Physician Preferences and Knowledge Gaps Regarding the Care of Childhood Cancer Survivors: A Mailed Survey of Pediatric Oncologists

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A B S T R A C T

Purpose

Little is known about physicians' attitudes and knowledge regarding the health care needs of childhood cancer survivors (CCS). We sought to obtain pediatric cancer physicians' self-reported attitudes and knowledge regarding this population.

Methods

A mailed survey was sent to 1,159 pediatric oncologists in the United States.

Results

A total of 655 surveys were returned (ie, 57% response rate). Median age of respondents was 47 years (range, 31 to 82 years); 57% were men. Respondents practiced for a median 14 years (range, 1 to 50 years) and reported seeing a median of 21 patients per week (range, 0 to 250 patients per week). When comfort levels in caring for CCS were described (ie, 1 = very uncomfortable; 7 = very comfortable), respondents were most comfortable with survivors ≤ 21 years (mean $\pm$ standard deviation, 6.2 ± 1.3 level), were less comfortable (5.0 ± 1.5 level) with those older than 21 years but less than 30 years old, and were uncomfortable with CCS ≥ 30 years (2.9 ± 1.7 level). In response to a clinical vignette of a 29-year-old woman treated with mantle radiation for Hodgkin's lymphoma at 16 years of age, and on the basis of available guidelines, 34% of respondents did not appropriately recommend yearly breast cancer surveillance; 43% of respondents did not appropriately recommend cardiac surveillance; and 24% of respondents did not appropriately recommend yearly thyroid surveillance. Those with greater self-reported familiarity with available long-term follow-up (LTFU) guidelines (odds ratio [OR], 1.33; 95% CI, 1.15 to 1.54) and with receipt of training in the care of CCS (OR, 1.73; 95% CI, 1.18 to 2.52) were more likely to have answered all three questions correctly.

Conclusion

Pediatric oncologists express a range of preferences with regard to LTFU of CCS. Many appear unfamiliar with LTFU surveillance guidelines.

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INTRODUCTION

Currently, almost 80% of children diagnosed with cancer are cured; disease-free survival rates are greater than 80% in childhood lymphoblastic leukemia, Wilms tumors, and most lymphomas.^{1,2} There are currently more than 270,000 childhood cancer survivors in the United States, and approximately one in 570 are between the ages of 20 and 39 years who have survived childhood cancer.³ As the earlier generations of childhood cancer survivors age, it has become well recognized that these survivors face significant life-long health risks and early mortality.⁴⁻⁶ Research indicates that virtually all organ systems can be affected by radiation and chemotherapy administered at a young age. These

therapies are known to lead to a wide array of potential late effects or therapy-related sequelae, including second malignant neoplasms (SMNs), organ dysfunction, endocrine abnormalities, and neuropsychological dysfunction.⁶⁻¹⁴ These health problems often are clinically silent for years or decades after the cancer treatment. Additional evidence suggests that many long-term survivors may be reluctant to engage in risk-based long-term follow-up (LTFU) care because of lack of knowledge of health risks and, in some instances, anxiety given previous cancer therapy. Given this, it is critically important that meaningful attempts be made to engage survivors in health care that is aimed at disease prevention, early detection, and appropriate interventions to minimize risk of early death and comorbidity.¹⁵

In 2003, the Institute of Medicine (IOM) published a report entitled "Childhood Cancer Survivorship: Improving Care and Quality of Life," which recognized childhood cancer survivors as a population that has specialized health care needs that are not being addressed properly.^{3,16} In addition, the IOM called for the development of evidence-based clinical practice guidelines for survivorship care. In response to these concerns, several groups, including the Children's Oncology Group (COG), developed clinical guidelines to highlight potential late effects and to provide screening guidelines to identify and minimize potential morbidities in childhood cancer survivors.¹⁷⁻¹⁹

Despite these recommendations and available practice guidelines, early evidence indicates that only a minority of survivors may be receiving appropriate risk-based health care.^{20,21} One well-described barrier to risk-based, survivor-focused health care is that childhood cancer survivors themselves are not well informed regarding their previous therapies or their potential risks for sequelae.^{22,23} In addition, although lack of appropriate physician knowledge regarding the long-term risks of cancer therapy has been suggested, there is limited information regarding whether the physicians who actually care for survivors long-term are comfortable with these often-complicated patients, are aware of the health care needs of this population, and have knowledge of the published guidelines for late-effects surveillance.^{24,25} Thus, to begin to understand physician attitudes and knowledge regarding the care of childhood cancer survivors as they transition into adulthood, we conducted a survey study of pediatric oncologists in the United States.

METHODS

Participants

University of Chicago and Dana-Farber Cancer Institute institutional review board approval was obtained before initiation of this study. Participants were selected from the 2008 COG Membership Directory as specializing in pediatric hematology/oncology and practicing in the United States. From the available directory, 1,172 potential survey participants with sufficient addresses for survey mailings were identified.

Survey Mailings

A survey prenotification letter was mailed to the 1,172 eligible participants. Through prenotification mailings, 13 physicians were eliminated because of incorrect mailing addresses or because physicians were no longer clinically active, which yielded a final sample of 1,159 survey participants. Two weeks after the prenotification letter, a self-addressed survey was mailed with a \$5 gift card (from Barnes and Noble Booksellers, New York, NY) as an honorarium for participants. A second set of surveys was sent to nonresponders.

Survey Instrument

The survey instrument was developed by the investigators. Survey content and format were based on prior surveys regarding physician knowledge, communication, and attitudes in patients with cancer.^{26,27} The survey included 10 questions and used both quantitative (ie, closed-ended questions) and semi-quantitative (ie, open-ended questions that asked for short, hand-written responses) items (Data Supplement, online only). The survey sought demographic information about participant age, sex, practice environment, years since completion of formal training, estimated number of patients with cancer and cancer survivors seen per week in clinical practice, and information regarding prior training in regard to childhood cancer survivorship. The definition of childhood cancer survivor was a patient who was at least 5 years from completion of cancer therapy and was malignancy free. Quantitative survey items queried participants regarding whether their practices were affiliated with an LTFU program for cancer survivors and if it was routine practice

to eventually refer their long-term survivors to other physicians. By using a 7-point Likert scale, physicians were asked about their comfort with caring for survivors at varying ages and were asked about their familiarity with the available monitoring guidelines for adolescent and young adult cancer survivors. Semi-quantitative questions queried self-reported attitudes toward caring for long-term childhood cancer survivors, referral pattern practices for their childhood cancer survivors, and their opinion of the best trajectory of care for childhood cancer survivors. The survey included a vignette (ie, patient example that was based on investigator anecdotal experience) of a 29-year-old woman treated at age 16 years for Hodgkin's lymphoma whose treatment included mantle radiation and anthracycline chemotherapy. Three follow-up questions sought physician self reports of knowledge of health risks caused by pediatric cancers and the physician understanding of appropriate surveillance for these health risks on the basis of the COG LTFU guidelines (which included breast cancer, cardiac, and thyroid surveillance).^{17,28} Finally, participants were asked to give a qualitative written response if they had anything else to add about their experiences with childhood cancer survivors or the survey itself. The survey was initially piloted in 10 pediatric oncologists to examine the clarity and validity of the instrument, and revisions were made after this pilot and before the described survey mailings.

The survey questions were printed on both sides of a sheet of cardstock and were mailed with a cover letter to explain the purpose of the study and how to return the survey. The survey was designed to be folded in thirds, sealed with an adhesive strip, and mailed back to study investigators.

Statistical Analyses

All survey data were coded and entered into a database by using standard statistical software (STATA, version 9.0; STATA, College Station, TX). Descriptive statistics reported included the following: proportions, means and standard deviations, or medians and ranges. For between-group comparisons of continuous or ordinal variables, *t* tests or nonparametric Wilcoxon rank sum tests were used as appropriate. For comparisons of categorical variables, χ^2 tests were used. In addition, univariate and multivariate logistic regression modeling was performed. Multivariate logistic regression models were developed by including all variables with $P < .10$ in the univariate analysis initially. Those variables with $P > .05$ in the full multivariate model were dropped sequentially until only those variables with P values $\leq .05$ remained.

RESULTS

The two survey mailings were completed between November 2008 and April 2009. Six hundred fifty-five surveys were returned, for a final survey response rate of 57%.

Demographic Data

Respondent demographic characteristics are listed in Table 1. The median age of respondents was 47 years; 57% were men. Respondents had been in pediatric oncology practice a median of 14 years and saw a median of 21 patients per week. A total of 74% of respondents reported their center has a LTFU program for survivors. Among the entire sample (ie, nonresponders and responders), 196 institutions were represented. Responders represented 170 different institutions; nonresponders represented 161 institutions. There was not a significant difference between responders and nonresponders on the basis of sex (ie, 43% of responders and 41% of nonresponders were women; $P = .53$) or across geographic regions (Table 2; $P = .071$).

Physician Preferences in Care of Childhood Cancer Survivors

Physicians were asked to choose one of four responses that best summarized their current attitudes towards caring for long-term survivors of childhood cancer (defined as those at least 5 years from the

Table 1. Demographic and Practice Characteristics of Eligible Study Respondents

Characteristic	Respondents	
	No. (N = 655)	%
Age, years		
Median	47	
Mean	48	
Range	31-82	
Sex		
Male	372	57
Female	281	43
Years in practice		
Median	14	
Mean	15	
Range	1-50	
Patients per week		
Median	21	
Mean	31	
Range	0-250	
Practice environment		
CH	418	69
CC	90	15
CH + CC	35	6
Private practice	22	4
Other	43	7
LTFU program at center		
Yes	485	74
No	170	26
Received training in LTFU care		
Yes	407	63
No	243	37
Educational experiences in the evaluation and management of childhood cancer survivors (in those that received LTFU training)		
CME conference	232	57
Formal training in fellowship	182	45
Journal article(s)	254	62
Other	70	17

Abbreviations: CH, children's hospital; CC, cancer center; LTFU, long-term follow-up; CME, continuing medical education.

Table 2. Response Rate by Region of the United States

Region	States	No. of Surveys Mailed	Response Rate (%)
New England	CT, ME, MA, NH, RI, VT	78	60.3
Mid-Atlantic	NJ, NY, PA	177	63.3
South-Atlantic	DE, DC, FL, GA, MD, NC, SC, VA, WV, Puerto Rico	204	59.8
East North Central	IL, IN, MI, OH, WI	177	54.8
East South Central	AL, KY, MS, TN	70	47.1
West North Central	IA, KS, MN, MO, NE, ND, SD	75	57.3
West South Central	AR, LA, OK, TX	131	48.9
Mountain	AZ, CO, ID, MT, NV, NM, UT, WY	55	67.3
Pacific	WA, OR, AK, CA, HI	191	52.4

NOTE. No statistical difference among region in the United States ($P = .071$).

Familiarity With LTFU Guidelines

Pediatric oncologists were queried about their familiarity with the available monitoring guidelines for adolescent and young adult cancer survivors by using a 7-point Likert scale. For these questions, the intent was to survey respondents regarding their knowledge of the COG guidelines (available at <http://www.survivorshipguidelines.org>). The definition of familiarity was left to the discretion of the individual respondent. A score of 1 meant a respondent was very unfamiliar, a score of 4 meant they were somewhat familiar, and a score of 7 reflected a respondent was very familiar. Overall, surveyed pediatric oncologists were a little more than somewhat familiar with the available guidelines, as the mean score ($\pm$ SD) was 4.7 ($\pm$ 1.3).

Comfort Levels of Caring for Childhood Cancer Survivors

Three survey items queried pediatric oncologists' comfort levels with caring for pediatric cancer survivors within three different age groups. Respondents were asked to report their comfort levels on a 7-point Likert scale. A score of 1 was associated with very uncomfortable; a score of 7 was associated with being very comfortable. Pediatric

completion of therapy and malignancy free). As depicted in Table 3, 38% prefer to follow long-term cancer survivors as long as possible, 21% prefer for the patients to be observed by a physician other than themselves, 1% prefers to refer cancer survivors and/or discharge them from their clinic at their first opportunity, and 25% are willing to observe childhood cancer survivors in the absence of a more suitable physician.

Referral Preferences

Respondents were asked to report if it was their practice to eventually refer their long-term cancer survivors to other physicians and 82% of respondents reported yes. Most (59%) of these respondents report referring long-term survivors to a long-term follow-up program, 35% report referring to a primary care physician (ie, pediatrician, family practitioner or internist), 19% responded that they refer to adult oncologists, and 7% reported referring to some other physician or health care provider.

Table 3. Responses to Survey Question About Current Attitude Toward Care for Long-Term Survivors of Childhood Cancer

Response	Respondents	
	No.	%
I prefer to be their doctor as long as possible.	242	38
Although I enjoy some of the social aspects of their clinic visits, I prefer these patients be seen by a physician other than myself.	131	21
I prefer to refer them and/or discharge them from my clinic at the first opportunity.	8	1
I am willing to see them and continue to care for them in the absence of a more suitable clinician.	159	25
Other	98	15

NOTE. Survey question was as follows: Please choose the single response which best summarizes your current attitude toward caring for long-term survivors of childhood cancer.

oncologists reported being most comfortable with caring for survivors who were 21 years of age or younger (mean $\pm$ SD, 6.2 ± 1.3 level), being less comfortable with survivors older than 21 years and less than 30 years (5.0 ± 1.5 level), and being uncomfortable caring for survivors 30 years or older (2.9 ± 1.7 level).

Knowledge of Guidelines for Late Effects and Second Cancer Surveillance

Pediatric oncologists' knowledge of the current LTFU guidelines for the surveillance of late effects and SMN were examined through a

Table 4. Clinical Vignette, Corresponding Questions, and Physician Responses

Question and Answer Choice	Patients	
	No.	%
Breast cancer surveillance question		
In thinking about this patient's medical care, how would you approach breast cancer screening?		
You would follow normal guidelines to begin yearly screening with mammogram when she turns 40 years old.	4	1
You would recommend yearly screening with mammograms starting this year.*	263	41
You would recommend every-other-year screening with mammograms starting this year.	94	15
You would recommend yearly screening with breast MRI and mammograms starting this year.*	165	26
You don't know.	118	18
Thyroid surveillance question		
You review C.L.'s labs from the past and see that she has undergone yearly thyroid function tests. They have all been normal. What would be your approach to thyroid screening at this time?		
Repeat TSH and free T4 and plan to check both yearly.*	497	77
Check TSH only and plan to check yearly.	72	11
Check TSH this year and then discontinue if test is normal.	4	1
Discontinue thyroid function tests, because they have been normal.	23	4
You don't know.	52	8
Cardiac surveillance question		
You see that C.L. has undergone an echocardiogram sometime after chemotherapy. The echocardiogram was normal. How would you approach cardiac care for this patient?		
You would not proceed with additional testing.	27	4
You would refer her at this time to a cardiologist for evaluation and stress testing.	107	17
You would recommend every-other-year echocardiogram.	365	57
You would recommend yearly echocardiogram.	104	16
You don't know.	37	6

NOTE. Clinical vignette is as follows: C.L. is a 29-year-old female patient treated for Hodgkin's disease when she was 16 years old. She received combination chemotherapy (including cumulative doxorubicin 150 mg/m^2 and cumulative cyclophosphamide 15 g/m^2) and radiation to her chest and neck (mantle radiation, 25 Gy). She recently moved to your area and comes to clinic today for follow-up. She was last seen by a physician more than 1 year ago. Her records regarding cancer treatment, including her doses of radiation and chemotherapy, were faxed to you prior to the visit from the treating institution. You take a full history and do her physical exam. You learn she is feeling well and recently married. Her physical exam was unremarkable.

Abbreviations: MRI, magnetic resonance imaging; TSH, thyroid-stimulating hormone.

*Denotes correct answer on the basis of Children's Oncology Group Long-Term Follow-Up Guidelines (<http://www.survivorshipguidelines.org>).

vignette that described a 29-year-old woman treated at age 16 years for Hodgkin's lymphoma with 25 Gy mantle radiation and anthracyclines (cumulative dose: 150 mg/m^2). Respondents were asked about breast cancer, thyroid surveillance, and cardiac surveillance (Table 4). On the basis of the COG LTFU guidelines, 34% of respondents did not appropriately recommend yearly breast cancer surveillance with mammogram or mammogram and magnetic resonance imaging, 43% of respondents did not appropriately recommend cardiac surveillance with echocardiogram every other year, and 24% of respondents did not appropriately recommend yearly thyroid surveillance with serum thyroid-stimulating hormone and free thyroxine (ie, T4). Overall, only 33% of respondents answered all three questions appropriately on the basis of the COG guidelines.

Univariate and multivariate logistic regression analyses were undertaken to examine factors independently associated with answering these knowledge questions correctly. The following covariates were explored: familiarity with available guidelines, sex, years of practice, number of patients seen per week, prior training in the care of childhood cancer survivors, practice location, available LTFU clinic, routine referral of survivors to other physicians, and indicators of whether they were very comfortable (ie, Likert score of 5 or higher) with survivors ≤ 21 years, older than 21 years but less than 30 years, and ≥ 30 years. The following factors associated with an increased likelihood of correctly responding to the breast cancer surveillance question (Table 5): better familiarity with the guidelines (odds ratio [OR], 1.48; 95% CI, 1.27 to 1.73; $P < .001$); reporting having received training in the care of childhood cancer survivors (OR = 1.89; 95% CI, 1.30 to 2.74; $P = .001$); being a woman (OR, 2.05; 95% CI, 1.39 to 3.01; $P < .001$); and to a lesser extent, with more years of practice (OR, 1.02; 95% CI 1.00-1.04; $P = .055$). Only reporting better familiarity with the LTFU guidelines was associated with correctly answering the cardiac surveillance question (OR = 1.20; 95% CI 1.05 to 1.36; $P = .005$). Both being a woman (OR, 1.97; 95% CI, 1.32 to 2.93; $P = .001$) and being more familiar with the guidelines (OR, 1.28; 95% CI 1.10 to 1.49; $P = .001$) were significantly associated with answering the thyroid surveillance question correctly. Lastly, multivariate modeling revealed that both reporting better familiarity with LTFU guidelines (OR, 1.33; 95% CI, 1.15 to 1.54; $P < .001$) and having received training in the care of childhood cancer survivors (OR, 1.73; 95% CI, 1.18 to 2.52; $P = .005$) were associated with answering all three surveillance questions correctly (Table 6).

Table 5. Multivariate Analysis of Correctly Answering Clinical Vignette Surveillance Questions

Physician Characteristic per Question Category	Odds Ratio	95% CI	P
Breast cancer surveillance			
Familiar with guidelines	1.48	1.27 to 1.73	< .001
Years of practice	1.02	1.00 to 1.04	.055
Received LTFU training	1.89	1.30 to 2.74	.001
Female	2.05	1.39 to 3.01	< .001
Cardiac surveillance			
Familiar with guidelines	1.20	1.05 to 1.36	.005
Thyroid surveillance			
Familiar with guidelines	1.28	1.10 to 1.49	.001
Female	1.97	1.32 to 2.93	.001

Abbreviation: LTFU, long-term follow-up.

Table 6. Multivariate Analysis of Correctly Answering All Three Clinical Vignette Surveillance Questions

Physician Characteristic	Odds Ratio	95% CI	P
Familiar with guidelines	1.33	1.15 to 1.54	< .001
Received LTFU training	1.73	1.18 to 2.52	.005

Abbreviation: LTFU, long-term follow-up.

DISCUSSION

The treatment of childhood cancers has been increasingly successful, and there is a rapidly growing population of long-term childhood cancer survivors.² Meanwhile, studies show that chemotherapy and radiation at a young age are associated with significant risk for developing SMN, damage to vital organ systems, early mortality, and overall diminished health status.^{4-7,10,29} To our knowledge, our survey is the first large study that examines physician attitudes toward and knowledge of risk-based health care, including surveillance of late effects and SMN, of childhood cancer survivors.

The data from this study reveal several notable findings. First, as pediatric cancer survivors age, pediatric oncologist–reported comfort levels in caring for them decreases. Yet, 38% of the pediatric oncologists in this study reported that they prefer to observe their survivors for as long as possible. These data speak to the difficult issues of the appropriate transition from pediatric to adult care in this population.³⁰ In other chronic diseases, such as cystic fibrosis and sickle cell disease, the transition from pediatric care is clearly recognized as complex; however, the primary illness and related need for care usually simply extends into adulthood.³¹⁻³⁴ The childhood cancer survivor population has been described as a new medical paradigm, different from other chronic disease models. Although these patients are cured of their childhood illness, the sequelae of treatment are often not realized until long after the time of completion of therapy.³⁵ As such, in many countries, including the United States, Canada, and the United Kingdom, most childhood cancer survivors are lost to follow-up and do not receive appropriate risk-based care.^{20,21,23} This clinically silent period between original treatment and the manifestation of long-term sequelae may, in fact, make the passing of the baton from a pediatric oncologist to an adult health care provider more difficult. This issue may be compounded by the profound attachment developed between the pediatric oncologist and the patient, which is observed in doctor-patient relationships in chronically or severely ill children.³⁶⁻³⁹ More research focused on learning how to better transition survivors to appropriate risk-based adult care (whether in a specialized LTFU program or a community-based primary care practice) is clearly needed. Such research could eventually be expected to help ensure that survivors maintain lifelong continual health surveillance beyond their childhood cancer therapy.

Second, the survey results suggest that many pediatric oncologists are not familiar with available LTFU guidelines regarding the need for surveillance for long-term sequelae of childhood cancer therapy. Only 33% of the respondents correctly answered our three vignette-based questions regarding surveillance recommendations on the basis of available COG LTFU guidelines. Only 43% of respondents appropriately recommended yearly breast cancer surveillance based

on these same guidelines. Reporting familiarity with the available LTFU guidelines and having received training in the care of childhood cancer survivors were both significantly associated with respondents correctly answering all three surveillance questions. Of note, a recent report described the breast cancer surveillance practices of 551 childhood cancer survivors exposed to chest radiation for their treatment.⁴⁰ Among this group of survivors, 63.5% of women age 25 through 39 years and 23.5% of women age 40 through 50 years had not had a mammogram in the past 2 years. That screening rates were highest among those survivors who reported a physician recommendation to do so highlights that surveillance practices in this population are likely to be dependent on physician awareness of SMN, late effects, and surveillance guidelines. Thus, studies and/or educational initiatives targeting ways to improve physician familiarity with LTFU guidelines would seem warranted. In addition, increasing pediatric oncologist and/or interested primary care physician training both in postdoctoral fellowship and in continuing education regarding late effects and late effects surveillance would seem appropriate to try and prevent or minimize cancer-related health risks in this population.

When our findings are interpreted, it is important to consider several limitations. First, the results are entirely based on pediatric oncologist self report of comfort levels with caring for and transitioning care for patients with childhood cancers. Thus, these results cannot necessarily be relied on to represent what occurs in actual pediatric oncologist clinical practice. In addition, these results cannot be relied on to represent the experiences of other physicians who may be involved in caring for long-term childhood cancer survivors (eg, primary care physicians). These results may be subject to response bias (ie, those with a stronger interest in the topic may have been more likely to have responded to our survey). Conversely, there was not a statistically significant difference in the sex or geographic location of responders compared with nonresponders, age, and time in practice of nonresponders was not knowable given the available COG information.

Given the limitations, it is important that additional studies be undertaken to explore physician attitudes and knowledge outside the cancer center–based pediatric oncology specialty to include physicians in adult oncology as well as in primary care, including pediatrics, internal medicine, and family medicine. Lastly, it must be highlighted that the current LTFU guidelines, on which our clinical vignette questions were created, are based on limited data and in many cases, expert opinion. Thus, as guidelines, they are not strict recommendations for all patients.

In summary, our study suggests that pediatric oncologists are increasingly uncomfortable with caring for survivors as they age and have suboptimal knowledge regarding the current surveillance recommendations for SMN and late effects. Findings from this study should provide a foundation for additional research and possible targeted interventions that hope to improve physician knowledge and comfort in caring for this growing and at-risk population.

AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

The author(s) indicated no potential conflicts of interest.

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