# Addressing Healthcare Affordability: Where Do We Start?

*Anna Hyde*
*Vice President of Advocacy and Access*
*Arthritis Foundation*

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# Objective

**Use patient data points to show the patient care experience and make the case for patient-centered solutions.**

Specifically, these slides will highlight:

- Affordability experience for patients
- Impact of health system policies on patient affordability
- Impact of transparency on affordability
- Patient experience and preferences with transparency
- **What good looks like and recommendations for regulators**

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# Affordability and Transparency: What Good Looks Like

- Capping out-of-pocket treatment costs
- Providing medical debt protections
- Ensuring cost-sharing counts towards deductibles
- Increasing access to Real Time Benefit Tools and other digital tools
- Right-sizing misaligned incentives (anti-competitive contracting, rebate walls)
- Incentivizing access to lower cost meds like biosimilars
- Focusing on health coverage literacy and consumer education

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# What Regulators Can Do

- Prioritize health coverage literacy and consumer education
- Leverage existing and forthcoming federal rules to enforce transparency standards
- Follow the 2023 court ruling requiring cost-sharing to count towards deductibles
- Work with your legislators on policies that could impact affordability
- Continue working within HCAM to identify and implement meaningful affordability policies for patients

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# Patient Affordability Snapshot: Arthritis Foundation Survey Data

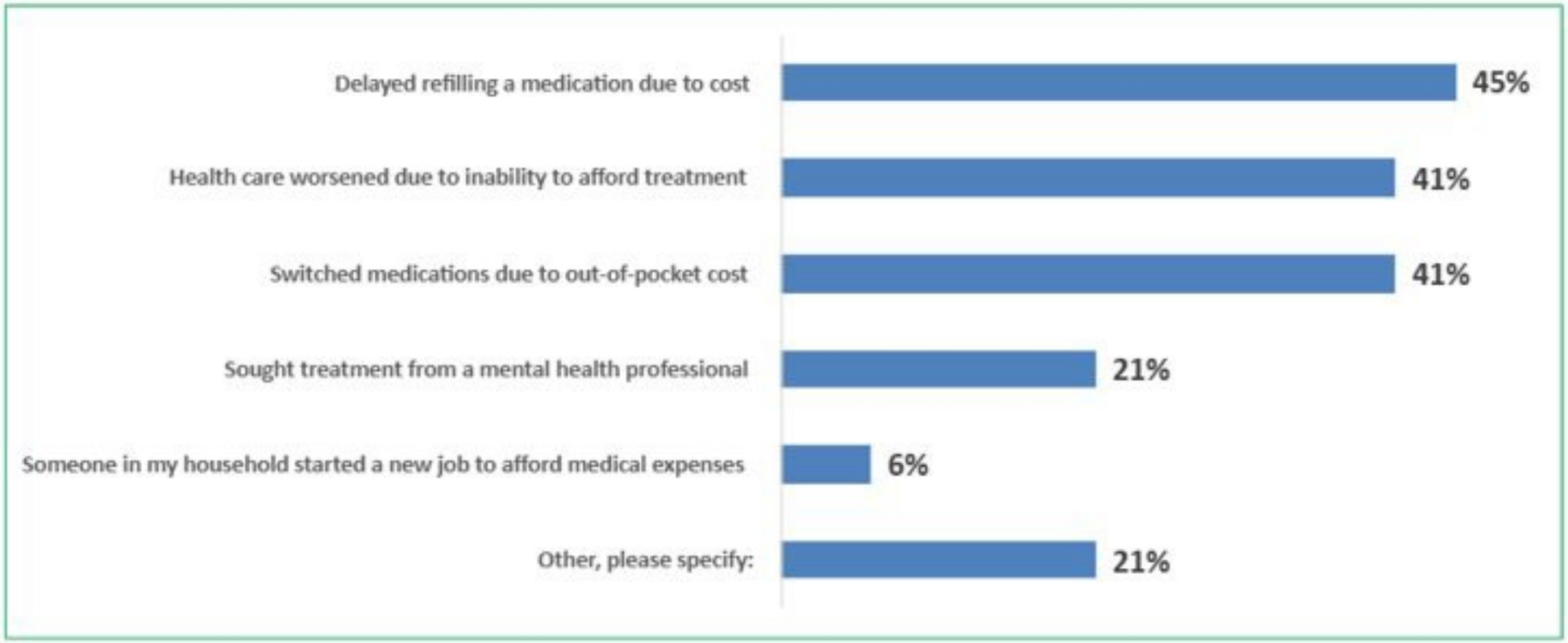
**37%**
Trouble affording OOP costs
in the past year

**54%**
Suffered medical debt or financial hardship
as a result

**50%**
Citing barriers to quality care say affordable meds main issue; then insurance costs

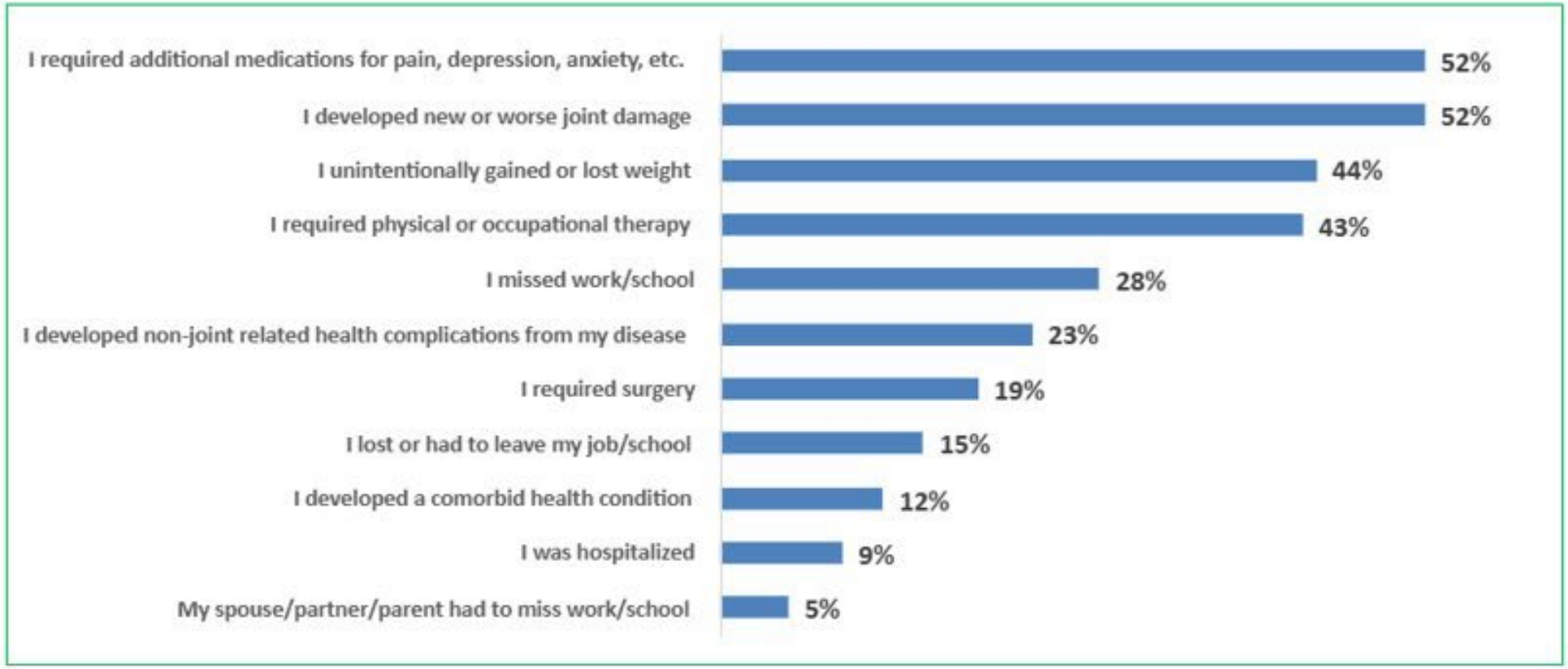
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# Trouble affording out-of-pocket medical expenses had an impact on care: 45% delayed refilling a prescription, 41% say their health care worsened, and 41% switched medications as a result.




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# When arthritis is not well-controlled with medication, the whole body is impacted: additional medications are needed, new or worse joint damage ma develop, weight may fluctuate, and additional PT/OT may be required.




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# The Intersection of Affordability and Transparency

"Approval does not equal transparency"

- Caregiver who received prior auth for her daughter's infusion but also received a bill for the full $52k cost, completely unsure what she is actually obligated to pay

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# Transparency

## The Gap Between What Patients Value and What They Experience

Transparency is universally important to arthritis patients, but the experience of receiving it proactively is rare. These four numbers frame everything that follows.

**100%**

Rate transparency as very or extremely important to their healthcare decisions

**97%**

Must advocate for themselves — only 1 person in 43 never has to ask

**74%**

Say improved information often or always helps them make better decisions

**70%**

Experienced delayed care due to unclear or missing information

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# Transparency Is Valued But Rarely Proactively Delivered

**How transparent is your experience?**

**14%** Very/extremely transparent — proactively informed

**51%** Moderately transparent — must ask questions

**16%** Slightly transparent — key details often missing

**7%** Not at all transparent

*Only 1 in 7 feels information comes without effort. The other 6 are doing the work themselves.*

**Adverse outcomes due to unclear info:**

**70%** Delayed care

**63%** Had to repeatedly follow up

**58%** Spent significant time understanding insurance

**56%** Received unexpected medical bills

**42%** Mistrust in providers or insurers

**30%** Confusion about treatment instructions

**16%** Duplicate tests or conflicting guidance

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# Where Patients Are Spending Their Time

Patients are performing substantial administrative labor to navigate a system that was designed to serve them. The tasks consuming the most time are almost entirely insurance- and billing-related.

**Top time-consuming tasks (% selecting as a major burden):**




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# Transparency Impacts on Patients

Gaps in transparency are not simply administrative challenges. They have real-world consequences for patient care, including delays, unexpected costs and reduced confidence.

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**63%** Had to repeatedly follow up for information

**58%** Spent significant time understanding insurance

**56%** Received unexpected medical bills

**42%** Mistrust in providers or insurers

**30%** Confusion about treatment instructions

**16%** Duplicate tests or conflicting guidance

**16%** Felt pressured to consent without understanding

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# The Intersection of Affordability and Transparency

- Proactive, clear info about costs, treatments, and timelines for any given condition or episode of care
- Airtight translation of records from one doctor or facility to another
- Knowing exactly who to talk to in order to resolve a problem and the reasons for delays and denials
- More shared decision-making and coordination across specialties
- Clearer descriptions of policies, preferably at a 3rd grade level

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# Continued…

- Advanced notice of prior auth so patients have time to go through the benefit verification process before the prescription or plan year expires

- Longitudinal access to patient records so it's easy to know what treatments you've tried and failed, even decades in the past

- "I want to be able to forget I have the disease day to day."

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# Applying These Principles to Current State Initiatives

- **All Payer Claims Databases**
  - Clear purpose for regulators and academics
  - Unclear purpose for patients
- **Treatment cost estimators**
  - Asking to search by CPT code
  - Providing list prices
- **Outreach and navigator services**
  - Analysis of Covered CA showed lower uptake based on edu and health status; higher uptake through facilitated enrollment programs

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# Putting it all Together

1. Adopt “I want to forget I have this disease” as your guiding principle
2. Focus on building trust so patients have confidence in the information and decisions they receive
3. Embrace “technology as a solution” where possible
4. Consider future transparency efforts through the lens of “transparency for what purpose”
5. Remember patients want to be part of the solution!

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