



CANCER SUPPORT COMMUNITY.®

A Global Network of Education and Hope

The Relationship between Unmet Psychosocial Needs and Emotional Distress:

Results from a national survey to assess the psychosocial needs of individuals diagnosed with melanoma

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Conflict of Interest Disclosure

I do not have any potential conflicts of interest to disclose.

Cancer Support Community

OUR MISSION:

To ensure that all people impacted by cancer are empowered by knowledge, strengthened by action, and sustained by community.



Frankly Speaking About Cancer®

- High quality, evidence-based educational programming for cancer patients, survivors, caregivers, and health care professionals.
- *Frankly Speaking About Cancer*
 - Provide easy to understand in-depth coverage of topics relevant to those affected by cancer.
 - Goals: To educate cancer patients, survivors, caregivers; and to encourage meaningful communication between them and their health care professionals.
 - Topics are tumor type-specific (e.g. melanoma, lung, metastatic breast, liver, colorectal, multiple myeloma) or cross-tumors (e.g. immunotherapy, clinical trials, treatments and side effects).
 - Provide up-to-date content and reflect new advances in knowledge.



Aims


The Cancer Support Community (CSC) conducted a survey study to:

- better understand the unique needs of individuals affected by melanoma and assess how needs are being met.
- explore the relationship between unmet psychosocial needs of melanoma survivors and melanoma-related distress.

Background

- Cancer patients and family caregivers seek information and support resources to cope with the uncertainties of cancer and its treatment (Arora 2002).
- Nearly one-third of melanoma patients experience psychological distress, including depression and anxiety (Beutel et al. 2015), as well as psychosocial needs that are typically unmet during treatment (Fishbeck et al. 2015).

Frankly Speaking About Cancer:
Melanoma




FRANKLY SPEAKING ABOUT CANCER Putting the Focus on Stage III Melanoma

In October 2015, the Cancer Support Community brought together twenty-four melanoma patients and caregivers for a two-day summit focused on stage III melanoma.

In small and large groups, over coffee and tea, during walks in the woods, participants took part in personal, respectful and heartfelt conversations about what it was like to receive a diagnosis of stage III—and for some, stage IV—melanoma, their cancer care, the caregivers' experience, and what they wish they had known at the time of their diagnosis. They also discussed what helped them, and what might help others become self-advocates as well as advocates for others in our communities.

This Stage III Melanoma Fact Sheet and its accompanying Melanoma Treatment Summary and Care Plan grew out of these discussions.



CANCER SUPPORT COMMUNITY

SUPPORT FOR FINDING INFORMATION ABOUT MELANOMA
AIM at Melanoma 877-246-2435 www.aimatmelanoma.org
Cancer Support Community 888-764-6555 www.cancersupportcommunity.org
Melanoma Research Alliance 202-364-8555 www.curemelanoma.com
Melanoma Research Foundation 800-673-1590 www.melanomafoundation.org
Melanoma International Foundation 800-463-6668 www.melanomainternational.org

Methodology

- In 2016, the Cancer Support Community (CSC), along with partnering melanoma advocacy groups, conducted a national online survey to assess the psychosocial needs of individuals diagnosed with melanoma.
- Participants were recruited through an outreach program that included patient advocacy organizations and social media.
- A total of 140 individuals with a history of melanoma enrolled in the study.

Analysis

- Descriptive statistics:
 - Sociodemographic and clinical history variables
 - Information/resources received
 - Unmet needs.
 - Melanoma-related distress
- Regression analysis to predict average distress score from total unmet needs score.
- Data analysis was conducted using Stata 14.2.



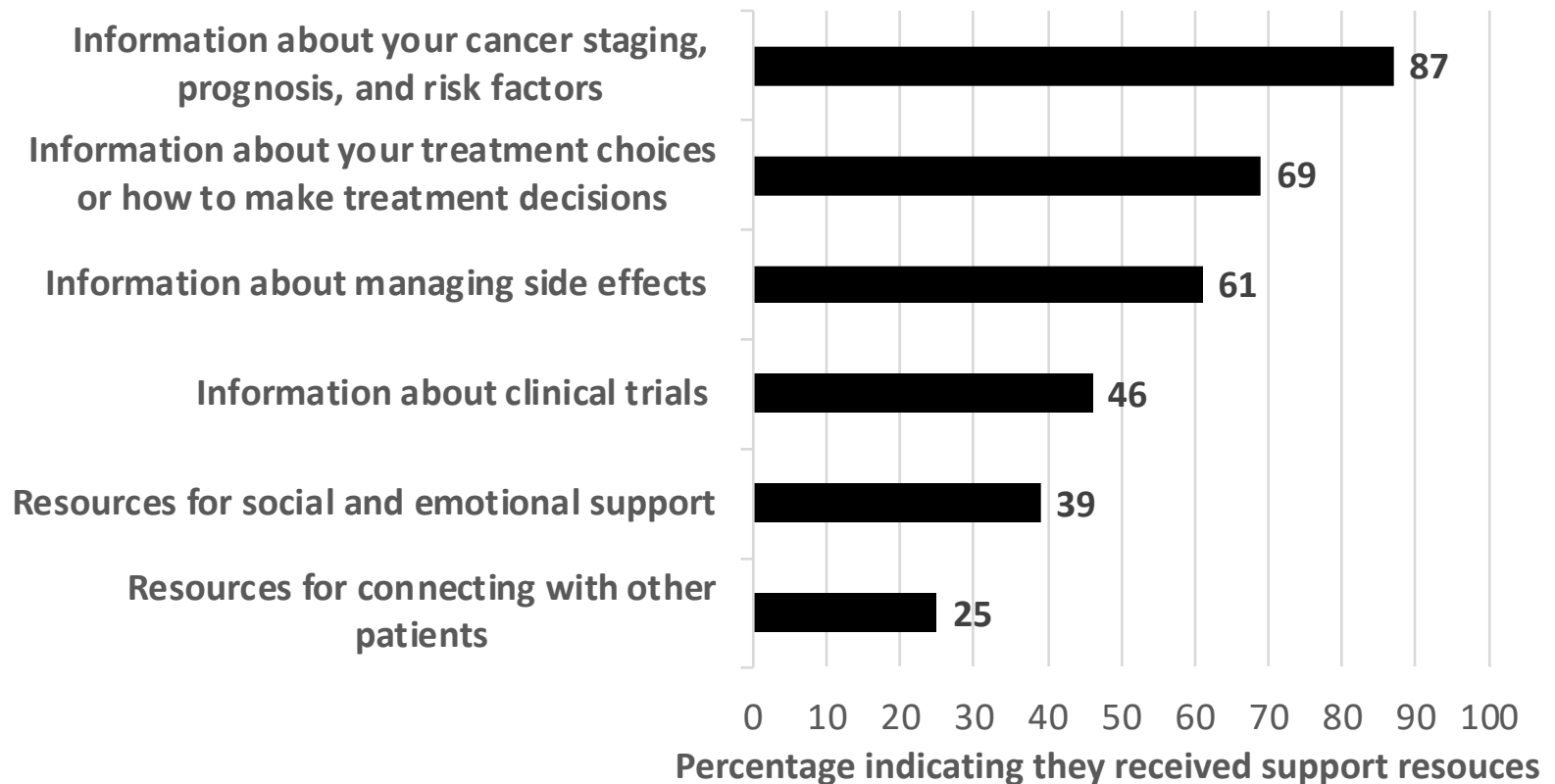
Demographics and Clinical History

- Demographics:
 - 87% female; 13% male
 - 97% White (2% Hispanic)
 - Average 49.2 years of age
 - 62% had college education or higher
 - Average participants were 5 years from receiving their diagnosis
- Clinical History:
 - 48% were diagnosed with metastatic melanoma.
 - 66% reported no clinical evidence of disease
 - 28% were currently in treatment for cancer
 - 5% had recurrent melanoma.



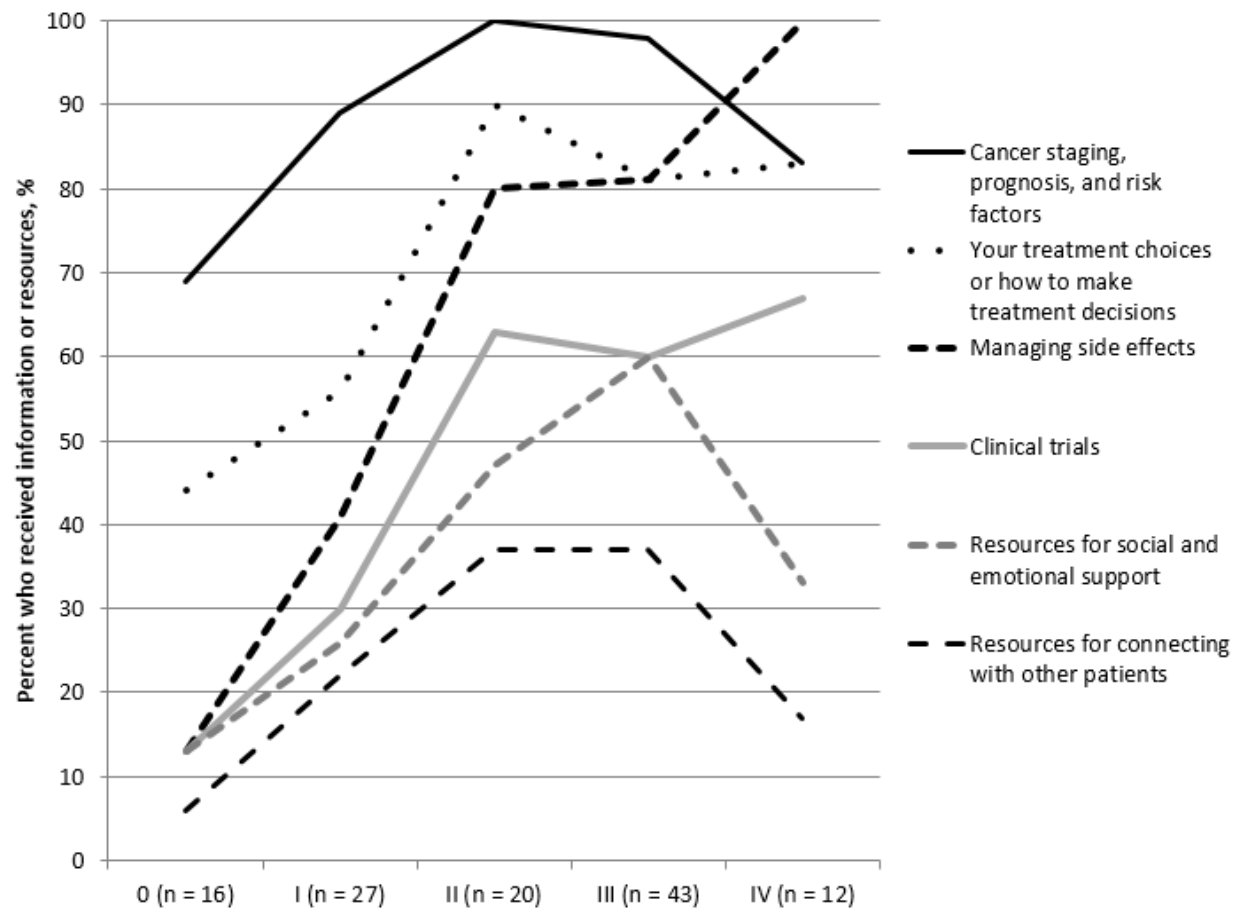
Findings: Type of Resources Received

- Figure 1. Percent who received various types of information and resources.



Resources Received By Stage at Diagnosis

- Figure 2. Percent who received various types of information and resources by stage of melanoma at diagnosis.

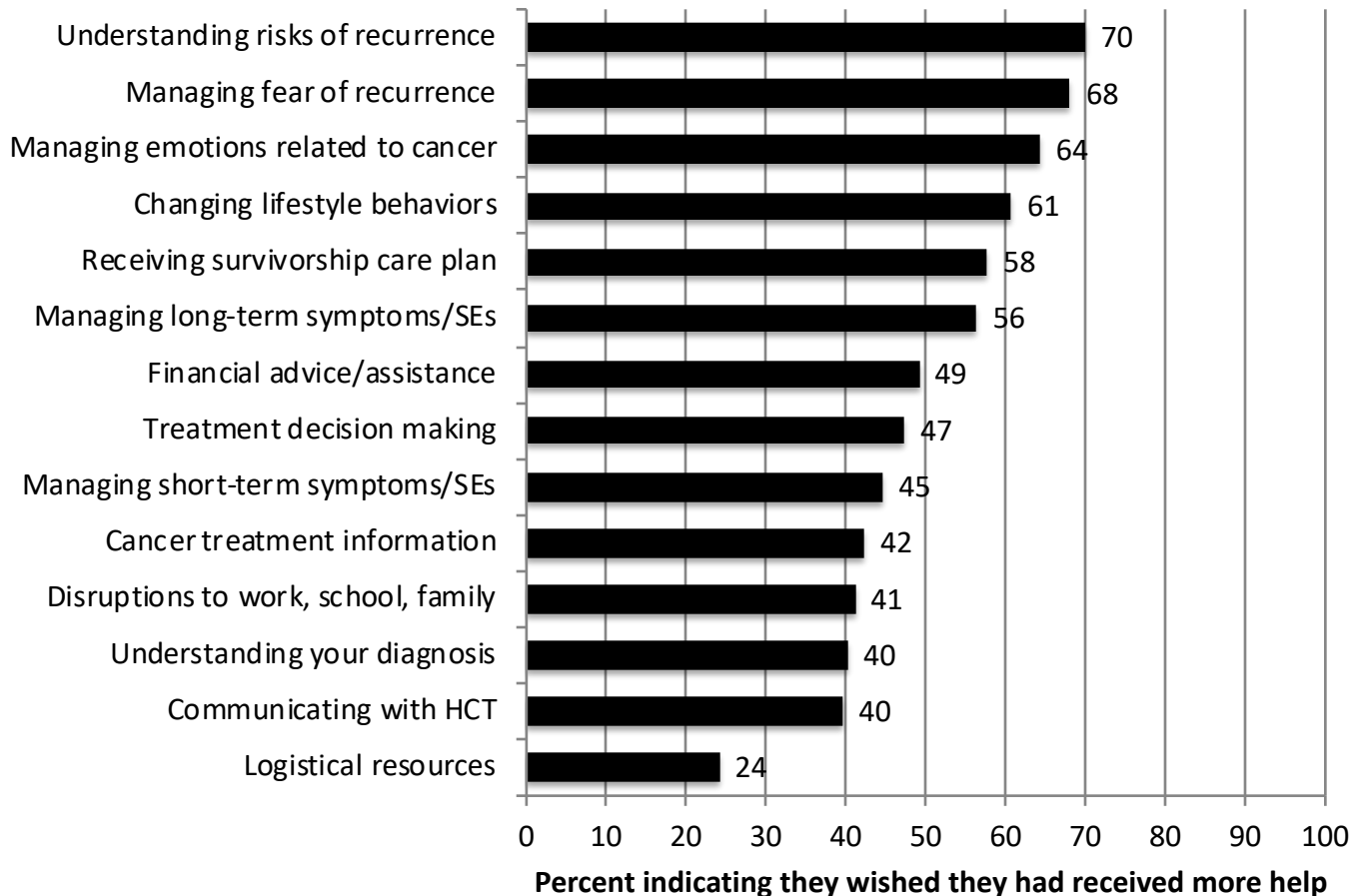


Unmet Needs

- Unmet needs was measured with questions assessing unmet informational and emotional support needs.
- The survey question was “Do you wish you had received more support (help or information) with any of the following?”
 - Options included: “understanding risks of recurrence”; “managing long-term symptoms/side-effects”; and “communicating with health care team”.
- A total unmet need score was calculated as the total number of items marked ‘yes’ (range 0-14).

Findings: Unmet Needs

- Figure 3. Unmet informational and emotional support needs of individuals affected by melanoma.



Cancer-Related Distress

- Cancer-Related Distress was measured with questions related to melanoma and its treatment, disease progression and recurrence, disruptions to work and family life, and body image.
- The survey question was: “Please indicate the extent to which the following are true for you regarding to melanoma-related distress,” with response options ranging from strongly disagree (1) to strongly agree (5).
- An overall distress score was calculated as the average of the eleven questions (range 1-5).

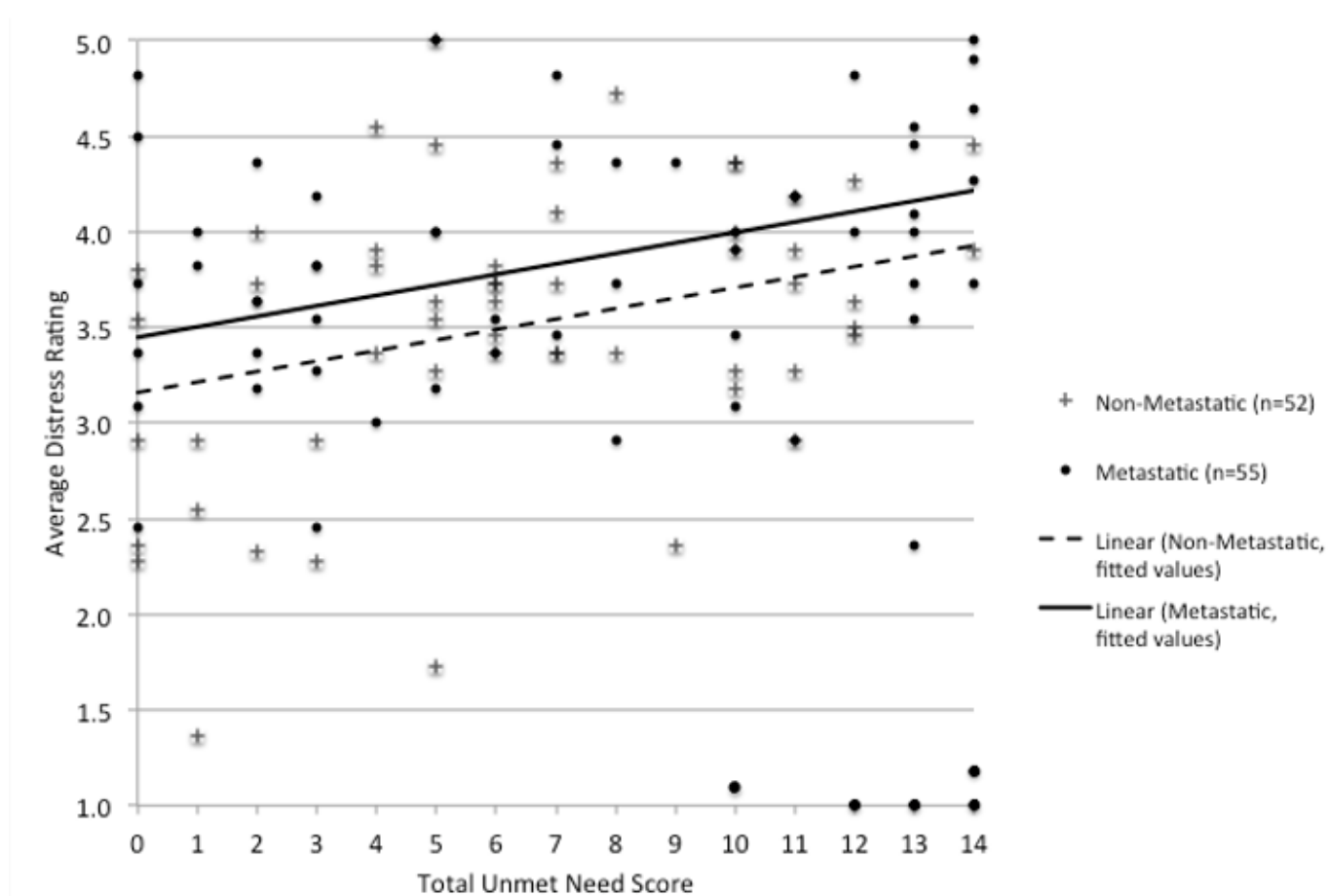
Findings: Melanoma-Related Distress

	Mean (SD)	% ⁱ
Average distress score	3.6 (0.88)	---
I have feared my melanoma would progress	4.3 (1.1)	90%
I have feared my melanoma could come back	4.4 (1.0)	88%
I have experienced distress as a result of melanoma diagnosis	4.2 (1.1)	88%
I have experienced distress as a result of my melanoma treatment	3.7 (1.3)	68%
I have experienced distress related to melanoma as a survivor	3.6 (1.2)	63%
I have experienced distress related to not being able to do my usual activities the way I would have liked to do them	3.4 (1.4)	57%
I experienced distress related to the reactions of others based on what they think it means to have melanoma	3.4 (1.3)	53%
I have experienced distress related to missed time from work	3.3 (1.3)	51%
Since my treatment for melanoma, I have felt more self-conscious about my appearance	3.2 (1.3)	48%
I have experienced distress related to relying on others to accomplish some usual activities	3.2 (1.4)	47%
I have been dissatisfied with the appearance of my scar	2.6 (1.2)	26%

ⁱ Percent of participants indicating “agree” or “strongly agree”.

- Nearly all melanoma survivors reported experiencing fear of cancer progression (90%) and fear of recurrence (88%).
- Participants reported experiencing distress as a result of having received a melanoma diagnosis (88%).

Findings: Unmet Needs and Distress



A multiple regression was run to predict average distress rating from total unmet needs score. Our results show that unmet need significantly predicted distress.

Conclusions

- Our findings indicate that there is a large unmet need for understanding risks of recurrence and managing fear of recurrence and that greater unmet psychosocial need predicts higher levels of distress among melanoma survivors.
- It is important to monitor the supportive care needs of melanoma survivors and provide them with information and resources to help manage psychosocial distress.
- Future studies could examine if these findings about unmet needs and distress levels of melanoma survivors differ from those of other patient populations.

Thank you!

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