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## Assessment of Financial Toxicity among Older Adults with Advanced Cancer

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## Abstract

**Importance:** Financial toxicity (FT) in cancer care is associated with negative consequences and increased risk of mortality. Older patients (70+) with cancer are at risk for FT. There are limited data on FT and whether FT is discussed in clinic with these patients.

**Objective:** Examine prevalence of FT in older adults with advanced cancer, its association with health-related quality of life (HRQoL), and cost conversations between oncologists and patients.

**Design:** Cross-sectional secondary analysis of baseline data from the COACH study (NCT02107443; PI: Mohile, N=541, 5 patients excluded due to missing data) conducted from October 29, 2014 to April 28, 2017.

**Setting:** Cluster randomized trial from 31 community oncology practices across the United States.

**Participants:** Included 536 patients (mean age 76.6 years (range 70–96 years), 48.9% female, 7.3% Black/African American, and 93.1% not employed) with advanced cancer. We utilized three questions to identify patients (> 70 years) experiencing FT. We conducted multivariable linear regression models to assess the independent associations of FT with HRQoL. We analyzed one audio-recorded clinic transcript within 4 weeks of enrollment for patients with FT. The Framework Method was used to identify frequency and themes related to cost conversations.

**Results:** Ninety-eight patients (18.3%) reported FT; average age was 76.4 years old; 60.2% were female, 14.3% Black/African American, 92.9% not employed, and 29.6% had Medicare alone. On multivariate regression analyses, FT was associated with higher levels of depression [ $\beta=0.81$ , 95% Confidence Interval (CI) 0.15, 1.48; potential range 0–15], anxiety ( $\beta=1.67$ , 95% CI 0.74, 2.61; potential range 0–21), and distress ( $\beta=0.73$ , 95% CI 0.08, 1.39; potential range 0–10), and lower HRQoL ( $\beta=-5.30$ , 95% CI -8.92, -1.69; potential range 0–108). Among those who reported FT, 49% had a conversation with their provider about costs. Most (79%) conversations were initiated by oncologists or patients. Four themes were generated from cost conversations - statements regarding cost of care, ability to afford medical prescriptions, negative impact of cost of care, and cost burden in non-treatment domains.

**Conclusions and Relevance:** Among older adults with advanced cancer, FT is associated with worse HRQoL. Almost half of conversations among patients reporting FT demonstrated costs are being actively discussed. Resources and interventions are needed to manage FT.

## Keywords

cost conversations; financial toxicity; health-related quality of life; cancer cost

## Introduction

Financial toxicity (FT) encompasses the monetary burden of paying for cancer care (e.g., chemotherapy, surgery) and the negative impact that such treatments have on patients'

financial security. FT is associated with immediate and long-term consequences including treatment non-adherence, decreased health-related quality of life (HRQoL), bankruptcy, and an increased risk of mortality<sup>1-4</sup>. In 2014, cancer care spending reached \$87.8 billion in the United States with \$3.9 billion direct spending by patients related to out-of-pocket expenses<sup>5</sup>. Older adults face a unique set of pressures compared to the general population. By 2020, approximately 63% of all individuals with cancer in the US will be 65 or older<sup>6</sup>. Their primary source of income is from Social Security and retirement savings (e.g., pension, 401(k)), which account for 84% of aggregate income<sup>6</sup>. Furthermore, while 93% of the population has coverage through Medicare, many are left with large copayments and deductible minimums<sup>7</sup>. In 2017, older adults spent 13.1% of total expenditures on healthcare costs<sup>8</sup>. The issue of an aging population and increasing cancer prevalence also affects worldwide populations in both developed and developing countries<sup>9</sup>. Using population projections, it is estimated that by 2035, cancer diagnosis in those 65 years and older are expected to grow from 6.7 million to 14 million new cancer cases globally<sup>9</sup>.

Two major themes have been identified from FT research. First, patients who report FT (on various scales and surveys) are more likely to have a lower HRQoL compared to those with no financial hardship<sup>10,11</sup>. For example, in the National Health and Aging Trend Study, which included 307 cancer survivors aged 65 and above, financial burden (based on six problems: paying off credit card balances, paying medical bills, receiving financial help from family or friends, receiving food stamps, receiving other food assistance, and receiving assistance with utilities) was associated with higher depressive symptoms, general anxiety, and self-rated health<sup>12</sup>. Second, patients express a desire to discuss out of pocket costs with their oncologist teams; however, conversations rarely occur during clinic visits, partially due to provider discomfort<sup>13,14</sup>. Many studies have used questions to identify patients with FT that focus on indirect costs of cancer care (e.g., travel, lodging, and employment), rather than questions that evaluate the ability of the patient to financially manage their basic needs of living (i.e., medicines, food, and clothing), which is more relevant to older adults with limited incomes<sup>15-17</sup>. However, given our current published information, much more is needed to understand FT and its true effect on this high risk population.

In this secondary analysis of a large national clinical trial, we aimed to 1) estimate the prevalence of FT in older patients (> 70 years of age) with advanced cancer enrolled in a clinical trial, 2) examine the association between FT with HRQoL, and 3) describe cost conversations between the oncologist and patients with FT. We hypothesized that FT was associated with worse HRQoL.

## Methods

### Study design, setting, and participants

The Improving Communication in Older Cancer Patients and Their Caregivers (COACH) study (URCC 13070; [clinicaltrials.gov: #NCT02107443](https://clinicaltrials.gov/ct2/show/study/NCT02107443), Principal Investigator: Mohile) was a cluster randomized trial that enrolled 541 older adults with incurable cancer from 31 community oncology practices in the University of Rochester Cancer Center National Cancer Institute Community Oncology Research Program (URCC NCORP) Research Base network<sup>18-22</sup>. Patients were eligible for the primary study if they were aged 70 or older,

diagnosed with incurable stage III or IV cancer, were considering or receiving cancer treatment, had at least one Geriatric Assessment (GA) domain impairment (e.g., function, cognition) excluding polypharmacy, had an adequate understanding of the English language, and had the ability to provide informed consent or had a health care proxy who could sign consent. This study was approved by the University of Rochester's Research Subjects Review Board (RSRB) and the review boards of the participating NCORP affiliates. All patients (or health care proxy designee), oncologists, and caregivers provided consent. Total study population had 541 subjects, but given FT data was incomplete for five subjects, they were removed from the analysis and this sub-study had only 536 patients. This study followed the guidelines based on the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) for cross-sectional studies as well as the Standards for Reporting Qualitative Research (SRQR) guidelines for qualitative studies<sup>23,24</sup>

### Participants and brief description of the primary study

Patients reported socio-demographics (race, ethnicity, educational attainment, marital status, insurance type, and annual household income), cancer type, and additional measures as described below. In practices assigned to the intervention arm, GA-guided recommendations tailored to the patient were provided to the oncology team, the patient, and caregiver. GA-guided recommendations were not provided in practices assigned to the usual care arm, but the GA was completed in those practices as well. Of note, the GA does not contain information on FT and financial recommendations were not provided in either arm. For all patients, one clinic visit between the patient and his/her oncologist was audio-recorded within 4 weeks of enrollment. In this secondary analysis, we utilized baseline data of the enrolled patients.

### Independent variables and covariates

Patients were asked three questions regarding financial hardship at baseline screening. Q1) "At any time in the past three months have you taken less medication than was prescribed for you because of the cost?" (DelayMed variable); Q2) "When you think about the amount of income that you have available in a typical month, is there enough for your food and housing costs?" (IncomeAvail variable); and Q3) "When you think about the amount of income that you have available in a typical month, is it enough for things you really need like clothing, medicine, repairs to the home or transportation" (Enough variable). If a patient answered "yes" to Q1 or "no" to Q2 or "no" to Q3, they were categorized as meeting criteria for FT. The questions included in the survey were selected due to ease of administration and to encompass the current definition of FT in the literature<sup>4</sup>. However, this survey was not validated in older adults in prior studies<sup>25,26</sup>. Covariates including age, gender, ethnicity, race, education, annual household income, employment status, marital status, insurance, cancer type, and cancer stage were also included. Bivariate analysis ( $\chi^2$  test) were conducted to select covariates with  $p < 0.1$ , then we included these significant covariates in the multivariable regression.

### Dependent variables: Health-related quality of life

Patients completed validated instruments that assessed HRQoL, including the Geriatric Depression Scale-15 (GDS-15), Generalized Anxiety Disorder- 7 (GAD-7), National

Comprehensive Cancer Network (NCCN) Distress Thermometer, and Functional Assessment of Cancer Therapy- General (FACT-G)<sup>27–30</sup>. The GDS-15 is a fifteen-question tool with scores ranging from 0–15; higher scores indicating greater depression severity. The GAD-7 is a seven-question tool with scores ranging from 0–21; higher scores indicating greater anxiety. The distress thermometer is a visual Likert-scale and measures subjective distress rated from 0 (no distress) to 10 (severe distress). The FACT-G measures four domains of overall HRQoL: physical well-being, functional well-being, emotional well-being, and social/family well-being with a total weighted score ranging from 0–108, with 108 representing the highest overall HRQoL. Minimally clinically important differences (MCID) were 1.2 points for the GDS-15, 3 points for the GAD-7, and 5–6 points for FACT-G<sup>31–33</sup>. No MCID data exists for the NCCN Distress Thermometer, however experts suggest a cutoff point of 3 to identify distress<sup>34</sup>.

### Qualitative analysis: Cost conversations

Audio-recordings of the clinic visits were transcribed and de-identified. Two independent coders (AA, male, medical student with qualitative research training; MW, female, health project coordinator with qualitative research training experience; neither interacted with the participants) reviewed transcripts line by line of patients that met criteria for FT. The Framework Method was employed to identify frequency and to code themes related to cost conversations<sup>35</sup>. The Framework Method is a means to organize, manage, and present research data through the process of summarization, and utilizes a matrix output of rows and columns where rows represent cases and columns represent concepts. Themes were coded until thematic saturation was achieved (no additional codes identified) from which four themes were identified<sup>36</sup>. Additional codes were developed to determine the party (patient, oncologist, caregiver) who initiated cost conversation and the response quality by the provider. Response quality was categorized as acknowledged, addressed, or dismissed<sup>18</sup>. Acknowledged was used when the provider offered any verbal cue indicating the patient/caregiver concern was heard. Addressed was used when the provider attempted to offer any intervention to ameliorate FT (e.g. providing free medication samples). Dismissed was used when the provider offered no verbal cue regarding the concern or pivoted to a separate topic. After coding was completed, the independent coders met to establish consensus. Consensus was achieved between the two coders, therefore there was no third party to address discrepancies.

### Statistical analyses

For the first aim, we described the characteristics of our study sample and prevalence of FT [mean (standard deviation) or N(%)] and compared the characteristics for patients who met criteria for FT versus those who did not using  $\chi^2$  test of independence.

For the second aim, we first examined the bivariate associations between clinically important covariates (age, gender, ethnicity, race, education, annual household income, employment status, marital status, cancer type, and cancer stage) and FT using  $\chi^2$  test of independence. The covariates that were associated with a  $p < 0.10$  were considered as potential confounders of association between FT and HRQoL<sup>37</sup>. We then conducted separate multivariate linear regressions to evaluate the associations of FT with HRQoL, adjusted for covariates

associated with  $p < 0.10$ . Additionally, we explored separate associations of Q1, Q2, and Q3 with HRQoL. Likelihood ratio tests from linear mixed models with practice site as random effects were not significant for all outcomes (all  $p > 0.50$ ), suggesting a limited clustering effect of practice site; therefore, the results from the original multivariable models were presented. Such modeling techniques follow a similar analytical strategy to previous work.<sup>20</sup> Residual plots were examined for normality, and although some deviations were present, all the model assumptions held well. A nonparametric sensitivity analysis was conducted, and all associations between FT and outcomes measures remained significant ( $p < 0.01$ ). All analyses were conducted using R software (Version 3.5.2).

For the third aim on conversations, we used a binary categorization for whether discussions of FT occurred during the clinical encounter and then sought to generate themes. Cohen's kappa measure of inter-rater reliability was calculated to measure the agreement between the coder's categorizations.

## RESULTS

### Characteristics of the sample

Among 536 patients (mean age 76.6 years [range 70–96], 48.9% female, 93.1% unemployed or retired, 7.3% Black/African American, and 18.8% with Medicare insurance alone), 18.3% (98 patients) reported FT.

Patients experiencing FT were on average 76.4 years old (range 70–92), 60.2% female, 92.9% unemployed or retired, 14.3% Black/African American, and 29.6% with Medicare insurance alone. Patients not experiencing FT were on average 76.6 years old (range 70–96), 46.3% female, 92.9% unemployed or retired, 5.7% Black/African American, and 16.4% with Medicare insurance alone. This suggests that patients who were female, Black/African American, single, with lower income and education, and covered by Medicare alone were more likely to report FT (all  $p < 0.05$ ) (Table 1). Nineteen patients responded yes to Q1 (DelayMed); 41 to Q2 (IncomeAvail); and 89 to Q3 (Enough). These add to  $>98$  because an individual patient may have responded Yes to  $>1$  question.

### Associations of financial toxicity with health-related quality of life

Compared to patients without FT, patients who reported FT were more likely to report higher levels of depression (mean GDS-15: 3.83 vs. 2.93,  $p = 0.008$ ), anxiety (mean GAD-7: 4.24 vs. 2.58,  $p = 0.001$ ), distress (mean distress: 3.55 vs. 2.75,  $p = 0.009$ ), and lower overall HRQoL (mean FACT-G: 75.40 vs. 81.78,  $p < 0.001$ ). In multivariate regression analyses, FT was associated with higher levels of depression, anxiety, and distress, as well as lower overall HRQoL. Patients reporting FT scored on average 0.81 [95% Confidence Interval (CI) 0.15, 1.48] points higher on the GDS-15 (indicating greater depression severity), 1.67 (95% CI 0.74, 2.61) points higher on the GAD-7 (indicating greater anxiety severity), 0.73 (95% CI 0.08, 1.39) points higher on the distress thermometer (indicating greater distress) (Table 2). Patients reported 5.30 (95% CI  $-8.92$ ,  $-1.69$ ) points lower on the FACT-G (indicating lower overall HRQoL), a result that is clinically significant (Table 2).

In exploratory analyses, each of the three individual FT measures was associated with lower HRQoL in separate multivariate models. Patients who delayed medications due to FT scored on average 1.48 (95% CI 0.15, 2.82) points higher on the GDS-15, 1.57 (95% CI 0.36, 3.50) points higher on the GAD-7, and 2.02 (95% CI 0.70, 3.33) points higher on the distress thermometer, and 6.70 (95% CI -13.84, -0.44) points lower on the FACT-G. Patients who reported insufficient income in a typical month for food or housing scored on average 1.70 (95% CI 2.73, 4.83) points higher on the GDS-15, 1.74 (95% CI 0.42, 3.05) points higher on the GAD-7, and 1.10 (95% CI 0.19, 2.01) points higher on the distress thermometer, and 4.33 (95% CI -9.40, 0.75) points lower on the FACT-G. Finally, patients who reported insufficient income in a typical month for clothing, medicine, repairs to the home, or transportation scored on average 0.93 (95% CI 0.24, 1.10) points higher on the GDS, 1.73 (95% CI 0.75, 2.71) points higher on the GAD-7, 0.81 (95% CI 0.13, 1.49) points higher on the distress thermometer, and 6.13 (95% CI -9.87, -2.38) points lower on the FACT-G (Supplemental Tables 1–3).

### Cost conversations

Of the 98 patients who reported FT, 94 transcripts were available to review (no audio recording were available for 4 patients). Among these 94 transcripts, 46 (48.9%) contained one or more conversation relating to cost, with a total of 63 distinct conversations. Conversations were initiated by oncologists (26/63, 41.3%), patients (24/63, 38.1%), caregivers (10/63, 15.9%), and nurses (3/63, 4.8%).

Four main themes emerged from the cost conversations. The first theme included statements regarding cost of care (medications and medical equipment), and was found in (31/63, 49.2%) of conversations. These were primarily patient and caregiver driven (18/31, 58.1%). The second theme focused on the effect of cost of care on ability to work or provide for family and was present in (9/63, 14.3%) of conversations. These were primarily patient and caregiver initiated (7/9, 77.8%). The third theme focused on the ability to afford prescribed care and was seen in (9/63, 14.3%) of discussions. Contrary to the other themes, these discussions were initiated by oncologists in 8/9 (88.8%) discussions. The final theme centered around cost burden in non-treatment domains including transportation, food, supplements, and supplements and was identified in (14/63) 22.2% of discussions. These were primarily patient driven conversations (8/14, 57.1%).

We also analyzed the oncologist response to cost concerns of patients and/or caregivers and determined whether concerns were acknowledged (explored by the oncologist) and/or addressed (with specific recommendations made). Of the 34 conversations initiated by patients or caregivers, oncologists acknowledged cost concerns in 47.1%, addressed in 41.2%, and dismissed in 11.8%. When oncologists did address financial issues, they recommended a variety of interventions including - offering medication samples, placing patients on patient assistance programs, and connecting families with social workers and financial specialists. Examples of direct statements from oncologists were shown in table 3.

## DISCUSSION

Older adults undergoing cancer care are at risk for FT. This study estimated the prevalence of FT amongst older adults with advanced cancer, assessed the impact of FT on HRQoL for this population, and highlighted the infrequency with which cost conversations are brought up at provider visits.

While there are FT screening tools currently accepted for use<sup>27–30,38</sup>, they require basic familiarity with the instrument as well as time to administer them during a patient visit. The most commonly used tool is the COST- FACIT (Comprehensive Score for financial toxicity – Functional assessment of Chronic Illness Therapy)<sup>38</sup>. We opted to use a three-question screen for FT for ease of recalling, administration, and efficiency. Our tool may effectively identify vulnerable older adults at risk for FT during cancer treatment with this screen, like other FT screens (e.g., COST tool) currently available<sup>38,39</sup>. All three questions are dichotomous, and the screening tool does not require specialized training for administration. Furthermore, these questions serve as a quick tool to identify FT for oncologists who do not feel equipped to engage in cost conversations with patients or feel visit times do not permit for lengthy screening tools such as the COST tool<sup>38,39</sup>.

Our results indicated close to 20% of older adults with advanced cancer experience FT. Majority of these patients were aged 70 years or older, female, had at least a college education, had lower average household income, and were not employed. From our analysis, we saw differences between the two groups on all four dependent measures (GDS-15, GAD-7, distress, and FACT-G). Further, we noted that on average individuals experiencing FT had more depression, anxiety, distress, and experienced an overall lower HRQoL compared with their peers. More importantly, we found there to be a minimal clinically important difference for FACT-G indicating that the individuals exhibiting FT were experiencing a clinically significant worse HRQoL of life state<sup>x</sup>. While important to see statistical significance, it is equally, if not more important, to note a clinically meaningful difference that impacts patients. By using the three questions on FT, providers can quickly identify the most vulnerable patients that are at the greatest risk for experiencing overall lower HRQoL.

The American Society of Clinical Oncology 2009 guidance statement cites “cost conversations as a key component of high-quality care.” However, cost conversations are infrequently brought up by the oncologist even though as much as 80% of patients expressed wanting a conversation regarding finances with their oncologist<sup>39,40</sup>. Our study found that among those who reported FT, only 49% of all visits had some mention of costs, indicating a potential gap between patient desires and practice. Based on our results, discussions for themes of statements about cost of care, effects of cost of care on the ability to work, and cost burden in non-treatment domains are more likely to be initiated by patient or caregiver. Patients and oncologists may be reluctant to bring up costs due to a variety of reasons. Patients may feel ashamed or embarrassed discussing personal finances and oncologists may not feel equipped or comfortable to handle these conversations<sup>41,42</sup>. While other studies have examined the desire for oncology patients to have conversations related to cost with



their providers, our study is one of the first to analyze transcript records to identify the frequency and themes directly related to costs from oncology visits in older adults.

While having cost conversations is important, it is equally important to understand and utilize interventions to assist patients. It is important to note that direct discussion regarding price awareness and inclusion of cost in treatment and goals of care discussion can be an effective method to intervene on FT<sup>43</sup>. Other local resources can include – patient navigators, social workers, financial counselors, support groups, transportation vouchers, and co-pay assistance<sup>44</sup>. Interventions regarding FT will also need to be addressed on a more national scale with appropriate stakeholders for consideration of policy changes<sup>44</sup>.

In our analysis, when concerns were addressed, patients were referred to social work, financial specialists, and medication assistance programs. Most institutions and practices have their own set of resources allocated to help patients through financial difficulties. One barrier for utilization of the programs is difficulty in assessing FT. If FT is not assessed, referral to appropriate services cannot occur. The three question FT survey is a useful strategy to identify and address high risk populations and helps to allocate resources to those at risk. Future studies should evaluate if interventions addressing FT will improve HRQoL and cancer care outcomes. Lastly, future studies may look at FT throughout an individual's cancer care continuum.

The major strength of this study is its novel approach of examining FT through a mixed-methods (quantitative and qualitative) lens in older adults with advanced cancer. To the best of our knowledge, this is the first study that focused on older adults with varying cancer subtypes in the community oncology setting and incorporated observations of cost conversations during clinic visits. Furthermore, neither the intervention nor control arm was provided educational information on FT which perhaps can limit potential bias.

### Study Limitations

There are several limitations with this study. First, the tool utilized in the present study to screen for FT has not been validated and was utilized due to ease of administration. While the three questions are not validated, we believe that the qualitative results provide an understanding that these questions may elucidate FT. Future research should compare with other measures such as the PSQ-18 in older adults with advanced cancer<sup>45</sup>. Second, only transcripts of those deemed to meet criteria for FT and not the whole study population were reviewed for cost conversations. Third, one visit was audio-recorded, and this snapshot may limit conclusions based on evolving conversations regarding FT that may be present. Fourth, we included primarily White patients, half of whom had at least some college education. Therefore, our findings may not be generalizable to non-White patients. Fifth, patients were at varying points in treatment (some had not started while others were at the end of treatment course) which could affect the amount the patient had already spent on treatment and indirect costs, and this may affect reporting of FT. Sixth, the cross-sectional design may limit causality of association or attribution of the findings. Seventh, we do not know what proportion of patients may have had cost conversations that did not report FT as our study only examined those who met criteria for FT. Finally, as the primary study only included

patients with stage 3 or 4 incurable cancer, our findings may not apply to patients with early stage cancer.

## CONCLUSIONS

Older adults with cancer may be at a higher risk for financial toxicity compared with those undergoing treatments for other chronic conditions<sup>46</sup>. This warrants future collaboration and research to create interventions to help reduce this burden. First, we must understand the prevalence of the situation. This present study established FT prevalence amongst older patients enrolled in a clinical trial receiving cancer treatments and described the negative associations of FT with HRQoL. Additionally, our study highlights the prevalence of cost conversations amongst patients experiencing FT and advocates that providers should be engaging patients and their families in these direct conversations. Second, we must provide an efficient screening tool to localize patients high at risk for FT. We suggest providers implement a screening tool like our three-question survey to broach the topic of FT amongst older patients. Ultimately, an intervention must be implemented to help those at risk to avoid FT from every developing. Future directions based on our paper can include validation of our three-question tool, and eventually a multi institutional collaborative effort to hypothesize and implement strategies to decrease financial toxicity from ever developing.

## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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### Key Points

**Question:**

Among older patients with cancer, what is the prevalence of financial toxicity (FT), its associations with health-related quality of life (HRQoL), and how often are conversations held regarding cost of care?

**Findings:**

In this secondary analysis of 536 older patients with advanced cancer, 18.3% reported FT. FT was associated with higher levels of depression, anxiety, distress, and lower HRQoL. Almost 50% of patients experiencing FT discussed it with their oncologists.

**Meaning:**

Oncologists should recognize that older patients with FT may be more likely to have lower overall HRQoL.

**Table 1.**

Demographics of patient characteristics at baseline

| Variables  | Patients (n= 536) | NO FT (n= 438) | FT (n=98)   | P values |
|--|-------------------|----------------|-------------|----------|
|  | N (%)             | N (%)          | N (%)       |          |
| <b>Age (Mean (SD))</b>   | 76.6 (5.19)       | 76.6 (5.13)    | 76.4 (5.44) |          |
| 70–79  | 398 (74.2%)       | 323 (73.7%)    | 75 (76.5%)  | 0.84     |
| 80–89  | 127 (23.7%)       | 106 (24.2%)    | 21 (21.4)   |          |
| 90   | 11 (2.1%)         | 9 (2.1%)       | 2 (2.1%)    |          |
| <b>Gender</b>  |                   |                |             | 0.01     |
| Female   | 262 (48.9%)       | 203 (46.3%)    | 59 (60.2%)  |          |
| Male   | 274 (51.1%)       | 235 (53.7%)    | 39 (39.8%)  |          |
| <b>Ethnicity</b>   |                   |                |             | 0.05     |
| Hispanic   | 1 (0.2%)          | 1 (0.2%)       | 0 (0.0%)    |          |
| Non-Hispanic/ Latino   | 530 (98.9%)       | 435 (99.3%)    | 95 (96.9%)  |          |
| Unknown  | 5 (0.9%)          | 2 (0.5%)       | 3 (3.1%)    |          |
| <b>Race (vs White)</b>   |                   |                |             | <0.01    |
| White  | 484 (90.3%)       | 405 (92.5%)    | 79 (80.6%)  |          |
| Black/African American   | 39 (7.3%)         | 25 (5.7%)      | 14 (14.3%)  |          |
| Other  | 13 (2.4%)         | 8 (1.8%)       | 5 (5.1%)    |          |
| <b>Education</b>   |                   |                |             | 0.01     |
| <High school   | 65 (12.1%)        | 44 (10.0%)     | 21 (21.4%)  |          |
| High school graduate   | 193 (36.0%)       | 161 (36.8%)    | 32 (32.6%)  |          |
| Some college or above  | 278 (51.9%)       | 233 (53.2%)    | 45 (46.0%)  |          |
| <b>Income (Annual Household)</b>                                   |                   |                |             | <0.01    |
| <\$20,000  | 61 (11.4%)        | 28 (6.4%)      | 33 (33.7%)  |          |
| \$20–50,000  | 201 (37.5%)       | 161 (36.8%)    | 40 (40.8%)  |          |
| \$50–100,000   | 128 (23.9%)       | 123 (28.1%)    | 5 (5.1%)    |          |
| >\$100,000   | 36 (6.7%)         | 34 (7.8%)      | 2 (2.0%)    |          |
| Declined to answer   | 108 (20.1%)       | 91 (20.8%)     | 17 (17.3%)  |          |
| Missing  | 2 (0.4%)          | 1 (0.1%)       | 1 (1.0%)    |          |
| <b>Employment</b>  |                   |                |             | 0.92     |
| Employed   | 37 (6.9%)         | 30 (6.8%)      | 7 (7.1%)    |          |
| No Employed  | 499 (93.1%)       | 408 (93.2%)    | 91 (92.9%)  |          |
| <b>Marital Status</b>  |                   |                |             | <0.01    |
| Married  | 346 (64.6%)       | 298 (68.0%)    | 48 (49.0%)  |          |
| Single (includes widowed)  | 190 (35.4%)       | 140 (32.0%)    | 50 (51.0%)  |          |
| <b>Insurance</b>   |                   |                |             | <0.01    |
| Medicare   | 101 (18.8%)       | 72 (16.4%)     | 29 (29.6%)  |          |
| (Medicare+Private) OR (Medicare+ Private + Health Savings Account) | 383 (71.4%)       | 329 (75.1%)    | 54 (55.1%)  |          |
| (Medicaid+Medicare) OR (Medicaid+Private)                          | 26 (4.9%)         | 17 (3.9%)      | 9 (9.2%)    |          |

| Variables                   | Patients (n= 536) | NO FT (n= 438) | FT (n=98)  | P values |
|-----------------------------|-------------------|----------------|------------|----------|
|                             | N (%)             | N (%)          | N (%)      |          |
| Private OR Veterans Affairs | 26 (4.9%)         | 20 (4.6%)      | 6 (6.1%)   |          |
| <b>Cancer Type</b>          |                   |                |            | 0.11     |
| Breast                      | 70 (13.1%)        | 55 (12.6%)     | 15 (15.3%) |          |
| Gastrointestinal            | 123 (22.9%)       | 100 (22.8%)    | 23 (23.5%) |          |
| Genitourinary               | 73 (13.6%)        | 67 (15.3%)     | 6 (6.1%)   |          |
| Lung                        | 136 (25.4%)       | 105 (24.0%)    | 31 (31.6%) |          |
| Other                       | 134 (25.0%)       | 111 (25.3%)    | 23 (23.5%) |          |
| <b>Cancer Stage</b>         |                   |                |            | 0.33     |
| Stage III                   | 47 (8.8%)         | 40 (9.1%)      | 7 (7.1%)   |          |
| Stage IV                    | 476 (88.8%)       | 390 (89.0%)    | 86 (87.8%) |          |
| Other                       | 12 (2.2%)         | 8 (1.9%)       | 4 (4.1%)   |          |
| Missing                     | 1 (0.2%)          | 0 (0.0%)       | 1 (1.0%)   |          |

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**Table 2:**

The association of financial toxicity with depression, anxiety, emotional distress, and quality of life.

| Independent variables   | Depression               | Anxiety                     | Distress                  | Quality of life               |
|---|--------------------------|-----------------------------|---------------------------|-------------------------------|
|   | Coefficient (95% CI)     | Coefficient (95% CI)        | Coefficient (95% CI)      | Coefficient (95% CI)          |
| <b>Patient demographics</b>                                     |                          |                             |                           |                               |
| <b>Financial toxicity (Vs. None)</b>                            | <b>0.81(0.15, 1.48)*</b> | <b>1.67 (0.74, 2.61)***</b> | <b>0.73 (0.08, 1.39)*</b> | <b>-5.30 (-8.92, -1.69)**</b> |
| Education (vs. <High school)                                    |                          |                             |                           |                               |
| High school graduate  | 0.02 (-0.79, 0.82)       | -0.07 (-1.20, 1.07)         | -0.40 (-1.20, 0.39)       | -0.09 (-4.46, 4.29)           |
| Some college or above   | -0.54 (-1.35, 0.26)      | -1.03 (-2.16, 0.11)         | -0.61 (-1.41, 0.19)       | 1.77 (-2.61, 6.14)            |
| Marital status (vs. married)                                    |                          |                             |                           |                               |
| Single  | -0.04 (-0.60, 0.52)      | -0.19 (-0.98, 0.60)         | -0.06 (-0.61, 0.49)       | 0.33 (-2.67, 3.33)            |
| Gender (female vs. male)  | -0.22 (-0.73, 0.29)      | 0.40 (-0.32, 1.12)          | 0.29 (-0.21, 0.80)        | 1.10 (-1.64, 3.83)            |
| Race  |                          |                             |                           |                               |
| African American vs Caucasian                                   | -0.19 (-1.14, 0.75)      | 0.00 (-1.33, 1.33)          | -1.22 (-6.61, 4.18)       | 3.95 (-1.20, 9.10)            |
| Other   | -0.69 (-2.23, 0.84)      | -1.75 (-3.92, 0.41)         | -0.74 (-6.67, 5.20)       | 1.04 (-7.13, 9.21)            |
| Insurance (vs. Medicare)  |                          |                             |                           |                               |
| (Medicare+Private) OR (Medicare+Private+Health Savings Account) | -0.35 (-0.98, 0.27)      | 0.03 (-0.85, 0.91)          | -0.33 (-0.94, 0.29)       | 2.42 (-0.95, 5.79)            |
| (Medicaid+Medicare) OR (Medicaid+Private)                       | -0.42 (-1.64, 0.80)      | -0.86 (-2.58, 0.86)         | -0.64 (-1.85, 0.56)       | 0.57 (-6.04, 7.17)            |
| Private OR Veterans Affairs                                     | -0.78 (-1.98, 0.41)      | -0.20 (-1.88, 1.48)         | -0.33 (-1.53, 0.86)       | -0.32 (-6.79, 6.15)           |
| Income (vs. <\$20,000)  |                          |                             |                           |                               |
| \$20–50,000   | -0.34 (-1.20, 0.52)      | 0.14 (-1.07, 1.36)          | -0.25 (-1.10, 0.60)       | 2.22 (-2.44, 6.88)            |
| \$50–100,000  | -0.18 (-1.17, 0.80)      | -0.07 (-1.46, 1.32)         | -0.05 (-1.03, 0.92)       | 4.33 (-1.00, 9.65)            |
| >\$100,000  | 0.11 (-1.17, 0.80)       | 1.27 (-0.53, 3.08)          | -0.23 (-1.50, 1.05)       | -1.28 (-8.15, 5.59)           |
| Declined to answer  | -0.04 (-0.97, 0.9)       | 0.12 (-1.19, 1.43)          | -0.50 (-1.42, 0.42)       | 1.19 (-3.85, 6.24)            |
| Ethnicity (vs. Hispanic)  |                          |                             |                           |                               |
| Non-Hispanic/ Latino  | 1.58 (-3.90, 7.06)       | 1.79 (-5.94, 9.52)          | -1.22 (-6.61, 4.18)       | -5.13 (-34.32, 24.06)         |
| Unknown   | 3.10 (-2.93, 9.13)       | 2.63 (-5.86, 11.13)         | -0.74 (-6.67, 5.20)       | -8.33 (-40.43, 23.77)         |

Note: Higher scores for the GDS-7, GAD-7, and ED indicate greater depression, greater anxiety, and greater emotional distress; while higher scores on the FACT-G indicate greater quality of life.

\*  $p$ -value<0.05

\*\*  $p$ -value<0.01

\*\*\*  $p$ -value<0.001

Abbreviations: ED - Emotional Distress Thermometer; FACT-G - Functional Assessment of Cancer Therapy-General; GAD-7 - Generalized Anxiety Disorder-7 Item Scale; GDS - Geriatric Depression Scale

Only patient covariates significant in bivariate analyses with the primary predictor of interest (FT3;  $p$ <0.10) were included in the final model

**Table 3:**

Themes identified from transcripts of patient visits with oncologists along with representative quotes matching each theme

| Themes  | Representative Quotes   |
|---|---|
| Statements about cost of care (medications and medical equipment) | Patient: "We don't have no \$480 a month" (copay for Capecitabine)  |
|   | Patient: "I was out of them (medications) for a while and I was so busy and I didn't fill them. [chuckles] And not only that, it's money sometimes that I don't... other things are more important. My son is more important than the darn medicine I was taking. That's the way I look at it." |
| Questions about ability to afford prescribed care                 | Oncologist: "So how much are you paying out of pocket?"   |
|   | Oncologist: "Now I'm going to ask you a few questions. You didn't pick up your Zofran; was it you thought you didn't need it or are there any issues with co-pays?"   |
|   | Oncologist: "Okay. Maybe [name de-identified], our social worker can help her financially if that's what she wants"   |
| Effects of cost of care on ability to work and provide for family | Oncologist: "I'll just write a prescription and you can... if it's too expensive than just tell the pharmacist you'll pick it up over the counter."   |
|   | Patient: "I've got a wife and two daughters and a granddaughter that I'm supporting"  |
| Cost burden in non-treatment domains                              | Patient: "Monday would be best. Because I want to be able to work Saturday, and Sunday if you can write me-"... "I have to have you write me a note"  |
|   | Patient: "Because.... because I don't have the money to pay somebody for gas to bring me. I have to have somebody with me."   |
|   | Doctor: "Where do you live? We have a shuttle bus at the hospital to bring you back to the hospital. Where do you live?"  |

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