

Discriminatory power of a 25-item distress screening tool CancerSupportSource™: A cross-sectional survey of 251 cancer survivors

Melissa F. Miller, Ph.D., MPH¹, C. Daniel Mullins, Ph.D.², Ebere Onukwugha, Ph.D.²,
Christopher Gayer, Ph.D.¹, Mitch Golant, Ph.D.¹, Joanne S. Buzaglo, Ph.D.¹

¹Cancer Support Community, Research and Training Institute, Philadelphia, PA, ²University of Maryland School of Pharmacy, Baltimore, MD

Background

- The IOM, the NCCN, and the American College of Surgeons Commission on Cancer have all recognized that screening for psychosocial concerns is critical to ensuring quality cancer care for the whole patient.
- However, distress screening that links patients to programs and services between cancer centers and the community are largely nonexistent.
- Distress screening tools must be effective in identifying those at risk for greater distress and in need of additional follow up services.
- 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.
- In 2011, CSC began developing an integrated model of community-based distress screening, referral, and follow-up via CancerSupportSource™.
- CancerSupportSource™ (version 2.0) is a 25-item Web-based tool designed to screen patients for distress in the community and connect them to appropriate resources.

Objective

The objective of this study was to test the discriminatory power of a 25-item distress screening tool **CancerSupportSource™** for use among cancer survivors.

Methods

- A total of 251 of 445 individuals contacted through the CSC affiliate network completed a web-based distress screening survey (response rate=56%).
- Participants were asked to rate each of 25 items according to the question "Today, how concerned are you about...?" using a five-point scale (0 not at all to 4 very seriously concerned) and to indicate what type of assistance they wanted for each item (online, written, or talk with a staff member).
- A distress summary score was calculated as the count of items rated ≥ 2 .
- The **item discrimination index (IDI)** was calculated as the difference between proportions of high and low scorers rating an item ≥ 2 .
- Cut-points at 13 and 4 yielded equal-sized groups and were used to classify participants as high (n=59) and low scorers (n=60).

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 | Categories | Proportion |
|----------------------|---------------------|----------------|
| Race | Caucasian | 87% |
| | Other | 10% |
| | African-American | 3% |
| Sex | Female | 90% |
| | Male | 10% |
| Education | Less than Bachelors | 24% |
| | Bachelors and above | 76% |
| Time since diagnosis | Less than 2 years | 32% |
| | ≥ 2 years | 68% |
| Total annual income | Less than 40k | 15% |
| | Above 40k | 85% |
| | | Average |
| Age (years) | Min=30; Max=83 | 56 |
| Time since diagnosis | | 3.5 years |

Results

Figure 1. Top Five Concerns

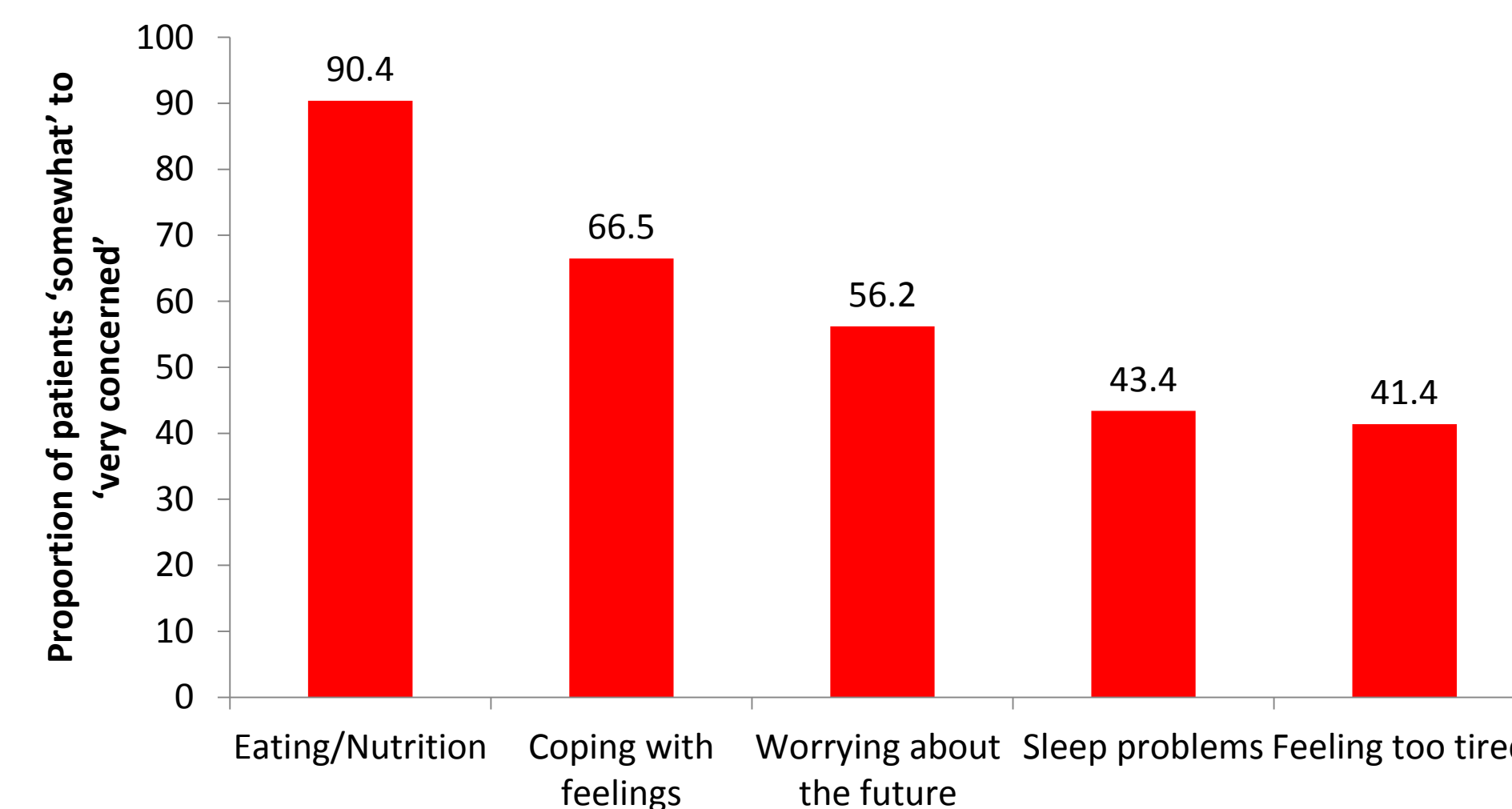


Figure 2. Top Five Requests for Assistance

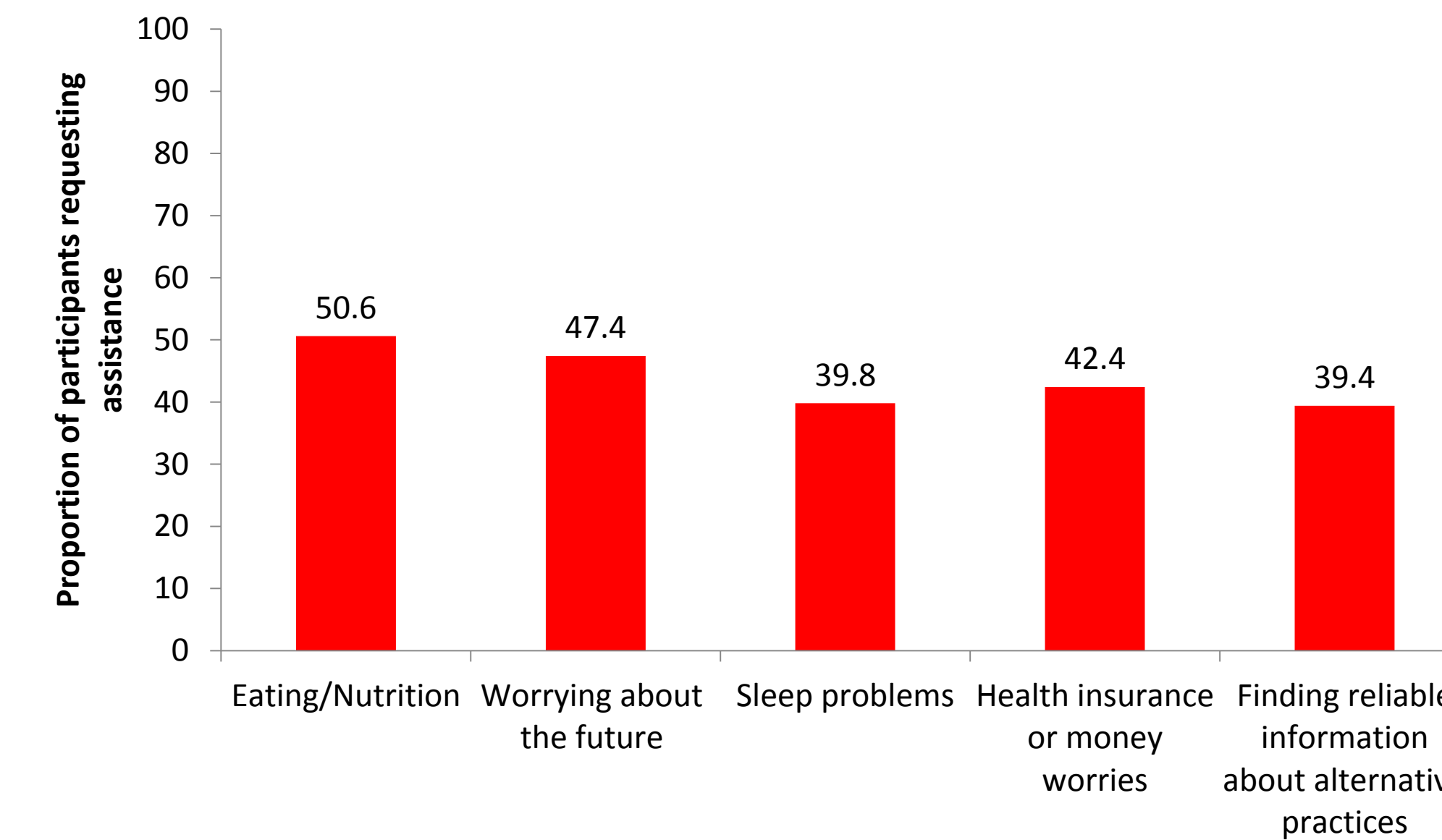


Table 1. Distribution of the distress summary score

| Count of items rated ≥ 2 | Frequency (n) | Percent (%) |
|-------------------------------|---------------|-------------|
| 0-3 | 60 | 23.9 |
| 4-6 | 51 | 20.3 |
| 7-9 | 47 | 18.7 |
| 10-12 | 34 | 13.6 |
| ≥ 13 | 59 | 23.5 |

Note: Distress summary score calculated by adding the number of items rated somewhat, seriously, or very seriously concerned.

Table 2. Item Discrimination Index for the 25 Items of CancerSupportSource™ and proportion of participants who rated they were somewhat to very seriously concerned about each item

| Problem-Related Distress Item | Item discrimination index | Somewhat to very seriously concerned |
|---|---------------------------|--------------------------------------|
| | | % |
| Changes or disruptions in work, school or home life | 0.86 | 39.4 |
| Feeling sad or depressed | 0.85 | 37.5 |
| Feeling too tired to do the things you need or want to do | 0.85 | 41.4 |
| Worrying about the future and what lies ahead | 0.85 | 56.2 |
| Feeling nervous or afraid | 0.81 | 32.3 |
| Ability to exercise or be physically active | 0.76 | 37.1 |
| Pain and/or physical discomfort | 0.75 | 31.5 |
| Worrying about family, children and/or friends | 0.71 | 33.1 |
| Body image and feelings about how you look | 0.71 | 40.6 |
| Sleep problems | 0.70 | 43.4 |
| Preparing for an upcoming treatment decision | 0.67 | 22.3 |
| Coping with your feelings | 0.67 | 66.5 |
| Coping with side effects of treatment (nausea, swelling, etc) | 0.64 | 24.3 |
| Health insurance or money worries | 0.62 | 33.1 |
| Knowing how to communicate best with your doctor | 0.61 | 35.5 |
| Feeling lonely or isolated | 0.61 | 21.1 |
| Moving around (walking, climbing stairs, lifting, etc.) | 0.61 | 25.9 |
| Finding reliable information about complementary or alternative practices | 0.55 | 33.1 |
| Recent weight change (gain or loss) | 0.49 | 31.5 |
| Problems in your relationship with your spouse/partner | 0.47 | 21.1 |
| Intimacy, sexual function and/or fertility | 0.47 | 34.7 |
| Transportation to treatment and appointments | 0.24 | 6.8 |
| Tobacco or substance use-by you or someone in your household | 0.22 | 7.2 |
| Eating and nutrition | 0.20 | 90.4 |
| Considering taking your own life | 0.07 | 1.6 |

Summary of Results

- Items with the greatest discriminatory power (IDI ≥ 0.8) were: changes or disruptions in work, school or home life; worrying about the future and what lies ahead; feeling too tired to do the things you need or want to do; feeling sad or depressed; ability to exercise or be physically active; and feeling nervous or afraid.
- Conversely, items with the lowest IDI included: eating and nutrition; tobacco or substance use; transportation to treatment and appointments; and considering taking your own life.

Conclusions

- These results highlight those items that identify individuals at greatest risk for psychosocial distress.
- Results suggest priority areas for support services and targeted screening items to identify those most at risk for distress.
- Future research should examine differences in the discriminatory power of items by cancer diagnosis and other demographic and clinical characteristics.

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