Creating An Integrative Biopsychosocial Screening Model For People With Cancer:
A Community Initiated Research Collaboration Demonstration Project

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Cancer Support Community

Introduction

- The medical community has recently recognized that distress screening is a critical factor in quality cancer care. The Institute of Medicine (2007) recommends psychosocial screening for all cancer patients to improve integration of care. In the United States, 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 and online.
- After 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 CSC 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 through the utilization of screening through a community-based Demonstration Project.

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/Purpose

- Using the CIRC model, the first phase of the Demonstration Project is (1) to adapt the existing 53-item *SupportScreen™* tool for the community context by reducing the number of questions and revising items as appropriate, and (2) to validate the distress items against gold standards.

Methods

- 350 participants completed pen-and-paper version of the 53-item *SupportScreen™*
- 10 sites nationwide:5 Wellness Communities, 3 Gilda's Clubs, CSC Colorado, and Exempla St. Joseph Hospital
- Participants had to be:
  - English-speaking, 18 years+ of age
  - Cancer outpatients in treatment or follow-up
- Survey included:
  - 53-item *SupportScreen™*
  - Center for Epidemiologic Studies Depression Scale (CES-D)
  - Patient Health Questionnaire-2 (PHQ-2)
  - Demographic and biomedical questions

Theoretical Framework Guiding Validation

- We used the following criteria to determine the validity of each of the 53 items included in *SupportScreen* ™

Statistical Criteria

- Does the item demonstrate:
  - Low endorsement for level of distress and/or request for assistance?
  - High correlation with other items (using Pearson correlation and factor loadings)?
  - Little contribution to unique variance in overall distress (using factor loadings)?

Theoretical Criteria

- Is the item:
  - Relevant to the patient at this time?
  - A problem or symptom that can be influenced?
  - Useful to maximize the benefit of the clinical encounter or ongoing medical care?
  - An essential element of the psychosocial program?

Sample Characteristics (N=350)

Mean Age: 60

79% Female

Ethnicity:
77% Caucasian
12% African-American/Black
5% Hispanic/Latino
2% Asian/Pacific Islander

Education:
2% <High School
14% HS Grad/GED
28% Some College
31% College Degree
24% Advanced Degree

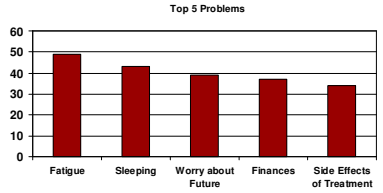
Income:
37% < 40K
32% 40-100K
15% > 100K

69% Active treatment within past 2yrs

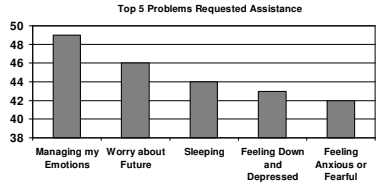
Cancer Type:
42% Breast
8% Gynecologic
8% Blood
7% Colorectal
6% Lung
4% Prostate
4% Head and neck

Results

•Based on % of participants who marked ≥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:



Results, cont.

- Six items comprised a depression scale which correlated strongly with the CES-D score for depression (R=0.72, p<0.001, n=343)
- Refined *SupportScreen™* 53-item measure to a total of 36-items using a statistical and theoretical criteria to meet community needs
- Reduced 19 items, revised six items, added two items Item candidates for removal or revision included:
  - Items in a particular factor that were weaker, i.e. lower factor loading, than other items;
  - Items that were included in multiple factors (individual factor loadings >0.4 and the difference between loadings >0.2), i.e. factors that are anomalous and did not perform well (do not contribute enough unique variance).
- First step in creating a reliable and standardized method of assessing psychosocial distress across a large network of community-based care providers

Future Directions

- The feasibility and validity of the 36-item community screening measure will be evaluated in the next phase of CSC's Screening Demonstration project
- The aims of this project are to:
  - Screen 100% of new patients for distress
  - Make appropriate referrals in the community
  - Provide follow-up care
- Screening will take place at:
  - Genesis Cancer Care Institute in partnership with Gilda's Club Quad Cities, Quad Cities, IA
  - Exempla St. Joseph's Hospital in partnership with CSC Colorado
  - CSC Florida Suncoast, Sarasota, FL

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Objectives: The Institute of Medicine (2007) recommends psychosocial screening for all cancer patients to improve integration of care. In the United States, 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.

Methods: Using the Community-Initiated Research Collaboration model, the first phase of a larger demonstration project is to validate and adapt an existing problem-related distress screening tool for the community. The screening tool asks cancer patients to identify and rate their practical, social, and emotional problems along with their medical, informational and referral resource needs. To validate this tool, a pen-and-paper version of a 53-item measure *(SupportScreen™)* and a standardized distress measure (Center for Epidemiologic Studies Depression Scale; CES-D) were administered to 350 patients at ten community-based sites nationwide.

Results: Patients reported the five most common causes of problem-related distress were fatigue (49%), sleeping (43%), worry about the future (39%), finances (37%), and side-effects of treatments (34%). The five most common problems for which participants requested assistance were managing my emotions (49%), worry about the future (46%), sleeping (44%), feeling down or depressed (43%), and feeling anxious or fearful (42%). Using statistical and theoretical criteria, 19 items were dropped from the screening tool, 6 items revised and 2 items added comprising a 36-item community version. Using results from factor analysis, 6 items comprised a depression scale which correlated strongly with the CES-D score for depression ($R=0.72$, $p<0.001$, $n=343$).

Conclusion: These findings provide a first step in creating a reliable and standardized method of assessing psychosocial distress across a large network of community-based care providers.

Research Implications: The promising findings of the validation study support next steps to validate the revised, 36-item version of the screening tool for use within the community.

Clinical Implications: Lessons learned around the feasibility and impact of implementing community-based distress screening can inform the establishment of quality standards and best practices for distress screening in the community.

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