Managing Financial Toxicity: Patient Experience, Gaps, and Unmet Needs

September 2026

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Escontrías, OA., Schoch, S., Witting, L., Lopez, C., & Quiroa, F. (2026, September). Managing financial toxicity: Patient experience, gaps, and unmet needs. National Health Council.

Executive Summary

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 2022.[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 in Table 1.

Table 1. 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.

This project was made possible with the support of Novartis, Bristol Myers Squibb, Johnson & Johnson, and Eisai Co., Ltd.

Background

Understanding financial toxicity is critical to improving health care delivery, shaping public policies, and informing treatments decisions that are meaningful to the patient community. Patients, caregivers, and advocates are uniquely positioned to offer insights into the real-world financial challenges that patients and families face. These challenges may include cost-sharing requirements and other out-of-pocket costs, insurance and access barriers, and the trade-offs individuals make when managing both their health and financial needs. Listening sessions with patient communities can help identify cost-sharing challenges, patient perspectives on financial toxicity, gaps in payer processes, and downstream treatment needs.

For the purposes of this work, the National Health Council (NHC) defines financial toxicity as: *financial distress that stems from competing demands between direct and indirect health care costs.*

Financial toxicity has become a serious issue, with rising health care costs over the last decade placing undue financial strain on patients.[5] For patients with lower household incomes in particular, health care costs may compete with other necessary expenses such as housing, transportation, and food. One source of financial pressure is cost sharing, requiring patients to pay a portion of covered health care costs through deductibles, copayments, and coinsurance. These requirements can increase patients' out-of-pocket expenses and create barriers to necessary care.[6] The impact of cost sharing is often evaluated primarily through an economic lens, without accounting for how other aspects of a patient's and caregiver's life are affected. Patients may also experience difficulty understanding the complexity of different programs, plans, or policies, and limited health insurance literacy often prevents patients from fully utilizing their benefits. These challenges can put patients at a disadvantage in managing their own care.

The NHC sought to explore patient advocate perspectives on financial toxicity and cost sharing to better understand the challenges individuals face when accessing and affording health care. As part of a two-phased approach, the NHC conducted a scoping review in 2025 of published and gray literature to identify existing evidence, key themes, and knowledge gaps related to financial burden in health care. Building on these findings, the NHC convened three virtual listening sessions in April 2026 with patient advocacy organizations and other nonprofits to gather perspectives on their constituents' experiences with navigating cost sharing, health care costs, insurance coverage, and financial decision-making. Together, these activities formed the basis for this report's findings and highlighted opportunities to advance patient-centered outcomes.

Objective

The aim of this project was to better understand how patient advocates perceive and address issues related to financial toxicity and health care cost sharing within the communities they serve. Through an in-depth scoping review and listening sessions, the NHC explored topics including:

- Patient and caregiver experiences with cost sharing, and how it informs patient organization policy priorities.
- Patient and caregiver experiences with lack of transparent pricing, coverage, confusion, and overlapping policy reforms.
- Further areas of research in cost sharing and financial toxicity.

Methods

The NHC employed a mixed-methods approach consisting of a scoping review of published and gray literature and a series of qualitative listening sessions. **The 2025 scoping review identified existing evidence, key concepts, and knowledge gaps related to financial toxicity and health care cost sharing. To build on these findings, the NHC convened three virtual listening sessions in 2026 with 23 patient advocates representing a range of disease areas and patient communitie**s. Findings from both activities were synthesized to identify common themes and recommendations.

To remain patient-centered and objective in all its research and programmatic activities, the NHC traditionally engages patient advocates and individuals familiar with the patient community to moderate or facilitate listening sessions, focus groups, and advisory committees. This project was conducted with the assistance of a patient moderator and a government relations & advocacy executive from a national patient advocacy organization.

During the listening session, the patient moderator reviewed the discussion guide, supportive documents, and led all the discussions. An objective facilitator affords participants the opportunity to share their perspectives openly. In turn, the NHC staff focused on observing, taking notes, and identifying emerging themes through a rigorously qualitative approach.

Timeline

January-October 2025	Project Initiated and Scoping Review Completion
April 2026	Three Listening Sessions Completed
June 2026	Synthesis of Findings Completed

Scoping Review Methodology

Scoping review methodology was applied to systematically explore available literature published between 2020–2025 that identified core topics and knowledge gaps. A thorough literature search was conducted across four databases and search platforms: ProQuest, Google Scholar, PubMed, and PoliticoPro. Search terms included patient experience, patient, cost sharing, financial burden, financial toxicity, payer, insurance, 340B, and utilization management. Sources were limited to English-language materials, including peer-reviewed articles journal articles, and gray literature such as white papers, policy documents briefs, and dissertations. A total of 100 sources were identified with 45 full text sources referenced. A mix of inductive and deductive analysis was used to identify major themes.

Listening Sessions Methodology

Each listening session was audio-recorded, transcribed, and qualitatively analyzed in a double-blind coding round by two mixed-method researchers. The NHC's Chief Programs & Research Officer and Senior Director of Research & Programs provided oversight of the analysis, and the Manager of Research & Programs conducted the scoping review.

All participants met the eligibility as described in Table 2.

Table 2. Eligibility

Inclusion Criteria
1. Participant is a representative of a current member of the NHC. 2. Participant is employed by a patient advocacy or research organization that is categorized as a nonprofit. 3. Participant can speak to community, research, or policy perspectives of cost sharing or financial toxicity.

Listening Sessions Recruitment

Recruitment efforts sought to capture diverse perspectives across disease and disability communities and organizational roles, with an emphasis on individuals with expertise in patient access, affordability, value, advocacy, and policy issues related to financial toxicity (Appendix I). A combination of purposive and convenience sampling was used to recruit participants. Participants were identified through professional networks and organizational outreach. The NHC also advertised recruitment through its weekly *Insider* newsletter and *NHC Connect* (online community for NHC membership).

The NHC sought to enroll participants with heterogenous backgrounds in terms of job role, dual patient/caregiver status, race and ethnicity, and gender/sex. In alignment with the NHC's Patient Engagement Fair-Market Value Calculator, participants were compensated $100 for their involvement in this project.

Ethics

Prior to each listening session, participants were informed about the purpose of the discussion and asked to provide verbal permission for the session to be audio recorded for notetaking and analysis. To promote open discussion and reduce the potential for bias, the NHC engaged an independent moderator with experience working alongside patient communities to facilitate the sessions, while NHC staff served in an observational and note-taking capacity.

Discussion Guide

The NHC utilized information and themes derived from the scoping review to prioritize the questions for the listening sessions. Main questions included:

1. Cost sharing mechanisms were an important factor that emerged as a way for patients to manage financial toxicity. How have patient experiences with these cost sharing measures informed your policy priorities?
2. Based on the themes that emerged from the scoping review, how have you seen issues like lack of transparent pricing, confusion over coverage, and overlapping policy reform efforts affect your organization and patient or caregiver constituency?
3. Looking at the four areas of further research that were found, do you agree with these gaps? Are there other topics of interest that you think should be considered?
4. What would you identify as a question for further research or want more information on a topic already identified?

Analytical Approach

A mixed deductive and inductive approach was used in the thematic analysis. After transcription coding, the frequency of each theme and subtheme was calculated for each listening session. Frequencies were then summed across all three listening sessions to determine the total number of occurrences for each theme and subtheme. Themes and subthemes were ranked based on their total frequency, and their percentages were calculated using the total number of coded occurrences (n=112).

Findings

Scoping Review

Cost sharing has evolved as a feature of health insurance benefit design. The Patient Protection and Affordable Care Act (ACA) enacted coverage provisions that took effect in 2014 as an attempt to establish protections and limits related to cost sharing as part of broader efforts to combat rising medical costs.[7] Over time, however, cost-sharing requirements and related insurance programs, plans, and policies have become increasingly complex, creating confusion for patients and prompting policy efforts to address these challenges.

Four overarching themes emerged from this scoping review: 1) Need for transparency, 2) Complexity of coverage, 3) Health insurance literacy, and 4) Overlapping policy reform.

1. Need for Transparency

The scoping review identified a need for clearer, more comprehensive communication on cost-sharing requirements, including pricing and benefits, and for greater transparency in data collection. Patients often face shifting cost of insurance plans and surprise billing for services, medications, treatments, or equipment, contributing to financial toxicity.[8] Some recommendations have proposed reforming payment models by bundling costs across the care continuum, from diagnosis through treatment, to give patients a clearer understanding of their financial responsibility.[9] Policies such as the *Patient Right to Shop Act*, the *Lower Costs, More Transparency Act*, and the *PATIENT Act* include overlapping approaches encouraging patients to choose lower-cost providers, strengthening hospital/insurer/pharmacy benefit managers (PBM) reporting, and promoting public online posts on pricing.[10–12]

In addition to confronting opaque pricing, patients must navigate insurance plans that vary widely in their coverage, making it difficult to understand their benefits. The *No Surprises Act* seeks to help patients make informed decisions by requiring an advanced explanation of benefits. However, this policy does not address the additional administrative work needed to comply with that request.[13] There have also been calls for additional transparency in data collection on the impact of cost sharing on patient affordability. Making these data publicly available would help stakeholders understand the impact of the adoption of new methods by providers.[14]

2. Complexity of Coverage

Tool like utilization management (UM) were employed by plans in an attempt to address high health care costs. However, these mechanisms are often not well understood by patients and have become increasingly complex to navigate. UM was first implemented to evaluate the necessity of medical services through mechanisms like prior authorization, concurrent review, and retrospective review curbing unnecessary drug use that could decrease costs.[15] Yet these mechanisms can vary across plans and research has shown that these processes, especially prior authorization, often do no align with clinical guidelines for specialty drugs and hinder patient access to necessary treatments.[16,17] Organizations such as America's Health Insurance Plans (AHIP), in collaboration with Centers for Medicare and Medicaid Services, released a 2025 statement indicating their commitment to advocating for prior authorization improvements including standardizing electronic prior authorization, ensuring continuity of care when changing health plans, and enhancing communication and transparency on determinations.[18]

The 340B Drug Pricing Program was established in 1992 by Congress to allow health care entities to purchase outpatient prescription drugs at lower prices from manufacturers. In October 2025, the U.S. Senate Committee on Health, Education, Labor & Pensions (HELP) held a hearing examining the impact of 340B noting that health care costs have risen as a result of the program due to limited oversight and making employer-sponsored care less affordable.[19] The Government Accountability Office (GAO) has made over twenty recommendations to reform the 340B program including establishing more specific guidelines on the definition of a 340B patient, strengthening criteria for hospitals to be eligible for the 340B program, and that should be issued to prevent duplicate discounts under Medicaid managed care. Although some analyses suggest that 340B revenue may support safety-net providers and community services, there is little empirical evidence demonstrating that these benefits are consistently realized at the individual patient level.[20] Most studies focused on system-level changes, including shifts in site of care and program spending, rather than patient-centered outcomes such as out-of-pocket costs, access to medications, or clinical quality. As such, significant gaps remain in understanding the program's impact on patients, particularly among vulnerable populations.

3. Health Insurance Literacy

Patients are still struggling with rising health care costs and often lack the support or knowledge needed to access the insurance plans that best support their care. For example, a significant amount of financial toxicity literature is focused in oncology, with Medicare Part D prescriber public use files indicating

that patients with cancer are disproportionately contributing to Part D drug spending compared to other disease categories.[21] When asked about financial burdens in a qualitative 2022 study, cancer patients often mentioned a fear of unknown costs or how their drug benefits were structured.[22] A 2024 survey study of over 1,500 patients with either a cancer diagnosis or auto-immune condition showed that a majority of patients facing financial toxicity wanted to have cost discussions but did not receive it and preferred when physicians considered outof-pocket costs, ensuring patients' affordability for prescriptions.[23] Additionally, a 2021 study focused on patients with headaches and migraines who were of lower socioeconomic status (SES) and diverse populations found that there was a lack of information on accessibility or reimbursement for nonpharmacological treatments.[24] A study on patient factors associated with adult primary care and across racial/ethnic groups revealed inequities in health care utilization dependent upon household income, copays, and distance from care during the COVID-19 pandemic.[25] People with disabilities exhibit significant disparities as un- or underinsured individuals who may not qualify for social security programs. If insured, plans for people with disabilities often do not cover needed health services or medical equipment.[26] A 2023 review explored the impacts of coverage expansion related to financial toxicity with cancer patients, however proposed coverage reforms, such as high-deductible plans, were still likely to increase out-of-pocket costs,[27] and patients were less likely to be knowledgeable of these coverage reforms. The fact that the attempts to address financial toxicity exacerbate the issue highlights a concerning need for further discussion on other possible cost-lowing interventions and unmet educational needs for patients to better understand benefits and access care.

4. Overlapping Policy Reform

Rising drug and treatment costs have driven more, and often overlapping, legislative approaches to cost sharing and utilization management, adding to the complexity patients already face. For example, the Safe Step Act introduced in 2025 addresses concerns with step therapy by requiring insurers to provide timely exceptions for medically necessary treatments. While there have been multiple proposals to improve price transparency, there remain differences in approach and lack of consensus across policies risk making an already complex system even harder to navigate, unintentionally adding to the financial toxicity burden. Given that prior authorization requests vary by program and request types, in 2026, the Centers for Medicare & Medicaid (CMS) updated its policy guidelines emphasizing transparency, and accessible reporting of prior authorization metrics across various payers. As policymakers consider next steps, there is an opportunity to focus on developing new tools to address financial toxicity and ensuring that proposed public policies are coordinated, patient-centered, and designed to make the system easier to navigate.

Areas for Further Research and Action

The health care system is difficult to understand for patients, and complicating factors like cost sharing, prior authorization, step therapy, and other cost concerns are not experienced in isolation. They are layered together in ways that can make it harder for patients to access care, understand their options, and plan for costs. This scoping review explored literature that highlighted four gaps in research on financial toxicity management.

1. Inconsistent Financial Toxicity Measurement Tools

While there is a need for more data transparency to measure the impact on financial toxicity, financial toxicity measurement tools themselves are not standardized to capture the patient experience. Within the clinical workflow, the patient desire for payment conversations does not align with provider expectations in initiating or handling financial conversations. A 2020 pilot survey of oncologists at an academic medical center found that OOPC and insurance design knowledge were associated with cost discussions, but lack of cost health literacy prevented physicians from feeling that they could impact financial toxicity.[28] Additionally, another 2020 survey of oncology residents from across the U.S. found that a majority were uncomfortable managing financial toxicity for patients.[29]

These conversations can be facilitated through validated financial toxicity measurement tools. Such tools include the DISCO app, which provides videos "about treatment costs, ways to manage costs, and the importance of discussing costs with oncologists" and can tailor imputed socio-demographic information into questions for patients to ask their providers.[30] A method often used to identify financial toxicity is the Comprehensive Score for Financial Toxicity (COST) tool, a self-reported survey assessment that correlates financial toxicity with healthrelated quality of life.[31] Yet this tool has been limited by time constraints and how providers can fit this into their clinical workflow which increases the need for more administrative support.[13,32]An abbreviated COST assessment reduces the number of questions asked which can shorten the time it takes to implement.[33] Other cost tools such as the Real Time Prescription Benefit are meant to connect to electronic health records and provide prescribers with cost information for them and the patient to make informed decisions, but currently do not have clear insurance or quality of information to effectively facilitate conversations or referrals.[34] Many of these tools require further validation, and their inconsistent use and a lack of standardized measurement is an area for further study.

2. Financial Toxicity Information Sharing in Care Delivery

Complex plans often dissuade patients from engaging in health systems, yet private and public assistance programs attempting to address patient needs often add another level of complexity that exacerbates financial toxicity. Copay accumulator and maximizer programs were created by insurance companies and PBMs to manage costs. However, these programs can increase out-of-pocket costs for people with lower incomes and shift costs from insurance to manufacturers, employers, and patients.[35]

Public assistance programs have also been on the rise; however they are often hindered by administrative burden, leading to increased wait times and medication delays.[36] These programs can also face unclear eligibility criteria for grants or other financial support which can discourage patients from applying.[26] A 2025 study interviewing payers and executive leadership in kidney care and dialysis centers about the expansion of Medicare Advantage to include end stage kidney disease found that it was not inclusive enough to incentivize patients to use the program, since other parts of their care teams, like dieticians, were not covered.[37] This particular example illustrates that programs developed for patients with complex or rare conditions need more patient engagement early in development to ensure patients have access all members of their care teams.

Navigating financial concerns often requires patients to understand substantial amounts of non-clinical information, raising questions about how that information should be communicated and what role providers should play. Physicians face substantial clinical and administrative demands, warranting further research on how other staff could provide additional administrative support.[38] Studies have begun examining the impact of shifting administrative burdens by providing patients with specialized staff who were equipped to answer financial questions. A 2022 study found that patient physical and mental outcomes were improved when nurse navigators and pharmacy technicians were trained to intervene on financial toxicity.[39] In 2023, initiatives such as equipping oncology staff for initial financial toxicity screening and utilizing other staff to help process and allocate resources could help ease patient economic burden.[40] A 2024 pilot program paired COST tools with referrals to financial social workers and ley hospital workers and reported significant patient satisfaction post-intervention.[41] Additional research is needed to explore the level of comfortability and trust between patients and their health care providers and other administrative staff when discussing financial decision-making.

3. Policy Improvements

As payers and programs are subject to oversight and regulation, changes in policy can have widespread impacts on how cost sharing evolves. For

example,addressing the need for clearer pricing transparency hinges on legal and regulatory barriers that “impede flow of price information,” which would require payers to provide updated pricing education or even abide by set prices instead of differing between insurers.[8,42] Other research examined potential reforms to restructure payment systems towards integrated or global payment models that would bundle all the payments through the care continuum into one number that could shift away from fee for service model and encourage collaboration.[9,43]

Monthly caps is a theoretical payment reform that has also been considered to clear patient expectations by cushioning them from varying deductibles and reducing financial strain for both one-time events or long-term care.[44] A 2022 study examining impacts from the first five years of the ACA implementation found that while the first three years showed an association with improved patient experience and decreased out-of-pocket costs for low income individuals, health care utilization and total cost of care did not rise which suggests that coverage changes may not be enough.[45] According to Congressional Budget Office estimates reported by the Center on Budget and Policy Priorities, the passage of H.R. 1 and changes to the ACA, including the expiration of the enhanced premium tax credits will result in roughly 15 million people losing health coverage by 2034, including approximately 7.5 million individuals losing Medicaid coverage.[46] These policy changes in coverage will have immediate, direct consequences, pushing the need for more evidence to understand long-term financial toxicity burdens within patient communities.

4. Understanding Patient Financial Priorities

Simplifying plan benefits and coverage opens the opportunity for financial prioritization for patients. Health insurance contracts and educational materials may describe cost-sharing requirements, but patients may still be expected to make complex coverage and payment decisions without the medical, legal, or actuarial expertise needed to understand their options.[42] Studies on the ACA expansion have found that total health costs were not significantly impacted while lowered out-of-pocket costs were offset by higher deductibles and premiums, leading to increasing prices incentivized by a fee-for-service care delivery system suggesting that insurance reform was insufficient to change the quality of care or ease financial burden of patients.[45,48] Further research is needed to support implementation of multi-disciplinary approaches, recentering patient priorities to incentivize value-based health care and investing in mental and social wellbeing.

Summary

Overall, the literature highlights patient frustration and confusion due to the complexity of cost-sharing mechanisms and the lack of transparency on coverage, pricing, and data sharing that monitors impact on finances. Utilization management processes and programs such as 340B were initially

created to help lower costs, but added complexity has led to widening disparities in vulnerable populations, exacerbating worsening health outcomes. Lack of alignment in policy development meant to address financial toxicity has led to four areas of further research: 1) Enhanced knowledge of standardization and validation of financial toxicity measurement tools, 2) Determining the responsibility of hospital systems and the role of the provider education regarding financial toxicity assistance and information, 3) Examining the efficacy of cost sharing public policies, and 4) Recentering patient priorities to guide care delivery reform. The central challenge of this review was the inherent complexity of defining financial toxicity, reflecting a burden on patients that is far broader and more systemic than medical debt alone. With a better understanding of the intricacies of the cost-sharing programs, plans, and policies that patients are subject to, we hope that active research and change to delivery systems can mitigate the financial impacts of seeking care.

Listening Session Results

Participants

Twenty-three individuals participated in the listening session. Among the 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%). See Appendix I for a list of conditions and areas of expertise represented by the participants.

Table 3. Listening Sessions Demographic characteristics

Variable	*Participants (N = 23)*	
	Frequency (*n*)	**%**
Sex		
Female	17	74%
Male	3	13%
Prefer not to disclose	1	4%
Unknown	2	9%
Race and ethnicity		
White (NonHispanic)	15	65%
African American/Black	2	29%
Hispanic/Latino	1	4%
Asian	1	4%
Two or more races	2	9%
Unknown	2	9%
U.S. geographic region		
Northeast	11	48%
South	5	22%
West	2	9%
Midwest	3	13%
Unknown	2	9%

Data source: Listening Sessions 1-3 for *Managing Financial Toxicity: Patient Experience, Gaps, and Unmet Needs*, National Health Council. 2026

Listening Session Themes & Subthemes

When discussing financial toxicity and cost sharing, participants most frequently highlighted the following areas of concern and opportunities for improvement:

- Policy and Structural Barriers
- Health Care System & Insurance Navigation
- Indirect Costs Related to Illness
- Emotional Impact of Financial Burden
- Financial Burden of Health Care
- Transparency and Communication
- Caregiver Burden
- Impact on Care Continuity

Note that the purpose of the listening sessions was to highlight the authentic experiences of patients and unpaid family caregivers, the views of their associated patient advocacy organizations, and the changes they would like to see in the system. If these perspectives and experiences do not align with current expectations or other expert perceptions, that gap represents an opportunity further research.

Defining Financial Toxicity

Policy and Structural Barriers

During the sessions, participants identified policy and structural barriers as major factors contributing to financial toxicity. Discussions showed that cost-sharing mechanisms, especially for people living with multiple chronic diseases, can create a cumulative financial burden as copayments and other out-of-pocket expenses increase over time. Participants also described a lack of transparency regarding health care costs, making it more difficult for patients to anticipate the financial impact of their care. Participants brought up systemic issues that work as drivers for financial toxicity. Financial assistance programs address the consequences of financial toxicity rather than the real issues that drive people to seek assistance. Gaps in policy implementation, limited enforcement, and unequal access to health care services can further increase financial strain for individuals who must travel long distances to receive care.

Table 4. Policy and Structural Barriers: Illustrative Quotes

Theme	Illustrative Quote
CostSharing Mechanisms	*"With heart disease…30 or 40% also have depression…[and] lots of metabolic conditions that… need to be addressed. So, I think that* ***it's really important to recognize that cost sharing can disproportionately impact the people who need the care the most****."* *- Participant 1.1 Female, Mental Health Organization Representative* *"…****we increasingly see patients have trouble meeting their cost-sharing. As well as the issues we see with accumulators, maximizers and AFPs [Alternative Funding Programs****]. We have had patients refinance their homes or cars just to afford their medications.****"*** *- Participant 3.3 Female, Patient-Centered Health Care Organization Representative*
Policy Implementation and Enforcement	*"****We often pass laws and then don't work on the implementation and enforcement side.****"* *-Participant 1.3 Female, Autoimmune/Chronic Pain Organization Representative* ***"Financial support and care delivery is about getting people financial assistance, as opposed to addressing the underlying causes of the need for financial assistance****."* *- Participant 3.5 Female, Cancer Organization Representative*
Transparency/Communication Issues	***"I think it is really important for patients to know if they are interacting with a real person or a bot [AI] for transparency purposes****. I think it falls into that category. Complexity of coverage. …… just with the prior authorizations, utilization management, you know, step therapy, all of that…it seems like there's bots on both*

Theme	Illustrative Quote
	sides now, in terms of denials and navigating denials. And then, again, understanding your health insurance, it's helpful to talk to a real person, and a person that has experience in your condition area." *- Participant 1.3 Female, Autoimmune/Chronic Pain Organization Representative* *"I think for our community, especially since we do a lot of copay assistance, too, and we deal with a lot of seniors and those on Medicare,* ***we see a lot of inability to anticipate what the cost is going to be, and they can't plan for deductibles, coinsurance, drug pricing, and they often get financial shock."*** *- Participant 1.4 Female, Patient Advocacy Organization Representative*
Access Inequalities	***"Patients are [navigating] multiple systems ... and some of them are going across state lines just to get what we would consider to be basic care.*** *But they don't have an option because [of] where they live."* *- Participant 2.4 Female, Autoimmune Diseases Organization Representative*

Data source: Listening Sessions 1-3 for *Managing Financial Toxicity: Patient Experience, Gaps, and Unmet Needs*, National Health Council. 2026

Health Care System Navigation / Insurance Navigation

Participants noted the challenges patients face when navigating a health care and insurance system that they do not understand. During the listening sessions, limited insurance knowledge, complex coverage policies, and administrative requirements were identified barriers to patients and caregivers accessing and affording care.

Table 5. Health Care System Navigation/Insurance Navigation: Illustrative Quotes

Theme	Illustrative Quote
Insurance Knowledge & Literacy	***"First is the confusion over coverage…they don't understand their coverage; they don't know how to navigate it****, and that creates a lot of different problems. Including being able to identify the problems that they're experiencing, they just don't know".* *- Participant 3.1 Male, Autoimmune Organization Representative* *"...* ***you're thrown into a system that hasn't been explained to you, that you didn't even know [how] to check within your insurance coverage for what treatment would look like.*** *So having that financial discussion as a walkthrough in the journey would be very helpful, and then, also offer that supportive arm, as there will be confusion over some of the coverage policies.* ***The fact that for an individual to even get lung cancer screening, they have to have this added step of, decision-making counseling. So, that has to happen before the screening can even happen.*** *So that's an overlap, that's a confusion.* ***In fact, when you look at decisionmaking actually is [being]***

Theme	Illustrative Quote
	reimbursed at a higher level than the actual lung cancer screening. There is some ridiculous overlapping and confusion just in the coverage structure, but as a patient, finding out suddenly that you have late-stage lung cancer, you need that transparency and you need a guide.*"* *- Participant 1.2 Male, Cancer Organization Representative*
Need for Support	*"We require [and contract with] social workers to be part of our Centers of Excellence. We've had to, as an organization. [**We] employ 120 social workers nationwide to help navigate [managed care], because families find it so challenging to navigate, finding care, the costs, being able to afford [care].** 90% of families with [rare condition] will be on Medicaid at some point, needing maybe 5 to possibly 15 years of nursing home care. So, it really compounds the complexity and confusion for families and really requires social work and care navigation support."* *- Participant 1.8 Female, Neurodegenerative Disease Organization Representative* *"...**if you live in a place that doesn't have specialists. You know, how do you get to that specialist? And when you do receive a diagnosis of some sort of condition in which your life is completely different from what you knew… you have to start thinking about how does this affect my job, my family, in the vision space, can I get the devices that I need to just navigate my world?** Even if that device is a car being driven by someone else, through Uber. I wish that there was a way to just kind of calculate all of those things, because it really is incredibly life-changing to just live with something, and then just get to the next step."* *- Participant 2.7 Female, Vision Loss Organization Representative*
Coverage Barriers	*"... **All kinds of cost sharing measures** from copay accumulators to prior authorization and step therapy. **All of those things can be huge barriers to care."*** *- Participant 3.7 Female, Cancer Support Organization Representative* *"Our patients also get confused whenever there's, non-medical switching or, you know, any changes to drug tiering and coverage for the medications they might be stable on. **On average, I think it takes our patient community around 2 to 3 years to get diagnosed in the first place, and then another 2 to 3 years to become stable on a medication**. **So this is a long process and very difficult to manage, but on top of that, just knowing what your insurance will cover within the span of that one year, but also beyond that, if coverage changes and different drugs are negotiated at different prices, just, you know, formulary changes or switching is really confusing.** And I would say enter in this direct-to-consumer, kind of model. I think **our patients have a lot of questions and are unsure of what counts and what doesn't, I looped that in with kind of the copay quicksand. Like, you just don't know what counts towards your deductible and what doesn't anymore. And then the other aspect, I would say, is if there is a problem and you do recognize it, and let's say your insurance is not complying with the letter of the law.** Understanding who to report that to."* *- Participant 1.3 Female, Autoimmune/Chronic Pain Organization Representative*

Theme	Illustrative Quote
Administrative	***"I think a lot of these [financial assistance] programs cause a huge administrative burden*** *for patients and families."* *- Participant 3.3 Female, Patient-Centered Health Care Organization Representative*
Appeals	*"Insurance education help[s] with navigating those things… like working with the regulators.* ***People don't understand the appeal process, they don't, you know, a lot of times they don't really understand, you know, how that next step works with going to regulators, whether they're going to be, you know, doing complaints with departments of insurance, or filing a complaint with Department of Labor for those ERISA plans, but it can be very can be very restrictive in some of their coverage policies.*** *So, that's just, you know, a bit of what we're doing there."* *- Participant 1.6 Female, Rare Diseases Organization Representative*

Data source: Listening Sessions 1-3 for *Managing Financial Toxicity: Patient Experience, Gaps, and Unmet Needs*, National Health Council. 2026

Indirect Cost Related to Illness

Participants noted that financial toxicity extends beyond medical expenses. The combined costs of health care and living expenses often leave patients in difficult financial situations. Transportation was mentioned not only as a barrier many patients face but also as a factor that increases the cost of care and living for patients, especially during periods of increased gas prices. Treatment and care can sometimes interfere with a patient's job—often more than they initially expect—and eventually affect their financial situation.

Table 6. Indirect Cost Related to Illness: Illustrative Quotes

Theme	Illustrative Quote
Transportation	*"When you're talking about gas, too, it's not just cars, it's people traveling to centers of excellence and large treatment centers who don't have it in the areas they live to, or they're going to see a specialist somewhere, and the cost to fly or participating in a clinical trial where not all costs are covered yet.* ***The cost to even fly or take a train or anything that is gas-powered with everything going on to get there just compounds the issues even more. It does, and it also removes their layer of support, because caregivers, or the family, or the friend, or the neighbor that would assist now also has to pull back, because it's hardship even for them."*** *- Participant 1.4 Female, Patient Advocacy Organization Representative* ***"There's also this long-distance, like, traveling to a new city, a new state, to get that treatment.*** *And so it's not only what's kind of at paper with the health insurance, but also those additional traveling costs. And*

Theme	Illustrative Quote
	there are some supports, but they are, very, very few and not necessarily accessible to all, so wanted to add that to kind of the picture of traveling to get, medical care." *- Participant 2.9 Female, Caregiving Organization Representative*
Daily living expenses	***"It's not just the medical costs, and whether that's, prescription drugs, whether that's hospital or physician care, it is these other costs.*** *You know, those issues, whether it's transportation, whether it's daycare, or whether it's missed work.* ***Those types of things are [impacting] whether or not people have access. It's not solely just the medical cost itself; it's everything that goes with it."*** *-Participant 3.1 Male, Autoimmune Organization Representative* ***"We all are talking from a general sense about the cost of high gas.*** *From patients, that's a whole other level of toxicity and concerns, because they already have trouble with transportation and access to their treatments.* ***Now you're adding the [compounding factor] of high cost for gasoline to get to their treatments.*** *That's something that no one in the system even thought about."* *- Participant 1.2 Male, Cancer Organization Representative*
Employment/Income Loss	*"At diagnosis of any type of chronic or serious medical condition, people typically are not yet experiencing financial toxicity,* ***because they haven't started treatment, they haven't gotten their first bill, they don't know that they're gonna have side effects that are going to keep them from working, which impact their income, which impacts their financial hardship."*** *- Participant 3.5 Female, Cancer Organization Representative* ***"A patient in our community who didn't realize he had glaucoma and he was a truck driver for the state of North Carolina. Well, clearly, he couldn't do that anymore."*** *- Participant 2.7 Female, Vision Loss Organization Representative*

Data source: Listening Sessions 1-3 for *Managing Financial Toxicity: Patient Experience, Gaps, and Unmet Needs*, National Health Council. 2026

Emotional Impact of Financial Burden

Financial toxicity comes with an emotional component in which patients and caregivers experience fear and anxiety related to the cost of care and unexpected expenses that they may not be able to afford. Managing health care, finances, work, and caregiving responsibilities simultaneously can create emotional stress, and perceived stigma associated with financial burden and inability to afford care often prevents patients from seeking help. Participants also expressed frustration that policy and advocacy efforts do not always lead to meaningful change, leaving many financial challenges unresolved for patients and caregivers.

Table 7. Emotional Impact of Financial Burden: Illustrative Quotes

Theme	Illustrative Quote
Fear of Cost	*"You have to deal with your health care diagnosis but then **trying to figure out how you're gonna receive care and pay for that care is just overwhelming for a lot of patients and caregivers."*** *- Participant 3.3 Female, Patient-Centered Organization Representative* *"I just want to note that lots of times **people want to make this point about preventive care, that if you go in for your preventive visit, it's free, but if you mention anything, or the doctor at that visit addresses any of your conditions, and again, if you have a chronic condition, they may do that, you wind up getting billed."*** *- Participant 1.1 Female, Mental Health Organization Representative*
Stress	***"There's just a lot of noise coming from a lot of different directions, and trying to manage that on top of the million other things our patients are already trying to manage can be exhausting**, and that's if you're doing everything right, and that's we have yet to discuss also, too, what happens if you are living with a chronic condition but are also a single parent, and are a caregiver for another person as well, and trying to navigate all of that and the differences there. **We hear a lot about all of that, and it can just be draining on every level."*** *- Participant 1.9 Male, Neurodegenerative Disease Organization Representative* ***"Then caregivers and patients are put in a really difficult situation of saying, yes, we can afford that, even though they rightly know that they can't, or it might be very difficult, so that their care recipient can get the treatmen**t that they need at the time that they need it."* *- Participant 2.9 Female, Caregiving Organization Representative* ***"Our patients...are embarrassed to share their financial situation**. So these end up being doorknob questions, you know, the health care provider's getting ready to walk out the door. **They say, everything's okay, you're good to go with this medicine, yes, I am, okay, great, and then the patient will have a look on their face of, there's distress, and then we start this whole conversation down what's happening and so, somehow there has to be, comfort in knowing that there's not a stigma that goes with sharing this information.** And there's a stigma, and patients don't, you know, they want help because they need it, but at the same time, they are having a hard time sharing this, you know, this situation with others."* *- Participant 3.6 Female, Respiratory Disease Organization Representative*

Theme	Illustrative Quote
Frustration	***"The frustration of not being able to get things done at the federal level, and our desire to get small wins at the state level does make our job harder, in lots of ways, because the small wins often compromise on language that we'd really rather prefer be at the federal level.*** *We leave out everybody who has a self-insured plan when we're trying to pass insurance mandates. And then that also creates patient confusion because they have been involved in the advocacy efforts and are excited about the win and only to learn that it actually doesn't apply to them."* *- Participant 3.5 Female, Cancer Organization Representative*

Data source: Listening Sessions 1-3 for *Managing Financial Toxicity: Patient Experience, Gaps, and Unmet Needs*, National Health Council. 2026

Financial Burden of Health Care

Participants noted that medical bills are not the only health care costs that patients face. Participants discussed the challenges that patients face in medication affordability, even with financial assistance programs or recent policy changes such as the Medicare Part D cap. Medication affordability was identified as an ongoing concern, especially for individuals with lower incomes.

Participants also discussed the difficult trade-offs patients are forced to make due to health care costs. Sometimes patients must choose between paying for medical care, medications, housing, food, and other necessities. These financial pressures can accumulate, and medical debt can become unavoidable for some patients. Patient advocates described feeling stuck because even though they recognize the growing burden of medical debt, they have limited options to help patients avoid it.

Table 8. Financial Burden of Health Care: Illustrative Quotes

Theme	Illustrative Quote
Medication Affordability	***"We hear this all the time with patients that call in, it's cost, and it is they can't afford their medications; they have to go without food, their children are suffering****."* *- Participant 2.4 Female Autoimmune Disease Organization Representative* *"As a patient assistance foundation, this is the core of what we do, in providing financial assistance to help people pay their portion…and so this is at the heart of the mission of the organization.* ***If I think about even the Part D, you know, up to $2,100 maximum amount this year, it's still unaffordable in many ways for those that we assist, especially being that most of those we assist has an income of about $50,000. We think about the percentage of their annual income that it takes to just afford their health care, and still try to figure out how they are going to survive."*** *- Participant 2.2 Female, Rare and Chronic Conditions Organization Representative*

Table 8. Financial Burden of Health Care: Illustrative Quotes

Theme	Illustrative Quote
Cost TradeOffs	*"I just think it is important to continue to recognize that **financial toxicity** is more than just not being able to afford their treatments and appointments etc., it also **includes not being able to afford food and housing and choosing between their care or ability to get food."*** *- Participant 3.4 Female, Bleeding Disorders Organization Representative* *"They see **more of their patients coming in baseline with needs for food, housing, [and] transportation needs**."* *- Participant 3.7 Female, Cancer Support Organization Representative* *"For people with COPD, the medications are extremely expensive**... many people are deciding whether to get their medicine or get food**."* *- Participant 2.8 Female, Respiratory Disease Organization Representative*
Medical Debt	***"There's also a lot of medical debt that I think patients face**, and there is maybe not as much conversation about how we are dealing with that."* *- Participant 2.5 Female, Cancer Organization Representative* ***"Ditto on medical debt. Transplantation...is kind of the gold standard for treating, some diseases and conditions, ...but then afterwards, there's not a lot of support within the health care system, and financially included, for the medications that are needed to take." -*** *- Participant 2.9 Female, Caregiver Organization Representative*

Data source: Listening Sessions 1-3 for *Managing Financial Toxicity: Patient Experience, Gaps, and Unmet Needs*, National Health Council. 2026

Transparency and Communication

Participants reported how a lack of clear, accessible, and transparent communication from insurance and health care systems makes it difficult for patients to navigate health care and make informed financial decisions. Although the *No Surprises Act* established protections against certain unexpected medical bills, participants indicated that patients still lack the information needed to anticipate and understand their costs. Patients struggle to understand what services are covered, which providers are in network, and how much they will have to pay. Additionally, participants reported problems such as patients not knowing what their care will cost until after they receive it, jargon and complex explanations used by insurance companies, and patients not being aware of their rights, including the ability to appeal coverage denials.

Table 9. Transparency and Communication: Illustrative Quotes

Theme	Illustrative Quote
Lack of Transparency in Pricing	***"And many times, there just wasn't transparent pricing for people because they thought they were in the network, and then they turn out not to be in the network.*** *So, we've had bills go through, we just had one pass that will shift the cost back to the insurer if they make that mistake on their directory. And then also the No Surprises Act really required more transparent pricing for people. I think even with that, it's very confusing to people, how they get coverage, whether that, you know, what they're gonna pay, ultimately as they go through, and a lot of times they wind up out of network, which is tram I mean, in our field, especially for something like psychiatry, tremendously expensive."* *- Participant 1.1 Female, Mental Health Organization Representative*
Accessible Language	*"Often* ***patients are just sitting here trying to understand their explanation of benefits, all the jargon that's in there****."* *- Participant 1.3 Female, Autoimmune/Chronic Pain Disease Organization Representative* ***"When we're developing materials…keeping in mind…on one hand readability [or] reading level, but also, multilingual design as well."*** *- Participant 1.5 Male, Caregiver Support Organization Representative*
Cost Information	***"One of the examples [is] when there is [no] transparency from the health care system around what the cost is going to be for, like, a cancer treatment."*** *- Participant 2.9 Female, Caregiving Organization Representative* ***"It's very confusing to people, how they get coverage, … what they're gonna pay, ultimately as they go through, and a lot of times they wind up out of network****, which is a tram, I mean, in our field, especially for something like psychiatry, tremendously expensive."* *- Participant 1.1 Female, Mental Health Organization Representative*
Patient's Rights Information	***"Most people don't know if their insurance is regulated*** *in the state level or on the federal level. They don't know how to contact the insurance commissioner, or whoever. They don't know their rights, basically."* *- Participant 1.3 Female Autoimmune/Chronic Pain Disease Organization Representative*

Theme	Illustrative Quote
	"I mean, I think it's something, even with, like, prior authorizations, 80% don't even realize that they can appeal… *and that most appeals are overturned, and they're able to get their medications, and just the lack of that knowledge alone, and the inability, or just the unawareness of where to go, and to even, like, when you're coming down, I mean, you know, cancer patients, for example, like, half the time you're fighting to survive, you're on chemotherapy, you can't even lift a pen to fill out that form, and so where to go to get the help, to even fill out that form. So, great points all around, even on enforcement. There's such a lack of enforcement, and how do we change that?"* *- Participant 1.4 Female Patient Advocacy Organization Representative*

Data source: Listening Sessions 1-3 for *Managing Financial Toxicity: Patient Experience, Gaps, and Unmet Needs*, National Health Council. 2026

Caregiver Burden

Participants described how financial toxicity can place a burden on caregivers who can face additional out-of-pocket expenses while helping loved ones navigate treatment and make financial decisions. Caregivers take on responsibilities such as coordinating care, navigating insurance, and assisting with financial decisions while providing emotional and physical support. Participants also noted that caregivers have limited information and resources to fulfill all these responsibilities, and the stress and financial burden they experience is not captured in caregiver burden measures.

Table 10. Caregiver Burden: Illustrative Quotes

Theme	Illustrative Quote
Family Impact	*"We're way behind the eight ball in terms of dialing in on how much this is actually going to cost a family, particularly as we're talking about with autoimmune diseases, it's impacting younger [populations]." -Participant 2.4 Female, Autoimmune Diseases Organization Representative* *"There's a lot of financial toxicity that comes from patients and caregivers making decisions, the best decision they can at the time they make them, but that doesn't mean that was the right way for them to spend their money...* ***you're spending money in the beginning because that's what you're doing, and then you're like, oh my god, I don't think I can do this for, like, a year. That would be $300,000. I must fix this."*** *- Participant 2.5 Female, Cancer Organization Representative*

Theme	Illustrative Quote
Caregiver Financial Burden	*"Caregivers are already incurring, on average, $7,200, out of pocket."* *- Participant 1.5 Male, Caregiver Support Organization Representative* *"When we're looking at caregiver burden, we're looking at the impact of caregiving.* ***Most of the measures, or the ones that are most commonly used, don't ask about financial situation, even though we know that's, like, a really big impact.*** *And so I just wanted to flag that for this conversation and this group, and even when* ***we have health care systems saying, like, we're administering the caregiver burden scale or the stress, those often are lacking questions or items around the financial situation of that diet?"*** *- Participant 2.9 Female, Caregiving Organization Representative*
Care Coordination Responsibilities	*"Caregivers often become de facto financial navigators without proper tools for interpreting pricing."* *- Participant 1.4 Female, Patient Advocacy Organization Representative*

Data source: Listening Sessions 1-3 for *Managing Financial Toxicity: Patient Experience, Gaps, and Unmet Needs*, National Health Council. 2026

Impact on Care Continuity

Participants reported that financial toxicity has a direct impact on care continuity. Not knowing how much treatment will cost may cause patients to delay, postpone, or avoid treatment because they are concerned about the financial burden.

Table 11. Impact on Care Continuity: Illustrative Quotes

Theme	Illustrative Quote
Delayed/PutOff Care	*"Early in the year, even with that $2,000 out-of-pocket cap. And then, you know, we see a lot of people delaying or foregoing care because of unclear cost, and they're hesitant to initiate treatment due to that."* *Participant 1.4 Female, Patient Advocacy Organization Representative*

Data source: Listening Sessions 1-3 for *Managing Financial Toxicity: Patient Experience, Gaps, and Unmet Needs*, National Health Council. 2026

Participant Recommendations

Stakeholder specific recommendations were derived from participants' descriptions, experiences, and suggestive/implied solutions during the discussions. These recommendations underscore a multifaceted approach to alleviating financial burden on patients.

Policy Makers

- Strengthening implementation and enforcement of health care affordability policies to ensure that patients are receiving intended benefits from insurance reforms.
    - *"**We often pass laws and then don't work on the implementation and enforcement side**."*
      - Participant 1.3 Female Autoimmune/Chronic Pain Organization Representative
    - *"**We as a [patient] community...need to be more vigilant about the actual implications of any of these policies...Because it's not working..."***
      - Participant 2.5 Female, Cancer Organization Representative
    - *"... **[In] states that have enacted biomarker coverage...we're now seeing walkbacks [changes that limit or weaken coverage]** ...we've not yet been able to explain to patients what to expect..."*
      - Participant 1.2 Male, Cancer Organization Representative
- Design policies that capture the full patient journey, including indirect costs such as transportation, caregiving responsibilities, lost income, and employment disruptions.
    - *"**I think policymakers...write these policies and don't really have a sense of what it means for the individual and the trade-offs** lead[ing] to greater costs."*
      - Participant 1.1 Female, Mental Health Organization Representative
    - *"...whether it's daycare, whether it's missed work, those types of things are driving…whether or not people have access. **It's not solely just the medical cost itself; it's everything that goes with it**."*
      - Participant 1.8 Female, Neurodegenerative Disease Organization Representative
- Reduce cumulative cost-sharing burdens for individuals that are living with multiple chronic conditions rather than addressing conditions individually.
    - *"When people have chronic conditions, they have multiple conditions, so the cost sharing is really compounded**...I really think that cumulative effect of cost-sharing policies really disadvantage people with multiple chronic conditions**."*
      - Participant 1.1 Female, Mental Health Organization Representative
    - *"When we did some polling...**over a quarter of respondents had at least five-plus chronic conditions that they were managing at any given time, so 100% that absolutely exasperates the cost-sharing conversation**."*
      - Participant 1.4 Female, Patient Advocacy Organization Representative

- *"Cost sharing can disproportionately impact the people who need the care the most...**if you have a chronic condition...high deductibles also can be a major disincentive along with co-payments for care**."*
  - Participant 1.1 Female, Mental Health Organization Representative

- 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.

  - *"Early in the year, even with that $2,000 out of pocket cap...**we see a lot of people delaying or foregoing care because of unclear cost**..."*
    - Participant 1.4 Female, Patient Advocacy Organization Representative

  - *"...**[patients] have been involved in the advocacy efforts, and are excited about the win, only to learn that it actually doesn't apply to them**."*
    - Participant 3.5 Female, Cancer Organization Representative

Providers

- Incorporate financial counseling into patient care so that patients can anticipate, understand, and manage health care costs.

  - *"I think health insurance literacy is missing...**there's this burden on health care professionals to be involved in the process...helping their patients understand their health insurance, the time that they spend navigating themselves the health insurance on behalf of their patient**"*
    - Participant 1.7 female, Gastroenterological Disease Organization Representative

  - *"**People don't understand how prior authorization work. Or why they are denied**."*
    - Participant 3.6 Female, Respiratory Disease Organization Representative

  - *"**We require social workers...to help navigate...because families find it so challenging to navigate**, finding care, the costs, being able to afford..."*
    - Participant 1.8 Female, Neurodegenerative Disease Organization Representative

- 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.

    - *"People don't understand the appeal process...whether they're going to regulators...or filing a complaint...**80-something percent don't even realize that they can appeal, and most appeals are overturned, and they're able to get their medications."***
      - Participant 3.6 Female, Respiratory Disease Organization Representative

    - *"...**there's just a lack of knowledge alone, and the inability, or just the unawareness of where to go**...cancer patients...half the time you're fighting to survive...you can't even lift a pen to fill out that form, and so where to go to get the help, to even fill out that form."*
      - Participant 3.6 Female, Respiratory Disease Organization Representative

    - *"**This is the number one area, financial need, is why people are reaching out to our caregiver help desk**..."*
      - Participant 1.5 Male, Caregiver Support Organization Representative

- Provide transparent and proactive education regarding all unexpected components of specialized care such as the need for specialty medication and treatments, more appointments, caregiving needs, etc.

    - *"**We see a lot of inability to anticipate what the cost is going to be**, and they [patients] can't plan for deductibles, coinsurance, drug pricing…they often get financial shock.","*
      - Participant 1.4 Female, Patient Advocacy Organization Representative

    - *"Finding specialized care is something that's very important because it's not very understood...**We have Centers of Excellence around the country, but families and caregivers struggle with getting to that site and then having a multidisciplinary team...and insurance understanding that specialized care is necessary**."*
      - Participant 1.8 Male, Neurodegenerative Disease Organization Representative

- Recognize transportation, caregiving, family impacts, and other non-medical barriers that may interfere with treatment and adherence to care.

    - *"**Transportation is a big issue for our community...people think, just get there and it'll be fine, but that's actually the start of the race**, not the end...you have to jump through all these hoops just to make the appointment, then there's the hoops that the appointment brings, and then there's the hoops that the bill brings."*
      - Participant 1.9 Female, Neurodegenerative Disease Organization Representative

- *"...what happens **if you are living with a chronic condition, but are also a single parent, and are a caregiver for another person as well...trying to navigate all that...it can just be draining on every level**."*
  - Participant 1.9 Female, Neurodegenerative Disease Organization Representative

- *"**There's also daycare, whether it's missed work, whether or not people have access. It's not solely just the medical cost itself;** it's everything that goes with it."*
  - Participant 1.1 Female, Mental Health Organization Representative

- Develop alternative administrative and financial strategies to provide care for patients who are experiencing financial toxicity.

  - ***"A lot of these [financial assistance] programs cause a huge administrative burden for patients and families."***
    - Participant 3.3 Female, Patient-Centered Organization Representative

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.

  - *"**Validated tools will show that financial toxicity percentages have gone up over time**, but they won't dig into it."*
    - Participant 3.7 Female, Cancer Support Organization Representative

  - *"**Current tools are very much post-crisis measurement tool**, as opposed to a prevention tool."*
    - Participant 3.5 Female, Cancer Organization Representative

  - *"**The tool is useful to identify people already in financial hardship...but it's not a comprehensive way to address financial hardship**."*
    - Participant 3.5 Female, Cancer Organization Representative

  - *"**As things change quickly in the health care landscape, those tools don't keep up."***
    - Participant 3.7 Female, Cancer Support Group Representative

  - *"**Less about how we measure financial toxicity and more about how we prevent it**."*
    - Participant 3.5 Female, Cancer Support Group Representative

- Patient organizations are encouraged to advocate for policies addressing the combined effects of financial toxicity, administrative burden, and time burden as well as advocating for policies to help reduce the overall burden on patients and caregivers.

    - *"Trying to figure out how you're gonna receive care and pay for that care is just overwhelming for a lot of patients and caregivers...The only thing I would add is …**looking at the intersection of how financial toxicity plays in with that administrative burden, as well as time toxicity**."*
      - Participant 3.3 Female, Patient-Centered Organization Representative

    - *"...engaging patients and caregivers...to understand the financial outcomes they experience during a health care journey...**it's not even just the financial costs...it's all of the indirect ripple effects...their jobs, their career, their social life, caregiving...thinking of it as a whole, not just the financial side**."*
      - Participant 3.3 Female, Patient-Centered Organization Representative

- Raising awareness on the financial challenges that caregivers experience and advocate for policies that address caregiver specific burdens such as missed work, travel, employment flexibility, and mental health.

    - *"**I would say from a caregiver perspective, the work that they may be missing, connected to travel and appointments, etc. It's one thing when we're talking about a population that, you know, is kind of in an office job and has a flexible schedule, but it's very different for shift workers**, and so I think it's an important consideration for us to take into account as part of that."*
      - Participant 1.5 Male, Caregiver Support Organization Representative

    - *"**Caregivers often become de facto financial navigators without proper tools for interpreting pricing**."*
      - Participant 1.4 Female, Patient Advocacy Organization Representative

    - *"**Caregivers are already incurring, on average, $7,200, out of pocket**."*
      - Participant 1.5 Male, Caregiver Support Organization Representative

    - *"...financial toxicity impacts family caregivers. **Financial toxicity can eventually impact the health and the wellness of the caregiver. And so, if the caregiver is saying… we're strapped for cash, we're gonna work on the medication and the treatment, I'm gonna miss my dentist appointments, my appointments…the health implications of delaying or foregoing care**…the additional cost of that. Looking at it longitudinally. **The ripple effects of this financial toxicity for the family, the caregiver, the family unit**."*
      - Participant 2.9 Female, Caregiver Organization Representative

- Advocate for policies that address indirect costs associated with illness.
    - *"One issue…is sometimes when people have chronic conditions, they have multiple conditions, so the cost sharing is really compounded.* ***And we saw that recently in terms of public policy, when there was a move to allow states to do cost sharing for the expansion population in Medicaid in particular, we were able to get mental health and substance use excluded, but so many of the folks that we advocate on behalf of have multiple physical health care issues, so they're still going to get hit with a lot of copayments, and so I really think that that cumulative effect of cost-sharing policies really disadvantages people with multiple, chronic conditions, or conditions****."*
      - Participant 1.1 Female, Mental Health Organization Representative
    - *"****From a policy perspective, we're not taking into consideration what actually happens when a diagnosis occurs.*** *I mean, suddenly, it's like, you don't have a number of problems, you have one problem. And that's your condition, and that's the disease that you're fighting, and that's how do you get to the next step in your care treatment plan, and what is the next step in your treatment plan. And I think that, you know,* ***when we're looking at all the indirect costs associated with how much it costs to just get through a journey, no matter what it is. We're not taking into consideration any of those things****."*
      - Participant 2.7 Female, Vision Loss Organization Representative
- Reduce financial struggle stigma through fostering open communication, building trusting relationships with patients, and connecting patients with appropriate financial support services.
    - *"...somehow there has to be comfort in knowing that there's not a stigma that goes with sharing this information [financial situation].* ***And there's a stigma, and patients want help because they need it, but at the same time, they are having a hard time sharing this****, you know, this situation with others, and I don't think there's anyone in a doctor's office that's the amenable one to go to. Unless the patient has trust with the group they're seeing.... There's a lot more communication, relationships, networking, and trust that have to go into this."*
      - Participant 3.6 Female, Respiratory Disease Organization Representative
- Make patients experiencing financial toxicity aware of financial assistance.
    - *"...a gap that* ***I'd like to add to the list is awareness and access to available financial assistance****. Well, that access isn't always through health insurance, so sometimes...it could be Medicare's Extra Help program, but also to other programs that help people, afford and stay on their medications..."*
      - Participant 1.4 Female, Patient Advocacy Organization Representative

- *"**But there's also a lot of medical debt that I think patients face, and there is maybe not as much conversation about how we're dealing with that**. And so we've been working on, primarily at the state level, because this administration's not so open to it. **There was a lot of effort in the Biden administration, but just around transparency to, you know, financial assistance that hospitals provide**..."*
  - Participant 2.5 Female, Cancer Organization Representative

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.

  - *"**I have a friend who's a Harvard-educated corporate attorney,** and he had to choose between a Medicare Advantage plan and a Medicare regular, and ended up choosing an Advantage plan. It took him 2 years to get out of it when he found out that the procedure that he needed wouldn't [be] cover[ed]. **I'm highly educated. How can I, if I can't navigate it, how is the normal patient going to be able to figure this out? Because it was all in the contract language. I didn't understand what it said**."*
    - Participant 2.4 Female, Autoimmune Disease Organization Representative

  - *"...**patients are just sitting there trying to understand their explanation of benefits and all the jargon that's in there**."*
    - Participant 1.3 Female, Autoimmune and Chronic Pain Organization Representative

  - *"Yeah, I think, like, **when we're developing materials, like, keeping in mind, like, on one hand, readability and, like, reading level**, but also, multilingual, design as well."*
    - Participant 1.5 Male, Caregiver Support Group Organization Representative

- Reduce financial barriers that lead to treatment delays, discontinuing care, and reduced adherence from integrated care models.

  - *"**Prior authorization and step therapy...all of those things can be huge barriers to care**."*
    - Participant 3.7 Female, Cancer Support Organization Representative

  - *"**The cumulative effect of cost-sharing policies really disadvantages people with multiple chronic conditions**."*
    - Participant 1.1 Female, Mental Health Organization Representative

- *"**We want the copays that we are paying on the patient's behalf to count toward their out-of-pocket maximum**..."*
  - Participant 2.2 Female, Rare and Chronic Conditions Organization Representative

- "**High deductibles also can be a major disincentive, along with copayments, for care**."
  - Participant 1.1 Female, Mental Health Organization Representative

- *"...**cost sharing [should be] contextualized in the actual experience of the patient, what they can financially afford**."*
  - Participant 2.5 Female, Cancer Organization Representative

- ***"The Medicaid reimbursement rate is so extremely low... with those increases in prices, it's even more out of patients' pockets to** make those appointments, especially if they have a long distance to cover."*
  - Participant 1.6 Female, Rare Diseases Organization Representative

- Consider waiving or lowering copayments that discourage access to medically necessary services in integrated care models.

  - *"**One of the areas that we see cost sharing be a problem is in integrated care models**, so when you get behavioral health care at your primary care, for example, and just the patient experience, one of the insurers who tried to implement this model, **over 50% of the people dropped out after the first copay, to the model, because you get extra co-pays from the behavioral health that you're already paying a copay to your primary care,** right? So they lost the patient experience. I can't afford this, and so they dropped out of the service, even though, ultimately, treating your mental health improves your physical health. So that has certainly informed our policy priorities in terms of working to get those co-payments waived."*
    - Participant 1.1 Female, Mental Health Organization Representative

Conclusions

Financial toxicity extends beyond the cost of medical bills. It affects nearly every aspect of patients' and caregivers' lives, such as emotional well-being, employment, familyresponsibilities, access to care, and ability to meet basic needs. Participants described how navigating complex health care and insurance systems while managing a serious illness creates additional burdens contributing to financial hardship. Although some policies such as the *No Surprises Act* and Medicare Part D out-of-pocket cap are intended to provide important financial protections, participants reported that affordability policies may be undermined by inconsistent implementation, insufficient monitoring and enforcement, and limited transparency. These gaps contribute to unexpected cost, confusion about insurance coverage, and more barriers to accessing care.

Support services such as financial assistance programs, social workers, patient navigators, and advocacy organizations play an important role in helping patients navigate these challenges. However, these resources help individuals manage the consequences of financial toxicity rather than address the underlying structural barriers that create it.

Together, the findings from this study suggest that financial toxicity from interconnected health care, insurance, financial, and personal factors that affect patients and caregivers throughout the health care journey. Reducing health care costs alone is not enough to curb financial toxicity. Efforts should also improve transparency about insurance coverage, cost-sharing requirements, and expected patient costs; simplify health care and insurance navigation; strengthen the implementation, monitoring, and enforcement of existing state and federal policies; and address the indirect costs and caregiving burdens that can impede access to ongoing care.

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Appendix I

Conditions/Organization Type Represented

1. Autoimmune and Chronic Pain
2. Respiratory Disease (3)
3. Autoimmune Disease (General) (2)
4. Bleeding Disorders
5. Cancer Support (General) (2)
6. Caregiver (2)
7. Gastroenterological Disease
8. Neurodegenerative Disease
9. Reproductive Health Related Conditions
10. Hepatic Disease
11. Cancer
12. Mental Health (General)
13. Patient Assistance Organization (General) (2)
14. Rare Diseases and Chronic Conditions (General)
15. Value Assessment (General)
16. Vision Loss

*All organizations are nonprofits