Financial Toxicity
Management as an adverse effect of cancer treatment

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Even when successfully treated, major illnesses, such as cancer, can have a tremendous negative financial impact on a patient and family. In addition to the direct costs of care, like hospital and provider charges, most families also face significant indirect costs, like parking and hotel stays, over-the-counter medicines and supplies, child care while receiving treatments, and loss of income from inability to work (Zafar & Abernethy, 2013a). Other terms used to describe this topic have included financial distress, hardship, burden, or catastrophic distress, defined as allotting 30% or more of household income toward medical expenses (Jan, Kimman, Peters, & Woodward, 2015). Specific to oncology, the term financial toxicity was coined to describe the increasingly frequent problems resulting from high medical payments combined with lower income because of job interruption (Zafar & Abernethy, 2013a).

The Extent of the Problem
The body of literature describing the prevalence and impact of financial difficulty facing patients with cancer is growing. For example, investigators at Duke Cancer Institute in Durham, North Carolina, conducted a survey of 300 patients receiving cancer therapy and found that 39% of respondents reported a greater financial burden associated with their care than expected, and 19% felt overwhelmed by financial distress (Chino et al., 2017). A systematic review (Gordon, Merollini, Lowe, & Chan, 2017) of the frequency of financial toxicity among cancer survivors in the past three years of global literature estimated that, despite a lack of standardization in the use of measures to quantify the problem, 28%–73% of patients reported this problem. The authors also reported that female patients, those recently diagnosed or of younger age, those receiving adjuvant therapy, or those with a low income before the cancer diagnosis were at higher risk for experiencing financial toxicity.

Financial strain also is reported among insured patients in the United States. According to the results of a study conducted by the Kaiser Family Foundation analyzing data from 6,015 households, many families in the United States reported difficulties affording the annual deductible expenses associated with current health plans (Claxton, Rae, & Panchal, 2015). Where a midrange plan’s annual deductible may be $2,400 for the family, only 53% of survey participants reported having sufficient household income to meet that amount. Only 45% reported the ability to meet a high-range annual family deductible of $5,000, which has been estimated to be a common annual out-of-pocket amount for patients receiving treatment for cancer (Bernard, Farr, & Fang, 2011; Davidoff et al., 2013).

The oncology community is becoming particularly attuned to this issue for several reasons (Zafar & Abernethy, 2013b). The older adult population, a large constituency among people diagnosed with cancer, is growing rapidly. The increasing availability of targeted therapies with more tolerable toxicity profiles is a welcome development, and they may be prescribed more readily to older adults (Elias, Karantanos, & Hartshorn, 2017). However, targeted therapies, including...
IV monoclonal antibody agents, such as immune checkpoint inhibitors, are expensive, thereby exposing patients to large copays.  
According to Andrews (2015), the cost for a typical patient receiving nivolumab and ipilimumab for one year, as administered in the CheckMate 067 study for advanced melanoma, was estimated at $300,000. If a patient was responsible for a 20% copay, out-of-pocket cost for those pharmacy charges alone would reach $60,000 (Andrews, 2015).

Evidence also is growing to link financial toxicity to negative outcomes, such as decreased quality of life and mortality. Zafar (2015) proposed that three factors among patients experiencing substantial financial toxicity may be related to increased mortality outcomes, including decreased health-related quality of life (HRQOL), poor perceived well-being (differentiated from HRQOL as significant undesirable lifestyle changes because of lack of funds), and suboptimal care, potentially related to intentional nonadherence to defray out-of-pocket costs. Several studies explored intentional nonadherence and identification of the copay price points at which patients may make the decision to forego filling a prescription for an oral cancer therapy because of out-of-pocket cost. Neugut et al. (2011) found that, among patients receiving hormonal therapy for early-stage breast cancer, monthly copays at the $30- to $90-level were associated with nonadherence compared to a co-pay of less than $30. In Dusetzina, Winn, Abel, Huskamp, and Keating’s (2014) study of a chronic myelogenous leukemia population taking imatinib, patients were 70% more likely to stop taking the drug when in a group with copays more than $53 per month.

Pricing Issues
Anticipating actual costs of different cancer therapies can be difficult for clinicians and patients because of a broad lack of pricing transparency across settings, resulting in what has been referred to as “a menu without prices,” where the impact is not known until the bill arrives after the fact (Henrikson & Shankaran, 2016). Although some efforts have been made to implement cost calculator tools in the private insurance sector that allow patients an upfront view of costs covered by insurance and out-of-pocket copays associated with a procedure, these tools are not yet widely available nor inclusive of all data that patients with cancer may need to review, such as manufacturer’s pricing across specific drug regimens.

Private insurers have been described as one entity with the opportunity to illustrate costs at the national level and push back in price negotiations with drug makers (Howard, 2016). The U.S. Food and Drug Administration (FDA), 2017) is not authorized by law to consider pricing as part of the approval process, nor to control prices set by manufacturers. In addition, under the terms of the Medicare Modernization Act of 2003, Medicare is obligated to pay for drugs approved by the FDA at the rate set by the manufacturer plus 6%, and prohibited from any price negotiations (Centers for Medicare and Medicaid Services, 2016; Cubanski & Neuman, 2017). Older adult patients with cancer covered only by Medicare Part B are responsible for a 20% copay of the drug price (Centers for Medicare and Medicaid Services, 2017). Although the FDA does attempt to stimulate competition through efforts to facilitate generic drug and biosimilars development, these manufacturers face obstacles beyond the wait times for drug patent protections to expire, such as difficulty obtaining sufficient supplies of the patented comparator drugs for clinical trials leading to FDA approval (Gottlieb, 2017).

How Nurses Can Support Patients
Nurses can work to establish a culture in which financial health is considered an aspect of patient well-being and encourage communication about cost and value between the patient and physician during treatment decision discussions; this is not about cost cutting, but rather about including cost estimates as one of the many decision points to consider when planning a new therapy. Patients may be concerned that raising the issue of costs may lead to being offered care options with subpar outcomes (Zafar & Abernethy, 2013a). Healthcare providers can routinely ask patients about their concerns about ability to pay for cancer treatment early in the decision-making process, which opens the addition, under the terms of the Medicare Modernization Act of 2003, Medicare is obligated to pay for drugs approved by the FDA at the rate set by the manufacturer plus 6%, and prohibited from any price negotiations (Centers for Medicare and Medicaid Services, 2016; Cubanski & Neuman, 2017). Older adult patients with cancer covered only by Medicare Part B are responsible for a 20% copay of the drug price (Centers for Medicare and Medicaid Services, 2017). Although the FDA does attempt to stimulate competition through efforts to facilitate generic drug and biosimilars development, these manufacturers face obstacles beyond the wait times for drug patent protections to expire, such as difficulty obtaining sufficient supplies of the patented comparator drugs for clinical trials leading to FDA approval (Gottlieb, 2017).

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that it would offer a 50% discount on the drug (Pollack, 2012).

On a broader level, the American Society of Clinical Oncology has published and updated a conceptual framework to assist oncologists in better defining and discussing the value of specific cancer treatment options with individual patients (Schnipper et al., 2015, 2016). The Oncology Nursing Society (ONS, 2017) also offers workshops for nurses with the ability to support patients and families through publication of one component of the Oncology Nurse Navigator Toolkit entitled “Helping Patients Navigate Financial Issues.” This free resource can be easily located on the ONS website (http://bit.ly/22N8NMI). Clinicians can use these tools to become better educated on the factors associated with financial toxicity and how to assess and support their patients in practice.

Conclusion

Although many terms and methods may describe and measure how cancer care affects patients financially, direct and indirect costs continue to rise. Clinicians must become increasingly literate about financial toxicity issues and can support patients through open communication, shared decision-making discussions that include value as well as cost, and proactive referrals to patient assistance and other support programs.

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REFERENCES


