Financial Toxicity:

The unseen side effect that can erode the efficacy of our cancer treatments

BY FUMIKO CHINO, MD, AND CAROL A. HAHN, MD

AS THE COSTS OF HEALTH CARE HAVE OUTSTRIPPED ECONOMIC GROWTH, the personal financial burden on patients and families paying for cancer care has been recognized as an increasingly significant issue. Cancer is currently the most expensive disease to treat,[1] with higher out-of-pocket costs than other chronic diseases.[2] As cancer treatment costs have risen, insurers have shifted more of the burden to patients in the form of deductibles, coinsurance and co-payments. In a 2017 national patient opinion survey, 70% of those surveyed felt that costs were the major barrier to receiving quality, timely cancer care,[3] and in 2018, survey data demonstrated that more Americans are worried about cancer's financial impact (57%) than of dying of cancer (54%).[4]

The term "financial toxicity" has emerged as a way to describe the toxic effects that out-of-pocket costs can create as side effects of cancer treatment.[5] In practical terms for our patients, this manifests as decreased overall well-being, quality of life and quality of care through accumulating economic burdens, compromised medical decision making — including decreased adherence due to costs — and ongoing financial stress through both end of life and survivorship. The ultimate downstream effect of severe financial burden is a greater risk of mortality.[6]

Due to changes in the insurance industry over the last several decades, more patients diagnosed with cancer today are underinsured, meaning they spend more than 10% of their income in out-of-pocket costs for their treatment.[7] Underinsurance and financial toxicity lead to delayed diagnosis and treatment start[8,9] and poor access to clinical trials.[10] Costs of cancer care extend beyond direct costs for medical care, with non-medical costs like travel and indirect costs like lost wages or poor productivity exacerbating the burden of increasing bills by decreasing household income. Examples of both direct and indirect costs are shown in the table on page 24.

Addressing financial toxicity has recently been called out as an unmet need within radiation oncology.[11] Prior research has shown that receiving radiation therapy has been associated with significant out-of-pocket costs,[12] and that a history of radiation treatment is associated with treatment-related financial problems.[13] One study specific to radiation patients found that almost a quarter had experienced financial toxicity, and more than half of radiation oncologists were concerned about treatment costs negatively affecting their patients.[14] In the first survey using a validated measure of financial toxicity, 15% of patients had grade 2-3 financial toxicity which corresponds to a moderate or severe impact on quality of life.[15] Highlighting the disconnect between intention of providers and patient experience, another study found that, while 43% of radiation oncologists reported someone in their practice often or always discusses financial burden with patients, of those patients who were worried about finances, almost three quarters indicated that physicians and their staff did not help.[16]

Solutions to financial toxicity exist along many frameworks, from government and health policy, to health systems and cancer society guidelines, to patient and provider relationships and shared decision making. Negotiated costs and bundled payments are seen as one way of controlling the ballooning costs of cancer treatment and thereby exerting downward pressure to reduce costs on a national level with trickle-down benefit to patients. Health policy mandating that pricing of new drugs and treatments must be based on their value to patients (i.e., the outcomes and quality provided by treatment related to cost) is also frequently proposed; however many fear that such a restrictive policy would dampen the development of new therapies and innovation. Insurance prior authorization has also been used as a cost control measure that, in theory, ensures that all planned treatment is evidence based; unfortunately, for many it shifts the burden onto

providers to ensure their patient's care is covered, resulting in treatment delays or compromises in treatment plans in order to meet insurance criteria.

Framework and guidelines are meant to support shared decision making and help drive conversations leading to patient-centered care. The ideal conversation helps physicians provide the highest quality of cancer care tailored to the unique concerns and values of each patient. However, given lack of provider training and unknown out-of-pocket costs, cost is rarely a substantial part of shared decision making. Both patients and providers may feel uncomfortable bringing costs into the conversation, leading some patients to "suffer in silence." Screening for financial toxicity (either with single question or validated 11-question measure) may help identify those who are struggling with or at risk for financial toxicity. A team-based approach including a social worker, nurse or financial navigator, financial services, and other support staff may help provide the manpower to actually identify what assistance may be available to patients.

Sadly, there is no single solution to financial toxicity. Finding systemic ways to lower health care costs may ultimately work to lessen the burden for patients as a whole, however, are doubtful to have a meaningful benefit for the patient at your next office visit who is struggling to pay for both rent and cancer treatment. Acknowledging that financial toxicity exists and normalizing cost conversations can be a meaningful way for us to ally ourselves with our patients. It starts with a willingness of physicians to work toward big and small solutions to treat and prevent financial toxicity.

"It's very expensive to be sick."

Interview with Heather Brinkerhoff, patient, as told to Fumiko Chino, MD

In early 2018, Heather Brinkerhoff was busy with her three-year-old son and building her personal training business; her husband, Jason, was an emerging artist with several well reviewed gallery shows. Their young family lived in a "fixer upper" in the Bay Area California, in a two bedroom with enormous potential but requiring Jason to do lots of work to make it the home of their dreams. In May 2018, Jason noted increasing headaches and was ultimately diagnosed with a glioblastoma multiforme. Months later, while still dealing with the stress of neurosurgery, radiation and chemotherapy for her husband, Heather noted increasing abdominal pain. In January 2019, she was diagnosed with pancreatic cancer. A young family faced with two devastating cancer diagnoses would be overwhelmed no matter what, but the financial burden of cancer hit the Brinkerhoffs particularly hard.

Heather Brinkerhoff took time between chemotherapy appointments to share part of her story with us:

I just want to start with saying that we both have always had health insurance. But we're a young family, and we're both self-employed. In the last 18 months, we were hit with two horrible cancers, two huge surgeries, radiation, chemotherapy… all while our house was — literally — in pieces. The first thing I realized is that our first insurance plan was tied to a hospital system that just wasn't able to care for me. I had a complicated hospitalization in January with jaundice and pain, I was in rough shape. I needed to get started with treatment pretty fast. Due to the complexities of my case, it just wasn't happening and that was very scary. I ended up transfering to another hospital and they were able to get me started quickly, but it was expensive, thousands of dollars. By doing the best thing for my health, and to treat my cancer, I ended up on the hook for $35,000. ***Read Heather's full story on www.RTAnswers.org/heatherbrinkerhoff.***

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Table 1: Direct and Indirect Costs of Cancer Treatment

Direct Costs of Treatment (Medical)	
Co-payments and coinsurance for cancer treatment	Costs for anti-cancer drugs, radiation, radiology studies, lab tests
Uncovered Treatments	Costs of treatment not covered by insurance or for those uninsured, including clinical trials and treatments considered "investigational" by insurers (protons, IMRT for breast cancer, etc.)
Complications	Costs due to treatment side effects including co-pays for medications for symptoms, hospitalizations or other medical care needed like skilled nursing facility/rehab
Over the Counter Medications	Costs for medications like acetaminophen, ibuprofen, senokot, docusate, topical creams like Aquaphor or Eucerin
Medical Equipment	Wheelchairs, bedside commodes, pumps for chemotherapy or feeding tubes; disposables, like bandages
Insurance	Higher co-pays and costs of "out of network" care; higher premiums due to needing adequate coverage of complex medical treatments
Direct Costs of Treatment (Non-Medical)	
Travel	Gas, vehicle wear and tear, tolls, parking, airfare, lodging/hotels
Food	Dining out while away from home (for both patient and family members); costs of special meals or wasted food
Indirect Costs of Treatment	
Employment	Lost wages for patient and/or spouse
Career Costs	Limited career growth due to absence, reduced hours, early retirement and/or "job lock" (limited movement between jobs due to concerns for maintaining health insurance)
Child/Eldercare	Hiring sitters, paying for daycare, nursing aides or day programs for adults

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