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Understanding the functional late effects and informational needs of adult survivors of childhood cancer

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Abstract

Purpose/Objectives—To report functional (physical & cognitive) late effects, experiences and information needs of adult survivors of childhood cancer. The increasing population of survivors makes understanding the effects of treatment and identifying needs vital to promoting health.

Design—Descriptive, mixed methods survey.

Setting—Two pediatric oncology programs in the Midwest.

Sample—Convenience sample of 271 young adult survivors.

Methods—Voluntary survey completion by young adult survivors regarding late effects, experiences and educational needs to develop appropriate comprehensive care programs for care provision before, during and after transition to adult care. Survey domains were identified from existing survivorship literature and focused on all aspects of survivorship; however, this paper focuses on results specific to the functional domain.

Main Research Variables—Functional late effects, experiences, information needs, age, gender and treatment intensity of young adult survivors of childhood cancer.

Findings—Response rate was 47.5%. Functional late effects, perceptions, and information needs all correlated with intensity of treatment (those survivors most heavily treated experiencing the most symptoms). Survivors wanted more information about late effects and how to deal with them. Females wanted more information about fertility-related topics and participants who received more intense treatment generally wanted more information. Brain tumor survivors perceived greater cognitive difficulties, cognitive late effects, fatigue, and financial difficulties.

Conclusions—Survivors experience myriad physical late effects and require ongoing access to information as needs change over time.

Implications for Nursing—Identifying new and innovative ways to reach survivors and better meet needs is important for care, research and program development.

Introduction

Adult survivors of childhood cancer are a rapidly growing demographic with an estimated 300,000 living in the United States (American Academy of Pediatrics, 2009). With improvements in survival rates comes the risk for the development of late effects. Survivors are at risk for functional (physical and/or cognitive) and psychosocial late effects of their treatment. Late effects are health problems attributable to cancer and its treatment and can vary based on treatment intensity, diagnosis, age at diagnosis and can affect any organ system in the body (Landier, 2007). Two thirds of adult survivors of childhood cancer will experience a late effect of their cancer. (American Academy of Pediatrics, 2009). While the risk for late effects increases with age, many are modifiable through ongoing care and evaluation (Oeffinger & Wallace, 2006). In addition to the need for ongoing evaluation of late effects, many survivors also require education regarding their diagnosis, treatment and screening recommendations (Oeffinger & Wallace, 2006).

In response to the growing numbers of survivors, the long length of life that these survivors anticipate, as well as their multiple health needs, more pediatric oncology programs are developing long-term follow-up programs to meet the unique needs of this expanding population. These programs exist to provide much needed education about late effects, develop and implement personalized follow up plans, and assist with the transition from pediatric care to the adult medical community. Another key role of long-term follow-up programs is educating survivors about their diagnosis and treatment history. The Children's Oncology Group (COG) recommends survivors have a comprehensive treatment summary encompassing the diagnosis, specific treatment given, complications or known late effects and recommendations for ongoing screening and follow-up (Landier, 2007). Organizations including the Institute of Medicine (IOM), the American Academy of Pediatrics (AAP), the American Society of Pediatric Hematology/Oncology (ASPHO) and COG have all advocated for the importance of life-long follow-up care for survivors (National Cancer Institute, 2012). Most recently, the importance of follow-up care and treatment summaries for survivors garnered the attention of the American College of Surgeons (ACOS). In their Commission on Cancer (CoC) program standards ACOS mandated the inclusion of treatment summaries and follow-up plans for survivors to be incorporated by all accredited institutions by 2015 (Commission on Cancer, 2011).

Despite these mandates by medical organizations, lack of knowledge about their diagnosis, treatment history, health risks and anxiety about cancer history may influence survivors' willingness to seek follow-up care (Henderson, Hlubocky, Wroblewski, Diller, & Daugherty, 2010; Landier, 2007). Young adult survivors may feel healthy, desire to leave their cancer experience behind them and not recognize the importance of routine follow-up (Landier, 2007). One particular benefit of long-term follow-up programs is the opportunity to intervene early to provide education and screening to promote active engagement for lifetime health.

Currently, 1.5 per 1000 young adults (20–39 years) in the United States is a survivor of childhood cancer and that number continues to grow (Hewitt, Weiner, & Simone, 2003). This number is important when one considers the impact of cancer survivorship on the emerging adult. The population of people 18–29 years is often identified as those in “emerging adulthood” (Arnett, 2000). Recognition that this time frame is separate and distinct from adolescence and adulthood is in progress. Emerging adulthood as a life-stage is characterized by exploration and change. Most persons younger than age 18 live at home and are unmarried, and most persons by age 30 live on their own and are in stable relationships. The time in between is widely variable. Many individuals in this stage seek additional education and delay marriage and family. With their focus on these other activities, cancer survivors in this group are often less interested in seeking survivor related information. This has implications for the educational and health programs that are developed to meet the needs of this population.

The purpose of this paper is to report the functional late effects, experiences and information needs of adult survivors of childhood cancer treated in two pediatric oncology programs in the Midwest. Our specific aims were to describe the self-reported 1) current healthcare practices, 2) treatment side effects, and 3) healthcare needs of adult survivors of childhood cancer.

Methods

Participants and procedures

Participants were recruited in collaboration between Children's Mercy Hospital and the University of Kansas Cancer Center pediatric oncology programs. The study was approved by both institutional review boards (IRB) with study personnel at both sites included in each application. The study was approved with a HIPAA waiver and waiver of consent.

An initial mailing was sent to adult survivors of childhood cancer entered in the tumor registries at both hospitals. Patients who did not receive treatment from an oncologist were excluded from the study. IRB-approved initial mailings included a paper survey marked only with a participant ID number, a letter of explanation, self-addressed pre-paid envelope, an optional form to request additional information and/or to agree to participate in future research, and a five-dollar cash incentive. Recipients also received instructions on how to complete the survey online if preferred. Security and participant anonymity for the online survey was maintained by using an institution-based survey tool with firewalls and protections appropriate for hospital records, requiring a password to view results, and privacy features which blocked users' personal information from being recorded. The online survey asked participants for the study ID as the only identifier. A second mailing occurred five weeks after the initial mailing to those individuals who had not responded and who had a presumed valid mailing address. No additional incentive was provided with the second mailing. Surveys were collected over a six month period of time after the first mailing.

Design and Survey

Descriptive, mixed methods design and self-report survey techniques were used to identify and explore variables of interest and to describe and report the results at different levels. A survey previously used to quantify the healthcare experiences and health outcomes of survivors of Non-Hodgkin's Lymphoma (NHL) provided the basis for survey design (Arora et al., 2007). Because the aggressive therapy and subsequent late and long-term side effects found in the NHL population correlate strongly to what is seen in the pediatric oncology population, this tool provided an appropriate guiding framework for survey development. The majority of the survey consisted of check-box questions. However, each area of exploration contained opportunities to gather qualitative data, such as space to write-in additional information about symptoms and experiences as well as places to add comments. These served to add depth to the data obtained without making the survey arduously long.

The final product was a 26-item self-report survey that was conceptualized to focus on both the medical late effects of treatment and the experiences that have impacted participants as survivors. Questions were simple and straightforward (e.g. "On a scale of one to five how is your health?"). The late effects included in the survey were derived from key stakeholders' input by the IOM, the Lance Armstrong Foundation and the Centers for Disease Control and Prevention, as well as the survivorship literature (Geenen et al., 2007; Hewitt, Greenfield, & Stovall, 2006; "A National Action Plan for Cancer Survivorship: Advancing Public Health Strategies," 2004; National Cancer Institute, 2012; Oeffinger et al., 2006). The survey encompassed the most common functional and psychosocial problems encountered by adult survivors of childhood cancer as identified by the literature and these stakeholders. To use terminology more familiar to participants, the term "side effects" was substituted for medical late effects in the survey. Experience questions focused on the challenges survivors reported facing as adults, including financial stress and difficulty in school. The survey's knowledge question requested input on 14 separate cancer-related topics were derived from consensus documents about essential components of survivorship care that had been prepared with stakeholder input. The survey captured demographic information, cancer history, treatment side effects, current health status, receipt of survivor treatment summary, and survivor experience and needs. For this paper, only late effects from the functional domain are reported.

Data analyses

Descriptive analyses were performed for all quantitative data. Missing data were treated as missing, and no data were imputed. For qualitative data, content analysis was utilized as a "data reduction and sense-making effort that takes a volume of qualitative material and attempts to identify core consistencies and meanings" (Patton, 2002). Using mixed methods allowed a broader picture of the participants' experiences to emerge. A majority of the qualitative data came in the form of phrases describing additional symptoms and experiences not adequately captured in the survey. However, many times, the additional qualitative data participants shared provided depth and detail to the existing data that aided in understanding the experience from survivor's perspective. For this study, the results of the content analysis served to support and enhance the "picture" that the quantitative data

painted rather than freestanding themes as is often the case on more purely qualitative studies.

In some cases, content analysis allowed the addition of symptoms to the list of existing symptoms for the purposes of inclusion in symptom analysis. While counting is not a usual outcome of qualitative analysis, in a case such as this, it is not inappropriate. In other cases, analyzing the statements that participants wrote in their surveys helped the providers understand the quantitative results more clearly.

Statistical analysis consisted predominantly of chi-square tests because the majority of the data generated from the survey were nominal. We were looking for relationships between variables of interest in this population, particularly information needs, experience of late effects, and intensity of treatment. Descriptive statistics also provided additional information about the population.

Among the items on the survey, participants reported what type of treatment(s) they received (chemotherapy, radiation therapy, surgery, bone marrow transplant, etc.). Analyzing self-reported treatment information from participants whose treatment spanned a timetable of approximately 20 years proved challenging. The strides that had been made in the treatment of childhood cancer over that timeframe came with changes in protocols and treatments.

Our analyses necessitated a method by which to rate the intensity of treatment received. Therefore, we used the Intensity of Treatment Rating Scale 2.0 (ITR-2) developed at the Children's Hospital of Philadelphia to classify the treatments received by our participant population (Werba et al., 2007). The ITR-2 allows practitioners to use information about diagnosis and treatment modalities to assign a level of intensity to treatment regimens. The tool includes treatment intensities from least (ex. Wilm's tumor with surgery only) to most intensive (ex. treatment including a stem cell transplant) (see Table 1). Developers of the scale report high inter-rater reliability ($r=0.83-0.87$) in their trials of the tool (Werba et al., 2007).

Two investigators on the study team, with 26 years of combined experience in pediatric oncology (W.M. and K.S.), independently scored all participants based on information provided about diagnosis, treatment received and relapse history. When scores were compared, there was 99% agreement between the two raters. Of the five cases in which there was not agreement, discussion of the treatment information provided by participants resulted in agreement. As the results demonstrate below, rating treatment intensity allowed differences among groups to emerge and helped identify higher risk groups that had not emerged in previous analysis.

Results

Of the 710 surveys that were mailed, 139 (20%) were returned due to undeliverable addresses. Of the remaining 571 surveys, 271 were returned for a response rate of 47.5%. Twelve participants chose to complete the survey online. Table 2 shows the demographics and Table 3 shows the cancer-related characteristics of the final participant group. A

majority of participants were White, non-Hispanic (91%). This percentage was slightly higher than was mailed the survey (85%). In the population that returned the survey, only four percent were Black while twelve percent of the population that was mailed the survey was Black. We condensed the remaining identified races into “Other” because the numbers of individual races were small and many participants self selected multiple races. The population ranged in age from 18 to 38 years, with a mean age of 24 years. Since this population was predominantly young adult, larger percentages were single and still in college. The mean age at diagnosis was 10 years of age. These survivors encompassed a wide range of diagnoses so for analysis purposes, we grouped them into leukemia/lymphoma (48%), solid tumors (33%) and brain tumors (19%). The majority of the population had not experienced relapse.

We surveyed participants regarding whether they had received a treatment summary. In this study, 28% percent reported having received a treatment summary, 39% reported not receiving a treatment summary and 32% were unsure whether they had received one. Since being unsure whether one had received a treatment summary means it is unlikely that it is being utilized in one's healthcare, this translates into 71% that essentially do not have a treatment summary to guide their future healthcare.

Intensity of treatment and Overall Health Status

Overall, this population received intense treatment as classified by the ITR-2 (Werba et al., 2007). Ninety-two percent of the study population received at minimum, moderately intensive treatment (such as that for lower stage neuroblastoma or Hodgkin lymphoma stage I–III) Fifty percent of that group received higher intensity treatment including relapse protocols or transplant. Not surprisingly, intensity of treatment correlated with the number of late effects experienced (Cramer's $V=.218$; Chi-sq = 24.452: df = 8; $p < .002$). Table 1 includes further detail about the relationship between intensity of treatment and number of late effects experienced. Those survivors who experienced more late effects also expressed greater desire for information about dealing with symptoms (Cramer's $V=.214$; Chi-sq = 11.527: df = 4; $p < .021$), the late effects themselves (Cramer's $V=.159$; Chi-sq = 6.383: df = 1; $p < .012$) managing late effects (Cramer's $V=.195$; Chi-sq = 9.669: df = 1; $p < .002$) and interestingly, dealing with anxiety about risk of recurrence (Cramer's $V=.176$; Chi-sq = 7.620: df = 1; $p < .006$).

Despite the intensity of treatment and fairly high incidence of late effects, this population of survivors reported good health. Eighty seven percent of the population rated their health as “good” or better, with sixty three percent rating their health as “very good” or “excellent.” One participant noted “Well doctors said I wouldn't be normal and I left the hospital as a quadriplegic. Now I can do everything everyone else can and I'm pregnant. I still have left side facial paralysis and hand eye coordination is slow.”

However, anxiety about recurrence was a frequent concern among participants despite the fact that most had been off therapy for many years. The more late effects the survivors experienced, the more their anxiety about recurrence increased. These findings suggest a knowledge deficit in this population regarding the likelihood of late effects compared to that of recurrence.

Physical late effects and experiences

Physical late effects specifically listed on the survey included problems associated with growth, weight, heart, liver or fertility; difficulty exercising, another form of cancer. Participants also had the option to write in any other self-identified physical late effects. They indicated a variety of physical late effects impacting many organ systems. In addition to the late effects specifically identified on the survey, examples of late effects survivors reported include: avascular necrosis and other orthopedic problems, renal/genitourinary problems, hearing loss, gastrointestinal issues, dental abnormalities, seizures, endocrine issues, respiratory problems, chronic pain and neurological issues such as weakness and ataxia.

Physical experiences specifically identified on the survey included “diminished physical strength” and “body does not look the same.” Survivors also had the option to write in any other experience they were having related to survivorship. Among the physical experiences that survivors identified were: endocrine issues, infertility, pain, hair loss, orthopedic surgeries, nerve damage, gastrointestinal problems, dental issues, speech impediment, vision loss, ataxia, weight gain and dealing with having scars.

Interestingly, despite the survey making a clear separation between late effects and experiences, the survivors themselves reported them interchangeably. Content analysis of the information that was written in under both categories revealed that often participants would not only identify the late effect specifically, but go on to explain the experience in daily life. For example, in addition to selecting experiences from the provided list, one survivor wrote about, “aches and pains most of the time, lack of sleep and proper rest due to Barretts (esophagus), cough up phlegm, unable to lie flat, constant sore throat, unable to get adequate medical care especially with physicians-most do not accept Kansas Medicaid. Have not seen endocrinologist in years.” This statement ties the symptoms, experiences, and implications for life together despite the question having asked only about experiences. Similar to the physical late effects, those participants who selected physical experiences from the topics provided or who wrote in other identified physical experiences under that question were also more likely to desire more information about late effects (Cramer's $V=.159$; Chi-sq = 6.318: df = 1; $p<.008$) and dealing with late effects (Cramer's $V=.212$; Chi-sq = 11.323: df = 1; $p<.001$).

Gender differences were seen for physical late effects and the physical experience of cancer. Females reported more late effects (59% vs. 41% for males; Cramer's $V=.144$; Chi-sq = 5.631: df = 1; $p<.012$) and more physical experiences (65% vs. 35% for males; Cramer's $V=.188$; Chi-sq = 9.534: df = 1; $p<.002$). Neither physical late effects nor experiences were statistically significantly related to present age or age at diagnosis.

Cognitive late effects and experiences

Correlation was seen between cognitive late effects and cognitive experiences. Cognitive late effects were defined as memory or learning problems and/or challenges maintaining concentration for the purposes of this survey. Cognitive experiences for this survey were defined as difficulties in school and/or having a hard time paying attention for a long time.

Unlike the physical late effects and experiences, survivors did not write in other cognitive late effects or experiences that differed from the topics provided. Cognitive late effects and cognitive experiences were correlated with each other (Cramer's $V=.498$; Chi-sq = 67.093; $df = 1$; $p<.000$).

Cognitive late effects (although not cognitive experiences) were also correlated with intensity of treatment. Those survivors who received more intense treatment reported more cognitive late effects. There were however, no differences in cognitive late effects and experiences by gender.

Significant correlation was seen between cognitive late effects and survivors of brain tumors. The overall incidence of cognitive late effects in our sample was 41% but among the brain tumor survivors it was 75% (Cramer's $V=.329$; Chi-sq = 29.300; $df = 2$; $p<.000$) with a similar picture in the experience of cognitive difficulties in the survivorship period. The reported incidence of cognitive difficulties experienced in the overall sample was 36%, but for the brain tumor survivors it was 61% (Cramer's $V=.251$; Chi-sq = 17.045; $df = 2$; $p<.000$). Table 4 demonstrates this burden further. When the study population is divided by diagnosis group, 34% of leukemia/lymphoma survivors and 32% of solid tumor survivors report cognitive late effects; 28% of leukemia/lymphoma survivors and 33% of solid tumor survivors report cognitive difficulties experienced while 75% of brain tumor survivors reported cognitive late effects and 61% reported cognitive difficulties experienced. This group experienced significantly greater financial difficulties than the other groups as well. The overall reported incidence of financial difficulties for the sample as a whole was 26% but the brain tumor population reported 41% (Cramer's $V=.170$; Chi-sq = 7.812; $df = 2$; $p<.020$).

While brain tumor survivors did not experience significantly greater physical side effects than the rest of the sample population, they did report greater amounts of fatigue than other survivors. The overall incidence of fatigue in survivors in this sample was 30% but brain tumor survivors reported 47% (Cramer's $V=.183$; Chi-sq = 9.066; $df = 2$; $p<.011$).

Desire for more information

Specific content areas in which survivors might want more information were included on the survey as well. Survivors were asked whether they would like more information about topics likely to be of interest to them. Overall, the results demonstrate that just over half of the survivors desire some information about what late effects to expect, and just under half want to know how to deal with late effects, what types of tests they might need to screen for late effects etc. Analysis for gender effects did not demonstrate differences except for the topics of fertility and concern for risk of cancer to family. Females demonstrated greater interest in knowing more about these topics (66.7% and 61.5% respectively). No other significant gender differences existed in these data. Areas where survivors desired more information are depicted in Table 5

Discussion

The results of this survey reveal a population of young adult survivors who received relatively intense treatment and are now experiencing a variety of functional (physical and cognitive) late effects. Despite their experience of late effects, this population rates their overall health as good. Education of both survivors and healthcare providers is essential to recognize and address late effects.

Ideally, education of survivors starts at diagnosis and continues throughout survivorship. Survivors in this survey were not particularly concerned about educational topics related to their cancer history and risks for late effects. Perhaps initiating education of survivors at a younger age could ensure that they were aware of their risks and screening needs prior to the time when they might become ambivalent about their cancer history. Early and ongoing education could create knowledgeable adult healthcare consumers. Long-term follow-up programs should assess survivors' information needs and have appropriate resources available for them to access.

Participants in this study did identify areas of educational need. A significant number of female survivors desired information about fertility and family risk of cancer. In addition, nearly half of participants wanted information about late effects and what to do about them. A significant number feared recurrence despite the fact that they were more than 5 years off therapy illustrating a lack of knowledge regarding risk for recurrence compared to risk for second malignancy, a more likely outcome in this population.

The population for this study included a significant number of emerging adults. This may explain some of the lack of desire for knowledge and demonstrates the need for both continued follow-up care and re-assessment of educational needs over time. As the emerging adult becomes more settled into adulthood, his/her needs and desire for information may change. The majority of this sample was between the ages of 18 and 25 years old and this emerging adult group was generally in school and exploring the adult world, not necessarily concerning themselves with their cancer history. The possibility exists that an older sample would be more concerned about these topics. Survivorship programs need to be sensitive to the developmental trajectory from childhood through adulthood, taking into account the unique needs of the adolescent and emerging adult survivor.

Transition of healthcare is another stressful event often occurring during adolescence and emerging adulthood. The increase in survivors necessitates that adult healthcare providers be prepared to care for this population. The transition is already a difficult one for survivors and family members as well as healthcare providers who may not feel equipped for this role. Two participants described this more eloquently than we could: "Doctors can't seem to find a cause or cure for my health problems despite constant doctor visits. My health is getting worse not better. Nothing is helping". This participant, a 24 year old female survivor, selected weight concerns, difficulty with exercising, heart problems, depression, anxiety, fatigue, diminished physical strength, inability to work and financial stress. She wrote in other health problems including "constant nausea, chest pains/tightening of chest" and "feeling overwhelmed with health issues". Another participant, a 19 year old female stated,

“I feel like most of my symptoms can't be explained by doctors when I look for help”. She selected memory problems, difficulty learning, challenges maintaining concentration, weight concerns, fertility concerns, difficulty exercising, liver problems, heart problems, depression, anxiety, fatigue, fear of recurrence, difficulty in school, fear of death, body does not look the same, change in relationships, hard to pay attention for a long time, feeling as if no one understands you and financial stress on her survey. While these late effects are clearly substantial, education of both survivors and healthcare providers can help mitigate both the late effects themselves and the feeling that no one can help.

Long-term follow-up programs are designed to prepare the survivors and families for this transition. These programs provide education about treatment history, late effects and health screening needs. In addition, long-term follow-up programs provide the survivor with a treatment summary to take to their adult provider to serve as a foundation for future healthcare. COG has developed Long-Term Follow-up Guidelines to give healthcare providers guidance when following survivors of childhood cancer. These electronic guidelines are available free of charge (Children's Oncology Group, 2008). Together, these tools provide a blueprint to ensure that survivors receive follow-up and screening appropriate to their unique cancer history and needs. Despite the obvious benefit of treatment summaries for survivors and their adult healthcare providers, our study demonstrated that many adult survivors do not have a treatment summary (American Academy of Pediatrics, 2009; Ganz, Casillas, & Hahn, 2008). The lack of treatment summaries needs urgent attention in order to maximize the future health of the survivor population.

This study demonstrated how a cancer registry can be leveraged to address the needs of cancer survivors. Pediatric cancer registries maintain contact with survivors until they are 27 years old. Each year contact is established to assess the overall health of the survivor. This annual contact could additionally be used to assess educational needs, provide further information, and connect survivors with healthcare professionals qualified to meet their needs. In addition, comprehensive cancer centers focus on cancer survivorship but rarely on pediatric cancer because of the low incidence. However, pediatric cancers represent 1–3% of all cancers and 80% will survive their disease. High survival rates coupled with a young age, makes a substantial group of survivors over time that would benefit from long-term survivorship care available in comprehensive cancer centers.

Limitations

This study provides self-reported information about survivors' functional late effects, experiences and information needs. However, the limitations of the study are those inherent in survey-based research. While survivors are in the best position to report their experiences, some do not recall the details of disease and treatment. While we did not have a large amount of missing data, not all questions were answered by all participants, and approximately 50% of delivered surveys were not returned. Survivorship research is inherently challenging in this area. It is difficult to say whether the non-respondents did not respond because they were doing so well, so poorly or were not interested. There is the slim

possibility that some are no longer living, however, both cancer registries have used multiple strategies to track deaths among former patients.

This survey was completed with survivors at two Midwestern healthcare facilities. In order to generalize results, replication in other parts of the United States would be appropriate. In addition, results might differ in countries where survivorship care is provided differently as well. We can all learn much from each others' attempts to best meet the needs of this growing population.

Additionally, treatment intensity data were based on clinician assessment of self-report data. While this allowed for a meaningful way to make sense of the treatment data provided, there was inherent margin for error. Another limitation to this study related to the desire for more knowledge questions. The way the questions were structured did not capture the difference between participants who already had adequate information and those who did not desire that information. Thus, answering the question with "no more information" might reflect a lack of need for more information or a lack of desire for more information. However, the difference could not be detected on the survey.

Additionally, adding a qualitative interview component, rather than the opportunity for participants to simply write in qualitative data would yield richer data and thus better understanding of the components of survivor care that are working best and not. Opportunities to engage the survivor population would afford a greater opportunity to understand the challenges that this group faces, as well as better understand the limits that many survivors face. However, the ability to mail a survey to a large group of survivors and receive input from nearly half of those surveyed is certainly one effective way to reach this group.

Implications for future practice/research

The emergence of the adult survivor of childhood cancer has provided both the need and opportunity for collaboration between pediatric oncology providers and adult primary care and specialty providers. Increased awareness of the unique needs of this population for screening, education and follow-up exist for practitioners and survivors alike. Identification of best practices for transition services between pediatric oncology and adult healthcare continues to be a need. Future directions include the development of educational materials appropriate for survivors and providers desiring more information. Long-term follow-up programs can serve as resources to adult healthcare providers from primary to specialty care. Future research should be aimed more specifically at determining adequacy of survivors' existing knowledge in addition to identifying education needs. Determining effective methods of reaching adult survivors and identifying their needs are of utmost importance. The growing number of adult survivors of childhood cancer coupled with the Commission on Cancer's focus on survivorship emphasizes the timeliness of this need.

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Table 1

Intensity of Treatment Associated With Number of Late Effects (N=255)

Treatment	N	Number of Late Effects					
		0		1-3		4-6	
		n	%	n	%	n	%
Least intensive	16	8	50	5	31	3	19
Moderately intensive	105	21	20	49	47	35	33
Very intensive	95	12	13	40	42	43	45
Most intensive	39	7	18	13	33	19	49

Note. Data for 17 participants could not be extrapolated.

Table 2

Sample Characteristics (n=272)

Characteristic	Mean	SD
Age (years)	24.33	4.89
Age at diagnosis (years)	10.24	5.22

Characteristic	n	%
Gender		
Female	144	53
Male	126	46
Missing data	2	1
Race		
Non-Hispanic White	245	91
African American	12	4
Other	12	4
Missing data	3	1
Marital Status		
Single	213	78
Married	48	18
Divorced or separated	7	3
Missing data	4	2
Education		
Less than high school	12	5
High school diploma or GED	60	22
Some college	122	46
Bachelor's degree	60	22
Master's degree	9	3
Doctoral degree	5	2
Missing data	4	2
Employment status		
Not currently employed outside the home	33	12
Student (FT or PT)	62	23
Employed PT	22	8
Employed FT	100	38
Student and employed PT	34	13
Student and employed FT	14	5
Missing data	7	3
Diagnoses (grouped)		
Leukemia or lymphoma	130	48
Solid tumor	90	33
Brain tumor	51	19
Missing data	1	<1
Relapse status		

Characteristic	n	%
No	220	81
Yes	39	14
Missing data	13	5

FT—full-time; PT—part-time

Note. PT is considered less than 35 hours per week. FT is 35 hours per week or more.

Note. Because of rounding, not all percentages total 100.

Table 3

Late Effects Experienced by Diagnosis Group (N=272)

Diagnosis	N ^a	Late Effect							
		Cognitive Side Effects		Cognitive Experiences		Physical Side Effects		Physical Experiences	
		n	%	n	%	n	%	n	%
Leukemia or lymphoma	130	44	34	37	28	80	62	44	34
Solid tumor	90	29	32	30	33	53	59	37	41
Brain tumor	51	38	75	31	61	33	65	27	53

Note. Participants could select more than one late effect.

^aData missing from one incomplete response.

Table 4

Informational Needs of the Study Population (N=272)

Variable	<u>No More Information</u>		<u>Some More Information</u>	
	n	%	n	%
Follow-up tests and procedures that you should have	146	58	106	42
Symptoms that should prompt you to call your doctor	151	60	101	40
What late and long-term side effects of cancer treatment to expect	121	48	130	52
Dealing with late and long-term side effects of cancer treatment	133	53	119	47
Decreasing the risk of having cancer again	146	59	103	41
Managing your anxiety about recurrence	193	79	53	22
Staying physically fit	178	71	73	29
Nutrition and diet	170	68	80	32
Cancer risks to your family	152	61	96	39
Dealing with sexual problems	204	83	42	17
Having children after cancer treatment	144	58	105	42
Complementary and alternative treatments	202	82	43	18
Talking about your cancer experience with family, friends, and coworkers	217	89	28	11
Getting or retaining health, life, or disability insurance after cancer	168	68	79	32

Note: Because of rounding, not all percentages total 100.

Note. Because of missing or incomplete data, not all rows total 272.