We commend Dr. Zafar for continuing to highlight the critical issue of financial toxicity in cancer care and the call to action for the development of interventions to minimize the financial burden families face while navigating cancer care (1). The negative impact of financial hardship on health outcomes (2,3) in general, and cancer-related outcomes (4,5) in particular, over and above traditional indicators of lower socioeconomic status (eg, low household income and low educational attainment) has been shown repeatedly in the research literature. As noted, oncologist communication and patient health literacy are key components of any intervention designed to reduce the financial burden of cancer care on families. However, additional research to inform the most appropriate intervention targets, content, and timing on the following is also warranted to fully address this call to action: 1) development of conceptual and measurement clarity of financial toxicity as families navigate cancer care and survivorship; 2) development of measures and systematic documentation of the socioeconomic context of the household across the cancer continuum from prediagnosis throughout survivorship; 3) fuller characterization of populations at greatest risk to minimize any differential impact of financial toxicity on health disparities populations to prevent the widening of disparities; and 4) delivery pathway research that clearly articulates the roles of multidisciplinary clinical and support team members to ensure cost discussions are part of treatment and survivorship care plans.

Health services researchers have called for more conceptual clarity and rigorous measures development on the impact of the costs of health care in general, and cancer care in particular, on households. As such, research on defining and measuring the financial consequences of cancer care has increased substantially in recent years (6). Yet, the conceptualization and measurement of the concepts in this area of research are not always clear. Terms such as financial burden (7), financial toxicity (8), financial hardship (9), and financial stress/distress (10–12) are all used to describe the multidimensional financial consequences of managing cancer care; the measures used across these concepts vary widely without much consideration for when in the care continuum (ie, immediately following diagnosis, during treatment, survivorship, and end-of-life care) they are used; and it is also unclear if these terms are attempting to describe/measure the same experience (concept validity) for patients and their families. To borrow frameworks from the health disparities literature (13), the financial well-being of households navigating cancer care includes the lack of material resources to cover out-of-pocket medical expenses, the potential psychological distress accompanying such lack of resources, and the coping behaviors a household adopts to manage cancer care costs. These domains appear to be distinct for families as they experience rising expenses and declining income and have been shown to be differentially associated with patient characteristics (14). Thus, the target, content, and timing of an intervention designed to address the material lack of financial resources will differ from an intervention designed to address psychological distress or financial coping behaviors (eg, skipping medications because of cost) and poor household financial management strategies; where the most comprehensive intervention will include components of each: material, psychological, and behavioral targets. Reliable and valid measures in these domains can help to more accurately identify households where the cost of care and navigating the health care system is “financially toxic.” In particular, such measures can serve as patient-reported “vital signs” of when health insurance coverage is not sufficient to prevent financial catastrophe for families. Thus, to move forward in this area we need a comprehensive mapping of standardized measures for material, psychological, and behavioral domains of the financial consequences of cancer as families navigate treatment and survivorship.

For households, the direct and indirect costs (eg, patient and caregiver time, productivity losses) of cancer care exist in a socioeconomic context and must be managed alongside other expenses and family obligations. As the costs of health care continue to grow relative to household income, these costs will increasingly strain household budgets as they compete for
financial resources with other basic necessities. This is especially problematic for low-income families, where even modest out-of-pocket expenses can cause a substantial financial burden. Additionally, while we agree about the need for improved patient-level health literacy and that greater attention to “cost-related health literacy” may help to determine what the patient (and the family) value and also how well they understand their diagnosis, it is important to recognize that health literacy (including health insurance literacy, financial literacy, and numeracy) is embedded in the socioeconomic context of patients and is socio-demographically patterned with those in poverty, racial/ethnic minorities, and those with low educational attainment reporting lower levels of financial (15) and health insurance (16) literacy, suggesting the need for targeted efforts.

Of course, health care institutions cannot be charged with poverty alleviation; yet if cancer care costs induce poverty and contribute to bankruptcies (17), these effects cannot be ignored by health care providers as such effects influence the timeliness of treatment as well as adherence to treatment (5,18,19). Therefore, interventions that clearly outline the roles for the multidisciplinary clinical and support care team members in the discussion of cancer care costs and help patients manage the financial toxicity of cancer care should help in answering the open question of when in survivorship and who should measure the financial toxicity of cancer care. Patients report wanting to discuss the costs of treatment (20), yet many oncologists report being uncomfortable with these discussions (21) and, given time demands, it is not currently clear which members of the health care team are best suited for these discussions. Several health care professional organizations (eg, American College of Surgeons, American Society of Clinical Oncology, and Association of Oncology Work) are currently developing frameworks/protocols for helping their members confront the costs of care and navigate health care cost conversations with patients. However, documentation of whether or not these conversations are occurring, as well as their content, are not generally recorded in patient records. A recent report from the Institute of Medicine, “Capturing Social and Behavioral Domains and Measures in Electronic Health Records,” asserts that “to provide better patient care, improve population health, and enable more informative research, standardized measures of key social and behavioral determinants need to be recorded in electronic health records (EHRs) and made available to appropriate professionals” (22).

We agree with Dr. Zafar that discussions about financial toxicity of cancer care should be initiated by an informed oncologist and managed by the entire healthcare team; and as noted, such discussions should ensure that patients do not feel that care is being denied (rationed) based on their ability to pay. Such issues must be further understood considering health care disparities where the quality of care has received different historically based on socio-demographic characteristics such as race and socioeconomic status (23). As efforts move toward intervention development to reduce the financial toxicity of cancers facing navigating cancer, several policies are currently in place that warrant additional attention such as the Affordable Care Act requirement for (nonprofit) hospitals to have financial assistance policies in place that are readily available to patients (24) and cost transparency laws that provide patients with the costs of the same procedures at multiple locations. The evidence of the impact of these policies has yet to be determined in the cancer care context. In other settings, it has been shown that after the location of care, most patients choose health care services based on their physician’s recommendation and not the overall price (25) or financial assistance policies; given the complexity and urgency of cancer care, price transparency may not necessarily be the most effective policy lever to address the financial toxicity of cancer care.

Addressing Dr. Zafar’s call to action begins with gaining greater conceptual clarity and better measurement of the material, psychological, and behavioral aspects of the financial toxicity of cancer care, which can improve the understanding and identification of potential modifiable factors to reduce the financial impact of cancer care on households. In particular, such clarity will elucidate the tradeoffs that families are actually making as they navigate cancer care, as well as explicate how families (even prior to cancer diagnosis and treatment) manage their financial resources. Without such clarity, what should happen when cancer care is deemed “financial toxic,” as well as the target for intervention, will remain ambiguous. More specifically, it will remain unclear whether the intervention should target the lack of financial resources to cover the direct and indirect costs of cancer care, and/or to address the psychological distress that is caused by the lack of needed financial resources to cover these costs, and/or to address the coping behaviors that families adopt to manage the financial burden of cancer care that too often leads to financial ruin of the household.

References


