

Medical Care in Long-Term Survivors of Childhood Cancer: A Report From the Childhood Cancer Survivor Study

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ABSTRACT

Purpose

To evaluate whether childhood cancer survivors receive regular medical care focused on the specific morbidities that can arise from their therapy.

Patients and Methods

We conducted a cross-sectional survey of health care use in 8,522 participants in the Childhood Cancer Survivor Study, a multi-institutional cohort of childhood cancer survivors. We assessed medical visits in the preceding 2 years, whether these visits were related to the prior cancer, whether survivors received advice about how to reduce their long-term risks, and whether screening tests were discussed or ordered. Completion of echocardiograms and mammograms were assessed in patients at high risk for cardiomyopathy or breast cancer. We examined the relationship between demographics, treatment, health status, chronic medical conditions, and health care use.

Results

Median age at cancer diagnosis was 6.8 years (range, 0 to 20.9 years) and at interview was 31.4 years (range, 17.5 to 54.1 years). Although 88.8% of survivors reported receiving some form of medical care, only 31.5% reported care that focused on their prior cancer (survivor-focused care), and 17.8% reported survivor-focused care that included advice about risk reduction or discussion or ordering of screening tests. Among survivors who received medical care, those who were black, older at interview, or uninsured were less likely to have received risk-based, survivor-focused care. Among patients at increased risk for cardiomyopathy or breast cancer, 511 (28.2%) of 1,810 and 169 (40.8%) of 414 had undergone a recommended echocardiogram or mammogram, respectively.

Conclusion

Despite a significant risk of late effects after cancer therapy, the majority of childhood cancer survivors do not receive recommended risk-based care.

J Clin Oncol 26:4401-4409. © 2008 by American Society of Clinical Oncology

INTRODUCTION

With contemporary therapy, 80% of children diagnosed with cancer will become long-term survivors.¹ Consequently, more than 270,000 survivors of childhood cancer are alive in the United States,² many of whom are at risk of long-term morbidity^{3,4} and premature mortality^{5,6} as a result of their therapy. We have estimated that by 30 years from their cancer diagnosis, 73% will develop at least one chronic physical health condition and 42% will develop a severe, life-threatening, or disabling condition or die from a chronic condition.⁴ Compared with their siblings, survivors are 10 times more likely to develop a serious chronic disease (eg, second cancer or heart disease), and the risk of morbidity and

premature mortality does not plateau.⁴ Because the risk for many serious health problems can be reduced by prevention or early detection, the Institute of Medicine (IOM) has recommended lifelong risk-based health care for all cancer survivors.² This requires a systematic plan for periodic screening, surveillance, and prevention that is adapted to the risks arising from the previous cancer, its therapy, genetic predispositions, lifestyle behaviors, and comorbid health conditions.^{2,7} The frequency and intensity of surveillance should be adapted to each survivor's risk, with those at low risk for sequelae requiring less contact and those at significantly increased risk of morbidity or premature mortality (eg, those treated with radiation therapy or stem-cell transplantation) requiring annual monitoring.

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Submitted March 4, 2008; accepted May 22, 2008.

Supported by Grant No. U24-CA-55727 (L.L. Robison, principal investigator) from the United States Department of Health and Human Services, funding to the University of Minnesota from the Children's Cancer Research Fund, and funding to St Jude Children's Research Hospital from the American Lebanese Syrian Associated Charities.

Presented in part at the 43rd Annual Meeting of the American Society of Clinical Oncology, June 1-5, 2007, Chicago, IL.

Authors' disclosures of potential conflicts of interest and author contributions are found at the end of this article.

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0732-183X/08/2627-4401/\$20.00

DOI: 10.1200/JCO.2008.16.9607

Table 1. Characteristics of the Study Cohort and Their Self-Reported Medical Care Within the Last 2 Years

Characteristic	Full Study Cohort (N = 8,522)		% of Patients			
	No.	%	No Medical Care (n = 953)*	General Medical Care (n = 4,882)	General Survivor- Focused Care (n = 1,166)	Risk-Based Survivor-Focused Care (n = 1,521)
Sex						
Male	4,273	50.1	15.6	55.8	12.7	15.9
Female	4,249	49.9	6.7	58.8	14.7	19.8
Race/ethnicity						
White, non-Hispanic	7,368	86.5	10.6	57.6	14.1	17.8
Hispanic	135	1.6	11.1	57.0	9.6	22.2
Black	231	2.7	18.6	61.5	9.1	10.8
Other	788	9.2	14.5	53.7	12.2	19.7
Age, years						
At diagnosis						
Mean			7.5	8.1	8.3	8.8
SD			5.5	5.8	5.9	6.1
At interview						
Mean			30.9	31.8	31.4	32.2
SD			7.1	7.5	7.8	8.1
Time since diagnosis, years						
Mean			23.4	23.7	23.1	23.4
SD			4.5	4.5	4.5	4.7
Annual household income						
< \$40,000	2,643	31.0	14.5	55.7	13.9	15.9
\$40,000-\$79,000	2,721	31.9	8.6	59.4	13.5	18.5
≥ \$80,000	1,957	23.0	7.8	59.4	12.5	20.2
Unknown	1,201	14.1	15.3	52.5	15.4	16.7
Educational attainment						
< High school	376	4.4	12.2	51.9	16.8	19.2
High school graduate	4,387	51.5	14.0	55.5	14.0	16.5
College graduate	3,666	43.0	7.8	60.0	12.9	19.3
Employment status						
Unemployed	1,023	12.0	11.3	44.8	21.1	22.8
Employed, student, caring for home	7,313	85.8	11.1	59.1	12.5	17.3
Health insurance status						
No, United States	971	11.4	28.5	51.3	10.4	9.8
Yes, United States	6,918	81.2	8.8	58.5	13.8	18.8
Canadian resident	559	6.6	9.3	53.0	17.5	20.2
Care at cancer center in last 2 years						
No	7,276	85.4	NA	63.8	11.0	12.3
Yes	1,246	14.6	NA	19.5	29.5	50.4
Cancer diagnosis						
Leukemia	2,910	34.1	13.0	61.1	11.8	14.1
CNS tumor	1,076	12.6	11.2	44.5	22.4	21.9
Hodgkin's disease	1,086	12.7	7.2	48.3	15.6	29.0
Non-Hodgkin's lymphoma	628	7.4	11.2	62.9	8.6	14.7
Wilms' tumor	794	9.3	11.1	65.5	8.6	14.7
Neuroblastoma	576	6.8	12.7	62.8	9.6	14.9
Soft tissue sarcoma	750	8.8	10.4	55.3	16.5	17.7
Osteosarcoma	481	5.6	10.6	60.1	13.3	16.0
Ewing's sarcoma	221	2.6	7.7	53.4	19.5	19.5
RT						
Brain	2,604	30.6	13.1	52.7	16.1	18.1
Chest	1,562	18.3	7.7	50.0	14.5	27.7
Other	1,213	14.2	9.7	57.4	14.6	18.4
None	2,873	33.7	11.9	65.6	10.4	12.1
Unknown	270	3.2	11.1	54.8	17.0	17.0

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Table 1. Characteristics of the Study Cohort and Their Self-Reported Medical Care Within the Last 2 Years (continued)

Characteristic	Full Study Cohort (N = 8,522)		% of Patients			
	No.	%	No Medical Care (n = 953)*	General Medical Care (n = 4,882)	General Survivor- Focused Care (n = 1,166)	Risk-Based Survivor-Focused Care (n = 1,521)
Cardiotoxic therapies						
Anthracyclines, no chest RT	2,408	28.3	12.2	58.4	12.5	16.9
Chest RT, no anthracyclines	1,035	12.1	8.1	48.6	15.6	27.4
Anthracyclines + chest RT	589	6.9	7.6	51.5	12.4	28.9
No anthracyclines, no chest RT	4,490	52.7	11.8	59.5	14.0	14.7
Alkylating agent dose†						
None	1,708	20.0	12.2	65.8	10.8	11.2
First tertile	733	8.6	12.1	65.9	9.7	12.3
Second tertile	270	3.2	10.7	64.8	10.0	14.4
Third tertile	162	1.9	9.9	62.9	9.9	17.3
Poor emotional health						
No	7,829	91.9	11.4	58.0	13.2	17.4
Yes	693	8.1	9.0	49.0	19.1	22.9
Cancer-related anxiety						
None, a small amount	7,756	91.0	11.5	58.5	13.1	17.0
Moderate, a lot, extreme	766	9.0	7.6	45.6	20.1	26.8
Cancer-related pain						
None, a small amount	7,821	91.8	11.6	58.8	12.7	16.9
Moderate, a lot, extreme	701	8.2	6.6	39.9	24.5	29.0
Poor physical health						
No	6,461	75.8	11.3	59.7	12.3	16.7
Yes	2,061	24.2	10.9	49.6	18.0	21.5
Chronic disease status, grade‡						
0, 1, 2	6,415	75.3	12.0	60.3	12.1	15.6
3, 4	2,106	24.7	8.6	48.2	18.4	24.8

Abbreviations: SD, standard deviation; RT, radiation therapy.

*Percentages calculated by row.

†Limited to those who did not receive radiation.

‡Grade 0, 1, 2: either no chronic condition (grade 0) or at least one grade 1 (mild) or grade 2 (moderate) chronic condition; grade 3, 4: at least one grade 3 (severe) or grade 4 (life-threatening or disabling) chronic condition.

The purpose of this study was to characterize the patterns and predictors of health care use among a large cohort of geographically and socioeconomically diverse childhood cancer survivors. In particular, we were interested in determining the proportion of individuals who received medical care that was focused specifically on addressing and reducing the risks arising from their prior cancer therapy.

PATIENTS AND METHODS

Childhood Cancer Survivor Study

The Childhood Cancer Survivor Study (CCSS) methodology and a description of the participants have been published.⁸ Briefly, the cohort includes individuals diagnosed with cancer before age 21 years at one of 26 centers (25 centers in the United States and one in Canada) from 1970 to 1986 who were alive at least 5 years from their original diagnosis. The eligible cohort consisted of 20,720 patients; 17,703 were successfully contacted and 14,366 (81.2%) enrolled in the study. There were no significant differences between participants and nonparticipants by sex, age at diagnosis or at cohort assembly, cancer type, or treatment.^{8,9} Detailed medical information was abstracted from participants' hospital records. Participants completed a comprehensive baseline questionnaire and several subsequent questionnaires. Eligibility for this analysis was limited to participants who completed a questionnaire in 2002 to 2003 that addressed health care use and for whom information regarding treatment for their original cancer was available. Questionnaires and

data abstraction forms are available at www.stjude.org/ccss. The study was approved by the institutional review board at each participating institution, and informed consent was obtained from each participant or parent/guardian.

Health Care Use

A series of questions was constructed to characterize the medical care received by survivors and to determine whether this care focused on the previous cancer and the risk of future health problems arising from its therapy. Participants were asked whether they had visited a health care provider (physician or nurse) within the preceding 2 years, whether the visit was related to their previous cancer, and whether their health care provider had given them advice on how to reduce their risks or discussed or ordered screening tests for cancer-related sequelae. Responses to these questions were used to categorize health care into one of four mutually exclusive groups: (1) no health care, (2) general medical care (patient reported one or more medical visits, none of which was related to their previous cancer), (3) general survivor-focused care (patient reported at least one visit related to their previous cancer, but did not report receiving advice on how to reduce risks or that screening tests for cancer-related sequelae were discussed or ordered), and (4) risk-based, survivor-focused care (survivor-focused care that included advice about how to reduce risks or discussion or ordering of screening tests for cancer-related sequelae). The hierarchy was constructed to classify levels of medical care related specifically to the prior cancer and its risks and is not intended to imply a level of quality of care for health issues unrelated to the previous cancer. Each participant was classified according to the highest category of care received during the 2-year study period. The assigned level of care was independent of

who delivered the care (cancer specialist or primary care clinician) or where the care was received (cancer center or community setting). Additionally, we classified a subset of the cohort as being at high risk for developing a cardiomyopathy (survivors who had received ≥ 300 mg/m² of an anthracycline or any anthracycline dose plus chest radiation) or breast cancer (females who had received radiation to the chest and who were ≥ 27 years old), two late effects for which there is general consensus concerning the need for regular surveillance with an echocardiogram or mammogram, respectively.¹⁰⁻¹²

Predictors of Health Care Use

Demographic and treatment information. Demographic data were obtained on the baseline questionnaire. Sociodemographic status (household income, health insurance, education, and employment status) was assessed in the 2002 to 2003 questionnaire. Disease and treatment variables were abstracted from medical records.

Chronic medical conditions and health status. We evaluated the association between health status, chronic medical conditions, and health care use. The severity of chronic health conditions reported on the baseline questionnaire was classified as (1) mild, (2) moderate, (3) severe, or (4) life-threatening or disabling, using the National Cancer Institute's Common Terminology Criteria for Adverse Events (version 3), as published previously.⁴ Health status was measured on the 2002 to 2003 questionnaire using a previously defined set of domains (emotional health,^{13,14} physical functioning,¹⁵ cancer-related pain, and cancer-related anxiety and fears¹⁴).

Statistical Analysis

Descriptive statistics were calculated for each of the sociodemographic, treatment, and health status variables. The probability of reporting a particular level of care, adjusted for age at interview and sex, was calculated by diagnosis using a generalized logit model, treating levels of care as nominal response variables.¹⁶ The relative odds of receiving no medical care versus any medical care, of receiving general medical care versus risk-based and survivor-focused care, and of not having either a mammogram or an echocardiogram, if indicated, were calculated in separate multivariable logistic regression models. A model was generated that included sociodemographic, health status, and chronic disease variables as predictors of the health care outcome, and a separate model was generated that included therapeutic exposures as predictors. Models evaluating the impact of therapeutic exposure were adjusted for age at diagnosis, age at interview, and sex. The frequency and percentage of those receiving either a mammogram or echocardiogram (if indicated)

were evaluated by level of care using a contingency table and compared with χ^2 statistics.

RESULTS

Characteristics of the Study Cohort

Of the 14,366 survivors who were enrolled in the CCSS, 1,773 did not have medical records available, 1,017 were dead at the time of the baseline assessment and had their questionnaire completed by a proxy respondent, and 462 died before the mailing out of the 2002 to 2003 questionnaire. Thus 11,114 survivors were eligible for this study of health care use. Of these, 1,919 (17.3%) were nonrespondents and 673 (6.1%) were lost to follow-up, resulting in 8,522 (76.7%) survivors being available for this analysis. The 8,522 participants did not differ from the 2,592 eligible nonparticipants by diagnosis, therapy, or current age, but were more likely to be female (79.8% of eligible females v 73.9% of eligible males; $P < .001$) and older when diagnosed with their original cancer (mean age, 8.2 v 7.5 years; $P = .006$). Demographic, treatment, and health status characteristics of the participants are presented in Table 1.

Health Care Use

During the 2-year study period, 953 survivors (11.2%) reported receiving no medical care, 4,882 survivors (57.3%) reported receiving general medical care, 1,166 survivors (13.7%) reported receiving general survivor-focused care, and 1,521 survivors (17.8%) reported receiving risk-based, survivor-focused care. Table 1 lists the percentage of survivors who reported each level of care by demographic, treatment, and health status variables. Only 1,246 patients (14.6%) received care at a cancer center. The probability of receiving a particular level of care according to cancer diagnosis is shown in Figure 1. General survivor-focused or risk-based survivor-focused care was most likely among survivors of CNS tumors. Survivors of neuroblastoma were most likely to have received no medical care.

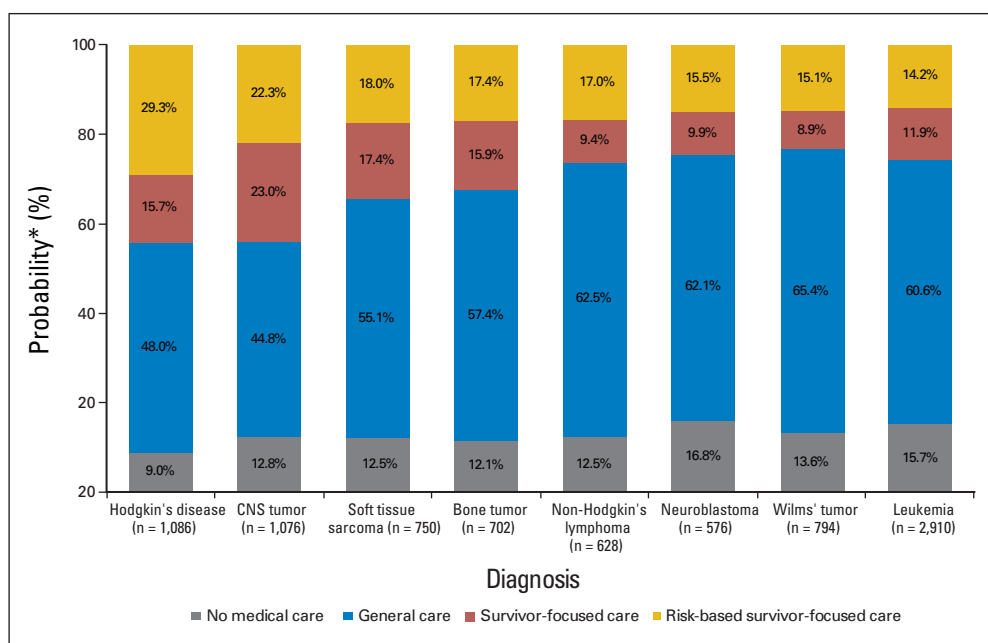


Fig 1. Probability of reporting a particular level of medical care according to initial cancer diagnosis. (*) Probabilities adjusted for sex, age at diagnosis, and age at time of interview using a generalized logit model.

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The relationship between demographic and health status variables and the odds of having received no medical care is summarized in Table 2. Male survivors, uninsured survivors, and those with a household income less than \$40,000/year were more likely to report no medical visits. In contrast, survivors who reported moderate to extreme cancer-related pain were more likely to have received care, as were those with a severe, life-threatening, or disabling chronic health condition. Age at diagnosis and at interview were not associated with having received medical care.

Additionally, Table 2 presents predictors of reporting general medical care rather than risk-based, survivor-focused care among survivors who reported some form of care (n = 7,569). Survivors who were older, male, black, or uninsured were more likely to report general care rather than risk-based, survivor-focused care. In contrast, survivors who reported moderate to extreme cancer-related pain or anxiety, poor physical health, or more serious morbidity were more likely to report risk-based, survivor-focused care. Among survivors who received some form of survivor-focused care, only the location of

Table 2. Relative Odds of Receiving No Medical Care Versus Any Care and of Receiving General Care Versus Risk-Based, Survivor-Focused Care by Demographic and Outcome Variables

Variable	No Medical Care (n = 953) v Any Care (n = 7,569)*		General Care (n = 4,882) v Risk-Based, Survivor-Focused Care (n = 1,521)*	
	OR†	95% CI	OR†	95% CI
Sex				
Male	2.5	2.2 to 2.9‡	1.1	1.0 to 1.3
Female (referent)	1.0		1.0	
Race/ethnicity				
White, non-Hispanic (referent)	1.0		1.0	
Hispanic	1.0	0.6 to 1.8	0.8	0.5 to 1.3
Black	1.4	0.9 to 2.0	2.1	1.3 to 3.3‡
Other	1.2	1.0 to 1.5‡	0.8	0.7 to 1.0‡
Age, years				
At diagnosis	0.99	0.97 to 1.01	0.97	0.95 to 0.98‡
At interview	1.01	0.99 to 1.03	1.03	1.02 to 1.04‡
Annual household income				
< \$40,000	1.4	1.2 to 1.8‡	1.1	1.0 to 1.4
\$40,000-\$79,000	1.0	0.8 to 1.2	1.1	0.9 to 1.2
≥ \$80,000 (referent)	1.0		1.0	
Unknown	1.6	1.2 to 2.1‡	1.0	0.8 to 1.3
Educational attainment				
< High school	1.0	0.7 to 1.5	1.0	0.8 to 1.4
High school graduate	1.5	1.3 to 1.8‡	1.1	1.0 to 1.2
College graduate (referent)	1.0		1.0	
Employment status				
Unemployed	0.9	0.7 to 1.1	0.7	0.6 to 0.8‡
Employed§ (referent)	1.0		1.0	
Health insurance status				
No, United States	3.4	2.8 to 4.0‡	1.7	1.3 to 2.2‡
Yes, United States (referent)	1.0		1.0	
Canadian resident	1.1	0.8 to 1.4	0.8	0.6 to 1.0‡
Poor emotional health				
No (referent)	1.0		1.0	
Yes	0.8	0.6 to 1.1	1.0	0.8 to 1.2
Cancer-related anxiety				
None, a small amount (referent)	1.0		1.0	
Moderate, a lot, extreme	0.8	0.6 to 1.1	0.6	0.5 to 0.8‡
Cancer-related pain				
None, a small amount (referent)	1.0		1.0	
Moderate, a lot, extreme	0.6	0.4 to 0.8‡	0.5	0.4 to 0.6‡
Poor physical health				
No (referent)	1.0		1.0	
Yes	0.9	0.7 to 1.1	0.7	0.6 to 0.8‡
Chronic disease status, grade				
0, 1, 2 (referent)	1.0		1.0	
3, 4	0.8	0.7 to 1.0‡	0.6	0.5 to 0.7‡

Abbreviation: OR, odds ratio.

*Adjusted for all other variables in the model.

†OR > 1 represents increased odds of receiving lower level of medical care.

‡Significant at P < .05.

§Employed, student, or caring for home.

Table 3. Comparison of Medical Care According to Chemotherapy or Radiation Exposure During Cancer Treatment

Variable	No Medical Care (n = 953) v Any Care (n = 7,569)*		General Care (n = 4,882) v Risk-Based, Survivor-Focused Care (n = 1,521)*	
	OR†	95% CI	OR†	95% CI
RT				
Brain	1.1	0.9 to 1.3	0.5	0.4 to 0.6‡
Chest	0.7	0.5 to 0.8‡	0.3	0.2 to 0.4‡
Other	0.8	0.6 to 1.0	0.5	0.4 to 0.6‡
None	1.0		1.0	
Unknown	0.9	0.6 to 1.3	0.5	0.4 to 0.8‡
Cardiotoxic therapies				
Anthracyclines, no chest RT	1.0	0.9 to 1.2	0.9	0.8 to 1.1
Chest RT, no anthracyclines	0.8	0.6 to 0.9‡	0.4	0.3 to 0.6‡
Anthracyclines + chest RT	0.6	0.5 to 0.9‡	0.5	0.4 to 0.6‡
No anthracyclines, no chest RT (referent)	1.0		1.0	
Alkylating agent therapy doses				
None (referent)	1.0		1.0	
First tertile	0.9	0.7 to 1.3	1.0	0.7 to 1.3
Second tertile	0.9	0.6 to 1.3	0.8	0.5 to 1.1
Third tertile	0.7	0.4 to 1.3	0.6	0.4 to 0.9‡

Abbreviations: OR, odds ratio; RT, radiation therapy.

*Adjusted for sex, age at diagnosis, and age at time of interview.

†OR > 1 represents increased odds of receiving lower level of care.

‡Significant at $P < .05$.

§Limited to those who did not receive radiation.

care (cancer center v other location; odds ratio = 1.52, 95% CI, 1.29 to 1.80) and “other” race (v white race; odds ratio = 1.38, 95% CI, 1.05 to 1.84) influenced whether this care was risk-based.

The relationship between therapeutic exposures associated with an increased risk of late effects and the level of care is summarized in Table 3. Patients treated with an alkylating agent or anthracycline (without chest radiation), two therapies that are strongly associated with long-term morbidity, were no more likely to report receiving any health care rather than no health care. Similarly, survivors who received an anthracycline (without chest radiation) were no more likely to receive risk-based, survivor-focused care than general care, although risk-based, survivor-focused care was more likely in survivors who received the highest tertile of alkylating agent dosing. In contrast, all survivors treated with radiation therapy were more likely to report risk-based, survivor-focused care.

An echocardiogram was indicated in 1,810 survivors and a mammogram was indicated in 414 women based on their high risk for developing a cardiomyopathy or breast cancer, respectively. However, only 511 (28.2%) of 1,810 survivors at risk for cardiomyopathy reported an echocardiogram. For women treated with chest radiation who were 27 years or older at the time of the 2002 to 2003 questionnaire and were younger than the age at which routine screening mammography is recommended for the general population (United States, age 40 years; Canada, age 50 years), 169 (40.8%) of 414 survivors reported receiving a mammogram. Survivors who were uninsured, Canadian, or not seen at a cancer center were more likely to not report an indicated echocardiogram, whereas those who had moderate to extreme anxiety after their cancer were more likely to have received an echocardiogram (Table 4). Only care outside of a cancer center was associated with not having received an indicated mammogram. Survivors who received care in a cancer center were more likely than those

who received their care elsewhere to report an indicated echocardiogram (53.2% v 22.3%) or mammogram (62.4% v 34.6%).

DISCUSSION

Only 17.8% of this cohort of 8,522 long-term survivors of childhood cancer reported a medical visit within the previous 2 years during which their health care provider specifically addressed the risks arising from their therapy. This low prevalence of risk-based care falls far below the goals advocated by the IOM.² Strikingly, 88.8% of survivors had at least one medical visit during the study period, reflecting that access to medical care was not a barrier for most. Rather, the care that they received did not focus on their specific risks and strategies to ameliorate them. Fewer than 15% of survivors received medical care at a cancer center; most received their care from a primary care clinician in a community setting. However, survivors cared for in the community were less likely to report risk-based, survivor-focused care or to have received indicated echocardiography or mammography. Because more than 70% of survivors will develop one or more chronic conditions related to their prior therapy,^{3,4} this low rate of risk-based, survivor-focused care suggests multiple lost opportunities to prevent or expeditiously detect and treat these sequelae. Thus efforts must be focused on providing primary care clinicians with the education and resources needed to provide risk-based care to this group of patients.¹⁷

Previous studies have shown that key barriers to appropriate survivor care include a lack of patient and physician knowledge about the long-term risks of cancer therapy.^{18,19} Survivors are often unaware of the details of their cancer therapy, preventing them from seeking care focused on specific risks. One study has reported that among

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Table 4. Relative Odds of Not Receiving Indicated Echocardiogram or Mammogram by Demographic and Outcome Variables

Variable	Did Not Receive Indicated Echocardiogram* (n = 1,299 of 1,810)		Did Not Receive Indicated Mammogram* (n = 245 of 414)	
	OR	95% CI	OR	95% CI
Care category				
No medical care	NA	NA	7.8	1.4 to 43.0†
General medical care	3.9	3.0 to 5.0†	2.5	1.5 to 4.2†
General survivor-focused care	2.1	1.5 to 3.0†	1.6	0.8 to 3.0
Risk-based survivor-focused care (referent)	1.0		1.0	
Sex				
Male	1.0	0.8 to 1.2	NA	NA
Female (referent)	1.0			
Race/ethnicity				
White, non-Hispanic (referent)	1.0		1.0	
Hispanic	0.6	0.3 to 1.2	0.3	0.1 to 1.5
Black	0.9	0.5 to 1.6	0.2	0.1 to 1.0
Other	1.1	0.7 to 1.6	2.2	0.9 to 5.4
Age, years				
At diagnosis (per each year)	1.02	0.98 to 1.05	0.99	0.94 to 1.04
At interview (per each year)	1.00	0.98 to 1.03	0.88	0.81 to 0.95†
Annual household income				
< \$40,000	1.5	1.1 to 2.1†	1.4	0.7 to 2.6
\$40,000-\$79,000	1.2	0.9 to 1.6	1.1	0.7 to 2.0
≥ \$80,000 (referent)	1.0		1.0	
Unknown	1.1	0.7 to 1.6	0.4	0.1 to 1.3
Educational attainment				
< High school	1.2	0.6 to 2.4	3.7	0.3 to 42.6
High school graduate	1.1	0.8 to 1.3	1.1	0.7 to 1.7
College graduate (referent)	1.0		1.0	
Employment status				
Unemployed	0.7	0.5 to 1.1	1.0	0.4 to 2.3
Employed‡ (referent)	1.0		1.0	
Health insurance status				
No, United States	2.0	1.2 to 3.2†	1.5	0.6 to 4.1
Yes, United States (referent)	1.0		1.0	
Canadian resident	1.7	1.1 to 2.8†	1.1	0.5 to 2.7
Poor emotional health				
No (referent)	1.0		1.0	
Yes	1.0	0.6 to 1.6	0.9	0.4 to 1.9
Cancer-related anxiety				
None, a small amount (referent)	1.0		1.0	
Moderate, a lot, extreme	0.6	0.4 to 0.9†	0.7	0.4 to 1.4
Cancer-related pain				
None, a small amount (referent)	1.0		1.0	
Moderate, a lot, extreme	0.9	0.6 to 1.3	1.3	0.6 to 2.8
Poor physical health				
No (referent)	1.0		1.0	
Yes	0.9	0.7 to 1.2	1.2	0.7 to 2.2
Chronic disease status, grade				
0, 1, 2 (referent)	1.0		1.0	
3, 4	0.8	0.7 to 1.1	1.2	0.7 to 1.9

Abbreviations: OR, odds ratio; NA, not applicable.

*Adjusted for all other variables in the model.

†Significant at $P < .05$.

‡Employed, student, or caring for home.

exposed survivors, fewer than one third recalled receiving anthracycline chemotherapy, which is associated with a risk of late cardiac toxicity.^{20,21} Similar knowledge deficits are likely in our study, as survivors who received anthracyclines were no more likely to get care than those who had not received anthracyclines. Only survi-

vors who had received chest radiation were more likely to receive such care, suggesting that care-seeking behavior among those at risk for cardiac disease is influenced by radiation exposure, but not anthracycline therapy. This observation is particularly concerning given that approximately half of children treated for cancer will

receive anthracycline chemotherapy. Similarly, survivors treated with low or moderate doses of alkylating agents, which have been associated with secondary leukemias²² and infertility,²³⁻²⁵ were no more likely to receive care than those not treated with these drugs.

Forty-one percent of females at increased risk for breast cancer reported a mammogram within the prior 2 years, despite evidence that by 45 years of age, 20% of women treated with chest radiation as children will develop breast cancer.²⁶ Only 28% of survivors at risk for a cardiomyopathy reported an echocardiogram. Self-report of mammography has been demonstrated to be valid in several studies, with 81% to 97% congruence between patient self-report and medical record audits.²⁷⁻³⁰ There are no published data on the validity of self-report of echocardiograms. Although patients who received their care at a cancer center had higher rates of appropriate surveillance, many patients treated at these specialized centers did not undergo the recommended tests. Whether the failure to perform a recommended echocardiogram in 47% and a mammogram in 38% of patients seen at a cancer center was due to lack of insurance coverage, inadequate physician knowledge, or an active decision not to heed the guidelines cannot be deduced from this study. The provision of a comprehensive survivorship care plan to all survivors, as recommended by the IOM,²⁷ may increase the number of survivors who receive recommended surveillance tests such as echocardiography or breast imaging.

As noted in studies of health care use in other diseases, male patients, the uninsured, and those with lower household incomes³¹ are particularly vulnerable, because they are at greater risk of receiving no medical care at all. Almost 30% of uninsured survivors had not received medical care in the previous 2 years, compared with 10% of insured survivors. In comparison, in a study of 1,718 survivors of adult cancer that used data from the National Health Interview Survey (1998 and 2000 surveys), 45.1% of uninsured survivors reported not getting needed medical care within the preceding year because of concerns about the cost of that care; in contrast, 16.7% of publicly insured and 4.4% of privately insured survivors did not receive needed care.³² Among survivors in our study who reported some form of care, those who had developed sequelae of their prior therapy (such as pain, anxiety, poorer physical health, or a severe chronic physical condition) were more likely to report a visit related to their previous malignancy, suggesting that these individuals may have been seeking care for extant symptoms. However, because the incidence of serious chronic health conditions increases as survivors age,^{3,4} even survivors who have not developed late effects may benefit from care focused on prevention and early detection.¹⁷

Several methodologic limitations should be considered when interpreting the results. First, data were obtained from self-reports. We cannot examine whether survivors' impressions about the purpose and content of their medical visit was concordant with their

caregivers' intentions. Second, the results are derived from 8,522 of 11,114 eligible survivors. This potential for selection bias is compounded by the observation that CCSS participants are a select group of survivors, likely better educated about the potential late effects of their cancer therapy than nonparticipants. Thus this study likely overestimates the proportion of survivors who receive appropriate care, and the poor compliance with recommended care demonstrated here is probably a best-case scenario. Third, this cohort of survivors received their therapy from 1970 to 1986. Caution should be exercised in generalizing to patients treated more recently. It is plausible that patients treated in the current era are better informed about the long-term risks of their therapy. The CCSS is currently recruiting a cohort of survivors treated from 1987 to 1999 to examine such questions.

In summary, despite a significant risk of late effects after cancer therapy, the majority of adult survivors of childhood cancer do not receive regular medical care focused on their long-term risks. Only a minority of survivors at the highest risk for developing cardiac dysfunction or breast cancer receive recommended surveillance tests. The majority of survivors receive medical care in a community setting where, they are less likely to receive risk-based care or recommended screening tests. Given the rapidly expanding population of childhood cancer survivors, it is imperative that efforts be focused on educating both survivors and the health care providers who will care for them as adults about the importance of regular, risk-based medical care.

AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

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

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Appendix

The Appendix is included in the full-text version of this article, available online at www.jco.org. It is not included in the PDF version (via Adobe® Reader®).