

# Developing a community-based screening instrument that measures problem-related distress

Melissa F. Miller<sup>1</sup> PhD, Joanne S. Buzaglo<sup>1</sup> PhD, Karen Clark<sup>2</sup> MS, Matthew Loscalzo<sup>2</sup> MSW,  
Kasey Dougherty<sup>1</sup> MA, Julie Taylor<sup>1</sup>, Victoria Kennedy<sup>1</sup> MSW, Mitch Golant<sup>1</sup> PhD

Affiliations: <sup>1</sup>Cancer Support Community (CSC), Research and Training Institute, Philadelphia, PA; <sup>2</sup> Sheri & Les Biller Patient and Family Resource Center, Department of Supportive Care Medicine, City of Hope, Duarte, CA

## Introduction

- The Institute of Medicine (2007) recommends psychosocial screening for all cancer patients to improve integration of care. In the U.S., up to 85% of patients are treated in the community rather than comprehensive cancer centers.
- However, distress screening for patients in the community is largely non-existent. To bridge this gap, the Cancer Support Community is testing the feasibility and effectiveness of community-based, comprehensive screening for cancer patients.

### Forming a Partnership



- The Cancer Support Community provides the highest quality emotional and social support through a network of nearly 50 local affiliates, more than 100 satellite locations as well as online.
- Based on 18 years of screening experience in hospital settings, City of Hope (COH), a NCI-designated Comprehensive Cancer Center, developed an automated touch-screen screening service for patients called *SupportScreen™*.
- Investigators from Cancer Support Community and COH collaborated in order to create a validated screening tool that will ensure that all cancer patients have access to community-based psychosocial care.



### Community Initiated Research Collaboration Model (CIRC)

- CIRC connects researchers with community members to enhance knowledge and integrate sustainable evidence-based programming into the community
  - Power is equal
  - Questions guided by needs of community
  - Mutual respect towards achieving research goals

## Objectives

- Using the CIRC model, the Demonstration Project includes 3 phases :
  - Phase (1) to refine the existing *SupportScreen™* 53-item problem-related distress screening tool for the community context by reducing the number of questions and revising items as appropriate.
  - Phase (2) to test the validity and reliability of the psychometric properties of the shortened 36-item tool (results presented here).
  - Phase (3) to test the feasibility of the 36-item problem-related distress screening measure and its use to link patients to available resources across five unique sites.

## Phase (2): Test Validity and Reliability

- 319 participants from 14 Cancer Support Community sites nationwide completed pen-and-paper version of the 36-item screening tool
- A subsample of 101 participants completed the 36-item screening tool a second time following the completion of the survey
- Eligibility Criteria:
  - English-speaking, 18 years+ of age
  - Cancer outpatients in treatment or follow-up
- Measures:
  - 36-item problem-related distress screening tool
  - Center for Epidemiologic Studies Depression Scale (CES-D)
  - Distress Thermometer (DT)
  - Functional Assessment of Cancer Therapy – General well-being scale (FACT-G; version 4)
  - Demographic and biomedical questions

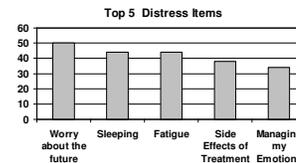
### Sample Characteristics (N=319)

<b>Mean Age: 59</b>	<b>Income:</b>	<b>Cancer Type:</b>
<b>84% Female</b>	<b>25% &lt; 40K</b>	<b>45% Breast</b>
	<b>35% 40-100K</b>	<b>9% Gynecologic</b>
<b>Ethnicity:</b>	<b>22% &gt; 100K</b>	<b>12% Blood</b>
<b>83% Caucasian</b>		<b>5% Colorectal</b>
<b>3% Afr-Am/Black</b>	<b>Education:</b>	<b>5% Lung</b>
<b>8% Hispanic/Latino</b>	<b>&lt;1% High School</b>	<b>3% Prostate</b>
<b>2% Asian/Pac Island</b>	<b>9% HS Grad/GED</b>	<b>70% Active treatment within past 2yrs</b>
	<b>24% Some College</b>	
	<b>39% College Degree</b>	
	<b>28% Advanced Degree</b>	

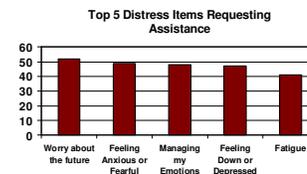
## Phase (2) Results

### Problems and Rankings

- Based on % of participants who marked  $\geq 3$  for a problem out of a 5-point scale (1=Not at All; 5=Very Severe), the top 5 distress-related problems were:



- The 5 most common problems for which participants requested assistance were:



### Validity

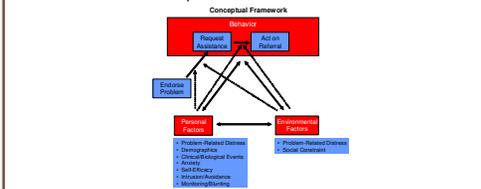
- A summary score of the 36 items correlated substantially with the FACT-G ( $R^2=0.58$ ,  $p<0.001$ ), the CES-D ( $R^2=0.48$ ,  $p<0.001$ ) and the DT ( $R^2=0.35$ ,  $p<0.001$ ).
- More than one-third (38%) of participants were depressed as indicated by a score  $\geq 16$  on the CES-D. The mean ( $\pm$  SD) number of screening items rated  $\geq 4$  was significantly ( $p<0.0001$ ) higher among those who were depressed ( $3.4 \pm 4.0$ ) than among those who were not depressed ( $0.8 \pm 1.7$ ).
- Similarly, 40% of participants indicated they were distressed by a score  $\geq 5$  on the DT

### Test-Retest Reliability

- Percent agreement between test and retest responses was high for all 36 items ranging in value between 71% and 99%.
- The intraclass correlation coefficient (ICC) was  $\geq 0.75$  for all 36 screening items except "ability to have children" in which the ICC was affected by a low prevalence of one or more responses.

## Next Steps: Phase (3) Test Feasibility

- Demonstrate that 5 unique community based sites can:
  - Screen 85% of new patients for distress
  - Make appropriate referrals
  - Provide follow-up care



## Next Steps: Phase (3) Methodology

- All new first or second-visit outpatients, (depending on study site) screened using 36-item community-validated screening tool on the *SupportScreen™* technology
- Patients (whether in the study or not) rescreened at 30-40 days from initial visit
- Study participants complete additional set of evaluation questions at baseline and at rescreen visit
- Program staff complete brief electronic survey after the initial screening and rescreening, and participate in monthly site-wide evaluation calls to discuss successes and challenges

## Future Directions

- Invest in 'cloud' based technology for screening
- Create flexible method to deliver in multiple settings:
  - Cancer Support Community affiliates
  - Community cancer centers
  - Oncology practices and hospitals
- Collaborate with organizations that are mandating psychosocial screening

## Acknowledgement of Funding



## **Developing a community-based screening instrument that measures problem-related distress**

Melissa Miller<sup>1</sup>, PhD, Joanne S. Buzaglo<sup>1</sup>, PhD, , Karen Clark<sup>2</sup>, MS, Matthew Loscalzo<sup>2</sup>, MSW, Kasey Dougherty<sup>1</sup>, MA, Julie Taylor<sup>1</sup>, Vicki Kennedy, MSW<sup>1</sup>, Mitch Golant<sup>1</sup>, PhD

**Background:** The IOM and NCCN recognized the importance of psychosocial domains as essential to quality cancer care. Screening has been recommended as an efficient way to identify symptoms and problems, communicate patient concerns to busy physicians during the clinical encounter, and standardize timely triage to available resources. Yet, screening rarely occurs in community cancer centers where 85% of cancer care occurs. The Cancer Support Community and City of Hope (COH) collaborated to test the feasibility of implementing screening in the community.

**Objective:** To test the validity and reliability of a screening instrument that measures problem-related distress in cancer patients that will be used in a community-based screening program.

**Methods:** 350 participants completed a pen-and-paper version of the COH 53-item problem-related distress screening tool at 10 US sites. Each item asked 1) "How much of a problem is this for you?" with a 5-item response scale (i.e., Not a Problem to Very Severe) and 2) "How can we best work with you on this problem?" Using statistical and theoretical criteria, 19 items were dropped, 6 items revised and 2 items added. The 36-item community version of the screening instrument was administered to 319 participants at 14 sites with the Functional Assessment of Cancer Therapy - General (FACT-G), the Center for Epidemiologic Studies Depression Scale (CES-D), and the Distress Thermometer. Among a subsample (n=101), the 36-item screening instrument was administered twice to measure test-retest reliability.

**Results:** A summary score of the 36 screening items correlated moderately with the FACT-G (R=-0.77, p<0.001), the CES-D (R=0.73, p<0.001) and the Distress Thermometer (R=0.60, p<0.001). The intraclass correlation coefficient was  $\geq 0.75$  for 35 of the 36 screening items.

**Conclusions:** These findings suggest the 36-item community screening tool is valid and reliable. Future research is needed to test if this instrument can enhance physician-patient interaction by rapidly identifying patients who are at risk for poorer outcomes without psychosocial intervention. Outcomes should evaluate the uptake of referrals, quality of care, cost, and feasibility of repeat screening and follow-up.