Using PROMIS, Neuro-QOL, SCI-QOL, and TBI-QOL in Neurorehabilitation

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What is it like having a traumatic injury? (such as SCI or TBI)

• Sudden
• Unexpected
Traumatic Injury

• DRAMATICALLY alters an individual’s life
Potential for Life-long Impairment

- Physical Function/Mobility
- Secondary Medical Complications
  - Bowel, Bladder, Pain, Pressure Ulcers, Respiratory
- Cognition
  - Executive Function, Memory, Communication
- Social Participation
  - Social roles, social activities, independence
How does this affect HRQOL?

- How *HASN’T* it?
- Wide range of potential functional, medical, emotional, and social outcomes
- Some symptoms/limitations are more universal (e.g., depression, pain) while others are very disability-specific (e.g., bladder management difficulties, respiratory complications)
How to Measure PRO in Rehabilitation Populations?

- Some symptoms/limitations are more universal (e.g., depression, pain) while others are very disability-specific (e.g., bladder management difficulties, respiratory complications)
Extending the PROMIS® measurement system into SCI or TBI?

• Distinction between chronic illness and a sudden traumatic injury
• How is quality of life impacted?
• How should it be measured?
Use PROMIS for Individuals with Traumatic Injury?

- In 2000, Andresen & Meyers outlined some major caveats to using HRQOL measures for individuals with disabilities

- PROMIS has improved some of the issues through item banking:
  - CAT administration
    - Decreases likelihood of inappropriate or offensive items, e.g.:
      - SWLS item “If I could live my life over, I would change almost nothing...”
      - SF-36 item “Does your health now limit you in...climbing several flights of stairs?”
  - Customized SF administration
    - Researcher/clinician can select items to match functioning to sample
Use PROMIS for Individuals with Traumatic Injury?

• How do we further the use of PROMIS in a population of persons with severe conditions?
• Does PROMIS cover the appropriate domains?
  – Are there unique, highly salient aspects that aren’t covered?
• Are PROMIS items appropriate for individuals with SCI or TBI?

• Qualitative research to find out!
SCI-QOL and TBI-QOL projects

- Started in 2006 (SCI) and 2007 (TBI)
- Partnership with Northwestern (including Drs. Cella, Gershon, Victorson, Nowinski, Choi, Lai)
- Partnership with SCI & TBI Model Systems
Focus Groups

• **SCI:**
  – 24 focus groups with 134 individuals with SCI
  – 4 focus groups with 42 clinicians

• **TBI:**
  – 7 focus groups with 33 individuals with TBI
  – 4 focus groups with 17 individuals who are caregivers or significant others of individuals with TBI
  – 2 focus groups with 15 clinicians
Unique Concepts

- So what domains are missing?
- Will PROMIS/NQ banks mean the same thing in SCI/TBI?
- Qualitative analysis steps:
  - Team-based codebook development (open & axial coding)
  - Two independent raters (selective coding)
  - Establish Inter-Rater Reliability
  - Coding Comparison & Reconciliation
  - Relative frequencies determined
Qualitative Analysis Results: SCI & TBI

• Some PROMIS domains are important:
  – Depression
  – Anxiety
  – Pain Interference
  – Ability to Participate in Social Roles & Activities
  – Satisfaction with Social Roles & Activities
  – Fatigue [TBI only]
  – Anger [TBI only]


Qualitative Analysis Results: SCI

- Some **PROMIS domains** are relevant but need modification:
  - Physical Function
    - Changing & Maintaining Body Position
    - Transferring (e.g., wheelchair to bed)
    - Bathing
    - Eating
    - Grooming
    - Toileting
    - Fine hand use (e.g., manipulating coins, phone buttons)
    - Wheelchair use (& maintenance)
    - Walking & Running
SCI-FI Item Development Process

Existing Items

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<thead>
<tr>
<th>Existing Items</th>
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<tr>
<td>AMPAC</td>
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<td>PROMIS AT</td>
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<td>Shriners</td>
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Literature

Focus Groups

Item Writing (k=619)

Cognition Debriefing

Translatability Evaluation

Reading Level Analysis

New SCI-FI Items, k=204

Field Testing (k=328)

Beginning Items

- Changing & Maintaining Body Position
- Transferring
- Walking & Running
- Wheelchair Use
- Bathing
- Eating
- Grooming
- Toileting
- Sexual Functioning
- Fine Hand Use/Manipulating Objects
- Communication Device Use

CFA: Confirm Models

- Basic Mobility
- Ambulation
- Wheelchair Mobility
- Self Care
- Fine Motor

CFA: Confirm Unidimensionality

<table>
<thead>
<tr>
<th></th>
<th>Basic Mobility</th>
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<th>Wheelchair Mobility</th>
<th>Self Care</th>
<th>Fine Motor</th>
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<td>Subset 2</td>
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</table>

Final Items k=275
Some New Domains are Needed:

- **Physical Function (SCI)**
  - Basic Mobility, Self Care, Fine Motor Function, Wheelchair Mobility, Ambulation
- **Physical/Medical Health**
  - Bladder Management Difficulties, Bowel Management Difficulties, Bladder Complications, Pressure Ulcers, Respiratory Complications*, Headache Pain
- **Emotional Health:**
  - Resilience, Grief/Loss, Self-esteem, Psychological Trauma
- **Social Participation:**
  - Independence, Asking for Help
- **Cognition**
  - Communication/Comprehension

*Items developed and tested but not calibrated.*
**Bold text** indicates SCI-specific domains
*Underlined text indicates TBI-specific domains*
Optimizing Relevant Item Banks

• Add supplemental content to fill gaps in item hierarchy
  • SCI Basic Mobility
    – “Are you able to move your upper body while lying down in bed?”
  • SCI Anxiety
    – “I felt trapped in my own body.”
Optimizing Relevant Item Banks

• Remove Clearly Inappropriate Items, e.g.:
  • PROMIS Pain Behavior Items
    – “Pain caused me to bend over while walking”
    – “When I was in pain I moved stiffly”
    – “When I was in pain I thrashed”
    – “When I was in pain I tried to stay very still”
Creating Supplemental Item Banks

- PROMIS instrument development standards, e.g.:
  - Literature Review
  - Content & Measurement Experts
  - Key Stakeholder Input – consumers, clinicians, caregivers
  - PROMIS item format
  - Qualitative Item Review (Expert Item Review & Cognitive Interviews)
  - Reading Level Review
  - Translatability Review
SCI-QOL/TBI-QOL Collaborators

- **Boston University**: Alan Jette, Mary Slavin, Pengsheng Ni
- **University of Michigan**: Denise Tate, Claire Kalpakjian, Marty Forchheimer
- **Kessler Foundation**: Steven Kirshblum, Trevor Dyson-Hudson, Denise Fyffe, Nancy Chiaravalloti
- **Rehabilitation Institute of Chicago**: Allen Heinemann
- **Northwestern University**: David Victorson, David Cella, Richard Gershon, Seung Choi, Jin-Shei Lai, Karon Cook
- **TIRR**: Mark Sherer, Angelle Sander
- **Bronx VA**: Ann Spungen
- **Craig Hospital**: Susan Charlifue, Gale Whiteneck
- **University of Washington**: Dagmar Amtmann, Charles Bombardier
- **Mt. Sinai Medical School**: Marcel Dijkers, Jeanne Zanca
- **Shepherd Center**: Jim Krause
- **University of Miami**: Elizabeth Felix
- **University of Louisville**: Dan Graves, Susan Harkema
- **New York University**: Tamara Bushnik
- **Rehabilitation Institute of Michigan**: Robin Hanks
- **Santa Clara Valley Medical Center**: Stephanie Kolokowsky-Hayner
## SCI: Item Pools to Calibration Testing

<table>
<thead>
<tr>
<th>Packet #</th>
<th>Domain</th>
<th>Included Item Pools</th>
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<tbody>
<tr>
<td>1</td>
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<td>Physical-Medical</td>
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<td>3</td>
<td>Emotional</td>
<td>Depression, Anxiety, PAWB, Stigma, Resilience, Grief/Loss, Self-esteem, Trauma</td>
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<tr>
<td>4</td>
<td>Social</td>
<td>Ability to Participate in SRA, Satisfaction with SRA, Independence, Sexual Function*</td>
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</table>

*Items developed and tested but not calibrated*
Packet 1: Physical Functioning Calibration Field Testing - Goals

- 750 cases (125 per site at 6 sites)

- Balanced Sample will be Stratified by:
  - Diagnosis (Paraplegia / Tetraplegia)
  - Severity (Complete / Incomplete)
  - Time Since Injury (<1 yr / 1 yr– 3 yrs / >3 yrs)

- Collect injury level / AIS scores for all participants
### Physical Functioning: Packet 1

#### Calibration Field Testing - Results

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<tr>
<td>Complete</td>
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<tr>
<td>Incomplete</td>
<td>408</td>
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<tr>
<td>Incomplete Paraplegia</td>
<td>161</td>
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<tr>
<td>Incomplete Tetraplegia</td>
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<td>Incomplete Tetraplegia</td>
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Total \( n = 854 \)
# TBI: Item Pools to Calibration Testing

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<td></td>
<td>Cognitive +</td>
<td>Cognition – General Concerns, Executive Function, Communication/Comprehension</td>
<td>569</td>
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<tr>
<td>4</td>
<td>Anger/EBD</td>
<td>Anger, Emotional &amp; Behavioral Dyscontrol</td>
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<td>4</td>
<td>Social</td>
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<tr>
<td></td>
<td></td>
<td>Sexual Function*</td>
<td></td>
</tr>
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</table>

*Items developed and tested but not calibrated*
Analyses

• **Preliminary Analyses**
  – Internal consistency
  – Missing data
  – Item-total correlations
  – Sparse cells
  – Violations of monotonicity

• **Dimensionality**
  – Factor loadings
  – Local item dependence (LID)

• **IRT parameter estimation and model fit**
  – Differential item functioning (DIF)
Preliminary Results

• SCI
  – 22 Item banks/scales
    • 4 from PROMIS
    • 4 from Neuro-QOL

• TBI
  – 20 Item banks/scales
    • 5 from PROMIS
    • 9 from Neuro-QOL
The Potential Problem

General Population
(Mean 50, SD 10)

Spinal Cord Injury
(Mean 50, SD 10)

Problem = Same score, different metric!

= 77.9 Fahrenheit
(Multiply by 9, then divide by 5, then add 32)

Or push the button
How to Preserve the PROMIS/Neuro-QOL Metric?

• Transform scores to original metric
  – Use of common, verbatim “anchor” items
  – STUIRT / Stocking-Lord methods used
    • “PROsetta Stone” methodology
    • In partnership with Northwestern
  – Linear transformation to PROMIS or NQ metric
## T-score Before and After Transformation

<table>
<thead>
<tr>
<th>SCI-QOL Bank</th>
<th>N</th>
<th>T-score Before Transformation</th>
<th>T-score After Transformation</th>
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<tr>
<td></td>
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<td>Mean</td>
<td>S.D.</td>
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<td>716</td>
<td>48.59</td>
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<td>Positive Affect and WB</td>
<td>717</td>
<td>51.15</td>
<td>9.61</td>
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<tr>
<td>Pain Behavior</td>
<td>757</td>
<td>49.94</td>
<td>9.60</td>
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<td>Pain Interference</td>
<td>757</td>
<td>48.65</td>
<td>9.26</td>
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<td>611</td>
<td>49.84</td>
<td>9.66</td>
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<td>50.46</td>
<td>9.76</td>
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<td>Social Role Satisfaction</td>
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<td>50.72</td>
<td>9.77</td>
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</table>

**T-Score:** Mean = 50, SD = 10
Scores produced *directly* on PROMIS Metric

- **SCI-QOL**
  - Depression
  - Anxiety
  - Pain Interference
  - Pain Behavior

- **TBI-QOL**
  - Depression
  - Anxiety
  - Pain Interference
  - Fatigue
  - Anger

The same method has been used to place some item bank scores (e.g., PAWB, Stigma, Executive Function) *directly* on the **Neuro-QOL** metric.
Scores produced on Neuro-QOL metric

• SCI-QOL
  – PAWB
  – Stigma
  – Ability to Participate
  – Satisfaction with SRA

• TBI-QOL
  – PAWB
  – Stigma
  – Ability to Participate
  – Satisfaction with SRA
  – Cognition: General Concerns
  – Executive Function
  – Emotional & Behavioral Dyscontrol
  – Mobility
  – Upper Extremity Fxn
New, Targeted Domains reference SCI/TBI

**SCI-QOL**
- Independence
- Grief/Loss
- Psychological Trauma
- Self-Esteem
- Resilience
- Bladder Complications
- Bowel Management Difficulties
- Bladder Management Difficulties
- Pressure Ulcers

**TBI-QOL**
- Independence
- Grief Loss
- Self-Esteem
- Resilience,
- Headache Pain
- Communication/Comprehension
## Final SCI-QOL v1.0

### Table 5  Linkages with PROMIS and Neuro-QOL

<table>
<thead>
<tr>
<th>Subdomain/Bank</th>
<th># SCI-QOL Items</th>
<th>Linked to</th>
<th># PROMIS Items</th>
<th># Neuro-QOL Items</th>
<th>Reference Population</th>
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<tr>
<td>Bladder Management Difficulties</td>
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### Table 3: Linkages with PROMIS and Neuro-QOL

<table>
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<tr>
<th>Subdomain/Bank</th>
<th>No. TBI-QOL items</th>
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<td>Neuro-QOL</td>
<td>0</td>
<td>12</td>
<td>General + Neuro</td>
</tr>
<tr>
<td>Communication/Comprehension</td>
<td>31</td>
<td>...</td>
<td>0</td>
<td>5</td>
<td>TBI</td>
</tr>
<tr>
<td>Ability to Participate in</td>
<td>46</td>
<td>Neuro-QOL</td>
<td>0</td>
<td>43</td>
<td>General</td>
</tr>
<tr>
<td>Social Roles and Activities</td>
<td></td>
<td></td>
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<td></td>
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</tr>
<tr>
<td>Satisfaction with Social Roles</td>
<td>41</td>
<td>Neuro-QOL</td>
<td>19</td>
<td>39</td>
<td>General</td>
</tr>
<tr>
<td>and Activities</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Independence</td>
<td>13</td>
<td>...</td>
<td>0</td>
<td>0</td>
<td>TBI</td>
</tr>
</tbody>
</table>
Options for Administration

• Each bank may be administered as:
  – Full bank
  – CAT
  – Fixed-length “Short form”

• Electronic Administration Options:
  – Assessment Center
  – NIH Toolbox App
  – REDCap*

*Contact SCI-QOL@udel.edu or TBI-QOL@udel.edu for access.

**SCI-QOL & TBI-QOL SF loading spreadsheets are currently available through SCI-QOL@udel.edu or TBI-QOL@udel.edu. All CATs & SFs expected to be added to REDCap library within the next year.
Barriers to Independent Self-Report

- Limited or no access to computer and/or internet
- Limited ability to interface with computer (e.g., for individuals with high tetraplegia)
- Cognitive difficulties impacting attention span
Administering PROMIS/SCI-QOL/TBI-QOL to Individuals with Disabilities

• Benefits of interview administration:
  – Does not require a person to access computer and/or internet
  – Does not require any hand or upper extremity functioning
  – Helps participants maintain attention to task (e.g., by redirecting)
  – Few to no missing data points

• Hard copy or electronic response cards used
Selected References


TBI-QOL: Development and Calibration of Item Banks to Measure Patient Reported Outcomes Following Traumatic Brain Injury

David S. Tulsky, PhD; Pamela A. Kisala, MA; David Victorson, PhD; Noelle Carlozzi, PhD; Tamara Bushnik, PhD; Mark Sherer, PhD; Seung W. Choi, PhD; Allen W. Heinemann, PhD; Nancy Chiaramonti, PhD; Angelle M. Sander, PhD; Jeffrey Englander, MD; Robin Hanks, PhD; Stephanie Kolakowsky-Hayner, PhD; Elliot Roth, MD; Richard Gershon, PhD; Mitchell Rosenthal, PhD; David Cella, PhD

http://journals.lww.com/headtraumarehab/Fulltext/2016/01000/TB_I_QOL___Development_and_Calibration_of_Item.6.aspx
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