

Original Article

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“It just never ends”: Childhood cancer survivors’ perceived psychosocial impacts of recurrence and second cancer

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Abstract

Objectives. Childhood cancer survivors are at risk of developing primary recurrences and new second cancers. Experiencing a recurrence and/or second cancer can be highly distressing for survivors and families. We aimed to understand the psychological impacts of experiencing a recurrence or second cancer and how this potentially influences survivors’ engagement with survivorship care.

Methods. We invited childhood cancer survivors or their parents if survivors were ≤ 16 years of age from 11 tertiary pediatric oncology hospitals across Australia and New Zealand to complete interviews. We conducted a thematic analysis facilitated by NVivo12.

Results. We interviewed 21 participants of whom 16 had experienced a recurrence, 3 had a second cancer, and 2 had both a recurrence and second cancer. Participants reported that a recurrence/second cancer was a stressful sudden disruption to life, accompanied by strong feelings of uncertainty. Participants tended to be less aware of their second cancer risk than recurrence risk. Some participants reported feelings of anxiousness and despair, describing varying responses such as gratitude or avoidance. Participants shared that the fear of cancer recurrence either motivated them to adopt protective health behaviors or to avoid information and disengage from survivorship care.

Significance of results. Some survivors and their parents have a poor understanding and expressed reluctance to receive information about their risk of second cancer and other treatment-related late effects. Improving the delivery of information about late effects to families may improve their engagement with survivorship care and surveillance, although care must be taken to balance information provision and survivors’ anxieties about their future health.

Introduction

Owing to advances in multimodal regimens and supportive care, a majority of children diagnosed with cancer are now surviving (Youlden et al. 2020a). However, many childhood cancer survivors experience physical and psychological late effects as a result of the intensive treatments that cured them (Kadan-Lottick et al. 2002; Robison and Hudson 2014; Force et al. 2019; Lam et al. 2019). Potentially life-threatening late effects include recurrence of their primary cancer and developing new second cancers, due to the mutagenic consequences of chemotherapy and radiotherapy or genetic predisposition (Robison and Hudson 2014; Lie et al. 2015; Youlden et al. 2020b). Childhood cancer survivors are at risk of developing a recurrence up to 20 years after their initial diagnosis, and their risk of second cancer continues to increase with age, which has resulted in higher morbidity and mortality compared to the general population (Armstrong et al. 2009; Wasilewski-Masker; Liu et al. 2009). Survivors are also 5 times more likely to develop a new second cancer, compared to the general population, with elevated risk continuing into their sixth decade of life (Kadan-Lottick et al. 2002; Robison et al. 2014; Wilkins and Woodgate 2008; Turcotte et al. 2015; Youlden et al. 2020b). Adolescent and young adult survivors diagnosed with a second cancer have 7 times greater risk of death compared to their peers with only a single cancer diagnosis (Armstrong et al. 2009; Chao et al. 2019).

Evidence-based guidelines on reducing survivors’ risks of second cancer recommend several protective health behaviors for survivors of childhood cancer such as surveillance, sun protection, and avoiding tobacco and alcohol (Kadan-Lottick et al. 2002; Parker et al. 2003; Wilkins and Woodgate 2008; Robison and Hudson 2014; Lam et al. 2019, Children’s

Oncology Group 2009). However, many survivors still report a limited understanding of their subsequent cancer risks and do not follow precautionary recommendations (Kadan-Lottick et al. 2002; Oeffinger and Wallace 2006; Wilkins and Woodgate 2008; Armstrong et al. 2009; Vetsch et al. 2017; Chao et al. 2019; Signorelli et al. 2019; Knighting et al. 2020). In many developed countries, only half of the survivor population are engaged in long-term survivorship care and are able to receive regular health advice and surveillance, limiting opportunities for early intervention should new diseases emerge (Oeffinger and Wallace 2006; Nathan et al. 2008; Armstrong et al. 2009; Hudson et al. 2013; Berg et al. 2016; Signorelli et al. 2016; Vetsch et al. 2017; Chao et al. 2019; Signorelli et al. 2019; Knighting et al. 2020).

Fears of a subsequent cancer diagnosis are prevalent in survivors of childhood cancer and are recognized as a debilitating psychological long-term effect of cancer therapy (Mahon and Casperson 1997; Hinds et al. 2002; Butow et al. 2018; Signorelli et al. 2019). In adult survivors of childhood cancer, experiencing a cancer recurrence is shown to contribute to high levels of psychological distress; however, there is insufficient literature on the psychosocial narratives of childhood cancer survivors and their experiences with cancer recurrence and second cancer (Mahon et al. 1990; Mahon and Casperson 1997; Vetsch et al. 2017; Butow et al. 2018; Signorelli et al. 2019). Therefore, this study aimed to explore childhood cancer survivors' perceived impacts of being diagnosed with a recurrence or second cancer (herein collectively referred to as a "subsequent cancer") and their experience of living with the risk of developing a subsequent cancer.

Methods

Participants

This study forms part of the ANZCHOG Survivorship Study (Signorelli et al. 2021). We invited childhood cancer survivors from 11 tertiary pediatric oncology centers across Australia and New Zealand to participate in this study. To be eligible, participants must have (i) been diagnosed with any type of cancer prior to the age of 16 years, (ii) completed curative treatment and be in remission, and (iii) survived at least 5 years since their primary diagnosis or (iv) be the parent of a child who met the above criteria. Parents were interviewed if survivors were unavailable or ≤ 16 years of age. Only one parent completed an interview, and just one interview was conducted per family. For inclusion in this analysis, survivors had to have experienced either a recurrence of their primary cancer, or a new second cancer, or both.

Data collection

Survivors or parents completed an initial questionnaire (Signorelli et al. 2021) in which they indicated their willingness to be interviewed. We mailed an information package and consent form to interested survivors and parents and contacted consenting participants by phone to arrange in-depth semi-structured interviews. We obtained written and verbal consent for participation and publication of information before audio recording interviews. We asked structured questions at the start of the interview to collect participants' demographic and clinical information, including survivors' age and primary and subsequent cancer diagnosis, followed by open-ended questions relating to their treatment experience, awareness of late effects, and worries about future health (Supplementary Table 1). Our team had no prior clinical or personal relationship with the participants.

Data analysis

We transcribed the interviews verbatim, and the transcripts were used for qualitative analysis. Author AL led the qualitative analysis, which was double-blind coded by author LT to support inter-coder reliability (99% agreement, $k = 0.8$). Demographic information was also extracted during the coding process. We categorized survivors according to whether they had experienced a primary recurrence, new second cancer, or both a recurrence and second cancer. We coded the transcripts using NVivo12 Pro and used reflexive iteration to derive common themes guided by Braun and Clarke (2006). The coding tree developed included themes that arose. We refined themes through critical appraisal and team discussion and undertook matrix coding to compare emergent themes between survivors who experienced a recurrence and survivors who experienced a second cancer, for example, "risk awareness" and "mental health outcomes." Any distinct differences that emerged between these groups are reflected both within and between themes. We used the consolidated criteria for reporting qualitative research checklist to guide the reporting of this study (Tong et al. 2007).

Results

Demographic and clinical characteristics

Of the 634 questionnaire-respondents, 370 (58%) expressed willingness to participate in an interview. We interviewed 143 participants, including 71 childhood cancer survivors and 74 parents of young survivors (≤ 16 years of age), and stopped the interview when we reached data saturation (i.e., no new information appeared to be arising). For this analysis, we had 21 participants (16%) who reported being diagnosed with a subsequent cancer. Of these, 16 participants (9 survivors and 9 parents) reported that they (or their child) had experienced a recurrence of their primary cancer (see Table 1). Three participants (1 survivor and 2 parents) reported that they (or their child) had experienced a new second cancer, and 2 survivors experienced both a recurrence and second cancer. Survivors with recurrences ranged in age from 13 to 35 (mean age = 21) and were 9–23 years from their first cancer diagnosis (mean years since primary diagnosis = 15 years). Survivors with second cancer ranged in age from 25 to 34 (mean age = 29) and were 19–30 years from their first cancer diagnosis (mean years since primary diagnosis = 22). All survivors who had second cancer were female, and the majority of second cancer was skin cancer. The main themes derived are survivors' experiences with being diagnosed with a subsequent cancer, psychological impacts related to subsequent cancers, awareness of subsequent cancer risk, healing and coping, and engagement with survivorship care.

Experiences of being diagnosed with a subsequent cancer

Most participants described their subsequent diagnosis as a sudden disruption to their life (see Table 2). Participants who had a recurrence tended to describe their experience as entering uncharted territory with "no protocol" (mother of a survivor with Ewing sarcoma of the rib and recurrence, age 14, male), as doctors often presented the course of their disease as largely unknown. Participants who had second cancer tended to recall their experience as an unexpected "surprise" (mother of medulloblastoma survivor with secondary sarcoma and basal cell carcinoma, age 25, female). Parents reported feeling that they made medical or treatment-related decisions under high pressure without being

Table 1. Demographic and clinical characteristics of childhood cancer survivors who had experienced recurrent and/or second cancers

	Recurrence only, N (%)	Second cancer only, N (%)	Recurrence and second cancer, N (%)
Gender of survivor			
Male	9 (6%)	0 (0%)	0 (0%)
Female	7 (5%)	3 (2%)	2 (1%)
Age of survivor (years)			
≤12	0 (0%)	0 (0%)	0 (0%)
13–20	10 (7%)	0 (0%)	0 (0%)
21–30	5 (4%)	2 (1%)	1 (1%)
30–40	1 (1%)	1 (1%)	1 (1%)
Primary cancer diagnosis			
Hematological	4 (3%)	1 (1%)	1 (1%)
Solid tumor	8 (6%)	1 (1%)	1 (1%)
CNS tumor	4 (3%)	1 (1%)	0 (0%)
Second cancer diagnosis			
Hematological	NA	0 (0%)	0 (0%)
Solid tumor	NA	1 (1%)	0 (0%)
CNS tumor	NA	0 (0%)	0 (0%)
Skin	NA	2 (1%)	2 (1%)
Years since first diagnosis			
5–10	3 (2%)	0 (0%)	0 (0%)
11–20	12 (8%)	1 (1%)	1 (1%)
>20	1 (1%)	2 (1%)	1 (1%)

NA = not applicable; N = number; CNS = central nervous system.

able to fully process their child's risks and side effects or appreciate the long-term effects that may have been communicated to them.

"I got handed a whole lot of forms to sign about the new chemo drugs... we had no time to debate the effects ... It's probably going to do this, a chance of this and that. But yeah, sign here. We need to get on with it." (mother of non-Hodgkin's lymphoma survivor with recurrence, age 16, male)

Participants shared both negative and positive experiences with medical care during the diagnosis and treatment of their or their child's recurrence and or second cancer. Negative circumstances appeared to significantly impact participants' experience of their (or their child's) subsequent cancer. One participant reported delays in getting her daughter tested by health professionals, which they felt resulted in a late diagnosis of secondary osteosarcoma and consequently a poorer prognosis.

"her endocrinologist wasn't too fussed about it... the radiotherapist didn't seem too concerned. By the time we actually had a diagnosis we were a couple of months down the track. Then it was all overgrown exponentially." (mother of medulloblastoma survivor with secondary sarcoma and basal cell carcinoma, age 25, female)

A few participants reported that staying on top of organizing appointments and seeking medical information was overwhelming and desired more guidance from hospital staff.

"Most distressing was that I felt we had to be on top of it (*treatment*) ourselves." (mother of neuroblastoma survivor with recurrence, age 16, female)

Conversely, some participants perceived their care to be of high quality, expressing immense gratitude, "we cannot thank our health system enough" (mother of Wilms' tumor survivor with recurrence, age 17, female), and described having strong "long-term relationship[s]" with their respective specialist (mother of acute lymphoblastic leukemia survivor with 2 recurrences, age 16, male).

Psychological impacts related to subsequent cancers

Most participants reported that a recurrence or second cancer had negative impacts on their or their child's well-being (see Table 3). Participants described generalized feelings of hopelessness, worry, and traumatic stress. Some participants directly associated their or their child's psychological distress to increased treatment intensity coupled with physical late effects.

"there has been a lot of depression from that (*infertility*) and the chronic pain." (rhabdomyosarcoma survivor with secondary basal cell carcinomas and benign pelvic tumors, age 26, female)

In addition, some participants also acknowledged the significant impact of non-medical factors such as their family and social situations on their, or their child's, well-being.

"with the cancer and now the divorce... he said I've broken up with a girl, all of the worst things happen to me." (mother of acute lymphoblastic leukemia survivor with recurrence, age 17, male)

Other survivors described feeling depressed and shared that they sought psychological care from private health services and/or school counsellors. One survivor with a recurrence described experiencing anxiety and actively seeking information for reassurance from her survivorship care providers.

"I imagine cancer being everywhere... they'll explain to me medically why I'm doing the scan but I don't think that they understand why I'm asking and how entirely how anxious I am about it." (survivor with sarcoma in the lung and recurrence of sarcoma in the neck, age 24, female).

No participants reported receiving professional psychological care from survivorship follow-up services specifically, although many reported a need and preference for such support.

"the only thing I think (*survivorship clinic*) could improve is the presence of a psychiatrist or psychologist" (survivor with sarcoma in the lung and recurrence of sarcoma in the neck, age 24, female)

Some participants who experienced a recurrence described having persistent post-traumatic stress symptoms years after treatment completion. One survivor reported "wetting the bed for about another 10 years" (astrocytoma survivor with recurrence, age 26, female), and some parents reported that their child had phobias of hospitals, nurses, and needles. Both participants who had a recurrence and second cancer reported feeling discouraged from enduring or watching their child endure constant health problems, such as benign tumors. For example, one participant reported "it just never ends" (mother of retinoblastoma survivor with secondary thyroid cancer, age 15, male). Many participants described

Table 2. Illustrative quotes related to the experience of being diagnosed with a subsequent cancer

Theme	Illustrative quotes
Sudden disruption to life	<p>“being clear of my first lot, I found that years after [first cancer] it was going good and then it went off tandem because of a relapse.” (acute lymphoblastic leukemia survivor with recurrence, age 26, male)</p> <p>“So we had a week when we were just in limbo and that was really dark. That was awful.” (mother of medulloblastoma survivor with secondary basal cell carcinoma and sarcoma, age 25, female)</p>
Urgent decision making	<p>“But then he relapsed... I got handed a whole lot of forms to sign about the new chemo drugs and things they were going to have to start giving them straight away... we had no time to debate if you like, the effects and things... It's probably going to do this. A chance of this and that. But yeah, sign here. We need to get on with it.” (mother of non-Hodgkin's lymphoma survivor with recurrence, age 16, male)</p>
Navigating uncharted territory	<p>“they couldn't tell us [if it was going to reoccur], because it [the cancer] was so rare.” (mother of survivor with Ewing sarcoma of the rib and recurrence, age 14, male)</p> <p>“we went on a special treatment um . Because it was relapse.” (mother of acute lymphoblastic leukemia survivor with recurrence, age 17, female)</p> <p>“The second time around... I was Australia's second stem cell transplant.” (brain germinoma survivor with recurrence, age 32, female)</p>
Positive experiences with health care during subsequent diagnosis	<p>“I don't think it can be improved really, by the time we got to the end 6 or 7 years of being in the system we kind of knew everything we kind of felt like we were on top of it as best as you could be.” (mother of acute lymphoblastic leukemia survivor with recurrence, age 17, female)</p> <p>“We're just very grateful we've lived in New Zealand and have had access to all of this... We cannot thank our health system enough... when you're sick, it is absolutely fantastic. Very, very grateful.” (mother of Wilms' tumor survivor, with recurrence age 17, female)</p> <p>“I know that Ronald McDonald House were – [my parents] say was excellent, so I think they did actually receive support from them.” (astrocytoma survivor with recurrence, age 26, female)</p>

being overwhelmed by the uncertainty of late effects. One participant who had a recurrence described feeling like she was “in no man's land” during survivorship and that “waiting for the all clear (after a follow-up scan)” was “kind of a rollercoaster” (astrocytoma survivor with recurrence, 26 year old, female). Such uncertainty also exacerbated worries about future health.

Healing and coping

To cope with the risks of developing further subsequent cancers, some participants appeared to adopt emotion-focused coping responses such as practicing gratitude and exercising resilience (see Table 3).

“I'm not bitter at all, because in my mind, the side effects I have are relatively small... I'm happy just to be alive.” (acute myeloid leukemia survivor with recurrence and secondary basal cell carcinoma and benign osteochondroma, age 28, female)

Some participants described wanting to regain a sense of “normality” in their life by actively moving on from their cancer experience. However, for some regaining a “normal” life meant coping by disengaging from survivorship care and not listening closely to health advice. One participant who had a second cancer said that their family chose to practice “that head in the sand thing” and not listen to advice on late effects as they “just wanted to move on” and “forget as much as (they) could” (mother of medulloblastoma survivor with secondary sarcoma and basal cell carcinoma, age 25, female) and that they were shocked when the survivor was diagnosed with a second cancer 22 years later.

Awareness of subsequent cancer risks

Being well informed of the risk associated with treatment late effects seemed to influence participants' level of preparedness when a subsequent cancer emerged. Participants who experienced

second cancer often described the diagnosis of a new malignancy as unexpected and being “quite shocked” (acute lymphoblastic leukemia survivor with secondary basal cell carcinoma and melanoma, age 34, female), with some feeling that they had not been properly informed of their risk of new malignancies (See Table 4).

“I don't remember ever talking about stuff like that [second cancers]... Maybe you just can't warn people about all the possible things.” (mother of medulloblastoma survivor with secondary basal cell carcinoma and sarcoma, age 23, female)

Conversely, participants who experienced a recurrence appeared to be less likely surprised by their relapse. Most described that regular scans during remission and survivorship care made them feel more aware of their risk of cancer recurrence, contributing to a perception of “preparedness.”

“he was scanned... every 3 months yeah so you know.” (mother of pilocytic astrocytoma survivor with recurrence, age 16, male)

Some participants who had a recurrence or second cancer attributed their subsequent cancer diagnosis to genetics or radiation exposure from previous treatment and were aware of such risk factors for a subsequent cancer. A few participants who had recurrences were aware that they or their child have a higher risk of developing second cancer compared to the general population; however, some participants were not aware of their future cancer risk. One participant who had a recurrence shared that he was “not sure” of his risk, guessing that his risk of developing second cancer in the future is “like everyone else” (acute lymphoblastic leukemia survivor with recurrence, age 24, male).

Table 3. Illustrative quotes relating to psychological impacts related to being at risk of subsequent cancers

Themes	Illustrative quotes
<i>Psychological impacts</i>	
Uncertainty	<p>“nobody can tell you that it’s not going to come back ... no one can give you that sort of self-hope... that sort of no man’s land... there’s going to be that next scan when – and you’ve got to wait for the all clear and kind of a rollercoaster in a way.” (astrocytoma survivor with recurrence, age 26, female)</p> <p>“It’s hard to say [whether he will experience late effects]. I mean everybody’s different.” (mother of Non-Hodgkin’s lymphoma survivor with recurrence, age 16, male)</p>
Feeling anxious	<p>“I imagine cancer being everywhere... they’ll explain to me medically why I’m doing the scan but I don’t think that they understand why I’m asking and how entirely how anxious I am about it.”</p> <p>“I’ve sought of have hassled [doctor] enough ... that I think that I have most of the information. I think it’s just my own sort of ongoing anxiety that um, makes more information. Not that I don’t have but that I’m always going to be anxious about that.” (survivor with sarcoma in the lung and recurrence of sarcoma in the neck, age 24, female)</p> <p>“we have quite a strong family history of depression and anxiety, so I kind of would have expected to maybe suffer from that anyway.” (Ewing sarcoma survivor with recurrence and secondary melanoma age 35, female)</p>
Feeling depressed	<p>“There’s been a lot of depression and that from that, obviously with the chronic pain. Then obviously realising well [having] children is not going to be an option.” (rhabdomyosarcoma survivor with secondary basal cell carcinoma and benign pelvic tumors, age 26, female)</p> <p>“I don’t know if it’s from the late effects of the chemo, but I’ve been feeling a lot of depression lately, like in the last few weeks.... Like up and downs, highs and lows.”</p> <p>“The depression hit me hard ... I had to go to a psychologist to try and work around it because I don’t know ...It goes up and down, like some days I’ll be really happy then there’ll be days I’ll just start crying for no apparent reason at all.” (acute lymphoblastic leukemia survivor with recurrence, age 26, male)</p> <p>“he sometimes gets very teary and upset without seemingly much reason or sometimes things bring back memories that upset him.” (mother of acute lymphoblastic leukemia survivor with recurrence, age 16, male)</p>
Worries or fears about subsequent cancers	<p>“you always worry. Or for quite some time afterwards there were worries about recurrence. With * there were worries about recurrence just a few years ago.” (mother of neuroblastoma survivor with recurrence, age 16, female)</p> <p>Interviewer “Would there be anything you that you are worried about finding out about?”</p> <p>Interviewee: “I am particularly worried about finding out about second cancers.” (mother of acute lymphoblastic leukemia survivor with recurrence, age 17, female)</p> <p>“I imagine cancer being everywhere... I don’t think they (health-care staff) understand my anxiety in that effect about recurrence or about you know why are you doing this scan.” (survivor with sarcoma in the lung and recurrence of sarcoma in the neck, age 24, female)</p> <p>Interviewer “Would there be anything you that you are worried about finding out about?”</p> <p>Interviewee: “Um, probably anything that was cancerous... Yeah. I’m terrified.”</p> <p>“You’re always waiting.. I think for 6 months you’re waiting for something dreadful to happen and then for a year – probably for the first year you’re waiting for something dreadful to happen.” (mother of medulloblastoma survivor with secondary basal cell carcinoma and sarcoma, age 25, female)</p>
<i>Coping responses</i>	
Resilience and gratitude	<p>“she said ‘I could end up with a colostomy but, you know, I’d rather poop in a bag than be dead.’” (mother of neuroblastoma survivor with recurrence, age 16, female)</p> <p>“I’m not bitter at all, because in my mind, the side effects I have are relatively small... at the end of the day I’m happy just to be alive. So if that means doctor’s appointments, then so be it.” (acute myeloid leukemia survivor with recurrence and secondary basal cell carcinoma and benign osteochondroma, age 28, female)</p> <p>“I’ve been a lot more grateful actually than anything.. when you look back and think geez we were so lucky, she’s still here.” (mother of Wilms’ tumor survivor with recurrence, age 17, female)</p> <p>“I don’t really worry about it because there’s nothing you can do really.. I sought of take each day as it comes sought of person.” (acute lymphoblastic leukemia survivor with secondary basal cell carcinoma and melanoma, age 34, male)</p> <p>“He’s been really brave about the growth thing, about how tall or short he’s going to be. That’s big in a teenage boy... We’re amazed at how well he’s doing at school. Because the side effects could have been so much worse, given how young he was and what they did to him.” (mother of non-Hodgkin’s lymphoma survivor with recurrence, age 16, male)</p> <p>“I think you’ve got to try and be positive, as positive as you can. I don’t know, just try and – it’s hard at the time, but you’ve just got to try and be quite hopeful and positive about stuff. We always tried to be good and happy around him.” (mother of hepatoblastoma survivor with recurrence, age 17, male)</p>
Avoidance	<p>“I don’t really like going to the doctor’s, so I don’t, I just would rather move on than dwelling on it.” (teratoma survivor with recurrence, age 25, female)</p>

(Continued)

Table 3. (Continued.)

Themes	Illustrative quotes
Moving on and seeking “normality”	<p>“We don’t necessarily need to know (late effects). If I don’t want to know I won’t ask. If I don’t need to know I won’t ask. It’s just too much information because sometimes you can just worry yourself sick about it all... We avoid talking about anything too deep about it.”</p> <p>“We probably had that head in the sand thing that we just wanted to move on... we needed to just forget as much as we could and just go on with our normal life.” (mother of medulloblastoma survivor with secondary basal cell carcinoma and sarcoma, age 25, female)</p> <p>“she didn’t want to do Camp Quality at the end of her treatment she just threw all those things aside she just wanted to be normal.” (mother of acute lymphoblastic leukemia survivor with recurrence, age 17, female)</p> <p>“he said to me the other day that oh, I don’t really want to do it anymore mum. I want to move on. I don’t want to be that cancer kid.” (mother of non-Hodgkin’s lymphoma survivor with recurrence, age 16, male)</p>

Table 4. Illustrative quotes relating to awareness of risks of subsequent cancers

Theme	Illustrative quotes
Aware of their risk of a subsequent cancer diagnosis	<p>“I remember having the discussion with the radiotherapist... You’re not going to say we’re not going to do it then .. but we were made aware of those things (late effects).” (mother of acute lymphoblastic leukemia survivor with recurrence, age 17, female)</p> <p>“I remember is the likelihood of him getting some other sort of cancer was sort of 10 per cent .. I’ve even got the little booklet that they gave us at the time, which is called long-term effects of cancer treatment.” (mother of acute lymphoblastic leukemia survivor with recurrence, age 16, male)</p> <p>“being a cancer survivor, I know that my chances of cancer are high anyway, I don’t need a geneticist to tell me that.” (acute myeloid leukemia survivor with recurrence and secondary basal cell carcinoma and benign osteochondroma, age 28, female)</p> <p>“there are all kinds of cancers that you run a bigger risk of... you always worry.” (mother of neuroblastoma survivor with recurrence, age 16, female)</p> <p>“they’ve [doctors] I guess informed me of all the sorts of things that they’re looking for that could potentially happen in the future. Primarily I guess thyroid cancer, breast cancer, and they do a whole brain MRI as a precautionary thing every 12 months.” (brain germinoma survivor with recurrence, age 32, female)</p> <p>“I have Gorlin syndrome, that makes you susceptible to skin cancers which I’ve had lots of, and also basal cell carcinomas which are benign, but because of having chemotherapy they say that it increases the risk of getting melanomas.” (rhabdomyosarcoma survivor with secondary basal cell carcinomas and benign pelvic tumors, age 26, female)</p>
Unaware of their risk of a subsequent cancer diagnosis	<p>“they said about other health concerns might come up but no necessarily that one [skin cancers] no... mum and dad were quite shocked when they [skin cancers] eventually came up.” (acute lymphoblastic leukemia survivor with secondary basal cell carcinomas and melanoma age 34, female)</p> <p>“They always talk about you can ... get cancerous moles, a thyroid was something we’ve been watching, but looking for lumps like that we haven’t really – I don’t remember ever talking about stuff like that ... Maybe you just can’t warn people about all the possible things that can go wrong.” (mother of medulloblastoma survivor with secondary basal cell carcinoma and sarcoma, age 25, female)</p> <p>Interviewer: “compared to the general population, do you think that you have a lower, a higher or a similar chance of developing a second cancer into the future?” Interviewee: “Um, I’m not probably sure. I probably, I think like everyone else, I think.” (acute lymphoblastic leukemia survivor with recurrence, age 24, male)</p>
Parents finding it difficult to encourage their child to adopt protective health behaviors	<p>“I think he’s probably one of those people who goes I’m trying to live my life you know, just let me deal with what I’ve got to deal with.”</p> <p>“This is tricky because * would probably go, I don’t care and I would go, yes I care.” (mother of pilocytic astrocytoma survivor with recurrence, age 16, male)</p> <p>“they are told all the things that they should or shouldn’t do but then they become teenagers and they think I’ll just do whatever I want.”</p> <p>“you try and educate your child as much as possible but you can only do it if they are willing.” (mother of acute lymphoblastic leukemia survivor with recurrence, age 17, female)</p>

Engagement in survivorship care

Some participants who had a recurrence shared that they felt reticent toward receiving further information about their subsequent cancer risk and preferred to move on from their cancer experience to avoid “worrying [themselves] sick” (mother of medulloblastoma survivor, age 23, female). Other participants were ambivalent and “in 2 minds” (mother of acute lymphoblastic leukemia survivor with recurrence, age 13, male) and described wanting to be

informed of their subsequent cancer risks and be mentally ready to receive such information but not wanting to live in anticipation of a devastating event that may never occur (See Table 5).

Participants who had second cancer were receptive to late-effect information, with one survivor sharing that she wanted to “be aware of symptoms, and get checked out quickly if [I] see those symptoms” (acute myeloid leukemia survivor with recurrence and secondary basal cell carcinoma and benign osteochondroma,

Table 5. Illustrative quotes relating to health behaviors and information seeking with regards to subsequent cancers

Theme	Illustrative quotes
Desires information and willing to adopt protective health behaviors	<p>“Oh it’s better to be safe than sorry you know. Just to double check everything. You don’t want to be – like say 10 years down the track you go to a GP and ... [they say] oh you have cancer again.. I see it [LTFU clinic] more as a way to understand what happened when you got sick.”</p> <p>“I’ve just gone along with the – eating healthy, making sure I get fit ... not drinking too much alcohol.” (acute lymphoblastic leukemia survivor with recurrence, age 26, male)</p> <p>“I’d still want to know about it in order to be aware of the symptoms, and get myself checked out quickly if I see those symptoms.” (acute myeloid leukemia survivor with recurrence, age 28, female)</p>
Resistant toward information and not following health precautions	<p>“I think he’s probably one of those people who goes I’m trying to live my life you know, just let me deal with what I’ve got to deal with.” (mother of pilocytic astrocytoma survivor with recurrence, age 16, male)</p> <p>“We don’t necessarily need to know.. If I don’t want to know I won’t ask. If I don’t need to know I won’t ask. It’s just too much information because sometimes you can just worry yourself sick about it all.” (mother of medulloblastoma survivor with secondary basal cell carcinoma and sarcoma, age 25, female)</p>
Engages with long-term follow-up care	<p>“there’s a range of benefits, but I would say one of them would be actually talking to someone about any issues you may have.” (unspecified brain cancer survivor, age 22, male)</p> <p>“by the time we got to the end 6 or 7 years of being in the (LTFU) system we kind of knew everything we kind of felt like we were on top of it as best as you could be.” (mother of acute lymphoblastic leukemia survivor with recurrence, age 17, female)</p> <p>“I see it (LTFU clinic) more as a way to understand what happened when you got sick. Because when you’re a kid you don’t really know what’s going on. But then when you’re older it allows you to get an understanding of what happened.” (mother of non-Hodgkin’s lymphoma survivor with recurrence, age 16, male)</p>

age 28, female). However, a few parent participants shared that they had difficulties encouraging their children to adopt protective health behaviors, even after experiencing a recurrence.

“teenagers... just do whatever (*they*) want... you try and educate your child as much as possible but you can only do it if they are willing.” (parent of acute lymphoblastic leukemia survivor with recurrence, age 17, female)

Some participants who experienced recurrences described being proactive in self-surveillance and seeking medical care when they noticed unusual signs such as moles and breast lumps.

“I ... saw something was obviously wrong and then took myself to the specialist.” (acute myeloid leukemia survivor with recurrence and secondary basal cell carcinoma and benign osteochondroma, age 28, female)

Not all participants appreciated the importance of surveillance for subsequent cancers. One survivor who had a recurrence shared that she did not attend survivorship care as she saw it as “a waste of time” (teratoma survivor with recurrence, age 25, female). However, the majority of participants did see value in surveillance for subsequent cancers; one survivor who had a recurrence shared that he saw survivorship care as “a way to understand what happened when you got sick (cancer)” and that he would attend the survivorship clinic if he “feels that something might be coming on” (acute lymphoblastic leukemia survivor with recurrence, age 26, male).

Discussion

This study explored childhood cancer survivors’ and their parents’ experiences with recurrences and second cancer and their engagement with survivorship care. For survivors and their families who have already begun their recovery and survivorship journey, encountering a subsequent cancer can be devastating. The disruptive nature of receiving an unexpected subsequent cancer diagnosis, sudden need for clinical care, and ambiguity surrounding treatment and prognosis left strong long-term impressions on

participants. This study found that the psychological impacts of a subsequent cancer on survivors and their parents include a range of experiences, from feeling overwhelmed with worries to having a sense of hopefulness and resilience. A common concern among participants was their uncertain future due to late-effects risks, especially subsequent cancers. Participant’s coping responses appeared to influence their engagement with survivorship care and attitudes such as seeking or resisting late-effects information.

Among our participants, there appeared to be less awareness of second cancer risks than the risk of cancer recurrences. Complementing our findings, studies show that more than 60% of Australian survivors are unaware that they have a greater risk of new malignancies than the general population and that parents and survivors have more unmet information needs about second cancers than cancer recurrence (Vetsch et al. 2017; Signorelli et al. 2019). The wide range of mental health experiences reported by participants with various intensities of recurrences and second cancers suggest that multiple dynamic aspects of survivor’s lives, including social circumstances and physical symptoms from treatment, may influence their well-being and psychological adjustments to a subsequent cancer diagnosis (Helgeson and Cohen 1996; Hinds et al. 2002; Parker et al. 2003, Lee and Santacroce 2007; Berg et al. 2016; Sharpe et al. 2018; Walker et al. 2019). Studies show that survivors who focus on “finding meaning” through gratitude or trying to live life to the fullest may experience a greater sense of well-being (Lee et al. 2009; Sharpe et al. 2018). However, it is also common for survivors and their families to worry about their future health, especially cancer returning (Butow et al. 2018; Wroot et al. 2020). Studies show that some survivors respond to anxieties surrounding the unpredictability of their future health by adopting protective health behaviors, similar to our participants who actively engaged in surveillance and sought reassurance from health-care professionals (Lee et al. 2009).

On the contrary, fears of cancer returning also appear to provoke avoidance of information on late effects and disengagement from survivorship care (Lee et al. 2009). Although studies by Signorelli and Gibson et al. found no significant

association between worries about future health and engagement in survivorship care, these studies did reveal that survivors who seldom worried about subsequent cancers seemed more likely to engage with survivorship care (Gibson *et al.* 2018, Signorelli *et al.* 2019). While avoiding the topic of cancer recurrence and second cancers may offer ideal short-term outcomes for survivors, such as an opportunity to “move on from cancer” and regain a sense of normalcy, literature shows that poor awareness of late effects is linked to low-risk perceptions (Tercyak *et al.* 2006; Wilkins and Woodgate 2008; Lee *et al.* 2009; Hudson *et al.* 2013; Vetsch *et al.* 2017; Gibson *et al.* 2018; Signorelli *et al.* 2019; Walker *et al.* 2019; Bradford *et al.* 2020; Wroot *et al.* 2020). Survivors having low-risk perceptions is a concern, as not practicing protective health behaviors can contribute to the development of subsequent cancers. For example, a study by Tercyak *et al.* showed that the least practiced health precaution among childhood cancer survivors was the use of sun protection, which is consistent with our results where the majority of the second cancers experienced were skin neoplasms (Tercyak *et al.* 2006; Hudson *et al.* 2013; Vetsch *et al.* 2017; Gibson *et al.* 2018). Hence, beyond being informed, survivors need to understand their risks in a way that triggers concern about their own health and an initiative to follow precautionary health guidelines (Lee *et al.* 2009; Gibson *et al.* 2018).

Our study demonstrates that despite having experienced a recurrence or second cancer, survivors can still feel ambivalent toward late-effects information and resist the encouragement of protective health behaviors. While survivors may understand the importance of being informed, studies show that hesitancy toward receiving late-effects information is common and may be due to fears of future uncertainty (Eiser *et al.* 1996; Berg *et al.* 2016; Bradford *et al.* 2020). Literature shows that incorporating psychoeducational programs in survivorship care can potentially help survivors adjust to living with the “new normal” of subsequent cancer risks (Landier *et al.* 2006; Tercyak *et al.* 2006; Hildenbrand *et al.* 2014; Lie *et al.* 2015; Dieng *et al.* 2016; Butow *et al.* 2018; Kelada *et al.* 2019; Sharpe *et al.* 2019; Knighting *et al.* 2020). Studies suggest that delivering information on late effects in a manner that educates survivors on the cause and management, rather than simply describing subsequent cancer risks, may provide assurance that solutions are available (Butow *et al.* 2018; Kelada *et al.* 2019). Therefore, further investigations on the educational delivery of late-effects information may improve receptivity and knowledge (Butow *et al.* 2017; Burm *et al.* 2019).

While this study was multisite and included participants with varying risk profiles, more studies are needed to obtain a comprehensive understanding of survivors’ experiences in different survivorship cohorts worldwide. Additionally, only long-term survivors were interviewed; thus, this study does not include the experiences of those who did not survive after a recurrence or second cancer. Parents’ reports may also underestimate or overestimate the survivor’s psychological distress and concerns, particularly if they themselves are anxious or distressed (Hinds *et al.* 2002; Hildenbrand *et al.* 2014; Boehmer *et al.* 2016; Signorelli *et al.* 2021). Furthermore, only English-speaking participants were interviewed; hence, this study lacks perspectives from culturally and linguistically diverse patients.

Experiencing a cancer recurrence and/or second cancer can be highly distressing for childhood cancer survivors and their parents, and this distress can continue years after treatment completion. This study highlights that not all survivors and their parents have a clear understanding of their second cancer risks and that some survivors feel reticent to receive information on late effects and

engage in survivorship care. Therefore, we recommend further investigations into psychoeducational interventions that improve the delivery of information on recurrence and second cancer risks, while mitigating anxieties about future health, thereby improving preparedness and engagement with survivorship care.

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Data availability statement. Data for this study are unavailable due to privacy of research participants.

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