

MONOGRAPH

Cancer-Related Care Costs and Employment Disruption: Recommendations to Reduce Patient Economic Burden as Part of Cancer Care Delivery

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Abstract

Cancer survivors are frequently unprepared to manage the out-of-pocket (OOP) costs associated with undergoing cancer treatment and the potential for employment disruption. This commentary outlines a set of research recommendations stemming from the National Cancer Institute's Future of Health Economics Research Conference to better understand and reduce patient economic burden as part of cancer care delivery. Currently, there are a lack of detailed metrics and measures of survivors' OOP costs and employment disruption, and data on these costs are rarely available at the point of care to guide patient-centered treatment and survivorship care planning. Future research should improve the collection of data about survivors' OOP costs for medical care, other cancer-related expenses, and experiences of employment disruption. Methods such as microcosting and the prospective collection of patient-reported outcomes in cancer care are needed to understand the true sum of cancer-related costs taken on by survivors and caregivers. Better metrics and measures of survivors' costs must be coupled with interventions to incorporate that information into cancer care delivery and inform meaningful communication about OOP costs and employment disruption that is tailored to different clinical situations. Informing survivors about the anticipated costs of their cancer care supports informed decision making and proactive planning to mitigate financial hardship. Additionally, system-level infrastructure should be developed and tested to facilitate screening to identify survivors at risk for financial hardship, improve communication about OOP costs and employment disruption between survivors and their health-care providers, and support the delivery of appropriate financial navigation services.

To reduce patient economic burden as part of cancer care delivery, it is critical to consider the costs of cancer care through a wide-angle lens that collectively accounts for out-of-pocket (OOP) costs for medical care, other myriad OOP expenses that individuals with cancer and their families are responsible for, and costs of employment disruption precipitated by cancer and its treatment. Ideally, cancer survivors (comprising those who are newly diagnosed, undergoing treatment, and long-term cancer survivors) should be proactively informed about their risk

and responsibility for different cancer-related costs. Additionally, they should be given the opportunity to consider these costs as part of treatment decision making. In reality, data on the different costs of cancer are rarely provided to patients, which precludes meaningful conversations that could influence treatment decision making and scheduling and trigger referrals to financial navigation and other relevant assistance (1-3). As a result, the complexity and exorbitance of OOP costs for medical care and other cancer-related expenses are

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often surprising and overwhelming for cancer survivors and their caregivers, putting them at risk for financial hardship (4-7). Employment disruption that leads to job loss, reduced income, or ineligibility for employer-sponsored health insurance further exacerbates this risk (8). It is estimated that more than 50% of working-age cancer survivors report at least some cancer-related financial hardship (9), with low- and underresourced individuals and those who work in low-wage jobs with inflexible schedules at highest risk of cancer-related financial hardship (9-12).

In this commentary, we summarize literature about survivors' OOP costs for medical care, other OOP costs frequently incurred during care, and risks for cancer-related employment disruption. This information is complemented by recommendations for future research to address cancer costs and improve patient outcomes. These concepts were originally discussed in the Employment Outcomes, Financial Hardship and Caregiver Economic Burden session of the National Cancer Institute's Future of Health Economics Research conference and further refined through a review of the literature and discussions with subject matter experts.

Out-of-Pocket Costs for Medical Care

Oncology drug prices have risen rapidly over time, and trends in the design of health insurance coverage increasingly shift costs to survivors, in what has been euphemistically named *cost sharing* (13-16). Survivors' OOP costs for medical care typically come from insurance premiums, co-payments, co-insurance, and deductibles, which were estimated at \$5.6 billion in 2018 (17). Monthly OOP cost estimates among cancer survivors ranged from \$180 to \$2598 per patient, with average monthly OOP costs of \$288 for medications alone (18). Because survivors are increasingly prescribed multiple drugs as part of combination therapy and receive active treatment for longer periods of time, these OOP costs tend to accumulate over time (13,19). As a result, even long-term cancer survivors tend to have higher OOP costs than individuals without a cancer history (20,21). High OOP costs for cancer care can prompt survivors to decrease spending in other areas and delay or forego care or take less medication than prescribed, to save money, potentially leading to adverse clinical outcomes (9,22). Financial hardship related to OOP costs is frequently a source of psychological distress and is associated with diminished quality of life, poor patient outcomes, and premature mortality, in extreme cases (4,23). As the scope of survivors' OOP costs for cancer care and the consequences of financial hardship are better understood, it will be critical to ensure that data about costs are collected and distilled in a way that will be useful and actionable for patients and providers. This work should be complimented by an investigation into modifiable factors that increase or decrease costs of cancer treatment.

Out-of-Pocket Cancer Management Costs

In addition to the cost of medical care, survivors frequently incur considerable OOP expenses related to transportation to and from care (eg, gas, parking, meals, and lodging) as well as the financial burden of additional household maintenance (eg, child or elder care), products to manage the side effects of treatment (eg, wigs and special clothing), and other cancer-related expenses (24-26). Transportation, in particular, is a common and recurring cost concern, especially for survivors living far from where they receive cancer care (26). Patient travel

expenses for each cycle of outpatient treatment have been estimated as \$40-\$100 (25). Parking fees at National Cancer Institute-designated cancer centers can be more than \$1600 for a single course of treatment (27). Although modest on the surface, for low-income survivors, these costs represent a significant expense (28). High OOP costs for cancer management are an important, yet understudied, contributor to a survivor's total OOP costs and can lead to poor psychosocial and clinical outcomes (4,23,29). Additional research is needed to build on the small extant literature to better characterize the scope of OOP costs for different survivor populations, defined by sociodemographic characteristics, treatment regimen, and time since diagnosis.

Costs of Employment Disruptions

Among cancer survivors who worked for pay at or since diagnosis, more than 41% report making employment changes such as taking extended time off, making schedule changes, or switching to a less demanding job (30). Across studies, rates of return to work after cancer vary widely, reflecting the differential impact of cancer type, stage, and treatment as well as job demands and access to workplace accommodations (10,31-35). Further, the time involved in undergoing cancer treatment and constraints on when clinic visits may be scheduled can also interfere with a person's ability to work the same number of hours as he or she did prior to the cancer diagnosis or to sustain employment during cancer treatment (20,36,37). For individual survivors, employment disruptions can lead to lost or decreased earnings, health insurance coverage interruptions, job loss, and lost productivity due to absenteeism and presenteeism, potentially exacerbating the economic impact of cancer on survivors and their families (38,39). Those survivors most at risk for financial hardship are also less likely to have access to paid sick leave, flexible work schedules, and other accommodations, leading to higher rates of job loss (11,38). To begin to address costs of cancer-related employment disruptions, it is critical to better understand the trajectory of employment outcomes associated with different treatment regimens, identify modifiable factors for different types of employment disruption, and better address the needs of survivors, especially those who lack paid sick leave and opportunities for workplace accommodations.

Recommendations for Addressing Cancer-Related Costs and Employment Disruption as Part of Cancer Care Delivery

Research is needed to improve the collection of data about survivors' OOP costs for medical care, other cancer management expenses, and risks for employment disruption and to incorporate these data into practice to reduce survivors' economic burden and improve outcomes. This research should inform interventions and approaches for addressing different cost concerns as part of cancer care delivery.

The Scope and Rigor of Cost Data Collection Should Be Improved to Inform Conversations Between Health-Care Providers and Survivors About Cancer-Related Costs and Employment Disruption

A key area where information is lacking is the true sum of cancer-related costs taken on by survivors and caregivers. A

comprehensive and nuanced understanding of survivors' OOP costs for medical care, other cancer-management expenses, and employment disruption depends on reliable and valid metrics and measures collected via research and routine clinical practice throughout cancer treatment and survivorship care. Microcosting is one approach that could be used in research studies designed to address this gap. Microcosting is typically used to measure overall costs of different health-related interventions, particularly at the health-system and societal levels; however, this approach could also be used to provide insight into the "true cost" of an intervention from the patient's perspective (40). For example, a recent study compared hospital to home administration of subcutaneous trastuzumab. The microcosting approach allowed the authors to evaluate health-care costs (eg, drugs, health-care facilities, time of health-care professionals), costs for the patient and family (eg, transportation, caregiving), and costs related to lost productivity (41). Applied to the evaluation of financial hardship in the United States, where sick leave is often unpaid, this approach could provide critical insights into the drivers of financial hardship for cancer survivors depending on their employment and/or insurance circumstances.

The prospective collection of relevant cost data in real-world oncology settings could support a microcosting analysis of the full extent of financial hardship associated with cancer and its treatment and provide much-needed information to inform cost-related conversations between survivors and their doctors. For practices participating in the Centers for Medicare & Medicaid Services Oncology Care Model, estimations of potential OOP costs are required as part of the care plan for beneficiaries initiating systemic therapy (42). However, this estimate is not a true microcosting approach, because it only includes billable costs and could underestimate the true OOP expenses related to cancer management and employment disruptions. Thus, prospective studies focused on quality of life and other patient-reported outcomes (PROs) should gather detailed information about OOP costs for medical care, other cancer-management expenses, and employment disruption, including time away from work and presenteeism. PRO measures of financial hardship, such as the COmprehensive Score for financial Toxicity (43), are particularly helpful for understanding the subjective burden experienced by survivors, but objective indicators of financial hardship, including an accurate assessment of OOP costs, are also needed. Additionally, the relationship between cancer, employment disruption, and financial hardship is not fully understood. Measures of employment status, absenteeism, and presenteeism should be embedded in studies of cancer survivors to understand the trajectory and risk factors for employment disruption in different patient populations (44). Obtaining the data with which to build a complete model of these interrelated outcomes could inform the development of interventions designed to abrogate cancer-related financial hardship by addressing employment disruption.

Prospective clinical trials comparing different cancer treatments could also help address this information gap by gathering data about costs and employment disruption as part of the PRO component (with allowances to account for differences between the clinical trial and real-world setting). Importantly, clinical trialists should gather detailed information about barriers to clinical trial participation that include costs, such as time spent away from work for frequent visits and other uncovered costs of study participation, as these could aid in addressing potential disparities in clinical trial participation because of financial concerns.

Research studies designed to characterize cancer-related costs and employment disruption or to test the effect of interventions on these outcomes should be done in large and representative populations of patients. Sampling methods and study invitation should ensure adequate representation of patients vulnerable to financial hardship by including questions assessing financial concerns in study screening data. Furthermore, financial barriers to research participation should also be addressed to enable participation (45). Strategies such as reimbursement for study-related participation costs (eg, transportation, lodging, productivity losses) are needed to make certain research results are socioeconomically generalizable (46). Through targeted invitation strategies and addressing financial barriers to participation, study results may be more generalizable. Furthermore, in the case of interventions, these strategies could aid in decreasing socioeconomic health disparities. These strategies are essential to fully understand and address the risk factors, scope, and consequences of high OOP medical costs, other cancer management expenses, and employment disruption.

Interventions Are Needed to Improve the Frequency and Impact of Communication About Cancer-Related Costs and Employment Disruption as Part of Cancer Care Delivery

Research to better understand and generate actionable information about survivors' OOP costs must be coupled with interventions to incorporate those data into cancer care delivery. Cost conversations are an important tool to mitigate the economic burden of cancer. The American Society for Clinical Oncology, President's Cancer Panel, and others have called for providers to help survivors consider cost as part of evaluating the value of treatment options (47,48). One study found that when cost conversations do occur, more than one-third contained a discussion of cost-reducing strategies such as treatment plan changes, co-pay assistance, and timing of expensive treatments after survivors meet their annual deductible (49). Another study found that more than half of patients report lower OOP costs because of cost conversations with their doctor (50). Yet, research suggests that less than one-third of survivors report having conversations with their physician about treatment costs (2). Discussions about cancer-related employment disruptions are also uncommon in the clinic setting. Approximately half of employed individuals with cancer are offered advice by their oncologist about work (51), and two-thirds of cancer survivors who were working at diagnosis discussed employment with any health-care provider (52).

Research is needed to inform meaningful cost communication that is tailored to different clinical situations. When there is clinical equipoise such that 2 different treatment options are viewed as nearly equivalent in terms of efficacy, a clinician or other health-care provider should help survivors understand and consider cost when selecting between the options. In these cases, cost information should be presented in a way that is clear and that allows survivors to consider costs broadly across different treatment options or for a single treatment regimen. Cost communication should address a survivor's anticipated OOP costs for treatment as well as other OOP costs they may encounter with different treatment options (eg, travel, dependent care). It is also important to engage working-age survivors in a conversation about employment and how the treatment schedule and anticipated side effects are going to interfere with the

essential functions of their job (44). Communication about work not only informs decision making but can also prepare survivors to talk with their employer about accommodations or the need to take a leave of absence. Identifying survivors who are at risk for losing their employer-sponsored health insurance can also spur identifying alternative health insurance coverage options to avoid gaps in treatment.

In situations where there is not clinical equipoise, and one treatment regimen is clearly superior, discussing cost can be more fraught. Even in these cases, however, patients may still prioritize treatment affordability (53). When a particular treatment regimen is clearly superior, cost communication can prepare survivors for what their treatment will cost. These discussions may also aid in identifying survivors who may benefit from co-pay assistance and patient assistance programs and to assist with applying for insurance coverage or optimizing existing benefits to lower OOP costs. Likewise, identifying survivors with transportation, child, and eldercare issues and those who are concerned about employment disruption can inform treatment scheduling and help patients strategize to mitigate the impact of treatment on their lives in a more comprehensive way (44). Regardless of the clinical situation, proactive communication about OOP costs and employment disruption will be particularly important for populations at increased risk for financial hardship and may be an important tool to minimize health disparities. Cost communication should follow the American Society for Clinical Oncology consensus guidelines for patient-clinician communication, which were developed to support oncologists in optimizing the patient-clinician relationship, as well as patient, clinician, and family well-being (54).

To improve the frequency and impact of communication about cancer-related costs and employment disruption as part of cancer care delivery, it will also be important to address several additional gaps in the literature. To provide meaningful communication, it is important to better understand patient preferences for when cost concerns and employment disruptions are addressed and how frequently these topics are assessed throughout care. Likewise, research is also needed to better understand patient and provider attitudes and preferences surrounding who is responsible for communicating with patients about cancer-related costs and employment disruptions, as well as ensuring patients receive appropriate financial navigation and other relevant assistance. Finally, there are presently few studies to inform the level of granularity with which OOP cost information is provided. For example, it is unclear whether having more general information about anticipated costs is sufficient for survivors and their families to make informed decisions and to trigger financial navigation and planning or if more detailed OOP cost estimates are needed. This is an important knowledge gap that needs to be addressed to support actionable cost communication.

System-Level Infrastructure Should Support Communication About Cancer-Related Costs and Employment Disruption and Financial Navigation

System-level infrastructure is needed to support conversations about cancer-related costs and employment disruption to address survivor concerns about financial hardship as part of cancer care delivery. Currently the lack of clear pathways to identify and connect survivors experiencing cost or employment concerns with services is an issue at many cancer centers (1,55). Research is needed to inform approaches for

systematically identifying survivors who are at risk for financial hardship because of the cost of their medical care, the burden of cancer management expenses, or financial vulnerability related to employment disruption. Screening for financial hardship also removes the burden on survivors to initiate conversations about the costs of their cancer care. Screening at each clinic visit or at regular intervals could be integrated into care in different ways depending on clinic resources, staffing, and workflows. For example, screening could be accomplished by incorporating questions into the patient portal or clinic intake form, assessing financial concerns as part of the routine questions asked at the point of care, or leveraging information about insurance coverage or socioeconomic status collected for other purposes.

In addition to developing robust screening practices, establishing new clinical workflows could facilitate the integration of conversations about cancer-related costs and employment disruption into clinical care. New workflows could also support proactive financial navigation to identify available assistance and strategies to minimize patient OOP cost responsibility. A recent paper by Henrikson et al. (56) suggests the need for different workflows to address various types of cost-related conversations, including those around treatment decision making, financial planning, and acute need. They found these conversations are best led by different types of health-care team members and require different types of data and resources (56). The establishment of clinical workflows should be complemented by training staff to address survivors' concerns about cost, the need for assistance with the many OOP costs associated with cancer, and negotiating rights for taking leave from work or requesting workplace accommodations. New workflows for addressing employment disruption, in particular, could also trigger referrals to rehabilitation services to decrease cancer-related functional decline that could lead to unnecessary job loss, absenteeism, and presenteeism (57). Ultimately, the optimal staffing model may be specific to its setting; however, it is important that staff roles and responsibilities are clear and that staff have sufficient capacity to address survivors' concerns.

The time and complexity of generating detailed OOP cost estimates for survivors is a barrier to price transparency and by extension cost conversations (1,56). Leveraging existing value frameworks may facilitate cost estimates and inform conversations about the value of different treatment options. Examples of these frameworks include the American Society for Clinical Oncology Value Framework, the National Comprehensive Cancer Network Evidence Blocks, the Institute for Clinical and Economic Review value framework, and Memorial Sloan Kettering Cancer Center's Drug Abacus (3,58-60). Although not without limitations, these frameworks provide various approaches to evaluating the value of different treatments and can facilitate cost communication as part of cancer care (61,62). Clinicians, other members of the health-care team, and other staff who will be involved in talking with survivors about their treatment decisions should be trained in using these tools to facilitate cost communication. Additionally, research is needed to evaluate what additional resources and tools are needed to support price transparency for patients and clear and actionable communication about treatment costs and cost-reducing strategies (61).

Recent policy changes may facilitate price transparency for patients and support cost communication. In January 2021, the Hospital Price Transparency rule went into effect, requiring hospitals to provide pricing information for the items and services they provide (63). Compliance with the policy has been mixed (64). Additionally, the complicated nature of many treatment

plans may pose challenges for calculating overall OOP costs for cancer therapy. Going forward, research will be needed to understand how patients and hospital staff will use this information and whether the availability of this information has a downstream effect on economic outcomes. In addition to maximizing OOP cost transparency, companion efforts are needed to identify tools to support transparency and communication about cancer management expenses and employment disruption associated with different treatment regimens and to identify strategies to address those issues.

Discussion

Cancer patients and their families are frequently unprepared to manage the OOP costs associated with undergoing cancer treatment as well as the potential for employment disruption. In many cases, we lack detailed metrics and measures of patients OOP costs and employment disruption, and data on the costs of care are rarely available at the point of care delivery to guide patient-centered treatment and survivorship care planning. This commentary outlines a set of research recommendations to reduce patient economic burden as part of cancer care delivery. These recommendations highlight the need to characterize and quantify patients' OOP costs and the impact of cancer and its treatment on employment disruption. These data should be incorporated into cancer care delivery and inform meaningful communication between patients and their health-care providers about patient OOP costs and employment disruption. Finally, system-level infrastructure should be developed and tested to facilitate screening to identify survivors at risk for financial hardship and support the delivery of appropriate financial navigation services.

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