

Financial Hardship and Quality of Life among African American and White Cancer Survivors: The Role of Limiting Care Due to Cost

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Abstract

Background: Financial hardship is common among cancer survivors and is associated with both limiting care due to cost and with poor health-related quality of life (HRQOL). This study estimates the association between limiting care due to cost and HRQOL in a diverse population of cancer survivors and tests whether limiting care mediates the association between financial hardship and HRQOL.

Methods: We used data from 988 participants (579 African American, 409 white) in the Detroit Research on Cancer Survivors (ROCS) pilot, a hospital-based cohort of breast, colorectal, lung, and prostate cancer survivors. We assessed associations between financial hardship, limiting care, and HRQOL [measured by the Functional Assessment of Cancer Therapy—General (FACT-G)] using linear regression and mediation analysis controlling for demographic, socioeconomic, and cancer-related variables.

Results: FACT-G scores were 4.2 [95% confidence interval (CI), 2.0–6.4] points lower among survivors who reported financial hardship compared with those who did not in adjusted models. Limiting care due to cost was associated with a –7.8 (95% CI, –5.1 to –10.5) point difference in FACT-G scores. Limiting care due to cost explained 40.5% (95% CI, 25.5%–92.7%) of the association between financial hardship and HRQOL overall, and 50.5% (95% CI, 29.1%–188.1%) of the association for African American survivors.

Conclusions: Financial hardship and limiting care due to cost are both associated with lower HRQOL among diverse cancer survivors, and this association is partially explained by limiting care due to cost.

Impact: Actions to ensure patients with cancer can access appropriate care could lessen the impact of financial hardship on HRQOL.

Introduction

Financial hardship is common among cancer survivors, with close to 50% reporting adverse financial outcomes related to cancer or cancer treatment (1). Cancer survivors may experience material financial hardship such as reductions in income, utilizing assets, and incurring cancer-related debt, as well as behavioral financial hardship, including measures of limiting care (e.g., forgoing or delaying treatment, limiting medication) due to cost (1–4). (From here forward, this paper will refer to material financial hardship as "financial hardship" and behavioral financial hardship as "limiting care due to cost.")

Cancer-related financial hardship is associated with poor health-related quality of life (HRQOL; refs. 3, 5–15), including lower physical, functional, mental, and emotional wellbeing

(3, 6, 8, 15, 16). Many patients with cancer worry about cost when making treatment decisions (17), and experiencing financial hardship is associated with forgoing or delaying medical care (18, 19). Limiting medical care because of cost concerns could be a plausible mechanism through which material financial hardship impacts HRQOL, but little is known about the association between limiting care due to cost and HRQOL. Its role as a potential mediator of the association between financial hardship and HRQOL has not been tested.

The objectives of this study are to estimate associations between financial hardship and limiting care due to cost and HRQOL among white and African American cancer survivors, and to test whether and to what extent observed associations between financial hardship and HRQOL are mediated by limiting care due to cost. We hypothesize that financial hardship and limiting care due to cost will each be associated with lower HRQOL and that limiting care due to cost will at least partially mediate the association between financial hardship and HRQOL.

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Materials and Methods

Study population

The Detroit Research On Cancer Survivors (ROCS) pilot is a hospital-based cohort study designed to investigate associations between medical history, health behaviors, financial hardship, and health-related outcomes among cancer survivors in Metropolitan Detroit (20). Participants were eligible to join the cohort if they were: white or African American; diagnosed with a first

primary, invasive colorectal, lung, prostate, or female breast cancer on or after January 1, 2013; ages 20 to 79 at diagnosis; and diagnosed and/or treated at the Karmanos Cancer Center in Detroit, MI. Participants were diagnosed a median of 17 (mean: 18.7; range: 1–54) months before completing the baseline survey. On average, lung cancer survivors were diagnosed more recently (14.9 months) than colorectal (18.8 months), prostate (18.9 months), or breast cancer survivors (20.2 months).

A flow diagram of participant recruitment appears in Fig. 1. A total of 1,475 potentially-eligible participants were identified through a data query of the Metropolitan Detroit Cancer Surveillance System (MDCSS; the Detroit registry of the Surveillance, Epidemiology and End Results Program). We contacted the physician of record for each potential participant asking if they objected to the patient being invited to participate. Participant invitation letters were sent if no objection was received 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 1,000 survivors enrolled into the cohort (response rate = 67.8%). Participants completed baseline surveys between March, 2015 and June, 2017. Analyses exclude participants missing information on financial hardship or limiting care due to cost ($N = 10$) or HRQOL ($N = 2$), for an analytic sample of 988 participants.

The Institutional Review Board at Wayne State University approved this research, which was conducted in concordance with the Belmont Report. Participants completing the survey online provided written informed consent. Phone participants

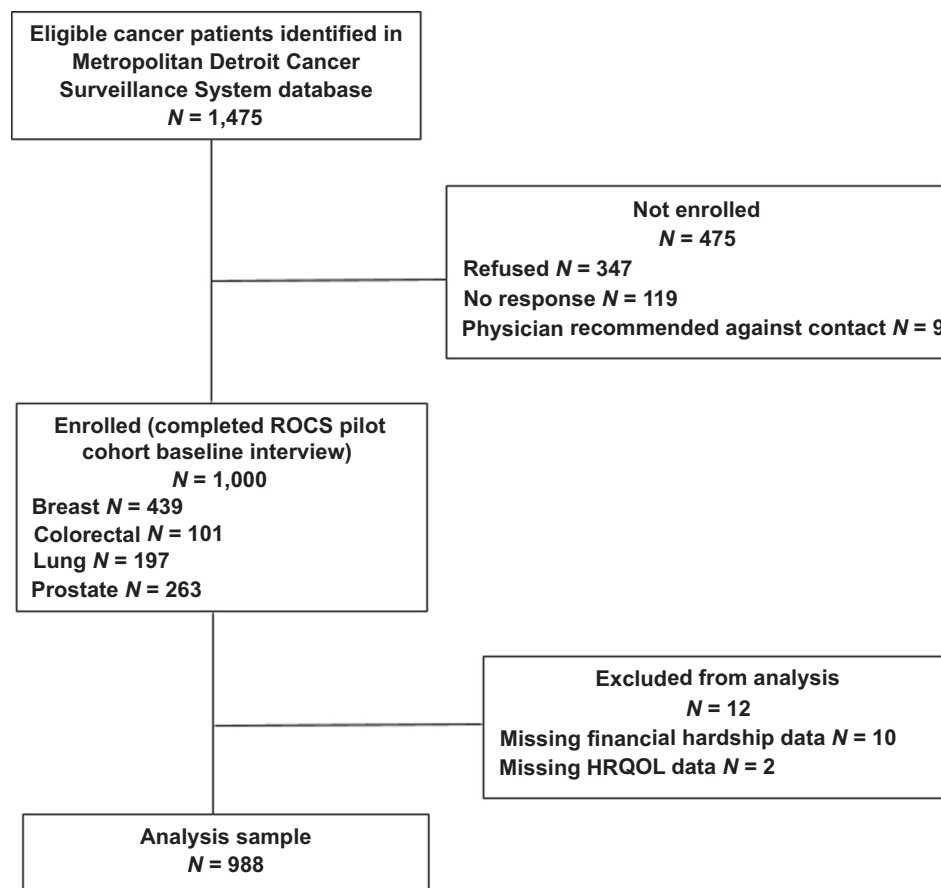
received a written study information sheet, which was reviewed by the interviewer, and provided informed consent orally.

Data collection

Information on individuals' demographic and socioeconomic characteristics, HRQOL, and experiences of financial hardship and limiting care due to cost was self-reported. Participants completed surveys online via Qualtrics or over the phone with a trained interviewer. We obtained cancer-related information including cancer site, stage, and time since diagnosis via linkage with MDCSS.

Financial hardship and limiting care due to cost. Financial hardship information was collected using a previously-developed multidimensional instrument assessing the financial experiences of patients with cancer (4). Participants were asked whether in order to pay bills related to cancer treatment they had to do any of the following, and were instructed to select all that apply: refinance or take out a second mortgage on their home, sell their home, sell stocks or other investments, or withdraw money from retirement accounts. 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 whether they were currently in debt due to expenses related to their cancer. We counted participants answering in the affirmative to any of the above items as experiencing financial hardship.

Figure 1. Flow diagram of study sample. The figure shows the recruitment flow of participants into the Detroit ROCS pilot cohort.



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Participants were considered to have limited care due to cost if they answered in the affirmative to any of the following questions: Did you 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? Did you ever skip doses of prescribed medication in order to save money? Was there a time in the past 12 months when you needed to see a doctor but could not because of cost?

In sensitivity analyses we separately excluded assets from the measure of financial hardship, and estimated associations between the number (0, 1, 2+) of financial hardships and care limitations reported and HRQOL, and estimated a per-hardship and per-care limitation association with HRQOL by modeling each as continuous predictors in linear regression models.

Health-related quality of life. HRQOL was measured using the Functional Assessment of Cancer Therapy—General (FACT-G; ref. 21), including 4 subscales: Physical Well-Being (PWB), Social/Family Well-Being (SWB), Emotional Well-Being (EWB), and Functional Well-Being (FWB). Each subscale includes 6 to 7 statements (e.g., "I have a lack of energy") and participants are asked to rate the extent to which each statement applied to them in the past 7 days using a 5-point scale (0 = "not at all" to 4 = "very much"). Responses are coded so that higher scores reflect higher quality of life. Cancer site-specific subscales assess concerns specific to survivors of individual cancers. Subscale scores are added to the FACT-G to produce total HRQOL scores for breast (FACT-B), colorectal (FACT-C), lung (FACT-L), and prostate (FACT-P) cancers.

The reliability and validity of the FACT-G and the site-specific measures have been extensively documented, with alpha coefficients for internal consistency measured at 0.60 to 0.90 and with consistent findings of sensitivity to changes in disease progression and performance status (22–25). A 2-point difference on the subscale scores and a 5-point difference on the total FACT-G score are associated with meaningful differences on clinical and subjective indicators (26). Differences of 2 to 3 points on the site-specific subscale scores, or 5 to 10 points for the site-specific FACT measures are associated with clinically meaningful differences in HRQOL (27–30).

Statistical analysis

We fit linear regression models with financial hardship or limiting care as the exposure and HRQOL measures as the outcomes of interest and utilizing robust standard errors. Age, sex, and race were determined *a priori* to be included as covariates. Additional covariates were selected using a directed acyclic graph (DAG) including relationships between financial hardship, limiting care, HRQOL, and each of the factors listed in Table 1 (31). Final models controlled for continuous, mean-centered age, in addition to sex, race, marital status, income, education, employment status, health insurance, number of comorbid conditions, cancer site, stage at diagnosis, and treatments received using categories presented in Table 1. Checks of variance inflation factors did not suggest problems with multicollinearity between covariates (<https://stats.idre.ucla.edu/stata/webbooks/reg/chapter2/stata-webbooksregression-with-statachapter-2-regression-diagnostics/> accessed December 10, 2018). In *post hoc* analyses, we tested for effect modification by time since diagnosis split approximately at the median (<18

months/18+ months) by including interaction terms between since diagnosis and financial hardship or limiting care.

Mediation analysis. We used causal mediation analyses to test whether observed associations between financial hardship and HRQOL were mediated by limiting care due to cost. These models use the *medeff* command (32) to estimate three parameters: (i) total effect of financial hardship on HRQOL; (ii) average causal mediated effect (ACME), or the effect of financial hardship on HRQOL acting through limiting care due to cost; and (iii) direct effect of financial hardship on HRQOL (33–35).

Estimates of the proportion mediated can be unstable and can even be greater than one or negative in the presence of inconsistent mediation (36). The mediation models require the strong assumption of sequential ignorability, or that there is no uncontrolled confounding of the association between the exposure and the mediator or outcome, or between the mediator and outcome (37). To address this, we present the results of sensitivity analyses (using the *medsens* command; ref. 32) estimating how large a departure from sequential ignorability would be required for the observed mediated effect to be zero (32–35).

All analyses were conducted using Stata, version 14.2.

Results

Participant characteristics and mean FACT-G scores by participant characteristics are presented in Table 1. The mean FACT-G score was 76.0 [95% confidence interval (CI), 74.9–77.2], lower than the mean of 80.1 from normative data for United States adults (38). Higher FACT-G scores were associated with being older, male, white, married or living with a partner, having higher levels of education and income, full- or part-time employment, fewer comorbid conditions, prostate cancer, not receiving chemotherapy or requiring multiple forms of cancer treatment, having private insurance and not reporting Medicaid coverage. Nearly all (99%) participants had some form of health insurance coverage at the time of study participation (data not shown).

Table 2 gives the prevalence of financial hardship and limiting care due to cost by participant characteristics. Financial hardship was more common among younger survivors, women, those with lower income and educational attainment, and unmarried survivors, as well those with breast cancer, those who received chemotherapy, and those with Medicaid coverage. Limiting care was more common among African American survivors, those with lower incomes, those on medical leave or disability, those with Medicaid and those without private insurance.

Table 3 describes the prevalence of overall and specific forms of financial hardship and limiting care due to cost for all survivors and stratified by race. Nearly half (46.1%) of participants reported experiencing some form of financial hardship associated with cancer. Financial hardship was more common in African American (50.0%) than white survivors [40.6%, risk ratio (RR) of financial hardship associated with being African American vs. white: 1.23; 95% CI, 1.06–1.43]. Experiencing a decrease in income was the most common form of financial hardship (29.4%), 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 (6.7%).

Table 1. Participant characteristics and mean FACT-G scores by participant characteristics

	White N (%)	African American N (%)	Total N (%)	FACT-G Mean (95% CI)
Age (mean, SD)	409 (41.4)	579 (58.6)	988 (100.0)	76.0 (74.9–77.2)
Age	59.7 (9.5)	59.5 (8.8)	59.6 (9.1)	
<60	190 (46.5)	292 (50.4)	482 (48.8)	73.3 (71.8–74.9)
60–69	153 (37.4)	215 (37.1)	368 (37.3)	77.2 (75.4–79.0)
≥70	66 (16.1)	72 (12.4)	138 (14.0)	82.3 (79.3–85.3)
Sex				
Women	258 (63.1)	352 (60.8)	610 (61.7)	74.7 (73.3–76.1)
Men	151 (36.9)	227 (39.2)	378 (38.3)	78.2 (76.3–80.0)
Race				
White	409 (100.0)	0 (0)	409 (41.4)	79.5 (77.8–81.2)
African American	0 (0)	579 (100.0)	579 (58.6)	73.6 (72.1–75.0)
Education				
Less than high school	24 (5.9)	88 (15.2)	112 (11.3)	67.2 (64.0–70.5)
High school/GED	96 (23.5)	200 (34.5)	296 (30.0)	74.1 (72.1–76.1)
Some college/2-year degree	133 (32.5)	210 (36.3)	343 (34.7)	77.3 (75.5–79.2)
College graduate/4-year degree	156 (38.1)	74 (12.8)	230 (23.3)	80.8 (78.5–83.1)
Missing	0 (0)	7 (1.2)	7 (0.7)	80.6 (67.6–93.6)
Income				
<\$20,000	58 (14.2)	335 (57.9)	393 (39.8)	68.1 (66.5–69.8)
\$20,000–39,999	68 (16.6)	100 (17.3)	168 (17.0)	77.5 (74.9–80.0)
\$40,000–59,999	60 (14.7)	53 (9.2)	113 (11.4)	80.6 (77.5–83.7)
\$60,000–79,999	37 (9.1)	32 (5.5)	69 (7.0)	82.4 (78.5–86.4)
\$80,000+	155 (37.9)	30 (5.2)	185 (18.7)	86.0 (83.6–88.4)
Missing	31 (7.6)	29 (5.0)	60 (6.1)	77.1 (72.9–81.3)
Employment status				
Employed full time	119 (29.1)	77 (13.3)	196 (19.8)	85.2 (82.9–87.5)
Employed part time	49 (12.0)	31 (5.4)	80 (8.1)	82.5 (78.9–86.0)
Homemaker	17 (4.2)	19 (3.3)	36 (3.6)	75.2 (69.9–80.5)
Unemployed	22 (5.4)	64 (11.1)	86 (8.7)	67.3 (63.8–70.7)
Retired	151 (36.9)	206 (35.6)	357 (36.1)	79.2 (77.5–80.9)
On medical leave/disability	48 (11.7)	172 (29.7)	220 (22.3)	64.1 (61.9–66.2)
Other/missing	3 (0.7)	10 (1.7)	13 (1.3)	73.8 (65.0–82.6)
Marital status				
Married or living with partner	297 (72.6)	159 (27.5)	456 (46.2)	80.9 (79.4–82.5)
Widowed	27 (6.6)	80 (13.8)	107 (10.8)	71.8 (68.5–75.1)
Divorced or separated	60 (14.7)	164 (28.3)	224 (22.7)	74.2 (71.9–76.5)
Never married	22 (5.4)	172 (29.7)	194 (19.6)	69.4 (66.9–71.8)
Missing	3 (0.7)	4 (0.7)	7 (0.7)	63.1 (50.3–76.0)
Comorbid conditions (mean, SD)	2.3 (1.8)	2.7 (1.8)	2.6 (1.9)	
Comorbid conditions				
None	74 (18.1)	58 (10.0)	132 (13.4)	81.9 (78.9–84.9)
1–2	167 (40.8)	218 (37.7)	385 (39.0)	79.0 (77.2–80.7)
3+	168 (41.1)	303 (52.3)	471 (47.7)	72.0 (70.4–73.6)
Cancer site				
Breast	172 (42.1)	264 (45.6)	436 (44.1)	75.3 (73.6–77.0)
Colorectal	51 (12.5)	49 (8.5)	100 (10.1)	74.9 (71.3–78.4)
Lung	100 (24.5)	92 (15.9)	192 (19.4)	74.7 (72.2–77.3)
Prostate	86 (21.0)	174 (30.1)	260 (26.3)	78.7 (76.5–80.9)
Any chemotherapy				
No	171 (42.1)	279 (48.5)	450 (45.9)	78.8 (77.1–80.4)
Yes	235 (57.9)	296 (51.5)	531 (54.1)	73.9 (72.4–75.4)
Any surgery				
No	117 (28.6)	175 (30.4)	292 (29.7)	75.6 (73.5–77.6)
Yes	292 (71.4)	400 (69.6)	692 (70.3)	76.3 (75.0–77.6)
Any radiation				
No	169 (42.3)	209 (36.3)	378 (38.7)	77.9 (76.1–79.7)
Yes	231 (57.8)	367 (63.7)	598 (61.3)	75.0 (73.5–76.4)
Multiple treatment types				
No	146 (36.2)	215 (37.4)	361 (36.9)	78.3 (76.5–80.2)
Yes	257 (63.8)	360 (62.6)	617 (63.1)	74.8 (73.4–76.2)
Time since diagnosis				
<18 months	205 (50.1)	304 (52.6)	509 (51.6)	76.5 (74.9–78.0)
18+ months	204 (49.9)	274 (47.4)	478 (48.3)	75.5 (73.9–77.2)
Any private insurance				
No	56 (13.8)	244 (42.7)	300 (30.7)	68.6 (66.7–70.6)
Yes	349 (86.2)	328 (57.3)	677 (69.3)	79.4 (78.1–80.7)

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Table 1. Participant characteristics and mean FACT-G scores by participant characteristics (Cont'd)

	White N (%)	African American N (%)	Total N (%)	FACT-G Mean (95% CI)
Any Medicare				
No	238 (58.6)	311 (54.3)	549 (56.1)	75.7 (74.2–77.2)
Yes	168 (41.4)	262 (45.7)	430 (43.9)	76.5 (74.8–78.2)
Any Medicaid				
No	366 (90.4)	402 (70.3)	768 (78.6)	78.5 (77.3–79.7)
Yes	39 (9.6)	170 (29.7)	209 (21.4)	67.1 (64.8–69.5)

NOTE: Column percents may not add up to 100 due to rounding.

Abbreviation: GED, general educational development.

Prevalence of some forms of financial hardship differed by race, with more African American than white survivors reporting still being in debt due to cancer (RR = 1.68; 95% CI, 1.32–2.13), and fewer African American than white survivors reporting utilizing assets to pay for care (RR = 0.68; 95% CI, 0.51–0.90). Prevalence of borrowing money from family or friends and experiencing a decrease in income did not differ by race. Limiting care due to cost was more common in African American than white survivors (RR = 1.41; 95% CI, 1.05–1.89), driven by differences in needing to see a doctor and not going due to cost.

Associations between both financial hardship and limiting care due to cost and HRQOL are presented in Table 4. FACT-G scores were 7.5 (95% CI, 5.2–9.8) points lower among survivors who experienced financial hardship compared with those who did not in an unadjusted model, and the difference was more than twice as great in African American compared with white survivors ($P_{\text{interaction}} = 0.011$). The association attenuated in adjusted models, particularly for white survivors, and results of the adjusted models did not differ by race.

FACT-G scores were 12.3 (95% CI, 9.4–15.2) points lower among all survivors, 15.3 (95% CI, 9.8–20.8) points lower among white, and 9.9 (95% CI, 6.4–13.3) points lower among African American survivors who limited care compared with those who did not in unadjusted models. These associations attenuated dramatically among white survivors but less so among African American survivors in adjusted models.

In sensitivity analyses we observed a dose–response association between both financial hardship and care limitations and HRQOL. FACT-G scores were 4.8 (95% CI, 2.2–7.5) and 11.2 points (95% CI, 8.0–14.3) lower for survivors who reported one or 2 or more forms of financial hardship, respectively, compared with those who reported none. Similarly, FACT-G scores were 10.4 (95% CI, 7.2–13.6) and 17.1 (95% CI, 11.5–22.8) points lower, respectively, for those reporting one or 2 or more care limitations (Supplementary Table S1). FACT-G scores were 2.4 (95% CI, 1.3–3.6) and 5.1 (95% CI, 3.3–6.9) points lower, respectively, for each additional financial hardship or care limitation reported (Supplementary Table S2).

Experiencing financial hardship was not associated with clinically meaningful differences in specific forms of wellbeing in adjusted models, but was associated with clinically meaningful differences in site-specific HRQOL for breast, and prostate cancer (Table 4). Limiting care due to cost was associated with clinically significant differences in physical and functional wellbeing and with lower site-specific HRQOL for breast and prostate cancer in adjusted models.

Results of the mediation models (Table 5) suggest that 40.5% (95% CI, 25.5%–92.7%) of the difference in FACT-G scores associated with financial hardship was due to limiting care due to cost. Limiting care explained half (50.5%; 95% CI,

29.1%–188.1%) of the association among African American survivors and 18.4% (95% CI, 9.7%–88.7%) among white survivors.

In *post hoc* sensitivity analyses, we tested whether the association between financial hardship and quality of life differed by time since diagnosis (Supplementary Table S3). These analyses revealed that among survivors diagnosed within the previous 18 months, FACT-G scores were 6.8 (95% CI, 3.7–9.9) points lower for those who reported financial hardship, but that financial hardship was not associated with differences in FACT-G scores for longer-term survivors (–0.6; 95% CI, –3.6 to 2.5; $P_{\text{interaction}} = 0.006$).

Discussion

Our results confirm previous findings of an inverse association between financial hardship and HRQOL among cancer survivors, and extend this work by including a large number of African American survivors and estimating race-specific associations. To our knowledge, this is the first work to establish an association between limiting care due to cost and HRQOL, finding clinically meaningful differences in HRQOL for survivors who limited care compared with those who did not. Mediation analyses suggest that 40% of the association between financial hardship and HRQOL is due to limiting care due to cost, and that limiting care explains half of the association between financial hardship and HRQOL for African American survivors. *Post hoc* analyses suggest effect modification in the association between financial hardship and HRQOL by time since diagnosis.

Previous work has examined the association between material financial hardship or financial distress and HRQOL using both the FACT-G (3, 5–7, 14, 16) and other measures (8–13, 15). This work has examined associations between financial reserves (16), financial strain (8, 9, 13), specific types of financial burdens (e.g., debt, bankruptcy; ref. 12), living expenses (10), work impacts (10, 11), and out-of-pocket medical expenses (11) and HRQOL among survivors of several types of cancer, including breast (8, 11), colorectal, (9, 13, 16) lung (8, 13, 16), and prostate (8). In each case, adverse financial impacts of cancer were associated with worse HRQOL.

To our knowledge, this is the first work to report on associations between financial hardship and HRQOL separately by race. Previous work suggests that financial hardship is more common among African American than white survivors (39, 40), but only one previous study into the association between financial hardship and HRQOL included a substantial proportion of African American participants (5), and none estimated race-specific associations.

Financial hardship was common in this population of cancer survivors even though nearly all had some form of health

Table 2. Financial hardship and limiting care due to cost by participant characteristics

	No financial hardship N (%)	Any financial hardship N (%)	No limiting care due to cost N (%)	Any limiting care due to cost N (%)
Age (mean, SD)	505 (53.9) 61.2 (8.9)	432 (46.1) 57.3 (8.9)	799 (82.4) 59.9 (9.2)	171 (17.6) 58.6 (8.6)
Age				
<60	214 (42.4)	253 (58.6)	378 (47.3)	93 (54.4)
60-69	197 (39.0)	151 (34.5)	299 (37.4)	63 (36.8)
≥70	94 (18.6)	30 (6.9)	122 (15.3)	15 (8.8)
Sex				
Women	286 (56.6)	287 (66.4)	495 (62.0)	108 (63.2)
Men	219 (43.4)	145 (33.6)	304 (38.1)	63 (36.8)
Race				
White	230 (45.5)	157 (36.3)	344 (43.1)	57 (33.3)
African American	275 (54.5)	275 (63.7)	455 (57.0)	114 (66.7)
Education				
Less than high school	66 (13.1)	39 (9.0)	87 (10.9)	23 (13.5)
High school/GED	147 (29.1)	137 (31.7)	231 (28.9)	57 (33.3)
Some college/2-year degree	156 (30.9)	168 (38.9)	282 (35.3)	56 (32.8)
College graduate/4-year degree	133 (26.3)	85 (19.7)	195 (24.4)	32 (18.7)
Missing	3 (0.6)	3 (0.6)	4 (0.5)	3 (1.8)
Income				
<\$20,000	174 (34.5)	200 (46.3)	283 (35.4)	103 (60.2)
\$20,000-39,999	82 (16.2)	80 (18.5)	135 (16.9)	29 (17.0)
\$40,000-59,999	64 (12.7)	43 (10.0)	97 (12.1)	14 (8.2)
\$60,000-79,999	34 (6.7)	33 (7.6)	59 (7.4)	9 (5.3)
\$80,000+	119 (23.6)	53 (12.3)	172 (21.5)	10 (5.9)
Missing	32 (6.3)	23 (5.3)	53 (6.6)	6 (3.5)
Employment status				
Employed full time	105 (20.8)	83 (19.2)	171 (21.4)	23 (13.5)
Employed part time	35 (6.9)	39 (9.0)	64 (8.0)	16 (9.4)
Homemaker	20 (4.0)	12 (2.8)	29 (3.6)	6 (3.5)
Unemployed	32 (6.3)	52 (12.0)	65 (8.1)	21 (12.3)
Retired	208 (41.2)	127 (29.4)	295 (36.9)	52 (30.4)
On medical leave/disability	99 (19.6)	113 (26.2)	164 (20.5)	51 (29.8)
Other/missing	6 (1.2)	6 (1.4)	11 (1.4)	2 (1.2)
Marital status				
Married or living with partner	266 (52.7)	170 (39.4)	393 (49.2)	54 (31.6)
Widowed	49 (9.7)	50 (11.6)	77 (9.6)	29 (17.0)
Divorced or separated	100 (19.8)	107 (24.8)	172 (21.5)	46 (26.9)
Never married	86 (17.0)	102 (23.6)	152 (19.0)	40 (23.4)
Missing	4 (0.8)	3 (0.7)	5 (0.63)	2 (1.2)
Comorbid conditions (mean, SD)	2.6 (1.9)	2.5 (1.8)	2.5 (1.8)	2.8 (2.0)
Comorbid conditions				
None	69 (13.7)	57 (13.2)	114 (14.3)	16 (9.4)
1-2	182 (36.0)	183 (42.4)	308 (38.6)	69 (40.4)
3+	254 (50.3)	192 (44.4)	377 (47.2)	86 (50.3)
Cancer site				
Breast	202 (40.0)	208 (48.2)	352 (44.1)	81 (47.4)
Colorectal	52 (10.3)	45 (10.4)	82 (10.3)	13 (7.6)
Lung	97 (19.2)	83 (19.2)	155 (19.4)	32 (18.7)
Prostate	154 (30.5)	96 (22.2)	210 (26.3)	45 (26.3)
Any chemotherapy				
No	269 (53.6)	151 (35.2)	375 (47.3)	69 (40.6)
Yes	233 (46.4)	281 (64.8)	418 (52.7)	101 (59.4)
Any surgery				
No	151 (30.0)	126 (29.4)	235 (29.6)	50 (29.2)
Yes	353 (70.0)	303 (70.6)	560 (70.4)	121 (70.8)
Any radiation				
No	210 (41.9)	151 (35.5)	307 (38.8)	63 (37.7)
Yes	291 (58.1)	274 (64.5)	485 (61.2)	104 (62.3)
Multiple treatment types				
No	207 (41.2)	133 (31.2)	300 (37.9)	57 (33.7)
Yes	295 (58.8)	293 (68.8)	492 (62.1)	112 (66.3)
Time since diagnosis				
<18 months	260 (51.5)	225 (52.2)	419 (52.4)	82 (48.2)
18+ months	245 (48.5)	206 (47.8)	380 (47.6)	88 (51.8)
Any private insurance				
No	126 (25.2)	162 (37.9)	223 (28.2)	71 (42.0)
Yes	375 (74.9)	265 (62.1)	567 (71.8)	98 (58.0)

(Continued on the following page)

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Table 2. Financial hardship and limiting care due to cost by participant characteristics (Cont'd)

	No financial hardship N (%)	Any financial hardship N (%)	No limiting care due to cost N (%)	Any limiting care due to cost N (%)
Any Medicare				
No	257 (51.2)	269 (63.0)	440 (55.6)	96 (56.8)
Yes	245 (48.8)	158 (37.0)	352 (44.4)	73 (43.2)
Any Medicaid				
No	413 (82.4)	314 (73.5)	635 (80.4)	118 (69.8)
Yes	88 (17.6)	113 (26.5)	155 (19.6)	51 (30.2)

NOTE: Column percents may not add up to 100 due to rounding.
Abbreviation: GED, General Educational Development.

insurance. Even among those with health insurance, out-of-pocket costs can pose a serious threat to cancer patients' finances. In 2018, 45% of American adults between the ages of 19 and 64 were underinsured, meaning that their out-of-pocket costs and/or deductibles were equivalent to at least 5% to 10% of their income (41). In one study of Medicare enrollees, out-of-pocket costs for cancer care ranged from more than \$2,000 per year among those with supplemental Medicaid coverage to more than \$8,000 per year for Medicare enrollees without supplemental coverage (42). For Medicare enrollees without supplemental coverage, these out-of-pocket costs equated to 23.7% of their household income (42).

These findings highlight the importance of underinsurance in the financial consequences of cancer. As Americans consider policy options to expand health insurance coverage more broadly, investigators in this area should work with policy makers to ensure that proposals to expand coverage also address underinsurance and its potential to impact cancer survivors' finances, their ability to access appropriate care, and subsequent impacts on HRQOL.

Improving patients' knowledge of treatment costs may also represent a promising strategy to improve financial outcomes. Although most patients with cancer want to discuss treatment costs with their physicians (43, 44), research suggests that cost discussions happen infrequently when patients and oncologists discuss treatment options, and may focus more on indirect costs such as missing work than on direct costs such as out-of-pocket costs and copayments (45). Improved cost discussions between patients with cancer and their oncologists could help patients make more informed treatment decisions (19, 46–48), connect

patients with financial support (49), and potentially reduce financial hardship related to cancer (19, 46, 47, 50).

It is important to consider how some features of this study design may impact our results and their interpretations. Although the ROCS pilot includes data on several forms of financial hardship and care limitations used in previous work, this is a cross-sectional study with self-reported, retrospective information about cancer survivors' experiences with financial hardship and care limitations. Given this design, it is possible that survivors who were negatively impacted by financial hardships and care limitations could be more likely to remember and report them than survivors for whom these problems were less severe, which could inflate our observed associations with HRQOL.

For survivors with adequate financial resources, utilizing assets to pay for cancer care may not represent a hardship. In supplemental analyses (Supplementary Table S1), we estimated the association between each individual form of financial hardship and HRQOL, finding that FACT-G scores were 5.2 (95% CI, 0.6–9.7) points lower among survivors who utilized assets to pay for care than those who did not. This is a clinically meaningful difference in HRQOL and is similar to the effect of experiencing a decrease in income, but weaker than the association observed for borrowing from friends and family or being in debt due to cancer (differences in FACT-G of 9.9–10.0). In an adjusted model, experiencing financial hardship other than utilizing assets was associated with –4.0 (95% CI, –6.2 to –1.9) point difference in FACT-G scores similar to the estimate including assets (Supplementary Table S4).

A unique contribution of this work is our attempt to estimate the proportion of the association between financial hardship and

Table 3. Prevalence of financial hardship and limiting care due to cost by race and risk ratios of reporting each form of financial hardship and care limitation associated with being African American vs. White

	Total N (%)	White N (%)	African American N (%)	African American vs. white RR (95% CI)
Any financial hardship	432 (46.1)	157 (40.6)	275 (50.0)	1.23 (1.06–1.43)
Borrowed money from family or friends	95 (9.7)	39 (9.7)	56 (9.8)	1.01 (0.68–1.48)
Remaining debt	249 (25.5)	74 (18.3)	175 (30.7)	1.68 (1.32–2.13)
Utilized assets to pay for cancer care	66 (6.7)	38 (9.3)	28 (4.8)	0.68 (0.51–0.90)
Refinanced or sold home	9 (0.9)	7 (1.7)	2 (0.4)	0.20 (0.04–0.97)
Sold stock or other investments	15 (1.5)	8 (2.0)	7 (1.2)	0.62 (0.23–1.69)
Withdrew money from retirement	56 (5.7)	31 (7.6)	25 (4.3)	0.57 (0.34–0.95)
Experienced a decrease in income	275 (29.4)	109 (28.0)	166 (30.5)	1.09 (0.89–1.33)
Any care limitations	171 (17.6)	57 (14.2)	114 (20.0)	1.41 (1.05–1.89)
Skipped doses of prescribed medication	71 (7.2)	23 (5.6)	48 (8.3)	1.48 (0.91–2.39)
Refused recommended treatment due to cost	49 (5.0)	21 (5.2)	28 (4.9)	0.94 (0.54–1.64)
Needed to see a doctor but did not go due to cost	111 (11.4)	33 (8.2)	78 (13.7)	1.66 (1.13–2.45)

NOTE: Responses are not mutually exclusive. "Any financial hardship" includes borrowing, debt, utilizing assets, and experiencing a decrease in income. "Any care limitations" includes skipping doses of prescribed medication, refusing recommended treatment, and needing to see a doctor but not going due to cost.

Table 4. Associations between financial hardship and limiting care due to cost and total and site-specific measures of health-related quality of life and physical, social, emotional, and functional wellbeing subscales

Observed range	Mean	SD	Financial hardship			Limiting care due to cost				
			Unadjusted		Adjusted	Unadjusted		Adjusted		
			Diff. in FACT-G score	95% CI	Diff. in FACT-G score	95% CI	Diff. in FACT-G score	95% CI		
FACT-G	76.0	18.0	-7.5	(-9.8 to -5.2)	-4.2	(-6.4 to -2.0)	-12.3	(-15.2 to -9.4)	-8.0	(-10.7 to -5.3)
White	79.5	17.9	-10.6	(-14.3 to -7.0)	-3.1	(-6.8 to 0.7)	-15.3	(-20.8 to -9.8)	-6.1	(-10.8 to -1.3)
African American	73.3	17.6	-4.6	(-7.5 to -1.7)	-4.4	(-7.2 to -1.6)	-9.9	(-13.3 to -6.4)	-9.0	(-12.3 to -5.6)
<i>P</i> _{interaction}				0.011		0.77		0.10		0.45
PWB	20.9	5.9	-2.6	(-3.3 to -1.8)	-1.5	(-2.3 to -0.8)	-3.5	(-4.5 to -2.5)	-2.5	(-3.5 to -1.6)
SWB	19.4	5.9	-1.0	(-1.8 to -0.3)	-0.7	(-1.5 to 0.0)	-2.3	(-3.3 to -1.3)	-1.3	(-2.2 to -0.3)
EWB	18.6	4.5	-1.4	(-2.0 to -0.8)	-0.7	(-1.3 to -0.1)	-2.3	(-3.0 to -1.5)	-1.7	(-2.5 to -0.9)
FWB	17.2	6.8	-2.5	(-3.4 to -1.6)	-1.2	(-2.0 to -0.4)	-4.3	(-5.3 to -3.2)	-2.6	(-3.5 to -1.6)
FACT-B	100.6	24.3	-10.0	(-14.6 to -5.4)	-4.9	(-9.3 to -0.4)	-18.7	(-24.2 to -13.3)	-12.5	(-17.9 to -7.1)
FACT-C	94.6	21.3	-7.8	(-16.4 to 0.8)	-1.8	(-11.4 to 7.8)	-10.7	(-24.9 to 3.4)	-6.4	(-21.7 to 8.9)
FACT-L	85.9	16.9	-5.5	(-10.5 to -0.5)	-3.8	(-8.9 to 1.2)	-6.5	(-13.3 to 0.3)	-2.7	(-8.5 to 3.0)
FACT-P	111.5	23.7	-12.9	(-19.3 to -6.6)	-5.7	(-12.1 to 0.6)	-20.5	(-28.2 to -12.7)	-14.0	(-21.4 to -6.7)

NOTE: Adjusted models control for age, sex, race, marital status, income, education, employment status, health insurance, cancer site, and treatments received.

Abbreviation: Diff., difference.

HRQOL due to a particular mechanism, finding that approximately 40% of the association is explained by limiting care due to cost. Limiting care explains half of the association for African American survivors and approximately 18% among white survivors. This finding has the potential to direct resources to minimize the impact of financial hardship among African American survivors, who experience more negative financial impacts of cancer than white survivors do (39, 40), and highlights the importance of ensuring patients with cancer can access necessary care.

Our finding that that limiting care is strongly associated with worse HRQOL, particularly for African American survivors, suggests that future work addressing the financial consequences of cancer should focus on ensuring all patients with cancer can access appropriate treatments without limitations related to cost concerns, both to improve survivors' HRQOL and to potentially reduce disparities in outcomes related to the financial consequences of cancer.

Estimates of the proportion mediated can be unstable and can even be greater than one or negative in the presence of inconsistent mediation (36). To address this instability, we conducted sensitivity analyses (32–35) and estimate that if 19% of the variation in FACT-G scores was due to unmeasured confounding, the mediation effect would no longer be observed. The mediation effect observed among African American survivors was more stable (larger absolute ρ value) than that among white survivors (Table 5).

In assessing whether differences in time since diagnosis influenced our findings, we discovered effect modification such that financial hardship was associated with HRQOL among survivors diagnosed within 18 months, but not among longer-term survivors in adjusted models (Supplementary Table S3). Previous work has examined longitudinal changes in HRQOL, finding that HRQOL improved more among patients without financial stress (6), but to our knowledge, our finding of effect modification is novel. Because late stage at diagnosis is associated with shorter expected survival, patients diagnosed with late-stage disease would be less likely to be included in this cohort than longer-term survivors. However, the stage distribution in this study population does not vary substantially by time since diagnosis (stages I, II, III, and IV disease account for 31.6%, 28.9%, 19.0%, and 20.6% of recently diagnosed and 26.2%, 39.4%, 19.3%, and 15.1% of longer-term survivors, respectively). These findings warrant further examination in future research, but suggest that the impacts of financial hardship on HRQOL may not be enduring, and that survivors who face financial difficulties may regain quality of life during longer-term survival. Interestingly, we observed no effect modification in the association between limiting care and HRQOL by time since diagnosis, suggesting that care limitations may have lasting negative impacts on survivors' HRQOL.

Important strengths of this study include its sample size sufficient to estimate associations between financial hardship and limiting care due to cost, and several measures of HRQOL; the inclusion of a large number of African American survivors, allowing for race-specific estimates; its high response rate, minimizing the potential for selection bias; and use of a detailed participant survey including validated HRQOL measures, and the ability to control for several potential confounders.

Additional limitations of this work should also be noted. Although the Detroit ROCS pilot cohort includes diversity in race, income, and cancer site, it is hospital-based, and therefore

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Table 5. Proportion of the association between financial hardship and health-related quality of life explained by limiting care due to cost

	ACME Mean (95% CI)	Direct effect Mean (95% CI)	Total effect Mean (95% CI)	Proportion mediated % (95% CI)	Sensitivity analysis (ρ)
FACT-G	-1.6 (-2.4 to -0.9)	-2.4 (-4.7-0.0)	-4.0 (-6.3 to -1.7)	40.5 (25.5-92.7)	-0.19
White	-0.8 (-1.8 to -0.1)	-3.6 (-7.4-0.2)	-4.4 (-8.1 to -0.7)	18.4 (9.7-88.7)	-0.12
African American	-2.1 (-3.4 to -1.1)	-2.1 (-5.2-1.1)	-4.2 (-7.3 to -1.1)	50.5 (29.1-188.1)	-0.23

NOTE: These models control for mean-centered continuous age and for sex, race, marital status, income, education, employment status, comorbid conditions, health insurance, cancer site, stage at diagnosis, and treatments received. Because the mediation models do not allow for dummy-variable adjustment, marital status, employment status, and stage at diagnosis were treated as binary variables (married/cohabitating vs. not; employed full- or part-time vs. not, stage I vs. stages II-IV, respectively), and ordinal income and education were treated as continuous variables.

not representative of the general population of cancer survivors. The financial hardship measures included here have been used in prior research (4), but they are self-reported and have not been validated against survivors' financial records. Additionally, information about survivors' prediagnosis household income or assets is not available. Although the FACT-G and its site-specific scales have demonstrated good reliability, validity, and sensitivity to change, the available information on minimally important differences was developed in reference to changes in individuals' scores over time rather than between groups. Although the questions about financial hardship and limiting care refer to experiences since diagnosis or in the previous year and the FACT-G asks survivors about their HRQOL in the previous 7 days, this study is cross-sectional, and information about financial hardship, limiting care, and HRQOL were all collected at the same time, limiting our ability to establish temporal relationships.

Financial hardship is common among cancer survivors and is associated with lower HRQOL. Our results suggest that this association is at least partly explained by limiting care due to cost, making care limitations a potentially important target for interventions aimed at reducing the adverse financial consequences of cancer, particularly for African American survivors. As investigators call for interventions to minimize the impact of financial hardship on cancer survivors (51), it is critical to better understand the potential mechanisms through which financial hardship impacts survivors' health outcomes and quality of life, and this is especially true for non-white populations where financial hardship is most common (39, 40). Measures that improve access to and affordability of care represent a promising strategy as investigators, clinicians, and policymakers aim to

reduce the burden of financial hardship and its impacts on health-related outcomes among cancer survivors.

Disclosure of Potential Conflicts of Interest

No potential conflicts of interest were disclosed.

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