

## ARTICLE

# Determinants and Consequences of Financial Hardship Among Adult Survivors of Childhood Cancer: A Report From the St. Jude Lifetime Cohort Study

I-Chan Huang, Nickhill Bhakta, Tara M. Brinkman, James L. Klosky, Kevin R. Krull, DeoKumar Srivastava, Melissa M. Hudson, Leslie L. Robison

See the Notes section for the full list of authors' affiliations.

Correspondence to: I-Chan Huang, PhD, Department of Epidemiology and Cancer Control, St. Jude Children's Research Hospital, MS-735, 262 Danny Thomas Place, Memphis, TN 38105 (e-mail: i-chan.huang@stjude.org).

## Abstract

**Background:** Financial hardship among survivors of pediatric cancer has been understudied. We investigated determinants and consequences of financial hardship among adult survivors of childhood cancer.

**Methods:** Financial hardship, determinants, and consequences were examined in 2811 long-term survivors (mean age at evaluation = 31.8 years, years postdiagnosis = 23.6) through the baseline survey and clinical evaluation. Financial hardship was measured by material, psychological, and coping/behavioral domains. Outcomes included health and life insurance affordability, retirement planning, symptoms, and health-related quality of life (HRQOL). Odds ratios (ORs) estimated associations of determinants with financial hardship. Odds ratios and regression coefficients estimated associations of hardship with symptom prevalence and HRQOL, respectively. All statistical tests were two-sided.

**Results:** Among participants, 22.4% (95% confidence interval [CI] = 20.8% to 24.0%), 51.1% (95% CI = 49.2% to 52.9%), and 33.0% (95% CI = 31.1% to 34.6%) reported material, psychological, and coping/behavioral hardship, respectively. Risk factors across hardship domains included annual household income of \$39 999 or less vs \$80 000 or more (material OR = 3.04, 95% CI = 2.08 to 4.46, psychological OR = 3.64, 95% CI = 2.76 to 4.80, and coping/behavioral OR = 4.95, 95% CI = 3.57 to 6.86) and below high school attainment vs college graduate or above (material OR = 2.22, 95% CI = 1.45 to 3.42, psychological OR = 1.75, 95% CI = 1.18 to 2.62, and coping/behavioral OR = 2.05, 95% CI = 1.38 to 3.06). Myocardial infarction, peripheral neuropathy, subsequent neoplasm, seizure, stroke, reproductive disorders, amputation, and upper gastrointestinal disease were associated with higher material hardship (all  $P < .05$ ). Hardship across three domains was associated with somatization, anxiety and depression (all  $P < .001$ ), suicidal ideation (all  $P < .05$ ), and difficulty in retirement planning (all  $P < .001$ ). Survivors with hardship had statistically significantly lower HRQOL (all  $P < .001$ ), sensation abnormality (all  $P < .001$ ), and pulmonary (all  $P < .05$ ) and cardiac (all  $P < .05$ ) symptoms.

**Conclusions:** A substantial proportion of adult survivors of childhood cancer experienced financial hardship. Vulnerable sociodemographic status and late effects were associated with hardship. Survivors with financial hardship had an increased risk of symptom prevalence and impaired HRQOL.

Over the past 50 years, incremental improvements in therapies have increased the survival rates of most childhood cancers (1). However, survivors often experience substantial burden from

chronic health conditions (2,3), physical and neurocognitive deficits (4,5), symptom prevalence, and suboptimal health-related quality of life (HRQOL) (6,7). The social and economic impact of

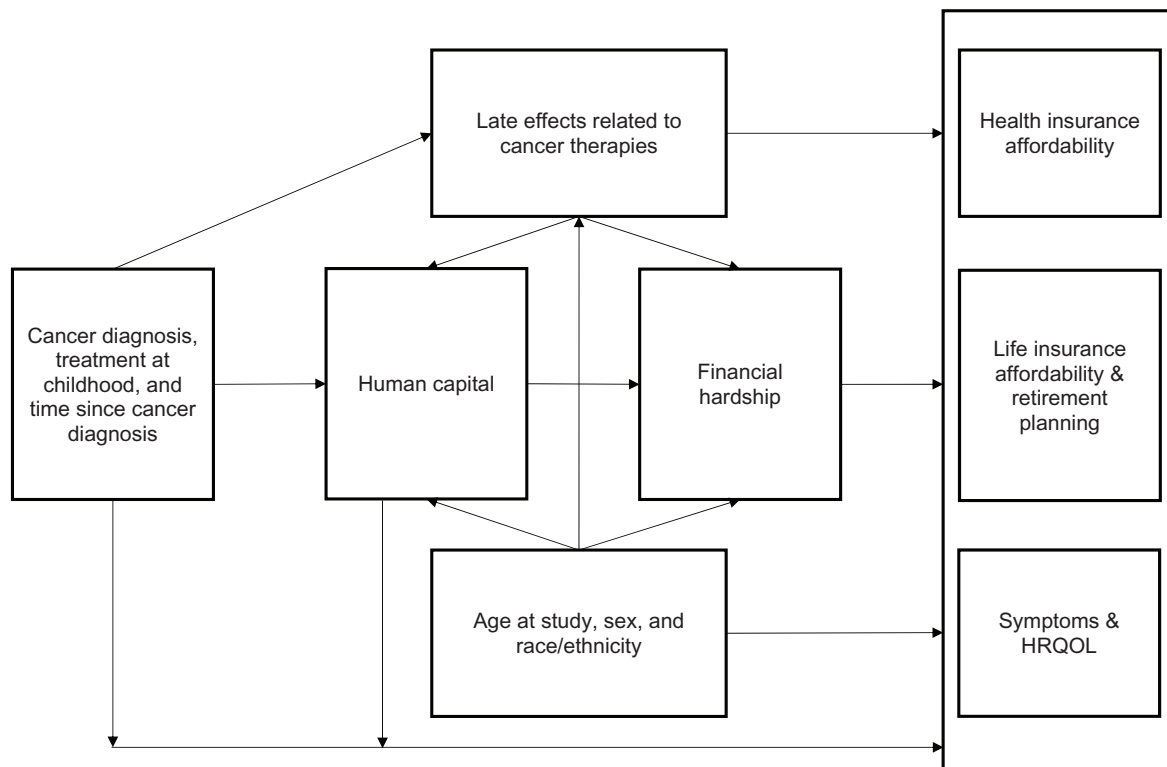


Figure 1. Conceptual framework for investigating financial hardship in adult survivors of childhood cancer. HRQOL = health-related quality of life.

this burden is considerable because survivors are less likely to graduate from college, assume higher-skilled occupations, or earn higher income than siblings (8–10). The Childhood Cancer Survivor Study (CCSS) has reported that survivors incur higher out-of-pocket medical costs than siblings (11).

“Financial hardship” (financial distress due to cancer diagnosis or treatment) and “financial toxicity” (adverse impact of financial hardship on health outcomes) are emerging concepts to describe financial issues faced by cancer populations. A taxonomy has recently been proposed to study these concepts: material conditions (expenses or bills related to medical care), psychological responses (worry/distress due to costs), and coping behaviors (skipped care or medications) (12). Approximately 30% of US adult cancer survivors have financial problems (13,14). Risk factors of material and/or psychological hardship among adult cancer survivors include middle age (41–65 years) at study participation (14,15), female sex (14–16), minority race/ethnicity (African American, Hispanic) (14–17), lower educational attainment (15,18) and household income (15,17,18), unemployment (17), shorter time since diagnosis (13), treated with chemotherapy or radiation therapy (13), and poor health conditions (17,18). Survivors cope with financial problems by withholding medical care (19). Consequently, financial challenge has been linked to suboptimal HRQOL (14) and increased bankruptcy (20).

The emergence of financial hardship in survivors of childhood cancer is unique, as treatment exposures and subsequent medical complications occurring during early stages of human developmental can jeopardize maturation of human capital (ie, educational attainment, employment, etc.). However, the impacts of treatment toxicity and human capital on financial hardship and the associations of hardship with acquiring

insurance, retirement planning, symptom prevalence, suicidal ideation, and HRQOL have been understudied. Medically verified late complications and associations with financial hardship have not yet been identified.

Using data collected from the St. Jude Lifetime Cohort Study (SJLIFE), we investigated the prevalence, determinants, and consequences of financial hardship in adult survivors of childhood cancer within a proposed conceptual framework. We hypothesized that 1) demographic (middle-aged at evaluation) and clinical factors (more intense treatment, developing treatment-related chronic health conditions) would increase risk of material, psychological, and coping/behavioral financial hardship; 2) human capital (lower educational attainment, lower household income, unemployment) would outweigh the influence of demographic and clinical variables on financial hardship; and 3) financial challenges could impact health/life insurance affordability, retirement planning, and health outcomes (symptom prevalence, suicidal ideation, and HRQOL).

## Methods

### Study Sample

This cross-sectional study utilized data collected from 2811 adult survivors of childhood cancer enrolled in SJLIFE, a retrospective cohort study with prospective clinical follow-up established to investigate etiologies and late treatment effects (3,21). Survivors received comprehensive risk-based medical evaluations consistent with the Children’s Oncology Group (COG) Long-term Follow-up Guidelines (22,23). Clinical assessment data were used to categorize 168 specific chronic health conditions using modified Common Terminology Criteria for

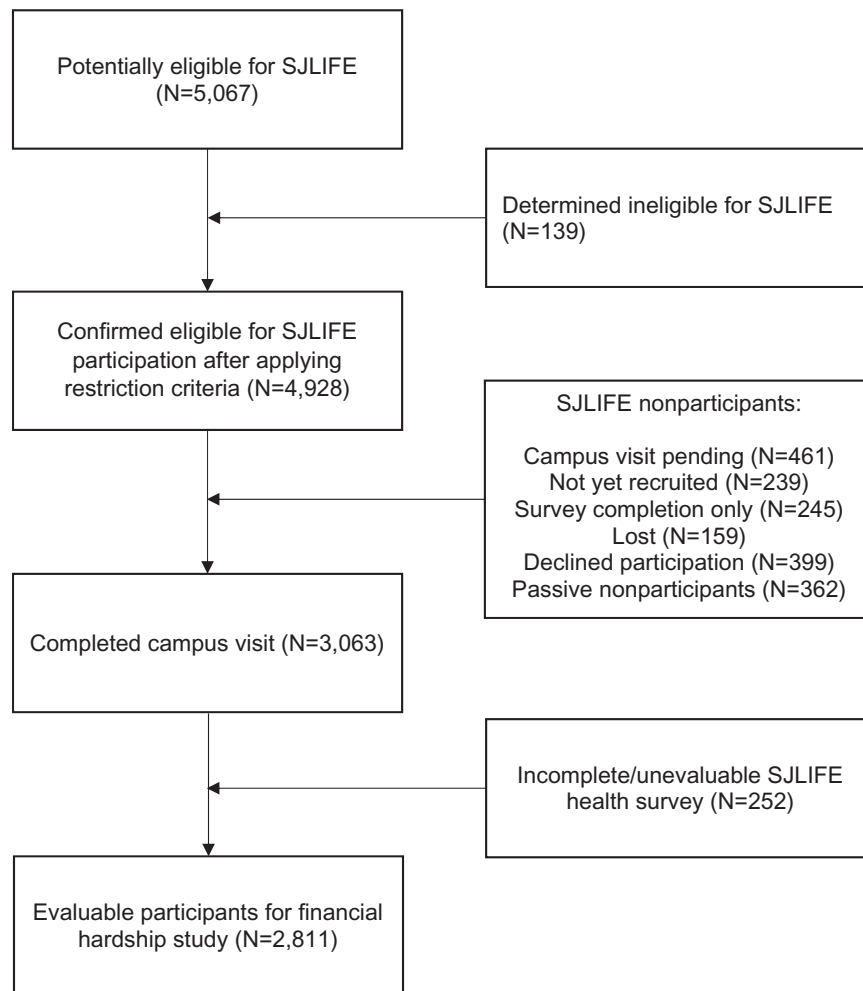


Figure 2. A consort diagram of study participant enrollment. SJLIFE = St. Jude Lifetime Cohort Study.

Adverse Events (CTCAE) grading; the severity of each condition was categorized as asymptomatic/mild (grade 1), moderate (grade 2), severe/disabling (grade 3), or life threatening (grade 4), as previously reported (24). During clinical evaluations, participants completed a survey that investigated financial situation, health and life insurance affordability, retirement planning, and patient-reported outcomes. Clinical and survey data collected during the first SJLIFE evaluation were used in this study. Figure 1 displays the conceptual framework developed from this study for investigating the determinants and consequences of financial hardship in adult survivors of childhood cancer.

### Data Collection

Eligible participants included survivors who were treated at St. Jude since 1962, survived 10 years or longer from diagnosis, and were age 18 years or older at study participation. As of June 2015, 5067 potentially eligible survivors were identified, 4928 were confirmed eligible, 3063 completed an on-campus clinical assessment, and 2811 were included in the analysis (Figure 2). The study protocol was approved by St. Jude's institutional review board, and all participants provided written informed consent for evaluations.

### Measures

We used three survey items to evaluate three domains of financial hardship. Material hardship: "Looking back over time since your cancer diagnosis, how much of an impact did your cancer experiences have on your financial situation?" As data related to medical bills/debts were not collected in the SJLIFE survey, we used this general financial impact item as a surrogate of material hardship. This item was derived from the Brief Cancer Impact Assessment (25) and contained five response categories (1 = very negative impact; 2 = somewhat negative impact; 3 = no impact; 4 = somewhat positive impact; 5 = very positive impact), which were further dichotomized into "hardship" (1–2) and "no hardship" (3–5). Psychological hardship: "Concern about ability to cover expenses for health care and prescribed medicine." This item contained five response categories (1 = very concerned; 2 = somewhat concerned; 3 = concerned; 4 = not very concerned; 5 = not at all concerned), which were further dichotomized into "hardship" (1–3) and "no hardship" (4–5). Coping/behavioral hardship: "You needed to see a doctor or go to the hospital but did not go due to finances." This item contained two response categories (yes and no).

One item from the SJLIFE survey was used to evaluate health insurance affordability ("Ever had difficulty obtaining health insurance because of your health history"). Two items were used

Table 1. Characteristics of study participants and nonparticipants

Characteristics	Survivors included in this study (n = 2811)	Survivors eligible but excluded from this study (n = 2117)*	P†
Mean age at cancer diagnosis (SD), y	8.3 (5.6)	8.4 (5.6)	.54
Range, y	1–24.8	1–28.6	
Mean age at evaluation (SD), y	31.8 (8.4)	—	
Range, y	18.3–64.5		
Mean time since cancer diagnosis (SD), y	23.6 (8.1)	—	
Range, y	10.0–48.0		
No. of people supported by household income (SD)	2.8 (1.4)	—	
Range	1–9		
Mean age at evaluation, No. (%)			
18–29.9 y	1301 (46.7)	—	
30–39.9 y	998 (35.9)	—	
≥40 y	485 (17.4)	—	
Mean time since diagnosis, No. (%)			
10–19 y	1012 (36.0)	—	
20–29 y	1127 (40.1)	—	
≥30 y	672 (23.9)	—	
Sex, No. (%)			<.001
Male	1454 (51.7)	1228 (58.0)	
Female	1357 (48.3)	889 (42.0)	
Race/ethnicity, No. (%)			<.001
White, non-Hispanic	2170 (80.1)	1658 (78.3)	
Black, non-Hispanic	359 (12.8)	339 (16.0)	
Hispanic	121 (4.3)	89 (4.2)	
Other‡	161 (5.7)	31 (1.5)	
Educational attainment, No. (%)			
Below high school	250 (9.7)	—	
High school graduate/GED	518 (20.0)	—	
Some college/training after high school	898 (34.7)	—	
College graduate and above	920 (35.6)	—	
Employment status, No. (%)			
Currently employed	1836 (65.3)	—	
Currently unemployed	975 (34.7)	—	
Annual household income, No. (%)			
≤\$39 999	1067 (44.5)	—	
\$40 000–\$79 999	779 (32.5)	—	
≥\$80 000	550 (23.0)	—	
Marital status, No. (%)			
Married/living as married	1083 (40.0)	—	
Status other than married	1627 (60.0)	—	
Health insurance status, No. (%)			
Insured	2141 (77.4)	—	
Uninsured	624 (22.6)	—	
Cancer diagnosis, No. (%)			
Acute lymphoblastic leukemia	947 (33.7)	590 (27.9)	<.001
Other leukemia	124 (4.4)	116 (5.5)	.05
Hodgkin lymphoma	348 (12.4)	219 (10.3)	.02
Non-Hodgkin lymphoma	207 (7.4)	175 (8.3)	.13
Central nervous system malignancy	285 (10.1)	247 (11.7)	.05
Sarcomas	364 (13.0)	273 (12.9)	.50
Wilms tumor	186 (6.6)	138 (6.5)	.47
Neuroblastoma	129 (4.6)	89 (4.2)	.28
Retinoblastoma	80 (2.9)	63 (3.0)	.43
Other solid malignancies	141 (5.0)	207 (9.8)	<.001
Chemotherapy, No. (%)			
Corticosteroids	1345 (47.9)	—	
Mercaptopurine, thioguanine	1098 (39.1)	—	
Methotrexate	1450 (51.6)	—	
Erwinia-/L-/Peg-asparaginase	943 (33.6)	—	
Cisplatin, carboplatin, oxaliplatin	342 (12.2)	—	
Anthracycline	1649 (58.8)	—	

(continued)

Table 1. (continued)

Characteristics	Survivors included in this study (n = 2811)	Survivors eligible but excluded from this study (n = 2117)*	P†
Alkylating agents	1668 (59.7)	—	
Vincristine	1940 (69.6)	—	
Any chemotherapy	2322 (82.6)	1737 (82.1)	.32
Radiotherapy, No. (%)			
Chest	1516 (54.0)	—	
Abdomen	1491 (53.1)	—	
Pelvis	1485 (52.9)	—	
Brain	1522 (54.3)	—	
Any radiotherapy	1583 (56.3)	1064 (59.1)	<.001
Invasive surgery, No. (%)	1945 (69.2)	1006 (47.5)	<.001
Burden of treatment modalities,§ No. (%)			
High-risk burden	1126 (40.2)	—	
Moderate-risk burden	1276 (45.5)	—	
Low-risk burden	400 (14.3)	—	
Chronic health conditions,   No. (%)			
Myocardial infarction	103 (3.7)	—	
Cardiac disorder	260 (9.3)	—	
Peripheral neuropathy	252 (9.0)	—	
Stroke	89 (3.2)	—	
Upper gastrointestinal disease	113 (4.0)	—	
Respiratory disorder	474 (16.9)	—	
Diabetes	193 (6.9)	—	
Chronic kidney disease	58 (2.1)	—	
Hepatic disorder	107 (3.8)	—	
Seizures	238 (8.5)	—	
Reproductive disorder	975 (34.7)	—	
Subsequent neoplasm	190 (6.8)	—	
Skeletal disorder	284 (10.1)	—	
Hearing loss	285 (10.1)	—	

\*See Figure 2 for the reasons for the exclusion of eligible participants. GED = General Equivalency Diploma.

†P values for the comparison between survivors included in this study and survivors eligible but excluded from this study were computed using chi-square tests (two-sided) for binary or categorical variables and Student t tests (two-sided) for continuous variables.

‡Other: American Indian, Alaska Native, Asian, and Pacific Islander.

§High-risk burden: chemotherapy, radiotherapy and invasive surgery, or radiotherapy plus invasive surgery. Moderate-risk burden: chemotherapy plus radiotherapy, chemotherapy plus invasive surgery, radiotherapy only, or invasive surgery only. Low-risk burden: chemotherapy only (Supplementary Methods, available online).

||CTCAE grades 2–4 chronic health conditions.

to evaluate life insurance and retirement issues (“Ever had difficulty obtaining life insurance because of health history”; “How much of an impact did your cancer experiences have on retirement plans”). Each item was categorized by two levels (yes and no).

Based on our previous publication (6), seven symptom domains were included: sensation abnormality, cardiac symptoms, pulmonary symptoms, pain, somatization, anxiety, and depression. The last three symptom domains were based on the Brief Symptom Inventory–18 (BSI-18) (26). Suicidal ideation (an item of the BSI-18) was examined independently. HRQOL was measured using the Medical Outcomes Study 36-Item Short-Form Health Survey (27). Physical component summary (PCS) and mental component summary (MCS) were calculated and normalized (mean = 50, SD = 10).

### Determinants/Covariates

Determinants of financial hardship included treatment exposures abstracted from medical records, demographics (age at evaluation, sex, and race/ethnicity), socioeconomic status

(education, employment, annual household income, number of household members, and marital status), time since diagnosis, and 15 groups of chronic health conditions collected from the clinical evaluation (Supplementary Table 1, available online). To summarize the burden of treatment modalities, each participant was assigned to a low-, moderate-, or high-risk burden group (Supplementary Methods and Supplementary Figure 1, available online). Chronic health conditions were categorized as present (CTCAE grades 2–4) or not present (no diagnosed chronic health condition or CTCAE grade 1) (24). These variables were adjusted in the analysis for associations of financial hardship with outcomes of interest.

### Statistical Analysis

Logistic regressions were performed to estimate odds ratios (ORs) for each financial hardship domain associated with individual determinants. Multinomial logistic regressions were performed to estimate relative risks (RRs) associated with determinants of having hardship in one, two, and three domains vs none. Multivariable logistic regression models were

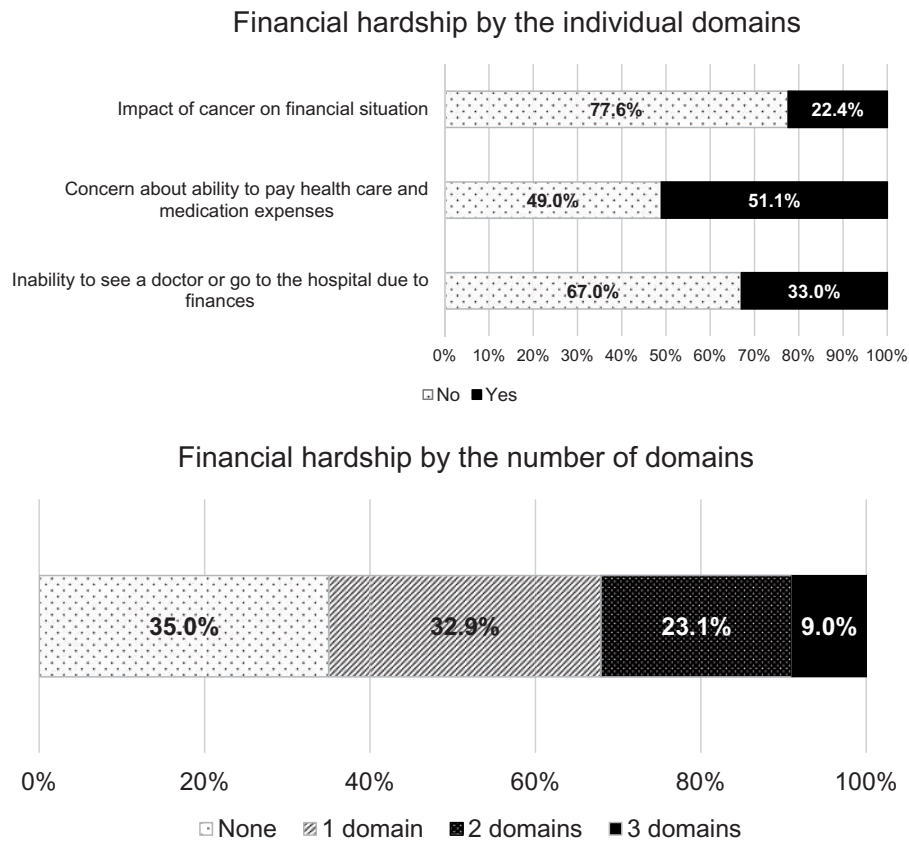


Figure 3. Prevalence of financial hardship in adult survivors of childhood cancer.

performed to estimate odds ratios for each outcome variable (difficulty in acquiring health and life insurance, retirement planning, and symptom prevalence) associated with each hardship domain, adjusting for the aforementioned covariates. Multivariable linear regression models were performed to test associations of hardship with HRQOL. The variance inflation factor (VIF) index (cutoff  $\geq 10$ ) was used to determine multicollinearity among variables associated with financial hardship. Statistically significant differences in analyses were determined by *P* values of less than .05. Cohen's metrics were used for comparing HRQOL differences, with 2.0–4.9, 5.0–7.9, and 8.0 or more points indicating small, medium, and large effect sizes (28,29). STATA v14.2 (College Station, TX) was used for all analyses. All statistical tests were two-sided.

## Results

### Participant Characteristics

Of 2811 survivors, 57.8% were treated for hematological malignancies, 32.0% for solid tumors, and 10.1% for central nervous system malignancies (Table 1). The mean age at evaluation (SD) was 31.8 (8.4) years, and the mean number of years since diagnosis was 23.6 (8.1). Approximately 30% of survivors had an education level of high school/GED or below, 35.6% had graduated college, 44.5% reported a household income below \$40 000, and 23.0% reported \$80 000 or above. Compared with nonparticipants, a higher proportion of participants were female, non-

Hispanic white, lymphoblastic leukemia leukemia survivors, and treated with invasive surgical procedures (all *P* < .001).

### Prevalence of Financial Hardship

Among survivors, 22.4% (95% confidence interval [CI] = 20.8% to 24.0%) reported material hardship, 51.1% (95% CI = 49.2% to 52.9%) psychological hardship, and 33.0% (95% CI = 31.1% to 34.6%) coping/behavioral hardship (Figure 3). Nearly 65.0% (95% CI = 63.9% to 67.5%) of survivors reported hardship in at least one domain.

### Determinants of Financial Hardship

Lower educational attainment, lower household income, and older age at evaluation were the most statistically significant predictors of financial hardship across the three domains (Table 2). An annual household income of \$39 999 or less increased risk of material (OR = 3.04, 95% CI = 2.08 to 4.46), psychological (OR = 3.64, 95% CI = 2.76 to 4.80), and coping/behavioral (OR = 4.95, 95% CI = 3.57 to 6.86) hardship (all *P* < .001), compared with a household income of \$80 000 or greater. Survivors who did not complete high school education had a higher risk of material (OR = 2.22, 95% CI = 1.45 to 3.42, *P* < .001), psychological (OR = 1.75, 95% CI = 1.18 to 2.62, *P* < .01), and coping/behavioral (OR = 2.05, 95% CI = 1.38 to 3.06, *P* < .001) hardship compared with those who graduated college or above. Older survivors (age  $\geq 40$  years) had elevated risks of psychological (OR = 1.98, 95% CI = 1.38 to 2.85) and coping/behavioral (OR = 2.08,

Table 2. Demographic, socioeconomic, and clinical determinants of financial hardship

Determinants of financial hardship	Material hardship*		Psychological hardship*		Coping/ behavioral hardship*		Any hardship	
	OR (95% CI)	P†	OR (95% CI)	P†	OR (95% CI)	P†	OR (95% CI)	P†
Age at evaluation, y								
18–29.9 y	1.00 (reference)		1.00 (reference)		1.00 (reference)		1.00 (reference)	
30–39.9	1.27 (0.93 to 1.73)	.14	1.41 (1.10 to 1.81)	.006	1.79 (1.37 to 2.34)	<.001	1.74 (1.33 to 2.27)	<.001
≥40	1.33 (0.85 to 2.08)	.21	1.98 (1.38 to 2.85)	<.001	2.08 (1.42 to 3.06)	<.001	2.41 (1.61 to 3.60)	<.001
Time since diagnosis, y								
10–19	1.72 (1.14 to 2.60)	.01	0.83 (0.60 to 1.15)	.27	1.73 (1.21 to 2.46)	.002	1.08 (0.75 to 1.54)	.69
20–29	1.38 (0.98 to 1.92)	.06	0.95 (0.72 to 1.24)	.70	1.44 (1.08 to 1.92)	.01	1.08 (0.80 to 1.45)	.64
≥30	1.00 (reference)		1.00 (reference)		1.00 (reference)		1.00 (reference)	
Sex								
Male	1.16 (0.91 to 1.47)	.24	0.88 (0.72 to 1.06)	.18	0.90 (0.74 to 1.11)	.33	0.83 (0.67 to 1.02)	.07
Female	1.00 (reference)		1.00 (reference)		1.00 (reference)		1.00 (reference)	
Race/ethnicity								
White, non-Hispanic	1.00 (reference)		1.00 (reference)		1.00 (reference)		1.00 (reference)	
Black, non-Hispanic	0.82 (0.57 to 1.18)	.28	1.09 (0.80 to 1.49)	.59	1.22 (0.89 to 1.66)	.21	1.15 (0.80 to 1.64)	.46
Hispanic	0.75 (0.37 to 1.49)	.41	1.30 (0.80 to 2.12)	.30	0.75 (0.42 to 1.33)	.32	1.28 (0.76 to 2.15)	.36
Other‡	0.66 (0.38 to 1.17)	.15	1.12 (0.75 to 1.68)	.58	1.13 (0.73 to 1.75)	.58	1.21 (0.78 to 1.86)	.39
Educational attainment								
Below high school	2.22 (1.45 to 3.42)	<.001	1.75 (1.18 to 2.62)	.006	2.05 (1.38 to 3.06)	<.001	3.35 (2.01 to 5.61)	<.001
High school graduate/GED	1.44 (1.03 to 2.02)	.03	1.46 (1.10 to 1.93)	.008	1.96 (1.46 to 2.64)	<.001	2.43 (1.76 to 3.34)	<.001
Some college/training after high school	0.94 (0.70 to 1.27)	.67	1.39 (1.11 to 1.74)	.004	1.88 (1.47 to 2.42)	<.001	1.62 (1.28 to 2.05)	<.001
College graduate or above	1.00 (reference)		1.00 (reference)		1.00 (reference)		1.00 (reference)	
Employment status								
Currently employed	1.00 (reference)		1.00 (reference)		1.00 (reference)		1.00 (reference)	
Currently unemployed	1.79 (1.33 to 2.41)	<.001	1.23 (0.93 to 1.62)	.15	1.08 (0.82 to 1.43)	.59	1.76 (1.24 to 2.48)	.001
Annual household income								
≤\$39 999	3.04 (2.08 to 4.46)	<.001	3.64 (2.76 to 4.80)	<.001	4.95 (3.57 to 6.86)	<.001	4.16 (3.12 to 5.54)	<.001
\$40 000–\$79 999	1.63 (1.11 to 2.39)	.01	1.79 (1.38 to 2.32)	<.001	2.07 (1.50 to 2.86)	<.001	2.00 (1.54 to 2.58)	<.001
≥\$80 000	1.00 (reference)		1.00 (reference)		1.00 (reference)		1.00 (reference)	
No. of people supported by household income	1.08 (0.99 to 1.18)	.10	1.04 (0.97 to 1.12)	.27	1.09 (1.00 to 1.17)	.04	1.04 (0.96 to 1.13)	.30
Marital status								
Married	1.00 (reference)		1.00 (reference)		1.00 (reference)		1.00 (reference)	
Status other than married	1.41 (1.08 to 1.85)	.01	1.38 (1.11 to 1.71)	.003	1.15 (0.92 to 1.45)	.22	1.54 (1.23 to 1.94)	<.001
Burden of treatment modalities§								
Low-risk burden	1.00 (reference)		1.00 (reference)		1.00 (reference)		1.00 (reference)	
Moderate-risk burden	1.49 (0.98 to 2.28)	.06	1.51 (1.12 to 2.02)	.007	1.19 (0.86 to 1.64)	.30	1.56 (1.15 to 2.12)	.004
High-risk burden	1.75 (1.14 to 2.68)	.01	1.57 (1.16 to 2.13)	.004	1.14 (0.82 to 1.60)	.43	1.58 (1.15 to 2.17)	.005
Chronic health conditions (CTCAE grades 2–4 vs grade 1 or no condition)								
Myocardial infarction	2.55 (1.53 to 4.25)	<.001	1.88 (1.12 to 3.15)	.02	0.90 (0.54 to 1.50)	.68	2.22 (1.19 to 4.15)	.01
Cardiac disorder	1.39 (0.96 to 2.00)	.08	1.22 (0.88 to 1.70)	.24	1.09 (0.77 to 1.53)	.63	1.25 (0.86 to 1.81)	.25
Peripheral neuropathy	2.26 (1.55 to 3.29)	<.001	1.08 (0.75 to 1.57)	.67	1.20 (0.84 to 1.73)	.31	1.55 (0.95 to 2.53)	.08
Stroke	2.17 (1.15 to 4.09)	.02	1.02 (0.57 to 1.84)	.94	0.64 (0.33 to 1.23)	.18	1.38 (0.68 to 2.78)	.37
Upper gastrointestinal disease	1.74 (1.03 to 2.93)	.04	0.94 (0.58 to 1.53)	.80	1.58 (0.97 to 2.57)	.07	1.52 (0.85 to 2.72)	.16
Respiratory disorder	1.14 (0.84 to 1.56)	.40	1.18 (0.91 to 1.54)	.22	1.08 (0.82 to 1.43)	.57	1.13 (0.84 to 1.52)	.41
Diabetes	1.22 (0.77 to 1.93)	.39	1.17 (0.81 to 1.71)	.40	1.03 (0.70 to 1.51)	.90	1.18 (0.78 to 1.79)	.44
Chronic kidney disease	0.57 (0.23 to 1.41)	.22	1.47 (0.75 to 2.90)	.27	0.99 (0.48 to 2.02)	.97	1.04 (0.49 to 2.18)	.92
Hepatic disorder	1.11 (0.62 to 1.97)	.73	1.15 (0.69 to 1.90)	.60	1.39 (0.84 to 2.30)	.20	1.86 (0.98 to 3.50)	.06
Seizures	1.74 (1.16 to 2.60)	.007	1.02 (0.71 to 1.48)	.90	0.68 (0.45 to 1.01)	.06	1.45 (0.94 to 2.22)	.09
Reproductive disorder	1.38 (1.08 to 1.77)	.01	1.27 (1.04 to 1.55)	.02	1.40 (1.13 to 1.74)	.002	1.36 (1.09 to 1.70)	.006
Subsequent neoplasm	2.29 (1.51 to 3.49)	<.001	1.18 (0.81 to 1.72)	.38	0.94 (0.63 to 1.40)	.75	1.59 (1.03 to 2.45)	.04
Skeletal disorder	1.36 (0.93 to 1.98)	.12	0.96 (0.70 to 1.33)	.82	1.20 (0.85 to 1.70)	.29	1.16 (0.82 to 1.65)	.41
Hearing loss	1.47 (1.00 to 2.14)	.05	0.76 (0.54 to 1.07)	.11	0.71 (0.49 to 1.04)	.08	1.05 (0.71 to 1.54)	.82
Amputation	2.15 (1.12 to 4.15)	.02	0.68 (0.37 to 1.23)	.20	1.00 (0.54 to 1.87)	.99	0.81 (0.43 to 1.53)	.52

\*Material hardship: "impact of cancer on financial situation"; psychological hardship: "concern about ability to pay health care and medication expenses"; coping/behavioral hardship: "inability to see a doctor or go to the hospital due to finances." CI = confidence interval; CTCAE = Common Terminology Criteria for Adverse Events; GED = General Equivalency Diploma; OR = odds ratio.

†P values were computed based on logistic regression models (two-sided).

‡Other: American Indian, Alaska Native, Asian, and Pacific Islander.

§High-risk burden: chemotherapy, radiotherapy and invasive surgery, or radiotherapy plus invasive surgery. Moderate-risk burden: chemotherapy plus radiotherapy, chemotherapy plus invasive surgery, radiotherapy only, or invasive surgery only. Low-risk burden: chemotherapy only (Supplementary Methods, available online).

**Table 3.** Associations of financial hardship with health and life insurance affordability and retirement planning

Type of financial hardship	Difficulty in acquiring health insurance		Difficulty in acquiring life insurance		Impact on retirement planning	
	OR (95% CI)	P*	OR (95% CI)	P*	OR (95% CI)	P*
<b>Bivariate analysis</b>						
Material hardship†	2.41 (1.98 to 2.92)	<.001	2.73 (2.15 to 3.47)	<.001	22.04 (17.00 to 28.58)	<.001
Psychological hardship†	2.89 (2.40 to 3.48)	<.001	1.97 (1.59 to 2.43)	<.001	2.48 (1.97 to 3.11)	<.001
Coping/behavioral hardship†	2.27 (1.90 to 2.72)	<.001	1.60 (1.29 to 1.99)	<.001	2.19 (1.76 to 2.71)	<.001
Any hardship	3.23 (2.60 to 4.01)	<.001	2.37 (1.87 to 3.00)	<.001	12.81 (8.11 to 20.23)	<.001
<b>Multivariable analysis‡</b>						
Material hardship	2.38 (1.84 to 3.07)	<.001	2.57 (1.88 to 3.50)	<.001	19.86 (14.11 to 27.94)	<.001
Psychological hardship	3.00 (2.37 to 3.79)	<.001	1.82 (1.40 to 2.35)	<.001	2.42 (1.79 to 3.28)	<.001
Coping/behavioral hardship	2.16 (1.71 to 2.71)	<.001	1.48 (1.13 to 1.95)	.004	1.86 (1.39 to 2.48)	<.001
Any hardship	3.13 (2.39 to 4.12)	<.001	2.12 (1.59 to 2.83)	<.001	10.22 (5.81 to 17.98)	<.001

\*P values were computed based on logistic regression models (two-sided). CI = confidence interval; OR = odds ratio.

†Material hardship: “impact of cancer on financial situation”; psychological hardship: “concern about ability to pay health care and medication expenses”; coping/behavioral hardship: “inability to see a doctor or go to the hospital due to finances.”

‡Analysis adjusted for age at evaluation, time since diagnosis, sex, race/ethnicity, educational attainment, employment status, annual household income, the number of people supported by household income, marital status, burden of treatment modalities, and 15 groups of chronic health conditions.

95% CI = 1.42 to 3.06) hardship (all  $P < .001$ ) vs younger survivors (18 to 29.9 years).

CTCAE grade 2–4 myocardial infarction ( $P < .001$ ), peripheral neuropathy ( $P < .001$ ), subsequent neoplasm ( $P < .001$ ), seizure ( $P = .007$ ), stroke ( $P = .02$ ), reproductive disorder ( $P = .01$ ), amputation ( $P = .02$ ), upper gastrointestinal disease ( $P = .04$ ), and hearing loss ( $P = .05$ ) were each associated with material hardship, with odds ratios ranging from 1.38 (reproductive disorder) to 2.55 (myocardial infarction). Predictors of psychological hardship included having a CTCAE grade 2–4 myocardial infarction ( $P = .02$ ) and reproductive disorder ( $P = .02$ ). Survivors treated with modalities associated with a high- (vs low-) risk disease burden had increased risk of material ( $P = .01$ ) and psychological ( $P = .004$ ) hardship. Lower educational attainment and household income, unemployment, older age at evaluation, and CTCAE grade 2–4 conditions (myocardial infarction, peripheral neuropathy, and reproductive disorder) were associated with a higher number of hardship domains (Supplementary Table 2, available online). VIFs for all determinants were approximately 2.5, suggesting a weak multicollinearity.

### Financial Hardship and Insurance Affordability and Retirement Challenge

Financial hardship across three domains was statistically significantly associated with difficulty in acquiring health and life insurance and poor retirement planning (Table 3). There was a three-, two-, and 10-fold greater risk, respectively, in acquiring health insurance, life insurance, and impact on retirement planning for those with hardship on one or more domains vs none (all  $P < .001$ ). A higher number of hardship domains was associated with more difficulty in acquiring insurance and retirement planning (Supplementary Table 3, available online).

### Financial Hardship and Symptoms

Financial hardship across three domains was statistically significantly associated with prevalence of physical and psychological symptoms (all  $P < .001$  for sensation abnormality, somatization, anxiety and depression; all  $P < .05$  for cardiac and

pulmonary symptoms and suicidal ideation) (Table 4). However, odds ratios of sensation abnormality, cardiac symptoms, somatization, depression, and suicidal ideation were higher for having coping/behavioral hardship (all  $P < .001$ ) than having psychological (all  $P < .01$ ) and material (all  $P < .05$ ) hardship. Risk of suicidal ideation was greater among those with coping/behavioral (OR = 3.40, 95% CI = 2.33 to 4.96,  $P < .001$ ), psychological (OR = 1.85, 95% CI = 1.26 to 2.71,  $P = .002$ ), and material (OR = 1.59, 95% CI = 1.08 to 2.34,  $P = .02$ ) hardship. An increasing number of hardship domains was associated with greater risk for symptom prevalence (Supplementary Table 4, available online).

### Financial Hardship and HRQOL

Financial hardship across all three domains was statistically significantly associated with lower PCS and MCS (Figure 4). After adjusting for covariates, decreased PCS between those with and without material, coping/behavioral, and psychological hardship were 5.2, 5.0, and 4.1 points (all  $P < .001$ ). Decreased MCS related to coping/behavioral, material, and psychological hardship were 5.8, 5.1, and 4.6 points (all  $P < .001$ ). With a higher number of hardship domains, larger decrements in PCS and MCS were observed (Supplementary Table 5, available online). Compared with the norm, there were small effect sizes of sub-optimal HRQOL among survivors having a single domain of hardship (approximately three points in both PCS and MCS), but large effect sizes among those having two domains (approximately seven points in both) and three domains (approximately 12 points in both) of hardship.

### Discussion

We used patient-reported and clinically ascertained data from a large cohort to investigate determinants of financial hardship and consequences in adult survivors of childhood cancer. This study is a secondary data analysis, and the financial hardship items were designed before the availability of validated tools for measuring financial distress (30) and coping behaviors (31). Evaluating material hardship is particularly challenging due to a lack of consensus regarding definition and measurement (12).



**Table 4.** Associations of financial hardship with symptom prevalence

Type of financial hardship	Physical symptoms				Emotional symptoms			
	Sensation abnormality OR (95% CI)	Cardiac symptom OR (95% CI)	Pulmonary symptom OR (95% CI)	Pain OR (95% CI)	Somatization OR (95% CI)	Anxiety OR (95% CI)	Depression OR (95% CI)	Suicidal ideation OR (95% CI)
<b>Bivariate analysis</b>								
Material hardship*	2.66 (2.21 to 3.20)	1.82 (1.45 to 2.29)	2.33 (1.68 to 3.25)	2.02 (1.58 to 2.57)	3.35 (2.72 to 4.12)	3.16 (2.49 to 4.01)	3.02 (2.42 to 3.77)	2.54 (1.89 to 3.41)
Psychological hardship*	1.89 (1.60 to 2.22)	2.02 (1.62 to 2.51)	2.65 (1.86 to 3.79)	2.43 (2.02 to 2.91)	3.57 (2.87 to 4.45)	3.04 (2.36 to 3.92)	3.54 (2.79 to 4.49)	2.60 (1.90 to 3.55)
Coping/behavioral hardship*	2.42 (2.05 to 2.86)	2.37 (1.92 to 2.93)	2.79 (2.02 to 3.86)	3.88 (3.06 to 4.93)	5.09 (4.14 to 6.26)	3.73 (2.95 to 4.72)	4.12 (3.31 to 5.12)	3.78 (2.82 to 5.07)
Any hardship	2.74 (2.28 to 3.32)	2.39 (1.84 to 3.08)	3.08 (1.98 to 4.80)	2.89 (2.41 to 3.47)	7.28 (5.25 to 10.09)	5.24 (3.66 to 7.51)	6.70 (4.71 to 9.53)	5.37 (3.36 to 8.58)
<b>Multivariable analysis†</b>								
Material hardship	1.90 (1.48 to 2.43)	1.50 (1.09 to 2.05)	1.64 (1.06 to 2.53)	1.31 (0.97 to 1.79)	2.41 (1.82 to 3.19)	2.60 (1.90 to 3.57)	2.20 (1.64 to 2.96)	1.59 (1.08 to 2.34)
Psychological hardship	1.66 (1.34 to 2.04)	1.56 (1.18 to 2.07)	1.98 (1.26 to 3.11)	2.03 (1.61 to 2.55)	2.96 (2.23 to 3.93)	2.06 (1.50 to 2.83)	2.39 (1.77 to 3.21)	1.85 (1.26 to 2.71)
Coping/behavioral hardship	2.40 (1.93 to 2.99)	2.17 (1.63 to 2.89)	1.97 (1.30 to 2.99)	2.93 (2.20 to 3.91)	3.56 (2.73 to 4.65)	2.35 (1.73 to 3.18)	2.89 (2.19 to 3.83)	3.40 (2.33 to 4.96)
Any hardship	2.28 (1.79 to 2.89)	1.84 (1.32 to 2.57)	2.27 (1.28 to 4.03)	2.38 (1.88 to 3.01)	5.32 (3.53 to 7.99)	2.88 (1.89 to 4.40)	3.57 (2.39 to 5.34)	3.87 (2.19 to 6.84)

\*Material hardship: "impact of cancer on financial situation"; psychological hardship: "concern about ability to pay health care and medication expenses"; coping/behavioral hardship: "inability to see a doctor or go to the hospital due to finances." CI = confidence interval; OR = odds ratio.

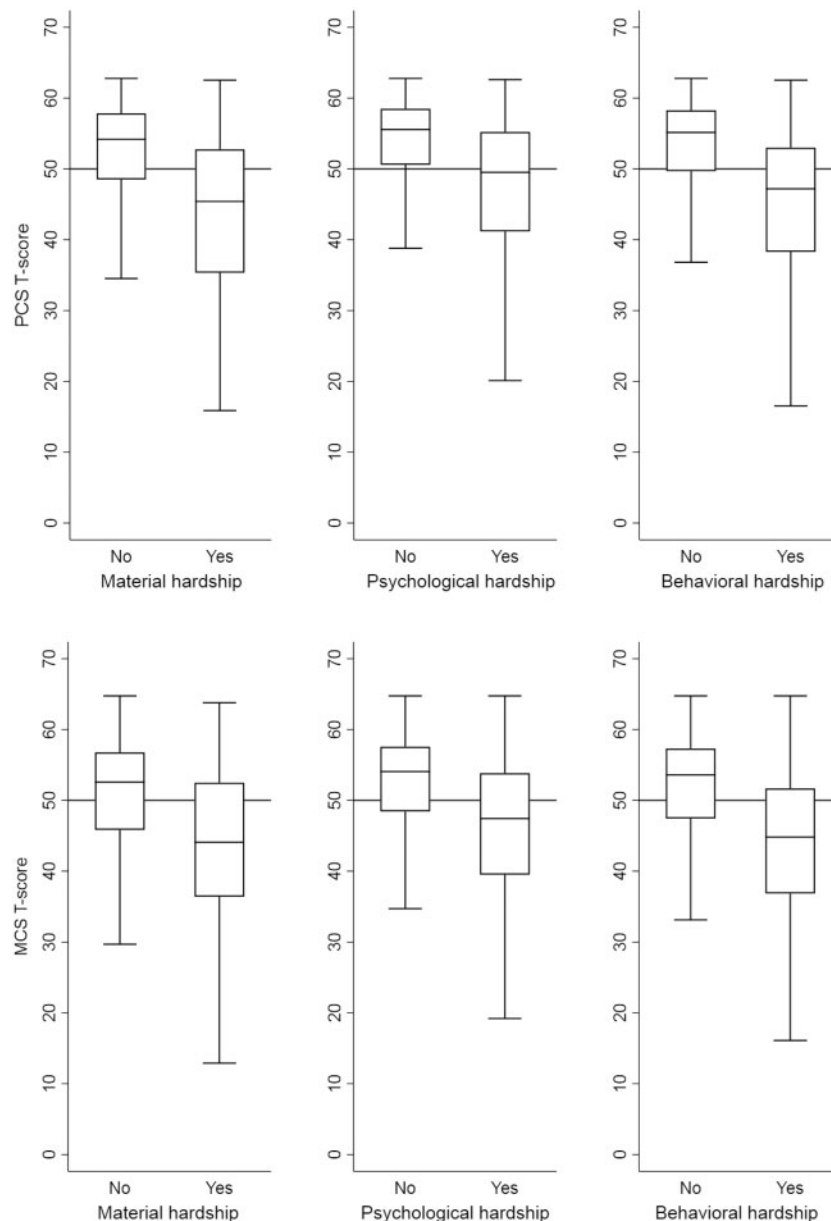
†Analysis adjusted for age at evaluation, time since diagnosis, sex, race/ethnicity, educational attainment, employment status, annual household income, the number of people supported by household income, marital status, burden of treatment modalities, and 15 groups of chronic health conditions.

Without data describing out-of-pocket medical costs or debts, we queried the degree to which cancer impacted the survivor's financial situation as a surrogate of material hardship. The use of this metric is more objective (impact) than subjective (distress), with a distinctive pattern of prevalence as compared with other hardship domains (Figure 3). Alternatively, collecting data related to retirement challenges (eg, shortage of retirement savings) as a result of cancer/late effects can also be used to measure material hardship. Despite these limitations, our data are the most comprehensive to date to stress the importance of financial issues among childhood cancer survivors.

It is important to note that we evaluated financial hardship by three domains rather than a composite score, as the latter could not inform how the hardship is related to available financial resources, financial distress, and/or reactions to financial difficulties (12). Overall, 22.4%, 51.1%, and 33.0% of our participants reported hardship in the material, psychological, and coping/behavioral areas, and 65% had hardship in at least one area. The pattern of hardship differs from survey data among adult-onset cancer survivors, where 20% reported material hardship (16), 21% to 23% worried about covering large medical bills (14,16), and 14% to 18% reported forgone/delayed medical care due to finances (13). The discrepancy between this and the national studies may be due to the use of different measures and the characteristics of our participants, who are economically vulnerable, including lower household income, educational attainment, employment rate, and health insurance coverage (32). But our findings reflect the unique financial challenge of childhood cancer survivors, who often develop treatment-related health problems younger than adult-onset cancer individuals (2,33).

Survivors who were older at evaluation, having a lower educational attainment and lower household income or developing late medical effects were more likely to experience financial hardship across three domains than their counterparts. The risk of hardship was higher in the middle-aged group than the young-aged group. Unlike younger survivors who may receive monetary support from parents, middle-aged survivors are more likely to be financially responsible for household expenses. It is evident that childhood cancer survivors have a higher risk of productivity loss than noncancer individuals (34,35), and lower productivity at early life stages has shown decreased earning mobility and financial security in later life (36,37). By extending beyond previous research (38), we identified that specific severe chronic health conditions exacerbated the risk of hardship, especially the material domain, by twofold vs those with no, asymptomatic, or mild conditions. Not surprisingly, this "double-hit" phenomenon places childhood cancer survivors in a disadvantaged situation of adverse psychosocial and health outcomes.

The negative association of financial hardship with acquiring life insurance and retirement planning has not been previously reported, suggesting the occurrence of compounding financial risks when childhood cancer survivors age into their elder years. We found that hardship across three domains decreased the likelihood of acquiring life insurance due to health history by 2.6-fold risk. This is in line with a Dutch study in which 20% of adult survivors endorsed difficulty obtaining life insurance; among them, 61% were rejected by insurance companies (39). Strikingly, the risk of difficulty with retirement planning was increased 20-fold among survivors with material hardship. Unlike older adult-onset cancer survivors who may have accumulated wealth (40), childhood survivors often



**Figure 4.** Associations of financial hardship with physical component summary (PCS; upper) and mental component summary (MCS; lower). The horizontal line indicates the norm 50 for the SF-36 PCS and MCS. The means (SD) of PCS and MCS of all participants were 50.1 (9.4) and 49.0 (9.6), respectively. The width of each box represents the interquartile range of PCS/MCS, with the upper line for the 75th percentile value, the middle line for the 50th percentile value, and the lower line for the 25th percentile value; the lines extended vertically from the box (whiskers) indicate the highest and lowest values of the study participants.

struggle earning money and securing employment, thereby contributing to a lack of planning for retirement.

Childhood cancer survivors are at higher risk of developing depressive symptoms (7) and suicidal ideation (41) compared with the general population, and suicidal thought has been linked to elevated all-cause mortality (42). The excess risks for depressive symptoms (2.2- to 2.9-fold) and suicidal ideation (1.6- to 3.4-fold) in relation to three hardship domains were independent of the influence of education and income variables found in previous studies (41,43). Interestingly, inability to access health care due to finances was more strongly associated with depressive symptoms and suicidal thought than concerns about the ability to pay medical expenses. Although the

mechanism through which financial issues affect symptoms is unknown, bankruptcy (44) and a lack of social integration/support (45) may play a mediating role.

The financial challenges observed in childhood cancer survivors, typically due to late medical effects, emphasize the importance of addressing this issue in a systematic manner (46,47). From the viewpoint of health policy, the Affordable Care Act's (ACA's) high-risk insurance plans and state-based exchanges provide subsidized coverage for uninsured cancer survivors; however, cost-sharing under these plans is higher for those who are underemployed (48). The only services covered under the ACA with no out-of-pocket costs are those that meet A/B categories as recommended by the US Preventive Services Task

Forces (49). Unfortunately, the ACA does not mandate screening tests for late effects, as recommended by the COG (eg, cardiac imaging for cardiomyopathy).

Without amendments to the current policy, early detection in the survivorship care setting, followed by appropriate interventions, becomes critical. In practice, simply asking survivors about their ability to pay for health care could alert the survivorship care team to explore the risks of financial problems (50). Additionally, identifying survivors who forgo/delay medical appointments due to finances and offering hardship-specific coping strategies (51) might prevent depression, suicidal ideation, and other adverse consequences. Useful coping practices/interventions include alleviating negative psychological responses to financial hardship (eg, job-club [52]), supportive education programs to increase financial literacy (53), and navigation systems to address financial barriers during survivorship care (47,54).

Several limitations should be considered when interpreting our findings. First, our results may not be generalizable to all childhood cancer survivors as participants were recruited from a single institution. Compared with the CCSS baseline survey (55), our study contained more participants who were older in age at evaluation, were racial/ethnic minorities, were leukemia and solid tumor survivors, and had no health insurance coverage. Second, financial hardship was measured by extent items included in the SJLIFE. As financial hardship is a new area and tools to measure this concept are still emerging, this limitation highlights an opportunity for future research. Third, the use of cross-sectional data precludes a temporal ascertainment between determinants and consequences of financial hardship. Collecting longitudinal data is necessary to quantify the change of financial status and establish a causal inference of financial hardship with outcomes.

In conclusion, financial hardship is prevalent in adult survivors of childhood cancer. Socioeconomic factors and late effects are related to financial hardship, which in turn affect insurance affordability, retirement planning, and various health outcomes. Future studies are warranted to establish effective strategies to mitigate the impact of financial hardship on childhood cancer survivors.

## Funding

This study was supported by US National Cancer Institute grants U01 CA195547 (Pis: MMH and LLR) and P30 CA021765–33 (CORE PI: CR).

## Notes

Affiliations of authors: Departments of Biostatistics (DS), Epidemiology and Cancer Control (ICH, NB, TMB, KRK, MMH, LLR), Global Pediatric Medicine (NB), Oncology (MMH), and Psychology (TMB, KRK), St. Jude Children's Research Hospital, Memphis, TN; Winship Cancer Institute, Emory University, Atlanta, GA (JLK).

The funders had no role in the design of the study; the collection, analysis, or interpretation of the data; the writing of the manuscript; or the decision to submit the manuscript for publication.

All the co-authors declare that there is no conflict of interest in relation to the work described.

Author contributions: concept and design: ICH; administrative support: TMB, JLK, KRK, MMH, LLR; provision of study

materials: MMH, LLR; collection and assembly of data: ICH, NB, MMH, LLR; data analysis and interpretation: ICH, DS; manuscript writing: ICH; editing and final approval of manuscript: all authors.

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