Rehabilitation for TBI in the U.S.

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Collaborators at the TBI Model Systems National Data & Statistical Center
The Traumatic Brain Injury Model Systems

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Traumatic Brain Injury Model Systems Centers

TBI Model Systems Leadership

• Federal Project Management
  – National Institute on Disability and Rehabilitation Research, A. Cate Miller, PhD, Project Manager

• National Data and Statistical Center
  – Craig Hospital, Englewood, CO, Cindy Harrison-Felix, PhD, Project Director

• TBI Model Systems Centers
  – Executive Committee Chair, John D. Corrigan, PhD
NIDRR TBI National Database

- Longitudinal study of long-term outcomes following rehabilitation for TBI
- Form I: Collected during inpatient rehabilitation: 182 variables
- Form II: Follow-ups conducted 1, 2, 5, and every 5 years thereafter; administered via telephone (primarily): 145 variables

NIDRR TBI National Database

- Form I – 11,758 cases (as of 3/31/2013)
- Form II – 38,343 follow-ups* - 24% attrition (3%**)
  - Year 1 – 11,204 – 18% attrition (2%**)
  - Year 2 – 9,981 – 21% attrition (4%**)
  - Year 5 – 7,321 – 25% attrition (6%**)
  - Year 10 – 3,361 – 25% attrition (4%**)
  - Year 15 – 883 – 23% attrition (6%**)
  - Year 20 – 307 – 12% attrition (0%**)
*There are some follow-ups in database that were performed at 3, 4, and 6 years post-injury.
**Additional percent attrition due to loss of center funding.

Database Inclusion Criteria

- Moderate to severe TBI (PTA>24 hrs or LOC>30 minutes or GCS in ED<13 or intracranial neuroimaging abnormalities)
- Admitted to system’s hospital emergency department within 72 hours of injury.
- 16 years of age or older at the time of injury
- Receives acute care and comprehensive inpatient rehabilitation within the model system hospitals.
- Informed consent is signed by patient, family or guardian.
TBI NDB Representativeness

- Applicability of TBIMS findings are dependent on the degree to which the TBIMS NDB reflects the larger population of people with TBI
- By definition, the TBI NDB focuses on persons with moderate to severe TBI receiving rehabilitation
- Concern that the TBIMS NDB has a biased sample of cases alleviated by recent comparison with national statistics compiled from the Uniform Data System for Medical Rehabilitation (UDS) and eRehabData

The Journal of Head Trauma Rehabilitation

Representativeness of the Traumatic Brain Injury Model Systems National Database

Few Differences between TBI Model Systems and U.S. Population Once Age Accounted For

16-64 year olds
- Vocational Status
  - Employed
- Rehab Length of Stay
  - 1-9 days

65 and older
- Age
  - 65-69
  - 80-89
- Vocational Status
  - Employed
  - Retired
- Primary Payment Source
  - Private Insurance
  - Medicare
- Rehab Length of Stay
  - 1-9 days

Yellow font = TBIMS had more
Age by Year of Rehabilitation Admission

Representativeness of the Traumatic Brain Injury Model Systems
National Database

Epidemiology of Adults Receiving Acute Inpatient Rehabilitation for a Primary Diagnosis of Traumatic Brain Injury in the United States

Life Expectancy following Inpatient Rehabilitation for Traumatic Brain Injury in the United States

Cynthia L. Harrison-Felix, Christopher R. Pretz, Flore Hammond, Jeffrey Cuthbert, Jonesta Bell, John D. Corrigan, A Cate Miller, Juliet Haahr-krupa

Cynthia L. Harrison-Felix, Christopher R. Pretz, Flore Hammond, Jeffrey Cuthbert, Jonesta Bell, John D. Corrigan, A Cate Miller, Juliet Haahr-krupa
Gender by Age
64% male; proportion of females increased with age

Vocational Status by Age
69% not employed (49% retired); youngest students, oldest retired

Marital Status by Age
58% not married; proportion married & previously married increased with age
Problem Substance Use by Age
Proportion of problem substance use decreased with age

Etiology by Age
51% falls; 41% vehicular; proportion of falls increased & vehicular decreased with age

US Population Estimates of Health and Social Outcomes 5 Years After Rehabilitation for Traumatic Brain Injury

John D. Corrigan, PhD; Jeffrey P. Cuthbert, PhD; MPH; MS; Cynthia Harrison-Felix, PhD; Gale C. Whitworth, PhD; Jonella M. Bell, MD; MPH; A. Cate Miller, PhD; Victor C. Corrigan, MD; MPH; Christopher R. Pretz, PhD

Studies by Cynthia L. Harrison-Felix, Christopher R. Pretz, Flora Hammond, Jeffrey Cuthbert, Jonella Bell, John D. Corrigan, A. Cate Miller, and Victor Manheimer Krupa

Outcomes for Adults in the U.S. Five Years after Rehabilitation for TBI

- TBI Model Systems subjects admitted to rehabilitation 10/01/2001 to 12/31/2007

- Status 5 years later (weighted for national population characteristics):
  - 84.4% known outcome
  - 10.0% lost to follow-up
  - 5.7% withdrew/refused/unknown
  - For 1 in 4, the known outcome is “dead”

21.7% dead within 5 years

Of the average annual 13,700 admissions to U.S. IRF's with a primary diagnosis of TBI, an estimated annual average of more than 2,965 died in the first five years after injury.

*October 1, 2001 and December 31, 2007*
John D. Corrigan, PhD  
October 2014

Methods

- 7,366 TBI Model Systems National Database subjects admitted for rehabilitation on 10/01/2001 or later and discharged by 12/31/2010 with vital status tracked until 12/31/2011. (20,314 person-years of data)

- Weighted for national population characteristics to represent 156,447 individuals admitted to U.S. inpatient rehabilitation facilities with a primary diagnosis of TBI ages 16+ during same time period.

- Used U.S. population mortality rates from 2005 and 2010 to calculate standardized mortality ratios and life expectancy.

<table>
<thead>
<tr>
<th></th>
<th>Observed Deaths</th>
<th>Expected Deaths</th>
<th>Standardized Mortality Ratio (SMR)</th>
<th>95% Confidence Interval</th>
</tr>
</thead>
<tbody>
<tr>
<td>All participants</td>
<td>1,325.4</td>
<td>594.7</td>
<td>2.23</td>
<td>2.11, 2.35</td>
</tr>
<tr>
<td>If alive 1 year post-injury</td>
<td>879.2</td>
<td>570.7</td>
<td>1.54</td>
<td>1.44, 1.64</td>
</tr>
</tbody>
</table>

- Individuals with TBI were 2.23 times more likely to die compared to individuals in US general population of similar age, gender and race.

- Excess mortality decreased for those who survived at least until their 1 year post-injury anniversary.

Overall Results

<table>
<thead>
<tr>
<th>Age at injury (years)</th>
<th>Observed Deaths</th>
<th>Expected Deaths</th>
<th>SMR</th>
<th>95% Confidence Interval</th>
</tr>
</thead>
<tbody>
<tr>
<td>15-19</td>
<td>7.6</td>
<td>0.7</td>
<td>11.58</td>
<td>3.37 - 19.79</td>
</tr>
<tr>
<td>20-24</td>
<td>17.1</td>
<td>2.5</td>
<td>6.86</td>
<td>3.60 - 10.31</td>
</tr>
<tr>
<td>25-34</td>
<td>26.9</td>
<td>5.3</td>
<td>8.24</td>
<td>5.12 - 11.35</td>
</tr>
<tr>
<td>35-44</td>
<td>46.6</td>
<td>4.9</td>
<td>9.56</td>
<td>6.82 - 12.31</td>
</tr>
<tr>
<td>45-54</td>
<td>104.2</td>
<td>12.2</td>
<td>8.55</td>
<td>6.91 - 10.18</td>
</tr>
<tr>
<td>55-64</td>
<td>107.5</td>
<td>21.3</td>
<td>5.04</td>
<td>4.09 - 5.99</td>
</tr>
<tr>
<td>65-74</td>
<td>245.1</td>
<td>55.6</td>
<td>4.41</td>
<td>3.86 - 4.96</td>
</tr>
<tr>
<td>75-84</td>
<td>530.0</td>
<td>200.8</td>
<td>2.64</td>
<td>2.41 - 2.86</td>
</tr>
<tr>
<td>85+</td>
<td>240.3</td>
<td>293.5</td>
<td>0.82</td>
<td>0.72 - 0.92</td>
</tr>
</tbody>
</table>

Generally, as age at injury increased, excess mortality decreased, but still remained elevated to age 84.
Males had greater excess mortality than females.

<table>
<thead>
<tr>
<th>Gender</th>
<th>Observed Deaths</th>
<th>Expected Deaths</th>
<th>SMR</th>
<th>95% Confidence Interval</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>871.1</td>
<td>335.7</td>
<td>2.60</td>
<td>2.42 - 2.77</td>
</tr>
<tr>
<td>Female</td>
<td>454.2</td>
<td>259.1</td>
<td>1.75</td>
<td>1.59 - 1.92</td>
</tr>
</tbody>
</table>

Independent risk factors for death

- Older age at injury
- Being male
- Divorced, widowed or separated
- Unemployed
- Less education
- Fall related TBI
- Later year of injury
- Not having a spinal cord injury
- Not discharged home
- Lower functional independence
- Greater disability

<table>
<thead>
<tr>
<th>Cause of Death</th>
<th>Actual Deaths</th>
<th>Expected Deaths</th>
<th>SMR</th>
<th>SMR 95% Confidence Limits</th>
</tr>
</thead>
<tbody>
<tr>
<td>Seizures</td>
<td>55.3</td>
<td>13.3</td>
<td>4.14</td>
<td>2.91, 6.00</td>
</tr>
<tr>
<td>Accidental Poisoning</td>
<td>103.6</td>
<td>21.5</td>
<td>4.77</td>
<td>3.29, 6.33</td>
</tr>
<tr>
<td>Sepsis</td>
<td>24.2</td>
<td>6.0</td>
<td>4.00</td>
<td>2.48, 6.36</td>
</tr>
<tr>
<td>Aspiration Pneumonia</td>
<td>58.6</td>
<td>10.7</td>
<td>5.46</td>
<td>3.65, 7.58</td>
</tr>
<tr>
<td>Fall</td>
<td>98.0</td>
<td>8.8</td>
<td>11.35</td>
<td>7.46, 15.38</td>
</tr>
<tr>
<td>Homicide</td>
<td>9.1</td>
<td>1.4</td>
<td>6.42</td>
<td>3.09, 8.55</td>
</tr>
<tr>
<td>Pneumonia</td>
<td>80.0</td>
<td>19.3</td>
<td>4.15</td>
<td>2.74, 5.58</td>
</tr>
<tr>
<td>All External Causes</td>
<td>324.8</td>
<td>106.6</td>
<td>3.08</td>
<td>2.47, 3.70</td>
</tr>
<tr>
<td>Vascular</td>
<td>179.6</td>
<td>51.6</td>
<td>3.46</td>
<td>2.61, 4.35</td>
</tr>
<tr>
<td>Suicide</td>
<td>20.1</td>
<td>8.4</td>
<td>2.41</td>
<td>1.46, 3.78</td>
</tr>
<tr>
<td>All Respiratory</td>
<td>176.6</td>
<td>67.5</td>
<td>2.62</td>
<td>2.23, 3.00</td>
</tr>
<tr>
<td>Mental/Behavioral</td>
<td>47.4</td>
<td>21.8</td>
<td>2.17</td>
<td>1.55, 2.79</td>
</tr>
<tr>
<td>Nervous System</td>
<td>63.8</td>
<td>35.9</td>
<td>1.78</td>
<td>1.34, 2.21</td>
</tr>
<tr>
<td>Digestive</td>
<td>27.4</td>
<td>16.2</td>
<td>1.68</td>
<td>0.94, 2.07</td>
</tr>
<tr>
<td>Circulatory</td>
<td>340.8</td>
<td>239.8</td>
<td>1.42</td>
<td>1.27, 1.57</td>
</tr>
</tbody>
</table>
Deaths due to Accidental Poisoning

<table>
<thead>
<tr>
<th></th>
<th>Opiate primary</th>
<th>Opiate involved</th>
<th>Alcohol primary</th>
<th>Alcohol involved</th>
</tr>
</thead>
<tbody>
<tr>
<td>Opiate primary</td>
<td>55%</td>
<td></td>
<td>23%</td>
<td></td>
</tr>
<tr>
<td>Opiate involved</td>
<td>64%</td>
<td></td>
<td>41%</td>
<td></td>
</tr>
</tbody>
</table>

In Summary

- Individuals with TBI are more than 2 times more likely to die compared to individuals in US of similar age, gender and race.
- Excess mortality decreases once surviving to 1 year post-injury.
- While there are more deaths with greater age, younger age groups have more excess mortality.
- There are opportunities to decrease the most common causes of death as well as the causes of greatest excess mortality.
Outcomes for Adults in the U.S. Five Years after Rehabilitation for TBI

• TBI Model Systems subjects admitted to rehabilitation 10/01/2001 to 12/31/2007

• Status 5 years later (weighted for national population characteristics):
  – 84.4% known outcome for 1 in 4, the known outcome is “dead”
  – 10.0% lost to follow-up
  – 5.7% withdrew/refused/unknown

Final Analyses

Re-weighted outcomes to reflect the U.S. population who were over the age 15 when they received inpatient rehabilitation with a primary diagnosis of TBI and are still alive 5 years later.

12.3% are institutionalized 5 years post-injury

Of the average annual 13,700 admissions to U.S. IRFs with a primary diagnosis of TBI, an estimated annual average of more than 1,680 were institutionalized 5 years after injury.
49.7% are re-hospitalized at least once in the first 5 years post-injury

Of the average annual 13,700 admissions to U.S. IRF's with a primary diagnosis of TBI, an estimated annual average of more than 6,810 were re-hospitalized in the 5 years after injury.

32.3% need assistance in at least one area of physical functioning 5 years post-injury

Of the average annual 13,700 admissions to U.S. IRF's with a primary diagnosis of TBI, an estimated annual average of more than 4,420 required assistance in at least 1 area of physical functioning 5 years post-injury.

34.6% require some supervision by another person each day at 5 years post-injury

Of the average annual 13,700 admissions to U.S. IRF's with a primary diagnosis of TBI, an estimated annual average of more than 4,735 required supervision 5 years after injury.
54.5% are not able to drive 5 years post-injury

Of the average annual 13,700 admissions to U.S. IRF's with a primary diagnosis of TBI, an estimated annual average of more than 7,460 were not able to drive themselves 5 years after injury.

55.3% of those employed pre-injury are not working 5 years post-injury

Of the average annual 13,700 admissions to U.S. IRF's with a primary diagnosis of TBI, an estimated annual average of more than 7,570 employed pre-injury were not working 5 years after injury.

14.2% misused alcohol in the 5 years since injury

Of the average annual 13,700 admissions to U.S. IRF's with a primary diagnosis of TBI, an estimated annual average of more than 1,945 have misused alcohol in the 5 years after injury.
5.1% have used an illegal drug in the 5 years since injury

Of the average annual 13,700 admissions to U.S. IRF’s with a primary diagnosis of TBI, an estimated annual average of 700 have used illegal drugs in the 5 years after injury.

29.1% are more dissatisfied than satisfied with life at 5 years post-injury

Of the average annual 13,700 admissions to U.S. IRF’s with a primary diagnosis of TBI, an estimated annual average of more than 5,320 were more dissatisfied than satisfied with life at 5 years post-injury.

8.4% have moderate to severely depressed mood 5 years post-injury

Of the average annual 13,700 admissions to U.S. IRF’s with a primary diagnosis of TBI, an estimated annual average of more than 1,145 had moderate to severely depressed mood 5 years post-injury.
57.8% have moderate or severe disability at 5 years since injury

Of the average annual 13,700 admissions to U.S. IRF’s with a primary diagnosis of TBI, an estimated annual average of more than 7,920 had moderate or severe disability 5 years after injury.

*October 1, 2001 and December 31, 2007

38.8% declined from an earlier outcome to their status at 5 years post-injury

Of the average annual 13,700 admissions to U.S. IRF’s with a primary diagnosis of TBI, an estimated annual average of more than 5,320 declined from an earlier outcome to status at 5 years post-injury.

*October 1, 2001 and December 31, 2007

Summary & Implications

- Strong interaction of aging with TBI to make medical & functional outcomes worse.
- Greater problems with age apparent despite “Survivor Bias” inflating outcome among those still alive.
- Unique quality of life issues for younger patients (limits on participation in society, poorer subjective well-being, greater substance misuse).
- Deterioration is not unique to older adults, though basis for loss may be different for younger versus older survivors.
Possible Sources of Deterioration

- TBI triggers a progressive, degenerative process (i.e., Parkinson’s Disease, Alzheimer’s Disease, Chronic Traumatic Encephalopathy).
- TBI causes loss of functional independence which interacts with normal aging to increase poor health.
- Frontal lobe damage endemic to TBI causes changes in self-regulation which lead to death and disability from risky behaviors.
- All, or some, of the above.

U.S. population more than 15 years old receiving rehabilitation for a primary diagnosis of TBI:

By 5 years after injury:
- 2 in 10 died
- 3 in 10 deteriorated from recovery attained 1-2 years after injury

Take Home Messages

- The TBI rehab population in the U.S. is getting older (will accelerate with the aging of Baby Boomers).
- Regardless of age there is significant mortality and morbidity in the years following TBI.
- Factors affecting mortality and morbidity are multi-faceted and include pre-injury, injury-related and post-injury contributions.
- For humanistic and economic reasons we need to take an aggressive, proactive approach to reducing mortality and morbidity.
- We do not yet have the evidence we need to create protocols for a disease management approach to TBI.
Further Resources about the TBI Model Systems

www.msktc.org

www.tbindsc.org