

Cancer-related Distress and Unmet Needs among Members of a Metastatic Breast Cancer Registry

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Introduction

- The Cancer Support Community (CSC) represents a global network of non-profit, community-based organizations that provide professionally led support and education to cancer patients and their families.
- An estimated 155,000 people are living with metastatic breast cancer (MBC) in the US.
- With new developments in treatment, people can live with MBC for many years often without their emotional and social needs being appropriately addressed.
- As distress screening becomes a quality standard of cancer care, little is known about the MBC patient experience around distress screening.
- The purpose of the current analysis was to understand the top distress-related concerns and unmet needs of people living with MBC.

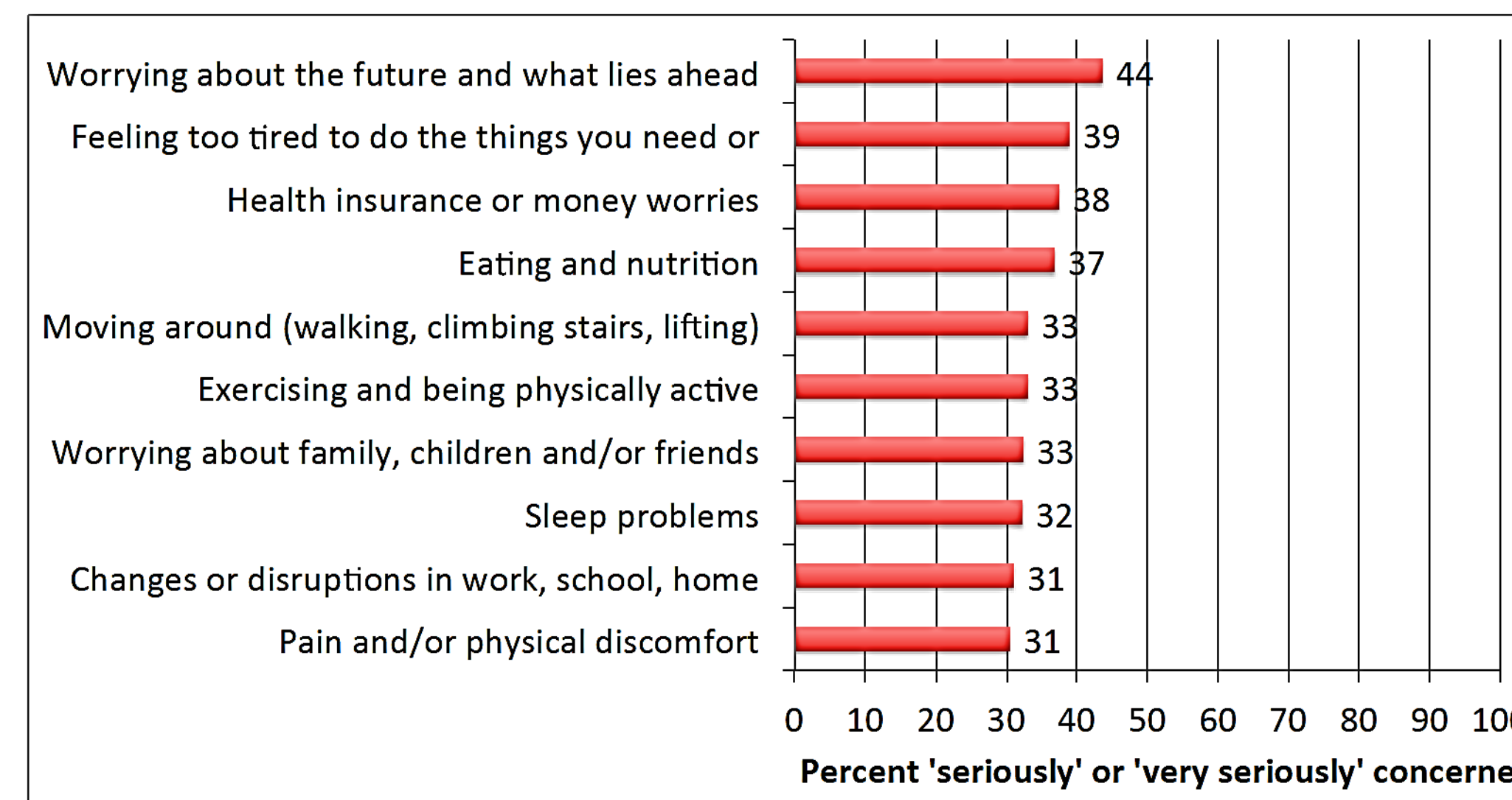
The Cancer Experience Registry

- CSC established the Cancer Experience Registry to track the immediate, ongoing and changing social and emotional experience of cancer survivors.
- The registry reaches cancer patients and survivors across the country and engages them to share their voices about issues identified by national advisors, including patient representatives, health care providers, advocates, industry representatives and researchers.
- Through the Cancer Experience Registry we are able to:
 - Garner, analyze and disseminate insights and knowledge in order to positively impact each individual's cancer experience;
 - Help inform the nation's health care systems to respond to the needs of cancer survivors; and
 - Accelerate and enhance the productivity of research to improve quality outcomes.

Currently, there are over 7,100 cancer patients and survivors in the Cancer Experience Registry from over 35 countries and representing more than 40 cancer diagnoses.

Results

Distress-related concerns



The top sources of distress were worry about the future, fatigue, and health insurance or money worries.

Because of the financial cost of cancer...

- 9% chose a treatment that was not as effective but cost less
- 20% postponed seeking psychological counseling or support
- 40% depleted their savings
- 16% downsized living accommodations
- 4% experienced home foreclosure
- 5% filed for bankruptcy
- 52% cancelled vacations, celebrations, and social events

46% of participants reported levels of stress-related intrusive ideation about the financial cost of cancer above the clinical cut-off (≥ 13)

Never asked about distress

Where care was received	Percent	P-value
Comprehensive Cancer Center	35	
Community cancer center, private oncology practice, other	50	0.002

A significantly greater proportion of respondents were asked about distress if they received part or all of their care at a Comprehensive Cancer Center.

Additional findings

- Factors that were independently associated with greater overall distress included younger age ($p < 0.001$), higher comorbidity ($p < 0.001$), lower income ($p = 0.001$).
- 49% reported fatigue was 'quite a bit' or 'very much' disruptive in their life.
- Among those who were asked about distress ($n = 340$): 62% received referrals to manage distress within their health care system, and 19% at a community-based organization; 47% reported their health care team helped coordinate distress-related care; 20% never received referrals for managing it.

Methods

- CSC convened and engaged a National Advisory Council of MBC stakeholders and experts to generate a survey around priority topics. The National Advisory Council included members of the MBC Alliance, representing over 15 advocacy organizations.
- 909 people living with MBC joined the Cancer Experience Registry at the time of this analysis. Currently, there are over 937 people with MBC enrolled.
- 599 registrants responded to questions about cancer-related distress.
- Distress-related concerns were measured using CancerSupportSourceSM, a 25-item validated web-based distress screening tool (Miller et al., 2014). Participants rated each of 25 items according to the question "Today, how concerned are you about...?" using a five-point Likert scale (0 not at all to 4 very seriously concerned).
- An overall distress summary score was calculated as the sum of problem ratings.
- Intrusive ideation about the financial cost of cancer was measured using the Impact of Events Scale (Horowitz et al., 1979). Levels ≥ 13 were considered clinically significant.

Sample Characteristics (n=599)

Characteristic	Proportion
Female	99.5%
Caucasian	94%
Education \geq Bachelor's Degree	69%
	Median
Age	55 (range: 24-92)
Time since MBC diagnosis	3 years

Conclusion and Future Directions

- There is an on-going need for coordinated care that integrates supportive services across health care systems.
- 20% of patients who asked for psychosocial referrals *never* received them
- While these findings are limited given that the sample is highly educated and Caucasian, many of these women, 3 years on average since diagnosis, are suffering from the long-term financial and emotional impact of their illness on their quality of life..



Anyone who has ever been diagnosed with cancer of any type can join the Cancer Experience Registry at:
www.CancerExperienceRegistry.org

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