Psychometric Properties of a 25-item Distress Screening Tool in a Community Sample of 251 Cancer Survivors

Melissa F. Miller[1], Joanne Buzaglo[1], Julie Taylor[1], Victoria Kennedy[1], Stephanie Singleton[2], Christopher Gayer[1], Mitch Golant[1]

[1]Cancer Support Community, Research and Training Institute, Philadelphia, PA

[2]Dynamic Clinical Systems, Hanover, NH

Introduction

• The Institute of Medicine (IOM), the National Comprehensive Cancer Network, and the American College of Surgeons recognized that screening, referral, and follow-up for emotional, physical and social concerns is critical to ensuring quality cancer care

• Distress screening in community settings, where up to 85 % of cancer patients are treated, is largely non-existent

• Cancer Support Community (CSC) represents a global network of non-profit, community-based organizations that provide professionally led support and education to cancer patients and their families

• Since 2008, CSC has been investigating the feasibility and effectiveness of distress screening, referral, and follow-up in the community

• In 2011, CSC began developing a sustainable model of integrated care with CancerSupportSource™(CSS), a 25-item, web-based psychosocial distress screening, referral, and follow-up program

Key Features of Cancer Support Source™ (CSS):

• CSS targets the 7 key areas of psychosocial needs identified in the IOM Report (2008):
  1) Getting cancer-related information
  2) Coping with emotions
  3) Managing illness and treatment
  4) Changing lifestyle behaviors
  5) Managing life disruptions
  6) Material/logistical concerns
  7) Financial concerns

• CSS asks survivors to rate their concerns today **and** to identify the type of support: (talk with a staff person, online resources, written information) they want to receive for addressing their concerns

• Reports are instantly generated including fact sheets and email alerts that can be customized for any institution

• CSS is HIPAA compliant and can be linked to the EHR using HL7 and web services interface

• CSS screening can be completed by the patient from home or on-site, using any type of browser

Sample Characteristics *(N=251)*

Convenience sample of 251 members from 10 CSC affiliate sites nationwide:

- Phoenix
- Central New Jersey
- East Tennessee
- Pasadena
- Greater Lehigh Valley
- Miami
- Philadelphia
- Quad Cities (IA)
- San Francisco Bay area
- Cincinnati/ N. Kentucky

Characteristic	Proportion
Race	
Caucasian	87%
African-American	3%
Sex	
Female	90%
Education	
Bachelors and above	76%
Time since diagnosis	
≥ 2 years	68%
Total annual income	
Less than 40k	15%
	Average
Age(30–83 years)	56
Time since diagnosis	3.5 years

Study Objective

Test the psychometric properties of CancerSupportSource ™ (CSS)
- Reliability, Validity, Sensitivity, and Specificity

Results

Figure 1. Top Five Concerns
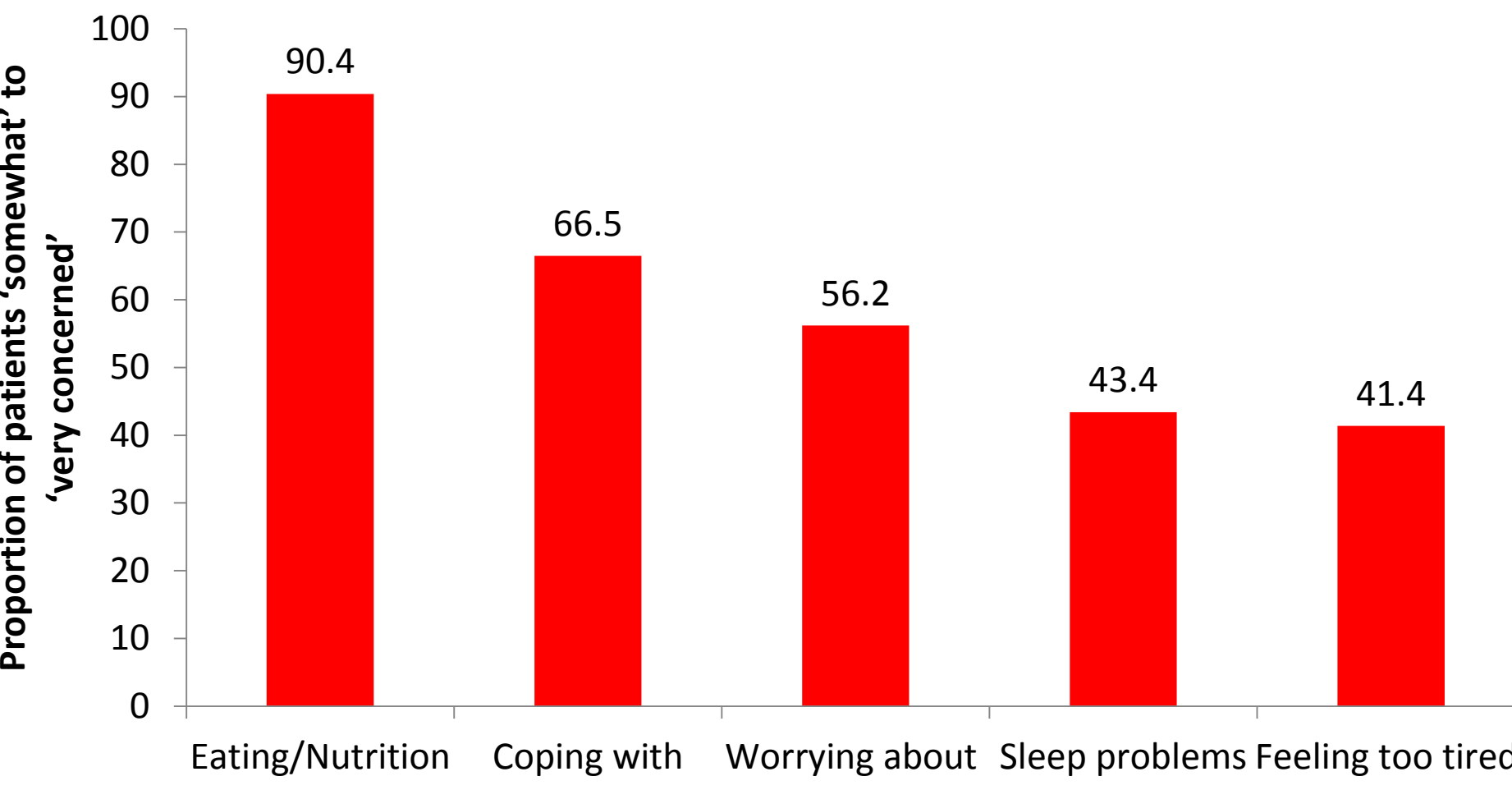
Figure 2. Top Five Requests for Assistance
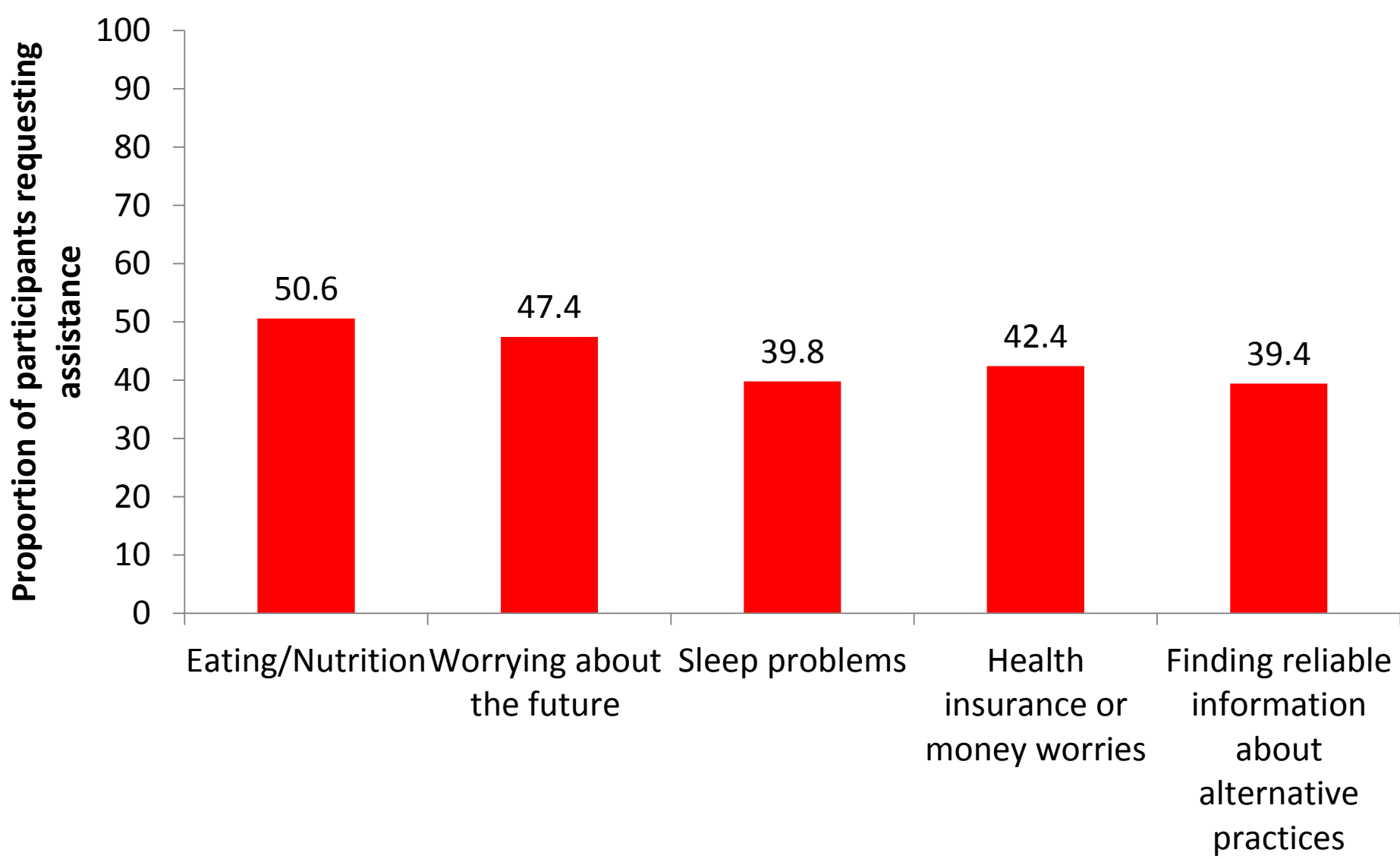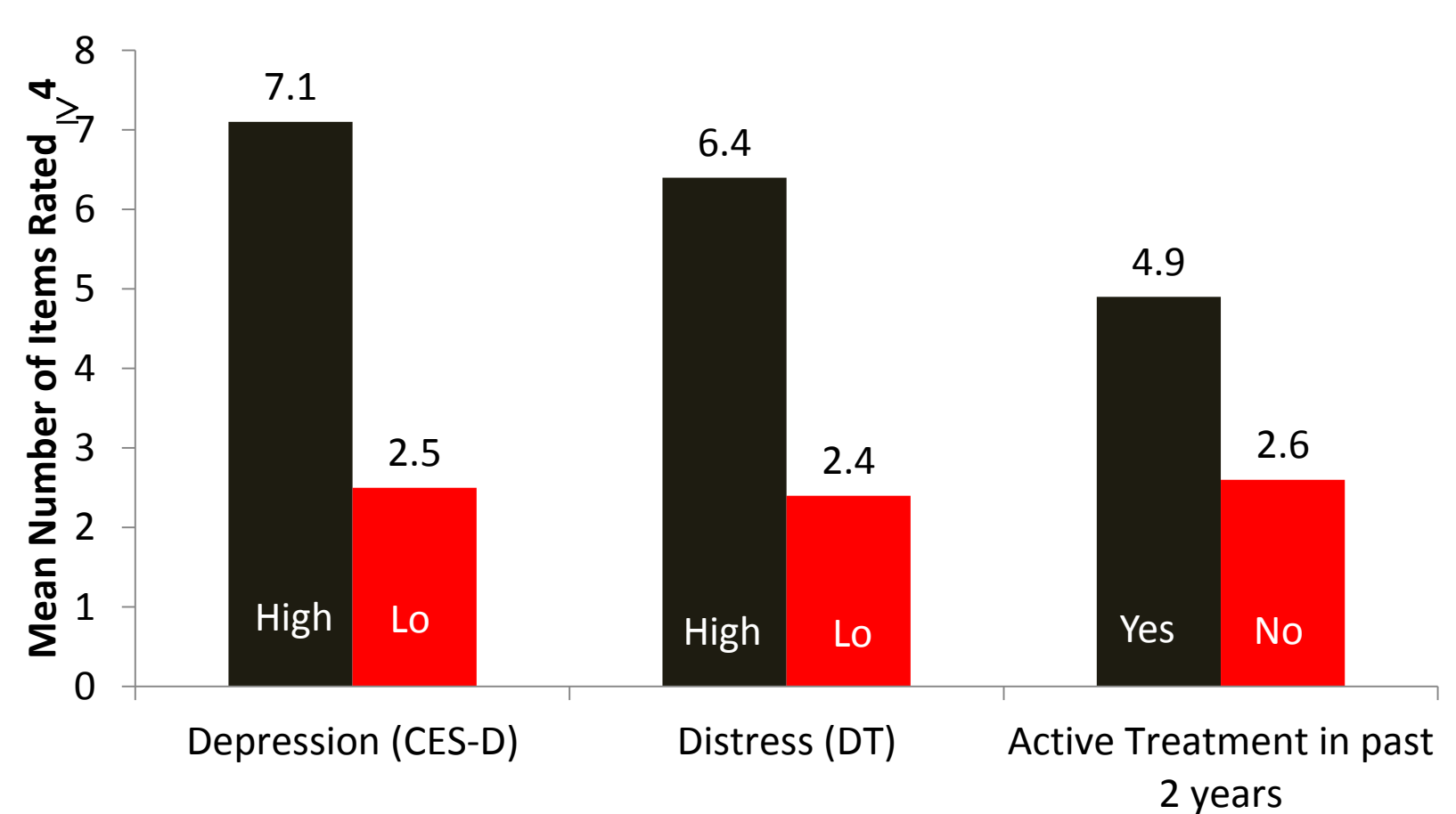
Figure 3. Mean Number of Items Rated 'Seriously' or 'Very Seriously Concerned' by Clinical Group*

Known-Group Validity Comparisons

*Notes:
1. Clinical Groups included those meeting vs. those not meeting the clinical cutoff for depression on the CES-D and the Distress Thermometer; and those in active treatment vs. those not in active treatment in past 2 years)
2. Clinical cutoffs for depression: CES-D ≥ 16; DT ≥ 4

Table 1. Sensitivity and Specificity for the Depression Subscale Using the CES-D ≥ 16 as the Criterion

Items	Number of items	Rating threshold	Number rated at threshold	Sensitivity	Specificity	AUC
lonely sad future nervous homelife fatigue	6	3	1	97	36	0.82
lonely sad future nervous homelife fatigue	6	3	2	84	59	0.82
lonely sad future nervous homelife fatigue	6	4	1	70	75	0.77
lonely sad future nervous fatigue	5	3	1	95	39	0.81
lonely sad future nervous fatigue	5	3	2	81	65	0.81
lonely sad future nervous fatigue	5	4	1	66	81	0.77
lonely sad nervous fatigue**	4	3	1	92	54	0.82
lonely sad nervous fatigue	4	3	2	69	78	0.82
lonely sad nervous fatigue	4	4	1	63	91	0.78
lonely sad nervous	3	3	1	81	67	0.79
lonely sad nervous	3	3	2	59	86	0.79
lonely sad nervous	3	4	1	53	93	0.74

Note: Exact wording of items was as follows: 1. feeling sad or depressed; 2.feeling lonely or isolated; 3. feeling nervous or afraid; 4. feeling too tired to do the things you need or want to do; 5. worrying about the future and what lies ahead and; 6. changes or disruptions in work, school or home life
** Across the CSC network, this metric is recommended for follow-up assessment of depression

Table 2. Correlations (R[2]) between CancerSupportSource and the FACT-G, CES-D and Distress Thermometer in Cancer Survivors (N=251)

	FACT-G	CES-D	Distress Thermometer
Summary scores			
Summary of problem ratings	0.49	0.48	0.38
Count of items rated somewhat to very seriously concerned	0.46	0.48	0.38
Count of items rated seriously or very seriously concerned	0.38	0.36	0.31

Additional Results

• The CSS demonstrated high internal consistency (Cronbach's alpha=0.92).

• Percent agreement between test and retest responses was acceptable (>66%) for 18 of the 25 items. The ICC was acceptable (≥0.75) for 16 of the 25 items.

• The total distress score created using summed item scores correlated substantially with the FACT-G (R-squared=0.49, p<0.001), CES-D (R-squared=0.46, p<0.001) and Distress Thermometer (R-squared=0.37, p<0.001) indicating strong concurrent validity and the ability to discriminate groups of clinical relevance.

Methods

• Internal reliability was estimated using Cronbach's alpha coefficient

• Test-retest reliability was assessed using the intra-class correlation coefficient (ICC)

• Concurrent validity was determined by correlations with the Functional Assessment of Cancer Therapy–General Well-Being Scale (FACT-G), the Center for Epidemiologic Studies Depression Scale (CES-D), and the Distress Thermometer (DT)

• A non-parametric analysis of variance was used to establish discriminant validity

Conclusion and Implications

• To our knowledge, CSS is the first web-based distress screening tool validated for use in the community setting

• The CSS shows moderate to strong psychometric properties

• This study takes an important step toward achieving psychosocial screening, referral and follow-up for all cancer survivors

• The present study addresses the screening chasm between the hospital and the community and is the first step in demonstrating the feasibility of screening in the community

Future Directions

• Evaluate the implementation of CSS in community-based organizations and clinical oncology settings

• Integrate CSS into electronic medical records and demonstrate the effectiveness of screening referral and follow-up on patient-reported and quality outcomes (adherence, emergency room visits, missed appointments)

• Test effectiveness and feasibility of CSS on more diverse sample of survivors