

Health Care of Young Adult Survivors of Childhood Cancer: A Report from the Childhood Cancer Survivor Study

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ABSTRACT

BACKGROUND We wanted to determine the type of outpatient medical care reported by young adult survivors of childhood cancer and to examine factors associated with limited medical care.

METHODS We analyzed data from 9,434 adult childhood cancer survivors enrolled in a retrospective cohort study who completed a baseline questionnaire. They had a mean age of 26.8 years (range 18 to 48 years), 47% were female, 12% were minorities, and 16% were uninsured. Four self-reported outcome measures were used to determine outpatient medical care in a 2-year period: general contact with the health care system, general physical examination, cancer-related medical visit, and medical visit at a cancer center.

RESULTS Eighty-seven percent reported general medical contact, 71.4% a general physical examination, 41.9% a cancer-related visit, and 19.2%, a visit at a cancer center. Factors associated with not reporting a general physical examination, a cancer-related visit, or a cancer center visit included no health insurance (odds ratio [OR] = 2.34; 95% confidence interval [CI], 1.97-2.77), male sex (OR = 1.65; 95% CI, 1.44-1.88), lack of concern for future health (OR = 1.57; 95% CI, 1.36-1.82), and age 30 years or older in comparison with those 18 to 29 years (OR = 1.56; 95% CI, 1.35-1.81). The likelihood of reporting a cancer-related visit or a general physical examination decreased significantly as the survivor aged or the time from cancer diagnosis increased. This trend was also significant for those treated with therapies associated with substantial risk for cardiovascular disease or breast cancer.

CONCLUSIONS Primary care physicians provide health care for most of this growing high-risk population. To optimize risk-based care, it is critical that cancer centers and primary care physicians develop methods to communicate effectively and longitudinally.

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INTRODUCTION

With improvements in treatment during the recent decades, survival rates for childhood cancer have increased to more than 70%, resulting in an increasing population of long-term survivors.¹ Currently, 1 in 900 young adults is a childhood cancer survivor.² With this growth in survivorship, there has been a developing recognition of the potential long-term health problems related to cancer therapy. All organ systems can be affected by radiation, chemotherapy, or surgery, leading to a wide array of potential late effects.

Long-term survivors of childhood cancer face considerable risk for late mortality, morbidity, and adverse health status secondary to their previous cancer therapy. In a retrospective analysis of 20,227 childhood cancer patients who had survived 5 years, Mertens et al³ reported an

absolute excess risk for mortality from second cancers (not including late recurrences), cardiac causes, and pulmonary causes of 1.26, 0.27, and 0.015 deaths, respectively, per 1,000 person-years. Morbidity secondary to late effects of chemotherapy or radiation is frequent and often serious. In 5 studies reporting on long-term survivors with a median age ranging from 15 to 23 years, 58% to 69% had at least one late effect of therapy, with 25% to 30% experiencing a moderate to severe late complication.⁴⁻⁸ Hudson et al⁹ found that 44% of adult survivors of childhood cancer reported at least one domain of their health status to be moderately to extremely adversely affected.

Survivors can benefit from early diagnosis and intervention or preventive care targeted at reducing risk for late effects, such as second malignant neoplasms of the breast,^{10,11} thyroid,^{12,13} and skin^{14,15} after radiation therapy; altered bone metabolism and osteoporosis^{16,17}; obesity-related health problems (dyslipidemia, hypertension, diabetes mellitus, cardiovascular disease)¹⁸⁻²⁰; liver failure secondary to chronic hepatitis C after blood transfusion²¹; and endocrine dysfunction after chest-mantle radiation.^{22,23} Longitudinal care addressing other late effects, such as infertility, musculoskeletal problems, cognitive dysfunction, and psychosocial issues, may also improve survivors' health outcomes and quality of life.

Most late effects increase in incidence with age, often becoming clinically apparent decades after therapy. Because this window of time offers the potential to modify severity of health outcomes by prevention or early intervention, there is consensus that survivors of childhood cancer should have longitudinal risk-based health care.^{4-8,24-26} In a recent report, *Ensuring Quality Cancer Care*,²⁷ the National Cancer Policy Board, established through the Institute of Medicine, recommended lifelong follow-up of all cancer survivors as a key component to improving the quality of cancer care. Expert opinion, based on limited evidence, recommends that risk-based health care include a systematic plan for screening, surveillance, and prevention, incorporating a survivor's risks based on the previous cancer or cancer therapy, genetic predispositions, lifestyle behaviors, and comorbid health conditions.^{24-26,28}

To date, the health care utilization patterns of young adult survivors have not been reported. It is unknown what percentage seek or receive medical care related to their previous cancer, and whether this care is risk based. The purpose of this exploratory study was to use a large cohort of young adult survivors to (1) determine the type of outpatient medical visits that survivors report in a 2-year period, and (2) examine factors associated with limited follow-up or medical visits.

METHODS

Subjects

The Childhood Cancer Survivor Study (CCSS) is a multi-institutional study of patients who survived for 5 or more years after diagnosis of a cancer. Eligibility criteria for the cohort included (1) confirmed diagnosis of 1 of the 8 primary cancer groups (leukemia, central nervous system malignancies, Hodgkin's disease, non-Hodgkin's lymphoma, kidney tumor, neuroblastoma, soft tissue sarcoma, or bone tumor); (2) diagnosis and initial treatment at 1 of the 25 collaborating institutions; (3) diagnosis between January 1, 1970, and December 31, 1986; (4) age less than 21 years at diagnosis; and (5) survived at least 5 years from diagnosis. The total eligible sample fulfilling these criteria was 20,276. Relying upon the last known address provided by the treating institution, a total of 7,913 (39%) required tracing to locate the eligible survivor or his or her parents. Of those survivors who required tracing, 4,917 (62%) were located; 2,996 (38%) were not despite intensive tracing efforts and were subsequently classified as lost to follow-up. The result was a total sample of 17,280 eligible survivors who were contacted regarding study participation.

The CCSS protocol and contact documents were reviewed and approved by the Human Subjects Committee at each participating institution. Baseline data were collected by mail or telephone for members of the study cohort using a 24-page questionnaire that was designed to capture a wide range of information, including sociodemographic characteristics, health habits, chronic medical conditions, and access and utilization of medical care. Information on the characteristics of the original cancer diagnosis was obtained from the treating institution. For all CCSS respondents who returned a signed medical release, information concerning primary cancer therapy and initial treatment was collected. Copies of the baseline questionnaire and the treatment abstraction form used in data collection are available for review and can be downloaded at <http://www.cancer.umn.edu/ccss>. Further details regarding the methodology and cohort characteristics were published previously.²⁹

Outcome Measures

Four dichotomous outcome measures were used to describe different types of outpatient medical care reported by survivors in a 2-year period: (1) general or nonspecific contact with a health care provider, (2) general physical examination, (3) cancer-related medical visit, and (4) medical visit at a cancer center. These outcomes were not mutually exclusive. To ascertain general or nonspecific medical contact, respondents

were asked whether they had contact with a physician, nurse, or other health care provider. Such contact could include a visit to a physician's office or a telephone call. To ascertain cancer-related medical visits and cancer center visits, respondents were asked how many of the visits to a physician's office were related to their previous cancer and whether any of the visits were at an oncology (cancer) center. The content or additional details about the medical visits were not ascertained, and it is possible that they incorporated screening related to the previous cancer treatment.

Independent Variables

Sociodemographic variables included age at time of interview, sex, race and ethnicity, education, health insurance, and household income. Because the number of black, non-Hispanic and Hispanic survivors was small, they were combined with other race and ethnic minorities and analyzed as a single group. Cancer-related variables included cancer type, age at diagnosis, time from cancer diagnosis to baseline questionnaire, subjective health status, pain or anxiety as a result of the cancer or its treatment, and concern for future health. To assess follow-up patterns for survivors who might be at higher risk for late effects, a high-risk treatment variable was created that consisted of those cases of patients who received one or more of the following treatments: radiation to the mantle or chest, anthracycline with a cumulative dose ≥ 300 mg/m², bleomycin, ifosfamide, or etoposide.

Analysis

Univariate analyses were performed to assess the associations of demographic and cancer-related variables with the medical care outcome measures. The Cochran-Armitage trend test was used for assessing trends in binomial proportions with aging or increasing time from cancer diagnosis. To determine the strength of association between the outcome variables and the demographic and cancer-related factors hypothesized to be significant a priori, regression analysis was used to estimate odds ratios (OR) with 95% confidence intervals (CI) for absence of each outcome. Specifically, generalized linear mixed models (logistic regression with institution-specific Gaussian random intercepts) were used to account for possible clustering based on institution. Data were analyzed with the SAS version 8 (SAS institute, Cary, NC) with 2-tailed statistical tests.

RESULTS

Of the 17,280 study subjects contacted, 14,054 (81%) responded by completing the baseline questionnaire. At the time of this analysis, 9,434 were alive and aged 18

years or older at interview. The demographics and cancer treatment of the 9,434 adult survivors are provided in Tables 1 and 2. The mean age at time of baseline questionnaire was 26.8 years (range 18 to 48 years), and the mean interval from diagnosis to completion of questionnaire was 17.4 years (range 6.4 to 29.4 years).

Tables 1 and 2 show the percentage of respondents who reported the 4 types of medical visits by each of the demographic and cancer-related variables. The older the survivor, the less likely he or she was to report a general physical examination ($P < .001$), a cancer-related visit ($P < .001$), or a visit to a cancer center ($P < .001$). Similarly, as the interval from cancer diagnosis increased, the survivors were less likely to report these types of visits ($P < .001$ for each outcome; Figure 1). For survivors who reported a general physical examination, the likelihood of also reporting a cancer-related visit decreased with age ($P < .001$) or with an increasing interval from cancer diagnosis ($P < .001$). The longer the interval from cancer diagnosis, the less likely survivors from 4 high-risk cancer groups (bone tumor, central nervous system tumor, Hodgkin's disease, leukemia) were to report a cancer-related visit ($P < .001$ for each group; Figure 2). Table 3 provides the final multivariate models of factors associated with limited contact or care. Findings in addition to those reported in Table 3 are described below.

Survivors who had received high-risk treatments were significantly more likely to have each type visit than other survivors (Table 4). As above, the likelihood of a general physical or a cancer-related visit decreased with age ($P < .001$ for both types of visits) or as the interval from cancer diagnosis increased ($P < .001$ for both types of visits).

Twenty-percent reported not having a general physical examination, a cancer-related visit, or a visit at a cancer center. A multivariate model estimated the following odds ratios for lack of at least 1 of these 3 types of medical visits: survivors 30 years or older in comparison with those less than 29 years of age (OR = 1.56; 95% CI, 1.35-1.81), male sex (OR = 1.65; 95% CI, 1.44-1.88), survivors without health insurance (OR = 2.34; 95% CI, 1.97-2.77), lack of concern for future health (OR = 1.57; 95% CI, 1.36-1.82), and high-risk treatment (OR = 0.64; 95% CI, 0.55-0.73).

DISCUSSION

This study is the first to report general and cancer-related health care visits in young adult survivors of childhood cancer in the United States and Canada. Four primary findings are discussed below: (1) most survivors reported some contact with the medical system, (2) the likelihood of a general physical examination or

a cancer-related medical visit decreased substantially as the survivor aged or the time interval from diagnosis increased, (3) less than 20% of survivors were seen in a cancer center, and (4) risk-based health care of adult survivors of childhood cancer is likely uncommon.

Almost 90% of adult survivors reported some contact with a health care clinician in the 2-year period, suggesting that access to general or nonspecific health care might not be an important issue for most young adult survivors in this cohort. Factors typically associated with lack of health care in the general population,³⁰⁻³³ such as lack of medical insurance, ethnic minority status, and male sex, were associated with limited nonspecific medical contact.

About 75%, 50%, and 25% of survivors in their younger adult years, 18 to 24 years, reported a general physical examination, a cancer-related visit, or a visit to a cancer center, respectively. The proportion of survivors reporting these types of visits decreased significantly with age and with increasing time from cancer diagnosis. This decrease in health care utilization

occurred at a stage in life when the incidence of many late effects of cancer therapy, including most second cancers, cardiovascular disease, osteoporosis, and endocrinopathies, are increasing. Encouragingly, those who needed follow-up the most, survivors treated with high-risk therapies, were more likely than other survivors to report a general physical examination, a cancer-related visit, or a visit to a cancer center. Even in this high-risk group, however, the likelihood of visits decreased significantly with age or increasing interval from the cancer diagnosis. Of note, ethnic or racial minority status was not associated with absence of these types of visits. In contrast, male and uninsured survivors were less likely to report such visits.

Although the content of these types of medical visits was not assessed in this study, 2 examples of medical care may be illustrative. Treatment with an anthracycline, used in the therapy for several childhood cancers, can lead to a late-onset cardiomyopathy, often occurring 10 to 20 years after the cancer therapy.^{34,35} The optimum and cost-effective methods to screen for left ventricular

Table 1. Percentage of Adult Survivors of Childhood Cancer Who Reported the Following Types of Outpatient Medical Care in a 2-Year Period: Sociodemographic Factors

Factor	Number	General Medical Contact (%)	General Physical Examination (%)	Cancer-Related Medical Visit (%)	Cancer Center Medical Visit (%)
Age at interview					
18-19 y	1,126	88.4	82.7	48.6	31.0
20-24 y	2,752	87.7	73.1	45.1	24.2
25-29 y	2,528	85.8	67.6	38.7	21.5
30-34 y	1,849	86.8	65.0	39.9	17.5
35-48 y	1,179	86.8	67.0	37.8	16.6
Sex					
Male	5,020	82.0	65.3	39.6	22.3
Female	4,414	93.6	75.8	44.5	21.9
Race/ethnicity					
White, non-Hispanic	7,886	87.7	70.2	41.8	21.5
Black, non-Hispanic	392	79.1	72.9	34.8	20.0
Hispanic	434	83.2	71.2	47.3	32.2
Others	273	82.6	69.0	45.1	24.7
Education					
< HS graduate	959	82.8	68.1	44.4	26.2
HS/some college	5,239	85.6	69.2	40.2	21.3
College graduate	2,723	90.5	72.2	43.7	22.7
Health insurance					
Yes	7,835	88.7	73.0	43.5	22.4
No	1,439	78.1	55.2	32.8	19.7
Household income					
< \$20,000	1,870	83.7	64.9	41.5	20.0
≥ \$20,000	6,403	88.5	72.3	41.9	22.3

< HS graduate = some high school, did not graduate; HS/some college = high school graduate or high school graduate with some college courses.

Note: Percentages are based upon the total with available data for each variable.

wall motion abnormalities are still being studied, but there is consensus that survivors who were treated with ≥ 300 mg/m² of an anthracycline should be observed closely longitudinally.^{34,35} In this analysis, only 51.7% of

survivors who had been treated with ≥ 300 mg/m² of an anthracycline reported a cancer-related medical visit.

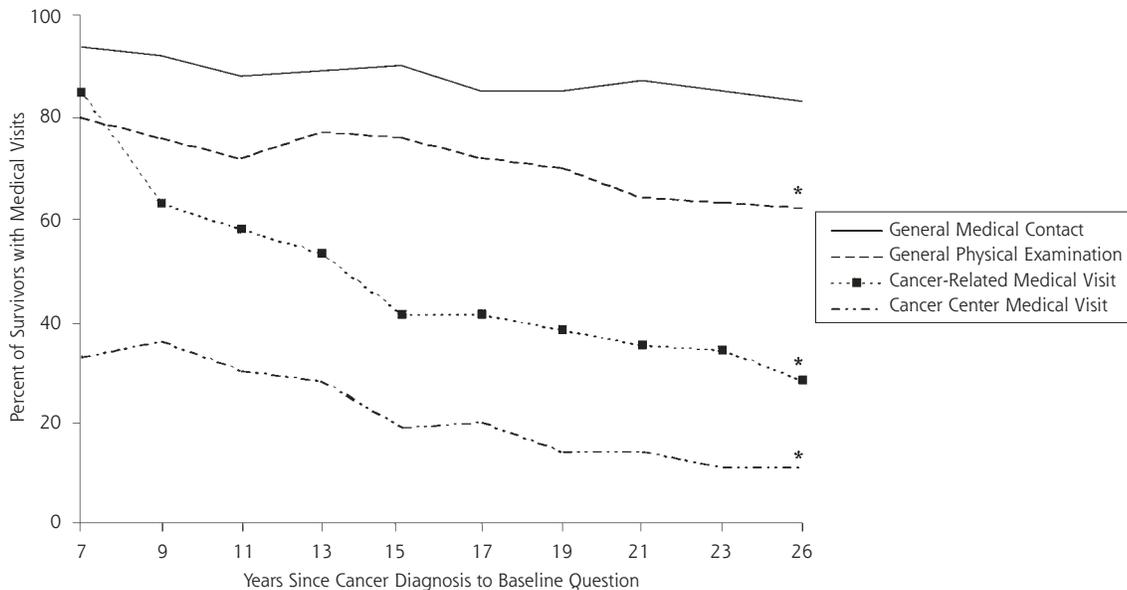
Care reported by Hodgkin's disease survivors, the cancer group that faces perhaps the most serious

Table 2. Percentage of Adult Survivors of Childhood Cancer Who Reported the Following Types of Outpatient Medical Care in a 2-Year Period: Cancer-Related Factors

Factor	Number	General Medical Contact %	General Physical Examination %	Cancer-Related Medical Visit %	Cancer Center Medical Visit %
Age at diagnosis					
0-4 y	2,426	86.0	72.4	36.4	18.2
5-9 y	2,336	86.2	71.6	41.1	23.3
10-14 y	2,540	87.2	68.4	43.5	23.6
15-21 y	2,132	88.6	69.0	46.9	23.2
Interval from cancer diagnosis					
	293	93.8	76.6	64.4	39.6
5-9 y	2,472	88.5	74.0	53.5	31.2
10-14 y	3,456	87.3	72.8	40.5	21.4
15-19 y	2,602	85.5	65.2	33.4	14.2
20-24 y	611	82.2	60.6	28.0	11.5
25-29 y					
Cancer diagnosis					
Leukemia	2,846	85.0	72.4	36.3	22.4
Central nervous system tumor	1,166	88.6	66.3	52.9	14.8
Hodgkin's disease	1,631	90.6	76.0	52.6	29.9
Non-Hodgkin's lymphoma	865	84.2	68.3	36.9	21.6
Wilms' tumor	630	88.2	68.8	33.7	18.0
Neuroblastoma	399	86.4	68.9	28.0	13.8
Sarcoma	894	75.0	67.8	39.9	19.6
Bone	1,003	88.4	65.4	43.8	24.9
Subjective health status					
Excellent	1,954	82.3	72.7	34.8	22.0
Very good	3,553	87.9	72.8	40.1	22.0
Good	2,834	88.6	68.7	45.1	22.4
Fair	844	87.9	63.7	51.8	21.6
Poor	146	89.7	51.1	62.1	24.4
Future health concerns					
Very concerned	2,787	88.9	73.5	48.0	23.9
Somewhat concerned	1,901	89.5	71.7	44.5	24.8
Concerned	2,298	87.1	70.0	40.4	21.7
Not very concerned	1,413	85.6	67.3	35.5	19.5
Not concerned at all	810	78.3	62.1	31.0	15.1
Cancer pain					
None	7,092	86.3	71.3	38.8	21.0
Small	976	90.0	69.9	49.9	25.0
Medium	608	89.4	67.3	54.2	26.6
A lot	232	88.7	67.3	59.3	27.9
Very bad	77	86.8	52.1	63.4	30.3
Cancer anxiety					
None	5,230	83.8	69.5	35.9	19.8
Small	2,513	91.8	72.7	47.3	23.6
Medium	808	91.7	71.7	55.5	27.2
A lot	300	90.9	73.1	59.3	30.4
Very many	73	90.4	61.4	48.5	31.8

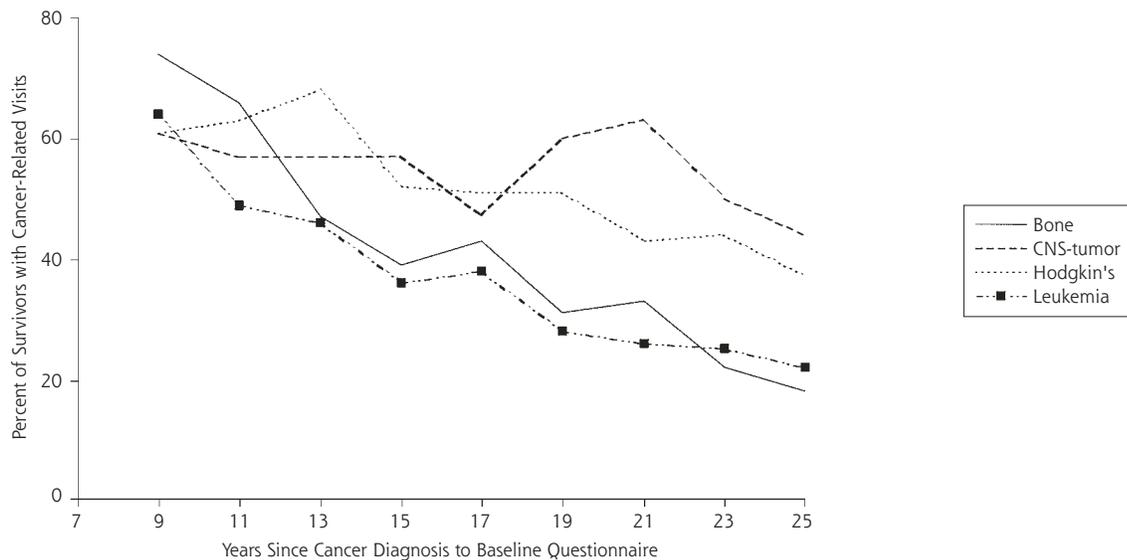
Note: Percentages are based upon the total with available data for each variable.

Figure 1. Percentage of adult survivors of childhood cancer with medical visits in a 2-year period by interval from cancer diagnosis to baseline questionnaire.



* Trend significant with $P < .001$ for general physical education, cancer-related medical visit, and cancer center medical visit by Cochran-Armitage trend test.

Figure 2. Percentage of adult survivors of 4 higher risk cancer groups with a cancer-related medical visit in a 2-year period by interval from cancer diagnosis to baseline questionnaire.



Note: Trend significant with $P < .001$ for bone tumor, central nervous system (CNS) tumor, Hodgkin's disease, and leukemia survivors by Cochran-Armitage trend test.

risks of childhood cancer survivors, serves as a second example. Depending on therapy, Hodgkin's disease survivors face a markedly increased risk for second cancers,^{10-13,36,37} endocrine dysfunction,¹² coronary artery disease,^{38,39} cardiac valvular disease,⁴⁰ ventricular

dysfunction,³⁵ infertility,⁴¹ and premature menopause.⁴² Though Hodgkin's disease survivors in this study were more likely to report cancer-related care than other survivors, nearly 50% reported no such care. As with the general survivor population, those in these 2 high-risk

Table 3. Multivariate Risk Factors for Absence of the Following Types of Outpatient Medical Care in a 2-Year Period in Adult Survivors of Childhood Cancer

Variable	Absence of							
	General Medical Contact		General Physical Examination		Cancer-Related Medical Visit		Cancer Center Medical Visit	
	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI
Age at interview								
18–19 y	1.00	Referent	1.00	Referent	1.00	Referent	1.00	Referent
20–24 y	1.18	0.90–1.56	2.06	1.62–2.61	1.11	0.92–1.33	1.31	1.07–1.61
25–29 y	1.47	1.11–1.95	3.12	2.45–3.97	1.67	1.38–2.02	1.88	1.51–2.34
30–34 y	1.59	1.18–2.15	3.75	2.91–4.82	1.74	1.42–2.14	2.79	2.19–3.56
≥35 y	1.71	1.23–2.37	3.64	2.78–4.76	2.29	1.83–2.87	3.43	2.61–4.51
Sex								
Female	1.00	Referent	1.00	Referent	1.00	Referent	1.00	Referent
Male	2.54	2.15–2.99	1.53	1.36–1.71	1.18	1.06–1.30	1.15	1.01–1.30
Ethnicity								
White, non-Hispanic	1.00	Referent	1.00	Referent	1.00	Referent	1.00	Referent
Minority	1.53	1.21–1.93	0.81	0.66–0.99	0.97	0.81–1.16	0.79	0.64–0.96
Education								
College graduate	1.00	Referent	1.00	Referent	1.00	Referent	1.00	Referent
HS/some college	1.48	1.22–1.79	1.21	1.06–1.38	1.16	1.03–1.31	1.25	1.08–1.44
< HS graduate	1.88	1.41–2.52	1.34	1.06–1.70	1.14	0.92–1.41	1.07	0.84–1.37
Health insurance								
Yes	1.00	Referent	1.00	Referent	1.00	Referent	1.00	Referent
No	2.14	1.78–2.57	2.19	1.87–2.56	1.64	1.40–1.92	1.41	1.16–1.70
Health status								
Good	1.00	Referent	1.00	Referent	1.00	Referent	1.00	Referent
Fair/poor	0.94	0.72–1.22	1.42	1.18–1.71	0.62	0.52–0.74	1.01	0.82–1.24
Concern for future health								
Concerned	1.00	Referent	1.00	Referent	1.00	Referent	1.00	Referent
Not concerned	1.44	1.21–1.71	1.38	1.21–1.58	1.51	1.33–1.71	1.53	1.31–1.79
High-risk treatment*								
No	1.00	Referent	1.00	Referent	1.00	Referent	1.00	Referent
Yes	0.73	0.62–0.86	0.72	0.64–0.81	0.59	0.52–0.65	0.45	0.39–0.51

OR = odds ratio; CI = confidence interval; < HS graduate = some high school, did not graduate; HS/some college = high school graduate or high school graduate with some college courses.

* High-risk treatment = treatment with any of the following: chest or mantle radiation, anthracycline ≥ 300 mg/m², bleomycin, etoposide, or ifosfamide.

groups were less likely to report either a general physical examination or a cancer-related visit as they aged or as the time from diagnosis increased.

These findings have important implications for cancer centers and primary care physicians. Whereas the incidence of many modifiable late effects increases with age, the likelihood of survivors having general physical examinations or cancer-related care appears to decrease, which implies that provision of risk-based care also decreases with time. There are 4 key obstacles contributing to this problem: many cancer centers do not provide survivors with adequate information about late effects, most survivors are unaware of their risks, primary care physicians are unfamiliar with the population, and there is little formal communication between cancer centers and primary care physicians. In the

1980s, with the burgeoning information regarding late effects of therapy, long-term follow-up programs were established in many cancer centers with the intent of providing survivors with screening, surveillance, and education about late effects. Transition of medical care for adolescent and young adult survivors from long-term follow-up programs to primary care physicians has been recommended.^{24–26} By 1997, however, only 53% of childhood cancer centers in North America had developed a long-term follow-up program.⁴³ Thus, most young adult survivors have not been seen in such a program.⁴⁴ Even though most survivors have a fair knowledge of their general diagnosis and whether they received chemotherapy or radiation therapy, few have a summary of their treatment or are aware of their risks for late effects of therapy.⁴⁴

Table 4. Percentage of Adult Survivors of Childhood Cancer Treated With Therapies Associated With Increased Risk for Late Effects Reporting an Absence of the Following Types of Outpatient Medical Care in a 2-Year Period, Compared With All Survivors

Variable	Total No.	Absence of											
		General Medical Contact			General Physical Examination			Cancer-Related Medical Visit			Cancer Center Medical Visit		
		%	OR	(95% CI)	%	OR	(95% CI)	%	OR	(95% CI)	%	OR	(95% CI)
Chest-mantle RT													
No	6,013	12.5	1.00	Referent	30.6	1.00	Referent	59.4	1.00	Referent	79.7	1.00	Referent
Yes	1,802	8.2	0.68	0.57–0.83	24.6	0.64	0.56–0.73	47.9	0.60	0.53–0.67	70.3	0.50	0.43–0.57
Anthracycline													
< 300 mg/m ²	6,459	11.1	1.00	Referent	29.4	1.00	Referent	53.6	1.00	Referent	72.6	1.00	Referent
≥300 mg/m ²	1,508	10.7	0.88	0.73–1.06z	27.4	0.96	0.84–1.11	51.7	0.77	0.68–0.88	69.8	0.65	0.56–0.75
Bleomycin													
No	7,642	12.2	1.00	Referent	29.4	1.00	Referent	58.4	1.00	Referent	81.5	1.00	Referent
Yes	581	7.8	0.58	0.42–0.81	25.7	0.80	0.65–0.99	40.8	0.48	0.40–0.58	67.0	0.47	0.38–0.57
High-risk therapy*													
No	4,304	13.2	1.00	Referent	31.3	1.00	Referent	61.9	1.00	Referent	83.1	1.00	Referent
Yes	3,449	10.0	0.70	0.60–0.82	26.4	0.74	0.66–0.83	50.7	0.58	0.53–0.65	71.1	0.45	0.39–0.50

Note: results adjusted for age, sex, and race; percentages are based upon the total with available data for each variable.

OR = odds ratio; CI = confidence intervals; RT = radiation therapy.

* High-risk therapy: treatment with any of the following: chest-mantle radiation, anthracycline > 300 mg/m², bleomycin, etoposide, or ifosfamide.

Although primary care physicians provide general health care for most survivors, there has not been a national effort to foster linkages between childhood cancer centers and primary care physicians to enhance risk-based care. There is a paucity of information about this population in primary care-based journals,⁴⁵ and there is no mention of this population in primary care textbooks, resident curricula, or continuing medical education monographs.²⁸ Finally, compounding this lack of dissemination of information, survivors represent a small percentage of a typical primary care physician's practice.⁴⁵ In addition, providing appropriate risk-based care to survivors, who are a heterogeneous group, is complicated by the variety of cancers diagnosed at different ages and treatment eras and by recommendations for screening and surveillance that are constantly evolving. As a result, there is a critical need for cancer centers, primary care physicians, and survivors to communicate and share information.

Readers are directed to <http://www.cancer.umn.edu/ltfu> for general information regarding risks of this population (see project newsletters). It is important that recommendations for risk-based care, based on current evidence, be disseminated in primary care journals and textbooks. As an example, Oeffinger et al⁴⁶ provided recommendations for primary care physicians caring for leukemia survivors. To optimize risk-based care of this vulnerable population, interventions to educate survivors, enhance their transition to primary care phy-

sicians, and foster ongoing communication between survivors, cancer centers, and primary care physicians need to be developed and tested.

There are several limitations of this study that are important to consider when interpreting the findings. First, health care utilization was based upon self-report by respondents and was not externally verified. Second, the determination of cancer-related medical visits was based upon the survivor's perception of the reasons for the medical visit. There are times when a health care professional might have seen a survivor and screened for late effects of therapy without the survivor understanding the rationale for testing. Similarly, the content of the visit as it pertained to appropriate risk assessment and screening based upon previous therapy and modifying factors, such as unhealthy behaviors or genetic predisposition for different diseases, was not determined from whether a survivor had a general physical examination or a cancer-related visit. Third, though nationally 25% of new childhood cancers are in patients of ethnic minorities,⁴⁷ only 12.2% of this survivor cohort belonged to an ethnic minority. Because the collaborating institutions did not regularly collect race and ethnicity information on all patients treated between 1970 and 1986, it cannot be determined whether this low percentage of ethnic minorities represents a selection bias, a limitation in generalizability, or a lower proportion of minority survivors treated at these institutions.

Despite these limitations, our findings likely overestimate the percentage of long-term survivors who are receiving risk-based health care. Completion of the lengthy questionnaire required a degree of sophistication and interest on the part of the responding survivors, and it is probable that the nonrespondents are even less likely to have adequate risk-based health care.

In conclusion, though most adult survivors of childhood cancer in this large cohort study reported some type of contact with the medical system, the likelihood of a cancer-related visit or a physical examination decreased at an age when the incidence of modifiable late effects are increasing. Primary care physicians provide health care for most of this growing high-risk population. To optimize risk-based care, it is critical that cancer centers and primary care physicians develop methods to communicate effectively and longitudinally.

To read commentaries or to post a response to this article, see it online at <http://www.annfamned.org/cgi/content/full/2/1/61>.

Key words: Survivors; neoplasms; delivery of health care; cohort

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