Medical Financial Hardship Intensity and Financial Sacrifice Associated with Cancer in the United States



Xuesong Han¹, Jingxuan Zhao¹, Zhiyuan Zheng¹, Janet S. de Moor², Katherine S. Virgo³, and K. Robin Yabroff¹

ABSTRACT

Background: With rising costs of cancer care, this study aims to estimate the prevalence of, and factors associated with, medical financial hardship intensity and financial sacrifices due to cancer in the United States.

Methods: We identified 963 cancer survivors from the 2016 Medical Expenditures Panel Survey - Experiences with Cancer. Medical financial hardship due to cancer was measured in material (e.g., filed for bankruptcy), psychological (e.g., worry about paying bills and finances), and behavioral (e.g., delaying or forgoing care due to cost) domains. Nonmedical financial sacrifices included changes in spending and use of savings. Multivariable logistic models were used to identify characteristics associated with hardship intensity and sacrifices stratified by age group (18–64 or 65+ years).

Results: Among cancer survivors ages 18 to 64 years, 53.6%, 28.4%, and 11.4% reported at least one, two, or all three

domains of hardship, respectively. Among survivors ages 65+ years, corresponding percentages were 42.0%, 12.7%, and 4.0%, respectively. Moreover, financial sacrifices due to cancer were more common in survivors ages 18 to 64 years (54.2%) than in survivors 65+ years (38.4%; P < 0.001). Factors significantly associated with hardship intensity in multivariable analyses included low income and educational attainment, racial/ethnic minority, comorbidity, lack of private insurance coverage, extended employment change, and recent cancer treatment. Most were also significantly associated with financial sacrifices.

Conclusions: Medical financial hardship and financial sacrifices are substantial among cancer survivors in the United States, particularly for younger survivors.

Impact: Efforts to mitigate financial hardship for cancer survivors are warranted, especially for those at high risk.

Introduction

Medical financial hardship, including problems paying medical bills, financial distress, and delaying or forgoing medical care due to cost, is a common lasting effect of cancer diagnosis and treatment for cancer survivors and their families (1–7). Medical financial hardship has been linked to higher symptom burden (8–10) and worse health-related quality of life (10–13). Extreme financial insolvency (i.e., bankruptcy) is associated with increased risk of mortality (14).

With rising prices for cancer care, especially oral and infused antineoplastic agents, and increasing patient cost-sharing, research describing medical financial hardship has increased rapidly (1), enriching understanding of its prevalence, risk factors, and health consequences. Depending on the study population and measurement of medical financial hardship, previous studies reported prevalence as high as two-thirds of cancer survivors. Risk factors include sociodemographic characteristics such as younger age, being female, racial/ethnic minority, lack of health insurance, high cost-sharing private

insurance plan, low family income, and employment changes (3, 7, 15). Clinical factors such as receipt of adjuvant therapy and recent treatment are also associated with hardship (1–3, 7, 16). However, prior research findings in clinical settings had limited generalizability as they often include only certain types of cancers from a single institute or city (1, 2). Previous studies using national survey data to compare cancer survivors and individuals without a cancer history did not distinguish between medical financial hardship due to cancer from other reasons (7, 15). Moreover, few national studies examined the intensity of medical financial hardship across multiple domains or other nonmedical financial sacrifices as a result of cancer, including changes in spending, use of savings, or changes to housing. This study addresses these gaps.

Implementation of the Affordable Care Act in 2014 has markedly changed the landscape of insurance coverage, a strong determinant of medial financial hardship, among cancer population (17–19). The Affordable Care Act expanded Medicaid eligibility to low-income residents of the states that opted in and offers affordable private insurance on the marketplace through subsidies to low- and middle-income families. It prohibits individual insurance plans from preexisting condition exclusions and lifetime and annual coverage limits. It also includes measures to close the "donut hole" in the Medicare Part D prescription drug plan for seniors. Identifying risk factors for financial hardship intensity and sacrifices post the Affordable Care Act can inform identification of cancer survivors at high risk for intervention in modern oncology and primary care settings.

Cancer-specific medical financial hardship was measured comprehensively in a nationally representative sample with the Medical Expenditures Panel Survey (MEPS) - Experiences with Cancer questionnaire (20) in 2016, with questions related to problems paying medical bills, bankruptcy, financial worries, delaying or forgoing care because of cost, and financial sacrifices due to cancer including

Note: Supplementary data for this article are available at Cancer Epidemiology, Biomarkers & Prevention Online (http://cebp.aacrjournals.org/).

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reducing spending on food, changes to housing, and using savings set aside for other purposes. Using these newly available data, we identified factors associated with the intensity of medical financial hardship and financial sacrifices in cancer survivors. Because of the age eligibility for Medicare insurance coverage in those aged 65+ years and the interrelationship between employment status and private health insurance coverage in those ages 18–64 years, we stratified our analyses by age group.

Materials and Methods

Data and sample

Adult cancer survivors were identified from the 2016 MEPS conducted by the Agency for Healthcare Research and Quality (https:// meps.ahrq.gov/mepsweb/index.jsp). The MEPS is a nationally representative sample of the U.S. civilian noninstitutionalized population. which collects detailed information on health insurance coverage, health care utilization and expenditures, and health conditions through an overlapping panel design. Each panel within the sample is interviewed at five rounds over 2 calendar years. Among the two panels of 34,655 participants in 2016, those aged 18 years or older who reported a cancer history were invited to complete the Experiences with Cancer self-administered questionnaire (SAQ) after confirmation of eligibility during round 3 of panel 20 and round 1 of panel 21. The survey included questions about the effects of cancer, its treatment, or the lasting effects of the treatment on finances, health insurance, and employment. Among MEPS respondents, the response rate for the cancer SAQ was 81.2% and the overall response rate for the 2016 MEPS was 46.0%, resulting in an overall response rate of 37.4%

Among the 1,236 cancer survivors, we excluded those diagnosed with only nonmelanoma skin cancer and/or skin cancer with unknown kind (n=267; almost all were non-Hispanic whites; other demographics were comparable with survivors included in the analysis). Also excluded were individuals aged 65+ years without Medicare (n=6) because of the small number, resulting in a total of 963 cancer survivors in the analysis.

Measures

The MEPS Experience with Cancer SAQ contains a series of questions about financial hardship associated with cancer, its treatment, or the lasting effects of that treatment (Supplementary Table S1). Consistent with earlier studies, we characterized medical financial hardship in three domains-material, psychological, and behavioral (1, 16). Material hardship was measured by three questions asking whether cancer survivors ever (i) had to borrow money or go into debt, (ii) were unable to cover their share of the cost of cancer care, and (iii) had to file for bankruptcy. Psychological hardship was measured by three questions asking whether survivors ever worried or were concerned about (i) having to pay large medical bills, (ii) their family's financial stability, and (iii) keeping their job and maintaining their income. Behavioral hardship was measured by a series of questions asking whether they ever delayed, forewent, or made other changes to their cancer care because of cost. Five types of care were assessed: prescription medicine, visit to specialist, treatment (other than prescription medicine), follow-up care, and mental health services, with an additional choice of "other". No specification for the "other" type was provided and it could apply to any other types of care related to cancer treatment or symptoms such as genetic counseling, dental care, eye glasses, and primary care. We generated a dichotomous summary measure for each financial hardship domain, and created an intensity measure of zero, one, two, and three domain(s) of medical financial hardship.

The MEPS Experience with Cancer SAQ also included questions about financial sacrifices made by survivors and their family members because of cancer, its treatment, or the lasting effects of that treatment: (i) reducing spending on vacation or leisure activities, (ii) delaying large purchases such as for a car, (iii) reducing spending on basics such as food and clothing, (iv) using savings set aside for other purposes such as retirement or educational funds, (v) making a change to their living situation such as selling or refinancing a home or moving to a smaller residence, and (vi) other. A dichotomous summary measure of any financial sacrifices was created.

We hypothesized that the following patient characteristics were risk factors of medical financial hardship intensity and financial sacrifice associated with cancer on the basis of published research (3, 7, 16): age, sex, race/ethnicity, marital status, educational attainment, family income as a percentage of the federal poverty level (FPL), health insurance coverage, number of comorbid conditions, and years since last cancer treatment. For adults ages 18–64 years, employment change due to cancer included taking extended paid time off from work or unpaid time off, or making a change in hours, duties, or employment status.

Statistical analyses

All statistical analyses were stratified by age group (ages 18–64 years and 65+ years). Descriptive statistics were used to characterize the sample. The percentages of cancer survivors reporting medical financial hardship and financial sacrifices were generated and compared between the two age groups. We fitted multivariable ordinal logistic regression models to identify survivor characteristics associated with medical financial hardship intensity and multiple logistic regression models for financial sacrifices, adjusting for age group, sex, race/ethnicity, marital status, education, family income, health insurance, number of comorbidities, year since last cancer treatment, and employment changes (for only survivors ages 18–64 years). Adjusted percentages and odd ratios (OR) were calculated for medical financial hardship intensity and any financial sacrifice.

To further account for the dynamic contribution of different items to a specific financial hardship domain, a sensitivity analysis was conducted (21). Principal factor analysis with Promax rotation was performed with the multiple items of each domain to generate a factor score for each participant. The factor scores of the three domains were summed and then trichotomized as <-1, -1 to 1, and >1 as a measure of medical financial hardship intensity and used in ordinal logistic regressions mentioned above.

All analyses accounted for the complex MEPS design and nonresponse using SAS 9.4 and STATA/IC 14.1. Statistical tests were two-sided with alpha set at 0.05.

Results

More than half (59.3%) of the cancer survivors were aged 65+ years (**Table 1**). The majority was female, non-Hispanic white, married, and had private health insurance coverage. A total of 23.9% of the survivors were diagnosed with female breast cancer and 15.2% were diagnosed with prostate cancer. Compared with cancer survivors aged 18–64 years, those aged 65+ years were more likely to be unmarried, had lower educational attainment, and more comorbid conditions. Among survivors aged 18–64 years, 40.1% were employed at or after diagnosis and did not have to make extended employment changes due to cancer and 31.6% were employed at or after diagnosis

Table 1. Characteristics of cancer survivors, MEPS 2016.

		Total	Age 18-64 years		Age 65+ years		χ^2
	N	Weighted %	n	Weighted %	n	Weighted %	P
Total	963	100.0	401	100.0	562	100.0	
Age group	303	100.0	701	100.0	302	100.0	
18–54	206	20.2	206	49.5	_	_	_
55-64	195	20.6	195	50.5	_	_	
65-74	270	28.5	_	_	270	48.0	
>75°	292	30.8	_	_	292	52.0	
≥73 Sex	232	30.6	_	_	292	32.0	
Male	366	38.8	119	31.8	247	43.6	0.002
Female	597	61.2	282	68.2	315	56.4	0.002
Race/ethnicity	397	01.2	202	00.2	313	30.4	
	6.46	011	240	70.1	400	07.0	0.05
Non-Hispanic white only	646	81.1	240	78.1	406	83.2	0.05
Other race/ethnicities ^b	317	18.9	161	21.9	156	16.8	
Current marital status							
Married	516	58.0	239	63.9	277	53.9	0.01
Not married ^c	447	42.0	162	36.1	285	46.1	
Education							
Less than high school graduate	178	13.7	68	10.5	110	15.9	0.004
High school graduate	292	30.0	111	25.8	181	32.9	
Some college or more	493	56.3	222	63.7	271	51.2	
Current family income as percentage of poverty line							
Low income ≤138%	248	19.5	111	20.0	137	19.1	0.07
Middle income 139%-400%	366	35.0	141	29.8	225	38.6	
High income >400%	349	45.5	149	50.2	200	42.4	
Employment changes ^d							
Employed at or after diagnosis without extended change due to cancer			134	40.1	_	_	_
Employed at or after diagnosis and took extended change due to cancer			127	31.6	_	_	
Not employed at or after diagnosis/missing			140	28.3	_	_	
Current health insurance for age <65 ^e							
Age <65, any private			259	74.9	_	_	_
Age <65, public only			121	21.7	_	_	
Age <65, uninsured			21	3.3	_	_	
Current health insurance for age 65+ ^e				5.5			
Age 65+ ^a , Medicare and private			_	_	288	56.5	_
Age 65+ ^a , Medicare and other public			_	_	85	11.0	
			_	_			
Age 65+ ^a , Medicare only			_	_	189	32.5	
Number of known MEPS priority conditions (excluding cancer) ^f	107	11.0	70	20.7	20	4.6	
0	107	11.2	79	20.7	28	4.6	<0.001
1	182	18.0	115	28.4	67	10.9	
2	175	20.2	74	21.7	101	19.2	
3-8	499	50.6	133	29.1	366	65.3	
Cancer site ^g							
Female breast	230	23.9					
Prostate	146	15.2					
Colon	75	7.8					
Cervix	67	7.0					
Melanoma	62	6.4					
Uterus	54	5.6					
Lung	31	3.2					
Lymphoma	28	2.9					
Bladder	25	2.6					
Other	193	20.0					
Multiple sites	52	5.4					
Years since last cancer treatment							
<1	232	23.6	108	26.6	124	21.6	0.55
1 to <5	186	18.4	87	18.0	99	18.7	0.33
>5 ^h	418	44.9	153	42.8	99 265	46.3	
_	418 127	44.9 13.1			265 74		
Never treated/missing	127	13.1	53	12.6	74	13.4	

Note: Bold font indicates statistical significance (P < 0.05).

 $^{^{\}mathrm{a}}$ Age top-coded \geq 85 by the MEPS.

^bOther race/ethnicities include Hispanic, non-Hispanic black, Asian, other race, or multiple races.

^cNot married includes widowed, divorced, separated, or never married.

^dEmployment change due to cancer was not considered for cancer survivors ages 65+ years because the majority was not employed.

ePublic insurance included Medicare, Medicaid, State Children's Health Insurance Program, and/or other public hospital/physician coverage. TRICARE/CHAMPVA was treated as private coverage, as were employer-based, union-based, and other private insurance.

Conditions include arthritis, asthma, diabetes, emphysema, heart disease (angina, coronary heart disease, heart attack, and other heart condition/disease), high cholesterol, hypertension, and stroke.

⁹Distribution of cancer site not shown by age group due to small cell sizes.

 $^{^{\}text{h}}\text{Years}$ since last cancer treatment top-coded at $\geq\!\!20$ by the MEPS.

Table 2. Weighted percentages of financial hardship associated with cancer, treatment, or lasting effects of treatment, by age group, MFPS 2016

	All ages (<i>N</i> = 963)	18-64 years (<i>n</i> = 401)	65 $+$ years a ($\emph{n}=$ 562)	χ ² P
Material financial hardship				
Had to borrow money or go into debt	7.1 (5.5-9.1)	10.9 (8.1-14.4)	4.4 (3.0-6.5)	< 0.001
Filed for bankruptcy	1.5 (0.9-2.6)	1.9 (1.0-3.7)	1.2 (0.6-2.6)	0.33
Unable to cover share of the costs of cancer care	11.4 (9.4-13.9)	16.8 (13.1-21.2)	7.8 (5.6-10.8)	< 0.001
Any material financial hardship ^b	15.5 (13.2-18.2)	23.1 (18.9-28.0)	10.4 (7.9-13.5)	< 0.001
Psychological financial hardship				
Worried about paying large medical bills	25.5 (22.4-28.8)	33.5 (28.2-39.1)	20.0 (16.5-23.9)	< 0.001
Worried about family's financial stability	22.6 (19.8-25.7)	30.7 (25.7-36.2)	17.1 (13.9-20.7)	< 0.001
Concerned about keeping job and income or earnings	15.0 (12.6-17.7)	23.5 (19.5-28.1)	9.1 (6.7-12.2)	< 0.001
Any psychological financial hardship ^c	30.8 (27.6-34.2)	41.1 (35.3-47.1)	23.7 (19.9-27.9)	< 0.001
Behavioral financial hardship				
Delay/forgo/make other changes to the following cance	r care because of cost:			
Prescription medicine	5.8 (4.3-7.7)	8.5 (5.8-12.2)	3.9 (2.6-5.8)	0.003
Visit to specialist	5.4 (4.1-7.2)	9.4 (6.6-13.1)	2.7 (1.6-4.6)	< 0.001
Treatment (other than prescription medicine)	3.3 (2.3-4.5)	3.7 (2.3-6.1)	2.9 (1.8-4.7)	0.50
Follow-up care	7.3 (5.8-9.0)	11.0 (8.3-14.3)	4.7 (3.2-7.0)	< 0.001
Mental health services	2.5 (1.6-3.8)	3.4 (2.1-5.6)	1.9 (0.9-3.7)	0.16
Other	12.8 (10.5-15.4)	11.3 (8.5-14.8)	13.8 (10.8-17.4)	0.27
Any behavioral hardship ^d	26.5 (23.4-29.9)	29.2 (24.1-34.9)	24.7 (20.9-28.9)	0.18

Note: All the percentages were unadjusted percentages. Bold font indicates statistical significance (P < 0.05).

and made extended changes in employment due to cancer. The remainder (28.3%) was not employed at or after diagnosis or data for employment were missing. In both age groups, approximately 40% of cancer survivors had their last cancer treatments within 5 years preceding the survey. Respectively, 26.6% and 21.6% of survivors aged 18-64 years and 65+ years were treated within a year prior to the survey.

Medical financial hardship

The overall percentages for reporting ever having any material, psychological, and behavioral financial hardship associated with cancer, its treatment, or the lasting effects of the treatment were 15.5%, 30.8%, and 26.5%, respectively (**Table 2**). Compared with adults aged 65+ years, those aged 18–64 years were more likely to report any material and psychological financial hardship (both P < 0.001). Within the domain of behavioral financial hardship, cancer survivors aged 18–64 years had higher percentages of reported delaying, forgoing, and/or making other changes to prescription drugs, visiting specialists, and follow-up care because of cost than those aged 65+ years (all P < 0.05). Younger cancer survivors also had higher percentages of two and three domain(s) of financial hardship (17.0%, and 11.4%, respectively) than older survivors (8.7%, and 4.0%, respectively; **Fig. 1**).

Analyses of medical financial hardship intensity are displayed in **Table 3** and Supplementary Tables S2 and S3 (adjusted percentages) and S4 (adjusted ORs). Among those 18–64 years, being younger (18–54 years), male, having lower educational attainment, lower family income, being uninsured or publicly insured, and experiencing a shorter time since last cancer treatment were

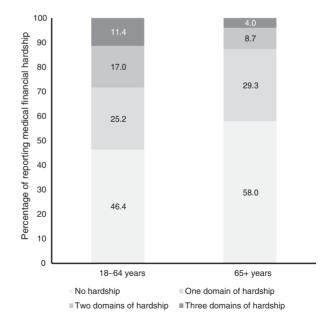


Figure 1. Medical financial hardship associated with cancer by age group, unadjusted (N = 963). Weighted percentages of reporting none, one, two, and all three domains of material, psychological, and behavioral medical financial hardship in cancer survivors, by age group. Data are from the MEPS 2016.

^aAge top-coded >85 by the MEPS.

^bAny material financial hardship was defined as having responded yes to one or more of the individual material financial hardship measures including had to borrow money or go into debt because of cancer, filed for bankruptcy because of cancer, and/or unable to cover share of the cost of medical care visits for cancer.

^cAny psychological financial hardship was defined as having responded yes to one or more of the individual psychological financial hardship measures including worried about paying large medical bills, worried about family's financial stability, and/or concerned about keeping job and income or earnings because of cancer.

^dAny behavioral financial hardship was defined as having responded yes to one or more of the adherence measures including prescription medicine, visit to specialist, treatment, follow-up care, mental health services, and/or other nonadherence.

Table 3. Adjusted weighted percentages of medical financial hardship intensity by age group, MEPS 2016.

	18-64 years ($n = 401$)				65 $+$ years ($n = 562$)				
	No hardship	One domain of hardship	Multiple domains of hardship	P	No hardship	One domain of hardship	Multiple domains of hardship	P	
Age group									
18-54	41.1	21.0	37.9	<0.001	_	_	_	0.05	
55-64	51.6	29.6	18.9	\ 0.00 1	_	_	_	0.05	
65-74	_	_	_		52.3	32.3	15.4		
>75°	_	_	_		62.9	26.5	10.5		
Sex					02.3	20.5	10.5		
Male	37.0	26.5	36.5	0.03	60.8	27.8	11.4	0.49	
Female	50.8	24.1	25.1	0.03	55.6	30.6	13.8	0.43	
Race/ethnicity	30.0	24.1	23.1		55.0	30.0	15.0		
Non-Hispanic white only	49.0	25.0	25.9	0.06	61.0	28.0	10.9	<0.001	
Other race/ethnicities ^b	36.6	27.0	36.5	0.00	41.9	37.0	21.1	<0.001	
Current marital status	30.0	27.0	30.3		41.9	37.0	21.1		
Married	44.4	25.2	30.4	0.56	58.4	29.1	12.5	0.98	
		23.9		0.30				0.96	
Not married ^c	50.3	25.9	25.7		57.4	29.6	13.0		
Education	70 F	70.4	70.1	0.007	C1 F	27.7	11.0	.0.001	
Less than high school graduate	30.5	30.4	39.1	0.003		27.3	11.2	<0.001	
High school graduate	47.9	17.3	34.8		55.0	30.8	14.1		
Some college or more	48.2	28.2	23.6		58.6	28.9	12.5		
Current family income as percentage of pove	-						40.0		
Low income ≤138%	39.9	27.0	33.0	<0.001		28.6	18.8	<0.001	
Middle income 139%–400%	39.5	27.1	33.4		55.6	27.5	16.9		
High income >400%	52.9	24.3	22.9		62.2	31.8	6.0		
Employment changes ^d									
Employed at or after diagnosis without	48.2	25.2	26.6	<0.001	_	_	_	_	
extended change due to cancer									
Employed at or after diagnosis and took	39.5	26.7	33.8		_	_	_		
extended change due to cancer									
Not employed at or after diagnosis/missing	47.0	25.5	27.6		_	_	_		
Current health insurance for age <65 ^e									
Age <65, any private	54.1	23.7	22.2	< 0.001	_	_	_	_	
Age <65, public only	36.4	27.2	36.4		_	_	_		
Age <65, uninsured	46.7	25.7	27.6		_	_	_		
Current health insurance for age 65+e									
Age 65+a, Medicare and private	_	_	_	_	56.6	30.9	12.5	< 0.001	
Age 65+a, Medicare and other public	_	_	_		77.0	12.3	10.7		
Age 65+a, Medicare only	_	_	_		52.8	33.0	14.3		
Number of known MEPS priority conditions (e	excludina ca	ancer) ^f							
0-1	51.1	24.1	24.8	0.26	70.4	22.0	7.6	0.006	
2-8	42.0	26.1	32.0		55.5	30.8	13.7		
Years since last cancer treatment		==::							
<1	42.1	26.1	31.8	<0.001	47.6	34.6	17.8	<0.001	
1 to <5	47.1	25.1	27.7	\U.U.U.I	50.2	33.5	16.3	\U.UU1	
≥5 ⁹	50.1	24.4	25.5		61.2	27.7	11.1		
					J1.2		1111		

Note: Three domains of financial hardship included material, psychological, and behavioral domains. Multivariable ordinal logistic models adjusted for age group, sex, race/ethnicity, marital status, education, family income, employment change due to cancer (only for 18-64 years), health insurance, number of conditions, and years since last cancer treatment. Bold font indicates statistical significance at alpha = 0.05.

 $^{^{\}mathrm{a}}$ Age top-coded \geq 85 by the MEPS.

^bOther race/ethnicities include Hispanic, non-Hispanic black, Asian, other race, or multiple races.

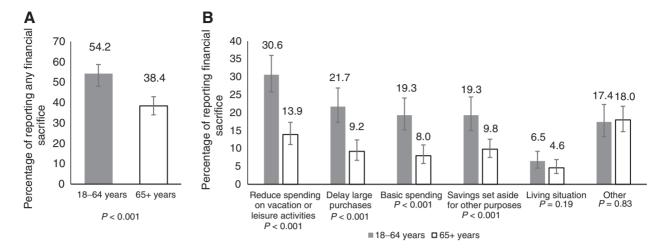
^cNot married includes widowed, divorced, separated, or never married.

 $^{^{}m d}$ Employment change due to cancer was not considered for cancer survivors ages 65+ years because the majority was not employed.

ePublic insurance included Medicare, Medicaid, State Children's Health Insurance Program, and/or other public hospital/physician coverage. TRICARE/CHAMPVA was treated as private coverage, as were employer-based, union-based, and other private insurance.

Conditions include arthritis, asthma, diabetes, emphysema, heart disease (angina, coronary heart disease, heart attack, and other heart condition/disease), high cholesterol, hypertension, and stroke.

 $^{^{\}rm g}$ Years since last cancer treatment top-coded at \geq 20 by the MEPS.



Financial sacrifice associated with cancer by age group, unadjusted (N = 963). **A,** Weighted percentages of individuals reporting any financial sacrifice. **B,** Percentages of individuals reporting separate measures of financial sacrifices. Data are from the MEPS 2016. χ^2 tests were used to compare between the two age groups and calculate the P values. Any financial sacrifices were defined as having responded yes to one or more of the individual financial sacrifice measures including reduce spending on vacation or leisure activities, delay large purchases, reduce basic spending, use savings set aside for other purposes, make a change to living situation, and/or other sacrifice because of cancer.

significantly associated with higher medical financial hardship intensity (Table 3). Moreover, survivors who were employed at or after diagnosis and took extended paid or unpaid leave or switched to part time due to cancer were most likely to report multiple domains of hardship compared with those who were employed but did not take extended leave or switch to part time or those not employed at or after diagnosis (Table 3).

Among the older group, minority race/ethnicity, higher education attainment, lower family income, Medicare insured only, two or more comorbid conditions, and shorter time since last cancer treatment were associated with higher medical financial hardship intensity (**Table 3**; all P < 0.01).

The sensitivity analysis with factor scores showed similar patterns with family income, insurance coverage, and time since last cancer treatment identified as strong predictors of financial hardship intensity in both age groups (Supplementary Table S5).

Financial sacrifices

Financial sacrifices associated with cancer, its treatment, or the lasting effect of the treatment, were more common among cancer survivors aged 18-64 years than among those aged 65+ years (54.2% vs. 38.4%; P < 0.001; **Fig. 2**). Compared with the older age group, younger cancer survivors were more likely to report reduced spending for vacation or leisure activities (30.6% vs. 13.9%), delaying large purchases (21.7% vs. 9.2%), reducing basic spending (19.3% vs. 8.0%), and utilizing savings set aside for other purposes (19.3% vs. 9.8%; all P < 0.05).

Among cancer survivors aged 18–64 years, being younger (18–54 years), male, considered a racial or ethnic minority, education less than high school graduate, and with moderate family income (139%–400% FPL) were associated with higher percentages of any financial sacrifices in adjusted analyses (**Table 4**). Cancer survivors who were employed at or after diagnosis and took extended paid or unpaid leave or switched to part time were more likely to report any financial sacrifice than those who were employed but did not take extended leave or switch to part time or who were not employed at

or after diagnosis. Among survivors aged 65+ years, financial sacrifices were more common among those with two or more comorbid conditions and those 1 to 5 years posttreatment (**Table 4**; Supplementary Table S6).

Discussion

Using data from a nationally representative survey, we document substantial medical financial hardship among cancer survivors in the United States. Among those aged 18-64 years, nearly a quarter reported trouble with material hardship including paying medical bills, borrowing money, or even filing bankruptcy due to cancer diagnosis and treatment. Over 40% had worries about their financial situation and nearly 30% could not adhere to prescribed cancer care because of cost. Among cancer survivors aged 18-64 years, 53.6% ever had any medical financial hardship, representing nearly 3.2 million cancer survivors in the United States in 2016. Cancer survivors also make nonmedical financial sacrifices, distinct from medical financial hardship, as they balance trade-offs under resource constraints. We found approximately 54% reported financial sacrifices in basic spending, using savings, changing living situation, or changing other spending, representing 3.2 million survivors in the United States. Medical financial hardship and financial sacrifices were less common in cancer survivors aged 65+ years, despite higher prevalence of comorbid conditions, likely reflecting Medicare insurance coverage, which can protect against medical financial hardship and other financial sacrifices. Nonetheless, 42.0% reported ever having had any medical financial hardship and 38.4% reported financial sacrifices, representing nearly 3.6 million and 3.3 million cancer survivors aged 65+ respectively in the United States in 2016.

We identified socioeconomic factors associated with higher medical financial hardship intensity and nonmedical financial sacrifices in cancer survivors, including low family income at the time of survey and education attainment. Minority cancer survivors were also more likely to report hardship intensity and sacrifices. Prior studies have

Table 4. Adjusted weighted percentages of any financial sacrifice, by age group.

	18-64 years (<i>n</i> = 401)			65 $+$ years ($\emph{n}=$ 562)			
	Adjusted %	95% CI	P	Adjusted %	95% CI	P	
Age group							
18-54	62.0	(54.2-69.8)	0.003	_	_	0.08	
55-64	46.8	(39.9-53.8)		_	_		
65-74	_	_		43.0	(35.6-50.3)		
≥75 ^a	_	_		34.2	(28.5-39.9)		
Sex							
Male	63.0	(53.5-72.5)	0.03	52.1	(42.1-62.2)	0.57	
Female	50.0	(43.2-56.8)		63.5	(58.4-68.6)		
Race/ethnicity							
Non-Hispanic white only	51.7	(45.1-58.3)	0.05	36.5	(31.4-41.6)	0.06	
Other race/ethnicities ^b	63.7	(54.4-73.0)		47.9	(37.8 - 57.9)		
Current marital status							
Married	57.3	(50.6-64.1)	0.11	40.3	(33.4-47.2)	0.44	
Not married ^c	48.4	(39.7-57.1)		36.1	(29.0-43.1)		
Education							
Less than high school graduate	79.5	(67.2-91.8)	<0.001	30.7	(19.9-41.4)	0.30	
High school graduate	58.2	(48.2-68.3)		39.4	(31.9-46.9)		
Some college or more	48.6	(41.4-55.8)		40.2	(33.6-46.8)		
Current family income as percent of poverty line							
Low income ≤138%	56.9	(44.1-69.7)	0.04	39.8	(29.7-50.0)	0.21	
Middle income 139-400%	64.3	(54.8-73.9)		43.8	(36.0-51.6)		
High income >400%	47.3	(38.5-56.1)		33.1	(25.4-40.7)		
Employment Changes ^d							
Employed at or after diagnosis without extended change due to cancer	45.4	(36.0-54.9)	< 0.001	_	_	_	
Employed at or after diagnosis and took extended change due to cancer	69.9	(60.9-78.8)		_	_		
Not employed at or after diagnosis/missing	49.4	(40.0-58.7)		_	_		
Current health insurance for age <65 ^e							
Age <65, any private	53.7	(47.2-60.2)	0.72	_	_	_	
Age <65, public only	54.5	(41.0-67.9)		_	_		
Age <65, uninsured	62.7	(41.5-83.8)		_	_		
Current health insurance for age 65+e							
Age 65+a, Medicare and private	_	_	_	38.9	(32.4-45.3)	0.70	
Age 65+a, Medicare and other public	_	_		32.4	(16.9 - 47.9)		
Age 65+a, Medicare only	_	_		39.7	(32.1-47.3)		
Number of known MEPS priority conditions (excluding cancer) ^f							
0-1	49.4	(41.9-57.0)	0.11	29.4	(20.4-38.4)	0.04	
2-8	58.5	(50.6-66.5)		40.1	(35.1-45.1)		
Years since last cancer treatment							
<1	56.3	(45.5-67.2)	0.62	38.7	(29.4-48.0)	0.00	
1 to <5	53.1	(41.6-64.6)		51.0	(38.4-63.6)		
≥5 ^g	55.9	(46.4-65.3)		37.4	(30.5-44.3)		
Never treated/missing	45.9	(32.9-58.9)		24.1	(14.4-33.9)		

Note: Any financial sacrifices were defined as having responded yes to one or more of the individual financial sacrifice measures including reduce spending on vacation or leisure activities, delay large purchases, reduce basic spending, use savings set aside for other purposes, make a change to living situation, and/or other sacrifice because of cancer. Multivariable logistic models adjusted for age group, sex, race/ethnicity, marital status, education, family income, employment change due to cancer (only for 18-64 years), health insurance, number of conditions, and years since last cancer treatment. Bold font indicates statistical significance at alpha = 0.05.

documented that these factors are associated with material, psychological, or any financial hardship (3, 22, 23). Our study contributes additional evidence related to hardship intensity and financial sacrifices for populations that have historically experienced disparities in access to cancer care and poorer outcomes following diagnosis. Additional research is needed to identify effective strategies at the

Abbreviation: CI, confidence interval.

 $^{^{}a}$ Age top-coded \geq 85 by the MEPS.

^bOther race/ethnicities include Hispanic, non-Hispanic Black, Asian, other race, or multiple races.

^cNot married includes widowed, divorced, separated, or never married.

dEmployment change due to cancer was not considered for cancer survivors ages 65+ years because the majority was not employed.

ePublic insurance included Medicare, Medicaid, State Children's Health Insurance Program, and/or other public hospital/physician coverage. TRICARE/CHAMPVA was treated as private coverage, as were employer-based, union-based, and other private insurance.

Conditions include arthritis, asthma, diabetes, emphysema, heart disease (angina, coronary heart disease, heart attack, and other heart condition/disease), high cholesterol, hypertension, and stroke.

 $^{^{9}}$ Years since last cancer treatment top-coded at \geq 20 by the MEPS.

national, state, health system, and provider levels to mitigate the risk of medical financial hardship and widening of disparities in cancer outcomes.

The more recently treated cancer survivors in both age groups were at greater risk of medical financial hardship and nonmedical financial sacrifices, consistent with previous findings on material and psychological financial hardships with the 2011 MEPS data (3). Cancer survivors were also prone to increased use of health care for posttreatment surveillance and for the lasting effects of cancer treatment (24). Affordable and reliable insurance coverage can protect frequent health care users from financial hardship, as suggested by the Oregon Health Insurance Experiment (25, 26) and by consistent findings of lower medical financial hardship among elderly survivors, who have more comorbidities but near-universal Medicare coverage (3, 7). Our findings related to health insurance coverage associated with hardship intensity in both younger and elder cancer survivors also demonstrate the protection effect of insurance. Since its implementation, the Affordable Care Act has reduced the uninsured rate among Americans (27, 28) and more specifically among patients with cancer (18, 19) and cancer survivors (17). Recent data have shown that the Affordable Care Act improved financial wellbeing, particularly for low- and middle-income Americans (29, 30). Aspects of the Affordable Care Act are undergoing revisions, such as removal of the individual mandate, introduction of short-term coverage plans (31) in the marketplace, and the addition of work requirements and costsharing within Medicaid in some states. These revisions may have led to an uptick in the uninsured rate in the United States (32). Besides coverage, health insurance benefit design may also influence financial hardship of beneficiaries. For example, our findings that elderly survivors with Medicare and public insurance had the least hardship compared with those with Medicare only or Medicare and private insurance suggest that cost-sharing plays an important role especially when healthcare needs are elevated due to multiple health conditions. Moreover, enrollment in high-deductible health plans (HDHP) is increasing (33), and HDHPs without health savings accounts is associated with delaying or forgoing health care as part of the behavioral domain of medical financial hardship (34). Future research will need to monitor the effects of ongoing changes of health policy and benefit design on medical financial hardship and nonmedical financial sacrifices among cancer survivors.

Other contributors to medical financial hardship and financial sacrifices among cancer survivors include limitations in ability to work caused by cancer diagnosis and/or treatment, and subsequent income reductions and loss of employer-sponsored health insurance coverage (35, 36). As our results showed, hardship intensity was most prominent among survivors who were employed and had to make cancer-related extended employment changes. Employer-level features such as health insurance offerings, availability of paid and unpaid sick leave, and workplace accommodations, can play a large role in medical financial hardship for employed cancer survivors and family members (16). Therefore, development of workplace accommodations and supportive programs at the employer-level has potential to mitigate financial hardship experienced by cancer survivors. Documenting the prevalence, effectiveness, and cost-effectiveness of workplace accommodations on employee health and retention will be important for future research.

Along with advancements in cancer treatment, the cost of new cancer therapies has escalated. The average price of anticancer drugs increased more than 5-fold in the past decade (37). Meanwhile, increased patient cost-sharing has led to rising patient out-of-pocket (OOP) costs (38), increasing the risk of financial hardship for

patients with cancer, survivors, and their families. Although most states have passed oral oncology parity laws to equalize cost-sharing for new oral cancer therapies to that of infused cancer therapies, evidence suggests that the impact of these laws is limited. They often benefit only those who already had low copayments (39-41). More targeted programs are needed to provide financial protection to those patients with cancer facing high OOP. Hospital/clinic-based financial navigation programs (42-45) and patient financial assistance programs administered by patient advocacy organizations (ref. 46; see a list of financial resources at https://www.cancer.net/navigating-can cer-care/financial-considerations/financial-resources) or pharmaceutical manufacturers (47-50), may help alleviate medical financial hardship for some patients with cancer and survivors. Other examples of future efforts in the healthcare system include systematic screening for financial hardship at diagnosis and tracking for financial status during treatment and follow-up care, which can be aided with electronic health record functionality and may require discussions about OOP cost and the total cost of cancer care (16). Although patientphysician cost discussions is desired by most patients with cancer (51-54) and recommended by the Institute of Medicine (55) and the American Society of Clinical Oncology (56), it still rarely happens due to multiple barriers such as insufficient time, limited training, lack of cost transparency, and lack of knowledge about costs of cancer care across multiple payers. Additional research and evaluation are needed to identify who in the care team should discuss these issues and when are the best times for the discussions (52, 57). The factors associated with high intensity of medical financial hardship identified in this study can help prioritize limited healthcare resources to those high-risk populations who need the financial screening, navigation, and assistance programs the most.

Our study's strengths include the recent nationally representative sample and well-designed questions to measure medical financial hardship due to cancer and its lasting effects. These strengths facilitated our ability to provide national estimates and identify risk factors for medical financial hardship intensity and evaluate financial sacrifices for the first time. Our study has limitations in common with other national survey studies including potential recall bias in self-reporting, relatively low response rate, and lack of data on the clinical features of cancers such as stage and treatment specifics. Although the questions specified experience "because of your cancer, its treatment or the lasting effects of that treatment," there might be variations and measurement errors when survivors attributing financial hardship from cancer or other health conditions. In addition, our measures of insurance coverage, family income, and number of comorbidities were current estimates at the time of the survey, whereas measures of financial hardship and sacrifices were defined as ever. We were also limited by sample size to analyze important subpopulations such as racial/ethnic minorities and survivors with HDHPs and/or health savings accounts. The associations we observed cannot infer causal relationships. Longitudinal studies are needed to elucidate the dynamic relationships of insurance coverage, family income, and health conditions with financial hardship and sacrifice after a cancer diagnosis.

In summary, we found that cancer survivors commonly experience material, psychological, behavioral hardship, and nonmedical financial sacrifices resulting from their cancer diagnosis and treatment. Extended employment change, insurance, and comorbidities were associated with intensity of medical financial hardship and financial sacrifices. Future research is warranted to monitor the effects of ongoing changes in health policy and benefit design, especially in light of ongoing implementation of the Affordable Care Act, on

financial hardship and sacrifices among cancer survivors. Our findings highlight a need for financial intervention at multiple levels, such as patient financial navigation and availability of patient assistance programs, physician-patient communication regarding care costs, improved employer accommodation, and state and federal policy ensuring affordable health insurance for cancer survivors. These interventions are important for preventing and addressing cancerrelated financial hardship among survivors and their families.

Disclosure of Potential Conflicts of Interest

No potential conflicts of interest were disclosed.

Authors' Contributions

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