“What Can Congress Do to End the Medical Debt Crisis in America?”
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Written Testimony

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My name is Fumiko Chino, and I’m an oncologist at Memorial Sloan Kettering Cancer Center. Every day, I use advanced radiation technologies to treat and cure patients with cancer; I also do research on how to make healthcare more affordable. I come to you today to speak about the harms of medical debt as an expert in the field, and also as someone with personal experiences with the financial devastation that patients and families feel after a cancer diagnosis. My testimony today represents my personal position and not necessarily those of my employer.

On the day after his 27th birthday, my husband Andrew started having pain and throwing up. When he was finally diagnosed months later, we learned that he had a fast-moving tumor that had spread throughout his body. We were young and in love, but more importantly we had health insurance. We had done everything right. We knew we’d have to make some sacrifices —nobody thinks cancer treatment is free. But we had no idea of the financial burden that cancer would force on us. Our subsequent struggle through the health care system highlighted dangerous holes in his coverage and left me realizing that many Americans are one diagnosis away from catastrophe. Even with health insurance, the high costs of health care are leaving many American families adrift in debt.

Within 6 months of Andrew’s diagnosis, we had maxed out his prescription benefit and had to start paying out of pocket for his medications; thousands of dollars a month. Another couple of months later we met the lifetime cap: his health insurance simply stopped paying for his treatment, and we were left on the hook to pay to keep him alive. I cashed out my 401k, we postponed our plans to start a family, we borrowed money from friends and family… we even considered moving to Canada. Nationalized health care was looking pretty good. But moving was a signal of defeat: it meant that Andrew wouldn’t be able to complete his PhD, he wouldn’t be able to start the promising career he had earned.

Here’s the thing I know now as an oncologist about when young people get cancer, their bodies are so healthy, they can handle so much aggressive treatment, their capacity to absorb set back after set back is so high… until suddenly they can’t. It was in the grey of winter that Andrew died at age 28, leaving me in an empty house, with an empty future, and a stack of bills.

Even though Andrew was gone, the debt remained. I was hounded by debt collectors, one even called me when I was at his funeral.

The debt was like a black cloud over my head; it followed me and cast a shadow over my entire future. It wasn’t until years later that I discovered that, despite the threatening phone calls and

letters, I wasn't legally responsible for Andrew's medical debt. The debt died with him. Even today, I get calls from collectors trying to cash in on his sickness.

Our experience made very clear the gaps in the US health care machine, a system that was seemingly designed to favor profits over people. After Andrew's death, I decided to go to medical school to try and fix the system from within. Fifteen years later, I am a treating physician and clinical researcher with a focus is on the "financial toxicity" of cancer care: how high costs can have real effects on quality of life and quality of care. The United States has a growing contingency of people who cannot afford their necessary healthcare: many consider selling their homes or declaring bankruptcy[1], forced to literally choose between their money and their lives.

There are more people worried about the financial costs of cancer care than of actually dying from cancer[2]. Forty percent of Americans have depleted their life savings within 2 years of a cancer diagnosis[3]. Our research has shown that costs drive 1 in 4 to place their cancer survival at risk by skipping appointments, scans, and medications—or avoiding treatment altogether[2,4-7]. Financial stress erodes quality of life[8], worsens symptom burden[9], reduces satisfaction with healthcare[10], and limits the ability to adhere to appropriate treatment and/or follow up plan[4]. I've seen the financial toxicity of cancer treatment in the patients I treat --lost jobs, lost homes, and lost independence. Many patients have to balance their health with the financial stability of their family; ultimately some lose both, leaving their families both emotionally and financially devastated.

Health care reform has brought out both passionate debate and political chest-beating. The specter of "death panels" continues to echo in the general public as fear that physicians may seal patients' fates based on cost calculations alone. In reality, understanding how costs and affordability barriers are part of the equation can be crucial to minimizing debt and improving health outcomes. Our research has found that unexpected costs were associated with decreased willingness to pay for care; this was even after controlling for the level of financial burden[11]. Through our teams efforts, we strive to connect patients with resources[12-15] but know that many who cannot afford effective healthcare do without, cutting corners with visits or medications.

Although far from perfect, the Affordable Care Act does include provisions that limit patient exposure to high costs. What happened to Andrew and me 15 years ago wouldn't be allowed today under the ACA. Health care plans are no longer allowed to have annual or lifetime caps and are required to limit patient out-of-pocket costs for healthcare; additionally, millions gained health insurance under Medicaid expansion. The Inflation Reduction Act promises further gains for our seniors by closing the Part D donut hole and mandating price negotiation for at least a small number of high-cost medications.

Hospital service and drug pricing is like the wild, wild west, with vast disconnect between the quality of care delivered and their costs: our price transparency research shows that the same service may be charged $300 at one center and $30,000 at a different center based on closed door negotiations with payors[16]. Small hospital systems and free-standing centers struggle to compete in a world of increasingly consolidated healthcare markets and insurance conglomerates, leading to both healthcare deserts (especially in rural areas) and huge price variation. Improved price transparency must lead to price stability to help bring the cost of healthcare down and make care more affordable for the average American family.

Value-based payment models should continue to be redesigned to decrease the cost of care and improve quality care and outcomes. Thus far, the Oncology Care Model —a bundled payment model introduced by CMS to increase coordination and reduce costs— has showed mixed benefits in terms of spending, hospitalizations, and ED visits[17,18]. The Radiation Oncology Case Rate

(ROCR) Value-Based Payment Program Act was just introduced in May 2024 and promises to incentivize high quality radiation treatments by aligning financial incentives with clinical guidelines. It aims to reduce disparities by helping underserved patients initiate, access and complete treatments.

In addition to strategies that prevent financial toxicity from forming, debt relief is needed now. Senator Sanders and colleagues recently introduced legislation aimed at eliminating medical debt for working class Americans. This is particularly important policy for people with cancer, who are uniquely at risk; we are curing more cancers than ever, but with higher costs that can haunt patients and families for years[6]. The American Cancer Society recently found that over one-half of surveyed patients reported medical debt related to their treatment. More than two-thirds carried their debt for over a year; about a one-third carried it for over three years. Over one-half of debt-holders faced collections, and 46% saw their credit score negatively impacted[19]. Prior research has shown that medical debt is associated with worse health and higher mortality[20].

Improving public health is good politics; investing in American health pays out in better long-term outcomes[21,22]. "Medicare for All" promises to disengage the pursuit of profits from the delivery of healthcare. And there are national advocacy efforts that span across the aisle, with the goals of preventing financial toxicity from forming and to treat it effectively when it already exists. I ask you to work together to improve access and affordability, evolve health insurance, protect pre-existing conditions, and enhance value in healthcare.

I've worked hard to reinvent myself with purpose. Today I am physician and a researcher on a mission to improve cancer care in America. To take the lessons that I learned from blood, sweat, and tears and turn it into a better future for the next patient who walks into my door. Ultimately, the fear that I share with many of my patients is that, without action, we may slip further into the abyss. We need to chart a path forward to where a new diagnosis doesn't automatically mean you will face financial ruin, so that no one else needs to make the difficult decisions of life over life-savings.

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