

CANCER SUPPORT COMMUNITY A Global Network of Education and Hope

Background

- Caring for people with cancer is accompanied by psychosocial distress and poorer health-related quality of life and is associated with poorer outcomes for caregivers and patients.
- Although caregiver burden measures exist, there are few validated instruments to identify and address psychosocial distress among cancer caregivers.

Aims

• We developed and tested the psychometric properties of CancerSupportSource-Caregiver (CSS-CG), a 47-item web-based distress screening and referral instrument, including a 4-item depression subscale.

Methods

- 246 caregivers from 10 Cancer Support Community affiliates rated their level of concern (0 = not at all, 4 = very seriously) regarding emotional experiences and self-care (27 items), caregiving tasks (11 items), and patient well-being (9 items). They also designated interest in in-person follow-up or written information for each concern.
- Concurrent validity was determined by correlations with the Distress Thermometer (DT), Center for Epidemiologic Studies Depression Scale (CES-D), SF-12 mental and physical component scores (MCS, PCS), Zarit Burden Interview (ZBI), and Caregiver Reaction Assessment Scale (CRA) subscales.
- ROC curve analysis was used to determine sensitivity and specificity for identifying risk for clinical depression using a 4-item depression subscale, compared to the CES-D (cut score: \geq 16). Test-retest reliability was assessed in a subsample (n = 115) using the intra-class correlation coefficient (ICC).

Participants

<i>N</i> = 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%
Adult child	29	12%
Hours of care provided weekly		
≤20	152	63%
21-80	57	24%
Care recipient received active treatment in past 2 years	199	82%

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Psychometric Properties of a 47-item Distress Screening Tool for **Caregivers of Cancer Patients in a Community-Based Sample**

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Results

Top Caregiver Concerns

Worry about the future Disruptions in home life Patient's pain/discomfort Changes in patient's mood/behavior Patient's eating and nutrition Patient's feelings of loneliness Exercising/physical activity Feeling sad or depressed Changes in patient's movement Feeling irritable Eating and nutrition



well-being) were represented among caregivers' top concerns.

Correlations with Validated Measures

Pearson's r	p
.54	<.001
.64	<.001
.54	<.001
.46	<.001
.42	<.001
.37	<.001
.27	<.001
27	<.001
52	<.001
24	<.001
	Pearson's r .54 .64 .54 .54 .42 .42 .37 .27 .27 .27 .27

Implications and Conclusions

- cancer caregivers.

References

% Moderately to Very Seriously Concerned

All three themes (caregiver emotional concerns/self care, caregiving tasks, and patient

• CSS-CG greater total distress was associated with greater distress as measured by the DT, more depressive symptoms, more caregiver burden, lower caregiver esteem and lower mental and physical well-being. These results provide evidence of concurrent validity.

• In these initial analyses, CSS-Caregiver demonstrates strong psychometric properties and can be considered a valuable community-based instrument to screen for distress among

• Next steps include shortening the scale via factor analysis and item discrimination, developing educational materials and referrals tailored to individual responses, validating and implementing the shortened tool in diverse settings, exploring dyadic (patient and caregiver) distress screening profiles and the implications for health-related outcomes using the patient and caregiver versions of CSS, and exploring the impact of caregiver distress screening, referral, and follow-up on health-related quality of life and cost outcomes.

Internal Consistency	# items	Cronbach's α
Overall screening tool	47	.96
Depression subscale	4	.76
Emotional concerns/self-care	27	.93
Caregiving tasks	11	.91
Patient well-being	9	.88
Test-Retest Reliability	# items	ICC
Overall screening tool	47	.85



- want to do.

. Miller et al. (2014). Discriminatory power of a 25-item distress screening tool: A cross-sectional survey of 251 cancer survivors. Qual Life Res, 23(10): 2855-63. 2. Stenberg U., Ruland C.M., & Miaskowski C. (2010), Review of the literature on the effects of caring for a patient with cancer. Psycho-oncology, 19:1013–25. 3. Zwahlen et al. (2012). Screening patients' family members with the Distress Thermometer (DT): A validation study. Psycho-oncology, 17: 959-966.

Internal Consistency and Test-Retest Reliability

CSS-CG and its subscales, including the 4-item depression subscale, demonstrated high internal consistency reliability.

• The scale also demonstrated excellent test-retest reliability, with 28 items demonstrating excellent reliability (ICC \geq .75) and 18 items demonstrating good reliability (ICC=.60-.74).

ROC Curve Analysis for Depression Risk Subscale and CES-D

• Depression risk subscale items included: 1) feeling sad or depressed, 2) feeling lonely or isolated, 3) feeling nervous or afraid, and 4) feeling too tired to do the things you need or

• Using a CES-D score \geq 16 as the criterion, a score \geq 5 for the 4-item depression risk subscale yielded a sensitivity and specificity of 90% and 72%, respectively (AUC=0.87). 56% of the caregivers in this sample were considered "at risk" for potential depression.