

Prevalence estimates for primary brain tumors in the United States by age, gender, behavior, and histology

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Prevalence is the best indicator of cancer survivorship in the population, but few studies have focused on brain tumor prevalence because of previous data limitations. Hence, the full impact of primary brain tumors on the healthcare system in the United States is not completely described. The present study provides an estimate of the prevalence of disease in the United States, updating an earlier prevalence study. Incidence data for 2004 and survival data for 1985–2005 were obtained by the Central Brain Tumor Registry of the United States from selected regions, modeled under 2 different survival assumptions, to estimate prevalence rates for the year 2004 and projected estimates for 2010. The overall incidence rate for primary brain tumors was 18.1 per 100 000 person-years with 2-, 5-, 10-, and 20-year observed survival rates of 62%, 54%, 45%, and 30%, respectively. On the basis of the sum of nonmalignant and averaged malignant estimates, the overall prevalence rate of individuals with a brain tumor was estimated to be 209.0 per 100 000 in 2004 and 221.8 per 100 000 in 2010. The female prevalence rate (264.8 per 100 000) was higher than that in males (158.7 per 100 000). The averaged prevalence rate for malignant tumors (42.5 per 100 000) was lower than the prevalence for nonmalignant tumors (166.5 per 100 000). This study provides estimates of the 2004 ($n = 612\,770$) and 2010 ($n = 688\,096$) expected number of individuals living with primary brain tumor diagnoses in the United States, providing more current and robust estimates for aiding healthcare planning and patient advocacy for an aging US population.

Keywords: brain tumors, prevalence, United States.

Despite published studies of population-based incidence, survival, and mortality, the full impact of primary brain tumors on the healthcare system in the United States has not been fully described. Although cancer prevalence is the best indicator of cancer survivorship and potential implications for long-term patient needs in the population, it is not a commonly reported measure. Few tumor registries meet the data requirements of both long-term incidence and follow-up specifically for nonmalignant brain tumors, which has frustrated efforts to estimate prevalence in a wider context.^{1–3} Defined as the proportion of new and existing disease cases in the population, prevalence rates represent the combined effects of disease incidence and survival. Even more importantly, they provide the basis for healthcare planning, such as decision making in drug manufacturing and research, funding for health services and research, and patient advocacy programs. These estimates are especially pertinent, because people diagnosed with brain tumors are likely to need significant supportive services.

Few publications have focused on prevalence studies involving primary brain tumors. Swedish researchers published prevalence estimates for the year 1984 for all primary brain tumors.² Population-based prevalence studies in the United States^{4–5} have been limited to malignant brain tumors with 1 exception. Davis et al.⁶ published prevalence estimates for all primary brain tumors for the year 2000, providing the first account of the magnitude of all primary brain tumors in the United States. However, the prevalence of nonmalignant tumors was grossly underestimated because of the voluntary reporting of nonmalignant brain tumors by state cancer registries at the time. Although this earlier study contributed to the description for prevalence of malignant brain tumors in the United States, dated content on nonmalignant tumors lessens its current usefulness.

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With the passage of the Benign Brain Tumor Cancer Registries Amendment Act (Public Law 107–260), collection of all primary brain tumors was required by law for cases diagnosed in 2004 and later. To capture this change in standardization of reporting and the subsequent improvement in incidence rate estimates, prevalence estimates for this report were calculated for the years 2004 and 2010 for all primary brain tumors using data from the Surveillance, Epidemiology, and End Results Program (SEER) and the Central Brain Tumor Registry of the United States (CBTRUS) population-based tumor registries.

Methods

For this study, brain tumor cases were defined as malignant and nonmalignant tumor histologies coded to a primary site in the brain, central nervous system, pituitary, and pineal glands, or olfactory tumors of the nasal cavity (C70.0–72.9, C75.1–75.3, and C30: 9522–9523).⁷ Incidence data for the year 2004 from 18 CBTRUS collaborating registries (AZ, CO, CT, DE, ID, ME, MA, MN, MT, NM, NY, NC, RI, SD, TX, UT, VA, WV) were combined with data from 2 state cancer registries participating in SEER, HI and IA. All other SEER regions either are CBTRUS state collaborators or are not statewide regions. SEER is nationally recognized as the gold standard for population-based cancer incidence and survival statistics for all cancer sites.⁸ CBTRUS has compiled population-based incidence data on all primary brain tumors, regardless of behavior, since 1991.⁷ On the basis of the population coverage of these state cancer registries,^{7,9} the incidence data in this study represent ~33% of the US population. Excluded from analyses were cases diagnosed at autopsy or identified by death certificate only and second primary brain tumors as they do not meet the definition of prevalence. Population estimates for each state for the year 2004 were obtained from the SEER-National Cancer Institute website¹⁰ to be used as denominator data for the incidence estimation.

Incidence estimates were calculated using Statistical Analysis Software¹¹ and SEER*Stat 6.4.4 software.¹² Crude age-specific incidence rates were computed for each of the 5-year age groups and used to calculate prevalence. Age-adjusted incidence rates were standardized to the 2000 US standard population and presented for each of the tumor groups.

Survival data for cases diagnosed from 1985 to 2005 were provided by 2 individual state cancer registries: the Connecticut Tumor Registry and the Utah Cancer Registry. These CBTRUS collaborating state registries were chosen because they have survival data spanning a minimum of 20 years for both malignant and nonmalignant primary brain tumors and they agreed to provide survival data for this study. Survival data were compiled and age-specific survival estimates were computed using SAS^R.¹¹ The product-limit method was used to compute observed survival rates.¹³ Survival estimates were based on the general population death rates for individuals up until the age at diagnosis. Population-level data on age

distribution for 2004, survival rates by age, and death rates for the year 2004 were obtained from the US Census Bureau by SEER.^{10,14} Postdiagnosis, 2 alternative assumptions were made when computing survival estimates based on tumor behavior and histologic category. The Population Survival assumption proposed that survival after the observed follow-up (beyond 20 years) was equivalent to survival within the general population. The No Survival assumption proposed that survival dropped to 0 after the observed follow-up (beyond 20 years). The Population Survival assumption was used to estimate survival for nonmalignant tumors, including meningiomas (97.3% were nonmalignant), as this assumption appeared to be the most reasonable reflection of those survival patterns. Both survival assumptions were used to estimate survival curves for malignant tumors, including glioma, and for tumors overall. This appeared appropriate because a subset of these brain tumors has a poor prognosis, whereas others do better long term, and these 2 estimates provide a range around the true survival curves.

A prevalent case was defined as any individual who had ever been diagnosed with a brain tumor and was reported to a participating tumor registry during the specified time period (excluding death certificate only cases). Estimates were calculated for all primary brain tumors and for the following subgroups: malignant (behavior code 3); nonmalignant (behavior codes 0 and 1); glioma (histology codes: 9380–9384, 9391–9460 regardless of behavior); meningioma (histology codes: 9530–9534, 9537–9539 regardless of behavior); pediatric (all tumors diagnosed before age 20 years); malignant pediatric (tumors with behavior code 3 diagnosed before age 20 years); adult (tumors diagnosed between ages 20–34, 35–64, or 65+); malignant tumors by gender; and nonmalignant tumors by gender. Age-specific prevalence was modeled 2 ways by inputting the age-specific incidence (2004 data from 20 cancer registries) and the 2 alternative survival rates (1985–2005 data from CT and UT) calculated as described above into a statistical model that took into account the projected age distribution in 2004. The first modeling strategy (Population Survival) was computed using the population survival assumption, whereas the second modeling strategy (No Survival) was computed using the no survival assumption. The statistical model for prevalence estimation was based on the conditional probability of having ever been diagnosed, given that one was currently still alive. A more detailed description of the statistical modeling and formulas used are available.⁶ Underlying survival assumptions and the additional assumption of a constant state with respect to incidence and survival rates preceded all calculations of prevalence estimates. Similar to the survival analyses, prevalence rates for nonmalignant tumors and meningioma were computed under the population survival strategy only, as this appeared appropriate for this class of tumors. Prevalence rates for malignant tumors and gliomas were computed using survival rates modeled under both assumptions to provide a range around the true prevalence rates.

Projected prevalence rates for the year 2010 were estimated using a method similar to that used to estimate the 2004 rates with 2 exceptions. Rates were based on the assumption of a decreased hazard ($HR = 0.9$) for survival rates for the year 2005 and onward. This is because brain tumor patients still alive after 2005 are predicted to have improved survival due to the initiation of new treatment regimens. Secondly, projected population age distribution data for 2010 were used to estimate US prediagnosis survival rates by age and death rates for the year 2010.

The expected number of individuals living with primary brain tumors in the United States in 2004 and 2010 was estimated by applying the category-specific prevalence rates to US population census estimates for the respective years. For malignant tumors, including gliomas, the category-specific prevalence rates used were averaged estimates from the 2 modeling strategies. The expected number of all primary brain tumors was estimated by summing the expected values for nonmalignant and malignant tumors. Population estimates for the year 2004 were obtained from SEER population estimates from the US Census Bureau¹⁰ and projected 2010 population census estimates were obtained directly from the US Census Bureau.¹⁵

Results

Data on over 18 000 newly diagnosed tumors were compiled (Table 1). More than two-thirds (68.4%) of the tumors among females were nonmalignant compared with 49.3% among males. The glioma subgroup was comprised of predominately malignant tumors (96.4%) with more than half being glioblastomas (53.5%; data not shown). Astrocytoma, NOS (7.1%), glioma malignant, NOS (6.9%), anaplastic astrocytoma (6.8%), and pilocytic astrocytoma (5.4%) were the next most frequent brain gliomas (data not shown). In contrast, an overwhelming majority of meningiomas were nonmalignant (97.3%; data not shown). Two-thirds of all reported tumors (66.2%) were either gliomas or meningiomas, and these 2 histology groups accounted for approximately equal proportions of the total number of tumors. Seven and a half percent of the brain tumors presented in those under 20 years of age and the majority of those were malignant (69.3%), as opposed to brain tumors in adults, where less than half (37.5%) were malignant (data not shown).

Incidence and survival rates are presented in Table 1. The incidence rate for primary brain tumors was 18.1 per 100 000 person-years (p-y). In females, there was a 2-fold higher rate of nonmalignant brain tumors

Table 1. Incidence^a rates from 20 state cancer registries and observed survival^b rates from 2 state cancer registries by selected primary brain tumor subgroups

Category	n ^a	2004 Incidence rate per 100 000 p-y (95% CI)	2-y Survival ^b (95% CI)	5-y Survival ^b (95% CI)	10-y Survival ^b (95% CI)	20-y Survival ^b (95% CI)
Primary brain	18 037	18.1 (17.8–18.4)	0.62 (0.61–0.63)	0.54 (0.53–0.55)	0.45 (0.44–0.46)	0.30 (0.29–0.31)
Age groups						
Pediatric (0–19 y)	1361	4.9 (4.6–5.1)	0.82 (0.80–0.84)	0.77 (0.75–0.79)	0.74 (0.72–0.77)	0.68 (0.65–0.71)
Adult (all ages 20+ y)	16 676	23.4 (23.1–23.8)	0.60 (0.60–0.61)	0.52 (0.51–0.53)	0.42 (0.41–0.43)	0.26 (0.25–0.28)
20–34 y	1523	7.3 (6.9–7.6)	0.87 (0.85–0.88)	0.78 (0.76–0.80)	0.69 (0.67–0.72)	0.56 (0.52–0.60)
35–64 y	8426	21.1 (20.7–21.6)	0.69 (0.68–0.70)	0.62 (0.61–0.63)	0.56 (0.54–0.57)	0.40 (0.38–0.42)
65+ y	6727	56.4 (55.0–57.8)	0.42 (0.41–0.44)	0.32 (0.31–0.33)	0.19 (0.18–0.20)	0.03 (0.02–0.04)
Tumor behavior						
Malignant	7194	7.2 (7.1–7.4)	0.36 (0.35–0.37)	0.28 (0.27–0.29)	0.23 (0.22–0.24)	0.17 (0.16–0.18)
Malignant male	3964	8.5 (8.3–8.8)	0.36 (0.35–0.38)	0.27 (0.26–0.28)	0.22 (0.21–0.23)	0.17 (0.15–0.18)
Malignant female	3230	6.1 (5.9–6.3)	0.37 (0.35–0.38)	0.29 (0.28–0.31)	0.24 (0.23–0.26)	0.18 (0.16–0.20)
Malignant pediatric	943	3.4 (3.2–3.6)	0.77 (0.75–0.80)	0.71 (0.69–0.74)	0.68 (0.65–0.71)	0.64 (0.60–0.67)
Nonmalignant	10 843	10.9 (10.7–11.1)	0.88 (0.87–0.89)	0.80 (0.79–0.81)	0.67 (0.66–0.68)	0.42 (0.40–0.45)
Nonmalignant male	3854	8.4 (8.1–8.7)	0.87 (0.85–0.88)	0.78 (0.77–0.80)	0.66 (0.64–0.68)	0.40 (0.36–0.43)
Nonmalignant female	6989	13.1 (12.7–13.4)	0.89 (0.88–0.89)	0.81 (0.80–0.82)	0.68 (0.66–0.69)	0.44 (0.41–0.47)
Selected histologic subtypes						
Glioma	6005	6.0 (5.9–6.2)	0.35 (0.34–0.36)	0.27 (0.26–0.28)	0.23 (0.21–0.24)	0.17 (0.16–0.18)
Meningioma	5932	6.0 (5.8–6.1)	0.90 (0.86–0.92)	0.82 (0.77–0.85)	0.64 (0.59–0.69)	0.39 (0.31–0.47)

Abbreviation: p-y, person-years; CI, confidence interval.

^aIncidence data reflects cases diagnosed in 2004 based on 18 collaborating CBTRUS registries and 2 SEER registries, HI and IA (excluding autopsy and death certificate only cases).

^bSurvival data contains follow-up data of CT and UT cancer registry cases diagnosed from 1985 to 2005.

(13.1 per 100 000 p-y) compared with malignant tumors (6.1 per 100 000 p-y). In contrast, males had similar rates of malignant (8.5 per 100 000 p-y) and nonmalignant (8.4 per 100 000 p-y) brain tumors. Brain tumors were more common in adults than in children, as shown by the almost 5-fold difference between incidence rates (23.4 vs 4.9 per 100 000 p-y).

The 2-, 5-, 10-, and 20-year observed survival rates for all primary brain tumors were 62%, 54%, 45%, and 30%, respectively (Table 1). The 10-year survival rates for gliomas and meningiomas were similar to the larger groups of malignant and nonmalignant tumors, respectively. Gender differences in survival were not apparent for these 2 broad behavior groupings. As expected, the pediatric group had better survival outcome than adults regardless of behavior type. Likewise, the youngest adult age group had better survival outcome than their older adult counterparts.

Table 2 summarizes estimated prevalence rates for the year 2004. Assuming that survival for all tumors approached that for the general population (Population Survival Method), the overall prevalence rate was 226.4 per 100 000 (data not shown). However, assuming that survival for all tumors after 20 years dropped to 0 (No Survival Method), the overall prevalence rate was 191.5 per 100 000 (data not shown). More realistically, we show an overall prevalence rate that averages the estimates using both assumptions for malignant tumors and then sums the average with nonmalignant rates. As such, our best estimate of the overall prevalence of all primary brain tumors is 209.0 per 100 000. Nonmalignant tumors had the higher prevalence rates in both genders with higher rates in females (225.4 vs

113.9 per 100 000) and higher rates in persons aged 65 years and older (564.2 vs 11.1–215.9 per 100 000). The prevalence rate for the year 2010 was projected to increase slightly and was estimated to be 221.8 per 100 000.

Comparison of modeled prevalence rate estimates for malignant tumors used both methods to illustrate an upper (59.9) and lower (25.1) estimate (Table 2). Rates computed from the No Survival Method underestimate the true prevalence, particularly for the 65 years and older age group (85.9 vs 17.0 per 100 000). The trend of increasing prevalence rates with increasing age, which was seen for nonmalignant tumors, was only apparent for malignant tumors when using the same modeling strategy (Population Survival Method). The large difference in magnitude and of rates for the oldest age group was likely a reflection of the large proportion of older cases compared with other age groups.

The expected number of persons living with a diagnosis of a brain tumor in 2004 and 2010 was estimated to be 612 770 and 688 096, respectively (Table 3). The number of persons estimated to be living with nonmalignant tumors (488 164) is approximately 4-fold greater than those living with malignant tumors (124 606). Almost twice as many women are living with brain tumors than men.

Discussion

Prevalence rates are ideally suited to provide an overall estimate of cancer survivorship and direction for health planning as they reflect the complex relationships

Table 2. Estimated prevalence rates^a per 100,000 for primary brain tumors for 2004 and 2010 in the United States

Category	All ^b	Nonmalignant ^c	Malignant ^c	Malignant ^d
Year 2004				
All	209.0	166.5	59.9	25.1
Age groups				
Pediatric (0–19 y)	35.4	11.1	25.1	23.3
All adults (all ages 20+ y)	278.1	228.4	73.4	25.8
20–34 y	91.7	51.4	55.6	24.9
35–64 y	269.9	215.9	78.9	29.1
65+ y	615.7	564.2	85.9	17.0
Gender				
Male	158.7	113.9	64.0	25.5
Female	264.8	225.4	56.4	22.4
Common histologic subtypes				
Glioma	34.3	—	47.1	21.4
Meningioma	—	70.7	—	—
Year 2010				
All ^e	221.8	177.3	61.9	27.1

^aRates assume a steady state for incidence and survival.

^bEstimates for all tumors are the sum of the nonmalignant estimates and the averaged prevalence rates for the malignant estimates from the 2 modeling strategies.

^cPostdiagnosis survival assumed to equal population survival after observed follow-up (Population Survival).

^dPostdiagnosis survival assumed to drop to 0 after observed follow-up (No Survival).

^eEstimates were based on postdiagnosis survival for year 2005 and later with hazard of 0.9.

Table 3. Expected numbers^a of US primary brain tumor cases for 2004 and 2010 by selected subgroups

Category	Estimates <i>n</i> for 2004	Projected estimates <i>n</i> for 2010 ^d
Primary brain ^b	612 770	688 096
Age groups ^b		
Pediatric (0–19 y)	28 844	na
Adult (all ages 20+ y)	588 772	na
20–34 y	55 694	na
35–64 y	309 522	na
65+ y	223 480	na
Tumor behavior		
Malignant ^c	124 606	138 054
Malignant male	64 468	na
Malignant female	58 963	na
Malignant pediatric	19 148	na
Nonmalignant	488 164	550 042
Nonmalignant male	164 272	na
Nonmalignant female	335 772	na
Common histologic subtypes		
Glioma ^c	100 565	na
Meningioma	207 286	na

na: expected numbers were not calculated for these subgroups.

^aExpected values are based on the prevalence rates reported in Table 2.^bExpected values are the sum of those derived from nonmalignant and malignant estimates.^cExpected values are based on the averaged prevalence rates from the 2 modeling strategies.^dExpected values are based on postdiagnosis survival for year 2005 and later with hazard of 0.9.

between incidence, survival, and population demographics and hence provide valuable information to the research and medical community. In the present study, we calculated prevalence rates and expected numbers for all primary brain tumors in the United States for the year 2004 and projected similar estimates for the year 2010; thus, addressing the healthcare planning needs for ‘best available’ estimates in light of changes in incidence reporting from the Benign Brain Tumor Cancer Registries Amendment Act and increases in survival over time. On the basis of the sum of nonmalignant and averaged malignant estimates, the estimated prevalence rate of all primary brain tumors was 209.0 per 100 000 in 2004 with approximately 600 000 cases living with a diagnosis of a brain tumor in the United States. By the year 2010, the projected number of cases is more than 680 000 with a rate of 221.8 per 100 000.

Our prevalence estimates exceed those published in the previous report⁶ for all tumor categories (except for malignant tumors using the No Survival Method), and the results allow the assessment of changes based on differences in incidence (1985–1994 vs 2004), survival (1985–1994 vs 1985–2005), and prevalence (2000 projected estimates vs 2004 estimates). The previous report determined prevalence rates for malignant tumors on the assumption that survival estimates

dropped to 0 after the observed follow-up period, the same assumption utilized for the No Survival Method in this study. Because the current report presented an alternate method for computing prevalence rates for malignant tumors (Population Survival Method), 2 separate prevalence rate comparisons were made for these tumor categories. The current overall prevalence rate for 2004 was estimated to range between 191.5 and 226.4 per 100 000, reflecting values 1.5–1.8 times higher than previously reported (130.8 per 100 000). When comparing incidence rates for the previous and current study, we found an appreciable difference in overall incidence (13.8 vs 18.1 per 100 000 p-y), primarily due to the standardization of ascertainment and reporting, especially for the nonmalignant brain tumors, with slight increases in 5- and 10-year survival rates (49% and 38% [previous] vs 54% and 45% [current]). A minimal difference in prevalence rates for malignant tumors was observed when comparing rates generated by using the No Survival assumption (29.5 vs 25.1 per 100 000). However, a 2-fold difference in prevalence rates was observed when the alternate, Population Survival assumption, was applied to compute 2004 rates (29.5 vs 59.9 per 100 000). This large difference in estimates is primarily due to the large number of cases with malignant tumors who do not survive 20 years postdiagnosis; therefore, the survival assumptions are applied to a greater portion of these tumors. Approximately a 3-fold difference in prevalence rates for the malignant pediatric group was observed regardless of the method used to compute 2004 rates (7.9 vs 23.3 or 25.1 per 100 000) with identical incidence rates of 3.4 per 100 000 p-y and slight increases in 5- and 10-year survival rates (65% and 62% vs 71% and 68%). Variation in population demographics during the different time periods provides an additional explanation for some of the variation in estimated prevalence rates.

Several explanations exist for the marked increase in prevalence estimates between the previous⁶ and current study. First, improvements in data collection reporting have resulted in higher incidence rates of nonmalignant tumors.⁷ The Benign Brain Tumor Cancer Registries Amendment Act (Public Law 107–260) legally mandated all cancer surveillance registries in the United States to expand primary brain tumor data collection to include brain tumors of benign and uncertain behavior beginning in January 2004.⁷ Although the incidence rates for all primary brain tumors were greater in the current study, the incidence rate for all malignant and malignant pediatric groups remained unchanged between the 2 study periods, thus confirming the contribution of regulated reporting of nonmalignant tumors to the increase in incidence rates. To assess how much change in prevalence rates was due to data reporting alone, a sensitivity analysis was performed. Prevalence estimates were recalculated using the same survival data and population demographic data from the current report but varying years of incidence data, 2000 and 2004. Using the Population Survival Method procedures, the change in prevalence due to data

reporting of incidence data was 40.2% (119.2 vs 167.1 per 100 000) for nonmalignant brain tumors (data not shown). This large change in prevalence was due almost exclusively to increased reporting of nonmalignant tumors. Similarly, in a study of pediatric brain tumor cases diagnosed from 1990 to 1993, Gurney et al.¹⁶ observed a 28% increase in incidence rates from 29.4 to 37.6 per 100 000 p-y upon inclusion of nonmalignant CNS tumors.

Second, the 2-, 5-, and 10-year survival rates modestly increased between the 2 survival periods, 1985–1994 and 1985–2005, which has led to an accumulation of people surviving longer after a brain tumor diagnosis. Survival estimates have improved more for nonmalignant tumors than malignant tumors.¹⁷ However, studies of malignant brain tumors have also noted improvement in survival over time.^{18–20} In the current study, pediatric groups had a modest increase in survival and minimal or no change in incidence but more than a 3.5-fold difference in prevalence, suggesting that minor improvements in survival can drastically affect prevalence. In addition, a comparison of 5- and 10-year overall survival rates from the current study (54% and 45%) to those from SEER for the years 1988–2004 (33.6% and 30.5%)²¹ provides a crude indication of the contribution of standardized reporting of nonmalignant tumors to survival rates, which has a cascading effect on prevalence rates.

Third, improvement in data modeling procedures because of the 10 years of additional follow-up (survival estimates through 20 years postdiagnosis) enabled the reassessment of long-term survival, especially for malignant tumors. Two survival assumptions were applied to the malignant tumor categories to illustrate that these numbers are estimates and to provide a range wherein the true prevalence estimates are likely to lie.

A higher prevalence rate of malignant brain tumors has been reported among males than among females in the United States.^{4,6} These findings are consistent with our results. Our current findings of higher overall prevalence rate for all primary brain tumors among females also agreed with estimates for 1984 (93 vs 68 per 100 000) from a Swedish study.² A study in France²² reported a higher prevalence rate of brain tumors for the year 2002 among females (15.9 per 100 000) than males (13.8 per 100 000), although the composition of behavior types was not reported. Because prevalence estimations rely heavily on the definition of tumors reported in incidence reporting, population distribution, and survival, which may vastly differ in other countries, international comparisons must be interpreted with caution. National proportions of the complete prevalence of malignant tumors for the year 2005 were higher for males (0.044%) than for females (0.038%),⁵ which paralleled estimates from the current study (males: 0.045% and females: 0.040%).

Our study has several strengths and limitations. The current study calculated prevalence estimates based on standardized reporting of nonmalignant tumors and 10 years of additional follow-up data (~20 years total), allowing a more accurate estimate of survival to be

used in the prevalence estimates. Twenty-year survival rates of primary brain tumors have only been reported for a few large-scale studies in children,^{23,24} for all ages,²⁵ and for selected histologies.²⁶ Additionally, prevalence estimates based on incidence data from 20 state cancer registries are likely more representative of the United States than the data from only 2 registries used in the previous study.⁶ Finally, the robustness of the dataset allowed additional stratification of tumor categories to identify possible variation between groups.

Despite the strengths of this study, inaccuracies in estimation may have occurred due to data limitations and assumptions employed to model prevalence estimates. A general limitation of prevalence estimation is the inability to account completely for all living cases, because some cases are diagnosed prior to the years of data used in the study. Specific to our study was the use of age-specific incidence data that were relatively current and survival data that spanned a 20-year period. However, current prevalence is not only based on current incidence and past survival but on past incidence as well,²⁷ and this is lacking in this study. Our method differs slightly from the more conventional approach of using multiple years of incidence and survival data from the same time period to estimate prevalence and may have added to the underestimation of the true value for persons with nonmalignant tumors who tend to live longer. However, this limitation was intentional in order to utilize 2004 data, which marked the first year of complete incidence reporting for nonmalignant primary brain tumors. The assumptions of stable incidence and survival may inaccurately estimate prevalence, because both measures increased over time. For example, incidence rates for malignant brain tumors increased by an average of 0.31% per year between 1973 and 2006 ($P < .05$).²⁸ Using the 2004 incidence rate for all years prior to 2004 would overestimate the prevalence of malignant tumors in the earlier years. In addition, owing to its racial and ethnic composition, the survival experience in Connecticut and Utah may not be representative of the US population, which may overestimate the true prevalence in the United States. The greatest uncertainty in our estimates surrounds the assumption of long-term survival for those with malignant brain tumors, which prompted dual computation of prevalence estimates. We believe that the survival assumption for the No Survival Method is too extreme and that the Population Survival Method probably better reflects the true prevalence rates for nonmalignant tumors, albeit overestimated by an unknown amount. For projected rates, we assumed that recent improvements in treatment due to the drug temozolomide translated into improved survival²⁹ and, therefore, assumed a decreased hazard ($HR = 0.9$) for postdiagnosis survival for year 2005 and later. The projected prevalence rate for the year 2010 was estimated to be 221.8 per 100 000 compared with 217.7 per 100 000 (data not shown) if survival rates did not change after 2004, representing a 1.9% increase in the overall prevalence rate if survival improves. This additional assumption may or may not

be accurate, potentially resulting in inaccurate projected prevalence rates.

These prevalence rates are higher than previously estimated.⁶ Results of this study suggest that the higher estimates are attributable to both improved ascertainment of nonmalignant tumors and improvements in survival. The new mandate on data reporting of incidence cases has resulted in more accurate incidence rates, thus the estimate of prevalence is improved over those in the previous report. Treatment, diagnostic, and surveillance effects should continue for all primary brain tumors. However, follow-up, quality of life, and survivorship studies need to emphasize the preponderance of nonmalignant cases and females associated with these diagnoses.

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