DO I HAVE CANCER? UNDERSTANDING THE NEEDS OF MYELOFIBROSIS PATIENTS

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Background

Myelofibrosis (MF) is a very rare type of blood cancer for which there is no known cause and there are no known risk factors. It is estimated that MF occurs in the US in 1.5 out of every 100,000 people annually. In 2010, MF was classified as a cancer by the World Health Organization (WHO), though the National Cancer Institute (NCI) still classifies this disease as a disorder.

By the WHO classification, myelofibrosis is one of three diseases classified as a myeloproliferative neoplasm (MPN). MPNs are blood cancers that overproduce blood cells in the bone marrow. Because of the different language by NCI and WHO there is often a lack of consistent information offered to patients when they are diagnosed.

Purpose & Objectives

The purpose of this research was two-fold. The Cancer Support Community (CSC) sought to better understand how those diagnosed with MF:

- Perceive themselves in terms of their identity as being affected by cancer
- Face the challenges of a MF diagnosis

Survey results informed the development of educational materials to meet the informational and emotional needs of this unique patient population.

Methods

In 2012, CSC conducted an online survey for MF patients. Recruitment for completing this 20-item survey was through CSC's affiliate network, patient advocacy partners, and social media. Within two weeks, 44 MF patients across the country responded to the survey.

Respondent characteristics:
- 61.4% Female
- 97.7% Caucasian
- 6.8% Hispanic/Latino
- Average age was 57 years old
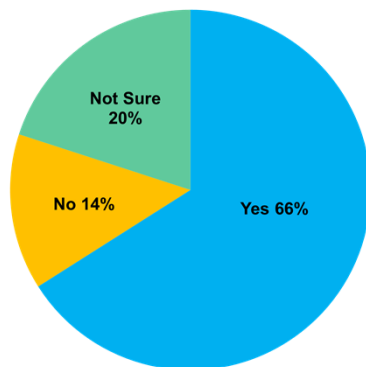- Average age at diagnosis was 51 years old

Acknowledgement of Funding

Patient Experience

Patients diagnosed with MF report feeling confused as to whether or not they have cancer. At diagnosis, 84.1% were told they did not have cancer. At the time of completion of the survey respondents indicated whether or not they currently considered themselves to have cancer. Results are illustrated below.
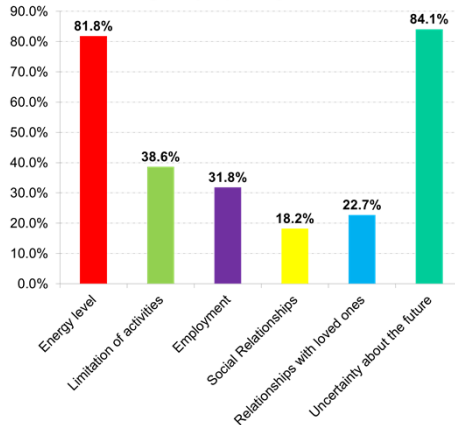

Do you currently consider yourself to have cancer?
- Yes 66%
- Not Sure 20%
- No 14%

Informational Needs

Since diagnosis, patients indicated a number of hard-to-find informational topics including: potential complications from MF (61%), treatment options (46%), and how to make treatment decisions (43%). The graph below illustrates a large gap between information desired and information received.

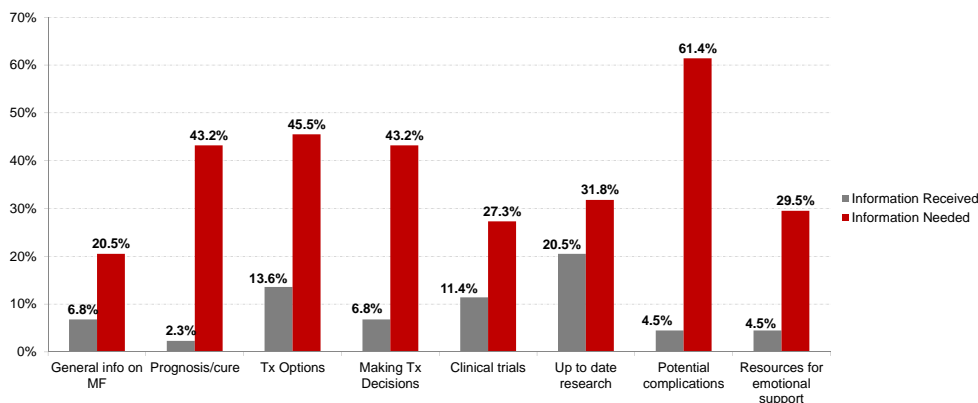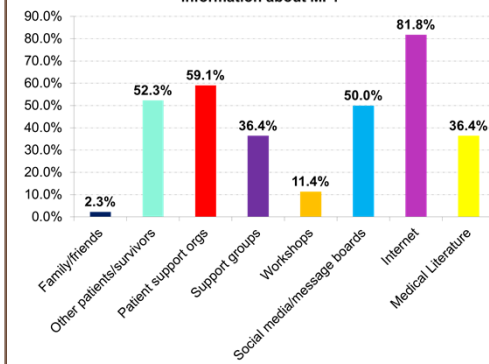| Category	Information Received	Information Needed
General info on MF	6.8%	20.5%
Prognosis/cure	2.3%	43.2%
Tx Options	13.6%	45.5%
Making Tx Decisions	6.8%	43.2%
Clinical trials	11.4%	27.3%
Up to date research	20.5%	31.8%
Potential complications	4.5%	61.4%
Resources for emotional support	4.5%	29.5%

Impact of Diagnosis

MF patients indicated that a decrease in energy level and uncertainty about the future as factors that most negatively impact their quality of life.

In what ways has your MF diagnosis most negatively impacted your life?
- Energy level: 81.8%
- Limitation of activities: 38.6%
- Employment: 31.8%
- Social Relationships: 18.2%
- Relationships with loved ones: 22.7%
- Uncertainty about the future: 84.1%

Information Seeking

Aside from health care team, where else do you seek information about MF?
- Family/friends: 2.3%
- Other patients/survivors: 52.3%
- Patient support orgs: 59.1%
- Support groups: 36.4%
- Workshops: 11.4%
- Social media/message boards: 50.0%
- Internet: 81.8%
- Medical Literature: 36.4%

Other than their health care team, participants overwhelmingly reported using the internet for information. Participants also relied heavily on other MF patients/survivors, patient support organizations, and support groups.

Summary

Key findings from the survey reiterate:
- That the MF experience is defined by a general lack of understanding and information, including confusion around whether or not an individual has cancer
- Disease and treatment information and education are important to MF patients, and MF patients want to be connected and learn from other MF patients/survivors

Survey data confirmed the need for patient education materials for MF patients, which address:
- What the disease is
- How patients can partner with their health care team to manage the disease
- Where patients can access social and emotional support

Results informed CSC's development of the education program: *Frankly Speaking About Cancer: Myelofibrosis*. This program has helped fill in informational gaps for the MF community

For More Information Contact CSC at 1-888-793-9355 or www.cancersupportcommunity.org