Central Brain Tumor Registry of the United States

- Years of life lost due to central nervous system tumor subtypes in the United States
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- Primary Tumors of the Brain and Central Nervous System in Adults and Children in Sub-Saharan Africa: Protocol for a Scoping Review
- Characteristics of long-term glioblastoma survivors diagnosed from 2010 to 2016 in the United States
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Central Brain Tumor Registry of the United States (CBTRUS)

www.cbtrus.org.

The Central Brain Tumor Registry of the United States, CBTRUS, is a not-for-profit corporation committed to providing a resource for gathering and disseminating current epidemiologic data on all primary benign and malignant brain and other central nervous system tumors for the purposes of accurately describing their incidence and survival patterns, evaluating diagnosis and treatment, facilitating etiologic studies, establishing awareness of the disease, and ultimately, for the prevention of all central nervous system tumors.

CBTRUS was established in 1992 to provide descriptive statistical data on all primary brain tumors. The database contains the largest collection of incidence data in the United States for primary brain and central nervous system tumors.

The Central Brain Tumor Registry of the United States (CBTRUS), in collaboration with the Centers for Disease Control and Prevention and National Cancer Institute, is the largest population-based registry focused exclusively on primary brain and other central nervous system (CNS) tumors in the United States (US) and represents the entire US population.

Utilizing incidence data from the Central Brain Tumor Registry of the United States (CBTRUS) Cioffi et al. analyzed the impact of the COVID-19 pandemic on primary brain and other CNS tumor incidence for the first year of the pandemic.

Methods: Monthly age-adjusted incidence rates and incidence trends for 2019 and 2020 were determined for age at diagnosis, sex, race, ethnicity, diagnostic confirmation, behavior, tumor histopathology, and county-level urbanization. Monthly incidence rate ratios comparing 2020 and 2019 were evaluated for the same factors.

Results: Overall, there was a notable decrease in incidence rates in March-May of 2020 when

compared to 2019. These decreases were driven by non-malignant tumors, with a 50% incidence decrease between March of 2020 and 2019. Individuals who were Black had a larger incidence decrease in early 2020 than individuals who were White. Radiographically confirmed tumors saw larger incidence decreases than histologically confirmed tumors. There were no changes in monthly incidence for glioblastoma in 2020 compared to 2019.

These data provide evidence that disruptions in medical care, such as governmental and health care mandates, in response to the COVID-19 pandemic resulted in overall decreased incidence for primary brain tumors in early 2020¹⁾.

Ostrom in 2019 reported the most up-to-date population-based data on primary brain tumors available and supersedes all previous reports in terms of completeness and accuracy. All rates are age-adjusted using the 2000 US standard population and presented per 100,000 population. The average annual age-adjusted incidence rate (AAAIR) of all malignant and non-malignant brain and other CNS tumors was 23.41 (Malignant AAAIR = 7.08, non-Malignant AAAIR = 16.33). This rate was higher in females compared to males (25.84 versus 20.82), Whites compared to Blacks (23.50 versus 23.34), and non-Hispanics compared to Hispanics (23.84 versus 21.28). The most commonly occurring malignant brain and other CNS tumors were glioblastoma (14.6% of all tumors), and the most common non-malignant tumor was meningioma (37.6% of all tumors). Glioblastoma was more common in males, and meningioma was more common in females. In children and adolescents (age 0-19 years), the incidence rate of all primary brain and other CNS tumors was 6.06. An estimated 86,010 new cases of malignant and non-malignant brain and other CNS tumors are expected to be diagnosed in the US in 2019 (25,510 malignant and 60,490 non-malignant). There were 79,718 deaths attributed to the malignant brain and other CNS tumors between 2012 and 2016. This represents an average annual mortality rate of 4.42. The five-year relative survival rate following diagnosis of a malignant brain and other CNS tumors was 35.8%, and the five-year relative survival rate following diagnosis of a non-malignant brain and other CNS tumors was 91.5%²⁾.

The CBTRUS website no longer directly hosts the CBTRUS Statistical Report. The Report is now published by Oxford University Press as a Supplement to the official journal, Neuro-Oncology, of the Society for Neuro-Oncology and is accessed online through a "Free to View" link. A printed publication is also available. This change enables the CBTRUS Reports to be easily referenced through a listing in PubMed. And referenced it is! The CBTRUS Report was at the top of the list of the most cited of Neuro-Oncology publications and has contributed to the journal's impact factor.

The CBTRUS Histology Grouping Scheme has been revised to reflect the most up-to-date WHO Classification of Tumours of the Central Nervous System. Analyses found in the CBTRUS Report with data from 2006-2010 are formatted according to the 2012 CBTRUS Histology Grouping Scheme.

Brain tumors are the:

most common cancer among those age 0-19 (leukemia is the second).

leading cause of cancer-related deaths in children (males and females) age 1-19 (leukemia is the

second).

Brain Tumor Statistics:

Nearly 78,000 new cases of primary brain tumors are expected to be diagnosed this year. This figure includes nearly 25,000 primary malignant and 53,000 non-malignant brain tumors.

It is estimated that more than 4,600 individuals between the ages of 0-19 will be diagnosed with a primary brain tumor this year.

Malignant brain tumors are the most common cause of cancer-related deaths in adolescents and young adults aged 15-39 and the most common cancer occurring among 15-19 year olds.

There are nearly 700,000 people in the U.S. living with a primary brain and central nervous system tumor.

This year, nearly 17,000 people will lose their battle with a primary malignant and central nervous system brain tumor.

There are more than 100 histologically distinct types of primary brain and central nervous system tumors.

Survival after diagnosis with a primary brain tumor varies significantly by age, histology, molecular markers and tumor behavior.

The median age at diagnosis for all primary brain tumors is 59 years.

Tumor-Specific Statistics:

Meningiomas represent 36.4% of all primary brain tumors, making them the most common primary brain tumor. There will be an estimated 24,880 new cases in 2016.

Gliomas, a broad term which includes all tumors arising from the gluey or supportive tissue of the brain, represent 27% of all brain tumors and 80% of all malignant tumors.

Glioblastomas represent 15.1% of all primary brain tumors, and 55.1% of all gliomas.

Glioblastoma has the highest number of cases of all malignant tumors, with an estimated 12,120 new cases predicted in 2016.

Astrocytomas, including glioblastoma, represent approximately 75% of all gliomas.

Nerve sheath tumors (such as acoustic neuromas) represent about 8% of all primary brain tumors.

Pituitary tumors represent 15.5% of all primary brain tumors. There will be an estimated 11,700 new cases of pituitary tumors in 2016.

Lymphomas represent 2% of all primary brain tumors.

Oligodendrogliomas represent nearly 2% of all primary brain tumors.

Medulloblastomas/embryonal/primitive tumors represent 1% of all primary brain tumors.

The majority of primary tumors (36.4%) are located within the meninges $^{3)}$.

1)

Cioffi G, Waite KA, Price M, Neff C, Kruchko C, Ostrom QT, Barnholtz-Sloan JS. The Impact of COVID-19 on 2020 Monthly Incidence Trends of Primary Brain and Other CNS Tumors. Neuro Oncol. 2024 Jan 3:noad235. doi: 10.1093/neuonc/noad235. Epub ahead of print. PMID: 38167948.

Ostrom QT, Cioffi G, Gittleman H, Patil N, Waite K, Kruchko C, Barnholtz-Sloan JS. CBTRUS Statistical Report: Primary Brain and Other Central Nervous System Tumors Diagnosed in the United States in 2012-2016. Neuro Oncol. 2019 Nov 1;21(Supplement_5):v1-v100. doi: 10.1093/neuonc/noz150. PubMed PMID: 31675094.

http://www.abta.org/about-us/news/brain-tumor-statistics/

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Last update: 2024/06/07 02:52