Managing Financial Toxicity: Patient Experience, Gaps, and Unmet Needs—Executive Summary

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Background

Financial toxicity—the physical, material, and psychological burden that results from the high costs of medical care—has emerged as one of the most consequential yet under addressed barriers to health for patients living with serious illness and the caregivers who support them. Studies have documented substantial financial hardship among patients and caregivers affected by serious illness; in one study, more than half of adult cancer survivors reported experiencing financial toxicity.[1–4]

In 2024, U.S. out-of-pocket health care spending exceeded $550 billion, a 5.9% increase from 2023.[5] One component of this spending is cost sharing, which requires patients to pay a portion of the cost of covered health care services through deductibles, copayments, and coinsurance. Although originally designed to encourage more efficient use of health care resources, cost-sharing obligations can create substantial affordability barriers for people who require ongoing care. As these obligations accumulate, patients and caregivers may face medical debt, depleted savings, workforce disruption, and cost-related coping mechanisms such as delayed care, skipping provider visits, and rationing medications.

Together, these financial consequences and resulting disruptions to care illustrate how financial toxicity undermines treatment adherence, erodes quality of life, and threatens the health and well-being of patients, caregivers, and their families. Addressing this burden requires a multisector, multistakeholder approach centered on patient and caregiver needs.

Approach

This project was initiated to understand perspectives on financial toxicity and health care cost sharing and the related challenges facing patient and caregiver communities. To inform this work, the NHC conducted a scoping review in 2025 of published and gray literature from 2020 to 2025 and convened three virtual listening sessions with patient advocates in April 2026 (n=23 total participants). Participants represented a range of disease and advocacy areas and professional roles, could speak to community, research, or policy perspectives, and were recruited through purposive and convenience sampling.

Participants

Among the 23 participants, 74% identified as female and 65% as non-Hispanic white. Participants also identified as Black or African Americans (29%), Asian Americans (4%), Hispanic or Latino (4%), or two or more races (9%).

Participants represented all four U.S. Census Bureau regions: Northeast (48%), South (22%), Midwest (13%), and West (9%). Geographic region was not reported for two participants (9%). Most participants represented patient organizations (87%) with others representing partners of patient organizations (13%).

Results

The scoping review identified four major factors contributing to financial toxicity: limited transparency in communication about cost sharing, complexity of coverage, gaps in health insurance literacy and support, and insufficient coordination across overlapping policy reforms. The findings from the listening sessions support these themes while also providing additional insight into how patients and caregivers experience these challenges in practice. Participants described policy and structural barriers, complex insurance navigation, indirect costs, caregiver burden, communication challenges, and emotional impact, all of which contribute to financial toxicity.

Both the scoping review and listening sessions highlighted the importance of transparent and accessible communication about cost-sharing requirements and insurance benefits. Unclear pricing, inaccessible language, and limited awareness of patient rights can create stress, fear of cost, and frustration among patients, caregivers, and the advocates who support them.

Listening session participants also described how financial toxicity can affect many areas of patients' and caregivers' lives, including their ability to access transportation, afford daily living expenses, maintain employment, and avoid income loss.

The complexity of health insurance requires patients to manage their health while also understanding their coverage and determining how to pay for treatment. At the same time, caregivers often act as health insurance navigators without training or support. Participants reported that patients and caregivers are forced to make important decisions without fully understanding their insurance benefits, appeal options, or rights. They also may encounter coverage and administrative barriers that vary according to their conditions or personal circumstances.

Many policies, including laws promoting price transparency and reforms to step therapy and prior authorization, aim to make health care more affordable. However, without sufficient coordination, these efforts can create inconsistent and overlapping rules that patients, caregivers, and providers must navigate, potentially contributing to financial toxicity. Participants reported that inadequate implementation and oversight can produce unintended consequences, for the very individuals they were designed to support, such as medication affordability issues, financial trade-offs, delayed care, and medical debt.

Together, these findings suggest that financial toxicity is shaped not only by the cost of care but also by how insurance coverage and affordability policies are communicated, navigated, implemented, and coordinated.

These findings informed the recommendations organized by stakeholder group below.

Recommendations for Key Stakeholders

Policy Makers	• Evaluate the real-world impact of insurance policies and policy changes on patients to ensure they achieve their intended goals and minimize unintended financial burdens. • Design policies that capture the full patient journey, including indirect costs such as transportation, caregiving responsibilities, lost income, and employment disruptions. • Reduce cumulative cost-sharing burdens for individuals that are living with multiple chronic conditions rather than addressing conditions individually.
Providers	• Incorporate financial counseling into patient care so that patients can anticipate, understand, and manage health care costs. • Ensure that patients have a centralized list with information on how to access services from financial navigators, patient navigators, social workers, and other support personnel throughout the care process. • Provide transparent and proactive education regarding all unexpected components of specialized care, such as the need for specific medication and treatments, additional appointments, or advanced caregiving needs. • Recognize transportation, caregiving, family impacts, and other non-medical barriers that may interfere with treatment and adherence to care. • Develop alternative administrative and financial strategies to provide care for patients who are experiencing financial toxicity.

Patient Organizations	• Develop and validate financial toxicity assessments that combine standardized measures with qualitative approaches to better understand and consider cost trade-offs, emerging health care challenges, patient experience, and other contextual factors. • Patient organizations should advocate for policies addressing the combined effects of financial toxicity, administrative burden, and time burden, as well as advocating policies to help reduce the overall burden on patients and caregivers. • Raising awareness on the financial challenges that caregivers experience and advocating policies that address caregiver-specific burdens, such as missed work, travel, employment flexibility, and mental health. • Advocate for policies that address indirect costs associated with illness. • Reduce financial -struggle stigma by fostering open communication, building trusting relationships with patients, and connecting patients with appropriate financial support services. • Make patients experiencing financial toxicity aware of financial assistance and charity care.
Health Insurers/Payers	• Improve communication and transparency of cost-sharing requirements, insurance benefits, coverage limitations, and patient financial responsibilities by using accessible and clear language. • Reduce financial barriers that lead to treatment delays, discontinuing care, and reduced adherence from integrated care models. • Consider waiving or lowering copayments that discourage access to medically necessary services in integrated care models.

Conclusions

Financial toxicity remains a barrier for patients and their caregivers across different disease areas. These findings suggest that financial toxicity is driven by interconnected health care, insurance, and policy barriers that affect patients throughout their health care journey. Reducing financial toxicity will require efforts that extend beyond lowering health care costs to include providing transparent, accessible information about cost-sharing requirements and insurance benefits, simplifying health care and insurance navigation, and strengthening the implementation and coordination of existing policies.