Letter to The Washington Post April 9, 2016

To the Editors:

For people facing cancer, financial toxicity has many faces. As the April 9 Health & Science article, <u>"Tackling the financial toll of cancer, one patient at a time"</u> points out, patients are increasingly impacted by the direct costs of their care and are making significant trade-off decisions as a result. Our research at the Cancer Support Community provides strong evidence that financial toxicity affects patients and caregivers in multiple, often less visible ways.

Over 50 percent of participants in our Cancer Experience Registry report that their cancer treatment has had a negative impact on their financial situation. Their responses range from lost income or even lost jobs, to the costs of childcare or transportation to hospitals and medical appointments. They tell us about depleted or exhausted savings, lost homes, bankruptcy, gutted retirement funds and the weddings, vacations and special events they can no longer afford. Our research shows that patients who experience a financial burden as a result of their cancer are two and a half times more likely to be a risk for depression. Patients who experience financial stress are also more likely to choose a less expensive-and less effective treatment--or to stop a treatment that is working.

Financial toxicity is one component of the overall patient and family social and emotional scenario and is one of the most well-known elements. However, the cancer experience is multifarious. The Institute of Medicine report "Cancer Care for the Whole Patient" stated that up to 43 percent of patients with cancer experience significant levels of social and emotional distress, yet psychosocial assessment and care remains the exception, rather than the rule, of standard practice. The Cancer Support Community and our partners have worked tirelessly to develop evidence-based screening tools which would allow for early recognition of distress-causing issues, including financial toxicity, and to ensure that patients and family receive the support they need. You have done an outstanding job highlighting exactly this type of work in your focus on the work of Dan Sherman.

The reality of the cancer experience is that it is complex. It is multifaceted. The need is urgent. Much investment continues in search for a cure to cancer. Innovation is one of the most frequently used words. Yet, the layering of social and emotional distress issues makes it unlikely and sometimes impossible for patients to be adherent to the very innovations which could lengthen or save their lives. In December of 2014, the Cancer Support Community reported findings from patients who participate in the Cancer Experience Registry and live with Chronic Myeloid Leukemia. This is a type of cancer which is highly controllable thanks to 'innovative' treatments. Yet, 32 percent of the patients report not taking their treatment as prescribed if they have financial toxicity – a full one-third of the patients. The picture becomes even bleaker in that when you combine financial toxicity with simply a risk for depression, a full 57 percent, or two-thirds of them report non-adherence to their treatment.

So where does this leave us? We must look at the comprehensive nature of the cancer patient experience and provide early detection of and intervention for patient's social and emotional as well as physical distress. Screening should be applied early in the journey and repeated at regular intervals. Screening should be included throughout points of care, including clinical trials, routine care and throughout the post treatment periods. Psychosocial care should be a part of required and reimbursed standard of care.

You have thoughtfully documented one of the challenges faced by Mr. Steiner. Let's work together to remedy this for all people impacted by cancer, so that no one faces cancer alone.