

# Understanding the Functional Late Effects and Informational Needs of Adult Survivors of Childhood Cancer

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**A**dult survivors of childhood cancer are a rapidly growing demographic with an estimated 363,131 living in the United States (Howlader et al., 2011). 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, and age at diagnosis, and can affect any organ system in the body (Landier, 2007). About 62% of adult survivors of childhood cancer will experience a late effect of their cancer (Oeffinger et al., 2006). Although 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 number of survivors and 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 (Landier, 2007). The Children's Oncology Group (COG) recommended that 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

**Purpose/Objectives:** To report functional (physical and cognitive) late effects, experiences, and information needs of adult survivors of childhood cancer.

**Design:** Descriptive, mixed methods survey.

**Setting:** Two pediatric oncology programs in the Midwest.

**Sample:** Convenience sample of 272 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 article 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 48%. Functional late effects, perceptions, and information needs all correlated with intensity of treatment (those survivors most heavily treated experienced the most symptoms). Survivors wanted more information about late effects and how to deal with them. Women 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.

**Knowledge Translation:** The findings of the research underscore the importance of continuous learning opportunities for adult survivors of childhood cancer. The findings also highlight the need for healthcare teams to better understand the current and long-term needs of this population. In addition to traditional communication approaches, technologies such as social media and telemedicine can provide innovative ways to deliver patient-centered care.

(Landier, 2007). Organizations including the Institute of Medicine, the American Academy of Pediatrics, the American Society of Pediatric Hematology/Oncology, and COG all have advocated for the importance of life-long follow-up care for survivors (National Cancer Institute, 2012). In addition, the American College of Surgeons, in their Commission on Cancer ([COC], 2011) program standards, mandated the inclusion of treatment summaries and follow-up plans for survivors to be incorporated by all accredited institutions by 2015.

Despite these mandates by medical organizations, lack of knowledge about their diagnosis, treatment history, and health risks, as well as 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 and have a desire to leave their cancer experience behind them and, therefore, may 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.

To date, 1.5 per 1,000 young adults (aged 20–39 years) in the United States is a survivor of childhood cancer, and that number continues to grow (Hewitt, Weiner, & Simone, 2003). That number is important when one considers the impact of cancer survivorship on the emerging adult. The population of people aged 18–29 years often is identified as those in “emerging adulthood” (Arnett, 2000). Recognition that this time frame is separate and distinct from adolescence and adulthood is ongoing.

Emerging adulthood as a life stage is characterized by exploration and change. Most individuals younger than age 18 years live at home and are unmarried; most individuals, 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 other activities (i.e., college and employment), cancer survivors in this group often are less interested in seeking survivor-related information. That has implications for the educational and health programs that are developed to meet the needs of this population.

The purpose of this article 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. The authors' three specific aims are to describe the self-reported current healthcare practices, treatment side effects, and healthcare needs of adult survivors of childhood cancer.

## Methods

### Participants and Procedures

Participants were recruited in collaboration between the pediatric oncology programs at Children's Mercy Hospitals and Clinics in Kansas City, MO, and the University of Kansas Cancer Center in Westwood, KS. The study was approved by both institutional review boards 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. Institutional review board–approved initial mailings included a paper survey marked only with a participant identification number, a letter of explanation, a self-addressed prepaid envelope, an optional form to request additional information and/or to agree to participate in future research, and a \$5 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 that blocked users' personal information from being recorded. The online survey asked participants for the study identification number 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 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 patients with NHL 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 Centers for Disease Control and Prevention and the LIVESTRONG Foundation (2004) and the Institute of Medicine, as well as survivorship literature (Geenen et al., 2007; Hewitt, Greenfield, & Stovall, 2006; 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 that 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 article, 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 used 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, p. 453). Using mixed methods allowed a broader picture of the participant 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, in many cases, the additional qualitative data participants shared provided depth and detail to the existing data that aided in understanding the experience from survivors' perspectives. For the current 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 existing list for the purposes of in-

clusion in symptom analysis. Although counting is not a usual activity 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. The authors 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 (e.g., chemotherapy, radiation therapy, surgery, bone marrow transplantation). Analyzing self-reported treatment information from participants whose treatment spanned a timetable of about 20 years proved challenging. The strides that had been made in the treatment of childhood cancer in that time frame came with changes in protocols and treatments.

The authors' analyses necessitated a method by which to rate the intensity of treatment received. Therefore, the authors 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 the 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 (e.g., Wilm's tumor with surgery only) to most intensive (e.g., treatment including a stem cell transplantation) (see Table 1). Developers of the scale reported 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, independently scored all participants based on information provided about diagnosis, treatment received, and relapse

**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.

history. When scores were compared, a 99% agreement was noted between the two raters. Of the five cases in which an agreement was not noted, discussion of the treatment information provided by participants resulted in agreement. As the results demonstrate, 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 mailed surveys, 139 (20%) were returned because of undeliverable addresses. Of the remaining 571 surveys, 271 were returned for a response rate of 48%. Twelve participants chose to complete the survey online. Table 2 shows the demographics and the cancer-related characteristics of the final participant group. A majority of participants were non-Hispanic White. That percentage was slightly higher than the percentage of non-Hispanic Whites who were initially mailed the survey (85%). Of the population that returned the survey, only 12 (4%) were African American, whereas 12% of the population that was mailed the survey was African American. The authors 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 18–38 years, with a mean age of 24.23 years. Because this population was predominantly young adult, a large percent were not married and still in college. The mean age at diagnosis was 10.24 years. These survivors encompassed a wide range of diagnoses, so, for analysis purposes, the authors grouped them into leukemia or lymphoma, solid tumors, and brain tumors. The majority of the population had not experienced relapse.

The authors surveyed participants regarding whether they had received a treatment summary. In this study, 75 participants (28%) reported having received a treatment summary, 105 (39%) reported not receiving a treatment summary, and 87 (32%) were unsure whether they had received one. Being unsure whether or not a treatment summary had been received makes it unlikely that one is being used in an individual's health care. That translates into 71% of participants that essentially do not have a treatment summary to guide their future health care.

### 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 (239 of 257) 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 transplantation. Not surprisingly, intensity of treatment correlated with the number of late effects experienced (Cramer's  $V = 0.218$ , chi-square = 24.452,  $df = 8$ ,  $p < 0.002$ ). Those survivors who experienced more late effects also expressed greater desire for information about dealing with symptoms (Cramer's  $V = 0.214$ , chi-square = 11.527,  $df = 4$ ,  $p < 0.021$ ), the late effects themselves (Cramer's  $V = 0.159$ , chi-square = 6.383,  $df = 1$ ,  $p < 0.012$ ) managing late effects (Cramer's  $V = 0.195$ , chi-square = 9.669,  $df = 1$ ,  $p < 0.002$ ), and, interestingly,

**Table 2. Sample Characteristics (N = 272)**

Characteristic	$\bar{X}$	SD
Age (years)	24.23	4.89
Age at diagnosis (years)	10.24	5.22
Characteristic	n	%
<b>Gender</b>		
Female	144	53
Male	126	46
Missing data	2	1
<b>Race</b>		
Non-Hispanic White	245	91
African American	12	4
Other	12	4
Missing data	3	1
<b>Marital status</b>		
Single	213	78
Married	48	18
Divorced or separated	7	3
Missing data	4	2
<b>Education</b>		
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
<b>Employment status</b>		
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
<b>Diagnoses (grouped)</b>		
Leukemia or lymphoma	130	48
Solid tumor	90	33
Brain tumor	51	19
Missing data	1	< 1
<b>Relapse status</b>		
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.

dealing with anxiety about risk of recurrence (Cramer's  $V = 0.176$ , chi-square = 7.62,  $df = 1$ ,  $p < 0.006$ ).

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 63% 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.

This participant is experiencing late effects of her treatment; however, she still considers herself to be in good health. 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, fertility, difficulty exercising, or 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 affecting 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 or genitourinary problems, hearing loss, gastrointestinal issues, dental abnormalities, seizures, endocrine issues, respiratory problems, chronic pain, and neurologic 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. Included 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 participants often 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,

Aches and pains most of the time, lack of sleep, and proper rest due to Barrett's (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 also were more likely to desire more information about late effects (Cramer's  $V = 0.159$ , chi-square = 6.318,  $df = 1$ ,  $p < 0.008$ ) and dealing with late effects (Cramer's  $V = 0.212$ , chi-square = 11.323,  $df = 1$ ,  $p < 0.001$ ).

Gender differences were seen for physical late effects and the physical experience of cancer. Women reported more late effects (59% versus 41% for men; Cramer's  $V = 0.144$ ; chi-square = 5.631,  $df = 1$ ,  $p < 0.012$ ) and more physical experiences (65% versus 35% for men; Cramer's  $V = 0.188$ , chi-square = 9.534,  $df = 1$ ,  $p < 0.002$ ). Neither physical late effects nor experiences were statistically significant related to present age or age at diagnosis.

### Cognitive Late Effects and Experiences

Correlation was noted between cognitive late effects and cognitive experiences. Cognitive late effects were defined, for the purpose of this article, as memory or learning problems and/or challenges maintaining concentration. Cognitive experiences were defined for this survey 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  $V = 0.498$ , chi-square = 67.093,  $df = 1$ ,  $p < 0.00$ ).

Cognitive late effects (although not cognitive experiences) also were correlated with intensity of treatment. Those survivors who received more intense treatment reported more cognitive late effects. No differences, however, were noted 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 the sample was 41% but was 75% among the brain tumor survivors

(Cramer's  $V = 0.329$ , chi-square = 29.3,  $df = 2$ ,  $p < 0.00$ ) 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 61% for the brain tumor survivors (Cramer's  $V = 0.251$ , chi-square = 17.045,  $df = 2$ ,  $p < 0.00$ ) (see Table 3). When the study population is divided by diagnosis group, 44 leukemia or lymphoma survivors (34%) and 29 solid tumor survivors (32%) reported cognitive late effects, 37 leukemia or lymphoma survivors (28%) and 30 solid tumor survivors (33%) reported cognitive difficulties experienced, and 38 brain tumor survivors (75%) reported cognitive late effects and 31 (61%) reported cognitive difficulties experienced. The brain tumor group experienced significantly greater financial difficulties than the other groups. The overall reported incidence of financial difficulties for the sample as a whole was 26% ( $n = 70$ ), but the brain tumor population reported 41% ( $n = 21$ ) (Cramer's  $V = 0.17$ , chi-square = 7.812,  $df = 2$ ,  $p < 0.02$ ).

Although 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% ( $n = 82$ ), but brain tumor survivors reported 47% ( $n = 24$ ) (Cramer's  $V = 0.183$ , chi-square = 9.066,  $df = 2$ ,  $p < 0.011$ ).

### 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 52% ( $n = 141$ ) of the survivors desire some information about what late effects to expect, and 47% ( $n = 127$ ) want to know how to deal with late effects and what types of tests they might need to screen for late effects. Analysis for gender effects did not demonstrate differences except for the topics of fertility and concern for risk of cancer to family. Women demonstrated greater interest in knowing more about these topics (67% and 62%, respectively). No other significant gender differences existed in the data. Areas where survivors desired more information are depicted in Table 4.

### 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 are 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 survivor 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, 47% ( $n = 127$ ) of the 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 five years after 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, which may explain some of the lack of desire for knowledge and demonstrates the need for both continued follow-up care and reassessment of educational needs over time. As the emerging adult becomes more settled into adulthood, his or her needs and desire for information may change. The majority of this sample was aged 18–25 years, 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

**Table 3. Late Effects Experienced by Diagnosis Group (N = 272)**

Diagnosis	N <sup>a</sup>	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

<sup>a</sup> Data missing from one incomplete response.

Note. Participants could select more than one late effect.

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 health care 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. According to a 24-year-old female survivor, "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 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. Although 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 health care. 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 (COG, 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, the current study demonstrated that many adult survivors do not have a treatment summary (American Academy of Pediatrics, 2009; Ganz, Casillas, & Hahn, 2008). The lack of

**Table 4. Informational Needs of the Study Population (N = 272)**

Variable	No More Information		Some More Information	
	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.

treatment summaries demands urgent attention so healthcare providers can 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 aged 27 years. Contact is established each year to assess the overall health of the survivor. This annual contact also could be used to assess educational needs, provide additional 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 creates a substantial group of survivors that, over time, 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. Although survivors are in the best position to report their experiences, some do not recall the details of disease and treatment. The authors did not have a large amount of missing data, but not all questions were answered by all participants, and about 50% of delivered surveys were not returned. Survivorship research is inherently challenging in this area. Saying whether the nonrespondents did not respond because they were doing so well, so poorly, or were not interested was difficult to ascertain. The possibility exists 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. 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.

In addition, treatment intensity data were based on clinician assessment of self-report data. Although this allowed for a meaningful way to make sense of the treatment data provided, an inherent margin for error existed. 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. Therefore, 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.

Adding a qualitative interview component, rather than the opportunity for participants to simply write in qualitative data, would yield richer data and, therefore, 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 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 about half of those surveyed is certainly one effective way to reach this group.

### Implications for Future Practice and Research

The emergence of the adult survivors of childhood cancer has created 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 exists 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. Identifying effective methods of reaching adult survivors and their needs are of utmost importance. The growing number of adult survivors of childhood cancer coupled with the COC's focus on survivorship emphasizes the timeliness of this need.

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### References

- American Academy of Pediatrics. (2009). Long-term follow-up care for pediatric cancer survivors. *Pediatrics*, 123, 906–915. doi:10.1542/peds.2008-3688
- Arnett, J.J. (2000). Emerging adulthood. A theory of development from the late teens through the twenties. *American Psychologist*, 55, 469–480.
- Arora, N.K., Hamilton, A.S., Potosky, A.L., Rowland, J.H., Aziz, N.M., Bellizzi, K.M., . . . Stevens, J. (2007). Population-based survivorship



- research using cancer registries: A study of non-Hodgkin lymphoma survivors. *Journal of Cancer Survivorship*, 1, 49–63. doi:10.1007/s11764-007-0004-3
- Centers for Disease Control and Prevention and the LIVESTRONG Foundation. (2004). *A national action plan for cancer survivorship: Advancing public health strategies*. Retrieved from <http://www.cdc.gov/cancer/survivorship/pdf/plan.pdf>
- Children's Oncology Group. (2008). Long-term follow-up guidelines for survivors of childhood, adolescent, and young adult cancers. Retrieved from <http://www.survivorshipguidelines.org>
- Commission on Cancer. (2011). *Cancer program standards 2012: Ensuring patient-centered care*. Chicago, IL: American College of Surgeons.
- Ganz, P.A., Casillas, J., & Hahn, E.E. (2008). Ensuring quality care for cancer survivors: Implementing the survivorship care plan. *Seminars in Oncology Nursing*, 24, 208–217. doi:10.1016/j.soncn.2008.05.009
- Geenen, M.M., Cardous-Ubbink, M.C., Kremer, L.C., van den Bos, C., van der Pal, H.J., Heinen, R.C., . . . van Leeuwen, F.E. (2007). Medical assessment of adverse health outcomes in long-term survivors of childhood cancer. *JAMA*, 297, 2705–2715. doi:10.1001/jama.297.24.2705
- Henderson, T.O., Hlubocky, F.J., Wroblewski, K.E., Diller, L., & Daugherty, C.K. (2010). Physician preferences and knowledge gaps regarding the care of childhood cancer survivors: A mailed survey of pediatric oncologists. *Journal of Clinical Oncology*, 28, 878–883. doi:10.1200/JCO.2009.25.6107
- Hewitt, M., Greenfield, S., & Stovall, E. (2006). *From cancer patient to cancer survivor: Lost in transition*. Washington, DC: National Academies Press.
- Hewitt, M., Weiner, S.L., & Simone, J.V. (2003). *Childhood cancer survivorship: Improving care and quality of life*. Washington, DC: National Academies Press.
- Howlader, N., Noone, A.M., Krapcho, M., Neyman, N., Aminou, R., Altekruse, S.F., . . . Cronin, K.A. (Eds.). (2011). *SEER cancer statistics review, 1975–2009*. Bethesda, MD: National Cancer Institute.
- Landier, W. (2007). *Establishing and enhancing services for childhood cancer survivors: Long-term follow-up program resource guide*. Arcadia, CA: Children's Oncology Group.
- National Cancer Institute. (2012). *PDQ late effects of treatment for childhood cancer*. Bethesda, MD: Author.
- Oeffinger, K.C., Mertens, A.C., Sklar, C.A., Kawashima, T., Hudson, M.M., Meadows, A.T., . . . Robison, L.L. (2006). Chronic health conditions in adult survivors of childhood cancer. *New England Journal of Medicine*, 355, 1572–1582. doi:10.1056/NEJMsa060185
- Oeffinger, K.C., & Wallace, W.H. (2006). Barriers to follow-up care of survivors in the United States and the United Kingdom. *Pediatric Blood and Cancer*, 46, 135–142. doi:10.1002/pbc.20614
- Patton, M.Q. (2002). *Qualitative research and evaluation methods* (3rd ed.). Thousand Oaks, CA: Sage.
- Werba, B.E., Hobbie, W., Kazak, A.E., Ittenbach, R.F., Reilly, A.F., & Meadows, A.T. (2007). Classifying the intensity of pediatric cancer treatment protocols: The Intensity of Treatment Rating Scale 2.0 (ITR-2). *Pediatric Blood and Cancer*, 48, 673–677. doi:10.1002/pbc.21184

### For Further Exploration

## Use This Article in Your Next Journal Club Meeting

Journal club programs can help to increase your ability to evaluate literature and translate findings to clinical practice, education, administration, and research. Use the following questions to start discussion at your next journal club meeting. Then, take time to recap the discussion and make plans to proceed with suggested strategies.

1. This study suggests that, at the time they completed treatment, most participants did not receive a survivorship care plan. Do you think that things have changed since then? How and why?
2. The participants in this study identified issues that they wanted more information about as well as those that they did not need additional education about. Were there issues that surprised you or were there issues that you felt were left out?
3. What are some of the challenges of transition care that you see with this population? What are the barriers to a successful move from pediatric to adult care and how can they be addressed?

Photocopying of this article for discussion purposes is permitted.

## Author Sheds New Light on Topics Discussed in This Article

With a simple click of your computer mouse, listen as *Oncology Nursing Forum* Associate Editor Diane G. Cope, RN, PhD, ARNP-BC, AOCNP®, interviews author Wendy McClellan, RN, BSN, about the physical late effects and educational needs of adult survivors of childhood cancer.

McClellan is a nurse coordinator for the Survive and Thrive Survivorship Program at Children's Mercy Hospitals and Clinics in Kansas City, Mo. Her research focus is on childhood cancer survivors and their needs as they progress into young adulthood.

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