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Patients Experience Financial Toxicity when Accessing Care

New National Health Care Report Outlines Causes and Potential Solutions to Help Patients Access Affordable Care

WASHINGTON, DC – Limited transparency, coverage complexity, gaps in health insurance literacy and support, and insufficient coordination across overlapping policy reforms are four major factors patients say contribute to financial toxicity according to a new report from the National Health Council (NHC).

“Financial toxicity, or the financial distress that stems from competing demands between direct and indirect health care costs, has emerged as one of the most consequential and under-addressed barriers to health for patients living with chronic disease or disability,” said Dr. Omar Escontrías, the NHC’s Chief Programs and Research Officer. “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.”

Managing Financial Toxicity: Patient Experience, Gaps, and Unmet Needs was developed to understand perspectives on financial toxicity and health care cost sharing and the related challenges facing patient and caregiver communities. To create the report, the NHC conducted a scoping review of published and gray literature and convened three virtual listening sessions with patient advocates. 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.

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.

Findings from the listening sessions supported 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.

“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,” asserted Dr. Escontrías.

According to the report, 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.

Click here to view the full report.

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Note: Please contact Jennifer Schleman if you are interested in speaking with a member of the National Health Council team about the report.

About the NHC: The National Health Council (NHC) unites nearly 200 national organizations—including leading patient groups, research institutions, providers, caregivers, and businesses across the health care sector—to drive patient-centered health policy. Representing 200+ million Americans with chronic diseases and disabilities, the NHC strengthens its members’ collective influence to expand access to quality, affordable, and equitable health care. The NHC fosters collaboration to shape policies that reflect the needs of patients. Learn more at: https://www.nationalhealthcouncil.org.