



## **Identification of gaps in resources and support for brain tumor patients and caregivers: Results from an online survey.**

**Background:** According to the Central Brain Tumor Registry of the United States (CBTRUS), funded by the National Brain Tumor Society, 69,720 new cases of primary brain tumors are expected to be diagnosed in 2013, including both malignant (24,620) and non-malignant (45,100) brain tumors. Given this life-changing diagnosis, there is a significant demand to meet the psychosocial needs of those affected by brain tumors. Currently, few educational programs are designed specifically for this population.

**Purpose/Objectives:** The purpose of this research is to investigate the experiences and needs of those affected by primary brain tumors. The results of the research will inform the development of a comprehensive educational program to meet the informational and emotional needs of those affected by brain tumors.

**Methods/Approach:** From December 2012 to January, 2013, 380 individuals affected by primary brain tumors (178 patients; 202 caregivers) completed an online survey developed by the Cancer Support Community (CSC) in partnership with the National Brain Tumor Society (NBTS). The survey assessed demographic characteristics, a variety of information about diagnostic and treatment history, and experiences and needs of those affected by brain tumors. Respondents were recruited online by CSC, NBTS and the Musella Foundation. Patients averaged 60.1 years old, and 36.4% were diagnosed with primary brain tumors since 2011. Most (75.1%) were female, Caucasian (93.3%), and resided in the U.S. (94.4%).

**Results:** At diagnosis, 52.0% patients reported the healthcare team provided them with information about brain tumors, and 24.4% did not understand their diagnosis. While most patients (65.7%) at one point received information about brain tumors, most reported specific information was difficult to obtain, including managing fear, managing financial/insurance concerns, and resources for emotional support. In addition to the healthcare team, most respondents searched for information online (89.5% patients; 94.6% caregivers) and spoke with others with brain tumors (54.1% patients; 44.0% caregivers). Overall, caregivers reported significant responsibilities and burden. 87.0% of caregivers are experiencing significant additional stress since becoming a caregiver.

**Conclusions:** Survey results point to the need for further educational materials and services for those affected by primary brain tumors. Taken together, survey responses suggest that the informational, social, and emotional concerns of patients and caregivers are not being fully addressed by healthcare professionals. Results will inform CSC's and NBTS's educational programming content, which will aim to help fill in informational gaps identified in the survey. In addition, further research is suggested in order to better understand the needs and ways to better serve those affected by primary brain tumors.



Identification of gaps in resources and  
support for brain tumor patients  
and caregivers:  
Results from an online survey

# Authors

## Cancer Support Community

Allison Harvey, MPH, CHES

Ivy Ahmed, MPH, MCHES

Anne Morris, MPH

Marni Amsellem, PhD

## National Brain Tumor Society

Michele Rhee, MBA, MPH

Kristina Knight

Larry Hand

# Cancer Support Community Mission

To ensure that all people impacted by cancer are:

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



# Background

- 69,720 new primary brain tumor cases expected in 2013
  - malignant (24,620)
  - non-malignant (45,100)
- Few educational programs tailored to adults (patients and caregivers) affected by primary brain tumors
- CSC and NBTS partnership

# Goals of Survey

- To investigate experiences and needs of adults affected by primary brain tumors
- Results to inform development of comprehensive educational book to meet informational and emotional needs of this population

# Survey Design & Content

- Online survey assessing experiences and needs of those with primary brain tumors and their caregivers
  - Tumor history, grade, diagnosis, and treatment
  - Treatment decision-making
  - Informational needs and sources of information
  - Psychosocial needs and sources of support
  - Impact of diagnosis
  - Demographics

# Recruitment and Respondent Overview

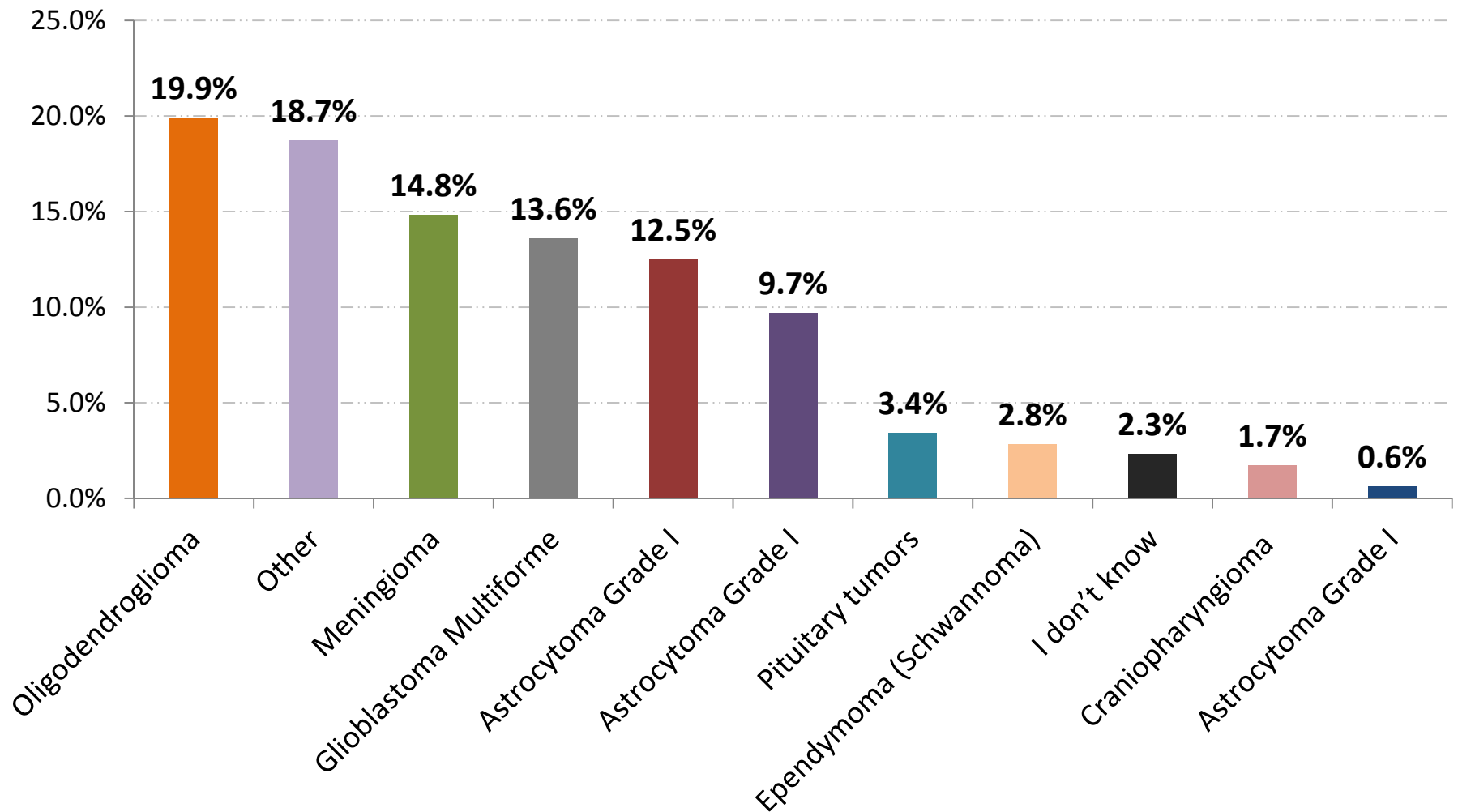
- Recruited online by Cancer Support Community (CSC), National Brain Tumor Society (NBTS), and Musella Foundation in Dec. 2012-Jan. 2013
- 380 individuals affected by brain tumors:
  - 178 (46.8%) individuals diagnosed with primary brain tumors
  - 202 caregivers



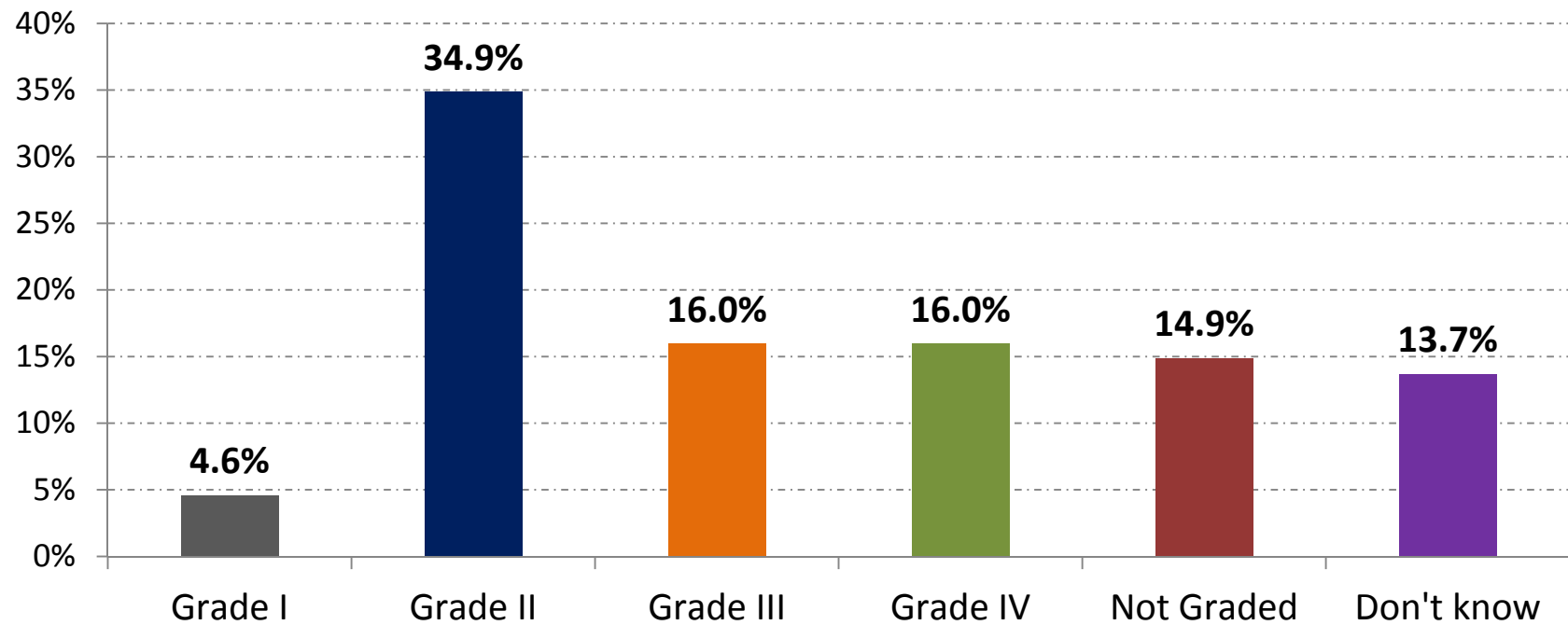
# Patient Characteristics

- N=178
- Avg age= 60.1 years (s.d. 9.6 years)
- Most respondents with brain tumors were:
  - Female (75.1%)
  - Caucasian (93.3%)
  - Reside in the U.S. (94.4%)
  - Currently had health insurance (92.7%)
  - College graduates (31.4%)
- Time since initial diagnosis:
  - 36.4% had been diagnosed since 2011
  - 49.6% diagnosed in 2009 or earlier

# Brain Tumor Diagnosis



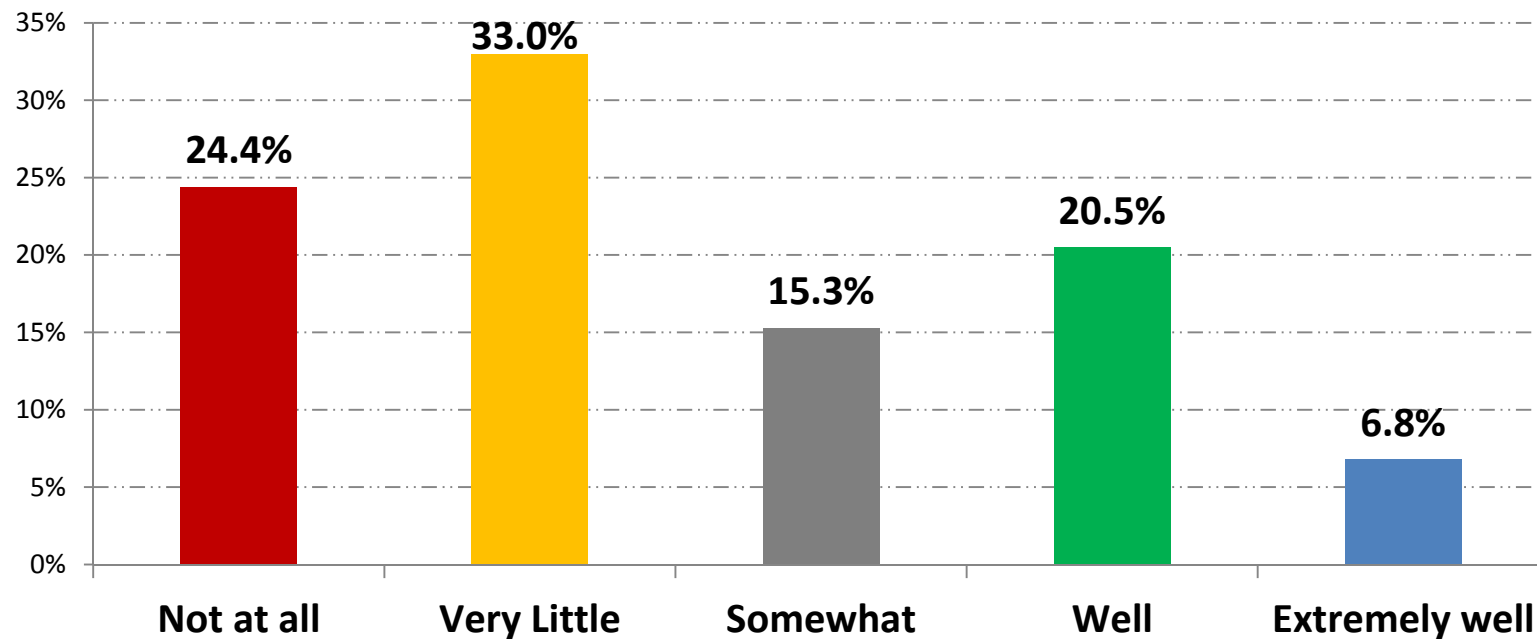
# Tumor Grade at Diagnosis



- 25.3% had experienced a recurrence

# Understanding of Brain Tumor Diagnosis at Time of Diagnosis

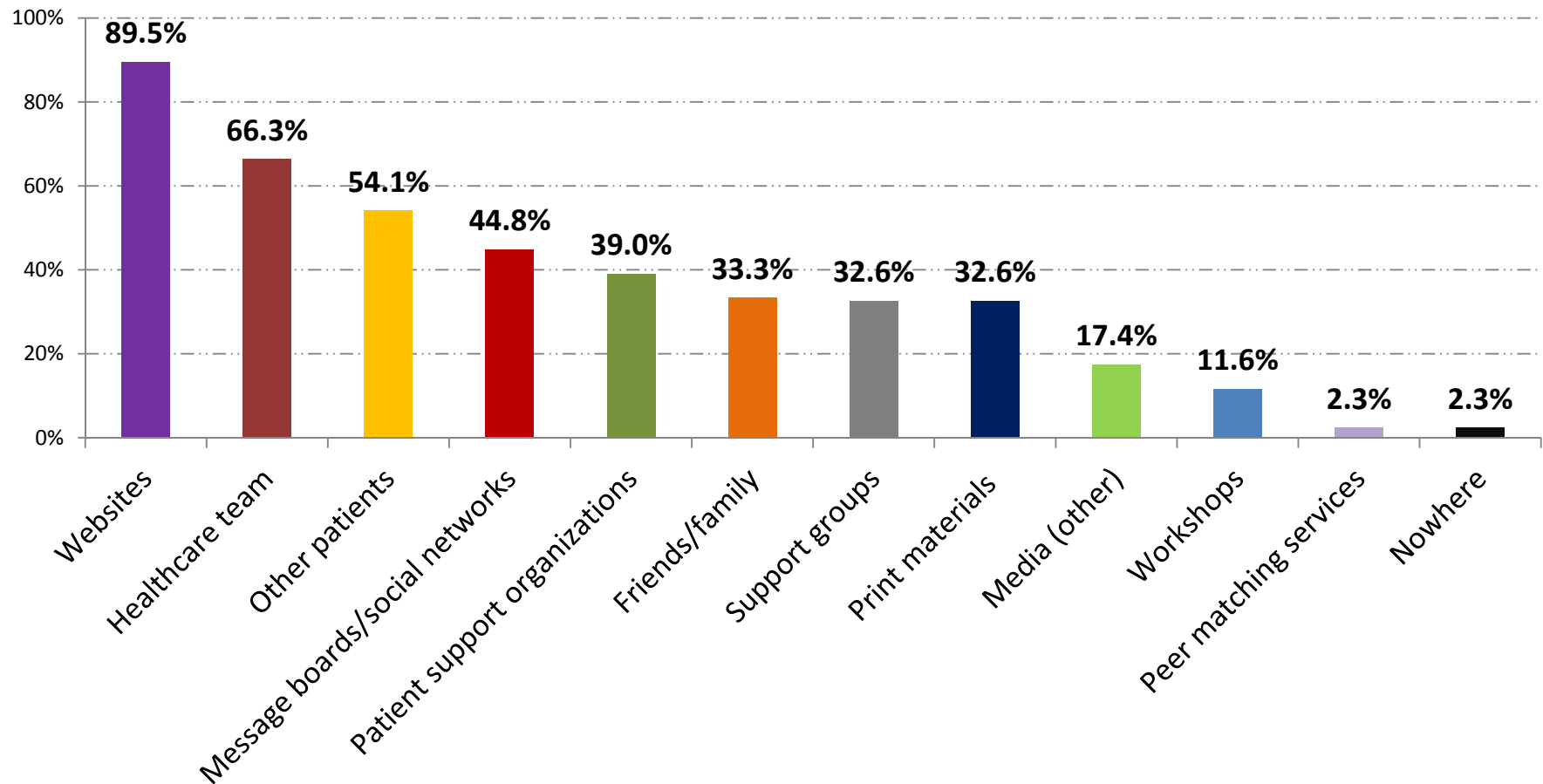
Patient understanding of diagnosis at diagnosis



52.0% of patients reported health care team provided them with information about brain tumors

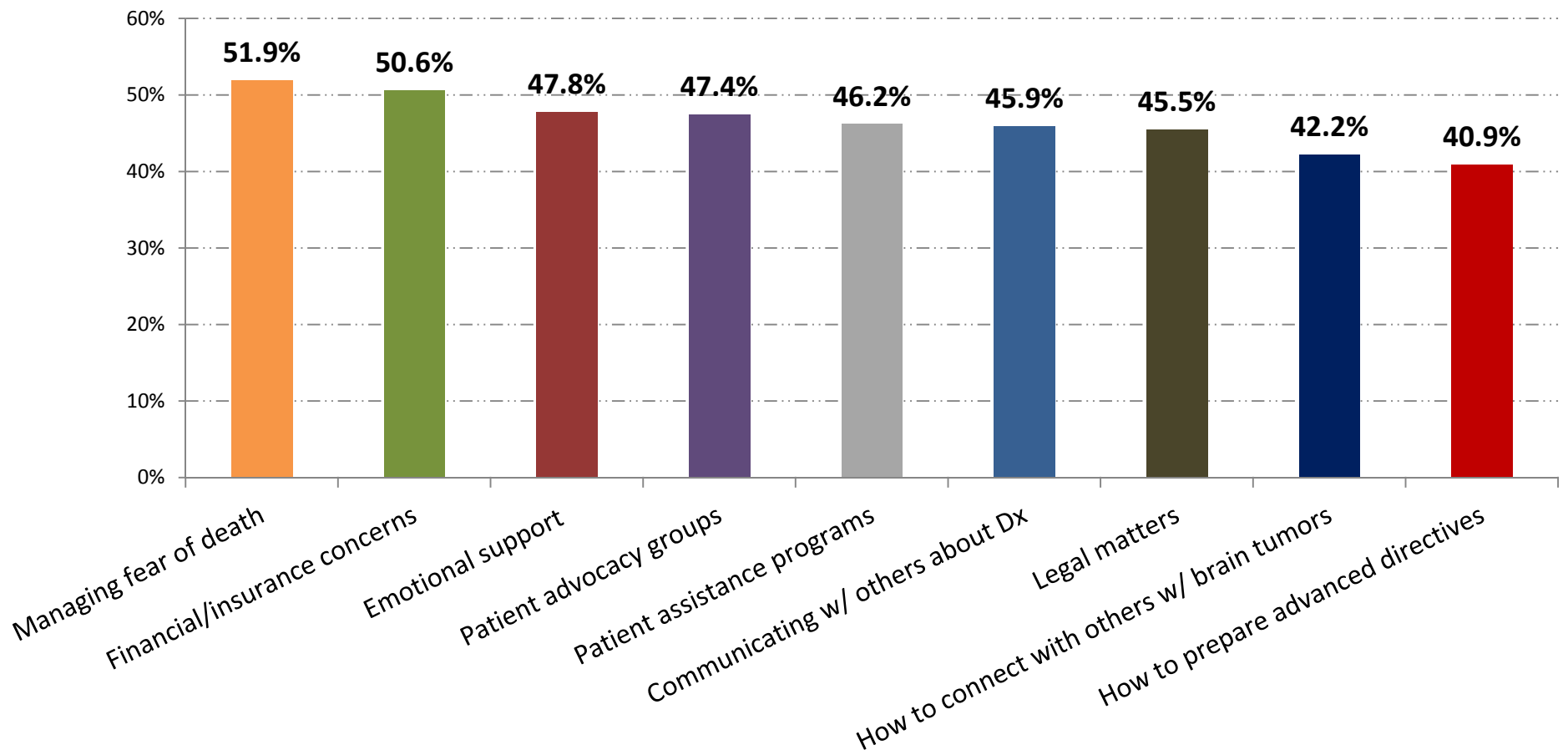
# Obtaining Brain Tumor Information

Where have you searched for information about brain tumors?



# Unmet Informational Needs

Information relevant to your care you have not received (but need)



# Patient Experiences

- Many reported positive effects of having a brain tumor:
  - spirituality (63.0%)
  - relationships with loved ones (70.9%)
- Negative impact of diagnosis (and treatment) on lives:
  - uncertainty about the future (69.9%)
  - employment (55.2%)
  - participation in activities (51.5%)

# Caregiver Characteristics

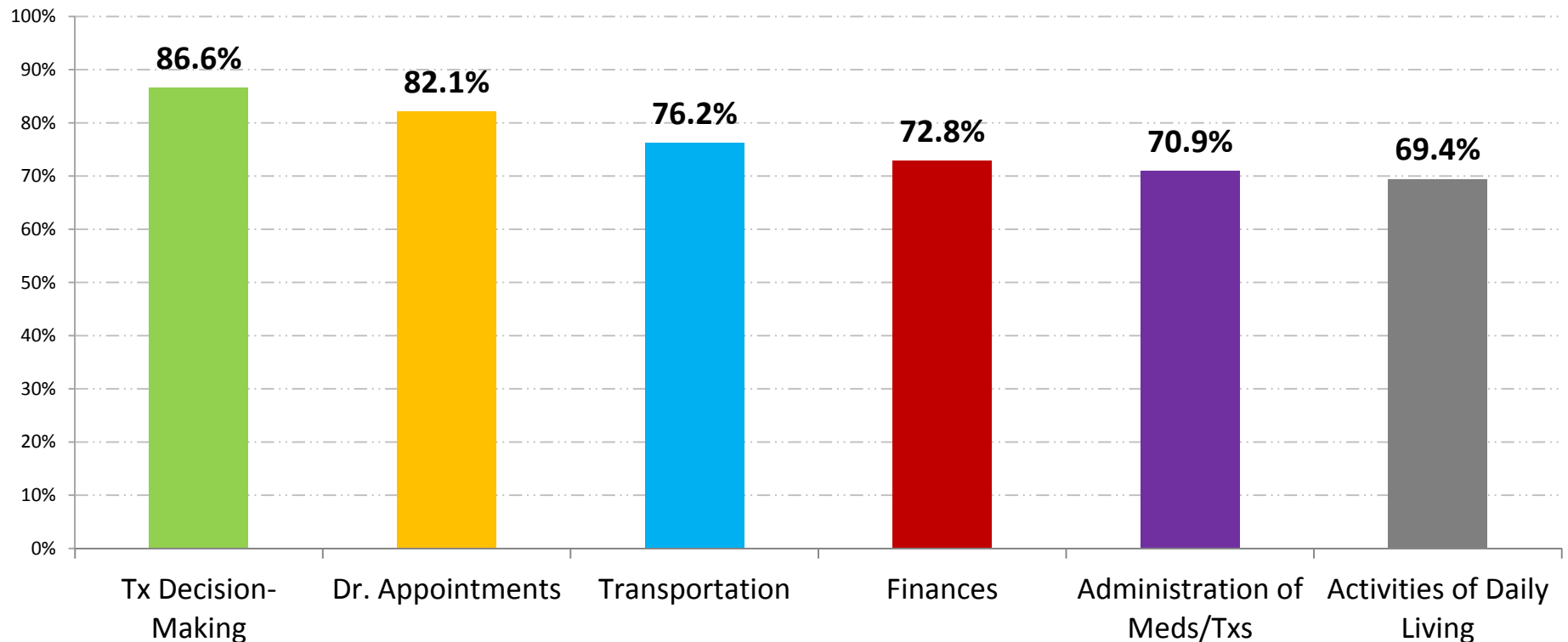
- N= 202
- Mean age 46.2 years (s.d.= 12.2 years)
- Caregivers were:
  - Female (83.3%)
  - Caucasian (93.5%)
  - Reside in the U.S. (91.3%)
  - Providing care to a spouse or significant other (43.3%)
- Care recipients:
  - Average age of care recipients was 49.8 years (s.d.=14.9)
  - Most (61.2%) were diagnosed with Grade IV brain tumors



# The Provision of Care

- 37.3% provide 40+ hours of care/ week
- A variety of care-related activities were provided

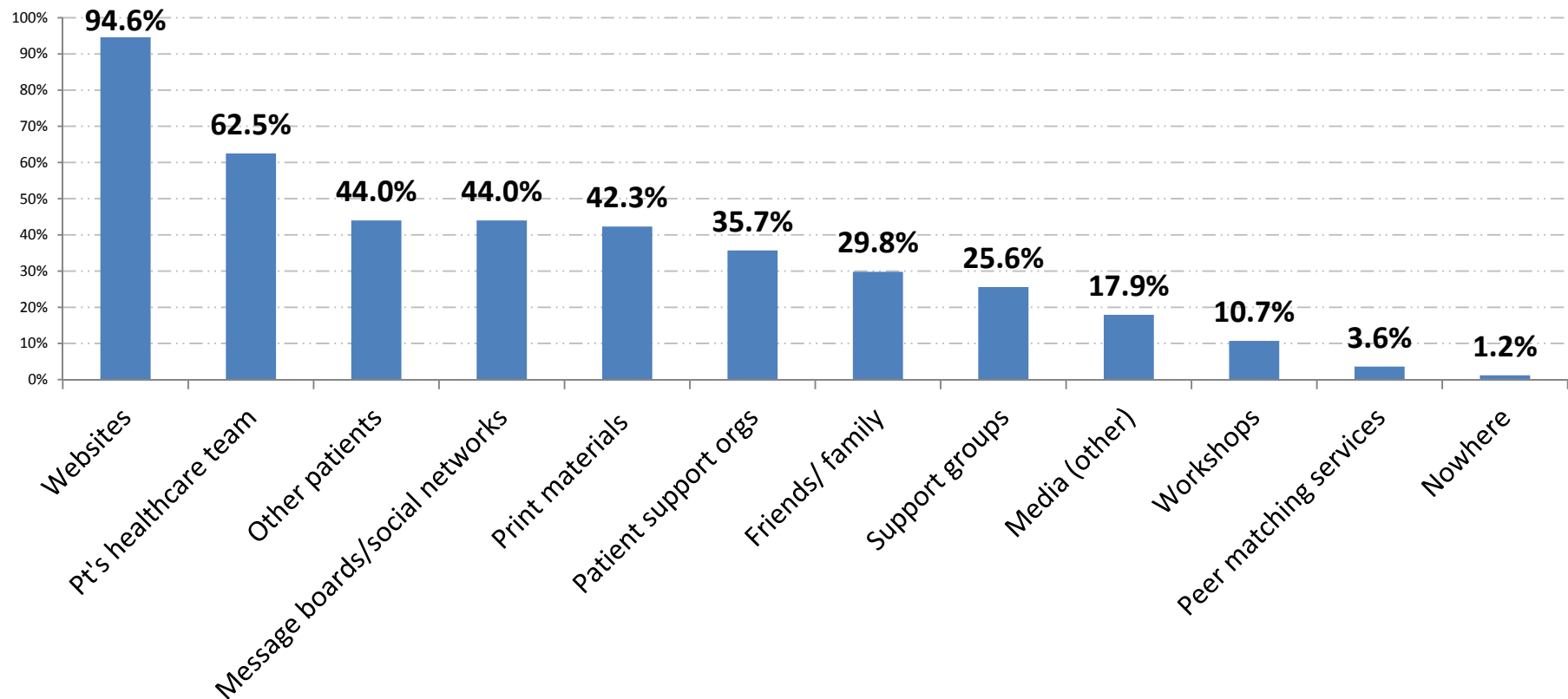
Type of care provided



# Obtaining Information: Caregivers

- 60.9% reported health care team provided info upon diagnosis
- 51.0% reported information was 'very' / 'extremely' useful

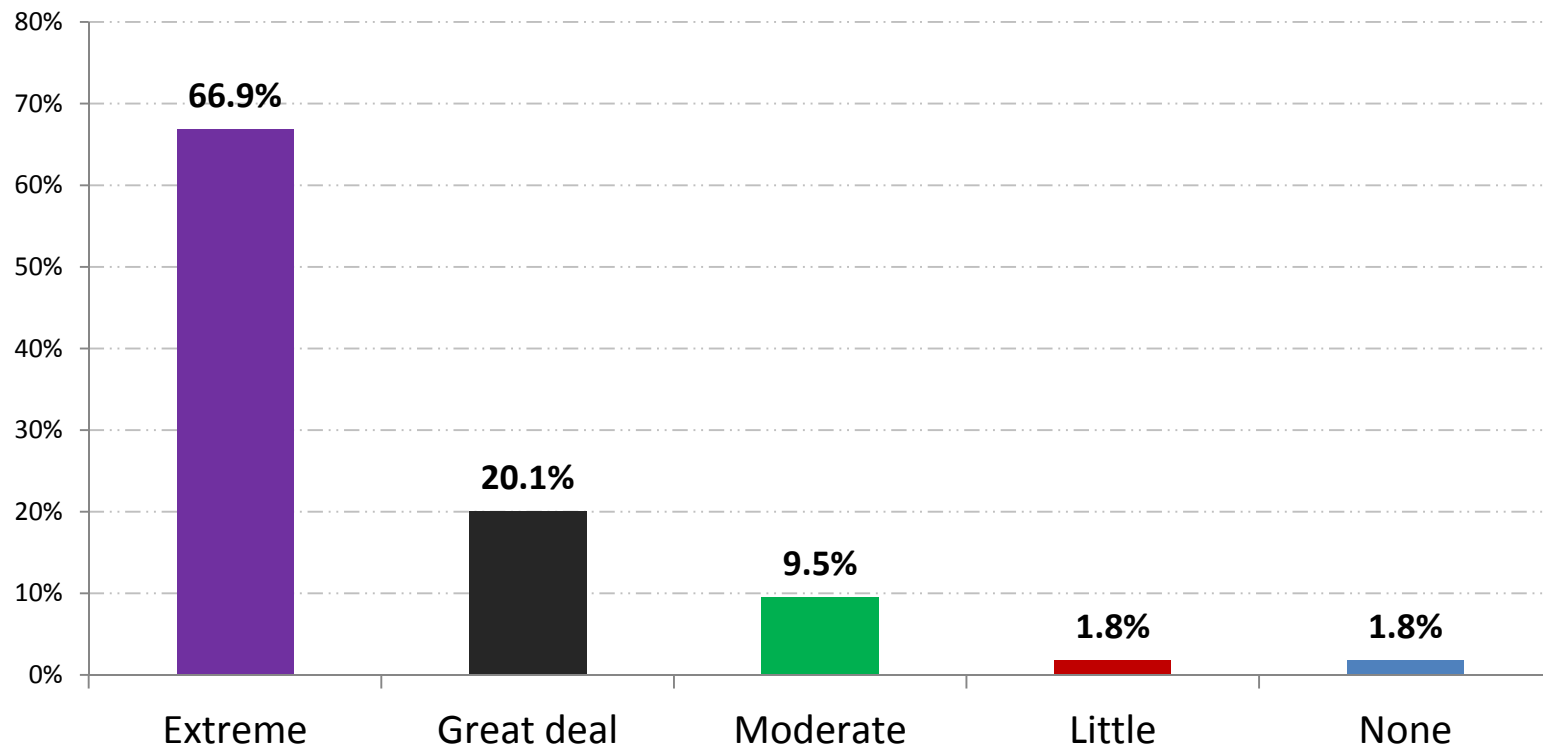
Where have you searched for information about brain tumors?



# Impact on Caregivers

- Nearly all (87.0%) experienced a significant level of additional stress due to loved one's diagnosis

**Additional stress because of brain tumor diagnosis**

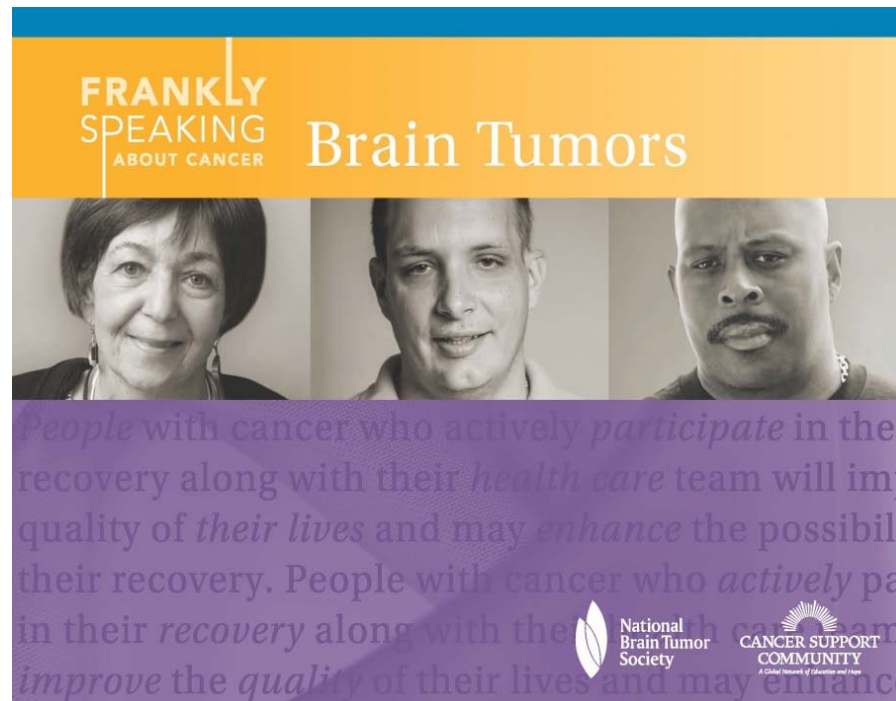


# Conclusions

- Survey results point to need for further educational materials and services for those affected by primary brain tumors
- Taken together, survey responses suggest that the informational, social, and emotional concerns of patients and caregivers are not being fully addressed by healthcare professionals
- Additional research can further explore ways to better serve those affected by primary brain tumors

# Next Steps

- Results informed CSC's and NBTS's educational book, which aims to help fill in gaps identified



# For More Information



1050 17<sup>th</sup> Street, NW Suite 500  
Washington, DC 20036  
Phone: 202-659-9709

[www.cancersupportcommunity.org](http://www.cancersupportcommunity.org)