



Data Highlights

A Cancer Health Outcomes Data Resource

Quality of Life in Individuals with Brain and Spine Tumors

The National Cancer Institute (NCI) defines **rare cancers** as those that affect fewer than 15 out of 100,000 individuals each year. Rare cancers can be more difficult to prevent, diagnose, and treat than more common cancers. Because there are fewer cases, research can be difficult. However, resources such as NCI’s Surveillance, Epidemiology and End Results-Medicare Health Outcomes Survey (SEER-MHOS) offer researchers opportunities to evaluate rare tumors, such as brain and spine tumors, and the quality of life for individuals living with these tumors.

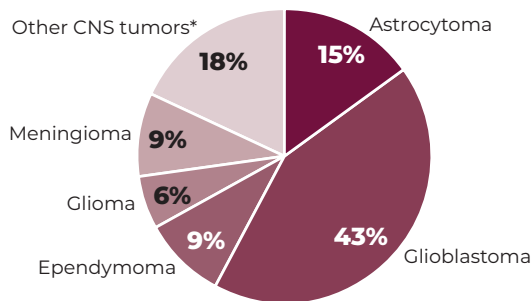
Primary central nervous system (CNS) tumors are tumors that begin in the brain or spinal cord. Primary CNS tumors account for less than 2% of all cancers, all being classified as rare tumors.¹

Sample Description

The SEER-MHOS data resource **population** includes 191 **Medicare beneficiaries (mean age: 67)** diagnosed with CNS tumors. A majority of SEER-MHOS participants have **grade IV (high-grade) tumors** (75%) and over half received **radiation and/or surgery**. Data was compiled from cohorts 1–20 of the 1998–2019 SEER-MHOS data resource.

SEER-MHOS includes data from individuals living with various types of CNS tumors, including exceptionally rare **tumor types (ex: ependymoma) that affect fewer than 2,000 individuals each year**.

Percentage of Cases by CNS Tumor Diagnosis



*Neuroepithelial, embryonal/primitive/medulloblastoma, nerve sheath, mesenchymal, chordoma/chondrosarcoma, unspecified neoplasm

Demographic and Clinical Characteristics

| | Number | Percentage |
|----------------------------|--------|------------|
| Sex | | |
| Female | 97 | 50.8% |
| Race/Ethnicity | | |
| White | 137 | 71.7% |
| Asian or Pacific Islander | 11 | 5.8% |
| Black or African American | 23 | 12.0% |
| Hispanic | 20 | 10.5% |
| Education | | |
| Some high school or less | 33 | 18.1% |
| High school graduate/ GED | 62 | 34.1% |
| Some college | 46 | 25.3% |
| College graduate or higher | 41 | 22.5% |
| Tumor Grade* | | |
| I-III | 17 | 24.6% |
| IV | 52 | 75.4% |

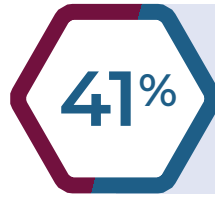
*SEER began to collect tumor grade information starting in 2014.

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Experiences of Living with Brain and Spine Tumors

Research has shown that individuals living with a brain or spine tumor are highly symptomatic.

One study found that “more than 50% of individuals reported at least 10 concurrent symptoms, and 40% of individuals reporting having at least 3 moderate-to-severe symptoms.”² Symptoms and functional changes can be a result of the tumor itself or from treatment and medications.

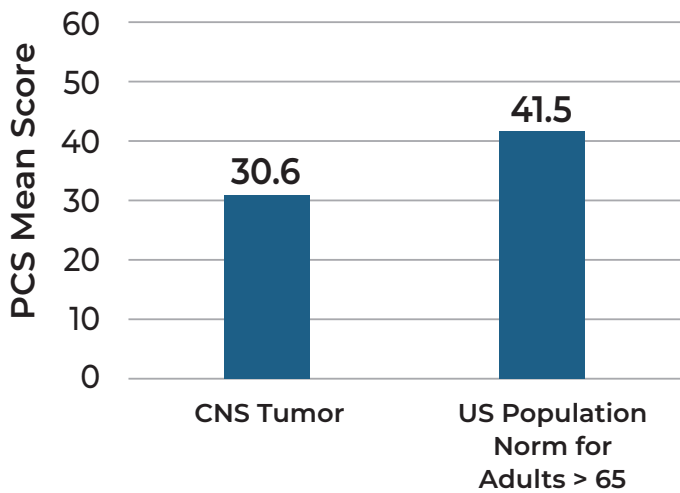


41% of individuals living with a brain or spine tumor report experiencing depressive symptoms.

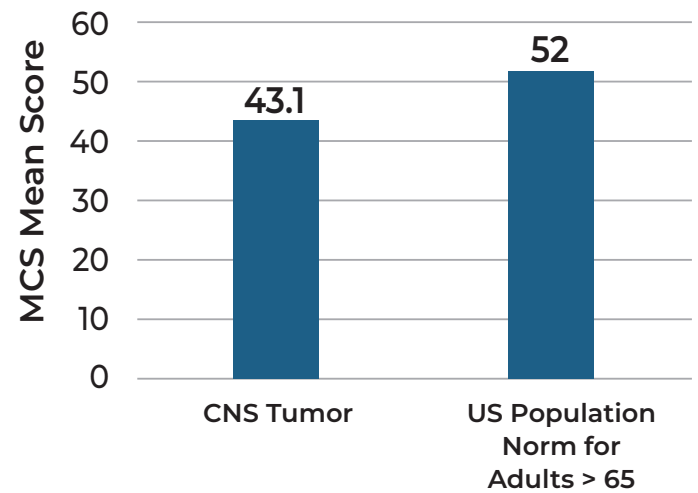
Physical and Mental Health

Physical component scores (PCS) and mental component scores (MCS) convey the physical and mental health of individuals. In individuals > 65 years old, the average PCS score is 41.5 and MCS score is 52.0. Average physical and mental health scores are lower for individuals with brain and spine tumors.

Physical Health



Mental Health



General Health

The Centers for Disease Control and Prevention (CDC) **Healthy Days Measure** captures an individual’s mental and physical health, as well as its impacts on regular activities, such as self-care, work, and recreation, over a 30-day period.



In the past 30 days, individuals with CNS tumors reported feeling unhealthy for over half of the month.

| CDC Healthy Days (N=150*) | Mean |
|---|------|
| Physically unhealthy days in past 30 days | 14.8 |
| Mentally unhealthy days in past 30 days | 9.4 |
| Unhealthy days in past 30 days | 17.6 |
| Days of limited activity due to poor health in past 30 days | 13.1 |

*There are some variations in sample size based on survey completion by sample population for each response.

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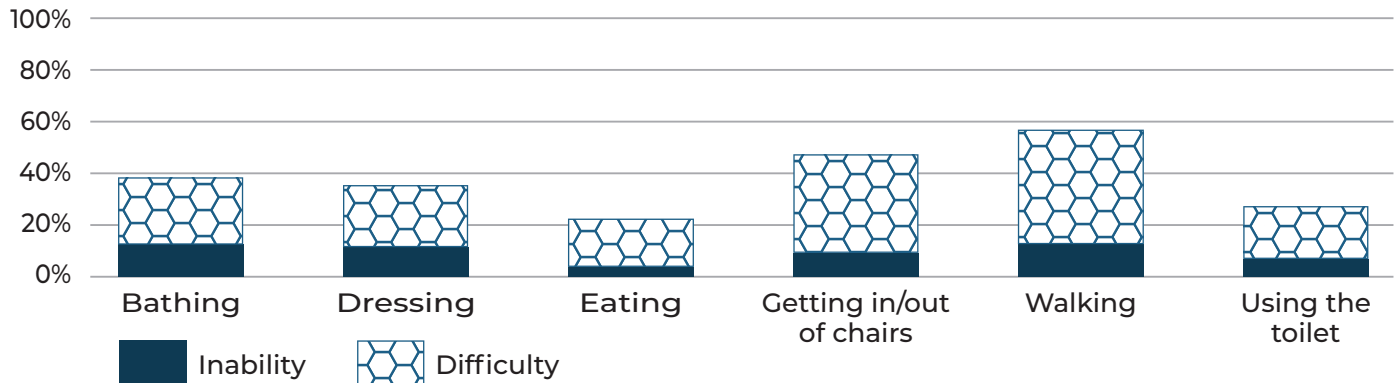
Activities of Daily Living

Activities of daily living (ADL) are the tasks of everyday life. A reported difficulty in ADLs can indicate a loss of self-care capabilities and negatively impact quality of life.



Over 45% of individuals report at least some difficulty with walking and getting in and out of chairs.

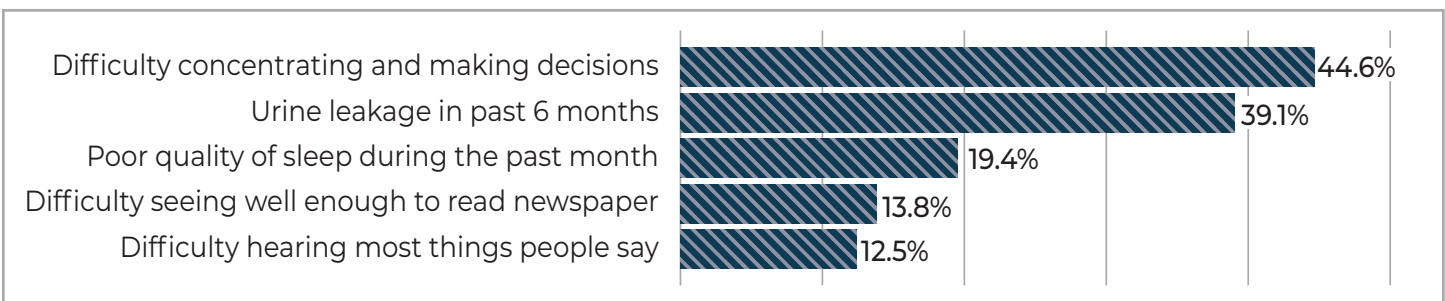
ADLs of Individuals Living with CNS Tumor



Symptom Burden

Individuals with brain and spine tumors report a variety of symptoms, with over 40% reporting difficulty concentrating and making decisions and screening positive for depression.

Symptom Experience of Individuals Living with CNS Tumor



About SEER-MHOS

SEER-MHOS is a publicly accessible data resource combining cancer registry and survey data on older adults diagnosed with cancer. This research provides a rich opportunity to examine cancer health outcomes, such as health-related quality of life and activities of daily living, along with clinical and epidemiologic information.

Contact Us

Researchers are strongly encouraged to request information and technical support at SEER-MHOS@hsag.com to obtain help understanding the data before making requests and undertaking any analyses.

To stay up to date on the data resource, please join the [SEER-MHOS Listserv](#).

References and Resources

Visit [NCI-CONNECT](#) to learn more how NCI aims to advance the understanding of rare adult CNS cancers. NCI-CONNECT has a particular interest in 12 tumor types, each with fewer than 2,000 individuals diagnosed per year.

¹ [NCI-CONNECT](#)

² Armstrong, T. S., Vera-Bolanos, E., Acquaye, A. A., Gilbert, M. R., Ladha, H., & Mendoza, T. (2016). The symptom burden of primary brain tumors: evidence for a core set of tumor- and treatment-related symptoms. *Neuro-Oncology*, 18(2), 252–260. <https://doi.org/10.1093/neuonc/nov166>

