COMMENTSARY

Financial Toxicity of Cancer Care: It’s Time to Intervene

S. Yousuf Zafar

Affiliation of author: Duke Cancer Institute; Sanford School of Public Policy, Duke University, Durham, NC.

Correspondence to: S. Yousuf Zafar, MD, MHS, DUMC 2715, 2424 Erwin Rd., Suite 602, Duke Cancer Institute, Durham, NC 27710 (e-mail: yousuf.zafar@duke.edu).

Abstract

Evidence suggests that a considerably large proportion of cancer patients are affected by treatment-related financial harm. As medical debt grows for some with cancer, the downstream effects can be catastrophic, with a recent study suggesting a link between extreme financial distress and worse mortality. At least three factors might explain the relationship between extreme financial distress and greater risk of mortality: 1) overall poorer well-being, 2) impaired health-related quality of life, and 3) sub-par quality of care. While research has described the financial harm associated with cancer treatment, little has been done to effectively intervene on the problem. Long-term solutions must focus on policy changes to reduce unsustainable drug prices and promote innovative insurance models. In the mean time, patients continue to struggle with high out-of-pocket costs. For more immediate solutions, we should look to the oncologist and patient. Oncologists should focus on the value of care delivered, encourage patient engagement on the topic of costs, and be better educated on financial resources available to patients. For their part, patients need improved cost-related health literacy so they are aware of potential costs and resources, and research should focus on how patients define high-value care. With a growing list of financial side effects induced by cancer treatment, the time has come to intervene on the “financial toxicity” of cancer care.

The term “financial toxicity” has been used to describe the harmful personal financial burden faced by patients receiving cancer treatment (1). As with any adverse effect of cancer treatment, the experience of financial toxicity is diverse and can range from subjective distress resulting from monthly copayments that prompt changes in household spending to personal bankruptcy. But what is the scale of the problem? Current evidence suggests that a considerably large proportion of patients is affected by treatment-related financial harm. According to the Centers for Disease Control and Prevention, one in three Americans experiences financial burden as a result of medical care (2). The burden is greater for cancer patients, who pay more out of pocket for care than those with other chronic illnesses (3). Indeed, 13% of nonelderly cancer patients spend at least 20% of their income on out-of-pocket expenses (3). Fifty percent of Medicare beneficiaries with cancer pay at least 10% of their income towards cancer treatment–related out-of-pocket costs (4). In other words, half of elderly cancer patients are underinsured. When framed this way, the true scale of the problem is evident.

Despite the millions who now have access to care as a result of the Patient Protection and Affordable Care Act (ACA), there is little evidence that cancer care is any more affordable than prior to the ACA. The Kaiser Family Foundation conducted a nationally representative survey of consumer finances to estimate the proportion of households that can afford cost-sharing requirements of the ACA (5). The study found that many households—particularly those with low incomes—lack the resources to cover the standard cost-sharing demands of today’s insurance plans available on the exchanges. For example, only 53% of all households had sufficient funds on hand to pay a median, mid-range, annual deductible of $2400 per family, and only 45% could pay a median, high-range deductible of $5000. This figure is particularly important as out-of-pocket costs for cancer care approach $5000 per year (3,4).

Keeping in mind that cancer treatment is likely to span more than one calendar year, it is not difficult to envision how even well-insured cancer patients find themselves struggling with medical debt.
As medical debt grows for some with cancer, the downstream effects can be catastrophic. Analyzing population-based data from Western Washington State, Ramsey et al. found that having a cancer diagnosis was associated with a 2.65-times greater likelihood of declaring personal bankruptcy. Recently, those investigators re-examined the same data to determine whether personal bankruptcy was associated with poorer health outcomes. They compared a sample of patients with cancer who declared bankruptcy to a propensity-matched sample of patients with cancer who had not declared bankruptcy. They found that those cancer patients who declared bankruptcy had a 79% greater mortality risk than those who had not (6). This finding is striking as it is among the first to demonstrate a link between extreme financial distress (manifested by a declaration of personal bankruptcy) and greater risk of mortality (7). However, this finding also begs the question: Why does this relationship exist?

How Does Financial Toxicity Worsen Outcomes?

At least three factors might explain the relationship between extreme financial distress and greater risk of mortality (Figure 1): 1) poorer subjective well-being, 2) impaired health-related quality of life, and 3) sub-par quality of care. The initial research in cancer treatment–related financial toxicity focused primarily on the relationship between financial burden and the resultant poorer subjective well-being of cancer patients. Subjective well-being has been defined as “different valuations that people make regarding their lives, the events happening to them, their bodies and minds, and the circumstances in which they live” (8). Numerous studies have found that because of high out-of-pocket expenses cancer patients and their caregivers face considerable detriment to their subjective well-being (9–11). To defray expenses, they are at risk of cutting back leisure activities, spending less on food and clothing, and working longer hours (1,12). These lifestyle changes are challenging for most people and even more so for those facing a new diagnosis of cancer. Beyond being challenging, evidence suggests that poor subjective well-being might impact health outcomes including survival (13,14).

Second, financial distress might worsen survival because of its impact on health-related quality of life (HRQOL), which is distinct from subjective well-being. HRQOL is defined as aspects of quality of life that relate specifically to a person’s health, including domains of physical, social, and mental functioning (15). At least two large studies have suggested an association between cancer treatment–related financial burden and poorer HRQOL. Fenn et al. studied data from 2108 cancer patients who participated in the National Health Interview Survey and found that compared with those with no financial hardship patients who reported “a lot” of financial problems due cancer care were more likely to report poor physical health, poor mental health, and less satisfaction with relationships (16). Importantly, greater financial hardship was the strongest independent predictor of reporting worse HRQOL. Another analysis of data from the demographically representative Cancer Care Outcomes Research and Surveillance Consortium study (17) found that among 1000 patients with lung or colorectal cancer high financial burden was associated with worse self-reported HRQOL (18). Because several studies have suggested that poor HRQOL is an independent negative prognostic marker for cancer patients (19,20), poor HRQOL might help explain the risk of shortened survival for patients with extreme financial distress.

Third, higher out-of-pocket costs can harm the quality of care. The effect of financial burden on adherence to medications is perhaps the most convincing contributor to the relationship between financial burden and mortality. As cost-sharing rises—in the form of greater copayments for prescription medication—patients with cancer are at risk of facing large bills as a result of their anticancer therapy. While the price of all chemotherapy, oral and IV, has risen dramatically over the past few decades (21), cost-related nonadherence is a concern as patients are faced with the more immediate decision of paying the copayment for the oral chemotherapy prescription or forgoing the treatment. Evidence suggests patients are experiencing difficulty in keeping up with those copayments. Neugut et al. found that among women receiving adjuvant hormonal breast cancer therapy higher monthly copayments ranging from $30 to $90 for those drugs were associated with greater odds of noncompliance (22). And greater noncompliance with hormonal therapy has been associated with increased mortality (23). Hormonal therapy for breast cancer is not the only example of high out-of-pocket costs leading to nonadherence. Among patients with chronic myeloid leukemia (CML), Dusetzina et al. found that those with higher copayments, classified as greater than $53 per month, were 70% more likely to discontinue imatinib within six months of initiation (24). Disturbingly, these studies suggest that relatively small changes to patients’ budgets—in the range of less than $100 per month—can induce nonadherence to potentially life-saving drugs.

A growing body of evidence supports the existence of financial toxicity resulting from cancer treatment, and recent research suggesting a link between financial toxicity and greater risk of mortality is compelling. Research on patient financial burden should focus on verifying the detrimental impact of financial distress on cancer-related outcomes, including mortality. More work can be done to better explain the relationship between financial distress and worse outcomes, with efforts to differentiate aspects of financial burden that contribute most to distress, including direct costs like coinsurance and indirect costs like time off work. While these descriptive studies are important, intervention work should proceed in parallel.

How Can We Intervene Today?

With a growing list of financial side effects induced by cancer treatment, the time has come to intervene. To reduce the personal financial burden of cancer treatment, interventions should be developed that focus on all involved parties. Others have written eloquently on how the pharmaceutical industry has a responsibility to lower the price of drugs, especially because drugs entering the market are priced with little correlation to improvement in outcomes (25,26). The government
could play a role if, for example, the Centers for Medicare and Medicaid Services was allowed to negotiate prices with drug makers, which some argue would result in lower drug prices in the United States (26). Another policy initiative could promote pricing based on outcome, where inadequate response to a drug would result in a refund (27). Payers must play a role as well. A greater proportion of costs has been shifting to patients in the form of higher premiums, deductibles, and tiered formularies. Average worker contributions to premiums have doubled since 1999, and over the past six years the average annual deductible has more than doubled, from $584 in 2006 to $1217 in 2014 (28). To prevent nonadherence because of cost sharing, payers should consider value-based insurance design that reduces or eliminates cost sharing for high-value treatment (like imatinib for CML) (29).

Realistically, any policy intervention directed at manufacturers or payers is unlikely to be implemented anytime soon. If we are to intervene on the financial toxicity of cancer treatment today, we must look to the provider and patients. The goal of enhancing shared decision-making to reduce costs has been championed by the Institute of Medicine as a high priority for oncologists (30,31), but this will require a paradigm shift with three components. First, to intervene today on high patient costs oncologists should focus on the value of care delivered. Specifically, this means discouraging use of interventions that have little benefit but high cost. Vocal clinicians focused on value can influence drug pricing, as evidenced by the case of ziv-aflibercept. (32). The drug, indicated for the treatment of metastatic colorectal cancer, was introduced at twice the price of existing treatment but without any comparative effectiveness data that supported its higher price. After the well-known, highly publicized effort by Memorial Sloan-Kettering physicians to not prescribe ziv-aflibercept for the treatment of metastatic colorectal cancer, the manufacturer, Sanofi, reduced the price of the drug to match prices of existing treatment. More recently, when the price of a toxoplasmosis drug was raised by 5000%, media attention generated by vocal infectious disease doctors forced a price reduction within days of the initial price hike (33).

Second, oncologists must initiate the conversation. As oncologists, we need to focus more on goals of care discussions early in the treatment course (34). Specific to costs, studies suggest physicians are interested in discussing costs with patients, but few feel comfortable or prepared to have that discussion (35,36). Yet simply asking patients if they have difficulty paying for their medical care is an important means for oncologists to ally themselves with patients. Many patients seek engagement with oncologists regarding costs but are unsure how to broach the topic in clinic. For example, our research found that half of patients surveyed were interested in discussing their cost burden with their oncologist, but only 19% followed through with a cost discussion (37). When asked what barriers hindered a cost discussion, 28% of patients stated they avoided the discussion because they wanted the best care regardless of cost. These data suggest some patients are concerned they might receive lesser quality care if they bring up costs with their oncologist. However, in most cases cost can be addressed without changing any treatment but rather by directing patients to financial resources and advocating on behalf of the patient with the insurance company (38). Hence, when appropriate and desired, communication-based interventions could promote discussions about out-of-pocket costs between patients and their physicians.

Third, if patients are prompted to broach the topic of costs, physicians must be prepared for the discussion. As such, interventions must focus on educating physicians on how to engage patients regarding value in cancer care. Oncologists know little about the out-of-pocket costs incurred from the treatments prescribed. One tool that presents a step in the right direction is the American Society of Clinical Oncology’s Value Framework, which calculates a Net Health Benefit score and displays it alongside potential costs to the patient (39). Even if oncologists do not know how much a prescription will cost, other members of the healthcare delivery team can find out. Pharmacists and financial counselors can check insurance coverage before patients leave clinic with expensive prescriptions and can identify financial resources for patients early in the course of care.

Fourth, to reduce financial toxicity, patients have a role to play. Patient-level interventions must focus on improving patients’ conceptual knowledge of health insurance and finance, also known as cost-related health literacy (40). According to the National Assessment of Adult Literacy, nearly 80 million Americans have health literacy that is considered “basic” or “below basic” (41). Specific to cost-related health literacy, Americans also fare poorly when it comes to basic knowledge about health insurance. In one national study, only 42% of participants could accurately describe a deductible, and only half were aware of the new exchanges established by the Affordable Care Act (42). Because of limited cost-related health literacy, insured patients are often surprised by the costs they face upon starting cancer treatment, and few know where to turn for help (43). Interventions should focus on educating patients on the basics of health insurance, potential costs they might face during treatment, and available resources like patient assistance programs. In addition to cost-related health literacy, research should focus on how patients define value and what aspects of their care they value most, relative to their personal experience. Without this work, value discussions initiated by oncologists will have limited effectiveness.

**Conclusion**

Financial toxicity is a concern for a growing proportion of patients, with half of all Medicare patients with cancer at risk of being underinsured. We now have an evidence-based list of harms that patients experience as a result of cancer treatment-related out-of-pocket costs. A recent study suggests that extreme financial distress as manifested by personal bankruptcy might be associated with worse mortality in cancer patients. That relationship between financial distress and worse outcomes is likely explained by the impact of cancer-related expenses on patient well-being, health-related quality of life, and adherence to anticancer therapy. Research should focus on verifying and further describing this relationship. Long-term solutions must include policy shifts involving how we set prices, negotiate prices, and establish by the Affordable Care Act (44). Because of limited cost-related health literacy, insured patients are often surprised by the costs they face upon starting cancer treatment, and few know where to turn for help (43). Interventions should focus on educating patients on the basics of health insurance, potential costs they might face during treatment, and available resources like patient assistance programs. In addition to cost-related health literacy, research should focus on how patients define value and what aspects of their care they value most, relative to their personal experience. Without this work, value discussions initiated by oncologists will have limited effectiveness.

**References**


