

BACKGROUND

Caregiver distress affects the quality of life and health of caregivers as well as the well-being of cancer patients. Supportive care is underutilized by cancer caregivers, in part due to systemic gaps in access and lack of time.

AIMS

We developed and psychometrically evaluated CancerSupportSource®-Caregiver (CSS-CG), part of a web-based distress screening and referral program. The goal of CSS-CG is to identify and respond to unmet caregiver need, enabling caregivers to better navigate care, practice self-care, and support patients.

METHODS

400 caregivers enrolled in Cancer Support Community's online Cancer Experience Registry® survey. Caregivers provided sociodemographic and caregiving history information, rated their level of concern for 33 CSS-CG items (0 = *Not at all*; 4 = *Very seriously*), and completed comparison validation measures: Patient-Reported Outcomes Measurement Information System-29 (PROMIS-29 v2.0); Patient Health Questionnaire-4 (PHQ-4); NCCN Distress Thermometer (DT); Zarit Burden Interview (ZBI-12); Caregiver Reaction Assessment (CRA).

Participants were randomly split into two samples for exploratory factor analysis and item reduction (N=250), and confirmatory factor analysis and evaluation of psychometric properties of the final scale (N=150).

Scale reduction was informed by item endorsement, iterative EFA and a CFA, Pearson correlations, item discrimination, and clinician input. Accuracy of 2-item depression and anxiety risk scales were assessed with area under the curve (AUC) and sensitivity/specificity analysis.

PARTICIPANTS

N = 400	Mean / n	SD / %
Age (years) (n = 359; Range: 20 - 89)	51	14
Race and Ethnicity		
Non-Hispanic White	332	83%
Non-Hispanic Black	10	3%
Hispanic, Latino/Latina	25	6%
Women	325	81%
Caregiver Relationship to Patient		
Caring for spouse	167	42%
Caring for parent	83	21%
Caring for child	29	7%
Currently Providing Care	254	64%
Hours of Care Provided Weekly		
≤20 hours	157	39%
21-80 hours	97	24%
>80 hours	78	20%
Years Providing Care		
<1 year	81	20%
1-2 years	111	28%
3-5 years	69	17%
6-10 years	34	9%
>10 years	26	6%

SCALE REDUCTION AND FINAL MEASURE



Factors and Items	N=400				N=250					
	%≥3	%≥2	IDI	Item-Factor r	F1	F2	F3	F4	F5	h2
EMOTIONAL WELL-BEING										
Feeling nervous or afraid [†]	27	49	.724	.871	.89					.77
Feeling sad or depressed [‡]	25	53	.795	.867	.80					.69
Feeling lonely or isolated [‡]	23	45	.805	.826	.69					.61
Worrying about the future and what lies ahead [†]	47	71	.635	.843	.68					.66
Changes or disruptions in work, school, or home life	27	53	.754	.756	.42					.47
PATIENT WELL-BEING										
Changes in the patient's mood or behavior	34	61	.726	.881	.89					.80
Changes in the patient's memory or thinking	29	52	.693	.831	.73					.61
The patient's pain or physical discomfort	41	62	.714	.849	.67					.60
The patient's eating and nutrition	37	61	.725	.840	.62					.58
CAREGIVING TASKS										
Coordinating medical care for the patient	23	42	.887	.930		.84				.88
Providing transportation to treatment and appointments	18	34	.763	.859		.80				.68
Providing physical or medical care to the patient	23	42	.856	.858		.63				.67
Making treatment decisions	22	42	.836	.867		.52				.69
FINANCES										
Managing health insurance and medical bills	26	44	.753	.942				.93		.86
Managing household finances	29	44	.762	.946				.83		.79
HEALTHY LIFESTYLE										
Exercising and being physically active	19	52	.357	.871					.78	.60
Keeping up with your health care needs	18	50	.387	.856					.76	.59
Eating and nutrition	13	53	.590	.827					.66	.56
TOBACCO & SUBSTANCE USE										
Tobacco, alcohol, or other substance use	3	14	.209	N/A						N/A

† Anxiety Risk Scale Item; ‡ Depression Risk Scale Item

- After iterative exploratory factor analyses (EFAs), we removed 14 items with limited variability, low endorsement, low factor loadings (<.30), or low validation measure correlations.
- 18 items remained representing 5 factors, plus 1 additional tobacco and substance use item that did not load on any factor.
- The final Exploratory Factor Analysis (EFA) explained 67% of model variance (RMSR=0.02, TLI=0.95, RMSEA=0.06).

EVALUATION OF PSYCHOMETRIC PROPERTIES

	# items	M/SD [†]	α	CSS-Caregiver Intercorrelations					PROMIS-29 Subscales							Caregiver Reaction Assessment				
				F1	F2	F3	F4	F5	Depression	Anxiety	Social Function	Physical Function	Fatigue	Sleep Disturbance	Pain Interference	DT	ZBI	Finance Impact	Schedule Impact	Health Impact
Total distress score (CSS-CG-18+)	19	29.15/15.55	.92	.82	.78	.83	.72	.52	.65	.66	-.51	-.29	.55	.46	.23	.61	.57	.47	.55	.52
F1: Emotional Well-Being	5	1.70/1.05	.89	---	.50	.53	.51	.33	.76	.79	-.54	-.27	.65	.54	.22	.73	.62	.39	.53	.52
F2: Patient Well-Being	4	1.88/1.16	.87		---	.61	.39	.26	.43	.42	-.40	-.22	.32	.30	.18	.42	.38	.24	.47	.35
F3: Caregiving Tasks	4	1.30/1.20	.90			---	.60	.28	.44	.43	-.35	-.26	.35	.28	.18	.38	.37	.37	.38	.38
F4: Finances	2	1.49/1.34	.88				---	.32	.45	.42	-.36	-.20	.38	.34	.18	.40	.41	.63	.39	.43
F5: Healthy Lifestyle	3	1.50/0.94	.81					---	.19	.23	-.14	-.06 [†]	.27	.18	.06 [†]	.23	.32	.18	.18	.22

All Pearson correlations significant $p < .01$, except [†] $p = NS$

CSS-CG Risk Scale	Comparison Measure	AUC	Risk Scale Cutoff	Sensitivity	Specificity	N
CSS-D2	PROMIS Depression (4a)	.888	≥ 3	.95	.66	347
	PHQ-2	.880	≥ 3	.95	.63	347
CSS-A2	PROMIS Anxiety (4a)	.872	≥ 4	.87	.68	352
	GAD-2	.867	≥ 4	.91	.66	347

- Confirmatory Factor Analysis confirmed the five-factor structure (CFI=0.94, TLI=0.93, RMSEA=0.07).
- CSS-CG had high internal reliability ($\alpha=.92$) and strong convergent validity: greater total distress was associated with poorer quality of life ($r=-.23-.66$) and greater caregiver burden ($r=.57$).
- 2-item depression and 2-item anxiety risk scales demonstrated high sensitivity (.87-.95) and adequate specificity (.63-.68), using cut-off scores of ≥3 for depression and ≥4 for anxiety.

CONCLUSIONS AND IMPLICATIONS

- CancerSupportSource-Caregiver (CSS-CG) is a psychometrically robust measure of caregiver distress.
- In its full program implementation, CSS-CG can facilitate distress screening, referral, and follow-up to rapidly assess caregivers' unmet needs and enhance well-being.
- Future implementation goals include understanding how to best engage caregivers in diverse settings, including oncology practices and ambulatory sites.

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