



HHS Public Access

Author manuscript

Gynecol Oncol. Author manuscript; available in PMC 2023 March 21.

Published in final edited form as:

Gynecol Oncol. 2021 May ; 161(2): 595–600. doi:10.1016/j.ygyno.2021.01.040.

Crowdsourcing to measure financial toxicity in gynecologic oncology

Katharine M. ESSELEN, MD, MBA,

Department of Obstetrics and Gynecology, Beth Israel Deaconess Medical Center, Boston, MA, USA; Department of Obstetrics, Gynecology and Reproductive Biology, Harvard Medical School, Boston, MA, USA

Ms. Hannah STACK-DUNNBIER, BS,

Department of Obstetrics and Gynecology, Beth Israel Deaconess Medical Center, Boston, MA, USA

Ms. Annika GOMPERS, MPhil,

Department of Obstetrics and Gynecology, Beth Israel Deaconess Medical Center, Boston, MA, USA

Michele R. HACKER, ScD, MSPH

Department of Obstetrics and Gynecology, Beth Israel Deaconess Medical Center, Boston, MA, USA; Department of Obstetrics, Gynecology and Reproductive Biology, Harvard Medical School, Boston, MA, USA

Abstract

Objective: To utilize a novel crowdsourcing method to measure financial toxicity and its effects amongst a national cohort of gynecologic cancer patients.

Methods: Crowdsourcing methods were used to administer an online survey to women in the United States with gynecologic cancers. We used the Comprehensive Score for Financial Toxicity (COST) tool to measure financial toxicity and the EQ-5D-3L to measure quality of life (QOL). Based on prior work, we defined high financial toxicity as a COST score ≥ 23 . We assessed correlation of COST scores with QOL. We used log-binomial regression to examine associations between high financial toxicity and cost-coping strategies.

Results: Among the final study sample of 334 respondents, 87% were white, median age at diagnosis was 55 (interquartile range 47-63), 52% had stage III or IV disease and 90% had private insurance or Medicare. Median COST score was 24 (interquartile range 15-32) and 49% of respondents reported high financial toxicity. Greater financial toxicity was correlated with worse

Corresponding Author: Katharine M. Esselen, MD, MBA, Beth Israel Deaconess Medical Center, 330 Brookline Avenue, Boston, MA 02215, kesselen@bidmc.harvard.edu, Tel: 617-667-4040; Fax: 617-667-4173.

Author Contributions: Katharine Esselen: Conceptualization, Methodology, Supervision, Writing – original draft preparation. Hannah Stack-Dunnbier: Investigation, Project administration. Annika Gompers: Formal analysis, Writing – reviewing and editing. Michele Hacker: Conceptualization, Methodology, Supervision, Writing – reviewing and editing.

Paper Presentation: This work was presented at the 39th Annual Meeting of the New England Association of Gynecologic Oncologists, Bretton Woods, NH, June 7-9, 2019 and was accepted for presentation at the Society for Gynecologic Oncology Annual Meeting in Toronto, Canada in March 2020, which was canceled due to COVID-19 travel ban.

Conflict of Interest: The authors report no conflict of interest.

QOL ($p < 0.001$). Participants reporting high financial toxicity were more likely to use cost-coping strategies, including spending less on basic goods (RR: 3.3; 95% CI: 2.1-5.1), borrowing money or applying for financial assistance (RR: 4.0; 95% CI: 2.4-6.9), and delaying or avoiding care (RR: 5.6; 95% CI: 2.6-12.1).

Conclusions: Crowdsourcing is an effective tool to measure financial toxicity. Nearly half of respondents reported high financial toxicity, which was significantly associated with worse QOL, utilization of cost-coping strategies and delays or avoidance of care.

Introduction:

Financial toxicity is a serious adverse outcome of cancer care. It encompasses both the objective financial burden and the subjective financial distress experienced by patients as a result of their cancer diagnosis and its associated treatments [1]. One systematic review of 74 observational studies of cancer patients reported that 49% of patients experience material or psychologic financial distress as a result of their cancer care [2], while another systematic review of financial toxicity and cancer survivors estimated that 28-48% of cancer survivors experience financial toxicity as assessed by monetary measures and 16-73% by subjective measures [3]. Commonly cited demographic factors associated with financial distress included female gender, low income, loss of income, younger age, undergoing adjuvant or antineoplastic therapies, more recent diagnosis, advanced cancer, lack of health insurance and farther distance from treatment centers [2-3].

Two recent studies, including a prior study at our institution, examined financial toxicity in gynecologic cancer patients and demonstrated high financial toxicity in one-third to one-half of patients surveyed. Both studies were single institution series containing a heterogeneous group of gynecologic oncology diagnoses and showed that younger age and lower income were significantly associated with increased financial toxicity, while health insurance was not protective in either study. Both studies demonstrated that high financial toxicity was associated with economic cost-coping strategies such as changing spending habits, borrowing money or applying for financial assistance [4-5]. Additionally, in our study, we showed that patients with high financial toxicity were 7.3 times more likely to report delaying or avoiding care [4]. Delay of care is a concerning behavioral coping mechanism, and there is limited understanding of its impact and the impact of financial toxicity on clinical outcomes. However, one particularly alarming study by Ramsey et al. demonstrated that cancer patients experiencing severe financial hardship may have increased risk of mortality in the first five years after diagnosis [6]. Limitations of our prior study and many others are the geographically homogeneous nature of single institution series, inclusion of a variety of different cancer diagnoses and limited detail on cost-coping strategies.

We sought to expand the understanding of financial toxicity in a more geographically diverse and larger cohort of gynecologic cancer patients compared to previous studies by utilizing novel crowdsourcing methods. Crowdsourcing in cancer research is a recently recognized and underutilized tool [7]. Methods of crowdsourcing include internet-based advertising and online surveys or questionnaires that aim to reach a large number of participants

in a relatively economic and efficient manner. Therefore, the aim of this study was to use an online crowdsourcing method to estimate the prevalence of financial toxicity and its association with quality of life and cost-coping measures. A secondary aim was to examine differences in financial toxicity and cost-coping strategies amongst the three major gynecologic cancer diagnoses (uterine, ovarian and cervical cancers).

Materials and Methods:

Crowdsourcing

After obtaining approval from the Institutional Review Board at Beth Israel Deaconess Medical Center, we selected the Facebook advertising platform to recruit participants. We chose Facebook because it is one of the largest social media platforms, with 1.79 billion daily active users and 2.6 billion monthly active users. In addition, 69% of adults in the U.S. claim they use Facebook [8]. Thus, we created a series of Facebook advertisements targeting women with ovarian, uterine, and cervical cancers. The advertisement included a link to a consent form and our online survey administered through REDCap – a secure, HIPAA compliant, web-based data collection tool [9]. We used Facebook’s advertising hub to target the advertisements to women over the age of 18 living in the United States. Six advertisements were run for a total of 7 weeks. Each ad targeted patients with a specific cancer type, i.e. ovarian, uterine and cervical cancer, and 2 ads were run for each cancer type at different time points. One of 2 advertisements for ovarian cancer patients was restricted to female users over the age of 18 who had “liked” the National Ovarian Cancer Coalition (NOCC) Facebook page. Following the administration of each ad, Facebook provided analytics for each ad, including a report of individual users reached and how many people clicked on the advertisement.

Survey design

The cross-sectional survey included demographic and disease questions, the Comprehensive Score for Financial Toxicity (COST) tool and the EQ-5D-3L to measure health-related quality of life (QOL). Demographic information collected included education level, insurance, and employment status, as well as changes to individual and caregiver employment. The COST tool is an 11-item questionnaire that assesses participant financial concerns, including self-reported financial stress, high out-of-pocket medical costs, and inability to meet monthly expenses. The tool is scored from 0 to 44, with a lower score corresponding to higher financial toxicity [10-11]. We included data from incomplete surveys if at least 6 of the 11 COST tool items were complete. In these instances, as validated previously, participants’ scores were divided by the number of questions answered and scaled accordingly [10-11]. The EQ-5D-3L is a validated tool that assesses health-related QOL [12]. It also asks patients to rate their overall health on a score from 0 to 100, with 0 being the worst health imaginable and 100 being the best health imaginable. In addition to these tools, patients were also asked about cost-coping strategies used to manage the cost of treatment. This survey was adapted from our original financial toxicity survey [4], and included disease and treatment questions specific to cancer type and was administered via REDCap [9].

Statistical analysis

Based on our prior work, we defined high financial toxicity as a COST score ≥ 23 . Data were stratified by high and low financial toxicity, and descriptive statistics were reported as median (interquartile range) or frequency (percentage). We used zip codes provided by the participants to assign a state and region along with a Community Need Index (CNI) score to each participant. The CNI is a tool that combines five socioeconomic variables, including income, ethnicity, education, insurance and housing status to assign a score (range 1-5) to each zip code as a proxy for socioeconomic need based on census data [13].

To compare demographic and disease characteristics between high and low financial toxicity groups, we used Chi-square or Fisher's exact test for categorical variables and Wilcoxon rank sum test for continuous variables. P values <0.05 were considered to be statistically significant. We calculated the Spearman correlation coefficient to quantify the association between COST score and self-reported overall health and QOL. We used log-binomial regression to calculate crude and adjusted risk ratios (RRs) and 95% confidence intervals (CIs). In one series of models we used change in work status as the exposure and financial toxicity as the outcome, while in another series of models we used association between high financial toxicity as the exposure and each cost-coping strategy as an outcome. We considered income, CNI score and insurance status as potential confounders, as we understand these variables to precede and potentially cause financial toxicity and cost-coping strategies. We therefore adjusted for income, CNI, and insurance, and retained in the model those variables that appreciably influenced the risk ratio. Consequently, all models were adjusted for income. We used SAS 9.4 (SAS Institute, Cary, North Carolina) for the analysis.

Results:

In total, 163,040 individuals were reached by the advertisements. Of those reached, 2,358 people clicked on the survey link and 895 took the survey for a conversion rate of 38%. Of these surveys, 72 were removed for not having a history of ovarian, uterine, or cervical cancer and 489 were removed for having an incomplete COST tool, leaving a final study population of 334. A total of \$2,426.73 was spent and the cost per individual reached was \$0.015, per individual who clicked on the link was \$1.03, per individual who took any part of the survey was \$2.71 and per analyzed participant was \$7.27.

The median age of respondents was 55 (47-63) years. Most respondents (87%) identified as white, 63% were married or partnered, and 75% had education beyond high school. Thirty-nine percent of respondents reported being retired, while an equal number (39%) reported full- or part-time employment. Approximately half of respondents had private insurance and 16% had Medicare with private supplemental and 25% had Medicare only. Nearly half of respondents had incomes $< \$60,000$. Respondents represented all regions of the United States with the greatest proportion (36%) of respondents coming from the South. More than half (65%) lived in Medicaid expansion states. (Table 1) High financial toxicity was significantly associated with younger age, race, employment status, insurance type, income, geographic region and Medicaid expansion state status (all $p < 0.05$).

Primary diagnoses included ovarian (63%), uterine (23%), cervical (15%) cancers. More than half of respondents had advanced stage at diagnosis and 72% reported having multi-modal therapies for their initial treatment. Median years since diagnosis was 5 (2-10) and 25% reported their cancer had recurred. In unadjusted analyses, high financial toxicity was significantly associated with cancer site of origin ($p<0.001$) and complications from surgery ($p=0.015$), but not with stage, years since diagnosis, type of initial treatment or surgery, disease recurrence or current status (all $p>0.05$). (Table 2)

The median COST score in the population was 24 (15-32). The high financial toxicity group (COST score of 23, 49% (162/334)) had a median score of 15 (10-20) and the low financial toxicity group (COST score 24, 51% (172/334)) had a median score of 31 (28-36). Sixty-seven percent of respondents with cervical cancer, 50% of respondents with ovarian cancer and only 33% of those with uterine cancer reported high financial toxicity. Greater financial toxicity was significantly correlated with poorer self-rated health ($r=0.39$; $p<0.001$) and worse QOL ($r=0.49$; $p<0.001$). Socioeconomic position, as measured by CNI score, was not significantly associated with financial toxicity or self-rated health.

Respondents had increased risk of high financial toxicity if they reported that since their diagnosis they moved from full to part-time employment (RR 1.9; 95% CI 1.5-2.3), needed to take unpaid time off (RR 1.7; 95% CI 1.3-2.2) or lost their job (RR 1.7; 95% CI 1.3-2.2). Meanwhile, there was no increased risk of high financial toxicity for those participants who reported taking paid time off (RR 1.1; 95% CI 0.8-1.4) or retiring early (RR 1.2; 95% CI 0.98-1.5). The same employment questions were asked about the primary caregivers, and only a caregiver taking unpaid time off was associated with high financial toxicity (RR 1.6; 95% CI 1.2-2.1).

A substantial portion of all survey respondents employed economically-based cost-coping strategies such as borrowing money, using savings, or reducing spending in order to pay for their care (Table 3). Patients with high financial toxicity were 4 times as likely to apply for financial assistance, 4 times more likely to file for bankruptcy or mortgage their home, twice as likely to report using savings and more than 3 times as likely to reduce spending on basic goods and leisure (Table 3). Notably, those with ovarian and cervical cancer and high financial toxicity were more likely to employ these economic coping strategies, while among those with uterine cancer there was not a significant association between financial toxicity and economic cost-coping strategies. Finally, respondents with high financial toxicity were 1.6 times more likely to want to discuss the cost of care with their providers (95% CI 1.2 - 2.1).

High financial toxicity was significantly associated with delaying and avoiding medical care. Notably, when adjusted for income, patients with high toxicity were 5.6 times (95% CI 2.6-12.1) more likely to delay or avoid medical visits and 4.0 times (95% CI 1.7-9.5) more likely to avoid filling prescriptions. Nine percent of patients reported delaying their surgery, chemotherapy, or radiation in the high financial toxicity group as opposed to 0% of patients in the low toxicity group. Of the 14 respondents who delayed surgery, chemotherapy, or radiation, the median COST score was 6.5 (4.0-12.1). When stratified by disease site, ovarian cancer respondents with high financial toxicity were 7.1 times (95% CI 2.6-19.3)

and cervical cancer respondents 5.9 times (95% CI 1.5-23.8) more likely to report delaying or avoiding care, while those with uterine cancer did not report increased risk of delays in care (RR 1.1; 95% CI 0.55-2.2).

Discussion:

We demonstrated that crowdsourcing was an effective tool to measure financial toxicity amongst a more geographically diverse population of gynecologic cancer patients. Nearly half of the respondents reported high financial toxicity that was significantly associated with worse QOL, increased utilization of cost-coping strategies and delays or avoidance of care.

Internet-based crowdsourcing is a relatively new concept and only recently recognized as a potential method for conducting cancer research [7,14]. Online crowdsourcing has the potential to reach large populations of patients in a relatively efficient manner. Compared to our single institution study conducted over 6 months with additional months spent completing data entry for 240 evaluable surveys, this study collected 334 completed surveys in 7 weeks [4]. Additionally, it was an effective way to reach a broader, more geographically diverse population with a specific disease. Our respondents represented all regions of the country with the greatest proportion from the South and the least from the Midwest. Furthermore, our conversion rate, the rate at which those who click the link then proceed to participate in the survey, was 38%, which is significantly higher than the median of 4% in a systematic review of Facebook recruitment for health research, perhaps suggesting that Facebook users with a gynecologic cancer diagnosis who click the link are motivated to participate in research. In this review, 35 studies met inclusion criteria and after excluding outliers, the cost per click was lower than ours at \$0.51 (our study \$1.07), but median cost per participant was \$14.41 (our study \$7.27). These costs are likely significantly less than other methods of recruitment.

The Facebook crowdsourcing method was a time and cost-efficient method of recruitment, but it is reliant on self-report, which raises concerns about the accuracy of the results. Additionally, the online nature of the survey may lead to sampling bias and therefore, the generalizability of the participants is harder to measure. The median age (55 years) is very similar to our original study, in which we recruited all women at our institution visiting the gynecologic oncology clinic (56 years), and in the Liang et al. analysis the mean age was 59 years. The distribution of stage and initial treatments appear consistent with standard presentations and therapies across all three cancer types. (Supplemental Table 2) For example, approximately 66% of ovarian cancer respondents reported stage III/IV disease, while 61% of endometrial cancer respondents reported stage I/II disease. However, the distribution of respondents' cancer diagnoses do not mirror the annual incidence (2017) of uterine (63%), ovarian (23%) or cervical (14%) cancer [15]. The disproportionate number of ovarian cancer respondents (63%) as compared to uterine (23%) and cervical (15%) cancer respondents may be a result of one of the two ovarian cancer advertisements that was specifically targeted to those who had "liked" the NOCC Facebook page. Alternatively, individuals with ovarian cancer may represent a group more likely to utilize Facebook and engage in an online survey. Of note, there is also a slight over-representation of white participants at 87% of respondents, while in 2017 approximately 82% of new

diagnoses of these cancer types were white [15]. Median income in the United States in 2019 was \$65,712 and 50% of our respondents reported an income less than \$60,000 [16]. As described above, the similarities to prior financial toxicity survey cohorts and national cancer statistics, suggest that this Facebook crowdsourcing cohort is a reasonably representative sample. Nonetheless, more work is needed to refine this novel crowdsourcing method to ensure accuracy of data and increase overall participation and diversity through improving conversion rates and broadening recruitment strategies.

The prevalence of high financial toxicity in this cohort (49%) was higher than in a cohort from our single institution (33%) [4]. However, this prevalence was very similar to Liang et al. who reported 54% of patients screening positive for financial distress at a slightly higher threshold of COST score (<26) and Smith et al. reporting 49% in a recent systematic review of financial burden experienced by cancer patients [2,5]. There are no well-established definitions of high and low financial toxicity using the COST score. We elected to use the same cutoff utilized in our original analysis, which is similar to those used in other studies. However, future work should continue to evaluate the clinical significance of various ranges of the COST score [4,5,7].

Interestingly, prevalence of financial toxicity clearly varied across the three major cancer diagnoses, but was not impacted by stage, years since diagnosis or initial treatment or cancer recurrence. Cervical and ovarian cancer patients were more at risk in this analysis, though type of gynecologic cancer has not previously been shown to be significant [4,5]. While extent of initial treatment and mode of surgery were not associated with high financial toxicity, surgical complications were. This may be an important risk factor to include in future investigations and to use when screening patients for financial toxicity in practice. As previously demonstrated across numerous studies, increased financial toxicity strongly correlates with worse QOL measures and self-rated health [2-5].

With regard to employment status, we found a higher proportion of part-time, unemployed and disabled participants in the high financial toxicity group, which was similar to prior reports [2,17]. When asked about changes in employment and compensation since diagnosis, those who needed to move from full- to part-time employment, took unpaid time off, or lost their job all were at increased risk of high financial toxicity. Meanwhile, those who did not have any change in employment status, took paid time off, or retired early were not at an increased risk for high financial toxicity. These findings suggest that improved sick leave policies may be an important intervention to protect cancer patients from financial distress or burden. We asked the same questions of participants with regard to the employment status of their primary support person or caregiver and found that only caregiver unpaid time off was associated with high financial toxicity for the participant.

Participants reporting high financial toxicity were significantly more likely to employ economic cost-coping measures to mitigate financial distress. Interestingly, when stratified by disease site, only those patients with high toxicity with a diagnosis of ovarian and cervical cancer were more likely to employ these economic cost-coping strategies such as reducing spending on leisure or basic goods, borrowing money, applying for financial assistance and using savings. Notably, there were no patients with a diagnosis of cervical

cancer with low financial toxicity who used any of these strategies, thus the risk ratios could not be calculated. Perhaps most worrisome is that participants with high financial toxicity were 4.2 times more likely to report drastic economic cost-coping strategies including mortgaging their homes or filing for bankruptcy. Ramsey et al. showed that cancer patients in Washington State had a 2.65 times greater chance of bankruptcy compared to those without cancer [18]. In a second analysis, using bankruptcy as a marker for severe financial distress, it was found that those cancer patients who filed for bankruptcy had a 1.8 times higher all-cause mortality rate as compared to those who did not. Of note, when this cohort was stratified by cancer type, uterine cancers did not have an increased risk of death as compared to breast, colon, lung and prostate cancers [6].

It has been hypothesized that severe financial distress may drive non-compliance with recommended care and therefore cause worse oncologic outcomes. A meta-analysis demonstrated almost twice the odds of cancer medication non-adherence in patients experiencing financial burden [2]. In our prior study, patients with high financial toxicity were 7.2 times more likely to report delaying or avoiding care. In the current study, after adjusting for income, patients with high financial toxicity were 3.8 times more likely to delay or avoid care, but when stratified by disease site, respondents with ovarian cancer or cervical cancer were 7.1 and 5.9 times more likely, respectively, to report delaying or avoiding care. In addition, among participants with high financial toxicity, many reported delaying or avoiding medical visits (31%), filling prescriptions (18%), and chemotherapy, radiation or surgery (9%). Among those who reported delaying or avoiding chemotherapy, radiation or surgery, median COST score was 6.5, an exceedingly low score suggesting the most severe toxicity. This may represent a group of patients most in need of an intervention and should be the focus of future screening and intervention studies. Currently, there are no well-studied, high impact interventions for financial toxicity, and proposed solutions range from health system reform to financial assistance programs [19]. One intervention with growing interest is the development of financial navigation programs.

The strengths of the study are that, to our knowledge, it is the first report of utilizing a crowdsourcing method to measure financial toxicity. We successfully reached a geographically diverse set of patients across the United States and the disease and demographic characteristics of the respondents were reasonably similar to the general population and to prior studies, as described above. The main limitation of our study is that the use of the Facebook platform may limit generalizability as it excludes patients without internet access or a Facebook account. Further, the proportions of individuals with gynecologic malignancies who have Facebook accounts or, more importantly, are regular users is unknown. However, it is reassuring that the overall findings and prevalence of financial toxicity in our study were similar to two previously reported single institution series, [4-5] thereby substantiating many of the findings. Another limitation was that the survey was advertised and conducted in English; thus, we were missing data from many patients, the illiterate and non-English speaking. Further, there may also be an element of survivor bias with respondents reporting a median of 5 years since diagnosis, thus this platform may miss those suffering from more severe disease or who die earlier in the course of their disease. Additionally, more than half of the people who clicked the link did not complete an adequate number of questions of the COST tool to be included in the analysis.

Therefore, future work needs to be done to optimize online advertising strategies in order to reach the most relevant participants while also understanding barriers to survey completion, particularly with respect to the COST tool.

In summary, crowdsourcing was a novel and feasible strategy for surveying cancer patients regarding their financial hardship. Financial toxicity impacts approximately 50% of individuals with gynecologic cancer nationwide. Respondents with ovarian and cervical cancer appeared to be more at risk as compared to those with uterine cancers, and tended to employ several economic cost-coping strategies to mitigate their financial burden. Unfortunately, they also were more likely to report delaying and avoiding their care. Additionally, we also showed that changes in employment such as changing from full to part-time employment, losing a job or needing to take unpaid time off work place individuals at higher risk for financial toxicity. This has important implications for future health policy considerations, such as enhanced paid leave policies for cancer patients, which may protect against financial toxicity. Furthermore, we identified that surgical complications may be a risk factor for financial toxicity, and should therefore trigger screening for financial toxicity. Given that financial toxicity affects 50% of patients with gynecologic cancer, much more investigation is needed to better identify individuals at risk, understand the impact on clinical outcomes, and develop interventions to meaningfully reduce toxicity.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Research Funding:

This work was supported by the Beth Israel Deaconess Medical Center Obstetrics and Gynecology Promising Young Investigator Grant and Harvard Catalyst | The Harvard Clinical and Translational Science Center (National Center for Advancing Translational Sciences, National Institutes of Health Award UL 1TR002541) and financial contributions from Harvard University and its affiliated academic healthcare centers. The funding source was not involved in the research or presentation of this manuscript.

References:

1. Carrera P, Zafar SY. Financial toxicity. In: Olver I, ed. *The MASCC Textbook of Cancer Supportive Care and Survivorship*. 2nd ed. New York: Springer; 2018:127–143.
2. Smith GL, Lopez-Olivo MA, Advani PG, et al. Financial burdens of cancer treatment: A systematic review of risk factors and outcomes. *J Natl Compr Canc Netw*. 2019;17(10):1184–1192. doi: 10.6004/jnccn.2019.7305. [PubMed: 31590147]
3. Gordon LG, Merollini KM, Lowe A, Chan R. A systematic review of financial toxicity among cancer survivors: We can't pay the co-pay. *Patient*. 2017;10:295–309. doi: 10.1007/s40271-016-0204-x. [PubMed: 27798816]
4. Bouberhan S, Shea M, Kennedy A, et al. Financial toxicity in gynecologic oncology. *Gynecol Oncol*. 2019;154(1):8–12. doi: 10.1016/j.ygyno.2019.04.003. [PubMed: 31053404]
5. Liang MI, Pisu M, Summerlin SS, et al. Extensive financial hardship among gynecologic cancer patients starting a new line of therapy. *Gynecol Oncol*. 2020;156(2):271–277. doi: 10.1016/j.ygyno.2019.11.022. [PubMed: 31771866]
6. Ramsey SD, Bansal A, Fedorenko CR, et al. Financial insolvency as a risk factor for early mortality among patients with cancer. *J Clin Oncol*. 2016;34(9):980–986. doi: 10.1200/JCO.2015.64.6620. [PubMed: 26811521]

7. Lee YJ, Arida JA, Donovan HS. The application of crowdsourcing approaches to cancer research: A systematic review. *Cancer Med*. 2017;6(11):2595–2605. doi: 10.1002/cam4.1165. [PubMed: 28960834]
8. Mohsin M. 10 Facebook statistics every marketer should know in 2020. Oberlo May 3, 2020. Accessed September 14, 2020. <https://www.oberlo.com/blog/facebook-statistics#:~:text=Here's%20a%20summary%20of%20the,60.6%20percent%20of%20internet%20users>.
9. Harris PA, Taylor R, Thielke R, Payne J, Gonzalez N, Conde JG. Research electronic data capture (REDCap) - A metadata-driven methodology and workflow process for providing translational research informatics support. *J Biomed Inform*. 2009;42(2):377–81. doi: 10.1016/j.jbi.2008.08.010. [PubMed: 18929686]
10. de Souza JA, Yap BJ, Hlubocky FJ, et al. The development of a financial toxicity financial toxicity patient-reported outcome in cancer: The COST measure. *Cancer*. 2014;120(20):3245–3253. doi: 10.1002/cncr.28814. [PubMed: 24954526]
11. de Souza JA, Yap BJ, Wroblewski K, et al. Measuring financial toxicity as a clinically relevant patient-reported outcome: The validation of the COmprehensive Score for financial toxicity (COST). *Cancer*. 2017;123(3):476–484. doi: 10.1002/cncr.30369. [PubMed: 27716900]
12. Rabin R, Gudex C, Selai C, Herdman M. From translation to version management: a history and review of methods for the cultural adaption of the EuroQol five-dimensional questionnaire. *Value Health*. 2014;17(1):70–76. doi: 10.1016/j.jval.2013. [PubMed: 24438719]
13. Roth R, Barsi E. The community need index. A new tool pinpoints health care disparities in communities throughout the nation. *Health Prog*. 2005;86:32–8f
14. Whitaker C, Stevelink S, Fear N. The use of Facebook in recruiting participants for health research purposes: A systematic review. *J Med Internet Res*. 2017;19(8):e290. doi: 10.2196/jmir.7071. [PubMed: 28851679]
15. United States Department of Health and Human Services, Centers for Disease Control and Prevention and National Cancer Institute. United States Cancer Statistics – Incidence: 1999-2017, WONDER Online Database. 2020. Accessed December 16, 2020. <http://wonder.cdc.gov/cancer-v2017>
16. United States Census Bureau. 2019 Median Household Income in the United States. United States Census Bureau website. September 17, 2020. Accessed December 16, 2020. <https://www.census.gov/library/visualizations/interactive/2019-median-household-income.html>
17. Zajacova A, Dowd JB, Schoeni RF, Wallace RB. Employment and income losses among cancer survivors: Estimates from a national longitudinal survey of American families. *Cancer*. 2015;121(24):4425–4432. doi: 10.1002/cncr.29510. [PubMed: 26501494]
18. Ramsey S, Blough D, Kirchhoff A, et al. Washington State cancer patients found to be at greater risk for bankruptcy than people without a cancer diagnosis. *Health Aff (Millwood)*. 2013;32(6):1143–1152. doi: 10.1377/hlthaff.2012.1263. [PubMed: 23676531]
19. Esselen K, Sinno AK, Varughese J, et al. Social needs in gynecologic oncology: A Society of Gynecologic Oncology (SGO) clinical practice statement. *Gynecol Oncol*. 2020;158(3):521–525. doi.org/10.1016/j.ygyno.2020.06.497 [PubMed: 32694062]

Table 1:

Demographic characteristics of respondents

Characteristics	All respondents (n=334)	High financial toxicity (n=162)	Low financial toxicity (n=172)	P value ^a
COST Score	24 (15-32)	15 (10-20)	31 (28-36)	<0.001
Age at diagnosis (years)	55 (47-63)	52 (42-59)	59 (51-65)	<0.001
Race				
White	290 (87)	132 (81)	158 (92)	0.045
Hispanic, Latina, or Spanish	9 (3)	6 (4)	3 (2)	
Black/African American	9 (3)	6 (4)	3 (2)	
Other or prefer not to say or missing	26 (8)	18 (11)	8 (5)	
Partnership status				
Married or partnered	212 (63)	98 (60)	114 (66)	0.13
Single, divorced, or widowed	102 (31)	50 (31)	52 (30)	
Other or missing	20 (6)	14 (9)	6 (3)	
Education level				
High school or less	71 (21)	38 (23)	33 (19)	0.37
Some college or associate's/technical degree	116 (35)	58 (26)	58 (34)	
Bachelor's degree or more	134 (40)	58 (36)	76 (44)	
Missing	13 (4)	8 (5)	5 (3)	
Employment status				
Employed, full time	90 (27)	44 (27)	46 (27)	<0.001
Employed, part time	39 (12)	26 (16)	13 (8)	
Not employed	27 (8)	18 (11)	9 (5)	
Retired	130 (39)	39 (24)	91 (53)	
Disabled, unable to work	48 (14)	35 (22)	13 (8)	
Insurance				
Private	163 (49)	89 (55)	74 (43)	<0.001
Medicare with supplement	53 (16)	11 (7)	42 (24)	
Medicare without supplement	82 (25)	39 (24)	43 (25)	
Medicaid or Uninsured	32 (10)	22 (14)	10 (6)	
Missing	4 (1)	1 (1)	3 (2)	
More than one month without insurance since diagnosis	38 (11)	26 (16)	12 (7)	0.01
Household income				
\$39,999	96 (29)	65 (40)	31 (18)	<0.001
\$40,000-\$59,999	60 (18)	30 (19)	30 (17)	
\$60,000-\$79,999	48 (14)	23 (14)	25 (15)	
\$80,000-\$99,999	49 (15)	23 (14)	26 (15)	
\$100,000	70 (21)	19 (12)	51 (30)	
Missing	11 (3)	2 (1)	9 (5)	

Characteristics	All respondents (n=334)	High financial toxicity (n=162)	Low financial toxicity (n=172)	P value ^a
Geographic region				
Northeast	68 (20)	25 (15)	43 (25)	0.008
Midwest	86 (26)	52 (32)	34 (20)	
West	55 (16)	26 (16)	29 (17)	
South	116 (35)	58 (36)	58 (34)	
Missing	9 (3)	1 (1)	8 (5)	
Medicaid expansion state	218 (65)	100 (62)	118 (69)	0.01
Hospital location				
Urban	187 (56)	81 (50)	106 (62)	0.06
Suburban	112 (34)	62 (38)	50 (29)	
Rural	33 (10)	19 (12)	14 (8)	
Missing	2 (1)	0 (0)	2 (1)	
CNI	3 (2-4)	3 (2-4)	3 (2-4)	0.43

Values reported as N (%) or median (interquartile range) Percentages may not add to 100 due to rounding

^a Chi-square or Fisher's exact test for categorical variables and Wilcoxon rank sum test for continuous variables.

Table 2:

Cancer and treatment characteristics of respondents

Characteristics	All respondents (n=334)	High financial toxicity (n=162)	Low financial toxicity (n=172)	P value ^a
Cancer site				
Ovarian	209 (63)	104 (64)	105 (61)	<0.001
Uterine	76 (23)	25 (15)	51 (30)	
Cervical	49 (15)	33 (20)	16 (10)	
Stage				
I	102 (31)	45 (28)	57 (33)	0.72
II	35 (10)	20 (12)	15 (9)	
III	132 (40)	64 (40)	68 (40)	
IV	40 (12)	21 (13)	19 (11)	
Not sure	25 (7)	12 (7)	13 (8)	
Years since diagnosis	5 (2-10)	5 (2-9)	5 (2-10)	0.74
Initial treatment				
Surgery and chemotherapy	195 (58)	95 (59)	100 (58)	0.76
Surgery followed by radiation	16 (5)	6 (4)	10 (6)	
Surgery followed by chemotherapy and radiation	22 (7)	10 (6)	12 (7)	
Chemotherapy and radiation	6 (2)	4 (2)	2 (1)	
Surgery only	88 (26)	43 (27)	45 (26)	
Chemotherapy only	5 (2)	2 (1)	3 (2)	
Other	2 (1)	2 (1)	0 (0)	
Type of initial surgery				
Open	211 (66)	98 (64)	113 (68)	0.32
Laparoscopic	95 (30)	46 (30)	49 (29)	
Not sure	15 (5)	10 (6)	5 (3)	
Complications from surgery	52 (16)	33 (21)	19 (11)	0.02
Cancer recurred	82 (25)	44 (27)	38 (22)	0.28
Current condition of disease				
In remission	193 (58)	84 (52)	109 (63)	0.08
On active treatment	94 (28)	55 (34)	39 (23)	
Receiving palliative care or hospice	3 (1)	2 (1)	1 (1)	
Other or missing	44 (13)	21 (13)	23 (13)	

Values reported as N (%) or median (interquartile range) Percentages may not add to 100 due to rounding

^aChi-square or Fisher's exact test for categorical variables and Wilcoxon rank sum test for continuous variables.

Table 3:

Risk of cost-coping strategies among those with high compared with low financial toxicity

Cost-coping strategies	High financial toxicity (n=162) N (%)	Low financial toxicity (n=172) N (%)	Crude risk ratio ^a (95% CI)	Adjusted risk ratio ^{a,b} (95% CI)
Delaying or avoiding at least one of the below	70 (43)	15 (9)	5.0 (3.0-8.3)	3.8 (2.2-6.6)
Medical visits	50 (31)	7 (4)	7.6 (3.5-16.2)	5.6 (2.6-12.1)
Filling prescriptions	29 (18)	6 (3)	5.1 (2.2-12.0)	4.0 (1.7-9.5)
Buying over-the-counter medications or medical supplies	37 (23)	6 (3)	6.5 (2.8-15.1)	5.4 (2.1-13.6)
Chemotherapy, radiation, or surgery	14 (9)	0 (0)	--	--
Borrowing money from friends, family, bank, or applying for financial assistance	79 (49)	16 (9)	5.2 (3.2-8.6)	4.0 (2.4-6.9)
Using savings	90 (56)	43 (25)	2.2 (1.7-3.0)	2.2 (1.6-3.0)
Reduced spending on basic goods	77 (48)	21 (12)	3.9 (2.5-6.0)	3.3 (2.1-5.1)
Reduced spending on leisure	95 (59)	29 (17)	3.5 (2.4-5.0)	3.4 (2.4-5.0)
Filing for bankruptcy or mortgaging house	14 (9)	3 (2)	3.1 (1.5-16.9)	4.2 (1.2-15.0)
Ovarian Cancer	N=104	N=105		
Delaying or avoiding care	38 (37)	5 (5)	7.7 (3.1-18.7)	7.1 (2.6-19.3)
Borrowing money or applying for financial assistance	43 (41)	6 (6)	7.2 (3.2-16.3)	7.5 (2.8-20.3)
Using savings	66 (63)	28 (27)	2.4 (1.7-3.4)	2.2 (1.5-3.3)
Reduced spending on basic goods	51 (49)	10 (10)	5.1 (2.8-9.6)	4.1 (2.2-7.7)
Reduced spending on leisure	67 (64)	17 (16)	4.0 (2.5-6.3)	3.8 (2.3-6.1)
Filing for bankruptcy or mortgaging house	5 (5)	1 (1)	5.0 (0.6-42.5)	5.0 (0.6-42.5)
Uterine Cancer	N=25	N=51		
Delaying or avoiding care	12 (48)	8 (16)	3.1 (1.4-6.5)	1.1 (0.55-2.2)
Borrowing money from friends, family, bank, or applying for financial assistance	17 (68)	9 (18)	3.9 (2.0-7.4)	2.0 (0.93-4.4)
Using savings	8 (32)	15 (29)	1.1 (0.5-2.2)	0.92 (0.41-2.1)
Reduced spending on basic goods	11 (44)	11 (22)	2.0 (1.0-4.0)	1.6 (0.76-3.3)
Reduced spending on leisure	11 (44)	12 (24)	1.9 (0.96-3.6)	1.9 (0.93-3.7)
Filing for bankruptcy or mortgaging house	3 (12)	1 (2)	6.1 (0.67-55.9)	3.9 (0.34-44.7)
Cervical Cancer	N=33	N=16		
Delaying or avoiding care	20 (61)	2 (13)	4.8 (1.3-18.2)	5.9 (1.5-23.8)
Borrowing money from friends, family, bank, or applying for financial assistance	19 (58)	1 (6)	9.2 (1.4-62.8)	7.3 (1.1-50.5)
Using savings	16 (48)	0 (0)	--	--
Reduced spending on basic goods	15 (45)	0 (0)	--	--
Reduced spending on leisure	17 (52)	0 (0)	--	--
Filing for bankruptcy or mortgaging house	6 (18)	1 (6)	2.9 (0.38-22.2)	--

^aLog binomial regression^bAdjusted for income