



# Uncovering the True Cost of Healthcare

## Quantifying the Cost of Stress for Patients and Caregivers

### Workshop #5 Learning Report

December 2025

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## **Uncovering the True Cost of Healthcare**

### **Quantifying the Cost of Stress for Patients and Caregivers**

#### **Workshop #5**

#### **Plain Language Summary**

Stress is the body's natural reaction to any kind of demand—good or bad. It's not just about emotions; stress affects the body, mind, and social relationships. Chronic or toxic stress happens when stress lasts for a long time. This type of stress can harm the brain, organs, and overall health, and can lead to problems like heart disease, depression, obesity, and trouble sleeping. Sometimes, serious health problems cause chronic stress, creating a cycle that's hard to break.

The Center for Innovation & Value Research hosted its fifth workshop on September 25, 2025. This workshop is part of a six-part series called [Uncovering the True Cost of Healthcare: Quantifying the Cost of Stress for Patients and Caregivers](#) brought together over 50 participants, including, but not limited to, patients, caregivers, and researchers. The workshop explored how to account for the financial impacts of stress in research.

Highlights from the workshop include:

- Claudia Chahin, patient advocate, shared her personal story to show how stress impacted her entire life. She faced challenges during two pregnancies and later with breast cancer. These experiences affected her physical health, career, and relationships.
- Rachel Gilgoff, pediatrician and researcher, shared research on the science of stress. While short bursts of stress can help us survive, chronic stress—often caused or made worse by things like poverty, racism, medical trauma, and childhood adversity—can harm the brain, immune system, and other body systems. This can lead to serious health problems.
- Toxic stress also has big financial impacts. Research shows stress linked to challenges experienced in childhood costs in the U.S. about \$14.1 trillion each year in medical bills and lost productivity.

Stress doesn't just affect health—it also creates big financial challenges for patients and caregivers. Stress can lead to missed work, extra costs like childcare and transportation, and emotional strain. Measuring these impacts is important because stress, health, and financial problems often feed into each other, making recovery harder.

To reduce these impacts, researchers and the healthcare system should:

- Measure stress like quality of life using patient surveys and time logs.
- Link stress data to cost-effectiveness models.
- Include stress-reducing strategies in care plans, such as trauma-informed care, healthy habits, digital navigation tools, and community support.

### Uncovering the True Cost of

**Healthcare** is a Center for Innovation & Value Research (Center) project exploring patient-centered economic impacts. We recognize that patients and caregivers are payers in the U.S. healthcare system and our research and decisions need to reflect that.

Through partnerships with patients, caregivers, researchers, and other decision-makers, we are seeking better ways to understand how healthcare costs affect patients and their families.

## Summary

The Center for Innovation & Value Research (the Center) convened its fifth virtual workshop—Quantifying the Cost of Stress for Patients and Caregivers—on September 25, 2025. This six-part series is part of the project [Uncovering the True Cost of Healthcare](#). With 55 participants representing a range of (and often overlapping) perspectives, the workshop explored the economic impacts that patients and caregivers experience from the challenges of navigating chronic stress from a healthcare condition.

Faculty members Rachel Gilgoff, Adjunct Clinical Associate Professor at Stanford

University School of Medicine, and Claudia Chahin, Attorney and Patient Advocate, shared their experiences and insights through a story share, panel presentation, and closing reflections.

This workshop focused on the economic impacts of stress – or the financial outcomes that patients, family members, and caregivers experience due to the chronic stress from navigating a healthcare condition or experience. The objective of this workshop was to identify potential ways to account for the financial impacts of stress in research.

*“Stress is an amplifier of all the costs in the Economic Impacts Framework.”*

– Workshop Participant

The workshop focused on the following key questions:

- What types of stress do patients and caregivers most commonly experience?
- How do patients and caregivers describe the economic impact of stress?
- What existing methods of measuring stress could we adapt to capture the economic impacts?

Workshop participants and faculty engaged in robust discussion through a small group exercise,<sup>a</sup> interactive polls, and Q&A. In this report, we highlight key learnings from the workshop.

<sup>a</sup> See Appendix B for breakout room case study and discussion questions.

## Defining Chronic Stress

Stress is the “body’s nonspecific response to any demand, whether pleasant or unpleasant.”<sup>b</sup> Every individual experiences stress at some point in their life. Stress is not just an emotional response, but involves other components, including a biological response (how the body physically reacts to stress), psychological (how the mind processes and manages stress), and social response (how relationships and environment influence the stress response). For purposes of this workshop, we focused on chronic or “toxic” stress, which is the *“prolonged activation of the stress response systems that can disrupt the development of brain architecture and other organ systems, and increase the risk for stress-related disease and cognitive impairment, well into the adult year...”*<sup>c</sup> Chronic stress can lead to many physical and psychological problems such as heart disease, depression, obesity, and insomnia.<sup>d</sup> Serious healthcare conditions can themselves cause stress which results in a cyclical pattern.

## Grounding in Lived Experience

To ground the discussion, faculty member Claudia Chahin shared her personal story of facing significant challenges during her two pregnancies and a recent breast cancer diagnosis. Claudia reflected on her journey and discussed how stress has significant impacts on her entire life – influencing her health, behavior, and relationships.

Physically, both of Claudia’s pregnancies resulted in bed rest and caused pain, sleep disruption, and uncertainty around delivery timing. Years later, her life was turned upside down when she was diagnosed with early-stage breast cancer. In addition to radiation side effects, cancer disrupted Claudia’s basic daily activities and responsibilities. Both conditions and prolonged stress weakened her immune system.

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*“Stress has been an uninvited but persistent presence in my life, shaped by experiences that tested both my mind, body, and spirit.”*

– Claudia Chahin, Workshop Faculty

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Emotionally, both health experiences triggered intense anxiety. During pregnancy and postpartum, Claudia experienced self-blame and depression, which affected the mother-infant bond, while breast cancer brought ongoing fear of recurrence and the unknown effects of treatment. These emotional burdens often translated into economic stress, with challenges like missing work, struggling to maintain routines, and adhering to medication or treatment plans.

<sup>b</sup> <https://www.stress.org/what-is-stress/>

<sup>c</sup> National Academies of Sciences, Engineering, and Medicine (2019). *Vibrant and healthy kids: Aligning science, practice, and policy to advance health equity*. The National Academies Press. <https://doi.org/10.17226/25466>

<sup>d</sup> <https://www.apa.org/topics/stress/chronic>

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*“I feel like we need a system that recognizes not just the medical needs, but also the economic strain that can come with illness.”*

– Claudia Chahin, Workshop Faculty

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The stress Claudia experienced also led to notable behavioral and social consequences. Claudia highlighted how some individuals may adopt unhealthy coping mechanisms. For her, it was a poor diet, but for others, this may lead to increased alcohol and substance use. Socially, Claudia discussed how stress strained her support network and

personal relationships, sometimes leading to isolation in her pregnancy and contributed to her divorce when her first child was only nine months old. Mental and emotional exhaustion interfered with healthy coping strategies, while financial pressures—like the need to quit work to care for a child or challenges in paying for medical expenses—compounded the overall burden on her family.

## Stress Overview

Following Claudia’s story, faculty member Rachel Gilgoff highlighted the science of stress and its three types:

- **Positive stress**, which is mild or moderate and short-lived, necessary for health development and builds resilience;
- **Tolerable stress**, which is more severe, prolonged, or excessive but limited in duration, and allows for recovery with support; and
- **Toxic stress**, which is prolonged, chronic, unbuffered, and can increase the risk for health issues.<sup>e</sup>

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*“Our bodies may sacrifice long-term health and wellness to survive today, and that leads over time to disruptions in our neurologic, endocrine, immune, metabolic, genetic, regulatory systems, and that’s what’s been termed toxic stress by the National Academies of Science and Engineering and Medicine.”*

– Rachel Gilgoff, Workshop Faculty

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While stress can be adaptive and even lifesaving in short bursts, prolonged activation of the stress response—often driven by factors like medical trauma, racism, poverty, and social isolation, and Adverse Childhood Experiences (ACEs)<sup>f</sup>—is not just a health issue but a profound economic one. A chronic or toxic stress response can disrupt

<sup>e</sup> Shonkoff JP, Garner AS; Committee on Psychosocial Aspects of Child and Family Health; Committee on Early Childhood, Adoption, and Dependent Care; Section on Developmental and Behavioral Pediatrics. The lifelong effects of early childhood adversity and toxic stress. *Pediatrics*. 2012 Jan; 129(1):e232-46. doi: 10.1542/peds.2011-2663. Epub 2011 Dec 26. PMID: 22201156.

<sup>f</sup> ACEs are potentially traumatic events that occur in childhood from 0-17 years such as physical, emotional, or sexual abuse; physical or emotional neglect; and household challenges such as growing up in a household with incarceration, mental illness, substance misuse or dependence, parental separation or divorce, or intimate partner violence.

neurological, endocrine, and immune systems, which can lead to a range of amplified health conditions, including but not limited to: inflammation, autoimmune diseases, diabetes, cardiac conditions, asthma, allergies, increased infection risk, learning and behavior issues, anxiety, depression, and suicide.<sup>g,h</sup> (See Figure 1)

This physiological burden translates directly into financial toxicity. Rachel presented the latest research on ACEs and their connection to toxic stress. The cumulative effects of toxic stress resulting from ACEs are linked to an estimated \$14.1 trillion annual cost in the U.S., including direct medical spending and lost productivity.<sup>i</sup> Furthermore, stress contributes to poor health and financial outcomes through several pathways including:

**Figure 1: Overview of the Toxic Stress Response**

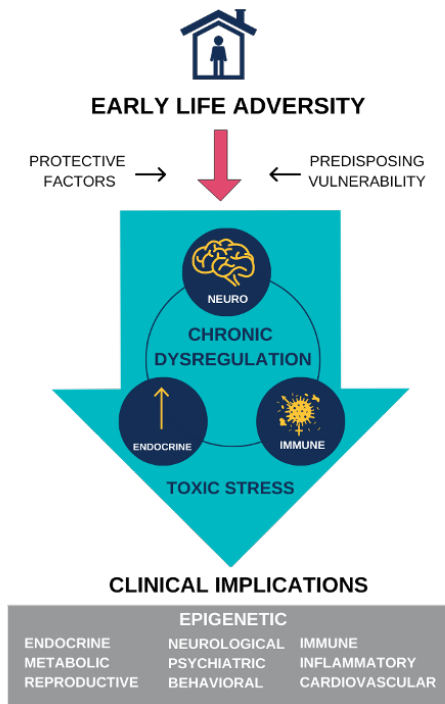


Image adapted from Bucci M, Marques SS, Oh D, Harris NB. Toxic Stress in Children and Adolescents. *Adv Pediatr*. 2016 Aug;63(1):403-28.

absenteeism, poor adherence, and overall system inefficiencies. These harms fall hardest on lower-income patients and marginalized communities, erode decision-making and health literacy, and even transmit across generations—amplifying long-term health and economic consequences.

## Key Considerations

Measuring the economic impact of stress on patients and caregivers is critical to understanding the full range of challenges families face during serious health conditions. Chronic stress not only worsens physical health, but also amplifies financial strain. Recognizing these ripple effects can guide the design and evaluation of programs aimed at reducing stress and improving treatment effectiveness. The workshop presentations and breakout room discussions highlighted the key considerations identified on Page 6.

g Gilgoff, R., Mengelkoch, S., Elbers, J., Kotz, K., Radin, A., Pasumarthi, I., ...Slavich, G.M. (2024). The Stress Phenotyping Framework: A multidisciplinary biobehavioral approach for assessing and therapeutically targeting maladaptive stress physiology. *Stress*, 27(1). <https://doi.org/10.1080/10253890.2024.2327333>.

h Hughes K, Bellis MA, Hardcastle KA, Sethi D, Butchart A, Mikton C, Jones L, Dunne MP. The effect of multiple adverse childhood experiences on health: a systematic review and meta-analysis. *Lancet Public Health*. 2017 Aug;2(8):e356-e366. doi: 10.1016/S2468-2667(17)30118-4. Epub 2017 Jul 31. PMID: 29253477.

i Peterson C, Aslam MV, Nolon PH, et al. Economic Burden of Health Conditions Associated with Adverse Childhood Experiences Among US Adults. *JAMA Netw Open*. 2023;6(12):e2346323.



## Stress is a Measurable Economic and Clinical Driver

Stress is not just background noise or a symptom of illness or system complexity. Stress is much more than that: it's a measurable economic driver, shaping patient outcomes, treatment adherence, and system costs. Chronic stress and financial strain reinforce each other in a vicious cycle.



## Economic Burden of Stress Ripple into Multiple Areas

Stress creates both direct and indirect costs, rippling through the expenses patients already face. Stress can lead to missed work and appointments (direct costs), and worsen other expenses, such as childcare costs, transportation costs traveling to and from appointments, administrative delays, and emotional toll (indirect costs). For example, Claudia had to quit her job for a few months before her leave under the Family Medical Leave Act had exhausted before her daughter was out of the hospital.



## Administrative and Navigation Burdens Amplify Stress

Prior authorizations, referral delays, insurance approvals, and fragmented care systems amplify stress and economic strain. Time was a recurring theme that exacerbates stress. Patients and caregivers cannot reclaim the time lost from administrative and navigation issues.

## Next Steps

Establishing rigorous methods to measure these impacts and develop scalable solutions to address them within the healthcare system is an essential first step. Workshop discussions identified key recommendations to incorporate the economic impacts of stress into research and clinical practice:

- **Consider treating stress as an intermediate outcome:**
  - Treat stress like quality of life—measure it as a bridge between patient experience and downstream costs
- **Explore existing measurement strategies to address stress:**
  - Patient-reported stress scores
  - Time logs for administrative tasks
  - Caregiver burden metrics
  - Integration with health economics and outcomes research tools (e.g., EQ-5D, PROMIS, WPAI)
  - Link stress data to cost-effectiveness and budget impact models
- **Include cost-impacts when implementing evidence-based interventions to reduce stress:**
  - Trauma-informed care (safety, trust, cultural sensitivity)
  - Stress busters (sleep, nutrition, physical activity, mindfulness, supportive relationships, experiencing nature, and mental health support)
  - Digital navigation tools and care coordination
  - Community-based strategies tailored for equity

Integrating stress assessment into routine clinical workflows and ensuring that the financial impacts of stress are captured in clinical effectiveness research will help quantify how stress influences treatment adherence, outcomes, and overall cost-effectiveness. Working together across multiple stakeholders, these strategies can transform stress from an overlooked challenge into a key driver of better health, economic efficiency, and improved patient well-being.



## Appendix A: Additional Resources

1. Felitti VJ, Anda RF, Nordenberg D, et al. Relationship of childhood abuse and household dysfunction to many of the leading causes of death in adults. *Am J Prev Med*. 1998;14(4):245-258. doi: 10.1016/s0749-3797(98)00017-8.
2. Hughes K, Bellis MA, Hardcastle KA, et al. The effect of a multiple adverse childhood experiences on health: a systematic review and meta-analysis. *Lancet Public Health*. 2017;2:e356-e366.
3. Gilgoff R, Schwartz T, Owen M, Bhushan D, Burke Harris N. Opportunities to Treat Toxic Stress. *Pediatrics*. 2023;151(1):e2021055591. doi: 10.1542/peds.2021-055591. <https://publications.aap.org/pediatrics/article/151/1/e2021055591/190226/Opportunities-to-Treat-Toxic-Stress>
4. Bucci M, Marques SS, Oh D, Harris NB. Toxic Stress in Children and Adolescents. *Adv Pediatr*. 2016;63:403-428.
5. Peterson C, Aslam MV, Niolon PH, et al. Economic Burden of Health Conditions Associated with Adverse Childhood Experiences Among US Adults. *JAMA Netw Open*. 2023;6(12):e2346323. doi: 10.1001/jamanetworkopen.2023.46323.

## Appendix B: Case Study Worksheet

### Purpose of the Activity

To guide researchers and patient advisors on identifying:

- Where healthcare system-related burdens create stress for patients;
- How that stress translates into economic impacts; and
- Which burdens are most important to measure in patient-centered comparative effectiveness research (CER).

### Case Study: Maria's Experience with System-Related Stress

Maria is a 43-year-old single mother of two who works full-time and has recently been diagnosed with a chronic autoimmune condition. After months of unexplained fatigue, joint pain, and brain fog, she was referred to a specialist by her primary care provider. The process of getting the referral was difficult—she had to take time off work, navigate multiple phone calls, and coordinate between offices to get her insurance to approve the visit.

Maria finally saw the specialist. During the visit, Maria had to retell her medical history, providing the same details she had shared with multiple providers. She felt that no one had really looked at her records or paid attention to her health struggles. Repeating her story, especially during moments of vulnerability, added emotional strain. The specialist recommended a new biologic treatment. Maria was hopeful—until she learned that insurance pre-authorization was required.

The specialist's office told her they would submit the request, but a week later, Maria received a letter stating that the request was denied due to incomplete documentation. Maria made multiple calls to both specialist's office and her insurance provider to understand the problem. She spent hours on hold, often during her lunch breaks or after work, trying to clarify what paperwork was missing and who needed to send it. The authorization was eventually approved – but then Maria struggled to find a pharmacy that stocked the medication. Each time she tried to pick it up, she was told to call ahead or come back another day. After multiple attempts by herself and her provider, Maria was able to secure the medication. She is currently waiting to understand whether or not the new treatment works.

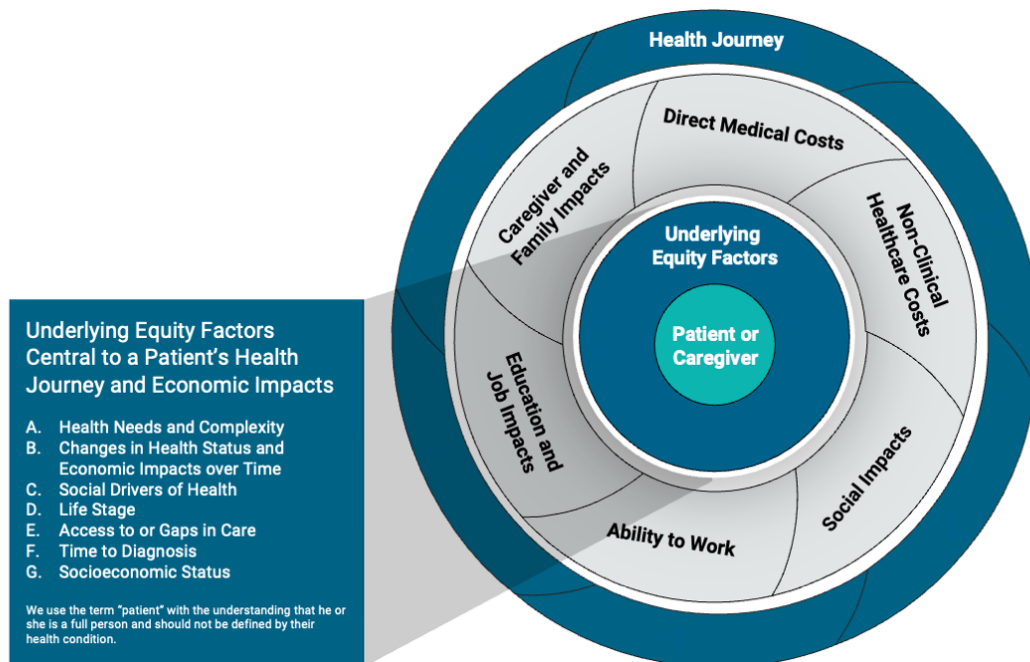
## Discussion Questions

1. The case study mentioned many stress points for Maria as she navigates her condition and the healthcare system. What were the major stress points for Maria related to administrative or navigation burdens?
  - From your own experience, what else is missing that could cause stress for someone in this situation?
2. What are the direct and indirect economic impacts of these stress points?
3. Which stressors are most important to measure—and why?
4. How could we measure these burdens in a patient-centered research study?

## Appendix C: Overview of Patient-Centered Economic Impacts

Patient-centered economic impacts are the financial outcomes that patients<sup>1</sup>, family members, and caregivers experience due to health conditions and healthcare treatment. In 2023, the Center and AcademyHealth partnered with stakeholders to produce [A Research Framework to Understand the Full Range of Economic Impacts on Patients and Caregivers](#). The framework helps us understand what we mean by “patient-centered economic impacts,” or the costs associated with seeking healthcare like time spent going to the hospital for a health emergency, medicine, travel to doctors’ appointments, or taking care of family members. Six main areas of patient-centered economic impacts identified include: 1) Direct Medical Costs, 2) Non-Clinical Healthcare Related Costs, 3) Impacts on Caregivers and Families, 4) Social Impacts, 5) Ability to Work, and 6) Education or Job Impacts.

Patients and caregivers must be at the center of understanding these economic impacts, and a person’s health journey is foundational to understanding economic impacts – which are often overlapping, complex, and difficult to measure. Further, underlying factors – health complexity, social drivers of health, time to diagnosis, and others influence the experience of these economic impacts. Appendix B in the Framework includes detailed examples of the kinds of costs that fit into these categories.



<sup>1</sup> The Center uses the term “patient” to refer to a person who has had an encounter with the healthcare system and has lived expertise in the healthcare system. We do not suggest that a person is their disease or that is a person’s only area of experience or expertise. We use them in recognition of their lived experiences and the importance of this experience to improving the healthcare system.

## Appendix C: Workshop Attendees

We are deeply appreciative of the insights and candor of the individuals who participated in this workshop. We are proud to include a wide range of experts in the field. The project is guided by a diverse Steering Committee and Community Advisory Board of patients, caregivers, researchers, payers, industry experts, and other stakeholders who provide insights, guidance, and co-leadership throughout the project. Individuals with an asterisk “\*” by their name are current members of the advisory committees for this project.

### Center for Innovation & Value Research Team

- Ushma Patel
- Erica deFur Malik
- Melanie Ridley
- Tiffany Huth
- Smita Sanwardeker

### Workshop Faculty

- Claudia Chahin, Attorney and Patient Advocate
- Rachel Gilgoff, Advisor with the California Access Aware Initiative, UCLA-UCSF ACEs Aware Family Resilience Network (UCAAN), and Office of the California Surgeon General; Adjunct Clinical Associate Professor at Stanford University School of Medicine

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- Estelle Michael, UCB
- Yadira Montoya, National Alliance on Caregiving
- Ana Rita Moreira, v-ATPase Alliance
- Casey Quinn, Patient-Centered Outcomes Research Institute
- Sandi Ring, Full Circle Consulting
- Melissa Rowley, Isaac Health
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- Madison Scott, Otsuka
- Jennifer Shumsky, JLS Consulting
- Stephanie Steele, Immune Deficiency Foundation
- Adam Thompson, Plain Speak Consulting, Inc.
- Shana Traina, Sanofi
- Karen Utley, International Foundation for CDKL5 Research
- Angie van Bemden, Musculoskeletal Research International
- Vanessa Vogel-Farley, Rare Epilepsy Network
- Joseph Washington, Washington Unlimited LLC
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- Dorothy Winningham, Winn2BHealthy LLCZ\*
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- Alexandra Zaleta, Cancer Care
- Marjan Zakeri, University of Houston College of Pharmacy



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