TBI as a Chronic Health Condition

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National Data & Statistical Center
Traumatic Brain Injury Model Systems Centers

Currently Funded
Follow-up Center
Previously Funded

NIDRR TBI National Database

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

NIDRR TBIMS National Database

• Form I – 12,659 cases (as of 3/31/2014)
• Form II – 41,733 follow-ups* - 24% attrition (4%**)
  – Year 1 – 12,041 – 18% attrition (3%**)
  – Year 2 – 10,761 – 21% attrition (4%**)
  – Year 5 – 8,167– 24% attrition (5%**)
  – Year 10 – 3,994 – 25% attrition (5%**)
  – Year 15 – 1,107 – 21% attrition (6%**)
  – Year 20 – 373 – 14% 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.
TBIMS 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.
- Received acute care and comprehensive inpatient rehabilitation within the model systems hospitals.
- 16 years of age or older at the time of injury
- Informed consent is signed by patient, family or guardian.

TBIMS 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 was 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

John D. Corrigan, PhD, Jeffrey P. Cuthbert, MPH, MS; Gale G. Whitenack, PhD; Marcel P. Bijlsma, PhD; Victor Cenname, MD, MPH; Allen W. Heimann, PhD; Cynthia Harrison-Felix, PhD; James E. Graham, PhD
Few Differences between TBI Model Systems and U.S. Population Once Age Accounted For

<table>
<thead>
<tr>
<th>16-64 year olds</th>
<th>65 and older</th>
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<tr>
<td>Vocational Status</td>
<td>Age</td>
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<td>✓ 65-69</td>
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<tr>
<td>✓ 1-9 days</td>
<td>✓ 80-89</td>
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<tr>
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<td>✓ Medicare</td>
</tr>
<tr>
<td></td>
<td>Rehab Length of Stay</td>
</tr>
<tr>
<td></td>
<td>✓ 1-9 days</td>
</tr>
</tbody>
</table>

Yellow font = TBIMS had more

Age by Year of Rehabilitation Admission

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

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. IRF’s with a primary diagnosis of TBI, an estimated annual average of more than 1,680 were institutionalized 5 years after injury.

*October 1, 2001 and December 31, 2007
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

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.
• Some or all of the above.
U.S. population more than 15 years old receiving inpatient rehabilitation for a primary diagnosis of TBI:

By 5 years after injury:
• 2 in 10 die
• 3 in 10 deteriorate from recovery attained 1-2 years after injury

2009 Institute of Medicine Report
Gulf War and Health Volume 7: Long-Term Consequences of Traumatic Brain Injury

Traumatic Brain Injury: A Disease Process, Not an Event
Brent E. Masel and Douglas S. Dillich

Traumatic Brain Injury as a Chronic Health Condition
John D. Corrigan, PhD. and Flora M. Hammond, MD.
Chronic Brain Injury (CBI)
2012 Galveston BI Conference:

“Injury to the brain can evolve into a lifelong health condition termed chronic brain injury (CBI). CBI impairs the brain and other organ systems and may persist or progress over an individual’s life span. CBI must be identified and proactively managed as a lifelong condition to improve health, independent function and participation in society.”

TBI as a Chronic Condition

Recovery Persistence Deterioration

Managing TBI as a chronic health condition

• clinical surveillance to allow early detection and intervention for health complications
• preventive interventions that target high incidence/high risk complications
• patient engagement & self-management training to improve health and well-being
• medical care access to treat complications
• rehabilitation services access to optimize function
The Case for Supported Management

- **Usual Care:**
  - Of 8,760 hours in a year, persons with chronic disability spend average 3 hours/year with health professionals
- **Need to activate, empower & build self efficacy**
  - Teach how to monitor, treat and when to call
  - Will need:
    - markers & protocols
    - Infrastructure redesign
    - Group education, written materials, technologies
    - Ability to identify who can perform & benefit from self management & who needs case management
    - Protocols for self management, dz mgmt, & CM approaches

Risk Stratification for Chronic Dz Mgmt

Target the right people with the right intensity

Comparison of Usual Care Vs. Disease Management

**Usual Care**
- Ready access for acute problems
- Short appointments
- Diagnosis
- Treat signs & symptoms
- Reliance on labs & Rx
- Brief didactic
- Patient initiated f/u

**Disease Management**
- Regular interactions
- Preventive
- Systematic assessments
- Treatment guidelines
- Behavioral support for self management
- Relevant teaching
- Clinic initiated f/u
Example of Proactive management: Follow up, Intensity & Case Management


Designing a “Disease Management” approach to Chronic Brain Injury

- Which brain injuries increase risk for negative outcomes?
- What pre-existing conditions require management?
- What conditions develop post-injury that could be prevented or detected early?
- How can the individual participate in their self-management?
- How can access to medical and rehabilitation care be used to reduce negative outcomes?
- How can community-based resources be accessed to improve function and reduce institutionalization?

THANK YOU

For further information about the TBI Model Systems:

www.msktc.org
www.tbinsc.org