

The Cost of Surviving Cancer

Cancer care is often understood through its clinical milestones. Doctors describe and measure the cancer journey through diagnosis, staging, treatment decisions, and survival outcomes. These are the visible parts of care, the ones that appear in reports, hospital records, and policy discussions.

But for most people, the experience of cancer is not only medical.

For a common family, cancer treatment is extremely expensive. Costs often begin in lakhs and, in many cases, can reach crores. For most households, building that kind of money takes years, sometimes generations. The financial pressure begins even before treatment starts. Diagnostic tests, scans, and consultations already require significant spending. Once treatment begins, expenses increase rapidly with surgery, chemotherapy, radiation, medications, and repeated hospital visits.

At the same time, life does not pause. Families still need to pay for rent, food, education, and daily living. In many households, one or more members begin working longer hours to support treatment costs. Others may leave their jobs to care for the patient. This creates a constant balancing act. Families are trying to earn enough to continue treatment while also trying to be present for their loved one during one of the most critical periods of their lives.

In some situations, people face painful choices. They may have to decide between buying medicines and managing basic household needs. Even middle-class families, who may appear financially stable, often struggle to arrange large amounts of money quickly. These realities rarely appear in medical records, but they shape how treatment is experienced and whether it can be sustained over time.

This is where financial toxicity becomes part of cancer care.

Financial toxicity refers to the financial stress people face during cancer treatment. It includes hospital bills, travel costs, lost income, and the overall strain of managing everyday expenses alongside treatment. Research shows that this is a widespread issue. A systematic review by *Donkor* found that around 57 percent of cancer patients in low- and middle-income countries experience financial toxicity. This highlights how common financial strain has become across different health systems. In the United States, *Ramsey* found that patients who went bankrupt after a cancer diagnosis were significantly more likely to die earlier than those who did not face such financial distress.

These findings show something important. Financial strain is not separate from treatment. It directly affects whether patients can access care, stay on treatment, and benefit from it.

When Treatment Costs Become Hard to Manage

Cancer treatment is not a one-time expense. It continues for months and often years. Patients go through multiple cycles of treatment, surgeries, follow-ups, and long-term monitoring. Even after the main treatment ends, regular check-ups and medications continue.

The financial burden builds over time.

Out-of-pocket costs are the expenses patients pay directly from their savings, without support from insurance or government programs. Families pay for consultations, medicines, tests, travel, and hospital stays, often all at once. Studies by de Moor and Williams show that in the United States, patients may spend between 180 and 2,598 dollars every month from their own pockets.

In countries like India, the situation is often more difficult. Research by *Prinja and Dixit* shows that many families pay for cancer treatment mostly through their own savings. This can lead to what is called catastrophic health expenditure. This means a family spends such a large portion of its income on healthcare that it affects their ability to afford basic needs like food, housing, and education. To manage these costs, families often use savings, borrow money, or sell assets like land or jewellery.

The burden goes beyond hospital bills. Patients and families spend on travel to treatment centers, accommodation near hospitals, caregiving support, and additional medicines. Over time, these costs make it harder to stay on treatment.

To reduce this burden, researchers highlight the importance of financial protection systems. *Knaul* explains that universal health coverage can help by pooling money at a system level, through taxes or insurance, so that individuals do not have to pay large amounts on their own during illness. Instead of each patient paying separately, the system shares the cost across the population.

Chokshi and Farley suggest simple steps. Governments can negotiate drug prices and buy medicines in bulk to reduce costs. When health systems take these steps, they can make treatment more affordable for patients.

These approaches show that affordability is not just an individual issue. Healthcare systems and policies shape how affordable care is. When strong financial protection exists, patients do not have to choose between treatment and basic needs. When it is weak, families are forced to make difficult trade-offs, such as delaying treatment, reducing doses, or cutting essential household expenses.

When Money Affects Treatment Decisions

Financial pressure directly affects treatment decisions.

Ramsey found that patients who faced severe financial distress, such as bankruptcy, had a higher risk of dying earlier. Increased mortality means a higher chance of death within a given period compared to others. This suggests that financial problems can indirectly affect survival.

Zafar helps explain why this happens. Their study found that patients facing financial stress were more likely to struggle with following their treatment plan. This could mean missing

appointments, not buying prescribed medicines, or stopping treatment earlier than recommended.

These are not careless decisions. Patients delay care, skip medicines, or hesitate to continue treatment because they simply cannot afford it.

This changes how we understand outcomes in cancer care. Survival does not depend only on how effective a treatment is. It also depends on whether patients can afford to stay on treatment.

One approach that has shown real impact is financial navigation. *Yezevski* studied programs where trained staff help patients understand treatment costs, access financial aid, and manage insurance processes. These programs helped patients receive nearly 39 million dollars in financial assistance.

This does not mean patients become financially prepared for cancer. Instead, it means they are supported early. They understand what costs to expect, what help is available, and how to manage expenses step by step. This reduces panic decisions and helps patients continue treatment with more clarity and stability.

When Cancer Affects Work and Income

Cancer affects a person's ability to work. Treatment schedules, physical side effects, and emotional stress make it difficult to maintain regular employment.

Studies by *de Moor and colleagues* show that more than 40 percent of cancer patients experience changes in their employment. Some reduce working hours. Others take long breaks or leave their jobs completely.

This creates added pressure on families. Expenses increase while income decreases.

Financial toxicity does not happen only because treatment is expensive. It also happens because families are spending more money while earning less at the same time.

Some studies, such as *Liu's*, show that emotional and social support can help people cope better with financial stress. However, support from family and friends cannot replace lost income.

Addressing this requires support beyond hospitals. Policies like paid medical leave, job protection, and income support can help families manage this phase. Financial counseling during treatment can also help patients plan their expenses and make informed decisions.

When New Treatments Are Too Expensive

Cancer treatment has improved significantly over time. New medicines and technologies have helped improve survival and quality of life. However, these advancements often come with high costs.

Wilson and Lin found that even experts often disagree when trying to measure the value of cancer treatments using tools like the ASCO value framework. At the same time, they noted that the prices of cancer drugs continue to rise steadily, often faster than people's ability to afford them.

This creates a difficult reality for many patients. A treatment may exist and work well, but it may not be affordable for many.

As a result, patients and families face uncertainty. They may question whether they can continue treatment or whether they need to switch to less expensive options.

To address this, policymakers and health systems are exploring ways to link the price of treatments to their actual benefit. Approaches like value-based pricing and price negotiation aim to make treatments more affordable without limiting innovation. However, these strategies need stronger implementation to make a real difference.

When Financial Stress Goes Unnoticed

Many patients do not openly talk about financial stress. They may feel uncomfortable discussing money or assume that nothing can be done to help.

Because of this, financial problems often remain hidden until they become severe.

Bell Brown shows that care teams do not always identify financial concerns early. When this happens, patients miss the support that could help them manage treatment more smoothly.

A simple solution is to include financial screening as part of regular care. Doctors or care teams can ask basic questions about financial concerns during consultations. This helps identify patients who may be struggling.

Once identified, patients can be connected to available support systems, such as financial counselors, government schemes, or assistance programs. This approach does not require complex systems, but it does require recognizing financial health as part of overall care.

What the System Still Misses

Research has helped us understand the extent of financial toxicity, but there are still important gaps.

Most studies focus on describing the problem rather than testing large-scale solutions. There is also limited research from low- and middle-income countries on what interventions work best in those settings.

Research does not fully capture the experiences of some groups, especially people in rural areas or those working in informal jobs. Their challenges may be different and more severe.

Clinical guidelines and policies do not consistently include financial toxicity as part of cancer care. This is not about blaming healthcare providers. It reflects a broader gap where financial aspects of care are still not fully integrated into system-level planning.

What Needs to Change

Reducing financial toxicity requires action at the policy level.

Governments play a key role in expanding insurance coverage, reducing out-of-pocket costs, and ensuring that essential cancer treatments remain affordable. Stronger price regulation and negotiation can help control the rising cost of medicines.

Healthcare systems can support this by integrating financial screening and financial navigation into routine care. This ensures that patients receive both medical and financial guidance during treatment.

At the same time, policies outside healthcare are equally important. Employment protection, paid leave, and income support systems help families manage the indirect impact of cancer.

This is not about placing responsibility on one part of the system. It requires coordination between healthcare providers, policymakers, and social support systems.

Why This Matters for Patients

Financial toxicity affects more than finances. It affects dignity, stability, and the ability to focus on recovery.

When patients have to think about money at every step, treatment becomes more stressful. Patients and families make decisions based not only on what is medically best, but also on what they can afford.

This creates a hidden form of inequality. Two patients with the same condition can go through completely different journeys, depending on their financial situation.

Patients and families actively adjust their lives to manage this burden. They take loans, reduce spending, and make difficult compromises. These efforts often go unnoticed, but they shape the entire treatment journey.

Recognizing this reality is not about expanding care unnecessarily. It is about making care more complete and more humane.

Sanjeevani: Where Treatment Meets Everyday Life

People often think of the cost of cancer as just the cost of treatment. However, for many patients, the strain extends far beyond hospital bills. It appears that the uncertainty between appointments, the cost of maintaining nutrition, the need for caregiving support, and the emotional stress that shapes decision-making and continuity of care. Much of this burden

unfolds outside clinical settings, where support is limited but deeply needed. This is where organizations like Sanjeevani...Life Beyond Cancer plays an important role.

Their work reflects a broader understanding of financial toxicity. Cancer is not only expensive to treat; it is also difficult to navigate. Patients often manage fatigue, income loss, travel, and emotional distress at the same time. When these pressures build, they can disrupt treatment itself. Support, therefore, needs to address not only medical care but also the conditions that allow patients to continue it.

One of the first ways this support takes shape is through financial guidance at the point of care. When a patient enters the system, Sanjeevani's in-house resource persons work closely with them to organize funds for treatment. They connect patients to central and state government schemes wherever they are eligible. When patients are not covered under these schemes, the team connects them with individual donors, ensuring that treatment is not denied or stopped due to a shortage of funds. This early support reduces uncertainty around treatment costs and helps patients stay on treatment more consistently.

This support continues through the CanSaarthi program, which focuses on helping patients navigate the treatment journey more clearly. It prepares individuals, many of whom have lived through cancer themselves, to guide patients through what to expect, how to plan, and when to act. When patients better understand their care, they are less likely to miss appointments, delay decisions, or struggle through the system. This helps reduce indirect costs such as repeated visits, last-minute arrangements, and disruptions in care. At the same time, the program also creates pathways for financial rehabilitation, as many CanSaarthis are able to take up structured roles after training, allowing them to regain financial stability while remaining connected to the cancer care ecosystem.

Sanjeevani's approach also extends into the community, where financial toxicity often begins much earlier than treatment itself. Many people are unsure about symptoms or where to go for help, which delays care and can make treatment longer, more complex, and more expensive. The Community Cancer Leadership Program addresses this by building awareness and support closer to where people live, helping individuals take timely steps toward care.

The program engages cancer survivors, caregivers, and community members who may not be able to work full-time but are willing to contribute even a small amount of time. They are trained as community cancer leaders and provided a part-time honorarium, creating a modest but meaningful source of financial support. The program has also expanded to include ASHA and Anganwadi workers, who are already trusted within the public health system. With additional training on cancer awareness, early symptoms, and next steps, they are able to integrate this knowledge into their everyday interactions. As a result, they become a first point of contact within the community, reducing uncertainty, encouraging earlier care-seeking, and preventing delays that can increase both medical and financial burden.

Alongside navigation and early support, Sanjeevani also addresses basic needs that directly affect a patient's ability to continue treatment. Nutrition is one of the most critical among them, yet it is often difficult to maintain during long and demanding treatment cycles. For

many patients, this becomes both a physical and financial challenge that can affect their ability to tolerate treatment.

The CanAhaar initiative responds to this gap by providing nutritional support designed for patients undergoing treatment. By helping patients maintain their strength, it enables them to continue treatment with fewer interruptions. This reduces the likelihood of complications, delays, and additional medical costs, making the overall treatment journey more stable and manageable.

Emotional well-being also plays an important role in how patients manage financial stress. Long treatment cycles and uncertainty can affect how individuals make care decisions. When patients feel overwhelmed, they may delay or discontinue treatment, not only because of cost but also because of distress. Initiatives like Adopt a Patient provide counseling, emotional support, and coping mechanisms that help patients stay engaged with treatment.

When individuals feel supported, they are more likely to continue care consistently rather than make rushed decisions driven only by financial pressure. This helps maintain continuity of care and reduces avoidable disruptions that can increase both emotional and financial strain.

Support also extends within hospital settings through the CanSahogi program, where many of the individuals recruited, trained, and placed in these roles are cancer survivors or caregivers themselves. This creates a dual impact. Patients receive practical, experience-based support that makes navigating care easier, while those who take up these roles gain a source of income after experiencing the economic impact of cancer. In this way, the program supports patients and also provides an added layer of financial security for survivors and caregivers.

At times, support also includes immediate and practical assistance, such as providing essential medical equipment to patients who may not otherwise afford it. These interventions help make day-to-day care more manageable and prevent complications that could lead to additional expenses.

Across these efforts, a clear pattern emerges. Financial toxicity is not only about the cost of treatment but also about everything that affects a patient's ability to access, continue, and complete care. When support is timely and well-integrated, it reduces disruptions, prevents avoidable costs, and allows patients to stay on treatment with greater stability.

In the end, addressing financial toxicity requires looking beyond direct expenses. It calls for attention to the everyday realities that shape how patients experience and continue treatment.

Conclusion

Cancer care has made significant progress in recent years. Treatments have improved, and survival rates have increased. However, these advances must be matched with systems that people can afford.

Research shows that financial toxicity is common and that it affects treatment decisions and outcomes. It also shows that solutions exist, from financial protection policies to patient support programs.

Improving cancer care requires a broader approach. It is not only about developing better treatments but also about ensuring that patients can access and continue them without overwhelming financial strain.

This does not reduce the importance of medical progress. It strengthens cancer care by making it more sustainable for patients and families.

In the end, cancer care is not only about treating the disease. It is also about supporting people through one of the most challenging periods of their lives in a way that is both effective and financially manageable.

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