

# Financial Toxicity:

A conversation with  
Yousuf Zafar, MD, MHS, and Dan Sherman, MA, LPC

**A**wareness has grown among both the public and providers about the risks of financial toxicity for patients with cancer and their families. At the same time, as healthcare reform evolves, understanding the financial implications of care has become increasingly complex. ACCC asked members of the Financial Advocacy Network (FAN) Advisory Committee Yousuf Zafar, MD, MHS, associate professor of Medicine, Duke Cancer Institute, and Dan Sherman, MA, LPC, clinical financial consultant, The Lacks Cancer Center, to share their perspectives on why addressing financial concerns with cancer patients is important and how the role of financial counselors is evolving.

**Q** Why is it important that we do a better job of helping patients with financial issues related to their cancer treatments?

**Dr. Zafar.** My primary goal is to make sure that any treatment I provide a patient first does no harm. Traditionally, we've thought about harm as physical harm, the physical side effects that patients can experience as a result of treatment. More and more, however, financial harm has to be a part of that consideration as well. So as an oncologist, if I'm prescribing a treatment for a patient, considering both the potential for physical and financial harms is well within my purview.

**Q** How do you think providers can do a better job in this area?

**Dr. Zafar.** I think the first step is engaging patients on the topic. There is evidence that just discussing financial harm or financial toxicity with their doctor can reduce the distress that patients feel. So really what this means is that patients like to know that they and their doctor are on the same page when it comes to what the patient is experiencing. That's the first step. The second is being aware of the resources around us that can help. As an oncologist I don't think my job is to know how

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much every MRI or every drug I prescribe is going to cost, but I should know where I can go for help. So understanding that I need to involve my colleagues that I work with—my pharmacists, social workers, and financial counselors—and know where those resources are to direct patients to when they ask is very important.

our patients is addressed at a level that truly meets the needs of our patients?" We would never accept using treatment models developed 20 years ago to address the complexity of cancer care when new treatments are far superior to the old ones. Far too often, however, we accept this in the realm of financial advocacy for our patients.

**Q** Dan, from the financial navigator's perspective, why is it important to do a better job helping patients with these issues?

**Dan Sherman.** Improvement in this area is needed because of what Dr. Zafar and researchers like him are finding regarding the alarming statistics of financial toxicity. We now know that financial toxicity and related anxiety are the top concern of oncology patients. The main concern is no longer dying from the disease; it's the financial worries that consume our patients. This financial toxicity also creates a barrier in providing care and unfortunately patients refuse the recommended treatments because we have failed the patients when it comes to addressing this issue well. We also know we need improvement in this area because even though most hospital settings that provide oncology care have financial counselors who have been tasked to deal with this problem, nonetheless, the problem remains. So it's fair to ask, "What are we doing wrong?" and "How can we improve so that the financial toxicity we create for

So how do we address this better? I think we need to start looking at having the financial navigator trained and not just "learning on the job." We also should look beyond the "20 years ago" solutions of Medicaid and charity care. It's not that these solutions are wrong for some patients, but they do not solve the problem for a high percentage of our patients. The financial navigators should also be critical members of the multidisciplinary team. They need direct access to the oncologist, RNs, and social workers so that when the treatment plan is generated, the pending financial toxicity that will soon occur is addressed within the treatment plan.

**Q** Why has it become more difficult to identify those patients at risk for financial toxicity?

**Dr. Zafar.** Speaking as a researcher who has investigated this topic, it's difficult to identify patients [at risk] because the traditional markers of socioeconomic disparity don't apply when it comes to financial toxicity. It's not like we can look at income, or zip code, or race

as markers to find patients who are at risk for receiving sub-par care as is traditionally done in health disparities research. The problem is that the patients who are at greatest risk are the patients who have poor quality insurance, and it's very difficult to know who has poor quality insurance until they are hit with that catastrophic illness. That is the only time the patient really finds out they are under-insured. That is why it is difficult to identify patients who are at risk for financial toxicity unless you ask some very pointed questions about their insurance coverage.

**Q** From the provider perspective, why is it critical to identify patients at risk?

**Dr. Zafar.** When I make patient treatment decisions, I do so primarily on the immediate oncologic benefit to that patient. How is this going to help treat the patient's cancer? But when cost to the patient is not a part of that consideration, and I don't know how much that patient might pay out of pocket for that treatment, I could be causing that patient a great deal of financial harm. And I have done that and I've spoken previously about it. I know of specific patients where I've given them what I believe to be the best treatment for their cancer, but as a result they have incurred thousands of dollars of medical debt because I did not address their potential for financial toxicity.

**Q** Dan, from your perspective, why is it critical to identify the patients at risk?

**Dan.** It is essential to know which patients will most likely experience financial toxicity because early intervention is critical to resolving the issue. If we wait for the medical bill to arrive 60-90 days later, the solutions that were available early on will most likely no longer be an option. I believe the financial advocacy process should replicate the medical model. We provide anesthesia prior to surgery not after. Yet with financial advocacy, we typically intervene after treatment has been initiated. We wait, and the toxicity created can no longer be alleviated. Early identification of patients at risk for financial

toxicity, allows us to proactively address the issue with the patient.

The model of financial advocacy that I use when meeting with patients is twofold: you address financial toxicity by (1) optimizing the patients' health insurance coverage and (2) optimizing external assistance programs. For this model to be effective, it's essential to address the pending toxicity prior to treatment. This accomplishes two things: first, it reduces the emotional distress of the patient and/or family and it does this as early on in the process as possible, and second, it reduces the out-of-pocket responsibilities for the patient. This results in a win for both the patient and provider. The patient receives the care they need with less financial distress and the provider is able to collect on the services provided.

To aid in early identification of patients at risk for financial toxicity, financial advocates must have a basic understanding of the clinical needs of patients. For example, I financially navigate a patient diagnosed with DCIS very differently than a patient with multiple myeloma. These patients have different needs on a different time table. Insurance optimization may be easier to accomplish with one diagnosis compared to the other. So incorporating the clinical needs of the patient plays a significant role in the early identification process. I often seek out patients with advanced stage disease as this type of diagnosis often results in financial distress. These patients also run the risk of losing their health insurance if they have coverage through a group policy from their employer. Early intervention in these cases is vital to protect them from the pending financial toxicity coming their way.

**Dr. Zafar.** Dan is definitely on the frontlines of intervening on this problem. As a provider, when I think about what it means to intervene on financial toxicity, again, I'm talking about patient engagement. While getting the patient to the financial counselor is where they will get the help oftentimes, as Dan mentioned earlier, the only person who can identify those patients is the physician who is about to prescribe the treatment. So in my mind, an intervention is as simple as asking a patient, "Do you have

prescription drug coverage?” In fact that is how I could have avoided one of my patients facing thousands of dollars in out-of-pocket costs by asking that one simple question.

However, from a research perspective, we are developing some more detailed and multi-faceted interventions that promote patient engagement around the cost of care with their providers, which can help educate patients and help them find the resources that they need. In the meantime, I would advocate that tomorrow in clinic providers ask the question without being afraid that they don’t know what the answer is.

**Q** Unfortunately cancer services are still fragmented in some communities. How can the cancer care team best work together to address unwanted side effects of financial toxicity?

**Dan.** When you have a fragmented healthcare system, the task of providing care without causing financial distress becomes more difficult. I am blessed to work in a facility where all the services are provided under the same roof. This makes it more practical for one person to have the responsibility of communicating the financial navigation plan to all the providers. This is not the case in many community cancer programs. From my perspective it comes down to effective communication, providers being more aware of the problem and having all the different departments (Medical Oncology, Radiation Oncology, and Surgery) consider this problem to be a high priority to deal with. I would recommend that you have a screening process where you can identify the most likely patients who will experience financial toxicity. This information will then need to be communicated to the financial advocate who then can address problems as early as possible. Many of the financial navigation steps can be managed over the phone if necessary. The key again is early intervention. In facilities where fragmented care is occurring, the problem is often that the right person does not know that a problem exists. Focused attention on identifying the patient at risk for financial toxicity is therefore recommended in this type of setting. As one of the physicians in our cancer program

recently stated, “Dan, we should treat every patient as if they do not have insurance. It makes us think through what we are doing to the patient.” If our providers started to think this way we would come a long way in decreasing financial distress for our patients.

**Q** Given the Commission on Cancer Standard mandating distress screening, would ensuring that financial issues were included in this screening help?

**Dr. Zafar.** I’m not sure distress screeners are as effective as we think they are. Many times, particularly in a busy clinic, they are not often reviewed the way they should be and it sort of falls into the mix of all the other symptoms that patient may be screened positive for. The problem in screening for financial toxicity, or any side effects for that matter, is how do you effectively capture and screen patients? And when do you do it? What is the right time to do it so that it impacts the treatment decision-making? I think it’s a step in the right direction to mandate symptom screening at our institution and we already include financial distress as part of that, but I don’t think we have good evidence as to how beneficial that is yet. That is part of what I’m working on is to see whether or not screening and identifying patients and prompting the physician, based on the patient’s screening results, is helpful.

**Q** How would you address concerns about disrupting or adding to the physician workflow and how providers and financial navigators can best work together?

**Dr. Zafar.** I want to be clear that this is just an example. It’s not going to fix the problem by any means, but it might help identify the issue for some and it is an example that resonates with a lot of providers. For example, in my clinic, if I’m going to prescribe a patient an oral anti-cancer drug, I will first stop by my pharmacist’s office before going into the patient’s room and let her know that this patient is going to get an expensive prescription. She will start looking up the patient’s

insurance to determine the patient's co-pay amount. While she is doing this, I am talking to the patient about the benefits and physical risks of that drug. When I'm finished, the pharmacist will come in the room and tell the patient what the drug will cost and ask whether this is affordable. If not, I get pulled back for another discussion of treatment alternatives. The process is actually very efficient. One other point I'd like to make: There is some preliminary data from one of my colleagues at Duke who has found that a discussion about personal financial burden related to cancer treatment on average lasts about 1 to 2 minutes.



**Dan, from your perspective, how does that communication work?**

**Dan.** Dr. Zafar's approach is pivotal, especially with oral oncolytics, which comprise around 30-35 percent of the oncology pipeline. We also need to be aware that on average 40-50 percent of your patient population will be in Medicare Part D. When you combine these new expensive oral cancer drugs (usually costing \$8,000- \$10,000 a month) and Medicare Part D, we know that the patient will most likely experience financial toxicity. A large number of these patients will end up refusing to fill their prescription when they discover that they face a co-pay of more than \$2,000 the first time they try to fill it.

At our facility we have the medical oncologists contact the financial navigator when they prescribe high-dollar oral oncolytics. We then verify the benefits and attempt to fill the prescription while the patient is still at the facility. With this process we will know, while the patient is present, if we need to address a co-pay problem. Currently there are several foundations that provide instant approvals for co-pay assistance so the problem can often be solved before the patient leaves the cancer center. We also have a list of specific diagnoses for which high-dollar oncolytics are often prescribed, so that when a patient comes in with that specific diagnosis, we will often proactively analyze the problem while the oncologist is meeting with the patient. This process expedites the patient's access to

the medication, it improves communication between the provider and support staff, and it decreases financial distress for the patient.

Dr. Zafar's solution is that before you walk into the room, you are starting to look at whether a financial barrier exists.

At our program, the financial navigator would be in close communication with the medical oncologist, and would try to address the co-pay issue while the patient was still here so that the patient leaves with a solution provided.



**What are some of the factors fueling financial toxicity for patients with cancer?**

**Dr. Zafar.** I think there are three factors that are contributing to higher costs. First, the drugs that we are prescribing are more expensive. Second, we're using more of them and patients are on treatment for longer. Third, there is greater cost sharing. Together all of these factors are coming to a head at the same time.

In terms of cost sharing, deductibles have doubled, premiums have increased tremendously in the past decade, and particularly important for our patients, we are seeing a huge surge in the number of multi-tiered formularies. A recent Kaiser study that found that the number of multi-tiered formularies had increased to about a quarter of plans surveyed. This is particularly important for our patients because many of the expensive anti-cancer medications and some of the expensive supportive care medications that we prescribe fall into the higher tiers, resulting in more co-pays for our patients. So I think there is a shift toward patients bearing a greater cost burden.



**And for some disease sites, patients have no choice but to reach for those higher cost, higher-shelf formulary drugs.**

**Dr. Zafar.** Right. When we talk about cost sharing, this concept was first developed to reduce use of unneces-

sary care. So tiered formularies become important when patients have alternatives. For example, if patients are thinking about buying two separate medications—one for hypertension and one for hyperlipidemia—vs. buying a much more expensive combined pill. But for cancer patients that option does not exist. There is one drug and there is no alternative other than the option of not receiving treatment. For many patients that is not a palatable option.

**Dan.** To deal with financial toxicity we need to move away from the one-size-fits-all mentality. This mindset, unfortunately, is dominant in the medical financial advocacy discipline. We don't treat every lung cancer patient in the same manner, as it depends on the type of stage of the cancer diagnosis. The treatments depend on the type and stage of the disease. However, with financial counseling, we often funnel patients through the same financial assessments and provide the same solutions to all the patients asking for help, which often ends in attempts to apply for Medicaid, charity, and co-pay assistance. This "one-size-fits-all" approach may help some patients, but we need to recognize that it does not work for all. If it did, financial distress would not be the number one concern of oncology patients. We need to start addressing the problem by customizing the patient's financial navigation plan. We do this with all other aspects of their care but we don't do it with something as important as their financial well-being.

**Dr. Zafar.** When I talk to oncologists about this topic, one of the first responses I often get is "I have no idea where to start. I don't know what anything costs. How am I supposed to help my patients if I don't have any answers?"

I think this is a reasonable concern. We don't have a lot of answers. There is not a lot of price transparency in our healthcare system. But that shouldn't prevent us from initially engaging our patients on this topic. We've got evidence to suggest that we're already doing it. We are already decreasing some of the cost burden that patients are facing by engaging people like Dan and engaging our pharmacists early on in the process. Our studies

have shown that more than half the time, when patients talk to their doctors about cost, those costs are reduced without changing care.



### What about the family's involvement in this issue?

**Dan.** The family's involvement plays an important role when it comes to customizing a financial navigation plan for the patient. We should acknowledge that the patient is overwhelmed with multiple issues on the day of consult. Adding in financial navigation services is critical, but at the same time, effective financial navigation services are often complex. It may be challenging for patients who are already overwhelmed to understand and absorb new terms and issues such as max out-of-pocket, co-insurance responsibilities, prior authorization requirements, and open enrollment guidelines. So I find it very helpful when family is present. Often family will play a significant role in helping me guide the patient to improved coverage for his or her treatments. There are also times when I will educate patients on how they can avoid large out-of-pocket responsibilities by purchasing health insurance policies that will provide improved coverage for their care. Patients can often do this when looking at ACA policies or Medicare plans. At times these policies come with a higher premium that the patient may not feel is affordable. When family is present and also informed, they may choose to assist their loved one with the increased cost of the premium. For all of these reasons, seeing the patient on the day of consult is beneficial, and family is usually present on this very important day. ■