Medical Financial Hardship among Cancer Survivors in the United States: What Do We Know? What Do We Need to Know?

K. Robin Yabroff, Jingxuan Zhao, Zhiyuan Zheng, Ashish Rai, and Xuesong Han

Abstract
Rising costs of cancer care have led to increased concerns about medical financial hardship for cancer survivors and their families in the United States. In this commentary, we provide an overview of research describing medical financial hardship and introduce a conceptual framework for identifying risk factors and research gaps at the patient and family, provider, and care team, health care system, employer, and state and national policy levels. We then use this framework to highlight measurement and data infrastructure gaps related to hardship, summarize existing interventions to minimize hardship, and identify opportunities for future intervention efforts.

Introduction
In 2010, there were approximately 13.8 million cancer survivors in the United States (1). The prevalence of cancer survivorship is projected to increase by more than 31% by 2020, reflecting an aging and growing population and earlier detection of cancer and improved treatments, resulting in longer survival following diagnosis. Based only on increased prevalence of cancer survivorship, the costs associated with cancer are projected to increase 27% between 2010 and 2020, from $124.6 billion to $157.8 billion (1). However, in recent years, the costs of cancer treatment have increased dramatically (2–4), and many treatments now have price tags of $100,000 or more annually (5, 6). Treatment intensity has also increased, and cancer patients are now treated with more agents and for longer periods of time (7, 8). Thus, earlier projections likely underestimate the health care costs associated with cancer for payers as well as for patients and their families.

Historically, cancer survivors have higher out-of-pocket (OOP) health care spending than similar individuals without a cancer history, even many years after diagnosis or the completion of treatment (9–11). They have also been more likely than individuals without a cancer history to report inability to work, more days lost from work, and more days spent in bed (9, 11). Cancer survivors may experience lost income from these productivity limitations and reduced access to employer-sponsored health insurance. Other recent trends, including increasing patient cost-sharing, with higher deductibles, copayments, and coinsurance rates (12, 13), and increased use of oral anticancer therapies (2, 3), for which patient OOP costs may be higher than for infused anticancer therapies, can increase patient burdens. Thus, cancer patients and their families are increasingly experiencing medical financial hardship associated with cancer, including problems paying medical bills, financial distress, and delaying or foregoing medical care due to costs (14–17).

In this commentary, we provide an overview of research describing medical financial hardship in cancer survivors and introduce a conceptual framework for identifying risk factors and research gaps. We then use this framework to highlight measurement and data infrastructure gaps related to hardship; summarize existing interventions to minimize hardship; and identify opportunities for future intervention efforts.

Overview of Research Addressing Medical Financial Hardship
In the past several years, published research addressing medical financial hardship has increased substantially (14–16). These studies generally address one or more domains of hardship including material conditions, psychologic response, and coping behaviors (14). Material conditions are typically measured as OOP expenses for medical costs, productivity losses, reduction in income and assets, medical debt, trouble paying medical bills, and bankruptcy (14). The majority of studies of financial hardship in cancer survivors conducted to date evaluate material measures (14–16). As many as half of adult cancer survivors report some form of material financial hardship (14). Psychologic response is typically measured as stress, distress, and worry resulting from paying medical bills or concerns about wages and wage loss associated with cancer. As many as 64% of cancer survivors report some form of psychologic financial hardship (14). Coping behaviors that survivors adopt in the face of increased OOP medical expenditures and distress are generally measured as delaying or foregoing medical care due to cost, and cost-related nonadherence to prescription medications for cancer and other conditions. Up to 45% of cancer survivors report some forms of behavioral financial hardship (14).

In published reviews, estimates of the prevalence of these domains of financial hardship vary widely and likely reflect underlying differences in study populations’ sociodemographic characteristics, including age, gender, race/ethnicity, educational background, insurance type, and region of the United States.

Corresponding Author: K. Robin Yabroff, American Cancer Society, 250 Williams Street, Atlanta, GA 30303. Phone: 202-585-3238; E-mail: Robin.yabroff@cancer.org

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attainment, marital status, income, geographic location, and health insurance coverage; clinical characteristics, including cancer type, stage of disease at diagnosis, comorbidity, treatment(s), time since diagnosis, and/or most recent treatment; methods of identifying cancer survivors; and measures of medical financial hardship evaluated (14–16).

Research Addressing Risk Factors for Medical Financial Hardship

In this section, we describe a conceptual framework for summarizing risk factors associated with medical financial hardship and identifying gaps in the current descriptive research literature that are needed to inform development of interventions to minimize hardship (Fig. 1). The framework has multiple hierarchical levels starting with cancer survivors and their families and caregivers in the center, surrounded by provider and provider care teams, health care systems, and state and national policy levels. We also include an employer level in the framework, because health insurance is mainly employer-based for the working age population, and paid and unpaid sick leave policies vary by employer. The employer level also intersects with all other levels in our conceptual framework because many large employers self-insure or select health insurance plans and provider networks, which are regulated by state and national policies.

Patient and family-level risk factors for medical financial hardship

At the patient and family level, socioeconomic characteristics associated with greater risk of financial hardship include lower household income and/or educational attainment (18–21), minority race/ethnicity (18, 19, 22–25), rural residence (26), and being unmarried or female in some populations (18, 23, 24, 27). Cancer and its treatment can limit employment (9, 11, 28, 29), resulting in lost wages and loss of employment-based health insurance, which can also increase the risk of financial hardship (18, 27). Among cancer survivors, younger age is associated with greater risk of hardship (18, 22, 27, 30, 31), with large differences between those ages 18 to 64 years and those ages 65 years and older who are age-eligible for Medicare coverage. In the younger group, uninsured cancer survivors report greater levels of financial hardship than their counterparts with private or public health insurance (18, 19, 27). Health insurance literacy—understanding of and ability to use information about premiums, deductibles, copayments, coinsurance, and provider networks in decision-making—is associated with selection and enrollment in health insurance plans (32), and so, also may be associated with financial hardship.

Clinical factors associated with hardship include cancer site (23, 33, 34) and type of treatment, with higher levels of hardship among survivors who received chemotherapy or radiotherapy (19, 23). More recent treatment and/or diagnosis is also associated with greater hardship (14–16). Other clinical factors associated with hardship include presence of comorbidity (18, 19) and more advanced stage at diagnosis (19, 33).

Although research addressing risk factors for financial hardship at the patient level is accumulating (14–16), there are a number of research gaps. Better understanding of the relative importance of risk factors for financial hardship, including socioeconomic characteristics, employer accommodations, health insurance coverage and benefit design, health insurance literacy, and clinical factors, is an important research gap at the patient and family level (Table 1). Informal caregivers, including spouses and partners, sibling, parents, and children, also experience productivity losses and financial hardship (35), but little research has addressed risk factors for hardship in caregivers. Caregiver burden is especially relevant for pediatric cancer patients and survivors (36). In addition, cancer patients and their families may face other nonmedical aspects of financial hardship, including food and housing insecurity.

Most published research addressing factors associated with financial hardship at the patient and family level is cross-sectional, and few longitudinal studies have addressed the trajectory of financial hardship and health outcomes following diagnosis for patients and caregivers or whether these trajectories vary for material, psychologic, and behavioral domains of hardship. In one of the few longitudinal studies, cancer survivors who filed for bankruptcy were at increased risk of mortality compared with similar cancer survivors who did not file for bankruptcy (33). However, little is known about the relationship between biological and behavioral risk factors and patient and caregiver outcomes, including health-related quality of life and survival. Finally, longitudinal observational research may lead to better understanding of not only which risk factors are most important and potentially modifiable, but also where in the cancer care continuum they may be most amenable to intervention, and the most feasible and efficient intervention approach.
Table 1. Examples of research questions addressing gaps in understanding of medical financial hardship in cancer survivors

<table>
<thead>
<tr>
<th>Level of framework</th>
<th>Example questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient and family</td>
<td>What are the strongest risk factors for financial hardship in patients and caregivers (e.g., socioeconomic characteristics, employer accommodations, health insurance coverage and benefit design, health insurance literacy, and clinical factors)? Which risk factors for financial hardship are potentially modifiable and thus could be addressed through intervention? What are the relationships between medical financial hardship and nonmedical aspects of financial hardship, such as food and housing insecurity? What are the associations between medical and nonmedical hardship and health outcomes? What is the trajectory of financial hardship following diagnosis for patients and caregivers? Does the trajectory vary for material, psychologic, and behavioral hardship?</td>
</tr>
<tr>
<td>Provider and care team</td>
<td>What are key provider and care team factors associated with higher prevalence of patient financial hardship (e.g., age, year of medical school graduation, training and specialty, geographic region, and practice setting)? Is EHR integration and use of system supports in practice associated with financial hardship? What are key barriers to full discussions of treatment costs, benefits, and effects on ability to maintain employment? Does perception of importance of financial hardship and referral to resources differ by provider specialty, training, patient volume, and other factors? Who is the best member of the provider team to discuss financial hardship? Is having a designated team member address treatment costs in practice associated with reduced prevalence of hardship?</td>
</tr>
<tr>
<td>Health care system</td>
<td>What are key health care system features associated with higher prevalence of patient financial hardship (e.g., breadth and depth of provider networks, benefit design, routine use of EHR functionality in quality improvement, and financial assistance infrastructure)? What aspects of health insurance benefit design are most important? What is the role of transparency of treatment cost and benefit in minimizing financial hardship? Is financial assistance infrastructure associated with reduced prevalence of hardship?</td>
</tr>
<tr>
<td>Employer</td>
<td>How does the prevalence of financial hardship among cancer survivors vary by employer features (e.g., health insurance coverage, paid and unpaid sick leave, workplace accommodations)? What is the role of benefit design for self-insured employers in development of financial hardship?</td>
</tr>
<tr>
<td>State and national policy</td>
<td>How do state-level policies, such as Medicaid eligibility threshold and expansion status, affect financial hardship? How do policies related to generic substitution, cost transparency, and oral parity affect financial hardship? Do policies related to availability of Marketplace coverage, essential health benefits, or elimination pre-existing coverage exclusions affect hardship?</td>
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Provider and care team risk factors for medical financial hardship

Little research evaluating provider factors associated with financial hardship has been conducted, and as a result, many research gaps exist. Other health services research has shown that provider characteristics, such as age (37, 38), year of medical school graduation (39, 40), training and specialty (37, 41), and practice characteristics, such as geographic region (42) and practice setting (41), are associated with treatment recommendations and patient outcomes. Presence of electronic health records (EHR) and systems strategies in a practice, including reminders and decision support, are associated with guideline-consistent care in other settings (43). Research evaluating whether these provider and practice characteristics, EHR and systems strategies, and perceptions are associated with recommendation of high-cost treatment and/or addressing financial hardship is a critical research gap. The Institute of Medicine and the American Society of Clinical Oncology have highlighted the important role of oncologists in discussions about the OOP costs of cancer care (44, 45). Although oncologists generally agree about their responsibility for these discussions (46), they are rare (46) and many oncologists feel uncomfortable engaging in them (46, 47). When asked about their attitudes regarding discussions of costs, more than 50% of patients desired discussions, but only about 33% actually had them (46). Insufficient physician time has been identified as a barrier to recommended care in other settings (48). Lack of cost transparency and provider financial knowledge may be additional barriers to cost discussions. Descriptive research on important and modifiable factors for incomplete discussions, such as identifying the member of the care team best suited for these discussions, if not the oncologist, will inform future intervention research.

Health care system–level risk factors for medical financial hardship

Little research on risk factors for financial hardship has been conducted at the organizational levels of health care systems. Research addressing other aspects of health systems and insurers has shown that benefit design at this level, such as the use of prescription drug formularies, step therapy, and patient cost-sharing, can affect receipt of treatment and treatment adherence (49–54). It is likely that health care system features, such as breadth and depth of provider networks, benefit design, routine use of EHR functionality in quality improvement, and financial assistance infrastructure, are associated with patient financial hardship, and these areas are important research gaps. Because many cancer survivors can be affected by relatively small changes at the health system and insurer level, these are especially important areas for future descriptive research not only to inform effective and cost-effective intervention strategies within systems, but also for broader dissemination and implementation of effective strategies at the state and national policy levels.

Employer-level risk factors for medical financial hardship

Employer-level features, such as whether they offer health insurance coverage to employees and the types of coverage offerings, availability of paid and unpaid sick leave, and workplace accommodations, potentially play a large role in medical financial hardship for employed cancer survivors. These same employer features, including health insurance offerings, sick leave, and accommodations, also affect employed family members and other informal caregivers (55), in their ability to support cancer survivors and provide health insurance coverage and income for the family. Some retirees also receive supplemental health insurance coverage and pension benefits from their former employers. Better understanding of employer features and their role in the development of hardship represent important research gaps. Because many working age and retired cancer survivors and their informal caregivers can be affected by aspects of employer-based insurance coverage (both primary and supplemental Medicare coverage) and sick leave policies, the employer level is an especially important area for future descriptive research. Development and evaluation of policies at the employer level may also inform
dissemination and implementation of effective intervention strategies at the broader state and national policy levels.

State and national policy–level risk factors for medical financial hardship

The state and national levels are especially relevant for research evaluating medical financial hardship because employment policies and health insurance policies related to the Medicaid and Medicare programs are enacted in states or nationally. The federal Family and Medical Leave Act (FMLA) entitles eligible employees working at a location where the employer has at least 50 employees within 75 miles with up to 12 weeks of unpaid leave for their own serious health condition or to provide care for a spouse, child, or parent with a serious health condition (56). The FMLA allows states to require additional, more generous provisions. For example, in 2018, four states (California, New Jersey, New York, and Rhode Island) require some employers to offer paid family and medical leave, and ten states and Washington, DC, require some employers to offer paid sick leave (57). Evaluation of the effects of these state-level FMLA policies will be important for future research.

The most recent significant changes in state and national health policy are related to the Affordable Care Act (ACA), including introduction of the Marketplace coverage and essential health benefit standards nationally; elimination of pre-existing condition exclusions and life-time and annual coverage limits; dependent coverage expansion allowing young adults to remain covered under a parents’ health insurance up until age 26 years; and expansion of Medicaid eligibility in some states. Although little research has explicitly evaluated Marketplace coverage, essential health benefits, or elimination of pre-existing coverage exclusions for cancer survivors, dependent coverage expansion as part of the ACA in 2010 was associated with improved access to some preventive services and earlier stage at diagnosis in young adults (58–61).

Several studies have demonstrated positive effects of state-level Medicaid expansions to 138% of the federal poverty level for low-income adults with and without children (62–65). Following expansion in 2014, cancer patients and survivors in expansion states were more likely to be insured, have access to care or diagnosed at an earlier stage of disease than those in nonexpansion states (65). Exploring the effects of Medicaid expansions or other aspects of the ACA on financial hardship in cancer survivors will be an important area for additional research.

Outside of Medicaid expansions, there is tremendous heterogeneity in how Medicaid programs are operated by states, including differences in managed care penetration, physician reimbursement, and use and level of patient cost-sharing (66). In addition, some state Medicaid programs restrict the number of covered physician visits (67) or prescriptions per month (68), and others have instituted work requirements for eligible beneficiaries (69).

Other state-level policies, such as generic substitution laws, can restrict if and how pharmacists can offer generic substitution when patients are prescribed a branded drug (70). More recent cost transparency laws require pharmaceutical manufacturers to provide information about cost increases (70, 71). Oral parity laws have passed in 43 states and the District of Columbia to make patient OOP costs equivalent for oral and infusion antineoplastic therapies for patients with private health insurance (72). In one of the few evaluations, patients in health plans subject to oral parity laws had increased use of oral agents and modest protection against high OOP costs for oral medications compared with patients in plans not subject to oral parity laws (73). These state- and national-level employment and health policies may affect underlying risk of medical financial hardship and warrant additional research to better understand their impact on cancer survivors.

Measures of Financial Hardship and Data Infrastructure

In this section, we use the conceptual framework to describe existing standardized measures of financial hardship and data infrastructure for descriptive and intervention research. To date, most research has not evaluated financial hardship with standardized self-reported measures, limiting comparison across patient populations and studies for prevalence and severity of hardship. Among the few validated measures are the InCharge Financial Distress/Financial Well-Being Scale (74) and the Comprehensive Score for Financial Toxicity measure (75, 76). Nationally representative surveys such as the National Health Interview Survey (NHIS; ref. 77), the Medical Expenditure Panel Survey (MEPS; ref. 78), and the Behavioral Risk Factor Surveillance System (BRFSS; ref. 79) contain items on medical financial hardship within material, psychologic, and behavioral domains that can be used in comparisons of individuals with and without a cancer history (80). In 2011 and 2016–2017, the MEPS Experiences with Cancer survey was fielded in cancer survivors with medical financial hardship items specific to cancer diagnosis, its treatment, and the lasting effects of treatment (81). Standardized measures and/or items from the publicly available NHIS, MEPS, and BRFSS can be used in studies with primary data collection to allow meaningful comparisons with other national or state populations.

Administrative claims data may contain information about patient cost-sharing, which can be used to estimate patient OOP costs. However, these data do not contain any information on services that are not covered by the insurer (where patients may pay 100% of the charges for services) and likely underestimate OOP costs. In the case of Medicare claims data, beneficiaries frequently have additional private supplemental coverage, and amounts listed as patient responsibility can include both patient OOP and contributions from other payers, although these amounts are not listed separately. Information about additional supplemental Medicare coverage is not available from claims. As a result, patient responsibility amounts from Medicare are not accurate representations of patient OOP. Finally, administrative claims do not contain information on income, wealth, assets, or other measures that might be used to inform understanding of material, psychologic, or behavioral domains of hardship.

As described in Table 2, there are a number of additional measurement and data infrastructure gaps impeding the assessment of medical financial hardship. Because of limited comparability across studies and few longitudinal studies of associations between financial hardship and health outcomes, little is known about the key measures of material, psychologic, and behavioral hardship and whether these measures should differ by type of cancer, time since diagnosis, or treatment for patients and caregivers. In addition, because patient-level data are generally not linked to longer-term outcomes, the associations between financial hardship and health outcomes, such as health-related quality of life and survival, are unclear. Further development of data
Medical Financial Hardship in Cancer Survivors

Table 2. Key measurement and data infrastructure questions to assess financial hardship

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<thead>
<tr>
<th>Level of framework</th>
<th>Example questions</th>
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<tbody>
<tr>
<td>Patient and family</td>
<td>What are key measures of material, psychologic, and behavioral hardship? How do measures of hardship differ by type of cancer, time since diagnosis, treatment, for patients and caregivers? How is health insurance literacy best measured? What is the best mechanism and timing to collect and record financial hardship data (e.g., tablet in waiting room, online)?</td>
</tr>
<tr>
<td>Provider and care team</td>
<td>How can provider and/or provider team assessment of patient costs of care and financial hardship be measured systematically? What is appropriate time period for measurement of financial hardship? How are patient responses about financial hardship best integrated with clinical workflow?</td>
</tr>
<tr>
<td>Health care system</td>
<td>What existing data sources and linkages can be used to assess financial hardship within a health system? Can measures of financial hardship be available in real time to inform decision-making and referrals? How can actions to address hardship be measured and their effects quantified? Is discussion of financial hardship a dimension of quality of care? Can data systems be used to prompt provider team about patient financial hardship (e.g., part of prior authorization for patients with health insurance coverage)?</td>
</tr>
<tr>
<td>Employer</td>
<td>How can employment trajectory following cancer diagnosis be measured? What are data sources for assessing the role of employer features (e.g., health insurance coverage, workplace accommodations, paid and unpaid sick leave) when evaluating financial hardship?</td>
</tr>
<tr>
<td>State and national policy</td>
<td>What existing data sources and linkages can be used to assess financial hardship? Which data sources and linkages can be used to evaluate the association between financial hardship and health outcomes, such as health-related quality of life and survival? Is discussion of financial hardship and action to minimize financial hardship a dimension of quality of care? Can quality measures be developed to compare providers and plans? How can existing surveys and research cohorts be enhanced to assess financial hardship?</td>
</tr>
</tbody>
</table>

linkages will inform this longitudinal research and help address other key questions, such as the optimal timing of measurement of hardship by domain or the best mechanism to collect and record sensitive financial data from patients (e.g., tablet in waiting room, in-person, online, phone).

We did not identify any standard measures of if and how medical financial hardship is ascertained and addressed at the provider, health care system, employer, or state and national levels. As a result, data may not be available in real time to inform care. Research at each of these levels is limited by lack of measures and data infrastructure. As health care payers are increasingly considering patients’ experience of care in quality measurement and payment, this is an important research gap. Although assessment of financial hardship and documenting actions to address it is not currently considered a quality of care measure, standardized measurement and evaluation by payers at multiple levels could incentivize the discussions of costs of cancer care, as recommended by professional organizations (44). Limitations in standardized measurement and data infrastructure at multiple levels underlie the many challenges facing the development of effective and cost-effective interventions to minimize medical financial hardship.

**Interventions to Minimize Medical Financial Hardship**

In this section, we use the conceptual framework to summarize intervention research addressing financial hardship and identify key research gaps and leverage points for intervention at each level. At the patient level, patient assistance programs, individual drug coupons, pharmacy-specific purchasing agreements, and savings card programs are increasingly common as means to reduce patient OOP cost and increase access to prescription drugs (82–84). Other patient assistance programs offer cancer survivors assistance with housing costs, medical bills, transportation to and from care, and temporary lodging for those who travel for care (85, 86). Many of these programs have limits on eligibility and restrictions on amount and duration of support, however. Data about the use of any of these programs are not systematically collected, and evaluations of the effectiveness of these programs in reducing

Table 3. Examples of research questions for developing and informing interventions to minimize financial hardship in cancer survivors

<table>
<thead>
<tr>
<th>Level of framework</th>
<th>Example questions</th>
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<tbody>
<tr>
<td>Patient and family</td>
<td>Does enrollment in patient assistance programs reduce hardship? Improve treatment adherence? Does offering detailed survivorship care planning minimize financial hardship and improve health outcomes? Can decision aids help patients understand aspects of health insurance and risk of financial hardship? What is the best timing for introduction of decision aids? Do they reduce hardship and improve health outcomes? What is the effectiveness and cost-effectiveness?</td>
</tr>
<tr>
<td>Provider and care team</td>
<td>How can providers and care team best discuss financial hardship with patients and their families? Are EHR reminders or prompts effective in improving communication about costs and benefits of treatment? What is the effectiveness and cost-effectiveness of financial navigators for a practice?</td>
</tr>
<tr>
<td>Health care system</td>
<td>What is the effectiveness and cost-effectiveness of financial navigators for a health system?</td>
</tr>
<tr>
<td>Employer</td>
<td>How can employers offer accommodations to support cancer survivors and their caregivers to minimize hardship?</td>
</tr>
<tr>
<td>State and national policy</td>
<td>What is the effectiveness and cost-effectiveness associated with interventions to reduce financial hardship from state perspective? Do effectiveness and cost-effectiveness vary from national perspective?</td>
</tr>
</tbody>
</table>
financial hardship or improving health outcomes have not been published (Table 3). Patient health insurance and financial literacy is sometimes cited as an important barrier to informed discussions of costs and benefits of different treatment options (32, 87), and improving it is a potential leverage point for intervention.

Several studies are exploring the role of financial navigators in minimizing financial hardship (88, 89), and practices are increasingly including components of financial navigation for their patients. Evaluations of financial navigation are ongoing. State Medicaid programs and insurers have implemented and evaluated value-based care models focusing on the quality rather than quantity of care and improving patient outcomes, including medical homes in oncology and oncology pathways (90–94). In 2016, the Oncology Care Model (OCM), a multipayer value-based payment model developed by the Centers for Medicare and Medicaid Services Innovation Center was implemented in approximately 200 practices across the United States to improve the quality of cancer care for Medicare beneficiaries (95, 96). The OCM includes a navigation component, and it may be possible to assess the association between financial navigation and other components of quality of care in participating practices (96).

Few interventions have been developed to specifically minimize medical financial hardship, although, as described above, state and national health policies can affect medical financial hardship. Similarly, given the broad support for discussion of the costs of cancer care by professional societies (44) and other organizations (45), inclusion of data elements addressing whether a conversation with the care team took place might be an important first step in assessing patient financial hardship. As interventions are developed and implemented, it will be important to evaluate their effectiveness and cost-effectiveness from the perspective of each level; this information will inform how payers, employers, and others make decisions about how best to minimize patient medical financial hardship and improve health outcomes. Information on comparative effectiveness and cost-effectiveness will also inform dissemination and implementation of interventions in other settings.

Discussion

In this commentary, we described emerging research on medical financial hardship in cancer survivors and highlighted the numerous research gaps at all levels, including patient, provider and care team, health care system, employer, and state and national policy levels. To date, the vast majority of research on medical financial hardship has been conducted at the patient level (14–16). Foundational descriptive research and surveillance at other levels will be important, especially as standardized measures and data infrastructure are developed. With trends toward increasing costs of cancer treatment (2–4) and greater patient cost-sharing, especially for oral medications (3, 97), risks of medical financial hardship associated with cancer will likely increase in the future.

Although research on risk factors for financial hardship is limited, even at the patient level, findings across these studies are consistent—medical financial hardship is more common among populations that have historically experienced disparities in access to care and health outcomes, including racial/ethnic minorities (18, 19, 22–25), the poor (27), and the underinsured and uninsured (18, 19, 27). Identifying additional risk factors and monitoring hardship in these populations will be critical to minimize the potential for widening disparities in health outcomes in the future.

We identified very few interventions to minimize financial hardship at any level. Using our multilevel conceptual framework, we summarized published studies and identified critical gaps in medical financial hardship research and intervention developments. Our framework illustrates the importance of considering the interrelationship of multiple levels. For example, limited patient health insurance and financial literacy might be an important and potentially modifiable risk factor for developing medical financial hardship. A decision aid might help patients develop sufficient financial and health insurance literacy to have an informed discussion with the provider team and make informed treatment decisions about their care. The success of such an intervention requires (i) understanding which member of the provider team is best suited for discussion about the costs and benefits of treatments, including expected cost-sharing; (ii) training provider team member(s) to have these discussions; and (iii) data infrastructure at the practice and plan level to support this discussion and record patient preferences. The success of the intervention also requires that the patient and/or family member are able to maintain employer-based health insurance coverage and have sufficient sick leave for patient and caregiver (paid and unpaid) to successfully complete the selected treatment(s). Policies at the health system and insurer, employer, state and national levels related to health insurance benefit design, and health care delivery are also potential levers for intervention.

As described in this commentary, foundational descriptive research at multiple levels is critical to inform understanding of risk factors for medical financial hardship and to develop, implement, and evaluate interventions to reduce financial hardship and improve patient health outcomes. Addressing measurement and data infrastructure gaps that may limit development of effective interventions is necessary for these efforts. Evaluation of the effectiveness and cost-effectiveness of interventions from the perspectives of the provider and care team, health system and insurer, employer, and state and national levels will inform decisions about how best to address the growing problem of medical financial hardship for cancer survivors in the United States.

Disclosure of Potential Conflicts of Interest

No potential conflicts of interest were disclosed.

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References


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