

CANCER



THE OTHER FIGHTS

by Michael Schroeder

Faced with cancer, patients battle more than the disease. Many struggle to pay for treatment that could save their lives. Others deal with the strain of traveling in search of the best care, or feel like they're moving mountains just to return to work, school and their lives before cancer took hold. Most endure side effects from treatment, ranging from intense pain to being laid low with fatigue. Some wrestle with a body changed by the surgeon's scalpel, while others endure anxiety and depression brought on by their diagnosis and all-consuming treatment. These are the other fights – and the stories of those taking them on.

Lauren Badua, 17

Diagnosed with lymphoma
in February 2014

After undergoing surgeries, chemo and radiation in her fight against cancer, Lauren's other battle doesn't involve a hospital room, but a classroom. "[I'm] trying to stay caught up with school, especially now because I'm a senior and I want to graduate on time," says Lauren, a high school student. She wants to go to college for nursing. "I want to be a pediatric oncology nurse ... because I love the way the nurses treated me."

THE COSTLY BATTLE

Diagnosed with an inoperable brain tumor in February 2014, James Turpiano and his wife Karen quickly exhausted \$17,000 in savings to pay for cancer treatment in the months that followed. As medical debt mounts, he worries about the burden placed on his family and isn't sure how he'll be able to afford care in the future. "Eventually, I'll probably have to file bankruptcy," says Turpiano of Winfield, Mo. "I'm trying not to though." With no savings left, he foresees a day where he might have to skip cancer treatments.

So far, radiation and chemotherapy have kept the roughly 6-centimeter mass in Turpiano's brain from spreading — it's not getting larger. However, the tumor hasn't shrunk, either. Turpiano says he currently owes about \$20,000 in medical debt. "It might as well be a million dollars to me. I'm bled out," says the 42-year-old military veteran.

The high cost of cancer care, which continues to rise faster than costs in other medical sectors, places many patients at a dire crossroads: deciding between getting treatment and being able to pay the bills, including the non-medical ones.

According to the American Cancer Society, about 1 in 4 put off treatment or tests because of cost. The problem extends not only to

low-income, uninsured patients but also to those in the middle class with insurance. The difficulty many face in paying for care stands as just one more potential fight for those already battling for their lives. The expense of treating cancer, which remains the second-leading cause of death in the U.S., can quickly add up for many patients. Some cancer drugs alone cost more than \$100,000 a year, and patients are stuck paying thousands of dollars out-of-pocket beyond what health plans cover.

Experts say there is help for many struggling to afford treatment, from copay assistance to negotiated discounts on bills and support from advocacy organizations. The caveat: Patients and experts say it takes ample doses of persistence to take on the financial fight. "I tell [patients] to call every [resource] out there," says Carol Rivera, a social worker at highly rated Winship Cancer Institute of Emory University in Atlanta. The institute provides

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Photo by Sid Hastings



"Nobody can help me at this point because I'm not broke enough."

James Turpiano



Tom Reece, 52

Diagnosed with pancreatic cancer in May 2011

“The emotional and mental battle, trying to stay focused on this for such a long time, takes its toll,” says Reece, noting the low survival rate for pancreatic cancer. He’s taking medication to treat depression, an issue commonly associated with cancer. Still, the financial services company CEO presses on. In addition to receiving care, Reece has begun experimental chemo treatment. He says his wife, Karen, has provided steady support through it all. “She has been by my side at every doctor’s appointment and every chemo treatment ... pretty amazing.”

some assistance and will continue to treat a patient who loses insurance during their care, she says. Still, much of the work Rivera and other social workers and financial experts do at hospitals and cancer centers involves helping patients take advantage of outside programs, from signing up for disability coverage to seeing if they qualify for financial aid.

The expensive care weighs heavily on patients like Turpiano who, due to side effects mainly from chemotherapy, can’t currently work to help provide for his family and pay medical bills. “I sleep all the time, I get massive headaches,” he says. After his diagnosis, Turpiano says his doctor told him that on average patients live about 13 years if chemotherapy works to shrink the tumor; less than half that time if it doesn’t. “It was difficult to process — I’ve been relatively healthy all my life,” Turpiano says. “All the sudden, now I’m a patient. I used to be able to take care of everybody.”

Understanding cancer costs

From diagnosis to the point a patient becomes cancer-free or dies from the disease, care for cancer routinely costs hundreds of thousands of dollars. A single surgery to treat prostate cancer can range widely between \$10,000 and \$135,000 across the U.S., according to one study. Treatment for pancreatic cancer runs, on average, more than \$90,000 in the first year following diagnosis, according to the National Cancer Institute. And some cancer drugs, such as Zaltrap and Yervoy, can cost around \$10,000 or more a month.

“Most patients don’t ask about their projected expenses until the bills start coming in,” says Dr. Thomas J. Smith, a professor of oncology at highly rated Johns Hopkins Kimmel Comprehensive Cancer Center in Baltimore. “Then there’s a sense of complete sticker shock, and ‘Oh my gosh, what are we going to do now?’ — adding another layer of stress to an already stressful time.”

Nationally, the total tab for cancer care annually stands at an estimated \$127 billion. That’s expected to rise to \$158 billion, and could go as high as \$207 billion, in 2020, according to NCI. Mounting bills lead some to scrimp on critical care, such as high priced and potentially lifesaving drugs. “Compliance with the medication goes down and the chance of the cancer coming back gets higher,”



4 in 5

patients calling the Patient Advocate Foundation are cancer patients. The group helps patients with issues such as negotiating medical debt.

Photo by Brandon Smith

Smith says. “Other people do spend pretty much all of their disposable income on their cancer treatment, leaving them with no savings, no ability to put their kids through college. People really do go without heat. They go without groceries.”

Smith suggests talking to doctors in advance about costs, from the necessity of hospitalization to alternative, lower-cost medications that provide similar benefit. “It will not destroy your patient-provider relationship, and better to find out about these things sooner, rather than later,” he says. “You do have some bargaining power.” Ask your doctor, too, if they get a percentage of the price of drugs they prescribe, which may incentivize him or her to recommend certain medications.

Affordable Care Act

ACA proponents remain hopeful that more patients will get care, thanks to provisions in the health law. In addition to increasing the number of insured, those provisions prohibit insurers from placing annual limits

on health care coverage and discriminating against patients. “There is no doubt that critical protections in the Affordable Care Act have improved access to affordable, meaningful health coverage that was out of reach to so many cancer patients, survivors and others impacted by chronic diseases before the law was passed,” says Kirsten Sloan, a senior director at the American Cancer Society Cancer Action Network. Still, Sloan says it’s too early to measure the impact. Gaps in coverage remain as costs continue to soar. The law limits annual out-of-pocket costs to \$6,600 for insured individuals and \$13,200 for families in 2015. Experts say those costs, with premiums, can still be hard to afford; and many plans don’t yet fall under the requirement.

Rosalind Roberts, a clinical financial specialist at A-rated Siteman Cancer Center in St. Louis, works with patients to determine if they qualify for assistance. She says insurance doesn’t cover all cancer treatments and increasingly requires patients to pay for a larger proportion of their care out-of-pocket.

Scraping to afford care

Turpiano speaks highly of the doctors he’s seen and the care he’s received at Siteman, which he’s been able to get at a 90 percent discount. “I think that was extremely generous of them,” he says of the center, which is affiliated with highly rated Barnes-Jewish

Hospital and Washington University School of Medicine. The discount comes in addition to financial aid he’s received for out-of-pocket costs associated with cancer drugs, which shaved \$400 off his \$800 responsibility every other month. His parents have also helped pay for treatment.

To date, Turpiano estimates he’s received roughly \$300,000 in care. Even with discounts and limited financial aid, he isn’t sure how he’ll keep up with medical expenses. “If you have insurance and you make a little bit of money, but not enough to live on, it’s really, really difficult to get assistance from other places,” Turpiano says, noting that he doesn’t yet qualify for aid through the Veterans Health Administration or Disabled American Veterans. “Nobody can help me at this point because I’m not broke enough.”

Finding resources

Experts encourage patients and families to work with oncology social workers and financial experts to ferret out all possible strategies and potential resources to pay for cancer care. Rivera at Winship Cancer Institute also suggests Cancer.net, which lists various financial resources.

Paying for cancer care routinely involves cobbling together many resources. That includes taking advantage of the Family and Medical Leave Act to hold onto a job and insurance coverage; using disability



585,720

Estimated number of people who died from cancer in 2014.

Source: American Cancer Society

coverage and multiple forms of health insurance; utilizing public and/or private assistance; taking out loans; and even holding fundraisers. Some patients also use cancer insurance, purchased prior to a diagnosis, but experts disagree on whether the coverage is worth the cost.

Turpiano still hopes for a day he can return to work. The support of his family, he adds, is what keeps him moving forward. “My expectations are to still be me, to not lose my mind — even if it’s in the short-term — and to not put my family through too much,” Turpiano says. “I’m trying to stay up on bills. Of course, the house payment, that’s the first thing I make.”



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\$127 billion

Estimated annual cost of cancer care.