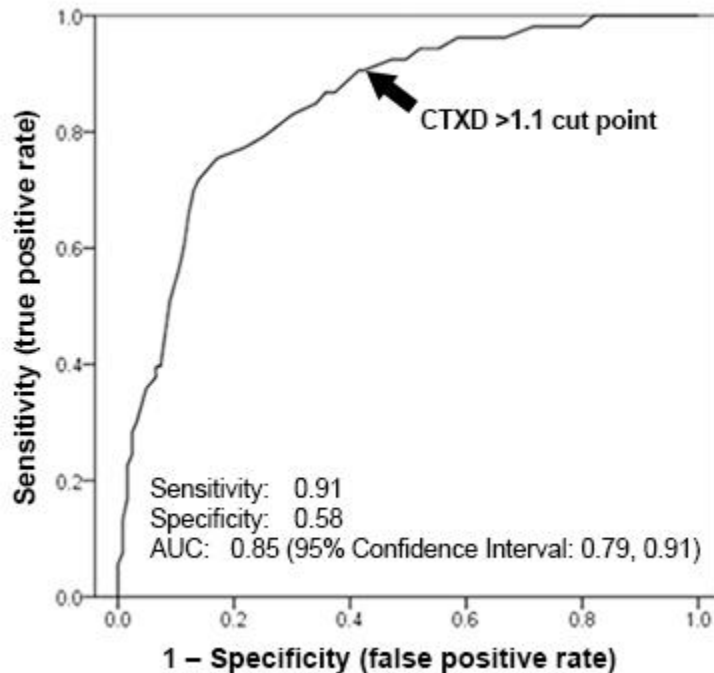# A more meaningful, less stressful, distress measure

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Receiver operator characteristic (ROC) analysis illustrates that a CTXD score cut point of 1.1 results in a sensitivity of 0.91 and a specificity of 0.58, using the Center for Epidemiological Studies Depression (CESD) standard cut point of 16. This indicates that the CTXD captures nearly all the cases of depression on the CESD (sensitivity) while also identifying elevated distress that is distinct from depression (specificity).

Image provided by Dr. Karen Syrjala

A cancer diagnosis is never an easy challenge, and the distress that follows is often fluctuating but enduring. It adversely affects the well-being of cancer patients from the initial finding, through treatment and follow-up to survivorship or end of life. This cancer-related stress impacts not only overall quality of life, but also satisfaction with medical care and adherence to treatment recommendations. Some studies have even demonstrated decreased survival rates with increased stress levels. The evidence for distress monitoring is compelling, but current standardized measures of anxiety and clinical depression account poorly for the wide-ranging complexity of cancer-related emotions.

Because of the high risk of long-term complications and death after hematopoietic cell transplantation (HCT), efforts have been made to evaluate the associated distress using a number of existing measures. However, one single, non-duplicative, non-overlapping measure that captures all important aspects for understanding cancer-related distress within one test would more likely provide a useful tool for routine screening. With this in mind, Drs. Karen Syrjala, Jean Yi, and Shelby Langer

from the Clinical Research Division set out to define a reliable and valid distress measure for HCT-treated cancer patients. Importantly, the measure needed to be minimally burdensome to patients. "To be useful in research or clinical care, it is important to be brief but relevant to people's experiences," Dr. Syrjala explained. The development and psychometric properties of the resulting Cancer and Treatment (CTXD) measure was recently published in *Psycho-Oncology*.

Potentially stressful aspects were revealed through qualitative interviews with 48 transplant recipients regarding feelings about the disease and related treatment, starting at the point before HCT when most transplant recipients experience peak distress. The first CTXD version comprised 46 items that were iteratively selected based on feedback from patients and additional input from physicians, nurses, and other healthcare providers. A cohort of 176 patients from 8 transplant centers then completed the baseline CTXD, along with other measures, and after statistical analysis the initial 46 items were reduced to 22. In this optimized version, 6 factors were distinguished that explained 69% of the variance in distress between patients: uncertainty, health burden, identity, medical demands, finances, and family strain. The tradeoff between sensitivity (true positive) and specificity (true negative) for identifying elevated distress was described through receiver operating characteristic (ROC) analysis. A large majority of cases of elevated depression, defined by the Center for Epidemiologic Studies Depression (CESD) scale, were captured by a CTXD score > 1.1 (sensitivity rate 91%). High-distress cases lacking parallel elevated depression were also identified (specificity 58%), indicating that the measured qualities of distress extended beyond depression.

The investigators hope that the new measure will improve the screening of distress among cancer patients for both research and clinical care, thereby expediting decisions about psychosocial interventions. "The measure can replace the screening of depression and anxiety separately, since it evaluates those aspects of clinical need, but also help to identify those patients needing psychosocial care for issues that might not be about clinical depression or general anxiety. Fear of recurrence, living with uncertainty about the future, and worry about finances and family are ever-present concerns for lots of people after a cancer diagnosis," Dr. Syrjala explained. Ideally, clinicians could use the information to personalize patient referral needs. "The bottom line goal is to use the routine assessment of distress to improve the care of our patients so they not only get a referral for psychosocial care when needed, but a referral to the right resources at the right time for them," she concluded.

The CTXD is not specific for HCT and may therefore also be useful in other settings. After having studied the measure over time after HCT, the team has proceeded with CTXD data collection from other cancer patients as well. The correlations found so far among different patient groups have

been quite surprising, according to Dr. Syrjala. "None of the items we needed were specific to the HCT experience, but were shared by patients with other cancers - like thoughts about dying or how the family would get through treatment and recovery."

Still, much remains to be investigated. Can the CTXD help predict who is at greater risk of poor outcomes during or after treatment? Will treatment improve the distress indicated by the CTXD? The researchers have many hypotheses to test before the full potential of the new distress measure is revealed. Hopefully, they are not too stressed out about it.

Syrjala KL, Yi JC, Langer SL. 2015. Psychometric properties of the Cancer and Treatment Distress (CTXD) measure in hematopoietic cell transplantation patients. *Psychooncology*. doi: 10.1002/pon.3861. [Epub ahead of print]