The cost of cancer care is growing faster than other sectors in health in the United States, and this is creating unintended financial consequences for cancer patients, the scope and scale of which are only beginning to be appreciated. Financial toxicity, a term recently emergent from the oncology literature, refers to the unintended financial consequences of patients embracing expensive treatments [1]. An estimated 1,660,290 new cases of cancer were diagnosed in 2013 and there are an estimated 13,027,914 people currently living with cancer in the United States [2]. Recent studies suggest that high proportions of these individuals are experiencing severe financial distress and even bankruptcy in the months and years following diagnosis. In addition, evidence is accumulating that patients are forgoing treatments due to costs, with potentially life threatening consequences. Below, we review the conceptual issues involved, and current research on the topic of financial toxicity in cancer, followed by discussions of strategies and policy initiatives to address the problem.

Individuals diagnosed with cancer face potential financial stresses on three fronts: 1) out-of-pocket expenditures for medical care (copays, coinsurance, deductibles, and premium) and related non-medical expenses (e.g., costs of transportation and parking); 2) loss of earnings for the affected individual; and 3) potential loss of household income of other family members due to caregiving needs. Compared to other health conditions, cancer is relatively unique in that the treatments for the disease, such as chemotherapy or radiation therapy, often make patients too sick to work or care for themselves for weeks or months on end. Even after succeeding the initial treatment, survivors often face long-term health consequences resulting from their disease or therapy and may require ongoing surveillance for disease recurrence and second cancers. Lingering effects, such as “chemo brain” and lymphedema, can leave patients at less than full function for months or years following treatment. Multiple studies demonstrate that family caregiving needs for cancer patients can be highly burdensome, necessitating some to reduce time at work to help their loved one. Many cancer patients and their families are thus forced to deal simultaneously with illness and financial distress for a sustained period of time. As individuals incur expenses and lose wages, even those with generous insurance coverage are likely to exhaust savings and accumulate debt.

Estimates from the 2001 Medical Expenditure Panel Survey reported the average annual mean expense per person with cancer to be $36,318 [3]. Approximately 4.6% of the total is paid directly out-of-pocket by patients [3]. The average does not reflect the variability in benefit designs across plans, or the relative impact on patients of varying socioeconomic status. Studies that have surveyed cancer patients about financial matters find that up to 40% experience severe financial distress, defined variably but usually including items such as remortgaging one’s house or emptying all savings [4-6]. The long-term consequences of financial distress for patients’ health and economic well-being are unknown.

Financial considerations related to the rising cost of cancer care also have direct impacts on patient’s choice of treatment and adherence to therapy plans. Numerous studies have demonstrated that, as out-of-pocket costs increase, fewer patients initiate treatment and those who do are more likely to discontinue early [7-9]. Sub-optimal adherence to treatment is directly associated with poorer disease outcomes, and potentially higher long-term costs due to recurrence and complications. To the extent that the financial burden of cancer is greater for those with lower incomes, it directly contributes to health disparities, as poorer patients are unable to access treatment due to financial barriers.

Cancer patients often have to take time away from work to attend medical appointments and recover from treatment. Forty to 85% of cancer patients stop working at some point during treatment [10]. Ongoing health problems and missed opportunities for advancement contribute to the finding that, on average, individual earnings of cancer survivors tend to fall during the 5-year period after diagnosis [11]. For younger cancer patients, stopping working or reducing hours can also result in disruptions or loss of insurance coverage. The financial burden of cancer is experienced not only by patients, but also by families and friends. Family members often act as informal caregivers and may also face loss of income. In a study designed to estimate the burden among partner caregivers of patients diagnosed with localized prostate cancer the work 4 hours of caregivers in the year post diagnosis declined significantly, resulting in an average loss of US$6063 (range US$571-US$47,105, in 2009 dollars) [12].

One of the most extreme manifestations of the financial burden of cancer is insurmountable debt leading to personal bankruptcy. Our group recently published a population-based analysis of the risk of bankruptcy and found that while just over 2% of patients diagnosed with cancer in the United States between 1995 and 2009 filed for bankruptcy in the 5-year post-diagnosis period, the risk is about 2.7-times greater than sociodemographically-matched people without cancer [13]. Younger cancer patients were at a significantly higher risk of filing for bankruptcy than patients diagnosed over the age of 65, suggesting that insurance, and specifically Medicare, may partly mitigate the risk of bankruptcy.

Several strategies have been proposed to reduce the financial burden of cancer for patients and their families. In 2010, a new Patients’ Bill of Rights took shape as part of the Affordable Care Act (ACA). While not all of the provisions have been fully implemented, the new legislation removes barriers to obtaining insurance coverage and annual and lifetime dollar limits to be paid by insurance. It also makes it illegal to deny insurance to people with pre-existing conditions. Another ACA provision that is especially beneficial for young cancer patients is the extension of dependent coverage to the age of 26. Increasing access to insurance should reduce the risk of financial devastation for individuals who previously would have been uninsured. These patient protections should lessen the financial burden of patients who previously would have reached the limit of their insurance benefits and those who would have been unable to get new or more coverage. In addition, by requiring insurance to cover screening, the cancer stage distribution for sites with effective screening technologies such as breast, cervical, colorectal, and most recently lung, should shift to earlier stages, which tend to be less expensive to treat than cancers diagnosed at more advanced stages.

Financial planning alongside the development of a treatment plan may also reduce the risk that unexpected expenses overburden cancer patients and their families. Full disclosure, as recommended in the recently published IOM Quality of Cancer Care report [14], that includes the costs and benefits of all available treatment options can potentially make cancer care more affordable to patients and their families. For this to occur, however, the costs of treatment and especially the expected out-of-pocket expenses must be readily available to patients and providers. Access to social workers, patient navigators, and financial counselors to guide financial planning and identify community resources that may offer assistance to cancer patients has shown to be effective at reducing treatment delays and discontinuation [15-17]. Moreover, the financial toxicity of treatments should become as commonly discussed as treatment side effects and efficacy.
Most importantly, the discussion must include the cost of all available treatment options that deliver similar overall benefit so that patients can reach informed decision making by incorporating their own value judgment. The quality of life of cancer survivors depends not only on their physical health but also on their economic and emotional well-being.

In summary, cancer poses both a health and a financial threat to patients and their families. Unintended consequences of the financial toxicity of cancer range from reduced spending on other items to medical debt leading to bankruptcy; at every stage suboptimal adherence and early discontinuation of cancer therapy may contribute to cancer related morbidity and mortality. More studies that estimate the cost attributes of cancer care and the associated cost drivers as well as sources of variations are needed to reduce the financial toxicity of cancer.

REFERENCES