Problem-related Distress and Quality of Life in Cancer Survivors Participating in a Community-based Screening Program

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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 (CSC) is testing the feasibility and effectiveness of community-based, comprehensive screening for cancer patients

- The Cancer Support Community provides professional led and evidenced based emotional and social support through a network of nearly 50 local affiliates, more than 100 satellite locations as well as online

- Investigators from Cancer Support Community and City of Hope (COH) collaborated to validate a 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

Broad 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 distress screening tool, the *Cancer Support Community Screener (CSCS;* 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

Purpose

- As part of a greater effort to validate a distress screening tool, the purpose of this analysis was to identify the sources of distress that have the greatest impact on quality of life (QOL)

Procedure/Measures

- 319 participants from 14 Cancer Support Community sites nationwide completed pen-and-paper version of the 36-item screening tool

- 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

- **Mean Age:**
  - 59 years old
- **Sex:**
  - 84% Female

- **Ethnicity:**
  - 83% Caucasian
  - 3% Afr-Am/Black
- **Income:**
  - 25% < 40K
  - 35% 40-100K
  - 22% > 100K

- **Cancer Type:**
  - 45% Breast
  - 9% Gynecologic
  - 12% Blood
  - 5% Colorectal
  - 5% Lung
  - 3% Prostate
- **Education:**
  - <1% <High School
  - 9% HS Grad/GED
  - 24% Some College
  - 39% College Degree
  - 28% Advanced Degree

- 70% Active treatment within past 2yrs

Analyses

- A series of forward step-wise regression analyses were conducted in order to test the impact of various sources of distress on quality of life

- All analyses conducted with $p \le .05$

Results

Sources of Distress that Impact Quality of Life

	Fact-G		Emotional Well Being		Physical Well Being		Functional Well Being		Social Well Being	
	β	t	β	t	β	t	β	t	β	t
Finding meaning/purpose in life	-3.47	-4.24					-2.16	-2.16	-1.05	-3.03
Feeling unsupported by partner	-2.65	-3.34							-2.04	-5.67
Feeling down or depressed	-2.87	-3.08	-1.44	-5.70						
Worry about the future	-3.36	-4.28	-.870	-3.75			-.936	-2.90		
Needing practical help at home	-2.73	-3.00	-.272	-1.18	-.87	-2.87	-.734	-1.87		
Fatigue	-3.65	-5.19			-2.13	-9.03	-1.34	-4.57		
Physical appearance	-1.74	-2.28	-.428	-1.98						
Sleeping	-2.50	-3.76					-1.33	-4.70		
Pain					-1.74	-7.32				
Side effects of treatment					-1.42	-6.50				
Finding community resources where I live					-.699	-2.52				
Feeling isolated/alone/abandoned									-1.60	-3.88
Feeling anxious or fearful			-1.03	-3.81						
Questions an fear about end of life			-1.10	-4.55						
Weight gain or loss			.435	2.38						
Talking with family/friends									-1.30	-3.75
Model Fit R2	F (8, 275) = 63.59 0.64		F(7, 285) = 67.84 0.62		F(5, 288) =101.78 0.63		F(5, 297) = 48.18 0.44		F (4, 290) = 45.46 0.38	

Note: All reported results represent inverse relationships (larger numbers suggest poorer Quality of Life).

Summary of Results

- **Six items predicted emotional well-being** (adjusted R^2=0.62; n=295): feeling anxious or fearful (p<0.001); worry about the future (p<0.001); feeling down or depressed (p<0.001); questions and fear about end of life (p<0.001); weight gain or loss (p=0.022); and physical appearance (p=0.048)

- **Five items predicted physical well-being** (adjusted R^2=0.63; n=294): Fatigue (p<0.001), pain (p<0.001), side-effects of treatments (p<0.001), needing practical help at home (p=0.004), and finding community resources near where I live (p=0.012)

- **Five items predicted functional well-being** (adjusted R^2=0.44; n=303): worry about the future (p=0.004), fatigue (p<0.001), finding meaning or purpose in my life (p<0.001), sleeping (p<0.001), and needing practical help at home (p=0.062) were significantly associated with functional well-being

- **Four items predicted social/family well-being** (adjusted R^2=0.38; n=295): feeling isolated, alone or abandoned (p<0.001); talking with family, children and friends (p<0.001); feeling unsupported by my partner (p<0.001); and finding meaning or purpose in my life (p=0.003)

Implications

- The Cancer Support Community Screener can be used to:
  - Screen for problems related to key components of QOL
  - Assess QOL over time among patients being treated in community settings

- Screening data can be used to inform programs, referrals and resources designed to reduce distress and improve QOL for cancer patients in the community

- Future efforts are needed to demonstrate the feasibility of screening in the community

Next Steps

- Building on these findings CSC has developed and validated a community based psycho-social cancer distress screening tool, Cancer Support Source™

- **Cancer Support Source™** is a 25-item web-based screening tool integrates a valid and reliable self-report measure with automated linkages to vital information and referral for support services reducing the social, emotional and practical barriers that can impede optimal cancer care

Problem-related distress and quality of life in cancer survivors participating in a community-based screening program

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PURPOSE: As part of an initiative to validate a distress screening tool, the purpose of this analysis was to identify the sources of distress that have the greatest impact on quality of life(QOL).

METHODS: A cross-sectional group of 319 survivors (84% female; 83% white) of mixed cancer diagnosis (45% breast) who participated in a screening study at 14 community-based affiliates of the Cancer Support Community completed the Functional Assessment of Cancer Therapy-General version (FACT-G) scale and the Cancer Support Community Screener (CSCS), a validated distress screening tool that asks participants to rate the severity of 36 problem-related distress items.

RESULTS: Findings from regression analysis showed eight items were significantly associated with QOL (adjusted R2=0.64; n=284): feeling down or depressed (p=0.002), worry about the future (p<0.001), needing practical help at home (p=0.003), fatigue (p<0.001), physical appearance (p=0.023), sleeping (p<0.001), finding meaning or purpose in my life (p<0.001), and feeling unsupported by my partner (p=0.001). Fatigue (p<0.001), pain (p<0.001), side-effects of treatments (p<0.001), needing practical help at home (p=0.004), and finding community resources near where I live (p=0.012) were significantly associated with physical well-being (adjusted R2=0.63; n=294). Four items predicted social/family well-being (adjusted R2=0.38; n=295): feeling isolated, alone or abandoned (p<0.001); talking with family, children and friends (p<0.001); feeling unsupported by my partner (p<0.001); and finding meaning or purpose in my life (p=0.003). Six items predicted emotional well-being (adjusted R2=0.62; n=295): feeling anxious or fearful (p<0.001); worry about the future (p<0.001); feeling down or depressed (p<0.001); questions and fear about end of life (p<0.001); weight gain or loss (p=0.022); and physical appearance (p=0.048). Finally, worry about the future (p=0.004), fatigue (p<0.001), finding meaning or purpose in my life (p<0.001), sleeping (p<0.001), and needing practical help at home (p=0.062) were significantly associated with functional well-being (adjusted R2=0.44; n=303).

CONCLUSIONS: The CSCS can be used to screen for problems related to key components of QOL.

RESEARCH IMPLICATIONS: The CSCS can be used to assess QOL over time among patients being treated in community settings. Future efforts are needed to demonstrate the feasibility of screening in the community.

CLINICAL IMPLICATIONS: These data can be used to inform programs, referrals and resources designed to reduce distress and improve QOL for cancer patients in the community.

Accepted for Poster Presentation