Financial Toxicity

Limitations and challenges when caring for older adult patients with cancer

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BACKGROUND: Financial toxicity refers to the unintended financial consequences and distress that patients and families can incur during treatment of cancer. Financial issues can add further stress to an already stressful situation.

OBJECTIVES: This article aims to increase awareness of the financial burden of cancer treatment in older adults with cancer and its effect on health-related quality of life for patients and their families and to increase knowledge of institutional and community resources to help patients manage financial concerns.

METHODS: A literature search was performed to investigate the burden of financial toxicity on older adults with cancer.

FINDINGS: High levels of financial burden have been linked to lower adherence to cancer treatments, shorter survival, poorer prognosis, and greater risk of recurrence. Older adults are particularly vulnerable and more likely to experience financial toxicity. Incorporating discussions about financial burden and exploring options to defray costs are key components of quality and patient-centered care.

KEYWORDS
financial toxicity; cancer treatment; cost; financial burden; older adults

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TREMENDOUS PROGRESS HAS BEEN MADE in the diagnosis and treatment of cancer, but advancements have led to dramatic rises in the cost of cancer care. Cancer is one of the top five most costly health conditions in the United States, with the highest annual mean expenditures per capita ($52.7 billion) following trauma (Soni, 2015). Assuming constant incidence, survival, and cost, it has been projected that there will be 18.1 million cancer survivors in 2020, with associated cancer care costs of greater than $177 billion. The largest number of survivors will be those diagnosed with prostate cancer (42%) and breast cancer (32%), both diseases that occur more often in older adults (Mariotto, Yabroff, Shao, Feuer, & Brown, 2011). Patients with cancer constitute 0.68% of the commercially insured population but account for 10% of healthcare costs incurred (Fitch & Pyenson, 2010). The rising cost of cancer care is being shifted to the patient through insurance premium increases, high deductibles, and high co-pays. Premiums and out-of-pocket healthcare costs for a family are projected to equal about half of the median household income in the United States (Kantarjian, Steensma, Rius Sanjuan, Elshaug, & Light, 2014). Patients with lower incomes, such as those on Medicare and Medicaid, spend a disproportionately higher percentage of income on out-of-pocket healthcare costs (Brooks, Wilson, & Amir, 2011; Davidoff et al., 2013). Even for patients with comprehensive health plans, the expense of cancer care can be substantial.

Medications make up a significant portion of costs for patients with cancer. Some newly approved cancer drugs cost an average of $10,000 per month, with some therapies (e.g., immunotherapy agents) costing as much as $30,000 per month. About a decade ago, the average cost per month of new drugs was about $4,500. Patients typically pay 20%–30% out of pocket for drugs, so the costs for a year's worth of new drugs could be $24,000–$36,000 (Bestvina, Zullig, & Yousuf Zafar, 2014). These increases also reflect a trend toward the use of expensive oral medications. The pipeline of oncology drugs in clinical development has expanded by 45% during the past decade; 87% are biologic monoclonal antibodies and targeted therapies, including oral small molecule kinase inhibitors (QuintilesIMS Institute, 2017).

Oral cancer medications are frequently covered under patient pharmacy benefits' specialty tier, usually requiring high coinsurance charges that patients must pay out of pocket. High cost-sharing coverage plans, including tiered outpatient prescription formularies (co-pays that differ for generic versus branded medications), may create specific hardship for patients prescribed oral medications (National Cancer Institute, 2018). These multitiered plans, in which expensive oral specialty drugs are associated with high

cost sharing, increased from 3% in 2004 to about 25% in 2013 (Meisenberg et al., 2015). A study by Zafar et al. (2013) stated that 42% of patients reported a significant or catastrophic financial burden because of out-of-pocket costs, with an average monthly out-of-pocket cost of $1,266. Forty-six percent of these patients reported that they had used all or part of their savings, and 35% of these patients reported borrowing money or using credit to afford their medications. Twenty percent reported taking less than their prescribed doses, 19% partially filled their prescriptions, and 24% did not fill their medications at all. Patients' inability to pay the high costs of cancer medications could result in increasing numbers of patients stopping or delaying necessary drug therapy.

Cost and Its Effect on Older Adults

Older adult patients are more likely to be at risk for adherence issues when taking oral cancer drugs (Kaisaeng, Harpe, & Carroll, 2014). Medicare Part D was intended to make prescription drugs affordable for older adult beneficiaries; however, a cross-sectional study by Kaisaeng et al. (2014) found that, despite the coverage provided by Medicare Part D, beneficiaries on oral medications experienced high out-of-pocket costs, and about 35%–70% of patients delayed or discontinued their therapies because of cost.

Along with paying for expensive anticancer medications, additional costs are incurred with over-the-counter and prescribed medications to treat side effects of therapy. Many patients also need to continue their medications to treat non–cancer-related comorbidities, such as hypertension, heart disease, and chronic lung conditions. Most comorbidities become more common with age; the likelihood of having two or more significant conditions is 60% by ages 75–79 years, and more than 75% by ages 85–89 years (Day, 2017). With comorbidities, patients are prescribed more medications; about 30% of adults aged 65 years or older in developed countries take five or more medications (Kim & Parish, 2017). Medications can be considered a direct cost of cancer care; other direct costs include doctors' fees, inpatient hospital charges, emergency department or urgent care visit charges, radiology charges, ambulatory clinic charges, and specialty care costs (e.g., counseling for mental health and fertility) (Bestvina et al., 2014).

Altice, Banegas, Tucker-Seely, and Yabroff (2016) conducted a systematic review of 45 studies published from 1990–2015 and summarized the financial hardship experienced by cancer survivors. Most of the studies reported financial hardship as a material condition relating to out-of-pocket costs, productivity loss, bankruptcy or debt; others described hardship related to behavioral conditions, such as skipping medications, delaying/missing a scheduled visit, and experiencing psychological worry or distress. Productivity loss includes limitations in activities and unpaid time off from work; the average patient with cancer misses 22.3 more work days per year than a person without cancer, often because of treatment or cancer-related side effects (Finkelstein, Tangka, Trogdon, Sabatino, & Richardson, 2009). In a study by Ekwueme et al. (2014), about one-third of cancer survivors experienced limitations in their ability to perform usual daily activities outside of work, and 12% had impeded ability to perform mental tasks associated with usual daily activities.

"High levels of financial burden have been linked to lower adherence to cancer treatment."

Survivors of cancer have been found to be more likely to have chronic conditions compared with adults without a cancer history, and the presence of chronic conditions is associated with substantially higher annual medical expenditures (Guy et al., 2017). The presence of four or more chronic conditions is associated with increased annual expenditures of $10,280 per survivor of cancer (Guy et al., 2017). Other indirect costs of cancer care include coinsurance payments, deductibles, travel costs (e.g., transportation to appointments, hotels, flights, parking), lost income, medical equipment/aids not covered by insurance, homecare providers, specialty diets, food/nutritional supplements, specialty clothing, wigs, protective wear, and childcare needs (Bestvina et al., 2014; Nardi et al., 2016).

Effects of Financial Burden

High costs have financial and clinical implications for patient care with short- and long-term effects. Studies describe adverse effects of financial burden on patients with cancer, including medical debts, delinquency on personal bills, or bankruptcy (Altice et al., 2016; Gordon, Merollini, Lowe, & Chan, 2017; Park & Look, 2018; Ramsey et al., 2013). Patients with cancer are 2.65 times more likely to go bankrupt than people without cancer (Ramsey et al., 2013). Although the overall percentage of cancer survivors reporting bankruptcy is small, it corresponds to about 1.5 million survivors nationally; these survivors reported worse physical and mental health-related quality of life (HRQOL) (Kale & Carroll, 2016). Financial burden has been linked to unintended negative health consequences for patients (Park & Look, 2018). Using data from the Medical Expenditure Panel Survey (a set of large-scale surveys conducted by the Agency for Healthcare Research), Park and Look (2018) examined the association between high financial burden and HRQOL. Of 6,799 patients with cancer, 15% and 6% experienced high financial burden exceeding 10% and 20% of

family income, respectively. Patients with cancer with high financial burden were more likely to have lower HRQOL and higher levels of nonspecific psychological distress compared to those without high financial burden. High financial burden has also been found to be associated with higher odds of depressed mood, psychological distress, and worry about cancer recurrence (Kale & Carroll, 2016).

For patients and their families, financial burden and associated distress can be devastating, even for those with insurance coverage. In a study by Meeker et al. (2016) on the relationships among financial, emotional, and overall distress in insured patients with cancer, 29% were found to have significant levels of financial distress, and 65% reported overall distress; the authors concluded that these constructs were interrelated. Others have found a prevalence of worry and stress about paying medical bills for cancer ranging from 23%–64% (Ell et al., 2008; Yabroff et al., 2016). Patients often find themselves prioritizing paying for cancer treatment rather than buying food, clothing, or household necessities (National Cancer Institute, 2018). Patients may also make treatment decisions based on affordability. High levels of financial burden have been linked to lower adherence to cancer treatment, such as foregoing or delaying medical care or avoiding filling prescriptions, which results in less effective treatment, shorter survival, poorer prognosis, and greater risk of recurrence (Altice et al., 2016; Guy et al., 2017; Kent et al., 2013; Park & Look, 2018; Zafar et al., 2013). Increasing financial distress can also change the content of patient–provider discussions and affect clinical decision making (Bestvina et al., 2014). Although many patients report a desire to discuss costs with their clinicians, few patients report having had such discussions. Barriers include lack of provider knowledge of out-of-pocket costs, difficulty accessing individual insurance status and costs during clinical encounters, insufficient encounter time, and concern about how cost discussions may affect the quality of care (Bestvina et al., 2014). Patients who are educated about the cost of cancer care can make informed decisions that will enhance their overall outcomes (de Souza & Conti, 2017).

FIGURE 1.
CASE STUDY

J.F. was a healthy, active 70-year-old man living on a fixed income with his wife in rural Ohio. He developed a lesion on the side of his right ear and saw a local general surgeon who excised the lesion in his office. Subsequently, J.F. developed another lesion on his nose that intermittently bled and was not healing. He returned to the same surgeon, who prescribed a cream and stated that a biopsy was not required and the lesion would heal with time. The lesion persisted for more than 6 months, after which time J.F.'s partner encouraged him to seek a second opinion. J.F. declined because the specialist was more than 80 miles away, and it was burdensome for J.F.'s daughter to take a day off from work to drive him. He worried about the price of gas and expense of the visit and travel. Eventually, J.F. saw his primary care physician, who suspected invasive skin cancer. He referred J.F. to an oncologist at the cancer center 80 miles away. The diagnosis was confirmed to be invasive skin cancer. It had grown deep into the tissue, and J.F. required extensive reconstructive surgery around his nose.

IMPLICATIONS FOR PRACTICE

- Assess older adults for financial distress and toxicity.
- Understand that high cost is a major factor associated with nonadherence to medications.
- Seek resources to help older adults find ways to afford cancer treatment.

Risk Factors for Financial Distress and Toxicity

Many factors affect treatment and its related costs, including cancer type, stage, and planned treatment. Generally, early-stage cancers have a finite number or cycles of treatments and related costs, whereas later-stage cancers may require long-term, ongoing treatments with mounting costs. Data suggest that cancer care in the last six months of life accounts for a large portion of the patient's medical bill, particularly with hospitalization (Nardi et al., 2016). Race, age, socioeconomic status, and employment history can also affect financial toxicity (Callahan & BrintzenhofeSzoc, 2015). Meeker et al. (2016) estimated that 28% of Medicare enrollees have out-of-pocket costs exceeding 20% of their income. Although insured through Medicare with 80% of medical costs generally covered, older adults are less likely to have a secondary insurance. They are more likely to live on a fixed income, have higher co-pay costs, have more comorbidities, have less social support, have higher risk for frailty, and experience barriers to transportation and caregiver support. They are also less likely to ask for assistance because of fear of being displaced from their homes. Older adults are also more likely to ration medications, food, and utilities (Bennett & Flaherty-Robb, 2003).

Minority patients are less likely to have adequate healthcare insurance, seek screenings for cancer or cancer care, and follow up with diagnostics; they are more likely to experience communication barriers and have generational challenges (Callahan & BrintzenhofeSzoc, 2015). Patients from lower-income households have a higher risk for financial distress. Those who work for lower wages tend to have less job stability, benefits for time off with pay, insurance, and ability to acquire savings (Carrera, Kantarjian, & Blinder, 2018).

Caregiving remains a challenge in older adults, particularly during cancer treatment, and can prevent them from receiving care. Older adults frequently rely on informal caregivers, such as family members, friends, civic clubs, senior centers, and faith communities—none of which are a covered benefit through healthcare insurance. The Older Americans Act of 1965 established federal funds directed at supporting older adults aged 60 years or older who need help with personal care, meals, taking care of the home, and caregiving based on financial need. In

FIGURE 2.
FINANCIAL RESOURCES FOR OLDER ADULT PATIENTS WITH CANCER AND THEIR FAMILIES

CANCER FINANCES
A free online toolkit to help navigate finances after a cancer diagnosis
- https://cancerfinances.org

CANCER FINANCIAL ASSISTANCE COALITION
A group of national organizations that provide financial help to patients and a searchable database of financial resources
- www.cancerfac.org

CANCER.NET
Information from American Society of Clinical Oncology about understanding costs related to cancer care
- https://bit.ly/2PmVE7T

CANCERCARE
Provides information, resources, and support to help patients better cope with cancer and offers detailed information on resources for older adults
- www.cancercare.org

ELDERCARE LOCATOR
A resource by the U.S. Administration on Aging that connects older adults and their families to local supportive services
- 1-800-677-1116
- https://eldercare.acl.gov/Public/Index.aspx

FAMILY CAREGIVER ALLIANCE
Offers a wealth of information on caregiver support and a state-by-state listing of services available
- www.caregiver.org

NATIONAL INSTITUTE ON AGING
Offers A–Z information on aging-related concerns that can be downloaded for free
- www.nia.nih.gov/health

NATIONAL RESOURCE CENTER ON LGBT AGING
Offers resource information and support for older adults who identify as LGBT
- www.lgbtagingcenter.org

ONCOLOGY NURSING SOCIETY
Provides a toolkit related to helping patients navigate financial issues
- www.ons.org/sites/default/files/ONS_ONN_Toolkit_Financial_Issues_050417.pdf

SAGE
Information and resources regarding advocacy and services older adults who identify as LGBT
- www.sageusa.org

TRANSLINE
Offers consultative services to medical professionals regarding guidance for caring for transgender patients and will provide case consultation across a broad range of clinical transgender issues
- http://project-health.org/transline

addition, older adults may have a caregiver benefit available through a private insurance policy. Nurses should identify possible caregiver support during assessment.

Patients should have local access to an interprofessional team of experienced oncology experts offering evidence-based cancer care. When faced with a life-threatening illness, patients may seek out clinicians who can offer them life-preserving and life-prolonging treatment. Patients living in rural or remote areas frequently need to travel great distances to find this type of specialty care, taking time away from work and support systems and causing additional out-of-pocket transportation costs that add to their financial distress. Patients may delay seeking treatment because of distance to be traveled and associated expenses. An example of this can be found in a case study of a patient from rural Ohio (see Figure 1). Patients may also travel long distances to seek care at academic and comprehensive cancer and medical centers. These facilities offer specialized surgical and medical oncologists, radiologists, interprofessional treatment teams, specialized equipment, access to clinical trials, programs for travel cost/transportation, care coordinators, and survivorship/wellness programs. Academic cancer centers have shown superior survival outcomes compared with community settings (Nardi et al., 2016).

Implications for Practice

The Institute of Medicine (2013) has highlighted the importance of providing information about cancer costs and quantifying the economic issues encountered by cancer survivors and their families (Ekwueme et al., 2014). They have also acknowledged the rising cost of cancer care as a major societal concern affecting the health and well-being of patients with cancer and directly contributing to financial distress. The American Society of Clinical Oncology ([ASCO], 2015) stated that communication with patients about the cost of care is a crucial component of quality care.

ASCO created the Value in Cancer Care Task Force in 2007 to address educational needs and develop tools and resources to better prepare oncology clinicians when discussing the cost of care with patients. The Comprehensive Score for Financial Toxicity (COST) tool is a reliable and valid screening tool to help identify patients at risk for financial distress, and the tool's correlation with HRQOL indicates that financial toxicity is a clinically relevant patient-centered outcome (de Souza & Conti, 2017; Meropol, 2013).

Professional education to allow clinicians to comfortably address the cost of care and related patient concerns is needed. Use of members of interprofessional teams is suggested. Nurses are pivotal in the care of patients with cancer; they provide relationship-based care, building an essential trusting relationship with patients. Nurses help identify issues that cause patients distress and direct them to the most appropriate resources available to help manage these concerns. As an integral part of the team, nurses are relied upon to recognize patients who are

experiencing financial distress. Their expertise is invaluable when it comes to sorting out the complex care needs of patients with cancer. Oncology nurse navigators specialize in the treatment and care needs of patients with cancer. They can work within ambulatory clinics, hospitals, and medical centers to help guide the patient's plan of care, identify patients with barriers to care, navigate complex insurance systems, coordinate care among providers, and assist in finding resources to help support the patient's clinical care needs. Nurses can also assess patient and family psychosocial care and emotional needs, referring them to internal and external resources for financial support and supportive counseling. Figure 2 highlights resources for clinicians to provide additional support for patients.

Conclusion

Oncology nurses should lobby to ensure that all older adult patients with cancer have access to affordable insurance, promoting policies that reduce costs and improve access to low- or no-cost prevention and early detection programs. Clinicians should also have conversations with all patients regarding the benefit of taking a proactive approach to their healthcare needs by using prevention programs. Ongoing assessment of financial well-being is important because costs and coverage plans may change over time.

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