Refining a Validated Distress Screening Tool of Caregivers of Cancer Patients in a Community-Based Sample

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Background

- Family caregivers of people with cancer face distress that can impact the patient and their own well-being.

- While validated distress screening for patients is essential for quality care, there is an absence of validated measures to identify and address unmet psychosocial needs of caregivers.

- We developed CancerSupportSource®-Caregiver (CSS-CG), a novel distress screening tool for cancer caregivers, that is based on our web-based distress screening and referral tool for people with cancer (CSS-Patient).

Aims

- The objective of this study was to refine the newly-developed 47-item CSS-CG using a multimodal approach.

Methods

- 246 family caregivers from 10 CSC affiliates rated distress on 47 items across 3 domains: emotional concerns/self-care (27 items), caregiving tasks (11 items), and patient well-being (9 items). They also indicated interest in talking to someone about each concerns

- We completed an exploratory factor analysis (EFA), item discrimination index (IDI) and test-retest analyses, and multiple iterations of expert review to reduce and refine the number of items in CSS-CG.

Participants

N = 246	n	%
Mean Age (SD)	52 (14) *Range: 22 – 83*	
Non-Hispanic White	204	88%
Female	165	68%
Cancer recipient relationship to caregiver		
Spouse/partner	141	58%
Parent/in-law	51	21%
Child	29	12%
Hours of care provided weekly		
≤20	152	63%
21-80	57	24%
Care recipient received active treatment in past two years	199	82%

Results

Performance of 47 CSS-CG items

Item	F1	F2	F3	F4	IDI	% Concern	% Talk	Test-Retest	Action
EMOTIONAL WELL-BEING									
Feeling irritable	.738				.696	48%	29%	0.65	Combine[1]
Feeling sad or depressed	.681				.846	50%	53%	0.77	Retain
Feeling lonely or isolated	.645				.600	30%	43%	0.67	Retain
Feeling angry or resentful	.626				.554	27%	48%	0.68	Combine[1]
Feeling unappreciated	.589				.372	26%	48%	0.83	Drop
Changes or disruptions in home life	.577				.759	59%	39%	0.57	Combine[2]
Relationship problems with the person for whom I am caring	.573				.509	29%	52%	0.73	Reword
Worrying about the future and what lies ahead	.571				.685	71%	38%	0.77	Retain
Feeling that I'm always "on"	.561	.313			.737	41%	34%	0.68	Drop
Feeling nervous or afraid	.560				.695	42%	51%	0.75	Retain
Balancing competing demands	.487	.378			.815	44%	45%	0.78	Combine[3]
Maintaining or improving my social connections	.469				.558	38%	29%	0.71	Drop
Feeling guilty	.410				.601	30%	45%	0.74	Retain
Feeling too tired to do the things I need or want to do	.398				.679	46%	39%	0.70	Retain
Intimacy, sexual function, and/or fertility	.382				.357	27%	26%	0.89	Reword
Finding meaning and purpose in life	.375				.554	26%	33%	0.87	Replace
Tobacco, alcohol or other substance use	.369				.139	6%	67%	0.79	Retain
My financial well-being	.359	.322			.636	44%	23%	0.89	Drop
Worry about family, children and/or friends	.352				.664	42%	34%	0.68	Drop
Sleep problems	.327				.478	35%	36%	0.82	Drop
Maintaining appearances or keeping it all together in front of others	.306				.648	40%	35%	0.62	Drop
CAREGIVING TASKS									
Getting or arranging medical care		.683			.539	23%	46%	0.74	Reword
Providing transportation to treatment and appointments		.681			.385	16%	39%	0.80	Retain
Managing health insurance and medical bills		.652			.643	33%	33%	0.77	Retain
Talking with the patient's doctors and health care team		.594			.586	32%	13%	0.73	Retain
Making a treatment decision		.569			.632	34%	47%	0.80	Reword
Managing money		.546			.709	34%	23%	0.75	Reword
Talking with or updating family and friends		.526			.570	24%	32%	0.77	Reword
Managing household or family activities (cleaning, yard work, cooking, child care, etc.)		.463			.786	42%	40%	0.68	Combine[3]
Changes or disruptions in work or school		.432			.684	34%	27%	0.78	Combine[2]
Managing care at-home (e.g., medications, bandage/dressing changes, feeding tubes, etc.)		.385	.318		.500	24%	36%	0.83	Reword
The patient's tobacco, alcohol or other substance use		.190			.154	8%	0%	0.91	Drop
PATIENT WELL-BEING									
The patient's pain and/or physical discomfort			.840		.666	59%	34%	0.77	Reword
The patient's weight change (gain or loss)			.748		.556	35%	37%	0.87	Drop
Changes in the patient's physical activity and movement			.672		.698	49%	37%	0.76	Drop
The patient's sleep problems			.654		.467	37%	32%	0.81	Retain
The patient's eating and nutrition			.602		.528	57%	30%	0.76	Retain
Managing side effects of treatment (nausea, swelling, etc.)			.592		.651	46%	38%	0.69	Reword
Changes in the patient's mood and/or behavior	.325		.468		.757	57%	53%	0.70	Reword
Changes in the patient's memory and/or thinking			.427		.605	44%	37%	0.77	Reword
The patient's feelings of loneliness or isolation			.408		.608	54%	39%	0.80	Drop
Gaining information about how to provide care (i.e., physical care, emotional support, etc.)			.342	.385	.753	40%	53%	0.68	Reword
SELF-CARE									
Eating and nutrition				.767	.530	48%	13%	0.73	Retain
Exercising and being physically active				.761	.455	54%	14%	0.81	Retain
Talking with my doctors/health care team about my health				.759	.464	29%	41%	0.77	Drop
Keeping up with my own health care needs				.737	.587	36%	32%	0.74	Retain
Pain and/or physical discomfort				.478	.323	18%	24%	0.76	Drop

Note. Bolded items were retained (in some form) in the revised measure; italicized items were dropped. Superscripts denote items combined in refined measure. Factor loadings are based on exploratory factor analysis using maximum likelihood and oblique oblimin (non-orthogonal) rotation. F1 = Factor 1; IDI = item discrimination index; % Concerned = % of caregivers who endorsed item as "somewhat to very seriously concerned"; % Talk = % of caregivers who endorsed item as "somewhat to very seriously concerned" and requested to speak with someone for more information; Test-retest values are intra-class correlation coefficients (ICC's).

Summary of Scale Refinement

- **Exploratory factor analysis** and thematic review suggested that caregiver distress items are distributed across four factors: 1) *Emotional Well-Being*, 2) *Caregiving Tasks,* 3) *Patient Well-Being,* and 4) *Self-Care.*

- **Items with high discrimination** included *feeling sad or depressed, balancing competing demands, managing household or family activities (cleaning, yard work, cooking, child care, etc.), changes or disruptions in home life,* and *changes in the patient's mood and/or behavior.*

- **Items that were conceptually similar** to each other have been combined in the reduced scale, or the item with stronger psychometric performance was retained.

- **Items that loaded on multiple factors, had low item discrimination indices, or had poorer test-retest performance** have been combined, reworded, or dropped to enhance clarity.

- **Items with mixed psychometric performance but clinical significance for risk assessment** (*e.g., tobacco, alcohol or other substance use*) were retained. We propose re-evaluating item performance as part of the reduced scale.

- **The refined and reduced scale, including combined and revised items, includes a total of 31-items**.

Implications and Conclusions

- These findings provide a useful framework for generating a reliable and sustainable screening tool, CancerSupportSource-Caregiver, to evaluate psychosocial distress among cancer caregivers across a large network of community-based care providers.

- Based on these analyses and multiple iterations of expert review, the scale has been reduced to 31 items, including a previously-validated 4-item depression subscale that mirrors the patient version of CancerSupportSource.

- Next steps include validation of the reduced scale, developing appropriate educational materials, implementing the CSS-Caregiver distress screening tool within the same digital platform as CSS-Patient, and exploring the impact of caregiver distress screening, referral, and follow-up on health-related quality of life and cost outcomes.

References
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