

The Establishment of an Intracranial Tumour Registry at the University Hospital of the West Indies

J Campbell¹, JR Jaggon², P Johnson¹, C Bruce¹, D Eldemire-Shearer³

ABSTRACT

In March 2010, the first Intracranial Tumour Registry (ITR) in the English-speaking Caribbean was started at the University Hospital of the West Indies (UHWI). This was deemed necessary as the already established Jamaica Cancer Registry only reports on malignant brain tumours. The ITR will collect data on all prospective intracranial tumours, benign and malignant, which are diagnosed histologically at the UHWI. Retrospective information dating back five years was also collected. Data collected so far reveal that between the years 2006 to 2010, a total of 317 cases were entered into the database. Of these, only 45 cases were considered eligible. The issues surrounding this discrepancy are discussed in this paper along with the many challenges experienced in the establishment of the ITR. From these experiences, the authors have also put forward several recommendations that may be useful to other researchers who wish to implement similar systems.

Keywords: Brain, intracranial, registry, tumour

Establecimiento de un Registro de Tumor Intracraneal en el Hospital Universitario de West Indies

J Campbell¹, JR Jaggon², P Johnson¹, C Bruce¹, D Eldemire-Shearer³

RESUMEN

En marzo del 2010, en el Hospital Universitario de West Indies (HUWI), se inició el primer Registro de Tumor Intracraneal (RTI) del Caribe anglófono. La creación de este registro fue considerada una necesidad por cuanto el ya establecido Registro de Cáncer de Jamaica solamente reporta tumores malignos del cerebro. El RTI recogerá datos de todos los tumores intracraneales prospectivos, tanto benignos como malignos, que sean histológicamente diagnosticados en HUWI. También se recopiló en retrospectiva información de cinco años atrás. Datos coleccionados hasta ahora revelan que entre los años 2006 a 2010, un total de 317 casos fueron introducidos en el banco de datos. De éstos, sólo 45 casos fueron considerados elegibles. En el presente trabajo se discuten los problemas en torno a esta discrepancia, junto con los numerosos retos enfrentados con la creación del RTI. A partir de estas experiencias, los autores hacen también varias recomendaciones que pueden ser útiles a otros investigadores deseosos de implementar sistemas similares.

Palabras claves: Cerebro, intracraneal, registro, tumor

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From: ¹Department of Surgery, Radiology, Anaesthesia and Intensive Care, ²Department of Pathology and ³Department of Community Health and Psychiatry, The University of the West Indies, Kingston 7, Jamaica.

Correspondence: Dr JR Jaggon, Department of Pathology, The University of the West Indies, Kingston 7, Jamaica. E-mail: jacqueline.jaggon@uwimona.edu.jm

INTRODUCTION

Intracranial or brain tumour registries have been established in many countries worldwide in order to provide epidemiological data on intracranial tumours so as to aid in research, treatment and predicting outcome. The data gathered in such registries should accurately describe the incidence and sur-

vival patterns of these various benign and malignant primary brain tumours, as well as evaluate diagnosis and treatment and eventually play a major role in their prevention and cure.

A hospital-based intracranial tumour registry (ITR) was established at the University Hospital of the West Indies (UHWI) in March 2010 with the intention that data would be collected prospectively as well as retrospectively. The information collected by the ITR covers both benign and primary malignant tumours arising in the brain, the skull base and pituitary gland. This registry was deemed necessary as the existing Jamaica Cancer Registry reports only on malignant brain tumours (1).

This paper reports on the challenges encountered in establishing the ITR as well as the initial findings. Recommendations have also been put forward which may be useful to other researchers planning to implement a registry.

METHOD

The ITR at the UHWI was started in March 2010 with funds received from the New Initiative Grant Fund offered by The University of the West Indies. It was started by three primary investigators from the Department of Surgery, Radiology, Anaesthesia and Intensive Care and the Department of Pathology, along with a research assistant. During the first month, several suitable registry databases were investigated; however, the cost in each case was beyond the budget of this registry.

The Centers for Disease Control and Prevention (CDC) suggested Registry Plus, a suite of publicly available free software programmes for collecting and processing cancer registry data (2), widely used throughout the United States of America (USA). From this suite, the software Abstract Plus was chosen.

Data were initially collected for the five-year period 2006 to 2010. Data sources included patient files, magnetic resonance imaging (MRI) request forms and histopathology report forms. Data entry began in April 2010. Information collected included patient demographics such as age, gender, occupation, registration number, year of diagnosis, as well as clinical presentation, radiologic findings, histologic diagnosis and treatment. Only cases with both preoperative MRI scans and histopathology reports were considered complete.

RESULTS

Data collected from all sources between the years 2006 and 2010 revealed a total of 317 patients with intracranial masses of which 62% were females and 38% were males (Fig. 1). Of these patients, 261 had their precise age documented. The age pyramid (Fig. 2) reveals a bimodal pattern for both males and females with the 51–60-year group being common to both; the first peak for males, however, was at a younger age (0–15 years) than that for females (31–40 years).

Of the total 317 patients, 286 had imaging available. From this population, only 155 patients had available preoperative MRI scans (Table 1). The rest had only post-

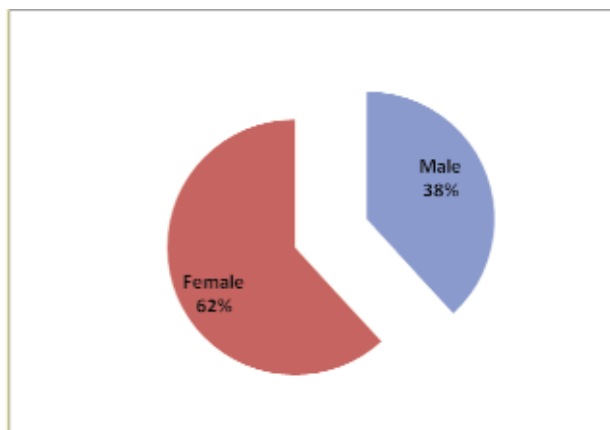


Fig. 1: Gender distribution of patients with intracranial masses at the UHWI 2006–2010.

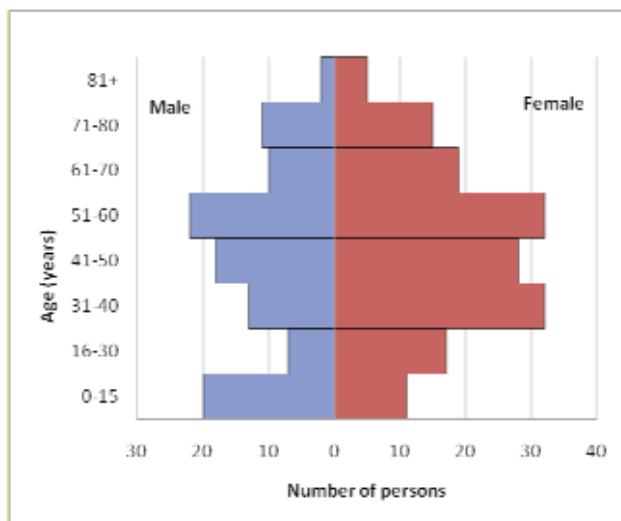


Fig. 2: Age pyramid for patients with intracranial masses at the UHWI 2006–2010.

operative MRI scans and/or computerized tomography (CT) scans. The surgical log book revealed that ninety-nine pa-

Table 1: The number of patient records retrieved from various data sources

Data sources	Patient records retrieved (n)
MRI preoperative scans	155
MRI postoperative scans only	57
CT scans (pre- and post-operative) only	74
Surgical log books	99
Histopathological reports/pre-op MRI scans	45

} 286 patients

tients had undergone surgery for intracranial masses at this institution. Table 2 lists the histologic diagnoses of these patients. However, only forty-five of these surgical patients

Table 2: List of histopathological diagnoses for patients undergoing surgery for intracranial masses at the UHWI 2006 – 2010

Histopathological Diagnosis	Total number of patients
Meningioma	40
Pituitary Adenoma	21
Glioblastoma multiforme	10
Astrocytoma NOS	6
Hemangioblastoma	3
Medulloblastoma	2
Glioma NOS	2
Oligodendroglioma	2
Metastatic Carcinoma NOS	2
Craniopharyngioma	1
Sarcoma	1
Chordoma	1
Capillary Hemangioma	1
Gliosis	1
Plexiform Neurofibroma	1
*NHL, T-cell phenotype	1
Epidermoid Cyst	1
Sample inadequate for diagnosis	2
Unable to make diagnosis	1
TOTAL	99

*NHL – Non-Hodgkin's Lymphoma

had both traceable preoperative MRI scans and histopathological reports and whose data are therefore considered complete (Table 1).

DISCUSSION

A cancer/tumour registry plays a pivotal role in the treatment and control of cancers. Its primary function is the maintenance of a register of all tumours occurring in a defined population in which the particulars of the patients along with the clinical and pathological characteristics of the tumours are documented. The data may then be analysed and information garnered on the epidemiology of specific tumours, treatment methods and outcome of patients; it may also be used by researchers in their bid to develop new treatment modalities as well as in the development of new methods of prevention

and cure (4).

Two types of tumour registries exist: a population-based registry and a hospital-based registry, with the ITR at the UHWI being an example of the latter. A population-based tumour registry records all new cases in a defined population (most frequently a geographical area) while the hospital-based registry records all cases in a given hospital, usually without knowledge of the background population. The hospital registry may eventually form the nucleus for a population-based cancer registration scheme (5).

Registry Plus is a suite of publicly available free software programmes developed by the CDC for collecting and processing cancer registry data, widely used by many tumour registries throughout the USA (2).

Abstract Plus is a component of Registry Plus and is an abstracting tool used to summarize medical records into an electronic report of cancer diagnosis and treatment, usually carried out by individuals who work with cancer data, referred to as abstractors (3). The advantages of utilizing this free software programme include the fact that the CDC provides an online training session that teaches abstractors how to fully utilize the software. Abstract Plus is also automatically backed-up online and can export data into Microsoft Access. From here, it may be converted into a Microsoft Excel programme.

Despite the many advantages of the chosen software, there were some disadvantages; the major one being that there are several non-modifiable data entry fields not applicable to the UHWI which limited the input of desired information.

At its inception, it was decided that this registry, being a hospital-based one, would initially gather retrospective information about all intracranial tumours at the UHWI. Only patients with available preoperative MRI scans as well as histology of their intracranial masses would eventually be included in this registry, as this would incorporate all patients initially diagnosed and treated at the UHWI. This decision was taken because many patients are referred to this tertiary care teaching institution from outlying hospitals. Patients are often referred for imaging only or for surgical management after being investigated elsewhere. It was also decided that as this registry expands, it would eventually become the nucleus for a population-based ITR, at which time all patients would be included even if diagnosed and/or treated at another institution.

A major setback in the gathering of retrospective data was the variation in the archiving systems used within each department. Archiving varied from electronically stored data (as done with MRI files) to file cards with handwritten data entered onto each (as exists within the Department of Pathology). Gathering information from the latter tended to be very tedious.

Noted from the results so far is the discrepancy between the number of patients who had preoperative MRI

scans for intracranial masses and the number of patients who had surgery, a difference of fifty-six patients or 36% (Table 1). Possible reasons include the fact that some patients had surgery at other institutions after being imaged here whilst others were lost to follow-up. Some of the patients imaged are still awaiting surgery. Subsequent papers will be published after detailed analysis of the data. Prospective data collection has been much simpler and more complete. However, the digitalizing of the archiving systems in all departments would be of great benefit to all researchers.

The registry database used was found to be useful for a hospital-based registry; however, the possibility of editing existing data fields to accommodate more appropriate fields for use at this institution would have been welcomed. As the registry expands and transforms into a population-based registry in the future, then a more appropriate registry software package may have to be sought.

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