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Correlates of financial toxicity in adult cancer patients and their informal caregivers

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Abstract

Background—Financial toxicity is commonly reported by cancer patients, but few studies have assessed caregiver perceptions. We aimed to validate the modified Comprehensive Score for Financial Toxicity (COST) in cancer caregivers, identify factors associated with financial toxicity in both patients and caregivers, and assess the association of caregiver financial toxicity with patient and caregiver outcomes.

Methods—Using a convenience sampling method, 100 dyads of adult cancer patients and a primary caregiver visiting outpatient oncology clinics (Jan–Sep 2019) were recruited. We assessed the internal consistency and convergent and divergent validity of the modified COST. Multivariable analyses identified correlates of financial toxicity. Association of financial toxicity

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Ethics approval The study was approved by Emory University Institutional Review Board (IRB approval # IRB00108258) and was Health Insurance Portability and Accountability Act (HIPAA) compliant.

Consent to participate Written informed consent was obtained from all participants.

Consent to publish Patients signed informed consent regarding publishing their data.

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with care non-adherence, lifestyle-altering behaviors (e.g., home refinance/sale, retirement/saving account withdrawal), and quality of life (QOL) was investigated.

Results—Recruited patient vs. caregiver characteristics were as follows: mean age: 60.6 vs. 56.5; 34% vs. 46.4% female; 79% vs. 81.4% white. The caregiver COST measure demonstrated high internal consistency (Cronbach $\alpha = 0.91$). In patients, older age (B , 0.3 [95% CI, 0.1–0.4]) and higher annual household income (B , 14.3 [95% CI, 9.3–19.4]) correlated with lower financial toxicity ($P < 0.05$). In caregivers, lower patient financial toxicity (B , 0.4 [95% CI, 0.2–0.6]) and cancer stages 1–3 (compared to stage 4) (B , 4.6 [95% CI, 0.4–8.8]) correlated with lower financial toxicity ($P < 0.05$). Increased caregiver financial toxicity correlated with higher care non-adherence in patients, increased lifestyle-altering behaviors, and lower QOL in patients and caregivers ($P < 0.05$).

Conclusion—The COST measure can also be used to assess caregiver financial toxicity. Caregivers' financial toxicity was associated with negative outcomes for both dyad members.

Keywords

Cancer; Caregiver; Financial toxicity; Health outcomes

Introduction

Cancer patients are at risk for financial toxicity, a term describing the psychological distress, negative coping behaviors, and material conditions (e.g., medical debt) patients experience due to high out-of-pocket (OOP) costs of treatment, increased cost-sharing, and decreased household income as a result of cancer and its treatment [1]. Financial toxicity affects 40–50% of cancer survivors [2, 3] and is associated with worse quality of life (QOL), increased nonadherence to cancer care and general medical care, and use of lifestyle-altering behaviors such as an increased home sale or refinance, decreased basic spending, and increased use of savings or retirement accounts [2–6]. In one study, patients who declared personal bankruptcy from cancer treatment costs had nearly twice the mortality risk as those who did not declare bankruptcy [5]. Patients with inadequate insurance coverage, low income, unemployment, long travel times to a healthcare facility, lower education, younger age, non-White race, and female gender are at higher risk for financial toxicity [2, 3, 7, 8].

Informal or familial caregivers are friends or family persons, most responsible for ongoing caregiving, regardless of the location of residence [9]. Similar to patients, these caregivers may experience negative effects of high OOP costs and reduced working hours related to cancer treatment [10–12]. In a prior study, cancer treatment was associated with an average of 10 h per week of informal caregiving [13]. Another study suggested that caregivers may lose approximately 50% of their potential workdays in any given month to assist with patient care [8]. The value of caregiver time increases in younger patients and those with a distant disease at diagnosis compared to those with local disease [8, 13]. Caregiving also reduces a person's chance of being employed resulting in lost income, and many caregivers are unable to work, need to take leave without pay, have fewer work hours, are in lower-paid jobs, or work from home to manage the caregiver demands [14]. However, there is limited literature on the contributory factors to financial toxicity among caregivers and its impact

on both caregiver and patient outcomes. Furthermore, the survey instrument used to measure financial toxicity is only validated in cancer patients, and not caregivers [15].

In the current study, we aimed to validate the modified Comprehensive Score for Financial Toxicity (COST) instrument in informal caregivers of cancer patients, identify factors associated with their financial toxicity, and assess the impact of their financial toxicity on patient and caregiver outcomes (care non-adherence, lifestyle-altering behaviors, and QOL).

Methods

This cross-sectional observational study was approved by Emory University Institutional Review Board (IRB approval # IRB00108258) and was Health Insurance Portability and Accountability Act (HIPAA) compliant. Written informed consent was obtained from all participants.

Study population

Adults 18 years with a known diagnosis of any stage solid tumor, regardless of time from diagnosis, visiting an outpatient oncology clinic in a tertiary referral health system in a Metropolitan city, who could identify an adult principal informal caregiver, regardless of the location of residence were eligible.

Non-English speakers, and those who were not thought to have the capacity to consent, based on their treating oncology provider assessment were excluded.

Design

Between January and September 2019, using a convenience sampling method, patients visiting our outpatient oncology clinic and their principal caregivers (as identified by the patient) were invited to participate in the study by a study coordinator, who explained the study, confirmed eligibility, and reviewed consent forms with them. Patients and caregivers completed a 15-min paper survey. They had the option of either completing the survey in the clinic or at home, mailing their completed survey using a provided pre-stamped return envelope.

Measurements

Financial toxicity was measured using an 11-item COST questionnaire (score range 0–44; the lower the score, the greater the financial toxicity) as well as a single summary item “My Illness has been a financial hardship to my family and me,” scored on a 5-point Likert scale [15]. For caregivers, the language of the questionnaire was modified to accommodate for the change in respondent’s role (i.e., words related to patients were changed to “loved one”).

Care non-adherence was measured in patients as a self-reported cost-related incident during the 3 months prior when recommended imaging test(s) were not performed, office visit(s) were skipped, or medication(s) were refused, filled late, doses skipped, or stopped as adapted from validated Agency for Healthcare Research and Quality (AHRQ) Medical Expenditure Panel Survey (MEPS) [16, 17].

Lifestyle-altering behaviors were measured in patients and caregivers as self-reported cost-related incidence of home refinancing, home or car sales, retirement or saving account withdrawals, credit card debt, money borrowing, forgoing making a big purchase, and filing for bankruptcy as adapted from validated AHRQ Medical Expenditure Panel Survey (MEPS) [16, 17].

Patients' QOL was assessed using the validated 27-item Functional Assessment of Cancer Therapy-General (FACT-G; score range 0–108; the higher the score, the better the QOL) [18]. Caregivers' QOL was assessed using the validated 30-item CareGiver Oncology Quality of Life questionnaire (CarGOQoL) (score range 0–100; the higher the score, the better the QOL) [19].

Type of cancer, months from diagnosis, cancer stage, types of therapy, and participation in clinical trials were assessed using a combination of surveys and electronic medical records. The number of ED or clinic visits or inpatient hospitalizations in the last 3 months was assessed using surveys. The relationship between patients and caregivers was recorded and given that most caregivers were spouses, the non-spousal relationships were collapsed into one category.

To assess convergent and divergent validity of the modified COST questionnaire used for caregivers, the caregiver survey also included a measure of psychosocial distress (10-item Brief Profile of Mood States (Brief-POMS), score range 0–40; high score = more distress) [20] and the Marlowe-Crowne Social Desirability Scale (MCSDS), a 33-item social desirability measure (score range 0–33; higher score = higher social desirability) [21]. Financial self-efficacy, defined as confidence in managing financial problems (e.g., unexpected expenses, retirement planning) was further assessed using a previously validated measure (score range 6–24; the higher the score, the higher the perceived self-efficacy) [22].

Statistical analyses

Descriptive statistics were generated for all numeric variables using mean, median, standard deviation (SD), and range, and for all categorical variables using frequencies and percentages. Both patient and caregiver, COST scores were approximately normally distributed.

Using the methodology reported by deSouza et al. [15], we assessed the internal consistency of the modified COST measure in caregivers by Cronbach α . Values > 0.90 were considered excellent. Convergent validity was assessed using the Pearson correlation coefficient (r) between the modified COST and the Brief-POMS [20], as well as the financial self-efficacy [22]. Divergent validity was assessed using correlations between the MCSDS [21] and the modified COST.

Patient and caregiver characteristics were compared with their COST score using chi-squared tests, Fisher's exact tests, Pearson's correlation coefficient, or analysis of variance (ANOVA) as appropriate. Multivariable linear regression analyses were performed using COST as a continuous outcome variable. Models included variables with statistical significance on the univariable analysis ($P < 0.05$) (supplementary material 1) and those

identified a priori (as noted in multivariable analysis Table 2). As one of the model assumptions, the normality of linear regression model residuals was checked and observed to be normally distributed. Statistical analyses were performed using SAS 9.4 (SAS Institute Inc., Cary, NC), and statistical significance was assessed at the 0.05 level.

Results

A total of 571 patients meeting eligibility criteria were approached; 17.0% (97/571) were excluded due to not having a caregiver. Of the remaining 474, a total of 100 patient-caregiver dyads completed the informed consent; all of them completed more than 80% of the survey (dyadic response rate of 21.1% [100/474]) (Fig. 1). Compared to patient non-respondents, respondents were more likely to have Medicare (45.9% vs. 36.9%) or Medicaid (7.1% vs. 1.7%) as primary insurance, and less likely to have private (excluding Affordable Care Act exchange) (40.8% vs. 49.9%), or Affordable Care Act exchange (5.1% vs. 7.4%) as primary insurance or be self-pay (0% vs. 3.6%) ($P = 0.008$). Furthermore, respondents were less likely to have participated in clinical trials (25.8% vs. 39.6%). Age, gender, race, and marital status did not differ significantly.

Table 1 summarizes patient and caregiver characteristics. Patients were a median of 63.0 years old (range = 21–88), 66% ($n = 66$) female, and 79% ($n = 79$) White. The median months from diagnosis was 22 months (IQR of 9–64). The most common cancer types included breast (34%; $n = 34$), gynecologic and genitourinary (35%; $n = 35$), skin (12%; $n = 12$), lung (6%; $n = 6$), gastrointestinal (6%; $n = 6$), and other types of cancer (7.0%; $n = 7$). A total of 51.1% ($n = 45$) of patients were stage 4, and 22.7% ($n = 20$) were receiving oral chemotherapy. 23.2% ($n = 22$) reported at least one ED or inpatient hospitalization in the past 3 months (Table 2). Mean patients' financial self-efficacy score was 14.6 (SD 5.7).

Caregivers were a median of 58.0 years old (range = 19–82), 53.6% female ($n = 52$), and 81.4% ($n = 79$) White. A total of 70% ($n = 70$) and 5% ($n = 5$) of caregivers were patients' spouses or partners, respectively. Mean caregivers' financial self-efficacy score was 15.0 (SD 5.6).

Financial toxicity in patients and caregivers

Median COST scores for patients and caregivers were 22 (range = 0–44) and 24 (range = 0–44), respectively. A total of 69.3% of patients and 57.4% of caregivers reported some degree of financial toxicity using the COST summary item “My/loved one illness has been a financial hardship to me and my family.” COST scores for patients and caregivers were correlated ($r, 0.55$; $P < 0.001$).

Reliability and validity of caregiver financial toxicity

The modified COST measure for caregivers demonstrated excellent internal consistency (Cronbach $\alpha = 0.91$). Internal consistency was comparable for men ($\alpha = 0.92$) and women ($\alpha = 0.91$). Worse financial toxicity correlated with higher psychological distress ($r = -0.59$; $P < 0.001$) and lower financial self-efficacy ($r = 0.79$; $P < 0.001$). Regarding divergent validity, the association between the modified COST measure and social desirability

(MCSDS) was -0.11 and not statistically significant ($P = 0.28$), confirming that the modified COST does not measure social desirability.

Factors associated with financial toxicity

Univariable analyses reported in supplementary material 1 informed the *multivariable models*. In the *multivariable model* for financial toxicity ($n = 83$), older patient age (B coefficient, 0.3 [95% CI, 0.1 – 0.4]; $P = 0.02$) and higher annual household income (B coefficient, 14.3 [95% CI, 9.3 – 19.4]; $P < 0.001$) were found to be significantly associated with lower financial toxicity (Table 3).

In the *multivariable model* for financial toxicity in caregivers ($n = 82$), lower patient financial toxicity (B coefficient, 0.4 [95% CI, 0.2 – 0.6]; $P < 0.001$) and stages 1–3 (compared to stage 4) (B coefficient, 4.6 [95% CI, 0.4 – 8.8]; $P = 0.03$) were significantly associated with lower financial toxicity (Table 3).

Financial toxicity and patient care non-adherence

Twenty patients (20.2%) reported care non-adherence due to treatment expenses, most commonly delaying the filling of prescription medication (14.3%). Some types of medication non-adherence and non-receipt of recommended imaging were reported by 15.5% ($n = 16$) and 4.1% ($n = 4$) of patients, respectively. Additionally, 12.2% ($n = 12$) reported skipping office visit(s).

Caregivers' financial toxicity was associated with patient care non-adherence (mean caregiver COST score 18.5 in patients with care non-adherence vs. 25.3 in patients who were adherent to care; $p = 0.01$).

Financial toxicity and lifestyle-altering behaviors

Overall, 60.8% ($n = 59$) of patients and 62.1% ($n = 59$) of caregivers reported decreases in family income due to the patient or caregiver underemployment or unemployment. In response to the financial burden from treatment expenses, 61.6% ($n = 61$) of patients and 57.6% ($n = 57$) of caregivers reported at least one lifestyle-altering behavior, with decrease in spending on leisure activities and withdrawal from saving accounts being the most common.

Patients' financial toxicity was associated with lifestyle-altering behaviors among caregivers (mean patient COST 17.4 in those whose caregivers adopted lifestyle-altering behaviors vs. 29.2 in those whose caregiver did not; $p < 0.001$). Similarly, caregivers' financial toxicity was associated with lifestyle-altering behaviors among caregivers (caregiver mean COST, 17.9 in those with lifestyle-altering behaviors vs. 32.3 in those without; $p < 0.001$), and patients (mean caregiver COST score 20.03 in patients with lifestyle-altering behaviors vs. 30.2 in those without; $p < 0.001$).

Financial toxicity and QOL

Patients' mean QOL score as measured by FACT-G was 72.3 ± 21.1 . The caregiver's mean QOL score as measured by CarGOQoL was 66.7 ± 14.4 . Caregivers' financial toxicity

correlated with patients' QOL ($r = 0.21$; $p = 0.04$), as well as caregivers' QOL score ($r = 0.63$; $p < 0.001$), suggesting increased caregiver financial toxicity is associated with decreased QOL in patients and caregivers. Patients' financial toxicity was not associated with caregivers' QOL.

Discussion

Surveying 100 dyads of adult cancer patients and their caregivers, our study validated the modified COST instrument as a measure of financial toxicity among caregivers of cancer patients. Our results demonstrated a moderate correlation between patients' and caregivers' financial toxicity and identified factors associated with caregiver financial toxicity.

Cancer caregiving creates financial toxicity for informal caregivers due to increased OOP expenses and lost income. In the current study, we found patients' financial toxicity and stage as factors associated with caregiver financial toxicity. Although patients' stage has not been identified as a predictor of patient financial toxicity in the current study and others [2, 23–26], its association with caregiver financial toxicity might be due to its impact on increasing caregiving time and caregiver burden. Our results are also consistent with prior studies identifying younger age and lower income as a risk factor for patient financial toxicity [2, 8, 23–26].

Given 69.3% of patients (compared to an average of 40–50% in literature) [2, 3] and 57.4% of caregivers (compared to 39% in a single study) [27] report financial toxicity in the current study, our study likely includes a more vulnerable patient population than general cancer patients. This is also confirmed by lower QOL in our patient population (mean of 72.3) compared to general cancer patients (mean of 80.9) [28], and inclusion of a higher proportion of underinsured compared to non-respondents.

The impact of patients' financial toxicity on their health outcomes including care non-adherence, lifestyle-altering behaviors, and QOL is well known [5, 6, 29–31]. Furthermore, a large body of literature focuses on the impact of caregiving on caregiver outcomes, including physical (immunological changes [32, 33] and mortality rate [34]) and emotional responses (depression [35] and difficulty sleeping [36]), but evidence regarding the impact of caregivers' financial toxicity on patient and caregiver outcomes remains modest. Our study shows that increased caregivers' financial toxicity correlates with increased lifestyle-altering behaviors, and decreased QOL among patients and caregivers as well as increased patient care non-adherence. This is consistent with a prior study showing a relationship between loss of savings and income in caregivers and caregivers' QOL [37]. Our findings suggest interventions aimed at improving patients' outcomes should be focused at the dyadic level of patients and caregivers, considering them as one unit [38].

Study limitations

A limitation of our study is that the study sample was drawn from a single tertiary referral healthcare center using a convenience sampling method. The dyadic response rate in our study was 21.1% and we did not include non-English speaking patients. Our analyses of data regarding non-participants have shown some degree of sample heterogeneity concerning

patients' insurance and participation in clinical trials. Particularly, patients with Medicaid and those not participating in clinical trials were more likely to participate in our study, suggesting that our results might be an overestimate of financial toxicity in the population. Our study included cancer patients regardless of type, stage, or time from diagnosis, thus introducing sample heterogeneity, but making our study more generalizable. Financial toxicity appears to increase during the first year of cancer treatment and then may decline depending on treatment response [2]. We accounted for these factors in our multivariable analysis where applicable. Finally, we did not collect information on secondary financial resources in patients or caregivers and did not assess caregiving characteristics such as the residence for caregivers and the amount of time spent per week with the patient.

Clinical implications

Our study suggests financial screening efforts should target both patients and their informal caregivers, to better identify patients at risk for poor outcomes; 72% of community oncology practices report some type of financial screening [3], but it is unclear how many of these practices also screen caregivers. Prior studies have suggested patient education, financial navigation, and price transparency as interventions that might improve financial toxicity [39–41]. Same strategies might improve caregiver financial toxicity. Future analyses of caregiver experiences would guide the type and content of educational, financial, supportive, and personnel services that might be most helpful in improving oncology caregiver financial toxicity and linked outcomes for patients and caregivers.

Conclusions

In summary, cancer exposes patients and their caregivers to risks of financial toxicity. The COST measure can also be used to assess caregiver financial toxicity. Patient and caregiver financial toxicity were correlated, and worse caregiver financial toxicity was associated with increased patient care non-adherence and increased lifestyle-altering behaviors, and lower QOL in both patients and caregivers.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Conflict of interest

Dr. Sadigh received salary support from AUR GERRAF. Dr. Carlos receives salary support from the *Journal of the American College of Radiology* and research support from the Neiman Health Policy Institute. Dr. Bilien has acted as a paid consultant for and/or as a member of the advisory boards of Exelixis, Bayer, BMS, Eisai,

Pfizer, AstraZeneca, Janssen, Genomic Health, Nektar, and Sanofi and has received grants to his institution from Xencor, Bayer, Bristol-Myers Squibb, Genentech/Roche, Seattle Genetics, Incyte, Nektar, AstraZeneca, Tricon Pharmaceuticals, Peleton Therapeutics, and Pfizer for work performed as outside of the current study. Dr. Meisel has acted as a member of the advisory boards of Pfizer and Puma and has received grants to her institution from Pfizer, Seattle Genetics, and Eli Lilly. Dr. Cella is the president of FACIT.ORG. Drs. Switchenko, Elchoufi, Lawson, Weaver, and El-Rayes do not report any conflict of interests.

Data availability

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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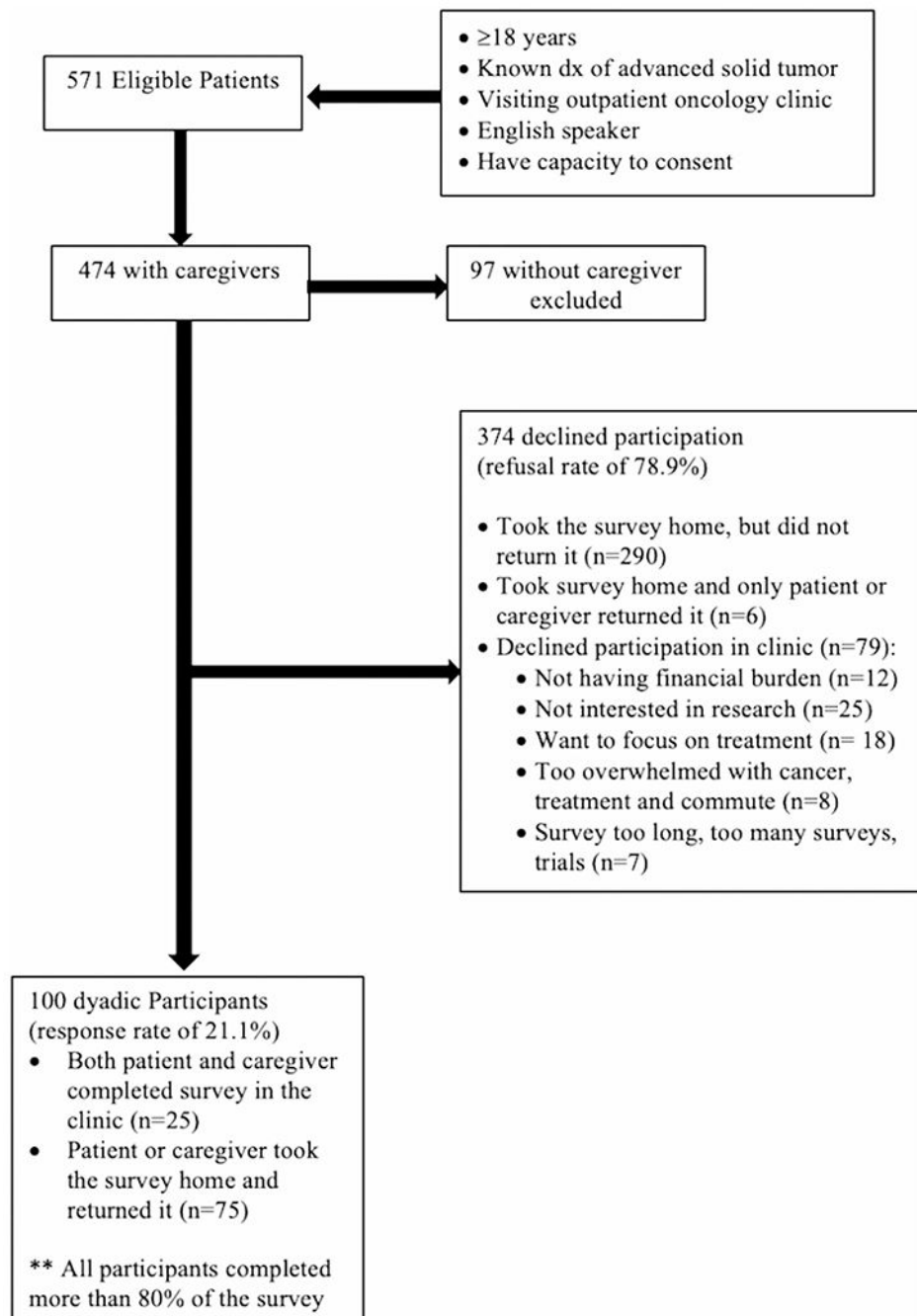


Fig. 1.
Study flowchart

Table 1

Patients' and caregivers' characteristics

	Patients (<i>n</i> = 100)	Caregivers (<i>n</i> = 100)
Age, years (mean ± SD)	60.6 ± 12.9	56.6 ± 14.5
Gender, <i>n</i> (%)	Missing = 0	Missing = 3
Male	34 (34.0%)	45 (46.4%)
Female	66 (66.0%)	52 (53.6%)
Race, <i>n</i> (%)	Missing = 0	Missing = 3
White	79 (79.0%)	79 (81.4%)
AA	15 (15.0%)	10 (10.3%)
Other	6 (6.0%)	8 (8.2%)
Ethnicity, <i>n</i> (%)	Missing = 6	Missing = 4
Hispanic, Latino, or Spanish	2 (2.1%)	2 (2.1%)
Not Hispanic, Latino, or Spanish	92 (97.9%)	94 (97.9%)
Marital status, <i>n</i> (%)	Missing = 0	Missing = 4
Married	75 (75.9%)	81 (84.4%)
Other	35 (35.0%)	15 (15.6%)
Education, <i>n</i> (%)	Missing = 2	Missing = 3
High school graduate or less	18 (18.4%)	12 (12.4%)
> High school graduate	80 (81.6%)	85 (87.6%)
Employment status, <i>n</i> (%)	Missing = 2	Missing = 3
Full-time or part-time	29 (29.6%)	51 (52.6%)
Other	69 (70.4%)	46 (47.4%)
Annual household income, <i>n</i> (%)	Missing = 3	Missing = 7
< \$60 k	38 (39.2%)	34 (36.6%)
\$60 k	59 (60.8%)	59 (63.4%)
Financial self-efficacy (mean ± SD)	14.6 ± 5.7	15.0 ± 5.6
Insurance type, <i>n</i> (%)	Missing = 4	
Medicare	45 (45.9%)	
Medicaid	7 (7.1%)	
Private	40 (40.8%)	

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	Patients (n = 100)	Caregivers (n = 100)
Other (Affordable Care Act exchange or military)	6 (6.1%)	

Table 2

Patients' disease burden

Patient disease burden	
Months from diagnosis, median (IQR)	22 (9–64)
Type of cancer, <i>n</i> (%)	Missing = 0
Breast	34 (34%)
Lung	6 (6%)
Gastrointestinal	6 (6%)
Gynecologic and genitourinary	35 (35%)
Skin	12 (12%)
Other ¹	7 (7%)
Stage, <i>n</i> (%)	Missing = 12
1–3	43 (48.9%)
4	45 (51.1%)
Participation in clinical trial, <i>n</i> (%)	Missing = 3
Yes	25 (25.8%)
No	72 (74.2%)
Receipt of oral chemotherapy, <i>n</i> (%)	Missing = 12
Yes	20 (22.7%)
No	68 (77.3%)
At least one ED or inpatient hospitalization in the last 3 months, <i>n</i> (%)	Missing = 5
Yes	22 (23.2%)
No	73 (76.8%)
Number of clinic visits in the last 3 months, Median (IQR)	3 (1–6)

¹Other cancers include brain (*n* = 3), skin (*n* = 1), thyroid (*n* = 2), and bone (*n* = 1)

Table 3

Multivariable analysis of factors significantly associated with COST financial toxicity scores in adult oncology patients ($N=80$) and their informal caregivers ($N=81$)

Factor	B coefficient (95% CI)	P value
Patient COST score ¹		
Patient age *	0.3 (0.1–0.4)	0.002
Patient annual household income		<0.001
<\$60 k	Reference	
\$60 k	14.3 (9.3–19.4)	
Caregiver COST score ²		
Patient COST score **	0.4 (0.2–0.6)	< 0.001
Patient stage		0.03
Stage 4	Reference	
Stages 1–3	4.6 (0.4–8.8)	

COST, Comprehensive Score for financial Toxicity (lower scored indicate greater financial toxicity)

¹Model included patient **age**, **race**, marital and employment status, **income**, cancer stage, prior clinical trial participation, and at least one ED or inpatient hospitalization in the last 3 months. In total, 83 patients included in this model

²Model included patient **education**, **income**, cancer stage, and **COST scores**, and caregiver **race**, **education**, **income**, and **relationship (spousal vs. non-spousal)**. In total, 82 patients included in this model

For both models, variables in bold are those significant in univariable analysis, and others are those identified as a priori. Only the variables that remained significant are presented in the table

* Age is included as a numerical variable; with every 1-year increase in age, the COST score will increase by 0.2

** Patient COST score is included as a numerical variable; with every unit increase in score, the caregiver COST score will increase by 0.4