

Scoring Manual for the Cancer and Treatment Distress (CTXD) scale.

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Overview

The CTXD is designed to assess distress specific to cancer and its treatment, as distinct from general anxiety or depression. It has been tested with hematopoietic stem cell transplant recipients (autologous and allogeneic) at the following time points with adequate to excellent reliabilities similar to those listed below: pretransplant, 3 months, 6 months, 1,2,3,5,10 years after transplant. Other researchers have used the CTXD with non-transplant cancer patients. However, we do not have these data at this time.

Items specific to a type of treatment or disease may be added to the CTXD. However the psychometric stability of the measure would then need to be re-tested.

Below are the psychometric reliability and factor loadings for the CTXD scale. Factor loadings represent the pattern matrix loadings for principal components analysis with promax rotation.

There are 2 versions of the CTXD, the *Acute* version is for patients entering or during treatment and acute recovery (when the acute symptom subscale is relevant). The *Follow-up* version deletes the acute items when they are no longer issues being faced by patients.

The response format is carefully laid out to optimize complete and accurate responses. Therefore the proper forms are required to accompany this scoring manual.

You might note that items specific to transplant, such as GVHD, bone marrow aspirations, donor concerns, infertility, isolation or Hickman catheters are missing. They were included in earlier versions but did not add unique variance or load on factors, and most had low means. Also they were specific to only subpopulations. Thus we have not found it necessary to keep them in but patients can add them in the additional item section if they like.

Administration

Patients are asked to complete the form on their own. The form also may be administered orally either for patients who have limited literacy or when done over the phone. It is always helpful to administer the first CTXD with a clinician/researcher available so that any questions can be readily answered.

Items 36 and 37 on the acute version (30 and 31 on the followup version), elicit additional stresses and rate the most distressing items. These additional stresses are not included in the scoring. However, the additional items are useful for informing updates or modifications that may result from either new populations of patients or from treatment changes. The last items on interference are in testing and are also not included in the scoring.

Scoring

Scoring is straightforward. Each item score, 1-35 (1-29 for followup), is computed into a Total Mean Score. Each item in a subscale is similarly computed into a Subscale Mean Score. Interference items can be scored as a mean also, but should not be included in the total. No scores are reversed or otherwise modified prior to calculating mean scores. Use of mean scores allows for missed items. All subscales and the total score require a minimum of 67% of the items to be answered to permit summary score use.

Final CTXD Factors & Reliability:

Results for the 4th Cohort tested with the CTXD

N = 176 for *Acute* version; N = 82 for *Follow-up* version:

The 4th cohort includes patients enrolled at 8 transplant centers: Fred Hutchinson Cancer Research Center, U of Michigan Comprehensive Cancer Center, Stanford U Medical Center, U of Florida, Rocky Mountain Cancer Center, Karmanos Cancer Institute, Wake Forest U Baptist Medical Center, U of Colorado, U of Utah Health Sciences Center.

In 4 Cohorts of hematopoietic stem cell transplant patients tested to date:

- Each cohort has an overall alpha reliability = .92-.94.
- The first and second cohort versions had had only one stable scale. 18 items remain consistent across all versions and cohorts tested.
- Subscales have become stronger with each cohort.
- Total N for all cohorts tested to date = 926.

4th Cohort overall $\alpha = .93$, 28 items in *Acute* version, 21 items in *Follow-up* version

These results are itemized below.

SUBSCALE	ALPHA RELIABILITY		FACTOR LOADINGS	
ITEM	ACUTE	FOLLOW-UP	ACUTE	FOLLOW-UP
UNCERTAINTY	$\alpha = .83$.86		
8. Not knowing what future will bring.			.89	.73
12. Thinking about possible things that could go wrong.			.67	.61
19. Thinking about the possibility of relapse.			.69	.88
24. Thoughts about the possibility of dying.			.88	.87
FAMILY STRAIN	$\alpha = .82$.83		
5. Wondering about the emotional toll on my family or other caregivers.			.80	.60
11. Not having the same responsibilities in the family.			.70	.88
15. The family having to help out more than in the past..			.74	.85
23. Being a burden to other people.			.82	.55
32. Wondering how my family will get through my treatment and recovery.			.76	
[item 30 is included only in the <i>Acute</i> version]				

SUBSCALE ITEM	ALPHA RELIABILITY		FACTOR LOADINGS	
	ACUTE	FOLLOW-UP	ACUTE	FOLLOW-UP
APPEARANCE & SEXUALITY	$\alpha = .75$.76		
[Only tested in Acute version: see below "items being tested" for update]				
6. Changes in my appearance.			.76	.83
13. Changes in my sex life because of treatment.			.58	.71
16. My hair thinning or falling out.			.90	
26. Not feeling as masculine or feminine as I used to feel.			.78	.80
HEALTH BURDEN	$\alpha = .84$.89		
3. Long term effects of treatment.			.76	.53
2. Not being able to do my usual activities.			.69	.58
14. Feeling tired and worn out.			.94	.99
28. Not having my usual energy.			.91	.90
MANAGING MEDICAL SYSTEM	$\alpha = .80$.84		
4. Dealing with the medical system.			.85	.72
10. Getting information when I need it.			.84	.77
20. Communicating with medical people.			.84	.92
FINANCES	$\alpha = .79$.83		
7. Dealing with insurance.			.86	.76
17. Wondering how to support myself and the family financially.			.76	.87
25. The cost of my health care.			.89	.80
ACUTE SYMPTOMS	$\alpha = .78$			
(Acute version only: before and during treatment)				
29. Getting through chemotherapy, radiation therapy or other treatments.			.70	
30. Difficulty eating or tasting food			.83	
31. Mouth or throat sores			.64	
33. Procedures I have to go through			.66	
34. Nausea and vomiting			.77	

ADDITIONAL ITEM FOR TOTAL SCORE IN BOTH VERSIONS: THE ITEM DOES NOT LOAD ON A SPECIFIC FACTOR, BUT HAS HIGH RESPONSE RATES FOR DISTRESS.

1. Medical problems

ITEMS BEING TESTED: THESE SHOULD NOT BE INCLUDED IN TOTAL SCORES OR SUBSCALES UNLESS YOU CONFIRM WITH YOUR OWN PSYCHOMETRICS

9. "Changes in my body" is being tested to potentially strengthen the Appearance and Sexuality subscale reliability.
16. "My hair falling out" loaded with Appearance and Sexuality for the *Acute* version and not the *Followup* version. We are testing the wording "my hair thinning or falling out" to be in both versions because 30% of women report long term thinning or bald hair.
18. "Losing 'myself' in all the changes" is being tested to potentially strengthen the Appearance and Sexuality subscale reliability.
21. "Returning to work" is being tested for the subscale on finances.
22. "Not being with friends in the same way" is being tested for family (and social relations).
27. "Pain related to my treatment or disease" is being tested because no pain items have been included previously except for mouth sores. It is unclear where or whether this item will load on a factor either in the *Acute* or *Followup* version. At this point we recommend it be included in both versions.
35. (29 in *Followup* version) "Physical symptoms such as fatigue, weight loss or weight gain, shortness of breath, sleepiness, constipation or diarrhea, dry mouth, or difficulty remembering" is being tested to capture this area from the NCCN distress components that we have not previously questioned.

Interference items 39-43 (33-37 for *Followup*): Measures of symptom severity have included interference as well as distress severity. To match this format and for possible value as a tool for clinical cutoffs in determining treatment need, we are testing these items.

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