Benign/Borderline Brain and ONS Tumors in the NAACCR Data

DURC Data Assessment Work Group

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History of Brain & ONS Tumor Surveillance

- 1992. Central Brain Tumor Registry of the United States (CBTRUS) was formed.
- 1998. BTWG forwarded 4 recommendations to the NCCCS.
- 2000. Dialogue between the clinical community and the surveillance community to standardize the site and histology definition.
- 2002. President signed public law 107-260, the benign brain tumor cancer registries amendment act.
- 2003. SEER and NAACCR agreed to report non-malignant brain tumors for cases diagnosed January 1, 2004 or later.

http://training.seer.cancer.gov/brain/non-malignant/history/
http://www.naaccr.org/LinkClick.aspx?fileticket=tm-wYbKcnIg%3D&tabid=95&mid=477
Reportable benign and borderline ONS tumor:

- Meninges (C70.0, C70.1, C70.9)
- Brain (C71.0- C71.9)
- Spinal cord, cranial nerves and other parts of ONS
  - Spinal Cord (C72.0), Cauda Equina (C72.1)
  - Cranial Nerves (C72.2-C72.5), Other ONS (C72.8, C72.9)
- Other endocrine glands and related structure
  - Pituitary Gland (C75.1), Craniopharyngeal Duct (C75.2)
  - Pineal Gland (C75.3)


Data Collection of primary central nervous system tumors: NPCR training material. 2004
Study Objectives

• Examine characteristics of the benign/borderline brain and ONS tumor data in the NAACCR Data
• Examine the completeness of the benign/borderline brain and ONS tumors by state
• Identify factors associated with completeness
Methods

• 2004 – 2007 brain and ONS cases (including endocrine glands and related structures) from the CINA Deluxe data set 1995 – 2007
  • 48 states and regions in U.S.
  • Benign/Borderline brain and ONS tumor (N=141,414)
  • Invasive brain and ONS tumor (N=91,261)
  • DCO and autopsy cases included

• Variables examined
  • Race, gender, age at diagnosis, metro status, education and poverty status at county level, surgery status, diagnostic confirmation, type of reporting source

• Analytical methods
  • Age-adjusted rates, Pearson correlation, coefficient of variation (CV)
  • Multiple linear regression with rate ratio of benign/borderline vs. malignant as outcome variable
Age Adjusted Rates for Benign/Borderline

Age Adjusted Rates by Year of Diagnosis

Age Adjusted Rates by Age Group

Age Adjusted Rates by Race

Age Adjusted Rates by Gender
Age Adjusted Rates for Benign/Borderline (Cont.)

Age Adjusted Rates by Site Group

- Meninges: 6.4
- Brain: 1.3
- Spinal Cord, Cranial Nerves, and other ONS: 2.8
- Endocrine Glands and related Structure: 1.8

Age Adjusted Rates by Metro Status

- Metro: 12.6
- Rural: 11.1

Age Adjusted Rates by Poverty Status

- <5.0%: 12.3
- 5.0%-9.9%: 12.6
- 10%-19.9%: 12.2
- 20+%: 12.4
Rates for Benign/Borderline vs. % Surgery

\[ \rho = -0.57, P < 0.001 \]
Rates for Benign/Borderline vs. % Microscopically Confirmed

\[ \rho = -0.52, P = 0.002 \]
%Surgery vs. % Microscopically Confirmed in Benign/Borderline

\[ \rho = 0.81, P < 0.001 \]
Rates for Benign/Borderline and Malignant

- Std Dev = 2.29, CV = 0.20
- Std Dev = 0.75, CV = 0.10
Rate Ratio (Benign/Borderline vs. Malignant)

\[ \rho = 0.84, \ P < 0.001 \]
Completeness of Benign/Borderline Brain and ONS Data

- Compared to malignant brain and ONS tumor, much larger variation of rates for benign/borderline cases indicates possible quality issues.
- If rates for benign/borderline cases were as reliable as the rates for malignant cases, it is reasonable to expect the rate ratios between benign/borderline and malignant cases are stable.
- The substantially high correlation between rate ratio and rates for benign/borderline tumors suggests incomplete data in registries with low rate ratios.
Benign/Borderline vs. Malignant

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Benign/Borderline</th>
<th>Malignant</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>%</td>
</tr>
<tr>
<td><strong>Surgery Status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Surgery</td>
<td>72182</td>
<td>51.0%</td>
</tr>
<tr>
<td>No Surgery</td>
<td>63393</td>
<td>44.8%</td>
</tr>
<tr>
<td>Unknown</td>
<td>5839</td>
<td>4.1%</td>
</tr>
<tr>
<td><strong>Diagnostic Confirmation</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Microscopical</td>
<td>80367</td>
<td>56.8%</td>
</tr>
<tr>
<td>Radiography</td>
<td>56477</td>
<td>39.9%</td>
</tr>
<tr>
<td>Lab/Visualization/clinic</td>
<td>1635</td>
<td>1.2%</td>
</tr>
<tr>
<td>Unknown</td>
<td>2935</td>
<td>2.1%</td>
</tr>
<tr>
<td><strong>Reporting Source</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hospital</td>
<td>135662</td>
<td>95.9%</td>
</tr>
<tr>
<td>Radiation</td>
<td>1121</td>
<td>0.8%</td>
</tr>
<tr>
<td>Lab/Office/Nursing</td>
<td>1507</td>
<td>1.1%</td>
</tr>
<tr>
<td>Autopsy/DC</td>
<td>3124</td>
<td>2.2%</td>
</tr>
</tbody>
</table>
Rate Ratio vs. % Surgery in Benign/Borderline

\[ \rho = -0.48, \ P < 0.001 \]
Rate Ratio vs. % Microscopically Confirmed in Benign/Borderline

\[ \rho = -0.51, P < 0.001 \]
Rate Ratio vs. % Age 65+ Old Population

\[ \rho = -0.32, \quad P = 0.025 \]
Rate Ratio vs. % Female Population

\[ \rho = -0.33, P = 0.020 \]
## Multiple Linear Regression Modeling Rate Ratio

<table>
<thead>
<tr>
<th>Coefficient</th>
<th>Full Model</th>
<th>Reduced Model</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Estimate(SE)</td>
<td>P value</td>
</tr>
<tr>
<td>%Microscopically Confirmed</td>
<td>-0.014 (0.006)</td>
<td>0.030</td>
</tr>
<tr>
<td>%Age 65+</td>
<td>-0.053 (0.032)</td>
<td>0.099</td>
</tr>
<tr>
<td>%Surgery</td>
<td>-0.005 (0.007)</td>
<td>0.489</td>
</tr>
<tr>
<td>%Reporting from Hospital</td>
<td>-0.011 (0.009)</td>
<td>0.289</td>
</tr>
<tr>
<td>%Black</td>
<td>-0.000 (0.005)</td>
<td>0.981</td>
</tr>
<tr>
<td>%Female</td>
<td>-0.094 (0.094)</td>
<td>0.323</td>
</tr>
</tbody>
</table>

\[ R^2 = 0.41, \]
\[ R^2 \text{ improve to } 0.51 \text{ if dropping Hawaii} \]

% Microscopically Confirmed and % Surgery are interchangeable in the reduced model.
Summary

• Data has improved since year 2004.
• Incomplete data for benign/borderline brain and ONS tumors are likely found in the NAACCR data, especially for the state registries with low rate ratios and low rates for benign/borderline.
• % microscopically confirmed cases and % surgery cases are inversely correlated with the rates for benign/borderline brain and ONS tumors and rate ratios between benign/borderline and malignant brain and ONS tumors.
• % older population is also inversely correlated with the rate ratios between benign/borderline and malignant brain and ONS tumors.
Discussion

• Why data are missing?
  • It is new; registrars are still getting used to the process.
  • Lots cases are diagnosed through imaging.
  • Discharge diagnosis code may not be updated or accurate.

• How much data are missing?
  • Compared to the Colorado registry which has been collecting benign/borderline brain and ONS tumor much longer, some registries may have missed substantial amount of cases.
  • The real amount of missing cases are hard to estimate.

• What can we do to improve the data?
  • Use % microscopically confirmed or % surgery as part of quality check. Higher level of % microscopically confirmed or % surgery indicates possible issues.
  • Higher % of older population with a lower rate is a indication of incomplete data
  • Similar as E-Path, electronic radiology reporting system may improve the data quality
Thank you!

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