

# Predictors of Distress Associated with Problems with Sexual Function among Breast Cancer Survivors: Findings from an Online, Community-based Registry

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## Introduction

- 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 develops and delivers a comprehensive menu of free, personalized support and education services to all people affected by cancer
- CSC created a series of questions focused on key areas identified in the seminal report, "Cancer Care for the Whole Patient" (IOM, 2007).
  - Key questions were included related to the survivor experience around distress and sexual function



- *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

### Sexual Dysfunction

- Sexual function problems are prevalent among breast cancer survivors and negatively impact quality of life (Krychman, 2008)
- Research suggests that poor sexual function is associated with negative health outcomes and quality of life

To download the Index, please visit:

[www.cancersupportcommunity.org/BreastCancerMAP](http://www.cancersupportcommunity.org/BreastCancerMAP)

To join the Cancer Survivor Registry, please visit:

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

## Objectives/Purpose

- Identify predictors of distress associated with sexual dysfunction
- Identify subgroups at high risk for distress related to sexual dysfunction
- Evaluate the need for distress screening associated with sexual dysfunction

## Sample Characteristics (n=972)

Characteristic	Proportion
Sex	
-Female	99%
Race	
-Caucasian	88%
-African American	6%
Education	
-Bachelors and above	76%
Comorbidities	
-At least one	76%
Tumors diagnosed	
-Stage II and up	58%
-Stage III and up	20%
	<b>Average</b>
Age	55
Years since diagnosis	4

## Methods

- Nearly 3,000 breast cancer survivors have joined the **Breast Cancer M.A.P. Project**, an online registry designed to examine the psychosocial impact of breast cancer
- In October 2010, registrants were emailed and asked to log into their *M.A.P. Project* account and answer study specific questions about:
  - Distress related to their cancer experience
  - Demographic information
  - Medical history information
- A total of 972 answered the question regarding sexual function (not a problem to very severe problem)
  - Those who answered sexual function item were an average of 4 years younger than those who did not answer the item ( $p=0.002$ )

## Results

Figure 1.1

### Distribution of Sexual Function Problem Ratings

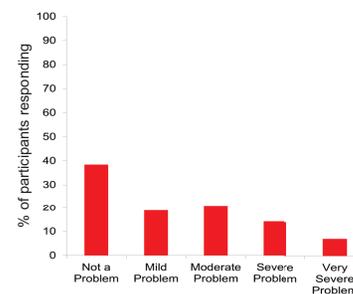


Figure 1.2

### Predictors of Distress Associated with Sexual Dysfunction

	Odds Ratio	95-Confidence Interval
Age	.96	.95 - .98
Chemo	1.86	1.24 - 2.79
Depression	2.79	1.95 - 4.00
Hormone Rec. +	2.12	1.35 - 3.34
White	2.02	1.05 - 3.87

## Summary of Results

- Participants with **depression** were nearly three times more likely than those without depression to rate sexual function as a severe or very severe problem ( $OR=2.80$ ;  $p<0.001$ )
- Those who self-identified as **non-Hispanic white** were 2 times more likely than non-white racial groups to report sexual function as a severe or very severe problem ( $OR=2.03$ ; 95 percent  $CI=1.06, 3.88$ ;  $p=0.033$ )
- The odds of rating sexual function as a severe or very severe problem were **two times greater among those who were hormone-receptor positive** compared to negative ( $OR=2.13$ ;  $p=0.001$ ) and 86% greater among those who received chemotherapy compared to those who did not ( $OR=1.86$ ;  $p=0.003$ )
- Note: 21% of breast cancer survivors indicated sexual function was a severe or very severe problem

## Implications

- Younger age, race, depression and treatment related variables predict higher levels of distress among breast cancer survivors
- Cancer related distress is associated with sexual dysfunction well beyond treatment for breast cancer, extending into survivorship
- These data highlight the need for all survivors throughout the survivorship continuum to be screened for distress-related problems with sexual function and provided appropriated referrals and follow-up
- Sexual dysfunction is a complex problem that can be addressed with a variety of intervention types:
  - education and lifestyle changes, sexual counseling, sexual aids, medications, and dietary supplements

## Future Directions

- Research needs to focus on:
  - Sub-groups at high risk for distress related to sexual function
  - The needs of various ethnic, geographic and culturally diverse populations
  - Impact of distress screening on quality of life, health, and cost outcomes
  - Screening for distress related sexual dysfunction that is more culturally sensitive and inclusive
- Programs around sexual function and cancer need to be made available in the community

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**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 R<sup>2</sup>=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 R<sup>2</sup>=0.63; n=294). Four items predicted social/family well-being (adjusted R<sup>2</sup>=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 R<sup>2</sup>=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 R<sup>2</sup>=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.

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