Navigating financial toxicity in patients with cancer: A multidisciplinary management approach

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Abstract: Approximately one-half of individuals with cancer face personal economic burdens associated with the disease and its treatment, a problem known as financial toxicity (FT). FT more frequently affects socioeconomically vulnerable individuals and leads to subsequent adverse economic and health outcomes. Whereas multilevel systemic factors at the policy, payer, and provider levels drive FT, there are also accompanying intervenable patient-level factors that exacerbate FT in the setting of clinical care delivery. The primary strategy to intervene on FT at the patient level is financial navigation. Financial navigation uses comprehensive assessment of patients’ risk factors for FT, guidance toward support resources, and referrals to assist patient financial needs during cancer care. Social workers or nurse navigators most frequently lead financial navigation. Oncologists and clinical provider teams are multidisciplinary partners who can support optimal FT management in the context of their clinical roles. Oncologists and clinical provider teams can proactively assess patient concerns about the financial hardship and employment effects of disease and treatment. They can respond by streamlining clinical treatment and care delivery planning and incorporating FT concerns into comprehensive goals of care discussions and coordinated symptom and psychosocial care. By understanding how age and life stage, socioeconomic, and cultural factors modify FT trajectory, oncologists and multidisciplinary health care teams can be engaged and informative in patient-centered, tailored FT management. The case presentations in this report provide a practical context to summarize authors’ recommendations for patient-level FT management, supported by a review of key supporting evidence and a discussion of challenges to mitigating FT in oncology care. CA Cancer J Clin. 2022;72:437-453.

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Case 1

Mr. A is a 64-year-old African American man who was diagnosed 3 years prior with locally advanced adenocarcinoma of the lung and was treated with chemotherapy and radiation. He has multiple comorbidities, including chronic kidney disease. Mr. A now has a locoregional recurrence that will require more chemotherapy. He is being evaluated for possible immunotherapy, which he did not receive with his initial course of treatment.

Mr. A relied on credit cards to pay for out-of-pocket medical bills during the initial course of treatment—mainly copays related to cancer diagnostic studies and cancer treatments. Three years after initial treatment, he still has several thousand dollars in persistent credit card debt that he cannot pay down. At diagnosis, the patient worked as a full-time custodian. He has been unable to sustain employment because of declining physical function since his cancer treatment. He initially retained employer-based health insurance, but the premium nearly doubled. After a qualifying period, he obtained Supplemental Security Income and Medicare coverage for beneficiaries with a disability. The patient is anxious about his upcoming...
65th birthday because he does not understand whether his health insurance premiums may increase and whether coverage will change. The patient depends on his wife to manage day-to-day household finances and health care bills, and her part-time administrative job now serves as their household’s primary income source. His wife developed chronic pulmonary disease during the same interval. The couple began cutting back on their day-to-day household spending on clothing and vacations to prioritize paying for medical bills. With Mr. A’s recent cancer recurrence and escalation of medical expenditures, the couple has begun regularly relying on food banks to ensure they have enough food.

Background: Portrait and Prevalence of Financial Toxicity in the United States

The economic burden shouldered by patients and survivors with cancer is known as financial toxicity (FT). This case presentation highlights that FT arises from the out-of-pocket medical spending, employment disruptions, productivity losses, and impaired livelihoods of individuals and their families that accompany cancer diagnosis, treatment, and survivorship. Estimated national spending associated with cancer is $200 billion annually in the United States and rising.1,2 The economic burden of cancer on the nation’s health system provides context for understanding the economic burden of cancer on individuals.3 Recognition of FT has accelerated in oncology professional communities, scientific literature, and the lay press.4-6 Initial characterizations focused primarily on patients’ out-of-pocket cost burden for cancer care;7 however, the current conceptualization of FT has evolved. FT includes not just material hardships of cancer care (eg, out-of-pocket medical expenditures and interruptions of income and employment) but also accompanying psychological burden (eg, financial worry) and coping behaviors (eg, reduction in spending on food and necessary medications).8-11

Across studies, an estimated one-half of patients with cancer and survivors experience FT.12-15 FT is most common among individuals who are socioeconomically vulnerable because of lower income as well as inadequate health insurance.14,16-21 FT affects people who are racial and ethnic minorities more frequently than people who are non-Hispanic White, likely reflecting their greater socioeconomic vulnerability in the United States.22,23 An analysis of 2010 National Health Interview Survey data identified that, among respondents with a history of cancer, significantly more non-Hispanic Black and Hispanic respondents (47% and 42%, respectively) reported a negative financial impact from cancer compared with 33% of non-Hispanic White respondents.31 These racial and ethnic disparities in FT, as well as rural-urban disparities, persist in contemporary data.22,24,25 Younger age at cancer diagnosis is also associated with more persistent and severe FT.26 In survivors of cancer from the 2011 US Medical Expenditure Panel Survey Experiences With Cancer questionnaire, the relative frequency of material and psychological financial hardship in respondents aged 18 to 64 years was approximately 2 times higher than the frequency in those aged 65 years and older.18 A recent survey conducted during the COVID-19 pandemic among adolescent and young adult (AYA) survivors who were treated for cancer before age 40 years at a mean interval of 8 years from diagnosis identified severe FT in one-half of all respondents.27

Although medical financial burden is not unique to individuals with cancer,28 specific aspects of cancer and its treatment contribute to the distinctive trajectory of FT in this population. The key contributors to out-of-pocket spending in patients with cancer include prescription drugs, hospital inpatient stays, emergency room visits, and provider and outpatient visits as well as other medical services.3 Taken all together, patients’ direct out-of-pocket costs can approach 10% of all medical care costs across payers (eg, Medicare, commercial insurance), equating to more than $10,000 in the first year after diagnosis.29 Multimodality treatments for cancer contribute collectively to costs that are increasingly shifting from payers to individuals.30,31 Maintenance therapies and unrelenting chronic therapies for metastatic disease can protract patients’ financial burdens. Additional financial stressors originate from acute care visits and unplanned hospitalizations needed to manage toxicities and symptoms related to treatment and the disease itself. Specialized oncologic care delivery may be geographically limited, and, as
a result, some patients must travel long distances for cancer treatment, generating ancillary costs for housing and transportation. Furthermore, the trajectory of disease is often unpredictable. Complications, relapse, or disease progression can require additional care costs for which it is difficult to plan. These aspects of cancer and its treatment are patient-level factors that exacerbate upstream causes of FT, such as high prices and intensive use of cancer care and drug therapy. Yabroff et al conceptualize how patient-level factors that drive FT are nested within additional multilevel system factors. Therefore, fully mitigating cancer-related FT will also require accompanying multilevel interventions that address upstream causes of cancer-related financial burdens at the state and federal, insurer/payer, employer, and provider/practice policy levels.

Nevertheless, faced with the high prevalence of patient FT, oncology clinicians and care teams are increasingly aware that this problem affects patients at an individual level and acknowledge their need to address patients’ financial concerns during care delivery. The following case discussions bridge this need by providing a practical context to summarize recommendations for and challenges of patient-level FT management and intervention. Recommendations are supported by a review of the key supporting scientific evidence on the emerging practices for FT screening and financial navigation as well as a review of key modifying factors and outcomes in individuals with cancer-related FT.

Emerging Practices for Multidisciplinary Management of Patient FT

Screening for FT

A large proportion of oncology practices report screening patients for financial hardship. Of respondents (17 centers) to a 2018 National Comprehensive Cancer Network (NCCN) member institution survey, 76% reported routine screening, 18% reported occasional screening, and 50% repeated screening for patient financial distress. In a 2017 survey of 221 National Cancer Institute Community Oncology Research Program sites, 72% reported financial screening. There are some limitations to interpreting the study’s finding, however. Although the Community Oncology Research Program includes facilities from 44 states, the District of Columbia, and the US territories of Puerto Rico and Guam, they may not comprehensively represent the entire spectrum of community oncology practices. These studies also did not distinguish whether screening was primarily structured to support facility collections, provide patient assistance, or serve multiple purposes. A common approach to screening is assessing for health insurance coverage, but this practice may miss or exclude uninsured or underinsured patients. Furthermore, studies still indicate that patients with cancer often perceive inadequate provider engagement with their financial needs and have unmet needs for communication about finances and during care delivery. This discrepancy between practice and patient perceptions of engagement suggests a continued need for close examination and refinement of financial hardship screening practices and more efficient linkage of FT assessment with needed counseling, navigation, and referrals.

Social workers, oncology nurses, or navigators typically conduct FT screening, most commonly based on psychosocial distress screening, using tools such as the NCCN Distress Thermometer. This thermometer captures patients’ self-reported psychosocial distress on a scale from 0 (least distress) to 10 (most severe distress). However, a recent analysis of screening characteristics based on a Distress Thermometer score alone yielded 48% sensitivity and 70% specificity for identifying severe FT developing within the subsequent 6 months. This result suggests that general distress screening alone is inadequate for identifying patients at high risk for FT. One alternative screening approach adds problem checklists, such as the NCCN Problem Checklist, for patients to identify physical, emotional, social, spiritual, as well as practical concerns (eg, with work, housing, insurance, transportation, having enough food, and finances). These checklists delineate specific needs for immediate intervention. An alternative is to screen using quantitative, patient-reported, subjective FT measures, such as the validated 15-item Economic Strain and Resilience in Cancer (ENRICH) or the 11-item Comprehensive Score for Financial Toxicity (COST) measures, which calculate respondents’ summary FT score. A recent study of patients with gynecologic cancer showed that risk-stratifying patients at the start of treatment as having mild (COST score, 14-25), moderate (COST score, 1-13), or severe (COST score, 0) FT captured 90% of patient financial hardship through 6-month follow-up. This evidence supports routine FT screening rapidly after the initiation of cancer care. Shorter screening instruments, including a single-item, global COST measure, have also been developed to allow brief, repeated assessments over the care trajectory. One retrospective, single-center analysis derived a 3-item financial hardship screener that yielded initial high sensitivity (89%) for predicting subsequent adverse financial events, such as loss of income/job or difficulty paying for meals, housing, or transportation. This short-screen model has not yet been prospectively tested or validated for dissemination across heterogeneous settings. However, it highlights an evolving direction toward brief FT assessment and growing understanding that screening needs to be an ongoing, dynamic process throughout the care trajectory. Direct comparisons of the different screening approaches are still needed. Accordingly, a pilot...
Management of financial toxicity

In practice, screening the patient in case 1 would likely indicate high FT risk, requiring multiple support resources. However, current screening approaches may fail to identify patient FT, or a patient’s perception of their FT may change over the course of care. For example, a patient’s treatment decisions may be driven initially by an at-all-costs mentality at diagnosis. Concerns may later arise as the affordability of care and acute and long-term impact on the patient’s financial stability, employment, and family members evolve. Accordingly, oncologists and clinical provider teams possess a unique opportunity to perceive and communicate about the dynamic aspects of FT through the provider–patient relationship and the trajectory of multiple care encounters. This concept is similar to the emerging model of routine structured assessment of other patient-reported outcomes, such as symptoms and toxicities linked with clinical encounters in oncology care.50,51 Analogously, routine assessment and re-assessment of FT concerns is needed, and novel developments toward implementing automated software systems and technological solutions to support the assessment of patient-reported outcomes may support its implementation. When providers identify unaddressed FT in their patients in clinical care, ad-hoc referral to social work and financial navigation is needed for expeditious and tailored FT management.45

Financial navigation

The primary strategy to mitigate FT at the patient level is financial navigation.38,39,52 Patient navigators traditionally guide patients one-on-one through aspects of care, such as communicating with providers, setting up appointments, or interacting with insurance companies, through screening, treatment, and follow-up. Whether coordinated by a social worker or an oncology navigator, financial navigation focuses on a structured, comprehensive assessment of patients’ risk factors for FT and guiding patients to resources and referrals to support their financial needs across cancer care. These resources include financial assistance (eg, mitigating prescription medication costs or nonmedical day-to-day expenses), education (eg, enhancing financial literacy or debt planning), and health insurance enrollment and optimization.53 The social worker or navigator may offer direct assistance and other resources, such as referral to specialty pharmacists to help obtain cost assistance for infusion and oral drugs or financial counselors to establish payment plans. Financial navigation should be a component of comprehensive biopsychosocial assessment and care. As a result, the social worker or navigator may also coordinate referrals for other patient needs, including psychological distress or symptom management. Additional resources may be needed to help relieve the burdens of the patients’ informal caregivers, who experience their own financial and psychological strains.54,55 Such collaborative work of health care team members is invaluable to accomplish financial navigation as a component of high-quality, high-value care delivery.53 Thus, while social workers or nurse navigators lead financial navigation, the synchronous support and collaboration of multidisciplinary team members, including the clinical team, are needed to optimize efforts to mitigate FT in care.

Table 1 summarizes recent prospective studies evaluating the effectiveness of patient-level financial navigation interventions.56-62 Studies were from single institutions with limited sample sizes, and almost all used a single-arm, preintervention-postintervention design. These results provide initial evidence that structured financial navigation demonstrates acceptability, enables high-fidelity provision of interventions, increases patient knowledge about resources, and improves patient-reported depressive and anxiety symptoms, cancer distress, and social support. The intervention by Wheeler et al also led to participants’ postintervention improvement of subjective FT measured using the COST measure.61

These early studies affirm the feasibility of navigation as a patient-based FT intervention strategy. Still, high-level evidence is required to determine the most necessary and effective components of financial navigation. Accordingly, the National Cancer Institute has funded ongoing, prospective studies of FT intervention across the United States.63 Table 2 presents studies with published intervention approaches, such as nurse-based financial navigation, focused health insurance literacy education and navigation, and enhanced self-management of employment-related barriers through a mobile app. Interventions are designed to be navigation-intensive, with repeated planned navigation cycles, such as monthly or bimonthly, lasting 4 to 6 months. Evaluation of these strategies compared with low-touch approaches (eg, providing information alone without intensive personal navigation) is ongoing. When completed, these studies will represent the first group of randomized trials to generate evidence to identify components of effective FT navigation. These studies will also provide better understanding of the resources needed and the potential for return on investment53 to support adequate training, implementation, and sustainability of financial navigator roles embedded within health systems or linked with third-party organizations that provide financial navigation. Such insight is needed given the current heterogeneity across settings in the services available, staff involved, and barriers to financial navigation in current oncology practice,52 as well as the only nascent development of professional and core knowledge standards for financial navigators and other multidisciplinary team members.64 Furthermore, successful
| AUTHOR, YEAR | DESIGN     | NO. OF PATIENTS | SETTING                           | CANCER TYPE | INTERVENTION                                                                 | CONTROL | OUTCOME MEASURES                      | KEY FINDINGS                                                                 |
|-------------|------------|----------------|-----------------------------------|-------------|-----------------------------------------------------------------------------|---------|--------------------------------------|------------------------------------------------------------------------------|
| Madore 201456 | Pre-post   | 20             | Urban medical center              | Breast, recent diagnosis | Breast CARES Program: multidisciplinary case management (live patient navigation: at least 5 sessions; psychosocial telephone counseling: up to 9 sessions) | None    | 1. Depression (CES-D), cancer-specific distress, perceived social support 2. Patient-reported financial barriers 3. Patient-reported transportation barriers | • Majority of patients reported program as helpful to overcome financial (73%) and transportation (60%) barriers to treatment • Postintervention psychosocial scores indicate a decrease in depression and cancer-related distress and an increase in social support |
| Shankaran 201857 | Pre-post   | 34             | Fred Hutchinson Cancer Center     | Nonmetastatic solid tumor, <6 mo of completing treatment | Financial education course (live group or video), monthly contact from Consumer Education and Training Services (CENTS) and Patient Advocate Foundation (PAF) case manager contact for 6 mo | None    | 1. Self-reported (subjective) financial burden 2. Self-reported anxiety related to cancer treatment costs | • Majority of patients (83%) reported high satisfaction with financial education course • Decrease (33%) in anxiety about treatment costs • No substantial change in self-reported financial burden |
| Nipp 201958   | Quasi-experimental | 260              | MGH, patients enrolled in clinical trial | All cancers | Equity intervention of financial assistance from nonprofit for travel and lodging related to trial participation | Matched by age, sex, cancer type, trial, phase | 1. Financial toxicity (COST) | • Patients in the intervention reported improvements in concerns regarding travel and lodging costs • No significant improvements in COST • No significant difference in COST of patients who had follow-up scores at 3 mo • Follow up sample size (n = 5) too small to make any valid conclusions |
| Sadigh 201959  | Pre-post   | 12             | Emory University, outpatient oncology clinics | Brain, diagnosis <2 mo | PAF case manager contact once monthly for 6 mo | None    | 1. Financial toxicity (COST) | • No significant difference in COST of patients who had follow-up scores at 3 mo • Follow up sample size (n = 5) too small to make any valid conclusions |
| Watabayashi 202060 | Pre-post   | 30 patients, 18 dyadic caregivers | Seattle Cancer Center Alliance | Solid tumor actively receiving or <6 mo of systemic therapy, caregiver is family or friend | Financial education video, monthly contact from CENTS and PAF case manager for 6-mo, referral to Family Reach for help with cost of living unpaid bills | None    | 1. Financial toxicity (COST) 2. Caregiver burden (Caregiver Strain Index [CSI]) | • COST and CSI measures did not change significantly |
| Wheeler 202061  | Pre-post   | 50             | North Carolina Cancer Hospital     | All cancers | Intake assessment, initial one-on-one consultation with FN (financial counselor or social work), triage to financial support services to generate resource checklist and associated paperwork, recontacted at 2-wk intervals to assess progress | None    | 1. Financial toxicity (COST) 2. Patient satisfaction, retention 3. Intervention fidelity | • Significant improvement in COST • Excellent patient satisfaction and retention • FN logs indicated high intervention fidelity |

(Continued)
patient intervention strategies will still need to be coupled with concurrent, multilevel solutions to address the causes of FT at system and policy levels to impact the direct out-of-pocket expenses of cancer care. However, expected results will be significant for providing insight on the optimal timelines and frequency needed for patient-level, structured FT navigation assessment and intervention (eg, one-time, ongoing throughout treatment, or across survivorship).

Table 3 presents a sample plan for Mr. A’s multiple areas of concern related to FT. A comprehensive financial navigation plan would include assessing his current insurance coverage and eligibility for dual coverage with Medicare and Medicaid. It would also have linkage to resources to enhance his financial literacy to help manage his credit card debt and financial planning, given his anticipated ongoing care needs. He would also benefit from referrals and support to apply for outside financial and prescription cost assistance resources. Internal referral to institutional financial services would enable setting up a payment plan to address outstanding hospital bills and help provide specific advice regarding which insurance plans would keep him in-network for his ongoing care. He would be assessed for Supplemental Nutrition Assistance Program (SNAP) eligibility and linked to local food banks and other community resources, such as cancer charities, for additional assistance. Incorporating the patient’s caregiver in the financial navigation is also critical. The patient is not unique in deferring the management of his medical bills and household finances to his spouse—his primary caregiver—because of either his disease/treatment or established household roles prediagnosis. This concept of dyadic intervention is the basis for the ongoing study A Randomized Trial Addressing Cancer-Related Financial Hardship Through Delivery of a Proactive Financial Navigation Intervention (CREDIT), which examines a financial navigation program for patients plus their spouses (Table 2), principally led by a coauthor (V.S.; ClinicalTrials.gov identifier NCT04960787; NIH grant/contract R01CA248656).

Finally, the patient’s financial navigation plans should be integrated with psychological distress assessment and support because a patient’s comfort and willingness to discuss financial concerns are integral parts of the intervention. Ongoing follow-up would consist of repeated FT assessments by the social worker or oncology navigator that are documented in the electronic medical record to enhance the accessibility of the navigation plan to clinical providers. Communication with the clinical provider team is essential because ongoing financial navigation can be synchronized with clinical follow-up encounters to streamline appointments and integrate with the clinical management plan.
| PRINCIPAL INVESTIGATOR | PROJECT NO. (AGENCY) | CLINICALTRIALS.GOV IDENTIFIER | Awardee Organization | Title | Intervention | Intervention Length |
|------------------------|---------------------|-------------------------------|---------------------|-------|--------------|---------------------|
| Blinder V              | 1R01CA214785, 5R37CA214785 (NCI) | NCT03572374 | MSKCC | Breast Cancer and the Workforce Communication App: RCT of an English/Spanish intervention to promote long-term job retention | - Delivery: Mobile app  
- Intervention components: Improve communication with clinicians to optimize symptom control, improve communication with employers to negotiate accommodations, and promote job retention | NA |
| Henrickson NB, Banegas MP (Multi-PI) | 1R01CA237322 (NCI) | NCT05018000 | Kaiser Permanente Northwest and Kaiser Permanente Washington | Cancer Financial Experience (CAFE): Clinic-based intervention to address financial hardship for people with cancer | - Delivery: Individual meetings with financial navigator (FN)  
- Intervention components: 1) proactive and comprehensive assessment of patient financial questions and concerns (eg, uncertainty around planning for out-of-pocket costs and/or when patients will need to pay), 2) personalized support and referrals, and 3) financial resource sheet outlining available organization and community resources | 1-3 intervention cycles 6 mo  
- Extra FN support available by request |
| Kirchhoff A            | 1R01CA242729 (NCI) | NCT04448678 | University of Utah | Improving Health Insurance Experiences for Adolescent and Young Adult Cancer Patients | - Delivery: Individual sessions conducted by patient navigator (PN) in person, over video, or by telephone  
- Intervention components: Education on health insurance terms and concepts, insurance coverage (insurance cards, bills, schedule, and explanation of benefits), health insurance laws, rights and the appeals process, budgeting, and resources | 4 sessions, bimonthly 2 mo |
| Park E                 | ACS                  | NCT04520061 | MGH | Developing a Health Insurance Navigation Program for Survivors of Childhood Cancer (HINT) | - Delivery: Videoconference visits with trained PN  
- Intervention components: education on survivorship needs, healthcare plans in relation to policy, navigating one’s own health care plan, overcoming insurance obstacles, and managing care costs | Four 30-min weekly sessions 1 mo |

(Continued)
Employment concerns are a common topic that working patients seek to discuss with their treating oncologists. Oncologists and provider team members can play a critical role in proactively inquiring about patients' employment as a component of social history and discussing patients' job duties and responsibilities that they may or may not be able to perform while on treatment. Because the patient in case 1 has had declining physical function, he is at high risk for permanent job disruption and adverse employment outcomes. Strong evidence exists on the negative impact of cancer treatment on employment outcomes like that observed in case 1. For example, in a survey study of 546 individuals with locally advanced colorectal cancer from the Surveillance Epidemiology and End Results registry who were working at diagnosis, 17% of respondents missed from 6 to 12 months of work because of their cancer diagnosis and treatment. Furthermore, only 55% of respondents retained their jobs after diagnosis. Job disruption has been reported across studies of patients with other cancer types, such as breast, endometrial, and head and neck cancer. The Surveillance Epidemiology and End Results registry, which was unique in identifying potential protective factors, where individuals who had paid sick leave and employer-based insurance, as well as those who maintained good health status, were more likely to retain their job. Oncologists thus have an opportunity to integrate practical concerns related to FT with patient-centered treatment decisions and planning. Notably, the patient in case 1 never received standard-of-care immunotherapy with his initial course of treatment, a scenario consistent with evidence for nationally persistent racial disparities in the receipt of lung cancer treatment. This scenario underscores that there are shared socioeconomic risk factors underlying FT and disparities in cancer care delivery. For the patient in case 1, the oncologist's treatment discussion and planning could involve the practical implications of immunotherapy dosing options (eg, a regimen approved for delivery every 6 weeks rather than every 3 weeks). It could integrate information about the treatment options' clinical harms and benefits with the oncologist's treatment discussion and planning. Newly, the patient in case 1 received standard-of-care immunotherapy with his initial course of treatment, a scenario consistent with evidence for the potential protective factors identified in the Surveillance Epidemiology and End Results registry, which was unique in identifying potential protective factors, where individuals who had paid sick leave and employer-based insurance, as well as those who maintained good health status, were more likely to retain their job.

### Financial Navigation Program to Improve Understanding and Management of Financial Aspects of Cancer Care for Patients and Their Spouses (CREDIT)

- **Delivery:** Online financial literacy training; individual meetings with CENTS counselor and PAF case manager
- **1-mo intervention components:** budget management, insurance enrollment and optimization, access to co-pay assistance, and other resources to manage medical and nonmedical out-of-pocket costs

### Addressing Cancer-Related Financial Toxicity in Rural Oncology Care Settings

- **Delivery:** Individual intake and visits with FN
- **Intervention components:** Explore all financial assistance resources and have received financial assistance benefits or referrals

**Abbreviations:** CENTS, Consumer Education and Training Services; FHCRC, Fred Hutchinson Cancer Research Center; MPI, multiple principal investigators; MSKCC, Memorial Sloan Kettering Cancer Center; NCI, National Cancer Institute; NA, not applicable; PAF, Patient Advocate Foundation; RCT, randomized controlled trial; PI, principal investigator; SWOG, Southwest Oncology Group; UNC, University of North Carolina Lineberger Comprehensive Cancer Center.
understanding of the expected clinical risks and benefits of potential treatment approaches. Depending on his goals of care, there could be relatively high costs and low benefits to pursuing aggressive therapy. A balanced discussion should also address the practical and clinical effects of the patient obtaining all multimodality treatment within a single specialty care institution if concern for fragmented care exists or, alternatively, undergoing co-managed care with local, community-based medical oncologists as a strategy to help maximize adherence to standard-of-care therapy while minimizing financial barriers to care.

The provider team’s anticipation of the patient’s need for streamlined care is simultaneously critical for his caregiver (his wife) to maintain her employment. She is now the primary income source, yet her caregiving duties for Mr. A will increase with time while she is facing her own health challenges. Together, these factors constitute a high-risk situation for the entire family unit accruing more medical debt, being unable to access care for financial reasons, and facing destitution. In this case, a distinct challenge for the oncologist is the extra consideration needed for the caregiver’s and family’s financial circumstances and trajectory. A recent pilot study of cancer patient-caregiver dyads found that, while 45% of patients described having lost or changed work, 39% of their caregivers were also affected and reported severe financial burdens.

A comprehensive discussion of the efficacy, feasibility, and acceptability of provider-level interventions to enhance cost communication extends beyond the scope of this review. However, it is important to acknowledge that increasing providers’ cost communication is another proposed strategy to help mitigate patient FT. Nevertheless, there is currently a lack of consensus about how and whether oncologists should have a role in directly communicating out-of-pocket cost estimates to their patients. There is also a recognized gap in oncologist and clinical provider training on incorporating cost discussions into care. Moreover, there is a recognized gap in establishing optimal clinical pathways to support providers’ understanding that costs of treatment need to be integrated with the comparative effectiveness data on treatment options. Finally, there remain simultaneous, related policy challenges of achieving price transparency in care delivery to inform cost discussions between patients and providers.

The challenge of multifaceted FT affecting clinical management highlights the complexity oncologists face when integrating FT into cancer care discussions and planning. This complexity underscores a need for multidisciplinary cooperation to implement FT interventions synchronously with clinical care delivery. The Levine Cancer Institute reported outcomes after implementing a practice-wide Financial Toxicity Tumor Board in 2019. The authors reported that a multidisciplinary team, including physicians, nurses, nursing and medical administrators, financial officers and staff, financial counselors, social workers, nurse navigators, and oncology pharmacy, participated in monthly patient case reviews to address FT problems, similar to multidisciplinary tumor conference discussions. The Financial Toxicity Tumor Board strategically developed widely applicable operating procedures to proactively intervene on paradigm insurance and financial barriers to care. This model of collaboration emphasizes the clinical team members’ critical role in advocating for investments in staffing, screening, and practical assistance resources to implement financial navigation. It also highlights the importance of clinical team members’ engagement in building and championing robust referral pathways to navigation so that patients can efficiently and seamlessly access the local support resources available to mitigate FT. The Financial Toxicity Tumor Board is one novel example of coordinated multidisciplinary management to address patient financial hardship factors in care delivery. Another novel example is the ongoing Cancer Financial Experience (CAFE) intervention trial (co-led by multi-principal investigator coauthor M.P.B.; ClinicalTrials.gov identifier NCT05018000; NIH grant/contract R01CA237322), which is examining financial navigation in the context of multidisciplinary care. In this trial, the financial navigator is a primary provider who not only addresses patient financial concerns but also becomes the centrally responsible individual to coordinate, communicate, and document the FT management plan with all team members (ie, financial counselor, pharmacy, and clinical provider team). Future studies may seek to test the effectiveness of combining these multidisciplinary coordination strategies to address paradigm barriers and tailor individual patient financial navigation plans.
### TABLE 3. Sample Financial Navigation Assessment and Referral Plan for Patient Case 1

| AREA OF CONCERN                      | NAVIGATION AND REFERRAL                                                                                                                                                                                                 |
|--------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Insurance Coverage                   | Address continuity of coverage through Medicare when the patient turns 65 years old  
1. Assess which Medicare program(s) patient is currently enrolled in and the payment system (fee-for-service vs. managed care)  
2. Assess eligibility and benefits under other plan types (HMOs, PPOs)  
3. Assess eligibility for dual coverage (Medicare and Medicaid)  
4. Provide resources (selected examples below):  
  - **Centers for Medicare and Medicaid Service**: Information about Medicare open enrollment period (cms.gov/Outreach-and-Education/Reach-Out/find-tools-to-help-you-help-others/Medicare-Open-Enrollment)  
  - **State Health Insurance Assistance Program (SHIP)**: National program that offers insurance coverage counseling and assistance to people with Medicare, and their families/caregivers (shiphelp.org)  
  - **Marketplace Health Plans** (healthcare.gov) |                                                                                                                                           |
| Managing Debt and Financial Literacy | 1. Foster patient’s understanding of the amount and type of debt they are facing through financial literacy and education  
2. Refer to the social work department or financial navigation program  
3. Identify debt reduction strategies, credit counsellors, or financial planners available within or outside the institution  
4. Discuss patient’s understanding of debt management strategies (some options include interest-only repayments, extending terms of loans, and payment by installments) |                                                                                                                                           |
| Direct Assistance                    | 1. Internal referrals and coordination  
- Business or financial services office to establish payment plan  
- Financial counselor, case manager, or specialty pharmacist can help identifying institutional, state, and national level programs that can provide direct assistance and also help connect with pharmaceutical assistance programs  
2. Provide external resources that assist cancer patients and caregivers managing cancer-related costs (selected examples below):  
  - **American Cancer Society**: Provides direct assistance, such as transport and lodging (cancer.org/treatment/finding-and-paying-for-treatment/managing-costs/programs-and-resources-to-help-with-cancer-related-expenses.html)  
  - **Triage Cancer**: Provides education and training for financial toxicity and resource guides for health insurance coverage, disability insurance, and employment (triagecancer.org)  
  - **Patient Advocate Foundation**: Provides direct patient services to assist with access to care, employment, and financial stability (patientadvocate.org)  
  - **CancerCare**: Provides free support services to patients and caregivers; provides help for cancer-related costs (cancercare.org/financial)  
  - **Patient Access Network (PAN) Foundation**: Provides assistance with medications’ out-of-pocket costs for people living with chronic and rare diseases (panfoundation.org)  
  - **Healthwell Foundation**: Provides financial assistance with health insurance, travel, and treatment costs (healthwellfoundation.org) |                                                                                                                                           |
| Medication Cost Savings              | 1. Link patients and caregivers to resources that assist with medication and supplement costs (selected examples below):  
  - **NeedyMeds Drug Discount Card**: Cost support for prescription medications (needymeds.org)  
  - **Abbott Nutrition Patient Assistance Program/Pathway Plus**: Provides supplemental products for patients experiencing financial difficulties. Pathway Plus assists with insurance coverage benefits verification, coding, and product availability (pathwayreimbursement.com)  
  - **Nestlé Health Science Patient Assistance Program**: Provides 90-day supply of medications (nestlehealthscience.us/patient-assistance-program)  
  - **Good Rx**: Provides free prescription drug coupons (goodrx.com)  
  - **Medicare Prescription Drug Costs**: Information for individuals on Medicare to enroll in a prescription drug coverage or Medicare Advantage drug plan (medicare.gov/drug-coverage-part-d/costs-for-medicare-drug-coverage/costs-in-the-coverage-gap)  
  - RxAssist.org: Information on using pharmaceutical company programs and other resources to help reduce medication costs (rxassist.org)  
  - Pharmaceutical companies may have their own assistance programs, in the form of coupons, discount cards and/or vouchers |                                                                                                                                           |
| Healthy Eating and Food Security     | 1. Assess eligibility for Supplemental Nutrition Assistance Program (SNAP; fns.usda.gov/snap/supplemental-nutrition-assistance-program)  
2. Refer to local food programs and food banks |                                                                                                                                           |
| Stress Management & Caregiving Burden| 1. Assess psychological distress over time and provide referrals for interventions (selected examples below):  
- Psychoeducation  
- Coping skills training  
- Cognitive-behavioral therapy (CBT)  
- Problem-solving interventions  
- Acceptance and commitment therapy (ACT) |                                                                                                                                           |

Abbreviations: HMOs, health maintenance organizations; PPOs, preferred provider organization
Correction added on 27 May 2022, after first online publication: Table 3 has been updated in this version.
long-term net worth and asset ownership. A spectrum of adverse health-related outcomes is also associated with FT. Individuals with more severe FT have decreased quality of life, more anxiety and depression, and lower adherence to FT. Individuals with more severe FT have decreased quality of adverse health-related outcomes is also associated with providers and patients on issues affecting FT (Table 4). This recognition serves as a valuable foundation to proactively empower patients, survivors, and oncologists to engage with this problem. It sets the stage for implementing patient-level FT navigation strategies embedded within multilevel systems and policy interventions to mitigate causal drivers of FT. Finally, it identifies a growing need for consensus professional guidelines to guide FT management in practice.

**Case 2**

Ms. B is a 29-year-old, otherwise healthy Latina woman with locally advanced cervix cancer who is undergoing concurrent chemotherapy and radiation therapy, which is expected to last 8 weeks. Because of a gap in health insurance while between jobs, she experienced a delay in diagnosis and amassed several thousand dollars of out-of-pocket self-pay medical debt from an emergency room visit for early symptoms that ultimately led to her diagnosis. She has received cash donations from her social network through crowdfunding. This support has helped relieve a portion of her transportation costs and daily living expenses while she completes treatment. Recently, she obtained state Medicaid insurance for breast and cervical cancer, covering current costs for cancer care. However, the patient is worried that she will lose coverage after cancer treatment is completed and may face ongoing financial stress for follow-up care in the years to come. She lacks any savings and has credit card debt and student loans. Although she is temporarily working as a cashier to make ends meet, Ms. B is unsure whether she will resume her vocational aspiration to become a teacher. She is also concerned about how treatment side effects she has experienced, such as neuropathy and chemo brain, will affect her lifetime career goals. She has discussed how to clinically manage these symptoms with her oncologists, although she did not bring up her concern that the symptoms could affect her ability to work long term. She declined a referral to social work because she was unfamiliar with the role of social workers and felt the referral was unnecessary.

**Special Considerations in Managing FT**

**Young adults**

Case 2 exemplifies several distinct considerations and the natural history of FT for young adults (YAs) with cancer. Gaps in and lack of insurance coverage can result in financial devastation for such patients. Because lack of or limited insurance coverage is associated with delays in diagnosis and more advanced-stage disease, securing and maintaining effective public or private insurance coverage is the most pressing issue to address in case 2 to ensure that this patient obtains comprehensive workup and treatment without delay.

Not all YAs (aged 18–39 years) have the public insurance option that this patient secured as part of the Breast and Cervical Cancer Prevention and Treatment Act, allowing states to offer Medicaid coverage for patients diagnosed with breast or cervical cancer through the National Breast and Cervical Cancer Early Detection Program. There are state-by-state variations in Medicaid expansion, eligibility criteria, and coverage type, and patients with other types of cancer do not necessarily have similar public insurance options. Ms. B’s young age and stage in life make her particularly vulnerable to financial hardship. Lack of or limited health insurance coverage, lack of employer-based health insurance benefits, and lack of savings are common among young individuals with cancer. Furthermore, adequate psychosocial support resources are more limited for this age group. To a large extent, this patient has already sustained long-term financial damage because she already has substantial debt. Furthermore, there is a considerable risk that her future earning potential and career trajectory have been negatively affected, demonstrating in this case one example of the many harms of FT for younger individuals with cancer.

Increasing evidence exists for the uniquely harmful impact of FT on AYAs (aged 15–39 years), not only during cancer treatment but well into survivorship. In the Adolescent and Young Adult Health Outcomes and Patient Experience (AYA HOPE) study, 51%, 70%, and 65% of survivors aged 15 to 20, 21 to 29, and 30 to 39 years reported that their disease had a negative financial impact. Under the Affordable Care Act, young patients can access private health insurance using parental plans’ dependent coverage provision until age 26 years. This policy may partially protect patients in this youngest subgroup from FT after a cancer diagnosis. For example, a recent study of AYA patients with cancer identified that individuals with cancer between ages 26 and 39 years were significantly more likely to report a negative financial situation than those between ages 15 and 25 years (77.8% vs 37.5%, respectively). Although dependent coverage has increased insurance coverage for AYAs in general, this case illustrates the particular financial vulnerability of YAs diagnosed or coping with disease after age 26 years.
### TABLE 4. Selected Informational Resources That Address Aspects of Care Delivery and Survivorship That Can Impact Financial Toxicity (FT)

| PROFESSIONAL SOCIETIES AND AGENCIES | RESOURCE | AUDIENCE(S) | ASPECTS OF CARE DELIVERY AND SURVIVORSHIP THAT CAN IMPACT FT |
|-------------------------------------|----------|-------------|----------------------------------------------------------|
| National Cancer Institute           | cancer.gov/about-cancer/managing-care/track-care-costs/financial-toxicity-pdq | Providers and patients | • Financial navigators’ role in community and academic oncology practice settings described  
• Price transparency concept described, but high-level evidence is not yet available whether providing price transparency would alter patient or clinician choices for cancer care  
• Value-based pricing concept described, including its use for other conditions (eg, hypertension, diabetes), with evidence supporting increased use of higher value services, although the concept has not been routinely applied in oncology care  
• Health insurance reform as a potential policy-based intervention strategy for reducing financial distress in patients with cancer described as a potential adjunct to patient (individual)-level intervention strategies |
| American Cancer Society             | cancer.org/treatment/finding-and-paying-for-treatment/managing-costs/the-cost-of-cancer-treatment.html | Patients | • Addresses discussions with the care team and health insurance coverage  
• Provides education and guidance on the sources of medical expenses related to cancer treatment, what to ask the health care team about the costs of cancer treatment, and what to ask related to health insurance coverage of treatment |
| Oncology Nursing Society            | voice.ons.org/news-and-views/aprns-can-help-address-global-financial-toxicity | Providers | Aspects of Oncology Care Model described, including the goals of improving quality and reduce health care expenses, increase their use of high-value services, and decrease their use of unnecessary services  
Cost discussions: Clinicians’ considerations for discussing costs with patients and ensuring that patients understand the goals of care, understanding the prevalence of financial burden, and recommendation to focus on eliminating the use of low-value tests and interventions are described |
| American Society of Clinical Oncology (ASCO) | cancer.net/sites/cancer.net/files/cancer_survivorship.pdf | Patients | Education/information resource for patients to:  
• Investigate other sources of income if unable to return to work (eg, long-term disability insurance, life insurance policies, retirement plans, Social Security Disability Insurance, etc)  
• Organize bills  
• Make an appeal to insurance or request to consider payment in full  
• Talk to creditors  
• Ask for help (formal sources, such as social worker, patient navigator; informal sources, such as friend, family) |
| ASCO                                | choosingwisely.org/wp-content/uploads/2015/02/ASCO-Choosing-Wisely-List.pdf | Providers and patients | Choosing Wisely Campaign identifies low-value or high-value clinical practices that are recommended, although no specific recommendations on the impact on or management for financial toxicity |
| National Comprehensive Cancer Network (NCCN) | nccn.org/patients/guidelines/content/PDF/distress-patient.pdf | Providers | NCCN Distress Thermometer and Problem List provided as a public resource and instrument to identify patient psychosocial distress and concerns; financial concerns are a subset of practical concerns |
| ASCO                                | asco.org/news-initiatives/current-initiatives/cancer-care-initiatives/value-cancer-care | Providers | Value framework presents a method to quantitatively assess relative value of cancer therapies by calculating Net Health Benefit scores and including outcomes and costs, although the perspective on cost burden is not solely patients’ perspective |
| National Comprehensive Cancer Network Evidence Blocks | nccn.org/guidelines/guidelines-with-evidence-blocks | Providers, patients, and other stakeholders involved in treatment decision making | Evidence blocks are a tool provided to convey consensus expert assessments of treatment efficacy, safety, quality and consistency of evidence, and affordability and help providers and patients make informed choices about therapies, although the perspective on cost burden is not solely patients’ perspective. |
Challenges exist to providing the comprehensive support for managing FT that younger adults need. It is imperative to understand all aspects affecting a young patient’s current and future financial stability, including financial stability and literacy, education and work experience, psychosocial health and support system, and clinical care needs, including oncofertility service and insurance coverage needs. The patient in case 2 needs similar immediate referrals as in case 1 for social work and navigation to assist her in securing and renewing health insurance and identifying resources for housing, transportation, food, and direct assistance. In addition, she may need further guidance about obtaining work accommodations and applying for disability benefits. Few young patients receive cancer treatment at a center with direct access to vocational counseling. Yet vocational counseling is a critical support need for this patient, who has just started her career and has concerns that she needs to pivot because of her treatment and its side effects. In the absence of integrated vocational counseling, online resources (eg, Cancer and Careers) also contain information to guide YAs in navigating cancer treatment and their professional careers. Given the relatively short treatment in this patient’s case, support should focus on maintaining and extending health insurance coverage along with her return to work or her need to pivot careers. An early return to stable employment and securing health insurance without gaps in coverage might mitigate ongoing financial hardship and help decrease the chance that long-term surveillance and survivorship care are not sacrificed in the future. A tailored financial navigation assessment and referral plan for case 2 would include an evaluation of Ms. B’s eligibility to remain covered under her Medicaid insurance after chemotherapy and radiation treatment are complete. It would also include a discussion of how she may obtain insurance with her current employer, Supplemental Security Income, or Health Insurance Marketplace options. The concept of a tailored approach to mitigating FT in younger patients with cancer is the subject of an ongoing trial (Improving Health Insurance Experiences for Adolescent and Young Adult Cancer Patient; ClinicalTrials.gov identifier NCT04448678) (Table 2).

Patients experience severe psychosocial distress from the cancer diagnosis itself combined with worry about their current and future ability to sustain treatment and financially support themselves and their dependents. As a result, FT can contribute to a cumulative emotional toll on YAs. Therefore, social work and navigation assessments are critical for connecting the patient with peer-support programs and community resources targeted to YAs (eg, Samfund/Expect Miracles Foundation, Elephants and Tea, Stupid Cancer, Cervivor.org, etc). These resources can provide complementary information and resources to address everyday financial challenges faced by YA cancer survivors—challenges because of the burden of student loans along with disruptions in school and delaying the first job, childcare needs or stressors related to becoming a new parent, and concerns about feeling behind peers.

Patients may not be fully aware of the roles and functions of the nonclinical adjacent professionals, including social workers, on their health care teams. In case 2, the patient declined social work referral. Clinicians can promote timely referral and encourage patients to use psychosocial care. Finally, as in case 1, the oncology provider team can integrate clinical management strategies into a comprehensive multidisciplinary FT management plan. For example, the patient in case 2 would benefit from her oncologists’ assessment of her ongoing peripheral neuropathy to address the impact of her symptoms on her ability to maintain activities of daily living, sustain current employment, and re-engage her long-term vocational aspirations. Benchmarks identifying whether FT in case 2 was addressed are whether the patient can live independently without financial support (such as from parents) and return to a career.

**Cultural factors**

Patients from under-represented and under-served populations, such as immigrants, minority groups, rural populations, and non-English speakers, face complex health systems challenges. One barrier to FT intervention can be patients’ reluctance to talk about financial issues related to medical mistrust among populations who have faced discrimination in health care. Furthermore, patients who speak English as a second language may need cultural tailoring of financial navigation services or language assistance to

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**TABLE 4. (Continued)**

| PROFESSIONAL SOCIETIES AND AGENCIES | RESOURCE | AUDIENCE(S) | ASPECTS OF CARE DELIVERY AND SURVIVORSHIP THAT CAN IMPACT FT |
|-------------------------------------|----------|-------------|--------------------------------------------------------------|
| Avalere Health (on behalf of Robert Wood Johnson) | essentialhospitals.org/cost-care/practice-briefs/ | Providers, patients, and other stakeholders involved in increasing cost of care discussions | Practice Briefs provided as actionable resources to clinicians, staff, and practice administrators; key topics:  
  - Information on the burden of indirect costs of care (eg, transportation, childcare, and lost wages)  
  - Suggestions for how to welcome cost-of-care conversations in practice and ready-to-use examples  
  - Considerations for workflow modifications and addressing barriers to cost-of-care conversations in organizations and clinical settings |

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complete complex paperwork to apply for insurance and financial resources. Undocumented immigrant patients who are unable to qualify for health insurance may have heightened FT risks. Oncology provider teams must also be aware that solely having a translator during oncologist visits may not be adequate for patients to fully understand and access the care and resources needed. In such instances, local community health workers and community organizations are critical partners to primary oncology providers and associated health systems. Community health partners can offer culturally specific resources accessible in the communities where patients live and work. Community health workers with cultural knowledge and experience can bridge patients’ understanding of medical and financial issues.103

Conclusion
Approaches to FT screening and management for patients with cancer highlight the clinical and nonclinical factors oncology providers must consider when integrating strategies to mitigate FT into clinical treatment decision making and coordinated care delivery. Therefore, social workers and nurse navigators who are leading financial navigation interventions need collaboration with multidisciplinary health care team members, including clinical providers, to implement financial navigation as a standard component of high-quality cancer care. Oncologists not only can champion the direct efforts of financial navigators but also can support a tailored navigation approach by incorporating patient needs based on age and stage in life, employment, socioeconomic and cultural factors, clinical trajectory, and goals of care when integrating FT factors into treatment decisions and streamlined care. Prospective and randomized studies are ongoing and remain needed to generate high-level evidence and novel insights for refining patient-level FT interventions in oncology practice.

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