Measurement in Chronic TBI

Developing Patient-Centered Measures for Self-reported Outcomes to Improve Long-term Symptom Tracking and Management

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Objectives

• Why is measurement important in clinical practice?
• What are the unique challenges of community-based, long-term assessment after brain injury?
• Why are patient-centered research techniques critical for improving outcomes assessment and intervention after brain injury?
• What are some innovative measurement strategies to improve long-term symptom tracking and management after brain injury?
Why is Measurement Important?
Purposes of Clinical Measurement

1. Evaluate change over time
   - Treatment effectiveness
   - Maturation or decline

2. Identify problems that require intervention
   - Screening
   - Diagnosis
   - Classification

3. Predict future functioning
   - Planning
   - Chronic Management
Measurement Development & Selection

1. What you intend to measure = What you actually measure
   - Construct of interest
   - Population of interest

2. Strong psychometric properties
   - Valid and Reliable in each specific population
   - Garbage In → Garbage Out
Desirable Qualities in Outcome Measures

- Easy for clinicians to access and apply
- Minimal inconvenience or discomfort for the patient/client
- Relevant and applicable across contexts
- Clearly defined standardized procedures
- Inform diagnosis, classification, goal setting, prognosis, treatment effectiveness, change
- Reflect relevance to rehabilitation
- Consistent quantifiable output
- Comparative data to norms and others with a condition
- Strong consistent measurement properties
Unique challenges of long-term assessment after brain injury

- Domain Specific
- Lengthy
- Simple
- Response Scale

Language accessibility
- Literacy level
- Translation
HOW?
Patient-centered research techniques for improving outcomes assessment and intervention after brain injury
Patient-Centered Outcomes Research

Research and development techniques to:

- Ensure that patients/clients and their caregivers understand health information, clinical assessments, clinical care options, and expectations of care.

- Allow consumers and stakeholders to voice their opinions and preferences.

- Promote the importance of patient participation in their own health care.

- Elevate the importance of patient/stakeholder perspectives for informed healthcare decisions.

Unique challenges of long-term assessment after brain injury
Why Behavior?

• The way in which a person acts in response to a specific situation
• Social interactions, life roles, goal-achievement
• Modifiable target for intervention
• Over 50% of individuals with TBI experience behavior disruptions that affect participation and quality of life.
The BAST (Behavioral Assessment Screening Tool)

Behavioral Assessment Screening Tool

- FrSBe
- AQ
- CISS
- PHQ9
- GAD7
- PANAS

Validated Tools

- Physiatrist
- Neuropsychologist
- Rehabilitation Counselor
- OT/PT/SLP

Rehabilitation Professionals

- Individuals with TBI
- Family Members

Content Validity Index = 89.3%
Average Relevance of items=4.3/5

# The BAST: Language

<table>
<thead>
<tr>
<th>Original Item</th>
<th>Initial Rewritten Item</th>
<th>Modified Item Based on Expert Panel</th>
<th>Modified Item Consumer Focus Groups</th>
<th>Modified Based on Pilot Testing</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sometimes I fly off the handle for no good reason</td>
<td>I get angry without reason.</td>
<td>I got mad easily.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feeling anxious, nervous, or on edge</td>
<td>I felt anxious or nervous.</td>
<td>I felt anxious</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Start things but fail to finish them, “peter out”</td>
<td>I complete activities that I start.</td>
<td>I finished things that I started.</td>
<td></td>
<td>[Removed]</td>
</tr>
<tr>
<td>Thinking things through before acting (for example, consider finances before spending money)</td>
<td>I act without thinking.</td>
<td>I acted without thinking.</td>
<td>[added]</td>
<td>I reacted without thinking.</td>
</tr>
<tr>
<td>Am slow moving, lack energy, inactive</td>
<td>I have low energy.</td>
<td>I had low energy.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>When I encounter a difficult, stressful, or upsetting situation, I come up with several different solutions to the problem.</td>
<td>In difficult situations, I can think of more than one possible solution.</td>
<td>When I had a problem to solve, I could think of multiple solutions.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>When I encounter a difficult, stressful, or upsetting situation, I “freeze” and do not know what to do.</td>
<td>When stressed, I &quot;freeze&quot; and cannot figure out what to do.</td>
<td>When I was stressed, I was unable to make decisions.</td>
<td>[Only ask if there is a positive response to “I felt stressed” item]</td>
<td></td>
</tr>
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<td>I acted without thinking.</td>
<td>[added] I reacted without thinking.</td>
<td>I reacted without thinking.</td>
</tr>
</tbody>
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Language Validation Process

1. Test literacy level of English
2. Modify English
3. Translate English to Spanish
4. Test literacy level of Spanish
5. Back-translate Spanish to English
6. Conduct cognitive interviews in English & Spanish
7. Modify English & Spanish for conceptual equivalence
8. Finalize low-literacy, conceptually equivalent English & Spanish
Language Validation Process

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To be more patient-centered, use:

Language validation
The Problem with Translation

Problems:
- Accuracy
- Literacy level differences
- Cultural equivalence

Consequences:
- Inaccurate communication
- Poor healthcare compliance
- Incorrect assessment and intervention

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The BAST: Translation Validation

<table>
<thead>
<tr>
<th>Original BAST</th>
<th>Original $\text{BAST}_{\text{Esp}}$</th>
<th>Changes made to:</th>
<th>Modified $\text{BAST}_{\text{Esp}}$</th>
<th>Modified $\text{BAST}_{\text{Esp}}$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Never</td>
<td>Nunca</td>
<td>X</td>
<td>Never</td>
<td>Nunca</td>
</tr>
<tr>
<td>Rarely</td>
<td>Raro</td>
<td></td>
<td>Rarely</td>
<td>Rara vez</td>
</tr>
<tr>
<td>Sometimes</td>
<td>A veces</td>
<td></td>
<td>Sometimes</td>
<td>A veces</td>
</tr>
<tr>
<td>Frequently</td>
<td>Frecuentemente</td>
<td></td>
<td>Frequently</td>
<td>Seguido</td>
</tr>
<tr>
<td>Always</td>
<td>Siempre</td>
<td></td>
<td>Very often</td>
<td>Muy seguido</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Original BAST</th>
<th>Original BAST \text{Esp}</th>
<th>Modified BAST</th>
<th>Modified BAST \text{Esp}</th>
</tr>
</thead>
<tbody>
<tr>
<td>I used drugs for non-medical reasons.</td>
<td>Usaba drogas sin razón médica.</td>
<td></td>
<td>Usaba drogas o pastillas para razones no médicas.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>I used recreational drugs.</td>
<td>Usaba drogas.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>I used medications not according to prescription.</td>
<td>Usaba medicamentos solamente por gusto o para razones no médicas.</td>
</tr>
</tbody>
</table>

The BAST: Cognitive Interviewing

The BAST: Cognitive Interviewing

Additional stressors

- Immigration status
- Family separation
- Social discrimination
- Too much work (long work hours)
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Innovative measurement strategies to improve long-term symptom tracking and management after brain injury
What is mHealth?

- “Medical and public health practice supported by mobile health devices, such as mobile phones, patient monitoring devices, personal digital assistants (PDAs), and other wireless devices” -WHO
- Use of voice and short messaging (SMS) as well as more complex mechanisms—apps, GPS, Bluetooth
“The use of mobile and wireless technology to support the achievement of health objectives (mHealth) has the potential to transform the face of health service delivery across the globe.”

-WHO
Smartphone apps

- Popular
- Widely available
- Acceptable to people
- Multifunctional
- May improve health and quality of life.

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Who Uses Smartphones?

• 77% of adults own a smartphone
• 67% of adults 65+ years old use a smartphone (+24% from 2016)
• >60% of adults with a household income <$30K per year own smartphones
• No differences in % of adults who own a smartphone based on race (white vs black)
Who Uses Smartphones?

• Of community dwelling adults with a history of moderate to severe TBI:
  – 75% use a smartphone to access the internet.
  – 64.3% use phone to look up health information
  – 42.1% look up information specific to brain injury

mHealth in TBI

- Familiarity with smartphone technology
  - Less impact of post-injury cognitive impairment
  - Relies on implicitly learned skills/memory

- Use of mobile technology after TBI is likely feasible and potentially effective as a memory aid
The science is still evolving...

- <1% of publicly available mobile apps are evidence-based.
- Commercially rather than scientifically driven
- Effectiveness, cost-effectiveness, security and privacy
- Methodology of development
Consumer Needs

• Importance of the human component to the mHealth interventions
• Need for content to be meaningful
• Need to consider and address potential cognitive sequelae post-TBI
  – learning/continuing to use
  – simplicity in app design

Our Findings

• Focus group results
  1. All-in-one app with customized features
  2. Communication with healthcare providers
  3. Cognitive strategies
  4. Accessibility and Privacy
  5. Education

• Clinicians...
  1. Adjunct to current therapy
  2. Currently recommending apps with limited guidance for app selection
  3. Need for infrastructure to support mHealth
Smartphone Apps for Symptom Assessment in Chronic TBI
Ecological Momentary Assessment (EMA)

- Repeated measures
- Natural environment
- Reduces errors
- Ecologically valid

- Real time
- Community-based
- Reduces bias
- Leverages technology

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<table>
<thead>
<tr>
<th>Sun</th>
<th>Mon</th>
<th>Tues</th>
<th>Wed</th>
<th>Thu</th>
<th>Fri</th>
<th>Sat</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Daily</strong></td>
<td><strong>Affect</strong></td>
<td><strong>Daily Mood</strong></td>
<td><strong>Daily Affect</strong></td>
<td><strong>Daily Mood</strong></td>
<td><strong>Daily Mood</strong></td>
<td><strong>Daily Affect</strong></td>
</tr>
<tr>
<td><strong>PANAS</strong></td>
<td></td>
<td><strong>PHQ-2 GAD-2</strong></td>
<td><strong>PANAS</strong></td>
<td><strong>PHQ-2 GAD-2</strong></td>
<td><strong>PHQ-2 GAD-2</strong></td>
<td><strong>PANAS</strong></td>
</tr>
<tr>
<td><strong>Fatigue</strong></td>
<td></td>
<td><strong>Fatigue</strong></td>
<td><strong>Fatigue</strong></td>
<td><strong>Fatigue</strong></td>
<td><strong>Fatigue</strong></td>
<td><strong>Fatigue</strong></td>
</tr>
</tbody>
</table>


**Diagram:**
- Participants communicate with a cloud-based system via SMS.
- The system provides web service API for administrator access.
- Administrator features include display answers, export data, build questions, and schedule delivery.

**Text:**
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Ecological Momentary Assessment (EMA)

- Data collected via EMA take on a hierarchical structure
- Allows for measurement of temporal variability in symptoms
- Multilevel modeling of EMA data provides between- and within-person variability in symptoms
Results

Over the 8 weeks of the study, participants reported significant within-person variability over time (p<.002).

Depressive Symptoms Exemplar

mHealth Conclusions

• EMA is an appropriate and feasible method to capture temporal variability of these symptoms post-TBI.
mHealth Conclusions

• Measurement of these symptoms at a single time point among adults with chronic TBI **may not adequately capture the temporal symptoms a person is experiencing** due to significant fluctuations in reporting of these symptoms **within individuals** over time.
Mhealth Conclusions

• Psychometric properties of previously validated measure (like those used in this study) need to be assessed in the context of EMA, potentially using a Multilevel Item Response Theory approach.

• NEW measures need to be developed specifically for this kind of measurement.
mHealth Conclusion

- Mobile technology rapidly outpacing research on clinical efficacy
- Challenges specific to TBI
  - Desire for greater simplicity and ease of use
  - Accessible (font size, literacy)
  - Human Component
Innovative measurement strategies to improve long-term symptom tracking and management after brain injury
Proactive vs Reactive

Proactive:
- Actively track symptoms on a regular basis
- Identify problematic symptoms earlier
- Trigger clinical follow-up in response to problematic symptoms

Reactive:
- Symptom assessment relies on retrospective memory
- Problematic symptoms identified at the point of crisis
- Clinical follow-up relies on individual in crisis or family members to initiate

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A Better (Proactive) Model

Clinical bio-behavioral risk identification

- **Not at Risk**
  - Monthly BAST via mHealth
    - Save $ in intensive tracking
    - Save $ and avoid risks for unnecessary medications/treatments
    - Efficient care

- **Borderline Risk**
  - Biweekly BAST via mHealth
    - **Remains Borderline**
      - Continue biweekly BAST via mHealth
      - Provide preventative intervention
        - Targeted and efficient telehealth monitoring
        - Efficient triage
        - Fewer health complications or rehospitalizations
        - Better participation outcomes
    - **Resolves to Not at Risk**
      - Standard follow-up
      - Increased value:
        - Save $ in intensive tracking
        - Save $ and avoid risks for unnecessary medications/treatments
        - Efficient care

- **High Risk**
  - Biweekly BAST via mHealth
    - Initiate clinic visit
    - Provide treatment or preventative intervention
    - Continue biweekly monitoring
      - Targeted treatment
      - Efficient triage
      - Fewer health complications/rehospitalizations
      - Better participation outcomes
      - Reduce caregiver burden and lost productivity

**Routine Clinic Visits**

**Intervention and biweekly BAST until resolution**
Measurement

**BAST risk identification**

Full BAST assessment at discharge or clinic visit and then monthly via mHealth

Established cut-off scores in each domain that indicate “risk”

<table>
<thead>
<tr>
<th>No “Risk”</th>
<th>“Risk”</th>
</tr>
</thead>
<tbody>
<tr>
<td>No “Risk”</td>
<td>BAST_{mHealth} EMA for 3-4 days</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>“No Risk”</th>
<th>No Risk during EMA</th>
<th>“Risk” during EMA</th>
</tr>
</thead>
<tbody>
<tr>
<td>“Borderline” Risk</td>
<td>“High” Risk</td>
<td></td>
</tr>
</tbody>
</table>
A Better (Proactive) Model

Clinical bio-behavioral risk identification

Not at Risk
Monthly BAST via mHealth
• Save $ in intensive tracking
• Save $ and avoid risks for unnecessary medications/treatments
• Efficient care

Borderline Risk
Biweekly BAST via mHealth

Remains Borderline
✓ Continue biweekly BAST via mHealth
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Resolves to Not at Risk
Standard follow-up
Increased value:
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High Risk
Biweekly BAST via mHealth
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Thank you!

A special thank you to my mentors, colleagues, students, and other collaborators!