



Financial hardship among cancer survivors in Southern New Jersey

Irina B. Grafova¹ · Sharon L. Manne² · Elisa V. Bandera² · Biren Saraiya² · Adana A. M. Llanos^{1,2} · Katie A. Devine² · Shawna V. Hudson² · Lisa E. Paddock² · Jennifer Tsui³ · Jennifer Elliott⁴ · Antoinette M. Stroup^{1,2} · Paul R. Duberstein^{1,2}

Received: 18 December 2020 / Accepted: 16 April 2021 / Published online: 4 May 2021
© The Author(s), under exclusive licence to Springer-Verlag GmbH Germany, part of Springer Nature 2021

Abstract

Purpose To identify predictors of financial hardship, operationalized as foregoing health care, making financial sacrifices, and being concerned about having inadequate financial and insurance information.

Methods Cancer survivors ($n = 346$) identified through the New Jersey State Cancer Registry were surveyed from August 2018 to September 2019. Multivariable logistic regression analyses were performed.

Results Cancer survivors with household incomes less than \$50,000 annually were more likely than those earning \$50,000–\$90,000 to report foregoing health care (15.8 percentage points, $p < 0.05$). Compared to retirees, survivors who were currently unemployed, disabled, or were homemakers were more likely to forego doctor's visits (11.4 percentage points, $p < 0.05$), more likely to report borrowing money (16.1 percentage points, $p < 0.01$), and more likely to report wanting health insurance information (25.7 percentage points, $p < 0.01$). Employed survivors were more likely than retirees to forego health care (16.8 percentage points, $p < 0.05$) and make financial sacrifices (20.0 percentage points, $p < 0.01$). Survivors who never went to college were 9.8 percentage points ($p < 0.05$) more likely to borrow money compared to college graduates. Black survivors were more likely to want information about dealing with financial and insurance issues ($p < 0.01$); men were more likely to forego health care ($p < 0.05$).

Conclusion Findings highlight the role of employment status and suggest that education, income, race, and gender also shape cancer survivors' experience of financial hardship. There is a need to refine and extend financial navigation programs. For employed survivors, strengthening family leave policies would be desirable.

Keywords Financial burden · Financial hardship · Financial consequences · Employment · Income · Cancer

Introduction

A cancer diagnosis, associated treatment, and its long-term side effects have profound impacts on the financial well-being of cancer survivors and their families [1]. One out of four cancer survivors report having to borrow money, go into debt, or declare bankruptcy following their diagnosis,

and one in three worry about medical bills associated with their cancer care [2]. Cancer survivors are at risk of financial hardship, including a higher risk of forgoing care to save money, making financial sacrifices that seem reasonable in the short-term but do not bode well over the long-term, and not seeking help or information even when resources are available. Financial hardship adversely impacts every aspect of the patient experience [3], including clinical outcomes, healthcare utilization [4], psychological distress [5–8], employment [6, 9], and quality of life [10, 11].

Although financial hardship is multi-dimensional [12–14], researchers have frequently measured it using aggregate scores [10, 15–23]. This approach has great appeal, as it allows researchers to quickly convey a lot of information in a single score. When researchers examine a single score, they can identify correlates of general financial hardship across multiple dimensions. One weakness of this approach is that it might lead researchers to ignore unique

✉ Irina B. Grafova
grafovib@sph.rutgers.edu

¹ Rutgers School of Public Health, Piscataway, NJ, USA

² Rutgers Cancer Institute of New Jersey, New Brunswick, NJ, USA

³ Department of Preventive Medicine, University of Southern California, Los Angeles, CA, USA

⁴ Edward J. Bloustein School of Planning and Public Policy, New Brunswick, NJ, USA

correlates of a particular dimension of financial hardship; for example, demographic subgroups that might not be adversely affected by one dimension of financial hardship but disproportionately affected by another dimension would be overlooked. Similarly, when researchers focus on specific, narrow dimensions of financial hardship, such as foregoing care due to cost [6, 24, 25], researchers and practitioners are left with an incomplete understanding of other dimensions of hardship, such as making financial sacrifices. In this study, we examined three dimensions of financial hardship. Two of these dimensions—foregoing health care and making financial sacrifices—reflect how cancer survivors may choose to cope with financial hardship. The third dimension—wanting more financial and insurance information—reflects a lack of access to information that cancer survivors can use to better cope with financial hardship.

Cancer survivors are a heterogeneous group, but most existing studies of financial toxicity in survivors pool together so-called early cancer survivors, who were diagnosed within the last 5 years, and longer term cancer survivors [4, 11, 18, 21, 22, 25–28]. Given that there are relatively few studies examining financial hardship among those in early survivorship [24, 29–32], we focus on that group.

We tested two hypotheses. First, we hypothesized that lower household income is related to a greater likelihood of foregoing care [25, 31]. Households with lower income are likely to have lower overall financial resources which can adversely affect their ability to pay for the cost of care, thereby increasing the likelihood of foregoing care. Second, we hypothesized that cancer survivors with greater educational attainment are less likely to incur debt than survivors with lower educational attainment [33]. We expected that cancer survivors with greater educational attainment would be more efficient in utilizing their household financial resources which would result in lower levels of borrowing. We also explored the roles of employment, race/ethnicity, and gender, as the literature does not strongly support directional hypotheses about these demographic characteristics.

Methods

We used data from a cross-sectional study of cancer survivors residing in southern New Jersey, which aimed to understand cancer burden, treatment outcomes, care needs, cancer prevention practices, health care access, and health information-seeking behaviors. This study and all study procedures were approved by the Rutgers Institutional Review Board.

Eligibility

Cancer survivors were eligible for study participation if they were (a) 18–85 years of age; (b) currently residing in one

of nine counties in southern New Jersey (Atlantic, Burlington, Camden, Cape May, Cumberland, Gloucester, Ocean, Salem, and Mercer Counties); (c) diagnosed in 2015 or 2016 with primary bladder, female breast, female gynecological, colorectal, lung, melanoma, prostate, or thyroid cancer; and (d) able to read and speak English.

Recruitment

Eligible participants were identified by the New Jersey State Cancer Registry (NJSCR). Treating physicians of potentially eligible participants were sent an informational letter about the study and asked to notify the NJSCR if there was a reason not to contact their patient(s). If a physician did *not* contact the NJSCR, prospective participants were mailed a study packet, including an informational cover letter, a paper version of the survey in English, two informational brochures about the NJSCR, a study-specific brochure with details about the study, study information sheets pertaining to informed consent and HIPAA, an agreement to contact form for the participant to sign, and a self-addressed postage-paid return envelope. One week later, the research team followed up with a telephone call to confirm receipt of the packet, ask if the participant had any questions, and encourage survey completion. Individuals were called 1–2 times per week at varying days and times to increase patient contact and participation, with a maximum of 8 calls. Prospective participants who could not be contacted were considered passive refusers. When reached, individuals who did not agree to participate were considered active refusers. In addition to follow-up phone calls, recruitment packets were re-sent up to 3 times during the recruitment period. A returned, completed survey was considered to be the participant's consent for inclusion in the study. Surveys were mailed out between August 2018 and September 2019. Of the 1473 individuals who were assessed for eligibility and study interest, 147 were later deemed ineligible, 105 were categorized as lost, 875 refused (249 active and 626 passive), and 346 participants were recruited to the study (28.3% response rate). This response rate is comparable to previous registry-based studies [34, 35]. Comparisons of the 346 acceptors and the 875 refusers based on available data (sex, race, age at diagnosis, cancer stage) did not indicate differences between participants and refusers (data not shown but available upon request).

Measures

Demographics Respondents self-reported age, gender, race, ethnicity, marital status, employment status (employed, unemployed, homemaker, disabled, retired), educational attainment, and number of comorbidities. Household income was measured on an interval scale (less than \$50,000, \$50,000–\$89,999, \$90,000 or more).

Cancer diagnosis and cancer treatment Respondents were asked to report the type and date of their first primary cancer diagnosis and report treatments they received (surgery, chemotherapy, radiation).

Financial hardship We examined three dimensions of coping-related financial hardship. To assess *foregoing care*, we asked participants if they had not seen a doctor in the past 12 months due to cost and whether they had not seen another healthcare provider in the past 12 months due to cost [36]. To assess *financial sacrifices*, we asked participants if they or their family members had to borrow money or incur debt because of cancer or its treatment and whether they or their family member made other financial sacrifices [37]. To assess concern about *not having adequate financial- and insurance-related information*, we asked participants if they wanted more information on (a) how to deal with financial issues related to cancer care and (b) getting or retaining health, life, or disability insurance after cancer [32]. Based on responses to these items, we created three dichotomous outcome measures of financial hardship with no financial hardship as the reference category in each.

Statistical analysis

Sample characteristics are presented as counts and proportions. The percentage of missing data was calculated for each variable. We used multinomial logistic regression to explore how the financial hardship outcomes were associated with sociodemographics and treatment characteristics. For each outcome, we excluded observations with missing data on the outcome variable or missing values for age, gender, race, ethnicity, marital status, education, and employment status. Given that data on household income and type of treatment received were missing in > 5% of cases, dummy variables indicating that the response was missing was included in the analysis. To assist in the interpretation of the multinomial logistic regression estimation results, we conducted a postestimation transformation and calculated the average marginal effect of each independent variable on the probability of the outcome using the *margins* procedure in Stata [38]. Statistical analyses were performed with StataMP 16 (StataCorp LP; College Station, TX, USA).

Results

Study sample characteristics

Table 1 shows that most of the survivors in the sample were women (61.0%), married (60.7%), and White (68.8%). Half (51.4%) were over age 65, 24.6% never attended college,

and 29.8% reported an annual household income less than \$50,000. The most common cancers were breast (17.9%), prostate (14.5%), and colon (12.1%). Most participants (79.8%) received surgical treatment; of those who received surgery, 58.0% also received chemotherapy and/or radiation. Figure 1 shows that 27.2% reported foregoing other health care due to cost during the past 12 months, 13% reported that cancer caused them and their family members to borrow money or go into debt, and 25.4% reported wanting more information about how to manage financial issues related to cancer care.

Foregoing health care due to costs

Compared to survivors residing in households with incomes between \$50,000 and \$90,000, those with household incomes under \$50,000 were 8.2 percentage points ($p < 0.05$) less likely to visit a doctor and 15.8 percentage points ($p < 0.05$) less likely to see other clinicians or utilize other health care services due to the cost of care (Table 2). In addition, compared to retired survivors, *employed survivors* were 16.8 percentage points ($p < 0.05$) less likely to see other clinicians or utilize health care services due to costs. Moreover, survivors who were *unemployed, disabled, or homemakers* were 11.4 percentage points less likely ($p < 0.05$) than retired survivors to see a doctor and 20.5 percentage points less likely ($p < 0.05$) to see another clinician due to costs. We also observed gender differences: women were 7.4 percentage points ($p < 0.05$) less likely than *men* to forego visiting a doctor.

Making financial sacrifices

Compared to retired survivors, those who were *employed* were 15.9 percentage points ($p < 0.01$) more likely to report that they or their family members had to borrow money or go into debt and 20.0 percentage points ($p < 0.01$) more likely to report that they or their family members made other financial sacrifices (Table 3). Survivors who were *unemployed, disabled, or homemakers* were more likely to borrow money, go into debt, or make other types of financial sacrifices compared to retirees. Survivors who *never attended college* were 9.8 percentage points ($p < 0.05$) more likely to borrow money or go into debt than those with a college degree. Women were 8.7 percentage points less likely ($p < 0.05$) than *men* to report that they or their family members borrowed money or went into debt.

Wanting more financial information

Compared to survivors residing in households with incomes between \$50,000 and \$90,000, survivors residing

Table 1 Sample characteristics ($N=346$)

	<i>N</i>	%
Age		
20–49 years	38	11.0
50–64 years	125	36.1
65–87 years	178	51.4
Missing	5	1.4
Gender		
Male	133	38.4
Female	211	61.0
Missing	2	0.6
Race and ethnicity ^a		
White non-Hispanic	238	68.8
Black non-Hispanic	65	18.8
Other race non-Hispanic	21	6.1
Hispanic	18	5.2
Missing	11	3.2
Marital status		
Married	210	60.7
Not married	131	37.9
Missing	5	1.4
Education		
Less than high school, high school, GED	85	24.6
Some college, no bachelor degree	89	25.7
College	161	46.5
Missing	11	3.2
Annual household income		
< \$49,999	103	29.8
\$50,000–\$89,999	71	20.5
\$90,000 or more	98	28.3
Missing income data	74	21.4
Employment status ^b		
Employed	149	43.1
Retired	147	42.5
Other (unemployed, homemaker, disabled)	43	12.4
Missing	7	2
Type of cancer		
Breast	62	17.9
Colon	42	12.1
Lung	18	5.2
Prostate	50	14.5
Thyroid	35	10.1
Urinary bladder	39	11.3
Melanoma	39	11.3
Gynecological and other cancer	61	17.6
Treatment ^c		
Surgery	160	46.2
Surgery, radiation, and chemotherapy	38	11.0
Surgery and chemotherapy	36	10.4

Table 1 (continued)

	<i>N</i>	%
Surgery and radiation	42	12.1
Other treatment	40	11.6
Missing treatment information	30	8.7
Number of health conditions ^d	346	1.9

^a 5 respondents indicated two races and 1 respondent indicated three races

^bIn other employment categories, 17 respondents are unemployed, 6 are homemakers, and 20 are disabled

^c “Other treatment” includes the following:

3 respondents who received chemotherapy and no surgery or radiation therapy

5 respondents who received chemo and radiation therapies

12 respondents who reported receiving no chemo, no surgery, and no radiation treatment

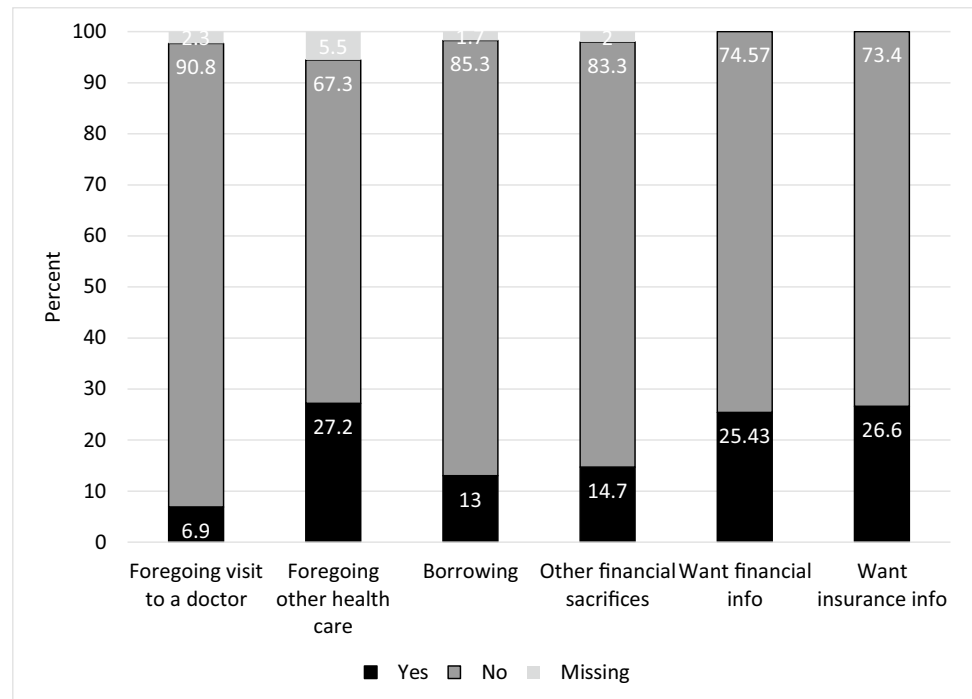
20 respondents who received radiation therapy but no surgery or chemotherapy

^dHealth conditions include diabetes; asthma; high blood pressure; emphysema or chronic bronchitis; heart disease, angina, or heart attack; depression; anxiety disorder; schizophrenia; bipolar disorder; post-traumatic stress disorder; high cholesterol; kidney problems; peripheral vascular disease; cerebrovascular disease; dementia; connective tissue disease; liver disease; AIDS. Number of health conditions is coded four for any respondents with four or more chronic conditions

in households with *incomes under \$50,000* were 14.7 percentage points ($p < 0.05$) more likely to report wanting more information on dealing with financial issues related to cancer care (Table 4). Survivors who were *unemployed, disabled, or homemakers* were 25.7 percentage points ($p < 0.01$) more likely to report wanting more information on getting or retaining health, life, or disability insurance after cancer than retired survivors. *Women* were less likely than men (11.1 percentage points ($p < 0.05$)) to report wanting more information about getting or retaining health, life, or disability insurance. *Black survivors* were more likely than White survivors to report wanting more information on dealing with financial issues related to cancer care ($p < 0.01$) and to report wanting more information getting or retaining health, life, or disability insurance ($p < 0.01$).

Discussion

This study aimed to improve our understanding of financial hardship risk factors among cancer survivors diagnosed within the past 5 years. Consistent with our hypothesis and prior research [27, 30, 31], survivor income was robustly associated with financial hardship. Specifically, survivors with lower household incomes were more likely than those in middle-income families to forego health care, and they were also more likely to report wanting information on

Fig. 1 Distribution of financial hardship outcomes ($N=346$)

how to manage the financial implications of cancer. This is consistent with the expectation that survivors with fewer resources are more likely to be adversely affected by cancer-related financial hardship and thus have a greater need of intervention [32]. Interestingly, lower income was not a significant predictor of debt financing spending. Instead, consistent with our second hypothesis, lower education was associated with borrowing or going into debt because of cancer; these findings suggest that financial literacy programs might be particularly helpful for those who did not complete high school.

Employment status emerged as a significant risk factor common to several dimensions of financial hardship, including foregoing care, making financial sacrifices, and having insufficient information. Compared to retirees, those who report being unemployed, disabled, or homemakers were less likely to see a doctor or utilize other health care services, more likely to report making financial sacrifices, and more likely to want health insurance-related information. Perhaps the families of retired cancer survivors have more resources than the families of unemployed, disabled, or homemaker survivors. Previous research has mainly focused on how cancer saps financial resources by adversely affecting the ability to work [9, 29, 39]. However, the employment findings reported here are independent of the effects of household income. Consequently, employment status may confer risk for financial hardship for reasons that are unrelated to income. For instance, it is possible that

individuals who are unemployed, disabled, or homemakers have less stable family income inflow than retirees; their greater degree of observed financial hardship can plausibly reflect greater income volatility. Prior research indicates that greater volatility is related to worse health outcomes [40, 41], including poorer management of chronic conditions, such as diabetes [42]. The potential implications of income volatility on financial hardship among unemployed, disabled, and homemaker cancer survivors need to be explored further and considered by policymakers.

Another potential explanation of the robust effects of employment status is related to how so-called “bargaining power” is distributed within families. Economic research suggests that spousal employment affects each spouse’s bargaining power [43, 44]. In turn, asymmetries in bargaining power can affect major financial decisions, such as family savings allocation [43], life insurance purchase decisions [45, 46], and decisions about everyday spending on food consumption [44]. If unemployed, disabled, or homemaker survivors have less bargaining power, on account of their employment status, then they can be adversely affected by family members’ decisions about healthcare spending. There is a pressing need for research to explore if and how bargaining power can impact survivors’ financial hardship. It is critically important to elevate the issue of intra-family resource allocation in future interventions and, for financial navigation, interventions to anticipate and be alert for any intra-family conflicts about resource allocation.

Table 2 Average marginal effects of predictors on the probability of foregoing care because of high cost

	<i>Foregoing visit to a doctor in the past 12 months because of cost</i>			<i>Foregoing other health care in the past 12 months because of cost</i>		
	Marginal effect	Standard error	<i>p</i> value	Marginal effect	Standard error	<i>p</i> value
Gender						
Female	−0.074	0.034	0.029	0.001	0.057	0.991
Male (reference category)						
Race and ethnicity						
White non-Hispanic (reference category)						
Black non-Hispanic	−0.004	0.032	0.910	0.022	0.061	0.713
Other race non-Hispanic	0.019	0.069	0.781	0.091	0.099	0.358
Hispanic	0.057	0.064	0.376	−0.025	0.114	0.824
Education						
Less than high school, high school, GED	0.002	0.041	0.967	0.115	0.059	0.051
Some college, no bachelor degree	0.053	0.035	0.131	−0.007	0.060	0.901
College (reference category)						
Annual household income						
< \$49,999	0.082	0.041	0.045	0.158	0.064	0.013
\$50,000–\$89,999 (reference category)						
\$90,000 or more	0.025	0.050	0.623	−0.088	0.079	0.263
Missing income data	−0.029	0.067	0.66	0.072	0.074	0.331
Employment status						
Employed	0.075	0.044	0.09	0.168	0.066	0.011
Retired (reference category)						
Other (unemployed, homemaker, disabled)	0.114	0.049	0.019	0.205	0.086	0.017
Sample size	309			298		

In the sample of 346 observations depicted in Table 1 and Fig. 1, there are 31 observations with missing values on one or more of the following variables: survivor age, gender, race, ethnicity, marital status, educational attainment, and employment status. Excluding these observations limits the sample to 309 observations. Since there are also survivors with missing data on some of the outcomes, the actual sample sizes for the regression analysis vary between 309 and 298 observations, depending on a specific outcome. Bolded estimates are significant at 5% significance level

Other covariates include age (20–49 years, 50–64 years (reference category), 65–87 years), marital status (married, not married (reference category)), treatment (surgery (reference category), surgery, radiation, and chemotherapy; surgery and chemotherapy; surgery and radiation; other; missing), and number of health conditions. All models are estimated as multivariate logistic regressions

Compared to retired survivors, employed survivors were more likely to forego health care and more likely to report making financial sacrifices. We are aware of one study from Ireland and one US-based study that also found that retirement is associated with lower levels of financial distress [10, 31]. There are several potential explanations for this result. The employed are more likely to forego care because they simply have less unscheduled time than retirees [47], the opportunity cost of seeking healthcare is greater [48], and they have greater levels of consumption commitment spending [31]. Beyond these relatively straightforward explanations, greater levels of actual or anticipated income volatility may also explain why employed survivors may be disproportionately burdened by financial hardship. Both employed and retired survivors contribute to family income either in the form of earnings or in the form of retirement income. Since the observed findings for employment status accounted for household income, the effects of employment

(vs. retirement) on the likelihood of foregoing care and making financial sacrifices could be due to income volatility. Whereas the inflow of retirement income is stable and predictable, the earnings of employed cancer survivors are at risk of instability. Worsening health status and health-related work absences increase employed cancer survivors' risk of becoming unemployed while also threatening future income inflow. In an average family, more than half of the family's budget consists of items that tend to remain fixed due to prior consumption commitments, such as housing expenses [49], so income volatility would be a significant source of financial hardship. Further research is needed to understand how employment status contributes to early survivors' financial hardship.

In addition to observing differences in financial hardship as a function of socioeconomic indicators (income, education, employment), we also found race and gender differences. Consistent with prior research [32], Black survivors

Table 3 Average marginal effects of predictors on the probability of making financial sacrifices because of cancer and its treatment

	<i>Borrowed money or went into debt because of your cancer or its treatment</i>			<i>Made any other kinds of financial sacrifices because of your cancer or its treatment</i>		
	Marginal effect	Standard error	<i>p</i> value	Marginal effect	Standard error	<i>p</i> value
Gender						
Female	-0.087	0.040	0.030	-0.015	0.045	0.739
Male (reference category)						
Race and ethnicity						
White non-Hispanic (reference category)						
Black non-Hispanic	0.059	0.040	0.135	0.074	0.043	0.088
Other race non-Hispanic	-0.057	0.095	0.547	0.018	0.078	0.818
Hispanic	0.104	0.072	0.147	0.047	0.085	0.578
Education						
Less than high school, high school, GED	0.098	0.043	0.024	0.008	0.048	0.871
Some college, no bachelor degree	0.018	0.044	0.683	-0.020	0.047	0.666
College (reference category)						
Annual household income						
< \$49,999	0.018	0.049	0.718	0.068	0.052	0.189
\$50,000–\$89,999 (reference category)						
\$90,000 or more	-0.026	0.054	0.629	-0.057	0.060	0.345
Missing income data	0.054	0.051	0.294	0.050	0.060	0.406
Employment status						
Employed	0.159	0.049	0.001	0.200	0.054	0.000
Retired (reference category)						
Other (unemployed, homemaker, disabled)	0.161	0.054	0.003	0.148	0.066	0.025
Sample size	310			309		

In the sample of 346 observations depicted in Table 1 and Fig. 1, there are 31 observations with missing values on one or more of the following variables: survivor age, gender, race, ethnicity, marital status, educational attainment, and employment status. Excluding these observations limits the sample to 309 observations. Since there are also survivors with missing data on some of the outcomes, the actual sample sizes for the regression analysis vary between 310 and 309 observations, depending on a specific outcome. Bolded estimates are significant at 5% significance level

Other covariates include age (20–49 years, 50–64 years (reference category), 65–87 years), marital status (married, not married (reference category)), treatment (surgery (reference category), surgery, radiation, and chemotherapy; surgery and chemotherapy; surgery and radiation; other; missing), and number of health conditions. All models are estimated as multivariate logistic regressions

were more likely to want information both about dealing with financial issues related to cancer care and about disability, life, and health insurance. It is plausible that this reflects racial differences in lack of access to financial information from trusted sources and may also reflect broader communication challenges in cancer care [50]. Cancer centers and community oncology clinics that serve larger proportions of Black patients should consider offering this information routinely and proactively.

Men were more likely than women to forego seeing a physician. This is consistent with a large body of literature on gender differences in healthcare utilization [51] and could reflect differences in emotional experience, emotional expression, patient-clinician communication, or generic help-seeking tendencies. Consistent with research on formal preparation for aging, retirement, and death [52], we also found that men were more likely to want information about life, disability, or health insurance; this could reflect

the fact that they were more likely than women to report debt financing. Interventions are needed to help men schedule and attend doctor’s appointments and furnish them with the information and resources required to plan for life’s vicissitudes.

Taken together, the results of this study underscore critical differences and important similarities in demographic correlates of key dimensions of financial hardship. Cancer survivor employment status emerged as a significant correlate of nearly every outcome assessed, highlighting the need to understand the contributions of real and anticipated financial volatility and intra-family bargaining [53–56] to the experience of financial hardship. Income, educational attainment, race, and gender had differential effects on various cancer-related outcomes, powerfully predicting some, but not all, aspects of financial hardship.

The employment findings draw attention to important gaps in policies protecting population health and

Table 4 Average marginal effects of predictors on the probability of wanting more information on health insurance and financial issues

	Want more information on dealing with <i>financial issues</i> related to cancer care			Want more information on getting or retaining <i>health, life, or disability insurance</i> after cancer		
	Marginal effect	Standard error	<i>p</i> value	Marginal effect	Standard error	<i>p</i> value
Gender						
Female	−0.053	0.053	0.320	−0.111	0.053	0.038
Male (reference category)						
Race and ethnicity						
White non-Hispanic (reference category)						
Black non-Hispanic	0.168	0.049	0.001	0.171	0.052	0.001
Other race non-Hispanic	−0.014	0.098	0.885	0.048	0.091	0.600
Hispanic	−0.087	0.124	0.484	−0.017	0.111	0.876
Education						
Less than high school, high school, GED	0.036	0.059	0.547	−0.003	0.060	0.956
Some college, no bachelor degree	0.059	0.055	0.286	−0.041	0.059	0.492
College (reference category)						
Annual household income						
< \$49,999	0.147	0.062	0.018	0.088	0.066	0.184
\$50,000–\$89,999 (reference category)						
\$90,000 or more	−0.067	0.074	0.364	−0.046	0.071	0.520
Missing income data	−0.004	0.074	0.957	0.034	0.073	0.638
Employment status						
Employed	0.082	0.066	0.211	0.061	0.067	0.367
Retired (reference category)						
Other (unemployed, homemaker, disabled)	0.120	0.083	0.149	0.257	0.081	0.001
Sample size	315			315		

In the sample of 346 observations depicted in Table 1 and Fig. 1, there are 30 observations with missing values on one or more of the following variables: survivor age, gender, race, ethnicity, marital status, educational attainment, and employment status. Excluding these observations limits the regression analysis sample to 315 observations. Bolded estimates are significant at 5% significance level

Other covariates include age (20–49 years, 50–64 years (reference category), 65–87 years), marital status (married, not married (reference category)), treatment (surgery (reference category), surgery, radiation, and chemotherapy; surgery and chemotherapy; surgery and radiation; other; missing), and number of health conditions. All models are estimated as multivariate logistic regressions

well-being. One example is the federal Family Medical Leave Act (FMLA), which can provide up to 12 weeks of unpaid leave during a 12-month period for caregivers and cancer survivors. Only a handful of states, including New Jersey, mandate paid family leave. Most states do not require paid sick leave either. As evidenced by our results, the lack of employment and income protection can expose cancer survivors to an elevated risk of financial hardship. In the absence of strong worker protection policies, financial navigation initiatives should consider utilizing the full range of existing policies and programs that can help cancer survivors as well as their families to cover medical and nonmedical spending. At a minimum, financial navigation programs mounted in states with paid family leave must ensure that families take advantage of that benefit.

A 2019 survey of the Directors of National Cancer Institute (NCI) Cancer Center Directors identified several key

goals of current financial navigation interventions, such as helping patients and family members understand medical bills, manage medical debt, receive guidance about legal protections, purchase insurance coverage, receive financial assistance for nonmedical costs, and apply for pharmaceutical assistance programs [57]. There have been many creative developments [58, 59], and there will be a need for continued refinement and targeted interventions as more is learned about how financial hardship affects family dynamics and how specific dimensions of financial hardship disproportionately impact particular demographic groups.

This study has several strengths and weaknesses. A strength is its focuses on multiple dimensions of financial hardship, including one that is rarely considered in this literature, worry about having inadequate financial and insurance information. The focus on so-called early survivors is relatively novel, as is the inclusion of patients with a wide

array of cancers in a population registry. The examination of current employment status is a strength; this variable has been ignored in several high-impact publications [4, 26, 60–62]. The lack of data on health insurance coverage is an important study limitation since having adequate insurance coverage might be more relevant to financial well-being in this context than income or employment. However, the presence of health insurance coverage is likely to be partially accounted for by employment status variables [63] and age. Adults 65 years of age or older are likely to have Medicare health insurance coverage, but those who are under 65 are more likely to be employed and therefore have employer-sponsored health insurance. We were unable to account for the effects of family assets, including liquid assets [64]; this is a common problem in the financial toxicity literature that should be addressed in future studies. This study is limited to survivors who are able to read and speak English; this is another common problem that deserves attention. Due to the relatively small sample size, we pooled unemployed, disabled, and homemaker survivors into a single category, potentially obscuring key differences between these groups. Finally, the cross-sectional design implies that estimation results indicate associations and may not necessarily imply causal relationships.

In closing, this study of multiple dimensions of financial hardship in a population-based registry of early cancer survivors highlights the role of employment status and also suggests that income, education, race, and gender all powerfully shape the experience of financial hardship. This information should inform the improvement of financial navigation programs, cancer care, and public policy.

Acknowledgements The author would like to acknowledge the leadership of Dr. Andrew Evens, the contributions of Sara Frederick, Anam Khan, and Carissa Greco from the Cancer Institute of New Jersey, and assistance from staff from the Cancer Surveillance Research Program, New Jersey State Cancer Registry. The registry is funded by the National Cancer Institute, the National Program of Cancer Registries, the Centers for Disease Control and Prevention, and the State of New Jersey and the Rutgers Cancer Institute of New Jersey.

Author contribution Study conception and design: Grafova, Duberstein, and Manne; Acquisition of data: Manne; Analysis and interpretation of data: Grafova, Duberstein, and Manne; Drafting of the manuscript: Grafova, Duberstein, and Manne; Critical revision: Grafova, Manne, Bandera, Saraiya, Llanos, Devine, Hudson, Paddock, Tsui, Elliott, Stroup, and Duberstein.

Funding Data in this study were collected using funding from the Surveillance, Epidemiology and End Results (SEER) Program of the National Cancer Institute under contract HHSN261201300021I, the National Program of Cancer Registries (NPCR), the Centers for Disease Control and Prevention under grant 5U58DP003931-02, and the State of New Jersey and the Rutgers Cancer Institute of New Jersey.

Data availability The data analyzed during the current study is available from the corresponding author on reasonable request.

Code availability Code is available from the corresponding author on reasonable request.

Declarations

Ethical approval All recruitment and study methods were approved by the appropriate Institutional Review Board (Approval Number: Pro2018000866).

Consent to participate N/A

Consent for publication N/A

Conflict of interest Biren Saraiya served on an advisory board for Eisai and Sanofi; conflict of interest forms are attached to the submission for all authors.

References

- Zafar S, Abernethy A (2013) Financial toxicity, Part I: a new name for a growing problem. *Oncology* 27(2):80–81, 149
- Ekwueme DU, Zhao J, Rim SH, Zafar JS, de Moor JS, Zheng Z, Khushalani JS, Han X, Kent EE, Yabroff RR (2019) Annual out-of-pocket expenditures and financial hardship among cancer survivors aged 18–64 years — United States, 2011–2016. *Morb Mortal Wkly Rep* 68(22):494–499. <https://doi.org/10.15585/mmwr.mm6822a2>
- Lentz R, Benson AB III, Kircher S (2019) Financial toxicity in cancer care: Prevalence, causes, consequences, and reduction strategies. *J Surg Oncol* 120(1):85–92. <https://doi.org/10.1002/jso.25374>
- Kent EE, Forsythe LP, Yabroff KR, Weaver KE, de Moor JS, Rodriguez JL, Rowland JH (2013) Are survivors who report cancer-related financial problems more likely to forgo or delay medical care? *Cancer* 119(20):3710–3717. <https://doi.org/10.1002/ncr.28262>
- Chan RJ, Gordon LG, Tan CJ, Chan A, Bradford NK, Yates P, Agbejule OA, Miaskowski C (2019) Relationships between financial toxicity and symptom burden in cancer survivors: A systematic review. *J Pain Symptom Manage* 57(3):646–660.e641. <https://doi.org/10.1016/j.jpainsymman.2018.12.003>
- Altice CK, Banegas MP, Tucker-Seeley RD, Yabroff KR (2017) Financial hardships experienced by cancer survivors: A systematic review. *J Natl Cancer Inst* 109(2). <https://doi.org/10.1093/jnci/djw205>
- Arastu A, Patel A, Mohile SG, Ciminelli J, Kaushik R, Wells M, Culakova E, Lei L, Xu H, Dougherty DW, Mohamed MR, Hill E, Duberstein P, Flannery MA, Kamen CS, Pandya C, Berenberg JL, Arne Grossman VG, Liu Y, Loh KP (2020) Assessment of financial toxicity among older adults with advanced cancer. *JAMA Netw Open* 3(12):e2025810–e2025810. <https://doi.org/10.1001/jamanetworkopen.2020.25810>
- Ahnquist J, Fredlund P, Wamala SP (2007) Is cumulative exposure to economic hardships more hazardous to women's health than men's? A 16-year followup study of the Swedish Survey of Living Conditions. *J Epidemiol Community Health* 61(4):331–336. <https://doi.org/10.1136/jech.2006.049395>
- Mols F, Tomalin B, Pearce A, Kaambwa B, Koczwara B (2020) Financial toxicity and employment status in cancer survivors. A systematic literature review. *Support Care Cancer*. <https://doi.org/10.1007/s00520-020-05719-z>

10. Ver Hoeve ES, Ali-Akbarian L, Price SN, Lothfi NM, Hamann HA (2020) Patient-reported financial toxicity, quality of life, and health behaviors in insured US cancer survivors. *Support Care Cancer*. <https://doi.org/10.1007/s00520-020-05468-z>
11. Cox-Martin E, Anderson-Mellies A, Borges V, Bradley C (2020) Chronic pain, health-related quality of life, and employment in working-age cancer survivors. *J Cancer Surviv* 14(2):179–187. <https://doi.org/10.1007/s11764-019-00843-0>
12. Yabroff KR, Bradley C, Shih Y-CT (2020) Understanding financial hardship among cancer survivors in the United States: strategies for prevention and mitigation. *J Clin Oncol* 38(4):292–301. <https://doi.org/10.1200/jco.19.01564>
13. Banegas MP, Schneider JL, Firemark AJ, Dickerson JF, Kent EE, de Moor JS, Virgo KS, Guy GP, Ekwueme DU, Zheng Z, Varga AM, Waiwaiole LA, Nutt SM, Narayan A, Yabroff KR (2019) The social and economic toll of cancer survivorship: a complex web of financial sacrifice. *J Cancer Surviv* 13(3):406–417. <https://doi.org/10.1007/s11764-019-00761-1>
14. Tucker-Seeley RD, Thorpe RJ Jr (2019) Material–psychosocial–behavioral aspects of financial hardship: A conceptual model for cancer prevention. *Gerontologist* 59(Supplement_1):S88–S93. <https://doi.org/10.1093/geront/gnz033>
15. Fischer KA, Walling A, Wenger N, Glaspy J (2020) Cost health literacy as a physician skill-set: the relationship between oncologist reported knowledge and engagement with patients on financial toxicity. *Support Care Cancer*. <https://doi.org/10.1007/s00520-020-05406-z>
16. Head B, Harris L, Kayser K, Martin A, Smith L (2018) As if the disease was not enough: coping with the financial consequences of cancer. *Support Care Cancer* 26(3):975–987. <https://doi.org/10.1007/s00520-017-3918-y>
17. Jones SMW, Yi JC, Jim HSL, Loren AW, Majhail NS, Uberti J, Whalen V, Leisenring WM, Flowers MED, Lee SJ, Syrjala KL (2020) Age and gender differences in financial distress among hematopoietic cell transplant survivors. *Support Care Cancer* 28(9):4361–4371. <https://doi.org/10.1007/s00520-019-05291-1>
18. Semin JN, Palm D, Smith LM, Ruttelle S (2020) Understanding breast cancer survivors' financial burden and distress after financial assistance. *Support Care Cancer* 28(9):4241–4248. <https://doi.org/10.1007/s00520-019-05271-5>
19. Sharp L, Timmons A (2016) Pre-diagnosis employment status and financial circumstances predict cancer-related financial stress and strain among breast and prostate cancer survivors. *Support Care Cancer* 24(2):699–709. <https://doi.org/10.1007/s00520-015-2832-4>
20. Spencer JC, Samuel CA, Rosenstein DL, Reeder-Hayes KE, Manning ML, Sellers JB, Wheeler SB (2018) Oncology navigators' perceptions of cancer-related financial burden and financial assistance resources. *Support Care Cancer* 26(4):1315–1321. <https://doi.org/10.1007/s00520-017-3958-3>
21. Zahnd WE, Davis MM, Rotter JS, Vanderpool RC, Perry CK, Shannon J, Ko LK, Wheeler SB, Odahowski CL, Farris PE, Eberth JM (2019) Rural-urban differences in financial burden among cancer survivors: an analysis of a nationally representative survey. *Support Care Cancer* 27(12):4779–4786. <https://doi.org/10.1007/s00520-019-04742-z>
22. Hong Y-R, Smith GL, Xie Z, Mainous AG, Huo J (2019) Financial burden of cancer care under the Affordable Care Act: analysis of MEPS-Experiences with Cancer Survivorship 2011 and 2016. *J Cancer Surviv* 13(4):523–536. <https://doi.org/10.1007/s11764-019-00772-y>
23. Pearce A, Tomalin B, Kaambwa B, Horevoorts N, Duijts S, Mols F, van de Poll-Franse L, Koczwara B (2019) Financial toxicity is more than costs of care: the relationship between employment and financial toxicity in long-term cancer survivors. *J Cancer Surviv* 13(1):10–20. <https://doi.org/10.1007/s11764-018-0723-7>
24. Hastert TA, Banegas MP, Hamel LM, Reed AR, Baird T, Beebe-Dimmer JL, Schwartz AG (2019) Race, financial hardship, and limiting care due to cost in a diverse cohort of cancer survivors. *J Cancer Surviv* 13(3):429–437. <https://doi.org/10.1007/s11764-019-00764-y>
25. Banegas MP, Dickerson JF, Kent EE, de Moor JS, Virgo KS, Guy GP, Ekwueme DU, Zheng Z, Nutt S, Pace L, Varga A, Waiwaiole L, Schneider J, Robin Yabroff K (2018) Exploring barriers to the receipt of necessary medical care among cancer survivors under age 65 years. *J Cancer Surviv* 12(1):28–37. <https://doi.org/10.1007/s11764-017-0640-1>
26. Yabroff KR, Dowling EC, Guy GP, Banegas MP, Davidoff A, Han X, Virgo KS, McNeel TS, Chawla N, Blanch-Hartigan D, Kent EE, Li C, Rodriguez JL, de Moor JS, Zheng Z, Jemal A, Ekwueme DU (2015) Financial hardship associated with cancer in the United States: findings from a population-based sample of adult cancer survivors. *J Clin Oncol* 34(3):259–267. <https://doi.org/10.1200/JCO.2015.62.0468>
27. Jeon S-H, Pohl RV (2017) Health and work in the family: Evidence from spouses' cancer diagnoses. *J Health Econ* 52:1–18. <https://doi.org/10.1016/j.jhealeco.2016.12.008>
28. Lu L, Gavin A, Drummond FJ, Sharp L (2020) Cumulative financial stress as a potential risk factor for cancer-related fatigue among prostate cancer survivors. *J Cancer Surviv*. <https://doi.org/10.1007/s11764-020-00906-7>
29. Bennett JA, Brown P, Cameron L, Whitehead LC, Porter D, McPherson KM (2009) Changes in employment and household income during the 24 months following a cancer diagnosis. *Support Care Cancer* 17(8):1057–1064. <https://doi.org/10.1007/s00520-008-0540-z>
30. Wheeler SB, Spencer JC, Pinheiro LC, Carey LA, Olshan AF, Reeder-Hayes KE (2018) Financial impact of breast cancer in black versus white women. *J Clin Oncol* 36(17):1695–1701. <https://doi.org/10.1200/JCO.2017.77.6310>
31. Shankaran V, Jolly S, Blough D, Ramsey S (2012) Risk factors for financial hardship in patients receiving adjuvant chemotherapy for colon cancer: a Population-based exploratory analysis. *J Clin Oncol* 30(14):1608–1614. <https://doi.org/10.1200/jco.2011.37.9511>
32. Beckjord EB, Arora NK, McLaughlin W, Oakley-Girvan I, Hamilton AS, Hesse BW (2008) Health-related information needs in a large and diverse sample of adult cancer survivors: implications for cancer care. *J Cancer Surviv* 2(3):179–189. <https://doi.org/10.1007/s11764-008-0055-0>
33. Grossman M (1972) *The demand for health: a theoretical and empirical investigation*. Columbia University Press. <https://doi.org/10.7312/gros17900>
34. Tangka FKL, Subramanian S, Jones M, Edwards P, Flanigan T, Kaganova Y, Smith KW, Thomas CC, Hawkins NA, Rodriguez J, Fairley T, Guy GP (2020) Insurance coverage, employment status, and financial well-being of young women diagnosed with breast cancer. *Cancer Epidemiol Biomark Prev* 29(3):616–624. <https://doi.org/10.1158/1055-9965.Epi-19-0352>
35. Andrykowski MA, Steffens RF, Bush HM, Tucker TC (2017) Post-traumatic growth and benefit-finding in lung cancer survivors: the benefit of rural residence? *J Health Psychol* 22(7):896–905. <https://doi.org/10.1177/1359105315617820>
36. National_Health_Interview_Survey (2015) Adult access to health care and utilization. https://ftp.cdc.gov/pub/health_statistics/nchs/Survey_Questionnaires/NHIS/2015/english/qadult.pdf. Accessed Mar 10 2021
37. Medical_Expenditure_Panel_Survey (2016) Your experiences with cancer. Agency for Healthcare Research and Quality. <https://>

- meps.ahrq.gov/survey_comp/hc_survey/paper_quest/2017/CancerSAQ_En.shtml. Accessed Mar 10 2021
38. Williams R (2012) Using the margins command to estimate and interpret adjusted predictions and marginal effects. *Stand Genomic Sci* 12(2):308–331. <https://doi.org/10.1177/1536867x1201200209>
 39. Han X, Zhao J, Zheng Z, de Moor JS, Virgo KS, Yabroff KR (2020) Medical financial hardship intensity and financial sacrifice associated with cancer in the United States. *Cancer Epidemiol Biomark Prev* 29(2):308. <https://doi.org/10.1158/1055-9965.EPI-19-0460>
 40. Elfassy T, Swift SL, Glymour MM, Calonico S, Jacobs DR, Mayeda ER, Kershaw KN, Kiefe C, Hazzouri AZA (2019) Associations of income volatility with incident cardiovascular disease and all-cause mortality in a US cohort. *Circulation* 139(7):850–859. <https://doi.org/10.1161/CIRCULATIONAHA.118.035521>
 41. Grasset L, Glymour MM, Elfassy T, Swift SL, Yaffe K, Singh-Manoux A, Zeki Al Hazzouri A (2019) Relation between 20-year income volatility and brain health in midlife. *The CARDIA study* 93(20):e1890–e1899. <https://doi.org/10.1212/wnl.00000000000008463>
 42. Basu S, Berkowitz SA, Seligman H (2017) The monthly cycle of hypoglycemia: an observational claims-based study of emergency room visits, hospital admissions, and costs in a commercially insured population. *Med Care* 55(7):639–645. <https://doi.org/10.1097/mlr.0000000000000728>
 43. Friedberg L, Webb A (2006) Determinants and consequences of bargaining power in households. *Natl Bureau Econ Res*
 44. Lundberg S, Startz R, Stillman S (2003) The retirement-consumption puzzle: a marital bargaining approach. *J Public Econ* 87(5):1199–1218. [https://doi.org/10.1016/S0047-2727\(01\)00169-4](https://doi.org/10.1016/S0047-2727(01)00169-4)
 45. Babiarz P, Ribb CA, Woodyard A (2012) Family decision making and resource protection adequacy. *J Consum Aff* 46(1):1–36. <https://doi.org/10.1111/j.1745-6606.2012.01224.x>
 46. Wong ES (2015) Marital bargaining in the demand for life insurance: evidence from the Health and Retirement Study. *Rev Econ Househ* 13(2):243–268. <https://doi.org/10.1007/s11150-013-9193-x>
 47. Galama T, Kapteyn A, Fonseca R, Michaud P-C (2013) A health production model with endogenous retirement. *Health Econ* 22(8):883–902. <https://doi.org/10.1002/hec.2865>
 48. Lucifora C, Vigani D (2018) Health care utilization at retirement: the role of the opportunity cost of time. *Health Econ* 27(12):2030–2050. <https://doi.org/10.1002/hec.3819>
 49. Chetty R, Szeidl A (2007) Consumption commitments and risk preferences. *Q J Econ* 122(2):831–877. <https://doi.org/10.1162/qjec.122.2.831>
 50. Shen MJ, Peterson EB, Costas-Muñiz R, Hernandez MH, Jewell ST, Matsoukas K, Bylund CL (2018) The effects of race and racial concordance on patient-physician communication: a systematic review of the literature. *J Racial Ethn Health Disparities* 5(1):117–140. <https://doi.org/10.1007/s40615-017-0350-4>
 51. Yousaf O, Grunfeld EA, Hunter MS (2015) A systematic review of the factors associated with delays in medical and psychological help-seeking among men. *Health Psychol Rev* 9(2):264–276. <https://doi.org/10.1080/17437199.2013.840954>
 52. Carr D, Khodyakov D (2007) End-of-life health care planning among young-old adults: an assessment of psychosocial influences. *J Gerontol B Psychol Sci Soc Sci* 62:S135–141. <https://doi.org/10.1093/geronb/62.2.S135>
 53. Lundberg S, Pollak RA (1996) Bargaining and distribution in marriage. *J Econ Perspect* 10(4):139–158. <https://doi.org/10.1257/jep.10.4.139>
 54. Attanasio O, Lechene V (2002) Tests of income pooling in household decisions. *Rev Econ Dyn* 5(4):720–748. <https://doi.org/10.1006/redy.2002.0191>
 55. Monheit AC, Grafova IB, Kumar R (2020) How does family health care use respond to economic shocks? Realized and anticipated effects. *Rev Econ Househ* 18(2):307–334. <https://doi.org/10.1007/s11150-018-9438-9>
 56. Blundell R, Chiappori P-A, Magnac T, Meghir C (2007) Collective labour supply: Heterogeneity and non-participation. *Rev Econ Stud* 74(2):417–445. <https://doi.org/10.1111/j.1467-937X.2007.00440.x>
 57. de Moor JS (2020) Current approaches for addressing medical financial hardship in the context of cancer care delivery. National Cancer Institute, Division of Cancer Control and Population Science, Healthcare Teams Cyber Discussion Series
 58. Shankaran V, Leahy T, Steelquist J, Watabayashi K, Linden H, Ramsey S, Schwartz N, Kreizenbeck K, Nelson J, Balch A, Singleton E, Gallagher K, Overstreet K (2018) Pilot feasibility study of an oncology financial navigation program. *J Oncol Pract* 14(2):e122–e129. <https://doi.org/10.1200/jop.2017.024927>
 59. Yezefski T, Steelquist J, Watabayashi K, Sherman D, Shankaran V (2018) Impact of trained oncology financial navigators on patient out-of-pocket spending. *Am J Manag Care* 24(5 Suppl):S74–s79
 60. Kale HP, Carroll NV (2016) Self-reported financial burden of cancer care and its effect on physical and mental health-related quality of life among US cancer survivors. *Cancer* 122(8):283–289. <https://doi.org/10.1002/cncr.29808>
 61. Fenn KM, Evans SB, McCorkle R, DiGiovanna MP, Pusztai L, Sanft T, Hofstatter EW, Killelea BK, Knobf MT, Lannin DR, Abu-Khalaf M, Horowitz NR, Chagpar AB (2014) Impact of financial burden of cancer on survivors' quality of life. *J Oncol Pract* 10(5):332–338. <https://doi.org/10.1200/jop.2013.001322>
 62. Zheng Z, Jemal A, Han X, Guy GP Jr, Li C, Davidoff AJ, Banegas MP, Ekwueme DU, Yabroff KR (2019) Medical financial hardship among cancer survivors in the United States. *Cancer* 125(10):1737–1747. <https://doi.org/10.1002/cncr.31913>
 63. Nekhlyudov L, Walker R, Ziebell R, Rabin B, Nutt S, Chubak J (2016) Cancer survivors' experiences with insurance, finances, and employment: results from a multisite study. *J Cancer Surviv* 10(6):1104–1111. <https://doi.org/10.1007/s11764-016-0554-3>
 64. Svyarenko R, Zhang Q, Kim H (2019) The financial burden of cancer: financial ratio analysis. *J Fam Econ Issues* 40(2):165–179. <https://doi.org/10.1007/s10834-018-9587-2>

Publisher's note Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.