West Virginia’s Traumatic Brain Injury Registry: A Rural State’s Chronological Exploration of TBI Trends

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Background
Effective October 2007, West Virginia State Code required acute care facilities to report limited patient information about moderate to severe traumatic brain injury (TBI) hospitalizations to the West Virginia University Center for Excellence in Disabilities (WVU CED) within 7 days of injury to be entered into the WV TBI Registry. The number of TBI hospitalizations reported varies widely by year (Table 1). As a matter of practice, the WVU CED mails a follow-up survey consisting of 12 closed-ended questions to all reported individuals.

Objective
This poster examines TBI hospitalization trends in WV over a 10-year period using data from the WV TBI Registry follow-up survey. Analysis of the data:

- Reveals mechanisms of injury
- Identifies the age groups affected
- Examines barriers faced by TBI survivors
- Provides support for program development to prevent injuries and additional services and supports to TBI survivors

Program Description
Since the inception of the WV TBI Registry in 2007, the WVU CED has mailed a follow-up survey to all patients reported by acute care facilities. Each survey includes a self-addressed stamped envelope and is accompanied with information about services available through the WVU CED TBI Services Program. All individuals submitted to the WV TBI Registry are eligible for WVU CED TBI services, but only a small proportion enroll.

Table 1
Number of WV Residents Reported to the TBI Registry and Follow-up Survey Response Rates by Year: 2007-2017

<table>
<thead>
<tr>
<th>Year</th>
<th>Reported to TBI Registry</th>
<th>Completed</th>
<th>Response Rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>2007(Partial Year)</td>
<td>762</td>
<td>112</td>
<td>14.7</td>
</tr>
<tr>
<td>2008</td>
<td>348</td>
<td>225</td>
<td>64.7</td>
</tr>
<tr>
<td>2009</td>
<td>406</td>
<td>115</td>
<td>28.3</td>
</tr>
<tr>
<td>2010</td>
<td>1361</td>
<td>124</td>
<td>9.1</td>
</tr>
<tr>
<td>2011</td>
<td>178</td>
<td>73</td>
<td>41.0</td>
</tr>
<tr>
<td>2012</td>
<td>1947</td>
<td>34</td>
<td>1.7</td>
</tr>
<tr>
<td>2013</td>
<td>1753</td>
<td>270</td>
<td>15.4</td>
</tr>
<tr>
<td>2014</td>
<td>1029</td>
<td>135</td>
<td>13.1</td>
</tr>
<tr>
<td>2015</td>
<td>1237</td>
<td>140</td>
<td>11.3</td>
</tr>
<tr>
<td>2016</td>
<td>943</td>
<td>119</td>
<td>12.6</td>
</tr>
</tbody>
</table>
Findings/Results

Mechanisms of Injury

- Centers for Disease Control (CDC) reports three major causes of TBI in the US: falls, auto accidents and being struck by/against an object.¹
- Between 2007 and 2017, falls and motor vehicle accidents accounted for 33.2% and 29.5% of WV’s TBI injuries, respectively (Chart 1).
- Nationwide, the young and the old are disproportionately affected by falls.¹
- In WV, falls accounted for over 30% of the injuries among children under 5 years of age and more than 70% of TBIs among those 70 and older between 2007 and 2017 (Chart 2).
- In 2007, the average age of hospitalization in WV due to TBI was 33 years old; by 2017, the average age of hospitalization due to TBI was 59, an increase of 26 years on average.

Medical Insurance

- Medicare coverage increased in WV among TBI survivors from 26.3% in 2007 to 51.0% in 2017, which corresponds to the increase in average age over time (Chart 3).
- In January 2014, WV expanded Medicaid coverage under the Affordable Care Act.²
  - 14.4% of respondents indicated that they had no insurance in 2007
  - By 2014, respondents reporting no insurance dropped to 2.4%.
- WV began offering a TBI Waiver program in February 2012 in addition to the A/D and IDD Waivers.³
  - This waiver was not included in the follow-up survey instrument.
  - TBI survivors apply for waiver coverage well after injury occurs; thus, rates of waiver coverage may not be adequately reflected in follow-up survey results.

Barriers

- The WV TBI Registry followup survey respondents could report multiple barriers to care and services after injury (Table 2).
- Most barriers have remained static from 2007 to 2017.
- Beginning in 2013, the number of individuals reporting the Lack of Insurance as a barrier has steadily declined, likely due to the Medicaid expansion under the Affordable Care Act.

Table 2
Barriers to Care and Services Post Traumatic Brain Injury: 2007-2017

<table>
<thead>
<tr>
<th>Barrier</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unaware of Services or Resources</td>
<td>15.2%</td>
</tr>
<tr>
<td>Difficulty Understanding How to Get Services/Benefits</td>
<td>13.8%</td>
</tr>
<tr>
<td>Unable to Pay for Services</td>
<td>12.9%</td>
</tr>
<tr>
<td>Services Not Available Locally</td>
<td>11.1%</td>
</tr>
<tr>
<td>Unable to Find Provider with TBI Experience</td>
<td>10.2%</td>
</tr>
<tr>
<td>Lack of Transportation</td>
<td>9.5%</td>
</tr>
<tr>
<td>Lack of Insurance</td>
<td>8.5%</td>
</tr>
</tbody>
</table>
Difficulty Completing Paperwork 7.3%
Lack of Support or Patient Advocacy 6.4%
Language Barrier 0.4%
Other Barriers 4.7%

Tracking Attrition from Registry to TBI Services Enrollment
- Between July 1, 2017 – Sept. 20, 2017:
  - 84 individuals were reported to the WV TBI Registry by acute care facilities
  - 24 individuals completed a TBI Registry Follow-Up Survey (28.6 response rate)
  - 17 individuals reported an interest in WVU CED TBI Services (20.2% of those reported to the WV TBI Registry)
  - 9 individuals enrolled in WVU CED TBI Services (10.7% of those reported to the WV TBI Registry)
  - 8 of 17 individuals interested in WVU CED TBI Services did not respond or have not completed enrollment (9.5% of those reported to the TBI Registry)

Limitations
- Not every TBI is reported and facilities are inconsistent in submitting moderate to severe TBI hospitalizations to the WV TBI Registry
- Only select facilities are mandated to report moderate to severe TBI hospitalizations
- Response rates to the follow-up survey have fluctuated but averaged 13.7% over the 10-year period
- Survey return rates from statewide assessments of TBI survivors are consistently low

Conclusions and Next Steps
Evaluation results show changes to the WV TBI Registry follow-up survey are warranted. These include:
- Implementing procedures to increase the survey response rate
- Updating and expanding the mechanisms of injury categories captured, e.g., adding self-harm and struck by/against
- Exploring methods to increase program enrollments by survivors reported to the WV TBI Registry
- Expanding evaluation efforts to assess the impact of enrolling in WVU CED TBI Services on the most frequently cited barriers:
  - Unaware of services or resources
  - Difficulty understanding how to get services/benefits

References
