

Time to Treat Financial Toxicity for Patients

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Abstract: Modern medical costs fall beyond most peoples' ability to pay and cause severe adverse effects that impact patients and families. It is time to team up with all stakeholders to provide solutions to systemic issues that thwart oncology's true goal to help patients survive their care and their cancer. Patients need realistic approaches that include (1) access to affordable treatments, (2) accountability and oversight toward patient costs and results in research, and (3) cost-effective drug supply once commercialized. Physicians play a critical role helping patients develop a plan that fits each person's medical, financial, and life situation.

Key Words: Bankruptcy, burden, cancer, debt, distress, drug pricing, financial toxicity, patient, treatment

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The costs of modern drugs and medical care fall beyond most peoples' ability to pay today, even with health insurance. Before coronavirus disease (COVID-19), at least 28% were underinsured in the United States.¹ After COVID-19, 40 million people have lost their jobs and now join the additional 27.46 million people who have no health insurance because it is primarily offered through US employers.²

Traditionally, oncologists rarely spoke about costs, but now it is imperative. Financial toxicity should be treated the way other adverse effects of cancer treatment are handled. It would then be classified as a serious adverse event because of its major ramifications on patient health. It even impacts survival as stated by Ramsey et al.,³ “Cancer patients who go bankrupt are nearly 80% more likely to die than patients who do not, and some cancers had significantly higher mortality rates.” Yet, financial toxicity is rarely recognized, often ignored, and certainly not treated. This has to change.

Economic issues have plagued cancer patients for decades, but have escalated much faster than monetary inflation since at least 2000. Financial toxicity has been used since 2009⁴ and was further developed in 2013 by Zafar et al.⁵ The current definition states “the objective financial burden and subjective financial

distress of patients with cancer, as a result of treatments using innovative drugs and concomitant health services,”⁶ such a sterile and esoteric phrase to describe something that tears people apart at the worst time of their lives. There is no pill to make it go away, although self-application of alcohol or other mind-numbing agents are sometimes utilized. It starts for most patients before or during active treatment, remains long after treatment is over, and can continue past their life spans, burdening families with crippling financial debt and an increasing rate of bankruptcies.^{7,8}

A comprehensive review of issues that surround the untenable costs of oncology drugs and treatments throughout the US research and medical care systems is too large to address in this one article. It is also true that other countries are increasingly discussing these issues, but the US laissez-faire approach to health care has created a toxic pool of medical debt for most people unlucky enough to become a cancer patient. It is time to recognize and treat financial toxicity, for patients' sake.

Do No Harm?

The ultimate goal of cancer treatment is to extend life, hopefully including better quality and well-being in addition to quantity. The social determinants of health that include conditions in which people are born, grow, live, work, and age⁹ are often discussed in academic circles, but our health care systems are not set up to address them in the United States and in many other countries.

While patients need strong pharmaceutical companies that are willing to invest in new agents, society cannot pay an unlimited cost for this luxury. Our current approach to pricing and paying for medical treatment is unsustainable for many reasons. The paucity of evidence for general patient populations and lack of comparative treatments, however, make it very difficult for providers, patients, and caregivers to determine which treatments offer actual value. Companies purport to foster “innovation” for new drugs, but their track record does not look so good.¹⁰ Companies need to provide value that matches the prices they charge, so patients do not end up with new products that do little overall.

The amount of funds that the public invests is also overlooked when companies that profit from this research determine their prices.¹¹ Efforts,¹² methods,^{13,14} and various value models¹⁵ have attempted to estimate financial toxicity, but inadequately measure true patient burdens. Groups such as the Institute for Clinical and Economic Review include public funding in its value framework,¹⁶ but this debate will continue for years to come.

Cancer patients need treatment that improves their lives, not just short-term survival. When people are diagnosed with cancer, these newly labeled “patients” (and caregivers) face simultaneous levels of physical, mental, emotional, and financial distress.¹⁷ Their choices are often limited—they seek answers and advice that help them weigh the potential benefits, risks, and costs for each option before shared treatment decisions are made. When costs are not discussed or considered, many find themselves in a medical “money pit” that often results in delaying treatment, cutting back medications, refusing treatment, and sometimes dying earlier than if they had been able to weigh their options realistically. Why do patients have to deal with this on top of a life-threatening diagnosis?

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It may be difficult for someone who makes a comfortable 6- or 7-figure income to understand the gravity of the situation their patients face. Perhaps those who experience massive student loans can relate a bit better, although their future prospects are much brighter than most of their patients. COVID-19 adds even more layers of complexity and consternation since studies show that cancer patients and survivors appear to be at higher risk of the disease and its complications. Here are some situations that may shed more light on the real-life decisions patients must face.¹⁸ Consider the following:

- the 43-year-old single mom who has to decide between that new ovarian cancer maintenance therapy of olaparib/bevacizumab or paying for the college her son was just accepted into¹⁹
- the 62-year-old business owner just diagnosed with colorectal cancer, who recently implemented a coinsurance plan so she would not have to lay off employees; surgery and treatment have been postponed because of COVID-19, but she is not sure she can afford it anyway
- the 25-year-old truck driver who has no insurance and was just diagnosed with Hodgkin lymphoma
- the 72-year-old grandfather who wishes someone knew which of the 6 to 8 new drugs for his acute myeloid leukemia might help him avoid a transplant²⁰
- the 50-year-old employee whose boss just rehired her as a “part-time” consultant to avoid paying rising health benefits; she also wishes that PARP (poly[ADP ribose] polymerase) inhibitor had been compared to carboplatin to know which option may better treat her breast cancer in a cost-effective way
- the 57-year-old dad who wishes the expensive prostate cancer oral agent had been compared to the chemotherapy with similar results so he can enjoy walking his daughter down the aisle at her wedding next year instead of worrying about where the money will come from²¹
- the 68-year-old widow diagnosed with de novo metastatic breast cancer who cannot afford to quit working after her husband died and cannot get coverage for abemaciclib because she did not file for Medicare’s Part D
- the 39-year-old professor whose father died of COVID-19 as he faces his own anaplastic lymphoma kinase–mutated lung cancer, copays, and decisions
- the 56-year-old bladder cancer patient who cannot get his treatment because of drug shortages caused by unintended regulatory consequences and raised prices²²
- the 78-year-old melanoma patient who would like to know when he can stop taking the latest expensive immunotherapy agent

The Least Discussed Adverse Effect

Financial toxicity is a major adverse effect for most cancer patients today. In fact, it has become so common that the National Cancer Institute devotes detailed pages on its website for providers and for patients.²³ Financial toxicity begs questions such as “What is an acceptable ‘grade’ level and for whom?” “Why is not it discussed with all patients?” “Why should people be expected to support medical research and clinical trials that end up creating drugs they cannot afford and, therefore, may never use?”

Patients appreciate shared decision making with providers²⁴ that (1) realistically lays out their options, (2) bases advice on potential benefits and risks for old and new treatments, (3) offers insights on costs and value, and (4) accepts their choice after they make tradeoff decisions.

US patients are caught in the middle of a broken health care system and are forced to manage their own care and expenses.

Varied costs for medical procedures and convoluted billing make it virtually impossible to apply “consumer” price shopping tactics for things such as magnetic resonance imaging scans, drugs, and even blood tests. A survey by the Henry J. Kaiser Family Foundation found that “the high cost of prescription medications, especially those to treat serious medical conditions such as cancer, is the top health concern of 77% of those Americans polled.”²⁵ In a survey from the Cancer Support Community, the top cost concerns for cancer patients included (1) out-of-pocket (OOP) for insurance premiums, (2) coinsurance for services such as laboratory work or physician visits, and (3) drug copays.²⁶

To put this in proper perspective, let us look at 2018, when an estimated 15.5 million people were living after a cancer diagnosis.²⁷ Surveys from the Livestrong Foundation found²⁸:

- Sixty-two percent worried about large bills.
 - That’s every single person in New York City and San Jose combined (9.6 million people).
- Forty percent had to make financial sacrifices to pay for their treatment.
 - That’s everyone in Los Angeles and Houston combined (6.2 million people).
- Thirty-four percent had to borrow money or go into debt to pay for therapy.
 - That’s everyone in Chicago, Phoenix, and Jacksonville combined (5.2 million people).
- Fifty-two percent said they owed \$10,000 or more.
 - That’s every person in Philadelphia and Denver combined (2.7 million people).

Additional studies have shown that many patients cut doses or forego medical treatment,^{29,30} even when they have insurance.²³ Those without insurance, or who are underinsured, are often charged list price for drugs and medical costs. Billing is undecipherable, especially to those with average insurance knowledge. They are far more likely to have problems with payments and end up skipping more procedures.³¹ In addition, many older Americans have multiple chronic medical conditions with medications for each,³² live on fixed incomes, and can spend up to 63% of their household income on OOP expenses.³³

How Treatment Costs Impact Patients and Their Families

There is much more to medical treatment than the cost of each drug,³⁴ although those costs are unreachable for many patients. Melissa Miller, Media Outreach Director of the Mesothelioma Center, explains, “People often only think up to surgery, but postoperative care is where the higher costs are. Dealing with complications and covering costs of scans, home care, and follow-up treatments such as chemotherapy is when it gets really expensive.”³⁵ People with jobs and insurance can rack up tens of thousands of dollars in medical debt. What is it like for more than 67.5 million uninsured or underinsured people when drug treatments can average \$150,000?

A cancer diagnosis affects all facets of life, including future plans. What patients really want, and need, is a treatment that works for them and, preferably, one that they can afford. This would allow them to enjoy life until they die a quick, relatively painless death, which is what most humans desire. Patients and their families are the only ones who see the whole picture that hinders them as they try to balance their lives, as the following examples (although not inclusive) show:

- Medical care costs include ongoing care in addition to the initial treatment.³⁶ This can include items such as genomic testing,

ongoing treatment (with unknown duration), medical procedures, tests and laboratories, supportive care, administration of treatment, and hospital/care center visits.

- Ongoing medical checks include OOPs and travel expenses. Each treatment has adverse effects. More medications and visits are needed to cover those adverse effects, some of which are debilitating and can keep them from working or functioning (fatigue does not mean just being tired). Each of these visits can cost hundreds or thousands of dollars.
- Treatment complications can land people in the hospital, and they have no control over what tests are ordered. The ensuing costs add up on their undecipherable bill. If they are uninsured, they are often charged list price for everything, creating an endless cycle of debt.
- Many cancer patients either have, or end up with, comorbidities, such as heart disease after doxorubicin. Comorbidities increase the amount of checks and tests, medications, and complications with treatments.
- Lost wages occur during treatment and sometimes last long after. More bills accumulate when no money comes in from a job.³⁷ The current US administration's efforts to repeal the Affordable Care Act, as well as unprecedented rates of unemployment due to the COVID-19 crisis, only exacerbate these problems. Cancer diagnoses often lead to being laid off, even though there are laws that supposedly protect people from this,³⁸ but it is extremely difficult to make a case refuting "performance issues."³⁹
- Families suffer too. Home care and caregiving for older adults, parents, or children often suffer or must be discontinued. Many families are put into debt for medical treatment that may or may not help their loved one.
- A recurrence, "second primaries," or metastasis linger in minds for years, even if they do not come to fruition. Many (perhaps even most) cancer survivors cannot count on being "cured." Treatment can help, but remission for life is unknown, and many are surprised years later.

Value: Eye of the Beholder

Part of the conundrum surrounding the cost of drugs and cancer treatment is the confusion caused when different definitions are used for different terms by companies, insurers, health systems, physicians, patients, and people. The terms "price" and "cost" are not the same, depending on whose perspective is being discussed. "Money" does not equal "value" either.

Everyone uses "value," but it means very different things to companies than it does to payers or patients. Ultimately, true "value" should refer to the results that reach patients and their families. The system, however, rarely takes their real-life circumstances into consideration during development and pricing strategies.

Unfortunately, a question that is regularly heard in patient communities is: "Why should we support research for drugs that no one can afford?" It is very difficult to answer this question, and yet the system relies on the support of patients and their families when trying to develop new agents, drugs, and treatments. Clinicians share these concerns, as evidenced by Carrera et al.,⁶ "...We are concerned about whether our patients will benefit or be priced out of the market because of high OOP costs for cancer drugs and high insurance premiums, which incorporate higher spending projections on cancer treatment."

This is why patient experience data and research are so important. Patients deal with much more than medical expenses as they try to keep living. These issues also show why it is critical for research to identify the correct dosage and regimen for each drug treatment within subpopulations of patients, whether single agent or combination therapy, and in what form. Oral medications

sound enticing at first, but not when the price is at least double while offering questionable results. Patients want and need better treatment, not just more of them. It is much better to know which treatments work for specific patient subtypes than it is to have many new drugs that no one knows how to use effectively.

Cancer patients do not receive measurable improvements commensurate to skyrocketing costs.⁴⁰ Many cancers have less costly treatment options that people should be informed of, how they compare in terms of benefit (e.g., extra survival, fewer long-term adverse effects), and how much each option costs. As Dr. Scott Ramsey stated, "Patients need to know... and... if they get into financial distress and stop their therapy, that's going to impact their survival."³⁷ Other terms and mindsets matter as well. Words used in research and medical settings, such as "adherence" or "compliance," actually represent more of an "endurance" test for patients.⁴¹ The true goal of oncology medicine is to help patients survive their care, not just their cancer.

Responsibility Belongs to All of Us

Patient needs rarely drive factors for drug development and medical care—the system has been set by medical billing codes and other misaligned incentives within research and medicine that do not necessarily result in better patient outcomes.

The fact is that none of the "stakeholders" are totally guiltless regarding the problems that need to be fixed. In other words, everyone involved in the system is responsible for problems that affect patients and should take responsibility to work together to rectify untenable and unsustainable issues, including

- patients and patient advocacy groups (PAGs)
- providers and health systems
- companies
- payers
- regulators and policy makers

Some patients and PAGs want access to anything that might work, no matter the cost. They believe in the hyperbole spread throughout the medical, research, and online worlds that the newest therapies are better, even though research has proven for decades that this is not always true. In fact, Derek Lowe⁴² comments, "The reasons for these failures appear to be unchanged: 75% to 80% are due to problems with efficacy and/or safety... showing just how much we do not know about what we are doing." For example, many patients want an immunotherapy based on exceedingly positive coverage, but do not realize those therapies only work for a small minority of patients and can come with serious adverse events.^{43,44} This is equally unsustainable with prices/costs that do not return useful results to patients. Some PAGs may also have conflicts of interest based on company payments, grants, or specific arrangements that do not always put patients first.⁴⁵ Accepting money from companies does not guarantee a conflict of interest, but full disclosure and transparency are imperative.

Providers often focus on "cure" even when it is not attainable. This manifests into frustration as they persuade patients to try numerous lines of treatment with diminishing returns. When it becomes about treating someone no matter what, patients are put in difficult and expensive positions. In fact, some patients would like to stop treatments that do not work but feel pressure from the medical community and sometimes from their own family to keep going, which exacerbates costs without gain. Feelings of guilt and hopelessness can add to their other burdens. Traditional oncology care models also created accusations that led the American Society of Clinical Oncology (ASCO) to propose a new payment model.⁴⁶ This only adds to unwelcome perceptions

when monetary conflicts of interest surface between physicians and companies.⁴⁷ In addition, health systems can include provider groups, hospitals, and other “cost of care” services, which are also out of control and look greedy.³⁶

Companies are incented to make profit, and their focus remains on product and regulatory requirements for commercialization. While reasonable profitability is acceptable, accountability and price transparency are missing. Although drug prices are not finalized until a new drug label is approved, inflated research and development costs are used as an excuse for high prices.⁴⁸ For instance, unrealistic prices for mergers and acquisitions go unchecked in relation to valuation and yet are passed on to payers (which include patients and their families) with no caps.⁴⁹ There are very few business fields that treat past failures as a justification for current market pricing,⁵⁰ even ones that are highly regulated.⁵¹ Many do not believe the excuse company lobbyists utter that price caps will lower innovation.⁵² In fact, analyses “found large pharmaceutical companies did not actually invent most of the drugs they sell.”⁵³

Many do not trust pharmaceutical companies to price drugs fairly and support government price negotiations, counter to current laws.^{12,29} For instance, Dr. Brian Druker asked, “When do you cross the line from essential profits to profiteering?” when discussing Gleevec in 2013.¹² Too many drug approvals also apply to “me too” drugs, not novel drugs for true unmet medical need.⁵⁴ In addition, company “rebates” confuse pricing issues,⁵⁵ and drug assistance programs are not only inaccessible to many patients who need them,⁵⁶ companies profit through “a triple boon for manufacturers, ...they increase demand, allow companies to charge higher prices, and provide public-relations benefits.”⁵⁷

Payers seek relief through new ways to mitigate costs, such as copays, coinsurance, and donut holes. This has led to “spread pricing” through pharmacy benefits managers,⁵⁸ who actually exacerbate costs by inflating health care spending.⁵⁹ This can create inequitable systems, though, especially for government payers and some employer “cost-sharing” plans.⁶⁰ These pharmacy benefits managers are responsible for the tiered formularies that now lead to exorbitant OOP costs.⁶¹ Employers limit their liabilities by switching from employees to “consultants,” changing from full-time employees

to part-time, and/or moving to cost sharing insurance plans that create true OOPs for patients.

Regulatory agencies have limited authority, with pieces so scattered that unintended barriers can be created between and even within entities such as Food and Drug Administration, Centers for Medicare & Medicaid Services, Department of Health and Human Services, Centers for Disease Control and Prevention, Office of Human Research Protection, National Institutes of Health, National Cancer Institute, and others. In addition, policy makers and economists want to follow “consumer” models that simply will not work when patients (as consumers) cannot shop for price or alternative treatments. Clearly, the whole picture that patients and their families face daily needs to be explored with all stakeholders together to create systemic changes that address each piece of this broken puzzle (Fig. 1).

What Patients Need From Physicians

Patients appreciate shared-decision making with health care providers²⁴ who (1) clearly lay out options for their situations, (2) advise on potential benefits and risks for old and new treatments, (3) offer insights and resources on costs and value, and (4) accept their patients' choice after making tradeoff decisions.

As a physician, there are several steps that you can take to help your patients,⁶² each and every time.

Here are a few suggestions, although even more are available:

- Follow practice guidelines such as ASCO's Choosing Wisely.⁶³ Many tests are ordered out of habit that simply waste your patients' time and money.
- Explain treatment options, how long each potentially adds to life and what patients must endure to get that life extension. This includes adverse effects, long-term effects and the cost of each treatment.
- Build financial toxicity into every treatment discussion, whether or not a clinical trial is involved. Many patients will not ask about it, but do not assume you have an accurate picture of their financial situation.

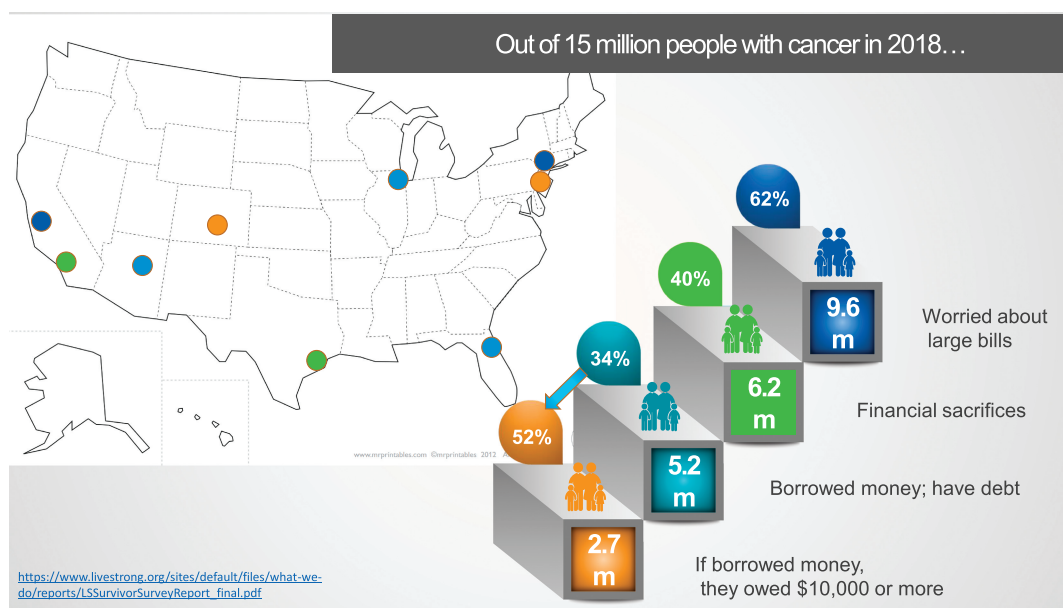


FIGURE 1. The number of cancer patients who have financial concerns.

- Find out what financial navigation services exist and help your patients find a financial counselor. The Oncology Nursing Society created a thorough Oncology Nurse Navigator Toolkit⁶⁴ that can help, while other sources focus on patient resources for useful information about financial toxicity and potential solutions.⁶⁵
- There are useful ways to discuss end-of-life care before someone is in that situation, to set better expectations with patients and their families.⁶⁶ Studies have shown that hospice, for example, can actually help patients live longer and better lives when their cancers refuse to stop. Unfortunately, many do not find that out until they are close to dying (within 1 to 2 weeks).⁶⁷ ASCO also provides tips for talking with patients about the benefits of end-of-life planning before they need it.⁶⁸

Your efforts are so important to your patients. Your guidance regarding financial toxicity can truly give them the best options to help patients develop a plan that fits each medical, financial, and life situation.

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