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Extensive financial hardship among gynecologic cancer patients starting a new line of therapy

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Abstract

Objective—Our objective was to evaluate the three domains of financial hardship (psychological response, material conditions, and coping behaviors) among gynecologic cancer patients receiving treatment.

Methods—We conducted a single-institution survey of gynecologic cancer patients starting a new line of therapy for primary or recurrent disease. Psychological response was measured using Comprehensive Score for Financial Toxicity, with score <26 indicating financial distress. We measured material conditions by patient-reported changes in employment or spending and coping behaviors by patient-reported medication non-adherence. We performed descriptive statistics, bivariate analysis, and multivariate logistic regression.

Results—Among 121 participants, the mean age was 59 years, 28% were African-American, 50% reported income <\$40,000, 74% had private insurance, 20% had only public insurance, and 7% were uninsured. Sixty-five (54%) participants screened positive for financial distress. Age <65

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MIL: Conceptualization, methodology, formal analysis, investigation, data curation, writing – original draft preparation, and project administration. MP: Conceptualization, methodology, and supervision. SSS: Investigation and data curation. TKB: Data curation. CTB: Data curation, and formal analysis. SB: Conceptualization, methodology, and supervision. WKH: Conceptualization, methodology, and supervision. All authors: Writing – review and editing.

Conflict of Interest Statement

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years (aOR 2.61, 95% CI 1.04–6.52) and income <\$40,000 (aOR 3.41, 95% CI 1.28–9.09) were associated with increased odds of screening positive for financial distress. Participants with financial distress were significantly more likely to report material hardship, including losing wages (46% vs. 18%, $p<0.01$), not paying bills on time (40% vs. 7%, $p<0.01$), and borrowing money (39% vs. 4%, $p<0.01$). Financial distress was not associated with coping behaviors, such as not taking (6% vs. 2%, $p=0.37$) or refilling medications (5% vs. 2%, $p=0.62$).

Conclusions—Financial distress affects over half of gynecologic cancer patients starting a new line of treatment and is associated with material hardship. Younger age and lower income can be used to identify patients at increased risk.

Keywords

Financial hardship; costs of care; gynecologic cancer; financial toxicity

Introduction

With rising overall health care costs and a growing proportion of patient cost sharing, there is increasing awareness of the financial hardship associated with cancer care [1–4]. This is a complex problem that can be conceptualized as described by Altice *et al.* into three distinct but overlapping domains [4]. These include: 1) psychologic response i.e., the distress or worry related to financial matters, 2) material conditions i.e., out of pocket costs, reduced income, or debt, and 3) coping behaviors i.e., maladaptive health-related behaviors, such as delaying care or not taking medications as prescribed due to cost [4].

Gynecologic cancer patients are not immune to these pressures and there are several reasons they may be particularly susceptible to experiencing financial hardship as a potential side effect of treatment [5]. First, patients often receive multiple lines of systemic therapy for recurrences and may receive other expensive treatment modalities, such as radiation. Second, patients may have fewer treatment holidays as use of maintenance therapy increases. Third, there have been expanding indications for expensive oral targeted therapies. Prior cross-sectional studies at single institutions have reported that approximately 40% of gynecologic oncology patients experience financial distress and that patients with high levels of financial distress were 12 times more likely to have borrowed money or applied for financial assistance and 7 times more likely to report delaying or avoiding medical care due to finances [6, 7].

Information on out of pocket costs and contributors to financial hardship for gynecologic cancer patients is limited. Estimates in ovarian cancer, for example, demonstrate particularly high overall healthcare costs ranging from \$66,000 to more than \$90,000 for initial treatment the year after diagnosis, including a patient out of pocket burden as high as \$5,000 even among the insured [8–10]. More than two-thirds of surveyed ovarian cancer patients reported worry about costs of treatment and time away from work and about one-third worried about transportation, which can all contribute to financial burden [11]. Moreover, the extent of financial hardship and the interaction of its three domains in gynecologic cancer patients is largely unknown, especially for women starting and actively receiving therapy in either the primary or recurrent setting. These knowledge gaps prevent an

understanding of the optimal financial distress screening strategies as well as the most effective timing and content of health system interventions to decrease financial hardship in gynecologic cancer patients.

In this paper, we used the Altice *et al.* proposed conceptual framework to better understand these three domains of financial hardship in gynecologic cancer patients [4]. Our first objective was to describe the frequency of financial distress (psychological response domain) among gynecologic cancer patients at the beginning of a new line of systemic therapy for new or recurrent disease and to determine risk factors associated with financial distress. Our second objective was to assess the relationship between financial distress (psychological response domain) and patient-reported changes in employment or spending (material conditions domain) and patient-reported medication use (coping behaviors domain).

Materials and Methods

Population

We obtained Institutional Review Board approval to conduct a longitudinal survey at our tertiary care, National Cancer Institute-designated Comprehensive Cancer Center. We followed participants over a 6-month period and administered surveys within 8 weeks of starting a new line of systemic therapy (baseline), at 3 months, and at 6 months. Herein, we report our baseline survey results collected between April 2018 and January 2019. We recruited patients diagnosed with any gynecologic cancer (ovarian, uterine, cervical, vulvar, or vaginal cancer) who were starting a new line of chemotherapy, targeted therapy, and/or immunotherapy for newly diagnosed or recurrent disease. Participants may have been receiving concurrent radiation or planning to undergo interval surgery. Participants on hormonal therapy alone were excluded. We recruited participants at our infusion unit through distribution of a study flyer and through in-person contact by research staff. Two trained study personnel through our institution's Retention and Recruitment Shared Facility administered all surveys over the phone or in-person at patient request. Participants were given a \$10 gift card incentive after completion of each survey.

Financial distress (psychological response domain)

The main outcome was financial distress (psychological response domain) measured by Comprehensive Score for Financial Toxicity (COST), a patient reported outcome measure that has been validated in cancer patients [12]. COST is an 11-item instrument that asks respondents to mark their answer on a five-point scale from "not at all" to "very much." We calculated COST based upon published guidelines and used COST <26 on a scale of 0–44 as a threshold for screening positive for financial distress [12]. We categorized financial distress based upon a proposed grading scale: mild (COST 14–25), moderate (COST 1–13), and severe (COST 0) financial distress [13].

Other financial hardship domains: material conditions and coping behaviors

To assess the other two domains of financial hardship, interviewers asked participants, "Due to your cancer diagnosis, have you had to do any of the following?" We surveyed

participants for changes in employment or spending (material conditions domain) due to their cancer diagnosis, including changing spending habits, sacrificing other things, losing wages or salary or benefits, not paying bills on time, borrowing money, applying for unemployment, taking a second job, selling a house or property, or declaring bankruptcy. We queried participants who were employed about the impact of their cancer diagnosis on their work productivity. We also surveyed participants for changes in medication use (coping behaviors domain) due to their cancer diagnosis, including not taking medications or not refilling medications as instructed.

Covariates

We surveyed participants for patient characteristics, including age (<65 vs. ≥65 years), race (Caucasian, African-American, or other), highest education level (high school diploma or less vs. more than high school diploma), marital status (married vs. not married), presence of a primary caregiver, annual household income, whether income was enough to meet basic needs or medical care needs, employment status among those in the labor force (employed vs. unemployed), insurance status (insured vs. uninsured), insurance type (only public insurance vs. any private insurance), distance traveled to our institution, and time traveled to and from our institution. We determined rural or urban residence based on zip code using rural-urban commuting area (RUCA) codes [14]. We abstracted disease and treatment characteristics from the medical record, including type of cancer (ovarian, uterine, cervical, or vulvar/vaginal cancer), days since initial diagnosis, line of therapy (first vs. subsequent line), and current treatment regimen. We collected and managed study data using REDCap electronic data capture tools (Vanderbilt University, TN).

Statistical Analysis

We performed all statistical analysis using SAS version 9.4 (Cary, NC). We calculated descriptive statistics for patient, disease, and treatment characteristics, including mean, standard deviation, median, range, frequency, and percentage. We obtained the percentage of respondents who screened positive for financial distress (COST ≥26) and who screened positive for moderate or severe financial distress (COST ≥14). For each individual COST item, we further determined percentage of each response category and calculated mean score on a scale 0–4 with a lower score corresponding to a higher level of concern (or less desired response).

To compare characteristics between groups based on financial distress using COST, we calculated Chi-square analysis or Fisher's exact tests for categorical variables and Wilcoxon rank sum for continuous variables, as appropriate. We then performed a multivariate logistic regression model for financial distress to estimate the effect of various factors on the odds of screening positive for financial distress (COST ≥26). We selected variables to include in the model that were significant on bivariate analysis (age ≥65, income <\$40,000) and variables that were thought to be clinically meaningful (uninsured status, marital status, cancer type, and subsequent vs. first line therapy). Finally, we performed unadjusted bivariate analyses to compare changes in material conditions or coping behaviors between groups based on financial distress using COST.

Results

Participant characteristics

We consented 125 participants to the study. Four participants withdrew prior to completing the baseline assessment leaving 121 evaluable participants. Table 1 summarizes participant characteristics. The mean age of participants was 59 years with 80 (66.1%) who were <65 years old. The majority of participants were Caucasian (86, 71.1%) followed by African-American (34, 28.1%). There were 33 participants (27.3%) who had a high school diploma or less, 63 (52.1%) who were married, and 69 (57.0%) who had a primary caregiver. Half of participants (55, 50.0%) had an annual household income <\$40,000 (250% of the 2019 federal poverty level of \$16,910 for a household of 2). There were 25 participants (20.8%) who reported their income was not enough for basic needs and 37 participants (30.8%) who reported their income was not enough for their medical care. A large number of participants (n=68) were not currently in the labor force (i.e., retired or homemakers); among 53 individuals considered in the labor force, most participants were employed (41, 77.4%). There were 8 participants (6.6%) who were uninsured. Among the 113 participants who had insurance coverage, most reported at least some private insurance coverage (89, 78.8%) compared to only public insurance (24, 21.2%). Participants traveled a median 100 miles in one direction to their oncologist's office and spent a median 8 hours of total time for each oncology appointment, which included the time traveling to and from the oncologist's office. There were 40 participants (33.1%) who resided in a rural area. All four major gynecologic cancer types were represented (ovarian 52.9%, uterine 28.1%, cervical 14.9%, and vulvar/vaginal 4.1%). The median days since cancer diagnosis was 219 and the majority of participants (70, 57.9%) were on their first line of systemic therapy. Type of treatment regimen is further summarized in Table 1.

Financial distress (psychological response domain) and associated risk factors

Within 8 weeks of starting a new line of therapy, 65 out of 121 participants (53.7%) had financial distress (COST <26), with 37% experiencing mild, 16% moderate, and 1% severe financial distress. Table 2 summarizes the percentage of responses and mean score for each of the COST items. There were 58% of participants who responded "not at all" to the question "I know that I have enough money in savings, retirement, or assets to cover the costs of my treatment." Approximately 4 in 10 participants (36–44%) responded "quite a bit" or "very much" to statements related to worry about future financial problems due to illness or treatment, having no choice about the amount of money spent on health care, and that out of pocket medical expenses were more than expected. There were 15% of participants who responded "not at all" or "a little bit" to being able to meet monthly expenses. Participants were most concerned about the statements "I know that I have enough money in savings, retirement, or assets to cover the costs of my treatment" (mean score 0.97) followed by "I am satisfied with my current financial situation (mean score 1.63). Participants were least concerned when presented with the statements "I am able to meet my monthly expenses" (mean score 2.47) and "I am concerned about keeping my job and income, including working from home" (mean score 3.29).

Participants who reported financial distress were significantly younger (mean age 57.1 vs. 61.5 years old, $p=0.02$), more likely to report annual household income $< \$40,000$ (63.3% vs. 34.0%, $p<0.01$), and more likely to report that their income was not enough for basic needs (32.8% vs. 7.1%, $p<0.01$) or for medical care (50.0% vs. 8.9%, $p<0.01$). The same risk factors, younger age (mean age 52.2 vs. 60.5 years old, $p<0.01$), annual household income $< \$40,000$ (79.0% vs. 44.0%, $p<0.01$), income not enough for basic needs (50.0% vs. 15.0%, $p<0.01$), and income not enough for medical care (90.0% vs. 19.0%, $p<0.01$) were associated with moderate or severe financial distress. An additional factor, being uninsured (25.0% vs. 3.0%, $p<0.01$), was identified when evaluating factors associated with moderate or severe financial distress, but not the presence of any financial distress (10.8% vs. 1.8%, $p=0.07$). Other patient, disease, and treatment characteristics were not associated financial distress (see Table 1). Younger age < 65 (aOR 2.61, 95% CI 1.04–6.52) and lower income $< \$40,000$ (aOR 3.41, 95% CI 1.28–9.09) remained significant risk factors on multivariate logistic regression when controlling for insured status, marriage status, type of cancer, and line of therapy (see Table 3).

Relationship between financial distress (psychological response domain) and material conditions or coping behaviors domains of financial hardship

Comparison of measures for material conditions and coping behaviors for participants based on financial distress measured by COST are summarized in Table 4. Participants who screened positive for financial distress were significantly more likely to report altering their spending habits (84.6% vs. 32.1%, $p<0.01$), sacrificing other things (69.2% vs. 17.9%, $p<0.01$), losing wages (46.2% vs. 17.9%, $p<0.01$), not paying bills on time (40.0% vs. 7.1%, $p<0.01$), or borrowing money (38.5% vs. 3.6%, $p<0.01$) due to their cancer diagnoses compared to participants who screened negative for financial distress. More extreme changes in material conditions, such as applying for unemployment (6.2% vs. 1.8%, $p=0.37$), getting a second job (1.5% vs. 0.0%, $p>0.99$), selling a house (1.5% vs. 0.0%, $p>0.99$), or filing for bankruptcy (0.0% vs. 1.8%, $p=0.47$) did not differ between participants who screened positive for financial distress and those who did not. These findings remained consistent when comparing participants with moderate or severe financial distress to those with mild or no financial distress (see Table 4). Among the 41 participants who were employed (data not shown), participants who screened positive for financial distress ($n=23$) were not significantly more likely than those who screened negative ($n=18$) to report that their cancer diagnosis affected the number of days missed from work (47.8% vs. 72.2%, $p=0.12$), motivation to work (34.8% vs. 22.2%, $p=0.38$), productivity of work (39.1% vs. 22.2%, $p=0.25$), or quality of work (30.4% vs. 16.7%, $p=0.47$).

In this cohort, participants who screened positive for financial distress were not significantly more likely to report coping behaviors in response to financial hardship, such as not taking medications (6.2% vs. 1.8%, $p=0.37$) or not refilling medications (4.6% vs. 1.8%, $p=0.62$) as instructed. Similarly, the frequency of coping behaviors did not differ between participants with moderate or severe financial distress compared to those with mild or no financial distress (see Table 4).

Discussion

We found that when screened for financial distress within the first 8 weeks of starting a systemic treatment, whether first or subsequent line, more than half of gynecologic cancer patients already demonstrated a psychological response related to financial hardship. This finding supports the need for proactive interventions early in the treatment course to reduce financial distress in a large proportion of our patients. Younger age and lower income were identified as risk factors for financial distress and could help identify a target population; whereas, the presence of insurance coverage was not protective. Financial distress was accompanied by a negative impact on patients' material conditions, such as losing wages and not paying bills on time. Thus, employment and non-medical necessities represent areas to focus upon in development of future interventions to minimize the impact of financial hardship on material conditions and reduce financial distress during cancer treatment.

The extent of financial distress found in our study is consistent with the higher end of prior estimates of financial distress among patients with gynecologic or other types of cancers. In a cross-sectional survey of 60 gynecologic cancer patients in all phases of care, of which half were actively receiving chemotherapy, 41% of patients screened positive for financial distress [7]. Among survivors of all cancer types, a systematic review found that between 18–49% of patients reported financial distress with estimates varying based on the validated measure used, including the COST instrument we used in this study [4, 12]. Another systematic review reported that 28–48% of cancer survivors experienced financial hardship using objective measures (i.e., medical spending to income ratios) and 16–73% using subjective measures [15]. The high occurrence of financial distress in our patient population who were all on active treatment may reflect a population that has higher current utilization of cancer services, and thus higher costs compared to other cancer survivors.

Significant risk factors for financial distress were age <65 years and annual income < \$40,000. These thresholds could be used to identify patients who are at increased risk for financial distress and may benefit from earlier or more intensive interventions. In a cross-sectional survey of 240 patients presenting to a gynecologic oncology practice, lower income, having only public insurance, and receiving chemotherapy as part of initial treatment, were associated with financial distress [6]. The population in that study, however, differs from ours as patients generally had higher income (annual income <\$50,000 in one-third but \$100,000 in another third of patients) and represented a more heterogeneous sample, including cancer patients undergoing active treatment and surveillance as well as 20% of patients who were being seen for precancerous or benign disease. While lack of insurance has been linked to financial distress [2], our study participants who were insured experienced financial distress as much as those who were uninsured or who only had public insurance. Uninsured status, however, was associated with a higher frequency of moderate or severe financial distress. This is consistent with other literature that demonstrates financial hardship even in the presence of a comprehensive public payer system. In Italy, for example, approximately one-third of the approximately 600 ovarian cancer patients enrolled in multi-center clinical trials reported having financial difficulties due to their physical condition or medical treatment [16]. Their findings show that even in a country with a National Health Service, cancer patients are not fully shielded from financial strain during treatment. In the

present study, we found that 90% of patients experiencing financial distress had insurance coverage, which further highlights the prevalence of underinsurance and may support a universal financial distress screening approach, regardless of insurance status. Other factors, including subsequent therapy, which would be associated with greater accumulation of cancer costs, and farther distance traveled, which would be associated with higher non-medical costs (i.e., transportation, lodging), were not predictive of financial distress in our study. Therefore, patient factors (i.e., age and income) may play a stronger role in the development of financial distress in gynecologic oncology patients than treatment or logistical factors.

Participants who demonstrated a psychological response to financial hardship frequently experienced a negative impact on their material conditions, including more than 80% altering their spending habits due to their cancer diagnosis and almost half of patients losing wages or not being able to pay bills on time. Evaluating the impact of financial distress interventions on the frequency of these events may allow an additional way to ensure that patients' needs are met. Among the employed participants of our study, however, financial distress was not associated with more missed days or decreased productivity. Therefore, ensuring that cancer patients maintain wages or utilize Family Medical Leave Act (FMLA) or disability benefits may be the most important goal to reduce financial distress, while intervening to reduce absenteeism and improve productivity may be less relevant. A survey of cancer patients in the United Kingdom found that those who successfully returned to work were significantly more likely to have received advice from their doctor about work or have been offered a return to work meeting with their employer [17]. Employment concerns extend into cancer survivorship as a systematic review found that survivors were at increased risk for unemployment, early retirement, and were less likely to be re-employed compared to patients without a history of cancer [18]. Additional education related to managing the impact of treatment on a patient's ability to work represent a potential area to target in the development of future financial distress interventions. Similarly, it would be important to expand resources specific to non-medical necessities, such as paying bills. Fortunately, extreme material hardship such as becoming unemployed or filing for bankruptcy were uncommon in our cohort. These findings align with LIVESTRONG and Medical Expenditure Panel Survey data in which 13% of cancer survivors borrowed money or went into debt (up to 34% when accounting for family members who also borrowed money or went into debt) and 2–3% who filed for bankruptcy [2, 19].

In contrast, patients experiencing financial distress reported little impact on health-related coping behaviors. This differs from prior studies that have demonstrated decreased adherence to medications or delays in care due to cost concerns [6, 7, 20]. Contrary to our study, many of these studies in other cancer types have evaluated oral therapies, which are covered under separate prescription benefits than traditional therapies administered as infusions in outpatient or inpatient settings. In addition, our institution routinely screens gynecologic cancer patients for financial distress during the intake process using a single question "Do you have trouble paying for any of your medications?" which may contribute to the lower frequency of patient-reported coping behaviors related to medications in our cohort. While we did not find a significant impact on health-related coping behaviors, future

evaluation of the impact of financial hardship on clinical outcomes, such as treatment delays or cancer survival, is warranted.

Our study shows that the use of the patient reported outcome measure, COST, to screen for financial distress appears feasible and relevant to our study population. However, further evaluation of its routine use within a busy clinical workflow may be necessary. Validation of clinically meaningful thresholds is also needed as patients with more severe financial distress may have different characteristics or needs than those with more mild financial distress. Implementation of serial financial distress screening would allow health care teams to track changes in financial distress, whether to identify patients who develop distress later or to confirm improvement after an intervention is provided. Data to inform the optimal screening interval is lacking; however, our future analysis evaluating the trajectory of financial distress over the course of treatment (i.e., at 3 and 6-month follow-up) will enhance our understanding of the appropriate timing for financial distress screening and follow-up. An alternative screening strategy that deserves evaluation would be to implement risk factor-based screening using characteristics such as age and income. Certain information, however, such as patients' household income may not always be readily available to the clinical care team, but the use of a proxy for income such as ZIP codes could also be considered.

Limitations of our study include non-response bias, which may overestimate the prevalence of financial distress as non-responders may have been more likely to feel unaffected by financial hardship than participants who responded. The survey is also limited by small sample size and was conducted at a single, tertiary care referral cancer center in the southeastern United States. In this cohort, patients traveled a median of 100 miles in one direction for their cancer care and had access to specific infrastructure and resources available at our institution. Thus, our findings may not be representative of patients receiving care in other geographic regions or health care settings. Unmeasured confounders, including patients' social support, concurrent psychologic/psychiatric conditions, and underlying financial health, may also have an impact on financial distress. Strengths of our study include a diverse patient population in terms of race and socioeconomic status as well as use of a validated patient reported outcome measure for financial distress. While there are other measures of financial distress, such as the InCharge Financial Distress/Financial Well-Being Scale; we selected COST because it is validated in cancer patients.[21]

Our study demonstrates that financial distress is common, affecting over half of gynecologic cancer patients starting a new line of systemic therapy. Ensuring that patients retain a source of wages and can pay for necessities, such as bills, represent areas to target in the development of future educational materials and resources. The subspecialty of gynecologic oncology is unique as the same health care team typically oversees the care of patients throughout the cancer care continuum, including through diagnosis, surgery, medical treatment, and survivorship; this medical approach provides numerous opportunities to prevent, identify, and address the financial hardship that cancer patients face. Ultimately, systematic efforts to implement universal screening or risk-stratification and subsequently to develop and evaluate novel interventions aimed at easing the financial burden that gynecologic oncology cancer patients experience represent a critical step to improving patient-centered cancer care delivery.

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Table 1.

Patient, disease, and treatment characteristics for all participants and based upon financial distress measured by Comprehensive Score for Financial Toxicity (COST)

	All participants	Screened positive for financial distress (COST <26)	Screened negative for financial distress (COST ≥26)	Chi-square or Fisher's exact test	Moderate or severe financial distress (COST <14)	Mild or no financial distress (COST ≥14)	Chi-square or Fisher's exact test
	n (%) avg +/- std dev median (min-max)			p-value	n (%) avg +/- std dev median (min-max)		p-value
Overall	121 (100.0)	65 (53.7)	56 (46.3)	-	20 (16.5)	101 (83.5)	-
Age (years)	59.1 +/- 10.5	57.1 +/- 10.0	61.5 +/- 10.6	0.02	52.2 +/- 8.6	60.5 +/- 10.3	<0.01
Age							
<65 years	80 (66.1)	50 (76.9)	30 (53.6)	<0.01	19 (95.0)	61 (60.4)	<0.01
65 years	41 (33.9)	15 (23.1)	26 (46.4)		1 (5.0)	40 (39.6)	
Race							
Caucasian	86 (71.1)	45 (69.2)	41 (73.2)	0.48	15 (75.0)	71 (70.3)	0.83
African-American	34 (28.1)	20 (30.8)	14 (25.0)		5 (25.0)	29 (28.7)	
Other	1 (0.8)	0 (0.0)	1 (1.8)		0 (0.0)	1 (1.0)	
High school diploma or less	33 (27.3)	20 (30.8)	13 (23.2)	0.35	5 (25.0)	28 (27.7)	0.80
Married	63 (52.1)	29 (44.6)	34 (60.7)	0.08	7 (35.0)	56 (55.5)	0.09
Has primary caregiver	69 (57.0)	36 (55.4)	33 (58.9)	0.69	11 (55.0)	58 (57.4)	0.84
Annual income <\$40,000	55 (50.0)	38 (63.3)	17 (34.0)	<0.01	15 (79.0)	40 (44.0)	<0.01
Income not enough for basic needs¹	25 (20.8)	21 (32.8)	4 (7.1)	<0.01	10 (50.0)	15 (15.0)	0.001
Income not enough for medical care²	37 (30.8)	32 (50.0)	5 (8.9)	<0.01	18 (90.0)	19 (19.0)	<0.01
Employed³	41 (77.4)	23 (69.7)	18 (90.0)	0.10	11 (64.7)	30 (83.3)	0.17
Unemployed³	12 (22.6)	10 (30.3)	2 (10.0)		6 (35.3)	6 (16.7)	

	All participants	Screened positive for financial distress (COST <26)	Screened negative for financial distress (COST >26)	Chi-square or Fisher's exact test	n (%) avg +/- std dev median (min-max)	p-value	Mild or no financial distress (COST <14)	Chi-square or Fisher's exact test
Insured	113 (93.4)	58 (89.2)	55 (98.2)	0.07	15 (75.0)	98 (97.0)	<0.01	
Uninsured	8 (6.6)	7 (10.8)	1 (1.8)		5 (25.0)	3 (3.0)		
Only public insurance ⁴	24 (21.2)	16 (27.6)	8 (14.6)	0.09	5 (33.3)	19 (19.4)	0.31	
Any private insurance ⁴	89 (78.8)	42 (72.4)	47 (85.5)		10 (66.7)	79 (80.6)		
Distance traveled to the oncologist's office (miles)	100.0(2–984)	100.0(2–984)	114.0(2–720)	0.85	105.0 (10–800)	100 (2–984)	0.67	
Total time spent for each oncology appointment, including traveling to and from the oncologist's office (hours)	8.0(0.1–96)	8.0(0.1–96)	8.0(0.1–60)	0.80	8.0 (0.1–96.0)	8.0 (0.1–80.0)	0.36	
Rural	40 (33.1)	22 (33.9)	18 (32.1)	0.84	6 (30.0)	34 (33.7)	0.75	
Urban	81 (66.9)	43 (66.2)	38 (67.9)		14 (70.0)	67 (66.3)		
Type of cancer								
Ovarian	64 (52.9)	30 (46.2)	34 (60.7)		10 (50.0)	54 (53.5)	0.14	
Uterine	34 (28.1)	20 (30.8)	14 (25.0)	0.42	3 (15.0)	31 (11.9)		
Cervical	18 (14.9)	12 (18.5)	6 (10.7)		6 (30.0)	12 (11.9)		
Vulvar/vaginal	5 (4.1)	3 (4.6)	2(3.6)		1 (5.0)	4 (4.0)		
Days since diagnosis	219.0(0–7231)	219.0(0–4046)	238.5(15–7231)	0.57	119.0(0.0–2812.0)	275.0(14.0–7231.0)	0.54	
First line systemic therapy	70 (57.9)	39 (60.0)	31 (55.4)	0.61	13 (65.0)	57 (56.4)	0.48	
Treatment regimen								
Chemotherapy alone	78 (64.5)	38 (58.5)	40 (71.4)	0.35	7 (35.0)	71 (70.3)	<0.01	
Chemotherapy + radiation	12 (9.9)	7 (10.8)	5 (8.9)	0.14	5 (25.0)	7 (6.9)	<0.01	
Chemotherapy + targeted therapy	18 (14.9)	12 (18.5)	6 (10.7)	0.74	7 (35.0)	11 (10.9)	0.03	
Targeted therapy alone	9 (7.4)	5 (7.7)	4 (7.1)	0.23	7 (35.0)	9 (8.9)	0.01	
				>0.99	0 (0.0)	9 (8.9)	0.35	

	All participants	Screened positive for financial distress (COST <26)	Screened negative for financial distress (COST ≥26)	Chi-square or Fisher's exact test	Moderate or severe financial distress (COST <14)	Mild or no financial distress (COST ≥14)	Chi-square or Fisher's exact test
	n (%) avg +/- std dev median (min-max)			p-value	n (%) avg +/- std dev median (min-max)		p-value
Immunotherapy	3 (2.5)	3 (4.6)	0 (0.0)	0.25	1 (5.0)	2 (2.0)	0.42
Oral PARP ⁵ inhibitor	1 (0.8)	0 (0.0)	1 (1.8)	0.46	0 (0.0)	1 (1.0)	>0.99

¹Excluding 1 participant who responded 'prefer not to answer' and 1 participant who responded 'I don't know'

²Excluding 1 participant who responded 'prefer not to answer'

³Excluding 68 not in labor force based on Bureau of Labor Statistics definition (https://www.bls.gov/cps/cps_hhgm.htm#why)

⁴Excluding 8 uninsured

⁵PARP = Poly(ADP)-ribose polymerase

Table 2.

Mean response to each item on the Comprehensive Score for Financial Toxicity (COST) patient reported outcome measure¹

Please circle or mark one number per line to indicate your response as it applies to the past 7 days (scale 0–4)	Not at all (%)	A little bit (%)	Some what (%)	Quite a bit (%)	Very much (%)	Mean
I know that I have enough money in savings, retirement, or assets to cover the costs of my treatment	58	11	14	12	6	0.97
I am satisfied with my current financial situation	33	9	29	18	10	1.63
*I am frustrated that I cannot work or contribute as much as I usually do	27	13	16	21	23	2.01
*I worry about the financial problems I will have in the future as a result of my illness or treatment	23	15	19	27	17	2.02
I feel in control of my financial situation	19	9	34	21	17	2.08
*I feel I have no choice about the amount of money I spend on care	31	16	14	25	14	2.24
*My out of pocket medical expenses are more than I thought they would be	29	14	22	24	12	2.25
*My cancer or treatment has reduced my satisfaction with my present financial situation	27	21	18	19	15	2.26
*I feel financially stressed	30	22	17	13	18	2.32
I am able to meet my monthly expenses	10	5	29	40	16	2.47
*I am concerned about keeping my job and income, including working from home	71	10	5	6	8	3.29

¹ Survey questions are shown from lowest to high score rather than the standard order displayed on the validated instrument

* Items have been reverse scored based on published scoring guidelines so that lower mean score corresponds to a higher level of concern (less desired response) for all questions

Table 3.

Multivariate logistic regression model to estimate the effect of various factors on the odds of screening positive for financial distress using Comprehensive Score for Financial Toxicity (COST) <26

Variable	Odds Ratio (95% CI)
Age <65	2.61 (1.04–6.52)
Income <\$40,000	3.41 (1.28–9.09)
Uninsured	2.81 (0.29–26.8)
Not married	0.88 (0.34–2.25)
Ovarian cancer ¹	0.54 (0.05–6.26)
Uterine cancer ¹	0.65 (0.05–7.94)
Cervical cancer ¹	0.63 (0.05–8.57)
Subsequent line of therapy ²	1.0 (0.44–2.28)

¹Reference group: Vaginal/vulvar cancer

²Reference group: First line of therapy

Table 4.

Changes in material conditions and coping behaviors based upon financial distress measured by Comprehensive Score for Financial Toxicity (COST)

Due to your cancer diagnosis, have you experienced any of the following?	Screened positive for financial distress (COST <26)	Screened negative for financial distress (COST ≥26)	Chi-square or Fisher's exact test	Moderate or severe financial distress (COST <14)	Mild or no financial distress (COST ≥14)	Chi-square or Fisher's exact test
Overall	65 (53.7)	56 (46.3)	-	20 (16.5)	101 (83.5)	-
Material conditions			p-value	n (%)	n (%)	p-value
Changed spending habits	55 (84.6)	18 (32.1)	<0.01	12 (60.0)	28 (27.7)	<0.01
Sacrificed other things	45 (69.2)	10 (17.9)	<0.01	12 (60.0)	15 (14.9)	<0.01
Lost wages or salary or benefits	30 (46.2)	10 (17.9)	<0.01	20 (100.0)	53 (52.5)	<0.01
Not paid bills on time	26 (40.0)	4 (7.1)	<0.01	18 (90.0)	37 (36.6)	<0.01
Borrowed money	25 (38.5)	2 (3.6)	<0.01	13 (65.0)	17 (16.8)	<0.01
Applied for unemployment	4 (6.2)	1 (1.8)	0.37	2 (10.0)	3 (3.0)	0.19
Took a second job	1 (1.5)	0 (0.0)	>0.99	0 (0.0)	1 (1.0)	>0.99
Sold a house or property	1 (1.5)	0 (0.0)	>0.99	1 (5.0)	0 (0.0)	0.17
Declared bankruptcy /	0 (0.0)	1 (1.8)	0.47	0 (0.0)	1 (1.0)	>0.99
Coping behaviors			p-value	n (%)	n (%)	p-value
Not taken medications as instructed	4 (6.2)	1 (1.8)	0.37	1 (5.0)	4 (4.0)	>0.99
Not refilled medications	3 (4.6)	1 (1.8)	0.62	2 (10.0)	2 (2.0)	0.13

/ 1 participant in the group who screened positive for financial distress responded 'prefer not to answer'