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Editorial

Treating the Whole Patient With Cancer: The Critical Importance of Understanding and Addressing the Trajectory of Medical Financial Hardship

K. Robin Yabroff, PhD [1,*] Ya-Chen Tina Shih, PhD,[2] Cathy J. Bradley, PhD[3]

[1]Surveillance and Health Equity Science, American Cancer Society, Atlanta, GA, USA; [2]Section of Cancer Economics and Policy, Department of Health Services Research, University of Texas MD Anderson Cancer Center, Houston, TX, USA, and [3]Colorado School of Public Health Administration, Department of Health Systems, Management & Policy, University of Colorado Comprehensive Cancer Center, Aurora, CO, USA

***Correspondence to:** K. Robin Yabroff, PhD, American Cancer Society, 3380 Chastain Meadows Pkwy NW Suite 200, Kennesaw, GA 30144, USA (e-mail: robin.yabroff@cancer.org).

The costs of cancer treatment have grown dramatically over the past decades (1-4). Among patients with health insurance coverage, cost-sharing, including deductibles, copayments, and coinsurance, has also increased, which resulted in increases in out-of-pocket burden that outpaced general inflation (1,4). As a result, patients and their families may need to make trade-offs between paying for their cancer care and basic household needs, such as food, housing, and utilities. Patients may also delay or forgo recommended cancer care as well as other needed medical services because they can no longer afford it. Thus, screening for and addressing financial hardship prior to and throughout cancer treatment is important for patients, providers, cancer centers, payers, and state and federal health policy makers.

To date, most research evaluating financial hardship has been cross-sectional and conducted in heterogeneous population-based samples of cancer survivors with different diagnoses, survival times, and treatments or among samples of patients receiving treatment within single institutions or geographic regions (5). Studies of long-term cancer survivors are limited for informing interventions to address financial hardship within cancer care settings.

In this issue of the Journal, the study by Shankaran and colleagues (6) makes a valuable contribution to our understanding of medical financial hardship among patients undergoing cancer treatment. The study enrolled a clinically homogeneous sample of patients with metastatic colorectal cancer initiating systemic treatment at National Cancer Institute Community Oncology Research Program (NCORP) sites across the United States. Major financial hardship was defined as debt accumulation, selling or refinancing a home, borrowing money from family and/or friends, or 20% or more income decline during the 12 months following study enrollment. Approximately 25% of patients reported major financial hardship at 3 months, and by 12 months, nearly three-quarters (71.3%) of patients reported hardship, highlighting the cumulative nature of this trajectory. New debt (57.6%), 20% or more income decline (26.6%), and new loans from family and/or friends (26.0%) were the largest contributors to the summary measure at 12 months. Patients with annual household incomes of less than $100 000 and with total assets less than $100 000 were more likely to experience hardship, compared with their counterparts with higher income and assets.

The study also adds to growing literature documenting adverse effects of financial hardship on health, including worse health-related quality of life (7,8). Patients who reported hardship at 3 months were more likely to report lower social functioning and lower overall quality-of-life scores at 6 months, controlling for these measures at 3 months. To date, few studies have assessed the association of financial hardship with longer-term health outcomes, such as recurrence and survival.

Study findings underscore the likelihood of financial hardship, even among socioeconomically advantaged patients. At least 60% of patients with annual incomes of $100 000 or more or assets $100 000 or more reported major financial hardship within 12 months. Median annual income was $57 687 in 2016, the year enrollment began for this study. Risk of hardship is surely greater for cancer patients with annual incomes below the median. Furthermore, comprehensive health insurance coverage is one of the strongest protections against financial hardship. Yet, nearly all patients in this study had health insurance coverage and still the vast majority reported major financial hardship, which suggests having health insurance may no longer be sufficient to protect patients and families from financial hardship and its adverse health sequelae.

How can findings from this study be used to improve cancer care delivery and patient outcomes? Screening for medical financial hardship is critically important. However, many

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Table 1. Summary of recommendations for addressing medical financial hardship

Audience	Recommendation
Cancer care providers	Conduct routine screening with validated instruments at all visits Document referrals for financial hardship and social needs and whether and how they are addressed
Cancer centers	Require comprehensive screening throughout cancer treatment and connecting patients to services Enhance partnerships with community safety net organizations Advocate for health policies that benefit patients and their families Record reasons eligible patients decline clinical trial participation and drop out prematurely Collect information about financial hardship in clinical trials and consider inclusion in adverse event reporting
Health policy	Increase options for comprehensive health insurance coverage Implement caps on patient out-of-pocket expenses Include financial hardship screening and connection with services as quality measures Require assessment of patient financial hardship and social needs as part of evaluation of value-based payment models
Research and surveillance	Develop validated financial hardship instruments for use at the point of care and integration in electronic health records Collect financial information prior to diagnosis, potentially through data linkages Evaluate interrelationship of financial hardship and social needs Assess associations of medical financial hardship and quality of cancer care, including diagnostic and treatment delays and completion of all recommended treatment and survivorship care Evaluate short- and long-term health effects of medical financial hardship, including health-related quality of life, cancer recurrence, and survival following diagnosis Evaluate the economic, social, and health effects of patient medical financial hardship on family and informal caregivers Conduct rigorous evaluation of value-based payment models to inform care delivery and health policy

providers and practices, including many NCORP practices, use uninsurance at a single visit to screen patients (9). This approach would have missed the majority of the metastatic colorectal cancer patients who reported hardship in this study. Additionally, because financial hardship is dynamic and often cumulative, screening should occur routinely. A one-time screening at 3 months would have only identified 24.9% of patients who had hardship but missed the additional 46.4% of patients who reported hardship at 12 months in this study. Assessing “changes from baseline” can offer additional insights on how hardship changes after the initiation of treatment. Cancer care provider organizations have emphasized the importance of discussing the cost of care with patients (10); we recommend routine and comprehensive screening for financial hardship and social needs (11) using validated instruments and documentation of referrals in electronic health records (Table 1).

These practices can be reinforced by cancer centers and community-based NCORP sites, which can require that all providers conduct comprehensive financial hardship screening from diagnosis throughout treatment and connect patients to services when hardship is detected, to help address patient needs. These efforts need to be consistently documented to allow for evaluation of their effectiveness and sustainability. Cancer centers can support community organizations that serve patients diagnosed with cancer and advocate for local and national policy initiatives to improve patient access to health insurance coverage and reduce financial exposure, such as caps on out-of-pocket costs. These actions reduce financial barriers for patients and stabilize local safety net organizations. Finally, given the critical role of cancer centers in conducting clinical trials and efforts to ensure equitable trial participation (12,13), more information about reasons for declining study enrollment or premature dropout should be recorded. Additionally, with emerging evidence of financial hardship among trial enrollees (14), financial hardship could be considered an adverse event in the reporting and evaluation of novel cancer therapies.

Policy solutions are needed to improve cancer care affordability, including efforts to limit patient financial burden through more comprehensive health insurance coverage options, caps on out-of-pocket expenses, and slowing the growth in cancer treatment costs. Payers, especially state and federal payers, can require documentation of routine screening of financial hardship and service referrals as quality measures (15). The Center for Medicare & Medicaid Innovation has the authority to develop, implement, and test payment models with the goal of providing better care, better health, and lower cost. We recommend adding measures of patient out-of-pocket costs and financial hardship to the list of outcomes that determine the effectiveness of payment models, including the Oncology Care Model and Medicaid demonstration projects. We also recommend that private payers assess patient financial hardship and evaluate its effects when they develop, test, and evaluate models of care.

Study findings also have important implications for research and surveillance. The patients included in this study were relatively advantaged socioeconomically, highlighting the need for more research in population-based samples that also represent socioeconomically disadvantaged patients, as they are more likely to report medical financial hardship (16,17) and other social needs (18). Financial hardship and social needs have independent adverse effects on access to care (19), yet little is known about how households make trade-offs between health care and other vital needs. Also, little is known about patients’ financial situations prior to cancer diagnosis or their longer-term health outcomes, including lasting financial effects for informal caregivers and/or family. This information is critically important for identifying patients who are financially vulnerable prior to cancer treatment who may need early and ongoing assistance. Prospective longitudinal data collection with patient reports and data linkages, such as those with credit report agencies and health insurance claims data, will be especially useful. Development of validated instruments, sensitive to changes in financial standing, that can be used at the point of care and integrated in electronic health records is also needed.

Medical financial hardship following cancer diagnosis and subsequent treatment is often considered a condition only affecting households without health insurance coverage or with very low income. This study demonstrates that financial hardship is widespread and may be experienced by many Americans newly diagnosed with cancer—approximately 1.9 million people in 2021 alone (20). Financial hardship will persist and perhaps worsen until it is addressed by providers, cancer centers, payers, and policy makers. Future interventions and policy initiatives require rigorous research to assess their effectiveness and sustainability to ensure that the remarkable advancements in cancer care are widely accessible without inflicting financial ruin for patients and their families.

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