

Community-Based Distress Screening: Findings from an Online Registry

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Introduction

- The IOM, the NCCN, and the American College of Surgeons have recognized that screening for emotional, physical and social concerns is critical to ensuring quality cancer care.

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

- Cancer Support Community (CSC) is an international nonprofit dedicated to ensuring that all people impacted by cancer are empowered by knowledge, strengthened by action, and sustained by community.

- CSC developed an online registry of nearly 3000 breast cancer survivors designed to examine the psychosocial impact of breast cancer.

- In November 2010, registrants were asked to evaluate 26 items of problem-based distress related to their cancer experience.

Objectives

- Identify top causes of distress among female breast cancer survivors
- Explore socio-demographic and clinical variables associated with distress

Sample Characteristics (N=1014)

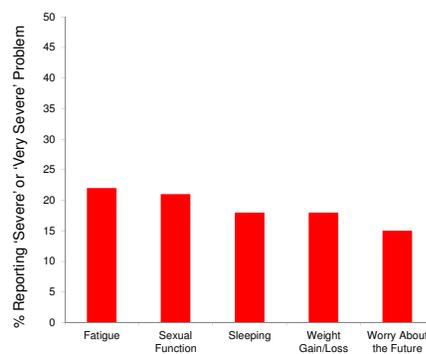
Characteristic	Proportion
Race	
Caucasian	83%
African American	6%
Education	
Bachelors and above	63%
Self-reported depression	24%
Comorbidities	
At least one	76%
Tumors diagnosed	
Stage II and up	58%
Recurrent breast cancer	13%
	Median
Age	54.9
Years since diagnosis	3.8

Methods

- Registrants were asked for 26 items:
 - **How much of a problem is this for you due to your breast cancer diagnosis?**
 - Rated items using a 5-point scale from 'not a problem' to a 'very severe problem'.
- Linear regression analysis was used to identify socio-demographic and clinical variables associated with greater distress.
- A summary score was calculated as the sum of the ratings for the 26 items.
- The distribution of the summary score was positively skewed so $[1/\sqrt{(\text{summary score})}]$ was modeled in regression analysis.

Results

Most Frequently Reported Problems Causing "Severe" to "Very Severe" Distress



Characteristics Associated with Greater Distress (n=926)

	t	p
Age	7.98	<.001
Time since diagnosis	2.70	.007
Stage of cancer at diagnosis	-5.93	<.001
Depression (self-report)	-14.05	<.001
Number of comorbidities	-7.23	<.001
Recurrent breast cancer	-5.70	<.001
Model Fit R ²	F (6, 919) = 673.12	= .323

Summary

- Younger age, less time since diagnosis, higher stage of cancer, self-reported depression and recurrent cancer were associated with greater overall distress.
- The average number of problems rated as severe or very severe was 2.5 (on a range from 0-19).
- 58% rated at least one item as a severe or very severe problem.
- 89% rated at least one item as a moderate or greater problem.

Implications

- These findings are consistent with previous research that shows breast cancer survivors struggle with several distress-related problems with high severity.
- Breast cancer survivors should be closely monitored for distress and provided appropriate resources to address distress-related problems throughout the continuum of care.
- Early identification of distress needs with prompt referral for follow-up is essential to removing barriers to optimal patient centered care.

Future Directions

- CSC is developing and delivering a community-based distress screening program CancerSupportSource™ for community-based hospitals, physician practices and advocacy organizations that integrates screening, referral and follow up care through a single, streamlined, web-based program.
- Future research should examine cost-savings to the health care system as a result of early identification of psychosocial distress and treatment through counseling and support services.

Acknowledgement of Funding



The Cancer Survivor Registry: the Breast Cancer M.A.P. (Mind Affects the Physical) Project has three main goals:

1. To better **understand** and **meet** the ongoing social and emotional needs of breast cancer survivors
2. To develop and disseminate effective programs resulting in improved long-term quality of life
3. To provide a vehicle for these survivor voices to be heard and positively impact health care policy through advocacy

To download the Index, please visit:

www.cancersupportcommunity.org/BreastCancerMAP

To join the Cancer Survivor Registry, please visit:

<https://csc.breastcancerregistry.org/>

Community-based distress screening: Findings from an online registry breast cancer survivors

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The IOM, the NCCN, and the American College of Surgeons have recognized that screening for emotional, physical and social concerns is critical to ensuring quality cancer care. Yet, distress screening in community settings, where up to 85 % of cancer patients are treated, is largely non-existent. The Cancer Support Community, the largest network of providers of psychosocial support to cancer patients in the US, recruited breast cancer survivors from the Breast Cancer M.A.P. (Mind Affects the Physical) Project, an online registry designed to examine the psychosocial impact of breast cancer, to identify top causes of distress among breast cancer survivors. In November 2010, registrants (N=1043) were asked to evaluate 25 psychosocial issues on a 5 point scale (not at all a problem-severe problem) from a validated community-based screening tool. The sample was 99% female, 88% Caucasian, the mean age was 55, and the average time since diagnosis was 5.5 years. 63% had at least a college degree. 58% were initially diagnosed with at least Stage II disease; 13% reported having had a recurrence. 87% rated at least one of the issues as a moderate or greater problem. 57% rated at least one item as a severe or very severe distress-related problem. The average number of problems rated as severe or very severe was 2.5 (on a range from 0-19). The most common problems that cause severe or very severe distress were: fatigue (22%), sexual function (21%), sleeping (18%), weight gain or loss(18%), and worry about the future (15%). Several other socio-demographic and clinical variables were independently and significantly (n=931; p<0.05) associated with greater overall distress. Those variables included: Younger age (p<0.001); less time since diagnosis (p=0.009); higher stage of cancer (p<0.001); self-reported depression (p<0.00); recurrent cancer (p<0.001). The findings validate other research in this area that show survivors struggle with several distress-related factors with high severity and affirm that survivors should be closely monitored for distress and provided appropriate resources to address distress-related problems throughout the continuum of care.