



Research Report

Piloting use of an out-of-pocket cost tracker among gynecologic cancer patients[☆]

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ARTICLE INFO

Keywords:

Out-of-pocket costs

Costs of care

Healthcare expenditures

Cancer

Financial toxicity

ABSTRACT

Objective: Our objective was to evaluate uptake and satisfaction with an out-of-pocket (OOP) cost tracker as a means for cancer patients to manage their personalized costs of care and to identify characteristics associated with usage.

Methods: Within a longitudinal survey evaluating financial toxicity among gynecologic cancer patients on active systemic therapy over a 6-month period, we provided paper worksheets for participants to voluntarily track expenses. We assessed usage and satisfaction at 3 and 6 months using frequency and percentage. We used Fisher's exact test and Wilcoxon rank sum analysis to evaluate patient characteristics based upon usage. Participants were encouraged to submit their completed cost tracker worksheets.

Results: Fifty-three of 121 (44%) participants reported ever using the OOP cost tracker. Most users reported it was easy to use (97%, 100%) and helpful (86%, 72%); however, fewer users rated it as useful for budgeting (42%, 26%) at 3 and 6 months, respectively. More patients who knew their insurance premium were users compared to non-users (74.4% vs. 54.4%, $p = 0.04$). Among thirteen users who submitted their completed cost tracker worksheets, non-medical costs (i.e., transportation) had the highest monthly out of pocket costs (mean \$213, range \$0–587). User feedback included suggestions to enhance the cost tracker with educational tutorials or a reminder system.

Conclusions: Future studies should explore if cost tracker uptake and satisfaction are enhanced with the addition of reminders and whether usage decreases financial toxicity or increases patient self-efficacy in managing the costs of cancer care.

1. Introduction

While the National Academy of Medicine recommends that cancer patients are provided with understandable information about the estimated costs of care, lack of cost transparency and complexities of payor coverage have made this aim challenging to achieve (Ganz, 2014). Since January 2021, the Centers for Medicare & Medicaid Services has required that hospitals provide clear and accessible pricing information online about the items and services they provide (Department of Health

and Human Services and Centers for Medicare & Medicaid Services, 2019). An early assessment found that only 60% of sampled hospitals were compliant with displaying their cash prices (Cram et al., 2021). Moreover, studies have shown that even when these tools are available, patient use is low (Gourevitch et al., 2021; Sinaiko and Rosenthal, 2016; Desai et al., 2017). In this context, alternative strategies to provide patients with information about their out-of-pocket (OOP) costs warrant further investigation. Limited studies have evaluated uptake of patient cost diaries and the impact of budget management support on financial

[☆] This paper was presented as a poster presentation at the American Society of Clinical Oncology Quality Symposium, San Diego, CA in September 2019.

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<https://doi.org/10.1016/j.gore.2022.101000>

Received 2 April 2022; Received in revised form 3 May 2022; Accepted 7 May 2022

Available online 11 May 2022

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toxicity among cancer patients (Zafar et al., 2013; Shankaran et al., 2018). Our objective was to pilot a simple and inexpensive OOP cost tracker among gynecologic cancer patients receiving systemic therapy who were participating in a financial toxicity study to determine rate of uptake and satisfaction as metrics for feasibility and to evaluate patient characteristics associated with OOP cost tracker usage.

2. Methods

2.1. Study design

This pilot study was approved by our Institutional Review Board (#300001189) and conducted as part of a longitudinal study evaluating financial toxicity among gynecologic cancer patients. We administered surveys within 8 weeks of starting a new therapy, at 3 months, and at 6 months (Liang et al., 2020). At the time of study consent, research staff provided a folder with blank OOP cost tracker worksheets and a written glossary of cost categories (Fig. 1). Research staff reviewed the format of the OOP cost tracker and described the categories of costs using the glossary. Participants were asked to voluntarily track their OOP costs as they went through treatment and to bring in completed worksheets whenever they came for in-person clinical visits. There was a formal one-time reminder to use the OOP cost tracker and bring in completed worksheets at the end of the script for the 3-month survey, but otherwise no additional education or incentive was provided. Copies of completed worksheets were made whenever participants independently brought their worksheets to in-person clinical visits and then the original was returned to the participant. Additional blank worksheets were provided if requested by participants.

2.2. Study population

We recruited patients diagnosed with gynecologic cancer who were starting a new line of systemic therapy for new or recurrent disease. Participants could undergo planned interval surgery or concurrent radiation but were excluded if they were on hormonal therapy alone. We discontinued follow-up if participants died or enrolled in hospice. We recruited participants at our infusion clinic through a study flyer and direct contact by research staff. Written informed consent was obtained from all participants. Trained research personnel from our institution’s Retention and Recruitment Shared Facility conducted all surveys over the phone or in-person based on participant preference. We gave participants a \$10 gift card after completion of each of the three surveys, but not for using or turning in the OOP cost tracker worksheets.

2.3. Patient uptake and satisfaction with the OOP cost tracker

During 3- and 6-month follow up surveys, participants were asked to respond to whether they used the OOP cost tracker and at what frequency (daily, weekly, every two weeks, or monthly). Among those who reported use, participants were asked to respond “yes”, “somewhat”, or “no” to whether they thought the cost categories were easy to understand and whether the OOP cost tracker was easy to use, helped track OOP costs, or helped plan how to pay medical bills or budget. For each of these questions, we asked participants an open-ended question to explain why they selected their response. We also asked two additional open-ended questions: “Do you have a different system of managing the costs of cancer care?” and “What could your health care team have done differently or better to help you track your costs or plan for future costs related to your medical care? These responses were recorded verbatim as free text.

Date	\$ paid out of pocket	Category		Details
		<input type="checkbox"/> Doctor or NP visit <input type="checkbox"/> Infusion or chemo visit <input type="checkbox"/> Blood work <input type="checkbox"/> Imaging <input type="checkbox"/> Procedure/Surgery <input type="checkbox"/> Emergency Room <input type="checkbox"/> Hospitalization	<input type="checkbox"/> Prescription meds <input type="checkbox"/> Over the counter meds <input type="checkbox"/> Medical supplies <input type="checkbox"/> Transportation/Parking <input type="checkbox"/> Lodging <input type="checkbox"/> Childcare <input type="checkbox"/> Other	

Doctor or NP (nurse practitioner) visit: A visit where you see your doctor or nurse practitioner

Infusion or chemo visit: A visit where you receive treatment through an IV (chemotherapy, targeted therapy, fluids, blood transfusion)

Blood work: May include checking labs or tumor markers

Imaging: May include an x-ray, CT or “CAT” scan, MRI, PET scan, or ultrasound

Procedure/Surgery: May include biopsy, port placement, radiation treatment, surgery, stent or nephrostomy placement

Emergency Room: A visit to an Urgent Care or Emergency Room. You may or may not be admitted to the hospital

Hospitalization: This includes being admitted to the hospital, usually at least one night

Prescription meds: A medication that requires a paper or electronic prescription from your doctor or nurse practitioner

Over the counter meds: A medication that does NOT require a paper or electronic prescription from your doctor or nurse practitioner

Medical supplies: A medical supply that requires a paper or electronic prescription from your doctor or nurse practitioner. May include canes, walkers, wheelchairs, oxygen equipment, hospital beds, commode chairs, or infusion pump/supplies for use at home

Transportation/Parking: Please specify form of transportation (car, bus, rideshare) and where you went and for what reason

Lodging: Costs for lodging to stay overnight in order to complete your treatment as directed by your doctor or nurse practitioner

Childcare: Costs for childcare to complete your treatment as directed by your doctor or nurse practitioner

Fig. 1. Patient out-of-pocket cost tracker and glossary.

2.4. Patient and disease characteristics

At baseline, we surveyed participants for patient demographics, including age, race, marital status, presence of a primary caregiver, highest education level, annual household income, employment status, and insurance status. Using the electronic medical record, we abstracted disease and treatment information, including cancer type, time since diagnosis, first versus subsequent line of therapy, and treatment type. We assessed patient numeracy using the Subjective Numeracy Scale (SNS) ability and preference questions on a scale of 1 (not at all good) to 6 (extremely good) (Fagerlin et al., 2007). We assessed health literacy using the single question, “How confident are you filling out medical forms by yourself?” on a scale from 1 (extremely) to 5 (not at all) (Chew et al., 2008), with a score of ≥ 3 indicating limited health literacy (Wallace et al., 2006). We assessed self-reported patient knowledge about their insurance characteristics, including premium, deductible, and OOP maximum.

2.5. Statistical analysis

We collected and managed study data using REDCap electronic data tools (Vanderbilt University, TN). Statistical analyses were performed using SAS version 9.4 (Cary, NC) with a 0.05 level of significance. Descriptive statistics, including mean, standard deviation, median, range, frequency, and percentage were calculated. We calculated the percentage of usage among the entire cohort and satisfaction with the OOP cost tracker among users. The responses “yes” and “somewhat” were combined to represent a positive response. To evaluate factors associated with usage, participants were categorized into two groups: any tracker use (patients who responded “yes” to usage at 3 and/or 6 months) versus no tracker use. To compare characteristics between these groups, we calculated Fisher’s exact test for categorical variables and Wilcoxon rank sum for continuous variables. Qualitative data from open-ended questions were reviewed to identify helpful and unhelpful characteristics as well as suggested improvements to the OOP cost tracker.

3. Results

3.1. Study population

Enrollment and patient characteristics for the entire cohort of 121 evaluable participants have been previously described (Liang et al., 2020). In brief, the average age was 49 years old, and 34 participants (28.1%) were African-American. The annual household income was $< \$20,000$ for 28 (23.1%) participants, $\$20,000$ – $\$39,999$ for 27 (22.3%) participants, $\$40,000$ – $\$59,999$ for 19 (15.7%) participants, $\$60,000$ – $\$79,999$ for 14 (11.6%) participants, and $\geq \$80,000$ for 22 (18.2%) participants. There were 8 participants (6.6%) who were uninsured. There were 9 participants (7.8%) who were currently enrolled on a clinical trial.

3.2. Patient uptake and satisfaction with the OOP cost tracker

Fifty-three of 121 participants (44%) ever used the OOP cost tracker. When asked if they used the OOP cost tracker during the last 3 months, there were 36/121 (30%) participants who reported use at 3 months and 44/121 (36%) participants at 6 months. Among the 53 users, the frequency of OOP cost tracker use was at least weekly (33%, 21%), every two weeks (36%, 26%), or monthly (31%, 52%) at 3 and 6-month follow up, respectively. Users responded positively (“somewhat” or “yes”) to whether the cost categories were easy to understand (100%, 100%), whether the OOP cost tracker was easy to use (97%, 100%), or whether the OOP cost tracker helped track OOP costs (86%, 72%) at each follow-up time point. At 3 and 6 months, respectively, 42% and 26% of users thought the OOP cost tracker helped them plan how to pay medical bills

or budget.

3.3. Factors associated with any OOP cost tracker usage

Knowing one’s insurance premium was more frequent among OOP cost tracker users compared to non-users (74% vs. 54%, $p = 0.04$); whereas, knowing one’s deductible and OOP maximum did not differ between groups. No other measured patient characteristics, including numeracy score or health literacy, were associated with any tracker use (Table 1).

3.4. Patient reported OOP costs

Out of 53 users, 13 (25%) participants returned at least one OOP cost tracker worksheet for review. This group of participants tracked OOP costs for a median of 5 months (range 4–10 months). Monthly patient-reported OOP costs were as follows: outpatient services (median \$0, mean \$65, range \$0–120); hospital services (median \$0, mean \$82, range \$0–458); medications and medical supplies (median \$4, mean \$39, range \$0–150), and non-medical costs (median \$14, mean \$213, range \$0–587).

3.5. User feedback

Helpful characteristics reported by users were that the tracker reminded participants about all categories of cost, prompted them to save receipts, and allowed them to compare bills received to payments made. Unhelpful characteristics reported by non-users were due to a perceived lack of need (i.e., minimal OOP expenses or already knew what OOP costs to expect) or patients not feeling well enough to track their costs and instead relying on caregivers to manage health expenses. Participants shared other cost tracking strategies, which included keeping receipts and bills in one folder, keeping notes in a cell phone or checkbook, and opening a savings account specifically to pay for health-related costs. To improve the utility of the OOP cost tracker, participants suggested development of a tutorial, phone help line, reminder system, or mobile application to help them track OOP costs.

4. Discussion

We found that 40% of gynecologic cancer patients who were receiving systemic therapy and enrolled in a financial toxicity study used an OOP cost tracker worksheet. Patient satisfaction was high (70–90%) for attributes such as ease of use and helpfulness; however, a much smaller percentage (25–40%) of participants reported that the OOP cost tracker helped with budgeting. This could be due the passive delivery of the intervention since participants suggested that the OOP cost tracker should be combined with other strategies, such as counseling over the phone or in-person or through application-based platforms that could integrate a reminder system or educational content. In a study of patients with solid tumors actively receiving treatment, a higher percentage of participants (63%) completed at least one monthly cost diary compared to our patient cohort, but only 13% completed all four that were required as part of the study (Zafar et al., 2013). Moreover, a recent study in which patient-reported OOP costs was the primary outcome, there was missing 3-month follow-up data over 70% of patients (Oury et al., 2021).

We recognize that use of an OOP cost tracker may only benefit a subset of the population, and in this pilot study, participants who used the OOP cost tracker were more likely to know their monthly premium. It is possible that patients who already know their insurance premium are more aware of their costs and the financial implications of cancer treatment and thus the cost tracker may not be used by those with the greatest need. In a study of private health insurance consumers, only 4% of those surveyed correctly defined all four insurance terms, which included deductible, coinsurance, co-pay, and OOP maximum (Policy

Table 1
Characteristics of patients with any out-of-pocket cost tracker usage.

	Any tracker use n = 53	No tracker use n = 68	p-value
Patient characteristics			
Age, mean (sd)	57.4 (10.5)	60.5 (10.4)	0.11
Race, n (%)			0.31
Caucasian	35 (66.0)	51 (75.0)	
African-American	18 (34.0)	16 (23.5)	
Other	0 (0.0)	1 (1.5)	
Married, n (%)	30 (56.6)	33 (48.5)	0.38
Has primary caregiver, n (%)	21 (39.6)	31 (45.6)	0.51
High school diploma or less, n (%)	15 (28.3)	18 (26.5)	0.82
Annual income <\$40,000, n (%) ^a	24 (50.0)	31 (50.0)	>0.99
Employment status among those in the labor force, n (%) ^b			0.52
Employed	16 (72.7)	25 (80.7)	
Unemployed	6 (27.3)	6 (19.4)	
Insurance coverage, n (%)			0.51
Only public	8 (15.1)	16 (23.5)	
Any private	41 (77.4)	48 (70.6)	
Uninsured	4 (7.6)	4 (5.9)	
Currently enrolled in clinical trial	6 (11.3)	3 (4.4)	0.18
Disease characteristics			
Type of cancer, n (%)			0.82
Ovarian	29 (54.7)	35 (51.5)	
Uterine	16 (30.2)	18 (26.5)	
Cervical	6 (11.3)	12 (17.7)	
Vulvar/vaginal	2 (3.8)	3 (4.4)	
Days since diagnosis, median (range)	73.0 (0.0–7231.0)	345.0 (15.0–2632.0)	0.09
Treatment, n (%)			0.22
First-line	34 (64.2)	36 (52.9)	
Subsequent-line	19 (35.9)	32 (47.1)	
Treatment regimen, n (%)			0.70
Chemotherapy alone	34 (64.2)	44 (64.7)	
Chemotherapy + radiation	4 (7.6)	8 (11.8)	
Chemotherapy + targeted therapy	10 (18.9)	8 (11.8)	
Targeted therapy alone	3 (5.7)	6 (8.8)	
Immunotherapy	1 (1.9)	2 (2.9)	
PARP inhibitor	1 (1.9)	0 (0.0)	
Subjective Numeracy Scale (SNS)			
SNS Ability - How good are you at working with fractions? mean (sd)	4.0 (1.5)	3.8 (1.7)	0.58
SNS Ability - How good are you at figuring out how much a shirt will cost if it is 25% off? mean (sd)	5.2 (1.2)	4.8 (1.4)	0.20
SNS Preference - How often do you find numerical information to be useful? mean (sd)	5.0 (1.4)	4.9 (1.4)	0.71
Health literacy			
How confident are you filling out forms by yourself? median (IQR)	3.7 (0.7)	3.6 (0.8)	0.37
Limited health literacy, n (%)			0.44
Yes	4 (7.6)	8 (11.8)	
No	49 (92.5)	60 (88.2)	
Insurance knowledge			
Knows premium, n (%) ^c	32 (74.4)	31 (54.4)	0.04
Knows annual deductible, n (%) ^d	18 (40.0)	21 (36.8)	0.74
Knows out-of-pocket maximum, n (%) ^e	16 (33.3)	11 (18.3)	0.07
Reported not having premium or reported not having deductible or reported not having OOP max, n (%)	11 (20.8)	14 (20.6)	0.98

^a Excluding those who responded “I prefer not to answer” or “I don’t know”.

^b Excluding those not in the labor force (retired or homemaker).

^c Excluding those who reported not having a monthly premium.

^d Excluding those who reported not having an annual deductible.

^e Excluding those who reported not having an out-of-pocket maximum.

Genius, 2019), suggesting insurance literacy may be low in the general population. Other patient characteristics that have previously been associated with use of a cost diary, such as older age and Medicare insurance coverage, were not associated with usage in our cohort (Zafar et al., 2013).

The 13 participants who turned in OOP cost tracker worksheets tracked their costs for a median of 5 months. From this patient-collected data, OOP costs for non-medical expenses, including transportation and lodging, were reported to be as high as \$500 per month. This represents an important observation for health care teams to prepare patients for the non-medical costs of cancer care and to consider identifying financial assistance resources for patients who have more frequent treatment schedules, live far away, or have other financial needs.

Limitations of this study involve inclusion of patients receiving care at a single institution who were participating in a study on financial toxicity. Given the small sample size, all analyses were univariate. Study participants may be more motivated than non-participants to use the OOP cost tracker resulting in non-response bias. Although we measured self-reported insurance knowledge, participants were not asked to demonstrate a correct understanding, which may overestimate patients’ knowledge based upon findings of other surveys (Policy Genius, 2019). In addition, only 10% of participants had low health literacy. A strength of the study is the availability of follow-up data for 75% of the cohort at 6 months and evaluating a group of patients with heterogeneous cancer types and treatments.

Our findings demonstrate that an OOP cost tracker worksheet is acceptable to cancer patients and could be integrated into more comprehensive patient-level interventions to help patients manage their costs of care. Given low to moderate uptake in our study and others that incorporated patient cost tracking, active reminders and more targeted education that were recommended by study participants are clearly needed to increase engagement and may explain the lower satisfaction with using the tool for budgeting.

Funding

Margaret I. Liang was supported by a National Institute of Child Health and Human Development Women’s Reproductive Health Research Career Development K-12 Grant (5K12HD001258) for this work. The Retention and Recruitment Shared Facility at O’Neal Comprehensive Cancer Center is supported by the Cancer Center Support Grant (P30CA013148).

CRediT authorship contribution statement

Margaret I. Liang: Conceptualization, Data curation, Formal analysis, Funding acquisition, Investigation, Methodology, Project administration, Writing – original draft, Writing – review & editing. **Sarah S. Summerlin:** Data curation, Formal analysis, Writing – review & editing. **Teresa K.L. Boitano:** Data curation, Writing – review & editing. **Christina T. Blanchard:** Formal analysis, Writing – review & editing. **Warner K. Huh:** Supervision, Writing – review & editing. **Smita Bhatia:** Supervision, Writing – review & editing. **Maria Pisu:** Conceptualization, Supervision, Writing – review & editing.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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