The NIDILRR-sponsored TBI Model System Program

Two NJ sites
TBI Model Systems Background

• The Traumatic Brain Injury Model System Centers (TBIMS Centers) program was created by National Institute on Disability Independent Living and Rehabilitation Research (previously National Institute on Disability and Rehabilitation Research) in 1987 to demonstrate the benefits of a coordinated system of neurotrauma and rehabilitation care and to conduct innovative research on all aspects of care for those who sustain TBI.

• The mission of the TBIMS Centers is to improve the lives of persons who experience TBI, and of their families and communities, by creating and disseminating new knowledge about the natural course of TBI and about rehabilitation treatment and outcomes following TBI.

• The influence of the TBIMS program continues to be expanded through collaborations with the US Departments of Veterans Affairs and Defense, the National Institute of Neurological Disorders and Stroke, and the Centers for Disease Control and Prevention.
TBIMS Centers

• NIDILRR funds 16 TBIMS Centers throughout the US.
• Centers **MUST** provide comprehensive systems of brain injury care to individuals who sustain TBI.
• Centers **MUST** conduct: 1) *site-specific research* and 2) *multi-site research* in collaboration with other TBIMS Centers.
• Centers **MUST** contribute/participate in the largest longitudinal TBI research effort to date - the TBIMS National Database (NDB).
  • Since 1989, the TBIMS Centers have collected and contributed information on common data elements for a centralized TBIMS NDB
  • TBIMS Centers have enrolled
    • 16,000+ participants in the TBIMS NDB at baseline
    • 15,000+ participants at 1-year post injury;
    • 13,000+ at 2 years post injury;
    • 10,144 at 5 years post injury;
    • 6,000+ at 10 years post injury;
    • 650+ at 20 years post injury.
New Jersey has 2 TBIMS Centers

• Hackensack Meridian Health: JFK-Johnson Rehabilitation Institute
  JFK Johnson Traumatic Brain Injury Model System

• Kessler Foundation / Kessler Institute for Rehabilitation
  The Northern New Jersey Traumatic Brain Injury Model System
Functional Changes in Activity Limitations In the Course of Traumatic Brain Injury Recovery

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Assessing Activity Limitations: Importance and Challenges

• Great diversity in injury and recovery.

• Different recovery trajectories.

• Functioning best assessed through everyday activity performance.

• Improvements in the ability to perform functional tasks and activities of daily living as a goal of TBI rehabilitation.

• Essential to be able to measure functional recovery over time and across treatment settings – a critical feature that is missing from the currently available functional measures.
Legislatively Mandated Assessment & Reporting

• Funding agencies want to be able to monitor quality of care and outcomes across the rehabilitation continuum

• Improving Medicare Post-Acute Care Transformation Act of 2014 (the IMPACT Act) – currently applies only to Medicare beneficiaries

• Rehabilitation facilities must “utilize and report cross-setting, longitudinal assessment measures that are standardized and interoperable, so as to allow for the exchange of such data among such post-acute care providers and other providers and the use by such providers of such data that has been so exchanges, including by using common standards and definitions in order to provide access to longitudinal information for such providers to facilitate coordinated care and improved Medicare beneficiary outcomes.”

• Rehabilitation facilities must provide specific and standardized data on admission and discharge functional assessment and care plan that addresses function.

• While currently this applies only to Medicare beneficiaries, other funding agencies are highly likely to follow suit.
Identifying a Need

• There is a demonstrated clinical and research need, and a legislative mandate, to implement functional assessment tools capable of capturing the occurrence of and changes in functional limitations over time to accurately assess patient needs.

• Furthermore, gathering data on functional recovery across settings, between patients, and over time will contribute to the yet limited understanding of post-TBI functional recovery.
Activity Measure for Post-Acute Care (AM-PAC)

• Functional outcomes system developed for use across post-acute care settings

• Developed with consideration of the multifaceted nature of activity functioning
  • measures activity limitation in three distinct functional domains: Basic Mobility, Daily Activities, and Applied Cognition
  • yields the assessment of multiple aspects of a person’s ability to perform specific daily activities: difficulty, need for assistance, and limitations

• Allows for tracking of patients’ functional status as they move across the continuum of care
AM-PAC: forms and items

• ~300 functional activities organized into three functional areas:
  • Basic Mobility
  • Daily Activity
  • Applied Cognitive

• Computer- and pen-and-paper-based

• The computer-adaptive testing (CAT) version reduces the length of overall administration, overutilization of resources, and patient-proxy burden.

• All AM-PAC forms and versions yield the same metrics allowing comparison across and between forms, patients, and settings.
AM-PAC: Validation and Application

• The AM-PAC has been validated in individuals with stroke, complex medication conditions, and orthopedic injuries.

• It has not been studied in individuals with TBI.
Scoring: for psychometric purposes

• T-score conversions
  • Mean = 50
  • SD = 10
• Range
  • Basic Mobility: 4.2-95.8
  • Daily Activity: 7.7-100
  • Applied Cognitive: 0-65.2
Scoring: Clinically Meaningful Interpretation

• Functional Stages
  • Provides a context for interpretation that may be more meaningful.
  • Scores for each domain are divided into ranges that represent functional stages.
  • Functional stage: profile of the types of activities a patient might be able to accomplish at different scale score levels
    • Hierarchical
    • Each consecutive stage represents increasingly more difficult activities
Basic Mobility Functional Stages

• **84 – 100 Strenuous Recreation/Sports:**
  • Your score suggests a high level of independence in moving about both at home and in the community. You may be able to participate in most physical activities without much difficulty.

• **66 – 83 Moving Around Outdoors:**
  • Your score suggests that you are able to walk inside your home and other buildings without any difficulty. You may be able to move about outdoors without any limitations. You should be able to bend over and pick up things without much difficulty. Activities that might be difficult to manage without assistance include climbing a full flight of stairs, bending, kneeling or stooping. Vigorous activities such as playing sports or walking several miles may be very difficult to complete.

• **52 – 65 Moving Around Indoors:**
  • Your score suggests that you may be able to move about on the ground floor of your home where you are familiar with the environment. Activities that might be difficult to manage without assistance include sitting and standing from a low chair, climbing stairs, bending, kneeling or stooping. You may have some difficulty moving about outdoors and in the community.

• **34 – 51 Limited Mobility Indoors:**
  • Your score suggests significant difficulty in moving about independently and the need for assistance. You may be able to move about in a small area of your home that has been adapted to eliminate safety hazards. You may have difficulty moving from a sitting to standing position, climbing stairs and you may have a great deal of difficulty moving about outdoors and in the community.

• **0 – 33 Limited Movement:**
  • Your score suggests you may have a lot of difficulty or are unable to get out of your bed, to stand for several minutes and/or to walk short distances. You might have some difficulty completing the most basic mobility tasks including repositioning yourself in bed.
Daily Activity Functional Stages

- **84 – 100 On Your Own:**
  - Your score suggests that you may not be having any difficulty completing the daily tasks of bathing, dressing, grooming and eating independently.

- **62 – 83 Getting Things Done:**
  - Your score suggests that you may require some assistance with housekeeping and laundry, but otherwise you may be able to complete daily tasks of bathing, dressing, grooming and eating independently without much difficulty.

- **53 – 61 Difficult Activities:**
  - Your score suggests some difficulty in the ability to perform daily tasks. You may be struggling with things such as bathing and dressing. Housekeeping tasks may be too difficult for you to perform. They may experience some difficulties with your fine motor skills such as buttoning clothes, using utensils and combing your hair.

- **41 – 52 Daily Tasks are a Struggle:**
  - Your score suggests that you may experience significant struggles with performing most daily tasks. You may have significant difficulties in getting dressed and bathed. Tasks that require fine motor skills such as buttoning a shirt or tying your shoes may be too difficult to complete.

- **0 – 40 No Independent Tasks:**
  - Your score suggests daily tasks that require fine motor skills may cause considerable difficulty to the extent that you may be unable to complete them. Bathing and dressing may be so difficult that you may be unable to complete these tasks without assistance. You may be able to feed and groom yourself but with difficulty. You may be unable to tie your shoes or button your shirt.
Applied Cognitive Functional Stages

• Applied Cognitive 56 – 65 On Your Own:
  • The score suggests that you may be able to complete complex tasks such as reading a newspaper, counting money, using a phone and having a conversation with another person without difficulty. You might be able to complete multi-step activities such as following a recipe or completing an insurance form without difficulty.

• 42 – 55 On the Move:
  • The score suggests that you may be able to complete complex tasks such as reading a newspaper, counting money, using a phone and having a conversation with another person without difficulty. You might have some difficulty in completing multi-step activities such as following a recipe or completing an insurance form.

• 34 – 41 Minor Difficulties:
  • The score suggests that you may have some difficulties that are noticed by people who know you well. Difficulties may arise in communicating with others, e.g. carrying on a conversation in a crowded restaurant. Reading and carrying out complicated tasks such as preparing a meal, looking up numbers or names in an address book, or managing a checkbook may also be a challenge.

• 29 – 33 Communication Limitations:
  • The score suggests that difficulties may be apparent to all of those who interact with you. These difficulties may include a decline in expressive communication skills and reading. You may need assistance in carrying out the tasks that require memory and organization such as managing money, food shopping, food preparation and filling out a form.

• 0 – 28 Limited Applied Cognitive Skills:
  • The score suggests you may have a lot of difficulty or are not able to complete tasks such as using a phone, reading printed material and having a conversation. You may not be able to communicate regarding topics that involve recent memory, attention or organized thought.
Evaluating the tool

• AM-PAC certainly meets the legislative requirements/standards and appears capable to help bridge the current gaps in evaluating functional recovery over time and across settings.

• However, it has not been evaluated in individuals with TBI.
Objective

Evaluate the applicability of AM-PAC for use in individuals with TBI and use it to assess the presence of and changes in activity limitations over the course of rehabilitation.
Aims/Hypotheses

• **AIM 1.** Evaluate the sensitivity of AM-PAC to measure longitudinal changes in activity limitations in individuals with TBI receiving acute rehabilitation (ACR) and post-acute rehabilitation (PACR).

• **AIM 2.** Examine the relationship between AM-PAC scales and traditional discipline/setting-specific measures of function (*convergent and discriminant validity*) in post-acute TBI settings.

• **AIM 3.** Evaluate agreement between patients and proxy respondents.
## Who is being enrolled

### Inclusion Criteria

| Documented TBI | \n|----------------|
| At least 18 years of age | \n| English-speaking | \n
#### ACR Sample

- Brain injury rehabilitation on the JRI Brain Trauma Unit
- Able to provide informed consent

#### PACR Sample

- Outpatient brain injury rehabilitation at JRI Center for Brain Injuries
- Able to provide informed consent
- Adequate communication skills and ability to allow completion of interviews and testing

### Exclusion Criteria

- Current cognitive complaints or neurological dysfunction precede the TBI
- Active psychiatric illness and/or substance abuse
Experimental Design

Inpatient

- BTU Admit:
  1. proxy AM-PAC
  2. FIM
- BTU D/C:
  1. proxy AM-PAC
  2. patient AM-PAC
  3. FIM
- 6-Month post-TBI:
  1. patient AM-PAC
- 1-Year post-TBI:
  1. patient AM-PAC
  2. PART-O

Outpatient

- Outpatient Admit:
  1. patient AM-PAC
  2. proxy AM-PAC
  3. Traditional Functional Assessment
- Outpatient D/C:
  1. patient AM-PAC
  2. proxy-AM-PAC
  3. Traditional Functional Assessment
Outcome Measures

• AM-PAC primary measure in this study for both samples.

• Inpatient (Admission – 1 year post-discharge)
  • Functional Independence Measure (FIM) is a functional ability measure that assesses the severity of disability (Admission and Discharge)
  • Participation Assessment with Recombined Tools-Objective (PART-O) is an outcome scale that measures participation in the community and is part of the TBI Model Systems form II follow-up assessment (1-year)

• Outpatient (Admission – Discharge)
  • Dynamic Gait Index (DGI) is a performance-based physical therapy measure of functional mobility. DGI will serve as an established performance-based measure of Basic Mobility.
  • Texas Functional Living Scale (TFLS) is a performance-based measure of functional competence with an emphasis on higher-level instrumental activities of daily living (IADLs) that are more susceptible to cognitive decline than basic activities of daily living. TFLS will serve as an established performance-based measure of Daily Activities.
  • Neuropsychological Assessment Battery: Daily Living scales (NAB) is a performance-based measure of functional cognitive skills intended to evaluate cognitive abilities in relation to real-life tasks. Each of the 5 domain-specific modules contains a specific test that involves real-world scenarios that are generalizable, targeted, and ecologically valid to demonstrate daily living skills in everyday situations. These NAB tasks will serve as an established performance-based measure of Applied Cognition.
  • Mayo-Portland Adaptability Inventory (MPAI-4) contains a rating of impaired self-awareness, which will be extracted for the purposes of secondary analysis in the proposed study. This MPAI-4 item has been shown to be equivalent to patient-family disagreement on a more extensive Awareness Questionnaire in monitoring and predicting outcomes after TBI.
Preliminary Findings

1 year of data collection
AIM 1: Evaluate AM-PAC sensitivity to longitudinal changes in activity limitations.
Inpatient

**Basic Mobility**
- Stage 1: limited mobility
- Stage 2: limited mobility outdoors
- Stage 3: moving around outdoors
- Stage 4: on the move

**Daily Activities**
- Stage 1: limited cognitive tasks
- Stage 2-3: daily tasks are a struggle-difficulty with activities
- Stage 4: getting things done

**Applied Cognitive**
- Stage 1: no independent tasks
- Stage 2-3: daily tasks are a struggle-difficulty with activities
- Stage 4: getting things done

*P = 0.011
Outpatient

T-Score

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### Basic Mobility

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AIM 2. Examine the relationship between AM-PAC scales and traditional discipline/setting-specific measures of function.
Inpatient: admission

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**COG**

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**PROXY**

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</table>

**TFLS:** Time

**TFLS:** Money & Calculation

**TFLS:** Communication

**TFLS:** Memory

**TFLS:** TOTAL

**NAB:** Driving Scenes

**NAB:** Bill Payment

**NAB:** Daily Living Memory - Immediate Recall

**NAB:** Map Reading

**NAB:** Judgment

**NAB:** Daily Living Memory - Delayed Recall
AIM 3. Evaluate agreement between patients and proxy respondents.
Inpatient (discharge only)
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</table>
NNJTBIS Site Specific Project:

Applying Strategy-based Techniques to Enhance Memory (STEM) to Treat New Learning and Memory Deficits in individuals with TBI

PI: Nancy D. Chiaravalloti, Ph.D.

Director of Centers for Neuroscience and Neuropsychology and Traumatic Brain Injury Research
Kessler Foundation
Research Professor of Physical Medicine and Rehabilitation
Rutgers, New Jersey Medical School
Traumatic Brain Injury

• Concomitants of TBI
  – Physical Deficits
  – Changes in Emotional Functioning
  – Behavioral changes
  – Cognitive Deficits
Why do we care about cognition?
Impact of Cognition on Daily Life

• **Cognitive deficits lead to:**
  – Depression, anxiety
  – Decreased participation
  – Increased unemployment
  – Decreased quality of life

• **Improving cognition could lead to:**
  – Decreased emotional symptomatology
  – Increased participation
  – Return to work
  – Improved quality of life
## Correlations between Measures of Cognition and Quality of Life in TBI

<table>
<thead>
<tr>
<th>Measure</th>
<th>SDMT</th>
<th>LC</th>
<th>PC</th>
<th>TMT-NS</th>
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</table>

*p<.05; **p<.001
Performance on a test of daily life (TIADL) from before to after SPT in TBI

* A lower number indicates faster (and thus better) performance.
Cognitive Changes following Traumatic Brain Injury

- Cognitive deficits are common
  - Executive Functioning deficits
  - Processing Speed Deficits
  - Working Memory Deficits
  - Attention Deficits
  - Memory dysfunction: cardinal feature post-TBI
Memory Process

Encoding  Consolidation  Retrieval
Memory dysfunction following TBI: A learning phenomenon

$p<.05$; DeLuca et al., 2000; similar to what is seen in MS
Treating the deficit

• Treat learning deficit
  - Improvement in memory functioning
  - Improved quality of life
  - Improved daily functioning
Strategy-based Techniques to Enhance Memory (STEM)

- Teaches persons and significant others how to apply novel techniques in daily life

- Teaching application of:
  - Generation effect
  - Spacing effect
  - Testing effect

- 8 session treatment protocol for:
  - Persons with MS
  - Significant Other
Strategy-based Techniques to Enhance Memory (STEM)

• Outcome Measurement
  – Neuropsychological tests
  – Questionnaires of everyday functioning
  – Patient and significant other report

• Focus is improving daily life
Why STEM?

• Importance of treating cognitive deficits post-TBI is emphasized
• CR is commonly used in inpatient and outpatient settings to treat cognition
• Evidence in support of CR is building
  – Across domains
    • Attention
    • Working memory
    • Executive functioning
  – Different outcomes
    • Objective cognitive performance
    • Everyday life
    • Neuroimaging
Why STEM?

• Despite the building literature, major holes remain
  – Class I evidence
  – Rigorous methodology
  – Randomized clinical trials

• Ultimate Goal: Impact reimbursement rates
Why STEM?

• Strategy training shows substantial promise
  – Consistent empirical support
  – Treatment gains are maintained

• STEM includes 3 strategies with the greatest empirical support
  – Each well grounded in the literature
  – Combination of strategies better than individual
Three strategies in STEM

• Self-Generation
• Spaced Learning
• Self-Testing

*Each has substantial literature base in healthy samples
Self-Generation

• Information that is self-generated is remembered better than information that is provided

*It is unlucky to walk under a ____________.*

*When you go to the store, please pick up that stuff we use to clean our teeth…*
Self-Generation in TBI

# Words correctly recalled

Delay

- TBI Generated
- TBI Provided
- HC Generated
- HC Provided
Spaced Learning

• New learning is significantly improved when trials are distributed over time (spaced) compared to consecutive learning trials (massed presentation)

A recent review of 317 SL studies across 184 articles concluded that “more than 100 years of distributed practice research has demonstrated that ... spaced (versus massed) learning consistently shows benefits, regardless of retention interval.”

Spacing Effect in TBI

Interaction of time x condition: $p < .05$
Retrieval Practice / Self-Testing

• Testing one’s memory for information results in greater retrieval of that information in the future than simply providing the information to the person multiple times

Everyday life examples → quizzing, index card method, PQRST
Testing Effect in TBI

• Significant learning condition (massed restudy, spaced restudy, retrieval practice) by group (TBI, healthy) interaction

• Only HC benefited from spaced restudy over massed restudy

• Both groups benefited from retrieval practice over massed and spaced restudy
STEM

• Teaches the application of these 3 techniques
• 8 sessions

<table>
<thead>
<tr>
<th>Session</th>
<th>Topic</th>
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</thead>
<tbody>
<tr>
<td>Session 1</td>
<td>Assessment results; memory education</td>
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<tr>
<td>Sessions 2-3</td>
<td>Self Generation</td>
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<tr>
<td>Sessions 4-5</td>
<td>Spaced Learning</td>
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<tr>
<td>Sessions 6-7</td>
<td>Self-testing</td>
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<tr>
<td>Session 8</td>
<td>Practice applying and combining techniques</td>
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</table>
Study Design

• RCT
• 80 participants with moderate – severe TBI
  – At least 1 year post-injury
  – Documented learning & memory deficits
  – TBIMS patients or non-TBIMS patients
• Randomized
  – Treatment Group
  – Placebo Control Group
Study Design

• Outcome Assessment
  – Objective Cognitive Functioning
    • Neuropsychological assessment
  – Everyday Life Functioning
    • Questionnaires
    • Objective Test
Pilot Data (Multiple Sclerosis)

Self-rated prospective memory on the PDQ from before to after STEM. (Lower score is better)

FAMS General Contentment from pre-post STEM

Change on the CVLT-II slope pre to post STEM
Modular Participation

• Every center must participate in at least one module
  – 10 ongoing modules
  – Select modules based on interests and resources
• Every module must have at least 4 participating centers
• Monthly Conference Calls
• Quarterly data submissions
## Modules for the 2017-22 Grant Cycle

<table>
<thead>
<tr>
<th>Study Type</th>
<th>Study Topics</th>
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<tbody>
<tr>
<td>Intervention</td>
<td>• Problem Solving Training (PST) for Care Partners of Adults with Traumatic Brain Injuries (TBI) during Inpatient Rehabilitation.</td>
</tr>
<tr>
<td>Assessment and Prediction of Outcomes</td>
<td>• Caregiver Resilience A Longitudinal Investigation</td>
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<tr>
<td></td>
<td>• Health Literacy Following Traumatic Brain Injury and Impact on Health-Related Outcomes</td>
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<td></td>
<td>• Menopause in Women with TBI</td>
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<td></td>
<td>• Return to Driving after Moderate-Severe TBI</td>
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<tr>
<td></td>
<td>• Partnering with Caregivers to Increase Knowledge of the Post-Acute Phase of Recovery From Severe TBI</td>
</tr>
<tr>
<td></td>
<td>• Physical Activity and its relationship with cognition and secondary conditions after TBI</td>
</tr>
<tr>
<td></td>
<td>• Trajectories of Cognitive Functioning Years after TBI</td>
</tr>
<tr>
<td></td>
<td>• Alexithymia Prevalence &amp; Relationships to Patient Characteristics &amp; Outcome in TBIMS Cohort</td>
</tr>
<tr>
<td>Analytical</td>
<td>• Development and Assessment of Crosswalks in the TBIMS Database</td>
</tr>
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</table>
Modular Projects

• Caregiver Resilience: A longitudinal investigation
  – Lead Center: Virginia Commonwealth University
  – Objective: This study examines the trajectory of caregiver resilience over the first two years post injury.

• Problem Solving Training for Care Partners of Adults with TBI
  – Lead Center: North Texas TBI Model System
  – Objective: assesses the feasibility and preliminary effectiveness of delivering problem solving training to care partners during inpatient rehabilitation.
Modular Projects

- **Health Literacy following TBI and Impact of Health-Related Outcomes**
  - Lead Center: TIRR Memorial Hermann (Houston, TX)
  - Objective: Determine the contribution of health literacy to health outcomes (chronic health conditions, quality of life, depression, and anxiety)

- **Menopause in Women with TBI**
  - Lead Center: University of Michigan
  - Objective: Examine symptoms of menopause (vasomotor, somatic, psychological, and cognitive) in women with TBI and the extent to which they differ from their non-injured peers.
Modular Projects

• Trajectories of Cognitive Functioning Years after TBI
  – Lead Center: Mount Sinai Medical Center (NY)
  – Objective: Characterize patterns of cognitive function over time among individuals who are 3-7 years post-TBI and identify whether factors such as age, injury severity, functional status, and medical conditions, are associated with patterns of change in cognitive functioning.

• Return to Driving after Moderate-Severe TBI
  – Lead Center: University of Alabama at Birmingham (UAB)
  – Objective: Characterize short- and long-term driving trends after moderate-severe TBI.