



Cancer-related distress and unmet needs among newly diagnosed and longer-term cancer survivors from a community-based distress screening program

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Introduction

The Cancer Support Community (CSC) represents a global network of nonprofit, community-based organizations that provide professionally led support and education to cancer patients and their families.

The Institute of Medicine (IOM), NCCN and the American College of Surgeons have recognized that screening for psychosocial concerns is critical to ensuring quality cancer care for the whole patient.

As survival rates increase among cancer patients, less is understood about quality of life needs and how they shift over time.

CSC has developed and implemented CancerSupportSourceSM (CSS) an evidence-based, web-based distress screening program that uses a validated distress screening tool and referral algorithm to link cancer patients to resources tailored to their needs.

Objective

The study objective was to describe the psychosocial concerns and unmet needs of cancer patients at different times since cancer diagnosis to help understand changing social and emotional needs over time and inform where there are gaps in care.

Method

The study population is members of the Cancer Support Community's (CSC) nationwide affiliate network. From Jan 2014-June 2015, 905 English-speaking cancer survivors, who attended one of 26 affiliates, completed the CSSSM distress screening tool (Miller et al., 2012) including a 4 item depression subscale.

Participants rated the level of concern (0 to 4) about 15 items and identified the help they wanted for each item (e.g. talk with a member of their healthcare team and/or connect them with online resources).

Overall distress was calculated as the sum of 15 items (range 0-60). Score for the depression subscale was calculated as the sum of 4 items. Participants were considered at high risk for depression if sum ≥ 5 .

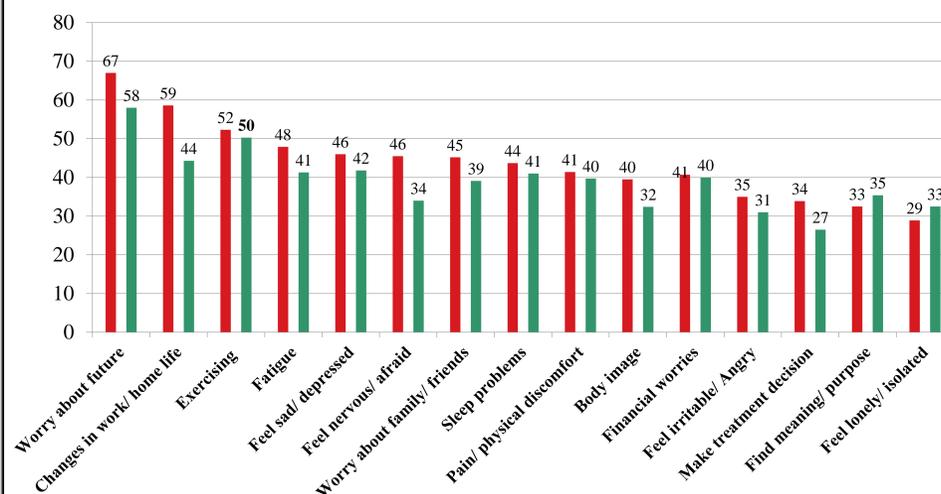
We used regression analysis, adjusting for age, to examine differences by time since diagnosis (<1 y; ≥ 1 y) in level of distress; type of concerns (rated ≥ 2); and items selected to talk about with the health care team.

Patient Characteristics (n=905)

Demographics	
Female	78%
Age (median)	57%
Race/ Ethnicity	73% White 10% Latino 9% Black
Income < \$40K	64%
Marital Status	56% married/cohabitating
Characteristic of Diagnosis	
Type of cancer	41% Breast 6% Lung 6% Colorectal
Time since diagnosis	61% <1 year 39% ≥ 1 year

Differences in distress by time since diagnosis

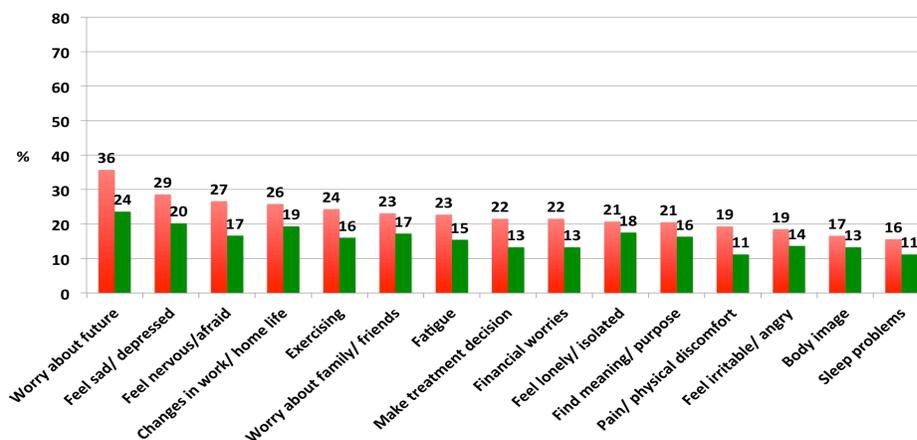
Figure 1. Percent moderately, seriously or very seriously concerned. Comparing those diagnosed < 1 year ago (n=507) vs. ≥ 1 year ago (n=331).



Those newly diagnosed (<1 y) were more likely (p<0.05) to be concerned about:

- Changes in work, school, or home life
- Feeling nervous or afraid
- Worry about the future
- Making a treatment decision

Figure 2. Percent indicating they want to discuss the concern with their healthcare team. Comparing those diagnosed < 1 year ago (n=507) vs. ≥ 1 year ago (n=331).



Those newly diagnosed (<1 y) were more likely (p<0.05) to want to discuss the following concerns with their healthcare team:

- Sad or depressed
- Pain
- Financial worries
- Exercising
- Fatigue
- Making a treatment decision
- Feeling nervous or afraid
- Worry about the future

Distress summary scores by time since diagnosis

Table 2. Overall distress and depression risk

Comparing those diagnosed < 1 year ago vs. ≥ 1 year ago

	<1 year (n=507)	≥ 1 year (n=331)	p-value
Overall distress score, mean (SD)	21.3 (11.5)	19.3 (12.6)	0.011
High risk for depression (%)	56%	45%	0.007

Note: The square root of overall distress was used to normalize the distribution.

Those newly diagnosed with cancer (<1 year) had significantly higher

- Levels of distress (p=0.011)
- Risk for depression (p=0.007)

Conclusion

• Cancer survivors newly diagnosed are more likely to experience distress across a range of concerns commonly experienced by cancer patients and are more likely to want to talk to their health care team about many of these concerns, including pain, financial worries, exercising, feeling sad or depressed, fatigue, making a treatment decision, feeling nervous or afraid, and worry about the future.

• These findings suggest that patients are more distressed and more likely to want to talk about their psychosocial needs within the first year of a cancer diagnosis.

• These findings also suggest that well over a third of cancer patients over a year from diagnosis and beyond continue to report moderate to very serious concerns across a range of issues, including worry about the future, exercise, and financial worries.

• Future research should evaluate efforts to: 1) provide tailored community-based resources within the first year of a diagnosis when distress levels are highest; 2) identify factors that predict those at greatest risk for ongoing and persistent distress; 3) evaluate best practices for repeat distress screening across the care continuum.

Acknowledgement of Funding

This project was sponsored by Amgen and Genentech.

Reference

Miller, M., Mullins, C., Onukwugha, E., Golant, M., & Buzaglo, J. (2014). Discriminatory power of a 25-item distress screening tool: a cross-sectional survey of 251 cancer survivors. *Qual Life Res*, 23 (10): 2855-2863.