

# Confusing and high bills for cancer patients add to anxiety and suffering

February 13 2019, by Mary Politi

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Credit: AI-generated image ([disclaimer](#))

Weeks after my father passed away from cancer in 2010, my newly widowed mother received a bill for US\$11,000.

Insurance retroactively denied a submitted claim for one of his last chemotherapy treatments, claiming it was "experimental." All of the

prior identical chemotherapy treatments he had received had been covered, and the doctors had received pre-authorization for the [treatment](#).

Was it suddenly experimental because it was not prolonging life anymore? Was it a clerical error, with one insurance claim submitted differently than the others?

As my mother and family grieved, we had this bill looming in the backs of our minds. We took turns calling the insurance company and the hospital billing office, checking websites, and deciphering billing codes on various pieces of paper.

Advances in [cancer](#) treatments have improved [patient outcomes](#) overall, but many of these interventions have [increased costs of care](#). Even when care is "covered," the definition of "coverage" can include [high deductibles, copayments, coinsurance, and surprise out-of-pocket bills](#) for patients. As one participant in a [recently published qualitative study](#) of cancer survivors told us, "You just have to call both parties and figure out, what are you chargin' me for? Plus ... you're getting billed for months ago."

By the time patients receive these delayed bills, they may be unable to recall the particular visit in question, which makes it exhausting for them to manage their finances and diagnosis. The problem is so significant that the National Cancer Institute has a term for this: [financial toxicity](#).

## **A scary disease, an opaque system**

In the U.S., cancer is [one of the most expensive diseases to treat](#); only heart disease [costs](#) more. This cost burden is often passed on to patients.

And to make matters worse, lack of transparency about cost and

coverage can be confusing. Seemingly arbitrary changes in insurance decisions can contribute to patients' [financial toxicity](#), or the hardship, psychological stress and behavioral adjustments associated with costs of care. For example, some patients have unexpected [bills](#) after they receive a diagnosis or abnormal result on a screening test.

In these cases, care that was previously categorized as preventive (and free from out-of-pocket costs) can become a diagnostic or surveillance test, with associated fees. Other patients are surprised when they receive a bill for physician time as well as a [hospital facility fee](#). It is difficult for patients to keep track of all of these changes and adjust cost expectations.

The impact of high care costs is substantial. People with high out-of-pocket costs are [less likely to receive necessary care](#), which can compromise [cancer treatment](#) and may affect overall or cancer-specific mortality. In a recent study, almost a third of adults said they [delayed or avoided care due to costs](#).

A patient participant in a [study we conducted](#) talked about the time she spent navigating the billing process, commenting, "The billing was extremely daunting. I kept a three-ring binder that was three inches thick ... tried to match things up. It was a mess." That time and effort could be spent healing or engaging in valued activities, she relayed to us.

## Hidden costs of care

In addition to direct costs of care, there are indirect costs of care, such as fees for transportation, parking, housing when needed, and the time spent managing the financial aspects of care on top of treatment.

My father had to pay between \$18 and \$30 per day just to park at the hospital in New York City where he received his treatments, depending

on how long he stayed. This parking fee was on top of tolls (\$15) and the time spent traveling to and from the hospital. For him, this meant anywhere from 45 minutes to two hours, depending on traffic and road conditions. Transportation and parking costs are typically not covered by insurance, though some hospitals, [health centers](#) and nonprofit organizations [offer assistance with these](#) indirect care costs.

Many other patients have to take time off work while they are undergoing cancer treatment or follow-up care. Cancer patients who are unemployed may even have [lower survival rates](#). One patient in [our study](#) commented, "It takes me two-and-a-half hours to get here. I was coming every month, then every two months. Now I'm every three months. Eventually, I go to six months, but I have to take off work every time to come." Another patient stated, "My vacation and sick time ran out ... I had to go on disability."

## Policy suggestions

Although addressing out-of-pocket care costs for patients requires multiple systemic changes, there are strategies that can help.

First, patients and their clinicians can discuss the costs of care and create [cost-saving strategies](#). Patient-clinician cost discussions can reduce overall costs to [patients](#), but many clinicians are hesitant to talk about costs with [patients](#).

If there is more than one treatment option available with equal effectiveness data, patients can ask, "is there a difference in price between options"? Developers of [patient-centered decision aids](#) can also add the relative costs of treatments so that patients can weigh cost along with other aspects of treatment to support their choice.

Health care institutions may be underutilizing [social workers](#), financial

navigators and other care center resources. Social workers, financial navigators and other care center resources staff with adequate training that promotes patients' access to care and assistance can help manage their out-of-pocket expenses. This process can yield positive outcomes for both patients and [health care institutions](#).

## Less may be more

Sometimes, treatments are not needed and may add burden to patients. For example, a shorter duration of radiation for early stage breast cancer works just as well as longer durations; chemotherapy might not benefit some patients at [earlier stages of cancer](#) or some [older adults](#); and some scans [may be excessive](#).

Until we change norms and engage patients, clinicians and systems to weigh the pros and cons of care that is considered unnecessary or even harmful, many patients and clinicians might fear less aggressive treatment. There's also the Choosing Wisely [campaign](#) which is designed to help by summarizing evidence in plain language and recommending commonly overused interventions.

Finding sustainable solutions to reducing cancer-related financial toxicity requires a collaborative effort between doctors, [patients](#), policymakers, health insurance companies and health care institutions. Easing the cognitive burden associated with the financial stress that comes with cancer care can lead to better outcomes for [cancer patients](#)' health and quality of life.

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