Original Article

Case Ascertainment of Pediatric Brain Tumors: The Alberta Experience

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Abstract: Estimates suggest that brain tumors are underreported in the Alberta Cancer Registry (ACR). While the reporting of malignant tumors is thought to be complete in cancer registries across Canada, the reporting of benign tumors is estimated at 33% of the actual number of cases expected within the country.[6] There are many international studies that highlight the issues of underreporting of benign brain tumors in cancer registries. This study had 3 objectives to investigate the amount of and potential reasons for underreporting: 1) overall case ascertainment of pediatric brain tumor cases present in physician databases captured by the ACR was assessed; 2) overall case ascertainment of all known pediatric brain tumors was assessed and summarized for the ACR and physician pediatric brain tumor databases; and 3) the expected number of unknown pediatric brain tumor cases was estimated so overall case ascertainment could be assessed. Brain cancer was defined using topography codes C70 through C72, C75.1 through C75.3, and C30.0 (with morphology codes 9522 and 9523). Databases with these codes from 2 physician practices making up the primary provincial referral network for this patient population were obtained and linked with the ACR for 2004 to 2011. Estimates of the expected number of cases were made using US incidence rates. The ACR captured 309 of the 317 known pediatric brain tumor cases (97%) while the physician databases captured 205 cases (65%). The ACR also captured 197 of the 205 cases in the physician databases (96%). The ACR captured 309 of the 346 expected cases (89%) while the physician databases captured 205 of the 346 expected cases (59%). As some patients may not have an initial diagnosis confirmed (by specialty physicians) and others are identified through cause of death searches some discrepancies between the databases are expected. The overall underreporting may reflect a lack of referrals from radiology clinics or the case definition used by registries may not be consistent with the definition used by clinicians in Alberta. While further work is required to better understand why some cases are not appearing in the ACR, confidence should exist that ACR information reflects most cases of pediatric brain tumors in Alberta.

Key words: *brain tumor, Canada, cancer registry, case ascertainment, data quality*

Introduction

Brain tumors are among the most disabling and lethal types of cancer. Although they constitute only about 2% of all cancers, brain tumors are associated with severe disability and a high risk of death.[1] Central nervous system (CNS) tumors are the second most common childhood cancer in Alberta, behind only leukemias,[2] which is of relevance as approximately 90% of CNS tumors in children develop in the brain.[3] In Alberta, 203 patients of all ages were diagnosed with brain cancer during 2011, of which children under the age of 17 years accounted for 21 cases (10%).[4]

Cancer registries across Canada have been useful at the regional level for understanding the burden of disease, evaluating trends in disease occurrence, and providing an infrastructure for clinical, epidemiologic, and health services research.[5] While the reporting of malignant tumors is thought to be complete in cancer registries across Canada, the reporting of benign tumors is estimated at only 33% of the actual number of cases expected within the country.[6] There are many international studies that highlight the issues of underreporting of benign brain tumors in cancer registries.[7,8,9]

Through discussions with brain tumor physicians, the Alberta Cancer Registry (ACR) department, and other cancer registries across Canada, the perception is that brain tumor cases are relatively more difficult to code in a cancer registry than most other types of cancer. While the reporting of all tumors is mandatory in Alberta,[10] it is thought that some brain tumors that are radiologically diagnosed or nonmalignant may not be captured. Even when the cases are captured, the demographic, diagnostic, and treatment information may not always be accurate. In addition, recent coding changes in Canada (Parliament of Canada private members bill M235, effective 2007[11]) and the United States (Public Law 107-260, effective 2004[12]) called for the creation of a national standard for the collection of all brain tumors so it is important to assess whether these coding changes are being followed. There is very little evidence in the literature looking at the completeness and validation of data within cancer registries, and, as such, it is not known to what degree this may be a problem. In Alberta, pediatric brain tumor physicians are collecting brain tumor information in their own databases so they have timely and accurate information.

In limited literature investigating this issue, when a comprehensive evaluation of a cancer registry is performed,

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studies show that underreporting of brain tumors is consistently observed. Studies performed in Germany,[13] Norway,[14] Finland,[7] Sweden,[15] the United Kingdom,[9] and Scotland[16] found underreporting of brain tumors ranging from 6% to 48%. Counsell et al (1997)[16] found that common predictors of registration in a cancer registry included patients who received an operation, were 60 years or older, and had a tumor requiring radiotherapy.

Woehrer et al (2013)[17] highlighted the need to collect data on benign and intermediate (between malignant and benign) brain tumors, as they were not consistently being collected. And while focused on hematological malignancies, not brain tumors, a study in the Thames region[18] highlights the disagreement that can be found when comparing physician databases to a cancer registry. This study assessed case ascertainment and diagnostic accuracy of physician databases compared to the Thames Cancer Registry and showed the cancer registry was missing 30% of cancer cases. A study by Yao et al[19] suggests that, despite heavy investment in health information technology products, the medical profession have been slow to embrace this information due to outdated classification systems, clinical coding not refined for complex disorders, or outpatient settings and administrative data not reflecting the clinical nuances and complexities of patients treated.

This literature supports the concerns expressed by local brain tumor physicians and Alberta Cancer Registry staff that brain tumors might be underreported in the Alberta Cancer Registry and highlights the need to further evaluate this issue in Alberta. As no studies have been performed in Canada to assess the case ascertainment of brain tumors, a significant gap of knowledge exists. Therefore, this study will serve 2 objectives: (1) to determine case ascertainment of pediatric brain tumor cases observed in physician and ACR databases and (2) to determine pediatric brain tumor case ascertainment of the combined ACR and pediatric physician databases.

Methods

First, a clearly defined brain tumor definition was established. The *International Classification of Diseases for Oncology*, third edition (ICD-O-3) is used by cancer registries to classify brain tumors. ICD-O-3 is a coding system used principally in cancer registries for coding the site (topography) and the histology (morphology) of neoplasms, usually obtained from pathology.[20] For the purposes of this study, brain cancer was defined using topography codes C70 through C72, C75.1 through C75.3, and C30.0 (with morphology codes 9522 and 9523). This brain tumor definition is used by the Central Brain Tumor Registry of the United States (CBTRUS) and was chosen as it is one of the more comprehensive methods used and would not be too restrictive in terms of what was defined as a brain tumor.

The study population included all brain tumor patients between the ages of 0 and 17 years, during the time period of 2004–2011. Patients must have been residents of Alberta at the time of diagnosis and only primary cancer diagnoses were considered for the purposes of this research study. Similar to other cancer registries, cancer recurrence and metastases are not recorded in a consistent and comprehensive manner.

The pediatric population was chosen as pediatric brain tumor physicians were interested in investigating this issue and they were willing to share data from the Edmonton and Calgary physician databases for this study. As their databases should capture all cases seen in Edmonton (Stollery Children's Hospital) or Calgary (Alberta Children's Hospital), the assumption was made that all pediatric brain tumor cases in the province would be captured in their databases due to the specialized nature of care and referrals for this patient population at the 2 sites which are intended to serve the provincial patient population. The age range of 0 to 17 years was chosen as both these sites provide care for patients 17 years and under.

The starting time frame of 2004 was chosen as that was the first year both the Edmonton and Calgary physician databases consistently began capturing brain tumors. A closing year of 2011 was chosen as the ACR had only reviewed potential cases for registration eligibility up until the end of that year.

Three main databases were used for this research study: the pediatric physician brain tumor database in Edmonton, the pediatric physician brain tumor database in Calgary, and the ACR. There were 112 pediatric brain tumor patients present in the Edmonton physician database and 93 pediatric brain tumor patients present in the Calgary physician database that met the study criteria. In addition, cases physician databases might miss must be considered. Assuming this, the ACR provided an additional 112 brain tumor patients that did not appear in either physician database. This led to a total of 317 pediatric brain tumor patients in the total study population.

All cases from the Edmonton and Calgary physician databases were linked to data from the ACR using the patient's unique lifetime identifier (ULI) number. For those with matching ULI numbers, their last names and dates of birth were compared to determine if the match was appropriate. When either the last name or date of birth did not match, a visual assessment of the patient's records was performed to determine if the match was appropriate. Only 8 cases were unsuccessfully linked from the physician databases to the ACR—1 case in Edmonton and 7 cases in Calgary. A chart review was performed on all cases present in the physician database that were unable to be linked to the ACR to investigate the reasons for the unsuccessful linkages. Alberta Netcare, a secure and confidential electronic system of Alberta patients' health information,[21] was used to perform the chart review and ACR staff provided assistance throughout this process to ensure the findings were accurate and comprehensive.

Initial analysis assessed overall case ascertainment of pediatric brain tumor cases present in physician databases captured by the ACR (Objective 1). A frequency table (Table 2) was created in Microsoft Excel to summarize the number and percentage of cases that linked from the physician databases to the ACR, broken down by Edmonton and Calgary physician databases. Confidence intervals of 95% were used to assess the results.

Table 1. Summary of Brain Tumours in Alberta

		Physician Database		
	Recorded?	**Yes**	**No**	
ACR	Yes	A	B	
	No	C	D	
				Total (EXP)

ACR, Alberta Cancer Registry; EXP, expected.

Table 2. Case Ascertainment of Pediatric Brain Tumours Cases Present in Physician Databases Captured by the Alberta Cancer Registry, by City

	Edmonton		*Calgary*		*Overall*	
	No.	%	No.	%	No.	%
Link	111	99	86	92	197	96
No Link	1	1	7	8	8	4
Total	112	100	93	100	205	100

Table 3. Observed Brain Tumours in Alberta

		Physician		
	Recorded?	**Yes**	**No**	**Total**
ACR	Yes	197	112	**309**
	No	8	?	**88**
	Total	205	112	**317**

ACR, Alberta Cancer Registry.

Next, overall case ascertainment of all known pediatric brain tumors was assessed and summarized for the ACR and physician pediatric brain tumor databases (Objective 2). To do so, we assessed how many pediatric brain tumors were captured in the ACR from 2004 to 2011 that were not captured within the physician databases. Table 1 depicts the potential findings.

As demonstrated in Table 1, the ideal scenario is when both the physician database and the ACR capture the brain tumor case (Scenario A) and this would equal the total brain tumors diagnosed in the population. When the ACR captures a case that the physician database is missing (Scenario B) or the physician database captures a case that the ACR is missing (Scenario C), it is not ideal but the case is still being captured somewhere.

This study was unable to pick up the cases when the ACR and the physician database both missed a case as those cases are unknown (Scenario D). Given the ACR received Gold Certification from the North American Association of Central Cancer Registries (NAACCR) in 16 of the past 17 years for achieving overall case ascertainment over 95% each year,[22] it is thought that the number of cases that are missed by both databases would be low. However, these cases must still be considered as the omission of these cases from the study will artificially inflate overall case ascertainment and the observed brain tumor study population will be smaller than reality. To investigate this issue further, this study attempted to estimate the expected number of pediatric brain tumor cases so that overall case ascertainment could be assessed (Objective 3).

In a Canadian study, Shaw et al (2014)[6] estimated the number of nonmalignant CNS tumors missing from the Canadian Cancer Registry by comparing the expected number of CNS tumors and observed number of CNS tumors. To do this, CBTRUS CNS tumor rates from the United States were applied to the Canadian population to estimate the expected number of CNS tumors for each province.

Similar methodology was used to estimate the total number of expected pediatric brain tumor cases (A + B + C + D) in this study. The total number of expected pediatric brain tumors was estimated by applying the CBTRUS incidence rate of pediatric and adolescent primary malignant and nonmalignant brain and CNS tumors in the United States[23] to the Alberta population. Each year from 2004 to 2011, the CBTRUS pediatric incidence rate was applied to the annual Alberta population aged 0 to 14 years, while the CBTRUS pediatric and adolescent incidence rate was applied to the Alberta population aged 15 to 17 years. Population data was obtained from the annual Alberta Cancer Registry Reports.[24]

Overall case ascertainment of the ACR and physician databases could then be estimated by comparing the observed cases in the ACR (A + B) plus the additional cases in the physician databases (A + C) to the estimated number of expected pediatric brain tumor cases. While imperfect, this allows an estimate of the potential cases missed by both the ACR and the physician databases (EXP – (A + B + C) = D).

Ethics approval for this work was obtained through both the University of Alberta Health Research Ethics Board—Health Panel and the Conjoint Health Research Ethics Board at the University of Calgary.

Results

The results for objectives 1 and 2 are presented below.

Case Ascertainment of Pediatric Brain Tumor Cases Present in Physician Databases Captured by the Alberta Cancer Registry

Case ascertainment of pediatric brain tumor cases present in physician databases captured by the Alberta Cancer Registry are summarized in Table 2.

Overall, 197 of the 205 cases in the physician databases were captured in the ACR (96%; 95% CI, 93%–99%). The ACR captured relatively more cases from the Edmonton physician database (99% case ascertainment; 95% CI, 97%–100%) compared to Calgary (92% case ascertainment; 95% CI, 87%–98%).

Overall Case Ascertainment of All Known Pediatric Brain Tumors

Overall case ascertainment of all known pediatric brain tumors for the ACR and physician pediatric brain tumor databases is summarized in Table 3. Overall, 317 pediatric brain tumor cases were captured by either the ACR or the physician databases from 2004 to 2011. The ACR captured

Table 4. Expected Number of Pediatric Brain Tumour Cases, 2004–2011					
Year	*Population Aged 0–14*[24]	*Rate (per 100,000)*[23]	*Population Aged 15–17*[24]	*Rate (per 100,000)*[23]	*Expected Brain Tumours*
2004	625,487	5.30	140,366	5.42	41
2005	633,084	5.30	142,071	5.42	41
2006	641,597	5.30	143,435	5.42	42
2007	657,480	5.30	146,047	5.42	43
2008	669,601	5.30	147,535	5.42	43
2009	688,161	5.30	148,249	5.42	45
2010	703,700	5.30	147,720	5.42	45
2011	719,415	5.30	148,213	5.42	46
					346

309 of the 317 know pediatric brain tumor cases (97%) while the physician databases captured 205 cases (65%). It should be noted that the number of cases that were missed by both the ACR and the physician databases is unknown.

Overall Case Ascertainment Using Expected Number of Pediatric Brain Tumors

Table 4 shows the CBTRUS incidence rate of malignant and nonmalignant pediatric brain tumors[23] applied to the Alberta population to estimate the total number of expected pediatric brain tumor cases from 2004 to 2011.

Assuming Alberta rates are similar to those of CBTRUS pediatric brain tumor rates, 346 brain tumor cases were expected to be diagnosed in Canada during the 2004 to 2011 study time frame. An estimated 29 cases were not captured by either database (346 expected, 317 observed).

It should be noted that while the CBTRUS pediatric brain tumor rates allow the cases that were missed by both the ACR and physician databases to be factored into the case ascertainment calculation, these rates may not be the best estimation of the actual reality in Alberta. The actual pediatric brain tumor rates in Alberta may be higher or lower and over time, as confidence grows in case ascertainment, the rates should stabilize and we will be able to better address this question.

As observed in Table 5, the ACR captured 309 of the 346 expected cases (89%) while the physician databases captured 205 of the 346 expected cases (59%). Therefore, it is estimated that the ACR is underreporting pediatric brain tumors by approximately 11% while the physician databases underreport an even higher percentage of cases.

Table 5. Observed Brain Tumours in Alberta

		Physician		
	Recorded?	**Yes**	**No**	**Total**
ACR	Yes	197	112	**309**
	No	8	29	**37**
	Total	205	141	**346**

ACR, Alberta Cancer Registry.

Discussion

Case Ascertainment of Pediatric Brain Tumor Cases Present in Physician Databases Captured by the Alberta Cancer Registry

The results presented in Table 2 showed the ACR captured the majority of pediatric brain tumor cases in Alberta and researchers and physicians should have confidence that the ACR is capturing most cases of pediatric brain tumors in Alberta. These results were in line with the underreporting of 6% observed in Norway (Larsen, 2009). Of all the published literature, the Cancer Registry of Norway captured the highest percentage of brain tumor cases and performed much better than the underreporting observed in the United Kingdom (48%)[9] and Scotland (46%).[16]

Overall Case Ascertainment of All Known Pediatric Brain Tumors

From Table 3, the higher case ascertainment demonstrated by the ACR was expected as physicians from across the province are mandated to report all brain tumor cases to the ACR[10] and the ACR has an entire department of staff dedicated to ensure the collection and proper coding of these cases in Alberta. As mentioned, it should be noted that the number of cases that were missed by both the ACR and the physician databases is unknown. While this number is not expected to be high, the omission of these cases will artificially inflate overall pediatric brain tumor case ascertainment percentages for both the ACR and the physician databases.

Overall Case Ascertainment Using Expected Number of Pediatric Brain Tumors

It should be noted that while the CBTRUS US pediatric brain tumor rates allow the cases that were missed by both the ACR and physician databases to be factored into the case ascertainment calculation, these rates may not be the best estimate of reality in Alberta. The actual pediatric brain tumor rates in Alberta may be higher or lower and any difference compared to the estimated rates being used by this methodology will have a direct effect on our estimate of case ascertainment of the ACR and physician databases.

Overall, this study was able to address the significant knowledge gap in this area and highlighted that overall,

the ACR should be considered a reliable database for physicians, researchers, and operational planners when pediatric brain tumor counts are required. Studies of this nature are important to perform on cancer registries as they provide measures of quality while at the same time, they can improve the data quality of the registry. Based on the findings of this study, ACR staff was able to locate the required radiology and pathology reports and register all 8 cases present in the physician databases that were missing in the ACR. As such, this exercise improved the overall ACR information for future data reporting.

Further investigation of all cases recorded in the ACR that were missed in the physician databases was performed by reviewing each patient's records to determine what factors may be affecting case ascertainment was performed (data not shown).[25] Some cases may have been appropriately missing if the diagnosis was not confirmed or if the brain tumor was diagnosed by a death certificate only, as there would have been no opportunity for the physician to record these cases. Other cases may have been missed for a few potential reasons.

First, a disproportionately larger percentage of patients aged 15 to 17 years were missed in the pediatric physician databases.[25] This may have occurred due to these patients opting for, or being referred to, nonpediatric physicians to avoid a potentially difficult transition in care. For example, when you reach your 17th birthday, pediatric brain tumor patients cannot be admitted to the Stollery Children's Hospital and must be admitted elsewhere. To further support this, the physician databases performed best at capturing pediatric brain tumor patients aged 0 to 2 years at the time of diagnosis.

Second, patients only captured in the ACR were less likely to receive chemotherapy and radiotherapy.[25] This is likely a reflection that these patients have fewer interactions with the health care system, thus decreasing the opportunities the physician will receive the required information to record the diagnosis.

Third, a large proportion of pediatric brain tumor cases missing in the physician databases occurred in Edmonton between 2004 and 2005, during the database's development stage.[25] The physician databases missed 46% of cases in 2004 and 2005, compared to 31% between 2006 and 2011. This was expected processes were being put in place so it was not a major surprise to learn that some cases were missed in the early years of the database.

Finally, and perhaps most importantly, while we used the CBTRUS brain tumor definition, this may not be consistent with the definition clinically used in Alberta. This lack of case definition consensus would explain why some cases recorded in the ACR were missing in the physician databases. Work is ongoing to focus on building a consensus on a brain tumor definition across Canada that is supported by physicians, researchers, and cancer registry staff.

It is important to note that this project only estimates the cases who are diagnosed with a brain tumor, but are not recorded in either the physician databases or the ACR (29 cases). Examples of these cases may include patients who had low-grade brain tumors removed during epileptic surgery, patients radiologically diagnosed seen by a primary care physician who elects for a "watch and wait" approach, or patients with an uncertain brain tumor diagnosis who do not receive any treatment. A focused study on this topic is required to better understand this issue.

Brain tumor physicians, health care professionals, and researchers across Alberta (and elsewhere in Canada) need to understand the quality of data in cancer registries so they can evaluate if the data are valid and reliable for specific research studies and operational planning. As previously mentioned, this is particularly relevant for brain tumors as the reporting of these tumors has changed relatively recently.[11,12] Incomplete or inaccurate brain tumor data have a direct effect on the ability of a province to accurately assign health care dollars by region, create centres of excellence for treatment, create efficiencies and plan for the greatest needs. The more that is known about the incidence of all types of brain tumors, will allow the enormous treatment cost to be planned for, targeted and reduced.[11] In addition, cancer registries need to understand the completeness of brain tumor case ascertainment to evaluate their performance and make process improvements, as required. This study has already had an immediate impact, improving the data quality of the ACR by generating an investigation into the 8 cases that were captured in the physician databases yet were missing in the ACR. The ACR staff was able to locate the required radiology and pathology reports and register all these cases in the ACR.

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