk of, although it doesn't surprise me, of the risks of these chemotherapy agents putting them at increased risk of things such as high blood pressure, renal failure, but also other forms of cancer in the future."

Category 2: Coordination of Care

The SCP was viewed as a useful resource to empower the survivor and to facilitate communication with FPs, ultimately improving the survivors' approach and engagement in their own cancer care. The utility of the SCP was highlighted for those survivors who will need to advocate for their own health care needs as they become more independent and transition from specialized oncologic to generalized healthcare. One survivor commented, "I was sick like between the ages of 9 and 12 so at that time my parents were handling everything, but having this survivorship plan in front of me that I can print off, keep in my own files, and it is so concise, it goes over the history of kind of what the disease was, how it affected you, what kind of drugs you got, what the side effects of the drugs are, it goes on to like how to be healthy, and what a healthy lifestyle is, so I think it's really important for the patient to have that as they kind of mature and grow older and start to take ownership of their own health care and stop relying on parents and stuff to book appointments and such, like I think it's really important to have that." (female, age 22). Parents/guardians and FPs likewise viewed the SCP as a valuable tool, providing concrete guidance and facilitating continuity of care. As per one parent, "And I think for [name] when he grows older, knowing that these drugs do cause different things, he can talk to his doctor about that and then the doctor would have more knowledge as to where do they go from here, instead of just coming in blind."

Correspondingly, one physician noted that, "information for the family doctor is crucial I think, in maintaining that continuity of care, and promoting the recovery, and maintaining the recovery."

Category 3: Barriers to Follow-up Care

Although survivors stated that the summary was a useful resource, some expressed concerns about a lack of confidence in the FP to meet the unique health care needs of a CCS. For example, one survivor noted, "I guess what is really challenging is that your family physician is your first point of contact but a lot of these areas of concern or focus aren't really applicable to a family doctor, you need to go to a specialist…" (female, age 28). For parents of non-dependent children, assuming a less active role in their child's health care was discussed as being challenging and concerns were raised about their child's willingness or motivation to follow up with a family physician with respect to their cancer care needs following discharge from the long-term follow-up clinic. As per one parent, "…she's an adult, so and she doesn't really welcome my involvement in it…" Parents/guardians also discussed concerns with a perceived lack of sharing of medical information among providers. For example, one parent noted a concern with her child's transition in care stating that, "…now that we have left the pediatrician and the (treatment center) I'm just worried about the information being transferred over properly and understanding what she went through properly, all the medications and what not." The utility of the SCP as a resource to mitigate these barriers was echoed.

In addition to a lack of knowledge and confidence in ability to adequately monitor, assess, and manage late-effects of childhood cancer treatments, FPs identified a perceived lack of patient communication, motivation to seek follow-up, and compliance, as barriers to care. With respect to providing follow-up care, one physician commented, "I think it's really going to depend on the individual patients' willingness to pursue it…" Physicians also noted that while the physical repercussions of the disease and associated treatments were well-described, the psychological impact and resultant patient needs lacked detail. Many physicians discussed the need to address the underlying fear and distress that many CCS continue to feel as a result of their childhood cancer experience—which may deter some from seeking/adhering to additional follow-up and testing. As per one physician, "…I think that they can struggle to communicate…I know that one of my patients is struggling with emotional issues."

Category 4: Suggestions for Improvement and Preferred Format

A consistent view across all stakeholder groups was the preference for a more detailed follow-up care plan with a comprehensive timeline outlining what tests should be conducted and when. Parents/guardians also noted that with the emergence of new research and a better understanding of the potential late-effects associated with treatment, having a living document that could be updated and provided to the survivor at regular intervals would be beneficial. One parent remarked, "I wonder though whether some of this changes with time. In that, like sort of long-term effects of some of these drugs maybe is an evolving thing, and one would presume as new information becomes available it would be made available." They also expressed concern over the inclusion of "generic" information on lifestyle behaviors and psychosocial support. While general health messages (e.g., "don't smoke") are not without value, there was a perceived need to better tailor these messages given each survivors' unique experiences. The suggestion of "joining a support group" was similarly viewed as a generic recommendation and the need for more specific resources was highlighted. Some parents/guardians stated that it was important to acknowledge that feelings of anxiety about a cancer recurrence or related health issues are normal and more detailed information and resources on how to manage such emotions were needed. One parent commented, "…they need to know that it's okay to talk to their doctor and that they can seek counseling or the doctor could pass them on for counseling…" FPs echoed the need for more detailed psychosocial screening, follow-up, and information on how to access supportive resources. FPs also noted a preference for greater detail with respect to an appraisal of risk or likelihood of a patient experiencing a late-effect as a result of their treatment. As per one physician, "…what's the risk? Is it 1% chance over your lifetime, is it a 22% chance over your lifetime, or is it 0.1%? Things like that would be of benefit."

With respect to preferred format, the majority of participants indicated that while they want a hard copy, they would prefer an electronic- or web-based format—one that could be saved, accessed, and shared as needed. FPs commented that a web-based version would permit rapid and more efficient access to additional guidelines and supportive care resources.

Discussion

This study offers a unique perspective on the needs, preferences, and perceived utility of an automatically generated, personalized SCP among CCS, their parents/guardians, and FPs with a known CCS in their practice. Consistent with available evidence, the SCP was well-received and valued as a concise and practical tool enhancing participant understanding of the disease, treatment(s) received, risk of late-effects, and need for follow-up surveillance [15, 20–23]. CCS and parents/guardians also recognized the value of the SCP to reinforce the importance of lifestyle behaviors and the survivors' personal responsibility for their health.

With an increasing number of CCS transitioning to the care of FPs, strategies for empowering survivors to advocate for their health care needs and to improve information sharing, physician-patient communication, and coordination of care will be required [10, 24]. Key findings of this study suggest that CCS, parents/guardians, and FPs viewed the SCP as an important resource to facilitate information sharing and communication as well as empowering both survivors and physicians to direct follow-up care. Similarly, Ezendam et al. [25] found that a SCP improved the frequency and quality of information provision between FPs, the medical specialist, and patients. Thus, while implementation studies of SCPs for CCS are few—the SCP may play an important role in facilitating the transition of care from the medical specialist to the FP [10, 21, 26].

Potential barriers to follow-up care were noted by all stakeholders. Consistent with previous studies, a perceived lack of FP knowledge of cancer-specific issues was noted by both CCS and FP as a prominent barrier in providing appropriate long-term follow-up care [27–31]. Concerns with information sharing, transitioning from the oncology specialist to the FP, and survivor compliance were likewise highlighted as potential barriers. Although no firm conclusions can be made, the findings of this and related studies suggest that the SCP may play an important role in mitigating some or all of these challenges [32–36].

While favorably viewed by each of the stakeholder groups, modifications to improve the SCP were suggested. Personalized information has been identified as a high priority for adult CCS [37], and while disease and treatment information was individualized, several survivors and parents/guardians viewed the healthy lifestyle information to be overly generic. Similar to the findings of LaGrandeur [14], the need for greater detail and information on how to access additional psychosocial support was also identified. With respect to format, the majority indicated a preference for an electronic- or web-based format highlighting the ease of access. Others have similarly advocated for a web-based design noting that it offers several advantages, including accessibility, document sharing, and the ability to tailor the document to meet the CCS personal preferences/needs [21]. Likewise, a web-based resource that is integrated with the electronic health record would address the stakeholder preference for a "living document"—one which offers the flexibility to add detail or revise as new knowledge of late-effects emerges or if new follow-up guidelines are developed [21, 23]. It would likewise ease the burden of information sharing and provide both CCS and FPs with access to an up-to-date, detailed risk-based assessment plan: a preference noted in this and similar studies [30, 31, 33, 38]. The findings from the present study provide valuable insight into the needs and preferences of CCS, their families, and FPs providing an opportunity to better tailor the SCP to optimize stakeholder acceptance and use.

Limitations

Given the relatively small sample size across each stakeholder group, and as not all CCS (e.g., brain cancer survivors) or treatment protocols were equally represented, the findings may not be generalizable across larger, ethnically diverse populations or institutions. Similarly, the findings of this study may not be generalizable to low- or middle-income countries where survivorship rates and experiences differ from high-income countries. Notwithstanding, while there is no clear consensus on the minimal sample size required to ensure data credibility, data from the current study was found to group into four main categories suggesting data saturation across each stakeholder group [16].

Conclusions

Findings from this qualitative investigation of CCS, parents, and FP in a high-income country provide insight into the value of a personalized SCP for providing long-term follow-up care for CCS to prevent or mitigate late-effects and address the potentially negative psychosocial consequences of surviving childhood cancer treatment. Given the lack of widespread implementation, additional research is needed to examine the standardized application a CCS SCP to improve coordination of care, risk-based health care, and quality outcomes as the CCS transitions from specialist pediatric oncology care to routine health care directed by adult health care providers and FPs [20]. Given the increasing numbers of CCS in high-income countries, expected to reach 500,000 in 2020 [39], barriers to appropriate and targeted survivorship care must be a priority for CCS and their pediatric oncologists, as well as their families and adult health care providers. A personalized SCP, which in general has been well-received by CCS, parents, and FPs in this and other studies [15, 20–23], is an important contribution to improved CCS long-term health care surveillance, but requires continued monitoring to establish its impact on CCS adult health.

Acknowledgements We would like to extend a special acknowledgement and thank you to the survivors, their family members, and physicians who made this study possible.

Funding This project received funding support from the Cancer in Young People Canada (CYP-C) program.

Compliance with Ethical Standards

Conflict of Interest The authors declare that they have no conflict of interest.

Ethical Approval and Consent to Participate Informed consent was obtained from all participants prior to inclusion in the study. The authors Institutional Review Board approved this study prior to implementation. All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

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