

## FEATURE STORY

# Medical Debt: An Unspoken Side Effect of Cancer Care

BY KATY HUMAN

*For many patients, “financial toxicity” is an unwelcome side effect of cancer care.*

Veena Shankaran, MD, was stunned when she read the email from a clinic social worker. A patient of Shankaran’s, an older man with stage 3 colon cancer, had recently filed for bankruptcy. Shankaran had just seen him. There was no hint that he’d been struggling financially.

“We talked about diarrhea, we talked about blood counts, but we didn’t talk about bankruptcy,” says Shankaran, an oncologist on staff at the Fred Hutchinson Cancer Research Center in Seattle and an assistant professor at the University of Washington School of Medicine. “It was striking to me that such a major side effect of his treatment went unmentioned between us.”

Between co-payments and uncovered prescriptions, lost work hours and the gas to fuel dozens of trips to doctors, even insured patients are struggling to keep up with cancer-related bills. In fact, according to one recent study led by Shankaran’s colleague, healthcare economist and researcher Scott Ramsey, MD, PhD, on average, bankruptcy rates increase fourfold within five years of a cancer diagnosis. “Compared to the general population, bankruptcy rates were nearly twice as high among cancer patients one year after diagnosis,” he says.

Many oncologists now refer to the personal economic consequences of cancer as the disease’s “financial toxicity,” analogous to the physical toxicity associated with chemotherapy and other cancer treatments.

And just as there are ways to lessen the physical effects of treatment, there are ways to decrease cancer’s financial toxicity. Nonprofit groups, disability programs, Medicaid and friends and family are just a few examples of available help.

Drug companies may provide low-cost or, sometimes, free medication to those who cannot otherwise afford it, and hospitals may lower bills when prodded. Finding help takes time, energy and know-how, and the process can be exhausting at a time when a patient may not have the energy to fill out forms or make phone calls.

“This is when you ask for help—from everyone: the pharmacist, the son you put through college, everyone,” urges Linda Lashley, a 68-year-old breast cancer survivor in Granbury, Texas. “Just don’t be too proud to ask for help. No, don’t

ask. Tell people. Tell them, ‘I need financial help.’”

## Empty Pockets

Medical bankruptcies have been on the rise in the past decade. In 2001, more than 46 percent of bankruptcies were medical; the figure jumped to 69 percent by 2007.

“We know that insurers are shifting more of the cost of cancer care to patients, so that even our insured patients are experiencing more out-of-pocket expenses,” says Yousuf Zafar, MD, an oncologist at the Duke Cancer Institute in Durham, N.C.

“In addition, cancer care is expensive, and cancer care is frequent, and it is multimodal,” Zafar says. “When I’m treating cancer patients, I sometimes see them weekly; I have to prescribe multiple medications, multiple interventions. The results add up rapidly.”

At the American Society of Clinical Oncology annual meeting in June, Zafar presented a survey of 216 cancer patients that showed they paid an average of \$712 per month in out-of-pocket expenses.

And to meet those expenses, they often made sacrifices that could have adversely affected their health, Zafar says. Twenty percent took less than the prescribed amount of medication. One in four patients didn’t fill at least one prescription at all. Nearly half of those surveyed said they used all or part of their savings, and more than half cut spending on food and clothing.

## Under Coverage

Then, too, increasing numbers of people lack health insurance at all or are “underinsured” with plans that fail to protect them from medical costs that may soar to 10 percent or more of their income, Zafar says.

Lashley did not have insurance when she found a lump in her left breast in 2005. Her husband had just been laid off after more than 25 years with an oil company, and Lashley’s current job with a small business in town didn’t offer coverage.

“The strange thing is we had always been overinsured,” Lashley says. “We both carried policies that carried each other and our children. We never wound up paying anything much for medical, dental, not even for visual.”

Without help, her bills would have been astronomical. Lashley had estrogen-positive breast cancer, so after surgery, she would need five years of hormonal treatment—at a cost of several thousand dollars a month—to starve any stray cancer cells of the estrogen they thrived on.

Hormone treatments can also cause osteoporosis: When Lashley needed a CT scan to check for bone loss, the cost was \$9,000. The gasoline to drive back and forth to Dallas from their home in North Central Texas—a trip Lashley and her husband ended up making more than 100 times—cost hundreds more per year.

“I earn 154 percent of the federal poverty level,” Lashley says. “We couldn’t have paid for this without help.”

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—Yousuf Zafar, MD

## Seek Help Early

Lashley began reaching out for help even before her suspected breast cancer was confirmed. After a mammogram and diagnostic ultrasound (\$500) revealed a suspicious lump, she went to the hospital’s business office and asked if the bill could be reduced.

After a little wrangling, she got the answer she needed. Lashley made two cash payments over the next two weeks that totaled a little more than \$300.

“I told them, ‘Keep in mind, otherwise, I’ll be going on the county [a local welfare/indigent healthcare program],’ and that wouldn’t help them at all.”

Shankaran says doctors can often prescribe alternative treatment plans when they know cost is an issue for a patient.

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“Many times, we can adjust,” she says. For some colon cancers, for example, the relatively new oral drug Xeloda (capecitabine) is often prescribed—it’s a pill and is convenient for patients. Because it’s an oral medication, some insurance companies won’t cover it or will cover it but with bigger out-of-pocket cost. Those companies that won’t cover the drug will instead cover the less convenient but equally effective infused drug 5-FU (fluorouracil).

But sometimes, there are few alternatives, she says. Nexavar (sorafenib) is the sole approved drug for liver cancer. It’s an oral drug, so if a patient doesn’t have prescription drug coverage, there’s no alternative.

Many cancer care groups have programs designed to help patients deal with financial struggles. The Duke Cancer Institute has financial care counselors who are wonderful at helping patients navigate the financial issues, Zafar says. “I’ve had patients work successfully with insurance companies to lower bills, and many of the drug companies have mechanisms to provide treatment for patients who cannot afford it.”

He and Shankaran have also seen patients helped by organizations such as the HealthWell Foundation, which provides assistance, when funds are available. HealthWell typically has a dozen or more “funds” available to assist patients with specific conditions, including certain types of cancer. Insured patients who cannot afford co-payments or deductibles or other types of cost-sharing can apply for help.

Legal assistance can be essential too—especially if a cancer diagnosis leads to job loss. At the Cancer Legal Resource Center (CLRC) in Los Angeles, experts can offer invaluable suggestions, such as the importance of keeping unnecessary information out of a patient’s records. A note about the patient enjoying a recent outing, for example, could have repercussions for disability coverage, says CLRC director Joanna Morales.

Lashley received help from many places, constantly seeking new resources when old ones no longer worked. She benefitted from a Medicaid program in Texas designed to help uninsured people within a few years of 65 (not yet eligible for Medicare). She’s gotten help from foundations and from HealthWell, and when she finally began receiving Medicare benefits, she got help when she hit the prescription “doughnut hole.”

“It’s all a lot of work,” Lashley admits. “I could do it, but I don’t think it will work for everyone because there are so many people who can’t fill out these forms.”

## Tough Talk

Meg Patterson, 50, is relying on the grace—and financial support—of family and friends. The Oregon resident has stage 4 breast cancer that has metastasized to her bones, and her stacks of unpaid bills have become uncomfortably high.

Patterson says the \$712 average out-of-pocket expense reported by Zafar’s team is about half of her own monthly out-of-pocket expenses. “Mine may be higher in part because I live in a rural area,” she says. It’s a two-hour drive to Portland for scans, for example. “Because of the pain in my cervical spine, where the metastasis is, I can’t do round-trip on the same day, and I have to stay in a hotel overnight.”

Patterson was uninsured when she received her diagnosis in 2008, despite a successful career in theater. “Even when I owned a small company, we didn’t have insurance,” Patterson says. “This is an issue for people in the arts.”



Meg Patterson has turned to family and friends for help in coping with medical expenses related to her cancer treatment. Photo by James Olson.

Today, Patterson is covered by Oregon’s program for low-income, uninsured women with breast or cervical cancer, and that means she can’t work as much as she’d like. “I have to remain low-income,” Patterson says.

She would like a steady sort of theater job, perhaps teaching at a community

college, a position that could include health insurance. But to teach, she needs a master's degree. And to go back to school, she needs a loan. And she can't get a loan because of bad credit from some of those unpaid medical bills.

In three years, she's had two lumpectomies and two recurrences and faced major decisions about costly and risky treatment. Patterson, a Princeton University graduate, dug through medical research on her own cancer type and eventually decided to decline chemotherapy and radiation. "Statistically, it might give me a month or two more, but my goal has been quality of life over quantity and length of life," she explained.

Still, she wasn't able to avoid the financial toxicity of cancer. Patterson recently put graduate school on hold. She stopped traveling, stopped gardening. "Not because I can't do it," Patterson says, "but I can't afford the plants."

"My mom helps me a lot, and I feel so guilty about this," Patterson says. "She could have retired by now. She tells me, 'Don't be ridiculous; this is what I want to do,' but it's just so sad."

It can also be difficult for patients to discuss cost with care providers. "It's possible they feel that if they bring up cost of care, care might be compromised," Shankaran says.

"There's also [some] evidence that doctors are reluctant to discuss the cost of care because they don't want patients to feel that they aren't providing the best possible care," Zafar says. "The first thing a patient can do at the start of treatment is to have this discussion. Broaching the topic may be uncomfortable, but it's critical."

## Diagnosis: Debt

Physicians may be able to help patients in a number of ways, the two oncologists say, and they definitely cannot help if they do not know that financial difficulties threaten their patient's well-being. A physician's institution may employ patient navigators or social workers, who can assist patients by finding help to pay for treatment itself or for food and transportation if lost work hours or a dwindling bank account threaten those basics. Doctors may be able to share information about where they found help, which they learned from other patients.

Patterson says that for more than a year, her diagnosis closed her down. "I wasn't communicating with people because I was so scared," she says.

"Learning to cast the net" was an incredibly powerful experience for her. Patterson began blogging and started a page on GiveForward, a grassroots fundraising website. "You realize everybody has a story; everyone has lost someone to cancer, and they want to help. You realize it makes them feel better."

She started the GiveForward fundraiser as a way to try to raise money for transportation and alternative therapies not covered by insurance.

"You just have to forget that you're afraid to ask for help," says Lashley, who is now volunteering with Granbury's Senior Circle to help elderly neighbors fill out forms and navigate medical issues. She's also letting politicians know about her

concerns.

“Look, we have people in Texas who have died in the heat because they were too embarrassed to ask for help paying the utility company,” she says. “So ask.”