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On Capturing Radiological Diagnoses of Brain Tumors to Provide Complete Population Data in Cancer Registries in Canada

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Abstract: Nonmalignant brain tumors are underreported by an estimated 60% in Canadian cancer registries. One explanation is that radiology facilities or their databases may not be adequately included in the cancer reporting infrastructure. A multidisciplinary stakeholder team met for 1 day, followed by teleconferences, to discuss the evidence for the importance of incorporating radiology diagnoses in brain tumor reports. A role for the neuroradiologist was delineated in brain tumor diagnosis and in ensuring that radiology report information is available to support cancer case ascertainment in the cancer surveillance system. It was noted that brain tumors identified through imaging are clinically managed depending on the diagnosis and prognosis of the disease, and that patient radiology reports become a part of a larger administrative information system. The proportion of nonmalignant brain tumors diagnosed using histology is lower in the United States (49.3%) than in Canada (59%), suggesting that a higher proportion of cases with nonhistologic (likely radiology) diagnosis are captured by the US system (eg, tumors of the sellar region, cranial and spinal tumors, and tumors of the meninges). Finding a way to use existing electronic radiology reports to identify nonmalignant brain tumors needs to be prioritized. This will require access to electronic radiology reports, as manual reporting is impractical. Once access is achieved, an electronic flag to identify new cases through a natural language processing algorithm could be pursued. As radiologists and cancer registrars become more familiar with each other's mandates and workflow demands, innovative and collaborative solutions to improve case ascertainment for brain and other cancers are likely to emerge.

Key words: *algorithm solution, electronic access, natural language processing, radiology reports, tumors*

Introduction

Brain and other central nervous system (CNS) tumors account for only approximately 2% of primary cancer diagnoses among Canadians annually.[1] However, these tumors cause a strain on the health care system that is disproportionate to their incidence.[2] Due to the anatomical location of these tumors, the associated clinical and public health burden is not limited to those classified as malignant. Recognizing this, including diagnoses of nonmalignant brain and other CNS tumors in comprehensive surveillance efforts for brain tumors has been mandated. For example, the Canadian House of Commons passed legislation (MB-235) in 2007 for the "creation of uniform national standards for all malignant and benign brain tumors."[3]

Provincial cancer registries are mandated to collect population-based data on cancer incidence, and aim to maintain high-quality databases so that patterns of disease generated from these data reflect all reportable cases within a jurisdiction. However, accuracy and completeness of cancer registry data is assessed using criteria developed by the North American Association of Central Cancer Registries (NAACCR), which only takes into account certain tumor sites and behaviors when calculating completeness, omitting nonmalignant tumors.[4] Therefore, provincial registries are able to meet the criteria for NAACCR certification while missing a large proportion of reportable brain tumor diagnoses. As a result, there is uncertainty regarding the extent to which nonmalignant brain tumors are missing from cancer registry data in Canada. Further, barriers to efficient capture of nonmalignant tumors in provincial registries designed to collect data on malignancies have not been clearly outlined or addressed.

A report by the Public Health Agency of Canada (PHAC) highlighted a potential barrier to nonmalignant CNS tumor registration related to the method of diagnosis for these tumors, which is predominantly through radiology.[5] In this report, PHAC suggested that radiology facilities may not have been sufficiently integrated into the reporting infrastructure.[5] A subsequent report compared the brain tumor cases captured in the Canadian Cancer Registry (CCR) during 2006 to 2010 to the number of expected cases based on incident rates from the Central Brain Tumor Registry of the United States (CBTRUS).[6] At that time, it found that Canada registered only 33% of expected nonmalignant brain cases. The Ontario Cancer Registry was the least complete in capturing nonmalignant brain tumors, while the Manitoba Cancer Registry was the most complete, capturing 73% of expected cases. Efforts are being made in Canada to fill these gaps. For example, in some provinces, hospital discharge records are now being used to supplement casefinding, which has significantly improved completeness of nonmalignant brain tumors.[2]

The Brain Tumour Foundation of Canada (BTFC) has made the establishment of a Canadian brain tumor registry a priority, with supporting funds from both Brain Canada and the BTFC. During an inaugural team meeting of affiliates of the registry in June 2017, the missing of radiologically diagnosed brain and other CNS tumors in Canadian cancer registries was determined to be a priority. The team decided to explore this further and identify potential solutions by inviting experts to a workshop aimed at gaining insight into the pathways to brain tumor diagnosis and registration, with a focus on the role of radiology.

Methods

Meeting Organization and Agenda

To review the current status of under-registration of nonmalignant brain tumors and radiological diagnosis in Canada and to discuss the role of radiology in current reporting infrastructure, we organized a meeting titled, "Capturing Radiology Diagnoses of Primary Brain Tumours" on April 24, 2018 in Edmonton, Alberta. Participants examined the issue through a series of presentations, including a surveillance data review, a review of neuroradiology diagnosis of brain tumor and its data flow in Alberta, the neuropathology diagnosis of brain tumor and its synergy with neuroradiology, and an example of available software that captures brain tumors by processing pathology and radiology reports. Group discussions followed, focusing on the current use of radiology data across provinces and challenges associated with incorporating brain tumor diagnoses from radiology reports.

Data Analysis

Surveillance data on the diagnostic methods associated with brain tumor diagnosis were compared for Canada (CCR data release 2015, version 1) and the United States (Table 6 of the 2016 CBTRUS statistical report) to better understand the contribution of radiology in brain tumor registration.[7,8] Canadian data were limited to malignant tumors.

Discussion Synthesis and Proposed Solutions

All presentations and discussions were recorded, and detailed notes were taken throughout the meeting and used to develop a draft of the discussion synthesis, which was then circulated for review by the attending cancer registrars, physicians, and epidemiologists. Meeting participants proposed solutions based on the information shared during the meeting. The proposed solutions were developed into a set of recommendations during follow-up discussions among the coauthors.

Results

Participants brought their experience and expertise to this discussion as the following 6 questions were explored.

What is the Current Status of Brain Tumor Diagnosis by Radiology Alone?

Neuroradiology has a critical role in the diagnosis and management of brain tumors.[9] Imaging procedures such as computed tomography (CT) and magnetic resonance imaging (MRI) are the most common clinical investigations used for the initial evaluation and characterization of suspected brain tumors.[9,10] The field of neuroimaging is rapidly expanding beyond traditional anatomical examinations to identifying nuanced functional, metabolic, and cellular-level abnormalities. In the future, multimodality imaging techniques such as magnetic resonance/positron emission topography (PET) may enable radiologists to make fairly accurate diagnoses of histological tumor types, grade brain tumors, and identify structural and physiological changes to brain parenchyma.[11,12] In light of recent changes to brain tumor classification by the World Health Organization,[13] which now incorporates both histology and molecular parameters, there has been an increased interest around the role of biology-driven MRI techniques for noninvasive exploration of the association between neuroimaging findings and molecular level tissue aberrations.[9,12]

Patient-related demographic and clinical factors—including age, sex, clinical history, anatomical location, tumor spread, calcifications, and contrast enhancement—guide the radiological diagnosis of brain tumors. For example, glioblastoma, a highly aggressive brain tumor, is characterized by presentation in old age, midline crossing, and ring enhancement. Imaging findings supplemented by relevant clinical history help the radiologist reach the most probable diagnosis from a list of differentials. Neuroimaging findings are also being analyzed in relation to genetic mutations. For example, MRI findings of high contrast enhancing/necrotic volume and increased perfusion are being associated with epidermal growth factor receptor amplification, which is a feature of glioblastoma tumors.[9]

Neuroradiology also plays a key role in clinical care, treatment protocol decisions, and evaluation of tumor progression. For example, the radiological diagnostic work up of grade III astrocytoma is supplemented by histological and molecular marker assessments to determine tissue diagnosis and help direct treatment planning. Nonmalignant tumors such as some meningioma can be typically followed-up for years on neuroimaging without undergoing biopsy and active treatment. These "wait and watch" tumor diagnoses are more likely to be missed by the cancer registries, leading to delayed reporting or underreporting of these tumors.

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How Does Radiology Reporting Affect Brain Tumor Surveillance Information?

In the United States, approximately a third of all registered brain tumors were malignant and two-thirds were nonmalignant during 2009–2013.[8] The proportion of malignant tumors identified through histology was similar in Canada during 2004–2015 to that of the United States (Table 1) and this proportion was also similar across Canadian provinces (Table 2). This suggests that the impact of a radiology diagnosis on case ascertainment may be mild, although the proportions of radiological confirmation of malignant brain tumors varied from 4.4% in Ontario to 20.5% in Manitoba (Table 2), raising concern about the comparability of data on malignant tumors across provinces. It should also be noted that radiology diagnosis still plays a significant part in the diagnosis of certain subtypes of malignant brain tumors both in the United States[8] and Canada: the CCR data showed that 16.7% of unclassified and 47.0% of glioma (not otherwise specified) malignant tumors were diagnosed radiologically during 2004–2015.

With respect to nonmalignant tumors, the proportion of tumors diagnosed by histology and radiology were similar (49.3% and 47.8%, respectively) in US data (Table 1). The proportion diagnosed by radiology varied by tumor type.[7] For example, 96.3% of tumors of the sellar region were confirmed using a nonhistological diagnosis. Other subtypes of brain tumors likely to be diagnosed without histological confirmation include tumors of cranial and spinal nerves (83.9%) and tumors of meninges (66.4%). Further, the proportion of nonmalignant brain tumors diagnosed using histology is lower in the United States (49.3%) compared to Canada (59%) (Table 1).

Assuming confirmation methods for nonmalignant brain tumors in the United States are similar to those used in Canada, this comparison suggests that Canada is missing nonmalignant cases, especially those diagnosed by radiology. In the United States, electronic capture of radiology reports for casefinding has been shown to improve case entertainment for CNS neoplasms compared to traditional methods (pathology reports and hospital discharge lists).[20]

How Do Radiology Report Results Move from Clinical to Administrative Databases?

Multiple information systems are involved in the creation, transmission, storage, and distribution of neuroradiology reports. Using Alberta as an example, the process is initiated when a neuroimaging referral containing patient information and brief clinical indication enters the Radiology Information System (RIS) database, which houses imaging requests and the final text reports. When a patient undergoes the requested radiological procedure, the resulting image is transmitted to the picture archiving and communication system and is then analyzed by a radiologist, who has available patient clinical information and previous imaging results in the system for review. The radiologist dictates an unstructured medical record that relays key imaging findings with an initial diagnosis. The dictated text report is then sent to the RIS database for storage and is further distributed to several electronic health record systems, including a provincial text result repository and physician electronic medical records database. However, currently there is no natural language processing solution available in Alberta to interpret the unstructured text data. It is unclear whether this is standard procedure across institutions or regions. These variations need to be better understood at the local level.

Table 1. Summary of Diagnostic Confirmation Methods of All Primary Brain Tumors

Diagnostic Confirmation	Malignant Tumors		Nonmalignant Tumors	
	US, 2009–2013	Canada, 2004–2015	US, 2009–2013	Canada, 2006–2010
Histology (%)	85.5	83.8*	49.3	59*
Radiology (%)	9.8	7.3	47.8	41
All other (%)	5.1	8.9	2.9	

* Defined as histology and cytology.

US data is cited from the CBTRUS Statistical Report 2016.[8] The summary of malignant tumours is based on the analysis of Canada Cancer Registry data available to the study authors (see Table 2 for details). The summary of nonmalignant tumors in Canada is based on Shaw's analysis (unpublished).[6]

Table 2. Method of Diagnosis of Malignant Brain Tumors in 4 Canadian Provinces (2004–2015)

Province	Microscopic Confirmation n (%)	Radiological Confirmation n (%)	Other* n (%)	Unknown n (%)	Total n
Alberta	2,600 (83.9)	475 (15.3)	25 (0.8)	0 (0)	3,100
British Columbia	3,650 (84.4)	305 (7.1)	370 (8.6)	0 (0)	4,325
Manitoba	885 (79.0)	230 (20.5)	5 (0.5)	0 (0)	1,120
Ontario	11,265 (84.0)	590 (4.4)	215 (1.6)	1,340 (10.0)	13,410
Total	18,400 (83.8)	1,600 (7.3)	615 (2.8)	1,340 (6.1)	21,955

Note: Quebec data is only available up to 2010 and thus is not included in the table. Numbers are randomly rounded in accordance with Statistics Canada requirements.

*Other category includes death certificate, clinically confirmed, surgically confirmed, autopsy, and positive lab marker.

Table 3. Pathways to Clinical Care and Cancer Registration When a Brain Tumor is Radiologically Diagnosed

Clinical Care	Cancer Registries	
Follow up/Treatment	Registration	Data Quality
Surgery and/or seen by oncologist	Yes	Accurate
Series of MRI studies over time. Diagnosis may or may not change. Surgery and/or oncology care involved during disease course.	Likely registered when pathology confirms diagnosis or oncologist prescribes treatment.	Level of accuracy varies; initial diagnosis delayed in reporting and information may not be accurately recorded
Series of MRI studies over time only, no surgery.	Not likely	Potential to miss a significant proportion of cases

MRI, magnetic resonance imaging.

Table 4. Legislation and Responsibility for Reporting and Registering Cancer Cases by Province

Province	Legislation	Healthcare professionals	Health Authority
Alberta	Cancer Act, 2009	"Shall report"	"May request"
British Columbia	Health Act, 2009	Not mandatory but "must comply with request"	"May request"
Manitoba	Public Health Act, 2009	"Must report"	"May request"
Ontario	Cancer Act, 1990	None	Ensure "adequate reporting of cases and the recording and compilation of data"
Quebec	Public Health Act, 2001	"Must report", "in the manner and within the time limits prescribed in the regulation"	"Record"

Where is the Gap between the Clinical Practice and Cancer Registration?

For a patient and clinician, the pathway to clinical care is most important, but for surveillance researchers and stakeholders, the completeness and accuracy of cancer registration is also important. Patients cared for by oncologists are routinely being registered, since oncologists are part of the cancer care system (Table 3). The question arises as to what happens when a radiologically diagnosed patient is not immediately seen by a surgeon or an oncologist. If new patients do not require this attention, confidence in surveillance data decreases. If repeated MRIs establish a diagnosis and a patient requires surgical or oncological care at a later date, the cancer registry information will be delayed and the level of accuracy is uncertain. If repeated MRIs indicate neither surgical intervention nor oncological care, the potential for that case to be missed in the surveillance system increases. This may help explain why information on malignant brain tumors appears to be complete and the information on nonmalignant tumors is incomplete.[4,5] As discussed above, underreporting varies by province and tumor subtype. Therefore, policymakers and researchers using these data need to be cautious with data interpretation.

How May Software Applications Be Used to Process Radiology Reports?

Natural language processing is increasingly being used to read pathology reports for case identification. Different solutions are being explored in different registries. For example, Manitoba, and Newfoundland and Labrador use Artificial Intelligence in Medicine Inc (AIM) and some institutions in Quebec uses the Systèm d'ARhivage des Données en Oncologie (SARDO) to process pathology reports. Both of these software packages are used to identify cancer cases for cancer surveillance purposes.

Recently, AIM developed an imaging interpreter software that uses natural language processing and artificial intelligence to detect reportable lesions in the central nervous system. This imaging interpreter software processes the unstructured narrative radiological reports of MRI and PET scans of the brain and CT scans of the head, selects relevant reports to be forwarded to the cancer registry or other authorized department, and provides coding assistance for registrars.

The AIM software processes the unstructured reports in several stages. The first stage uses text analysis and context determination to identify concepts such as cancer terms based on terminology and specific terms from the International Classification of Diseases for Oncology, third edition (ICD-O-3), such as metastatic or mention of history. It assigns every report a yes/no value for each of the 4 categories: *primary tumor, previously known, metastatic,* and *past history of cancer*. In the second stage, a logic module is applied to all reports using these category values previously assigned to determine 1 of 5 classes: *negative, negative but has* *history, metastatic, positive but previously known*, and *positive*. Cancer registries choose different classes depending on the output desired. When all 4 classes are included from history to positive, sensitivity and specificity are excellent (typically 98% to 99%). When the system has to differentiate between classes (eg, metastatic and history), the accuracy declines. Users are provided with tables showing the confidence levels reached by class.

What is the Cancer Registry's Legal Responsibility and Approach in Case Ascertainment?

All provincial health authorities in Canada operate a centralized cancer registry that is responsible for collecting and managing data for residents diagnosed with cancer in the province under provincial law. Although the House of Commons passed legislation (MB-235) to mandate the collection of all malignant and nonmalignant brain tumors, cancer registration is a provincial responsibility governed by provincial legislation. A summary of relevant legislations in the 5 participating provinces is provided in Table 4.[14-19] There are noticeable differences in these legislative acts, which have contributed to differences in cancer registration practices. While none of these acts specifically mandates the role of radiologists or the use of radiology reports, the general reporting requirement by health care professionals subsumes this specialty.

Discussion

The information provided highlights the importance of including radiology diagnosis data in the pathway to brain tumor registration. CBTRUS reports a significant increase in incidence of radiographically confirmed nonmalignant brain tumors from 2004 to 2009, which was believed to be due to improvement in collection of nonmalignant cases in general, as well as improved collection of radiographically diagnosed cases specifically.[8] Similar to our findings in Canada, variations in benign and borderline brain tumors were found when comparing the 47 US population-based cancer registries, which were believed to be largely attributable to differences in casefinding strategies between the different registries.[20]

Primary brain tumor subtype categories with a high proportion of malignant cases typically have a high proportion of histologic confirmations and low proportion of radiology confirmations at diagnosis (Tables 1 and 2). In contrast, primarily nonmalignant histology types are less likely to be histologically confirmed and more likely to have other forms of diagnostic confirmations (Table 1). These categories of nonmalignant tumors, such as tumors of the sellar region, tumors of cranial and spinal nerves, and tumors of meninges, are at considerable risk of being underreported if radiology results are not in the cancer registration pathway.

Our review of provincial legislation indicates that, while the language regarding responsibility of reporting is general, there is a role for the neuroradiology professionals in ensuring that reportable conditions identified through radiology are reported to a cancer registry. Each province needs to clarify whether this is a direct or indirect role. Given the advances in radiology diagnosis (particularly for brain tumors), it is important to recognize that provincial legislation allows creating new options for case reporting as relevant to today's clinical practice.

Artificial intelligence solutions for analyzing radiology reports need to be considered in the context of busy, high-volume radiology practices where identifying a rare brain tumor is like looking for a needle in a haystack. Any manual approach would put a significant burden on individual radiologists/clinics and cancer registry systems. These diagnoses also may involve repeat imaging and may be inconclusive, making data extraction more complex. As general systems for electronic radiology reports exist, building new information solutions (electronic or manual) to address cancer case ascertainment may be feasible with collaboration between the cancer registry community and the radiology community. An electronic approach could be developed within provincial health information/surveillance systems. While unstructured radiology reports make information extraction difficult, natural language processing solutions are beginning to emerge.

In the long term, it might be helpful to explore adopting a form of synoptic reporting for radiology reports,[21] which has been shown to help the flow of clinical information and increase the overall completeness for case capturing in pathology reporting.[22] However, the advantages would need to clearly outweigh the staff burden of doing so in such a high-volume environment, and the structure of the synoptic report should not require radiologists to oversimplify descriptions of complex cases to the point they become less accurate.

With the passing of MB-235, provincial cancer registries are undertaking the added responsibility for the collection of all primary brain tumors in the cancer registry system without additional resources. Radiologists, by extension, have a role in reporting nonmalignant (as well as malignant) brain tumors and cancer registries have the freedom to create options for high-quality reporting processes for these tumors. Doing this effectively will dramatically improve the surveillance information on nonmalignant brain tumors, but it could also improve the completeness of case registration for other types of malignant tumors. Some potential solutions for better using radiologists and radiology reports at the provincial level were discussed:

- *British Columbia*: Engage all clinical staff at hospitals, diagnostic and laboratory departments, and other diagnostic facilities, to update, educate, and advise compliance with registry guidelines regarding reportable cases (as per CCR). Update coding and abstracting guidelines and associated reference material to match national and international standards; work with tumor registrars to ensure understanding of and adherence to the updated guidelines. Create and improve algorithms to capture cases from radiology and other reports based on brain terminology, while collaborating with information management and information technology department(s) to flag appropriate radiology reports for the registry.

- *Alberta*: Explore the opportunity to search radiology reports to find a solution for notifying the cancer registry of brain tumors found on imaging.
- *Manitoba*: Engage the radiology community; discuss their understanding of the provincial legislation and work to find a solution for notifying the cancer registry of nonmalignant brain tumors found on imaging.
- *Ontario*: Conduct a quality control/proof-of-concept study in 1 institution having high-volume neuroimaging as a starting point for understanding the magnitude of issues and opportunities. Incidentally, develop physician champions during this process.
- *Quebec*: Varied. Each hospital registry will try a strategy and compare the effectiveness of different approaches, in addition to ongoing efforts to develop SARDO so it can process imaging reports and report cancer cases to the registers.

Conclusion and Recommendations

Radiologically diagnosed nonmalignant brain tumors are disproportionally underreported in Canada. Registries need to adopt new casefinding strategies to capture clinically diagnosed cases from a range of data sources, including radiology information. This review highlights that cancer registries are free to modify case reporting strategies within the context of their provincial law in order to ensure high-quality cancer surveillance. It also becomes clear that an electronic solution is likely, given that manual review of radiology reports is impractical.

Finding a way to use existing electronic radiology reports to identify nonmalignant brain tumors should be prioritized in the near future, as using some form of electronic text search or natural language processing approach seems readily doable. Specific solutions will vary by province, but must involve cancer registry access to radiology reports and ways to use the information in electronic radiology reports. Another question to explore for the longer term would be to find out whether synoptic reporting in radiology, as being used in pathology reporting, would have any advantage with respect to improved data quality and data completeness for cancer registration and other purposes.

As radiologists and cancer registrars become more familiar with each other's mandates and workflow demands, innovative and collaborative solutions to improve case ascertainment for brain and other cancers are likely to emerge.

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