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CHILDHOOD CANCER SURVIVORS' PRIMARY CARE AND FOLLOW-UP EXPERIENCES

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Abstract

Purpose: Although most childhood cancer survivors see a primary care provider (PCP), little is known about these encounters. We explored themes related to survivors' 1) experiences with primary care; 2) communication with their PCPs about their cancer; and 3) their knowledge and impressions about follow-up care, including their interest in a survivor care plan (SCP).

Methods: From April to July 2012 we conducted in-depth, semi-structured telephone interviews with 53 adult survivors recruited from the Utah Cancer SEER Registry. Participants were randomly selected from sex, age, and rural/urban strata and were younger than 21 years at time of

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diagnosis. Participants were asked if they had a PCP; whether they discussed their cancer history with their provider; and their interest in a SCP. Interviews were recorded, transcribed, and content analyzed.

Results: The average age at interview was 39.1 years (SD=11.2). Most survivors had a current PCP (83.0%). Almost half were not worried about their health despite having had cancer. Discussions about cancer history with PCPs were rare, and 12.2% of survivors reported never talking with their PCP about their cancer. Few survivors had a follow-up care plan, but half thought a SCP could empower their medical decision-making. However, one-third of survivors were skeptical about the usefulness of a SCP and some were worried about health care costs.

Conclusions: Childhood cancer survivors need better care coordination. Of concern is that most do not discuss their cancer history with their current PCPs and most have no SCP.

Keywords

Childhood cancer survivors; primary care; risk-based care; survivor care plans

Introduction

In 2005, the Institute of Medicine (IOM) released the seminal report, “From Cancer Patient to Cancer Survivor: Lost in Transition,” identifying primary care providers (PCPs) as an integral part of cancer survivors’ long-term care [1]. Survivors of childhood cancers, in particular, require comprehensive long-term care due to health problems that can arise from their cancer therapy. These health problems range from conditions, such as infertility, psychosocial issues, and learning difficulties, to life-threatening diseases such as second cancers and cardiomyopathies. More than 73% of childhood cancer survivors develop at least one chronic condition within 30 years after their initial diagnosis, and their risk of life-threatening conditions is approximately 8-fold higher than their siblings [2].

To identify and manage health problems – known as ‘late effects’ – risk-based follow-up care is recommended for childhood cancer survivors throughout their lives. Most Children’s Oncology Group institutions provide late effects services, but the availability and extent of long-term follow-up care varies and is utilized by a small number of eligible survivors [3, 4]. As a result, many childhood cancer survivors do not receive risk-based health care [5]. While 90% of childhood cancer survivors report receiving general medical care [5], fewer than 20% go to a cancer center or see an oncologist [6]. Thus, most childhood cancer survivors access health care in the community setting, typically from PCPs.

Recognizing this reality, current models of survivor care include a shared care model that focuses on care coordination between PCPs and cancer specialty providers [7]. However, certain patient and provider challenges exist for establishing shared care. Childhood cancer survivors often lack basic information about their diagnosis, treatment, and the importance of preventive care and regular surveillance for late effects [8]. From the provider side, PCPs are willing to care for childhood cancer survivors [9, 10], but they report knowledge gaps and lack of time to address survivors’ complicated needs and to provide appropriate risk-based screening [11–14].

In Utah, the majority of younger childhood cancer patients are treated at Primary Children's Hospital (PCH) in Salt Lake City [15], which serves as the primary pediatric tertiary care center for a large geographic area in the Intermountain West that includes Utah and parts of Idaho, Wyoming, Nevada, Colorado, Arizona, and Montana. Additionally, adolescents are often treated outside of PCH by community oncology providers [15]. While the Huntsman Cancer Hospital, part of the University of Utah, has a late effects clinic, this clinic was started in 2010. Patients who completed routine post-therapy surveillance prior to 2010 most likely do not know about this clinic. Instead, these patients likely see community health care providers for their health care. However, we are aware of no studies that have assessed the primary care and other health care experiences of adult survivors of childhood cancer in this large geographic area, which is a necessary step for promoting appropriate risk-based care.

Here we report on findings from semi-structured interviews with 53 long-term adult childhood cancer survivors from Utah. We describe survivors' primary health care experiences including the types of providers they currently see for their routine health care, and whether they report communication challenges with their PCPs about their cancer history. We assess survivors' need for information to facilitate appropriate follow-up care, including their interest in a survivor care plan (SCP), which provides an overview of cancer treatment and the timing and content of recommended follow-up care to use in their interactions with their providers [1].

METHODS

This analysis was conducted as part of an exploratory study on Utah childhood cancer survivors. We developed a semi-structured interview guide that included both closed and open-ended questions on health insurance, health care utilization, and other outcomes. We pilot-tested the interview with five survivors recruited from the Huntsman Cancer Hospital's Pediatric Cancer Late Effects Clinic and modified it based on feedback. For the current analysis we focused on interview questions pertaining to survivors' discussions about their cancer history with their PCPs or other providers, their experiences with primary and survivor-specific health care services, their current use of health care services, and their interest in SCPs. The study protocol was approved by the Institutional Review Board at the University of Utah.

Participants and recruitment strategy

Potential participants were identified by the Utah Cancer Registry, a population-based registry that is part of the National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) Program. Eligible participants were diagnosed between January 1, 1973 and December 31, 2005, were ≤21 years of age at time of diagnosis, were between 18–60 years old at the time of the interview, and spoke English. We limited participants to survivors born in Utah to have access to updated contact information via the Utah Cancer Registry resources. All participants met eligibility criteria for the International Childhood Cancer Classification system, which is the standard classification system for pediatric and adolescent cancers [16].

There were 2,686 eligible participants. To obtain a geographically diverse sample that included adequate numbers by gender and current age, we randomly selected participants from gender, county at diagnosis (urban/rural), and current age (18–29, 30–45, and 46–60) strata. Letters were sent to 150 potential participants; of these, 70 had outdated contact information based on returned envelopes, 3 were deemed ineligible, and 14 refused to participate. The remaining 63 were contacted and agreed to participate.

Data collection and analysis

Informed consent was obtained by two research team members (ACK and ELW) who completed telephone interviews from April 2012-July 2012. These single-session interviews lasted 30–45 minutes. Participants were sent a $20 gift card. We finalized recruitment at 53 interviews when thematic saturation was obtained (i.e., when no new themes emerged) [17].

The interview transcripts were transcribed and entered into QSR Nvivo for descriptive thematic coding and content analysis by two members of the research team (ACK and ELW) [18]. The two coders read each interview and developed a list of codes that were revised through discussion. Our initial focus was on understanding survivors' use of health care (both primary and survivor-specific). However, as analyses developed, we also recognized unique themes from our questions pertaining to survivors' discussions about their cancer history with their PCPs and their interest in SCPs. ACK and ELW each coded the same ten interviews, and as inter-rater agreement was high (kappa=0.93), the remaining interviews were divided and coded independently. Disagreements were resolved by discussion with REM. Themes were examined by gender, current age, and time since treatment. Results did not differ by gender, but we report on differences by current age and time since treatment.

RESULTS

Study Population

As shown in Table 1, a total of 53 survivors were interviewed. Survivors were on average 39.1 (SD=11.2) years old at interview, ranging from ages 18–56. Approximately half were female; 94% were non-Latino white. Mean age at diagnosis was 13.0 years (SD=6.7) and median time since diagnosis was 26.1 years (range 7–39). The most common diagnosis was lymphoma (24.5%).

Themes

Three major themes emerged. Survivors reported (1) varied primary health care experiences, (2) communication difficulties with PCPs about cancer history, and (3) a need for survivor-focused care, with special attention paid to interest in a SCP.

CURRENT PRIMARY HEALTH CARE EXPERIENCES

Of the 53 survivors, 44 (83.0%) reported having routine medical care (defined as a visit within the past two years) with a provider they considered their primary provider. While 22.6% received care exclusively from a family practice physician, internal medicine physician, or nurse practitioner, 11.3% saw a family practice or internal medicine physician along with an oncologist, 34.0% saw a family practice or internal medicine physician along with at least one specialist, and 15.1% received primary care from a specialty provider that was not an oncologist.

The remaining 17.0% of survivors who did not regularly see a PCP fell into two groups: 4 had recently moved, had their provider retire or relocate, or were uninsured, while 5 felt they were healthy and did not need regular health care. For example, when asked about her use of primary care, a Wilms tumor survivor in her 20s stated, *"I'm pretty healthy, so I don't have to stay on top of all that."* Survivors without a PCP tended to be younger, with 35.7% of those ages 18–29 and 26.3% ages 30–45 without a PCP compared to less than 10.0% of those ages 46–56.

Among the 44 survivors who routinely saw a PCP, a small number (8.3%) described that their PCP encouraged or facilitated connections with oncology providers to manage their care. Specifically, these survivors had been encouraged by their PCP to visit a cancer specialist. One woman stated, *"[My primary provider says] because of my history with the cancer, they want me to see a more of a cancer specialist to make sure things are okay."* Others had PCPs who directly connected with their oncologists: *"My oncologist and my general practitioner, they kind of confer with each other and trade information back and forth."*

CANCER-RELATED COMMUNICATION WITH PCPs

Of the 44 survivors who had seen their PCP at least one time in the past two years, 68.2% reported discussing their cancer history with their PCP at this visit. However, these conversations varied by time since diagnosis. Of the four survivors who were 7–10 years from their original cancer diagnosis, all had regular discussions with their PCPs about their cancer history and the need to receive screening for health problems. These survivors also reported receiving active surveillance for health problems. However, only 37.7% of survivors who were ≥10 years from diagnosis reported discussing their cancer with providers. For these survivors, this discussion typically occurred as part of their medical decision-making due to emerging health problems.

The remaining 29 survivors reported a lack of regular or detailed discussions pertaining to their cancer history with their PCPs. Of these, a total of 41.4% indicated that they only talked with their PCPs about their cancer briefly during the "general history" discussion taken at the initial visit when establishing medical care with a new physician. One female leukemia survivor reported, *"With [my] new doctor, I wrote down the [cancer] history…but nothing was really discussed about any of it."* Another female survivor who had a Wilms' tumor said: *"[Providers] usually just ask about [my cancer] as a history wide thing, just that I had it and what surgeries, but they usually don't go into much of it."*

One-fourth of the 29 survivors reported that they had not discussed their cancer with their PCP for years and that it rarely resurfaced during visits: *"There hasn't been any talk about [my cancer with my provider] in lots and lots of years."* Other survivors thought that their providers were probably aware that they had cancer, but nevertheless, did not discuss it: *"I* *don't think [we've] ever had any conversations about [my cancer]."* One woman described a time when she was transitioning to a new provider who reacted in a surprised manner when she disclosed her history of leukemia. When asked whether or not this led to discussion, she answered: *"Nope, we do not discuss my cancer. [My provider is] just curious that I've had it…But that's mostly just curious–amazed I guess, that I'm a survivor. That's mostly all."* A few survivors (12.2%) had never told their PCP about their cancer history.

KNOWLEDGE AND IMPRESSIONS ABOUT SURVIVOR CARE

Almost half of survivors (41.5%) were not aware of potential late effects from their cancer. This knowledge did not differ by time since diagnosis. Several survivors stated that since their cancer had occurred years ago, they thought any health problems would have already developed. One woman's view was: *"It's been so long since I've had [cancer]. It's not like I really worry about [health problems]. I was 20. That's been 35 years ago."* Other survivors (58.5%) had health problems, and for some of these survivors, a lack of knowledge about late effects resulted in complications with accessing appropriate health care. For instance, a woman with a history of neuroblastoma described several years of thyroid problems that were left untreated until she sought out an endocrinologist:

> "I had radiation therapy as an infant, and my thyroid is caput. I had a tumor in my rib cage, and being so small there's a high possibility that the thyroid was then ruined by radiation therapy. But, I didn't know that until I was talking with the endocrinologist."

Almost all survivors (90.6%) did not have a care plan that extended beyond five years after their cancer treatment ended. However, 49.1% felt a tool like a survivor care plan would be very useful to their current health care decision-making and communication with their PCPs and other providers. Of primary interest was having a longitudinal plan that detailed when to go for specific types of health care visits: *"I like the idea of [knowing] screenings that I should have. If there is something I should do, I don't know unless somebody tells me medical-wise.*" Other survivors described struggling with understanding their cancer and treatment because they were very young at diagnosis. One woman reacted positively to the idea of a SCP because, *"My mother was the one who took care of me when I was diagnosed, I have no clue how to get through my own medical life…It is a big responsibility for one who has gone through so much."*

However, quite a few survivors (32.1%) were more skeptical about SCP usefulness. Some stated that for a care plan to be helpful, it would need to show what specialty services were covered by their insurance and how much the care would cost them. Others felt that the window of opportunity for a care plan to be valuable had passed: *"At this point, I think it's a little bit far out, but at the time [of my cancer, a care plan] would've been great."* The remaining 13.2% of survivors were unsure about usefulness of a SCP.

Discussion

As childhood cancer survivors age into adulthood, many may lose connections with or move away from the setting where they received their cancer treatment. While most pediatric oncology clinics provide some follow-up care, the majority of childhood cancer survivors end up receiving most of their health care from PCPs within several years following the end of their cancer therapy [5]. The coordination of childhood cancer survivor care is a challenge, as these survivors transition from both cancer-focused care to general care and from pediatric to adult care. PCPs, oncologists, and patients all have different expectations about the role of PCPs in survivorship care [19, 20]. Our interviews with Utah childhood cancer survivors suggest several important concerns related to survivors' primary care experiences that require better care coordination.

Similar to earlier reports [6], we found that most childhood cancer survivors described having some interaction with the medical system and seeing a PCP in the past two years. Yet, despite the greater risk of health problems with increasing age [2], over 60% survivors in our sample who were ten or more years from diagnosis reported very limited discussions with their PCPs regarding their cancer. This discussion was often limited to a one-time, routine health history. Often, these discussions had occurred years ago. While a few survivors described informal coordination between their oncology provider and their primary care provider, this was rare.

We also found that many of the survivors we interviewed desired information on post-treatment follow-up care, similar to earlier studies on survivors of both childhood and adult cancers [21, 22]. Approximately half of the survivors in our sample felt a survivor care plan would be useful for their medical decision-making. PCPs feel more confident and prepared in managing survivors after receiving a SCP [23], meaning that a care plan could provide an important medical decision-making tool for childhood cancer survivors who see a PCP for their health care.

Two recent developments may facilitate the provision of SCPs and risk-based care for childhood cancer survivors. In 2012, the Centers for Medicare & Medicaid Services released two Healthcare Common Procedure Coding System codes for cancer treatment planning and care coordination. Although this does not guarantee payment, it provides an avenue for provider reimbursement and care coordination services. In addition, the internet-based *Passport for Care* SCP is used in over 100 late effects clinics nationwide. *Passport for Care* was developed using the Children's Oncology Group risk-based clinical guidelines for follow-up care [24]. *Passport for Care* is also directly accessible to survivors as a tool to improve their follow-up care.

However, long-term survivors who do not receive follow-up care from oncology providers may lack access to treatment-related information for generating a SCP. One potential avenue for supplementing this information is state cancer registries. Utah's registry started in 1966 and although historical records (pre-1980) are less comprehensive, diagnosis and summary treatment information are kept in perpetuity and represent a potentially untapped resource for survivors. One-third of our participants, however, did not think that a SCP would be useful and were worried about costs associated with accessing survivor-focused health care. Out-of-pocket medical costs are a worry for this population [25] and future studies are needed to understand the impact of financial concerns on survivor-focused health care. In addition, as we found that 17.0% of our participants did not report any recent visits with a

PCP, programs that supply survivors with SCPs must also provide tailored education on the need for regular health care.

Our study has limitations. Our participants included a small number of uninsured and publically insured survivors, were relatively well educated and were all English speakers. This limits our ability to identify themes pertaining to the most underserved survivors, who may be in poorer health. We had few ethnic/racial minority survivors as over 94% of our sample was white. This is similar to the distribution of the overall childhood cancer population in Utah and parallels the demographics of Utah where historically the vast majority of residents are overwhelmingly non-Hispanic white [26]. Also, the majority of our sample was more than 10 years from diagnosis. As national attention to late effects has increased over the past decade, it is possible that survivors diagnosed more recently may be more likely to talk about their cancer history with their providers and have a greater knowledge of late effects than our participants.

In addition, as our sample was drawn from Utah cancer survivors, our results may be less applicable to survivors in other areas of the Intermountain West where access to long-term follow-up care differs. As we focused on the perspective of survivors, we did not document receipt of care via medical records. However, this study provides unique information on the health care experiences of childhood cancer survivors from the Intermountain West, which is a large and understudied geographic area. Coupled with our earlier report demonstrating that rural childhood cancer survivors from Utah face concerns with accessing quality care in their communities and often travel long distances to obtain specialty care [27], these findings demonstrate a need to develop evidence-based interventions to promote appropriate risk-based care for survivors in the Intermountain West.

Although PCPs will continue to play a significant role in the care of childhood cancer survivors, we found that many survivors report not receiving personalized survivorship care. To ensure optimal long-term care, oncology clinicians should assist childhood cancer patients in connecting with PCPs that are familiar with post-cancer care. In addition, many of the survivors in our study appeared to lack awareness about their health care needs related to late and long-term effects of cancer treatment, but believed a SCP could empower them to improve their health and health care. While obtaining treatment information from survivors' original oncologist or cancer center may not be feasible, national efforts must be made to find novel ways of obtaining cancer information through registries and to provide PCPs with the resources to manage survivors' unique health care needs.

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References

1. Institute of Medicine. From Cancer Patient to Cancer Survivor: Lost in Transition. Washington D.C.: Committee on Cancer Survivorship: Improving Care and Quality of Life 2006.
2. Oeffinger KC, Mertens AC, Sklar CA, Kawashima T, Hudson MM, Meadows AT et al. Chronic health conditions in adult survivors of childhood cancer. The New England journal of medicine. 2006;355(15):1572–82. [PubMed: 17035650]
3. Aziz NM, Oeffinger KC, Brooks S, Turoff AJ. Comprehensive long-term follow-up programs for pediatric cancer survivors. Cancer. 2006;107(4):841–8. doi:10.1002/cncr.22096. [PubMed: 16886175]
4. Eshelman-Kent D, Kinahan KE, Hobbie W, Landier W, Teal S, Friedman D et al. Cancer survivorship practices, services, and delivery: a report from the Children’s Oncology Group (COG) nursing discipline, adolescent/young adult, and late effects committees. J Cancer Surviv. 2011;5(4):345–57. doi:10.1007/s11764-011-0192-8. [PubMed: 21894490]
5. Nathan PC, Greenberg ML, Ness KK, Hudson MM, Mertens AC, Mahoney MC 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):4401–9. [PubMed: 18802152]
6. Oeffinger KC, Mertens AC, Hudson MM, Gurney JG, Casillas J, Chen H et al. Health care of young adult survivors of childhood cancer: a report from the Childhood Cancer Survivor Study. Annals of family medicine. 2004;2(1):61–70. [PubMed: 15053285]
7. Oeffinger KC, McCabe MS. Models for delivering survivorship care. J Clin Oncol. 2006;24(32):5117–24. doi:10.1200/JCO.2006.07.0474. [PubMed: 17093273]
8. Kadan-Lottick NS, Robison LL, Gurney JG, Neglia JP, Yasui Y, Hayashi R et al. Childhood cancer survivors’ knowledge about their past diagnosis and treatment: Childhood Cancer Survivor Study. JAMA : the journal of the American Medical Association. 2002;287(14):1832–9. [PubMed: 11939869]
9. Nathan PC, Daugherty CK, Wroblewski KE, Kigin ML, Stewart TV, Hlubocky FJ et al. Family physician preferences and knowledge gaps regarding the care of adolescent and young adult survivors of childhood cancer. J Cancer Surviv. 2013. doi:10.1007/s11764-013-0271-0.
10. Meacham LR, Edwards PJ, Cherven BO, Palgon M, Espinoza S, Hassen-Schilling L et al. Primary care providers as partners in long-term follow-up of pediatric cancer survivors. J Cancer Surviv. 2012;6(3):270–7. doi:10.1007/s11764-012-0224-z. [PubMed: 22562474]
11. Bober SL, Recklitis CJ, Campbell EG, Park ER, Kutner JS, Najita JS et al. Caring for cancer survivors: a survey of primary care physicians. Cancer. 2009;115(18 Suppl):4409–18. doi:10.1002/cncr.24590. [PubMed: 19731354]
12. Nissen MJ, Beran MS, Lee MW, Mehta SR, Pine DA, Swenson KK. Views of primary care providers on follow-up care of cancer patients. Family medicine. 2007;39(7):477–82. [PubMed: 17602321]
13. Del Giudice ME, Grunfeld E, Harvey BJ, Piliotis E, Verma S. Primary care physicians’ views of routine follow-up care of cancer survivors. J Clin Oncol. 2009;27(20):3338–45. doi:10.1200/JCO.2008.20.4883. [PubMed: 19380442]
14. Henderson TO, Friedman DL, Meadows AT. Childhood cancer survivors: transition to adult-focused risk-based care. Pediatrics. 2010;126(1):129–36. doi:10.1542/peds.2009-2802. [PubMed: 20547645]
15. Albritton KH, Wiggins CH, Nelson HE, Weeks JC. Site of oncologic specialty care for older adolescents in Utah. J Clin Oncol. 2007;25(29):4616–21. doi:10.1200/JCO.2006.08.4103. [PubMed: 17925557]
16. Steliarova-Foucher E, Stiller C, Lacour B, Kaatsch P. International Classification of Childhood Cancer, third edition. Cancer. 2005;103(7):1457–67. doi:10.1002/cncr.20910. [PubMed: 15712273]
17. Guest G, Bunce A, Johnson L. How many interviews are enough? An experiment with data saturation and variability. Field Methods. 2006;18:59–82.
18. Krippendorff K. Content analysis: an introduction to its methodology- 3rd ed Thousand Oaks, CA: SAGE Publications, Inc.; 2013.

19. Hudson SV, Miller SM, Hemler J, Ferrante JM, Lyle J, Oeffinger KC et al. Adult Cancer Survivors Discuss Follow-up in Primary Care: 'Not What I Want, But Maybe What I Need'. Annals of family medicine. 2012;10(5):418–27. doi:10.1370/afm.1379. [PubMed: 22966105]
20. Cheung WY, Neville BA, Cameron DB, Cook EF, Earle CC. Comparisons of patient and physician expectations for cancer survivorship care. J Clin Oncol. 2009;27(15):2489–95. doi:10.1200/JCO.2008.20.3232. [PubMed: 19332716]
21. Hewitt ME, Bamundo A, Day R, Harvey C. Perspectives on post-treatment cancer care: qualitative research with survivors, nurses, and physicians. J Clin Oncol. 2007;25(16):2270–3. doi:10.1200/JCO.2006.10.0826. [PubMed: 17538172]
22. Zebrack BJ, Eshelman DA, Hudson MM, Mertens AC, Cotter KL, Foster BM et al. Health care for childhood cancer survivors: insights and perspectives from a Delphi panel of young adult survivors of childhood cancer. Cancer. 2004;100(4):843–50. [PubMed: 14770443]
23. Shalom MM, Hahn EE, Casillas J, Ganz PA. Do survivorship care plans make a difference? A primary care provider perspective. Journal of oncology practice / American Society of Clinical Oncology. 2011;7(5):314–8. doi:10.1200/JOP.2010.000208.
24. Horowitz ME, Fordis M, Krause S, McKellar J, Poplack DG. Passport for care: implementing the survivorship care plan. Journal of oncology practice / American Society of Clinical Oncology. 2009;5(3):110–2. doi:10.1200/JOP.0934405.
25. Park ER, Kirchhoff AC, Zallen JP, Weissman JS, Pajolek H, Mertens AC et al. Childhood Cancer Survivor Study participants' perceptions and knowledge of health insurance coverage: implications for the Affordable Care Act. J Cancer Surviv. 2012. doi:10.1007/s11764-012-0225-y.
26. Gibson C, Jung K. Historical Census Statistics on Population Totals By Race, 1790 to 1990, and By Hispanic Origin, 1970 to 1990, For The United States, Regions, Divisions, and States Accessed on January 6, 2013 http://www.census.gov/population/www/documentation/twps0056/tab59.pdf
27. Warner EL, RE M, Stroup A, Kinney AY, Kirchhoff AC. Health care concerns of rural childhood cancer survivors. In Press. J Health Care Poor Underserved. 5 2014.

Implications for Research/Programs:

Childhood cancer survivors require support, such as survivor care plans, to engage with primary care providers in risk-based medical care.

Table 1:

Demographic and Cancer-Related Characteristics (N=53)

	N (%)
Age at interview, years	
18–29	14 (26.4)
30–45	19 (35.9)
46–60	20 (37.7)
Age at cancer diagnosis, years	
0–4	10 (18.9)
5–9	6 (11.2)
10–14	4 (7.6)
15–20	33 (62.3)
Female	29 (54.7)
White, Not Hispanic/Latino	50 (94.3)
Cancer diagnosis	
Lymphoma	13 (24.5)
Gonad/germ cell	10 (18.9)
Leukemia	9 (17.0)
Sarcoma	6 (11.3)
Thyroid	5 (9.4)
Other	10 (18.9)
Education	
High school or less	10 (18.9)
Some college or technical school	28 (52.8)
College graduate or more	15 (28.3)
Insured	47 (88.7)
Urban County at Diagnosis[a]	27 (50.9)
Urban County at Interview[a,b]	33 (70.2)

[a] Rural=living in a county with <75% of population in an urban area [population ≥2,500]

[b] Missing for five participants