



Barriers and Facilitators of Risk-Based Health Care for Adult Survivors of Childhood Cancer: A Report From the Childhood Cancer Survivor Study

Jennifer S. Ford, PhD ¹; Emily S. Tonorezos, MD, MPH ²; Ann C. Mertens, PhD³; Melissa M. Hudson, MD⁴; Jacqueline Casillas, MD, MPH⁵; Barbara M. Foster, PhD⁶; Chaya S. Moskowitz, PhD²; Stephanie M. Smith, MD, MPH⁷; Joanne F. Chou, MPH²; George Buchanan, MD⁸; Leslie L. Robison, PhD⁴; and Kevin C. Oeffinger, MD⁹

BACKGROUND: Optimal risk-based survivor health care includes surveillance for late effects and education targeted at reducing or preventing risky health behaviors. Understanding the reasons for a lack of risk-based follow-up care is essential. **METHODS:** Adult participants from the Childhood Cancer Survivor Study were surveyed about having a cancer-related visit in the past 2 years and the likelihood of having a cancer-related visit in the future. Additional factors thought to be related to the primary outcomes were also assessed. **RESULTS:** Nine hundred seventy-five survivors completed the survey. Twenty-seven percent (95% confidence interval [CI], 24%-30%) had a cancer-related medical visit in the previous 2 years, and 41% (95% CI, 38%-44%) planned to have such a visit within the next 2 years. The likelihood of having had a cancer-related visit within the last 2 years was higher among survivors assigning greater importance to these visits (relative risk [RR], 1.2; 95% CI, 1.1-1.3), perceiving greater susceptibility to health problems (RR, 1.2; 95% CI, 1.1-1.3), having a moderate to life-threatening chronic health problem related to their cancer (RR, 2.1; 95% CI, 1.7-2.7), seeing a primary care provider for a cancer-related problem (RR, 1.3; 95% CI, 1.0-1.6), having a cancer treatment summary (RR, 1.3; 95% CI, 1.0-1.6), and endorsing greater confidence in physicians' abilities to address questions and concerns (RR, 1.2; 95% CI, 1.0-1.3). **CONCLUSIONS:** Educational interventions improving awareness of treatment history and susceptibility to cancer-related late effects and corresponding risk-based care are likely to be beneficial for survivors of childhood cancers. *Cancer* 2019;0:1-9. © 2019 American Cancer Society.

KEYWORDS: barriers, cancer survivor, childhood cancer, risk-based care.

INTRODUCTION

Improvements in cancer treatment have led to increases in the childhood cancer survivor population.¹ Many survivors are at risk for serious late effects from their cancer treatment, including second cancers, cardiovascular disease, and respiratory problems.²⁻⁴ Optimum survivor health care includes a risk-based strategy of screening and management for late effects.⁵ Ideally, monitoring is combined with education targeted at reducing or preventing behaviors that may contribute to risk.⁶

The Institute of Medicine has delineated follow-up recommendations^{7,8} that specify the need for lifelong risk-based health care and integrate the cancer and survivorship experience with individuals' overall health needs. The incidence and severity of many late effects can be substantially reduced through prevention and early detection.^{9,10} Because potential cancer-related health complications are associated with decreased quality of life and early mortality, survivorship-focused care can have an important impact on survivors.

Childhood cancer survivors have unique health care needs that are not being met because few receive appropriate risk-based care.¹¹⁻¹³ Multiple studies have demonstrated that survivors do not know the relevant details of their cancer treatment, understand the risks that they face, or present for appropriate surveillance.^{11,14-16}

In the general population, barriers such as distance to the provider, insurance status, comorbidities, and psychosocial factors (eg, perceived susceptibility to health problems) are related to health care utilization.¹⁷⁻¹⁹ However, targetable barriers for childhood cancer survivors have been understudied. Therefore, we surveyed adult survivors of childhood cancer to identify factors associated with inadequate risk-based follow-up care.

Corresponding author: Jennifer S. Ford, PhD, Department of Psychology, Hunter College, City University of New York, 695 Park Avenue, HN-611, New York, NY 10065; jennifer.ford@hunter.cuny.edu

¹Hunter College and Graduate Center, City University of New York, New York, New York; ²Memorial Sloan Kettering Cancer Center, New York, New York; ³Emory University School of Medicine, Atlanta, Georgia; ⁴St Jude Children's Research Hospital, Memphis, Tennessee; ⁵University of California Los Angeles School of Medicine, Los Angeles, California; ⁶American Board of Obstetrics and Gynecology, Dallas, Texas; ⁷Stanford University School of Medicine, Palo Alto, California; ⁸University of Texas Southwestern Medical Center, Dallas, Texas; ⁹Duke University, Durham, North Carolina

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MATERIALS AND METHODS

Participants

Participants were from the Childhood Cancer Survivor Study (CCSS), a multi-institutional, retrospectively ascertained, prospectively followed cohort study. Participants had survived 5 or more years after treatment for childhood cancer and met the following eligibility criteria: 1) diagnosis of leukemia, brain cancer, Hodgkin lymphoma, non-Hodgkin lymphoma, kidney cancer, neuroblastoma, soft-tissue sarcoma, or malignancy of the bone; 2) diagnosis and initial treatment at a collaborating CCSS institution; 3) diagnosis date between 1970 and 1986; and 4) age <21 years at diagnosis. Detailed descriptions of the methodology and cohort characteristics have been reported previously.^{20,21} For this ancillary study, a randomly selected subset of 1600 survivors from the CCSS, oversampling ethnic and racial minorities, from 10 geographically diverse CCSS institutions in the United States were eligible for participation. The study was approved by the institutional review board at each participating institution, and informed consent was obtained from participants.

Measures

The survey was an 82-item, self-administered questionnaire based on 3 health behavior theories: the Health Belief Model, the Multidimensional Health Locus of Control, and the Behavioral Model of Health Utilization.²²⁻³⁰ A 4-step iterative process was used to develop the questionnaire; items were generated, reduced, refined, and edited for clarity. It was piloted among non-CCSS survivors of childhood cancer.

Age at cancer diagnosis, diagnosis, time since diagnosis, and cancer therapy information were obtained through a chart review. The final survey assessed sociodemographics, cancer-related variables, and the primary outcomes: having a cancer-related visit in the past 2 years and the likelihood of having a cancer-related visit in the future. Health care utilization was assessed by several questions about medical professionals seen over the prior 2-year period. Health care motivation was assessed by questions about their interest in going to a physician for a routine medical checkup and the importance of having routine checkups. For the influence of survivorship media, there were 6 questions assessing participants' exposure to media (eg, newspapers and television programs) describing potential long-term health problems of childhood cancer survivors and whether such media exposures motivated going for a checkup. Questions assessing beliefs about health and

health care, including whether they believed a cancer-related health problem was likely and whether they had confidence in their physicians, were also asked.

Two items focused on chronic health problems. We asked, "Do you have any chronic health problems (that have lasted longer than six months) related to your cancer or cancer treatment?" Those who responded *yes* were asked to rate their main health problem as mild, moderate, severe, or life-threatening and were provided descriptive anchors for the responses.

Health concerns/worries were calculated as a composite from several items assessing concerns about health and getting sick, uncertainty about future health, worry about cancer recurrence, worry about health problems being discovered in routine checkups, feeling different from others because of cancer, wanting to forget about cancer, and worry about being labeled as a complainer or hypochondriac.

Health locus of control was measured with the Multidimensional Health Locus of Control scale,²⁶ which assessed the degree to which survivors believed that they could control what would happen to them. Three types reflected the sources of motivation for health-related behaviors: internal motivation, a matter of chance, and motivation due to the control/influence of powerful others.²⁶

Assessed health care barriers included difficulties in finding a physician, transportation, health insurance, communication with a physician, and painful memories of cancer. The Health Care Needs Survey can be downloaded at https://ccss.stjude.org/content/dam/en_US/shared/ccss/documents/survey/survey-health-care-needs.pdf.

Outcomes

The primary outcomes for this study were having a cancer-related visit in the past 2 years and the likelihood of having a cancer-related visit in the next 2 years. The overall medical care of participants has been reported elsewhere.³¹ To assess primary outcomes, participants were asked whether they had a medical visit in the previous 2 years that was related to their cancer (yes or no) and what the likelihood was of their going to a physician to check for health problems related to their cancer in the next 2 years (on a 5-point Likert scale ranging from "very likely" to "very unlikely"). Secondary outcomes included any care at a cancer center or with a primary care physician (PCP).

Statistical Analyses

Because of oversampling of racial/ethnic minorities, all statistical models were constructed with weighted percentages and means. The sampling weights consisted of 2 components: a base weight and a nonresponse adjustment

factor. The base weight was adjusted for the unequal probability of selection in this study due to the oversampling of minorities. Thus, the base weight was calculated separately for minorities and non-Hispanic whites as the inverse of the probability of selection into this study. The nonresponse adjustment factor was included to reduce nonresponse bias. In a response propensity modeling analysis,³² logistic regression was used to model the probability of participation as a function of sex, race/ethnicity, and highest attained education level. The inverse of the probability of participation was taken as the nonresponse adjustment factor. The final weight was the product of the base weight and the nonresponse adjustment factor.

Independent variables in the models included the following: sex, age at the time of the survey, age at diagnosis, interval from diagnosis to the time of the survey, race/ethnicity, educational attainment, cancer type, cancer therapy, and presence or absence of chronic medical conditions.

To assess the relationship between the independent variables and the primary outcomes, Poisson regression with robust variance estimates was used.^{33,34} The Poisson regression models provided estimates of the relative risks and their corresponding 95% confidence intervals (CIs). For both outcomes, separate multivariable models assessed variables that were potentially associated with the outcomes at the univariate level.

All statistical analyses were performed with SAS 9.1 (SAS Institute, Inc, Cary, North Carolina) with 2-sided statistical inferences and a significance level of $P \leq .05$. SAS procedures SURVEYFREQ and SURVEYMEANS were used to compute percentages, means, and variances. Both procedures use Taylor expansions to estimate sampling errors of the estimators.^{35,36}

RESULTS

Of the 1600 eligible survivors contacted, 975 (60.9%) completed the survey. Participants were more likely than nonparticipants to be older at time of the study (30.7 vs 29.8 years; $P = .01$), be older at diagnosis (9.1 vs 7.9 years; $P < .001$), be female (53% vs 41%; $P < .001$), be white and non-Hispanic (75% vs 63%; $P < .001$), have at least a high school education (57% vs 44%; $P < .001$), and have health insurance (88% vs 81%; $P < .001$).

Approximately half the participants were female, and 52% were younger than 30 years old (Table 1). Nineteen percent were minorities, 13% had no health insurance, and 47% were not educated beyond high school. The median interval from the cancer diagnosis was 20.8 years

TABLE 1. Characteristics of the Participants (n = 975)

Characteristic	%	95% CI
Current age		
17-19 y	4.6	3.2-6.0
20-29 y	47.6	44.4-50.9
30-39 y	35.3	32.2-38.3
40-52 y	12.5	10.4-14.6
Race/ethnicity		
White, non-Hispanic	80.9	78.7-83.1
Minorities	19.1	16.9-21.3
Health insurance		
Yes	86.9	84.7-89.2
No	13.1	10.8-15.3
PCP ^a		
Yes	87.2	84.9-89.4
No	12.8	10.6-15.1
Education		
≤High school graduate	47.4	44.2-50.7
Some college or vocational training	29.7	26.8-32.7
College graduate	22.9	20.3-25.4
Cancer diagnosis		
Leukemia	35.3	32.2-38.4
Central nervous system	9.1	7.2-10.9
Hodgkin lymphoma	15.3	13.0-17.5
Non-Hodgkin lymphoma	10.1	8.2-12.1
Neuroblastoma	4.1	2.8-5.4
Wilms tumor	8.9	7.0-10.7
Soft-tissue sarcoma	8.5	6.7-10.3
Bone cancer	8.8	7.0-10.6
Age at cancer diagnosis		
0-9 y	58.2	55.1-61.4
10-20 y	41.8	38.6-44.9
Interval from diagnosis to survey		
10-14 y	2.3	1.3-3.3
15-19 y	40.7	37.5-43.9
20-24 y	33.3	30.2-36.3
≥25 y	23.7	21.0-26.4
Cancer therapy		
Chemotherapy		
Any	76.5	73.8-79.3
Alkylating agents, moderate/high dose	9.5	7.6-11.3
Anthracyclines ≥300 mg/m ²	11.5	9.4-13.5
Radiation therapy		
Any	62.6	59.4-65.7
Cranial	26.2	23.3-29.0
Chest	17.7	15.2-20.1

Abbreviations: CI, confidence interval; PCP, primary care physician.

Percentages and 95% CIs have been adjusted for sampling weights and calculated with respect to the weighted total (n = 4903: 2343 females and 2560 males).

^aPCP or nonemergency medical care.

(range, 14.3-32.4 years); nearly one-quarter had survived at least 25 years.

Nearly three-quarters of the participants reported seeing a health care professional within the previous 2 years (Table 2). However, only 27.3% (95% CI, 24.4%-30.2%) reported a medical visit related to their previous cancer or treatment, and 40.7% (95% CI, 37.5%-43.9%) planned to have a visit within the next 2 years. Survivors were disconnected from the cancer center where they were treated: 30.6% (95% CI, 27.6%-33.6%) had a cancer center visit in the past 4 years, and 41% (95% CI,

TABLE 2. Cancer-Related Health Care Practices (n = 975)

	%	95% CI
Cancer-related medical visit		
Within last 2 y	27.3	24.4-30.2
Planned in next 2 y	40.7	37.5-43.9
Health care within last 2 y		
Any medical visit	74.0	71.1-76.8
PCP	59.5	56.3-62.6
OB/gynecologist	15.7	13.4-17.9
Cancer center or oncologist	10.3	8.3-12.2
Other specialist	10.3	8.3-12.2
Emergency room	16.7	14.2-19.1
Hospitalization	14.8	12.6-17.1
Primary care		
Seen PCP since finishing treatment ^a	33.1	30.1-36.2
PCP can handle cancer-related problems ^b	35.4	32.2-38.5
Cancer care		
Cancer center visit within last 4 y	30.6	27.6-33.6
Live >200 miles from cancer center	41	38.2-44.6
Have cancer treatment summary	17.9	15.4-20.3
Chronic health problem related to cancer		
None	71.8	68.9-74.7
Mild	7.9	6.2-9.7
Moderate	15.2	12.9-17.5
Severe/life-threatening	5.0	3.6-6.4

Abbreviations: CI, confidence interval; OB, obstetrician; PCP, primary care physician.

Percentages and 95% CIs have been adjusted for sampling weights and calculated with respect to the weighted totals (n = 4903: 2343 females and 2560 males).

^aFor a problem thought to be related to the previous cancer.

^bVery often or almost always.

38.2%-44.6%) lived more than 200 miles away. Fewer than 1 in 5 survivors 17.9% (95% CI, 15.4%-20.3%) had received a cancer treatment summary.

Most survivors (87.2%; 95% CI, 84.9%-89.4%) had a PCP, but only one-third (33.1%; 95% CI, 30.1%-36.2%) had seen this physician for a cancer-related problem since they had finished their treatment. A similarly low percentage (35.4%; 95% CI, 32.2%-38.5%) thought that their PCP could "very often or almost always" handle a cancer-related problem.

Approximately 20% of the survivors reported having a moderate (15.2%; 95% CI, 12.9%-17.5%) or severe/life-threatening chronic health problem (5.0%; 95% CI, 3.6%-6.4%) related to their cancer or treatment (Table 2). In this subgroup, 47% reported having a cancer-related medical visit within the previous 2 years and intended to have another within the next 2 years. In the entire cohort, 19% reported a prior visit and planned another, whereas 51% did not have a cancer-related medical visit within the last 2 years and did not plan to have one within the next 2 years.

Survivors' perspectives of health care are presented in Table 3. Overall, survivors expressed moderate interest in

TABLE 3. Health Care Perspectives (n = 975)

	Mean	95% CI
Health care motivation		
Interest in routine medical visit	3.3	3.2-3.4
Importance of cancer-related visit	3.4	3.4-3.5
Beliefs about health and health care		
Cancer-related health problem likely	2.9	2.8-3.0
Health concerns and worries ^a	2.7	2.6-2.7
Confidence in doctors ^b	3.7	3.6-3.8
Health locus of control		
Internal	24.9	24.6-25.2
Chance	17.2	16.8-17.5
Powerful others	17.8	17.4-18.2
Influence of survivorship media ^c	2.0	1.9-2.1
Health care barriers		
Difficulty finding a doctor	2.0	1.9-2.1
Transportation problems	1.3	1.3-1.4
Health insurance problems	2.2	2.1-2.3
Doctors too rushed for questions	3.4	3.3-3.4
Painful memory of cancer treatment	3.5	3.4-3.6

Abbreviation: CI, confidence interval.

Means and 95% confidence intervals have been adjusted for sampling weights and calculated with respect to the weighted total (n = 4903); means are on a scale of 1 to 5 except for health locus of control (scale, 6-36).

^aHealth concerns and worries includes the following: concerned about health, concerned about getting sick, having uncertainty about future health, worrying about recurrence, worrying that health problems will be discovered at a routine checkup, feeling different from others because of cancer, wanting to forget cancer and be like everyone else, and worrying about being called a complainer/hypochondriac.

^bConfidence in doctors includes the following: the patient can ask the doctor questions about cancer, and cancer-related concerns have been addressed by doctors/nurses.

^cInterest in a checkup increased after survivorship-related media were seen; this was limited to those seeing survivorship-related media within the last 2 years.

routine medical visits and the importance of cancer-related medical visits; both were greater among females (Table 3). In the univariate analysis, a variety of health care practices and beliefs were associated with having a cancer-related medical visit within the last 2 years (Table 4) and planning a visit within the next 2 years (Table 5). Having a PCP, having a cancer center visit in the past 4 years, having a treatment summary, having a moderate/life threatening chronic condition, believing that cancer problems were likely, and having health concerns were each significantly related to having a cancer-related visit within the past 2 years and planning a visit in the next 2 years.

In the multivariable analysis (Table 6), the likelihood of having a cancer-related visit within the last 2 years increased among survivors who assigned greater importance to visits and perceived greater susceptibility to cancer-related health problems. Those who reported a chronic, moderate/life-threatening cancer-related health problem were twice as likely as those who reported no/mild problems to have a cancer-related visit within the last 2 years. Additional related factors included the following: seeing a PCP for a cancer-related problem, having

TABLE 4. Factors Associated With Reporting a Cancer-Related Medical Visit Within the Last 2 Years

Characteristic	Cancer-Related Medical Visit Within Last 2 y		Univariate Model		
	Yes (n = 264), %	No (n = 679), %	RR	95% CI	P
Sex					
Female (referent)	28.7	71.3	1.0		
Male	26.1	73.9	0.9	0.7-1.1	.38
Current age, mean, y ^a	31.1	30.0	1.1	0.9-1.1	.07
Race/ethnicity					
Minorities (referent)	32.0	68.0	1.0		
White, non-Hispanic	26.2	73.8	0.8	0.7-1.0	.08
Health insurance					
No (referent)	20.2	79.8	1.0		
Yes	27.8	72.2	1.4	0.9-2.0	.11
PCP					
No (referent)	17.2	82.8	1.0		
Yes	29.1	70.9	1.7	1.1-2.6	.02
Education					
≤High school graduate (referent)	25.8	74.2	1.0		
Some college or vocational training	29.1	70.9	1.1	0.9-1.4	.48
College graduate	28.8	71.2	1.1	0.8-1.3	.59
Age at cancer diagnosis, mean, y ^a	9.5	8.6	1.1	0.9-1.2	.05
Interval from diagnosis to survey					
10-14 y (referent)	28.9	71.1	1.0		
15-19 y	27.0	73.0	1.0	0.8-1.2	.85
20-24 y	25.0	75.0	0.9	0.7-1.1	.25
≥25 y	31.2	68.8	1.2	0.9-1.5	.13
Cancer therapy					
Chemotherapy					
Any	25.4	74.6	0.8	0.6-1.0	.09
Alkylating agents, moderate/high dose	24.7	75.3	1.1	0.8-1.7	.49
Anthracyclines ≥300 mg/m ²	32.1	67.9	1.4	1.0-1.9	.03
Radiation therapy					
Any	29.1	70.9	1.4	1.1-1.8	.02
Cranial	27.5	72.5	1.0	0.8-1.3	.74
Chest	32.2	67.8	1.3	1.0-1.6	.06
Primary care					
Seen PCP since finishing treatment	43.4	56.6	2.2	1.8-2.8	<.001
PCP can handle cancer-related problems	27.4	72.6	1.0	0.8-1.2	.90
Cancer care					
Cancer center visit within last 4 y	42.8	57.2	2.1	1.7-2.6	<.001
Live >200 miles from cancer center	25.0	75.0	0.9	0.7-1.1	.15
Have cancer treatment summary	38.4	61.5	1.5	1.2-2.0	<.001
Chronic health problem related to cancer					
None/mild (referent)	18.4	81.6	1.0		
Moderate/severe/life-threatening	62.9	37.1	3.4	2.8-4.1	<.001
Health care motivation ^b					
Interest in routine medical visit	3.6	3.1	1.3	1.2-1.4	<.001
Importance of cancer-related visit	4.0	3.2	1.4	1.3-1.6	<.001
Beliefs about health and health care ^b					
Cancer-related health problem likely	3.6	2.7	1.5	1.4-1.6	<.001
Health concerns and worries	3.0	2.5	1.6	1.4-1.8	<.001
Confidence in doctors	3.9	3.6	1.2	1.1-1.3	.01
Health locus of control ^c					
Internal	23.8	25.3	0.9	0.9-0.9	<.001
Chance	17.5	17.1	1.0	0.9-1.0	.28
Powerful others	18.8	17.5	1.1	1.0-1.1	.01
Influence of survivorship media ^b	2.1	1.9	1.1	0.9-1.2	.11
Barriers ^b					
Difficulty finding a doctor	1.9	2.0	0.9	0.8-1.0	.11
Transportation problems ^d	1.4	1.3	1.4	1.0-1.8	.04
Health insurance problems	2.3	2.2	1.0	0.9-1.1	.23

TABLE 4. Continued

Characteristic	Cancer-Related Medical Visit Within Last 2 y		Univariate Model		
	Yes (n = 264), %	No (n = 679), %	RR	95% CI	P
Doctors too rushed for questions	3.4	3.3	1.1	0.9-1.2	.21
Painful memory of cancer treatment	3.8	3.4	1.2	1.1-1.3	<.001

Abbreviations: CI, confidence interval; PCP, primary care physician; RR, relative risk.

Row percentages and means have been adjusted for sampling weights and calculated with respect to the weighted totals (1295 for yes and 3446 for no; the weighted sum is less than 4903 because of missing values).

^aRR for each 5-year increase in age.

^bRR for each 1-unit increase on a 5-point Likert scale (1, not at all/almost never; 5, extremely/almost always).

^cRR for each 1-unit increase on a 36-point scale.

^dRR for moderate/quite a bit/extreme versus none/a little bit.

a cancer treatment summary, having greater confidence in physicians' ability to address cancer concerns, and having more painful treatment memories.

In a second multivariable model (Table 6), survivors who had a cancer-related medical visit within the last 2 years were 1.5 times more likely to plan another within the next 2 years. Those who were planning a visit assigned greater importance to such visits, perceived greater susceptibility to cancer-related health problems, and had greater confidence in physicians in comparison with those who did not. Prior treatment with radiation was associated with planning a visit within the next 2 years but not with having one within the past 2 years. Survivors who were treated with moderate- to high-dose anthracyclines or alkylating agents were no more likely to have had or plan a visit than those who were not exposed to these toxic agents. Race/ethnicity, health insurance, education, sex, age at the time of the study, and interval from diagnosis to study were not associated with either outcome in univariate or multivariable models.

DISCUSSION

In a large population of childhood cancer survivors, nearly three-quarters reported no cancer-related health care visit in the 2 years preceding the survey. A modestly larger proportion planned to have a cancer-related visit in the next 2 years. Survivors with health problems, PCPs, and higher perceived susceptibility to late effects were more likely to be receiving or planning cancer-related care.

Most survivors were disconnected from their cancer treatment centers, and the need to identify another facility for cancer-related care may present a major barrier. Our data suggest that pediatric cancer treatment centers should not be relied upon to provide most cancer-related long-term follow-up care. It is of concern that survivors do not have the necessary information to facilitate follow-up care; fewer than 20% reported

having a cancer treatment summary. Given this, our findings of anxiety related to late effects, and the low confidence in PCPs, the lack of a relationship between a history of high-risk treatment and cancer-related visits is not surprising.

Although we anticipated that the age at study would be related to our primary outcomes on account of the consistent increase in grade 3 or higher late effects with increasing age, we may not have found this result because we included chronic, moderate/life-threatening cancer-related health problems as a separate variable in our multivariable analyses. Although factors such as transportation barriers and a lack of health insurance have been found to be relevant to medical visits in noncancer populations,¹⁵⁻¹⁷ such factors were not relevant to cancer-related care in our study even though data were collected before the Affordable Care Act. Survivors considered transportation and health insurance issues to be "extremely unimportant," and this sentiment was consistent with another study reporting that survivors had trouble obtaining insurance coverage and had high out-of-pocket expenses but described low coverage expectations and relative satisfaction with insurance.³⁷ Low expectations may help explain why systemic factors were not associated with cancer-related care in this study.

This study has some limitations. Although there were nearly 1000 participants, the response rate was 61%. Participants had a lower prevalence of chronic health problems than previously reported in the literature for this population,² and this may indicate a healthier cohort. In addition, participants were more likely to have health care access than nonparticipants. Therefore, our findings are likely a conservative estimate of the lack of cancer-related follow-up care. Participants self-reported health care utilization; however, we do not anticipate that a reporting bias would influence reporting of prior health care visits or barriers to care.

TABLE 5. Factors Associated With Planning a Cancer-Related Medical Visit Within the Next 2 Years

Characteristic	Planning Cancer-Related Medical Visit Within Next 2 y		Univariate Model		
	Yes (n = 397), %	No (n = 566), %	RR	95% CI	P
Sex					
Female (referent)	43.0	57.0	1.0		
Male	38.5	61.5	0.9	0.8-1.0	.16
Current age, mean, y ^a	30.8	30.1	1.0	0.9-1.1	.15
Race/ethnicity					
Minorities (referent)	44.4	55.6	1.0		
White, non-Hispanic	39.8	60.2	0.9	0.8-1.1	.20
Health insurance					
No (referent)	35.0	65.0	1.0		
Yes	41.7	58.3	1.2	0.9-1.6	.19
PCP					
No (referent)	22.5	77.5	1.0		
Yes	43.3	56.7	1.9	1.4-2.7	<.001
Education					
≥High school graduate (referent)	40.7	59.3	1.0		
Some college or vocational training	39.6	60.4	0.9	0.8-1.1	.63
College graduate	42.5	57.5	1.1	0.9-1.3	.54
Age at cancer diagnosis, mean, y ^a	9.5	8.6	1.1	1.0-1.2	.02
Interval from diagnosis to survey					
10-14 y (referent)	35.7	64.3	1.0		
15-19 y	41.2	58.8	1.0	0.9-1.2	.77
20-24 y	40.3	59.7	1.0	0.8-1.2	.87
≥25 y	40.7	59.3	1.0	0.8-1.2	.98
Cancer therapy					
Chemotherapy					
Any	40.5	59.5	1.1	0.8-1.3	.65
Alkylating agents, moderate/high dose	45.1	54.9	1.2	0.9-1.6	.13
Anthracyclines ≥300 mg/m ²	44.2	55.8	1.1	0.9-1.5	.26
Radiation therapy					
Any	44.7	55.3	1.5	1.2-1.8	<.001
Cranial	43.3	56.7	1.1	0.9-1.3	.23
Chest	53.1	46.9	1.4	1.2-1.7	<.001
Primary care					
Seen PCP since finishing treatment	54.3	45.7	1.6	1.4-1.9	<.001
PCP can handle cancer-related problems	40.7	59.3	0.9	0.8-1.2	.81
Cancer care					
Cancer-related medical visit within last 2 y	67.7	32.3	2.2	1.9-2.6	<.001
Cancer center visit within last 4 y	58.5	41.5	1.8	1.5-2.1	<.001
Live >200 miles from cancer center	38.4	61.6	0.9	0.8-1.1	.19
Have cancer treatment summary	52.5	47.5	1.4	1.2-1.6	<.001
Chronic health problem related to cancer					
None/mild	33.8	66.2	1.0		
Moderate/severe/life-threatening	67.0	33.0	2.0	1.7-2.3	<.001
Health care motivation ^b					
Interest in routine medical visit	3.8	2.9	1.4	1.3-1.5	<.001
Importance of cancer-related visit	4.2	2.9	1.7	1.6-1.8	<.001
Beliefs about health and health care ^b					
Cancer-related health problem likely	3.4	2.6	1.3	1.3-1.4	<.001
Health concerns/worries	3.0	2.4	1.6	1.5-1.8	<.001
Confidence in doctors	3.9	3.6	1.1	1.1-1.2	<.001
Health locus of control ^c					
Internal	24.5	25.2	0.9	0.9-1.0	.03
Chance	17.5	16.9	1.0	0.9-1.0	.16
Powerful others	19.1	16.9	1.0	1.0-1.1	<.001
Influence of survivorship media ^b	2.2	1.8	1.2	1.1-1.3	<.001
Health care barriers ^b					
Difficulty finding a doctor	1.9	2.1	0.9	0.8-1.0	.04
Transportation problems ^d	1.3	1.3	1.0	0.8-1.3	.95
Health insurance problems	2.2	2.3	0.9	0.9-1.0	.37

TABLE 5. *Continued*

Characteristic	Planning Cancer-Related Medical Visit Within Next 2 y				
	Yes (n = 397), %	No (n = 566), %	Univariate Model		
			RR	95% CI	P
Doctors too rushed for questions	3.4	3.3	1.1	0.9-1.2	.06
Painful memory of cancer treatment	3.7	3.4	1.1	1.1-1.2	.01

Abbreviations: CI, confidence interval; PCP, primary care physician; RR, relative risk.

Row percentages and means have been adjusted for sampling weights and calculated with respect to the weighted totals (1969 for yes and 2872 for no; the weighted sum is less than 4903 because of missing values).

^aRR for each 5-year increase in age.

^bRR for each 1-unit increase on a 5-point Likert scale (1, not at all/almost never; 5, extremely/almost always).

^cRR for each 1-unit increase on a 36-point scale.

^dRR for moderate/quite a bit/extreme versus none/a little bit.

TABLE 6. Multivariable Models of Factors Associated With Reporting a Cancer-Related Medical Visit Within the Last 2 Years and Planning a Cancer-Related Medical Visit Within the Next 2 y

Characteristic	Cancer-Related Medical Visit Within Last 2 y			Cancer-Related Medical Visit Within Next 2 y		
	RR	95% CI	P	RR	95% CI	P
Cancer therapy						
Radiation therapy, any				1.2	1.0-1.5	.03
Primary care						
Seen PCP since finishing treatment	1.3	1.0-1.6	.019			
Cancer care						
Cancer-related medical visit within last 2 y	NA			1.5	1.3-1.8	<.001
Have cancer treatment summary	1.3	1.0-1.6	.035			
Chronic health problem related to cancer						
None/mild (referent)	1.0					
Moderate/severe/life-threatening	2.1	1.7-2.7	<.001			
Health care motivation ^a						
Importance of cancer-related visit	1.2	1.1-1.3	<.001	1.5	1.4-1.7	<.001
Beliefs about health and health care ^a						
Cancer-related health problem likely	1.2	1.1-1.3	<.001	1.1	1.1-1.2	<.001
Confidence in doctors	1.2	1.0-1.3	.004	1.1	1.0-1.2	.01
Health care barriers ^a						
Painful memory of cancer treatment	1.1	1.0-1.2	.046			

Abbreviations: CI, confidence interval; NA, not applicable; PCP, primary care physician; RR, relative risk.

Models do not include "cancer center visit within last 4 years" because of a correlation with outcomes of interest.

^aRR for each 1-unit increase on a 5-point Likert scale (not at all/almost never to extremely/almost always).

This survey of long-term adult survivors of childhood cancer found that those with serious medical conditions and those with higher perceived vulnerability to late effects were more likely to have received cancer-related care. Treatment factors that increase the risk of late effects, such as high-risk chemotherapy, were not related to receipt of appropriate care, but perceived susceptibility was important. Educational interventions and improving awareness of treatment history and corresponding cancer-related care are likely to be beneficial.

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AUTHOR CONTRIBUTIONS

Jennifer S. Ford: Conceptualization, formal analysis, validation, visualization, writing—original draft, and writing—review and editing. **Emily S. Tonorezos:** Writing—original draft and writing—review and editing. **Ann C. Mertens:** Writing—review and editing. **Melissa M. Hudson:** Conceptualization, investigation, methodology, and writing—review and editing. **Jacqueline Casillas:** Writing—review and editing. **Barbara M. Foster:** Conceptualization, methodology, and writing—review and editing. **Chaya S. Moskowitz:** Data curation, formal analysis, software, and writing—review and editing. **Stephanie M. Smith:** Data curation, formal analysis, software, and writing—review and editing. **Joanne F. Chou:** Data curation, formal analysis, software, and writing—review and editing. **George Buchanan:** Conceptualization and writing—review and editing. **Leslie L. Robison:** Conceptualization, funding acquisition, supervision, and writing—review and editing. **Kevin C. Oeffinger:** Conceptualization, funding acquisition, investigation, methodology, project administration, supervision, validation, writing—original draft, and writing—review and editing.

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