

Optimizing Community and Hospital Services Using the Cancer Support Source Program

Journal of Patient Experience
2020, Vol. 7(1) 96-104
© The Author(s) 2018
Article reuse guidelines:
sagepub.com/journals-permissions
DOI: 10.1177/2374373518808309
journals.sagepub.com/home/jpx


Emily J Ross, MA¹, Chelsea H Wiener, MS¹,
Diane Robinson, PhD^{1,2}, and Jeffrey E Cassisi, PhD¹

Abstract

Background: The Cancer Support Community developed the Cancer Support Source (CSS) to assess the needs of cancer patients with distress. Each item on this self-administered questionnaire represents an area of concern which the patient rates and indicates their need for action with a “staff person,” but no details about the category of staff is given. **Objective:** To examine the factor structure of the CSS and to increase its utility to triage patients for referral to services based on a needs assessment. **Methods:** Data from 690 patients who completed the CSS over a 1-year period were analyzed. In study 1, an exploratory principal component analysis was conducted. In study 2, the fit of this proposed model was evaluated with confirmatory factor analysis (CFA). **Results:** Three factors were retained in the final CFA: emotional distress, physical health concerns, and resource needs. This model demonstrated adequate fit, Root Mean Square Error of Approximation (RMSEA) = 0.056, Comparative Fit Index (CFI) = .907, Standardized Root Mean Square Residual (SRMR) = 0.050. **Conclusions:** Three factors are proposed as CSS subscales to guide referral and coordinate services: Emotional Distress/Patient and Family Counselor, Physical Health Concerns/Medical Care Provider, and Resource Needs/Case Management–Clinical Social Worker. The clinical utility of these referral subscales should be established with additional research.

Keywords

cancer, distress screening, oncology, psychosocial distress, quality of life, survivors

Introduction

Research suggests 30% to 40% of patients with cancer will endure elevated levels of psychosocial distress during the course of illness, with the magnitude of distress varying by individual due to cancer treatment side effects, disease progression, and other psychosocial factors (1–7). Distress burden associated with cancer diagnosis and treatment may manifest as hopelessness, vulnerability, panic, social isolation, depression, anxiety, spiritual and existential crisis, and deteriorating quality of life (QoL) (4) and is associated with increased length of hospital stays, treatment costs, and suicidality, morbidity, and mortality rates (8–10). Patients with high levels of distress may be more likely to engage in at-risk behaviors, less likely to adhere to health protection behaviors, and experience reduced capability to adhere to their medical plan and treatment (11–13). Clearly, addressing psychosocial needs is crucial for improving QoL among patients with cancer (14,15).

The largest nonprofit network of cancer support is the Cancer Support Community (CSC) (16). The CSC is

dedicated to addressing the social and emotional needs of all people impacted by cancer and has over 170 locations in major metropolitan areas worldwide (<https://www.cancersupportcommunity.org/FindLocation>). The web site describes that 85% of cancer patients are treated in CSC-affiliated sites. The CSC Research and Training Institute conducts psychosocial, behavioral, and survivorship research and provides patient advocacy through its Cancer Policy Institute, informing public policy in Washington, DC and across the nation. The CSC Research and Training Institute developed the Cancer Support Source (CSS) tool which has been widely implemented to screen for psychosocial distress at

¹ Department of Psychology, University of Central Florida, Orlando, FL, USA

² Orlando Health UF Health Cancer Center, Orlando, FL, USA

Corresponding Author:

Emily J Ross, Department of Psychology, University of Central Florida, 4111 Pictor Lane, Orlando, FL 32816, USA.
Email: ejayneross@gmail.com



CSC affiliates, hospitals, and community-based cancer centers in line with new continuum of care standards adopted in 2015 by the American College of Surgeons Commission on Cancer. Standard 3.2, Psychosocial Distress Screening, mandates that each patient with cancer be screened for a range of psychological, physical, and social needs in tandem with their cancer treatment at least once. Ideally this screening is conducted on intake and a review of the patient's needs is to be discussed at a medical visit. If screening reveals moderate to severe psychosocial distress, then the facility must document that adequate resources and/or referrals have been offered.

The CSS is a computer-administered questionnaire containing 25 items (alternative short forms are available). The CSS is easily accessible and user-friendly; patients may complete it onsite or at home online (17). Two methods of scoring the CSS have been delineated. In the first method, the respondents rate their level of concern for each item on a 5-point Likert scale from 1 (not at all) to 5 (very seriously). Items rated as "somewhat concerned" or above (2 or greater) are then summed for a "Total Distress Score." In the other method, responses to each item are reviewed with the patient if they indicate in a second column that they are requesting action in that specific area of concern. There is no summary score for these action items. An individualized "My Care Plan" is formulated from their responses and patients are then provided with opportunities for a broad range of services that correspond to their specific needs (18). What differentiates the CSS from other QoL assessments is that the patient indicates the level of response they would like; it is self-administered; and is developed for use across a broad spectrum of consumer-led groups, patient advocacy programs, physician practices, community-based hospitals, as contrasted with instruments designed solely for use by health service providers and specialists.

To increase clinical efficiency in identifying patients with notable distress, the authors of the CSS designed a 4-item "Depression subscale" (18). This subscale is correlated highly with the Functional Assessment Scale of Cancer Therapy-General Well-Being Scale (FACT-G), Center for Epidemiologic Studies Depression Scale (CES-D), and Distress Thermometer (DT) (19). The internal consistency for the Depression subscale was 0.89 and the sensitivity and specificity for depression were 91.8% and 69.0%, respectively, if the depression score (sum of 4 problem ratings) was ≥ 7 (18). These findings suggest the CSS has potential for subscale development. As it stands, the idiographic approach of this survey does not summarize information efficiently. Critically, development of subscales may further increase clinical utility by suggesting appropriate ways to triage patients to particular services within the health-care team. As stated above, appropriate referral postscreening is mandated by accepted treatment guidelines (20-22).

Health service providers who receive referrals from CSCs based on CSS responses would follow-up with additional validated assessment of QoL and patient-reported outcomes

(PROs) appropriate to the individual treatment plan and goals. The use of the CSS as a PRO is illustrated by a recent study which found a group of patients who had received their diagnosis within the past year reported significantly higher level of distress and depression than a group diagnosed over a year prior (23). In another study, survivors who had been diagnosed over a year exhibited a depression risk of 45%. Thus, utilization of the CSS may help identify population trends in psychosocial distress both on intake and in later stages of treatment.

The focus of this article is on making the CSS more useful as part of an individual patient needs assessment. No studies have examined the factor structure of the CSS or used other dimension reduction approaches to increase its utility to triage patients for referral to services. In study 1, an exploratory principal component analysis (PCA) is conducted to suggest likely underlying dimensions. In study 2, the fit of this proposed model is evaluated using confirmatory factor analysis (CFA). Results suggest the recommendation for CSS referral subscales.

Methods

Measure

Version 2 (25-items) of the CSS was the primary measure used in this study. Ratings for each item are on a Likert rating scale, ranging from 1 (not at all) to 5 (very seriously), with higher ratings reflecting greater concern (24). The full CSS can be found at <http://www.cancersupportcommunity.org>. The initial psychometric properties of the CSS have been investigated with a community-based sample of 319 cancer survivors (19). It demonstrates high internal consistency (Cronbach's $\alpha = 0.91$) and test-retest reliability (Intra-class Correlation Coefficient ≥ 0.75). The CSS has also demonstrated good correlation with the DT ($R^2 = 0.35$), the FACT-G ($R^2 = 0.58$), and the CES-D ($R^2 = 0.48$) (19,20).

Participants

Participant data were obtained from an archival data set obtained from the CSC program at the Orlando Health UF Health Cancer Center clinics. The Cancer Center is designated as a center of excellence by the State of Florida and it is one of the top 5 academic cancer centers in the State and accredited by the Commission on Cancer. This site has utilized the CSS to conduct psychosocial distress screening since January 1, 2015.

The Cancer Center is located in Florida, which has the second highest cancer burden in the nation (25). The patient mix closely matches the national age-adjusted incidence rates by cancer site, that is, number of new cases per 100,000 people, for 2011 to 2015, provided by the National Cancer Institute (26).

The study was reviewed by the Orlando Health Institutional Review Board and analyses were conducted on a de-identified data set from patients who took the CSS for the first

Table 1. Cancer Location Table for Groups 1 and 2.

Cancer Location	Frequency (%)	
	Group 1	Group 2
Breast	122 (37.2)	123 (36.3)
Blood	15 (4.6)	18 (5.3)
Lung	27 (8.2)	25 (7.4)
Head and neck	38 (11.6)	53 (15.6)
Gynecologic	40 (12.2)	44 (13.0)
Gastrointestinal	12 (3.7)	10 (2.9)
Skin	10 (3.0)	15 (4.4)
Prostate	23 (7.0)	7 (2.1)
Liver	2 (0.6)	5 (1.5)
Brain and spine	4 (1.2)	5 (1.5)
Pancreatic	1 (0.3)	3 (0.9)
Multiple	34 (10.4)	31 (9.1)
Total	328 (100)	339 (100)

time over a 12-month period in 2015. The data set contained responses from patients diagnosed with breast, blood, lung, head and neck, gynecologic, gastrointestinal, skin, prostate, liver, brain and spine, or pancreatic cancer and patients diagnosed with multiple cancers. This patient data set included cancer location, patient gender, and CSS item responses.

Data Split

The total data set of 690 was randomly split into two subsamples (group 1, $N = 332$; group 2, $N = 358$). Group 1 was used in study 1, while group 2 was used in study 2. The data were divided using the SPSS cross-tabulation function (50% of cases). This does not necessarily produce exactly equal numbers for the subsamples because of independence of group assignment from one patient to the next. The 2 sample groups were compared to ensure they were not significantly different on the available measures. Chi-square tests were conducted to assess for any significant differences in gender, depression risk subscale score, and cancer location between the 2 groups. No significant differences were found between the 2 randomized groups concerning the frequency of gender, $\chi^2(2, N = 690) = 1.17, P = .56$ (72.0% female group 1, 70.9% female group 2) in depression risk, $\chi^2(2, N = 690) = 1.25, P = .54$, nor in cancer location $\chi^2(11, N = 690) = 14.85, P = .19$ (see Table 1 for cancer location by group information). Next, independent-samples Mann-Whitney U tests were conducted on the 25 CSS items for the 2 randomized subsamples. There was no evidence for differences between groups on these measures and the randomization was deemed successful. In study 1, a PCA was conducted using the group 1 subsample. In study 2, a CFA was conducted using the group 2 subsample.

Missing Data

Initially, there were 332 patients in the study 1 sample data set. Patients with 3 or more missing items were eliminated

($N = 4$). Those with 2 or fewer missing responses ($N = 57$) were retained in the data set and mean replacement was used for the missing items. Following Roth et al (27) and Tabachnick and Fidell (28) recommendations, mean substitution is a strategy that is especially applicable to self-report measures in which all items that are indicators of a specific concept or construct are assumed to be closely and positively correlated. Therefore, the final data set in study 1 included 328 patients.

Initially, there were 358 patients in the study 2 sample data set. Patients with 3 or more missing items were eliminated ($N = 19$). Those with 2 or fewer missing responses ($N = 41$) were retained in data set and mean replacement was used for the missing items. Therefore, the final data set in study 2 included 339 patients.

Study 1 Statistical Analyses

A PCA was conducted on the study 1 data set using SPSS (version 23). Specifically, Tabachnick and Fidell (2013) recommend using a PCA to discover latent dimensions within a set of variables in a descriptive manner (28). An oblique rotational procedure (Promax) was conducted as it was expected the factors extracted in this current study would correlate due to their relation with distress. Rotational procedures are utilized in factor analysis to aid in interpretation and produce a simplified and more reliable factor structure (29). Furthermore, Promax rotation is recommended due to its conceptual simplicity, expedient nature with larger data sets, and its ability to achieve a simple structure (30). The appropriateness of the data set for PCA was examined in several ways. Tabachnick and Fidell (28) recommend minimum value for the Kaiser-Meyer-Olkin Test for Sampling Adequacy (KMO) index (ranging from 0 to 1) is 0.6 to conduct an adequate factor analysis. The KMO index for this data set was 0.94, which indicates the data set is well-suited for factor analysis. Bartlett's test of sphericity was significant, $\chi^2(300) = 3847.50, P < .05$, therefore the null hypothesis that the correlation matrix is an identity matrix was rejected (28). Additionally, all diagonal items in the anti-image correlation matrix met the recommended criteria of above 0.5 (28), indicating all items could be retained for factor analysis. The extracted factors were evaluated to determine the percentage of variance, that is, communalities. The recommended minimum value for communalities (0.30-0.40) was met (28), confirming data set test items had adequate shared common variance and relation with extracted factors and could all be retained for subsequent analysis. Tabachnick and Fidell (28) criteria also suggest an adequate factor model will present with less than 50% of nonredundant residuals with an absolute value greater than 0.5, which is confirmed in this data set as 35.0% of nonredundant residuals were found with absolute values greater than 0.5.

Table 2. Principle Component Analysis of Items in the CSS Program With Communalities (h^2) of Each Item.

No.	Item	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5	h^2	Mean	SD
1	Eating and nutrition	0.00	0.67	0.00	0.00	0.00	.54	2.96	1.33
2	Feeling irritable	0.71	0.00	0.00	0.00	0.00	.58	2.05	1.16
3	Moving around (walking, climbing stairs, lifting, etc)	0.50	0.45	0.45	0.00	0.00	.57	1.91	1.18
4	Communicating with your doctor	0.00	0.60	0.52	0.00	0.00	.54	2.08	1.40
5	Sleep problems	0.66	0.00	0.41	0.00	0.00	.52	2.22	1.31
6	Changes or disruptions in work, school, or home life	0.63	0.61	0.54	0.43	0.00	.57	2.17	1.29
7	Feeling sad or depressed	0.84	0.49	0.41	0.00	0.00	.71	1.98	1.17
8	Transportation to treatment and appointments	0.00	0.00	0.81	0.00	0.00	.70	1.45	.98
9	Pain and/or physical discomfort	0.70	0.50	0.47	0.00	0.00	.56	2.32	1.30
10	Body image and feelings about how you look	0.63	0.67	0.00	0.00	0.00	.56	2.00	1.21
11	Feeling nervous or afraid	0.76	0.43	0.00	0.42	0.00	.68	2.13	1.22
12	Worrying about the future and what lies ahead	0.85	0.58	0.00	0.00	0.00	.76	2.45	1.31
13	Making a treatment decision	0.61	0.56	0.58	0.46	0.00	.55	2.14	1.29
14	Intimacy, sexual function, and/or fertility	0.00	0.00	0.00	0.74	0.00	.60	1.63	1.11
15	Feeling lonely or isolated	0.67	0.00	0.42	0.00	0.00	.47	1.45	.87
16	Health insurance or money worries	0.57	0.48	0.47	0.00	0.00	.38	2.35	1.34
17	Problems in your relationship with your spouse/partner	0.00	0.00	0.55	0.42	0.48	.57	1.30	.79
18	Feeling too tired to do the things you need or want to do	0.77	0.50	0.46	0.00	0.00	.65	2.20	1.23
19	Managing side effects of treatment (nausea, swelling, etc)	0.73	0.61	0.49	0.00	0.00	.64	2.32	1.29
20	Worrying about family, children, and/or friends	0.70	0.43	0.64	0.00	0.00	.62	2.01	1.22
21	Recent weight change (gain or loss)	0.52	0.69	0.00	0.00	0.00	.56	1.80	1.11
22	Exercising and being physically active	0.60	0.78	0.00	0.00	0.00	.66	2.18	1.24
23	Tobacco or substance use—by you or someone in your household	0.00	0.00	0.00	0.00	0.76	.63	1.18	.72
24	Finding reliable information about complementary or alternative practices	0.43	0.56	0.62	0.48	0.00	.55	1.72	1.11
25	Finding meaning and purpose in life	0.59	0.55	0.63	0.00	0.00	.50	1.62	1.12
% of variance		39.60	5.80	4.97	4.32	4.01			
Alpha		0.92	0.75	0.68					

Abbreviation: SD, standard deviation.

*N = 328. Initial factor labels are: F1, Emotional Distress; F2, Physical Health Concerns; F3, Resource Needs; F4, Reproductive Health; F5, Substance Use. The factor pattern coefficients of 0.40 and below were replaced by zeros.

Study 1 Results

The PCA with Promax rotation produced 5 extracted factors with eigenvalues greater than 1. We followed Field (31) recommendations for interpreting a PCA. There are several steps for interpretation. A structure matrix can be reviewed for consideration of an item loading on a particular factor, as it provides correlations between each variable and each factor. A scree plot is a more qualitative way of interpreting factors, as it provides a visual representation of the possible number of factor solutions to retain.

The structure matrix suggested five factors for interpretation. The structure matrix was the primary matrix utilized for interpretation due to its ability to find correlations between factors and variables (32,33). However, the pattern matrix was also consulted to reveal replicability and consistency across factor loadings. The pattern matrix contains the rotated factor loadings for oblique rotation. These are interpreted in the same way as the structure matrix, as correlations between each variable and each factor. A visual inspection of the structure matrix indicated high factor loadings for 5 factors: factor 1 (14 items), factor 2 (5 items), factor 3 (4 items), factor 4 (1 item), and factor 5 (1 item).

The first factor explained 39.60% of the variance, the second factor 5.80% of the variance, the third factor accounted 4.97% of the variance, the fourth factor accounted for 4.32% of the variance, and the fifth factor accounted for 4.01% of the variance. The five extracted factors accounted for 58.69% of the cumulative variance. See Table 2 for item loadings, in boldface, across the five extracted factors.

The utilization of a scree plot with eigenvalues results in a visual representation of the possible number of factor solutions (point of diminished return or elbow). A visual inspection indicated a leveling off of eigenvalues after 5 extracted factors; however, visual interpretation of the graph was difficult since the first extracted factor explained a disproportional amount of the variability. Due to the subjective nature of interpreting the screen plot, and since factors 2 through 5 explained a significant amount of variance and were theoretically coherent, emphasis was placed on the structure matrix to determine appropriate number of extracted factors.

Study 2 Statistical Analyses

Utilizing Mplus (version 7.2), a CFA was conducted on the study 2 data set (N = 339) to confirm and refine the

Table 3. Cancer Support Source Program Items Associated With Each Latent Factor.^a

Scale	Final CFA
Emotional Distress/ Patient and Family Counselor Referral	(2) Feeling irritable, (6) Changes or disruptions in work, school, or home life, (7) Feeling sad or depressed, (10) Body image and feelings about how you look, (11) Feeling nervous or afraid, (12) Worrying about the future and what lies ahead, (15) Feeling lonely or isolated, (17) Problems in your relationship with your spouse/partner, (20) Worrying about family, children, and/or friends, (25) Finding meaning and purpose in life
Physical Health Concerns/ Medical Care Provider Referral	(1) Eating and nutrition, (3) Moving around (walking, climbing stairs, lifting, etc), (4) Communicating with your doctor, (5) Sleep problems, (9) Pain and/or physical discomfort, (13) Making a treatment decision, (18) Feeling too tired to do the things you need or want to do, (19) Managing side effects of treatment (nausea, swelling, etc), (21) Recent weight change (gain or loss), (22) Exercising and being physically active
Resource Needs/Case Management-Clinical Social Worker Referral	(8) Transportation to treatment and appointments, (16) Health insurance or money worries, (24) Finding reliable information about complementary or alternative practices

Abbreviations; CFA, confirmatory factor analysis; PCA, principal component analysis.

^aItems 14 and 23 are not included as these corresponded to the 1-item fourth PCA factor, and 1-item fifth PCA factor, respectively.

exploratory model. An aim of this study was also to facilitate development of subscales for the CSS to improve clinic operations. An initial CFA was conducted, informed by the factors derived from the PCA in study 1. Only items from factors 1 to 3 were included in analyses, as these were the only factors that could be used to develop multi-item subscales (see Table 3). A robust maximum likelihood estimator was utilized to account for non-normal data in generating model results (34).

Fit indices for the initial CFA were evaluated in light of proposed criteria from Hu and Bentler (35). Specifically, recommended cutoff values included 0.06 (or below) for RMSEA, 0.95 (or above) for CFI (raised from the previous “rule of thumb” of 0.90), and 0.08 (or below) for SRMR, which were proposed to be indicative of well-fitting models. Fit indices for the initial CFA included: Root Mean Square Error of Approximation (RMSEA) = 0.06, Comparative Fit Index (CFI) = .894, Standardized Root Mean Square Residual (SRMR) = 0.053, $\chi^2(227) =$

502.264, $P < .01$. Thus, RMSEA and SRMR values were well within the proposed limits, and the CFI value was below the proposed 0.95 cutoff and previous 0.90 “rule of thumb” (35). All items loaded significantly with the proposed factors in the expected directions. Thus, while initial results were promising, fit index results prompted reexamination of the proposed factors.

Study 2 Results

Given that all items loaded on the proposed factors in the initial CFA, model changes at the item level were then made on a conceptual basis, with a particular emphasis on clinical utility. Decisions were made in light of where referrals would be made for the specific concerns (represented by the survey items), with the idea that scores on any derived subscales could inform what type(s) of referrals could best address a patient’s needs. Items focused on emotional concerns were retained with or shifted to factor 1 (Emotional Distress/Patient and Family Counselor Referral), items with a focus on physical concerns were retained with or shifted to factor 2 (Physical Health Concerns/Medical Care Provider Referral), and items with a focus on resource concerns were retained with or shifted to factor 3 (Resource Needs/Case Manager-Clinical Social Worker Referral). Table 3 displays which items were associated with each factor in the revised model. Note that items related to reproductive health and substance use are not included in the final model, as these corresponded to 1-item factors. We advocate for an idiographic review of these items and referral to specialists in those areas, or multidisciplinary teams (Specialist Referral).

Model fit indices for the revised CFA included: RMSEA = 0.056, CFI = 0.907, SRMR = 0.050, $\chi^2(227) = 468.476$, $P < .001$. All items loaded significantly with the proposed factors in the expected directions (see Table 4 for factor loadings). RMSEA and SRMR statistics were well within proposed criteria and improved from the previous model. The CFI value met the conventional cutoff criteria of 0.90, though did not reach the most stringent threshold of 0.95. Standardized correlations between factors were 0.871 between factors 1 and 2, 0.939 between factors 2 and 3, and 0.916 between factors 1 and 3.

Given the robust conceptual support and preliminary statistical support for the model, the model was retained to inform future clinical development of the CSS. Specifically, it is proposed that the 3 factors outlined here may serve as a template for 3 CSS Referral subscales (Emotional Distress/Patient and Family Counselor Referral, Physical Health Concerns/Medical Care Provider Referral, Resource Needs/Case Management-Clinical Social Worker Referral), with indicators of each latent variable serving as the items comprising the corresponding subscale (eg, indicators of the Emotional Distress/Patient and Family Counselor Referral latent variable would be the items on that subscale). Subscale scores are simply computed by summing items

Table 4. Standardized Factor Loadings for Indicators (Cancer Support Source Program Items) of Each Latent Factor.^a

Item	β (SE)
Emotional Distress/Patient and Family Counselor Referral	
Feeling irritable	0.710 (0.034)
Changes or disruptions in work, school, or home life	0.722 (0.031)
Feeling sad or depressed	0.795 (0.027)
Body image and feelings about how you look	0.605 (0.042)
Feeling nervous or afraid	0.758 (0.032)
Worrying about the future and what lies ahead	0.744 (0.024)
Feeling lonely or isolated	0.729 (0.035)
Problems in your relationship with your spouse/partner	0.498 (0.060)
Worrying about family, children, and/or friends	0.660 (0.037)
Finding meaning and purpose in life	0.653 (0.046)
Physical Health Concerns/Medical Care Provider Referral	
Eating and nutrition	0.420 (0.047)
Moving around (walking, climbing stairs, lifting, etc)	0.640 (0.042)
Communicating with your doctor	0.526 (0.050)
Sleep problems	0.586 (0.042)
Pain and/or physical discomfort	0.722 (0.037)
Making a treatment decision	0.658 (0.040)
Feeling too tired to do the things you need or want to do	0.720 (0.037)
Managing side effects of treatment (nausea, swelling, etc)	0.711 (0.034)
Recent weight change (gain or loss)	0.571 (0.049)
Exercise and being physically active	0.700 (0.036)
Resource Needs/Case Management-Clinical Social Worker Referral	
Transportation to treatment and appointments	0.531 (0.056)
Health insurance or money worries	0.663 (0.042)
Finding reliable information about complimentary or alternative practices	0.574 (0.043)

Abbreviation: SE, Standard Error.

^aAll factor loadings significant at the .01 level.

comprising of a scale and dividing by the number of items on that scale. Correlations between all subscales were significant at the 0.01 level: $r = 0.77$ for Emotional Distress/Patient and Family Counselor Referral and Physical Health Concerns/Medical Care Provider Referral, $r = .70$ for Emotional Distress/Patient and Family Counselor Referral and Resource Needs/Case Management-Clinical Social Worker Referral, and $r = .69$ for Physical Health Concerns/Medical Care Provider Referral and Resource Needs/Case Management-Clinical Social Worker Referral.

Discussion

Results from these 2 studies may help inform clinical utility of the CSS by establishing subscales based on referral need. Specifically, the proposed CSS Referral subscales are: Emotional Distress/Patient and Family Counselor Referral,

Physical Health Concerns/Medical Care Provider Referral, and Resource Needs/Case Manager and Clinical Social Worker Referral.

As currently used, the CSS is often scored and utilized by examining individual items in an idiographic approach. This allows clinicians to address specific service needs of individual patients. While useful, this may fail to capture the broader meaning a subscale can portray. Emotional Distress, Physical Health Concerns, and Resource Needs are complex constructs with many facets and implications that should be explored with specialists.

Specifically, the construct of Emotional Distress may include a continuum of symptoms. The National Comprehensive Cancer Network defines distress as "... common normal feelings of vulnerability, sadness, and fears to problems that can become disabling, such as depression, anxiety, panic, social isolation, and existential and spiritual crisis (36) (p. 344)." Distress may have significant negative effects on an individual's QoL and emotional, physical, and functional domains. The psychosocial needs of patients may be met with licensed professionals such as mental health counselors, family therapists, clinical social workers, and clinical psychologists depending on the site staffing and organization. Many oncology sites organize these specialists into Integrated Behavioral Health teams.

It is clear that there are numerous ways in which cancer and related treatment may affect Physical Health Concerns. For example, estimates suggest that over 50% of patients with cancer may experience related pain (37) and report symptoms of insomnia (38–40). Evidence suggests that over 80% of patients undergoing radiation or chemotherapy may experience fatigue (41,42). Patients with cancer also describe decreased physical activity related to treatment, though they report interest in exercise and wanting additional information about how to do so (43,44). These types of services may be met with nurse practitioners, physician assistants, and oncology physicians which are collectively termed medical care providers.

In addition to Emotional Distress and Physical Health Concerns, cancer patients may also face significant barriers with Resources Needs. Barriers such as insurance coverage, other financial concerns such as high copayments for prescriptions, and transportation have been identified as important examples of points of intervention (45). Unmet patient resource needs may result in "financial toxicity"—harmful financial burden experienced by many patients with cancer who receive treatment and which is associated with poorer QoL (46-49). Relevant to the present study, patients report interest in complementary and alternative medicine (vitamins, special diets, yoga, etc) and connecting individuals with these resources may help patient-reported needs (50,51). In an oncology clinical setting, case management services are typically provided by nurse navigators.

These referral subscales should be seen as a first step for the integrated treatment team. Each team member informs

the other about the patient's status and facilitates handoffs between types of services. For example, physical exercise needs to be first cleared by the medical care provider, but a structured walking program may then be implemented by a member of the behavioral health team. In another example, a medical care provider may rule out treatment changes to improve sleep and refer the patient for Cognitive Behavior Therapy for Insomnia.

In conjunction with the use of the Referral subscales, it is recommended the individual Action ratings be retained and used as currently indicated. The Action ratings give the CSS its distinctive ideographic quality. This is especially true with 2 items that were not included in the Referral subscales: tobacco or substance use—by you or someone in your household, and intimacy, sexual function, and/or fertility. These are 2 items which may be best referred to specialists with additional training in Addiction and Reproductive Health.

Conclusion

We currently cannot evaluate a patient's level of need on a particular subscale in comparison to normative values. Furthermore, these normative values may vary among different cancer populations. Cutoffs should be established to indicate when referral for services is indicated. High correlations between the 3 proposed subscales (ranging 0.69-0.77) reflects the interrelated nature of distress, and patients may require multiple referrals. At this point, we do not know if the CSS referral subscales proposed here will influence treatment outcomes. Thus, we do not know the impact on referral patterns or if that changes PROs. This can be accomplished with repeated assessment with the CSS, use of other patient experience measures, and debriefing of random samples of patients from facilities. We are currently examining if the use of these CSS referral subscales impacts on PROs. Further clinical investigation utilizing the proposed subscales will further inform this topic.

Future research may also examine the extent to which clinical variables (eg, age, stage/type of treatment) are associated with increased referral needs assessed by the CSC. The current study was limited to the available clinical variables (such as cancer type, stage of cancer, duration, and type of cancer treatment). The distribution of cancer types was consistent with the National Cancer Institute and the American Cancer Society findings (25,52). For example, breast cancer (37.2% in group 1 and 36.3% in group 2) was the highest and most prevalent cancer location in the data set. It is difficult to fully establish the generalizability of these data because more demographic information is not routinely collected as part of the CSS. We recommend that all future versions of the 25-item CSS include such information. We hope the findings presented here will be utilized in future research refining CSS items and utility of the instrument in practice.

Acknowledgment

The authors would like to thank Christine M. Cassisi, MBA, director of Patient Experience at UF Health Shands in Gainesville, Florida for her comments and feedback on the final draft of the manuscript.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) received no financial support for the research, authorship, and/or publication of this article.

References

1. Bultz BD, Carlson LE. Emotional distress: the sixth vital sign in cancer care. *J Clin Oncol*. 2005;23:6440-41.
2. Carlson LE, Angen M, Cullum J, Goodey E, Koopmans J, Lamont L, et al. High levels of untreated distress and fatigue in cancer patients. *Br J Cancer*. 2004;90:2297-304.
3. Hegel MT, Moore CP, Collins ED, Kearing S, Gillock KL, Riggs RL, et al. Distress, psychiatric syndromes, and impairment of function in women with newly diagnosed breast cancer. *Cancer*. 2006;107:2924-31.
4. National Comprehensive Cancer Network. NCCN Clinical Practice Guidelines in Oncology: Distress Management Version 1.2017. 2017.
5. Phillips MR. Is distress a symptom of mental disorders, a marker of impairment, both or neither? *World Psychiatry*. 2009; 8(2):91-92.
6. Weis J. Cancer-related fatigue: prevalence, assessment and treatment strategies. *Exp Rev Pharmacoecon Outcomes Res*. 2011;11:441-46.
7. Zabora J, Brintzenhofesoc K, Curbow B, Hooker C, Piantadosi S. The prevalence of psychological distress by cancer site. *Psychooncology*. 2001;10:19-28.
8. Pinquart M, Duberstein PR. Depression and cancer mortality: a meta-analysis. *Psychol Med*. 2010;40:1797-810.
9. Richardson JL, Shelton DR, Krailo M, Levine AM. The effect of compliance with treatment on survival among patients with hematologic malignancies. *J Clin Oncol*. 1990;8:356-64.
10. Spiegel D, Giese-Davis J. Depression and cancer: mechanisms and disease progression. *Biol Psychiatry*. 2003;54(3):269-82.
11. Andersen BL, Kiecolt-Glaser JK, Glaser R. A biobehavioral model of cancer stress and disease course. *Am Psychol*. 1994; 49(5):389-404.
12. Costanzo ES, Ryff CD, Singer BH. Psychosocial adjustment among cancer survivors: findings from a national survey of health and well-being. *Health Psychol*. 2009;28(2):147-56.
13. Pirl WF, Muriel A, Hwang V, Kornblith A, Greer J, Donelan K, et al. Screening for psychosocial distress: a national survey of oncologists. *J Support Oncol*. 2007;5:499-504.
14. Institute of Medicine Committee on Psychosocial Services to Cancer Patients/Families in a Community Setting. The National Academies Collection: Reports funded by National Institutes of Health. In: Adler NE, Page AEK, eds. *Cancer Care*

- for the Whole Patient: Meeting Psychosocial Health Needs. Washington, DC: National Academies Press (US) National Academy of Sciences; 2008.
15. Institute of Medicine. Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs. In: Adler NE, Page AEK, eds. Washington, DC: The National Academies Press; 2008:454.
 16. Cancer Support Community. 2017 [updated 2018; cited 2018 Jan 1]. Retrieved from: <http://www.cancersupportcommunity.org>.
 17. Buzaglo JS, Miller MF, Golant M, Longacre ML, Kennedy V. Discriminatory Power of a 15-Item Distress Screening Tool Among Those at Risk for Depression: Implications for Triage Post Distress Screening. Hollywood: National Comprehensive Cancer Network; 2016.
 18. Buzaglo JS, Miller MF, Gayer C, Morris A, Golant M. Cancer Support Source™: Validating a Web-based Distress Screening Tool in the Community. Hollywood: National Comprehensive Cancer Network; 2013.
 19. Miller MF, Buzaglo JS, Clark KL, Loscalzo MJ, Kennedy V, Taylor J, et al. Demonstrating the psychometric properties of a problem-related distress screener in a community sample of 319 cancer survivors. *Psychooncology*. 2013;22:1249-1257.
 20. Carlson LE. Screening alone is not enough: the importance of appropriate triage, referral, and evidence-based treatment of distress and common problems. *J Clin Oncol*. 2013;31:3616-17.
 21. Carlson LE, Groff SL, Maciejewski O, Bultz BD. Screening for distress in lung and breast cancer outpatients: a randomized controlled trial. *J Clin Oncol*. 2010;28:4884-91.
 22. Carlson LE, Waller A, Mitchell AJ. Screening for distress and unmet needs in patients with cancer: review and recommendations. *J Clin Oncol*. 2012;30:1160-77.
 23. Buzaglo JS, Miller MF, Kennedy V, Longacre M, Golant M, Robinson PA. Cancer-related distress and unmet needs among newly diagnosed and longer-term cancer survivors from a community-based distress screening program. Paper presented at: ASCO Cancer Survivorship Symposium: Advancing Care and Research: San Francisco; 2016.
 24. Vodermaier A, Linden W, Siu C. Screening for emotional distress in cancer patients: a systematic review of assessment instruments. *J Natl Cancer Inst*. 2009;101:1464-88.
 25. Noone AM, Howlader N, Krapcho M, Miller D, Brest A, Yu M, et al. SEER Cancer Statistics Review, 1975-2015. Bethesda: National Cancer Institute; 2018.
 26. Florida Department of Health. Florida Annual Cancer Report: 2015 Incidence and Mortality. Tallahassee: Florida Department of Health.
 27. Roth PL, Switzer FS III, Switzer DM. Missing data in multiple item scales: a Monte Carlo analysis of missing data techniques. *Organ Res Methods*. 1999;2:211-32.
 28. Tabachnick BG, Fidell LS. Using Multivariate Statistics. 5th ed. Boston: Allyn & Bacon; 2006.
 29. Costello AB, Osborne JW. Best practices in exploratory factor analysis: four recommendations for getting the most from your analysis. *Practical Assessment, Research & Evaluation*. 2005; 10:1-9.
 30. Abdi H, Williams LJ. Principal component analysis. *Wiley Interdiscip Rev Comput Stat*. 2010;2:433-59.
 31. Field A. Discovering Statistics Using IBM SPSS Statistics. Thousand Oaks: Sage; 2013.
 32. Beavers AS, Lounsbury JW, Richards JK, Huck SW, Skolits GJ, Esquivel SL. Practical considerations for using exploratory factor analysis in educational research. *PARE*. 2013;18(6):13.
 33. Rietveld T, van Hout R. Statistical Techniques for the Study of Language and Language Behaviour. Berlin: De Gruyter; 1993.
 34. Muthén LK, Muthén BO. Mplus user's guide. Seventh Edition. Los Angeles, CA: Muthén and Muthén. 1998-2012.
 35. Lt Hu, Bentler PM. Cutoff criteria for fit indexes in covariance structure analysis: conventional criteria versus new alternatives. *Struct Equ Modeling*. 1999;6:1-55.
 36. Network NCC. Distress management. Clinical practice guidelines. *JNCCN*. 2003;1:344.
 37. van den Beuken-van Everdingen MH, de Rijke JM, Kessels AG, Schouten HC, van Kleef M, Patijn J. Prevalence of pain in patients with cancer: a systematic review of the past 40 years. *Ann Oncol*. 2007;18:1437-49.
 38. Palesh OG, Roscoe JA, Mustian KM, Roth T, Savard J, Ancoli-Israel S, et al. Prevalence, demographics, and psychological associations of sleep disruption in patients with cancer: University of Rochester Cancer Center-Community Clinical Oncology Program. *J Clin Oncol*. 2010;28:292-98.
 39. Savard J, Villa J, Ivers H, Simard S, Morin CM. Prevalence, natural course, and risk factors of insomnia comorbid with cancer over a 2-month period. *J Clin Oncol*. 2009;27:5233-39.
 40. Savard J, Savard MH. Insomnia and cancer: prevalence, nature, and nonpharmacologic treatment. *Sleep Med Clin*. 2013;8: 373-87.
 41. Hofman M, Ryan JL, Figueroa-Moseley CD, Jean-Pierre P, Morrow GR. Cancer-related fatigue: the scale of the problem. *Oncologist*. 2007;12:4-10.
 42. Lawrence DP, Kupelnick B, Miller K, Devine D, Lau J. Evidence report on the occurrence, assessment, and treatment of fatigue in cancer patients. *J Natl Cancer Inst Monogr*. 2004;32: 40-50.
 43. Blaney JM, Lowe-Strong A, Rankin-Watt J, Campbell A, Gracey JH. Cancer survivors' exercise barriers, facilitators and preferences in the context of fatigue, quality of life and physical activity participation: a questionnaire-survey. *Psychooncology*. 2013;22:186-94.
 44. Murnane A, Geary B, Milne D. The exercise programming preferences and activity levels of cancer patients undergoing radiotherapy treatment. *Support Care Cancer*. 2012;20:957-62.
 45. Schwaderer KA, Itano JK. Bridging the healthcare divide with patient navigation: development of a research program to address disparities. *Clin J Oncol Nurs*. 2007;11(5):633-39.
 46. Zafar SY, Abernethy AP. Financial toxicity, part I: a new name for a growing problem. *Oncology*. 2013;27:80-149.
 47. Yousuf Zafar S. Financial toxicity of cancer care: it's time to intervene. *J Nat Cancer Inst*. 2016;108:djv370-djv.
 48. Fenn KM, Evans SB, McCorkle R, DiGiovanna MP, Pusztai L, Sanft T, et al. Impact of financial burden of cancer on survivors' quality of life. *J Oncol Pract*. 2014;10:332-38.

49. Zafar SY, McNeil RB, Thomas CM, Lathan CS, Ayanian JZ, Provenzale D. Population-based assessment of cancer survivors' financial burden and quality of life: a prospective cohort study. *J Oncol Pract.* 2014;11:145-50.
50. Liu R, Chang A, Reddy S, Hecht FM, Chao MT. Improving patient-centered care: a cross-sectional survey of prior use and interest in complementary and integrative health approaches among hospitalized oncology patients. *J Altern Complement Med.* 2016;22:160-65.
51. Scarton LA, Del Fiol G, Oakley-Girvan I, Gibson B, Logan R, Workman TE. Understanding cancer survivors' information needs and information-seeking behaviors for complementary and alternative medicine from short- to long-term survival: a mixed-methods study. *J Med Libr Assoc.* 2018;106:87-97.
52. Siegel RL, Miller KD, Jemal A. Cancer statistics, 2018. *CA Cancer J Clin.* 2018;68:7-30.

Author Biographies

Emily J Ross, MA, is a PhD student at the University of Central Florida. Her research interests include psycho-oncology, health behaviors in individuals with chronic diseases, facilitating

integration of psychology in medical settings, and cognitive and emotional processes involved in well-being and adjustment to stress.

Chelsea H Wiener, MS, received her master's degree in clinical psychology from the University of Central Florida (UCF). She is currently a Ph.D. student at UCF, with clinical and research focuses in health psychology, behavioral medicine, and integrated care.

Diane Robinson, PhD, a health psychologist with a focus in psycho-oncology, is Program Director of the Integrative Medicine Department at Orlando Health UF Health Cancer Center. Her research includes exploring the variables associated with healthy aging, improvement of health system processes, and factors lessening the impact of stress during treatment and recovery from major medical illnesses.

Jeffrey E Cassisi, PhD, is a licensed clinical psychologist, Professor, and director of the Health Psychology Laboratory in the UCF Department of Psychology. His current and future research priorities are to examine the influence of cultural factors in the practice of medicine and health psychology, and to combine his psychophysiological and multicultural interests into studies of pre-chronic and chronic diseases.