

Factor Structure and Validity of CancerSupportSource®: A Revised 25-item Distress Screening Tool For Cancer Survivors

Alexandra K. Zaleta, PhD, Melissa F. Miller, PHD, MPH, Shauna McManus, BS, Mitch Golant, PhD, Joanne S. Buzaglo, PhD Cancer Support Community, Research and Training Institute, Philadelphia, PA USA

Background

 In response to consensus from NCCN, NAM, and ACoS CoC about the importance of cancer-related distress screening, Cancer Support Community developed CancerSupportSource® (CSS), a distress screening, referral, and follow-up program used at community-based cancer support organizations and hospitals nationwide. CSS assesses distress across multiple domains, including emotional, physical, social, and practical concerns

Aims

 This study examined the psychometric properties and multidimensionality of a revised 25-item version of CSS

Methods

- 1436 cancer survivors enrolled in the Cancer Support Community's online Cancer Experience Registry, provided demographic and clinical history, and rated their level of concern about 25 CSS items (0 = Not at all, 1 = Slightly, 2 = Moderately, 3 = Seriously, 4 = Very seriously), plus one item assessing concern about thinking clearly, and completed the PROMIS-29, a measure of quality of life
- Pearson correlations and exploratory factor analysis were used to examine scale psychometric properties and dimensionality

Participants

<i>N</i> = 1436	Mean / n	SD / %				
Age (years)	58.4	11.1				
7 (go (youro)	Range: 19.	71–87.24				
Non-Hispanic White	1291	90%				
Female	1035	72%				
Diagnosis						
Breast	504	35%				
Multiple Myeloma	281	20%				
CLL	127	9%				
Lung	65	5%				
Prostate	54	4%				
Ovarian	50	3%				
Time since diagnosis (years)	4.6	5.3				
		Range: 0– 52				
Ever metastatic	302	26%				
Ever experienced recurrence/ relapse	261	22%				
Currently receiving treatment	770	54%				

Results

Factor Loadings and Communalities

ltem	F1	F2	F3	F4	F5	Communalities	% Rated ≥2
EMOTIONAL WELL-BEING							
Feeling nervous or afraid	.82	05	.08	06	.11	.71	24.7
Feeling sad or depressed	.77	.10	02	.06	06	.71	30.6
Worrying about the future and what lies ahead	.77	.02	.08	03	.04	.67	47.6
Feeling lonely or isolated	.71	.06	03	.17	07	.68	26.9
Finding meaning and purpose in life	.56	.00	.06	.23	.03	.58	28.3
Worrying about family, children and/or friends	.43	.13	.09	.06	.15	.46	36.1
Health insurance or money worries	.39	.18	.04	.07	.08	.37	42.1
Feeling irritable	.34	.06	.17	.20	.11	.46	33.6
SYMPTOM BURDEN AND IMPACT							
Pain and/or physical discomfort	.04	.77	03	01	.04	.62	35.6
Moving around (walking, climbing stairs, lifting, etc.)	16	.74	.14	.01	.08	.59	39.8
Feeling too tired to do the things that you need or want to do	.16	.69	.09	.06	10	.72	46.9
Managing side effects of treatment (nausea, swelling, etc.)	.15	.55	.00	01	.15	.50	28.2
Changes or disruptions in work, school or home life	.25	.45	.01	.15	.04	.56	37.0
Thinking clearly (e.g., "chemo brain," "brain fog")	.15	.39	.10	.06	.07	.38	40.2
Sleep problems	.25	.30	.07	.10	.02	.37	41.0
Transportation to treatment and appointments	.16	.30	07	.07	.27	.33	9.7
BODY IMAGE AND HEALTHY LIFESTYLE							
Exercising and being physically active	06	.28	.61	.09	02	.65	50.0
Recent weight change (gain or loss)	.15	.04	.60	01	.03	.50	30.1
Body image and feelings about how you look	.27	.01	.53	.06	04	.53	38.0
Eating and nutrition	.01	11	.49	.31	.06	.37	57.8
HEALTH CARE TEAM COMMUNICATION							
Communicating with you doctor	.01	.19	.04	.48	.15	.45	21.3
Making a treatment decision	.36	.15	02	.43	.00	.53	26.9
RELATIONSHIPS AND INTIMACY							
Problems in your relationship with your spouse/partner	.00	03	01	.03	.82	.64	19.5
Intimacy, sexual function and/or fertility	.04	.05	.12	03	.54	.43	33.5

- For the revised 25-item scale, five factors (F1-F5) were suggested with eigenvalues >1.0: 1) Emotional Well-Being; 2) Symptom Burden and Impact; 3) Body Image and Healthy Lifestyle; 4) Health Care Team Communication; 5) Relationships and Intimacy
- Tobacco/substance use did not load >.30 on any factor but was retained due to clinical significance for risk assessment. An infrequently endorsed item (finding information about complementary/alternative practice) was dropped and replaced with a new item assessing concern about thinking clearly
- The model explained 52% of the variance and demonstrated good fit (RMSEA=0.06, 90% CI=0.057– 0.063; SRMR=0.03; $\chi^2(185)=1137.79$, p<.001)

Scale and Factor Inter-Correlations and Internal Consistency Reliability

	# items	M/SD	Intercorrelations					α
			F1	F2	F3	F4	F5	G.
Total distress score (CSS-25)	25	27.9/19.1	.92	.90	.79	.70	.64	.94
F1: Emotional well-being	8	1.17/0.93		.73	.63	.60	.57	.90
F2: Symptom burden and impact	8	1.16/0.86			.64	.61	.49	.87
F3: Body image and healthy lifestyle	4	1.41/0.97				.47	.45	.77
F4: Health care team communication	2	0.82/1.00					.37	.63
F5: Relationships and intimacy	2	0.90/1.05						.68

Internal consistency reliability denoted via Cronbach's alpha (α)

- The five factors demonstrated medium to large inter-correlations, but were not redundant
- Internal consistency reliability for the full 25-item scale was excellent ($\alpha = .94$)

CSS Correlations with PROMIS Subscales

	PROMIS Subscales						
	Dep	Anx	Soc	Phys	Fat	Sleep	Pain
Total distress score (CSS-25)	.70	.69	67	52	.67	.49	.59
F1: Emotional well-being	.77	.76	56	38	.57	.45	.46
F2: Symptom burden and impact	.58	.58	74	64	.72	.52	.70
F3: Body image and healthy lifestyle	.44	.44	49	38	.49	.35	.40
F4: Health care team communication	.42	.45	40	31	.38	.23	.37
F5: Relationships and intimacy	.42	.41	39	25	.34	.27	.29

Values reported are Pearson correlation coefficients (r). PROMIS-29 subscales include:

(1) Depression; (2) Anxiety; (3) Social Function; (4) Physical Function; (5) Fatigue; (6) Sleep Disturbance; (7) Pain Interference

- Total distress was associated with all PROMIS subscales (rs = -.67 to .70, ps < .001)
- All factors were associated with PROMIS subscales, with stronger associations exhibited between similar domains (e.g., Emotional Well-Being was most highly correlated with anxiety and depression subscales, rs=.76 to .77, ps<.001; Symptom Burden and Impact was most highly correlated with fatigue, pain interference, and physical and social function, rs -.74 to .72, ps <.001)

Conclusions

- CancerSupportSource® is a reliable and valid multidimensional measure of distress
- The study results support the multidimensional assessment of distress, which allows for meaningful referral to providers and support services that are most relevant to patients' concerns

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- A PROGRAM of the CANCER SUPPORT COMMUNITY

REGISTRY.

CANCER EXPERIENCE

- The Cancer Experience Registry is an online research initiative that captures the immediate and ongoing or changing social and emotional experiences of cancer survivors and their caregivers.
- The Registry is for all cancer survivors and caregivers, but also includes 10 disease-specific surveys.
- Findings contribute toward advancing research, health care and policy.
- Over 12,000 cancer survivors and caregivers are registered in the Cancer Experience Registry.

Learn more or join the Registry at www.CancerExperienceRegistry.org