

## The Role Of Primary Care Physicians in Childhood Cancer Survivorship Care: Multiperspective Interviews

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### ABSTRACT

**Background.** Primary care physicians (PCPs) are well placed to provide holistic care to survivors of childhood cancer and may relieve growing pressures on specialist-led follow-up. We evaluated PCPs' role and confidence in providing follow-up care to survivors of childhood cancer.

**Subjects, Materials, and Methods.** In Stage 1, survivors and parents (of young survivors) from 11 Australian and New Zealand hospitals completed interviews about their PCPs' role in their follow-up. Participants nominated their PCP for an interview for Stage 2. In Stage 2, PCPs completed interviews about their confidence and preparedness in delivering childhood cancer survivorship care.

**Results.** Stage 1: One hundred twenty survivors (36% male, mean age: 25.6 years) and parents of young survivors (58% male survivors, survivors' mean age: 12.7 years) completed interviews. Few survivors (23%) and parents (10%) visited their PCP for cancer-related care and reported similar

reasons for not seeking PCP-led follow-up including low confidence in PCPs (48%), low perceived PCP cancer knowledge (38%), and difficulty finding good/regular PCPs (31%). Participants indicated feeling "disconnected" from their PCP during their cancer treatment phase. Stage 2: Fifty-one PCPs (57% male, mean years practicing: 28.3) completed interviews. Fifty percent of PCPs reported feeling confident providing care to childhood cancer survivors. PCPs had high unmet information needs relating to survivors' late effects risks (94%) and preferred a highly prescriptive approach to improve their confidence delivering survivorship care.

**Conclusion.** Improved communication and greater PCP involvement during treatment/early survivorship may help overcome survivors' and parents' low confidence in PCPs. PCPs are willing but require clear guidance from tertiary providers. *The Oncologist* 2018;23:1–10

**Implications for Practice:** Childhood cancer survivors and their parents have low confidence in primary care physicians' ability to manage their survivorship care. Encouraging engagement in primary care is important to promote holistic follow-up care, continuity of care, and long-term surveillance. Survivors'/parents' confidence in physicians may be improved by better involving primary care physicians throughout treatment and early survivorship, and by introducing the concept of eventual transition to adult and primary services. Although physicians are willing to deliver childhood cancer survivorship care, their confidence in doing so may be improved through better communication with tertiary services and more appropriate training.

### INTRODUCTION

Cancer survivors have complex and ongoing follow-up care needs [1]. Childhood cancer survivors (CCS) are at risk of treatment-related health complications affecting their

physical and psychological functioning [2–4]. Survivors' risks of developing morbidities continue to rise as they age [5]. Long-term follow-up care is recommended for the

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surveillance and management of potential lifelong, cancer-related health conditions [6–8]. Although hospital-based, oncologist-led models of care are generally preferred by survivors and health professionals [9–11], they are often resource-intensive and can have insufficient staffing and funding [12, 13]. Survivors report significant barriers to accessing follow-up, including logistical factors (e.g., costs, distance) and low motivation (e.g., low perceived late effects risk) [14]. As few as 25% of CCS are engaged in specialized cancer survivorship care [15, 16]. Disengagement from follow-up may be due to a reluctance to transition from pediatric care [17], or low perceived pediatric survivorship experience/knowledge among primary care physicians (PCPs) [18, 19]. Many survivors are therefore lost to follow-up upon transitioning from family-focused pediatric to patient-centered, often PCP-led adult care, resulting in many survivors with poor knowledge and skills to advocate for their care in the adult system [20].

A reliance on hospital-based, specialist-led follow-up is not ideal, with a lack of resources prompting transition of lower-risk survivors to follow-up in primary care [12, 21]. For many survivors, there are advantages to being transitioned to primary care. PCPs are well placed to provide holistic care and appear willing to deliver survivorship care to CCS [22]. Survivors engaged in PCP-led care compared with oncologist-led care demonstrate similar physical and emotional outcomes, despite receiving less survivorship-focused follow-up [23, 24]. However, PCPs report difficulty caring for CCS, complicated by their rarity in any one PCP practice [22]. There is little literature on survivor-reported barriers to, and optimal delivery of, PCP-led childhood cancer survivorship care. Furthermore, it is unclear whether these barriers may affect PCPs' confidence in providing care to this population.

We aimed to explore the feasibility of PCP-led survivorship care from survivors'/parents' and their PCPs' perspectives through a two-stage study: Stage one describes survivors' and parents' reported reasons for (not) accessing PCP-led survivorship care, and Stage two evaluates PCPs' reported needs (e.g., communication, support, and information) for delivering survivorship care and their perceived confidence in delivering care to CCS. The study outcomes, which take into account survivors' and PCPs' preferences and needs, will inform the development of a new, potentially more feasible and sustainable model of long-term shared follow-up care for CCS.

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## SUBJECTS, MATERIALS, AND METHODS

### Design

This cross-sectional study had two stages and was approved by ethics at each participating hospital. Stage 1 participants from a larger study, the ANZCHOG Survivorship Study, agreed to complete an optional in-depth interview after completing surveys [25], and nominated their PCP to be interviewed, which formed Stage 2. This study adheres to the COREQ guidelines for qualitative research (supplemental online Fig. 1).

### Participants

We identified eligible survivors from electronic hospital records who were diagnosed with cancer before 16 years of age and were treated at one of 11 participating Australian and New Zealand hospitals; were diagnosed at least 5 years prior; had completed active treatment; were English speaking; and were in remission. We invited parents of young survivors under the age of 16 to complete the interview on behalf of their child. We invited Australian PCPs, nominated by Stage 1 participants, by post. We obtained informed consent from all participants.

### Data Collection

A multidisciplinary team developed the interview guides (Table 1). Clinical psychologists and trained researchers piloted and conducted the semi-structured telephone interviews. We collected survivors' clinical/demographic data in the survey (Table 2). Survivor/parent interviews included questions on participants' follow-up engagement and reasons for accessing/not accessing PCP-led care. In PCP interviews, we collected PCPs' demographic and practice-related data, and asked about PCP receipt and use of survivorship care plans (SCPs) and oncologist letters, information, support and communication needs, and confidence understanding survivors' current and future follow-up needs and delivering survivorship care to CCS compared with adult cancer survivors. We audio-recorded and transcribed all interviews verbatim.

### Statistical Analysis

We used SPSS 24.0 (IBM, Armonk, NY) to conduct descriptive analysis and chi-square tests and *t* test analyses for respondent/nonrespondent and group comparisons. We used NVivo11 (QSR International Pty Ltd) to guide qualitative analysis. We categorized the qualitative data according to predetermined themes guided by our research questions for each Stage. We conducted thematic content analysis, informed by the Miles and Huberman methodology [26], which allowed the thematic organization of participant responses. We used matrix coding to explore themes across participant groups and characteristics (e.g., comparing survivor and parent data). Three researchers (C.S., J.F., A.T.) double coded 30% of interviews for consistency. Given the study size and high concordance (96.8%,  $k = 0.8$ ), one author (C.S.) coded the remainder of interviews. We resolved disagreements through discussion until consensus was achieved.

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## RESULTS

### Stage 1: Survivor/Parent Perspectives

#### Sample Characteristics

Of 612 ANZCHOG Survivorship Study respondents, 358 (58.5%) opted to be interviewed. We interviewed participants until we reached data saturation in each group at 57 adult CCS (48%; average age: 25.6 years, standard deviation [SD] = 6.2; average time since diagnosis: 18.6 years, SD = 7.8) and 63 parents of survivors under 16 years

**Table 1.** Interview schedule for Stage 1 (survivors and parents) and 2 (primary care physicians)

Survivor and parent interview guide
1) Have you seen your primary care physician for cancer specific care? [Prompts: If not, why? If yes, what has been your pattern of attendance? Do you attend regularly? Have there been periods of time in which you have not attended this service/seen this health professional? Why was this the case if so?]
2) Is there anything that you can think of that would make you more likely to see your primary care physician for cancer-specific care? [Prompts: Any suggestions of how to make this easier/improve care? What would have to change to make it more likely that you would see them for cancer-specific care?]
3) How confident are you that your primary care physician understands your current and future health needs?
4) Has your primary care physician given you any information about how you should manage your health into the future? [Prompts: Written handouts, verbally discussed; this information might be about preventing late effects, screening schedules, etc.]
Primary care physician interview guide
1) How confident are you that you understand [ <i>nominating survivor's</i> ] current/future health needs?
2) Do you believe [ <i>nominating survivor's</i> ] risk of developing late effects will decrease as time passes, or do you believe his/her risk will increase as he/she age?
3) Do you currently care for any other childhood cancer patients (i.e., diagnosed with cancer before the age of 18)? [Prompt: If so, approximately how many? Patients both on/off treatment; clarify if any are survivors?]
4) Do you care for any patients who are survivors of adult cancers? [Prompt: If so, approximately how many?]
5) How confident do you feel providing care to adult survivors of cancer?
6) How confident do you feel providing care to survivors of childhood cancer?
7) Some hospitals give survivors a treatment summary or survivorship care plan, also sometimes called a health passport; have you ever seen a summary or plan for patient [ <i>nominating survivor</i> ]? [Prompts: If so, how useful was it to you? Did it clearly guide you on their needs for ongoing surveillance? Was it prescriptive enough to be useful? How could it be improved, what additional information would you like to see included?]
8) Have you ever received letters from the treating oncologist about patient [ <i>nominating survivor's</i> ] surveillance needs? [Prompts: If so, how useful was it to you? Did it clearly guide you on their needs for ongoing surveillance? Was it prescriptive enough to be useful? How could it be improved? What additional information would you like to see included?]
9) Would you have liked to receive more information about [ <i>nominating survivor's</i> ] a) Surveillance needs or a copy of the relevant recommended surveillance schedules? b) Risk of developing late effects, including second cancers? [Prompts: If so, how would you have liked to receive this information? Letter, phone call, patient held record?]
10) Would additional information about this topic be useful to you (i.e., not related to your patient)? [Prompts: If so, how would you have liked to receive this information? Newsletter, seminar, website, webinar?]

Interviews were semi-structured and questions sometimes varied between participants. This schedule is therefore a guide and questions/prompts may or may not have been asked for every participant.

(53%; average child age: 12.7 years, SD = 2.0; average time since diagnosis: 10.2 years, SD = 2.1). Table 2 summarizes interviewees' demographic/clinical characteristics. Interview respondents were significantly younger (mean age 25.6) than nonrespondents (28.4 years,  $t(212) = 2.233$ ,  $p = .003$ ). We observed no other significant differences between interview respondents and nonrespondents in sex, rurality, marital and employment status, education, cancer diagnosis, treatment, and time since diagnosis/treatment completion.

Thirty-nine percent of older survivors (>16 years) and 81% of young survivors (<16 years) were engaged in oncologist-led follow-up, and few had visited their PCP for cancer-related care since finishing cancer treatment (23% and 10%, respectively). Survivors and parents reported similar reasons for not accessing PCP-led follow-up including little perceived PCP cancer knowledge and low confidence in PCPs, associated with PCPs' limited involvement during the treatment/early survivorship period. We therefore grouped responses for analysis. Table 3 provides illustrative quotations.

### **Reasons for (Not) Accessing PCP-Led Care**

Of the reasons raised by 61 participants for not visiting PCPs for survivorship care, participants most frequently mentioned low perceived PCP knowledge about their cancer history and long-term survivorship needs (38%). Some perceived PCPs to lack specialist knowledge about cancer survivors (28%), making them less suitable for survivorship care compared with the oncology team who "know what to look for at specific times whereas the PCP doesn't know" (mother of acute lymphoblastic leukemia [ALL] survivor, aged 15). Participants deemed PCPs more suitable for general health care (13%). Participants also cited not visiting PCPs for follow-up due to difficulty finding a good or regular PCP (31%) to build rapport with and who was familiar with their medical history. However, even some survivors with regular PCPs reported feeling detached (20%) from them following diagnosis: "The PCP that connected us to the hospital had nothing to do with us after that" (mother of ALL survivor, aged 15).

Another barrier was low confidence in PCPs' ability to deliver survivorship care (48%). Participants' confidence

**Table 2.** Clinical and demographic characteristics of adult and young survivor interviewees

Characteristic	Survivors, n = 57 (47.5%)	Parents of young survivors, n = 63 (52.5%)
Survivor sex, n (%)		
Male	22 (36)	29 (58)
Female	39 (64)	21 (42)
Relationship to survivor, n (%)		
Father	—	6 (14)
Mother	—	38 (86)
Ethnic background, n (%)		
Australian/New Zealand	41 (67)	30 (60)
European	1 (2)	8 (16)
Asian	2 (3)	1 (2)
Other	17 (28)	11 (22)
Area of residence, n (%) <sup>a</sup>		
Major city	39 (80)	32 (78)
Inner/outer regional	10 (20)	9 (22)
Education, n (%)		
No postschool qualifications	22 (36)	6 (12)
Postschool qualifications	39 (64)	44 (88)
Employed, n (%)		
Yes	14 (23)	6 (13)
No	47 (77)	40 (87)
Income, n (%)		
<AUD \$60,000	34 (61)	12 (25)
>AUD \$60,000	22 (39)	35 (75)
Diagnosis, n (%)		
Leukemia	18 (32)	17 (38)
Lymphoma	9 (16)	4 (9)
Brain	4 (7)	4 (9)
Other	25 (45)	20 (44)
Treatment received, n (%)		
Surgery	31 (54)	22 (45)
Chemotherapy	60 (98)	47 (94)
Radiation	27 (47)	18 (38)
Bone marrow transplant	12 (21)	12 (26)
Age of survivor in years, mean (SD)	25.6 (6.2)	12.7 (2.0)
Range	17–45	8.0–15.0
Time since diagnosis in years, mean (SD)	18.6 (7.8)	10.2 (2.1)
Range	6–42	6.0–14.0
Time since treatment completion in years, mean (SD)	16.3 (7.8)	8.5 (2.2)
Range	5–41	4.0–13.0
Number of years as PCP's patient, mean (SD)	9.3 (8.6)	8.5 (5.1)
Range	0.3–34.0	1.0–20.0

Numbers and percentages may not add up due to missing values and rounding errors.

<sup>a</sup>According to Area of Remoteness Index Australia classifications [39].

Abbreviations: —, not assessed or not applicable; PCP, primary care physician; SD, standard deviation.

appeared related to good communication and relationships with the oncology team, and to the time they had known their PCP, as it increased familiarity with their cancer history. Participants who reported confidence in PCPs attributed it to a good rapport, often developed over a long time. Those who did have a good relationship with their PCP described feeling “really lucky” (mother of ALL survivor, aged 13), recognizing the importance and rarity of this relationship. Participants preferring oncologist-led care (26%) occasionally even delayed seeking medical advice from a PCP ( $n = 4$ ), instead “saving” it for their next clinic appointment. Participants reported negativity toward PCPs alongside feelings of separation and isolation from the oncology team, with fear of getting “lost” in the system, particularly following transition to adult care.

Other barriers to seeking PCP-led follow-up included having an aversion to doctors after treatment ( $n = 4$ ), perceiving PCPs as too busy ( $n = 11$ ) for their complex needs, or due to out-of-pocket expenses ( $n = 3$ ). One recurring suggestion to alleviate barriers and low confidence in PCPs was earlier involvement of PCPs: “If when [my son] was diagnosed the PCP was more involved...that would make me feel more confident to go to him” (mother of brain tumor survivor, aged 14).

## Stage 2: Physicians' Perspectives

### Sample Characteristics

Of 160 eligible and contactable PCPs nominated by Stage 1 survivors/parents, 74 opted-in for an interview (46%). We reached data saturation after interviews with 51 PCPs determined by two authors (C.S., J.F.) conducting analysis alongside data collection. Twenty-nine (57%) PCPs were male, 33 (65%) worked in practices in major cities, and on average had 28.3 years' experience (range = 8–60, SD = 11.7) at the time of study participation. On average, PCPs had cared for 2.3 CCS in their career (range = 1–11, SD = 2.1). Nonrespondents were more likely to be male. We observed no other differences between nonrespondents and respondents in PCP-related factors (i.e., practice location) or survivor-related factors (i.e., sex, age, diagnosis, years as PCPs' patient, and years since primary diagnosis or treatment completion) [27].

Many (67%) recalled receiving letters from the survivor's treating oncologist about their cancer history and current medical needs. Few PCPs recalled receiving a treatment summary or SCP for their patients (12%). All PCPs felt confident providing care to adult cancer survivors, whereas only 54% of PCPs reported feeling confident providing care to CCS. Table 4 provides illustrative PCP quotes.

### PCPs' Communication/Information Needs

Twenty PCPs had read/used their survivor's letters since receiving them from oncologists, and 75% found them useful. Letters facilitated communication between the PCP and tertiary treating team, making them “very useful...quite easy to communicate with his treating team and get advice” (male PCP, practicing 17 years). The letters facilitated communication both with the oncology team and with the patient. PCPs noted additional benefits of such letters, including patient

**Table 3.** Survivor and parent reasons for not accessing PCP-led care and low confidence in PCPs

Theme	Illustrative quotation(s)
PCPs uninformed about cancer history	<p><i>"I've seen a couple of PCP's in Sydney who I've explained my history to. But I don't know that they completely comprehend the situation..."</i> (female soft tissue sarcoma survivor, aged 19)</p> <p><i>"I don't think through a PCP or anything like that would be any good because my PCP is very oblivious to the treatment that I had and the side effects that may come up from it"</i> (female ALL survivor, aged 33)</p> <p><i>"[PCPs] hardly ever see children with cancer....they don't have that the amount of knowledge that would be needed"</i> (mother of ALL survivor, aged 14)</p> <p><i>"I don't think they fully understand some of the late effects. I feel like I have to advocate for her."</i> (mother of NB survivor, aged 12)</p>
Lack of specialist care	<p><i>"My experience is that PCPs aren't very good...some of them are, but the majority... wouldn't know AML from non-Hodgkin's lymphoma for instance. And they wouldn't know the effect of the specific chemotherapy drug that I had"</i> (male AML survivor, aged 28)</p> <p><i>"I don't know whether he has been re-educated on side-effects of childhood cancer...if I have brought up any issues that I thought might be related he often you know laughs it off or puts it to the side and blames something else"</i> (female ALL survivor, aged 33)</p> <p><i>"We've got very good doctors but there are some things that they feel are outside of their expertise."</i> (mother of NB survivor, aged 12)</p> <p><i>"I have confidence in my PCP too. It's just that specialist care has always come from [my oncologist]"</i> (mother of ALL survivor, aged 12)</p>
Reliance on oncologist	<p><i>"If I was going to anyone about cancer-related issues it would be oncology...that makes sense"</i> (female NB survivor, aged 25)</p> <p><i>"I just feel in better hands with the people that know my record."</i> (female NB survivor, aged 19)</p> <p><i>"I prefer to deal with [anything cancer-related] through the hospital. We kind of wait for our long term follow up clinic meeting, and anything that comes up that we're concerned of, that might have a link, we'll raise it there rather than go to the PCP"</i> (mother of NHL survivor, aged 14)</p> <p><i>"I understood that with the long-term follow-up [clinic] that was the place to go at the top of care"</i> (mother of survivor, aged 14)</p> <p><i>"I mean, I would go [to the PCP] if I had to, but the truth be told is I much prefer the hospital; they know the history—it's a very rare form of cancer—he's received a lot of weird and unusual treatment"</i> (mother of JMML survivor, aged 10)</p>
Irregular PCP	<p><i>"A good PCP is rare to find"</i> (female Wilm's' tumor survivor, aged 30)</p> <p><i>"I see quite a few different PCPs trying to find a decent one because I live out in the country. The same PCPs don't stick around for very long"</i> (female HL survivor, aged 33)</p> <p><i>"At the moment he's got a collection of two or three PCPs that we would see. Whoever's available at the time. So we haven't developed a relationship with any one of them from that period... So I see the PCP as a very separate service to the one that we go to the hospital for"</i> (mother of NHL survivor, aged 14)</p>
PCPs better for noncancer care	<p><i>"You go to PCPs and they just treat the one particular thing. But I think it's probably quite likely that a lot of the things that I experience you know might be part of a bigger, a bigger picture."</i> (female Wilms' tumor survivor, aged 30)</p> <p><i>"I take him to PCPs for other ailments...I've told PCPs about the condition [my child] had...they just don't have the facilities to monitor that"</i> (father of LCH survivor, aged 14)</p>
PCPs disconnected after diagnosis	<p><i>"The problem with PCPs and childhood cancers is that basically they get left out of it... they might be involved with diagnosis or when the kid's sick, and they don't see the kid for ages because the kid gets consumed into a clinic setting...and the PCP may get the odd correspondence, or sometimes not at all... and the PCP just loses contact and kind of get lefts out as this superfluous person, and then after many years they get asked to be involved with their kids from a late-effects point of view... you can see why the parents wouldn't necessarily have confidence because [PCPs] haven't been involved along the way."</i> (mother of NB survivor, aged 13)</p> <p><i>"I'm confident he's a good PCP, I'm not confident that he's really familiar with what's gone on with [my child] because he hasn't had to be"</i> (mother of NB survivor, aged 13)</p> <p><i>"If when [my son] was diagnosed, the PCP was more involved...then that would make me feel more confident to go to him when a problem did arise"</i> (mother of brain cancer survivor, aged 14)</p>
PCPs too busy	<p><i>"[My PCP] sees thousands of patients, so he won't remember my medical history let alone the intricacies of it... I also don't think that he, even if he does remember my history, he understands what that treatment actually means"</i> (male AML survivor, aged 28)</p> <p><i>"[PCPs are] just interested in getting you out so they can get another one in...you've got no element of care there"</i> (father of LCH survivor, aged 14)</p>

(continued)

Table 3. (continued)

Theme	Illustrative quotation(s)
	<i>"Most PCPs, they're very busy...it's in and out, they make their diagnosis and tell you who to deal with it by the time you've got your first sentence out...they want to get you through, out the door"</i> (mother of HL survivor, aged 15)
Feeling "lost" in the system	<i>"I was pretty much left to look after my own health. My records were sent to my then current PCP who gave them to me, because I don't think she knew what to do with them. I don't think it is helpful to pass on a long-term survivor's health care to a PCP who doesn't really know what is expected in relation to long-term side effects and what health problems to look out for...I feel like once you are no longer a sick child you are no longer as important, which is sad because survivorship is increasing and there will only be a growing number of adult survivors who want to find answers to questions in relation to their future health."</i> (male ALL survivor, aged 34)
	<i>"A lot of the PCPs that I have seen are just—I don't know. They're not very personal. They read the notes and then they kind of think that they get a grip on you... I just feel in better hands with the people that know my record."</i> (female NB survivor, aged 21)
	<i>"Sadly, I think once you go into an adult system, you're a little bit lost in a crowd"</i> (mother of brain cancer survivor, aged 18)
	<i>"You become a number rather than [in] oncology, you're almost like a VIP"</i> (mother of JMML survivor, aged 10)
	<i>"After he finished treatment he got really sick...I do remember calling the hospital, but really they didn't want to know...and the PCP dealt with it, but just, yeah. It was just like—'okay, we are actually on our own now'"</i> (mother of ALL survivor, aged 13)

Abbreviations: ALL, acute lymphoblastic leukemia; AML, acute myeloid leukemia; HL, Hodgkin's lymphoma; JMML, juvenile myelomonocytic leukemia; LCH, Langerhans cell histiocytosis; NB, neuroblastoma; NHL, non-Hodgkin's lymphoma; PCP, primary care physician.

education and personal reassurance about the patient's care plan. However, 25% of PCPs did not find oncologist letters useful, criticizing them for lacking information and instruction about the survivor's follow-up and surveillance needs. Of the six PCPs who reported receiving a summary or care plan, all found them useful, describing them as a "roadmap" for delivering follow-up care and "essential" (male PCP, practicing 29 years).

PCPs who had not received SCP or oncologist letters attributed nonreceipt to losing SCPs among other paperwork or to patients commonly changing PCPs and practices. For some, the interview was the first time PCPs had sighted the summary or care plan at all, despite it being on file. Many PCPs noted a breakdown in communication during their patient's treatment, as "The hospital tend[ed] to just take over from me, and we don't have much to do... with their treatments" (female PCP, practicing 19 years). Poor communication during the treatment period appeared to translate into a general lack of knowledge about survivors' ongoing risks and, consequently, about survivors' ongoing surveillance needs.

Most PCPs reported unmet information needs about their patients' risk of developing late effects (94%) and recommended surveillance schedule (77%), and about general childhood cancer survivorship information (76%, i.e., not patient-specific), emphasizing the importance of brevity. The remainder simply admitted "It's not high on my list" (male PCP, practicing 60 years) and noted the clinical utility of more general information undermined its importance, given the small patient load in their practices. PCPs overwhelmingly requested a prescriptive approach with clear directions for care from the treating oncologist, and distinct patient-specific instructions "in black and white" (male PCP, practicing 43 years) reinforcing oncologist recommendations into a clear plan for care.

### Confidence

Despite all PCPs describing confidence providing follow-up for adult cancer survivors, PCPs' confidence caring for CCS appeared less robust. Many (63.2%) PCPs reported feeling confident that they specifically understood survivors' current and future health needs, generally portrayed as having a simple or "basic idea" (male PCP, practicing 57 years) of survivors' needs. Most PCPs (79%) reported feeling comfortable assuming full responsibility for the follow-up of CCS, if the survivor stopped attending survivorship clinics. Yet, PCPs' confidence and willingness to assume full responsibility for CCS appeared to depend on various factors, including being part of a team or having clear direction from oncologists. PCPs' confidence in survivors' future health needs was also somewhat superficial, with one PCP commenting about their patient: "If he's not complaining of anything I'm confident that there's nothing wrong" (male PCP, practicing 27 years). Low confidence appeared to be related to poor knowledge about the specific protocols recommended for each survivor, particularly "the kind of routine follow-up I should do or what sort of anticipatory care [is needed]" (male PCP, practicing 25 years). When asked if they believed survivors' risk of developing late effects increases or decreases as they age, 14% of PCPs believed it decreased with time. Thirty percent "did not know" and reported "It's never clicked for me that childhood cancer was a high-risk thing" (male PCP, practicing 43 years).

Qualitatively, PCPs attributed their lack of specific knowledge, and therefore confidence, to their inexperience and the few CCS they had seen in their career compared with adult cancer survivors. PCPs' confidence was not associated with PCPs' years of experience practicing ( $t(46) = -0.808, p = .808$ ) and the number of CCS they had cared for in their career ( $t(44) = -0.699, p = .488$ ).

**Table 4.** PCPs' perspectives of their role in childhood cancer survivorship care

Theme	Illustrative quotation(s)
Information/support	
Unmet information needs	<p><i>"What I would really like help with is what can I predict? What are her likely complications going to be?"</i> (female PCP, practicing 39 years)</p> <p><i>"Yeah. I think if there's specific information about what his risks are of those secondary cancers, and how they might change over time. I suppose, also, toxic effects on hearts or other organs and how that might change how over time, then that would be helpful."</i> (male PCP, practicing 17 years)</p> <p><i>"[Oncologist letters] just tell what he checked already and that they'll see him again in a year, they don't suggest we do anything at all."</i> (female PCP, practicing 24 years).</p>
Prescriptive instructions	<p><i>"Give me a piece of paper and I'll follow it"</i> (female PCP, practicing 39 years)</p> <p><i>"I sort of tend to rely on their recommendations in terms of long-term follow up."</i> (male PCP, practicing 30 years)</p> <p><i>"I guess if there was a protocol that they were all following, it would have been nice to see the total protocol to see what they're doing in adhering to the protocol...and the timelines of doing that, some things you wouldn't do every year, you might do them every 2 or 3 or 5 years"</i> (male PCP, practicing 43 years)</p> <p><i>"...Rather than guessing or looking it up myself, it would be good to get from her specialist maybe this is what you need to look out for, this is what you need to be doing for her"</i> (female PCP, practicing 10 years)</p> <p><i>"The best thing I can get is a detailed and accurate and intelligent summary of what's happening and what they recommend...they're like textbooks and resources and they last for a long time."</i> (male PCP, practicing 37 years)</p>
Preferred mode of communication	<p><i>"A letter...would scan it into the chart as well, and then it would be highlighted as cancer survivor follow-up... and it would be there for everybody who needs it—not just me."</i> (female PCP, practicing 24 years)</p> <p><i>"The patient [should] remain responsible for it—for the very simple reason that patients move around"</i> (male PCP, practicing 27 years)</p> <p><i>"There's just web pages all over the place out there, which don't get updated."</i> (male PCP, practicing 35 years)</p> <p><i>"[Oncologist letters are] useful as an indication of where to put my attention but also even more importantly that it's given to [patients] to look at and read and appreciate and you know...it is reassuring every now and again when I don't see [a patient] for a while you get a letter from the hospital saying that he has attended"</i> (male PCP, practicing 46 years)</p>
PCPs disconnected	<p><i>"I don't have any old notes from where he was diagnosed."</i> (female PCP, practicing 19 years).</p> <p><i>"It's very important to get this regular correspondence all the time, and that, to give us a good insight of what's happening and what needs to be done, and to get us connected, uh, to the patient, and to the other team to be our—make us feel we're in the loop with other team as well, in terms of his management and long-term management."</i> (male PCP, practicing 23 years)</p> <p><i>"We need to be in contact with the patient. Quite often now they're stolen away from you and you don't see them...mostly they're pushed out of your hands and you're lucky if you might see them."</i> (male PCP, practicing 37 years)</p>
Clarification of roles	<p><i>"What seems to be happening is they're doing some of the things that are on [the care plan] so there's an overlap of who's actually responsible. They're doing a lot of blood tests and they've just done the thyroid, whereas I would have been happy to do it. So probably a little bit of clarity surrounding who's responsible for it all."</i> (male PCP, practicing 12 years)</p> <p><i>"Whether they would recommend different screenings...or whether it's, you know, just a matter of looking out for those symptoms, and investigating if they occur, or whether they want PCPs to be more proactive, and you know, be doing surveillance."</i> (male PCP, practicing 12 years)</p>
Confidence	
Confidence with adult cancers	<p><i>"Probably more confident than I would [be] with children, just because of the—yeah, I'd be more used to dealing with them."</i> (female PCP, practicing 19 years)</p> <p><i>"My confidence is higher for the survivors of adult cancer just through experience and I guess greater familiarity with the types of cancers that adult survivors of cancer tend to have."</i> (male PCP, practicing 12 years)</p>
Confidence with childhood cancers	<p><i>"I have a fairly good understanding of what he's been through [but] the future for him, I think, is probably a bit difficult [to understand]"</i> (female PCP, practicing 19 years)</p> <p><i>"I don't have that many so, no, I don't feel particularly confident what I should be looking out for or what I should be checking, things like their thyroid or their bone mineral density"</i> (male PCP, practicing 39 years)</p> <p><i>"I am very confident as long as I'm part of a team"</i> (male PCP, practicing 41 years)</p>
Child versus adult care	<p><i>"In some ways, when we're seeing her...we probably don't view her as a cancer survivor"</i> (female PCP, practicing 14 years)</p> <p><i>"I treat [childhood cancer survivors] in a way just like I treat the adults"</i> (male PCP, practicing 46 years)</p>

Abbreviation: PCP, primary care physician.

## DISCUSSION

Although PCPs are best placed to provide holistic care, survivors and parents lack confidence in PCPs and reported many barriers to accessing PCP-led follow-up, including lack of involvement from their PCP during treatment and early survivorship. Many PCPs received oncologist letters, but few reported receiving SCPs. Most had unmet information needs regarding survivors' current/future survivorship needs. PCPs reported lacking confidence in delivering cancer-related care to CCS, and confidence appeared to depend on receiving very clear instructions for each patient regarding their specific ongoing surveillance needs and late effects risk.

### Survivors'/Parents' Perspective

Fewer survivors in our study engaged with PCPs than those in other studies [24]. Australia's dispersed nature and distance to survivorship clinics further highlights the need to encourage having regular PCPs among this high-needs population [28]. Consistent with existing literature, survivors reported reluctance in visiting PCPs for cancer-related care due to low perceived experience and pediatric survivorship knowledge [29, 30], as well as to strong feelings of detachment from PCPs after diagnosis. Strong PCP relationships in adult cancer patients are built on trust and rapport, most notably developing over time [31]. Such relationships may be less common in CCS who develop strong relationships with their oncologist and may prefer never to transition to adult care [12, 17]. Encouraging early involvement of PCPs and better communication with PCPs throughout the treatment and early survivorship phases may facilitate rapport building with the PCP. Increased PCP involvement may also reduce delayed visits among survivors "saving" health concerns for their annual or sometimes bi-annual clinic visit at the hospital, which can lead to poorer prognoses for otherwise preventable or easily treatable conditions. Encouraging PCP involvement by the oncologist or tertiary hospital multidisciplinary team may improve survivors' confidence and reduce potential anxiety induced by transition to adult (often primary) care, when many survivors become disengaged from any follow-up [20, 32]. Disengagement results in missed opportunities to monitor for, and possibly prevent, treatment-related complications. Feelings of isolation/separation from their oncology team following transition may be negatively projected onto PCPs, which might be alleviated by introducing the concept of transition earlier to families to potentially lessen their reluctance and increase their long-term engagement and satisfaction with PCP-led care [19].

### PCPs' Perspective

PCPs' small CCS load and the time-poor nature of PCPs in our sample may explain PCPs' preference for patient-specific and prescriptive information, compared with general childhood cancer survivorship information. PCPs in our sample who had previously received SCPs and oncologist letters highly valued their instruction to guide their patient's follow-up. Improved SCPs and letters directed to PCPs with clear follow-up plans may assist them in

delivering higher-quality risk-based care, including referral to specialists where needed and the coordination of survivors' potentially complex ongoing care [29]. This could be facilitated through the standardization of SCPs, which currently differ nationally and internationally [12]. The crucial nature of good communication for the effective delivery of evidence-based care has also been emphasized in recent literature [33].

Over half of the PCPs in our study reported feeling confident delivering survivorship care and understanding survivors' health care needs. However many indicated a lack of true understanding of the risks/needs unique to CCS, possibly a consequence of poor communication resulting in high information needs, which may be alleviated by providing PCPs detailed SCPs [34]. PCPs' poor knowledge of survivors' follow-up needs is well documented [19, 35, 36]. Their general-level knowledge, and low awareness of issues pertinent to pediatric cancer survivorship, may be due to their being less "invested" in this population due to the small number of CCS in any primary care practice. This contrasts with their high self-reported knowledge and confidence (100%) for adult cancer survivors. A significant minority of PCPs are unwilling to accept exclusive responsibility for cancer survivors, either adult or children [37, 38]. Rather, PCPs prefer a shared care follow-up model, which evidence suggests helps survivors overcome distrust in providers [32]. Further clarification of primary and tertiary providers' responsibilities is needed, and may improve the confidence of all parties and the quality of care delivered by reducing overlap or missed opportunities for surveillance [39, 40].

### Limitations/Strengths and Future Directions

Stage 1 represented many survivors engaged in specialist-led follow-up care. The literature suggests survivors/parents typically prefer the model of care in which they are engaged, possibly influencing the results [41]. Survivors' and PCPs' confidence may have also been influenced by other factors not explored in detail here (e.g., survivors' level of risk), and further systematic evaluation is required. Although we did not observe any notable differences in adult or parent responses based on their sex or time since diagnosis, future studies should more systematically assess these factors and their potential influence on barriers to PCP-led care. Identifying factors associated with survivors'/parents' willingness to receive follow-up from their PCP may assist in identifying more targeted approaches to enhance self-management and engagement in follow-up. Future research should target male survivors, who were somewhat underrepresented in our study.

The moderate Stage 2 response rate may be considered a limitation; however, we observed no systematic differences in nonrespondents (besides gender), and we collected data until we achieved a broad sample and reached thematic saturation [42]. Although we collected PCPs' years practicing, we did not ask their age, which may influence their responses. PCPs' receipt of SCPs and patient letters may have been subject to potential recall bias and therefore misrepresented. However, we encouraged PCPs to conduct interviews in front of their medical records, and

some PCPs admitted to seeing these documents for the first time during interviews. Improving SCP content/format as suggested by PCPs may increase their utility and transfer between health professionals. This highlights the importance of the oncology team educating survivors and equipping them as advocates for their health as they traverse the adult health care system.

## CONCLUSION

Survivors and parents lack confidence in PCPs to provide their ongoing survivorship care. Involving PCPs at all stages, and introducing the notion of transition, with shared-care, to PCPs to survivors earlier (i.e., during treatment and early survivorship), may improve the familiarity and importance of adult follow-up while decreasing reluctance to seek PCP-led care. PCPs are well placed to offer holistic care but also lack confidence. PCPs proposed additional support, more appropriate training, highly personalized and prescriptive instructions, and ongoing liaison from tertiary services to improve their confidence and ability to deliver survivorship care. In turn, this may also increase survivors'/parents' confidence in them, reducing disengagement particularly after transition from the pediatric setting. Equipping survivors with knowledge and skills to advocate for their care is an important step in the process. Together, these efforts may ultimately reduce the pressure on oncologist-based follow-up from the growing population of CCS, while encouraging participation in long-term, personalized follow-up for survivors of all levels of risk.

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## DISCLOSURES

The authors indicated no financial relationships.

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