Integrating Financial Toxicity Assessment in Cancer Treatment: Implications for Medical Oncology Training

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Abstract

Financial burden or toxicity associated with cancer treatment is defined as problems a patient may face related to the costs of medical care. Financial toxicity has been widely documented in the oncology literature and has been associated with a host of negative outcomes, including impaired quality of life, treatment non-adherence and greater risk of mortality. These negative outcomes prompted a call to action among oncology providers to take the lead in discussions of financial burden and costs of care among patients. However, to date, oncologists feel ill prepared to initiate these discussions and few patients feel this is part of their routine oncologic care. Moreover, little attention has been given to the training of future clinicians in oncology to effectively discuss costs of care. The development and implementation of provider communication training programs and integration of appropriate financial toxicity screening will enable cost of care discussions to become routine and help dissipate patient discomfort.

Keywords: Financial Toxicity, Financial Toxicity Assessment, Medical Oncology Training

1. Introduction

Among patients with cancer, the experience of financial toxicity generally represents problems a patient may face related to the costs of medical care¹. Financial burden or toxicity associated with cancer treatment has been widely documented in the literature^{2,3}, including increasing costs associated with precision medicine⁴ and burden associated with clinical trial participation⁵. Prior research has also documented notable rates of treatment non-adherence due to financial toxicity, including skipping or under-dosing cancer-directed medications⁶. In a 2016 US study, Ramsey found that 2.2% of more than 230,000 patients diagnosed with cancer had filed for bankruptcy in a 14-year period up to 2009⁷. In this registry-based study, the authors utilized propensity score matching to

identify a significant association between bankruptcy and a greater risk of mortality among patients.

Evidence from the Centers of Disease Control and Prevention suggests that one in three Americans experience financial burden due to medical care⁸. In a nationally representative survey of consumer finances to estimate the proportion of households that can afford cost sharing requirements of the American Care Act conducted by the Kaiser Family Foundation, only 53% of all households had sufficient funds on hand to pay a median, mid-range deductible of \$2400 per family and less than half (only 45%) could pay a median, high-range deductible of \$5000⁹. Importantly, research suggests that merely possessing insurance does not protect patients from experiencing financial toxicity, as under-insurance or inadequate coverage may persist. In a study by

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Zafar and colleagues of a cohort of 254 cancer patients with insurance, 75% had applied for drug copayment assistance and 42% reported significant or catastrophic subjective financial burden¹⁰. With the out of pocket costs of cancer care rapidly approaching \$5000 a year⁹, it can be understood how patients with cancer, even with insurance, can be subjected to financial toxicity during their cancer treatment as a result of high cost-sharing.

Financial toxicity has also been associated with a myriad of negative psychosocial outcomes, including increased rates of depression and anxiety¹¹, lower satisfaction with care¹², delays in care and impaired Quality Of Life (QOL)¹³. These effects may not be uniform, with prior analyses suggesting that certain patients are at greater risk of experiencing financial toxicity, including those who are male, younger and unmarried, as well as those with low educational obtainment, low socioeconomic status, or without paid employment¹⁴. This data is summarized in (Figure 1).

Financial-related stress can be exacerbated by the ambiguous nature of out of pocket medical costs for patients, especially given the specialized multidisciplinary scope of cancer care that can result in varying costs among patients with various insurance coverages. In addition to direct medical costs, such as co-pays, coinsurance, and medications, non-medical costs such as transportation, lodging, and childcare¹⁵, can represent a substantial degree of burden over a course of treatment.

Research has also documented the potential vulnerability of many patients, with evidence suggesting that even seemingly small changes in copayments can represent a barrier to care. Neugut found that among women receiving adjuvant breast cancer therapy, those with copayments ranging from \$30 to \$90 for their



Figure 1. Financial toxicity flow chart.

hormonal treatment had high rates of nonadherence¹⁶. Additionally, in a patient population of those diagnosed with Chronic Myeloid Leukemia (CML), Dusetzina found that those with copayments greater than \$53 were 70% more likely to discontinue imatinib within six months of starting treatment¹⁷. This data suggests that relatively small costs each month can be associated with nonadherence to potentially lifesaving drugs, and thus the need for providers to educate patients concerning not only the anticipated side-effects of treatment, but also the potential financial consequences.

2. Financial Toxicity Screening in Oncology

The term financial toxicity is broad and can include both out-of-pocket costs and loss-of-income, and evidence suggests the number of individuals suffering from some form of financial toxicity is increasing³. This emerging issue has led to the development of several validated research assessment tools that can help identify patients at higher risk for financial toxicity and quantify their degree of burden. The Comprehensive Score for Financial Toxicity (COST) Patient Report Outcome Measure (PROM) was originally created and utilized by De Souza¹⁸, while Veenstra and colleagues developed a similar PROM among a cohort of 956 patients with a history of stage III colorectal cancer¹⁹.

Recently, Borno and colleagues adapted the COST to include 3 highly rated items and thus be more suitable for routine financial toxicity screening in the clinical oncology setting. A pilot intervention that was implemented among a group of oncology fellows increased the rate of patients screened from 0% to 32% during the intervention period²⁰. Qualitative feedback from fellows suggested that low response rates were due to lack of provider familiarity with financial toxicity, busy clinic visits, and difficulty remembering to implement the screening in their workflow. Thus, despite the availability of these various assessment tools, a lack of consensus as to the most appropriate measure to use in clinical practice and insufficient familiarity and training among providers have hampered routine integration of assessment or screening of financial toxicity in oncology practice to date²¹.

3. Discussions of Financial Toxicity in Oncology Practice

The growing body of evidence outlined above has prompted a call to action among oncology providers to take the lead in discussions of financial burden and costs of care among patients^{15,22,23}. This sentiment has been echoed by the Institute of Medicine and American Society of Clinical Oncology who issued joint guidelines signifying that cost of care discussions were essential to high quality cancer care²⁴.

Despite this urging, evidence suggests that oncologists infrequently discuss costs of care with patients, feel largely unprepared to hold such discussions, and that few patients feel this is part of their routine oncologic care²³. As a result, discussion of care costs remains an unmet informational need among patients²⁵. Studies have shown that oncologists frequently underestimate the financial burden that patients may experience²⁶, for example, among a cohort of women diagnosed with breast cancer, nearly half of those surveyed reported moderate financial distress; yet only 14% of patients had discussed finances with their doctor and nearly every patient surveyed felt it was an important part of their overall care²⁷. In a further study, researchers at Mayo Clinic analyzed over 500 recordings of healthcare conversations between physicians and patients to examine if the cost of cancer treatment was discussed²⁸. They found that less than a third of patients questioned the cost of the proposed cancer treatment, while only 60% of physicians warned patients that the cost of care may represent a challenge.

Importantly, patients generally desire information about the costs of care. Ellis and colleagues reported that patients desire for information regarding the subsequent financial burden their care may impose was greater than that for diagnostic or prognostic information²⁹. In an analysis of 529 clinical visits at multiple academic oncology centers, Warsame³⁰ and colleagues found that only 28% of visits mentioned costs of care. Even among those that did, such conversations tended to last less than two minutes, be acknowledged by the provider only 60% of the time and acted upon in 25% of cases. The authors identified several themes in their data, including patients inquiring about insurance eligibility and processes, the costs associated with care (e.g. drug costs), and most critically, how such information may inform and influence treatment decision making.

4. Barriers to Financial Discussions in Oncology Practice

Several barriers to financial discussions in oncology have been documented in the literature. Firstly, physicians report a lack of explicit training or competency in this domain, as well as discomfort broaching cost-based issues with patients^{3,31}. Indeed, some physicians feel that addressing costs in the context of cancer encroaches on their duty of care, may rupture the provider-patient relationship, and ultimately compromise the quality of care the patient may receive³¹⁻³³. For example, whereas less than a third of oncologists surveyed in one study felt comfortable discussing costs of care, 80% of patients reported being open to discussing such information³⁴. Finally, the complexity of the medical care payment system in the US is widely acknowledged and may represent a further barrier to oncologists feeling confident in discussing specific costs of care.

Whereas medical governing bodies have endorsed financial discussions as an important aspect of quality care, there has been no guidance regarding who should be responsible for such discussion, when they should take place, and what content should be addressed³⁵. As a result, there has been highly variable degrees of integration of financial discussions in clinical care. For example, one study found distinct specialty-based differences; with approximately half of medical oncologists and radiation oncologists reporting that someone in their practice often or always discussed financial burden with patients, while only 15.6% of surgeons reported similar efforts³⁶. In a recent study, Pisu and colleagues³⁷ conducted interviews with patients and cancer center staff regarding financial toxicity discussions. The majority of both patients and staff felt that social workers and financial counselors were best suited to discuss the costs of care with patients, with many noting the fact that oncologists possessed little or no training in conducting such conversations. That said, studies have shown that many patients will place greater weight on discussions and health care recommendations made by physicians, and thus there will remain an important role for oncologists in addressing financial toxicity, regardless of who ultimately assesses the patient³⁸. Moreover, Henrikson, et al., study indicated that patient's preferred that oncology providers initially raise discussions concerning costs of treatment, as opposed to financial counselors or insurance representatives who are unequipped to address questions concerning clinical need³⁹.

Perhaps one of the greatest barriers to developing a formal medical education curriculum for cost of care discussions is the accessibility of treatment costs for patients. Prices established for cancer drugs take into account the amount invested for research and development phases as well as an additional amount for profit. "Justification" for lowering drug prices for affordable treatment may be challenging given that economic data is rarely collected for clinical trials and not required by the US FDA in making regulatory decisions about drug approval⁴⁰.

Financial ambiguity also exists when trying to make a "uniform" cost for cancer treatments which are often variable and individualized. When explaining costs, it's important to note that cost of care estimates depend on several factors including, but not limited to: length and type of cancer treatment, extent of health insurance, and/ or any eligible discounts or cost reduction programs patients may be eligible which can also vary among drug companies, hospitals, and communities which patients may have access to. Moreover, location and availability of financial resources within a state or community may also systematically challenge the efforts of an oncologist to assist patients with financial toxicity. Even with routine screening for financial distress implemented⁴¹, addressing financial toxicity in practice necessitates the availability of resources throughout the cancer care system. Spencer and colleagues noted the historically low rates of referrals to medication assistance programs and of those financial navigators involved in their study, less than half of them felt that patients were ultimately able to access some kind of financial assistance⁴².

5. Cost-based Advocacy in Oncology

The financial consequences of cancer also represent an opportunity for advocacy among the motivated clinicians and researchers, with this topic receiving increasing attention among professional bodies such as ASCO. In June 2017, ASCO released a position statement where physicians outlined their financial concerns with the costs of healthcare, including the unaffordable nature of insurance coverage and the high Out Of Pocket (OOP) expenses associated with oncology drugs⁴³. The recommendations of the multidisciplinary group included advocating for the development and use of generic and biosimilar drugs, increased transparency in drug costs, and heightened negotiations with insurance companies⁴⁴.

Several examples of advocacy within the oncology realm exist. In 2013, a team of chronic myeloid leukemia experts published an editorial highlighting the high prices of cancer drugs, with providers globally signing a follow-up commentary that reiterated the urgency to address these dramatically increasing costs of therapeutics⁴⁵. In 2013, health care providers Memorial Sloan Kettering Cancer Center (MSKCC) identified a disturbing trend among a group of patients which advanced-stage colorectal cancer who were treated with either ziv-aflibercept or bevacizumab. The team noted that although the two treatments possessed similar clinical efficacy; ziv-aflibercept was twice as expensive as bevacizumab⁴⁶. Through drawing attention to this price discrepancy, by deciding to not restock ziv-aflibercept, the responsible pharmaceutical company reduced the price of ziv-aflibercept by half.

Providers have also found that in some cases, switching patients from oral therapies to infusion treatments can also offset costs because the former is covered as a prescription cost (which may need separate, supplemental insurance) and the latter is covered as a medical benefit cost (which is covered by the patient's main insurance)⁴⁷. Finally, in the context of often complex and arbitrary health coverage policies, Hunter and colleagues found that by switching patients from oral therapies, which were associated with high copayments, to intravenous infusion therapies that had little to no copays, helped significantly reduce the OOP costs of care for a cohort of nearly 700 breast cancer patients⁴⁸. These examples suggest that motivated oncologists and oncology teams can act as effective patient advocates, exert influence on health care pricing and policy, and ultimately help offset the growing financial burden of cancer care among our patients.

6. Communication Training in Graduate Medical Education

Despite the documented patient need, recognition by professional bodies and ill-preparation reported by providers, little attention has been given to the training of future clinicians in oncology to effectively discuss costs of care. A growing body of literature dedicated to the delivery of high-value, cost conscious care now exists⁴⁹, however if financial discussions are to become a routine aspect of comprehensive cancer care, the role of Graduate Medical Education and training must be examined. Limited clinician and training resources currently exist to address this issue and guide fellowship directors in how to best prepare clinicians to conduct such discussions in a culturally sensitive manner⁵⁰.

To date, there have been no standardized training programs or interventions developed or implemented to help guide oncologists' discussions of costs of care with their patients. Importantly, an expanding literature has been supportive of implementing communication skills in the health care setting⁵¹. This includes a deeper literature concerning communication training at the end of life, and thus may serve as a model for the development and implementation of such communication training around costs of care in fellowship and beyond. Kissane and colleagues developed and implemented an advanced communication skills training program for oncology faculty and trainees within a large comprehensive cancer center^{52,53}. The nine modules developed as part of the program addressed challenging areas of patient-provider communication, including breaking bad news, conducting a family meeting, and discussing death and dying. Each module includes role-play exercises to practice and gain confidence in utilizing effective communication skills, and participation has increased trainees' confidence in engaging in such discussions in the clinic. The potential inclusion of a similar skills-based module concerning costs of care and financial toxicity in graduate medical education can help prepare clinicians for a future in which such discussions become an important part of providing comprehensive patient-centered care.

Finally, the growing movement towards promoting value-based medical care may also play a role in guiding clinicians and trainees' approach to discussing financial toxicity and burden. In a recent review of the literature, Stammen and colleagues⁴⁹ identified nearly 80 studies of programs designed to help guide physicians to provide high-value care. As such interventions become more routinely integrated into medical training and clinical care, it is hoped that clinicians will develop greater awareness of the potential cost burden of their recommendations, and in turn, a greater sense of responsibility to discuss costs of care with their patients. Benefits of provider-patient financial toxicity discussions are summarized in (Table 1).

| oncologists | | |
|---|---|---|
| Measures | Scoring Tool | Source |
| -clinical efficacy -toxicity -symptom palliation | Overall Net Health Benefit (NHB*) | American Society of Clinical Oncology (ASCO) <u>https://www.advisory.</u> <u>com/research/oncology-</u> <u>roundtable/oncology-</u> <u>rounds/2015/09/asco-</u> <u>health-benefit-score</u> |
| -clinical efficacy -toxicity -quality of life -survival | European Society for Medical Oncology Magnitude of Clinical Benefit Scale (ESMO- MCBS*) | European Society of Medical Oncology (ESMO) https://www.esmo.org/ <u>ESMO-Magnitude-of-</u> <u>Clinical-Benefit-Scale</u> |
| -efficacy -toxicity/ safety -quality of evidence -consistency of evidence -affordability | Evidence blocks | National Comprehensive Cancer Network (NCCN) <u>https://www.nccn.org/</u> <u>evidenceblocks/pdf/</u> <u>EvidenceBlocksFAQ.pdf</u> |
| -yearly cost for drug -toxicity discount -rarity multiplier -population burden of disease -cost of development -prognosis -unmet need | Drug Abacus (interactive online tool that helps calculate and compare over 50 cancer drugs) | Memorial Sloan Kettering Cancer Center (MSKCC) https://drugpricinglab.org/ tools/drug-abacus/ |
| -comparative clinical effectiveness -incremental cost- effectiveness -other benefits or disadvantages (subjective based on patient preferences) -contextual | Value Assessment Framework | Institute for Clinical and Economic Review (ICER) https://icer-review.org/ methodology/icers- methods/icer-value- assessment-framework-2/ http://icer-review.org/wp- content/uploads/2018/05/ ICER-value- framework-v1-21-18 pdf |

| Table 1. | Summary of various costs of care tools available to |
|----------|---|
| | oncologists |

* Two different types have been developed – one for advanced disease therapies and another for adjuvant therapies (potentially curable).

7. Resources for Providers to Estimate Cancer Treatment Value

Whereas work remains in ensuring costs of care become a routine component of comprehensive patient-centered oncology care, several resources have been developed to help guide oncologists in discussions. ASCO's Value in Cancer Care Task Force recently developed a framework that can help guide costs of care discussions between physicians and patients. This model prompts providers to be more transparent with costs for anticancer agents by comparing drugs based on several criteria including clinical efficacy, toxicity, and symptom palliation. Once these parameters are estimated, an overall Net Health Benefit (NHB) score can be generated⁴³. This tool can help physicians to better draft individualized patient plans based on patient specific preferences and circumstances. Similarly, the European Society of Medical Oncology (ESMO), MSKCC, and the Institute for Clinical and Economic Review have developed their own comparison tools that utilize a similar set of parameters to assess the value of cancer treatment regimens (Table 1)⁴³.

Tools, like those noted above, can help providers create a treatment plan that aligns with patient preferences, increase transparency in value-based cost of care discussion and hopefully, help minimize fears that providers may withhold more clinically effective treatment options from patients based on income status.

8. Conclusion

As the treatment landscape shifts towards further personalized and expensive care choices, the financial burden of treatment will become increasingly important to our patients and their families. Therefore, it is critical to address financial toxicity as part of medical oncology clinical management. The development and implementation of provider communication training programs and integration of appropriate financial toxicity screening will enable cost of care discussions to become routine and help dissipate patient discomfort. Similar hesitancy concerning challenging discussions in oncology has of course existed in the past. Once we acknowledge that financial toxicity is a factor that can greatly impact the lives of our patients, both in the short and long term, then it is, by its very nature, part of our duty of care.

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