

New tool for cancer patients measures the stress of expenses

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For many patients, the uncertainty and stress that can come with cancer treatment is compounded by what is now known as "financial toxicity," the anxiety and distress that follow health care and medication expenses, often compounded by reduced ability to work.

In the October 5, 2016, issue of the journal *Cancer*, a team of specialists demonstrates how a survey can measure a patient's risk for, and ability to tolerate, financial stress.

With data from 233 [patients](#) going through treatment for advanced cancers, the researchers showed that the COST (COmprehensive Score for financial Toxicity) questionnaire identified patients at [financial distress](#), which was found to be a "clinically relevant patient-centered measure."

"As expected, we found a strong association between a patient's use of [health care resources](#) and his or her sense of financial toxicity," said the study's lead author Jonas de Souza, MD, MBA, a head-and-neck cancer specialist and health services researcher at the University of Chicago Medicine. "This is something we need to look for, to recognize early and make sure it does not become a barrier to care."

More than two admissions to the hospital, for example, had a significant impact on a patient's sense of financial toxicity. "This is reasonable," de Souza said. "Hospital care is much more expensive than office-based care. We now know that it also impacts a patient's self-reported financial

feelings."

The research team kept the COST questionnaire short and simple. It includes 11 brief statements about costs, resources and concerns. For each question, patients were asked to circle one of five possible responses that help determine their level of concern.

Faced with statements such as: "I feel financially stressed," or "My out-of-pocket medical expenses are more than I thought they would be," patients had to choose the answer that best described their situation.

The questionnaires revealed several factors that were closely tied to financial toxicity. Employment status was at the top of the list, followed by household income, psychological distress, the number of hospital admissions, and race. African-American individuals tended to have more financial toxicity, on average, than Caucasians.

One surprise was the lack of a perceived financial benefit from participation in clinical trials. "Usually the maker of an innovative device or the company that supplies a new drug will pick up the costs related to the investigational drug," de Souza said. "But that did not reduce our patients' sense of financial toxicity. We've added that to our model."

The next step is to go back to our patients and understand the factors that drive financial toxicity for each kind of cancer," said de Souza. "Then we need to learn how to intervene. How can we help these patients, perhaps with financial counselors? And how can we decrease the costs of what we do to treat cancer overall and, at the same time, lessen the financial burdens that fall on the patient.

"It's important to note that the financial distress identified by the COST scale captures a unique set of stressors affecting patients above and beyond the physical and psychological strains of their disease," notes

Lauren Hersch Nicholas, PhD, a health economist at the Johns Hopkins School of Public Health and member of the study team. "Being able to quantify this burden is an important step towards giving patients, their families and care team the information necessary to make the best treatment decisions for each patient's situation."

"As society increasingly considers the costs incurred by patients with cancer as a side effect of treatment, instruments to measure financial toxicity should be patient centered, scientifically derived, and clinically relevant," the authors wrote. "It is time to start measuring and talking about the costs of care for patients as we would with any other side-effect," De Souza said.

Or, as the Irish mathematical physicist Lord Kelvin put it in 1883: "When you cannot measure it, when you cannot express it in numbers, your knowledge is of a meagre and unsatisfactory kind."

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