How patient and caregiver informational and psychosocial needs are being met in practice: Results from a national melanoma survey

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Background and Overview

Cancer patients and caregivers often have significant psychosocial and informational needs. Many healthcare providers and navigators make referrals to educational and support resources, but how well are the concerns of those affected actually being met in practice?

The Cancer Support Community (CSC) and its partners asked that question to those affected by melanoma to better understand this population's unique needs and how they are being met. The survey results are informing a survivorship program for those at high risk for melanoma recurrence as well as CSC's *Frankly Speaking About Melanoma* educational program.

In Spring 2016, 140 individuals diagnosed with melanoma and 64 melanoma caregivers participated in a national online survey developed by the CSC, reporting melanoma-related beliefs, information-seeking, provision of information, informational preferences, behaviors, and other melanoma-related experiences.

Objective

- To ascertain the information-seeking and information-receiving experiences of those faced with melanoma
- To better understand how to meet the needs of those facing melanoma and to identify potential unmet needs

Frankly Speaking About Cancer Program Background

The *Frankly Speaking About Cancer* (FSAC) series provides in-depth coverage of topics relevant to those affected by cancer often not otherwise available in a comprehensive format.

Topics covered include: metastatic breast cancer, lung cancer, cancer treatments and side effects, immunotherapy, colorectal cancer, advanced skin cancer, and coping with the cost of care. *Frankly Speaking About Cancer* is delivered through in-person workshops, print publications, online content and through a weekly radio show.

CSC's *Frankly Speaking About Cancer: Melanoma* program is designed to educate and to empower patients and caregivers on the topic of melanoma.

For more information: www.CancerSupportCommunity.org

A 2015 Melanoma Patient Summit helped inform the current *Frankly Speaking About Melanoma* educational content.

Methods

Survey Design and Administration
In Spring 2016, CSC along with a team of experts developed a survey of those affected by melanoma. 140 individuals diagnosed with melanoma and 64 melanoma caregivers participated in a national online survey

Respondents:
Individuals with melanoma (n=140) and melanoma caregivers (n=64)

Assessment of Melanoma-related needs and resources received:

- Emotional distress related to melanoma
- Discussion of emotional distress with HCP
- Receipt of referrals for emotional distress
- Receipt of a survivorship care plan (SCP)
- Melanoma-related information received
- Psychosocial-related resources received
- Unmet needs of patients
- Sources of caregiver information
- Psychosocial needs of caregivers

Respondent Characteristics

Patients

- Average Age = 49.2 years (s.d.=10.5)
- Sex: 87.9% female
- Race: 95% Caucasian

Cancer History:

- 28.5% in active treatment
- 48.1% diagnosed with metastatic melanoma
- 47.6% had recurrent melanoma
- 66.4% considered "NED" (No evidence of disease)
- 18.9% have been diagnosed with other cancers
- Time since first diagnosis:
  26.4% diagnosed within past year
  35.3% diagnosed 5+ years ago

Caregivers

- Average Age = 47.1 years (s.d.=14.8)
- Sex: 90.1% female
- Race: 90.4% Caucasian
- 60% identify "strongly" a caregiver
- Care recipient relationship:
  - 35% spouse
  - 21% parent
  - 22% child

Melanoma-related Distress

- Respondents with melanoma reported a high level of distress, with most experiencing depression (53.6%) or anxiety (60%)
- 52.7% were asked by their healthcare team about their cancer-related distress
- 42.0% reported that healthcare team provided referrals to help manage their distress
- Only 8.9% of those with melanoma received a survivorship care plan (SCP)

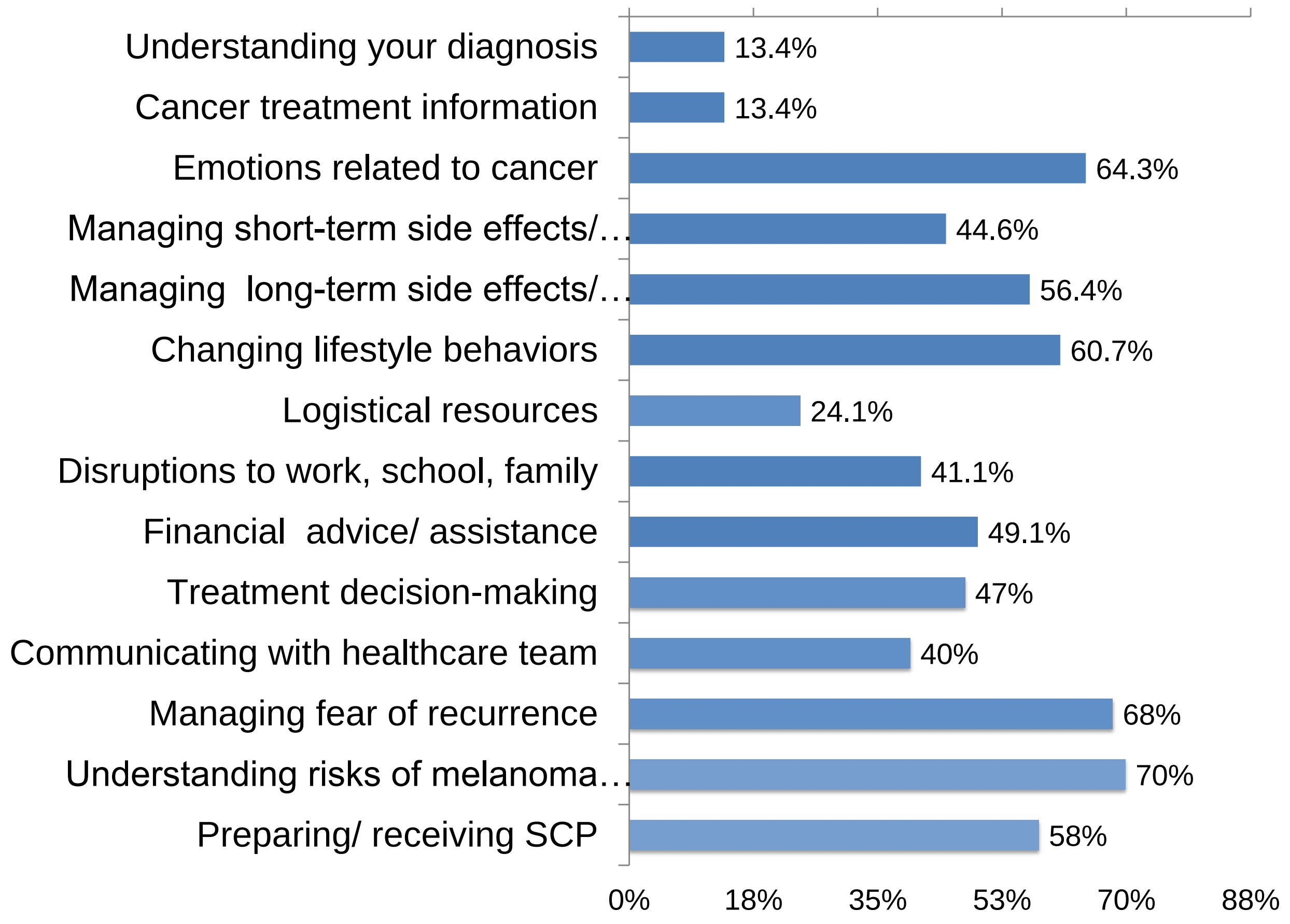
Resources Received (Patients)

Did you receive?	*Yes*	*No*	*I don't know*	*Not Applicable*
Information about your cancer staging, prognosis, and risk factors	*87.3%*	*9.5%*	*0.8%*	*2.4%*
Information about clinical trials	*46.8%*	*36.3%*	*3.2%*	*13.7%*
Information about your treatment choices or how to make treatment decisions	*69.6%*	*19.2%*	*1.6%*	*9.6%*
Information about managing side effects	*61.6%*	*24.0%*	*1.6%*	*12.8%*
Resources for connecting with other patients	*25.8%*	*66.9%*	*0.8%*	*6.5%*
Resources for social and emotional support	*39.5%*	*54.0%*	*0.8%*	*5.6%*

While most (69%) received information about treatment options, less than half received resources for social and emotional support or for connecting with other patients (39.5% and 25.8%, respectively).

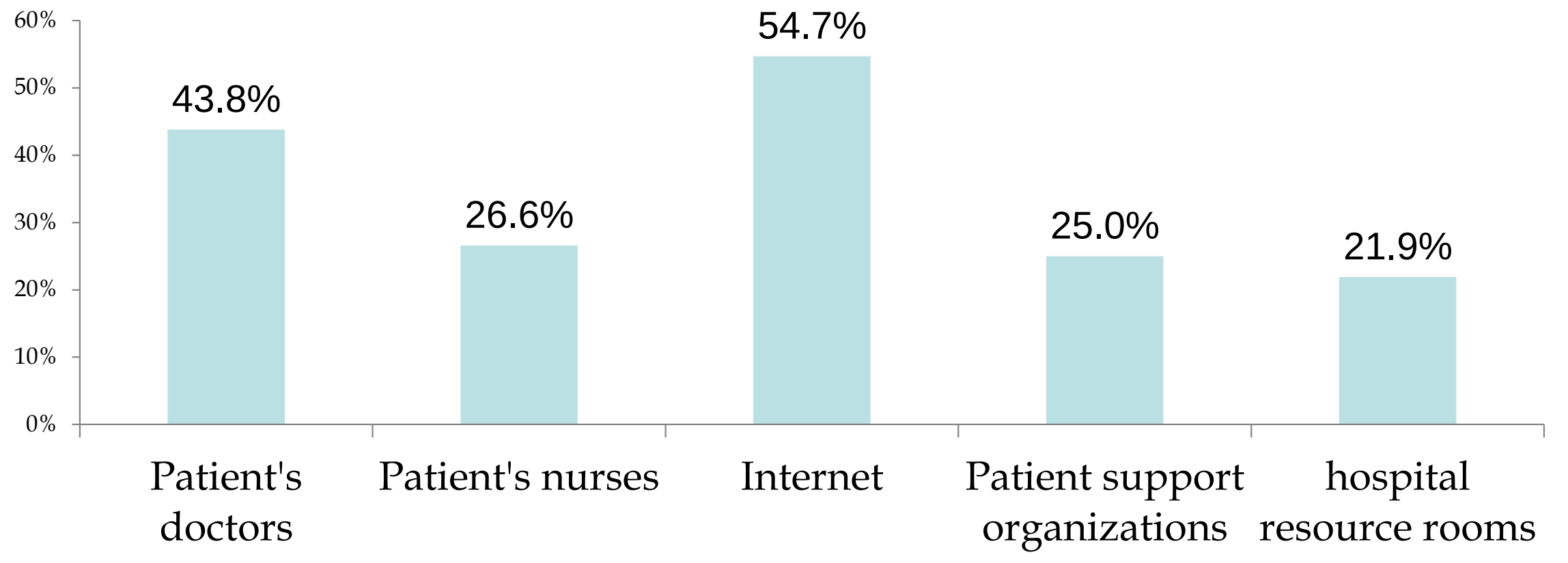
Unmet Needs (Patients)

Individuals with melanoma reported resources they would have liked to had received, but did not:



Most wished they had received more help understanding recurrence risk (70%) and managing fear of recurrence (68%) and cancer-related emotions (64.3%).

Caregiver Resources and Needs



Sources of Melanoma Information for Caregivers

- 83.7% of caregivers experience fear that the patients' melanoma will recur or progress; 30.6% of caregivers report experieicing distress related to the burden of providing care
- Many reported they would benefit from getting support for themselves (53.8%), managing stress (46.2%), or taking better care of themselves (44.2%)
- Only 12.2% received referrals to help manage distress

Summary

- Many individuals diagnosed with melanoma report experiencing emotional distress related to the diagnosis, but not all distress is addressed by the healthcare team
- Results explore the depth and breadth of information and support needs of those affected by melanoma.
- While many diagnostic and treatment-related informational needs are met, psychosocial needs are often not addressed, leaving both patients and caregivers desiring more
- Caregivers report a variety of sources for melanoma-related information

Conclusions & Implications

- Findings highlight what it would mean to provide comprehensive and relevant information and support resources for melanoma patients and caregivers, particularly resources for understanding risk and managing fear of recurrence and distress-related referrals.
- Results support the need for a psychoeducational workshop containing information addressing complex issues around psychosocial needs and survivorship
- Results support the notion that providing clear, relevant, and comprehensive information as well as targeted referrals will best meet needs of this population

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