



Financial toxicity among people with metastatic cancer: findings from the Cancer Experience Registry

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Abstract

Purpose This study describes financial toxicity (FT) reported by people with metastatic cancer, characteristics associated with FT, and associations between FT and compensatory strategies to offset costs.

Methods Cancer Support Community's Cancer Experience Registry data was used to identify respondents with a solid tumor metastatic cancer who completed the Functional Assessment of Chronic Illness Therapy COMprehensive Score for Financial Toxicity (FACIT-COST) measure. Multivariable logistic regression analyses examined associations between respondent characteristics and FT, and FT and postponing medical visits, nonadherence to medications, and postponing supportive and/or psychosocial care.

Results 484 individuals were included in the analysis; the most common cancers included metastatic breast (31%), lung (13%), gynecologic (10%), and colorectal (9%). Approximately half of participants (50.2%) reported some degree of FT. Those who were non-Hispanic White, Hispanic, or multiple races (compared to non-Hispanic Black), and who reported lower income, less education, and being less than one year since their cancer diagnosis had greater odds of reporting FT. Individuals with any level of FT were also more likely to report postponing medical visits (Adjusted Odds Ratio [OR] 2.58; 95% Confidence Interval [CI] 1.45–4.58), suboptimal medication adherence (Adjusted OR 5.05; 95% CI 2.77–9.20) and postponing supportive care and/or psychosocial support services (Adjusted OR 4.16; 95% CI 2.53–6.85) compared to those without FT.

Conclusions With increases in the number of people living longer with metastatic cancer and the rising costs of therapy, there will continue to be a need to systematically screen and intervene to prevent and mitigate FT for these survivors.

Keywords Financial toxicity · Cancer survivors · Financial hardship · Metastatic cancer

Introduction

The National Cancer Institute (NCI) defines a cancer survivor as any individual from the time of cancer diagnosis through the balance of life, including those who are receiving or have completed treatment, and who may have periods with and without active disease [15]. Collectively, there are over 18 million cancer survivors in the United States [3]. A growing population of survivors are people living with

advanced or metastatic cancers; current estimates suggest that over 620,000 people in the United States are living with the most common types of metastatic cancers [9]. Advances in cancer therapies have transformed the survival trajectory of many metastatic cancers, with people living longer through periods with and without active disease, on and off treatment, and with evolving needs.

With survivors living longer and the cost of care and treatment rising, many experience substantial negative financial impact, even years after their initial cancer diagnosis [10]. There have been many terms used to describe financial impact, including financial hardship and financial toxicity. Financial hardship has been characterized as (1) material conditions (e.g., out-of-pocket costs, productivity loss, medical debt, bankruptcy) arising from cost of care and lower income due to employment effects during and after cancer treatment; (2) psychological responses to the increase in expenses or decreases

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in income; and (3) compensatory responses by patients and survivors to manage increased expenses or decreased income [2]. Financial toxicity describes the objective financial burden and subjective financial distress of patients with cancer as a result of treatment and health services [4].

People living with advanced or metastatic cancer may be particularly vulnerable to substantial financial impact [19]. Newer treatments including targeted and immunotherapies can be costly, leading to greater impact on individuals requiring these treatments, particularly as cost burdens continue to be shifted to patients [27]. Additionally, survivors and their caregivers may incur substantial out-of-pocket costs [27] and disruptions in employment related to medical care or treatment side effects [25]. Research in heterogeneous populations of cancer survivors suggests that financial impacts are associated with forgoing care, lack of adherence to prescription medications, and adverse health outcomes [2], including at least one study suggesting severe financial distress is associated with mortality [17]. Such impacts may be especially pronounced among underserved communities, where financial toxicity has been shown to perpetuate existing health disparities among those living with advanced cancer [22].

Despite the well-documented trend in rising cancer costs and disproportionate impact on vulnerable communities, there remains a dearth of evidence on people with advanced or metastatic disease, and its impact on adherence to treatment and healthcare utilization [19]. Of existing evidence, one study of 145 women with metastatic breast cancer showed that most experience financial toxicity [18], and another study found that those who were underinsured had significantly worse financial hardship [30]. Similarly, individuals with metastatic non-small cell lung cancer reported that over half reported two or more types of financial hardship (psychological, behavioral, material), and the most common out-of-pocket costs were medical, transportation, and lodging [12]. Limitations of the existing evidence for metastatic survivors are its focus on a single cancer type, care setting (e.g., academic medical center), and small sample sizes.

Given limitations of current evidence regarding financial impacts among survivors of advanced or metastatic cancer, the purpose of this study was to (1) describe financial toxicity reported by people with metastatic cancer; (2) identify clinical and sociodemographic characteristics associated with financial toxicity; and (3) examine associations between financial toxicity and compensatory strategies to offset costs, including postponing treatment, care, or supportive services.

Methods

Study population

Cancer Support Community's (CSC's) Cancer Experience Registry (CER) is an online, community-based research

initiative designed to investigate the emotional, physical, practical, and financial impact of cancer. Adults (18 years or older) ever diagnosed with any cancer type are eligible to participate and invited to complete the open, web-based survey. Participants are recruited through CSC's networks, including Cancer Support Community and Gilda's Club partners, hospital and healthcare partners, advocacy partnerships, and social media. Eligibility criteria for study sample inclusion were: (1) participation in the CER survey from August 2017 to August 2021, (2) lived in the U.S., (3) completed the Functional Assessment of Chronic Illness Therapy Comprehensive Score for Financial Toxicity (FACIT-COST) measure, and (4) self-identified as having solid tumor metastatic cancer. Exclusion criteria included: (1) hematological malignancies; and (2) respondents who had missing data on the COST measure. Ethical and Independent Review Services (E&I, Independence, MO) served as the IRB of record (Study #16036). All procedures were in accordance with the ethical standards of the institutional research committee for studies involving human participants and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. Informed consent was obtained from all participants.

Measures

Financial toxicity Financial toxicity was measured using the FACIT-COST, a valid and reliable patient-reported measure of financial impact comprised of 11 items rated on a 5-point Likert scale (0 = *Not at all*; 4 = *Very much*) [6]. Responses were coded and summed (range: 0–44); lower scores indicate worse financial toxicity. This analysis utilized the COST measure as a dichotomous variable, where the cut-points are < 23 (mild, moderate, or severe financial toxicity) versus ≥ 23 (no financial toxicity), based on previous work where this approach has been documented to have high sensitivity (0.85) and specificity (0.82) to predict financial toxicity [8, 11, 23].

Postponing care Participants rated how frequently (*Never, Rarely, Sometimes, Often, Always*) they used compensatory strategies to reduce the cost of cancer treatment by: (1) postponing doctors' appointments; (2) postponing follow-up screening and/or blood work; (3) postponing filling prescriptions; (4) skipping dosages of prescribed drugs; (5) delaying follow-up on recommendations for supportive care (e.g., physical therapy, occupational therapy, nutrition counseling); and (6) postponing seeking psychological counseling or support. Items were collapsed into dichotomous categories for each item (0 = *Never*; 1 = *Rarely to Always*). Conceptually similar strategies were grouped into three categories: postponing medical visits (items 1 and 2), postponing or skipping medication (items 3 and 4), and postponing

allied health and/or psychosocial support care (items 5 and 6). The three categories were each recoded into dichotomous index variables, indicating whether a participant endorsed at least one of the two strategies (0 = neither strategy; 1 = one or both strategies).

Socio-demographics and clinical history Participants provided information about age, gender identity, race, Hispanic ethnicity, annual household income, education, employment status, and insurance coverage. Rural–Urban Commuting Area (RUCA) codes were determined for all respondents who provided their zip code, using census data from March 2020. RUCA codes combine population density with commuting patterns to classify geographies from 1 (most urban) to 10 (most rural); geographical residence was categorized as rural (RUCA code ≥ 4), suburban (RUCA code 2 or 3), and urban (RUCA code 1) [28]. Participants also reported clinical history including primary cancer diagnosis, year first diagnosed with cancer, whether they were currently receiving treatment, and where they received treatment. Current comorbidities (yes/no) were assessed from a list of 12 common medical problems (back pain, diabetes, heart disease, high blood pressure, kidney disease, liver disease, lung disease, obesity, osteoarthritis, osteoporosis, rheumatoid arthritis, ulcer or stomach disease) modified from the Self-Administered Comorbidity Questionnaire [20]. The number of comorbidities was categorized as none, 1 or 2, and 3 or more.

Metastatic cancer status Participants were classified as having metastatic cancer if they reported 1) having ever been diagnosed with metastatic (stage IV) cancer, 2) that their most recent cancer was stage IV at diagnosis, 3) that metastatic breast cancer (MBC) was their primary diagnosis, or 4) that their cancer was currently metastatic (stage IV).

Analysis

Data analysis was conducted using Stata, version 17.0 (Stata-Corp LLP). Descriptive statistics were calculated for the full sample and by presence of financial toxicity. The comparability between groups with and without financial toxicity was assessed using bivariate two-sample *t*-tests (means) and Wilcoxon rank-sum tests (median) for continuous variables and chi-square tests and Fisher's Exact test (if cell size < 5) for categorical variables. Next, logistic regression was used to analyze the relationship between socio-demographic and clinical history variables and presence of financial toxicity (0 = no financial toxicity; 1 = mild, moderate, or severe financial toxicity), adjusting for all other variables. Finally, three logistic regression models assessed predictors of postponing care were conducted. In these models, financial toxicity (Yes/No) was the predictor variable and (1) postponing

medical visits, (2) postponing or skipping medication, and (3) postponing supportive care and/or psychosocial support services were the response variables, respectively, adjusting for all previously mentioned socio-demographic and clinical history variables. Missing data were imputed using multivariate normal distribution such that the full sample was retained in regression models. The STATA suite of *mi* commands created 50 imputed data sets and averaged results across these data sets for final estimates. The variables with the highest proportion of missing information were income (19%), age (5%), and geographical residence (5%). All analytic variables were included in the imputation model. A *p*-value of < 0.05 was considered statistically significant.

Sensitivity analysis To account for incongruous self-reported responses regarding history of metastatic disease, a sensitivity analysis was conducted excluding those individuals who answered 'no' or 'don't know' to ever having been diagnosed with metastatic (Stage IV) cancer, or did not answer the question, but indicated most recent cancer was stage IV at diagnosis, primary diagnosis was MBC, or current metastatic cancer (stage IV). Inferential analyses were conducted on the smaller sample, who indicated 'yes' to ever having been diagnosed with metastatic cancer, to confirm consistency in magnitude and direction of observed associations.

Results

Participant characteristics A total of 484 individuals met inclusion criteria (Table 1; Fig. 1). A third of respondents had MBC (31%); other highly represented cancers included lung (13%), gynecologic (10%), colorectal (9%), and prostate (7%). The mean age of respondents was 60 (range 21–88 years), and most respondents identified as female (71%) and non-Hispanic White (83%). Over half of the sample completed the survey two or more years after their initial cancer diagnosis (61%) and were currently receiving treatment for their cancer (78%).

Financial toxicity Half of participants reported mild, moderate, or severe financial toxicity on the FACIT-COST measure (50%; Table 1). Factors significantly associated with financial toxicity in the bivariate analyses included age, gender identity, annual household income, education, employment status, insurance coverage, number of comorbidities, and receiving treatment at an academic medical center or comprehensive cancer center. Adjusting for age, gender identity, race/ethnicity, annual household income, urban/rural status, education, employment status, insurance coverage, currently receiving treatment, time since diagnosis, cancer type, number of

Table 1 Sample characteristics of individuals with metastatic cancer in the Cancer Experience Registry by financial toxicity level, 2017–2021 (*N*=484)

Characteristic	All respondents, <i>N</i> =484 <i>n</i> (%)	Bivariate		<i>p</i> value**	Multivariable ^a	
		No financial toxicity COST ≥ 23 <i>n</i> =241 <i>n</i> (%)	Mild, moderate, or severe financial toxicity COST < 23 <i>n</i> =243 <i>n</i> (%)		Adjusted OR	95% CI
Age, years (range 21–88)	M=60.0; SD=11.3	M=63.0; SD=11.0	M=57.1; SD=10.8	<0.001 (t-test)	0.95	0.92–0.98
Age group				<0.001		
<40 years	24 (5%)	7 (3%)	17 (7%)			
40–64 years	274 (57%)	115 (48%)	159 (65%)			
65 or more years	160 (33%)	103 (43%)	57 (23%)			
Missing	26 (5%)	16 (7%)	10 (4%)			
Gender identity						
Male	139 (29%)	86 (36%)	53 (22%)	0.001	Ref	
Female	345 (71%)	155 (64%)	190 (78%)		1.60	0.87–2.95
Race/ethnicity						
Non-Hispanic White	402 (83%)	206 (85%)	196 (81%)	0.401	3.56	1.32–9.58
Non-Hispanic Black	27 (6%)	13 (5%)	14 (6%)		Ref	
Hispanic, any race	29 (6%)	12 (5%)	17 (7%)		4.42	1.19–16.43
Non-Hispanic other or multiple races selected	20 (4%)	7 (3%)	13 (5%)		6.78	1.45–31.75
Missing	6 (1%)	3 (1%)	3 (1%)		–	–
Annual household income						
\$80 K or more	133 (28%)	91 (38%)	42 (17%)	<0.001	Ref	
\$40–79.9 K	121 (25%)	56 (23%)	65 (27%)		2.52	1.37–4.64
<\$40 K	136 (28%)	41 (17%)	95 (39%)		4.35	2.18–8.70
Prefer not to share/ don't know/missing	24 (19%)	53 (22%)	41 (17%)		–	–
Region						
Rural	79 (16%)	45 (19%)	34 (14%)	0.071	Ref	
Suburban	86 (18%)	34 (14%)	52 (21%)		3.20	1.46–7.02
Urban	295 (61%)	149 (62%)	146 (60%)		2.39	1.23–4.65
Missing	24 (5%)	13 (5%)	11 (5%)		–	–
Education						
Less than college	266 (55%)	110 (46%)	156 (64%)	<0.001	2.09	1.12–3.89
College degree	110 (23%)	62 (26%)	48 (20%)		1.58	0.81–3.08
Graduate degree or higher	101 (21%)	67 (28%)	34 (14%)		Ref	
Prefer not to share/ missing	7 (1%)	2 (1%)	5 (2%)		–	–
Employment status						
Employed (full-time or part-time)	152 (31%)	78 (32%)	74 (31%)	<0.001	1.70	0.87–3.33
Retired	171 (35%)	115 (48%)	56 (23%)		Ref	
Not employed	155 (32%)	45 (19%)	110 (45%)		2.74	1.40–5.35
Prefer not to share/ missing	6 (1%)	3 (1%)	3 (1%)		–	–

Table 1 (continued)

Characteristic	All respondents, N=484 n (%)	Bivariate		p value**	Multivariable ^a	
		No financial toxicity COST ≥ 23 n=241 n (%)	Mild, moderate, or severe financial toxicity COST < 23 n=243 n (%)		Adjusted OR	95% CI
Insurance coverage						
Private	221 (46%)	115 (48%)	106 (44%)	0.013	Ref	
Government	193 (40%)	85 (35%)	108 (44%)		1.23	0.67–2.26
Private and govern- ment	61 (13%)	39 (16%)	22 (9%)		1.25	0.55–2.88
Not insured	6 (1%)	1 (0%)	5 (2%)		3.93	0.32–47.76
Missing	3 (1%)	1 (0%)	2 (1%)		–	–
Currently receiving treatment						
Yes	378 (78%)	187 (78%)	191 (79%)	0.658	0.69	0.39–1.21
No	104 (22%)	54 (22%)	50 (21%)		Ref	
Don't know	2 (0%)	0 (0%)	2 (1%)		–	–
Time since diagnosis, years	M=4.4; SD=5.8	M=4.9; SD=6.3	M=4.0; SD=5.2	0.333 (median test)		
Time since diagnosis						
<1 year	84 (17%)	32 (13%)	52 (21%)	0.134	2.64	1.29–5.42
1 year	91 (19%)	47 (20%)	44 (18%)		1.14	0.59–2.18
2 to 4 years	149 (31%)	77 (32%)	72 (30%)		0.92	0.53–1.60
5 or more years	143 (30%)	76 (32%)	67 (28%)		Ref	
Missing	17 (4%)	9 (4%)	8 (3%)		–	–
Diagnosis						
Breast	152 (31%)	71 (29%)	81 (33%)	0.059	Ref	
Lung	63 (13%)	30 (12%)	33 (14%)		0.94	0.44–2.01
Gynecologic	49 (10%)	27 (11%)	22 (9%)		0.70	0.32–1.54
Colorectal	45 (9%)	22 (9%)	23 (9%)		1.01	0.43–2.39
Prostate	32 (7%)	24 (10%)	8 (3%)		0.77	0.23–2.53
Head and Neck	21 (4%)	13 (5%)	8 (3%)		0.80	0.24–2.72
Other	122 (25%)	54 (22%)	68 (28%)		1.33	0.69–2.58
Number of comorbidities (from list of 12)						
None listed among 12	84 (17%)	55 (23%)	29 (12%)	0.001	Ref	
1 or 2	233 (48%)	117 (49%)	116 (48%)		2.29	1.22–4.28
3 or more	167 (25%)	69 (29%)	98 (40%)		2.36	1.19–4.70
Received all or some treatment at academic or comprehensive cancer center						
No	184 (38%)	103 (43%)	81 (33%)	0.038	Ref	
Yes	292 (60%)	135 (56%)	157 (65%)		1.19	0.74–1.92
Missing	8 (2%)	3 (1%)	5 (2%)		–	–

Bold entries indicate significant findings

OR odds ratio, 95% CI 95% confidence interval, M mean, SD standard deviation

** p value refers to Chi² or Fisher's Exact test; among valid responses

^aMultivariable models indicate odds ratios of higher financial toxicity

comorbidities, and receiving all or some treatment at an academic or comprehensive cancer center, multivariable modeling revealed several factors that were significantly

associated with financial toxicity, including age, race/ethnicity, annual household income, rural/urban residency, education, employment, time since diagnosis, and number

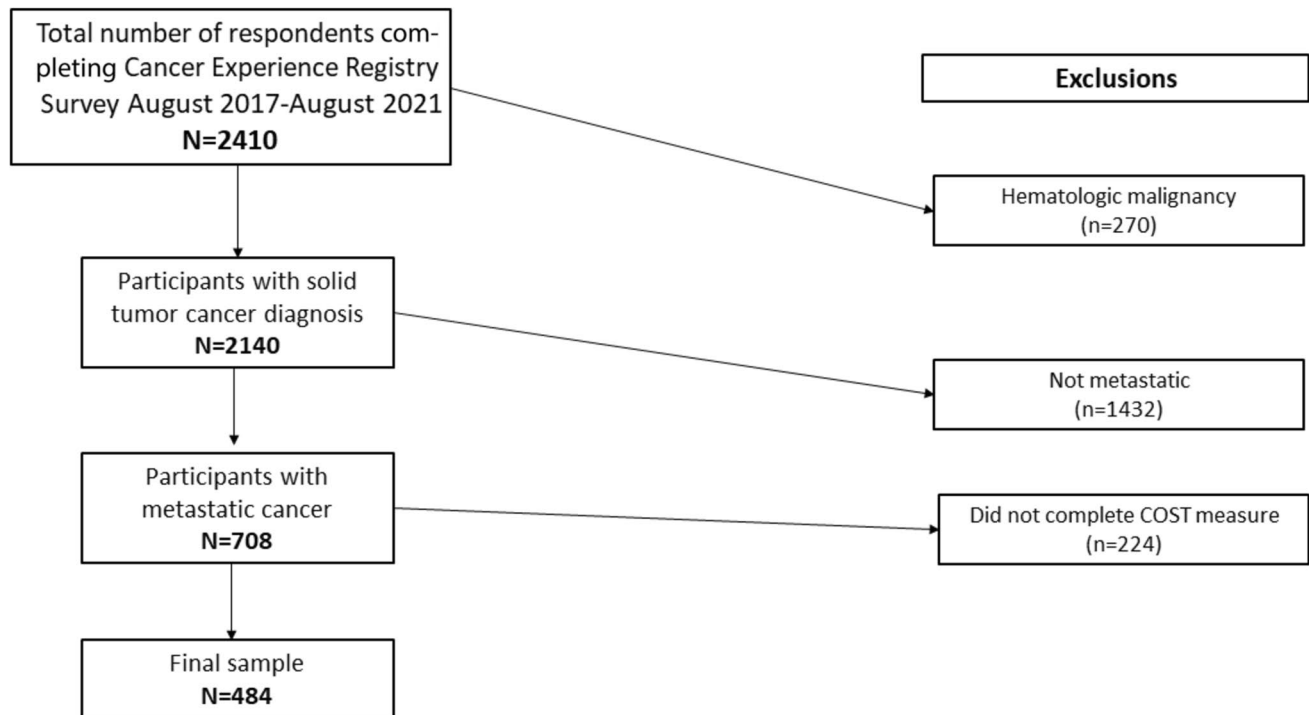


Fig. 1 Cohort selection

of comorbidities. Specifically, older age was associated with lower odds of financial toxicity (OR 0.95; 95% CI 0.92–0.98) (Table 1). Conversely, compared to non-Hispanic Black respondents, individuals who identified as non-Hispanic White (OR 3.56; 95% CI 1.32–9.58), Hispanic (OR 4.42; 95% CI 1.19–16.43), or multiple races (OR 6.78; 95% CI 1.45–31.75) had higher odds of financial toxicity. Respondents with an annual household income of <\$40,000 per year (OR 4.35; 95% CI 2.18–8.70), whose educational attainment was less than a college degree (OR 2.09; 95% CI 1.12–3.89), and who were not employed (OR 2.74; 95% CI 1.40–5.35) also had higher odds of financial toxicity compared to those with higher income, greater education, and current employment, respectively. Cancer type was not associated with level of financial toxicity; however, being less than one year since cancer diagnosis (OR 2.64; 95% CI 1.29–5.42) was associated with higher odds of financial toxicity as compared with five or more years since diagnosis. Further, having 1–2 comorbidities (OR 2.29; 95% CI 1.22–4.28) or 3+ comorbidities (OR 2.36; 95% CI 1.19–4.70) were each associated with greater odds of financial toxicity than those without comorbidities.

Postponing care Participants endorsed postponing or delaying care (*Rarely to Always*) to offset care costs, including postponing doctor’s appointments (21%); postponing follow-up screening and/or blood work (16%); postponing filling prescriptions (18%); skipping dosages

of prescribed drugs (17%); delaying follow-up on recommendations for supportive services (26%); and postponing seeking psychological counseling or support (28%). Individuals with financial toxicity were significantly more likely to report postponing or delaying each type of care compared to those without financial toxicity (Table 2). After adjusting for age, gender identity, income, education, employment, insurance type, and the number of comorbidities, these associations remained statistically significant. When collapsing the six items into three different categories (postponing medical visits, suboptimal medication adherence, and postponing supportive services and psychosocial support), the odds of postponing care in each category were significantly higher for respondents with financial toxicity versus those without (postponing medical visits adjusted OR 2.58, 95% CI 1.45–4.58; suboptimal medication adherence adjusted OR 5.05, 95% CI 2.77–9.20; and postponing supportive services adjusted OR 4.16, 95% CI 2.53–6.85) (Table 3).

Sensitivity analysis A total of 375 patients indicated ‘yes’ to ever having been diagnosed with metastatic (Stage IV) cancer; 95 patients answered ‘no’ and 14 responded ‘don’t know’, or skipped the question, but also indicated their most recent cancer was stage IV at diagnosis, primary diagnosis was MBC, or they currently had metastatic cancer (stage IV). Bivariate or multivariable analysis on the smaller sample ($n = 375$) did not alter the conclusions (results not shown).

Table 2 Odds ratios and 95% confidence intervals for postponing care among those experiencing any financial toxicity compared to those not experiencing financial toxicity: individual postponing/delaying items

	All respondents <i>N</i> =484 <i>n</i> (%) ^a	No finan- cial toxicity (COST ≥ 23) <i>n</i> (%) ^b	Any finan- cial toxicity (COST < 23) <i>n</i> (%) ^c	Odds of postponing care for those with any financial toxicity compared to those with no financial toxicity	
				Unadjusted OR (95% CI)	Multivariable- adjusted OR (95% CI) ^d
Rarely, sometimes often or always...					
Postpone doctor's appointments	101 (21.0)	28 (11.7)	73 (30.2)	3.27 (2.02–5.29)	2.35 (1.32, 4.20)
Postpone follow-up screening and/or bloodwork	75 (15.7)	15 (6.3)	60 (25.0)	4.98 (2.74–9.06)	3.11 (1.58, 6.13)
Postpone filling prescriptions	87 (18.2)	16 (6.7)	71 (29.7)	5.92 (3.32–10.50)	4.43 (2.29, 8.57)
Skip doses of prescribed drugs	82 (17.2)	13 (5.5)	69 (28.6)	6.91 (3.71–12.90)	4.07 (2.08, 7.95)
Delay follow-up on recom- mendations for supportive care (e.g., physical therapy, occupational therapy, nutri- tion counseling)	126 (26.3)	35 (14.6)	91 (37.9)	3.56 (2.28–5.55)	3.18 (1.88, 5.40)
Postpone seeking psychological counseling or support	131 (27.6)	31 (13.1%)	100 (42.0%)	4.79 (3.03–7.57)	3.65 (2.15, 6.19)

OR odds ratio, 95% CI 95% confidence interval

^aPercentage calculated out of the number of valid responses to each item for total sample; *n* ranges from 474 (psychological counseling support) to 482 (doctor's appointments)

^bPercentage calculated out of the number of valid responses to each item for those with no financial toxicity; *n* ranges from 236 to 240

^cPercentage calculated out of the number of valid responses to each item for those with any financial toxicity; *n* ranges from 238 to 242

^dAdjusted for age, gender identity, income, race/ethnicity, geographic region, education, employment, insurance type, time since diagnosis, currently receiving treatment, cancer diagnosis, care received at academic or comprehensive cancer center, and number of comorbidities

Table 3 Odds ratios and 95% confidence intervals for postponing care among those experiencing any financial toxicity compared to those not experiencing financial toxicity: combined postponing/delaying items

	Total sample <i>N</i> =484 <i>n</i> (%) ^a	No finan- cial toxicity (COST ≥ 23) <i>n</i> (%) ^b	Any finan- cial toxicity (COST < 23) <i>n</i> (%) ^c	Odds of postponing care (combined items) for those with any financial toxicity compared to those with no financial toxicity	
				Unadjusted OR (95% CI)	Adjusted OR (95% CI) ^d
Rarely, sometimes, often, or always for at least 1 of the 2 items...					
Postpone medical visits	108 (22.4)	28 (11.7)	80 (33.1)	3.74 (2.32–6.02)	2.58 (1.45–4.58)
Suboptimal medication adherence	108 (22.5)	21 (8.8)	87 (36.0)	5.89 (3.51–9.90)	5.05 (2.77–9.20)
Postpone supportive care (physi- cal, occupational, and/or nutrition therapy), and/or psychosocial sup- port services	163 (33.8)	43 (17.9)	120 (49.6)	4.51 (2.98–6.83)	4.16 (2.53–6.85)

Postponing medical visits includes doctor's appointments, follow-up screening and/or blood work; Suboptimal medication adherence includes filling prescriptions and skipping dosages of prescribed drugs; Postponing supportive and/or psychosocial support services refers to physical therapy, occupational therapy and/or nutrition counseling, and psychological counseling or support

OR odds ratio, 95% CI 95% confidence interval

^aPercentage calculated out of the number of valid responses to each item for total sample; *n* ranges from 481 (suboptimal medication adherence) to 482 (postpone medical visits; postpone supportive care)

^bPercentage calculated out of the number of valid responses to each item for those with no financial toxicity; *n*=240 for all three items

^cPercentage calculated out of the number of valid responses to each item for those with any financial toxicity; *n* ranges from 241 to 242

^dAdjusted for age, gender identity, income, race/ethnicity, geographic region, education, employment, insurance type, time since diagnosis, currently receiving treatment, cancer diagnosis, care received at academic or comprehensive cancer center, and number of comorbidities

Discussion

In this study of survivors with metastatic cancer, financial toxicity was common and significantly associated with postponement of medical and supportive care services. Self-reported lower income, being uninsured, being unemployed, and having less than a college degree were associated with greater odds of financial toxicity in this population. These findings build upon previous studies conducted among smaller samples of people living with metastatic breast and advanced lung cancers [12, 30] and are consistent with trends documented in survivors across the cancer continuum [31]. Vulnerabilities related to insurance and employment status, income, and educational attainment, coupled with length of treatment and treatment advances that can improve survival, may predispose people with advanced and metastatic disease to experience additional costly treatment and out-of-pocket costs throughout the trajectory of care. In addition, there may be great uncertainty in treatment plans and prognosis, making it difficult for individuals with advanced disease to prepare for the long-term financial burden of cancer and its treatment.

Contrary to other studies [31], the findings showed that people with metastatic cancer who identified as non-Hispanic White, Hispanic, or more than one race had greater odds of financial toxicity compared to those identifying as non-Hispanic Black. These results may be influenced by sampling artifacts or other unmeasured contextual factors. For example, a recent survey on racial bias in oncology care delivery showed that, while Black respondents more often reported negative care experiences compared to White respondents, they also reported the highest rates of oncologist conversations about cost of treatment and insurance coverage as compared to other races [21]. The intersection of race/ethnicity, financial toxicity, and other contextual factors remains an important area of study, and future research may center on those who would most benefit from tailored support to prevent, identify, and mitigate financial toxicity.

Given the role of financial toxicity in perpetuating health disparities [22], the consistent associations between financial toxicity and postponement of care by people with metastatic cancer is notable. Those who reported financial toxicity were more than five times more likely to postpone filling prescriptions or skipping doses of their medications, and more than twice as likely to postpone medical care. Prior research has suggested that associations between financial toxicity and mortality for cancer survivors may be due in part to treatment non-adherence [17]. In addition, higher out-of-pocket costs have been associated with greater odds of non-adherence to oral anticancer

medications [29] and general prescription utilization [5]. These results demonstrate the critical impact of financial toxicity on accessing healthcare services and medications and underscore the importance of identifying and addressing financial hardship early.

Additionally, those reporting financial toxicity had four times greater odds of delaying follow-up recommendations for receiving supportive care and psychosocial services. Comprehensive whole-person care, including distress management [7] and rehabilitation services [24], have been recommended for all people with cancer, and there is growing recognition of the importance of this care for people with advanced and metastatic cancer in particular [26]. By postponing these services, people may experience worse health-related quality of life and severe physical or psychosocial impairments. Future research should examine the care decisions that individuals make after a cancer diagnosis, both during treatment and in long-term follow-up care, and the impact of financial toxicity on those decisions. Prospective longitudinal research is also needed to clarify what predicts improved or worsening financial toxicity and coping behaviors over time in people living longer with advanced and metastatic cancer, to inform future interventions.

Collectively, the results demonstrating a link between financial toxicity and care postponement among people with metastatic cancer underscore the need for cancer care delivery and healthcare policy solutions. Indeed, there is growing consensus that routine screening for financial toxicity should be embedded into oncology care [1, 2, 4, 31] and that high quality care should include patient-provider communication about cost of treatment as part of informed decision making [1, 13]. Ideally, a multi-level approach to prevent and mitigate financial hardship at the patient, provider, practice, employer, and policy levels should be implemented to address the growing cost of care for people with cancer [31]. In the near term, research is needed that identifies effective navigation for financial burden, including how to best support health care teams in discussing care costs in a manner that takes into account metastatic patients' perspectives and preferences. It is important to note two recent efforts to further research focused on people living with metastatic cancer. NCI recently released a request for application (RFA): *Research to Understand and Address the Survivorship Needs of Individuals Living with Advanced Cancer*, to support research that includes strategies to understand and/or address financial concerns among this population [16]. Additionally, CancerX is a public-private partnership to boost innovation in the fight against cancer. Its efforts include the development of evidence, best practices, and implementation projects to reduce the burden of cancer [14]. Future research on financial toxicity for people living with metastatic cancer may leverage these opportunities.

The strengths of the current analysis include participation by a broad population of metastatic cancer survivors, representing over 25 diagnostic cancer types from across the United States. This expands upon previous literature that recruited people living with advanced and metastatic cancer from a single care setting and/or one cancer type. The results, however, should be viewed in light of certain limitations. Selection bias may be present as the web-based survey was shared widely and survey participation required internet access. Survey respondents may be more engaged with healthcare and supportive services than those who did not participate. While the current sample includes geographically diverse participants, the sample is not nationally representative of all people living with metastatic cancer in the U.S. as study participants were predominantly female and identified as non-Hispanic White. Additionally, the use of the COST measure as a dichotomous outcome (no financial toxicity versus mild, moderate, or severe financial toxicity) may overestimate risk for mild financial toxicity and underestimate risk for moderate-severe financial toxicity particularly for individuals who may be financially vulnerable due to low income or lack of employment. We also acknowledge limitations in potential errors of self-reported data in terms of cancer history and stage.

In summary, this study revealed that financial toxicity is common for many people with metastatic cancer and is associated with postponing medical visits, suboptimal medication adherence, and postponing supportive care services. With increases in the number of people living longer with metastatic cancer, the growing evidence that financial toxicity perpetuates health disparities, and the rising costs of cancer-directed therapies, there will continue to be a need to systematically screen and intervene to prevent, identify, and mitigate financial impact for this population.

Author contributions MAM, AZ, LG, KC, RB, ET, PJ, MM were responsible for research conceptualization; MM conducted the analyses; MAM and MM wrote the main manuscript text in collaboration with all authors; All authors reviewed the study design, results, and the manuscript.

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

Declarations

Ethics approval Ethical and Independent Review Services (E&I, Independence, MO) served as the IRB of record (Study #16036). All proce-

dures were in accordance with the ethical standards of the institutional research committee for studies involving human participants and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. Informed consent was obtained from all participants.

Consent to publish The authors affirm that human research participants provided informed consent for publication of the data in all tables.

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This study has not been previously presented.

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References

- Abrams HR, Durbin S, Huang CX, Johnson SF, Nayak RK, Zahner GJ, Peppercorn J (2021) Financial toxicity in cancer care: origins, impact, and solutions. *Transl Behav Med* 11:2043–2054
- Altice C (2017) BAneegas M, Tucker-Seeley R, Yabroff K. Financial hardships experiences by cancer survivors: a systematic review *J Natl Cancer Inst* 109:1–17
- American Cancer Society (2022) Cancer facts & figures. American Cancer Society, Atlanta, GA
- Carrera PM, Kantarjian HM, Blinder VS (2018) The financial burden and distress of patients with cancer: understanding and stepping-up action on the financial toxicity of cancer treatment. *CA Cancer J Clin* 68:153–165
- Chan K, Sepassi A, Saunders IM, Goodman A, Watanabe JH (2022) Effects of financial toxicity on prescription drug use and mental well-being in cancer patients. *Explor Res Clin Soc Pharm* 6:100136
- de Souza JA, Yap BJ, Wroblewski K, Blinder V, Araújo FS, Hlubocky FJ, Nicholas LH, O'Connor JM, Brockstein B, Ratain MJ, Daugherty CK, Cella D (2017) Measuring financial toxicity as a clinically relevant patient-reported outcome: the validation of the COMprehensive Score for financial Toxicity (COST). *Cancer* 123:476–484
- Donovan KA, Deshields TL, Corbett C, Riba MB (2019) Update on the implementation of NCCN guidelines for distress management by NCCN Member Institutions. *J Natl Compr Canc Netw* 17:1251–1256
- Esselen KM, Stack-Dunnbier H, Gompers A, Hacker MR (2021) Crowdsourcing to measure financial toxicity in gynecologic oncology. *Gynecol Oncol* 161:595–600
- Gallicchio L, Devasia TP, Tonorezos E, Mollica MA, Mariotto A (2022) Estimation of the number of individuals living with metastatic cancer in the United States. *J Natl Cancer Inst* 114(11):1476–1483. <https://doi.org/10.1093/jnci/djac158>

10. Guy GP Jr, Ekwueme DU, Yabroff KR, Dowling EC, Li C, Rodriguez JL, de Moor JS, Virgo KS (2013) Economic burden of cancer survivorship among adults in the United States. *J Clin Oncol* 31:3749–3757
11. Huntington SF, Weiss BM, Vogl DT, Cohen AD, Garfall AL, Mangan PA, Doshi JA, Stadtmauer EA (2015) Financial toxicity in insured patients with multiple myeloma: a cross-sectional pilot study. *Lancet Haematol* 2:e408–416
12. McLouth LE, Nightingale CL, Levine BJ, Burris JL, McDougall JA, Lycan TW Jr, Gabbard J, Ruiz J, Farris M, Blackstock AW Jr, Grant SC, Petty WJ, Weaver KE (2021) Unmet care needs and financial hardship in patients with metastatic non-small-cell lung cancer on immunotherapy or chemoimmunotherapy in clinical practice. *JCO Oncol Pract* 17:e1110–e1119
13. Meropol N, Schrag D, Smith T, Mulvey T, Langdon R, Blum D, Ubel P, Schnipper LE (2009) American Society of Clinical Oncology guidance statement: the cost of cancer care. *J Clin Oncol* 23:3868–3874
14. Moffitt Cancer Center (2023) CancerX. Moffitt Cancer Center, Tampa, FL. <https://cancerx.health/>. Retrieved January 2, 2024
15. National Cancer Institute (2023) Office of cancer survivorship: definitions. National Cancer Institute, Bethesda, MD. <https://cancercontrol.cancer.gov/ocs/definitions>. Retrieved January 4, 2024
16. National Cancer Institute (2022) RFA-CA-22-027: Research to understand and address the survivorship needs of individuals living with advanced cancer (R01 Clinical Trial Optional). National Institutes of Health, Bethesda, MD. <https://grants.nih.gov/grants/guide/rfa-files/RFA-CA-22-027.html>. Retrieved January 4, 2024
17. Ramsey S, Bansal A, Fedorenko C, Blough D, Overstreet K, Shankaran V, Newcomb P (2016) Financial insolvency as a risk factor for early mortality among patients with cancer. *J Clin Oncol* 34:980–986
18. Rosenzweig M, West M, Matthews J, Stokan M, Yoojin Kook YK, Gallups S, Diergaarde B (2019) Financial toxicity among women with metastatic breast cancer. *Oncol Nurs Forum* 46(1):83–91. <https://doi.org/10.1188/19.ONF.83-91>
19. Rotter J, Spencer JC, Wheeler SB (2019) Financial toxicity in advanced and metastatic cancer: overburdened and underprepared. *J Oncol Pract* 15:e300–e307
20. Sangha O, Stucki G, Liang MH, Fossel AH, Katz JN (2003) The Self-Administered Comorbidity Questionnaire: a new method to assess comorbidity for clinical and health services research. *Arthritis Rheum* 49:156–163
21. Schatz AA, Brooks-Coley K, Harrington E, Murray MS, Carlson RW (2022) Patient, caregiver, and oncologist experiences with and perceptions of racial bias and discrimination in cancer care delivery. *J Natl Compr Canc Netw* 20(1092–1098):e1092
22. Shah K, Zafar SY, Chino F (2022) Role of financial toxicity in perpetuating health disparities. *Trends in Cancer* 8:266–268
23. Sidey-Gibbons C, Pfob A, Asaad M, Boukvalas S, Lin YL, Selber JC, Butler CE, Offodile AC 2nd (2021) Development of machine learning algorithms for the prediction of financial toxicity in localized breast cancer following surgical treatment. *JCO Clin Cancer Inform* 5:338–347
24. Stout NL, Santa Mina D, Lyons KD, Robb K, Silver JK (2021) A systematic review of rehabilitation and exercise recommendations in oncology guidelines. *CA Cancer J Clin* 71:149–175
25. Tevaarwerk AJ, Lee JW, Terhaar A, Sesto ME, Smith ML, Cleeland CS, Fisch MJ (2016) Working after a metastatic cancer diagnosis: factors affecting employment in the metastatic setting from ECOG-ACRIN's symptom outcomes and practice patterns study. *Cancer* 122:438–446
26. Tometich DB, Hyland KA, Soliman H, Jim HS, Oswald L (2020) Living with metastatic cancer: a roadmap for future research. *Cancers* 12:3684
27. Tran G, Zafar SY (2018) Financial toxicity and implications for cancer care in the era of molecular and immune therapies. *Ann Transl Med* 6:166
28. United States Department of Agriculture (USDA) (2013). 2013 Rural-urban continuum codes. USDA Economic Research Service. USDA, Washington, DC. <https://www.ers.usda.gov/data-products/rural-urban-continuum-codes/>. Retrieved December 11, 2023
29. Vyas A, Descoteaux A, Kogut S, Parikh MA, Campbell PJ, Green A, Westrich K (2022) Predictors of adherence to oral anticancer medications: an analysis of 2010–2018 US nationwide claims. *J Manag Care Spec Pharm* 28:831–844
30. Williams CP, Pisu M, Azuero A, Kenzik KM, Nipp RD, Aswani MS, Mennemeyer ST, Pierce JY, Rocque GB (2020) Health insurance literacy and financial hardship in women living with metastatic breast cancer. *JCO Oncol Pract* 16:e529–e537
31. Yabroff KR, Bradley C, Shih YT (2020) Understanding financial hardship among cancer survivors in the united states: strategies for prevention and mitigation. *J Clin Oncol* 38:292–301

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