

Improving Completeness of Benign Brain Tumor Reporting by a Linkage with Hospital Inpatient Discharge Data - Louisiana Tumor Registry's Experiences

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ABSTRACT

Background: Benign/borderline brain & CNS tumors (BBT) diagnosed in 2004 and after are reportable to population-based cancer registries in the US. Many BBT cases are diagnosed by radiology and image; and surgery usually is not performed. However, cancer registries do not routinely conduct case-finding in radiology centers. **Objectives:** linking registry data with Louisiana hospital inpatient discharge data (HIDD) to identify potential missed BBT cases and assessed the effectiveness of this linkage by following back with medical records. **Methods:** We linked the BBT cases identified in HIDD data file with BBT cases diagnosed in 1988 and after in LTR database using Link Plus software. **Results:** We identified 731 BBT cases from HIDD file. After linking these BBT cases in HIDD file with 6,027 BBT cases in LTR database, we found that 349 (47%) cases from HIDD were not in our database, which were considered as possible missed BBT cases. After reviewing medical charts, we found that 161 (46%) cases were missed reportable BBT cases. **Conclusions:** Linking LTR data with HIDD data is a cost-effective way to improve the reporting of BBT.

BACKGROUND

Benign/borderline brain & CNS tumors (BBT) diagnosed in 2004 and after are reportable to population-based cancer registries in the US. Many BBT cases are diagnosed by radiology and imaging; surgery usually is not performed until the tumor becomes life threatening years after. Due to limited resources, cancer registries do not routinely conduct case-finding in radiology centers; therefore underreporting of BBT has been a well-recognized reality. Thus seeking more cost-effective way to capture BBT cases is a high priority of Louisiana Tumor Registry (LTR).

OBJECTIVES

Linking LTR data with Louisiana hospital inpatient discharge data (HIDD) to: (1) identify potentially missed BBT cases and improve the completeness of BBT tumor reporting, and (2) assess the effectiveness of this linkage by following back with reviews of medical records.

DATA RESOURCES

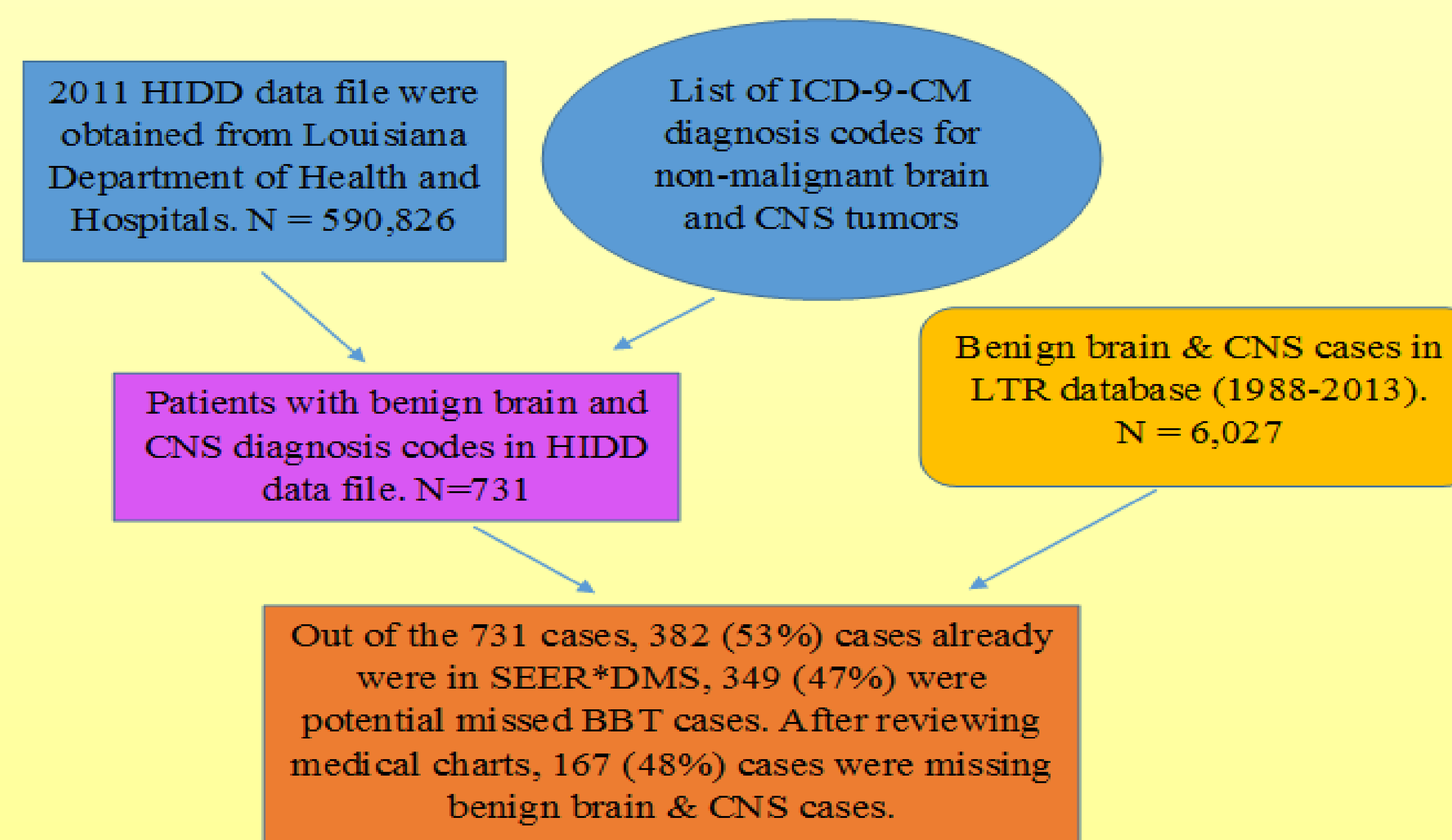
The HIDD for the year of 2011, which covered 75% of the cases discharged from acute care facilities in Louisiana, were obtained from the Louisiana Department of Health and Hospitals. BBT cases were extracted from the HIDD based on the ICD-9-CM diagnosis codes (i.e., 225, 225.0-225.9, 227.3, 227.4, 237, 237.0, 237.1, 237.5-237.7, and 237.9), which were obtained from the SEER case-finding list (<http://training.seer.cancer.gov/brain/non-malignant/casefinding.html>).

The ICD-O-3 codes (C700-C709, C710 -C719, C720-C729, and C750-C759, excluding 9050-9055, 9140, and 9590-9992), and behavior codes (0 and 1) were used to extract BBT cases diagnosed in 1988 and after from the LTR database; the LTR maintains statewide cancer cases diagnosed since 1988.

METHODS

We used the Link Plus 2.0 software to link the BBT cases from the HIDD file with BBT cases from the registry database by last name, first name, social security number, and date of birth.

Figure 1. Linkage flowchart



If a BBT case in the HIDD data file matched with a BBT case in LTR database, it indicated that the case was not missed. If a BBT case in the HIDD data file, but not in the registry database, we considered it a potentially missed case. LTR abstractors investigated all potentially missed cases by reviewing medical charts to confirm whether they were truly missed.

RESULTS

1. From the 590,826 records in the 2011 HIDD data file, 731 possible BBT cases were identified.
2. After linking the 731 BBT cases from the HIDD file with 6,027 BBT cases from the registry database, we found that 349 (47%) cases were in HIDD file but not in the registry data file, which were considered as potential missed BBT cases.
3. After reviewing medical records, we confirmed that 161 (46%) of the 349 cases were truly missed; 124 cases have been abstracted so far.

CONCLUSIONS

The linkage of registry data with hospital discharge data is a cost-effective way to identify missed BBT cases. It can be used to improve the reporting of BBT cases.

LIMITATIONS

Based on the CNS ICD-9-CM diagnosis codes, we can identify the potentially missed BBT cases from the HIDD file, but we don't know whether they are truly reportable. To confirm the reportability of BBT cases from HIDD, registry staff have to review the medical charts for additional information, which can be a time-consuming endeavor.

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