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COMMENTARY

The financial burden of cancer patients: time to stop averting our eyes

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> CECIL GRAHAM. What is a cynic?
> LORD DARLINGTON. A man who knows the price of everything and the value of nothing.
> CECIL GRAHAM. And a sentimentalist… is a man who sees an absurd value in everything…
> Oscar Wilde, *Lady's Windermere's Fan*, 1893

In the modern practice of oncology, we meet both of Wilde's archetypes: cynics and sentimentalists. The cynics view cancer care through the prism of 'unsustainable' costs [1], sounding the alarm over high cancer costs and the consequent adverse impacts on health system budgets. Conversely, the sentimentalists are those among us who have been trained, either explicitly or through peer group socialization, to regard consideration of costs as an unworthy distraction from our sacred mission to heal [2]. The time has come to merge the two views because it is increasingly apparent that our profession's individual and collective reluctance to take steps to restrain cancer costs is inducing harm in the patients we are pledged to serve; a phenomenon recently described as 'financial toxicity' [3].

Self-reported 'financial burden' or 'financial stress' is common among cancer patients. In surveys, 47 % of patients reported 'significant' or 'catastrophic' levels of financial burden [4], and 38 % describes one or more financial hardships as a result of cancer treatment such as reducing retirement funds, refinancing a home or borrowing money [5]. There are medical as well as economic consequences of financial distress. Financial burden is associated with medication non-adherence [6], poor overall patient satisfaction [4] and mental health problems. Indeed, patients reporting financial strain have a threefold higher risk of depression and an eightfold higher risk of severe depression [7].

Financial toxicity is long lasting, continuing beyond the end of active therapy and adding to survivorship burdens. Ongoing medical expenditures are 260 and 160 % higher than non-cancer controls in men and women, respectively [8].

Financial toxicity is not a just an American phenomenon. A study of patients receiving imatinib for CML in Japan, a nation of universal health coverage, found the incidence of problematic financial burden increased from 41.2 % in 2000 to 75.8 % in 2008 [9]. Nearly 32 % of patients considered discontinuing imatinib because of cost though only 3.1 % actually did so. Similar rates of financial burden and strain has been reported in Ireland [7] and Canada [10].

Communication between doctor and patient about costs of care is less than ideal. Two surveys of ASCO members showed that 54 % of medical oncologists believed they were aware of their patients' financial well-being at least 'most of the time' [11] and 43 % stated that they 'always' or 'frequently' discussed cancer care costs [12]. But surveys of patients reveal a different picture. In a survey of insured patients, only 19 % of patients reported discussing costs of care with their doctors, though 52 % reported a desire to do so [13]. Another study conducted by interview indicated that 72 % of patients reported never having a discussion about costs with any health care provider [14], a result similar to the experiences of breast cancer patients in Australia [15].

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Table 1 Uncertainties about patient insights into costs of cancer care

Do patients *apriori* regard less expensive therapies as inferior?
Are patients' decisions about cancer care sensitive to costs; either society's costs or their own?
Will the phenomenon of 'anticipated regret' (thinking now about how they might feel in the future if a less costly alternative does not deliver the cure they are hoping for), cause patients to demand treatment regardless of costs.
In what way, and at what time, will patients benefit most from costs of care discussions?
What presentation of data is most helpful in understanding these issues
Do the answer to these questions vary by age, gender, nation and culture?

But concerned oncologists have barriers to communication about costs. These include ethical concerns about trading off lower costs with the potential for less efficacy, uncertainty about prices for drugs and services and about details of individual patient cost-sharing arrangements, and the worry that saving on upfront costs might increase subsequent costs [16]. Other reasons include a lack of expertise in interpreting comparative effectiveness research [17] and a feeling of helplessness over cancer costs. Indeed, payers, industry and medical centers/hospitals all participate in a system that generates high costs and have a role to play in devising solutions.

But despite the awareness raised by recent studies, we still have an incomplete picture of the financial burden of cancer care. For example, we do not know how much of the patient financial burden is remediable by shifting to lower-cost regimens because some financial harms are related to incidental costs of treatment or inability to work due to symptom burden. Particularly lacking is an understanding of patient attitudes toward costs. If patients indeed want financial issues to be discussed, as surveys indicate, what is the best way to do so? Table 1 indicates a few of the questions that will need to be answered by additional research.

While we wait for these answers, we continue to observe how the high cost of drugs, tests and procedures thrusts many patients into a cruel irony: the longer they live, the more their finances deteriorate. Cancer patients often question the "value" of recommended treatments, wondering if the purported benefit is worth taking out a second home mortgage, worth cancelling family vacations, worth postponing retirement, and worth liquidating savings intended as an inheritance. Patients are experienced in making financial decisions such as these but need the benefit of oncologists' clinical experience to be fully informed. What is the oncologist's responsibility in such cases? I believe we should encourage these discussions even though we ourselves have incomplete information on costs or relative 'value'. Knowing that patients with metastatic disease frequently overestimate the chance of cure from chemotherapy by a large margin [18], we have a duty to be more open about the uncertainty about relative cost/benefit value of varying regimens. When I bring up this topic with patients, I am careful to frame the issue as one of concerns for the patient's welfare, unrelated to concerns about societal costs. When framed in that way, I find patients appreciate the opportunity to express concerns that were on their minds already.

The best practitioners of cancer care have long concerned themselves with minimizing patient harm while treating cancer regardless of whether in palliative or curative mode. The time has come to include financial toxicity as one of the harms oncologists should acknowledge, discuss and minimize. We have a duty to introduce the subject of potential financial toxicity with our patients and to acquire the skills and knowledge to excel at introducing this dialogue, just as we aim to be excellent in other aspects of our professional life.

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