

New Tool Predicts Financial Pain for Cancer Patients

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Key Points:

- University of Chicago cancer specialists have developed a tool—11 questions, assembled and refined from conversations with more than 150 patients with advanced cancer—to measure a patient’s risk for, and ability to tolerate, financial stress.
- Learning how a patient responds may help caregivers determine who is likely to need education, financial counseling, or referral to a support network, and who is likely to have financial problems and will require interventions.

In an online report in the journal *Cancer*, a team of University of Chicago cancer specialists have described the first tool—11 questions, assembled and refined from conversations with more than 150 patients with advanced cancer—to measure a patient’s risk for, and ability to tolerate, financial stress. The researchers refer to the expense, anxiety, and loss of confidence confronting cancer patients who face large, unpredictable costs, often compounded by decreased ability to work, as “financial toxicity,” and they have named their patient-reported outcome measure COST (C**OM**prehensive Score for financial Toxicity).

Launching the Discussion

“Few physicians discuss this increasingly significant side effect with their patients,” said lead study author **Jonas de Souza, MD**, a head-and-neck cancer specialist at [The University of Chicago Medicine](#). “Physicians aren’t trained to do this. It makes them, as well as patients, feel uncomfortable,” he said. “We aren’t good at it. We believe that a thoughtful, concise tool that could help predict a patient’s risk for financial toxicity might open the lines of communication. This gives us a way to launch that discussion.”

Financial pain may extend beyond treatment. A recent study from the Centers for Disease Control and Prevention found that 30% of cancer survivors are not able to return to work, or have decreased ability to work. Annual medical expenditures increase by more than \$4,000 for males who have had cancer and by nearly \$3,300 for females.

“We need better ways to find out which patients are most at risk,” Dr. de Souza said. “Then we can help them get financial assistance. If patients know what to expect, they may want their physicians to consider less costly medications.”

Brief but Thorough Questionnaire

Development of the COST questionnaire began with a literature review and a series of extensive interviews. Dr. de Souza and colleagues spoke with 20 patients and six cancer professionals, as well as nurses and social workers. That produced a list of 147 questions. The researchers pared the list down to 58 questions. Then they asked 35 patients to help them decide which of the remaining questions were the most important. The patients narrowed the list down to 30.

“In the end, 155 patients led us, with some judicious editing, to a set of 11 statements,” de Souza said. “This was sufficiently brief to prevent annoying those responding to the questions but thorough enough to get us the information we need.”

All 11 entries are short and easy to understand. For example, item 2 states: “My out-of-pocket medical expenses are more than I thought they would be.” Item 7, more optimistic, states: “I am able to meet my monthly expenses.” For each question, patients choose from five potential responses: not at all, a little bit, somewhat, quite a bit, or very much.

Learning how a patient responds may help caregivers determine who is likely to need education, financial counseling, or referral to a support network. The quiz may also predict who is likely to have problems and will require interventions.

Minimal Impact of Income

All patients who helped develop the study had been in treatment for at least 2 months and had received bills. Excluding the top 10% and the bottom 10%, patients in the study earned between \$37,000 and \$111,000. The median annual income for these patients was about \$63,000.

The researchers expected that financial toxicity would correlate with income. “But in our small sample that did not hold up,” Dr. de Souza said. “People with less education seemed to have more financial distress, but variations in income did not make much difference. We need bigger studies to confirm that, but at least we now have a tool we can use to study this.”

The researchers are now conducting a larger study to validate these findings and correlate the newly developed scale with quality of life and anxiety in cancer patients.

First Step

“We need to assess outcomes that are important for patients,” Dr. de Souza said. The cost burden cancer patients experience is definitely one. Measuring this toxicity is the first step toward addressing this important issue. “At the end,” he added, “this is another important piece of information in the shared decision-making process.”

The National Institutes of Health funded the study through a Clinical and Translational Science Award to the University of Chicago Institute for Translational Medicine. Dr. de Souza is the corresponding author, and his coauthors include **Bonnie Yap, MS**, **Fay Hlubocky, MA, PhD**, **Kristen Wroblewski, MS**, and **Christopher Daugherty, MD**, from The University of Chicago Medicine; as well as **David Cella, PhD**, from [Northwestern University Feinberg School of Medicine](#).

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