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Family physician preferences and knowledge gaps regarding the care of adolescent and young adult survivors of childhood cancer

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Abstract

Purpose Childhood cancer survivors are at risk for long-term morbidity and early mortality. Since most adult and some adolescent survivors of childhood cancer will receive their long-term care from a primary care physician, we sought to determine family physicians' comfort with caring for this population.

Methods A survey was mailed to 2,520 United States (US) and Canadian family physicians to assess their attitudes and knowledge regarding the care of adolescent and young adult survivors of childhood cancer.

Results One thousand one hundred twenty-four family physicians responded (704 US, 420 Canadian). Median age was 53 years; 63 % were men; 81 % had cared for ≤2 childhood cancer survivors in the past 5 years. Of those who had cared for a survivor, 48 % had never or almost never received a treatment summary from the referring cancer center; 85 % preferred to care for survivors in consultation with a cancer center-based physician or long-term follow-up program. Only 33, 27, and 23 % of respondents were very comfortable caring for survivors of childhood Hodgkin lymphoma, acute lymphoblastic leukemia or osteosarcoma, respectively. Only 16, 10, and 74 % of respondents correctly identified the guideline recommended surveillance for secondary breast cancer, cardiac dysfunction and hypothyroidism in response to a vignette describing a Hodgkin lymphoma survivor. Respondents rated access to clinical care guidelines and receipt of a patient-specific letter from specialists with surveillance recommendations as the modalities most likely to assist them in caring for survivors.

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Conclusions Most family physicians are willing to care for childhood cancer survivors in consultation with a cancer center, and with specific tools to facilitate this care.

Implications for Cancer Survivors Adult and adolescent survivors of childhood cancer who receive their follow-up care from a family physician must be empowered to choose a physician who is comfortable with caring for survivors. Further, the survivor must ensure that their physician has access to a treatment summary as well as to patient-specific recommendations for surveillance for late effects of cancer therapy.

Keywords Cancer · Pediatric · Survivors · Primary care · Long-term care · Delivery of health care · Family physician

Introduction

Over 80 % of children and adolescents diagnosed with cancer will become long-term survivors [1, 2]. There are currently more than 325,000 survivors in the United States (US) [3], and approximately 35,000 in Canada. Many of these survivors are at risk for chronic morbidity and premature mortality as a consequence of their cancer therapy [4–7]. Long-term survivors are over eight times more likely than their siblings to develop a severe or life threatening health condition within 30 years of their original cancer diagnosis [6]. These include second malignant neoplasms, organ and cognitive dysfunction, and endocrinopathies [8].

In 2003, the Children's Oncology Group (COG) published guidelines for the care of childhood cancer survivors (www.survivorshipguidelines.org). These document potential late effects of therapy and provide surveillance guidelines aimed at minimizing morbidity and premature mortality through early detection and intervention [9]. Despite these recommendations, many adult survivors of childhood cancer do not receive appropriate care focused on the risks arising from their prior cancer therapy [10, 11]. Numerous factors contribute to poor compliance with guidelines, including poor survivor knowledge of their prior cancer therapies and risks for late effects [12], difficulty obtaining health insurance [13], and psychological barriers to seeking follow-up care [14]. Importantly, physician knowledge of the long-term health sequelae and guidelines for the care of survivors is suboptimal, even among pediatric oncologists [15]. Since most adult and some adolescent survivors of childhood cancer will receive their follow-up care from a community-based primary care physician (family physician or general internist) rather than at a cancer center [10], the objective of this study was to examine the experiences, attitudes, and knowledge of North American family physicians regarding the care of childhood cancer survivors.

Methods

Participants

After obtaining Institutional Review Board approval, we conducted parallel survey studies of family physicians in the US and Canada. We randomly selected 1520 US family physicians from the 2010 American Academy of Family Physicians' (AAFP) membership directory of physicians listed as practicing more than 50 % of the time. We randomly selected 1,000 Canadian participants (family physicians and general practitioners) from provincial medical college directories stratified by practice setting (urban vs. rural) and region (Western Canada, Ontario, and Eastern Canada).

Survey mailings

We utilized a modified Dillman methodology [16]. Potential participants received a stamped self-addressed survey accompanied by a small incentive. The survey booklet was mailed with a cover letter explaining the purpose of the study. Second and third copies were mailed to non-responders. All mailings were sent between December 2010 and October 2011.

Survey instrument

The survey was adapted from prior surveys assessing physician knowledge, communication, and attitudes regarding the care of patients with cancer [15, 17–19]. It was comprised of 11 questions focused on the care of adolescent and young adult (AYA) survivors of childhood cancer. "Childhood cancer survivor" was defined as a patient diagnosed with cancer at or prior to 21 years of age who is alive at least 5 years from initial diagnosis. The survey sought information about family physician demographics, medical education and practice structure. Respondents were asked about the number of AYA survivors of childhood cancer that they had cared for in the last 5 years, and how frequently they had received a cancer treatment summary and care plan (documenting the survivor's diagnosis, cancer therapy, and plan for follow-up) from a referring cancer center prior to the survivor's first visit after completing their cancer therapy. Quantitative survey items utilized a seven-point Likert scale to query respondents about their comfort with caring for AYA survivors of specific cancers (acute lymphoblastic leukemia [ALL], Hodgkin lymphoma [HL], and osteosarcoma). Available ratings ranged from "Very uncomfortable" (scored as 1) to "Very comfortable" (scored as 7). Respondents were asked whether they prefer to care for survivors independently; in consultation with a cancer center-based physician or long-term follow-up clinic; or not to care for them, but to refer them to a cancer center-based physician or to another primary care physician. Respondents rated their level of familiarity with the available surveillance guidelines on a seven-point Likert scale. The survey included a hypothetical vignette describing a 26-year-old female survivor of HL whose therapy included mantle radiation and anthracycline chemotherapy at age 16 years. Respondents were asked about their approach to breast cancer, and thyroid and cardiac dysfunction surveillance in this patient, and their answers were compared to the COG survivorship guidelines. Finally, respondents were asked to rate the usefulness of 11 tools that might assist them in caring for such a survivor independently.

Statistical analysis

Data were summarized overall and across groups. Comparisons between US and Canadian respondents were performed using chi-square tests for categorical variables, two-sample *t* tests for continuous variables, and Wilcoxon rank-sum tests for ordinal variables. Multivariate linear and ordinal logistic (i.e. proportional odds) regression analyses were performed to examine factors associated with level of comfort with treating survivors of ALL, HL, or osteosarcoma (dependent variable defined as the comfort level rating on a Likert scale with a range of 1–7 for each of the three cancer types) and surveillance guideline knowledge (dependent variable defined as the number of surveillance guideline questions correctly answered; range 0–2 after combining 2 and 3 correct due to small number with 3 correct), respectively. We chose, a priori, to evaluate the following covariates: gender, years of practice, total number of patients seen per week, having seen at least one survivor in the last 5 years, and practice environment and location (solo vs. group/academic vs. other; Canada vs. US). Age was highly correlated with years of practice ($r=0.92$) and so was not included in the multivariate models. Other than those variables chosen a priori, no additional covariates were considered in the regression analyses. For the ordinal logistic regression analyses, the proportional odds assumption was verified using a likelihood-ratio test. Due to the large sample size and to strike a balance between false negative and false positive rates, a p value<0.01 was considered statistically significant. Statistical analyses were performed using Stata Version 12 (StataCorp., College Station, TX).

Results

Of the 2,520 family physicians contacted, 1,124 (45 %) responded—704/1520 (46 %) in the US, and 420/1000 (42 %) in Canada. The accrued sample size permits estimation of proportions (e.g., proportion of respondents who saw at least one survivor in the past 5 years) with excellent precision. Specifically, the half-width of the 95 % confidence interval for any reported proportion is no larger than 0.03.

Demographic data

Demographic characteristics are listed in Table 1. US participants were more likely to be male, were older and had been in practice longer than Canadian participants. Canadian participants were more likely to be members of a solo or group practice, and reported seeing a larger volume of patients on a weekly basis.

Among US physicians, there was no significant difference between responders and non-responders in terms of gender or geographic region. Among Canadian physicians, there was no significant difference between responders and non-responders in terms of gender, geographic region, or urban vs. rural practice location.

Experience with caring for childhood cancer survivors

Eighty-one percent of respondents reported that they had cared for two or fewer childhood cancer survivors over the 5 years preceding the survey. Only 58 % had cared for at least one survivor in that period, and fewer than 5 % had cared for 6 or more (Table 2). Among respondents who reported having cared for one or more survivors, 48 % reported that they never or almost never received a treatment summary prior to the survivor's first visit. US respondents were significantly more likely than Canadian respondents to report never or almost never receiving a treatment summary (55 vs. 35 %; $p<0.01$).

Physician preferences for the care of childhood cancer survivors

Only 9/1,092 physicians (1 %) preferred to care for survivors independently. The majority (928 [85 %]) preferred to care for them in consultation with a cancer center-based physician or a long-term follow-up program. One hundred and twenty six (11 %) stated that they would prefer to refer survivors to a cancer center or another primary care physician.

Comfort with caring for childhood cancer survivors

Respondents were most comfortable caring for survivors of HL (mean [standard deviation (SD)]=3.7 [1.7]), followed by ALL (3.4 [1.6]) and osteosarcoma (3.3 [1.6]). Only 33, 27, and 23 % of respondents rated their comfort as 5 or greater for caring for survivors of HL, ALL, and osteosarcoma, respectively. Based on multivariate analyses, family physicians that had seen at least one survivor in the past 5 years were significantly more comfortable caring for survivors of ALL and osteosarcoma, while female family physicians were less comfortable caring for either group. Comfort with caring for survivors of HL was significantly greater in family physicians

Table 1 Demographic characteristics of respondents

	Entire cohort (*N*=1124)	US participants (*N*=704)	Canadian participants (*N*=420)	*p* value (US vs. Canada)
Gender [*N* (%)]				
M	703 (63)	492 (70)	211 (50)	<0.01
F	410 (36)	203 (29)	207 (50)	
Not reported	11 (1)	9 (1)	2 (0)	
Age (years) [median (IQR)]	53 (43–60)	57 (46–61)	48 (40–57)	<0.01
Years in practice [median (IQR)]	22 (11–30)	25 (12–31)	19 (10–28)	<0.01
US census region [*N* (%)][a]				
Northeast		105 (15)		
Midwest		221 (31)		
South		235 (33)		
West		143 (20)		
Canadian geographic region [*N* (%)][b]				
West			141 (34)	
Ontario			139 (33)	
East			140 (33)	
Practice type [*N* (%)]				
Solo/2 person practice	336 (30)	179 (25)	157 (37)	<0.01
Group practice (≥3)	436 (39)	210 (30)	226 (54)	
Multi-specialty practice	158 (14)	148 (21)	10 (2)	
Academic practice	60 (5)	58 (8)	2 (0)	
Other	117 (10)	97 (14)	20 (5)	
Not reported	17 (1)	12 (2)	5 (1)	
Number of patients/week [median (IQR)]	100 (60–120)	80 (50–100)	120 (80–150)	<0.01

IQR interquartile range, *N* sample size; *US* United States

[a] Based on regions defined at www.census.gov/geo/www/us_regdiv.pdf

[b] *West* British Columbia, Alberta, Saskatchewan, Manitoba; *East* New Brunswick, Nova Scotia, Newfoundland, Prince Edward Island

that cared for a higher volume of patients, had been in practice longer, and had seen at least one survivor in the last 5 years. As with the other two diagnoses, females were less comfortable caring for survivors of HL.

Familiarity with published long-term follow-up guidelines

Respondents rated their familiarity with the published guidelines for the care of survivors at a mean of 2.6 (SD=

Table 2 Respondents experience with caring for survivors of childhood cancer

	Entire cohort (*N*=1124)	US participants (*N*=704)	Canadian participants (*N*=420)	*p* value (US vs. Canada)
Number of adolescent and young adult survivors of childhood cancer cared for in last 5 years [*N* (%)]				
None	459 (41)	265 (38)	194 (46)	<0.01
1–2	455 (40)	284 (40)	171 (41)	
3–5	153 (14)	108 (15)	45 (11)	
6–9	28 (2)	24 (3)	4 (1)	
≥10	18 (2)	15 (2)	3 (1)	
Not reported	11 (1)	8 (1)	3 (1)	
Frequency with which physician received a treatment summary from the cancer center prior to each survivor's first visit [*N* (%)][a]				
Never	189 (29)	141 (33)	48 (22)	<0.01
Almost never	124 (19)	96 (22)	28 (13)	
Sometimes	95 (15)	56 (13)	39 (17)	
Often	61 (9)	40 (9)	21 (9)	
Almost always	96 (15)	58 (13)	38 (17)	
Always	82 (13)	37 (9)	45 (20)	
Not reported	7 (1)	3 (1)	4 (2)	

N sample size, *US* United States

[a] Among those respondents who reported having seen one or more survivor in the preceding 5 years

1.3) on a 7-point scale. Only 9 % of respondents scored their familiarity as 5 or higher. Subsequently, we evaluated respondents' knowledge of the surveillance guidelines as applied to a hypothetical 26-year-old HL survivor. When compared to the COG Long-Term Follow-Up Guidelines recommendations, 16 % identified the recommended breast cancer surveillance (annual breast MRI and mammogram, or mammogram alone), 10 % identified the recommended cardiac surveillance (biennial echocardiogram) and 74 % identified the recommended thyroid function surveillance (annual T4 and TSH). Only 2 % of respondents identified all three surveillance strategies correctly. Seeing a greater volume of patients overall was associated significantly with answering more questions correctly (Table 3).

When compared to the 655 US pediatric oncologists surveyed in our prior study that used an identical vignette [15], family physicians in the current study were less likely to identify the recommended surveillance for breast cancer (16 % of family physicians identified correct surveillance strategy vs. 66 % of pediatric oncologists; $p<0.001$) and cardiac dysfunction (10 % vs. 57 %; $p<0.001$). Identification of appropriate thyroid function surveillance did not differ between the two groups (74 % vs. 77 %; $p=0.16$).

Table 3 Multivariate ordinal logistic regression model of factors associated with identifying a greater number of surveillance strategies correctly

	Odds ratio[a]	95 % CI	*p* value
Location			
US	Referent		
Canada	0.95	0.73–1.25	0.73
Gender			
Male	Referent		
Female	1.29	0.98–1.69	0.07
Number of patients seen per week (per ~65[b] patient increase)	1.36	1.15–1.62	<0.01
Number of years in practice (per ~10[b] year increase)	1.06	0.93–1.21	0.37
Number of survivors seen in past 5 years			
0	Referent		
≥1	1.34	1.04–1.72	0.02
Practice type			
Solo	Referent		
Group/academic	0.83	0.63–1.09	0.18
Other	0.66	0.41–1.05	0.08

[a] Interpreted as the odds of meeting a given performance criterion (i.e., at least 1 correct or at least 2 correct) for one group compared to the referent, or for a 1 standard deviation increase

[b] Number indicates 1 standard deviation

Usefulness of various modalities for facilitating the care of survivors

Access to guidelines for the clinical care of childhood cancer survivors, and receipt of a patient-specific standardized letter from specialists with surveillance recommendations for the family physician were rated as the most useful of the 11 modalities considered (Table 4).

Educational and personal experience in the care of survivors

Overall, educational experiences of the family physicians regarding the management of survivors were quite limited. Thirty-eight percent reported having communicated with a colleague regarding the care of survivors, 33 % reported having attended relevant continuing medical education activities and the same proportion reported having read one or more journal articles regarding survivorship. Twenty-three percent reported attending a formal lecture during their medical training, and 18 % had attended a session at a professional conference. Ten percent or less had reported reading a monograph from the AAFP, or had visited an internet site that addressed the topic. US participants were significantly more likely than their Canadian counterparts to report continuing medical education activities, attending a session at a professional conference, or having read a monograph or journal article regarding cancer survivorship. Canadian participants were more likely to have attended a formal lecture during their medical training or to have visited a relevant internet site (data not shown).

Continuing medical education activities, monographs and talking with a colleague were ranked as the best educational modalities for learning about the long-term care of survivors by 24, 19, and 10 % of respondents, respectively, while none of the other modalities described above was endorsed as being the best by more than 10 % of respondents.

Discussion

Although the majority of children and adolescents with cancer receive follow-up care in a cancer center during their pediatric years, most receive care from a primary care physician once they reach adulthood [10]. However, over 80 % of the 1,124 North America family physicians who responded to our survey reported having cared for two or fewer childhood cancer survivors in the preceding five years. This inexperience in caring for survivors was reflected in respondents' discomfort with caring for these patients, and in their lack of awareness regarding the

Table 4 Perceived usefulness of various modalities for assisting the family physician's ability to care for childhood cancer survivors (on a scale of 1 [not at all useful] to 5 [very useful])

	Mean ranking (standard deviation)	Percentage of respondents ranking modality as useful or very useful (4 or 5 out of 5) (%)
Patient-specific standardized letter from specialist(s) with surveillance recommendations for the primary care physician	4.7 (0.7)	94
Access to long-term follow-up guidelines for pediatric cancer survivors	4.7 (0.7)	93
Ability to telephone or email specialist for advice	4.3 (0.9)	82
Expedited routes of re-referral to cancer specialists	4.3 (0.9)	81
Patient-specific standardized letter from specialist(s) with surveillance recommendations given to the patient	4.3 (0.9)	79
Website with information and opportunity for questions/answers	4.0 (1.0)	74
Expedited access to investigations for suspected recurrence	4.0 (1.0)	69
Medical education seminars or courses regarding cancer follow-up care	3.9 (1.1)	66
Expedited access to support services e.g. social work, psychology etc.	3.8 (1.0)	62
Pamphlets on follow-up cancer care	3.4 (1.1)	47
More medical/support staff in primary care office	3.2 (1.1)	35

published surveillance guidelines. Despite this inexperience, most family physicians (85 %) stated they would be willing to care for survivors if they would be able to consult with a cancer center-based physician or survivorship program. Only 1 % of respondents would prefer to care for these patients independently. In contrast, prior research by members of our team demonstrated that more than 50 % of family physicians are willing to assume exclusive responsibility for the care of survivors of *adult* malignancies such as breast, prostate, and colorectal cancer [19]. However, follow-up of survivors of adult malignancies is largely concerned with the detection of cancer recurrence, whereas recurrence is rarely a concern in adult survivors of childhood cancer who are more likely to suffer from late complications of therapy.

A third of respondents to our survey indicated that they are comfortable (a score of ≥5 on a 7-point scale) with caring for survivors of HL, while considerably fewer were comfortable with caring for survivors of ALL or osteosarcoma. This may reflect the fact that HL is a relatively common diagnosis among young adults and geriatric patients, while ALL is predominantly a disease of childhood, and osteosarcoma is rare. Despite this relative comfort with caring for HL survivors, only 2 % of respondents correctly identified all the recommended surveillance guidelines for breast cancer, and cardiac and thyroid dysfunction.

A survey of 156 North American pediatric cancer centers revealed that only 35 % follow adult survivors of childhood cancer indefinitely [20]. Thirty-one percent transition survivors when they are ready, while the remainder transition at a specific age, varying from 18 to 30 years old. Importantly, 68 % of centers reported providing survivors with a survivorship care plan or a summary of their treatment exposures. Such care plans have been endorsed by the Institute of Medicine in order to improve survivors' awareness of late effects and their implications for long-term health [21]. Respondents to our survey rated the provision of such a letter to the family physician and access to clinical guidelines for the care of pediatric cancer survivors as the two most useful tools. Yet, of those who reported having seen one or more survivors in the preceding 5 years, 48 % reported never or almost never having received such a letter. Further, although the guidelines published by COG have been available since 2003 [9], less than 10 % of survey respondents reported being very familiar with guidelines for childhood cancer survivor care. These deficiencies provide two targets for improving the care of childhood cancer survivors—namely, ensuring that all family physicians receive a treatment summary at the time a survivor is transferred to their care, and increasing awareness of the guidelines. Since these guidelines for the long-term follow-up care of survivors are predominantly consensus based, it is unclear what impact (if any) this will have on primary care practitioners' willingness to adopt them. Beyond improving family physicians' access to treatment summaries and guidelines, pediatric oncologists must ensure that survivors are aware of their cancer history and empower them to advocate for appropriate medical care prior to their transition out of a pediatric cancer center.

Our findings should be interpreted in the context of the study's limitations. Most notably, only 45 % of family physicians that were surveyed responded. However, this response rate is reasonably comparable to other surveys of family physicians conducted by the AAFP, which have reported 53 to 58 % response rates [22–25], and to the 51 % response rate observed in a prior study of Canadian family physicians' comfort with caring for survivors of adult cancers [19]. The survey may be susceptible to response bias if those family physicians with a greater interest in the care of childhood cancer survivors were more likely to respond. Consequently, it is plausible that the low levels of comfort and knowledge reflected by respondents to our survey may represent a best-case scenario. In the US, both family physicians and general internists function as primary care physicians. We have recently completed a survey of US general internists which will be published separately.

Despite the relatively small population of childhood cancer survivors relative to survivors of adult cancer, childhood cancer is second only to breast cancer in the number of life-years impacted by cancer at a population level [26]. Although the population of childhood cancer survivors continues to expand, there are still too few survivors for these patients to comprise more than a small group in any single family physician's practice. However, since most adult survivors of childhood cancer will seek their long-term care from such a family physician and most family physicians in our study indicated that they are willing to care for this population, initiatives are needed that will provide these physicians with the appropriate tools to care for these patients. Based on our results, a shared care model that allows for a family physician to care for survivors in consultation or collaboration with a cancer center would appear to address the needs of the survivor and the physician. Such models have been implemented with success in the pediatric setting in the Netherlands [27]. Unfortunately, not all pediatric cancer centers have the resources necessary to provide support to multiple family physicians, each caring for small numbers of childhood cancer survivors. Thus, providing detailed treatment summaries and care plans (including contact information for the cancer center) at the time of transfer is essential. Further, pediatric oncologists and co-operative groups such as the COG must implement strategies to better disseminate long-term follow-up guidelines to primary care physicians, including the development of tools that facilitate easy access to appropriate guidelines for individual survivors.

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