The Hidden Costs of Cancer

"I'm not looking for a hand out; I'm looking for a hand up"

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Bill Sandillo was living the American dream. This 48-year-old husband and father of two was in the best shape of his life—and his business, a professional baseball training company, was on the up and up. Bill has been training for the past 21 years and built a thriving business for his family. Then, tragedy struck.

He landed in the local emergency room with what he thought was a heart attack. Fortunately, after hours of tests, the doctors determined that he wasn't having a heart attack. Instead, doctors diagnosed him with stage IV melanoma and told him that the cancer had already invaded three organs.

The next few months were a whirlwind. He started interleukin-2 and after two grueling rounds his three tumors had multiplied into ten and his doctor told him to get his affairs in order; he had about six months to live.

But he refused to give up. After a surgical resection that removed his adrenal glands and half of a lung he enrolled in a trial of vemurafenib, a targeted therapy known as a BRAF signal transduction inhibitor. The remaining tumors melted away. He started thinking beyond six months and was ready to get his life back on track.

Then, the bills started to come.

The first bill was over $28,000 and more were on the way. While his wife and his kids had insurance, he had cancelled his policy about 12 months earlier.

"Sometimes, you make tough decisions as a small business owner. It was just too expensive, and I couldn't make a living and provide for my family while paying the premiums," said Sandillo. "A fundraiser my brother hosted helped, but I ended up using my kids' college fund to pay bills. It really put us at ground zero."

Unfortunately, Sandillo's experience is not unique. In fact, this issue is so pervasive experts have coined the stress, anxiety, and depression faced by cancer patients as "financial toxicity." The National Cancer Institute estimates that between 33 percent and 80 percent of cancer survivors

exhaust their savings to finance their medical expenses. Up to three percent of survivors file for bankruptcy, 260 times more frequently than similar households not affected by cancer. Not only is this financially devastating for families, this hardship was the strongest predictor of the quality of life for cancer survivors. In another study, almost 50 percent of cancer patients were not adhering to treatment due to costs, meaning that financial toxicity is impacting the care people receive.

Many cancer patients also report discrimination in the workplace, such as being demoted, skipped over for promotion, or a lack of flexibility needed to attend medical appointments. It can also be difficult for cancer patients to return to the workplace after seeking treatment. This makes it even harder for patients to get back on their feet.

According to the Agency for Healthcare Research and Quality, cancer is one of the most expensive conditions to treat in the United States. Due in part to better treatments and longer survival rates, the already-high costs are only expected to rise. Parallel to this, commercial insurance providers have shifted an increasing portion of medical costs to patients through cost sharing measures like higher premiums, deductibles, and copayments. Between 2005 and 2015, a Kaiser Family Foundation analysis found that out-of-pocket costs grew by 66 percent while wages grew by only 31 percent in the same period. This means that even insured patients are paying an increasing amount for their care.

While tempting, we can't over simplify this problem. Yes, drugs are expensive—but they are also dramatically improving the lives of people with cancer, including people with melanoma. Today, melanoma patients have access to eleven more FDA approved therapies than they did just ten years ago. Together, these new treatments have increased the five-year survival rate for some late-stage melanoma patients and have given patients and their families renewed hope.

These issues aren't unique to melanoma patients, but cancer does highlight the rough edges of our health care system and the need for improvement. And, according to researchers in the Journal of Clinical Oncology, "addressing financial toxicity will require tackling multiple issues simultaneously." With the current political deadlock, a policy prescription is unlikely, but there are a few things that patients and their families can do to mitigate and manage the impact of financial toxicity while facing cancer:

1. Meet with a care navigator or do your own research to learn about your health insurance, cost-saving programs, and patient assistance funds (some options are included below) that you may be eligible for.
2. Ask questions so that you understand the costs you will be responsible for from the beginning with each of your providers. Be sure you understand what parts of your clinical trial are covered and what parts you will be responsible for.
3. Talk with your providers if you think costs could be a burden. Your doctor is your partner in care, they may know resources to direct you to.

While news headlines tout the many advances of modern oncology, for many patients like Sandillo, the stress of paying for this progress isn't getting any easier. "I went from stage IV melanoma to NED (no evidence of disease). I'm still here," says Sandillo. "I'm not looking for a hand out; I'm looking for a hand up."

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