CANCER SUPPORT COMMUNITY

A Global Network of Education and Hope

# Understanding the multiple myeloma experience: Results from an online survey.

**Background:** According to the American Cancer Society, nearly 22,000 people were diagnosed with multiple myeloma in 2012. Those affected by multiple myeloma face unique challenges, even compared to other cancer patients. Due to the rare nature of this cancer, there is a limited understanding of the needs and the impact of disease on those affected by multiple myeloma and few educational programs developed specifically for this population.

**Purpose/Objectives:** The purpose of this research is to investigate the unique needs and experiences of those affected by multiple myeloma. The results of the research will inform the development of comprehensive patient education materials specifically to address the needs of those affected by multiple myeloma.

**Methods/Approach:** In September and October 2012, the Cancer Support Community (CSC) conducted an online survey to investigate the unique needs and experiences of those affected by multiple myeloma. 158 individuals, including 119 multiple myeloma patients and 39 caregivers answered questions assessing cancer history, treatment, informational needs, psychosocial concerns, and demographic characteristics. Respondents were recruited online via CSC and partner organizations. Patients were 60.1 years old, and were diagnosed with multiple myeloma 4.6 years ago, on average. Most (59.1%) were female and Caucasian (95.6%).

**Results:** Only 21.2% of patients had heard of multiple myeloma before their diagnosis, and most (77.9%) reported having little or no understanding about their diagnosis initially. While most patients were provided general (86.5%) and treatment-related information (70.3%) at diagnosis, they received information less frequently on more specific topics including financial concerns (12.6%) and emotional support resources (22.5%). In addition to information from their healthcare team, most reported searching for information online (85.5%), patient support organizations (60.9%), and other multiple myeloma (59.1%) patients. Most patients (89.9%) and caregivers (68.8%) reported wanting to receive subsequent educational materials about multiple myeloma.

**Conclusions:** Survey results point to the need for additional patient education materials and services for those affected by multiple myeloma. Results will also inform the content of a program being developed by CSC. Taken together, survey responses demonstrate the need for further resources.

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# Understanding the multiple myeloma experience: Results from an online survey

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# Cancer Support Community Mission

To ensure that all people impacted by cancer are:

- Empowered by Knowledge
- Strengthened by Action
- Sustained by Community

# Background

- What is multiple myeloma (MM)?
- Over 20,000 new cases of MM each year
- Currently limited understanding of needs of those affected by MM

# Goals of Survey

- To investigate the unique needs and experiences of those affected by multiple myeloma
- Results will inform the development of comprehensive education program addressing the needs of those affected by MM

# Survey Design & Content

- Online survey (September-October 2012)
- Assessing experiences and needs of those affected by MM (patients and caregivers)
  - Diagnostic history and treatment
  - Treatment decision-making
  - Informational needs and sources of information
  - Psychosocial needs and sources of support
  - Impact of MM on their lives
  - Demographics

# Respondent Overview

158 individuals:

- 119 multiple myeloma patients
- 39 caregivers






# Patient Characteristics

- N=178
- Avg age= 60.1 yrs (s.d. 9.6 yrs)
- Most patients were:
  - Female (59.1%)
  - Caucasian (95.6%)
  - Married (76.5%)
- Avg time since initial diagnosis= 4.6 yrs
- 74.5% currently undergoing treatment

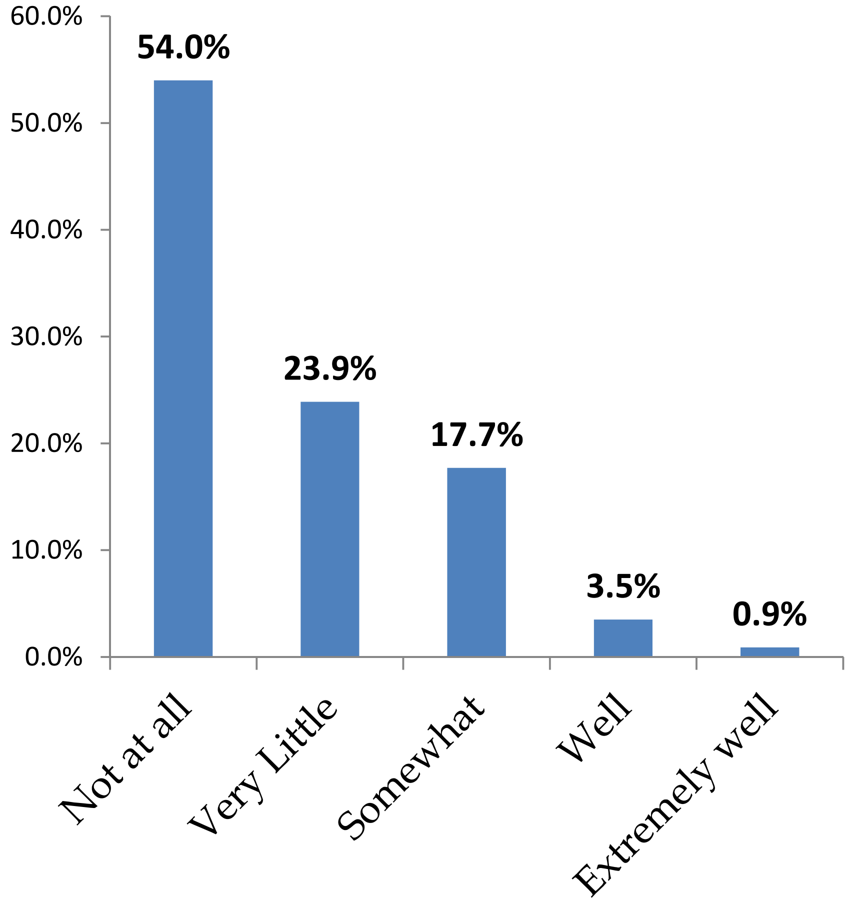
# Caregiver Characteristics

N= 39 caregivers

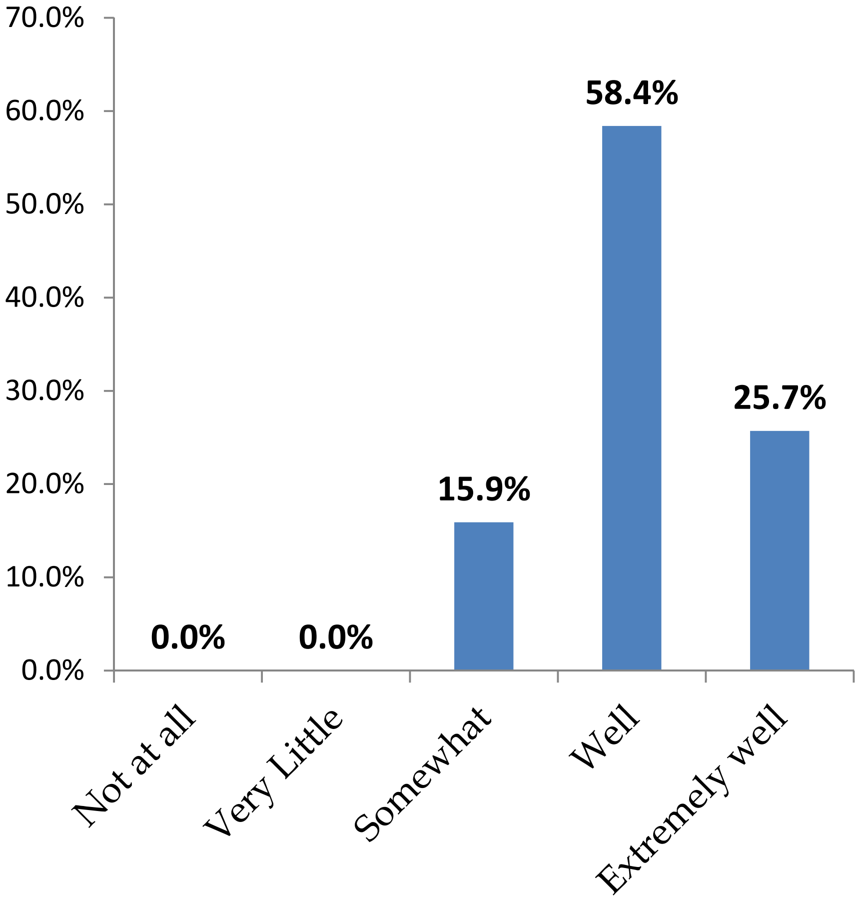
- 51.4% providing care to a spouse or significant other
- 89.7% identify as cancer caregivers in meaningful way
- 78.9% have been in this role for greater than one year

# Patient Understanding of MM

## At Diagnosis



## Current Understanding

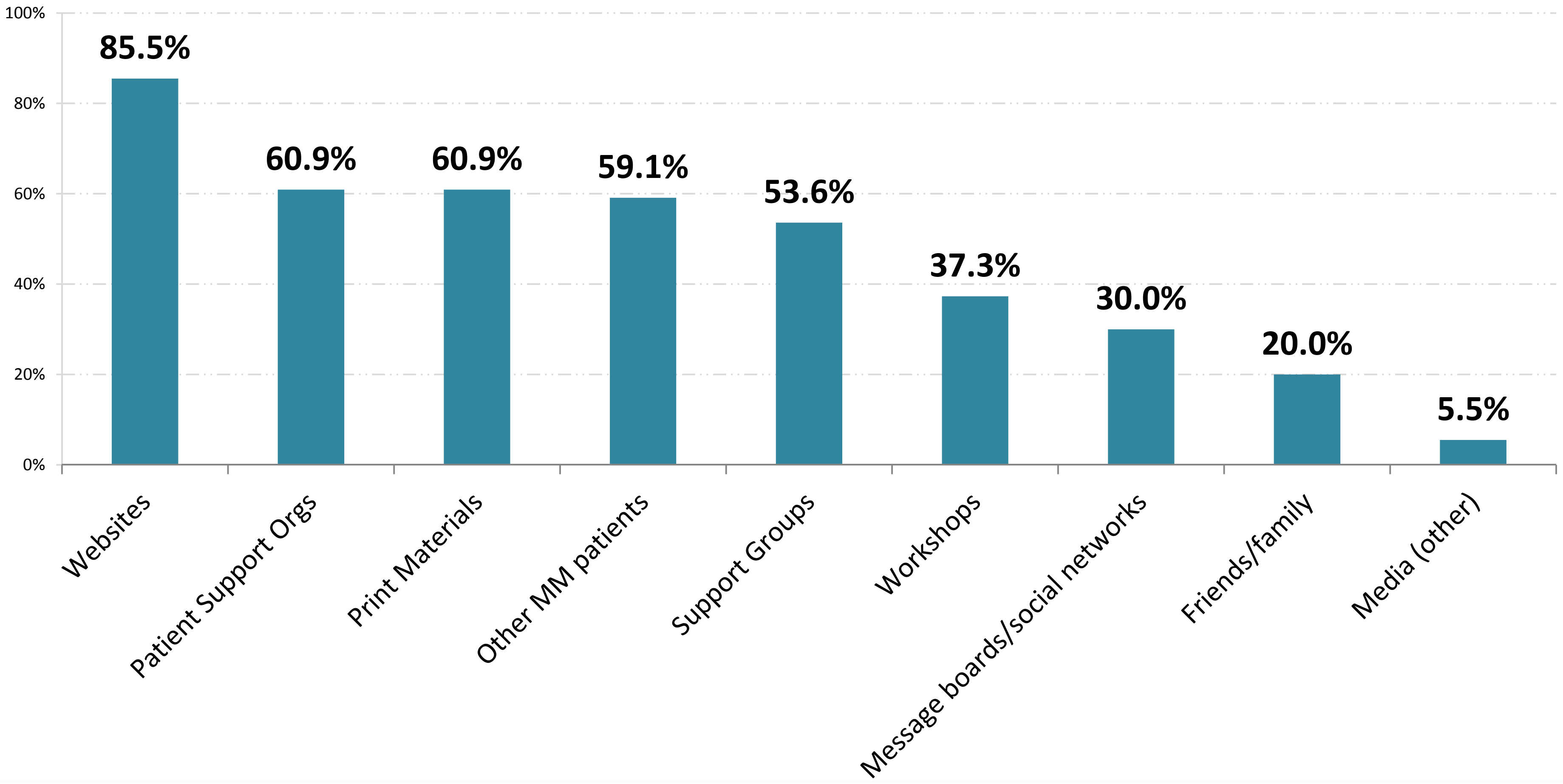


# Information Received

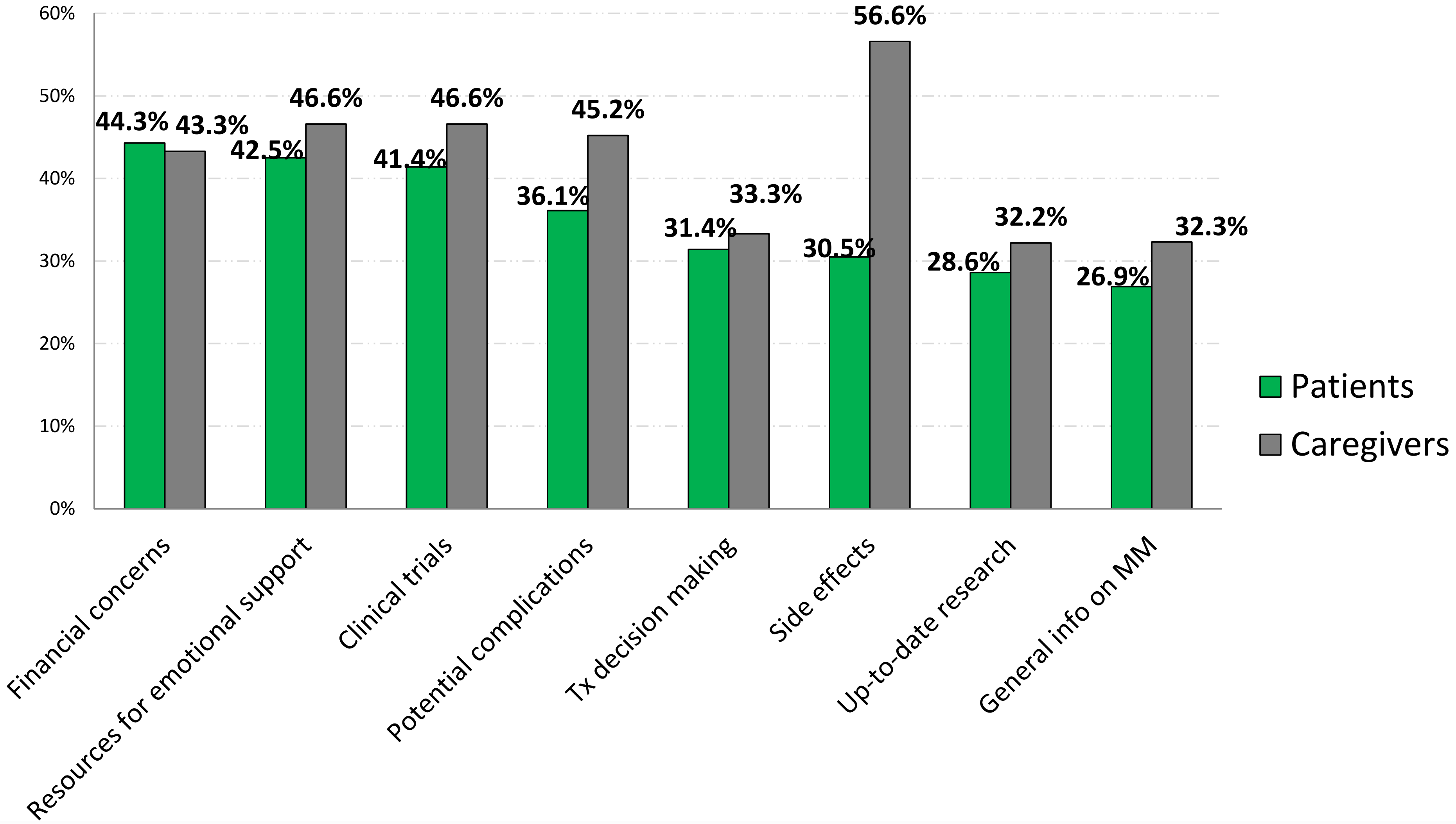
- At diagnosis, most patients were provided general (86.5%) and treatment-related information (70.3%).
- However, they received information less frequently on more specific topics, including:
    - How to connect with others with MM (24.3%)
    - Emotional support resources (22.5%)
    - Clinical trials (19.8%)
    - Patient assistance programs (16.2%)
    - How to make treatment decisions (18.9%)
    - Financial concerns (12.6%)

# Information Resources for Patients

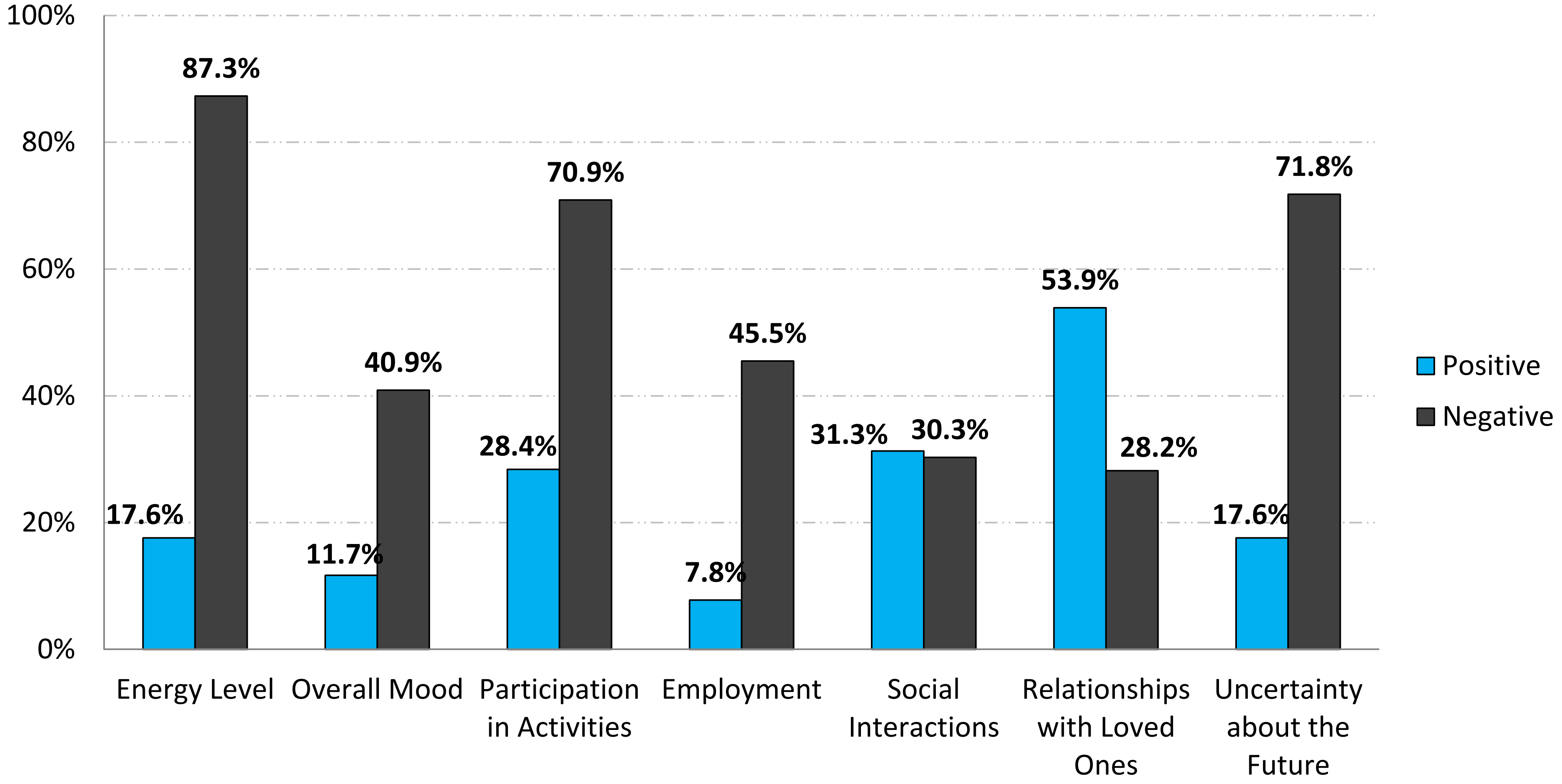
**(Aside from Dr.) Where did you search for MM information?**



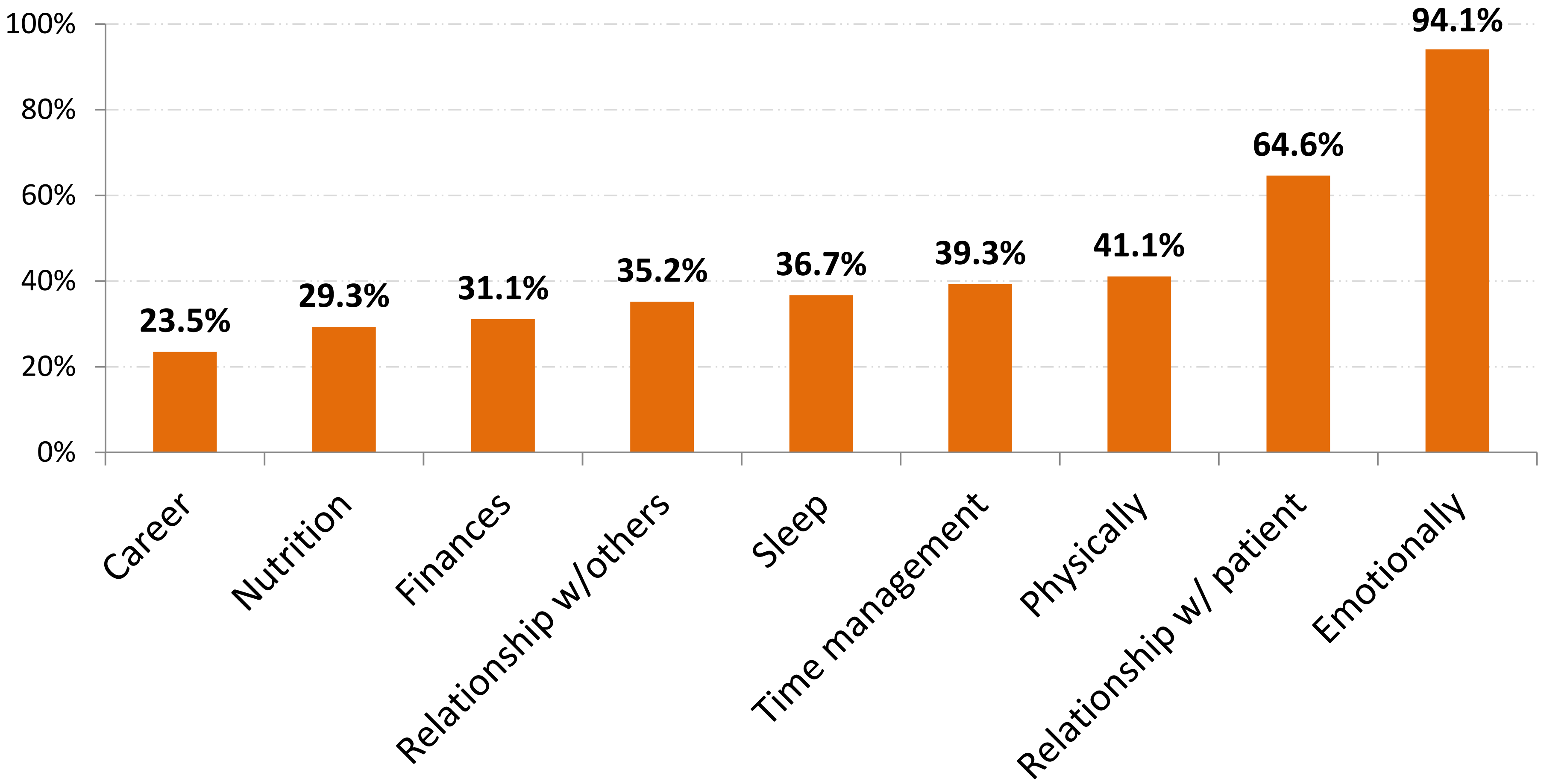
# Difficulty Obtaining Information



# Impact on Patients



# Impact on Caregivers



# Most Challenging Aspect of Living with MM

- Keeping up with the changing landscape of treatment options and potential side effects. It is a highly individualistic disease and thus, patients must educate themselves so they can make the best treatment decisions.
- Planning for the future.
- Conveying to others, especially other patients, that Multiple Myeloma does not define who I am, but rather that I am "living" with multiple myeloma and enjoying every day that I live.

# Advice from MM Caregivers

- You are not alone. There is help out there.
- You have to really research. Info is available but can be hard to find.
- Understanding cancer and understanding the role of the caregiver is important. What has been important to know is that Multiple Myeloma is treatable and people are able to be in remission for a long time with the proper care and treatment.

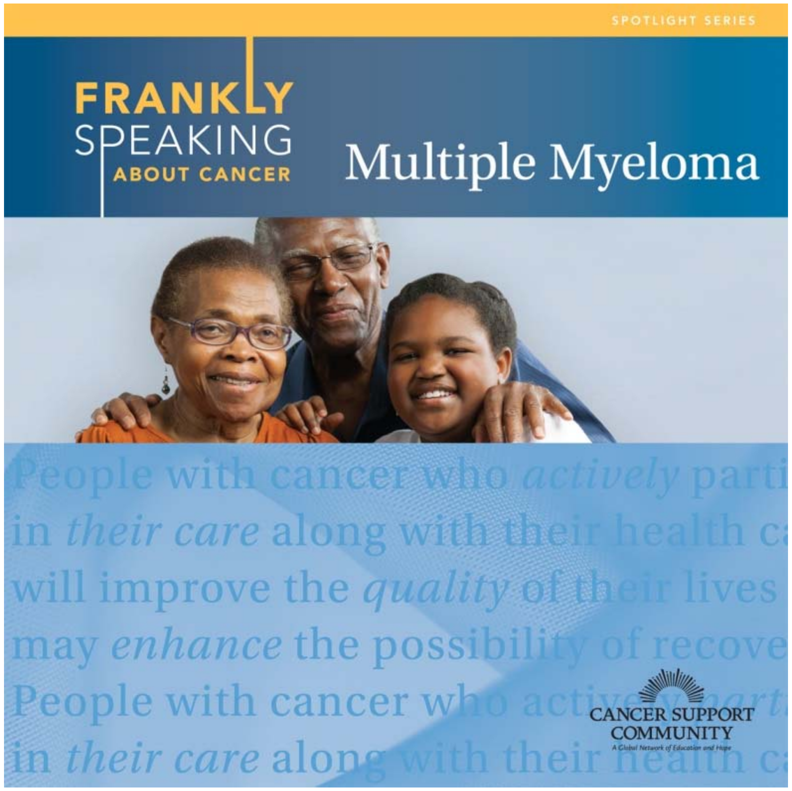
# Conclusions

- Survey results point to need for additional patient and caregiver programs and services for those affected by multiple myeloma

- Survey responses demonstrate the need for additional research on the social and emotional impact of multiple myeloma

# Next Steps

- Results informed CSC's educational program, which aims to help fill gaps identified in the survey



# For More Information

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