Does Cancer Treatment-Related Financial Distress Worsen Over Time?

S.M. Qasim Hussaini, Fumiko Chino, Christel Rushing, Greg Samsa, Ivy Altomare, Jonathan Nicolla, Jeffrey Peppercorn, S. Yousuf Zafar

BACKGROUND Patients with cancer are at risk for both objective and subjective financial distress. Financial distress during treatment is adversely associated with physical and mental well-being. Little is known about whether patients' subjective financial distress changes during the course of their treatment.

METHOD This is a cross-sectional study of insured adults with solid tumors on anti-cancer therapy for ≥1 month, surveyed at a referral center and three rural oncology clinics. The goal was to investigate how financial distress varies depending on where patients are in the course of cancer therapy. Financial distress (FD) was assessed via a validated measure; out-of-pocket (OOP) costs were estimated and medical records were reviewed for disease/treatment data. Logistic regression was used to evaluate the potential association between treatment length and financial distress.

RESULTS Among 300 participants (86% response rate), median age was 60 years (range 27-91), 52.3% were male, 78.3% had stage IV cancer or metastatic recurrence, 36.7% were retired, and 56% had private insurance. Median income was $60,000/year and median OOP costs including insurance premiums were $592/month. Median FD score (7.4/10, SD 2.5) corresponded to low FD with 16.3% reporting high/overwhelming distress. Treatment duration was not associated with the odds of experiencing high/overwhelming FD in single-predictor (OR = 1.01, CI [.93, 1.09], P = .86) or multiple predictor regression models (OR = .98, CI [.86, 1.12], P = .79). Treatment duration was not correlated with FD as a continuous variable (P = .92).

LIMITATIONS This study is limited by its cross-sectional design and generalizability to patients with early-stage cancer and those being treated outside of a major referral center.

CONCLUSION Severity of cancer treatment-related financial distress did not correlate with time on treatment, indicating that patients are at risk for FD throughout the treatment continuum. Screening for and addressing financial distress should occur throughout the course of cancer therapy.

While advances in cancer treatment have improved outcomes for many patients with cancer, the associated rise in the cost of care due to new, expensive treatments has resulted in a growing financial burden borne by patients. These treatment-related expenses affect many aspects of patients' lives, causing them to seek more work for additional income, spend less on food or clothing, and use their savings to pay for treatment [1]. Studies have also shown that relatively small increases in out-of-pocket health care costs can result in non-adherence to cancer treatment [2-4]. Treatment-related financial burden is adversely associated with physical and mental well-being [5-7]. A cancer diagnosis results in a 2.65 times higher risk of declaring personal bankruptcy [8]. The negative impact on patients' well-being can cause such considerable distress that the term "financial toxicity" has been introduced to describe the negative side effects of high out-of-pocket costs in cancer care [9-11].

Studies have demonstrated that cancer treatment costs follow a U-shaped curve in which costs are highest in the year after diagnosis and in the last year of life, and lower in the intervening years [12]. These trends are consistent with higher-intensity treatments shortly after diagnosis, and the high costs of end-of-life care. The dimensions of these curves depend upon cancer site, stage at diagnosis, and type of treatment utilized. Much work remains to be done in describing whether personal, treatment-related financial burden varies over the course of cancer treatment [13]. Furthermore, the health system in its current form is often unable to identify patients before they fall into medical debt [14]. Understanding timing of financial burden would help health care providers identify patients who may benefit from targeted intervention to avoid financial toxicity.

In this study, we conducted a cross-sectional survey to explore the relationship between financial distress and the length of time the patient had been receiving anti-cancer treatment, and whether there are any patient or disease-related factors that increase the risk of financial distress.

Methods

Participants

Study design and methods have been previously described in detail [15-17]. Enrollment for the study occurred between November 2012 and June 2013 at a university-based cancer treatment center and three affiliated rural oncology clinics. Eligible patients had public or private insurance coverage, had a confirmed solid tumor cancer diagnosis, and were receiving anti-cancer hormonal therapy or chemotherapy for at least one month at the time of enrollment. Patients were excluded from the study if they were uninsured, were receiving radiation therapy, or did not speak English. Uninsured patients were excluded because we were focused primarily on the experiences of patients who were insured but were still at risk of financial distress. Underinsured patients were especially important to study because the hazard of being underinsured may remain despite the Affordable Care Act [18]. Underinsured was defined as having medical expenses greater than 10% of total income [19]. Patients receiving radiation were excluded due to the relatively short nature of a typical course of radiation therapy. The survey utilized in this study was pilot tested in a group of 20 patients at the Duke Cancer Institute and was approved by the Duke University Medical Center Institutional Review Board.

Study Design

A convenience sample of 349 patients who met eligibility criteria were approached while waiting in the clinic waiting room or receiving chemotherapy. Those who agreed to participate in the study were consented and given the survey in person by a trained interviewer. On rare occasions, the patient was enrolled and the survey administered on a second visit. Participants were given a gift of $10 for completion of the survey.

Main Outcome Measures

Demographic data such as cancer diagnosis, stage of disease, type of treatment (oral or IV chemotherapy or both), and duration of treatment were abstracted from the medical record. Patient-reported demographics were collected including annual household income, education, employment, medical costs, cost-related decision-making, and medication non-adherence [15-17]. Participants completed the InCharge Financial Distress/Financial Well-Being Scale, which is a validated, 8-item questionnaire that measures financial distress on a continuum [20]. Items were scored on a scale from 1 to 10 with 1 indicating overwhelming financial distress/lowest financial well-being, and 10 indicating no financial distress/highest financial well-being. From that a binary measure, "high/overwhelming financial distress" versus "low/average financial distress" was created. Time on treatment was abstracted from the medical record and defined as the length of time the patient had been receiving anti-cancer treatment at the time of study enrollment.

Statistical Analysis

The primary question of interest was whether time on treatment was related to subjective financial distress (FD). The correlation of months on treatment and continuous FD was tested using the Pearson correlation coefficient. To test for differences between those most affected by financial distress and those least affected, a binary version of the FD variable was created using < 4 as "high/overwhelming" distress and values of 4 or higher as "low/average" distress. Logistic regression was used to model binary FD. Patients were grouped by the binary FD variable and potential differences in demographic, clinical, and financial characteristics were evaluated using Wilcoxon rank sum tests for continuous variables and Fisher's Exact or χ^2 tests for categorical variables. To obtain appropriate odds ratios, two nested logistic models were fit: the base model with time on treatment as the sole predictor; and a second model (the anchor model) that adjusted for early versus late stage and receipt of oral chemotherapy. Both determined *a priori* to be important covariates. All statistical analyses were performed in SAS v9.4 (Cary, North Carolina).

Results

Patient demographics

As previously reported, 349 consecutive patients were approached in the clinic setting, and 300 were eligible and agreed to participate (86% response rate, Table 1) [15-17]. Median age was 60 years, 52.3% were male, and 72.3% had at least some postsecondary education. Full-time employment rate was 26.7% among participants, with 36.7% retirees. Overall, 40% of patients were underinsured and the median reported household income of study participants was $60,000. Of the 300 study participants, 290 (96.7%) had prescription drug coverage. All patients who participated in this study were receiving chemotherapy or hormonal therapy at the time of enrollment, with 72.3% receiving intravenous chemotherapy, 5.3% receiving oral anti-cancer agents, and 21.7% receiving both intravenous and oral therapies. Overall, 24.3% patients had metastatic recurrence and 54% were stage IV at diagnosis. As briefly reported in our previous work with this cohort (not included in this study), 22% did not fill a prescription because of cost; 52% expressed some desire to discuss treatment-related out-of-pocket costs; 19% had spoken to their doctor about costs; 57% reported lower out-of-pocket costs as a result of cost discussions; and there is 31% versus 10% relative cost of care for patients with high or overwhelming distress versus those with no, low, or average financial distress [15-17].

Time on Treatment and Financial Distress

The median duration of treatment was 4.6 months (range 1-156 months, Table 1). Although 4% of patients were on therapy for greater than five years, 73.7% were on chemotherapy or hormone treatment for a year or less with

TABLE 1.

Demographic and Clinical Characteristics of Patient Cohort in Cross-Sectional Study Investigating Financial Distress

Characteristic	%, unless otherwise noted	n
Median Age (range)	60.0 (27 – 91)	300
Male	52.3	157
White	76.3	229
Not Hispanic or Latino	97.3	292
Completed High School/GED	93.7	281
At least some college	72.3	217
Underinsured	40.0	120
Not Underinsured	31.7	95
Employed Full-time	26.7	80
Retired	36.7	110
Unemployed and Not Seeking	26.3	79
Married	66.3	199
At Least $60,000 or More	79.7	239
Receiving Chemotherapy or Hormonal Therapy	100.0	300
Metastatic recurrence	24.3	73
Stage IV	54.0	162
IV Chemotherapy	72.3	217
Oral Chemotherapy	5.3	16
Both IV and Oral Chemotherapy	21.7	65
Prescription Drug Coverage	96.7	290
Palliative Care	79.3	238
Median Household Income ($)	60000	215
Median Monthly OOP Costs ($)	591.5	300
Median Relative Cost of Care (range)	0.1 (0 – 71.5)	213
Median Months on Treatment (range)	4.6 (1 – 156.4)	300
Median QOL Score (range)	8.0 (1 – 10)	300
Median Financial Distress Score (range)	7.4 (1 – 10)	300
Higher Financial Burden Than Expected	39.3	118
Financial Burden Not Higher Than Expected	56.7	170
Missing Objective Financial Burden	4.0	12
High/Overwhelming FD	16.3	49
Low/Average FD	83.7	251

Note. GED, general education diploma; OOP, out of pocket; QOL, quality of life; IV, intravenous; FD, financial distress.

55.3% on therapy for six months or less. Sixteen percent of patients (n = 49) classified their financial distress as high or overwhelming. The median financial distress score was 7.4, which corresponds to low degree of financial distress. The median monthly out-of-pocket expense was $591.50 (including insurance premiums).

Factors associated with financial distress

Factors associated with high financial distress are summarized in Table 2. Of respondents that had high-to-overwhelming financial distress, 57.1% were divorced, widowed, separated, or never married (versus 26.3% of respondents in the low-to-average FD group, P < .001). Similarly, employment was associated with financial distress. In participants with low-to-average financial distress, there was a 33.5% employment rate, with 42.2% retired and 20.3% unemployed and not seeking employment. In participants with high-to-overwhelming FD, there was a 28.6% employment rate with 8.2% retired and 57.1% unemployed and not seeking employment. Finally, underinsurance was associated with high financial distress (61.2% underinsured with high financial distress versus 35.9% underinsured with low financial distress, P < .001). These findings have been previously reported elsewhere by our group [17].

Multivariate Analysis

Logistic regression on duration of treatment, early versus late stage, and receipt of oral anti-cancer therapy demonstrated that early stage cancer was associated with a higher probability of high or overwhelming financial distress than late stage cancer (OR = 2.22 ; 95% CI, 1.11–4.43, P = .02) (Table 3). There was no association between time on treatment and binary financial distress on adjusted analysis.

Comparison of the continuous financial distress to

TABLE 2.
Factors Associated with Financial Distress Defined as Low to Average versus High to Overwhelming

Characteristic Variable	P-value	Low to Average Financial Distress (n = 251)	High to Overwhelming Financial Distress (n = 49)
Median Age	<0.0001	62.00	53.00
Race	0.1272	20.72 % Nonwhite	34.69 % Nonwhite
		78.09 % White	65.31 % White
		1.20 % unknown	0 % unknown
Gender	0.1465	45.82 % Female	57.14 % Female
		54.18 % Male	42.86 % Male
Ethnicity	0.1538	1.20 % Hispanic or Latino	4.08 % Hispanic or Latino
		98.01 % Not Hispanic or Latino	93.88 % Not Hispanic or Latino
		0.80 % Unknown	2.04 % Unknown
Education	0.5044	29.88 % Associates Degree or Some College	22.45 % Associates Degree or Some College
		23.51 % Bachelor's Degree	24.49 % Bachelor's Degree
		20.32 % High School/GED	26.53 % High School/GED
		20.72 % Master's Degree or other Advanced Degree	16.33 % Master's Degree or other Advanced Degree
		5.58 % Some high school or less	10.20 % Some high school or less
Marriage	0.0004	10.36 % Divorced	32.65 % Divorced
		2.39 % Living with a partner in a marriage-like relationship	0 % Living with a partner in a marriage-like relationship
		70.92 % Married	42.86 % Married
		7.17 % Never married	6.12 % Never married
		0.40 % Refused	0 % Refused
		1.99 % Separated	4.08 % Separated
		6.77 % Widowed	14.29 % Widowed
Marriage, Binary	<0.0001	73.31 % Married or Married-Like	42.86 % Married or Married-Like
		26.29 % Not Married or Married-Like	57.14 % Not Married or Married-Like
		0.40 % Refused	0 % Refused
Employment	<0.0001	28.69 % Employed full-time	16.33 % Employed full-time
		4.78 % Employed part-time	12.24 % Employed part-time
		0.80 % Homemaker	2.04 % Homemaker
		2.39 % Other	4.08 % Other
		42.23 % Retired	8.16 % Retired
		0.40 % Student	0 % Student
		20.32 % Unemployed and not seeking	57.14 % Unemployed and not seeking
		0.40 % Unemployed and seeking	0 % Unemployed and seeking
Employment, Binary	0.5040	33.47 % Employed part or full time	28.57 % Employed part or full time
		66.53 % Not Employed	71.43 % Not Employed

duration of treatment yielded no evidence of a correlation (P = .92).

Discussion

A large portion of cancer patients undergoing anti-cancer therapy experience financial distress as a direct result of their treatment [1, 21, 22]. In this cross-sectional study, we found no correlation between severity of their financial distress and duration of treatment. However, having early-stage cancer was associated with a higher level of financial distress.

Our data suggest that, unlike systemic costs, subjective financial burden does not necessarily vary over the course of treatment. The potential for financial distress regardless of time on treatment is supported by studies that suggest long-term cancer survivors are also at risk for experiencing financial burden. Kent and colleagues, using data from the National Health Interview Survey, found that 32% of cancer survivors reported cancer-related financial problems [21]. Guy and colleagues found that the financial burden related to cancer treatment, including direct and indirect costs, remained high years after diagnosis [23]. An explanation for the durability of financial burden might relate to employment in survivorship as well: De Boer and colleagues found that cancer survivors were more likely to be unemployed than healthy control participants [24-26]. Indeed, our current study shows unemployment is significantly associated with financial distress.

While duration of treatment was not associated with severity of financial distress, stage might serve as a more predictable marker of financial burden for certain types of cancers [27]. This may be due to higher costs incurred in

TABLE 2. *CONTINUED*
Factors Associated with Financial Distress Defined as Low to Average versus High to Overwhelming

Characteristic Variable	P-value	Low to Average Financial Distress (n = 251)	High to Overwhelming Financial Distress (n = 49)
Income Range	0.0001	9.96 % Less than $20,000	32.65 % Less than $20,000
		16.33 % At least $20,000 but less than $40,000	24.49 % At least $20,000 but less than $40,000
		16.33 % At least $40,000 but less than $60,000	12.24 % At least $40,000 but less than $60,000
		49.80 % At least $60,000 or more	24.49 % At least $60,000 or more
		7.57 % missing	6.12 % missing
Income, Binary	0.0023	49.80 % $60,000 +	24.49 % $60,000 +
		42.63 % < $60,000	69.39 % < $60,000
		7.57 % Missing	6.12 % Missing
Stage	0.1043	1.20 % Localized	2.04 % Localized
		23.11 % Metastatic recurrence	30.61 % Metastatic recurrence
		1.20 % Regionally advanced	0 % Regionally advanced
		2.39 % Stage I	4.08 % Stage I
		5.18 % Stage II	10.20 % Stage II
		8.37 % Stage III	16.33 % Stage III
		57.37 % Stage IV	36.73 % Stage IV
		1.20 % Unresectable	0 % Unresectable
Early stage vs late stage	0.0235	18.33 % Early stage	32.65 % Early stage
		81.67 % Late stage	67.35 % Late stage
Prescription Coverage	0.1534	1.59 % No Prescription Drug Coverage	6.12 % No Prescription Drug Coverage
		97.21 % Prescription Drug Coverage	93.88 % Prescription Drug Coverage
		1.20 % Unknown	0 % Unknown
Insurance	0.0118	5.98 % Medicaid	14.29 % Medicaid
		39.04 % Medicare	18.37 % Medicare
		1.20 % Other	0 % Other
		53.78 % Private insurance	67.35 % Private insurance
Insurance, Binary	0.0802	46.22 % Insurance Not Private	32.65 % Insurance Not Private
		53.78 % Private Insurance	67.35 % Private Insurance
Underinsured	0.0002	36.25 % Not underinsured	8.16 % Not underinsured
		35.86 % Underinsured	61.22 % Underinsured
		27.89 % Unknown	30.61 % Unknown
Median Household Income ($)	<0.0001	65000	26400
Median Monthly OOP Costs ($)	0.0676	565.00	728.00
Median Months on Treatment	0.4249	4.86	4.14

Note. GED, general education diploma; OOP, out of pocket.

the initial period following diagnosis [12, 27]. This is further underscored by the increasing frequency of plans with higher deductibles (promising lower premiums) as well as new, expensive oral regimens. Oral medications have become an increasingly common mode of anti-cancer drug delivery compared to traditional intravenous chemotherapy. This has presented unique challenges for the patient including medication adherence and cost partly due to limited prescription drug coverage [28-30]. Financial assistance continues to remain small in such cases [30]. Similarly, our study suggests that lack of prescription drug coverage is associated with financial distress. It is an area that will require greater scrutiny and policy-level changes [31]. As previously reported [6, 7, 17] and demonstrated in this study, characteristics such as age and marital status might

be useful for targeting early interventions in patients who are at risk for treatment-related financial distress. This is not unique to patients in the United States. Similar results were reported in a study evaluating financial distress in patients with advanced cancer in France [32].

An alternative to patients making significant lifestyle changes to accommodate unexpected out-of-pocket costs, clear predictors of financial distress could help providers anticipate distress and direct patients to the appropriate resources. Our results indicate that patients are at risk for significant financial distress throughout their care and that health care providers should intermittently inquire about financial well-being during a patient visit as they would about medication side effects or new symptoms. Recently developed measures have demonstrated reliability and valid-

TABLE 3.
Multivariate Analysis with Comparison between Time on Treatment, Early Stage vs Late Stage, and Mode of Therapy

	Model 1: Single predictor				Model 2: Anchor			
Comparison	OR Estimate	95% confidence limits		P-value	OR	95% confidence limits		P-value
Months on Treatment unit = 6 months	1.01	0.93	1.09	0.86	1.03	0.95	1.11	0.54
Early stage vs late stage					2.22	1.11	4.43	0.02
Receiving Oral Chemo: Y vs N					0.88	0.42	1.82	0.72

ity in measuring financial toxicity in patients with advanced cancer [33, 34]. These measures have shown correlation to health-related quality of life and may be utilized in the clinical setting to help guide efforts with patients.

Limitations

This study has several limitations. First, we reported a cross-sectional analysis of the sample population at one point in their treatment, which may not account for changes in financial distress over time. Second, financial distress was self-reported, leading to the possibility of recall bias and socially desirable response bias. Third, there were fewer than 50 total patients who reported high to overwhelming distress, limiting the power to detect differences. Fourth, we surveyed a consecutive but nonrandom sample of cancer patients, most of whom were treated at a major referral center. However, the study had a high response rate and non-responders only differed to responders in age, suggesting that at least within this center, this was a representative population. Fifth, the median monthly out-of-pocket cost estimates provided by study participants approximated those from larger, population-based studies [35, 36]. This study was conducted at a large referral center and three rural oncology clinics, and median annual household income in the study was higher than median household income in the United States. However, that suggests that financial distress might be even higher in a more nationally representative population. Sixth, since our patient cohort included majority advanced cancer patients, it may not adequately represent financial distress in patients with early stage cancer. Furthermore, uninsured patients were excluded in this study since we were focused primarily on the experiences of patients who were insured but were still at risk of financial distress. Patients receiving radiation were excluded due to the relatively short nature of a typical course of radiation therapy. Finally, since not all potentially eligible patients were approached due to study staff availability, selection bias might have been introduced.

Conclusion

In this study, duration of cancer treatment was not found to be associated with treatment-related financial distress, suggesting patients may be at risk for developing financial distress throughout their treatment continuum. Receiving curative-intent treatment was found to be significantly associated with high financial distress, independent of treatment duration. Underinsurance, unemployment, and single/divorced/widowed marital status were other factors found associated with high financial distress. Further research is needed to develop and apply innovative interventions to identify patients at risk for treatment-related financial burden. NCMJ

S.M. Qasim Hussaini, MD, MS hematology-oncology fellow, Sidney Kimmel Comprehensive Cancer Center, Johns Hopkins Hospital, Baltimore, Maryland; former internal medicine resident, Department of Internal Medicine, Duke University Medical Center, Durham, North Carolina.
Fumiko Chino, MD radiation oncologist, Department of Radiation Oncology, Memorial Sloan-Kettering Cancer Center, New York City, New York.
Christel Rushing, MS biostatistician, Duke Cancer Institute, Durham, North Carolina.
Greg Samsa, PhD professor of biostatistics and bioinformatics, Department of Biostatistics and Bioinformatics, Duke University School of Medicine, Durham, North Carolina.
Ivy Altomare, MD associate professor of medicine, Duke University School of Medicine; member, Duke Cancer Institute, Durham, North Carolina.
Jonathan Nicolla, MBA project director, Duke Cancer Institute, Durham, North Carolina.
Jeffrey Peppercorn, MD, MPH associate professor of medicine, Massachusetts General Hospital, Boston, Massachusetts.
S. Yousuf Zafar associate professor of medicine, Duke University School of Medicine; member, Duke Cancer Institute, Durham, North Carolina.

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