



Addressing the Cost of Cancer: Policy Solutions to “Financial Toxicity”

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OCRFA
Ovarian Cancer
Research Fund Alliance

Agenda

- **Financial toxicity**
 - Overview, evidence, and impact
 - Community response
 - Root Causes and potential fixes
- **Surprise medical billing**
 - Overview
 - Background and key concepts
 - Federal protections and gaps
 - State landscape
 - Intersection with cancer
 - Tying it all together
- **Advocacy Case Study: New York**

What's “financial toxicity”?

- Describes the toxic effects of financial cost of cancer on patients and their recovery
- Coined in 2013 by researchers at Duke University School of Medicine
- Two key factors:
 - 1) Objective financial loss
 - 2) Subjective financial distress

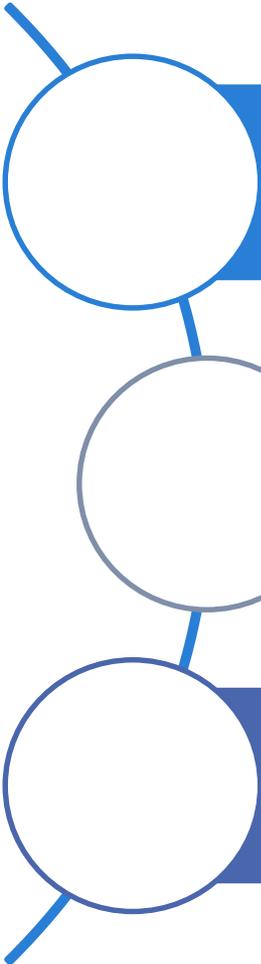
Evidence and impact

- A 2013 study found that nearly half of insured cancer patients cut back on basics on food/clothing or dipped into savings to pay for their treatment
 - The majority cut back on leisure activities.
 - Three-quarters of them received financial assistance with their drug copayments. (Zafar SY et al.)
- Another study found:
 - Cancer survivors were 2.7 times more likely to file for bankruptcy than individuals without a cancer history.
 - Cancer patients who filed for bankruptcy had a **79% higher mortality rate compared to those who had the same cancer and did not file for bankruptcy.** (Ramsey et al.)
- Other studies show cost is a barrier to treatment adherence

Cancer patients are underinsured

- Cancer patients pay more out-of-pocket (OOP) than others with chronic illness
- 13% of non-elderly cancer patients spend at least 20% of their income on OOP expenses
- 50% of Medicare beneficiaries spend at least 20% of their income toward OOP cancer treatment-related expenses

Headlines



“The burden of cancer isn’t just cancer” (Washington Post, Apr. 8, 2017)

“Not Just Nausea And Vomiting: Cancer Docs Now Worry About ‘Financial Toxicity’” (NPR, Feb. 27, 2017)

“Soaring costs force cancer patients skip drugs treatment” (USA Today, Mar. 15, 2017)

Response by the community

- Targeted assistance programs/non-profit organizations provide financial aid & counseling
- Pharmaceutical assistance programs
- Growing number of cancer treatment centers offering “financial navigation” services
- Tools & resources for assessing costs/value of cancer treatment (e.g. ASCO Value Framework)

Root causes

- No single issue is driving financial toxicity; the following factors play a role:
 - Treatments are less toxic & regimens are longer
 - Aging populace → More people have cancer and a higher proportion of cancer patients are receiving treatment (including those previously too frail)
 - Tiered prescription drug formularies
 - Oral parity (75% of cancer drugs in pipeline are orals)

Potential fixes

- Because of this, there's not an easy fix or single remedy
 - Long-term solutions → making policy changes that address unsustainable drug prices & promote more innovative insurance models
 - Short-term solutions → encouraging oncologists to engage patients on treatment cost/value and improving patient cost-related health literacy

Medical costs taking toll nationwide

- 1 in 3 Americans experienced financial burdens as a result of medical care in 2012 (CDC)
- Among those struggling to pay medical bills, out-of-network (OON) care was a contributing factor about one-third of the time (Kaiser Family Foundation, 2017)
- Too often, OON care is delivered at in-network hospitals without the patient's knowledge/consent → resulting in **“surprise medical bills”**

Background and key concepts

- **Provider networks:**
 - Health plans contract with doctors, hospitals, and other providers for their participation in a plan network
 - Providers get expectation of higher patient volume
 - Insurers lock in discounted rates for services
 - Insurer's ability to exclude high-cost providers from network gives them leverage in rate negotiations
 - In-network charges subject to an ACA-established overall annual limit on out-of-pocket (OOP) spending

Background and key concepts

- Network vs. OON –
 - Network providers may *not* bill plan enrollees more than specified level of cost-sharing (as a term of their contract)
 - Non-network providers may charge what they think the “market can bear” for services – these amounts are typically 2-3 times negotiated rates with plans
- The extent to which a plan covers OON care depends on the plan type:
 - HMOs (health maintenance organizations) & EPOs (exclusive provider organizations) → don’t cover OON care at all*
 - **PPOs (preferred provider organizations) → provide limited coverage for OON care**

What does this mean for patients?

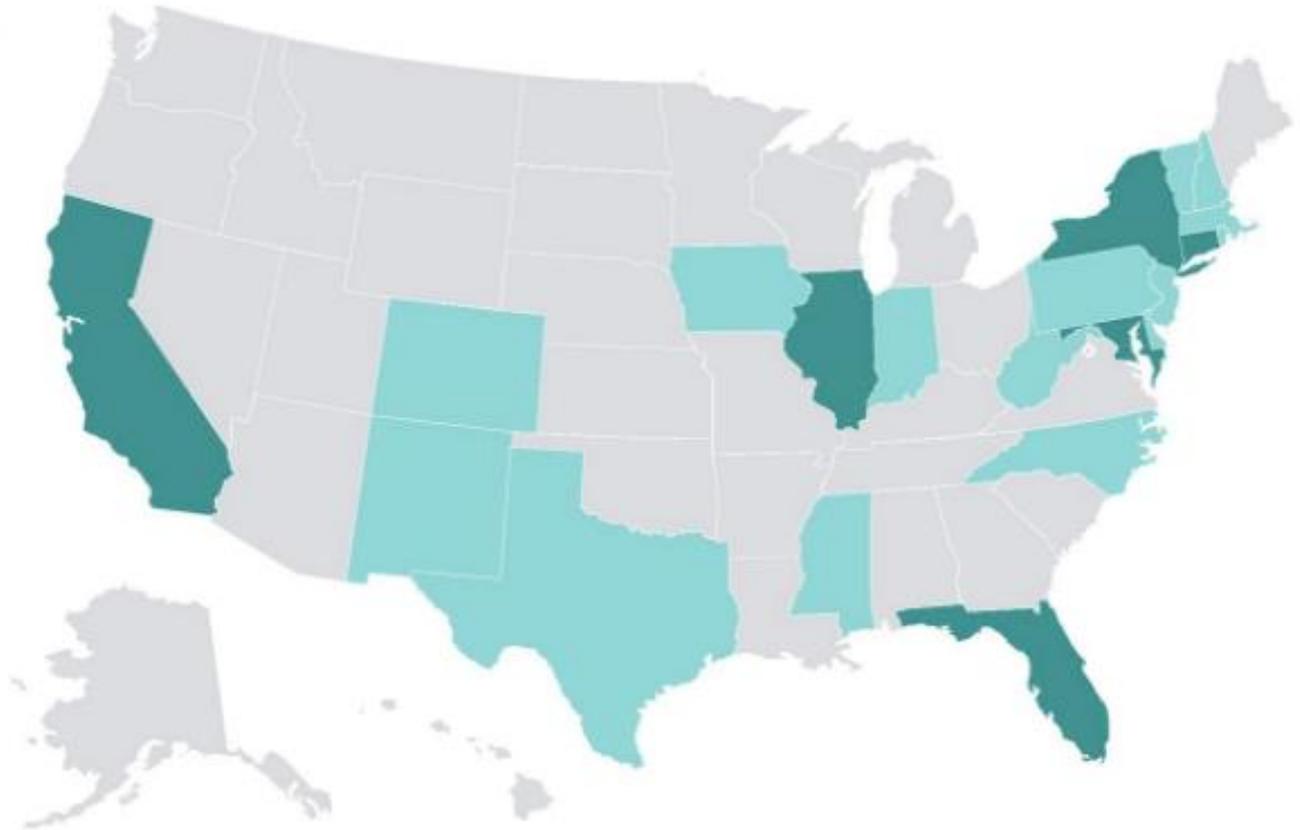
- Patients can be hit with very expensive bills for OON services
- This is due to 3 factors:
 1. Providers charge more for OON services
 2. Plans pay a smaller share of OON bills
 3. Patient is subject to “balance billing” → meaning patient is hit with a bill for whatever the plan won’t pay

Federal protections & gaps

- **OON emergency care:**
 - ACA requires private plans to cover OON emergency care services and apply in-network levels of cost sharing (even if the plan otherwise provides no out-of-network coverage – e.g. HMOs/EPOs)
- **Medicare:**
 - Rules limit patient exposure to balance billing → Non-Medicare providers can balance bill patients to **no more than 15% of Medicare's established fee schedule amount for the service**
 - No limit on OOP costs to patients

State Laws Protecting Against Balance Billing by Out-of-Network Providers in Emergency Departments or In-Network Hospitals

- States with partial protections (15 states)
- States with comprehensive protections (6 states)
- States without protections (29 states and D.C.)



Source: Data collection and analysis as of January 2017 by researchers at the Center on Health Insurance Reforms, Health Policy Institute, McCourt School of Public Policy, Georgetown University.

Tying it all together

- OCRFA gets a LOT of calls about coverage gaps/treatment costs → Priority issue
- Financial toxicity and surprise medical billing have different causes and policy prescriptions
- BUT both center on **the potential for unwieldy OOP costs to patients and call into question the plan structure/benefit design**
- In this sense, the surprise medical billing issue offers valuable take-aways for grassroots advocacy around the OOP costs of cancer care broadly

Advocacy Case Study: New York

- New York's law protecting against surprise medical billing is **strongest** nationwide – what was the on-the-ground advocacy strategy and how did it all come together?

Carrie Tracy, JD

Senior Director, Health Initiatives Department,
Community Service Society of New York

Community Service Society of New York



CSS's Health Initiatives department's approach is a three-legged stool, serving New York consumers through:

- One-on-one assistance

- Community Health Advocates – NY's health consumer assistance program
- CSS Navigator Network – statewide enrollment assistance for NY State of Health marketplace



- Policy Reports

- Advocacy

- Coordinates Health Care For All New York, coalition of over 170 groups fighting for quality, affordable coverage for all

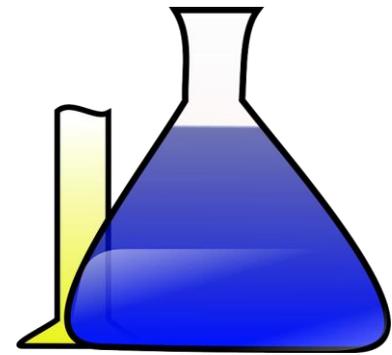
HCFANY is NY's consumer health coalition



The **Actors Fund**,
for everyone
in entertainment.



New York's Formula for Success



- 2012 NYS Financial Services Department report
→ Define the problem & build evidence
- Crafting the legislation → Identify a solution
- **Elevating the issue → Create sense of urgency to act**
- Procedural strategy → Identify the path for passage
- Partnerships & Alliances → Link up with larger community

Advocates Used Many Tactics During Legislative Campaign

- During the Legislative Session in 2014, HCFANY and other advocates:
 - Recruited consumers to tell their stories at 2 press conferences
 - Joined DFS in asking Gov. Cuomo to include in budget and State of the State address
 - Compiled consumer stories in “New Yorkers Speak Out about Surprise Medical Bills” report
 - Submitted public testimony
 - Collected sign-on letters to legislators
 - Asked consumers to email their legislators
 - Met with key policymakers
 - Shared consumer stories in a “speakout” at the capitol
 - Purchased ads in Albany paper

NYS Emergency and Surprise Bill law victory!

Emergency bills

- Consumer pays in-network cost-sharing for out-of-network (OON) emergency bills
- Providers and plans take OON disputes to Independent Dispute Resolution (IDR)

Surprise bills

- An in-network physician refers the patient to an OON provider **and** patient doesn't know the provider is OON
- Consumer pays in-network cost-sharing
- Providers and plans take OON disputes to IDR

Implementation

- CSS and HCFANY participated in the law's implementation
 - Reviewed and improved state notices, participated in state workgroup, presented data to state
- Next steps for NY consumer advocacy:
 - Improvements to the surprise billing law
 - ✓ Plan misinformation about network
 - ✓ Provider misinformation about being in-network
 - Out-of-network coverage in marketplace
 - Require plans and providers maintain network for plan year

Zooming in on the Patient's Role

- Patient is essential to elevating the issue. How?
 - Tracking experiences with surprise medical billing & sharing stories with legislators and others in community
 - Raising awareness of issue locally through LTEs, op-eds, social media, etc.
 - Participating in speakouts, press conferences, lobby days, and other events
 - Stories, stories, stories!

Coverage issues?

- Here's what OCRFA can do for you:
 - Write a letter to your plan's carrier on your behalf
 - Engage your Member of Congress to do the same
 - Direct you to potential financial assistance opportunities & resources

Contact Information

Chad Ramsey, Vice President, Policy, OCRFA

cramsey@ocrfa.org

202-517-6404

Vanessa Cramer, Associate Director, Policy, OCRFA

vcramer@ocrfa.org

202-517-6405