ADVANCES IN DRUG DEVELOPMENT

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The Impact of Financial Toxicity on Cancer Care



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H&O What is financial toxicity, and how does it impact cancer therapy?

JP Financial toxicity is a term used to describe the burdens, barriers, and distress that patients with cancer can experience owing to high costs of care. Financial burdenand cost-related barriers to access have been described for decades, but the term "financial toxicity" was coined in 2013 by Zafar and colleagues to emphasize that, just as patients can experience physical side effects of cancer treatments, or "toxicity," they can also be harmed by high out-of-pocket costs associated with some treatment decisions.1 Patients with cancer who face high medical bills often experience a higher rate of distress and worse quality of life. This financial strain may lead them to cut back on recommended aspects of care, such as taking all of their prescribed medication, going to all of their medical visits, and getting all recommended tests.² We are increasingly seeing that, for many patients, the financial impact can be as significant as the physical side effects of the drug in terms of quality of life and treatment outcomes.

H&O What clinical studies have been conducted to evaluate financial toxicity in cancer care, and what were the results?

JP There have been hundreds of studies of financial toxicity. Our original 2013 paper, where we coined the term "financial toxicity," has been cited nearly 1000 times. A PubMed search of "financial toxicity and cancer" yields more than 13,000 results.¹ If I had to briefly summarize this growing literature, I would say that financial toxicity is a real and relatively common issue experienced in virtually every cancer setting.

However, it is not universal. Not all patients with cancer report financial distress, even those who have high out-of-pocket costs. As a rough estimate, I would say that in many settings, about 40% to 50% of patients in the United States face some degree of financial distress, and 15% to 25% report moderate to severe financial distress.² In a study we reported at the 2023 American Society of Clinical Oncology annual meeting, we surveyed more than 1000 patients with cancer who were recipients of copay assistance grants. We found that despite assistance, 56% reported mild financial distress on a validated scale, and 27% reported moderate to severe distress.³ Close to 40% reported spending more than 10% of their annual household income on healthcare costs. This is again despite receiving grants to help cover the cost of their current cancer treatment, and despite the fact that the vast majority (96%) had Medicare.

In one now-famous study that helps capture the potential scale of this problem, Ramsey and colleagues found that patients with cancer are more than 2.5 times more likely to file for bankruptcy compared with patients without cancer.⁴

H&O What key factors contribute to the financial toxicity experienced by cancer patients, and how do they differ by cancer type and stage?

JP Financial toxicity is essentially a function of 3 factors:

the costs of care, including medication, surgery, radiation, tests, and hospitalization; the level of insurance coverage and the portion of the cost that the patient has to pay directly, often referred to as "out-of-pocket expenses"; and the patient's baseline financial status. Any patient with cancer can experience financial toxicity, regardless of cancer type, if a high-cost medication is required. Financial toxicity can also apply to those who need surgery or radiation, depending on their insurance coverage. It can also apply to patients regardless of stage or where they are in the cancer care trajectory.

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Studies have demonstrated financial toxicity even among newly diagnosed patients with early-stage breast cancer who are considering surgery and radiation therapy.⁵ It is perhaps more common among patients with advanced cancer simply because their treatment often extends over longer periods, sometimes years, and can involve high copayments. As we increasingly bring expensive drugs from the metastatic setting to the early-stage adjuvant setting, we also expand the potential for patients to face financial hardship.

Research has shown that in general, cancer survivors experience greater financial burdens than their peers without a history of cancer. This is particularly true for adult survivors of childhood cancers, who can face major ongoing financial consequences of their diagnosis.⁶ Patients with a history of childhood cancer have a higher likelihood of spending more than 10% of their income on healthcare, which is associated with more problems paying medical bills, higher rates of skipping treatments or visits, and greater consideration of bankruptcy.⁶

H&O Does financial toxicity affect patient behavior and treatment outcomes?

JP Financial toxicity, or the degree of distress related to costs of care, has been associated with changes in patient behavior, including decreased adherence to medication

and decreased follow-up for medical visits and tests.^{1,7,8} In our initial 2013 study, we found that patients reporting financial burdens not only reduced spending on food, clothing, and leisure activities, but they took less or completely stopped prescribed medications.¹ Other researchers have also shown that higher copayments for oral breast cancer therapy are associated with higher rates of stopping the medication early. Even for the treatment of chronic myeloid leukemia, which can now be controlled with oral therapy, higher copayments were associated with a near-doubling in the risk of stopping the medication.^{7,8}

Multiple studies have now shown that financial toxicity is associated with worse quality of life and worse mental and physical health.^{2,9,10} A recent review and meta-analysis looked at 31 studies representing more than 13,000 patients with cancer from 9 countries and found that higher financial toxicity was associated with worse scores for physical health, mental health, social functioning, and overall quality of life.¹¹

H&O How do advances in cancer treatment and diagnosis impact financial toxicity?

JP As an oncologist, I should make 2 points. First, we still badly need advances in cancer treatment and early detection so that we can improve cure rates, extend survival, and reduce the overall morbidity and mortality associated with cancer. This is the top priority. Second, financial toxicity-defined as the costs, burdens, and distress experienced by patients and their families-is not inherently associated with any new advance, it is a function of what we charge for the treatment and insurance coverage, which determines the portion of cost passed on to the patient. If we could develop new drugs that either cost the same as existing therapy while offering better outcomes, and/or make sure that these new advances are available to patients without imposing high copays or direct costs, we could advance cancer care without any increase in financial toxicity. Financial toxicity is not inherent in care, but rather is a function of our healthcare system.

That said, studies have shown the cost of new drugs tends not to be set based on the degree of improvement in outcomes, or the "value" of the drug, but rather is based on what the last drug sold for and what the market will bear, or what the manufacturer can charge.¹² Similarly, we do not yet have an insurance system where we guarantee access to newer and more effective drugs without high copayments. There is a lot of work to do in this area. I believe that everyone generally supports both innovation and access, with no distress for patients, but we have debates over how best to achieve these goals. At this time, I am afraid that new treatments or diagnostic tests often come with new out-of-pocket costs for patients.

H&O How does financial toxicity vary among countries outside the United States?

JP Although there are many ways that healthcare, including cancer care, is covered or not covered around the world, I can make a few general statements about global variations in financial toxicity. First, even in countries with a national health system, there are concerns over access to new high-cost cancer therapies.¹³ In the United Kingdom, where the national health services cover most direct costs for cancer therapy, there have been multiple studies documenting the financial burdens of cancer, often due to indirect costs related to loss of employment, travel, special diets, and other cancer-related challenges.¹⁴ These are not directly related to the cost of drugs but reflect a growing awareness internationally of the financial burdens of a cancer diagnosis, and these tend to be grouped in the literature under the heading of financial toxicity because they are directly related to cancer, if not to the drugs or tests themselves.

There are now studies of financial toxicity from all corners of the globe. The common theme is that patients with cancer also face economic challenges that go above and beyond the disease itself. In countries where cancer care is well covered by insurance, this tends to be in the form of indirect economic impacts such as employment and costs of travel for care. In countries where patients pay a portion of the cost or where they tend to have private insurance to supplement the public system, financial toxicity is very similar to that experienced in the United States. I think the most important point to make is that this phenomenon is not restricted to the United States, but the financial challenges of cancer care are magnified in a system where access to care is not guaranteed and when costs of care are passed on to patients in the form of copayment or high deductibles.

H&O What social determinants of health are associated with the financial toxicity felt by cancer patients?

JP Financial toxicity has been shown to be greater, not surprisingly, among those with less economic security—in particular, those with lower income, younger patients with cancer who are not yet established in their careers, and people who are single. In addition, financial toxicity is greater among members of racial/ethnic groups who have experienced structural racism, among members of sexual and gender minority groups, among those with lower health literacy, and among those living in more rural areas.²

H&O What role do healthcare providers, institutions, and/or private entities play in alleviating the financial burden on patients, or do they make it worse?

JP Starting with clinicians, I believe we have the capacity to make financial toxicity better or worse depending on whether and how we discuss and consider costs with our patients. If we ignore costs of care entirely, as I believe clinicians were trained to do for many years in the past, then we can make it worse by prescribing low-value treatments and tests, where some of the costs will be passed on to our patients with no or little benefit, or even by prescribing appropriate care but not considering the costs to our patients. Often, if we do discuss costs, and in particular if we ask about any financial barriers to patients getting the care they need, we can recognize the need to refer some patients to financial assistance programs, and often potentially large out-of-pocket costs can be reduced or eliminated.¹⁵ At the institutional level, the story is similar-if clinics or hospitals ignores costs, they will almost certainly contribute to making the problem worse. In contrast, financial navigation programs have been shown to be effective in helping lower costs and helping patients get the care they need.¹⁶⁻¹⁸ Institutions can implement systems where patients are screened for financial toxicity, can identify members of the cancer care team who can address any issues identified, and can streamline methods to help reduce financial toxicity. Private entities are a broad term that includes everything from drug manufacturers to forprofit insurance companies to copayment assistance foundations. I will simply say that if the whole system focuses more on reducing financial barriers and out-of-pocket costs related to high-value cancer care, patients will likely have better outcomes and lower financial burdens.

H&O In terms of healthcare policy, what changes could be implemented to reduce the impact of financial toxicity and ensure equitable access to treatments and supportive services?

JP At the policy level, this question comes down to how we continue to support innovation in cancer care while controlling costs, particularly direct costs to patients. This means in part recognizing the importance of a profit incentive to support innovation for both drug companies and other health science companies and for the flow of capital that supports innovation, while also making sure that current and future cancer care is available to all who need it, without imposing financial burdens that both magnify the distress that is already associated with cancer. There is no single simple policy solution. However, continuing a system where any meaningful innovation is

approved and then covered by insurance, at any cost, with a portion of that cost passed on to patients, is neither fair nor sustainable.¹² As a result of the Inflation Reduction Act of 2022 in the United States, we are now embarking on a period of greater government engagement with healthcare costs in the form of negotiation between the government as the largest payer for healthcare services through Medicare and drug manufacturers. This involves health technology assessment to help determine value and sustainable cost. Although this approach is relatively new in the United States, many countries have embraced this for decades. This will shift, but not end, debates over what cancer care should cost and how much of the cost patients should have to pay. The related policy solution, beyond drug costs alone, is to better define high- and low-value care and to try to eliminate any financial barrier or burden associated with high-value care.

Any policy solution involves values and choices. I hope we can agree that shifting costs of cancer care to patients, whether owing to high costs of treatment or gaps in insurance coverage, is not a choice we want to make. We need to solve the challenge of ongoing support for innovation and sustainable healthcare budgets and insurance coverage without trapping patients in the middle.

Disclosures

Dr Peppercorn's spouse is employed by GSK.

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