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

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Abstract

Background: Optimal risk-based survivor health care includes surveillance for late effects and education targeted at reducing or preventing risky health behaviors. Understanding reasons for lack of risk-based follow-up care is essential.

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Methods: Adult participants from the Childhood Cancer Survivor Study (CCSS) were surveyed about having a cancer-related visit in the past two years and likelihood of having a cancer-related visit in the future. Additional factors thought to be related to the primary outcomes were also assessed.

Results: 975 survivors completed the survey. 27% (95% CI, 24–30) had a cancer-related medical visit in the previous two years and 41% (95% CI, 38–44) planned to have such a visit within the next two years. The likelihood of having had a cancer-related visit within the last two years was higher among survivors perceiving greater importance of these visits (RR=1.2; 95% CI, 1.1–1.3), 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 doctors' 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 of cancer-related late effects and corresponding risk-based care are likely to be beneficial for survivors of childhood cancers.

Condensed abstract:

Among 975 adult survivors of childhood cancer, nearly three-quarters reported no cancer-related health care visit in the preceding two years. Survivors with health problems, primary care providers, and higher perceived susceptibility to late effects were more likely to be receiving or planning cancer-related care; factors such as transportation and lack of health insurance were unrelated to cancer-related care.

Keywords

childhood cancer; cancer survivor; barriers; 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 delineated follow-up recommendations[7, 8] that specify the need for lifelong risk-based health care, integrating 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] Recognizing that potential cancer-related health complications are associated with decreased quality of life and early mortality, survivorship-focused care can have an important impact for survivors.

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

In the general population, barriers such as distance to provider, insurance status, comorbidities, and psychosocial factors such as 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.

METHODS

Participants

Participants were from the Childhood Cancer Survivor Study (CCSS), a multi-institutional retrospectively ascertained prospectively followed cohort study. Participants survived five or more years from treatment for childhood cancer and met the following eligibility criteria: a)diagnosis of leukemia, brain cancer, Hodgkin lymphoma, non-Hodgkin lymphoma, kidney cancer, neuroblastoma, soft tissue sarcoma, or malignancy of the bone; b)diagnosis and initial treatment at a collaborating CCSS institution; c)diagnosis date between 1970–1986; and d)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 ten 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 three health behavior theories: Health Belief Model, Multidimensional Health Locus of Control, and the Behavioral Model of Health Utilization.[22–30] A four-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 chart review. The final survey assessed sociodemographics; cancer-related variables; and the primary outcomes: having a cancer-related visit in the past two 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 two-year period. Health care motivation was assessed asking interest in going to a doctor for a routine medical checkup and importance of having routine checkups. Influence of survivorship media consisted of six questions assessing participants' exposure to media (e.g., newspapers, television programs, etc.) 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 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?” For those who responded ‘yes’, they were asked to rate their main health problem as mild, moderate, severe, or life-threatening and 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 by the Multidimensional Health Locus of Control scale,[26] assessing the degree to which survivors believed they could control what happens to them. Three types reflect the sources of motivation for health-related behaviors and include internal motivation, a matter of chance, or motivation due to the control/influence of powerful others.[26]

Health care barriers assessed 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

Primary outcomes for this study were: having a cancer-related visit in the past two years and the likelihood of having a cancer-related visit in the next two years. Overall medical care of participants has been reported elsewhere.[31] To assess primary outcomes, participants were asked if they had a medical visit in the previous two years that was related to their cancer (yes/no) and the likelihood of going to a doctor to check for health problems related to their cancer in the next two years (5-point Likert scale: very likely-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 using weighted percentages and means. The sampling weights consist of two components: a base weight and a nonresponse adjustment factor. The base weight adjusts 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 in order 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 gender, race/ethnicity, and highest attained education level. The inverse of the probability of participation was taken as the nonresponse adjustment factor. The final weight is the product of the base weight and the nonresponse adjustment factor.

Independent variables in the models included: gender, age at time of survey, age at diagnosis, interval from diagnosis to time of 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 [RR] and their corresponding 95% confidence intervals [95% CI]. 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 version 9.1 (SAS Institute Inc., Cary, North Carolina), using 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 non-participants to be older at time of study (30.7 vs 29.8 years, p=0.01), older at diagnosis (9.1 vs 7.9 years, p<0.001), female (53% vs 41%, p<0.001), white, non-Hispanic (75% vs 63%, p<0.001), have at least a high school education (57% vs 44%, p<0.001) and have health insurance (88% vs 81%, p<0.001).

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 cancer diagnosis was 20.8 years (range, 14.3–32.4 years); nearly one-quarter had survived at least 25 years.

Nearly three-quarters of participants reported seeing a health care professional within the previous two years (Table 2). However, only 27.3% (95% confidence interval [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 two years. Survivors were disconnected from the cancer center where they were treated: 30.6% [27.6%–33.6%] had a cancer center visit in the past 4 years, and 41.4% [38.2%–44.6%] lived more than 200 miles away. Less than one in five survivors (17.9% [15.4%–20.3%]) had received a cancer treatment summary.

Most survivors (87.2% [84.9%–89.4%]) had a PCP, but only one-third (33.1% [30.1%–36.2%]) had seen this doctor for a cancer-related problem since finishing treatment. A similarly low percentage (35.4% [32.2%–38.5%]) thought their PCP could “very often or almost always” handle a cancer-related problem.

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

Survivors' perspectives of health care are presented in Table 3. Overall, survivors expressed moderate interest in routine medical visits and importance of cancer-related medical visits, both of which were greater among females (Table 3). In univariate analysis, a variety of health care practices and beliefs were associated with having a cancer-related medical visit within the last two years (Table 4) and planning a visit within the next two years (Table 5). Having a PCP, cancer center visit in the past four years, treatment summary, moderate/life threatening chronic condition, belief that cancer problems are likely, and health concerns were each significantly related to having a cancer-related visit within the past two years and planning a visit in the next two years.

In the multivariable analysis (Table 6), the likelihood of having a cancer-related visit within the last two years increased among survivors who perceived greater importance of visits and greater susceptibility to cancer-related health problems. Those who reported a moderate/life-threatening chronic, cancer-related health problem were twice as likely as those who reported none/mild problems to have a cancer-related visit within the last two years. Additional related factors included: seeing a PCP for a cancer-related problem, having a cancer treatment summary, greater confidence in doctors' ability to address cancer concerns, and more painful treatment memories.

In a second multivariable model (Table 6), survivors who had a cancer-related medical visit within the last two years were 1.5 times more likely to plan another within the next two years. Those who were planning a visit perceived greater importance of such visits, greater susceptibility to cancer-related health problems, and greater confidence in doctors than those who did not. Prior treatment with radiation was associated with planning a visit within the next two years, but not with having one within the past two 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, gender, age at time of study, and interval from diagnosis to study were not associated with either outcome in univariate or multivariable models.

DISCUSSION

Among a large population of childhood cancer survivors, nearly three-quarters reported no cancer-related health care visit in the two years preceding the survey. A modestly larger proportion planned to have a cancer-related visit in the next two 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. Of concern, 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 low confidence in PCPs, the lack of relationship between a history of high-risk treatment and cancer-related visits are not surprising.

Although we anticipated that age at study would have been related to our primary outcomes, because of the consistent increase in grade 3 or greater late effects with increasing age, we may not have found this result because we included moderate/life-threatening chronic, cancer-related health problems as a separate variable in our multivariable analyses. While factors such as transportation barriers and lack of health insurance have been found relevant to medical visits in non-cancer populations,[15–17] such factors were not relevant to cancer-related care in our study, despite data being collected prior to the Affordable Care Act. Survivors considered transportation and health insurance issues to be “extremely unimportant,” a sentiment 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. While 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 may indicate a healthier cohort. Additionally, participants were more likely to have health care access than non-participants. 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 report of prior health care visits or barriers to care.

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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Table 1.

Characteristics of participants (N=975)[*]

Characteristics	%	95% CI
Current age		
17–19 y	4.6	3.2–6.0
20–29y	47.6	44.4–50.9
30–39 y	35.3	32.2–38.3
40–52y	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[*]		
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		
0–9y	58.2	55.1–61.4
10–20y	41.8	38.6–44.9
Interval from diagnosis to survey		
10–14y	2.3	1.3–3.3
15–19y	40.7	37.5–43.9
20–24y	33.3	30.2–36.3
≥25y	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

Characteristics	**%**	**95% CI**
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

Notes:

Percentages and 95% confidence intervals (CI) adjusted for sampling weights and calculated with respect to weighted total (N=4903; females, N=2343; males, N=2560)

[*] Have a primary care physician (PCP) or non-emergency medical care

Table 2.

Cancer-related health care practices (N=975)

	%	95% CI
Cancer-related medical visit		
Within last 2 years	27.3	24.4 – 30.2
Planned in next 2 years	40.7	37.5 – 43.9
Health care within last 2 years		
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 [*]	33.1	30.1 – 36.2
PCP can handle cancer-related problems [†]	35.4	32.2 – 38.5
Cancer care		
Cancer center visit within last 4 years	30.6	27.6 – 33.6
Live>200 miles from cancer center	41.6	38.5 – 44.7
Have a cancer treatment summary	18.3	15.9 – 20.7
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

Notes:

Percentages and 95% confidence intervals (CI) adjusted for sampling weights and calculated with respect to weighted totals (all, N=4903; females, N=2343; males, N=2560)

[*] For a problem thought to be related to the previous cancer

[†] Very often or almost always

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[*]	2.7	2.6–2.7
Confidence in doctors[†]	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[§]	2.0	1.9–2.1
Health care barriers		
Difficult to find 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

Notes:

Means and 95% confidence intervals adjusted for sampling weights and calculated with respect to weighted total (N=4903); Means on a scale of 1–5, except health locus of control (scale of 6–36)

[*] Health concerns and worries: concerned about health; concerned about getting sick; uncertainty about future health; worry about recurrence; worry that health problems will be discovered at routine checkup; feel different from others because of cancer; want to forget cancer and be like everyone else; worry about being called a complainer/hypochondriac

[†] Confidence in doctors: can ask doctor questions about cancer; cancer-related concerns have been addressed by doctors/nurses

[§] Interest in checkup increased after seeing survivorship-related media; Limited to those seeing survivorship-related media within last 2 years

Table 4.

Factors associated with reporting a cancer-related medical visit within the last two years

	Cancer-related medical visit within the LAST 2 years				
	Yes (N=264)	No (N=679)	Univariate Model		
Characteristic	**%**	**%**	**RR**	**95% CI**	**P-value**
Sex					
Female (referent)	28.7	71.3	1.0		
Male	26.1	73.9	0.9	0.7–1.1	0.38
Current age[*]					
Mean	31.1	30.0	1.1	0.9–1.1	0.07
Race/ethnicity					
Minorities (referent)	32.0	68.0	1.0		
White, non-Hispanic	26.2	73.8	0.8	0.7 – 1.0	0.08
Health insurance					
No (referent)	20.2	79.8	1.0		
Yes	27.8	72.2	1.4	0.9–2.0	0.11
Primary care physician					
No (referent)	17.2	82.8	1.0		
Yes	29.1	70.9	1.7	1.1–2.6	0.02
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	0.48
College graduate	28.8	71.2	1.1	0.8–1.3	0.59
Age at cancer diagnosis[*]					
Mean	9.5	8.6	1.1	0.9–1.2	0.05
Interval from diagnosis to survey					
10–14y (referent)	28.9	71.1	1.0		
15–19y	27.0	73.0	1.0	0.8–1.2	0.85
20–24y	25.0	75.0	0.9	0.7–1.1	0.25
≥ 25y	31.2	68.8	1.2	0.9–1.5	0.13
Cancer therapy					
Chemotherapy					
Any	25.4	74.6	0.8	0.6–1.0	0.09
Alkylating agents, moderate/high dose	24.7	75.3	1.1	0.8–1.7	0.49
Anthracyclines≥300 mg/m^2	32.1	67.9	1.4	1.0–1.9	0.03
Radiation therapy					
Any	29.1	70.9	1.4	1.1–1.8	0.02
Cranial	27.5	72.5	1.0	0.8–1.3	0.74
Chest	32.2	67.8	1.3	1.0–1.6	0.06
Primary care					
Seen PCP since finishing treatment	43.4	56.6	2.2	1.8–2.8	<0.001

	Cancer-related medical visit within the LAST 2 years				
	Yes (N=264)	No (N=679)	Univariate Model		
Characteristic	**%**	**%**	**RR**	**95% CI**	**P-value**
PCP can handle cancer-related problems	27.4	72.6	1.0	0.8–1.2	0.90
Cancer care					
Cancer center visit within last 4yrs	42.8	57.2	2.1	1.7–2.6	<0.001
Live>200 miles from cancer center	25.0	75.0	0.9	0.7–1.1	0.15
Have cancer treatment summary	38.4	61.5	1.5	1.2 – 2.0	<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	<0.001
Health care motivation[†]					
Interest in routine medical visit	3.6	3.1	1.3	1.2–1.4	<0.001
Importance of cancer-related visit	4.0	3.2	1.4	1.3–1.6	<0.001
Beliefs about health and health care[†]					
Cancer-related health problem likely	3.6	2.7	1.5	1.4–1.6	<0.001
Health concerns and worries	3.0	2.5	1.6	1.4–1.8	<0.001
Confidence in doctors	3.9	3.6	1.2	1.1–1.3	0.01
Health locus of control[¶]					
Internal	23.8	25.3	0.9	0.9–0.9	<0.001
Chance	17.5	17.1	1.0	0.9–1.0	0.28
Powerful others	18.8	17.5	1.1	1.0–1.1	0.01
Influence of survivorship media[†]	2.1	1.9	1.1	0.9–1.2	0.11
Barriers[†]					
Difficulty finding a doctor	1.9	2.0	0.9	0.8–1.0	0.11
Transportation problems[§]	1.4	1.3	1.4	1.0–1.8	0.04
Health insurance problems	2.3	2.2	1.0	0.9–1.1	0.23
Doctors too rushed for questions	3.4	3.3	1.1	0.9–1.2	0.21
Painful memory of cancer treatment	3.8	3.4	1.2	1.1–1.3	<0.001

Notes:

Row percentages and means adjusted for sampling weights and calculated with respect to weighted totals (yes, N=1295; no, N=3446; weighted sum is less than 4903 due to missing values)

[*] RR for each 5-year increase in age

[†] RR for each 1-unit increase on a 5-point Likert scale (1=not at all/almost never; 5=extremely/almost always)

[¶] RR for each 1-unit increase on a 36-point scale

[§] RR for moderate/quite a bit/extreme vs. none/a little bit

Table 5.

Factors associated with planning a cancer-related medical visit within the next two years

	Plan cancer-related medical visit within the NEXT 2 years				
	Yes (N=397)	**No (N=566)**	**Univariate Model**		
Characteristic	**%**	**%**	**RR**	**95% CI**	**P-value**
Sex					
Female (referent)	43.0	57.0	1.0		
Male	38.5	61.5	0.9	0.8–1.0	0.16
Current age *					
Mean	30.8	30.1	1.0	0.9–1.1	0.15
Race/ethnicity					
Minorities (referent)	44.4	55.6	1.0		
White, non-Hispanic	39.8	60.2	0.9	0.8–1.1	0.20
Health insurance					
No (referent)	35.0	65.0	1.0		
Yes	41.7	58.3	1.2	0.9–1.6	0.19
PCP					
No (referent)	22.5	77.5	1.0		
Yes	43.3	56.7	1.9	1.4–2.7	<0.001
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	0.63
College graduate	42.5	57.5	1.1	0.9–1.3	0.54
Age at cancer diagnosis *					
Mean	9.5	8.6	1.1	1.0–1.2	0.02
Interval from diagnosis to survey					
10–14y (referent)	35.7	64.3	1.0		
15–19y	41.2	58.8	1.0	0.9–1.2	0.77
20–24y	40.3	59.7	1.0	0.8–1.2	0.87
≥25y	40.7	59.3	1.0	0.8–1.2	0.98
Cancer therapy					
Chemotherapy					
Any	40.5	59.5	1.1	0.8–1.3	0.65
Alkylating agents, moderate/high dose	45.1	54.9	1.2	0.9–1.6	0.13
Anthracyclines≥300 mg/m^2	44.2	55.8	1.1	0.9–1.5	0.26
Radiation therapy					
Any	44.7	55.3	1.5	1.2–1.8	<0.001
Cranial	43.3	56.7	1.1	0.9–1.3	0.23
Chest	53.1	46.9	1.4	1.2–1.7	<0.001
Primary care					
Seen PCP since finishing treatment	54.3	45.7	1.6	1.4–1.9	<0.001

	Plan cancer-related medical visit within the NEXT 2 years				
	Yes (N=397)	No (N=566)	Univariate Model		
Characteristic	**%**	**%**	**RR**	**95% CI**	**P-value**
PCP can handle cancer-related problems	40.7	59.3	0.9	0.8–1.2	0.81
Cancer care					
Cancer-related medical visit within last 2y	67.7	32.3	2.2	1.9–2.6	<0.001
Cancer center visit within last 4y	58.5	41.5	1.8	1.5–2.1	<0.001
Live>200 miles from cancer center	38.4	61.6	0.9	0.8–1.1	0.19
Have cancer treatment summary	52.5	47.5	1.4	1.2–1.6	<0.001
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	<0.001
Health care motivation[†]					
Interest in routine medical visit	3.8	2.9	1.4	1.3–1.5	<0.001
Importance of cancer-related visit	4.2	2.9	1.7	1.6–1.8	<0.001
Beliefs about health and health care[†]					
Cancer-related health problem likely	3.4	2.6	1.3	1.3–1.4	<0.001
Health concerns/worries	3.0	2.4	1.6	1.5–1.8	<0.001
Confidence in doctors	3.9	3.6	1.1	1.1–1.2	<0.001
Health locus of control[¶]					
Internal	24.5	25.2	0.9	0.9–1.0	0.03
Chance	17.5	16.9	1.0	0.9–1.0	0.16
Powerful others	19.1	16.9	1.0	1.0–1.1	<0.001
Influence of survivorship media[†]	2.2	1.8	1.2	1.1–1.3	<0.001
Health care barriers[†]					
Difficulty finding a doctor	1.9	2.1	0.9	0.8–1.0	0.04
Transportation problems[§]	1.3	1.3	1.0	0.8–1.3	0.95
Health insurance problems	2.2	2.3	0.9	0.9–1.0	0.37
Doctors too rushed for questions	3.4	3.3	1.1	0.9–1.2	0.06
Painful memory of cancer treatment	3.7	3.4	1.1	1.1–1.2	0.01

Notes:

Row percentages and means adjusted for sampling weights and calculated with respect to weighted totals

(yes, N=1969; no, N=2872; weighted sum is less than 4903 due to missing values)

[*] RR for each five-year increase in age

[†] RR for each 1-unit increase on a 5-point Likert scale (1=not at all/almost never; 5=extremely/almost always)

[¶] RR for each 1-unit increase on a 36-point scale

[§] RR for moderate/quite a bit/extreme vs. none/a little bit

Table 6.

Multivariable models of factors associated with reporting a cancer-related medical visit within the LAST two years and planning a cancer-related medical visit within the NEXT two years

	Cancer-related medical visit within LAST 2 y			**Cancer-related medical visit within NEXT 2 y**		
Characteristic	**RR**	**95% CI**	**P-value**	**RR**	**95% CI**	**P-value**
Cancer therapy						
Radiation therapy						
Any				1.2	1.0–1.5	0.03
Primary care						
Seen PCP since finishing treatment	1.3	1.0–1.6	0.019			
Cancer care						
Cancer-related medical visit within last 2y	NA			1.5	1.3–1.8	<0.001
Have cancer treatment summary	1.3	1.0–1.6	0.035			
Chronic health problem related to cancer						
None/ mild (referent)	1.0					
Moderate, severe, life-threatening	2.1	1.7–2.7	<0.001			
Health care motivation†						
Importance of cancer-related visit	1.2	1.1–1.3	<0.001	1.5	1.4–1.7	<0.001
Beliefs about health and health care†						
Cancer-related health problem likely	1.2	1.1–1.3	<0.001	1.1	1.1–1.2	<0.001
Confidence in doctors	1.2	1.0–1.3	0.004	1.1	1.0–1.2	0.01
Health care barriers†						
Painful memory of cancer treatment	1.1	1.0–1.2	0.046			

Notes:

Models do not include “cancer center visit within last 4 y” due to correlation with outcomes of interest

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