

Falling through the cracks. A thematic evaluation of unmet needs of adult survivors of childhood cancers

Jennifer White¹  | Joanne Park^{2,3,4} | K. Brooke Russell^{3,4} | K.A. Reynolds⁵ | A. Madani⁶ | Linda E. Carlson^{3,4} | Janine Giese-Davis^{3,4}

¹Department of Physiotherapy, Monash University, Melbourne, Victoria, Australia

²Department of Psychology, University of British Columbia, Vancouver, British Columbia, Canada

³Department of Oncology, University of Calgary, Calgary, Alberta, Canada

⁴Tom Baker Cancer Centre, Psychosocial Resources, Calgary, Alberta, Canada

⁵Alberta Children's Hospital, Calgary, Alberta, Canada

⁶Provincial Health Services Authority, Vancouver, British Columbia, Canada

Correspondence

Jennifer White, Department of Physiotherapy, Monash University, 400 Warrigal Rd, Melbourne, Victoria 3192, Australia.
Email: jenni.white@monash.edu

Funding information

Alberta Cancer Foundation; Canadian Cancer Society Alberta/NWT Division

Abstract

Objective: The population of adult survivors of childhood cancers (ASCCs) is growing, resulting in unique long-term challenges. This study explored experiences of perceived unmet ASCC survivorship needs.

Methods: We invited ASCCs to complete surveys sent through the cancer registry. Four open-ended questions allowed participants to write in comments. We analyzed responses to these open-ended questions thematically, employing a process of constant comparison.

Results: Our sample included 94 ASCCs who completed open-ended questions (61 female; aged 20–78 years, mean age = 34.47, SD = 11.84, mean = 23.27 years post diagnosis). Identified themes included (1) overlooked experiences of distress; (2) lack of counseling: system, patient, and family barriers; (3) difficulty negotiating future life milestones exacerbated by lack of knowledge; and (4) dissatisfaction with service provision: past and present. Prevalent issues identified by participants included lack of supportive care to address needs, distress due to missed developmental milestones as a result of cancer, lack of knowledge about late-term and long-term effects of cancer treatment, and concern over absence of organized long-term follow-up.

Conclusions: Adult survivors of childhood cancers continue to experience unmet needs during their cancer diagnosis, treatment, and long into survivorship due to the treatment for cancer and ongoing side effects. Solutions could focus on addressing the needs of survivors to bridge system gaps and barriers. Specifically, there is a need to improve psychological interventions and transitions from pediatric to adult-care facilities.

KEYWORDS

cancer, psychooncology, qualitative, surveys, survivor, unmet needs, oncology, adult survivors of childhood cancer, pediatric oncology, late effects

1 | INTRODUCTION

There is a growing population of adult survivors of childhood cancers (ASCCs) due to advances in successful therapies.¹ Many ASCCs live with treatment-related health consequences including disease

recurrence,^{2,3} fertility issues,^{4,5} and other chronic diseases.^{6–8} Psychosocial adjustment is also a significant health concern, being associated with delayed social maturation,⁹ academic and employment barriers,¹⁰ psychological disturbances,^{11,12} and health-risk behaviors such as tobacco and alcohol abuse, inactivity, and obesity.¹¹ Further, survivor

uncertainty and fear of recurrence can interfere with activities of daily living.^{13,14} Adult survivors of childhood cancers' experience of ongoing needs, which remain undetected and undertreated in clinical and community health-care settings, is concerning.¹⁵

Adult survivors of childhood cancers experience unmet needs that impact life transitions and can lead to increased psychosocial distress and decreased compliance with follow-up and screening.^{1,15,16} Common predictors of unmet needs include geographic isolation from health services, lack of social support, and poor health status.¹⁷ Large-scale studies exploring prevalence, incidence, and severity of chronic health conditions in ASCCs noted that between 62.3% and 75% experienced at least 1 chronic health condition, and between 27.5% and 40% experienced severe and life-threatening conditions such as congestive heart failure, second malignant neoplasm, or cerebrovascular accident.^{18,19} One study estimated the cumulative burden of chronic illness by age 45 at 95.5%.²⁰

Systematic follow-up of ASCCs' medical, psychosocial, and preventive care is important to cancer-free survival and to help cancer survivors and their families cope throughout the cancer trajectory. Many models of follow-up care exist with some following ASCCs for life through pediatric hospitals,²¹ while in others, ASCCs transition from pediatric to adult services (adult cancer hospitals or family-physician follow-up). In adult-oriented systems, survivors may fall through the cracks and not receive adequate follow-up care, screening, or education regarding potential late effects or long-term health risks.²² Adult survivors of childhood cancers may have knowledge deficits regarding their diagnosis, treatment, late effects,²³ and preventive health behaviors. Family physicians may lack knowledge about managing late effects of pediatric cancer treatment.^{24,25} In response, the International Late Effects of Childhood Cancer Harmonization Group provides common recommendations for ASCCs once they transition to adult health-care services.²⁶

One study reported that two-third of ASCCs do not engage in any follow-up specific to their primary disease or experience of late effects.²⁷ A recent systematic review found that only 11.5 to 81.0% of ASCCs followed screening guidelines and that female sex, radiation exposure, higher socioeconomic status, private health-care access, chronic-health problems, and older age were important drivers of health-care usage.²⁸ Growing evidence also highlights that ASCCs' adherence to crucial follow-up decreases with age and time from diagnosis.^{29,30} The best model of follow-up care and what resources ASCCs require to attain optimal physical, psychological, educational, vocational, and social health and wellbeing are unknown.^{31,32}

As part of a larger quantitative study of ASCCs' unmet needs,¹⁵ we aimed to conduct a thematic analysis of open-ended survey questions to understand ASCCs' unmet-need experiences in their own words. This study took place in Alberta, Canada, where northern survivors were followed for life through a pediatric hospital, but southern survivors were discharged to family-physician follow-up.

2 | METHODS

This qualitative study examined 4 open-ended questions as part of that larger survey using standardized questionnaires assessing

ASCC unmet needs (for complete procedures¹⁵). In brief, Alberta's Cancer Registry mailed survey invitations to all Alberta ASCCs. Eligibility criteria included age 19 years or older, histologically confirmed childhood diagnoses, and excluded in situ and nonmelanoma skin cancers. Among 1562 eligible registry-identified ASCCs, 36% ($n = 563$) were deceased or had incorrect mailing addresses. Three refused (unknown reasons), reducing the eligible number to 996. Eight hundred thirty-seven did not respond for unknown reasons. Of 159 responding ASCCs, 117 completed online or mailed surveys (11.75% of total; 73.6% of responders), with 2 excluded (age at diagnosis >18) totaling 115. Using aggregated registry data to examine generalizability, we found no significant differences between our sample and nonparticipants by cancer type, $X^2(3,1041) = 3.24$, $P = .36$, or age, $t(1039) = 1.18$, $P = .24$, but significantly more women completed surveys, $X^2(1,1041) = 7.55$, $P = .01$. Ninety-four of 115 (81.7%) wrote in qualitative responses to at least one open-ended question (Table 1). The University of Calgary Conjoint Health Research Ethics Board approved the study (E-22516). Adult survivors of childhood cancers consented online or on paper.

2.1 | Data generation

The participants answered demographic, medical, cognitive function, and standardized questionnaires. Four open-ended items asked them to describe experiences: "What are your other unmet needs?" ($n = 43$ completed, 37%), "How did it affect your education/work?" ($n = 49$, 43%), "What problems did we miss in these questionnaires?" ($n = 39$, 34%), and "If you could change one thing about the healthcare services you received, what would it be?" ($n = 79$, 69%).

2.2 | Data analysis

We used SPSS Statistics, version 20 for descriptive statistics (Table 1). To compare responders with nonresponders, we used independent sample t tests for continuous and Fisher exact test for categorical variables. For qualitative analysis, we copied written responses to the 4 open-ended questions verbatim to word documents with identifying data removed and analyzed them by using inductive thematic analysis.³³ This involved (i) identifying units of meaning by reading the transcripts line by line; (ii) grouping units into categories to assist with data retrieval (for instance, labeling the experience of reduced confidence "CONF"), irrespective of the research question; and (iii) examining relationships between codes to form themes. Three researchers (JP, KBR, and JW) identified units of meaning by reading each transcript line by line, manually developing initial codes, and creating separate codebooks. Following regular meetings and discussion, we refined these codes into categories and merged into a single word document. We negotiated any researcher-perspective differences, and, if necessary, regrouped and recoded until reaching consensus. Our final step examined relationships between categories to form themes. We made decisions regarding thematic saturation during this process, paying formal attention to reflexivity—involving coders' professional backgrounds (JP, KBR psychology students, and

TABLE 1 Demographics for respondents to open-ended questions compared with nonrespondents in adult survivors of childhood cancer (N = 115)

	Respondents to Open-Ended Questions(n = 94)		Nonrespondents to Open-Ended Questions(n = 21)		P Value	Total (N = 115)	
	N	M (SD) or %	N	M (SD) or %		N	M (SD) or %
Gender					.008		
Female	61	64.9	7	33.3		68	59.1
Age							
Mean (SD)	94	34.47 (11.84)	21	38.08 (12.81)	.216	115	35.13 (12.05)
Median		31.16		34.82			32.30
Min-max		20.05-77.97		20.61-61.05			20.05-77.97
Time since diagnosis							
Mean (SD)	94	22.68 (13.20)	21	25.90 (12.01)	.278	115	23.27
Median							
Min-max		4.10-62.68		3.68-50.77			3.68-62.68
Developmental stage at diagnosis					.331		
Early-childhood (0-5 years old)	18	19.1	7	33.3		25	21.7
Middle-childhood (6-12 years old)	18	19.1	4	19.0		22	19.1
Adolescence (12-18 years old)	58	61.7	10	47.6		68	59.1
Ethnicity							
White	81	86.2	19	90.5	.596	100	87.0
Minority/mixed	13	13.8	2	9.5		15	13.0
Education					.222		
<High school	7	7.4	3	14.3		10	8.7
High school	31	33.0	7	33.3		38	33.0
Trade school	8	8.5	4	19.0		12	10.4
Postsecondary	48	51.1	7	41.2		55	47.8
Marital status					.099		
Single	53	57.0	8	38.1		61	53.5
Married	34	36.6	13	61.9		47	41.2
Divorced	6	6.5	0	0.0		6	5.3
Employment status					.405		
Full-time	52	55.3	12	57.1		64	55.7
Part-time	18	19.1	7	33.3		25	21.7
Student	10	10.6	0	0.0		10	8.7
Not currently working	9	9.6	1	4.8		10	8.7
Cannot work—disability	5	5.3	1	4.8		6	5.2

JW, an occupational therapist) and how these could influence data interpretations.

3 | RESULTS

Adult survivors of childhood cancers were 4 to 63 years post diagnosis. The 94 responders did not differ significantly from the 21 nonresponders in age, ethnicity, education, employment, or marital status (Table 1). However, women were significantly more likely to complete open-ended questions (Table 1).

Four key themes emerged: (i) overlooked experiences of distress; (ii) lack of counseling: system, patient, and family barriers; (iii)

difficulty negotiating future-life milestones: exacerbated by lack of knowledge; and (iv) dissatisfaction with service provision: past and present.

4 | OVERLOOKED EXPERIENCES OF DISTRESS

Many participants reported experiencing emotional distress during treatment and in long-term survivorship. Feelings of loneliness during treatment were linked to being “alone most of the time” and away from family and friends during hospitalization. Adult survivors of childhood cancers commonly reflected that they could have benefitted

from greater peer support during treatment, to talk about experiences and coping strategies with same-age peers—especially because continuity with previous friends was disrupted or lost.

"[It would have been good] to have people around my age so that we could have discussed issues and things that were bothering me." (Participant (P) 0317, Female (F), leukemia, age 34)

They reported more pronounced distress when having no one either their own age or experiencing a similar cancer—leading to feeling isolated and out of place in hospital with, "A lot of older persons within it." (P0317, F, leukemia, age 34).

Some feelings of distress continued into survivorship due to difficulties making social and work adjustments. Residual disabilities that persisted posttreatment compounded their maladjustment, leading to altered self-esteem—especially when participants felt self-conscious about being treated differently.

"I just want a job where people will work with you and your disability and not put you down or treat you differently." (P0933, F, brain, age 24)

The participants also wrote about distress and ongoing feelings of shame and guilt about surviving when other people had died or about not living up to their own expectations to make the best of their life. In these cases, the participants reported feeling that they did not deserve to survive, especially if they had achieved nothing of significance.

"It's really hard to adjust to the fact that I beat cancer twice and that I didn't do something spectacular after I was cured. [So much so] I felt I should have just died anyway." (P0193, F, lymphoma, age 24)

5 | LACK OF COUNSELING: SYSTEM, PATIENT, AND FAMILY BARRIERS

Many participants lamented lack of referral to supportive care, especially counseling. The participants reported that receiving counseling at diagnosis, during, and after treatment might have alleviated struggles. The participants recalled that counseling was either not available or that clinicians did not sufficiently encourage or refer to supportive services.

"I feel counselling could have helped [if I had access to it], as I lived in the [hospital] for a long time." (P0102, F, lymphoma, age 56)

"I guess there was nothing, either nothing or I thought I didn't need anything." (P0003, F, lymphoma age 44)

The participants reported that at diagnosis, their age or limited understanding likely impacted either clinicians' referrals for counseling or their acceptance. Some participants indicated that they had declined counseling but in hindsight felt that it "Would have helped tremendously in the short and long term." (P 0857, M, testicular, age

35). In fact, their responses indicated a continued need for counseling during survivorship.

"I am 28 years old now and would like access to counselling, as I struggle with hurtful memories, guilt and anger, and often want to discuss the things I didn't as a young teen." (P0572, F, lymphoma, age 29)

Adult survivors of childhood cancers frequently noted their dependence on parents as a reason for lack of access to counseling and regretted their parents declining services on their behalf. As a result, most felt that referral to counseling should be routine, and even "obligatory," to help manage the full spectrum of cancer needs including long-term adjustment and body image. If a patient declined counseling, the participants felt that clinicians could offer other opportunities—especially when parents were absent.

"I wish that counselling services would have been more openly discussed with me, and more than once, by my health-care providers. Unfortunately, I was asked only one time to talk to a psychologist. My mother and I regretfully said no." (P0771, F, lymphoma, age 33)

The participants also reflected on the distress they witnessed in loved ones, especially parents and siblings, and wished more counseling had been available—especially for financial and emotional support.

"My mom had to quit her job to take me back and forth to treatments, my dad had to work twice as much and was never home, and my siblings paid for it while I was in treatment, there's no support for kids in this situation... I don't know if she [mom] was offered any sort of support group for other parents going through the same thing." (P0751, F, lymphoma, age 24)

6 | DIFFICULTY NEGOTIATING FUTURE LIFE MILESTONES: EXACERBATED BY LACK OF KNOWLEDGE

The participants noted that experiences during and after cancer treatment impacted crucial future developmental hopes and milestones. For many, cancer obstructed short-term and long-term school and university attendance. Some ASCCs repeated grades or reported lost time at school during treatment that separated them from peers. This meant starting new classes or universities without the comfort of undertaking this transition with friends in the same situation.

"I wasn't to finish classes at the school with my other classmates." (P0317, F, leukemia, age 34)

"[I] didn't start university with friends from school - I felt lost [without them] and couldn't focus on studies when I started." (P0545, F, thyroid, age 49)

In addition to temporal delays, they experienced physical and cognitive deficits such as memory impairments, which slowed academic

progress. Written reports suggested that schools offered limited support for managing their learning difficulties.

"[I] had learning difficulties that the teacher didn't know how to deal with." (P0108, F, lymphoma, age 25).

An adolescent cancer diagnosis, when developing new friendships and romantic relationships was important, led the participants to report social difficulties. Even long-term survivors wrote about uncertainty pursuing new relationships and whether to share personal information about their cancer experience.

"I question when will the cancer return and [how this will impact] new relationships -how much information to divulge." (P1368, F, gynecologic, age 47)

Their ability to achieve valued milestones was another concern. One participant documented having reduced upper-limb function and was concerned how this affected her parenting ability. The perception of not being able to function like other able-bodied mothers created feelings of self-doubt.

"I do not have full use of my left arm now nor will ever. I am having my second child, and I will not be able to carry my son and a baby around and this is a huge concern for me. Not being able to live up to being the mother I want to be." (P0399, F, bone, age 23)

Having children was a significant concern post cancer treatment compounded by lack of knowledge. The participants reported a desire to have children but were afraid and lacked knowledge about whether they could have children and if there were any "Dangers to having children." (P1310, F, Wilms, age 22)

"I don't know if I will be able to have children or not because of the chemotherapy that I had in the affected area." (P0267, M, bone, age 28)

Other ASCCs were unable to engage in employment due to their experience of long-term physical disabilities due to treatment side effects and cancer relapses/second cancers as they progressed into adulthood. Their inability to achieve this milestone was noted as a key loss.

"No one had ever indicated that I might be vulnerable to subsequent cancers as a result of my radiation treatments [and not be able to work]." (P1429, F, thyroid, age 51)

"Am on oxygen now... only 25% VC [vital capacity] and not able to keep up to a job of any kind." (P0157, M, bone, age 48)

Overall, the participants wrote that they had difficulty being able to envision and plan their futures after their cancer experience, even as long-term survivors.

"The unmet needs are more related to finding a way to deal with not expecting to live this long without relapse and not really planning as a result." (P1036, M, leukemia, age 24)

7 | DISSATISFACTION WITH SERVICE PROVISION: PAST AND PRESENT

While some participants recalled having positive relationships with health-care providers that helped them overcome cancer-related challenges, many expressed dissatisfaction. Dissatisfaction with patient-provider interactions was linked to the experience of lack of empathy, poor communication and a "failure to listen." (P0758, F, bone, age 24)

Dissatisfaction occurred along a spectrum of care from treatment to survivorship. The most common complaint was delay when waiting for test results and treatment. Indeed, some participants felt that delays resulted in cancer progression and less than ideal treatment and surgery options.

"If only diagnosis had been faster [but I was operated on urgently] which meant my plastic surgeon wasn't able to be involved in my original surgery....now I am not a candidate [for breast reconstruction] as my skin is too thin and would need to stretch a lot which could result in the skin splitting and infection resulting." (P0687, F, bone, age 74)

Central to the experience of dissatisfaction was the transition from pediatric to adult services and feeling forgotten and abandoned by the health system. This was most evident when the participants felt they had to arrange their own long-term follow-up appointments or wait for openings.

"I would have liked the follow up visits to have been booked and followed up on, instead of me arranging them.... I felt lost in the system and unless I had a reason to go then it didn't matter [to the health care provider] if I went or didn't." (P 1017, M, skin, age 39)

"I was very frustrated as obtaining a family physician [with open books] is near to impossible these days." (P 1167, F, skin, age 31)

Some participants reported that their cancer center allocated follow-up surveillance to family physicians who they perceived as being unfamiliar with their specific cancer, treatments, potential long-term and late effects, as well as risks for future cancers. As a result, some participants felt the need to research their own ongoing medical needs.

"Family physicians don't know much about long-term effects of cancer therapies, therefore take long periods of time to determine what the problem is or why it might be happening... I have learned to research my problem on the Internet then request to be referred to a specialist when I think it is necessary." (P 0471, F, lymphoma, age 30)

Overall, the participants wanted their follow-up care to address their long-term health concerns more effectively. There was a common perception that regular follow-up appointments would have assisted with or alleviated fears of recurrence, provided more information, and assisted with referrals to specialists.

"As I grew up, I had lots of questions and no answers or help trying to understand my cancer/treatments or what to expect[There] should be a lifetime follow-up to help people cope with their cancer survivorship. After being cancer free many have other issues and concerns related to their cancer years down the road." (P 0316, M, bone, age 44)

8 | DISCUSSION

This study deepened our understanding of ASCCs' unmet needs occurring during their cancer experience and long into survivorship. The participants reported that their treatment for cancer and ongoing side effects negatively affected their cancer experience. The social isolation and educational gaps caused disruptions to reaching key developmental milestones and left long-standing psychosocial issues that they found difficult to overcome. The participants expressed uncertainty about how to navigate new friendships and relationships, and they regretted parental decisions declining potentially beneficial counseling. This transition may be more difficult for ASCCs due to disruptions in building normative social relationships while undergoing cancer treatment, often leading to a lag behind same-age peers. Further, sustained fear of recurrence among some participants created barriers to moving on with their lives and reaching for important goals. Results from this study suggest that many ASCCs continue to experience difficulty finding and accessing support posttreatment and would benefit from counseling. Our study highlights the importance of improving services to better address ASCC resource needs. These results support others' efforts to improve health literacy among ASCCs and community health-care providers including increasing knowledge, facilitating better communication between health-care providers and survivors, and addressing health-care delivery gaps.³⁴

In our quantitative analyses of these data,¹⁵ only 4.3% of participants scored moderate or above clinical cut-offs for depression on a standardized scale. Here our findings highlight a range of burdensome experiences and coping strategies that may mask distress to providers and families. Reports of isolation, distress, and avoiding stigma due to lack of support are symptoms of shame that can occur when the social self is devalued.³⁵ Shame can lead to lack of disclosure of distress, yet can profoundly underlie continued trauma experiences.³⁶ Our results suggest that it may benefit survivors for providers and families to probe further for the possibility of mood disturbance and the hidden impact of shame.

Our identification of survivors' ongoing service-delivery-gap experiences echoes previous research showing that only 31.5% of ASCCs receive follow-up care specific to their cancer diagnosis and treatment.²¹ Adult survivors of childhood cancers' feelings of anxiety and uncertainty about the late and long-term effects of their cancer diagnosis and treatment, especially regarding fertility, can increase with lack of continuity of care. Adult survivors of childhood cancers may never have understood completely what their cancer or treatments meant for their long-term health and fertility because their parents made their decisions. Likewise, a previous study showing that

as ASCCs age, they do not recall talking with staff about potential reproductive problems and adult health risks⁴ highlights the need for more effective communication with health-care providers and parents.

The participants received treatment from 2 cancer centers, 1 that follows them for life, and 1 that discharges to family physicians for follow-up. Unfortunately, we did not ask the participants which center provided their care. However, we learned that those discharged to family physicians felt that their providers lacked proper knowledge to manage long-term and late effects of cancer. Evidence-based guidelines for follow-up of ASCCs are readily available and promoted by both the International Late Effects of Childhood Cancer Harmonization Group²⁶ and the Children's Oncology Group.³⁷ It is concerning that these participants reported inadequate follow-up care.²⁶ As in adult studies, these survivors preferred receiving follow-up from oncologists³⁸ or having better ongoing communication or shared care. Family physicians must be adequately trained, confident, and experienced to manage follow-up cancer care. Health-care capacity issues and funding ASCC lifetime follow-up care programs may require investing in nationwide models of standardized care.³⁹

8.1 | Clinical implications

Results identify the need for greater access to early psychological counseling and peer-support processes beginning at diagnosis through to long-term follow-up care. Likewise ongoing education and prevention are necessary, especially as survivors grow older and gain independence. Research efforts could focus on understanding which models of adult survivorship-care best suit the medical and psychosocial needs of these survivors throughout their lifetimes.¹⁵

The strength of this study lies in access to a large sample of long-term survivors averaging 23 years postdiagnosis and the emotional richness of responses. We believe that these qualitative responses deepen our understanding of inadequacies in long-term survivorship care and compliment our quantitative results documenting the impact of developmental stage, cognitive impairment, and time from diagnosis.

8.2 | Study limitations

Despite this study's methods utilizing open-ended questions on self-report measures, ASCCs reported rich details of their struggles and unmet survivorship needs. Interview methods may have provided deeper insights into the timing of these difficulties and their coping attempts, and we encourage further interview studies. We acknowledge that more women than men commented, as is often the case in psychosocial research.

8.3 | Future research

Because our study sample spanned a time period in which treatment practices changed,⁴⁰ future research could isolate unmet needs for survivors who received higher doses of radiation (older practice guidelines) from those receiving lower doses as a way to ensure that all survivors receive the care most needed in survivorship.

9 | CONCLUSIONS

Adult survivors of childhood cancers have supportive-care needs specific to their stage in life and age at diagnosis. These include long-term negative consequences due to developmental trajectory delays, feelings of isolation, lack of psychosocial support, lack of knowledge about the long-term impact of cancer diagnosis and treatment, and lack of support for transitioning from childhood to adult cancer care. Future studies could specifically identify gaps, barriers, and solutions to address ASCCs' unique survivorship needs.

ACKNOWLEDGEMENTS

A grant from the Enbridge Research Chair in Psychosocial Oncology, cofunded by the Canadian Cancer Society Alberta/NWT Division and Alberta Cancer Foundation (held by Linda E. Carlson), supported this research, including salary support to the last author. Jennifer White held a University of Calgary "Eyes High" Postdoctoral Scholarship. The authors thank the ASCC participants and Kate Collie for suggestions.

CONFLICT OF INTEREST

The authors report no conflicts of interest.

ORCID

Jennifer White  <http://orcid.org/0000-0003-1875-1040>

REFERENCES

- Hovén E, Lannering B, Gustafsson G, Boman KK. The met and unmet health care needs of adult survivors of childhood central nervous system tumors. *Cancer*. 2011;117(18):4294-4303.
- Armstrong GT, Liu Q, Yasui Y, et al. Late mortality among 5-year survivors of childhood cancer: a summary from the childhood cancer survivor study. *J Clin Oncol*. 2009;27(14):2328-2338.
- Mostoufi-Moab S, Seidel K, Leisenring WM, et al. Endocrine abnormalities in aging survivors of childhood cancer: a report from the childhood cancer survivor study. *J Clin Oncol*. 2016;34(27):3240-3247.
- Zebrack BJ, Casillas J, Nohr L, Adams H, Zeltzer LK. Fertility issues for young adult survivors of childhood cancer. *Psychooncology*. 2004;13(10):689-699.
- Green DM, Sklar CA, Boice Jr JD, et al. Ovarian failure and reproductive outcomes after childhood cancer treatment: results from the childhood cancer survivor study cohort: a review of published findings. *J Clin Oncol*. 2009;27(14):2374-2381.
- Diller L, Chow EJ, Gurney JG, et al. Chronic disease in the childhood cancer survivor study cohort: a review of published findings. *J Clin Oncol*. 2009;27(14):2339-2355.
- Mulrooney DA, Armstrong GT, Huang S, et al. Cardiac outcomes in adult survivors of childhood cancer exposed to cardiotoxic therapy: a cross-sectional study of cardiac outcomes in survivors of childhood cancer after cardiotoxic therapy. *Ann Intern Med*. 2016;164(2):93-101.
- Phillips SM, Padgett LS, Leisenring WM, et al. Survivors of childhood cancer in the United States: Prevalence and burden of morbidity. *Cancer Epidemiol Prev Biomark*. 2015;24(4):653-663.
- Stam H, Grootenhuys MA, Last BF. The course of life of survivors of childhood cancer. *Psychooncology*. 2005;14(3):227-238.
- de Boer AGEM, Verbeek JHAM, van Dijk FJH. Adult survivors of childhood cancer and unemployment. *Cancer*. 2006;107(1):1-11.
- Zebrack BJ, Zeltzer LK, Whitton J, et al. Psychological outcomes in long-term survivors of childhood leukemia, Hodgkin's disease, and non-Hodgkin's lymphoma: a report from the childhood cancer survivor study. *Pediatrics*. 2002;110(1):42-52.
- Cox CL, Zhu L, Ojha RP, et al. The unmet emotional, care/support, and informational needs of adult survivors of pediatric malignancies. *J Cancer Surviv*. 2016;10(4):743-758.
- Lee-Jones C, Humphris G, Dixon R, Bebbington Hatcher M. Fear of cancer recurrence—a literature review and proposed cognitive formulation to explain exacerbation of recurrence fears. *Psychooncology*. 1997;6(2):95-105.
- Humphris G, Ozakinci G. The after intervention: a structured psychological approach to reduce fears of recurrence in patients with head and neck cancer. *Br J Health Psychol*. 2008;13(2):223-230.
- Park JL, Brandelli Y, Russell KB, et al. Unmet needs of adult survivors of childhood cancers: associations with developmental stage at diagnosis, cognitive impairment, and time from diagnosis. *J Adolesc Young Adult Oncol*. 2018;7(1):61-71.
- Meeske KA, Patel SK, Palmer SN, Nelson MB, Parow AM. Factors associated with health-related quality of life in pediatric cancer survivors. *Pediatr Blood Cancer*. 2007;49(3):298-305.
- Harrison JD, Young JM, Price MA, Butow PN, Solomon MJ. What are the unmet supportive care needs of people with cancer? A systematic review. *Support Care Cancer*. 2009;17(8):1117-1128.
- Oeffinger KC, Mertens AC, Sklar CA, et al. Chronic health conditions in adult survivors of childhood cancer. *N Engl J Med*. 2006;355(15):1572-1582.
- Geenen MM, Cardous-Ubbink MC, Kremer LM, et al. Medical assessment of adverse health outcomes in long-term survivors of childhood cancer. *JAMA*. 2007;297(24):2705-2715.
- Hudson MM, Ness KK, Gurney JG, et al. Clinical ascertainment of health outcomes among adults treated for childhood cancer. *JAMA*. 2013;309(22):2371-2381.
- Nathan PC, Greenberg ML, Ness KK, et al. Medical care in long-term survivors of childhood cancer: a report from the childhood cancer survivor study. *J Clin Oncol*. 2008;26(27):4401-4409.
- Shaw AK, Pogány L, Speechley KN, Maunsell E, Barrera M, Mery LS. Use of health care services by survivors of childhood and adolescent cancer in Canada. *Cancer*. 2006;106(8):1829-1837.
- Syed IA, Klassen AF, Barr R, et al. Factors associated with childhood cancer survivors' knowledge about their diagnosis, treatment, and risk for late effects. *J Cancer Surviv*. 2016;10(2):363-374.
- Oeffinger KC, Mertens AC, Hudson MM, et al. Health care of young adult survivors of childhood cancer: a report from the childhood cancer survivor study. *Ann Fam Med*. 2004;2(1):61-70.
- Nathan PC, Daugherty CK, Wroblewski KE, et al. Family physician preferences and knowledge gaps regarding the care of adolescent and young adult survivors of childhood cancer. *J Cancer Surviv*. 2013;7(3):275-282.
- Kremer L, Mulder RL, Oeffinger KC, et al. A worldwide collaboration to harmonize guidelines for the long-term follow-up of childhood and young adult cancer survivors: a report from the international late effects of childhood cancer guideline harmonization group. *Pediatr Blood Cancer*. 2013;60(4):543-549.
- Wilson CL, Cohn RJ, Johnson KA, Ashton LJ. Tracing survivors of childhood cancer in Australia. *Pediatr Blood Cancer*. 2009;52(4):510-515.
- Van Breeschoten J, Lourenco RDA, Signorelli C, et al. Patterns and drivers of health care use in long-term childhood cancer survivors: a systematic review. *Crit Rev Oncol Hematol*. 2017;120:60-76.
- Arvidson J, Söderhäll S, Eksborg S, Björk O, Kreuger A. Medical follow-up visits in adults 5–25 years after treatment for childhood acute leukaemia, lymphoma or Wilms' tumour. *Acta Paediatr*. 2006;95(8):922-928.
- Council NR. *From Cancer Patient to Cancer Survivor: Lost in Transition*. National Academies Press; 2005.

31. Campbell C, Craig J, Eggert J, Bailey-Dorton C. Implementing and measuring the impact of patient navigation at a comprehensive community cancer center. *Oncol Nurs Forum*. 2010;37(1):61-68.
32. Rainbird K, Perkins J, Sanson-Fisher R, Rolfe I, Anseline P. The needs of patients with advanced, incurable cancer. *Br J Cancer*. 2009;101(5):759-764.
33. Braun V, Clarke V. Using thematic analysis in psychology. *Qual res psychol*. 2006;3(2):77-101.
34. Dahlke DV, Fair K, Hong YA, Kellstedt D, Ory MG. Adolescent and young adult cancer survivorship educational programming: a qualitative evaluation. *JMIR cancer*. 2017;3.
35. Dickerson SS, Gruenewald TL, Kemeny ME. When the social self is threatened: shame, physiology, and health. *J Pers*. 2004;72(6):1191-1216.
36. Ginzburg K, Butler LD, Giese-Davis J, et al. Shame, guilt, and posttraumatic stress disorder in adult survivors of childhood sexual abuse at risk for human immunodeficiency virus: outcomes of a randomized clinical trial of group psychotherapy treatment. *J Nerv Ment Dis*. 2009;197(7):536-542.
37. Landier W, Bhatia S, Eshelman DA, et al. Development of risk-based guidelines for pediatric cancer survivors: the children's oncology group long-term follow-up guidelines from the children's oncology group late effects committee and nursing discipline. *J Clin Oncol*. 2004;22(24):4979-4990.
38. Howell D, Hack T, Oliver T, et al. Models of care for post-treatment follow-up of adult cancer survivors: a systematic review and quality appraisal of the evidence. *J Cancer Surviv*. 2012;6(4):359-371.
39. Signorelli C, Wakefield CE, McLoone JK, et al. Models of childhood cancer survivorship care in Australia and New Zealand: strengths and challenges. *Asia Pac J Clin Oncol*. 2017;13(6):407-415.
40. Mertens A, Whitton J, Neglia JP, Green DM, Gibson TM, Stovall M, et al. Temporal changes in treatment exposures in the childhood cancer survivor study (ccss). American Society of Clinical Oncology. 2015

How to cite this article: White J, Park J, Russell KB, et al. Falling through the cracks. A thematic evaluation of unmet needs of adult survivors of childhood cancers. *Psycho-Oncology*. 2018;27:1979-1986. <https://doi.org/10.1002/pon.4754>