







CancerSupportSourceTM-Caregiver: Development of a distress screening measure for cancer caregivers

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Abstract

Objective: Given the substantial demands of cancer caregiving, practical and psychometrically sound tools to evaluate distress among cancer caregivers are needed. CancerSupportSourceTM-Caregiver is a distress screening, referral, and support program designed to identify the unmet needs of cancer caregivers and link caregivers to desired resources and support. This study refined and finalized the CancerSupportSource-Caregiver screening measure and examined its psychometric properties.

Methods: Using an analytic sample of 400 caregivers to people with cancer, we first performed item reduction by assessing exploratory factor analysis, external/internal item quality, and judging theoretical and practical implications of items. Confirmatory factor analysis along with reliability and validity analyses were then conducted to corroborate dimensionality and psychometric properties of the final measure. Nonparametric receiver operating characteristic curve analyses determined scoring thresholds for depression and anxiety risk subscales.

Results: Scale refinement resulted in an 18-item measure plus one screening item assessing tobacco and substance use. Items represented five domains of caregiver concerns: emotional well-being, patient well-being, caregiving tasks, finances, and healthy lifestyle. Our analyses showed strong internal consistency and test-retest reliability, a replicable factor structure, and adequate convergent, discriminant, and known groups validity. Sensitivity of 2-item depression and 2-item anxiety risk subscales were 0.95 and 0.87, respectively.

Conclusions: CancerSupportSource-Caregiver is a reliable and valid multidimensional measure of caregiver distress that also screens for risk for clinically significant depression and anxiety. It can be implemented within a distress screening, referral, and follow-up program to rapidly assess caregivers' unmet needs and enhance caregiver well-being across the care continuum.

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KEYWORDS

anxiety, cancer, caregivers, depression, psychosocial oncology, psychosocial support, screening

1 | BACKGROUND

Caregivers are an essential national healthcare resource.¹ In oncology, caregivers serve a critical patient and family support role before, during, and after treatment.^{2,3} This support role places caregivers at risk for substantial distress and unmet needs, which can affect the quality of life and health of caregivers as well as the well-being of patients.⁴⁻⁹ At the same time, supportive care is underutilized by cancer caregivers due to systemic gaps in access and lack of caregiver time.^{10,11} Further, while many measures of caregiver burden exist, a well-documented gap exists in practical tools to identify unmet need and link caregivers to appropriate support. As a result, there is increasing recognition of the need for systematic approaches to facilitate the screening and support of caregivers.¹²

To this end, Cancer Support Community developed CancerSupportSource™-Caregiver (CSS-Caregiver), a web-based distress screening, referral, and support program for cancer caregivers. The goal of CSS-Caregiver is to rapidly identify and respond to unmet caregiver need, thereby better enabling the caregiver to practice self-care, navigate care and treatment, and provide support for the needs of the patient. Within CSS-Caregiver, caregivers are asked to rate their level of concern about a series of items related to their caregiving tasks, emotional well-being, healthy lifestyle needs, finances, and the patient's well-being. For each concern, caregivers choose desired support (e.g., receive additional information; speak to a staff member; no action needed). After screening, caregivers immediately receive a report with customized resource materials and links. A clinician report is generated summarizing key concerns; respondents at risk for clinically significant depression or anxiety are flagged for staff. CSS-Caregiver is a standalone caregiver support program that can serve as a companion screening program to CancerSupportSource™, a patient distress screening, referral, and support program.¹³

CSS-Caregiver has undergone initial development and testing through Cancer Support Community's network partners, the largest professionally led nonprofit network of cancer support worldwide, by leveraging the input of cancer caregivers, supportive care providers, and psychosocial research experts. Initial item pool development and psychometric properties of preliminary versions of CSS-Caregiver have been previously described.^{14,15} Furthermore, a preliminary 33-item version of CSS-Caregiver has been shown to be feasible, acceptable, and well-received by caregivers at a National Comprehensive Cancer Center, with nearly 90% of caregivers approached agreeing to complete the screener, emphasizing the need for and interest in such programs.¹⁶

Developing distress screening measures that are psychometrically sound and feasible for respondents and providers is important for implementation.¹⁷⁻¹⁹ Brief measures that retain psychometric fidelity can increase accessibility of distress screening while reducing participant and staff burden. Thus, the aims of the current study were

to: (1) refine and shorten the preliminary version of CSS-Caregiver into a final measure using exploratory factor analysis and item reduction, and (2) examine the psychometric properties of the final CSS-Caregiver measure via confirmatory factor analysis and evaluation of internal consistency and test-retest reliability, convergent and discriminant validity, and known groups validity.

2 | METHODS

2.1 | Participants and procedures

Data were collected through the Cancer Support Community's Cancer Experience Registry® (CER), an online, community-based research initiative examining the emotional, physical, practical, and financial impact of cancer. Recruitment occurred through Cancer Support Community's networks, including Cancer Support Community and Gilda's Club partners, hospital and healthcare partners, social media, and advocacy partnerships. Caregivers who enrolled were invited to complete a caregiver-specific survey. Participants included family and friend caregivers, ages 18+, who completed the survey from June 2017 to April 2021 and lived in the U.S. Potential participants for the current study included 505 caregivers; we limited the sample to those completing at least 32 of 33 CSS-Caregiver items, resulting in a total sample of $N = 400$. This sample ensured near-complete data on CSS-Caregiver items across participants to inform item reduction decisions. Compared to the caregivers who provided basic background information but did not complete the minimum number of items ($n = 105$), the analytic sample of 400 caregivers were more likely to be Non-Hispanic White (83% vs. 58%, $p < 0.001$) and less likely to have a college degree (70% vs. 82%, $p < 0.05$).

Ethical and Independent Review Services (E&I) served as the IRB of record (Study #16036). All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. Informed consent was obtained from all participants.

2.2 | Measures

CancerSupportSource-Caregiver. CSS-Caregiver is a 33-item distress screening measure developed by Cancer Support Community.¹⁶ For each of the 33 items, participants rated their level of concern (0 = *Not at all*, 1 = *Slightly*, 2 = *Moderately*, 3 = *Seriously*, 4 = *Very seriously*). A total distress score was calculated as the sum of item ratings; if participants were missing a response, the mean of available items for each individual was used in calculating the total score. The depression risk score was calculated by summing two items (feeling

sad or depressed; feeling lonely or isolated), and the anxiety risk score was calculated separately by summing two items (feeling nervous or afraid; worrying about the future and what lies ahead). Request for follow-up services was not assessed for the current study. Participants were asked to complete CSS-Caregiver again at the end of the survey (30–90 min later) to examine test-retest reliability; CSS-Caregiver was the only measure administered twice, and only the first administration data were considered when deriving the study analytic sample.

Participants also completed the following cross-validation measures:

*Patient-Reported Outcomes Measurement Information System 29 Profile V2.0 (PROMIS-29).*²⁰ PROMIS-29 was used to assess self-reported symptoms and functioning across seven domains: Depression ($\alpha = 0.91$); Anxiety ($\alpha = 0.93$); Pain Interference ($\alpha = 0.96$); Fatigue ($\alpha = 0.95$); Sleep Disturbance ($\alpha = 0.85$); Physical Function ($\alpha = 0.90$); and Ability to Participate in Social Roles and Activities ($\alpha = 0.94$). Each domain is comprised of four items, rated on a 5-point scale. Participants rate their experiences over the past 7 days, except for function domains which have no timeframe. Scale scores are transformed into standardized *T*-scores (mean = 50, *SD* = 10); normative reference groups are the U.S. general population, except Sleep Disturbance, where comparisons are to a mix of the U.S. population and people with chronic illness.

*NCCN Distress Thermometer (DT).*²¹ Participants rated their distress in the past week. Responses ranged from 0 (no distress) to 10 (extreme distress).

Zarit Burden Interview Short Form (ZBI-12). The ZBI-12 is a measure used to assess caregiver burden.²² Responses, ranging from 0 (*never*) to 4 (*nearly always*), were summed to generate a total burden score ($\alpha = 0.91$).

Caregiver Reaction Assessment (CRA). The CRA²³ captures positive and negative dimensions of caregiving across five subscales: impact on finances ($\alpha = 0.79$); impact on schedule ($\alpha = 0.84$); impact on caregiver health ($\alpha = 0.75$); lack of family support ($\alpha = 0.81$); and self-esteem ($\alpha = 0.77$). Likert responses (1 = *strongly disagree*; 5 = *strongly agree*) were summed within subscales; higher scores indicated greater financial impact, more schedule interruptions, greater health impact, less family support, and greater esteem.

PHQ-2 and GAD-2. Two additional measures captured depression and anxiety risk: the Patient Health Questionnaire-2 (PHQ-2) 2-item depression screening measure ($\alpha = 0.88$),²⁴ and the Generalized Anxiety Disorder-2 (GAD-2) 2-item screening measure ($\alpha = 0.90$).²⁴ Scores for each measure range from 0 to 6, with a score of ≥ 3 on either scale indicating risk for depression or risk for anxiety, respectively.

Sociodemographic and caregiving characteristics. Participants provided information on age, gender identity, race, Hispanic ethnicity, educational attainment, annual income, and employment status. Additionally, participants reported their caregiving history, including relationship to care recipient, whether they currently provided care, hours of care provided weekly, years of care provided, cancer type of patient, years since cancer diagnosis, cancer stage of patient, and history of cancer recurrence.

2.3 | Analysis

Data analysis was conducted using IBM SPSS Statistics 24.0 (IBM Corp), Stata 16.1 (StataCorp), and R 3.6.2 (R Foundation for Statistical Computing), with GPArotation,²⁵ psych,²⁶ and lavaan²⁵ R packages. Analyses were performed in two phases to: (1) support CSS-Caregiver refinement; and (2) evaluate the psychometric properties of the final CSS-Caregiver measure, including scoring thresholds for depression and anxiety risk subscales. For exploratory (EFA) and confirmatory (CFA) factor analyses, the sample was randomly split into two groups (EFA $n = 250$; CFA $n = 150$). All other analyses were conducted based on the full sample of $N = 400$ participants.

2.3.1 | Exploratory factor analysis and item reduction

Our first goal was to refine and shorten CSS-Caregiver, using an iterative process guided by best-practice guidelines to inform item retention.²⁷ EFA was conducted with direct oblique rotation and principal axis factoring extraction ($n = 250$). We assessed dimensionality and determined the number of factors needed to best represent variability in the data using Cattell's scree test and fit indices. Overall model fit was assessed using goodness of fit criteria: RMSEA, Standardized Root Mean Square Residual (SRMR), and TLI. The models were considered to have good fit if RMSEA was <0.06 , SRMR <0.08 , and TLI >0.95 , while RMSEA <0.08 and TLI >0.90 were considered acceptable fit.^{28,29} Cross-loaded items and items with a factor loading <0.30 were not included in the final factor structure. To evaluate internal item quality, we considered level of item endorsement, item discrimination indices, inter-item and inter-factor correlations, factor loadings and structure, and item communalities ($N = 400$). To evaluate external item quality, we calculated Pearson correlations of each CSS-Caregiver item with PROMIS-29, DT, ZBI-12, and CRA subscales ($N = 400$). Additionally, when making scale reduction decisions, the theoretical and practical implications of each item were assessed independently by authors and reconciled in a series of consensus meetings.

2.3.2 | Confirmatory validation analysis and evaluation of psychometric properties

Our second goal was to corroborate the dimensionality and psychometric properties of the reduced CSS-Caregiver measure. To accomplish this goal, we performed the following analyses, as described below: (1) CFA ($n = 150$); (2) evaluation of internal consistency and test-retest reliability, convergent validity, discriminant validity, and known groups validity ($N = 400$); and (3) nonparametric receiver operating characteristic (ROC) curve analyses ($N = 400$).

CFA was conducted using maximum likelihood factor extraction, fixing factor loadings for the first indicator in each factor to 1.0. We evaluated goodness of fit with absolute and relative fit indices, using

goodness of fit criteria described above.^{28,29} Once the final factor structure was confirmed with CFA, we evaluated CSS-Caregiver psychometric properties using the full sample of 400 participants, including Cronbach's alpha to evaluate internal consistency reliability and intraclass correlation coefficients (ICCs) to evaluate test-retest reliability ($n = 295$ completed re-test). Convergent and discriminant validity were evaluated through Pearson correlations of the final factors with PROMIS-29, DT, ZBI-12, and CRA subscales. Correlations were considered large if $r \geq 0.50$, medium if $r = 0.30-0.49$, and small if $r = 0.10-0.29$.³⁰ Known groups validity was examined using Hedges' g to estimate effect sizes between identified groups for gender identity, annual income, and hours of care provided weekly, and Pearson correlations to examine associations with age (modeled continuously). We hypothesized that younger age, female gender, lower annual income (<\$40K vs. \$40K+), and greater number of hours of care provided weekly (≤ 20 h vs. 21+ h) would be associated with greater total distress.³¹⁻³³

Finally, we conducted nonparametric ROC curve analyses to determine scoring thresholds for the 2-item CSS-Caregiver depression and anxiety risk scales. The criterion scores used included PROMIS depression ($T \geq 60$) and anxiety ($T \geq 62$) scales,^{34,35} as well as PHQ-2 (total score ≥ 3) and GAD-2 (total score ≥ 3).²⁴

3 | RESULTS

3.1 | Participant characteristics

Descriptive statistics for sociodemographic and caregiving characteristics are presented for the full sample ($N = 400$) in Table 1. Respondents were predominantly female (81%) and Non-Hispanic White (83%), with an average age of 51 years (range: 20–89). The majority of participants were highly educated (70% with college or higher), employed full-time (65%) and currently providing care (64%). More than 40% reported their spouse as the care recipient. Nearly 40% of participants reported fewer than 20 hours of care provided per week, while 20% reported more than 80 h weekly. Average years of care provided was 3.88 ($SD = 5.34$).

3.2 | Exploratory factor analysis and item reduction

EFA ($n = 250$) was conducted on the 33-item CSS-Caregiver. Scree plots and fit indices supported a five-factor solution. Following a series of iterative EFA models, we removed 14 items with limited variability, low endorsement, low factor loadings (<0.30), or low validation measure correlations. Eighteen items were retained, with at least two items per factor. An additional item on tobacco and substance use did not load on any of the five factors, but was retained due to clinical significance for risk assessment. Results from the final five-factor EFA with 18 items plus the substance use item are shown in Table 2. We labeled the five factors as: (1) Emotional Well-Being; (2) Patient Well-Being; (3)

TABLE 1 Descriptive characteristics and caregiving history of the sample ($N = 400$)

	M/n	SD/%
Age ^a	51.1	13.6
Gender identity		
Female	325	81%
Male	72	18%
Other	3	1%
Race and ethnicity		
White	332	83%
Black or African American	10	3%
Hispanic or Latino/a, any race	25	6%
Asian	18	5%
American Indian or Alaskan Native	2	<1%
Other	2	<1%
Multiple races	3	<1%
Prefer not to share/Missing	8	2%
Education		
No college	44	11%
Some college	73	18%
College degree	157	39%
Graduate or professional degree	125	31%
Missing	1	<1%
Relationship to care recipient		
Caring for spouse	167	42%
Caring for parent/parent-in-law	83	21%
Caring for child	29	7%
Other	51	13%
Missing	70	17%
Annual income		
<\$20K	33	8%
\$20–39K	50	13%
\$40–59K	50	13%
\$60–79K	41	10%
\$80–99K	40	10%
\$100K+	103	26%
Prefer not to share/Missing	83	21%
Employment		
Full-time	217	54%
Part-time	44	11%
Retired	73	18%
Not employed	55	14%
Prefer not to share/missing	11	3%

TABLE 1 (Continued)

	M/n	SD/%
Currently providing care		
Yes	254	64%
No	88	22%
Missing	58	14%
Hours of care provided weekly		
≤20 hours	157	39%
21–80 hours	97	24%
>80 hours	78	20%
Missing	68	17%
Years providing care		
<1 year	81	20%
1 year	75	19%
2 years	36	9%
3–5 years	69	17%
6–10 years	34	9%
11+ years	26	6%
Missing	79	20%
Primary cancer diagnosis of care recipient		
Breast	58	15%
Lung	54	14%
Hematologic	44	11%
Colorectal	32	8%
Head and neck	22	6%
Prostate	22	6%
Brain	21	5%
Pancreatic	20	5%
Esophageal	13	3%
Kidney	13	3%
Ovarian	10	3%
Liver	9	2%
Bladder	8	2%
Other ^b	70	18%
Missing	4	1%
Years since diagnosis of care recipient ^a	3.88	5.34
Stage of care recipient ^c		
0	6	2%
I	19	5%
II	31	8%
III	44	11%
IV	140	35%

TABLE 1 (Continued)

	M/n	SD/%
Patient's cancer doesn't have a stage	33	8%
Other	17	4%
Don't know	31	8%
Missing	79	20%
Care recipient ever experience recurrence		
Yes	121	30%
No	175	44%
Don't know	20	5%
Missing	84	21%

^aSubsample sizes: age ($n = 359$), years since diagnosis ($n = 284$).

^bOther cancer diagnoses included endometrial, cervical, melanoma, stomach, sarcoma, testicular, and anal, among others.

^cCurrent cancer stage; if no longer providing care, denotes care recipient stage at diagnosis.

Caregiving Tasks; (4) Finances; and, (5) Healthy Lifestyle. The four items comprising the depression and anxiety risk subscales were included in the Emotional Well-Being factor along with a fifth item on disruptions in work, school, or home life. Each Emotional Well-Being item loaded adequately on the factor, and item-factor correlations were strong, ranging from 0.76 to 0.87. The Patient Well-Being factor includes four items on changes in patient mood or behavior, changes in patient memory or thinking, patient pain and discomfort, and patient eating and nutrition. Each item had a high loading on the factor, and item-factor correlations were strong ($r_s = 0.83$ – 0.88). The Caregiving Tasks factor includes four items on coordinating care, providing transportation, providing physical/medical care, and making treatment decisions; items loaded at ≥ 0.50 , and item-factor correlations ranged from 0.86 to 0.93. The two-item Finances factor includes one item on managing insurance and bills and a second item on managing household finances. Each item had a high factor loading, and item-factor correlations were 0.94 and 0.95. Finally, the Healthy Lifestyle factor includes three items on physical activity, keeping up with health needs, and eating/nutrition. Again, item-factor correlations were strong, ranging from 0.83 to 0.87 with high factor loadings for all three items. Table 2 also includes item endorsement and item discrimination for the final 18 items plus the tobacco and substance use item. The final EFA was found to explain 67% of the model variance and the model demonstrated good fit (RMSEA = 0.06 [CI = 0.05–0.08], SRMR = 0.02, TLI = 0.95).

3.3 | Confirmatory validation analysis and evaluation of psychometric properties

3.3.1 | Confirmatory factor analysis

CFA confirmed the five-factor structure of CSS-Caregiver ($n = 150$) with acceptable to good model fit (RMSEA = 0.07 [90% CI = 0.06–

TABLE 2 Item endorsement, item discrimination, item correlations ($N = 400$), and exploratory factor analysis factor loadings and communalities for the final CSS-Caregiver measure ($n = 250$)

Factors and items	Item characteristics ($N = 400$)					EFA ($n = 250$)					
	% ≥ 3	% ≥ 2	IDI	Item-total r	Item-factor r	F1	F2	F3	F4	F5	h^2
Emotional well-being											
Feeling nervous or afraid ^a	27.0	48.5	0.72	0.61	0.87	0.89					0.77
Feeling sad or depressed ^b	24.8	52.6	0.80	0.66	0.87	0.80					0.69
Feeling lonely or isolated ^b	23.1	44.9	0.81	0.62	0.83	0.69					0.61
Worrying about the future and what lies ahead ^a	46.8	71.0	0.64	0.65	0.84	0.68					0.66
Changes or disruptions in work, school, or home life	27.1	53.4	0.75	0.61	0.76	0.42					0.47
Patient well-being											
Changes in the patient's mood or behavior	33.5	61.3	0.73	0.64	0.88		0.89				0.80
Changes in the patient's memory or thinking	29.1	51.5	0.69	0.57	0.83		0.73				0.61
The patient's pain or physical discomfort	40.6	62.4	0.71	0.63	0.85		0.67				0.60
The patient's eating and nutrition	37.3	61.3	0.73	0.61	0.84		0.62				0.58
Caregiving tasks											
Coordinating medical care for the patient	22.6	42.4	0.89	0.73	0.93			0.84			0.88
Providing transportation to treatment and appointments	18.3	34.3	0.76	0.62	0.86			0.80			0.68
Providing physical or medical care to the patient	23.4	42.1	0.86	0.70	0.86			0.63			0.67
Making treatment decisions	22.3	41.8	0.84	0.71	0.87			0.52			0.69
Finances											
Managing health insurance and medical bills	26.3	43.9	0.75	0.62	0.94				0.93		0.86
Managing household finances	29.3	44.4	0.76	0.62	0.95				0.83		0.79
Healthy lifestyle											
Exercising and being physically active	18.5	52.0	0.36	0.32	0.87					0.78	0.60
Keeping up with your health care needs	18.3	50.3	0.39	0.36	0.86					0.76	0.59
Eating and nutrition	13.1	52.8	0.59	0.48	0.83					0.66	0.56
Tobacco, alcohol, or substance use											
Tobacco, alcohol, or other substance use	3.3	13.6	0.21	0.23	N/A						N/A

Note: % ≥ 3 = seriously to very seriously concerned; % ≥ 2 = moderately to very seriously concerned.

Abbreviations: h^2 , communality; IDI, item discrimination index between upper and lower quartiles, based on total distress score; Item-total r , corrected item-total correlation.

^aItem is part of anxiety risk screening subscale.

^bItem is part of depression risk screening subscale.

0.09], SRMR = 0.06, CFI = 0.94, TLI = 0.93, $\chi^2 = 216.12$). The items were stable, with equivalent or higher loadings on their factors.

Once confirmed, we examined the final CSS-Caregiver measure psychometric characteristics with the full sample of 400 participants to evaluate internal consistency and test-retest reliability, as well as convergent, discriminant, and known groups validity. Table 3 shows factor descriptive characteristics, inter-correlations, internal consistency and test-retest reliability values (Cronbach's α and ICCs), and Pearson correlations of CSS-Caregiver factors with comparison validation measures.

3.3.2 | Internal consistency and test-retest reliability

CSS-Caregiver had high internal consistency ($\alpha = 0.92$). Test-retest reliability was 0.85 for the 18-item measure and 0.86 when including the optional tobacco and substance use item, while individual factor ICCs were ≥ 0.72 . Inter-factor correlations ranged from 0.26 to 0.61 representing small to large correlations; though factors are related, each factor is distinct, confirming multi-dimensionality. Additionally, each factor was strongly correlated with the total distress score ($r_s = 0.52$ – 0.83 ; $p < 0.001$).

TABLE 3 CSS-Caregiver measure and factor descriptive characteristics, internal consistency and test-retest reliability, and convergent and discriminant validity inter-correlations (N = 400)

	# items	M (SD) ^a	α	Validation measure correlations																			
				Factor intercorrelations					PROMIS-29					CRA									
				F1	F2	F3	F4	F5	Dep	Anx	Soc	Phys	Func	Fat	Sleep	Pain	Int	DT	ZBI	FI	SI	HI	LFS
Total distress score (CSS-CG-18)	18	28.72 (15.32)	0.92	0.85	0.81	0.78	0.84	0.72	0.52	0.64	0.65	-0.50	-0.29	0.55	0.46	0.23	0.61	0.57	0.46	0.55	0.52	0.40	-0.20
Total distress score + tobacco (CSS-CG-18+)	19	29.15 (15.55)	0.92	0.86	0.82	0.78	0.83	0.72	0.52	0.65	0.66	-0.51	-0.29	0.55	0.46	0.23	0.61	0.57	0.47	0.55	0.52	0.41	-0.20
F1: Emotional well-being	4	1.70 (1.05)	0.89	0.87	--	0.50	0.53	0.51	0.33	0.76	0.79	-0.54	-0.27	0.65	0.54	0.22	0.73	0.62	0.39	0.53	0.52	0.39	-0.22
F2: Patient well-being	3	1.88 (1.16)	0.87	0.78	--	0.61	0.39	0.26	0.43	0.42	-0.40	-0.22	0.32	0.30	0.18	0.42	0.38	0.24	0.47	0.35	0.30	-0.12 ^b	
F3: Caregiving tasks	4	1.30 (1.20)	0.90	0.75	--	0.60	0.28	0.44	0.43	-0.35	-0.26	0.35	0.28	0.18	0.38	0.37	0.37	0.37	0.38	0.38	0.30	-0.13 ^b	
F4: Finances	2	1.49 (1.34)	0.88	0.78	--	0.32	0.45	0.42	-0.36	-0.20	0.38	0.34	0.18	0.40	0.41	0.63	0.39	0.43	0.31	0.43	0.31	-0.14	
F5: Healthy lifestyle	5	1.50 (0.94)	0.81	0.72	--	0.19	0.23	-0.14	-0.06 ^b	0.27	0.18	0.06 ^b	0.27	0.18	0.06 ^b	0.23	0.32	0.18	0.18	0.22	0.16	-0.12 ^b	

Note: CRA subscales: FI = finance impact; SI = schedule impact; HI = health impact; LFS = lack of family support; SE = self esteem.

^aMean/SD based on averaged factor scores, except for the total distress score, which is summed. α = Cronbach's alpha; ICC = intraclass correlation coefficient (test-retest reliability); subsample size for those participating in test-retest: n = 295. All factor intercorrelations significant $p < 0.001$; all Pearson r correlations between factors and validation measures significant $p < 0.01$, except where ^bdenotes $p = NS$.

3.3.3 | Convergent and discriminant validity

Pearson correlations of CSS-Caregiver factors with validation measures confirmed strong convergent validity. Specifically, a strong correlation (absolute value of $r \geq 0.50$) was observed in the relationship of total CSS-Caregiver distress with: PROMIS Depression, PROMIS Anxiety, PROMIS Fatigue, DT, ZBI, CRA Schedule Impact, and CRA Health Impact. Overall, greater total distress, as captured by CSS-Caregiver, was associated with poorer health-related quality of life ($r_s = -0.50$ to 0.65), greater caregiver burden ($r = 0.57$), and greater distress as measured by the DT ($r = 0.61$). CSS-Caregiver total score and factors were only weakly correlated with caregiver self-esteem ($r_s = -0.22$ to -0.12), supporting measure discriminant validity.

3.3.4 | Known groups validity

Several comparisons supported known-groups validity based on total distress score, with directional differences consistent with hypothesized directions. CSS-Caregiver total distress score was significantly ($t = 3.67, p < 0.001$) higher among participants with lower (<\$40K) annual income ($n = 83$) than those with greater annual income (\$40K+; $n = 234$, Hedges' $g = 0.47$); among female ($n = 325$) than among male participants ($n = 72, t = 2.26, p < 0.02$, Hedges' $g = 0.29$); and among caregivers providing 21+ hours of weekly care ($n = 125$) than those providing ≤ 20 hours weekly ($n = 157, t = 6.27, p < 0.001$, Hedges' $g = 0.75$). While the effect size was small, younger age was also significantly correlated with greater total distress ($r = -0.14, p < 0.01, n = 359$).

3.3.5 | Receiver operating characteristic curve analysis

Results from ROC analyses are shown in Table 4. Using PROMIS Depression and PHQ-2 criterion scores described above, we found that a score of ≥ 3 (out of a maximum score of 8) on the 2-item CSS-Caregiver depression risk subscale (CSS-D2) yielded high sensitivity (94.5%–95.0%) and adequate specificity (63.0%–66.4%). The areas under the curve (AUC) were 0.888 with PROMIS Depression and 0.880 with PHQ-2. Based on the cutoff score of ≥ 3 , 35% of CSS-Caregiver participants were at risk for clinically significant levels of depression. Similarly, using PROMIS Anxiety and GAD-2 criterion scores described above, we found that a score of ≥ 4 (out of a maximum score of 8) on the 2-item CSS-Caregiver anxiety risk subscale (CSS-A2) yielded high sensitivity (86.7%–90.6%) and adequate specificity (66.0%–68.0%). The AUC were 0.872 with PROMIS Anxiety and 0.867 with GAD-2. Based on the cutoff score of ≥ 4 , 45% of participants were at risk for clinically significant levels of anxiety. Additionally, Cronbach's alpha was $\alpha = 0.79$ for the depression subscale and $\alpha = 0.83$ for the anxiety subscale, confirming internal consistency reliability. The Pearson correlation between the scales ($r = 0.78$) confirmed that these subscales are related but conceptually

TABLE 4 Calculations of sensitivity and specificity for CancerSupportSource-Caregiver 2-item depression and 2-item anxiety risk subscales

CSS risk score	Comparison measure	<i>r</i>	% ≥ comparison measure threshold score	AUC	Cutoff	Sensitivity	Specificity	Negative predictive value	Positive predictive value
CSS-D2	PROMIS Depression (<i>n</i> = 347)	0.77	35.2	0.888					
					2	98.4	45.6	98.1	49.2
					3	95.0	66.4	96.2	60.2
					4	84.3	80.1	90.5	69.4
					5	60.3	89.8	80.9	76.0
	PHQ-2 (<i>n</i> = 347)	0.88	31.2	0.880	2	99.1	43.7	99.0	44.6
					3	94.5	63.0	96.2	53.9
					4	84.4	76.1	91.4	61.7
					5	63.3	87.8	83.9	70.4
CSS-A2	PROMIS Anxiety (<i>n</i> = 352)	0.78	44.9	0.872					
					2	98.7	29.4	96.6	53.2
					3	94.9	52.6	92.7	62.0
					4	86.7	68.0	86.3	68.8
					5	74.1	86.6	80.4	81.8
	GAD-2 (<i>n</i> = 347)	0.90	39.8	0.867	2	99.3	26.8	98.2	47.2
					3	97.1	49.8	96.3	56.1
					4	90.6	66.0	91.4	63.8
					5	74.6	81.3	82.9	72.5

Note: *r* = Pearson correlation between CSS depression and anxiety risk subscale total scores and comparison measure total scores. Negative predictive value = proportion of respondents with negative test results who are correctly diagnosed. Positive predictive value = proportion of respondents with positive test results who are correctly diagnosed. Area under the curve (AUC) = a measure of accuracy based on a receiver operating characteristic curve; higher values indicate higher accuracy, and a perfect test has an AUC = 1.

distinct. The ROC analyses, therefore, confirm the utility of the brief subscales for flagging caregivers at risk for clinically significant depression and anxiety.

4 | DISCUSSION

Caregivers serve a crucial role in cancer care and may experience heightened levels of distress and reduced quality of life.^{1,4-9} At the same time, caregivers' needs are often overlooked and supportive care is underutilized due to care access barriers.¹⁰ Thus, to better identify unmet needs of cancer caregivers and link them with tailored resources and support, Cancer Support Community developed CSS-Caregiver, a web-based distress screener that not only assesses caregivers' concerns but also evaluates their desired support. The goals of the current study were to create a final version of the CSS-Caregiver screening measure and analyze its psychometric properties.

Overall, our findings confirm that CSS-Caregiver is a reliable, valid, multi-dimensional screening measure for distress among cancer caregivers. The 18 items comprising CSS-Caregiver evaluate

caregivers' concerns across five dimensions: Emotional Well-Being, Patient Well-Being, Caregiving Tasks, Finances, and Healthy Lifestyle, plus an additional optional item evaluating substance use to be included as needed based on the setting of implementation. Psychometric properties of the 18 versus 19 item measure when including the optional substance use item were virtually identical; for consistency in research applications of the measure, we suggest calculating total distress based on the core 18 measure items. Robust psychometric analyses showed strong internal consistency and test-retest reliability, a replicable factor structure, and adequate convergent, discriminant, and known groups validity. Finally, we find psychometric support for the embedded depression and anxiety risk subscales, intended to identify caregivers at risk for clinically significant levels of depression and anxiety.

4.1 | Clinical implications

Our results support the use of CSS-Caregiver as a measure to identify caregivers' needs and link them with their desired method of

support. The distress and burden associated with caregiving may carry long-term repercussions for the well-being of cancer caregivers.³³ By identifying caregiver needs and providing desired follow-up, these individuals would be better supported and thus better positioned to maintain their own health and well-being. Indeed, there is growing recognition for the need to evolve the focus of healthcare systems from a patient focus to a family focus³⁶ and to routinely document caregiver data within healthcare settings.¹² CSS-Caregiver has been successfully implemented by Cancer Support Community's network partners, where typical administration time for the full CSS-Caregiver program, including questions about desired support resources for each item, ranges from 5 to 8 minutes. Moving forward, future goals for implementation include understanding how to best engage caregivers in diverse settings, including oncology practices, ambulatory sites, and other venues to rapidly assess caregivers' concerns and connect them with resources aligned with their unmet needs along various points in the cancer caregiver continuum.

Screening caregivers for distress may also improve patient outcomes. Although research on caregiver-patient dyads is limited, previous studies suggest a dynamic interplay whereby caregiver distress is not only impacted by patient well-being but contributes to patient outcomes.³⁷ Caregivers are best suited to provide the support that patients need—for patient physical health, treatment decisions, therapy adherence, and psychological well-being—when their own health and well-being are regarded. Thus, supporting caregivers, addressing their concerns, and reducing their psychosocial distress may empower caregivers, contributing to more positive clinical implications for the patient. Future research should follow caregiver and patient dyads and explore the clinical and psychosocial outcomes of tandem distress screening.

4.2 | Study limitations

Limitations of this study include the need to consider the psychometric properties of CSS-Caregiver in a diverse population, particularly in terms of race/ethnicity and socioeconomic status. Similarly, our sample was predominantly women. Known groups validity testing suggested significantly higher distress, as captured by CSS-Caregiver, for women as compared with men, pointing to a need for future work to examine the intersection of gender identity with various aspects of caregiving. Importantly, the analytic sample was limited to individuals who self-selected into the Cancer Experience Registry, which requires Internet access. Furthermore, though a range of cancer diagnoses and stages are represented, the sample is not representative of all cancer caregivers. We also did not restrict the sample based on current caregiving status; future work comparing unmet needs of current and former cancer caregivers would support the further development of relevant support resources. Additionally, the time interval for test-retest reliability was relatively short, although CSS was administered after multiple questionnaires to reduce the effect of memory. Future work is also needed to understand the implementation of the measure and

program across diverse care settings. The current study did not examine participants' desired follow-up on items (e.g., information or talking to a staff member); these will be explored in future implementation studies.

5 | CONCLUSION

As distress screening in oncology becomes standard,^{38–40} care providers should also consider screening caregivers as the substantive role demands and heightened distress among these individuals have been well-documented. Here, we show clear psychometric support for use of CSS-Caregiver, a multidimensional distress screening measure that allows for rapid screening of cancer caregivers' unmet needs across key areas of life.

AUTHOR CONTRIBUTIONS

Alexandra K. Zaleta: Conceptualization; Funding Acquisition; Investigation; Methodology; Project Administration; Supervision; Writing – original draft; Writing – review & editing. **Melissa F. Miller:** Conceptualization; Data Curation; Formal Analysis; Investigation; Methodology; Validation; Writing – original draft; Writing – review & editing. **Erica E. Fortune:** Formal Analysis; Investigation; Methodology; Validation; Writing – original draft; Writing – review & editing. **Julie S. Olson:** Writing – original draft; Writing – review & editing. **Kimberly Papay Rogers:** Investigation; Writing – original draft. **Kelly Hendershot:** Investigation; Writing – original draft. **Susan Ash-Lee:** Investigation; Writing – original draft.

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CONFLICTS OF INTEREST

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DATA AVAILABILITY STATEMENT

Cancer Support Community retains full control of all primary data.

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