Addressing Financial Toxicity for Patients and Families Facing Serious Illness

Position from the Center to Advance Palliative Care (CAPC)

CAPC recognizes the untenable financial toll that serious illness takes on patients and families. While the problem has deep roots, we recommend requirements for screening, financial navigation, and greater accountability for charity care as policies to mitigate the issue.

The Problem of Financial Toxicity

"Financial toxicity" is a term used to characterize the difficulties that patients and their caregivers face related to the high costs of their medical care.[1] First used by researchers at the Duke Cancer Institute, financial toxicity encompasses the physical, material, and financial hardships that can accompany expensive treatment for serious illness.[2] Because the U.S. health care system is uniquely marked by excessive pricing for both services and medications, the prevalence of financial distress for patients and caregivers can climb as high as 53%, depending on diagnosis.[3-6] Some studies have found disparities in serious illness-related financial challenges associated with gender, race, and income status.[7-10]

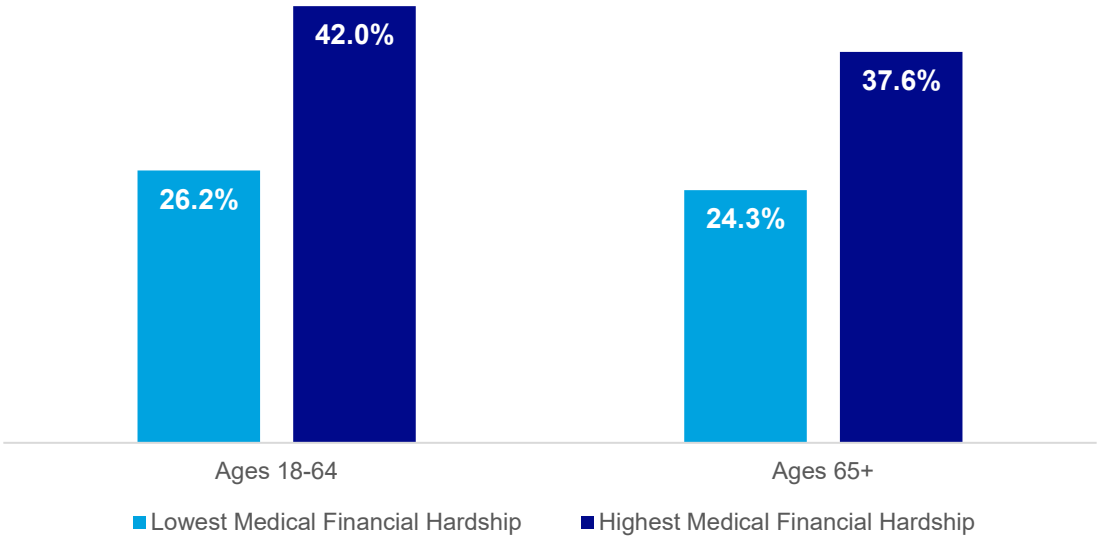
Financial toxicity manifests in medical debt, insufficient assets and savings for emergency expenses, low credit scores, and bankruptcy.[11-15] Living with a serious illness can also impact employment, as some patients and caregivers find it harder to maintain employment or stay locked in jobs to maintain health insurance.[16-18] This has a dramatic effect on material quality of life; many patients experiencing financial toxicity report an inability to afford housing and food.[11,13,19]

These financial burdens also negatively impact patient and caregiver health and health-related behaviors. Several studies have found an association between financial toxicity and anxiety, depression, and post-traumatic stress.[20-22] Cost-related coping mechanisms, such as delaying or forgoing medical treatment, missing doctor's visits, and taking less of (or skipping) prescription medications, can hurt both the patient and their caregivers.[9,16,19,23,24]

The Impact on Payers and Hospitals

The fact that financial toxicity negatively impacts both patient and caregiver health status has significant business repercussions for both payers and providers. Depression, anxiety, and poor treatment adherence ultimately increase health care costs. For example, among more than 10,000 cancer survivors surveyed in the National Health Interview Survey, those with the highest levels of medical financial hardship had significantly more visits to the emergency department in a given year.[25]

Proportion of Cancer Survivors with Emergency Department Visits[25]

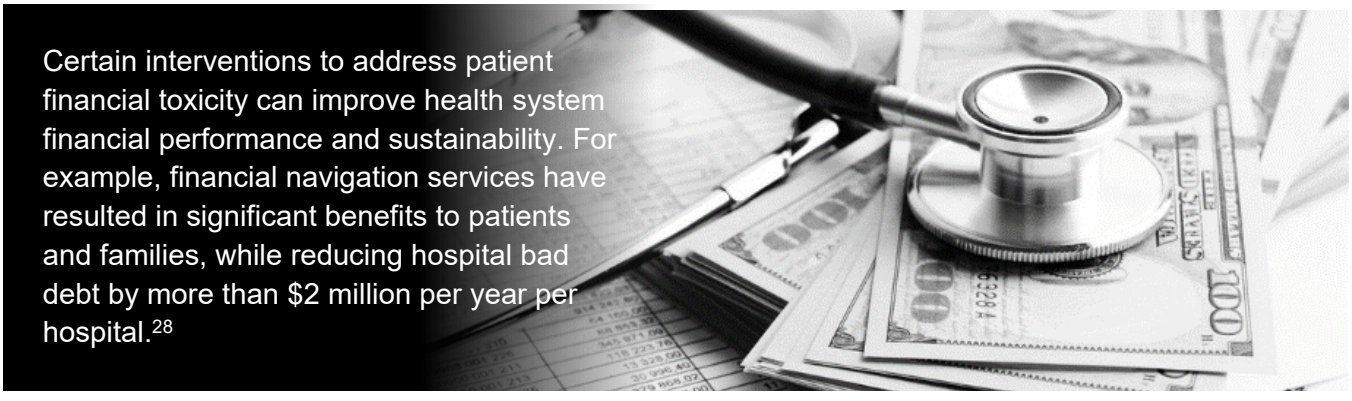


Not only does this drive higher medical expenses for payers (and raise prices for purchasers), but financial toxicity dramatically impacts the financial health of hospitals. A 2022 Crowe Analytics report highlights stark increases in hospital bad debt across the country:[26]

→ From 2018 to 2021, the share of bad debt from self-pay-after-insurance climbed from 11.1% to 57.6%.

→ In that same time span, patient statements with balances greater than $14,000 nearly quadrupled to 17%.

And, as expected, hospitals with the highest levels of un- and undercompensated care have operating margins 6.2 percentage points lower than those with the lowest levels, resulting in higher levels of financial instability.[27]



In the next section, you can see that hospital-driven interventions to address financial toxicity can benefit hospital financial performance.

Effective Provider-Based Interventions Exist

As noted, the issue of financial toxicity largely stems from the U.S. health care payment structure. Putting that larger issue aside, we have identified a number of hospital actions that can mitigate financial toxicity for patients while improving health system financial performance. Relatively simple measures, like hospital formulary management, have lowered prices for patients and total costs for hospitals, while embedded pharmacy patient assistance programs can lead to substantial health system-level cost savings.[29,30] Other replicable, impactful, and sustainable interventions are listed below:

INTERVENTION	ACTOR(S)	OUTCOMES
Medical-Legal/Financial Partnerships, with a focus on benefits and tax credit enrollments[31-35]	→ Hospitals → Clinics → Insurers → Local legal resources	For patients and families: → Millions of benefits and tax credits for families – ROI calculated at 673% → Reductions in hospitalizations of nearly 40% → Improved health status For the health care system: → Reductions in total health care costs
Screening and linkage to trained Financial Navigators Variations include: EMR order set for referral, remote navigation, and community health worker (CHW) screening[28,36-42]	→ Hospitals → Clinics → Sometimes CBOs	For patients and families: → Again, substantial amounts of credits and benefits secured → Reduction in mortality (44% risk of death) → Improved quality of life and measurable reduction in financial toxicity For the health care system: → Significant reductions in hospital bad debt
Financial Toxicity Tumor Board[43]	→ Hospital	For the health care system: → Substantial cost avoidance (at an average of $33,000 per patient)

Financial navigation is the most studied intervention and has the most evidence for impact, while studies on screening and referral/linkage have highlighted the efficiency of targeting navigation interventions to those with the greatest financial need and toxicity.[44] In particular, financial navigation services have resulted in significant benefits to patients and families, while reducing hospital bad debt by more than $2 million per year per hospital.[28] Less studied but still with significant results, collaborations between health care providers and legal/tax/insurer organizations can have a substantial impact on both patients and providers.

While there is some literature and clinical guidance encouraging clinicians to discuss expected out-of-pocket costs when recommending treatment and prescribing, this should not be a priority intervention.[45] Clinicians struggle to anticipate out-of-pocket costs for patients, particularly as individualized information is rarely available during the patient encounter. Instead, other members of the care team can help patients and families understand potential costs and can coordinate with the clinician when treatment alternatives should be considered.

Existing Policy Interventions

Given the burden of high medical costs on patients, federal and state policymakers have implemented protections aimed at improving hospital price transparency, regulating billing practices, and expanding financial assistance. At the federal level, Hospital Price Transparency Rules require all hospitals in the U.S. to publicly list their service prices, and the Consumer Financial Protection Bureau recently finalized a rule that will ban the inclusion of medical debt on credit reports used by lenders.[46,47] Additionally, nonprofit hospitals must meet charity care and community benefit requirements under IRS rules.[48] However, loopholes and weak enforcement in transparency laws, charity care mandates, and other policies allow many hospitals—for-profit and nonprofit alike—to obscure real costs and continue to charge high prices.

Some states have taken additional steps to curb financial toxicity and its consequences by proactively connecting patients to payment resources, capping facility fees, enforcing stricter charity care requirements, and banning aggressive debt collection practices. For example, several states (e.g., Idaho, New Mexico, and Ohio) mandate screening for insurance eligibility and other programs such as charity or discounting policies, while others retroactively extend benefits to patients who become eligible after the debt was incurred (e.g., Wyoming and North Dakota).[49-54] Illinois mandates minimum charity care spending for tax-exempt hospitals and caps the annual amount that hospitals may collect from certain patients to 20 percent of the patient's family income.[55-56] States like Maryland have experimented with hospital rate-setting models, aiming to control excessive pricing across both for-profit and nonprofit hospitals.[57] And other states, such as Indiana, Massachusetts, and Oklahoma, are currently pursuing legislation to limit hospital prices and/or cap payments to hospitals.[58] However, gaps remain in these hospital regulations—many states lack uniform charity care regulations, and only a few actively enforce hospital price transparency compliance; it remains to be seen how price caps will be enforced.[59] Additionally, in states that have not expanded Medicaid, more patients remain uninsured and vulnerable to crushing medical debt.[60]

CAPC Recommendations

People living with serious illness in the U.S. face overwhelming financial burdens that can independently exacerbate poor health outcomes for themselves and their caregivers. The financial costs extend beyond individuals and families, affecting employers, communities, and the broader health system. To address this crisis, CAPC suggests the following to mitigate the impact of financial toxicity on both patients and providers:

- → All acute care hospitals should screen all patients with serious illness diagnoses (including cancer, heart disease, kidney disease, and dementia) for financial toxicity using a simple screening tool—preferably validated—to facilitate identification and referral to financial assistance.
- → All patients who screen positive for financial toxicity should then have access to trained financial navigators with the ability to secure benefits, pharmacy assistance programs, tax credits, and other financial assistance. Application to the treating hospital's own financial assistance program should be mandatory prior to any debt collection.
- → States can support these recommended provider actions by adding requirements for financial screening in their licensure processes and by supporting local or statewide centralized financial navigation services.
- → States should pass laws to limit hospital prices for services, anchoring prices to factors such as a percentage of Medicare rates and including strict enforcement with meaningful consequences for noncompliance.
- → States should facilitate consumer-friendly billing reforms, such as requiring the utilization of the Healthcare Financial Management Association (HFMA) standardized, easy-to-understand financial communication.[61]
- → States should create minimum standards for charity care for tax-exempt hospitals, with stringent enforcement.
- → CMS should strengthen oversight and penalties for noncompliance with price transparency laws (including better publicizing how members of the public can submit complaints) to help ensure patients have access to clear cost estimates.
- → The IRS should allow flexible spending accounts to be used by caregivers, regardless of the declared dependent status of the care recipient.

The U.S. is reaching a point of crisis in health care affordability, and hospitals, states, and federal agencies must act quickly to ensure hard-working Americans do not suffer in the gaps of our current system.

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