

## Talking About the Costs of Care

### A Guide for Health Care Professionals and Patient Navigators

Prepared by the National Patient Advocate Foundation  
With support from the Robert Wood Johnson Foundation

This guide aims to help health care providers, case managers and advocates understand the importance of talking about the costs of care and provide tools for having these conversations. We see this as a living document that we will continue to update as we move forward with our own work.

### Why are Cost of Care Conversations Important?



*“We need to talk about financial toxicity in the same way we talk about other side effects of treatment. When you document a side effect of treatment, you have an obligation to treat it. The same is true of financial toxicity.” Alan Balch, PhD*

Today, virtually every person facing a serious or chronic illness experiences some level of financial toxicity. Patients and caregivers feel the impact of the costs of their care in a variety of ways. These include:

- Direct costs of care, such as copays for medications, procedures, laboratory work and doctor’s appointments

- Out of network costs, high deductibles and other uncovered expenses
- Costs of transportation, lost work time, childcare and other indirect expenses related to their care
- Having to choose between basics such as groceries, utility bills, rent and paying for medical care, or depleted savings, debt, or inability to do the things that are important to people and their families.
- Emergence of new, expensive but effective treatments for a range of conditions
- Patients living longer with conditions that have now become chronic, and thus incurring expenses over longer periods of time, affecting a broad range of life situations.

*“We hear it from our callers every day. People are having to choose between buying groceries and paying their medical bills. They call and say I have this shoe box full of bills and I don’t even know where to start.” Rita, Patient Advocate Foundation Case Manager*

Financial toxicity is not limited to people who are uninsured. It affects people who are underinsured or have insurance plans with limited or inadequate coverage as well as people with good insurance who find their lives altered by their condition.

It is important to have conversations about the cost of care with every patient and to include caregivers in these discussions. The costs of care can influence treatment decisions and are a critical component of shared decision making.

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Suleika Jaouad had just graduated from college and was looking forward to life in New York City and her career as a journalist. Then she was diagnosed with acute leukemia. She underwent aggressive chemotherapy and a bone marrow transplant. She survived and has become an advocate and spokesperson on the experience of young adults facing cancer. Her successful treatment, however, came at great cost, financially, physically and emotionally. She accumulated thousands of dollars in medical bills as a result of copays and out of network charges. Her mother quit her job to move to New York to be her daughter’s caregiver. Suleika shared her cancer experience in a series of blog and video posts in the New York Times called *Life, Interrupted*, available on her website, [suleikajaouad.com](http://suleikajaouad.com).

*“Even if you have good insurance as I did, the costs of care both in terms of treatment and the impact on your life can be overwhelming.” Suleika Jaouad, survivor and advocate*



Tom Ema lived with an indolent form of lymphoma for many years. When his disease became more aggressive, he and his wife decided to move from Colorado to Virginia to be closer to their family. There, they encountered significant problems in finding adequate insurance coverage, confounded by the fact that Tom was self-employed. They thought they had signed up for good insurance and had an oncologist in network but the bills kept mounting. Tom's treatment cost \$10-15000 a month, and they were told that it was not covered. At one point, Tom decided to stop treatment because he didn't want to leave his family with these huge bills. It took intensive intervention from the Patient Advocate Foundation to resolve these issues, and keep Tom alive long enough to benefit from a new drug specifically for his condition.



*“I reached the point where I decided to stop treatment because I couldn't afford to live anymore.” Tom Ema*

Tammy Taylor, PhD, is a nurse practitioner who works in a community-based health care practice in the Mississippi Delta, specializing in cardiac care. Most of her patients are either on Medicaid or have no insurance. In addition to providing health care, Dr. Taylor also has to work closely with her patients to help them access and afford their medications and treatment. She tells of one young woman with postnatal heart disease who had to choose between taking care of her three children and the heart care that was essential to her own health and life. Her patient understood the risks, but like so many mothers, put her children's wellbeing over her own.

*"We have a huge problem with non-adherence. We have a huge problem with people missing appointments. So often what you see is a tradeoff."*  
Tammy Taylor, PhD

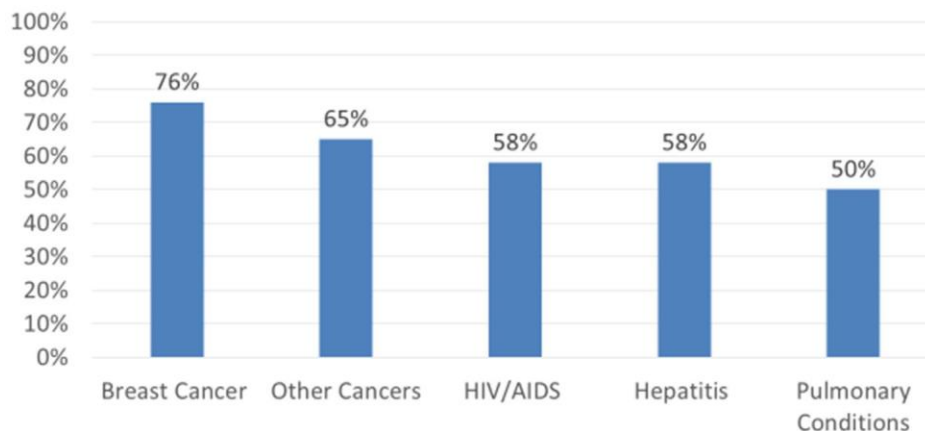


### What the Data Say

- In a Patient Advocate Foundation Survey, over 70 percent of patients say they want to discuss the costs of their care with their health care providers. These data from PAF show the impact of financial toxicity on patients.

## Prevalence & Severity

***In the past year, have you experienced a financial hardship due to the cost of your medical care? (percentage selecting “yes”)***

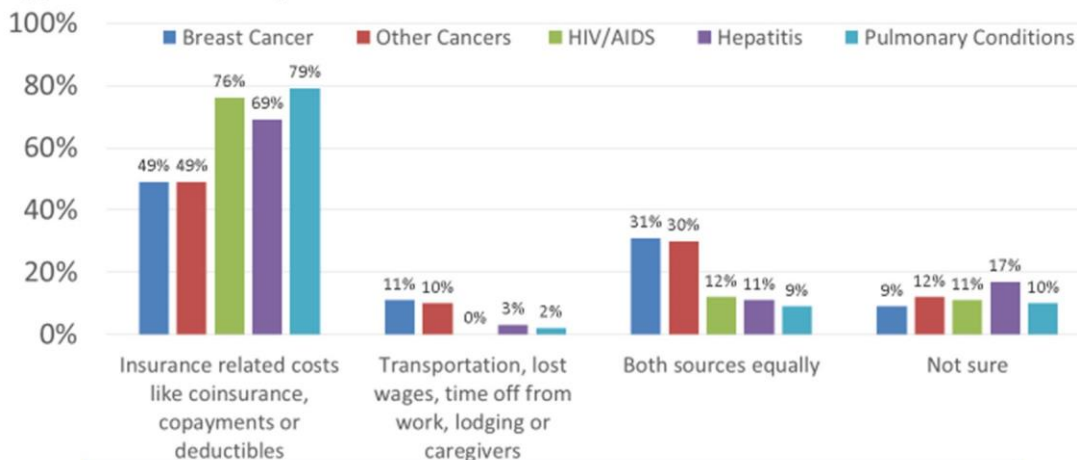


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## Out of Pocket Expenses

***Thinking about the last 12 months and the costs you have experienced related to your medical care – please pick the type of expenses that were the greatest source of financial strain to you.***



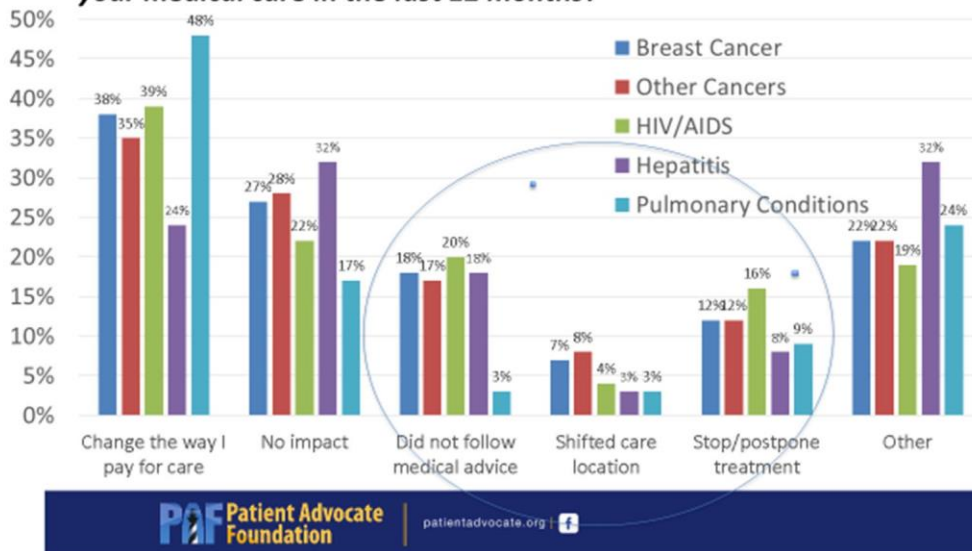
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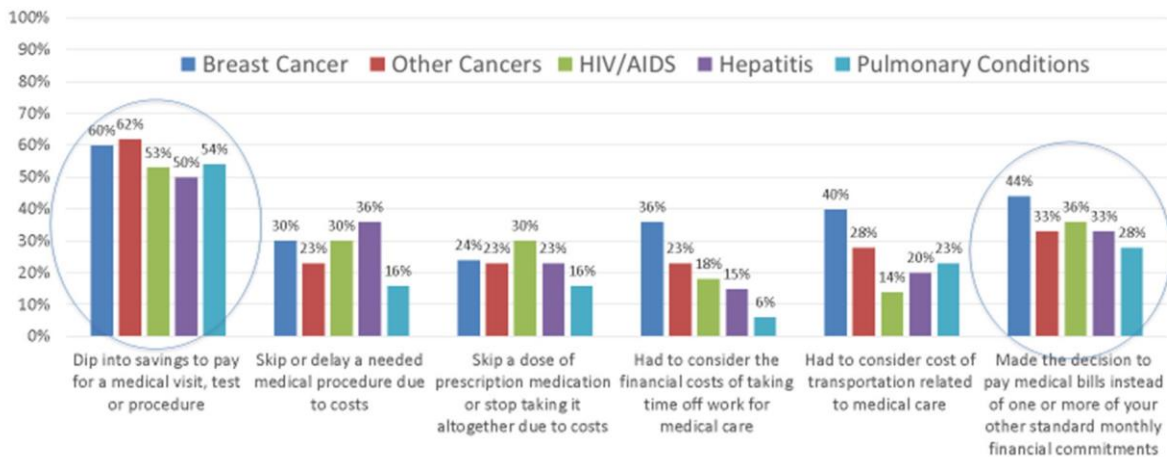
## Impact on Medical Care

*If you experienced a financial hardship, then what impact did it have on your medical care in the last 12 months?*



## Impact on Finances

*Have you had to do any of the following in the last 12 months?*



## Key Points

- **Financial toxicity can affect almost everyone--including people with good insurance plans**
- **Patients want to discuss the costs of their care with their doctors and health care providers**
- **Changes in the health care delivery system, insurance plans and patient choices about their plans are adding to out of pocket costs**
- **Costs of care affect every aspect of people's lives, often resulting in choosing between necessities and paying medical bills**
- **Costs of care affects decisions about treatment**
- **Both patients and their providers need to be more aware of the importance of discussing the costs of their care**

## Barriers and Challenges to Cost of Care Conversations

### Patients and Caregivers

- Don't know that they can ask their providers about costs
- Fear that raising concerns about money will lead to less than optimal treatment. This is especially true of patients who are uninsured, on Medicaid or under-insured.
- Don't think their providers have time for those discussions
- Don't have usable real time information on costs before and at the time they are making treatment decisions
- May be reluctant to talk about money issues, which they consider personal
- May not realize that costs not directly related to care delivery, such as food, rent and utilities are included in the overall cost of care discussion
- May not realize there are resources available to help them
- May not realize that there are less expensive drugs, options that require fewer clinic visits or procedures
- May face social or cultural barriers that make talking about money difficult or unacceptable

*"I think in many instances immigration status plays into cost of care discussions. Immigrants are afraid to open up about their financial status or discuss family issues because they fear the repercussions." Provider, Center for Health Care Progress*

## Physicians and Health Care Providers

- May not believe that talking about the cost of care is part of their job
- View time constraints as a critical barrier
- May not be aware of what that costs of care actually are
- May not have the skills or training to discuss these issues with their patients
- May not be aware of available resources or how to access them
- May not be aware of the social and cultural barriers that prevent patients from raising their concerns about cost of care
- May face resistance from administrators who view cost of care conversations as slowing the workflow without contributing to either patient or business-related outcomes

*“I didn’t know I could say ‘how much does it cost to come here.’ I didn’t know physicians had anything to do with the cost part of care.” patient, Consumer Reports, RWJF Funded Research*

*“We recognized that patients were having cost issues but didn’t appreciate the scope of the challenges patients were facing.” Physician, Consumer Reports, RWJF Funded Research*

*Research shows that cost of care conversations do not add significantly to the time physicians spend with their patients. Many take a minute or less.*

*Simply providing patients with a list of prices related to their care is not adequate. In theory, this information contributes to transparency and helps patients make decisions, but in reality, most patients do not have the knowledge base or context to evaluate these data and apply them to their individual situations. Pricing information should be available, but it is not a substitute for discussing the actual costs of a person’s care.” NPAF Case Manager*



## The Consequences of NOT Talking about Costs of Care

- Patients may stop taking medications, skip doses or appointments
- Patients may not have access to important resources that can help address their financial toxicity
- Patients may not have access to treatment options that can lower their costs without affecting their quality of care
- Patients may have to choose between their medical care and key issues such as paying the rent or buying food for their children

## Key Take-Aways

- **Both patients and providers face significant barriers to having cost of care discussions**
- **It is important for providers and case managers to be aware of these challenges and barriers when they consider cost of care conversations**
- **Patients often don't realize that they can talk about their financial concerns with their providers**
- **Failing to discuss costs of care often has serious implications for patients' ability to adhere to treatment recommendations and access available resources**

## Having the Conversation

*“Health care providers most often say the most important factor for them in having cost of care conversations is knowing what resources are available to help their patients. Doctors don't like to be in the position of raising issues about financial toxicity without having answers about what they can do to address these problems.” Alan Balch*



Either the patient or provider can initiate a conversation about the cost of care. Many patients are more comfortable when their provider opens the door to these discussions and asks if there are any concerns about paying for treatment, handling issues such as transportation, child care or lost work time, or the impact of medical costs on that person's life.

## Keys to Having Cost of Care Conversations for Providers

*"We need to systematically screen for financial issues, just like we screen for depression or pain," Physician, University of Rochester Medical Center*



*"Twenty-five percent of employers offer only high deductible plans right now, and according to a recent survey, another quarter are contemplating offering only these plans. This makes even more important that we talk to patients about out of pocket expenses and help them decisions." Peter Ubel, MD, Duke University*

- Normalize these conversations. Make them a standard part of talking to patients about their treatment options and their values. Use standardized screening questions to identify and assess financial toxicity.
- Help make patients comfortable by telling them that talking about the cost of their care is a topic that is important for everyone and that it will not affect the quality of their care. These conversations should be as normal as asking patients if they are experiencing pain or having side effects from their treatment.
- Be aware that especially at the beginning of the treatment process, most patients do not have a good idea of what their insurance does and does not cover.
- Be proactive in providing patients with information about their costs and the resources that are available to them, both in terms of the actual costs, lower cost options and available resources to help pay for medical or life-related costs.

- Understand that having these conversations can be difficult for vulnerable populations. It's important to be aware of the barriers that can make it difficult for people to discuss financial issues.
- While patients look to their physicians to provide information on treatment decisions, it is important to involve other members of the care team in cost of care discussions. Nurses, nurse practitioners, social workers and financial counselors often have more time for conversations, may be more aware of what is happening in a patient's life and of the available resources.
- Cost of care discussions are not "one off" events. It is important to make this a topic from the beginning of care but to continue it throughout the duration of treatment and at every key decision-making point.

*"We often find out at the next visit that our patients didn't fill their prescription and the reason is, it cost too much. But they didn't want to tell us that in the visit." Medical Assistant, University of Rochester Medical Center*

*"I finally realized that it makes sense to speak up during the appointment. You've got to tell your doctor that you don't have \$100 for the medication he is prescribing instead of waiting until you get to the pharmacy, or never going at all. There's no shame in the game. You have to communicate." Shirley, cardiac patient*



## **Keys to Having Cost of Care Conversations for Patients and Caregivers**

- It's critical that patients know what benefits they have, what their insurance covers, what kinds of copays and deductibles they face before they start treatment. Most people, even those who are highly educated and have good insurance simply do not know this important information until after the bills arrive.
- Patients also need to understand that there frequently are less expensive options for their treatment. This can mean less expensive drugs, fewer office visits or procedures, more telephone consults.

- Patients also need to be aware that there are often resources available to help pay for medical expenses--including copay pay relief, coupons, transportation vouchers and even funding for life expenses. Many medical centers have financial counselors to help patients identify and access these resources.
- If the provider doesn't ask about financial concerns, patients need to feel comfortable bringing up these issues--at any point during their care.



Joan's husband has a good job, and an employee-based insurance plan. It was not until Joan was diagnosed with breast cancer, however than she learned that there was a \$25000 cap on coverage for any single condition. The diagnosis was frightening but the prospect of not being able to afford her care or bankrupting her family was terrifying. Joan's doctor assured her they would work with her and that she would get the best available treatment regardless of her ability to pay. It made a big difference for Joan as she went through the process, but her experience also played a major role in turning her into an advocate.

*"I had just learned my diagnosis, and then the insurance coverage issue came up. There was no way that twenty-five thousand dollars was going to cover my treatment, even if there were no complications. I thought to myself....I just can't afford to have cancer." Judy, breast cancer patient*



Rita, Patient Advocate Foundation Case Manager

*“It’s really critical to know what your insurance plan covers, what your deductibles are going to be, your copays, how the plan deals with out of network charges. Most people don’t think about this until they have a shoe box full of bills they don’t understand and cannot pay. You want to try to be proactive in knowing in advance what kind of medical expenses you are going to face, and you can’t do that unless you talk to your doctors and your insurance company from the beginning.”*

## **How to Save Money Before, During and After Your Doctor’s Appointment**

### **10 Essential Questions to Ask**



Today, most Americans live one large medical bill away from serious financial hardship. What can you do to keep yourself as safe as possible? Remember these questions throughout your health care journey:

## Before Your Appointment

- Is this the right insurance plan for me? Whether you're on an employer, individual or Medicare plan, you may have multiple options during open enrollment. Don't just check your monthly premium: other factors will contribute to out-of-pocket costs, like your deductible, copay and coinsurance rates. Make sure any preferred providers are in-network. Finally, evaluate the plan's drug formulary to ensure that any preexisting prescriptions will be covered in the upcoming year. Checking for all these rates may take time -- and a lot of phone calls -- but it will save you time and money.
- Are you in-network? An in-network provider will cost less. Before your appointment, check with your insurer about your provider's network status -- and then call the provider's office as well.
- What are my treatment goals? The more your treatment plan is personalized to you, the more it will work for you both physically and financially. But according to our survey work, 25% of patients say they had no opportunity to discuss what was important to them with their doctors when they made their treatment plans. Prepare for your appointment by thinking about your goals for treatment and how you can express them to your physician.

## During Your Appointment

- What are my other options? Ask about alternative treatment plans, along with their side effects and efficacy, that may be lower-cost for you or more fully covered by your plan.
- How can I limit my transportation needs for this treatment? Transportation is an enormous barrier for many people. Let your provider know if you have limited or unreliable transportation. If your treatment plan includes frequent or long-distance travel to a specialist, talk about alternative options.
- Can we lower my drug costs? If your plan involves medications, ask about generics or other alternatives that may lead to lowering your out-of-pocket costs.

## After Your Appointment

- Is this my final bill? If you get a large bill, don't panic right away. The provider may send you a bill before they receive payment from your insurer. Don't pay anything until you've received an Explanation of Benefits and know that your insurance plan has covered its share.

## Key Takeaways

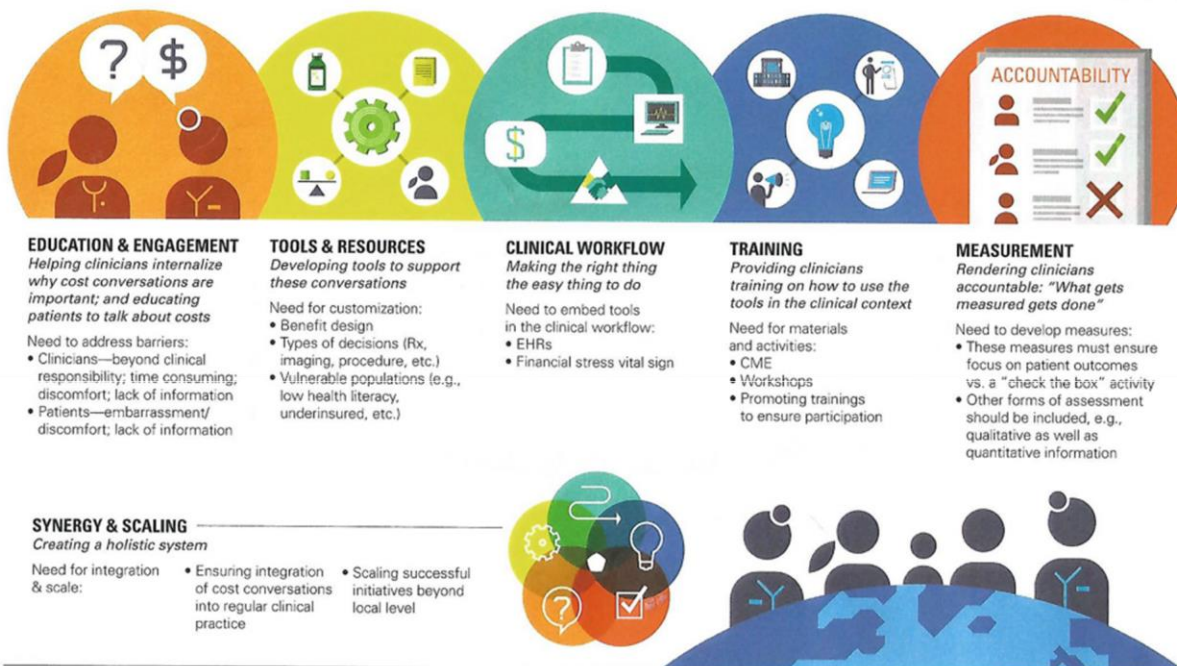
- **Cost of Care Discussions are most effective when:**
  - They are normal, standard part of the treatment decision making process for all patients
  - Both patients and providers proactively inform themselves about potential costs, options and available resources
  - Patients are provided with usable, timely materials in advance to help them understand out of pocket costs
  - Multiple members of the health care team are involved in screening for and addressing financial concerns
  - Cost of care discussions take place at every key treatment making decision point

## Key Steps to Improve Patient-Clinician Cost-of-Care Conversations



**W**ith growing out-of-pocket spending for care, patients are increasingly interested in knowing, upfront, how much their care will cost them. Various barriers—such as competing priorities during short clinical encounters, limited training on appropriate communication and shared decision-making (SDM) skills, and a lack of usable information on the costs of care—often prevent these conversations from occurring during routine clinical encounters. Avalere Health is conducting research on barriers surrounding patient-clinician

cost-of-care conversations and the current state of activities in the field on behalf of The Robert Wood Johnson Foundation. Though not the sole focus of this research, we are particularly interested in how to support vulnerable and marginalized populations in these conversations. In the graphic below, we outline six broad priorities for improving patient-clinician cost-of-care conversations.



Graphic courtesy of Avalere Health

**For additional on Cost of Care Discussions and the RWJF Funded Research**

[www.patientadvocate.org](http://www.patientadvocate.org)

[www.NPAF.org](http://www.NPAF.org)

[www.Youtube.com/NPAF](http://www.Youtube.com/NPAF)

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