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## Are Survivors Who Report Cancer-Related Financial Problems More Likely to Forgo or Delay Medical Care?

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### Abstract

**BACKGROUND**—Financial problems caused by cancer and its treatment can substantially affect survivors and their families and create barriers to seeking health care.

**METHODS**—The authors identified cancer survivors diagnosed as adults ( $n = 1556$ ) from the nationally representative 2010 National Health Interview Survey. Using multivariable logistic regression analyses, the authors report sociodemographic, clinical, and treatment-related factors associated with perceived cancer-related financial problems and the association between financial problems and forgoing or delaying health care because of cost. Adjusted percentages using the predictive marginals method are presented.

**RESULTS**—Cancer-related financial problems were reported by 31.8% (95% confidence interval, 29.3%–34.5%) of survivors. Factors found to be significantly associated with cancer-related financial problems in survivors included younger age at diagnosis, minority race/ethnicity, history of chemotherapy or radiation treatment, recurrence or multiple cancers, and shorter time from diagnosis. After adjustment for covariates, respondents who reported financial problems were more likely to report delaying (18.3% vs 7.4%) or forgoing overall medical care (13.8% vs 5.0%), prescription medications (14.2% vs 7.6%), dental care (19.8% vs 8.3%), eyeglasses (13.9% vs 5.8%), and mental health care (3.9% vs 1.6%) than their counterparts without financial problems (all  $P < .05$ ).

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**CONFLICT OF INTEREST DISCLOSURES**

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**CONCLUSIONS**—Cancer-related financial problems are not only disproportionately represented in survivors who are younger, members of a minority group, and have a higher treatment burden, but may also contribute to survivors forgoing or delaying medical care after cancer.

### Keywords

cancer; health disparities; survivors; access to care; financial burden

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## INTRODUCTION

The financial burden that cancer and its treatment poses to families can be substantial, including lost income, increased insurance premiums, deductibles, copayments, transportation costs, and childcare expenses.<sup>1</sup> The impact of these costs may be exacerbated in low-income and minority survivors, for whom financial hardship may predate a cancer diagnoses,<sup>2</sup> and in survivors who are at younger ages at the time of diagnosis.<sup>3</sup> In addition to estimating the actual costs associated with cancer treatment for individual patients, it is also important to understand the financial burden of cancer from the perspectives of survivors themselves.<sup>4,5</sup> Financial stress and strain in survivors have been linked to worse health-related quality of life<sup>6–9</sup> and greater depression and anxiety.<sup>8</sup>

Health-related financial problems may be obstacles to preventive care or treatment. High treatment costs, including out-of-pocket medication costs, have been linked to lower adherence to cancer treatment.<sup>10,11</sup> Delaying or forgoing care can have drastic consequences for patients undergoing cancer treatment, resulting in less effective treatment and shorter survival.<sup>12</sup> Delaying or forgoing care may also affect surveillance for disease recurrence, screening for second cancers, and care for late and long-term effects of cancer treatment.<sup>13,14</sup>

In the current study, we used national data to characterize individuals with a history of cancer who reported cancer-related financial problems and examined the relationship between these problems and forgoing or delaying health care because of cost. Understanding those most financially affected by cancer is an important first step in identifying intervention strategies to prevent inadequate medical care, an increasingly important task given the growing number of cancer survivors living in the United States.<sup>15,16</sup>

## MATERIALS AND METHODS

We used data from the 2010 National Health Interview Survey (NHIS), an in-person nationally representative survey of health and health behaviors in the United States.<sup>17</sup> A sample of the civilian, noninstitutionalized population was derived using a complex, multistage sampling framework. One adult per household was chosen to complete the Sample Adult Questionnaire, which in 2010 included the Cancer Control Supplement and yielded a conditional response rate of 77.3% and a final response rate (accounting for household nonresponse) of 60.8%. Recent articles have used these data to characterize receipt of psychosocial care<sup>18</sup> and health-related quality of life<sup>19</sup> among cancer survivors. A total of 1822 individuals reported a history of any cancer (excluding nonmelanoma and unknown skin cancer). Survivors who were diagnosed only at an age <22 years ( $n = 52$ )

were excluded due to differences in treatment settings for childhood and adolescent cancer and to focus on financial problems incurred for adult-onset cancers. Individuals with missing data regarding cancer-related financial problems ( $n = 214$ ) and other covariates ( $n = 38$ ) were also excluded, bringing the final analytic sample to 1556.

## Measures

Cancer-related financial problems was based on the question “to what degree has cancer caused financial problems for you and your family?” Responses were dichotomized (a lot, some, a little vs none) to account for individual variability in perception of financial burden.

Forgoing or delaying care was based on affirmative responses to the following yes/no questions asked about the past 12 months (items in brackets were asked as separate questions):

“Was there any time when you needed (prescription medicines, mental health care or counseling, eyeglasses, dental care [including check-ups]), but couldn’t afford it?”

“Was there any time when you needed medical care, but did not get it because you couldn’t afford it?”

“Has medical care been delayed for you because of worry about the cost?”

## Covariates

Our analysis examined the relationship between cancer-related financial problems and the following self-reported factors: age at last cancer diagnosis (because available treatment data refer to the most recent cancer only); sex; marital status; race/ethnicity; education; whether health insurance paid for all or part of cancer treatment; residential region; recurrence or multiple cancers; time since most recent cancer diagnosis; history of surgery, chemotherapy, or radiation; and number of comorbidities. We used an index of non-cancer comorbid health conditions (ever diagnosed) based on previous research linking these conditions to poorer health-related quality of life: hypertension, heart disease, stroke, diabetes, lung disease, and arthritis.<sup>19,20</sup> Although we report on household income at the time of survey in the description, we did not include income as a covariate in our analyses for multiple reasons: 1) neither income before cancer diagnosis nor change in income from the time of diagnosis to the survey was available in NHIS, making the association between cancer-related financial problems and income difficult to interpret; 2) income was missing for approximately 25% of participants; and 3) income was found to be significantly correlated with educational status ( $r = 0.36$ ;  $P < .001$ ).

## Statistical Analysis

Multivariable logistic regression modeling using the predictive marginals method was used to estimate the association between covariates and cancer-related financial problems.<sup>21</sup> Analyses also investigated the possibility of individual interactions between health insurance coverage for treatment, race/ethnicity, history of chemotherapy and treatment, and comorbidities with age at last cancer diagnosis (<65 vs ≥65 years) to determine whether the associations between these variables and cancer-related financial problems differed by age,

given documented higher rates of financial hardship among younger cancer survivors.<sup>3</sup> Multivariable logistic regression was also conducted to assess whether self-reported cancer-related financial difficulties were associated with delaying or forgoing medical care (overall medical care, mental health care, eyeglasses, prescription medications, and dental care). This analysis only included individuals who reported not having received treatment within the previous 12 months ( $n = 1276$ ) because the relationship between financial burden and delaying or forgoing care may differ for those still receiving cancer treatment. The analysis was adjusted for variables previously shown to be associated with forgoing or delaying care: age at last cancer diagnosis, sex, race/ethnicity, education, and comorbidities,<sup>22</sup> as well as others included in the model of cancer-related financial problems (marital status; whether insurance paid for cancer treatment; residential region; recurrence or multiple cancer history; years since last cancer diagnosis; and history of surgery, chemotherapy, or radiation). Weighted percentages represent the population percentage of each group reporting cancer-related financial problems after covariate adjustment. An analysis comparing variables for those missing and not missing data regarding cancer-related financial problems was conducted to examine nonresponse bias. Analyses were conducted using the Statistical Analysis Software (SAS) callable version (SAS Institute Inc, Cary, NC) of SUDAAN 10.0 (RTI International, Research Triangle Park, NC) to incorporate sampling weights and account for the complex sampling design. Statistical analyses were deemed significant for a 2-sided test  $P$  values of  $<.05$ .

## RESULTS

### Sample Characteristics

Approximately 19.5% of the survivor sample was aged 39 years at the time of the most recent cancer diagnosis, 50.5% were aged 40 years to 64 years, and 29.9% were aged 65 years (Table 1). Reflective of previous population-based studies of US cancer survivors,<sup>16,23</sup> greater than one-half of the participants were female, married/living as married, and reported some college education. Most survivors were non-Hispanic white. Although the majority of participants reported a household income (at time of survey)  $>200\%$  of the federal poverty level (adjusted for household size), 8.0% reported an income of  $<100\%$  of the federal poverty level. Approximately 7.0% of participants reported that their cancer treatment was not covered by insurance. Approximately 18.2% of survivors reported having experienced a cancer recurrence or multiple cancers and 14.6% reported having received treatment within the past 12 months. Surgical treatment was reported by 62.6% of participants; 23.0% reported receiving chemotherapy and 24.6% reported receiving radiation. Approximately 48.0% of participants reported 2 or more comorbidities.

Approximately 31.8% of survivors reported cancer-related financial problems. Participants missing a response to the cancer-related financial problems item were more likely to have undergone cancer treatment that was not covered by health insurance, to not have experienced a recurrence or have multiple cancers, and to have reported a lower household income at the time of the survey (all  $P < .05$ ).

### Cancer-Related Financial Problems

Age, race/ethnicity, time since diagnosis, recurrence or multiple cancers, and history of chemotherapy or radiation were all found to be significantly associated with cancer-related financial problems in multivariable analyses (Table 2). Specifically, 43.4% of survivors aged <40 years at the time of diagnosis and 39.8% of individuals aged 40 years to 64 years reported financial problems, compared with 21.7% of individuals aged ≥ 65 years ( $P < .0001$ ). Minority survivors (non-Hispanic black: 46.6%; Hispanic: 42.1%; and other racial/ethnic background: 46.1%) were more likely to report financial problems than non-Hispanic white survivors (33.1%;  $P = 0.006$ ). Survivors reporting disease recurrence or multiple cancers were also more likely to report cancer-related financial problems (40.9% vs 33.7%;  $P < .049$ ). Survivors reporting a history of chemotherapy (47.2% vs 30.8%;  $P < .0001$ ) and radiation (44.7% vs 31.4%;  $P < .001$ ) were more likely to report financial problems. None of the interaction terms (health insurance coverage for treatment, race/ethnicity, history of chemotherapy or radiation, or comorbidities) with age was found to be significantly associated with cancer-related financial problems (data not shown).

### Delaying or Forgoing Care

After adjustment for covariates, participants who reported financial problems were more likely to report delaying medical care (18.1% vs 7.4%;  $P < .0001$ ) or forgoing overall medical care (13.5% vs 5.1%;  $P < .0001$ ), prescription medications (13.8% vs 7.7%;  $P = .001$ ), dental care (20.0% vs 8.3%;  $P < .0001$ ), eyeglasses (13.7% vs 5.9%;  $P < .0001$ ), or mental health care (9.4% vs 7.1%;  $P = .03$ ) (Fig. 1).

## DISCUSSION

In what to our knowledge is one of the first national studies on this topic, we observed that nearly one-third of adult cancer survivors reported cancer-related financial problems. The results of the current study elucidate several factors that are significantly associated with financial burden, including younger age at diagnosis and minority race/ethnicity. In addition, clinical factors that may be indicators of a greater cancer impact (including a history of chemotherapy or radiation treatment, recurrence, and shorter time from diagnosis) also emerged as important correlates to financial burden. Survivors reporting financial problems were more likely to report forgoing or delaying recent medical care, prescription medications, dental care, eyeglasses, or mental health care within the past year, specifically because of concerns about cost. The association between these 2 variables is striking because the majority of survivors in the study were >5 years beyond their most recent cancer diagnosis.

Expenditures attributable to cancer, including out-of-pocket spending, can be substantial, even for long-term survivors.<sup>23,24</sup> As shown in the current study and others,<sup>25</sup> survivors who are of working age at the time of diagnosis (broadly aged <65 years) may be at particular risk for financial problems, with 40% to 43% reporting cancer-related financial problems. Racial disparities in cancer-related financial problems have been reported in other studies of African American<sup>22</sup> and Hispanic/Latino<sup>26</sup> survivors. Studies have found higher treatment costs for racial/ethnic minority cancer patients, which suggest that inequitable cost burden

may contribute to disparities in cancer-related financial problems.<sup>27–29</sup> The lack of difference in financial problems between married and unmarried survivors in the current study is surprising given research documenting the financial protections associated with marriage<sup>30,31</sup>; this may suggest that marriage-related financial protection is outweighed by other factors, or it may be an artifact due to the finding that marital status was collected at the time of the interview, not diagnosis. Future interventions for survivors experiencing financial difficulties should consider predisposing factors such as race/ethnicity, time since diagnosis, and age.

The association between radiation history and financial problems is a novel finding and may reflect the out-of-pocket costs (travel and lost productivity, as well as possibly accommodations for survivors who live far from treatment centers) associated with sometimes long-lasting and daily treatment. Alternatively, it may reflect the lasting or late-onset health effects that therapeutic radiation can cause in survivors,<sup>32</sup> as has been shown for chemotherapy.<sup>10,33</sup> Recurrence or multiple cancer diagnoses present major financial challenges to survivors, often requiring additional time away from employment, added out-of-pocket expenditures, and a potential threat to their ability to maintain health insurance (possibly as a result of job loss). Although an observed lower likelihood of financial problems in longer-term survivors was evident in the current study, other studies have documented the persistence of severe financial problems (although not specifically cancer-related) well into posttreatment survivorship.<sup>34</sup>

Building on a prior analysis that found higher rates of forgoing medical care among individuals with a history of cancer (7.8%) compared with those without cancer (5.2%),<sup>22</sup> the results of the current study add that among survivors, patients reporting cancer-related financial problems also are more likely to forgo or delay their current medical care. This suggests that difficulties accessing care appear to be related specifically to cancer-related financial variables. Another population-based study found that survivors of a younger age and lower household income and those who were unemployed were more likely to report treatment nonadherence,<sup>10</sup> suggesting that financial challenges may compromise cancer outcomes. Given that higher treatment burden (ie, receiving either more intensive, more frequent, or longer-in-duration treatment) and recurrence are associated with a higher propensity for both serious and lasting late effects and perceived financial burden, the association between forgoing or delaying medical care and previous chemotherapy or radiation treatment is concerning. The importance of these findings is further enhanced given the potential for financial problems to affect the entire family system of cancer patients.<sup>35,36</sup>

The development of interventions to aid cancer survivors and their families as they confront financial stress is challenging, in part because it entails expansion of existing models of survivorship care as well as multilevel intervention efforts. Key challenges to identifying survivors in financial distress include a lack of standardized methods to assess need and the necessity of accounting for changing needs over time.<sup>37</sup> A recently proposed model of cancer rehabilitation that recognizes the need for comprehensive care, including attention to social and vocational needs, suggests that expanding survivorship care to include services that both promote self-management and encourage survivors to remain or return to the

workforce has the potential to reduce overall cancer costs as well as costs to individual survivors<sup>38</sup> and should be considered as a way to reduce financial burden.

The current study is limited by its cross-sectional data and cannot provide causal inferences regarding the association between financial problems and forgoing medical care. The NHIS is designed to be representative of the general US population but may differ somewhat in terms of its generalizability to members of the US population with a history of cancer. In addition, the NHIS relies on self-reported cancer diagnoses, which may account for different prevalence estimates of cancer observed based on NHIS data compared with registry data.<sup>15</sup> Participants may have mistakenly included preclinical lesions; however, it is unlikely that a large percentage of these individuals would also report financial problems. As a result, our estimates may underestimate the prevalence of financial problems.

Given the cross-sectional nature of the data in the current study, the often large gap in time between cancer diagnosis and income assessment, and the strong connection between income and financial burden, we chose not to examine whether cancer-related financial problems were more common among survivors who report low income; however, other studies have reported higher perceived financial burden among low-income cancer patients.<sup>10,39,40</sup> In addition, income and educational attainment were found to be associated in our data set, and we believe that the latter was a more stable predictor of socioeconomic status and was less affected by missing data.

The sample in the current study is widely representative of the general US population of cancer survivors, but it may underrepresent certain groups. For example, the approximately 10% of survivors who did not respond to the question regarding financial problems tended to be uninsured and poorer, and given that individuals in poorer health are less likely to respond to the NHIS,<sup>41</sup> the current study may have underestimated financial burden. Finally, financial burden was assessed with a single item that may have been variably interpreted by participants and warrants further exploration. Cognitive testing of this question, however, did not reveal any difficulties in interpretation. Future qualitative research to help elucidate those factors individuals consider as financial difficulties as the result of their cancer experience is needed. Regardless, the results of the current study provide nationally representative population-based estimates of the prevalence of this easily interpretable measure, and subjective financial burden has been significantly associated with objective measures, such as requesting copayment assistance.<sup>3</sup> Future studies that incorporate objective measures in addition to patient perceptions, such as changes in income and employment, would help to further classify and quantify the financial effects of cancer.

The current study found that approximately one-third of cancer survivors in the United States report cancer-related financial problems and that these problems are associated with an increased likelihood of forgoing or delaying medical care. Future research should investigate whether certain survivor groups (eg, younger survivors, those of minority racial/ethnic status, and those with a higher treatment burden) are less likely to receive guideline-based follow-up and routine preventive care. When possible, future studies should also use longitudinal study designs, such as those found in the Agency for Healthcare Research and Quality's Medical Expenditure Panel Survey,<sup>42</sup> to examine economic trajectories of

survivors and their caregivers and to examine whether cancer survivors who receive inadequate care because of cost experience worse health outcomes.

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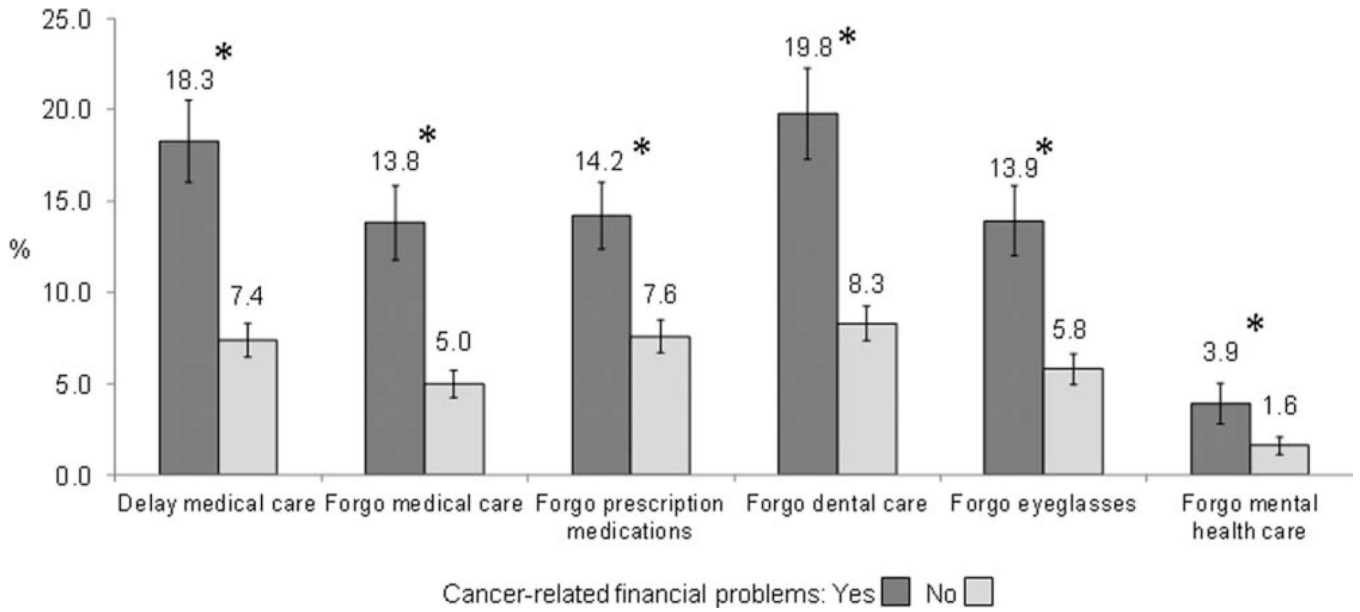
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**Figure 1.**

The percentage of survivors reporting forgoing or delaying care because of cost who also reported that cancer caused them financial problems is shown, adjusted for other covariates (age at last cancer diagnosis; sex; marital status; race/ethnicity; education; whether insurance paid for cancer treatment; residential region; recurrence or multiple cancer history; years since last cancer diagnosis; history of surgery, chemotherapy, or radiation; and number of comorbidities). Only survivors who reported not receiving cancer care within the previous 12 months ( $n = 1276$ ) were included.  $*P < .05$ .

TABLE 1

Characteristics of Survivors of Adult Cancers in the United States (n = 1770)

Variable	Level	No.	Weighted %	95% CI
Age at last cancer diagnosis, y	<39	335	19.5	17.2–22.0
	40–64	883	50.5	47.6–53.4
	65	552	29.9	27.4–32.6
Sex	Male	664	42.1	39.4–44.9
	Female	1106	57.9	55.1–60.6
Race/ethnicity	Non-Hispanic white	1297	83.0	81.2–84.6
	Non-Hispanic black	241	8.3	7.1–9.6
	Hispanic	164	6.0	5.0–7.1
	Other	68	2.8	2.1–3.8
Marital status	Married/living as married	858	63.5	60.9–65.9
	Never married/widowed/divorced/separated	911	36.5	34.1–39
	Data missing	1	0	0–0.3
Education	<High school	296	13.5	11.8–15.5
	High school/GED	484	28.7	26.2–31.3
	Some college+	980	57.3	54.5–60.1
	Data missing	10	0.4	0.2–0.9
Current household income (% of federal poverty level) <sup>a</sup>	100%	217	8.0	6.8–9.5
	100–199%	326	16.3	14.4–18.4
	200–399%	466	28.0	25.5–30.8
	400%	512	33.2	30.6–35.9
	Data missing	249	14.4	12.6–16.5
Insurance paid for all or part of cancer treatment	Yes	1365	77.8	75.4–80.0
	No	145	7.0	5.8–8.4
	Unknown/data missing	260	15.2	13.2–17.4
Region	Northeast	299	18.4	16.0–21.0
	Midwest	436	25.4	23–27.9
	South	637	35.7	32.9–38.6
	West	398	20.5	18.2–23.1
Most recent cancer site	Female breast	398	19.9	17.8–22.2
	Prostate	260	15.5	13.8–17.4
	Melanoma	147	10.1	8.6–11.8
	Colorectal	142	7.6	6.3–9.2
	Hematologic	99	6.1	4.9–7.7
	Short-survival cancers <sup>b</sup>	102	5.6	4.6–7.0
	All other	539	30.5	28.2–32.8
	Unknown	83	4.6	3.6–5.9
Recurrence/ multiple cancers	Yes	309	18.2	16.4–20.2
	No	1461	81.8	79.8–83.6
Recent treatment (past 12 mo)	Yes	262	14.6	12.8, 16.7

Variable	Level	No.	Weighted %	95% CI
Y since most recent diagnosis	No	1362	76.8	74.3–79.0
	Data missing	146	8.6	7.1–10.3
	<2	341	19.0	17.0–21.2
	2–5	473	28.6	26.1–31.2
	6–9	270	15.1	13.0–17.5
Surgery	10	686	37.3	34.7–40
	Yes	1111	62.6	59.7–65.4
	No	489	27.3	24.9–29.9
Chemotherapy	Data missing	170	10.1	8.5–11.9
	Yes	411	23.0	20.9–25.3
	No	1189	66.9	64.3–69.5
Radiation	Data missing	170	10.1	8.5–11.9
	Yes	445	24.6	22.3–27.1
	No	1155	65.3	62.7–67.8
Noncancer comorbidities	Data missing	170	10.1	8.5–11.9
	0	394	23.9	21.8–26.1
	1	479	27.2	24.7–29.7
	2	881	48.0	45.3–50.8
	Data missing	16	0.9	0.5–1.7
Cancer-related financial problems	Yes	574	31.8	29.3–34.5
	No	1024	57.9	55.1–60.7
	Data missing	172	10.2	8.7–12.1

Abbreviations: 95% CI, 95% confidence interval; GED, General Educational Development test; Y, years.

<sup>a</sup>Current household income (percentage of the federal poverty level) was calculated by comparing reported household income with the 2010 federal poverty level (eg, \$22,050 for a family of 4).<sup>21</sup>

<sup>b</sup>Short-survival cancers included cancers with a relatively short survival time (esophagus, liver, lung, pancreas, and stomach).<sup>17</sup>

TABLE 2

Factors Associated With Cancer Survivors Reporting That Cancer Caused Them Financial Problems ( $n = 1556$ )<sup>a</sup>

Factor		Predictive Marginal (%) <sup>b</sup>	95% CI	Wald $P^c$
Age at last cancer diagnosis, y	39	43.4	36.9–50.2	<.0001
	40–64	39.8	35.8–44.0	
	65	21.7	17.9–26.0	
Sex	Male	36.1	31.8–40.7	.58
	Female	34.5	30.9–38.3	
Marital status	Married or living with partner	35.8	32.0–39.8	.53
	Never married/widowed/divorced/separated	34.1	30.3–38.1	
Race/ethnicity	Non-Hispanic white	33.1	29.9–36.5	<b>0.006</b>
	Non-Hispanic black	46.6	38.4–55.0	
	Hispanic	42.1	32.2–52.7	
	Other	46.1	30.8–62.1	
Education	<High school	40.2	33.3–47.6	.17
	High school or GED	37.3	32.2–42.7	
	Some college+	33.0	29.2–37.1	
Insurance paid for all or part of cancer treatment	Yes	34.8	31.7–38.1	.51
	No/unknown	37.5	30.4–45.1	
Region	Northeast	29.3	24.4–34.8	.09
	Midwest	36.2	30.0–42.8	
	South	38.7	33.5–44.2	
	West	32.8	27.6–38.5	
Recurrence/multiple cancers	Yes	40.9	34.4–47.7	<b>.049</b>
	No	33.7	30.6–37.0	
Y since last cancer diagnosis	<2	45.2	37.4–53.2	<.0001
	2–5	40.0	34.9–45.4	
	6–9	34.7	28.4–41.5	
	10	27.9	24.1–31.9	
Surgery	Yes	34.5	31.2–38.0	.48
	No	36.6	31.7–41.8	
Chemotherapy	Yes	47.2	41.1–53.5	<.0001
	No	30.8	27.6–34.1	
Radiation	Yes	44.7	39.0–50.6	<.001
	No	31.4	28.2–34.9	
No. of comorbidities	0	32.5	27.8–37.6	.51
	1	35.5	30.1–41.2	
	2	36.4	32.1–40.8	

Abbreviations: 95% CI, 95% confidence interval; GED, General Educational Development test; Y, years.

<sup>a</sup> Adjusted  $r^2 = 0.16$ .

<sup>b</sup> Predictive marginals adjust for all other variables in the model and are weighted to account for the complex sampling design.

<sup>c</sup> Bold type indicates statistical significance.

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