Financial Toxicity: A Common but Rarely Discussed Treatment Side Effect

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My Story

The most memorable part of my San Francisco trip was stopping at the crest of each hill, small or large, to “admire the view.” In truth, my legs were leaden and I was gasping for air. As I trudged up the famously crooked Lombard Street, I was disheartened that I could not keep up with my friends. Despite exercising regularly, I was short of breath and had to stop to stretch out my cramping left leg. Two days later, my breathing had not improved. I visited my internist, who quickly diagnosed me with a pulmonary embolism. Luckily, after 3 days in the hospital, I was discharged home. Six months later, I finished warfarin therapy and tried to put the experience behind me.

Years later, when I became pregnant, I was prescribed low-molecular-weight heparin (LMWH) to prevent a deep vein thrombosis, given my history of pulmonary embolism. In my first pregnancy, my LMWH copay was \$50 a month. Then, shortly before I became pregnant with my second child, my insurance plan changed. I remember chatting with the pharmacy technician as she rang me up for my first LMWH prescription during my second pregnancy. I was expecting a \$50 copayment again, not realizing that my new insurer categorized LMWH differently. This time, the cost to me would not be a predefined copayment amount but instead would be coinsurance, calculated as a percentage of the medication cost. A few taps on the cash

register later, I received my bill: \$1,200 for 1 month of medication. I was stunned. I asked the pharmacy technician if she had billed my insurance, and her response is seared into my memory: “Yup. It’s \$3,800 without insurance.”

Luckily I had a few days before I was to start the injections. I went home, evaluated my plan, and calculated that I would reach my out-of-pocket (OOP) spending cap in 3 months’ time. Until then, I would need to pay \$1,200 per month for my medication. I called my obstetrician to get her opinion on whether unfractionated heparin was an appropriate substitute, given its low cost compared with LMWH. She noted that, given the severity of my previous pulmonary embolism, available guidelines (1) and my successful previous pregnancy while using LMWH, she would recommend that I stay the course if at all possible. After listening to her reasoning and weighing my concerns—*what if I switched to unfractionated heparin and had a clot, or a miscarriage? Would I blame myself? Is the cost savings worth it?*—I decided to continue with LMWH. My husband and I decided that we would spend down our savings, then, as needed, put the remaining balance onto our credit cards. We are lucky—we had the savings and available credit to pay for the medication. But not everyone has the available resources to pay for their medication and navigate financial toxicity, or the financial distress that can accompany medical treatment.

Financial Toxicity: A Side Effect for Many Patients

The concept of financial toxicity captures the financial impact of illness in different realms—how often people go into debt, declare bankruptcy, or change their lifestyle simply because they cannot afford the treatment costs associated with their care (2). Essentially, financial toxicity occurs when the financial impact of a patient’s care overwhelms his or her available resources.

Most research on financial toxicity has focused on cancer care. There is an established correlation between health-related quality of life, psychosocial distress, and measures of financial toxicity among patients with advanced cancer (3). Cancer survivors report having debt as the result of treatments and reduced medication adherence because they cannot afford medications (4). Other research has found that cancer survivors have a higher risk of personal bankruptcy than people without a diagnosis (5) and a higher risk of mortality after personal bankruptcy (6). The need to discuss the costs of cancer care has been recognized by the American Society of Clinical Oncology (7), and the National Cancer Institute has issued Physician Data Query guidelines for patients on how to handle the financial distress that often accompanies a cancer diagnosis (8). It is important to note that financial toxicity can persist after a patient’s death and affect surviving family members as well. One study found that among households that

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recently experienced a cancer death, one-third of the households had exhausted their savings and 22% reported that cancer treatment was a major financial burden (9).

There are limited data on the extent of financial toxicity for people living with pulmonary diseases such as asthma, chronic obstructive pulmonary disease, pulmonary hypertension, or idiopathic pulmonary fibrosis (IPF). One study calculated that some patients pay more than \$500 per year OOP for their asthma medications (10). Evaluating inhaler use among older adults with chronic obstructive pulmonary disease and/or asthma, Castaldi and colleagues noted that an OOP expense greater than \$20 per month was associated with cost-related nonadherence to inhaler therapy compared with patients with no OOP inhaler costs (11). Another study found that among patients with group 3 pulmonary hypertension, prescription medication comprised 33% of healthcare spending, second to inpatient hospitalizations (35.4%) but more than the 26.5% attributed to outpatient care (12). Although pharmacy benefit managers can help patients with IPF manage the high cost of medications such as nintedanib and pirfenidone (13), to date there are no published studies evaluating how the costs of IPF medications directly affect patients and their families.

My Patients' Experience with Financial Toxicity

Previously, I worked at a specialty pharmacy where most of the patients had received a solid organ transplant or were living with cancer, HIV, or hepatitis. I felt confident working with the patients to manage their complex medication regimens and brainstorm the best ways to mitigate the frequent side effects of the medications. But there was one side effect I had no idea how to manage, and that was financial toxicity.

Some of my patients' struggles to pay for their medication were particularly heartbreaking. One patient had overwhelming nausea and vomiting associated with intravenous chemotherapy. His doctor prescribed an oral chemotherapy agent, erlotinib, to replace the other chemotherapy regimen. As I explained management of potential side effects to the patient, he leaned in and said, "I want to throw up knowing how much this drug is costing me."

I had no idea what to say. Although he had insurance and was enrolled in the manufacturer's patient assistance program, he still had a considerable copay. Over time, the costs of cancer treatment had added up, so that by the time he received the erlotinib prescription he had no savings left. Another patient, prescribed lapatinib for metastatic breast cancer, ruefully noted that if she was going to die anyway, then there was no point in bankrupting her family to pay for her healthcare—and depleted resources was not the legacy she wanted to leave behind.

These exchanges stayed with me long afterward, because I was flummoxed. Although I had plenty of strategies for different physical side effects, there was little I could do for my patients' financial difficulties. Although we enrolled patients in manufacturer copay assistance programs, such programs are not a panacea. Recent studies have noted a lack of transparency in eligibility for assistance programs (14) and that a small number of prescriptions actually receive assistance from such programs (15). The advent of the Affordable Care Act helped lessen out-of-pocket burden by introducing spending caps for commercially insured patients, expanding the Medicaid program, and closing the Medicare Part D donut hole (16). Although this is progress, it does not eliminate financial toxicity. For example, should patients reach the catastrophic coverage portion of Medicare spending, then only 15% of medication costs are covered, and commercially insured patients may see a shift from copays to coinsurance, as I experienced with my LMWH prescription.

Screening for Financial Toxicity: Starting the Conversation

It may be difficult to consider having a conversation regarding costs of care. First and foremost, it is important to consider costs in the larger context of the patient's quality of life and goals of care. Eliciting the patient's hopes for treatment and the rest of their life, plus determining their worries and stressors, will help frame treatment decisions and an assessment of financial toxicity. The conversation can then progress to discussing the benefits and risks of available treatment, given the patient's preferences. For example, the antifibrotic agents pirfenidone and nintedanib for IPF are expensive treatments

that may slow disease progression, but they have unclear morality benefits (17). Both drugs come with significant side-effect profiles that may be unacceptable for some patients—thus, a frank discussion weighing benefits (potentially slowing disease progression) versus risks (side effects, expense) would allow patients to make a more informed decision as to whether a treatment plan that includes one of these drugs is acceptable to them.

Understandably, clinicians may worry about how a conversation regarding costs of care may be received or perceived by patients. Available research suggests that costs are a pressing concern for patients, and the majority would like clinicians to engage with them regarding costs of care (18, 19). Professional society guidelines encourage such conversations; for example, the American Society of Clinical Oncology notes: "clinicians should explore whether cost of care is a concern for patients with cancer" (20). Simply asking, "This medication is expensive and might impact your finances. Are you worried about that?" could open the door for discussion.

Considering financial toxicity to be a side effect of treatment may help incorporate its impact into treatment discussions. An alternative therapy or care plan may be needed, by considering a different medication or a referral to resources to help pay for medications. Groups such as the Patient Assistance Network Foundation (panfoundation.org) can assist patients with cancer, asthma, or IPF, and Family Reach (familyreach.org) focuses on helping families affected by cancer. Pharmacists can also be engaged with the issues of cost; a recent study demonstrated that pharmacists located in specialty academic clinics were able to increase patient access to medications by working with pharmacy benefit managers helping with insurance rejections and by enrolling patients into manufacturer assistance programs (21).

An assessment of cost burden, alongside routine questions about patient symptoms and side effects of medications, should be a standard part of usual care. The costs of care can accumulate quickly, and medications are not the only source of financial strain—imaging tests, hospital stays, and copays for outpatient visits all contribute to cost. Communicate openly with your patients about costs, encourage them to do the same, and be aware of local

resources for patients struggling with the costs of care. Finally, consider financial toxicity as a side effect that may necessitate a therapeutic substitution to improve patient quality of life.

Patient, Pharmacist, Researcher: Connecting It All

Although clinicians often recognize polypharmacy as a concern for the drug–drug interactions and adverse events that may accompany it, we do not look at how the cumulative cost of medications affects patients. In my experience with high

medication costs, I understand that I was lucky—my medication was only needed for a short period of time, and I had the resources to pay for it. Before my encounters with the patient receiving erlotinib, I never thought to ask if medication costs were a struggle for patients and if the cost of their medications created financial difficulty in other parts of their lives. It took becoming a patient for this lesson to be abundantly clear to me.

As a health services researcher, addressing the financial burden of care is a primary focus in my research. I look for ways to optimize safe medication use for

patients, addressing the physical side effects of medications as well as the financial ones that may be much longer lasting. Medication adherence and patient well-being are affected by financial toxicity, and finances may impact a patient's decision-making and goals of care. By asking about whether patients are having any problems managing the costs of their care, we can ensure that we are on the same page as our patients to provide high-quality, patient-centered care. ■

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