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Financial Toxicity, Part I: A New Name for a Growing Problem

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"We don't travel; we don't do anything now because it's a $100,000 illness. And it sucks.… What are you going to do? Caught between a rock and a hard spot." A 67-year-old, insured woman with metastatic breast cancer— let's call her "Janet"— recently described how her life changed due to costs of cancer care. We all hear about the cost of care at every turn; healthcare reform is at the forefront of the national debate. The debate is carried on in medical journals, which are flooded by editorial pieces on how to bend the cost curve. Indeed, this journal has recently published commentaries on the rising cost of cancer treatment, [1] healthcare financing, [2] and the value of care. [3] But where in this mix is Janet? Buried somewhere in the sheaves of dire projections and cost trends, her daily experience with the cost of cancer treatment is lost. However, Janet's experience does not fall on deaf ears. Oncologists who treat patients daily listen to similar life-altering, cost-related complaints, along with reports of fatigue, nausea, and pain. However, to date most of us have not considered financial distress in the same vein as chemotherapy-induced toxicity, nor do we have the training to alleviate that distress. In this, the first part of a two-part series, we will describe the patient-level impact of the cost of cancer care, what we call "financial toxicity." In Part II we will consider potential interventions to alleviate financial toxicity.

Before we describe the patient experience around costs, we must first ask, are patients paying more out of pocket for their cancer care? The answer, quite simply, is yes, because: 1) cancer treatment is more expensive; 2) this expensive treatment is overutilized; and 3) as a result, the rising costs are passed on to the patient. The rising cost of cancer has been described in detail. In the United States, cancer is one of the most expensive diseases to treat, second only to heart disease, [4] and cancer-related expenses are rising. [5] Cancer expenses are rising for four main reasons: an aging populace, more patients with access to treatment, innovation, and overutilization. Our population is aging, and older patients are at greater risk of developing cancer, resulting in more people with cancer requiring therapies. Once diagnosed, patients have improved access to care due to the development of less toxic treatment and optimized supportive care; hence, older and frailer patients are now candidates for anticancer therapy, and therefore a greater proportion of cancer patients are receiving therapies. [6] But innovative treatments come at a cost. In fact, cancer drugs marketed today are more expensive than they have ever been. [7] When a growing, aging population has

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access to more expensive interventions, costs to society begin to rise, especially if those interventions have minimal benefit or are used contrary to the evidence base.

The rising costs of cancer care are most often discussed at the level of health policy with an eye towards societal financial burden. But let's return to Janet, an insured patient. Even though cancer is an expensive disease, her insurance should cover her costs. Yet, we hear more and more stories like Janet's of debilitating out-of-pocket expenses. So why are insured patients facing increasing out-of-pocket costs for cancer care? The answer to this question links back to the rising societal costs of care. As third-party payors bear an ever-growing cost burden, they have shifted a portion of those costs to patients. Cost sharing can trace its history back to the RAND Health Insurance Experiment (HIE) from the 1970s, through which several thousand families were randomized to health insurance with varying levels of coinsurance. [8] After 5 years of follow-up, the study concluded that coinsurance decreased health care delivery costs without negatively impacting health. Based on these findings about cost sharing, insurers in the modern age have continued to pass on costs to patients. Insurance itself has also become more expensive for patients, with premiums increasing nearly 170% between 1999 and 2011 (compared with worker earnings increasing only 50%). [9] Prescription drug copayments have increased as well, with a focus on tiered formularies: between 2000 and 2012, the proportion of workers whose drug plan had three tiers increased from 27% to 63%. [10] While the trend towards greater cost sharing is supported by the RAND HIE study, that study was focused on the typical primary care patient and his or her care needs. Patients with cancer, like Janet— who are sicker and need care that is more intensive care than standard primary care interventions— are not necessarily represented by the RAND HIE results. Indeed, cancer patients experience a higher out-of-pocket financial burden than those with other chronic diseases. [11] So what happens to an insured cancer patient like Janet when she receives expensive treatment and encounters the cost-sharing model?

An expanding body of evidence suggests that cancer patients with insurance, like Janet, are dealing with cost implications as a part of their cancer experience. In fact, out-of-pocket expenses might have such an impact on the cancer experience as to warrant a new term: “financial toxicity.” Out-of-pocket expenses related to treatment are akin to physical toxicity, in that costs can diminish quality of life and impede delivery of the highest quality care. Existing data have identified both objective financial burden and subjective financial distress as key components of financial toxicity.

First, cancer treatment received by patients with insurance can still result in a considerable objective financial burden. Nationally representative data have shown that among adults younger than 64 years, 13% of cancer patients reported high objective financial burden, compared with 9.7% of those with other chronic conditions. [11] Elderly patients with cancer also report high out-of-pocket expenses for cancer treatment, and those expenses are higher than expenses incurred by elderly patients without cancer. [12] High out-of-pocket expenses are most commonly due to prescription drugs, followed by outpatient care and hospitalizations. The out-of-pocket cost of oral chemotherapy alone can be over $500/year, even for patients with private insurance. [13] Evidence suggests that mean out-of-pocket expenses for cancer care, including premiums, can be over $5,000/year. [11] Approximately

a quarter of patients in a study by Shankaran et al were in debt due to treatment-related expenses, and those patients reported a mean debt of $26,860. [14] Also important to the overall calculation of financial burden is the time patients spend receiving care rather than working or engaging in other activities, also known as “patient time costs.” Depending on the type of cancer and phase of care, patient time costs range from hundreds to many thousands of dollars per year. [15]

Not all patients experience the same objective financial burden; certain subgroups of the population are at higher risk for paying more out-of-pocket. In a study of patients receiving chemotherapy for colorectal cancer, younger patients and those with lower household income were predisposed to experience greater financial burden. [14] In addition, other sociodemographic characteristics, including type of insurance, race, marital status, education, geographic location, and comorbidity, all contribute to higher out-of-pocket expenses.

In addition to objective financial burden, the second key component of financial toxicity is subjective financial distress. Compared to objective burden, much less has been published on subjective financial distress and its impact on the cancer experience. Based on available evidence, financial distress affects patients' well-being and quality of care. [16] Nonadherence is one of the best-studied outcomes resulting from higher costs. Neugut et al found that among patients with breast cancer, higher co-payments for aromatase inhibitors were associated with higher rates of nonadherence. [17] Similar results have been seen with oral chemotherapy prescriptions: insurance plans that require high cost sharing are associated with a higher risk of prescription abandonment. [18] Beyond nonadherence, financial distress has been linked to changes in treatment-related decision making. Markman et al found that among patients with cancer, 19% believed that the cost of treating their cancer caused their family a large amount of distress. [19] Eleven percent considered the costs of treatment “a great deal” when choosing a treatment course, and 9% decided against a treatment course because of cost. Our recently completed national study of cancer patients (most of whom had applied for copayment assistance) found that a large proportion reported either a “significant” or “catastrophic” financial burden. These patients, all of whom had health insurance, were spending their savings, canceling vacations, and working more hours in order to afford their cancer care. [20]

According to mounting evidence, Janet is not alone in feeling “caught between a rock and a hard spot” when it comes to paying for cancer care. The cancer experience seems to be altered by financial hardship for many, but more work needs to be done. Costs of care continue to rise; new cancer drugs are more expensive than ever before, and more patients are being treated with these drugs. While patients and claims datasets consistently report an association between financial burden and quality of care, the impact on traditional disease-related outcomes— survival, for example— have not been assessed. Another critical aspect of financial toxicity that remains largely unstudied is patients' expectations of including costs in treatment decision making. Do patients want to talk about costs with their doctors? Chemotherapy-related physical toxicity is addressed early and often, but how and when should financial toxicity be included in the decision-making process? The second part of this two-part series will address these questions.

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Biographies

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