Race financial hardship and limiting care due to cost in a diverse cohort of cancer survivors



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bstract

Purpose Estimate prevalence of types of cancer-related financial hardship by race and test whether they are associated with limiting care due to cost.

Methods We used data from 994 participants (411 white, 583 African American) in a hospital-based cohort study of survivors diagnosed with breast, colorectal, lung, or prostate cancer since January 1, 2013. Financial hardship included decreased income, borrowing money, cancer-related debt, and accessing assets to pay for cancer care. Limiting care included skipping doses of prescribed medication, refusing treatment, or not seeing a doctor when needed due to cost. Logistic regression models controlled for sociodemographic factors.

Results More African American than white survivors reported financial hardship (50.3% vs. 41.0%, p = 0.005) and limiting care (20.0% vs. 14.2%, p = 0.019). More white than African American survivors reported utilizing assets (9.3% vs. 4.8%, p = 0.006), while more African American survivors reported cancer-related debt (30.5% vs. 18.5%, p < 0.001). Survivors who experienced financial hardship were 4.4 (95% CI: 2.9, 6.6) times as likely to limit care as those who did not. Borrowing money, cancer-related debt, and decreased income were each independently associated with limiting care, while accessing assets was not.

Conclusions The prevalence of some forms of financial hardship differed by race, and these were differentially associated with limiting care due to cost.

Implications for Cancer Survivors The ability to use assets to pay for cancer care may protect survivors from limiting care due to cost. This has differential impacts on white and African American survivors.

Keywords African American · Cancer · Disparities · Financial hardship · Limiting care · Race

Introduction

Nearly half of cancer survivors in the USA report some form of financial hardship related to cancer [1]. Previous work has identified three broad domains of financial hardship, including material, behavioral, and psychological [1]. Material financial hardship (referred to as financial hardship" throughout this

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manuscript) can take many forms, including using savings to pay for cancer care [2], the inability to cover medical and household bills [3], and experiencing high levels of debt or filing for bankruptcy [4–8], even among survivors with health insurance [5, 6]. Financial hardship due to cancer has been associated with poorer access to medical care [7, 8], which can lead to poor quality of life [9, 10] and even mortality [11].

One way that patients may cope with financial hardship related to cancer is to limit the medical care they receive (behavioral financial hardship [1]). This may include delaying treatment or not seeing healthcare providers when necessary, taking less than the prescribed amount of medications, and refusing treatments [1, 12]. Cancer survivors are more likely than adults with no history of cancer to forgo several types of care, including medical, dental, and mental health care and prescription medications [7]. Financial problems are associated with forgoing cancer care due to cost [8, 13]; specifically, high out-of-pocket costs and other financial strains are



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associated with nonadherence to prescription medications among cancer patients and survivors [13–16], and with not receiving recommended surveillance after a cancer diagnosis [17].

There is evidence that financial hardship is most common among racial/ethnic minority and low-income survivors [3, 8, 18–21]; however, less is known about whether the types of financial hardship experienced differ by race [3, 22]. Additionally, previous work has not established whether the association between financial hardship and limiting care due to cost varies by type of financial hardship. Different forms of financial hardship may have different implications for decisions around accessing care. Specifically, needing to borrow money or take on cancer-related debt may have different implications for limiting care than being able to pay for necessary treatment using existing financial resources.

The purpose of this study is twofold: (1) to estimate the prevalence of both material financial hardship and limiting care due to cost (behavioral financial hardship) and test whether the prevalence of each type of financial hardship and care limitation differs by race and (2) to estimate the association between total and specific types of financial hardship and limiting care due to cost. We hypothesize that the types of financial hardship experienced will differ by race, and that all forms of financial hardship will be associated with limiting care due to cost.

Methods

Study cohort

The Detroit Research on Cancer Survivors (Detroit ROCS) pilot is a hospital-based, prospective cohort study designed to investigate the associations between comorbid conditions, medical history, health behaviors, social support, financial well-being, and health-related outcomes among African-American and white cancer survivors [23]. Participants were eligible to join the cohort if they were between the ages of 20 and 79; diagnosed with a primary, invasive colorectal, lung, prostate, or female breast cancer on or after January 1, 2013; and diagnosed and/or treated at the Karmanos Cancer Center (KCC) in Detroit, Michigan.

A flow diagram of participant recruitment appears in Fig. 1. Data queries of the KCC cancer registry between September 2015 and January 2016 identified 1475 potentially eligible participants. We contacted the physician of record for each asking if they objected to the patient being invited to participate. We sent participant invitation letters if we did not receive a physician objection within 3 weeks. Nine survivors were excluded due to physician objection, 347 refused, and 119 did not respond to repeated invitations, for a total of 1000 survivors enrolled into the cohort (response rate = 67.8%).

Response rates were higher in African American (69.6%) than white survivors (65.4%) and in breast (70.2%) and lung (70.6%) cancer survivors compared with survivors of colorectal (66.4%) and prostate (62.8%) cancer. Response rates did not differ by stage (67.7% among local/regional disease vs. 68.2% for distant stage disease) or time since diagnosis (67.8% within 15 months of diagnosis and 15+ months since diagnosis). Participants completed baseline surveys online using Qualtrics (30.3%) or over the phone with a trained interviewer (69.7%) between March 2015 and June 2017. Analyses exclude participants missing information on all measures of limiting care due to cost (N = 6), for an analytic sample of 994 participants. Included participants had complete data for all measures of financial hardship.

Data collection

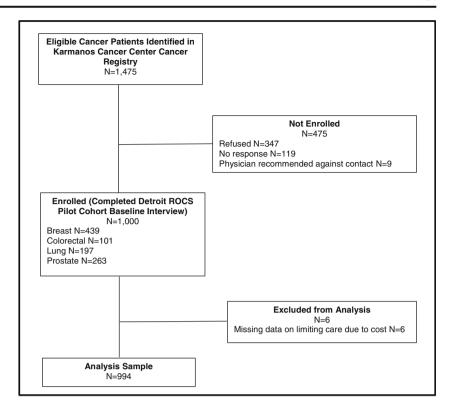
Participant demographic and socioeconomic characteristics including race, sex, income, education, marital status, employment, and cancer treatments received were self-reported using categories included in Table 1 and reflect information at the time of survey completion rather than at cancer diagnosis unless otherwise noted. Health insurance information regarding private insurance, Medicare, and Medicaid coverage is from self-reported responses to the question, What kind of health insurance do you currently have?" with response options of Medicare only, Medicare plus other insurance, private insurance through an employer, private insurance not through an employer, Veterans Affairs, Medicaid, no insurance, and other. Information related to experiencing financial hardship and limiting care due to cost was also self-reported using previously developed measures, as described below [20, 24]. Age at diagnosis and additional cancer-related information including site, stage, and time since diagnosis were obtained through linkage with the Metropolitan Detroit Cancer Surveillance System.

Financial hardship

Participants were asked whether, in order to pay bills related to their cancer treatment, they had to do any of the following, and were instructed to select all that apply: (1) refinance or take out a second mortgage on their home, (2) sell their home, (3) sell stocks or other investments, or (4) withdraw money from retirement accounts. Selected items were coded as yes," and items left blank were coded as no." They were separately asked whether their income had declined since their cancer diagnosis, whether they or any member of their family had to borrow money from friends or other family members to help pay for their cancer treatment, and/or whether they were currently in debt due to expenses related to their cancer. Participants were considered to have experienced financial hardship if they answered in the affirmative to any of the



Fig. 1 Flow diagram of the study sample



above items. In sub-analyses, measures of having to borrow money, currently being in cancer-related debt, and experiencing a decrease in income were each considered separately. Participants were counted as accessing assets if they indicated that they refinanced or sold their home, sold stocks or other investments, or withdrew money from retirement accounts to pay for cancer care. All of the financial hardship questions are based on previous work by Shankaran et al. [20].

Limiting care due to cost

Three items assessed whether participants limited care related to their cancer diagnosis due to cost: (1) Was there a time in the past 12 months when you needed to see a doctor but could not because of cost?"; (2) Did you ever turn down treatments (chemotherapy, radiation, pain medications, anti-nausea medications, anti-diarrhea medications, or other recommended cancer treatments) because you were concerned about the cost?"; and (3) Did you ever skip doses of a prescribed medication to save money?". The first question is from the Behavioral Risk Factor Surveillance System [24], and the others are based on previous work by Shankaran et al. [20]. Participants were considered to have limited care due to cost if they answered in the affirmative to any of these items.

Statistical analysis

Odds ratios (ORs) and 95% confidence intervals (CI) of the associations between any and specific types of financial

hardship and limiting care due to cost were estimated using logistic regression models. We present results of models controlling only for age at diagnosis and sex, and models additionally controlling for income, employment status, marital status, health insurance, and cancer site, all using the categories presented in Table 1. These factors were included a priori based on previous literature describing predictors of financial hardship among cancer survivors. We further considered education, time since diagnosis, and cancer treatments received as additional covariates, but none were associated with limiting care due to cost in adjusted models and none changed the overall observed association between financial hardship and limiting care, so they were excluded from our analyses.

Finally, models of individual types of financial hardship were also mutually adjusted for each of the other forms of financial hardship (e.g., the model of the association between borrowing money and limiting care due to cost controls for debt, utilizing assets, and reporting a decrease in income).

In sensitivity analyses, we assessed whether differences in types of financial hardship by race remained after controlling for household income. We further assessed whether observed associations between financial hardship and limiting care differed by race by fitting adjusted models separately among white and African American survivors. A test for interaction was conducted by including an interaction term (financial hardship × race) in the model of any financial hardship and limiting care due to cost. We used the same procedure to test for interaction by time since diagnosis split at the median of 18 months. All statistical tests were two-sided. Analyses were



Table

(continued)

Characteristic	Total		White		African American	
	N=9	94	N=411		N = 583	
	\overline{N}	%	N	%	\overline{N}	%
Race						
African American	583	58.7	583	100	_	_
White	411	41.4	_	_	411	100
Sex						
Female	615	61.9	260	63.3	355	60.9
Male	379	38.1	151	36.7	228	39.
Age at diagnosis						
<55	265	26.7	121	29.4	144	24.
55–59	218	21.9	70	17.0	148	25.4
60–64	207	20.8	77	18.7	130	22.
65+	304	30.6	143	34.8	161	27.
Income			-			•
< 20,000	395	42.4	58	15.3	337	60.
20,000–39,999	169	18.1	68	17.9	101	18.
40,000–59,999	114	12.2	61	16.1	53	9.6
60,000–79,999	69	7.4	37	9.8	32	5.8
80,000+	185	19.9	155	40.9	30	5.4
Education	103	17.7	133	10.5	50	5.1
Less than high school	115	11.7	24	5.8	91	15.
High school/GED	297	30.1	97	23.6	200	34.
Some college	345	35.0	134	32.6	211	36.
College degree	230	23.3	156	38.0	74	13.
Marital status	230	23.3	130	36.0	/-	13.
Married/living with partner	457	46.3	298	73.0	159	27.
Widowed	108	10.9	298	6.9	80	13.
		23.0	60			
Divorced/separated Never married	227		22	14.7	167	28.
	195	19.8	22	5.4	173	29.
Employment status	107	10.0	120	20.2	77	12
Employed full time	197	19.8	120	29.2	77	13.
Employed part time	80	8.1	49	11.9	31	5.3
Homemaker	37	3.7	17	4.1	20	3.4
Unemployed	86	8.7	22	5.4	64	11.0
Retired	360	36.2	152	37.0	208	35.
Medical leave/disability	221	22.2	48	11.7	173	29.
Other/missing	13	1.3	3	0.7	10	1.7
Any private health insurance						
No	302	30.8	56	13.8	246	42.
Yes	680	69.3	350	86.2	330	57
Any Medicare						
No	552	56.0	239	58.6	313	54.
Yes	433	44.0	169	41.4	264	45.
Any Medicaid						
No	771	78.5	367	90.4	404	70.
Yes	211	21.5	39	9.6	172	29.

Characteristic	Total		White $N = 411$		African American N=583	
	N=9	94				
	N	%	\overline{N}	%	\overline{N}	%
Breast	439	44.2	174	42.3	265	45.5
Colorectal	101	10.2	51	12.4	50	8.6
Lung	194	19.5	100	24.3	94	16.1
Prostate	260	26.2	86	20.9	174	29.9
Cancer stage at diagnosis						
I	286	28.9	112	27.5	174	29.9
II	337	34.0	120	29.4	217	37.3
III	190	19.2	83	20.3	107	18.4
IV	177	17.9	93	22.8	84	14.4
Cancer treatments						
Surgery						
Yes	696	70.3	294	71.5	402	69.4
No	294	29.7	117	28.5	177	30.6
Chemotherapy						
Yes	535	54.2	235	57.6	300	51.8
No	452	45.8	173	42.4	279	48.2
Radiation						
Yes	601	61.2	232	57.7	369	63.6
No	381	38.8	170	42.3	211	36.4
Time since diagnosis						
< 12 months	161	16.2	76	18.5	85	14.6
12-17 months	352	35.5	129	31.4	223	38.3
18-23 months	228	23.0	97	23.6	131	22.5
24+ months	252	25.4	109	26.5	143	24.6

conducted using Stata 14.0 (StataCorp LP, College Station, TX).

Results

A majority of participants were women (61.9%), younger than 65 at diagnosis (69%), and African American (58.7%) (Table 1). More than 40% of participants reported incomes below 20,000 per year. Approximately one-quarter (27.9%) were employed full or part time at baseline. A majority (69.3%) reported having some form of private health insurance coverage, either on its own or in combination with other coverage, while 44% were enrolled in Medicare and 21.5% were enrolled in Medicaid. The most common cancer in the cohort was breast (44.2%), followed by prostate (26.2%), lung (19.5%), and colorectal (10.2%).

Table 2 gives the prevalence of financial hardship and limiting care due to cost by participant sociodemographic and



 Table 2
 Material financial hardship and limiting care due to cost by participant sociodemographic and cancer-related characteristics

	Any financial hardship			Any limiting care due to cost		
	\overline{N}	%	P	N	%	P
Total	436	46.4		171	17.6	
Sex						
Female Male	291 145	50.6 39.8	0.001	108 63	17.9 17.2	0.786
Age at diagnosis						
< 55	146	57.0	< 0.001	49	19.1	0.111
55–59	109	51.4		44	20.4	
60–64	93	48.4		39	19.2	
65+	88	31.5		39	13.1	
Income						
< 20,000	201	53.6	< 0.001	103	26.6	< 0.001
20,000–39,999	81	50.0		29	17.7	
40,000–59,999	45	41.7		14	12.5	
60,000–79,999	33	49.3		9	13.2	
80,000+	53	30.8		10	5.5	
Education	4.1	20.7	0.005	22	20.5	0.25
Less than high school High school/GED	41 138	38.7 48.6	0.007	23 57	20.7 19.8	0.27
Some college	169	52.0		56	16.5	
College degree	85	39.0		32	14.1	
Marital status	65	37.0		32	17.1	
Married/living with partner	171	39.1	< 0.001	54	12.1	< 0.001
Widowed	51	51.5	< 0.001	29	27.4	< 0.001
Divorced/separated	109	52.4		46	21.0	
Never married	102	54.3		40	20.8	
Employment status						
Employed full time Employed part time	85 39	45.0 52.7	0.001	23 16	11.8 20.0	0.023
Homemaker	12	37.5		6	17.1	
Unemployed	52	61.9		21	24.4	
Retired	129	38.5		52	15.0	
Other/missing	6	50.0		2	15.4	
Medical leave/disability	113	53.1		51	23.6	
Any private health insurance						
No	163	56.6	< 0.001	71	24.2	< 0.001
Yes	268			98	14.7	
Any Medicare						
No	272	51.6	< 0.001	96	17.9	0.76
Yes	159	39.4		73	17.1	
Any Medicaid						
No	318		0.002	118	15.6	0.002
Yes	113	56.2		51	24.8	
Cancer site						
Breast Colorectal	211 45	51.2 46.4	0.016	81 13	18.6 13.7	0.72
	43 84	46.7		32	17.1	
Lung Prostate	96	38.4		32 45	17.1	
	70	JU. 1		73	1/./	
Cancer stage at diagnosis						

Table 2 (continued)

	-	Any financial hardship			Any limiting care due to cost		
	\overline{N}	%	P	N	%	P	
I	88	33.5	< 0.001	46	16.3	0.63	
II	153	47.7		57	17.2		
III	99	54.7		38	20.9		
IV	95	55.9		30	17.5		
Cancer treatments							
Surgery							
Yes	306	46.5	0.85	121	17.7	0.95	
No	127	45.9		50	17.5		
Chemotherapy							
Yes	281	54.9	< 0.001	101	19.4	0.11	
No	152	36.1		69	15.5		
Radiation							
Yes	278	41.8	0.032	104	17.6	0.82	
No	151	49.0		63	17.0		
Time since diagnosis							
< 12 months	69	45.4	0.82	27	17.3	0.71	
12-17 months	157	47.0		55	15.9		
18-23 months	105	48.4		39	17.8		
24+ months	104	44.3		49	19.6		

cancer-related characteristics. Nearly half of participants (46.4%) reported experiencing any financial hardship associated with cancer, and 17.6% limited care due to cost. Financial hardship was more common among women, younger survivors, those from lower income households, and those who were not married or living with a partner. Financial hardship also varied by employment, marital status, and health insurance coverage, and was most common among breast cancer survivors, those diagnosed with late-stage disease, and those who received any chemotherapy. Predictors of limiting care due to cost included younger age, being unmarried, being unemployed or on disability, and having Medicaid coverage.

Financial hardship was more common in African American (50.3%) than white survivors (41.0%, p = 0.005) (Table 3). Experiencing a decrease in income was the most common form of financial hardship (29.5%), followed by still being in cancer-related debt (25.5%), borrowing money from family or friends (9.7%), and utilizing assets to pay for cancer care (6.6%).

The prevalence of some types of financial hardship differed by race (Table 3). More African American (30.5%) than white (18.5%) survivors reported currently being in debt due to cancer (p < 0.001), while more white (9.3%) than African American (4.8%) survivors reported utilizing assets to pay for cancer care (p = 0.006). These differences were evident for refinancing or selling a home (1.7% of white vs. 0.3% of African American survivors; p = 0.026) and withdrawing



Table 3 Prevalence of financial hardship and limiting care due to cost by race

	Total $N = 994$		White I	V=411	African American $N = 583$		
	N	%	\overline{N}	%	N	%	P^{a}
Any financial hardship	436	46.4	159	41.0	277	50.3	0.005
Borrowed money from family or friends	95	9.7	39	9.7	56	9.7	0.98
Remaining debt	250	25.5	75	18.5	175	30.5	< 0.001
Utilized assets to pay for cancer care	66	6.6	38	9.3	28	4.8	0.006
Refinanced or sold home	9	0.9	7	1.7	2	0.3	0.026
Sold stock or other investments	15	1.5	8	2.0	7	1.2	0.34
Withdrew money from retirement	56	5.6	31	7.5	25	4.3	0.028
Experienced a decrease in income	276	29.5	110	28.2	166	30.4	0.47
Any care limitations	171	17.6	57	14.2	114	20.0	0.019
Skipped doses of prescribed medication	71	7.2	23	5.6	48	8.3	0.11
Refused recommended treatment due to cost	49	5.0	21	5.1	28	4.8	0.83
Needed to see a doctor but did not go due to cost	111	11.4	33	8.2	78	13.6	0.008

Note: responses are not mutually exclusive

money from retirement savings to pay for cancer care (7.5% of white vs. 4.3% of African American survivors; p = 0.028).

The most common form of limiting care due to cost was needing to see a doctor but not going due to cost (11.4%), followed by skipping doses of prescribed medication to save money (7.2%), and refusing recommended treatment due to cost (5%) (Table 3). More African American (20%) than white (14.2%) survivors reported limiting care due to cost (p = 0.019), driven by a higher proportion reporting that they needed to see a doctor but did not go due to cost (13.6% vs. 8.2%; p = 0.008).

Table 4 presents odds ratios (OR) and 95% confidence intervals (CI) for the associations between any financial hardship and limiting care due to cost. In fully adjusted models, participants who experienced any financial hardship were 4.4 (95% CI: 2.9, 6.6) times as likely to report limiting care as those who did not. Financial hardship was associated with skipping doses of prescribed medication (OR: 2.7, 95% CI: 1.5, 4.9), refusing treatment (OR: 5.9, 95% CI: 2.6, 13.7), and needing to see a doctor but not going due to cost (OR: 4.1, 95% CI: 2.4, 6.9). In a mutually adjusted model, borrowing money (OR: 3.9, 95% CI: 2.2, 6.9), debt (OR: 3.0, 95% CI: 1.9, 4.6), and experiencing a decrease in income (OR: 1.8, 95% CI: 1.1, 2.6) remained independently associated with limiting care; however, utilizing assets was no longer associated with limiting care when controlling for the other forms of financial hardship.

In sensitivity analyses, we observed no significant (p < 0.05) difference in the types of financial hardship experienced by race or in the association between overall or individual types of financial hardship and care limitations by race or

by time since diagnosis split at the median of 18 months (data not shown).

Discussion

Financial hardship was common in this diverse cohort of cancer survivors, and the prevalence of some forms of financial hardship differed by race, with more African American survivors reporting lasting cancer-related debt and more white survivors reporting utilizing assets to pay for cancer care. Financial hardship was strongly associated with limiting care due to cost, and borrowing money from friends or family and remaining in debt due to cancer remained strongly associated with limiting care even after adjusting for other forms of financial hardship.

Our finding that experiencing financial hardship is associated with limiting care due to cost is consistent with previous findings that financial problems were associated with forgoing or delaying medical care [8], and especially with nonadherence to prescription medications [13], including oral oncolytics [13–16].

While several previous studies have reported higher prevalence of financial hardship among non-white compared with white cancer survivors [3, 8, 18, 20, 21], less is known about how specific types of financial hardship differ by race. Similar to our findings, in a longitudinal study of breast cancer survivors, Jagsi et al. reported that more white (90%) than African American (81%; p < 0.001) survivors used income and/or savings to pay for cancer care, while more African American (15%) than white (9%; p = 0.03) survivors faced cancer-related debt [3].



^a P values reflect the two-sided Wald test of differences in prevalence of financial hardship or care limitation by race

Table 4 Odds ratios (OR) and 95% confidence intervals (CI) of the association between overall and types of financial hardship and limiting care due to cost

	Age- and sex-adjusted OR (95% CI)	Fully adjusted OR (95% CI)	Mutually adjusted OR (95% CI)
Any financial hardship			
Any care limitations	5.0 (3.4, 7.4)	4.4 (2.9, 6.6)	_
Skipped doses of prescribed medication to save money	3.2 (1.9, 5.4)	2.7 (1.5, 4.9)	_
Refused treatment due to cost	7.5 (3.3, 16.9)	5.9 (2.6, 13.7)	_
Needed to see a doctor but did not go due to cost	5.4 (3.3, 8.8)	4.1 (2.4, 6.9)	_
Borrowed money from friends or family to pay for cancer care			
Any care limitations	8.1 (5.1, 12.6)	7.6 (4.6, 12.6)	3.9 (2.2, 6.9)
Reported still being in debt due to cancer			
Any care limitations	6.2 (4.3, 8.8)	4.9 (3.4, 7.2)	3.0 (1.9, 4.6)
Used assets (investments, home equity, retirement savings)			
Any care limitations	2.0 (1.4, 3.0)	2.2 (1.4, 3.5)	1.1 (0.6, 1.9)
Experienced a decrease in income			
Any care limitations	2.8 (2.0, 4.0)	2.7 (1.8, 4.0)	1.8 (1.1, 2.6)

ully adjusted models control for age at diagnosis, sex, income, employment status, marital status, health insurance, and cancer site using categories in Table 1. *Mutually adjusted* models add the other forms of financial hardship (borrowing, debt, assets, and/or reduction in income), as appropriate (e.g., models of the associations between borrowing money and care limitations are further adjusted for debt, assets, and decrease in income)

Our finding that the types of financial hardship experienced differed by race is not surprising given estimates that the median net worth of white adults is approximately 13 times that of black adults in the USA [25]. This disparity in net worth means that, on average, white adults may be better able to absorb a financial shock such as a cancer diagnosis by accessing assets to avoid cancer-related debt than African Americans.

A recent manuscript by Wheeler et al. [22] reported that, compared with white women, greater proportions of black breast cancer survivors experienced income loss, financial barriers, transportation barriers, job loss, and insurance loss related to breast cancer. Associations between race and income loss and transportation barriers remained even after controlling for socioeconomic status; however, race was no longer associated with other forms of hardship after controlling for socioeconomic factors. In sensitivity analyses controlling for household income, we no longer observed a difference in prevalence of individual forms of financial hardship or limiting care by race (data not shown). However, the purpose of these analyses is to reflect the reality faced by diverse cancer survivors in the context of race-based differences in socioeconomic status, rather than to propose that the association between race and financial hardship is causal or exists independent of socioeconomic factors.

Importantly, our results further suggest that the types of financial hardship that differed by race were also differentially associated with limiting care due to cost. While utilizing assets to pay for cancer care was more common among white survivors, it was not associated with limiting care due to cost independent of other forms of financial hardship. On the other hand, cancer-related debt, which was more common in African American survivors, was strongly associated with all forms of limiting care due to cost even after accounting for other forms of financial hardship. This may suggest that patients with assets are able to utilize them to avoid limiting care due to cost, while those who go into debt to pay for cancer care also limit care due to cost concerns.

Although the number of uninsured Americans decreased by 20.2 million after the enactment of Affordable Care Act (ACA) in 2010, approximately 24.4 million adults ages 18-64 years were uninsured in early 2016 [26], and others remained underinsured due to high cost-sharing requirements [27]. Additionally, it is uncertain whether individuals will be able to purchase health coverage that will effectively cover the costs of cancer care in the future. Changes to the coverage available through the ACA, Medicare, and/or Medicaid that result in higher enrollee costs and/or limits to the types of services covered are likely to expose cancer patients to greater financial hardship. This could impact survivors ability to access to cancer-related care, particularly for survivors who are not able to use assets to pay for care, and could both negatively impact cancer outcomes and widen the racial disparities in those outcomes in the future.

Limitations of this work should be noted. The measures of financial hardship and care limitations included here have been used in previous work [20], but are self-reported and have not been validated against survivors financial records. Additionally, information about participants assets is not available. A participant who indicated they did not use assets



to pay for care could have either had the asset but not needed to use it, or not had the asset available. The hospital-based design of this cohort may limit the generalizability of our results. KCC is in the City of Detroit, and acts as a community cancer hospital for the city s large African American population; however, many of the hospital s white patients travel from surrounding areas to be treated at a Comprehensive Cancer Center. These patients may have additional resources and/or represent more complex cancer cases than other patients in the metropolitan area. Differences between participants in this cohort and the broader population of cancer survivors are unlikely to bias the strong associations observed here between experiencing financial hardship and limiting care due to cost.

Strengths of this study include the large number of African American and low-income survivors enrolled, allowing for an examination of the association between financial hardship and forgoing care in populations that are often underrepresented, as well as enabling assessment of the associations between individual types of financial hardship and care limitations. The robustness of the available data allowed us to control for several important demographic, socioeconomic, and cancer-related variables.

Our findings suggest that borrowing and going into debt to pay for cancer care are both strongly associated with limiting care due to cost, independent of other forms of financial hardship. As the literature describing the financial consequences of cancer develops, emphasis is being placed on going beyond describing patterns and moving to intervene to prevent adverse outcomes related to financial hardship [28]. Patients who borrow money or take on cancer-related debt in order to pay for care may represent a priority group to target with interventions to reduce the number of patients who limit care due to cost. This can have implications for providers and hospitals interested in developing and implementing such interventions in their patient populations, and may also have policy implications by motivating continued efforts to ensure that cancer patients with limited financial resources can access recommended care.

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ompliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

Ethical approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional research committee and with the 1964 Helsinki declaration and its later amendments.



Informed consent Informed consent was obtained from all individual participants included in this study.

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