

Financial Burden in Survivors of Childhood Cancer: A Report From the Childhood Cancer Survivor Study

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A B S T R A C T

Purpose

Survivors of childhood cancer may experience financial burden as a result of health care costs, particularly because these patients often require long-term medical care. We sought to evaluate the prevalence of financial burden and identify associations between a higher percentage of income spent on out-of-pocket medical costs ($\geq 10\%$ of annual income) and issues related to financial burden (jeopardizing care or changing lifestyle) among survivors of childhood cancer and a sibling comparison group.

Methods

Between May 2011 and April 2012, we surveyed an age-stratified, random sample of survivors of childhood cancer and a sibling comparison group who were enrolled in the Childhood Cancer Survivor Study. Participants reported their household income, out-of-pocket medical costs, and issues related to financial burden (questions were adapted from national surveys on financial burden). Logistic regression identified associations between participant characteristics, a higher percentage of income spent on out-of-pocket medical costs, and financial burden, adjusting for potential confounders.

Results

Among 580 survivors of childhood cancer and 173 siblings, survivors of childhood cancer were more likely to have out-of-pocket medical costs $\geq 10\%$ of annual income (10.0% v 2.9%; $P < .001$). Characteristics of the survivors of childhood cancer that were associated with a higher percentage of income spent on out-of-pocket costs included hospitalization in the past year (odds ratio [OR], 2.3; 95% CI, 1.1 to 4.9) and household income $< \$50,000$ (OR, 5.5; 95% CI, 2.4 to 12.8). Among survivors of childhood cancer, a higher percentage of income spent on out-of-pocket medical costs was significantly associated with problems paying medical bills (OR, 8.9; 95% CI, 4.4 to 18.0); deferring care for a medical problem (OR, 3.0; 95% CI, 1.6 to 5.9); skipping a test, treatment, or follow-up (OR, 2.1; 95% CI, 1.1 to 4.0); and thoughts of filing for bankruptcy (OR, 6.6; 95% CI, 3.0 to 14.3).

Conclusion

Survivors of childhood cancer are more likely to report spending a higher percentage of their income on out-of-pocket medical costs, which may influence their health-seeking behavior and potentially affect health outcomes. Our findings highlight the need to address financial burden in this population with long-term health care needs.

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INTRODUCTION

In recent years, cost sharing in the United States health care system has brought renewed attention to the issue of high out-of-pocket medical expenditures.¹ Most health insurance plans do not cover all health care–related expenses, and cost sharing in the form of copayments, deductibles,

and coinsurance may add substantially to the out-of-pocket costs incurred by patients. Although the Affordable Care Act (ACA) was created to improve access to affordable health care, including provisions to promote care for patients with preexisting medical conditions, high-deductible health plans may still leave patients underinsured.^{2,3} Underinsurance pertains to people who incur significant out-of-pocket

ASSOCIATED CONTENT



Appendix
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medical expenses, generally > 10% of their family's yearly income.⁴⁻⁹ Underinsured patients may be at a particularly high risk of experiencing financial burden, especially when faced with a serious illness, such as cancer.

The rising cost of cancer care and growing out-of-pocket medical expenses for adult patients with cancer have led to an increased focus on the financial burden experienced by these individuals.^{4,5,10} Research has demonstrated that the financial burden experienced by patients with cancer may negatively impact their treatment outcomes, including quality of life, symptom burden, and survival.¹¹⁻¹³ Patients who experience financial burden may not properly adhere to prescribed therapies in an effort to defray costs¹⁴⁻¹⁶ and, thus, jeopardize their health care.¹⁷⁻¹⁹ Whereas these studies among adults with cancer provide compelling evidence with regard to the adverse effects of financial burden in this population, efforts to understand the financial burden among survivors of childhood cancer are lacking.

Despite advances in treatment and survival for children with cancer, many survivors of childhood cancer develop chronic health conditions, which results in a need for long-term medical care and places them at elevated risk for premature mortality²⁰⁻²³; however, survivors of childhood cancer frequently experience challenges obtaining necessary follow-up health care. Previous research using data from the Childhood Cancer Survivor Study (CCSS) demonstrated that many survivors reported restrictive and costly health insurance plans.²⁴ Research suggests that uninsured survivors received less risk-based, survivor-focused care than those with health insurance.²⁵ A qualitative study that involved CCSS participants demonstrated that uninsured survivors expressed considerable worry about the financial burden imposed by high health care costs.²⁶ Thus, survivors of childhood cancer often encounter obstacles obtaining adequate insurance coverage, thereby putting them at risk for high out-of-pocket expenditures and, ultimately, financial burden.

In the present analysis, we sought to evaluate financial burden as a result of medical costs among survivors of childhood cancer and a sibling comparison group, and identify the relationship between high out-of-pocket medical costs (≥ 10% of annual household income) and adverse consequences of financial burden. In a previous study, we found that survivors report higher out-of-

pocket expenses compared with siblings, particularly uninsured survivors.^{26a} Although prior work has used high out-of-pocket costs as a surrogate for financial burden, few studies have examined the relationship between out-of-pocket costs and the adverse consequences of financial burden, such as jeopardizing medical care or changing lifestyle to cope with the burden, particularly among survivors of childhood cancer. Moreover, factors associated with the vulnerability of survivors to high out-of-pocket costs have not been fully examined. By identifying risk factors for high out-of-pocket medical costs and studying the consequences of these costs, we hope to aid in the development of interventions that will address the financial burden experienced by survivors of cancer.

METHODS

Study Design

Between May 2011 and April 2012, we performed a cross-sectional study of a randomly selected, age-stratified sample of survivors and a sibling comparison group who were enrolled in the CCSS. The institutional review boards of St Jude Children's Research Hospital and Massachusetts General Hospital and Partners Healthcare approved the study.

Study Population

The CCSS is a multi-institutional cohort study with longitudinal follow-up to describe and compare health outcomes of survivors of childhood cancer with those of siblings. Eligible survivors included those who were diagnosed with cancer before 21 years of age, received their initial treatment between 1970 and 1986, and survived ≥ 5 years from diagnosis. The CCSS includes survivors of leukemia, Hodgkin lymphoma, non-Hodgkin lymphoma, Wilms tumor, tumors of the CNS, neuroblastoma, soft-tissue sarcoma, and bone tumor. The original CCSS cohort had 14,357 survivors and 4,023 randomly selected nearest-age siblings.^{27,28} Participants for the current analysis were identified from the original cohort's 25 participating centers in the United States.

Data Collection

For the current study, we randomly selected 1,101 survivors from three age strata (current age younger than 30 years, 30 to 39 years, ≥ 40 years of age). Participants completed surveys either by mail or online. The sample (Fig 1) included 698 completed survivor surveys (63.4% response rate) and

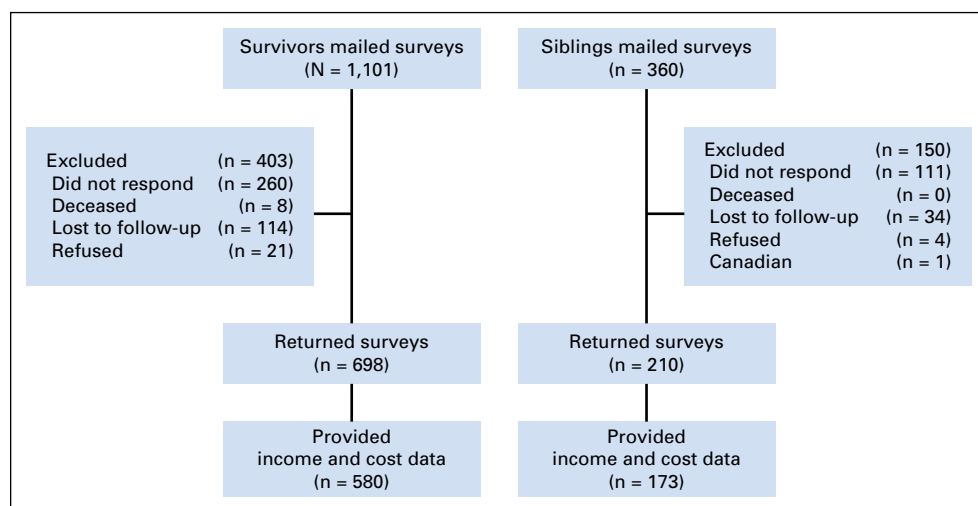


Fig 1. Flow diagram.

210 sibling surveys (58.3% response rate). For the current study, we had information about income and out-of-pocket medical costs for 580 survivors and 173 siblings. Compared with those who did not provide their income and/or out-of-pocket medical costs, survivors who did report this information were more likely to be married, with more education, and have higher household incomes (Appendix Table A1, online only).

Survey Measures

We developed surveys by adapting national surveys on insurance and financial burden, such as the National Health Interview Survey, Medical Expenditure Panel Survey, and Commonwealth Fund Health Insurance Survey, and with an initial qualitative study.^{26,29-33} On the basis of participants' responses to the first survey question, "Do you currently have health insurance that covers doctor and hospital care?" we asked them to complete either an insured or an uninsured version of the survey.³⁴ Surveys assessed participants' current marital status, employment status, household income, and insurance characteristics. We obtained data about sociodemographic, health care use, and cancer and treatment-related factors from CCSS baseline and follow-up surveys. We used the most recent follow-up survey to collect information regarding the severity of chronic health conditions (eg, heart failure, cognitive impairment, coronary artery disease, renal failure) classified as none, mild, moderate, severe, or life-threatening or disabling using the National Cancer Institute's Common Terminology Criteria for Adverse Events (version 3), as previously published.²⁰

Issues Related to Financial Burden

We asked participants to answer "yes," "no," or "don't know" to issues related to financial burden listed in the following questions (Appendix Table A2, online only): "In the past year, have you/your family had any problems paying your medical bills?"; "In the past year, have any of the following happened because of medical expenses?"; and "In the past year, was there a time when you did any of the following because you were worried about the cost?" We also asked participants, "In the past year, how much did you worry that?" with the following responses: "a great deal"; "a fair amount"; "a little"; or "not at all."

Out-of-Pocket Medical Costs

We collected information about participants' out-of-pocket medical costs and household income over the past year, then took the ratio of these variables to determine the percentage of household income spent on out-of-pocket medical costs. To assess out-of-pocket medical costs, we asked participants, "During the past year, about how much did you/your family spend out-of-pocket for your medical care? Include out-of-pocket expenses for prescription drugs, copayments, and deductibles, but do not include health insurance premiums or any costs paid by your health insurance." We defined higher out-of-pocket medical costs to be $\geq 10\%$ of household income, which was consistent with previous studies.⁴⁻⁹

Statistical Analysis

We used descriptive statistics to describe the sociodemographic and clinical characteristics for survivors and siblings. We also compared survivors with a higher and lower percentage of income spent on out-of-pocket medical costs, but not for siblings, given the small number of siblings ($n = 5$) with higher out-of-pocket medical costs. To identify characteristics associated with higher out-of-pocket medical costs, we conducted multivariable logistic regression analysis, simultaneously evaluating those characteristics associated with spending $\geq 10\%$ of their household income on out-of-pocket medical costs during the past year in univariate analyses.

To examine associations between a higher percentage of income spent on out-of-pocket medical costs and issues related to financial burden, we used logistic regression models, adjusting for potential confounders (eg,

marital status, presence of insurance, employment, and household income). We fit models with each indicator of financial burden as the outcome and used out-of-pocket medical costs $\geq 10\%$ of household income as the key risk factor. All reported P values are two-sided and considered significant at an α -level of .05. All analyses incorporated weighting to account for the stratified sampling design so that results were representative of the age distribution in the CCSS cohort.³⁵

RESULTS

Participants

Survivors in our sample were more likely to be male (46.7% ν 37.1%; $P = .025$), unmarried (35.4% ν 24.6%; $P = .008$), and have severe to life-threatening chronic medical conditions (39.7% ν 17.1%; $P < .001$) compared with siblings (Table 1). Survivors were more likely to have Medicare (5.8% ν 1.1%; $P = .011$) and Medicaid/state insurance (11.5% ν 4.6%; $P = .008$). Among survivors, mean time since cancer diagnosis was 30.2 years. Ten percent (58 of 580) of survivors had higher out-of-pocket medical costs, defined as spending $\geq 10\%$ of their household income on out-of-pocket medical costs during the past year, which was significantly greater than the proportion of siblings with higher out-of-pocket medical costs (2.9% [5 of 173 siblings]; $P < .001$). In both unadjusted and adjusted models, survivors had significantly greater odds of experiencing a higher percentage of income spent on out-of-pocket medical costs compared with siblings (Table 2).

Characteristics Associated With a Higher Percentage of Income Spent on Out-of-Pocket Medical Costs

Survivors with a higher percentage of income spent on out-of-pocket medical costs were more likely to be female (70.4% ν 51.5%; $P = .01$), unmarried (54.7% ν 33.4%; $P = .003$), and have private insurance (17.6% ν 6.2%; $P = .007$) compared with those with lower out-of-pocket medical costs (Table 1). Survivors with a higher percentage of income spent on out-of-pocket medical costs were more likely to have severe to life-threatening chronic medical conditions (52.8% ν 38.3%; $P = .009$). In addition, those with a higher percentage of income spent on out-of-pocket medical costs were less likely to be employed (51.9% ν 78.5%; $P < .001$) and to have health insurance (79.6% ν 91.8%; $P = .011$). We also found differences between those with higher and lower percentage of income spent on out-of-pocket medical costs regarding race/ethnicity ($P = .005$), household income ($P < .001$), and type of cancer ($P = .018$). Of note, we found no difference between the higher and lower out-of-pocket medical cost groups regarding the receipt of prior chemotherapy, radiation, or surgery.

To identify survivor characteristics associated with a higher percentage of income spent on out-of-pocket medical costs, we conducted a multivariable analysis adjusting for characteristics that differed between those with higher and lower percentage of income spent on out-of-pocket medical costs during the past year (Table 2). We found that household income $< \$50,000$ (odds ratio [OR], 5.5; 95% CI, 2.4 to 12.8) and being hospitalized at least once in the past year (OR, 2.3; 95% CI, 1.1 to 4.9) were independently associated with a higher percentage of income spent on out-of-pocket medical costs.

Financial Burden in Survivors of Childhood Cancer

Table 1. Demographic and Clinical Characteristics of Survivors of Childhood Cancer Versus Sibling Comparison Group and Survivors With High Versus Low OOP Medical Costs

Characteristic	Childhood Cancer Survivors v Siblings			Among Survivors OOP Medical Costs, % of Household Income		P†
	Survivors (n = 580)	Siblings (n = 173)	P*	< 10% (n = 522)	≥ 10% (n = 58)	
Age at survey, years			.071			.270
22-29	177 (11.2)	48 (12.6)		155 (10.8)	22 (14.8)	
30-39	184 (41.1)	57 (33.9)		171 (42.1)	13 (31.5)	
40-62	219 (47.7)	68 (53.4)		196 (36.2)	23 (46.3)	
Sex			.025			.010
Male	269 (46.7)	65 (37.1)		251 (48.5)	18 (29.6)	
Female	311 (53.3)	108 (62.9)		271 (51.5)	40 (70.4)	
Race/ethnicity			.995			.005
White, non-Hispanic	533 (92.8)	152 (93.3)		480 (93.1)	53 (92.5)	
Black, non-Hispanic	14 (2.1)	3 (1.8)		10 (1.3)	4 (7.5)	
Hispanic/Latino	21 (3.1)	6 (3.0)		20 (3.2)	1 (0.0)	
Other	11 (2.1)	3 (1.8)		11 (2.3)	0 (0.0)	
Marital status			.008			.003
Unmarried	231 (35.4)	50 (24.6)		195 (33.4)	36 (54.7)	
Married	346 (64.6)	123 (75.4)		325 (66.6)	21 (45.3)	
Household income, US\$.053			< .001
< 20,000	78 (11.7)	10 (5.2)		53 (9.0)	25 (38.9)	
20,000-39,999	92 (14.9)	22 (10.9)		74 (13.2)	18 (31.5)	
40,000-59,999	91 (16.1)	30 (16.7)		86 (16.6)	5 (9.3)	
60,000-79,999	88 (15.9)	27 (16.1)		84 (16.4)	4 (9.3)	
80,000-99,999	68 (11.4)	23 (12.1)		65 (12.0)	3 (5.6)	
> 100,000	155 (29.4)	60 (39.1)		152 (31.9)	3 (5.6)	
Don't know	6 (1.1)	0 (0.0)		6 (0.8)	0 (0.0)	
Education			.345			.714
≤ High school	69 (11.9)	13 (8.8)		61 (11.6)	8 (15.6)	
Some postgraduate college	152 (26.8)	42 (23.9)		137 (27.1)	15 (24.4)	
Completed college	306 (61.3)	104 (67.3)		279 (61.3)	27 (60.0)	
Employment status			.023			< .001
Employed	435 (76.1)	136 (79.9)		404 (78.5)	31 (51.9)	
Unemployed and looking for work	33 (5.4)	7 (3.4)		25 (4.8)	8 (13.5)	
Unable to work because of illness/disability	51 (8.7)	4 (2.9)		43 (7.7)	8 (17.3)	
Other	54 (9.8)	24 (13.8)		45 (9.0)	9 (17.3)	
Health insurance status			.317			.011
Insured	519 (90.7)	157 (93.1)		475 (91.8)	44 (79.6)	
Uninsured	61 (9.3)	16 (6.9)		47 (8.2)	14 (20.4)	
If Insured, type of insurance						
Employer sponsored	451 (80.8)	145 (86.8)	.073	415 (82.4)	36 (64.7)	.004
Individual private	45 (7.2)	15 (7.5)	.891	34 (6.2)	11 (17.6)	.007
Medicare	37 (5.8)	2 (1.1)	.011	31 (5.4)	6 (9.8)	.205
Medicaid/state	73 (11.5)	9 (4.6)	.008	65 (11.0)	8 (15.7)	.353
Don't know	3 (0.4)	1 (0.6)	.681	1 (0.20)	2 (2.0)	.172
Type of cancer						.018
Leukemia	202 (33.3)	—		173 (31.1)	29 (52.7)	
Hodgkin lymphoma	65 (14.2)	—		62 (15.0)	3 (7.3)	
CNS	77 (13.1)	—		70 (13.3)	7 (10.9)	
Wilms (kidney) tumor	62 (9.2)	—		60 (9.9)	2 (3.6)	
Soft tissue sarcoma	46 (9.0)	—		42 (8.9)	4 (9.1)	
Bone	38 (8.2)	—		37 (8.7)	1 (1.8)	
Non-Hodgkin lymphoma	32 (6.7)	—		30 (7.0)	2 (3.6)	
Neuroblastoma	58 (6.4)	—		48 (6.1)	10 (10.9)	
Years since diagnosis, mean (SD)	30.2 (4.6)	—		30.3 (4.6)	29.7 (4.5)	.351
Any chemotherapy	432 (76.9)	—		384 (76.0)	48 (86.8)	.086
Any radiation	334 (65.9)	—		296 (65.3)	38 (73.1)	.285
Any surgery	432 (80.7)	—		390 (81.6)	42 (71.7)	.098
Recurrence of cancer	76 (12.9)	—		67 (12.9)	9 (13.0)	1.000
Second cancer	24 (4.8)	—		20 (4.6)	4 (7.4)	.318
Chronic medical conditions			< .001			.009
None	95 (15.2)	53 (30.3)		94 (16.5)	1 (1.9)	
Mild to moderate	264 (45.2)	94 (52.6)		235 (45.2)	29 (45.3)	
Severe to life-threatening	221 (39.7)	26 (17.1)		193 (38.3)	28 (52.8)	
Hospitalized at least once in past year	78 (14.0)	19 (10.6)	.270	62 (12.3)	16 (30.6)	.002

NOTE. Data are presented as No. (% weighted) unless otherwise noted. Total numbers in the table might not add up to the full cohort because of missing data. Percentages are weighted to reflect the population age distribution of the full Childhood Cancer Survivor Study cohort.

Abbreviations: OOP, out of pocket; SD, standard deviation.

*P value is comparing survivors of childhood cancer with the sibling comparison group.

†P value is comparing OOP < 10% to OOP ≥ 10% among survivors of childhood cancer.

Table 2. Association Between Survivorship, Demographics, and Clinical Characteristics With Out-of-Pocket Medical Costs $\geq 10\%$ of Household Income

Characteristic*	Unadjusted		Adjusted	
	OR	95% CI	OR	95% CI
Model with both survivors and siblings				
Survivor	5.07	1.69 to 15.23	4.33	1.38 to 13.52
Female sex	1.83	1.03 to 3.25	1.68	0.89 to 3.17
Unmarried	2.46	1.42 to 4.25	1.33	0.67 to 2.62
Household income < \$50,000	6.08	3.19 to 11.60	4.90	2.32 to 10.36
Unemployed	3.56	2.04 to 6.22	2.78	1.46 to 5.28
Government-sponsored insurance	2.15	1.08 to 4.28	0.55	0.24 to 1.30
Severe to life-threatening chronic conditions	1.96	1.14 to 3.36	1.26	0.68 to 1.34
Model limited to survivors only†				
Black race	5.93	1.73 to 20.36	1.74	0.40 to 7.63
Unmarried	2.38	1.34 to 4.21	1.21	0.61 to 2.40
Household income < \$50,000	6.15	3.10 to 12.22	5.52	2.38 to 12.78
Unemployed	3.34	1.86 to 6.00	1.91	0.96 to 3.81
Severe to life threatening chronic conditions	1.78	1.01 to 3.12	1.04	0.53 to 2.04
Hospitalized in the past year	3.08	1.59 to 5.99	2.31	1.09 to 4.88

Abbreviation: OR, odds ratio.

*Includes characteristics that differed between survivors and siblings on the basis of descriptive statistics ($P < .05$).

†Includes characteristics that differed between survivors with < 10% and those with $\geq 10\%$ of their household income spent on out-of-pocket medical costs during the past year on the basis of descriptive statistics ($P < .01$).

Financial Burden

Figure 2 shows the prevalence of survivors' and siblings' self-reported financial burden. Survivors with a higher percentage of income spent on out-of-pocket medical costs were more likely to report problems paying medical bills (68.5% v 17.6%; $P < .001$) compared with those with lower percentage of income spent on out-of-pocket medical costs. In addition, survivors with higher percentage of income spent on out-of-pocket medical costs were more likely to report deferring care (58.0% v 23.7%; $P < .001$); skipping a test, treatment, or follow-up (50.0% v 23.0%; $P < .001$);

worrying about affording health insurance (38.1% v 12.0%; $P < .001$); taking a smaller dose of medication than prescribed (36.7% v 10.4%; $P < .001$); and thoughts of filing for bankruptcy (34.0% v 5.4%; $P < .001$).

In both unadjusted and adjusted regression models, we found that survivors with out-of-pocket medical costs $\geq 10\%$ of their annual household income were significantly more likely to report issues with financial burden compared with both siblings and survivors with lower out-of-pocket medical costs (Table 3). Because only five siblings spent $\geq 10\%$ of their household income on

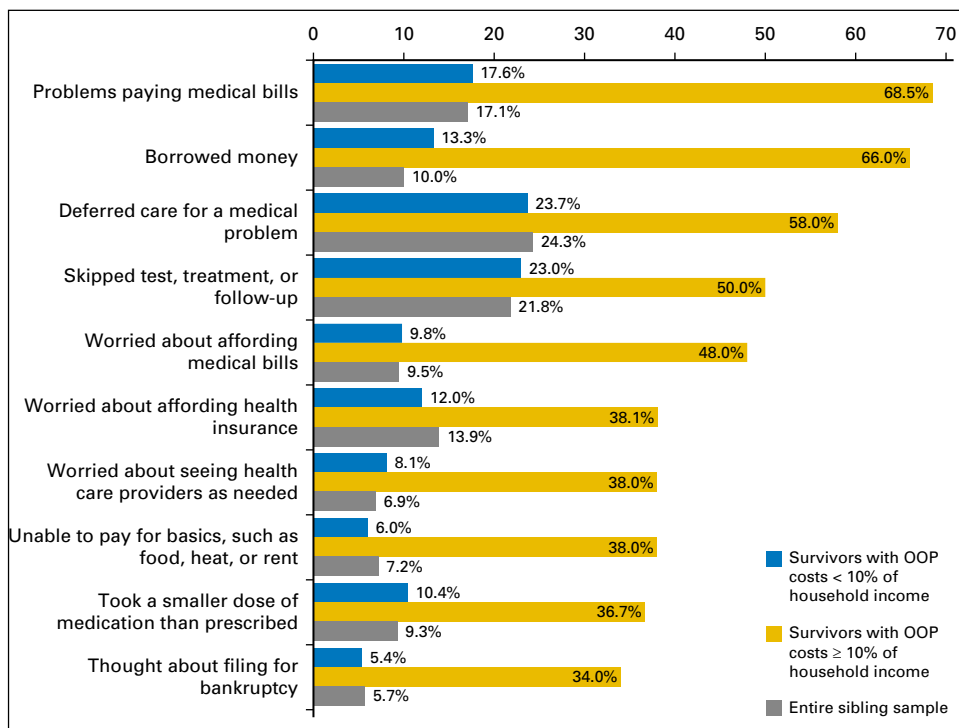


Fig 2. Financial burden among survivors of childhood cancer and siblings. OOP, out of pocket.

Financial Burden in Survivors of Childhood Cancer

Table 3. Associations Between Out-of-Pocket Medical Costs ≥ 10% of Household Income and Indicators of Financial Burden for Survivors and Siblings

Indicator of Financial Burden	Siblings		Survivor < 10%				Survivor ≥ 10%			
	OR	95% CI	Unadjusted		Adjusted		Unadjusted		Adjusted	
			OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI
Models with both survivors and siblings										
Problems paying medical bills	—	—	1.05	0.67 to 1.66	0.99	0.62 to 1.60	10.87	5.40 to 21.89	8.67	4.01 to 18.73
Worried a great deal about										
Affording medical bills	—	—	1.03	0.58 to 1.85	0.96	0.52 to 1.78	8.60	4.06 to 18.25	4.96	2.19 to 11.23
Seeing health care providers as needed	—	—	1.19	0.61 to 2.33	1.12	0.55 to 2.26	8.23	3.62 to 18.73	4.46	1.81 to 11.02
Affording health insurance	—	—	0.84	0.50 to 1.42	0.78	0.45 to 1.36	3.82	1.78 to 8.20	2.21	0.97 to 5.01
Did the following as a result of medical bills										
Borrowed money	—	—	1.38	0.89 to 2.40	1.31	0.73 to 2.33	17.30	8.03 to 37.25	11.38	5.02 to 25.80
Unable to pay for basics such as food, heat, or rent	—	—	0.81	0.41 to 1.61	0.69	0.34 to 1.42	7.83	3.48 to 17.66	4.44	1.83 to 10.78
Thought about filing for bankruptcy	—	—	0.94	0.44 to 1.98	0.88	0.41 to 1.90	8.37	3.50 to 19.98	5.76	2.27 to 14.63
Did the following due to worries about cost										
Took smaller dose of medication than prescribed	—	—	1.13	0.63 to 2.02	1.10	0.61 to 2.00	5.77	2.66 to 12.53	3.93	1.74 to 8.85
Deferred care for a medical problem	—	—	0.96	0.65 to 1.44	0.89	0.58 to 1.36	4.28	2.21 to 8.29	2.76	1.34 to 5.68
Skipped test, treatment, or follow-up	—	—	1.07	0.71 to 1.62	1.01	0.66 to 1.56	3.510	1.81 to 6.81	2.24	1.11 to 4.54
Survivor ≥ 10%										
					Survivor < 10%		Unadjusted		Adjusted	
					OR	95% CI	OR	95% CI	OR	95% CI
Models limited to survivors only										
Problems paying medical bills					—	—	10.35	5.57 to 19.24	8.78	4.39 to 17.56
Worried a great deal about										
Affording medical bills					—	—	8.32	4.45 to 15.57	5.23	2.63 to 10.34
Seeing health care providers as needed					—	—	6.90	3.59 to 13.26	3.90	1.86 to 8.21
Affording health insurance					—	—	4.54	2.30 to 8.97	3.04	1.47 to 6.30
Did the following as a result of medical bills										
Borrowed money					—	—	12.56	6.34 to 23.76	8.72	4.35 to 17.47
Unable to pay for basics such as food, heat, or rent					—	—	9.66	4.90 to 19.06	6.11	2.85 to 13.10
Thought about filing for bankruptcy					—	—	8.92	4.43 to 17.98	6.36	2.95 to 13.71
Did the following due to worries about cost										
Took smaller dose of medication than prescribed					—	—	5.12	2.68 to 9.78	3.42	1.71 to 6.83
Deferred care for a medical problem					—	—	4.44	2.44 to 8.07	3.10	1.60 to 5.98
Skipped test, treatment, or follow-up					—	—	3.27	1.81 to 5.91	2.14	1.13 to 4.07

NOTE. Models adjusted for marital status, presence of insurance, employment, and household income. Abbreviation: OR, odds ratio.

out-of-pocket medical costs during the past year, we were unable to group siblings by high and low percentage of income spent on out-of-pocket medical costs. In adjusted models, survivors with a higher percentage of income spent on out-of-pocket medical costs were more than eight times as likely to report problems paying medical bills compared with siblings (OR, 8.7; 95% CI, 4.0 to 18.7) and the group of survivors with lower out-of-pocket medical costs (OR, 8.8; 95% CI, 4.4 to 17.6). We also found significant associations between a higher percentage of income spent on out-of-pocket medical costs and other self-reported indicators of financial burden, which included worrying about seeing health care providers as needed, thoughts of filing for bankruptcy, deferring care, and taking a smaller dose of medication than prescribed.

DISCUSSION

In a national cohort of adult survivors of childhood cancer, we identified a relatively high prevalence of financial burden and demonstrated that survivors with a higher percentage of income spent on out-of-pocket medical costs carry a significantly disproportionate financial burden compared with both a sibling

comparison group and those with lower percentage of income spent on out-of-pocket costs. Of note, we found that survivors of cancer with higher percentage of income spent on out-of-pocket costs were more likely to report worries about seeing health care providers as needed, thoughts of filing for bankruptcy, and actions that may jeopardize their health, such as deferring care and not adhering to prescribed treatment. Importantly, survivors in our study, on average, were > 30 years from their cancer diagnosis and yet many still struggle with high out-of-pocket medical costs and resulting financial burden. Collectively, these findings demonstrate that survivors' out-of-pocket medical costs put them at risk for experiencing adverse effects related to financial burden, which underscores the need to address high out-of-pocket medical expenditures in this population.

Of importance, our findings demonstrate that survivors have a greater risk for spending a higher percentage of their income on out-of-pocket medical expenses compared with a sibling control group. In addition, we identified characteristics of survivors who were more likely to spend ≥ 10% of their income on out-of-pocket medical expenses. Specifically, those with a higher percentage of income spent on out-of-pocket costs were more likely to be unemployed, hospitalized in the past year, have more severe chronic medical conditions, and have lower incomes. These are

vulnerable populations at particularly high risk for experiencing financial burden related to high medical costs who may ultimately suffer worse health outcomes by foregoing medical care.^{19,36-38} Thus, we have identified patient characteristics that can be used to proactively target these individuals with programs to address their financial concerns.

To our knowledge, this is the first study to report associations between a higher percentage of income spent on out-of-pocket medical costs and financial burden in adult survivors of childhood cancer. The behaviors adopted by survivors in our study in response to financial burden may have detrimental impacts on their survivorship care, quality of life, and even survival.¹¹⁻¹⁹ A more comprehensive understanding of the relationship between high out-of-pocket medical expenses and adverse effects of financial burden on survivors of cancer could be instrumental in identifying those who are at risk for spending a higher percentage of their income on out-of-pocket medical costs to address their financial burden and improve health outcomes; informing policy change to help meet the unique needs of survivors of cancer; and understanding how both higher out-of-pocket costs and financial burden influence patients' approaches to their medical care and decision-making. Therefore, our study identifies the unique and most commonly endorsed issues related to financial burden in survivors of cancer with a higher percentage of income spent on out-of-pocket medical costs, and underscores the need to better understand and address high out-of-pocket costs in this population when striving to improve the quality of their care.

Our study marks the first step in understanding the prevalence, risk, and magnitude of financial burden in adult survivors of childhood cancer, and our findings have important policy implications. Survivors of childhood cancer represent a population with preexisting health conditions who are at particularly high risk for financial burden, which can negatively influence health outcomes, especially as cost sharing increases.^{13,16,36,37} Future research is needed to determine the extent to which survivors may experience greater financial burden as insurance plans are restructured and barriers to affordable health care persist. Efforts to ensure the systematic assessment of survivors' financial concerns may become increasingly important, and health systems should encourage early and ongoing communication between clinicians and patients about the financial consequences of their care. Future efforts to address the financial burden of survivors of cancer should investigate the efficacy of incorporating financial discussions within survivorship clinics and/or care plans and focus on developing programs that involve financial services, patient navigators, and/or social work.

Several limitations of our study warrant discussion. First, we collected data from a cohort with limited racial and ethnic diversity; thus, our findings may not generalize to more diverse populations. Second, this is a cross-sectional study, and, therefore, we cannot confirm the directionality of the associations we found. Moreover, we asked participants to self-report their out-of-pocket medical costs, and these estimates may be limited by their ability to accurately recall out-of-pocket expenses. Of note, we followed the standard self-report practice of national surveys, including the Medical Expenditure Panel Survey and National Health Interview Survey, in asking participants to recall their income and out-of-pocket expenses.^{30,32,39} Third, we may have underestimated the strength of the relationship between a higher

percentage of income spent on out-of-pocket medical expenses and issues related to financial burden, as the survivors who reported their income and out-of-pocket costs had higher incomes and more education than did those for whom we lack this information. Fourth, we lack longitudinal data regarding changes in financial burden and out-of-pocket medical costs, and studies suggest that financial burden may vary throughout the survivorship course.^{19,38} In addition, we conducted the survey before the launch of the ACA health insurance exchanges, and, therefore, future investigators should study how the ACA influenced both high out-of-pocket medical costs and financial burden among survivors of cancer. Although the ACA seeks to protect those with preexisting conditions, prior work suggests that survivors of childhood cancer lack understanding of the ACA and have concerns about potential cost increases.^{35,40} We hope that our findings help to serve as a comparison for future efforts to understand the impact of current policy decisions on the financial burden experienced by survivors of cancer.

In summary, we identified that financial burden is common among adult survivors of childhood cancer and demonstrated associations between financial burden and a higher percentage of income spent on out-of-pocket medical costs. Of note, a substantial minority of survivors in our cohort spent $\geq 10\%$ of their household income on out-of-pocket medical expenses. Importantly, we found that survivors with a higher percentage of income spent on out-of-pocket medical costs were more likely to have lower incomes and to be hospitalized in the past year. In addition, we demonstrated that those with higher out-of-pocket medical costs were more likely to report financial burden and were at risk for behaviors that were potentially detrimental to their health outcomes. These findings underscore the long-term risks of high out-of-pocket medical expenses and potential economic threats to survivors' quality of life after a diagnosis of childhood cancer. Future research that focuses on addressing the adverse consequences of the financial burden experienced by survivors of cancer is warranted and should account for the impact that out-of-pocket medical costs can have on this vulnerable population with long-term health care needs.

AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

Disclosures provided by the authors are available with this article at jco.org.

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Financial Burden in Survivors of Childhood Cancer: A Report From the Childhood Cancer Survivor Study

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Appendix

Table A1. Comparison of Survivors With and Without Income and/or Out-of-Pocket Medical Costs Information

Characteristic	Without Income and/or Out-of-Pocket Cost Data (n = 118)	With Income and Out-of-Pocket Cost Data (n = 580)	P*
Age at survey, years			.429
22-29	37 (11.9)	177 (11.2)	
30-39	44 (48.3)	184 (41.0)	
40-62	37 (39.8)	219 (47.7)	
Sex			.188
Male	45 (39.8)	269 (46.7)	
Female	73 (60.2)	311 (53.3)	
Race/ethnicity			.161
White, non-Hispanic	113 (97.4)	533 (92.8)	
Black, non-Hispanic	0 (0.0)	14 (2.1)	
Hispanic/Latino	3 (2.6)	21 (3.1)	
Other	1 (0.0)	11 (2.1)	
Marital status			< .001
Unmarried	68 (55.7)	231 (35.4)	
Married	47 (44.3)	346 (64.6)	
Household income, US\$			< .001
< 20,000	13 (13.3)	78 (11.7)	
20,000-39,999	14 (14.4)	92 (14.9)	
40,000-59,999	13 (14.4)	91 (16.1)	
60,000-79,999	7 (7.8)	88 (15.9)	
80,000-99,999	11 (14.4)	68 (11.4)	
> 100,000	6 (8.9)	155 (29.4)	
Don't know	30 (26.7)	6 (0.7)	
Education			.001
≤ High school	29 (25.5)	69 (11.9)	
Some postgraduate college	27 (26.5)	152 (26.8)	
Completed college	46 (48.0)	306 (61.3)	
Employment status			.224
Employed	75 (68.1)	435 (76.1)	
Unemployed and looking for work	11 (8.6)	33 (5.4)	
Unable to work as a result of illness/disability	15 (12.9)	51 (8.7)	
Other	15 (10.3)	54 (9.8)	
Health insurance status			.066
Insured	100 (84.7)	519 (90.7)	
Uninsured	18 (15.3)	61 (9.3)	
If insured, type of insurance			
Employer sponsored	76 (70.9)	451 (80.8)	.021
Individual private	9 (9.1)	45 (7.2)	.552
Medicare	19 (15.5)	37 (5.8)	.001
Medicaid/state	21 (16.4)	73 (11.4)	.154
Don't know	3 (0.9)	3 (0.4)	.412
Type of cancer			.002
Bone	7 (7.7)	38 (8.1)	
CNS	27 (23.9)	77 (13.1)	
Hodgkin lymphoma	6 (6.8)	65 (14.2)	
Wilms (kidney) tumor	4 (2.6)	62 (9.2)	
Leukemia	53 (43.6)	202 (33.3)	
Neuroblastoma	9 (4.3)	58 (6.4)	
Non-Hodgkin lymphoma	7 (6.8)	32 (6.7)	
Soft tissue sarcoma	5 (4.3)	46 (9.0)	
Years since diagnosis, mean (SD)	30.465 (4.745)	30.228 (4.579)	.416
Any chemotherapy	84 (75.5)	432 (77.0)	.712
Any radiation	67 (63.6)	334 (65.9)	.661
Any surgery	83 (76.4)	432 (80.7)	.299

(continued in next column)

Table A1. Comparison of Survivors With and Without Income and/or Out-of-Pocket Medical Costs Information (continued)

Characteristic	Without Income and/or Out-of-Pocket Cost Data (n = 118)	With Income and Out-of-Pocket Cost Data (n = 580)	P*
Recurrence of cancer	11 (7.6)	76 (12.9)	.121
Second cancer	6 (6.8)	24 (4.8)	.364
Chronic medical conditions			
None	16 (15.4)	95 (15.2)	
Mild to moderate	55 (45.3)	264 (45.2)	
Severe to life threatening	47 (39.3)	221 (39.7)	
Hospitalized at least once in the past year	19 (18.1)	78 (14.0)	.291
Financially motivated behaviors			
In the past year, have you/your family had any problems paying your medical bills?	22 (21.2)	126 (22.3)	.958
Had to borrow money	18 (14.9)	99 (17.9)	.500
Had a medical problem but did not go to a health care provider or a clinic	20 (18.8)	149 (26.5)	.096
Skipped medical test, treatment, or follow up	23 (21.1)	136 (25.4)	.344
You wouldn't be able to pay for medical bills	14 (13.6)	72 (13.2)	.878
Health insurance would become so expensive you wouldn't be able to afford it	13 (15.8)	64 (14.1)	.636
You wouldn't be able to go to the health care providers you wanted	16 (14.5)	59 (10.7)	.251
Been unable to pay for basic necessities, such as food, heat, or rent	6 (6.0)	50 (8.6)	.458
Took a smaller dose/fewer pills than prescribed	10 (7.0)	69 (12.7)	.110
Thought about filing for bankruptcy	4 (2.6)	42 (7.9)	.044

Table A2. Financial Burden Measures

Financial Burden Question	Response
In the past year, have you or your family had any problems paying your medical bills?	We compared yes v no, don't know
In the past year, how much did you worry that	We compared worried a great deal v a fair amount, a little, not at all
You or your spouse would lose your job A change in job or school would result in loss of or lower-quality health insurance coverage You wouldn't be able to pay for medical bills You wouldn't be able to get a medical procedure that you needed You wouldn't be able to go to the health care providers you wanted Health insurance would become so expensive you wouldn't be able to afford it Your health insurance plan would change terms (eg, costs that were once covered will no longer be covered) You would need some health care services that were not covered	
In the past year, have any of the following happened because of medical expenses?	We compared yes v no, don't know
Put off major purchases, such as a new home or car Been unable to pay for basic necessities, such as food, heat, or rent Had to take money out of savings Spent more than 10% of your income on medical expenses Had to borrow money Took on credit card debt Took out a mortgage against your home or took out a loan Thought about filing for bankruptcy Filed for bankruptcy	
In the past year, was there a time when you did any of the following because you were worried about the cost?	We compared yes v no, don't know
Skipped a medical test, treatment, or follow-up Had a medical problem but did not go to a health care provider or a clinic Did not see a specialist Put off or postponed preventive care Put off or postponed dental care Put off or postponed vision care Put off or postponed mental health Had no primary care provider Did not fill a prescription Took a smaller dose/fewer pills than prescribed	