Measuring Outcomes in TBI

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Outcome Measures Used

What measures are used depends on the setting (acute or long-term rehabilitation)

Acute settings frequently use:

- **Functional Independence Measure (FIM)**: An 18-item scale used to assess the patient's level of independence in mobility, self-care, and cognition
- **Glasgow Outcome Scale (GOS)**
- **Disability Rating Scale (DRS)**: Measures general functional changes over the course of recovery after TBI
What about long-term?

• No measures are universally agreed upon

• Some measures frequently used include:
  • Mayo Portland Adaptability Inventory (MPAI)
  • Supervision Rating Scale (SRS)
  • Community Integration Questionnaire (CIQ)
  • Disability Rating Scale (DRS)
  • Independent Living Scale (ILS)

And many more
Difficulties

• What outcomes are the most significant/important?
  • The goals of rehabilitation are individualized making it difficult to identify a universal outcome

• The complexity of the cases makes it difficult to make causal references
  • Substance abuse, multiple treatment modalities, social support, etc.
Questions about the accuracy of self-report

• Some researchers have found that in people who have suffered TBIs, self-report is not a reliable measure.
  • Language deficits
  • Awareness
  • Abstract Reasoning
  • Memory
Our Measures

‘Can I run in yards?’
Standardized Measures

Bancroft is a member of the Pennsylvania Association of Rehabilitation Facilities (PARF), a collaborative data collection and outcomes measurement project designed to:

- Enhance clinical evaluation
- Verify the treatment provided produces the desired outcomes
- Allow providers to make better decisions regarding program/service components
- Provide aggregate data to funders to assist with evaluation of needs and services

In conjunction with our PARF colleagues, we utilize three standardized outcome measures: Mayo-Portland Adaptability Inventory (MPAI-4, Malec, J., 2005); Supervision Rating Scale (SRS, Boake, C., 2001); and most recently the World Health Organization Quality of Life Index (WHOQOL-BREF, WHO, 2004). A project to develop standardized satisfaction surveys is in progress.
Supervision Rating Scale

• Measures the level and type of supervision that a patient/subject receives from caregivers
• The SRS rates level of supervision on a single 13-point ordinal scale
• SRS ratings have shown consistent relationships with type of living arrangement and with independence in self-care and instrumental ADL
WHOQOL-BREF

- The WHOQOL-BREF instrument comprises 26 self-reported items, which measure the following broad domains: physical health, psychological health, social relationships, and environment.

- Research has found that the WHOQOL-BREF has strong psychometric properties.

- Raw scores on the measure can range from 24 to 120, with higher scores being indicative of a higher quality of life.
**MPAI-4**

MPAI-4: Ability Index
- Mobility
- Use of hands
- Audition
- Vision
- Motor speech
- Dizziness
- Verbal

Communication
- Nonverbal Communication
- Memory
- Attention/
  concentration
- Fund of information
- Novel Problem-solving
- Visuospatial abilities
Continued

MPAI-4: Adjustment Index
• Anxiety
• Depression
• Irritability, anger, aggression
• Pain/headache
• Fatigue
• Sensitivity to mild symptoms

• Inappropriate social interaction
• Impaired self-awareness
• Family/significant relationships
• Initiation
• Social contact
• Leisure activities
Continued

MPAI-4: Participation Index

• Initiation
• Social contact
• Leisure activities
• Self care
• Residence
• Transportation

• Employment
• Managing Money
MPAI-4 Database Project

• Initiative to develop an electronic national database for MPAI-4 scores
  • Would allow different rehab centers to combine data to study changes in outcomes over the course of post-acute rehabilitation
Difficulties and New Ideas
Challenges

• Goals related to the abilities scale in the MPAI-4 are difficult to obtain in a sub acute rehab population

• In general the MPAI-4 is useful for detecting significant long-term changes in functioning. Not as useful as an immediate measure of progress

• WHOQOL-BREF has robust findings, but still suffers from concerns over self-report.
Future Ideas

• Continue to explore how to measure satisfaction
• A specific measure of financial capacity
• Better measures of risk assessment
New Findings and Research Ideas

Among individuals with severe TBI, we examined:

1. The **extent of self-reported comparisons** (relative to available norms for other groups),

2. The **internal consistency** of social comparison responses, and the **stability of these reports over one year**, 

3. Relations between **social comparisons**, executive functioning, and treatment outcomes; relations were tested both **cross-sectionally and prospectively** (over 1 year).
Continued

• Self-reported social comparison orientation (i.e., tendency to make comparisons) on the INCOM showed **high internal consistency** across overall ($\alpha = 0.88$), upward ($\alpha = 0.86$), and downward ($\alpha = 0.87$) comparison scales at baseline.

• The average INCOM overall score for the present sample was 36.04 ($SD = 8.80$) out of a possible 55 for overall social comparison orientation (SCO; see Table 1). Scores were **comparable to those of healthy adults** in the United States.\(^5\)

• Participants who endorsed **more frequent negative responses to downward comparisons** showed *better* ability to generate novel solutions to problems (NAB), less severe impairment in community participation, and less overall impairment (MPAI).

• Those with **more frequent negative responses to upward comparisons** demonstrated *worse* impulse control (Trails), and more severe participation and overall impairment ($r_s = -0.34$-$0.37$).
Implications

- This study represented a necessary first step toward increasing knowledge about social influences on outcomes in severe TBI rehabilitation.

- Findings from this study confirm that individuals with severe TBI can report on their social comparisons by demonstrating that existing self-report measures have adequate psychometric properties in this group.

- Findings also indicate that self-reported comparisons are associated with concurrent functioning and outcomes at one-year follow-up.

- Further investigation of social comparisons in severe TBI is warranted, and greater attention to comparisons in long-term rehabilitation may improve clinical outcomes for this population.