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An exploration of financial toxicity among low-income patients with cancer in Central Texas: A mixed methods analysis

Original Article

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Abstract

Objective. Financial toxicity is of increasing concern in the United States. The Comprehensive Score for Financial Toxicity (COST) is a validated measure; however, it has not been widely utilized among low-income patients and may not fully capture financial toxicity in this population. Furthermore, the relationships between financial toxicity, quality of life (QOL), and patient well-being are poorly understood. We describe the experience of financial toxicity among low-income adults receiving cancer care. We hypothesized that higher financial toxicity would be associated with less income and lower quality of life. Qualitative interviews focused on the financial impact of cancer treatment.

Method. This study was conducted at a cancer clinic in Central Texas. Quantitative and qualitative data were collected in Fall and Spring 2018, respectively. The quantitative sample ($N = 115$) was dichotomized by annual income (<\$15,000 vs. >\$15,000). Outcomes included financial toxicity (COST), quality of life (FACT-G), and patient well-being (PROMIS measures: Anxiety, Depression, Fatigue, Pain Interference, and Physical Function). Associations between quality of life, patient well-being, and financial toxicity were evaluated using linear regression. Sequential qualitative interviews were conducted with a subsample of 12 participants.

Results. Patients with <\$15k had significantly lower levels of QOL and patient well-being such as depression and anxiety compared to patients with >\$15k across multiple measures. A multivariate linear regression found QOL ($B = 0.17$, 95% CI = 0.05, 0.29, $p = 0.008$) and insurance status ($B = -3.79$, 95% CI = −7.42, −0.16, $p = 0.04$), but not income, were significantly associated with financial toxicity. Three qualitative themes regarding patient's access to cancer care were identified: *obtaining healthcare coverage, maintaining financial stability*, and *receiving social support.*

Significance of results. Low-income patients with cancer face unique access barriers and are at risk for forgoing treatment or increased symptom burdens. Comprehensive assessment and financial navigation may improve access to care, symptom management, and reduce strain on social support systems.

Introduction

Financial toxicity has increasingly been used to describe financial hardship experienced by patients with cancer due to the high cost of cancer treatment such as expensive medications, procedures, and scans (Zafar, 2016; Carrera et al., 2018). The high financial burden resulting from cancer treatment can result in anxiety, poor quality of life (QOL), emotional distress, mortality, and decreased treatment adherence (Ramsey et al., 2016; Chino et al., 2017; Carrera et al., 2018). Insurance status and household income can significantly impact individuals' access to cancer care and QOL outcomes, placing them at increased risk of financial toxicity (Arozullah et al., 2004; Gordon et al., 2017). For example, population-based data suggests 18% of cancer survivors experienced considerable financial hardship, while 37% of uninsured patients reported financial difficulties related to cancer care (Davidoff et al., 2015).

While financial distress, the subjective experience of high-cost medical treatments on cancer patients, is well-documented, the construct of financial toxicity is not fully understood (Zafar et al., 2015; Choi et al., 2016; Nipp et al., 2016; Altice et al., 2017). According to Carrera et al. (2018), financial toxicity is defined as "the objective financial burden and subjective financial distress of patients with cancer, as a result of treatments using innovative drugs and concomitant health services" (p. 153). In other words, the objective financial burden of cancer expenditures has a subjective impact on patients due to a reduction in wealth as well as the physiological experience of cancer treatment itself. However, the financial toxicity framework has not been adequately explored among low-income cancer populations, and seems to assume that patients have access to income and wealth such as savings or assets. One study conducted with medically underserved, African American women identified access to insurance as a major factor in financial toxicity (Darby et al., 2009). For example, uninsured women were unable to receive diagnostic work-ups for lumps discovered under their arm or breast. Additionally, after receiving a cancer diagnosis, women's inability to afford a $15 co-pay or make payments toward an outstanding debt resulted in treatment delays. These findings highlight the unique experiences of low-income patients surrounding the objective financial burden of cancer expenditures, and this struggle can exist even prior to an official cancer diagnosis.

As researchers develop validated measures for financial toxicity, more consideration should be given to the unique needs of low-income populations that experience financial hardship well before their cancer diagnosis. Current financial toxicity measures such as the Comprehensive Score for Financial Toxicity (COST) have not been validated with safety-net populations such as the uninsured or low-income populations. Safety-net health systems are in place for socioeconomically disadvantaged or uninsured patient populations who would not otherwise be able to access health care (Sabik and Bradley, 2013). However, the validation study of the COST did not include an uninsured population, and only 12% of the sample had incomes <200% of federal poverty level (de Souza et al., 2017). Furthermore, the COST includes questions related to savings, retirement, and assets, which may be more relevant for middle- or upper-income adults. Therefore, it is important to understand how financial toxicity may impact cancer treatment for low-income patients.

Additionally, it is important to consider how quality of life may impact financial toxicity, as the current model acknowledges that anxiety and physical discomfort may impact subjective financial distress (Carrera et al., 2018). The traditional biomedical model of disease does not consider all of the interrelated and complex variables that influence patient outcomes after a cancer diagnosis. To improve the quality of cancer care, healthcare professionals must consider a more integrative framework which includes psychosocial factors such as quality of life and patient well-being. A systematic review of existing literature provided the foundation for this analysis by incorporating theoretical, clinical, and empirical work on coping with cancer, particularly research grounded in biopsychosocial, stress, and adaptation models (McCubbin et al., 1996; Bolton and Gillett, 2019). The conceptual model of adaptation to illness, treatment, and quality of life in cancer describes how particular psychological, physical, practical, social, and environmental variables are necessary for a comprehensive assessment of patient and family needs (Molassiotis, 1997; Parker et al., 2003). Therefore, it is important to consider the relationship between patient well-being, quality of life, and financial toxicity, particularly for low-income patients with cancer, as these relationships have been previously unexplored within the literature.

Based on the gaps in the literature regarding an exploration of financial toxicity among low-income patients with cancer, the purpose of this mixed methods study was two-fold: (1) to understand the relationship between financial toxicity, quality of life, and patient well-being among low-income adults receiving cancer care; and (2) to describe the experience and meaning of financial toxicity among low-income adults receiving cancer care. We hypothesized that financial toxicity would be higher (COST scores would be lower) among people with less income, and conducted a secondary data analysis to test this assumption. We also hypothesized that as financial toxicity increased, quality of life, and patient well-being would decrease. Additionally, we hypothesized that the COST may not fully capture financial toxicity among low-income patients with cancer due to its focus on retirement, savings and assets, and conducted qualitative interviews with a subsample of patients.

Methods

This is a secondary data analysis of a cross-sectional study (Phillips et al., 2021). The aim of the original study was to identify correlates of QOL among socioeconomically disadvantaged patients with cancer receiving care in a "safety-net" health system. Patients ($n = 115$) receiving drug therapy for cancer completed a series of Patient-Reported Outcome measures (PROs) including: Functional Assessment of Cancer Therapy (FACT-G), PROMIS (Anxiety, Depression, Fatigue, Pain Interference, and Physical Function), and COST. Inclusion criteria included 18 years of age or older; cancer diagnosis and receiving drug therapy. Exclusion criteria included not speaking English or Spanish and cognitive deficits or inability to complete study measures based on the oncologist assessment and report. Due to issues related to informed consent, people with cognitive deficits are often excluded from studies that are not directly focused on cognitive impairment (Prusaczyk et al., 2017).

Convenience, purposive sampling was used as the primary recruitment methodology, where the clinic schedule was reviewed and patients that met inclusion criteria were informed about the study. Patient surveys were completed on an iPad in the clinic with the assistance of study personnel. Some additional data was collected through medical record review and extraction with appropriate IRB approval. Patients were compensated with a $20 gift card for their participation.

While conducting the original study in Fall 2018, the researchers hypothesized that the COST assessment may not be relevant for patients with low income due to questions about assets and savings. The vast majority of patients in the original study struggled to afford low-cost co-pays or basic needs such as housing and transportation. Therefore, we conducted a sequential mixed methods study where the qualitative design was based on quantitative findings. The authors drew on the initial quantitative findings to develop interview questions to elaborate on trends discovered in participants' survey responses, and qualitative interviews were conducted in Spring 2018 (Phillips et al., 2021). Additionally, we conducted a secondary quantitative analysis, to further explore financial toxicity among low-income patients with cancer. The institutional review board of the university and hospital approved the study protocol for both the original study and the follow-up analyses (2018-08-0081).

Quantitative

Secondary data analysis was conducted to better understand the relationship between income, psychosocial outcomes, and financial toxicity. To understand how financial toxicity impacted patients with low income, we dichotomized the sample based on an individual's income. Due to missing information related to income, 19 patients were removed from the sample ($n = 96$). Household income was not collected, so individual income was the best measure available to assess how socioeconomic status may impact financial toxicity. Therefore, we split the sample by those who earn less than $15,000 annually (<$15k) and those who earn more than $15,000 (>$15k). This cutoff is approximately the annual income of someone making minimum wage at a full-time job in Texas, which is $7.25 an hour, $290 a week, or $15,000 a year before taxes (U.S. Department of Labor, 2021). Insurance status was originally categorized as none, public, and private; however, the public and private insurance categories were combined due to the cell sizes being insufficient when dichotomized by income. Previous literature has well documented that people with insurance experience financial toxicity, and our analysis was more focused on those without insurance and annual income less than $15k.

The sample size for the original study was determined to be adequate based upon a power analysis incorporating the effect size for change in FACT-G Total based on Brucker et al. (2005). With an alpha = 0.05 and power = 0.80, the projected sample size needed with this effect size (GPower 3.1) is approximately $N = 80$ for the within-group comparison (Faul et al., 2007). According to a power analysis for the secondary data analysis, total sample for the multivariate regression analysis was recommended at 109 with an alpha = 0.05, effect size $f^2 = 0.15$ (medium effect size), and power = 0.80. For an independent *t*-test with effect size $d = 0.5$ (medium effect size), alpha = 0.05, and power = 0.80, suggested sample size was 64 per group.

Quantitative measures

The primary outcomes in this analysis were financial toxicity, QOL, and patient well-being. Financial toxicity was measured using the COST, an 11-question survey with a 5-point Likert scale that ranges from "not at all" (0) to "very much" (4) (de Souza et al., 2017). The original psychometric analyses found the COST to have high levels of internal consistency with a Cronbach alpha of 0.92. Lower scores represent higher levels of financial toxicity (de Souza et al., 2017). An additional analysis found that 17.5 was a clinical cut off for COST scores with acceptable sensitivity and specificity (Ng et al., 2021).

QOL was measured using the raw (non-standardized) Functional Assessment of Cancer Therapy-General (FACT-G), a 25-item scale that includes four domains: Physical, Social/Family, Emotional, and Functional Well-Being (Cella et al., 1993). Each subscale ranges from 0 to 28, where higher scores indicate better QOL. Previous studies have indicated internal consistency for each of the subscales (range 0.69–0.82) and total score (alpha = 0.89) in addition to high reliability (test–retest correlation coefficients were 0.82–0.92) (Cella et al., 1993). One study suggests that declines in FACT-G scores are associated with increasing disease status, and a cutoff score of 62 or less could indicate clinically low quality of life (Pearman et al., 2014).

Patient well-being was measured using Patient-Reported Outcomes Measurement Information System (PROMIS) a NIH Roadmap Initiative, created to advance the assessment of patient-reported outcomes and often used in cancer studies (Cella et al., 2010; Cook et al., 2016). PROMIS data was collected through a computerized adaptive testing (CAT), which adapts to the participant, and questions are selected based on the respondent's previous answers. Therefore, each participant answered a different set of questions and the final report provided *t*-scores and standard errors. PROMIS Cancer measures captured the following domains: anxiety, depression, pain interference, fatigue, and physical function. Each domain utilized the probe, "In the past 7 days…" and a 5-point Likert scale, that ranges from "never" to "always"; "not at all" to "very much"; or "without any difficulty" to "unable to do." Higher scores indicate lower levels of patient well-being except for physical function, where higher scores indicate higher levels of patient well-being. Previous studies have indicated the PROMIS measures to be reliable (reliability coefficients were all greater that 0.95 except fatigue, which was 0.76) and valid (construct validity was measured by comparing results to similar measures, with a range of 0.56–0.95 for correlation) (Cella et al., 2010; Jensen et al., 2015; Cessna et al., 2016).

Quantitative analysis

Descriptive statistics were calculated to evaluate demographic information for the full sample, as well as the separate income groups using independent samples *t*-tests for continuous variables and Pearson X^2 for categorical variables. Scatter plots were generated for each outcome to visually assess distribution and no potential outliers were identified for further investigation (Aguinis et al., 2013). Cronbach's alphas were used to test to the internal consistency of the COST and FACT-G measures for the full sample and with each income group, since this is the first study that has assessed the COST with a low-income population to our knowledge. It is generally suggested that Cronbach's alpha ranges from 0.71 to 0.95 to indicate high internal consistency (Tavakol and Dennick, 2011). Mean difference scores were calculated and *t*-tests were used to compare the primary outcomes of QOL, patient well-being, and financial toxicity between income groups. Multivariate linear regression was then used to explore the relationship between financial toxicity (COST) demographic variables (age, race, gender), economic variables (income, insurance status), FACT-G, and PROMIS measures. A standard stepwise, backward selection model building process was utilized and regression diagnostics were performed (Keith, 2019). Variables that did not contribute to the model were eliminated one at a time to identify the most parsimonious model. Analyses were completed in R (R Core Team, 2013) and Stata (Stata, 2017). The original sample included 115 patients with cancer; however, 19 patients did not report income, so only 96 were included in the dichotomized analysis. Chi-square tests were used to assess whether the two income groups were significantly different.

Qualitative

Qualitative interviews were conducted approximately 6–8 months after the original study was completed. Convenience, purposive sampling was used as the primary recruitment methodology where English-speaking patients that had previously participated in the PRO study were identified. Trained graduate social work students approached patients in the clinic and invited them to complete follow-up interviews. Patients provided written consent and received a $10 gift card.

In person, semi-structured interviews were conducted to explore the lived experience of financial toxicity among 12 adults receiving cancer treatment, and to better understand the financial impact of cancer treatment on low-income individuals. The interview schedule was created by the PI and other authors based on the financial toxicity literature. Interview questions focused on the financial impact of cancer treatment on patients receiving infusion therapy. Some example questions include, "Has cancer affected how you spend your money? If yes, can you give me some examples of how it changed?" Refer to Supplementary Appendix 1 for the full interview schedule. Graduate students were trained in content analysis, and the PI provided guidance and supervision throughout the process. All interviews were digitally recorded, professionally transcribed, and reviewed for accuracy by the research team. Interviews ranged from 15 to 30 min.

Qualitative analysis

A multi-phased process was used to analyze the transcribed interviews, based on content analysis methods (Krippendorff, 1980, 2009). In phase one, all responses to questions were collated, and separated by unit of analysis. Each unit of analysis was considered a complete idea. Therefore, some sentences were separated into multiple parts and individually analyzed. None of the data was discarded during phase one. Once all units of analysis were identified, phase two involved open coding of all units of analysis. This involved organizing units into themes based on shared elements and responses. Responses were then grouped into a working set of themes for an initial codebook. The team utilized "in-vivo coding," which uses a participant's own words to define themes. In phase three, open-codes were merged into themes based on cohesion and code saturation across participants. Sub-themes further elaborated participants' experiences. Throughout the process, themes were developed, refined, and reorganized to ensure best fit of the data. Researchers who conducted interviews performed analysis independently; then, the two coders came together to meet consensus. Notes were taken during each meeting and reviewed with a third member of the research team before moving on to the next step. We used inductive thematic saturation guidelines, which suggests that saturation has been met when no new themes are identified in subsequent interviews, and each theme has at least three quotes from different individuals (Saunders et al., 2018).

Results

Quantitative

Sample demographics ($n = 115$) appear in Table 1. The majority of participants were non-Hispanic, white middle-aged females. Approximately half of participants had annual incomes less than \$15,000 (45%). The uninsured accounted for 45% of the population and 62% were diagnosed with Stage IV cancer.

Bivariate analyses of outcomes dichotomized by income are shown in Table 2. As previously mentioned, 19 patients did not report income information. Therefore, the bivariate analyses had a slightly smaller sample ($n = 96$). There were no significant demographic differences between income groups. Cronbach's alpha scores were calculated for the COST with the full sample (0.84), and each income group (<\$15k = 0.87 and >\$15k = 0.81). Cronbach's alpha scores were also calculated for the FACT-G total score for the full sample (0.92) and each income group (<\$15k = 0.90 and >\$15k = 0.87). The <\$15k group had a lower, average COST score (M = 16.1, SD = 10.1) compared to the >\$15k group (M = 17.4, SD = 8.8), although this difference was not statistically significant ($t(94) = -0.68$, $p = 0.49$). Both of these average COST scores would be considered clinically significant according to a recent analysis (Ng et al., 2021). Patients with <\$15k had significantly lower quality of life as measured by FACT-G (mean = 71.8, SD = 19.2) than patients with >\$15k ($t(94) = -2.66$, $p = 0.00$). Neither of these average FACT-G scores reached the clinical cutoff that was identified in a previous analysis (Pearman et al., 2014). They also had lower levels of patient well-being, including lower levels of physical functioning ($t(94) = -3.57$, $p = 0.00$), higher levels of anxiety ($t(94) = 2.69$, $p = 0.00$), depression ($t(94) = 2.08$, $p = 0.04$), fatigue ($t(94) = 2.35$, $p = 0.02$), and pain interference ($t(94) = 4.39$, $p = 0.00$) than patients with > \$15k.

The associations between quality of life, patient well-being, and financial toxicity (COST) were evaluated using multivariate linear regression (Table 3). Holding all other variables constant, an increase in FACT-G score (QOL) was significantly associated with a higher COST score, or lower levels of financial toxicity, where each 10-point increase in FACT-G was associated with a 1.7-point increase in COST ($\beta = 0.17$, 95% CI = 0.05, 0.029, $p = 0.008$). Uninsured study participants also had higher financial toxicity with COST scores 3.79 points lower than publicly or privately insured participants ($\beta = -3.79$, 95% CI = −7.42, −0.21, $p = 0.04$). Income was not significantly associated with financial toxicity.

Qualitative

Sample demographics for the qualitative interviews ($n = 12$) are reported in Table 4. Half of respondents were women and one third of respondents were married or partnered. The majority of respondents were white (83%) with income less than \$15,000 (67%). 42% of the sample was uninsured, 33% had public insurance, and 25% had private insurance. The majority of respondents had stage IV cancer (58%), and cancer diagnoses were grouped into gynecological (includes breast and endometrial cancers), gastrointestinal (includes colon and rectal cancers), hematological (includes multiple melanoma and Hodgkins Lymphoma), and other (includes prostate and head and neck).

We identified three themes related to financial toxicity and accessing cancer care: *obtaining healthcare coverage, maintaining financial stability,* and *receiving social support*. For each theme, participants explained either protective experiences or experiences that further complicated affording cancer care.

Obtaining Healthcare Coverage: "I'm Glad I Got the Coverage Otherwise I'd Be Up the Creek Without a Paddle"

Obtaining healthcare coverage emerged as essential in accessing cancer care. Participants unable to maintain employment due to treatment schedules and/or side effects, lost access to health insurance, "It's been pretty rough, I've lost a pretty good job. I was trying to get on permanent with the company and get their insurance" (P096, 53 yo, gynecological). Those who were previously uninsured or lost health insurance, sought access to the county indigent care program, Medical Access Program (MAP) or Medicaid was necessary, "[Without MAP] I wouldn't have been able to take any treatments or anything…we couldn't afford it" (P068, 18 yo, hematological). Obtaining health insurance coverage was challenging, especially for low-income individuals, "I'm one of the fortunate ones that actually got the Medicaid" (P096, 53 yo, gynecological). Additional benefits of MAP and Medicaid coverage were no premiums and low out-of-pocket costs, "With the insurance I have now, I don't pay anything just about—I mean I walk in, they give me everything free…well it's not free but it's paid for through the insurance" (P024, 55 yo, GI). As one respondent described, "my Medicaid takes care of

Table 1. Demographics for full sample and income groups

Variables	Full sample ($n = 115$)	Income <$15,000	Income ≥$15,000	Income Missing	p[a]
Age (years) mean (SD)	54.6 (11.6)	56.1 (9.4)	54.3 (11.6)	51.2 (16.2)	0.40
Gender *n* (%)					
Male	49 (43)	23 (47)	19 (43)	7 (37)	
Female	66 (57)	29 (44)	25 (57)	12 (63)	0.85
Race/Ethnicity *n* (%)					
White	71 (62)	32 (62)	30 (68)	9 (47)	
Black	19 (16)	9 (17)	6 (14)	4 (21)	
Asian	3 (3)	1 (2)	0	2 (11)	
Others[b]	22 (19)	10 (19)	8 (18)	4 (21)	0.29
Hispanic *n* (%)					
No	68 (59)	35 (67)	23 (52)	10 (53)	
Yes	47 (41)	17 (33)	21 (48)	9 (47)	0.27
Household Income *n* (%)					
$0 to $14,999	52 (45)	52 (100)	—	—	
$15,000 to $24,999	19 (16)	—	19 (43)	—	
$25,000 to $49,000	8 (7)	—	8 (18)	—	
$50,000 to $74,999	2 (2)	—	2 (5)	—	
$75,000 to $100,000	—	—	—	—	
>$100,000	15 (13)	—	15 (34)	—	
Declined to answer	19 (17)	—	—	19 (100)	—
Cancer Diagnosis *n* (%)					
Gastrointestinal	27 (23)	13 (25)	13 (30)	1 (5)	
Hematological	17 (15)	5 (10)	6 (14)	6 (32)	
Lung	23 (20)	10 (19)	9 (20)	4 (21)	
Breast	19 (17)	8 (15)	7 (16)	4 (21)	
Others[c]	29 (25)	16 (31)	9 (20)	4 (21)	0.30
Cancer Stage *n* (%)					
I	5 (4)	2 (4)	3 (7)	0	
II	12 (10)	3 (6)	5 (11)	4 (21)	
III	15 (13)	6 (11)	7 (16)	2 (10)	
IV	71 (62)	35 (68)	26 (59)	10 (53)	
Missing	12 (10)	6 (11)	3 (7)	3 (16)	0.56
Insurance Status *n* (%)					
None (MAP, self-pay, or charity)	52 (45)	24 (46)	18 (41)	10 (53)	
Public/Private	63 (55)	28 (54)	26 (59)	9 (47)	0.68

SD, Standard Deviation; MAP, Medical Access Program (a county-based indigent care program).

[a] This *p*-value represents the difference between the <$15k and >$15k income groups.

[b] Due to small sample size, the following racial categories are included in the "other" category: Asian; Native Hawaiian or Pacific Islander; American Indian or Alaska Native; Others.

[c] Other cancer diagnoses included Head & Neck, Pancreatic, Prostate, Melanoma, and Rhabdomyosarcoma.

the finances for me" (P030, 43 yo, GI). However, another participant noted, automatic Medicaid coverage is limited to certain cancer diagnoses, "If I had gotten any other kind of cancer, Medicaid wouldn't have kicked in and picked it up. So, I think it's kind of unfair, why are the rules only stipulated to breast and cervical cancer?" (P096, 53 yo, gynecological). This acknowledges how many low-income patients with cancer are left uninsured by the current Medicaid structure in Texas.

Having previously unpaid bills and out-of-pocket costs were risk factors to affording treatment. Financial challenges ranged from exorbitant diagnostic work-ups, to routine lab work, co-pays, and prescriptions. Many participants described unpaid

Table 2. Financial toxicity, quality of life, and well-being for income and income subgroups[a]

Variables	Income <$14,999 ($n = 52$) Mean (SD)	Income ≥$15,000 ($n = 44$) Mean (SD)	t statistic
COST[c]	16.1 (10.1)	17.4 (8.8)	−0.68
FACT-G[d]	71.8 (19.2)	82.1 (18.8)**	−2.66
PROMIS Measures[e]			
Anxiety	52.5 (9.7)	47.1 (9.8)**	2.69
Depression	48.0 (9.5)	44.2 (8.3)*	2.08
Fatigue	52.4 (11.1)	47.7 (7.8)*	2.35
Pain Interference	57.8 (9.8)	49.4 (8.8)***	4.39
Physical Function	41.0 (9.3)	47.7 (8.7)***	−3.57

COST, Comprehensive score for financial toxicity; FACT-G, Functional assessment of cancer therapy; PROMIS, Patient-reported outcomes measurement information system.

[a] Independent samples *t*-test.

[b] 19 participants did not provide income response (Phillips et al., 2021).

[c] COST: Higher scores represent lower levels of financial toxicity.

[d] FACT-G: Higher scores indicate better quality of life.

[e] PROMIS: Mean *t*-scores and standard errors are reported. Higher scores indicate lower levels of patient well-being, except for physical function.

*$p < 0.05$.

**$p < 0.01$.

***$p < 0.001$.

Table 3. Multivariate regression model of variables associated with COST[a]

Variables	β	95% CI	p
FACT-G (Total)	0.17	(0.05, 0.29)	0.008
Uninsured			
Reference: Insured (Public/Private)	−3.79	(−7.42, −0.16)	0.04
Income ≥$15,000			
Reference: <$15,000	−2.13	(−0.6, 1.7)	0.27
PROMIS Measures			
Anxiety	−0.08	(−0.37, 0.21)	0.59
Depression	0.06	(−0.23, 0.35)	0.69
Fatigue	−0.2	(−0.46, 0.07)	0.15
Pain Interference	−0.06	(−0.33, 0.21)	0.66
Physical Function	−0.02	(−0.26, 0.24)	0.9

COST, Comprehensive score for financial toxicity; FACT-G, Functional assessment of cancer therapy; PROMIS, Patient-reported outcomes measurement system.

[a] Linear regression controlled for age, race, and gender.

Table 4. Demographics for qualitative sample ($n = 12$)

Variables	Mean (years)
Age	51.8
Gender	n (%)
Male	6 (50)
Female	6 (50)
Race	n (%)
White	12 (83)
Black	2 (17)
Hispanic	n (%)
No	10 (83)
Yes	2 (17)
Household Income	n (%)
$0 to $14,999	8 (67)
$15,000 to $24,999	1 (8)
Declined to answer	3 (25)
Cancer Diagnosis	n (%)
Gastrointestinal (GI)	3 (25)
Hematological	3 (25)
Gynecological	4 (33)
Others	2 (17)
Cancer Stage	n (%)
I	1 (8)
II	2 (17)
III	1 (8)
IV	7 (58)
Missing	1 (8)
Insurance Status	n (%)
None (MAP, self-pay, or charity)	5 (42)
Public	4 (33)
Private	3 (25)

medical bills from their diagnostic work-up, “Before I got on the Medicaid…I didn't have insurance. So, to get my mammogram, and my biopsy and all that, they want money for that” (P100, 57 yo, gynecological). Furthermore, participants were not always informed of what their insurance would cover, “I thought well my insurance should be paying this” (P024, 55 yo, GI). Patients frequently navigated medical debt and unpaid medical bills:

> I was under the understanding that I wouldn't get any bills because they knew that I do not have money like to take care of this. But, I've just ignored them [medical bills] because there is nothing I can do about them. (P097, 54 yo, hematological)

Participants also reported high prescription costs and strategies for acquiring their medications, “[Pharmacists] are like, ‘Oh, it will be $84,’ but fortunately, they have this coupon so they brought it down to $26 which isn't free but its manageable” (P100, 57 yo, gynecological). Many participants could not afford their co-pays, “The lab work wasn't covered for MAP and everything, so they've gone to collections” (P024, 55 yo, GI). Not only do these financial burdens cause additional stress or delay necessary treatment, they can also impact participant's long-term financial stability such as their credit score. Lastly, participants reported delays due to high out-of-pocket deductibles:

> Some of the deductibles is like it's high, it's $3,000. And when you're trying to do a procedure, and they call you two days before…then they want $500 right then and there, and it's just like how do you pull it out of thin air in the middle of the week? (P098, 43 yo, gynecological)

Financial Stability: “It Just Wiped Me Out”

Maintaining financial stability was the second theme identified by participants in regard to affording cancer care. Three factors impacted patients' ability to maintain financial stability: access to income through employment or disability, non-medical costs/debt, and connection to financial resources.

Multiple participants discussed difficulty maintaining financial stability once they lost their main source of income, "I had to quit – I had my own business and I had to stop…it just wiped me out. I used all my savings and then got on MAP" (P025, 58 yo, prostate). Others relied on social security disability as a source of income once they could no longer work. However, participants that received disability through Medicaid were even more limited financially, "You have to stay below a certain income to keep your Medicaid…And then you got to get well, you got to go through the treatment but if you go over a certain income, then you can lose that [Medicaid]" (P096, 53 yo, gynecological).

While there were some participants who worked throughout treatment, taking time off for treatment created financial constraints, "Sometimes I have to take the day off to get the treatments so I lost time and money" (P068, 18 yo, hematological). Other participants talked about how difficult it was to work and remain eligible for Medicaid, an income-based program:

> Well I didn't qualify for [Medicaid], I was just a little bit over making too much. So I went to my boss and said, "Could you pay me a little bit less money in exchange for an extra day a month off? (P100, 57 yo, gynecological).

A few participants even shared their limited income to support family members, "Sometimes I have to take the day off to get the treatments so I lost time and money. And I sometimes help my dad or someone who needs the money more than me to pay the bills or something" (P068, 28 yo, hematological).

For participants with little or no savings, financial assistance from the hospital could be a helpful resource, although not a panacea, "Fortunately, the hospitals have worked with me understanding the situation, although there is still pending amounts" (P025, 58 yo, prostate). However, there were limits to financial assistance, and applications could be a time-consuming process, "So I dealt with that yesterday and it took probably about three hours to get it done, because I had to refill out the application and resend them paperwork and then make copies of paperwork that they requested" (P096, 53 yo, gynecological). Another shared, "[Financial assistance] kind of helps a lot but I'm always stressed about money, because I don't want to be the next person on the street" (P098, 43 yo, gynecological).

Many participants reported financial burdens outside of medical care for "all your regular normal bills that aren't related to the [breast] cancer" (P096, 53 yo, gynecological). Participants were forced to sell personal items to afford rent, "I sold personal items to cover rent and stuff. I mean mortgage and everything and luckily I made it through" (P025, 58 yo, prostate). Many stated they had to cut back other expenditures to make ends meet, "You got to tighten up, tighten the belt up. Not as much out to eat, no vacations, no spending, cutting back" (P095, 59 yo, head and neck). Another shared how their daily activities had changed due to their cancer treatment, "I'm only working part-time now. So, all my money counts…do I spend $20 on lunch or medications? I'm not doing things I normally do. I just stay home and wait until it's time for work or treatments" (P097, 54 yo, hematological).

Social Support: "I Can't Do It Alone"

Finally, social support was identified as a third component of accessing cancer care. Participants shared ways in which they felt supported by connections to others, as well as ways they felt unsupported. Gratitude around receiving emotional and financial help from family and friends was a recurring theme. Some acknowledged they would not have made it through treatment without support from loved ones, "If I didn't have this support system I don't know how I would have done it. Because I've had my days and he [points to partner] pulls me up" (P098, 43 yo, gynecological). At the same time, some stated they felt there were limits to what they could expect from others, "In the beginning they would help with rides to appointments and they helped with food. Money-wise, they didn't really help at all. Didn't want to ask them" (P024, 55 yo, GI). Others were limited to support from their healthcare professionals, "You do get lots of emotional support, but without family here it is…really rough" (P096, 53 yo, gynecological).

Participants mentioned healthcare professionals as instrumental in their coping process. One individual talked about seeing a psychiatrist to help manage emotional stress and substance use:

> I've progressed a lot…he's got me down to where I'm doing really well. After work to de-stress…I was like 6–10 beers a day and now I'm down to like, one or two. It's really hard because your emotions go crazy. (P096, 53 yo, gynecological)

A number of participants described medical professionals as helpful in navigating complicated billing processes:

> It would be good to have something where somebody can break it down it's like; this is what this code means; because I don't understand. What's the difference between procedures and why are they costing the same? It doesn't make sense. (P098, 43 yo, gynecological)

All participants who utilized nurse navigators reported positive experiences, "I've just been really fortunate with my navigators helping me out" (P096, 53 yo, gynecological). Nurse navigators played many roles: simplifying complex systems, advocating for patient needs, and providing emotional support. A participant shared:

> I actually have [a] patient navigator to help me understand the bill. And advocate for me to talk to some of these different clinics because this isn't just a doctor bill, it's the anesthesiologist bill those types, different ones. (P097, 54 yo, hematological)

Another participant felt strongly that all patients with cancer should take advantage of this support:

> They need to really utilize their nurse navigator and if they don't have one, they need to do the research to get one, because those people have resources and have the time and tools to pull every possible resource for them on the financial end (P096, 53 yo, gynecological)

Social support, whether through family, friends, or healthcare providers, enabled many participants to obtain tangible resources and emotional support instrumental to their cancer care.

Discussion

From the initial coining of financial toxicity, oncology literature has highlighted the detrimental effects cancer treatment has on economic stability, treatment adherence, QOL, and mortality rates (Zafar and Abernethy, 2013; Zafar et al., 2015; Ramsey et al., 2016; Altice et al., 2017; Gordon et al., 2017). Research has explored the impacts of financial toxicity on physical and psychosocial symptom clusters, yet the current literature fails to capture the unique experiences of low-income people with cancer (Lu et al., 2019; Perry et al., 2019; Drury et al., 2020). Therefore, the purpose of this study was three-fold: (1) to explore the relationship between financial toxicity, quality of life, and patient well-being among low-income patients with cancer, (2) whether the COST was able to fully capture the impact of financial toxicity among low-income patients, and (3) better understand their unique experiences through qualitative interviews.

Quantitative analyses in this study explored the relationship between income, financial toxicity, QOL, and well-being for low-income individuals. Independent *t*-tests compared each of these outcomes based on household annual income (less than \$15,000 vs. ≥\$15,000). There was a trend that patients with <\$15k had higher levels of financial toxicity, but the difference was not statistically significant. Cronbach's alphas for the COST were acceptable for both income groups (0.87 and 0.81, respectively), suggesting that the COST is internally consistent (Tavakol and Dennick, 2011). Additionally, patients with <\$15k had significantly lower levels of patient well-being across symptom measures including physical functioning, anxiety, depression, pain interference, and fatigue. While multivariate analyses did not find income to be significantly associated with financial toxicity, quality of life, and lack of insurance had statistically significant associations with financial toxicity. This suggests that access to insurance may be more important than access to income in terms of higher quality of life and lower financial toxicity. This further supports the idea that health insurance coverage and Medicaid expansion are important policy interventions for reducing financial toxicity among low-income patients with cancer (Han et al., 2018, 2020).

Qualitative findings from this study provided novel insight into the impact that financial toxicity has on low-income individuals diagnosed with cancer. While the COST is a validated measure, its focus on retirement, savings, and other assets makes assumptions about the financial standing of respondents, and may not be as relevant for low-income populations. One major issue identified among our sample in terms of affording cancer care was gaining access to health insurance coverage. Some individuals did not have insurance when initially diagnosed with cancer, which meant accumulating large amounts of medical debt or delayed diagnostic testing, before they even started cancer treatment. Furthermore, some patients lost insurance coverage and became uninsured due to job loss, which led to gaps in healthcare coverage before enrollment in public health insurance like Medicaid. The majority of participants entered their cancer diagnosis facing uncertain access to medical care and the risk of losing basic needs like housing and transportation. These types of issues are not currently captured by the COST.

Participants were grateful for Medicaid and/or Social Security Disability benefits, yet they also found they restricted employment opportunities and earning potential. Access to county and state funded insurance programs offered some financial respite; however, it proved far from a panacea. These income-based programs failed to cover every medical procedure, prescription, or specialist provider, leaving many participants to forgo or delay necessary medical care similar to previous studies (Kent et al., 2013; Kale and Carroll, 2016; Ramsey et al., 2016). Further, county-based healthcare coverage did not retroactively cover previous medical debt and Medicaid only provides retroactive coverage for the 3 months prior to enrollment. Therefore, patients without access to savings, retirement, or health insurance prior to their cancer diagnosis are at substantial risk of accumulating higher amounts of medical debt, or delaying their initial treatment. The way the COST is currently structured, it is challenging to capture the full experience of low-income cancer patients as it relates to financial toxicity.

Emotional strain related to financial toxicity was also reported, including worries about missed medical care, worries about unpaid bills, and the impact of medical debt on patient or family financial stability (Sharp et al., 2013; Schröder et al., 2020). While these themes are not necessarily unique to low-income patients, the stress of paying for basic needs such as housing, food, and transportation are more relevant to people who live paycheck to paycheck or lack access to savings. Most participants discussed being forced to place medical treatment before food, rent, or utility bills. Individuals portrayed an inability to afford household expenses and transportation let alone luxury items or vacations (Kent et al., 2013; Tran and Zafar, 2018). Loss of income also limited engagement in activities that formerly brought joy (Head et al., 2018). These findings were supported by the quantitative data that found lower-income individuals had significantly lower QOL compared to higher income groups.

Although participants faced a myriad of stressors resulting from financial strain, they also identified protective factors. Family and friends appeared instrumental in meeting emotional needs and basic needs such as housing, medication, and transportation (Head et al., 2018). However, family support could also come with a cost, where some patients reported the need to share income with family members, which limited their ability to pay for cancer treatment. Furthermore, patients that did not have family support relied heavily on healthcare providers and financial assistance programs to address their needs. Healthcare providers such as nurse navigators and social workers offered support by providing access to insurance, financial assistance, and prescription drug programs (Head et al., 2018; Shankaran et al., 2018; Pearce et al., 2019). Additional factors that promoted QOL included the sense of purpose garnered through employment and additional income (Peteet, 2000; Rasmussen and Elverdam, 2008; Abbott et al., 2017).

Limitations

While this study contributes important findings to the literature, there are multiple limitations to consider. First, this was an exploratory study that utilized secondary, quantitative data from a convenience sample. Therefore, we used a backward, stepwise regression to identify variables for our model as opposed to other regression models that are appropriate for explanatory hypotheses (Keith, 2019). Our study sample was relatively small, including quantitative data from 115 participants and qualitative interviews with 12 participants. Based on the power analysis, we had an adequate sample size for the multivariate analyses conducted (109 recommended, 115 included), however we had a slightly smaller sample size for the *t*-test (64 recommended, 52 and 44 were included in each income group). Our quantitative analysis was cross-sectional in nature, and the significant findings do not indicate causation. Furthermore, the majority of data included in this study was self-reported, which may be biased. We were unable to calculate Cronbach's alphas for the PROMIS measures, due to using computerized adaptive testing that did not ask the same set of questions to each participant. However, the PROMIS measures are highly validated with cancer patients as evidenced by several papers (Jensen et al., 2015; Cessna et al., 2016; Cook et al., 2016; Rothrock et al., 2020). Therefore, these findings may not be generalizable to the larger population and future studies are needed with larger, representative samples, random sampling, and longitudinal data.

This study was a sequential mixed methods study so there was a lag between the collection of quantitative survey data and qualitative survey data. This is common when qualitative interviews are informed by quantitative data, however it may have influenced our findings, and a concurrent data collection process could be beneficial in future studies. Additionally, we only conducted one qualitative interview with a subsample of English-speaking participants during active treatment, and our qualitative sample was somewhat homogeneous in terms of race and ethnicity. Ideally, future qualitative studies would include a larger, more diverse sample. Moreover, a qualitative study design with multiple interviews throughout the cancer treatment process could further explore different patterns in healthcare access, social support, and financial stability.

While our study focused on low-income individuals, this study utilized individual annual income, and did not include household income, wealth, or assets. Income was also collected as a categorical variable, which limited the power of our analyses. Individual annual income is not an ideal measure of socioeconomic status, especially for people living with others such as a spouse or family member; however, it is commonly used within research studies (Krieger et al., 1997). As previously reviewed in the literature, more thorough assessments of income and wealth are important to incorporate in health research, particularly with low-income populations (Braveman et al., 2005; Shavers, 2007). Additionally, we do not have information about the number of people in the household, which impacts the number of earners in the household as well as the number of people depending on household income. Lastly, we had missing income data for 19 of the 115 patients (15%), and this could have influenced our quantitative results. Income commonly has a high non-response rate due to the sensitive nature of the question (Davern et al., 2005). Future studies should conduct more comprehensive assessments of income and wealth such as the collection of a continuous income variable, number of household members, and household income in order to better understand the impact of financial toxicity on low-income patients with cancer.

Another consideration is that this study took place within a county that offers a supplementary income-based insurance option, which may have influenced more favorable access to care, as well as physical and psychosocial outcomes. Not all communities have access to this additional insurance option for those who fall outside state, federal, or private insurance parameters. Therefore, these findings may be more generalizable to other states that have not expanded Medicaid, and require patients with cancer to be eligible for Social Security Disability. Future studies could compare how geographic location and Medicaid expansion impact financial toxicity.

Future research should also incorporate a more diverse sample of patients with cancer, including people with varied immigration status. This is particularly important in Texas, where approximately 29% of people speak Spanish at home (U.S. Census, 2015). Immigration status plays a vital role in ability to access healthcare and financial assistant programs; thus, creating additional potential for medical debt. Additionally, the majority of patients in the original study (approximately 70%) had a stage IV cancer diagnosis, and approximately 60% of the qualitative respondents had stage IV cancer. While this has been shown to significantly impact QOL and patient outcomes, stage of cancer diagnosis was not significantly associated with financial toxicity in our multivariate analysis (Blumen et al., 2016; Wood and Taylor-Stokes, 2019). Future studies should consider all relevant factors including race, ethnicity, immigration status, insurance, cancer type, and stage.

Conclusion

This study provides insight into the experience of financial toxicity among low-income patients with cancer. Study findings suggest the need for targeted screening of financial distress that captures the nuanced challenges of low-income patients. Novel cancer financial navigation programs as well as psychosocial interventions appear to reduce financial strain and enhance access to both financial and emotional resources (Chi, 2019; Pearce et al., 2019). Oncology healthcare providers should sensitively invite dialogues regarding debt, access to financial resources, and barriers to treatment. These dialogues throughout treatment and survivorship may elicit opportunities for interventions that impact quality cancer care.

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