CANCER*care*®

Over 80 Years of Help and Hope

BEHIND THE BARRIERS

PATIENT VOICES ON ACCESS TO TREATMENT

A Cancer*Care* Focus Group Series

June 2026

MICRO INSIGHTS, MACRO IMPACT INITIATIVE

Micro Insights, Macro Impact is a national initiative led by Cancer*Care*, designed to harness the power of patients' personal "micro-level" insights to create "macro-level" impact through storytelling, empowerment and collective advocacy.

ADVISORY COMMITTEE

Stephanie Broadnax Broussard, DSW, LCSW-S, APHSW-C
Director of Social Work,
Thyme Care

Matthew J. Butler, MD
Associate Professor of Medicine, Division of Hematology/Oncology, Mays Cancer Center, University of Texas at San Antonio

Jon Fox
Cancer Survivor,
Patient Advisor

Elizabeth Goss
Founder and CEO, Cancer Leadership Council

Kay Hsu
Health Insurance Advocate,
Patient Advisor

Rifeta Kajdić Hodžić, CHPM
Senior Program Manager Oncology, Association of Cancer Care Centers

Gary Puckrein, PhD
President and CEO, National Minority Quality Forum

Vilmarie Rodriguez, MSW, LCSW
Vice President of Patient Assistance and Community Engagement, Cancer*Care*

Ashira Vantrees, Esq.
Director of Legal Strategy and Advocacy, Aimed Alliance

Alexandra Zaleta, PhD
Vice President of Research and Insights, Cancer*Care*

REPORT STAFF

Kim Czubaruk, JD
Vice President of Policy
Project Lead

James Duden
Social Services Project Coordinator

Catherine Favorite
Associate Director of Communications

Sara Grisales Jaramillo, MSW, LCSW, OSW-C
Insight & Call Center Program Manager

Jonni Nazarian, MPH, CHES
Education Program Manager

Amanda Shlosberg
Senior Director of Communications

> “You ***shouldn’t have to fight*** for your medicine and tests when the doctors order them.”

EXECUTIVE SUMMARY

For too many people, a life-altering cancer diagnosis is quickly followed by insurance barriers that prevent or delay them from getting the treatment their doctors prescribe.

Known collectively as utilization management, these hurdles often come in the form of prior authorization, coverage lapses or step therapy, among other barriers. Cancer*Care*'s 2025 Insurance Red Tape Report confirmed the scope and impact of these practices.

In 2026, Cancer*Care* conducted a series of focus groups to uncover the real-life impact behind the data, exploring how insurance barriers reshape patients' daily lives, financial stability and emotional well-being.

Through in-depth conversations with people navigating cancer under commercial insurance, Medicare and Medicaid, several key themes emerged:

KEY THEMES

→ Patients face confusing and limited insurance options, forcing them into difficult trade-offs and unclear coverage decisions.

→ Amid the stress of cancer and mounting bills, patients encounter frequent barriers to accessing the treatment their doctor prescribed.

→ The constant administrative and emotional burden reshapes daily life—disrupting routines and eroding relationships.

→ Across focus group discussions, out-of-pocket costs emerged as patients' foremost access barrier.

→ Financial strain worsens cancer patients' physical and emotional health.

→ Patients feel dehumanized by dismissive interactions with insurance.

KEY QUOTES

"*I had to take a salary cut* to take time off while maintaining coverage just to stay afloat."

"One second a medication is covered, the next it's not. How did that just change overnight? *It's like the stock market.*"

"You *lose* a lot of friends."

"Where am I *going to get the money* to pay this?"

"*Stress* brings the cancer back."

"I felt like I was just a number, not a *person.*"

METHODOLOGY

Cancer*Care* conducted a series of focus groups with people living with cancer, either currently or previously undergoing treatment, and caregivers.

Participants were identified through Cancer*Care*'s database of clients from across the United States and selected based on their experience with access barriers to cancer treatment. A total of 12 people participated—both men and women of all ages, with different cancer types and treatment plans.

In February and March 2026, three 90-minute focus groups were conducted over Zoom. Each focus group consisted of four participants who shared the same insurance type. Insurance types represented include:

- Commercial, employer-sponsored
- Medicare, both traditional with supplemental Part D coverage, and Medicare Advantage
- Medicaid

The objective of the focus groups was to capture real-life, personal challenges and barriers that patients experienced in accessing their cancer care and treatment, and to augment and contextualize learnings from the Red Tape study with additional patient insights.

> “Insurance companies are ***behind the scenes*** playing all these games.”

COVERAGE CONFUSION

KEY TAKEAWAY

Patients face confusing and limited insurance options, forcing them into difficult trade-offs and unclear coverage decisions.

COMMERCIALLY INSURED PATIENTS

For patients obtaining insurance through their employer, selecting a plan may feel less like a choice and more like resigning themselves to the “least bad” option.

Patients described toggling between two or three plans during open enrollment, discouraged by the steep trade-offs that each seemed to require. High monthly premiums or deductibles marred every choice, patients noted. One participant put it bluntly: “The ‘D’ word—‘deductible’—it’s one of the most ruthless words you’ll ever encounter.”

Patients expressed frustration over health plan “math tricks.” As one person said, “If you’re not paying more per month, you pay more upfront.” The trade-offs weren’t confined to cost. Patients described holding onto jobs they’d outgrown or sacrificing career opportunities for fear that changing employment might lead to weaker coverage. One woman shared that her husband—the family’s policyholder—wanted to move up professionally but held off. “He’s afraid insurance may get worse,” she explained.

Once patients selected a plan, their confusion only deepened. “How do you not go crazy trying to understand the explanation of benefits on the website?” one participant asked. Even when provided with clear numbers by their insurance, patients noted, the costs don’t always line up. “The bills I get never match what they say they will be,” one participant explained.

MEDICARE CHALLENGES

For some participants with Medicare coverage, understanding their benefits can feel like a part-time job in and of itself. “The bills would roll in without clear expectations,” one patient recalled.

Patients described feeling trapped in an exhausting and circular communication loop—being bounced from health plan representative to clinic staff to pharmacist with no clear answers. “They just pointed fingers back and forth,” one participant said, with another recalling that, “Everyone kept referring me back to someone else.”

MEDICAID EXPERIENCES

Participants with Medicaid emphasized the limitations of their coverage, which sometimes ended with their name at the bottom of a wait list. When trying to see a specialist, one patient was told he could “either wait five months or pay $500 cash.” Reflecting on his experience, he explained that, with Medicaid, “you have to wait a very long time for appointments.”

Patients also described being pushed toward less expensive, second-choice treatment options. “It’s like…always go with the cheapest cost,” one patient reflected. Another recalled her experience trying to get care. “They’re [insurance] trying to send me to a different place that doesn’t even offer the treatment I need,” she said.

Patients who tried to find clear, helpful resources often hit a dead end. “It’s hard to navigate the system,” one patient shared. He pointed to a major gap in support: “There’s a lot of information and workshops on Medicare, but not Medicaid.”

> “It’s a ***complicated*** dance between physician, pharmacy and insurance company.”

BARRIERS & BURDENS

> “It’s ***hitting*** us on every front—financial, emotional, social.”

KEY TAKEAWAY

Amid the stress of cancer and mounting bills, patients encounter frequent barriers to accessing the treatment their doctor prescribed.

Throughout focus group discussions, patients described how high out-of-pocket costs, coverage delays and sudden medication switches disrupted their care and created a ripple effect that extended far beyond their health care needs.

AGAINST DOCTORS’ ORDERS

Patients entered the health care system assuming their doctors—experts on their condition—would be in the driver’s seat. One patient said, “my expectation was that, if a doctor is ordering a test or procedure, they’re ordering it for a reason.” Patients struggled to understand why their doctors were routinely overruled by insurance. One participant’s cardiologist said she needed a specific medication, but insurance refused to cover it. “Are you being serious?” she recalled thinking.

One Medicare patient described recent issues with a medication she’s been taking for months. “Every prescription that goes in,” she explained, “they want prior authorization.” Another patient needed a minimally invasive procedure, but insurance refused to cover it—until his doctor picked up the phone. Others were required to try generic substitutions even after their doctors prescribed something different—substitutions that, for some, did more harm than good. One patient’s heart issue worsened after being switched, while another developed a severe rash when insurance only covered the cheaper treatment option. As one patient put it, “Why they approve one pill but not another, I still don’t know.”

When people think of cancer treatment, they often think first of chemotherapy. But patients explain that managing the side effects that accompany chemo can be where insurance coverage often falls short. One patient was denied coverage for an ointment to treat a painful allergic reaction and forced to pay $400 out-of-pocket. “The pharmacy was unrelenting,” she explained. The patient ultimately turned to an online, direct-to-consumer platform for her medicine.

Another patient’s cancer medication was affecting her heart, but insurance refused to cover an echocardiogram to diagnose the problem. She reflected, “I don’t know why they think they know more than my doctors.”

For patients, these denials and delays weren’t just inconveniences. They put patients at risk for worse health outcomes and even life-or-death consequences. One Medicaid patient has spent more than a year waiting for a bone marrow stem cell procedure, requiring her to undergo round after round of chemotherapy. “My care is on hold until they authorize my treatment,” she explained. “I’m just left here in the middle, waiting.”

KEY TAKEAWAY

The constant administrative and emotional burden reshapes daily life—disrupting routines and eroding relationships.

LIVES REWRITTEN

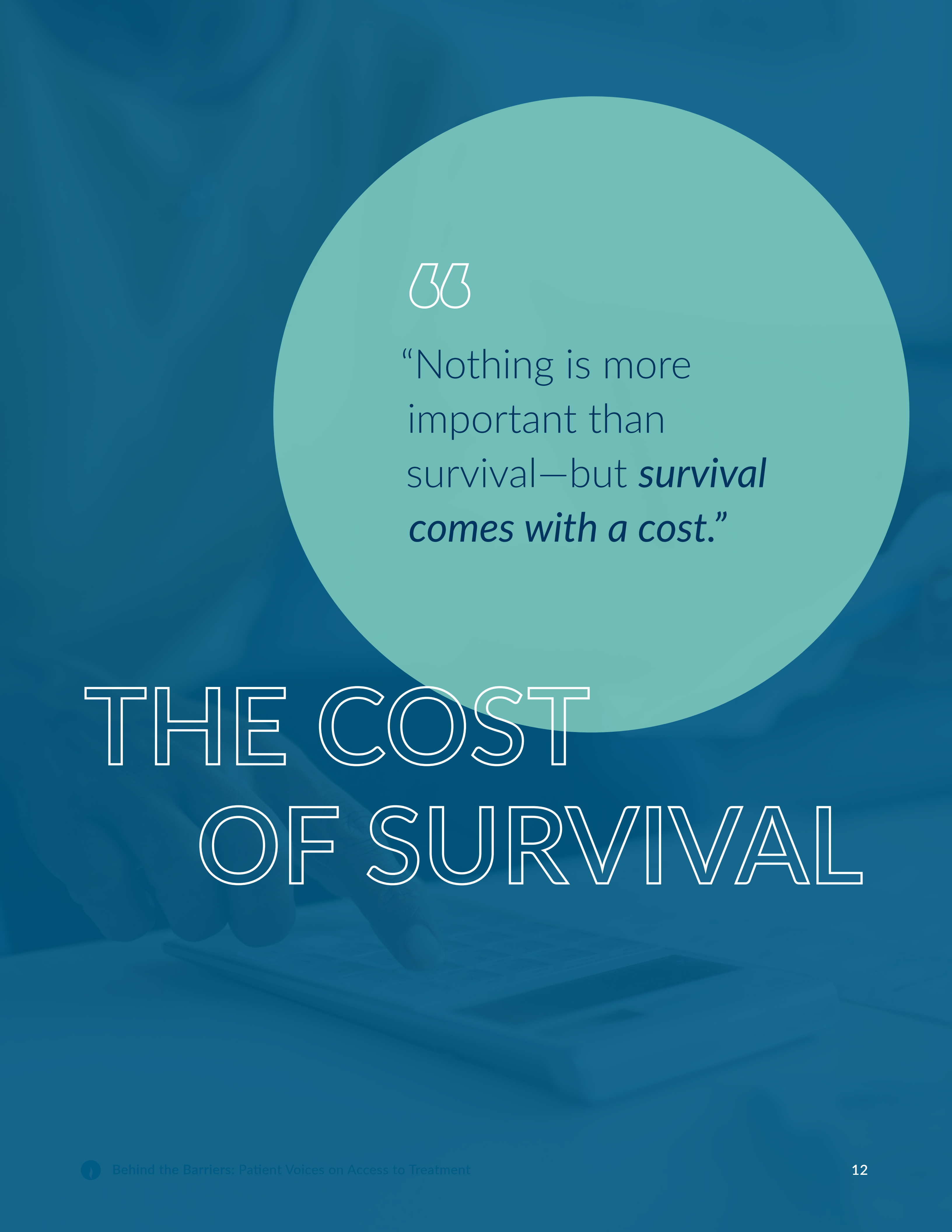
For many participants, battling cancer and insurance barriers reshaped their daily lives.

The constant cycle of appointments, insurance phone calls, medication switches and financial problem-solving—on top of the physical toll of cancer and treatment—consumed them. What used to be second nature, such as exercising, doing the dishes, spending time with friends, became impossible. Hobbies faded away. One patient recalled his love for running. “I ran for years,” he said. “But now I can’t.”

Some extroverted people felt too exhausted to maintain social ties. “I don’t have a social life,” one patient explained.

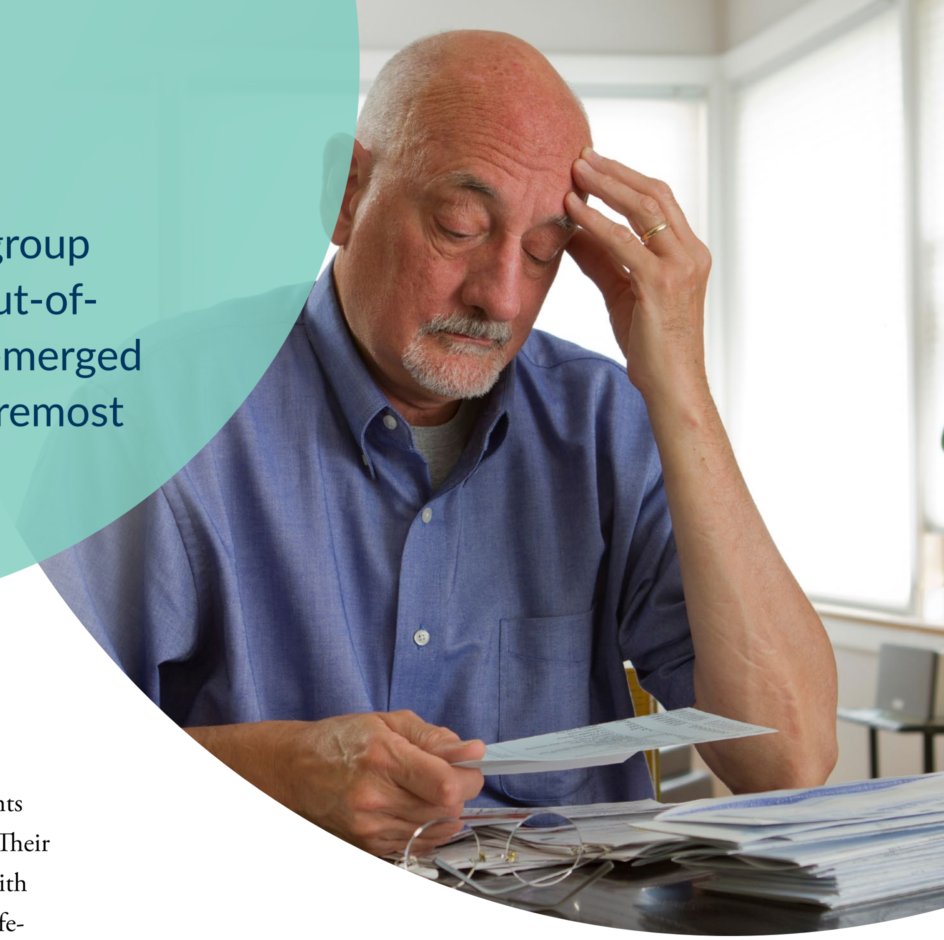
Careers took the back seat. One participant loved his work as an engineer. “I want to go back,” he explained, “but physically and mentally I’m 40% of what I used to be.”

> “Before the cancer, I was traveling and going out. Now, I don’t have the ***energy.***”



> “Nothing is more important than survival—but ***survival comes with a cost.***”

THE COST OF SURVIVAL



KEY TAKEAWAY

Across focus group discussions, out-of-pocket costs emerged as patients' foremost access barrier.

OUT OF POCKET, OUT OF CONTROL

The cost of staying alive is overwhelming, with patients facing relentless bills, debt and impossible sacrifices. Their experiences echo a broader reality for many people with cancer, where medical bills escalate into long-term, life-altering debt.

For many participants, the financial burden of cancer care was immediate. Even with insurance, high copays or deductibles drained patients' resources. Patients also described expenses stacking up in ways they never anticipated: paying for transportation and lodging for treatment days, medication to manage side effects and nourishing whole foods recommended by the doctor. As one participant quipped: "Do you know how much it costs just to stay healthy?" For many participants, the answer was: too much.

Debt and uncertainty mounted, patients explained, but the bills kept rolling in. "It got to the point where they referred me to a collection agency," one patient shared. "Every decision we make now," she explained, begins with, "'We have this bill.'"

> "I had to ***forfeit*** my retirement savings."

Some patients had to stop working because of their cancer. "I had a good job," one recalled, "but I couldn't keep that job." One Medicaid participant worried that going back to his career, even part-time, would risk his coverage. "I want to make income," he explained, "but I'm scared to lose my insurance." Others couldn't afford to slow down and risk losing both their income and their health insurance. One patient described working through intense rounds of chemotherapy, even logging work hours from bed. "I felt too sick to work," she recalled, "but the bills don't stop coming."

Several patients described having to forfeit their everyday basics and financial future to cover out-of-pocket expenses. One Medicare participant, ultimately forced to sell her house, explained, "Now I'm in an apartment. I'm thankful for a warm apartment, but it's not the same."

Participants who previously strived for future stability now faced the harsh reality of affording the immediate costs of their life-saving care. "I had to forfeit my retirement savings," one 29-year-old patient explained. "I had to deplete it for the sake of living."

As one patient summarized, "It always comes back to the money."

KEY TAKEAWAY

Financial strain worsens cancer patients' physical and emotional health.

COMPOUNDING STRESS

As one patient summed it up, "Stress brings the cancer back."

Another participant described the stress of a trip to the pharmacy. "I'm holding up the pharmacy drive-thru line, looking for a [copay] coupon" she recalled. Exasperated drivers in the cars behind her honked their horns.

Other patients said the fear of not being able to afford treatment led them to delay care. "I was leery to come back for treatment," one patient recalled. "I'm scared I'm not going to be seen if I don't pay the full balance," another agreed.

One participant secured financial assistance to continue treatment, but that entailed yet another delay. "It took a month to get approved," she said.

> "I'm on a ***tightrope*** of managing my budgets—treatment, gas, food."

"A NUMBER, NOT A PERSON"

For many participants, navigating insurance while simultaneously facing down cancer left them feeling stripped of their humanity. What they expected to be a source of support instead became another layer of disillusionment. "I was truly disappointed and let down by insurance," one participant shared, adding, "They don't care about my children's college funds or bills."

Others echoed the sense of being dismissed, with one noting, "Nobody wants to meet me halfway." Across patients' stories, a common sentiment emerged: Patients perceived a health insurance system that viewed them as transactions, not people with lives and families. "I felt like I was just a number, not a person," one participant said. "Just another dollar sign or code in the system."

Some patients realized they needed to take on the added responsibility and challenge of advocating for their own cancer care. "The responsibility was on me to look for grants and help," one patient described, adding, "It was horrible."

KEY TAKEAWAY

Patients feel dehumanized by dismissive interactions with insurance.

DISCUSSION AND KEY TAKEAWAYS

A cancer diagnosis is inherently overwhelming, and utilization management barriers exponentially compound that burden with added fear, uncertainty and stress.

Across the focus groups, participants emphasized that navigating insurance while simultaneously managing cancer was all-consuming, taking a significant and multifaceted toll on their physical, financial, emotional and mental health.

Within a confusing and often counterproductive system, many patients had to become their own advocates. When asked what message they would share with policymakers, participants urged leaders to humanize the person behind the diagnosis and take a more comprehensive approach to care. They stressed that people living with cancer are more than case numbers or billing codes—they are parents, neighbors, friends and colleagues.

> "If this was your family member, is this the type of ***care*** you'd want them to have?"

> *"Peace of mind.* That's what having no insurance barriers would give me."

The stories shared illustrate the real-life consequences of a confusing, high-cost, barrier-ridden system. They also highlight the urgent need for policy reforms that break down harmful barriers and replace them, instead, with policies that reflect the purpose of insurance and the needs of patients, namely: Insurance should be the bridge to timely access of life-saving treatments, not another obstacle cancer patients are forced to confront and overcome.

CANCER*care*®

ABOUT CANCER*CARE*®

For over 80 years, Cancer*Care* has empowered millions of people affected by cancer through free counseling, resource navigation, support groups, educational resources, advocacy and direct financial assistance. Our oncology social workers improve the lives of people diagnosed with cancer, caregivers, survivors and the bereaved by addressing their emotional, practical and financial challenges.

Cancer*Care* serves people affected by any type of cancer in all 50 states and U.S. territories, regardless of age, gender, ethnicity, or religion. In 2025, the organization's master's level oncology social workers fielded nearly 1,000 calls and emails per week from cancer patients, caregivers, and family members throughout the country.

To learn more, visit CancerCare.org or call 800-813-HOPE (4673).

CONTACT INFORMATION

Cancer*Care*
485 Madison Avenue
New York, NY 10022

800-813-HOPE (4673)
Fax: 212-712-8495

PRESS INQUIRIES

Please direct any press requests to press@CancerCare.org.