The NIH PROMIS: Measuring Health Related Quality of Life in Children and Adults with CP

Anna Kratz, Ph.D.

Department of Physical Medicine & Rehabilitation
University of Michigan
January 30th, 2013
Overview

- Brief overview of PROMIS
- Preliminary findings: PROMIS validity in CP
- Ongoing and future studies
**Patient Reported Outcomes Measurement Information System**

- *Domain* focused, not *disease* focused
- Goal = to be able to measure a feeling, function, or perception (e.g., anxiety, mobility, self-efficacy) *across* medical conditions and the general population.
- A universal system
  - T-Metric: General US Population $M = 50$, $SD = 10$
Measurement Terminology: Item Bank

- A large collection of items measuring a single domain
- Items cover a wide range
- Item banks make computer adaptive test (“smart test”) administration possible.
Computer Adaptive Test (CAT)

- Selects questions based on person’s answers to previous questions
  - administers only the *most informative items*
  - a kinder way to measure
- Iteratively estimates a person’s score on a domain
  - Administers items until:
    - Reaches maximum number of items allowed
    - Reaches critical standard error
- High level of precision with minimum number of items
Computer Adaptive Test (CAT)

- Assessment Center – online measure administration and data capture platform

In the past 7 days

How much did pain interfere with your household chores?

- Not at all
- A little bit
- Somewhat
- Quite a bit
- Very much
Short Form

- A static set of items from the item bank
- Can use PROMIS pre-set short form or select new customized set of items
PROMIS Administration

- **Pediatric:** 8-17 years old
  - Self-report
  - Proxy (parent) report
- **Adult:** 18+ years old
  - Self-report
- **Languages**
  - Available: English, Spanish, German, French
  - Other language development is ongoing.
PROMIS Domain Framework

Self-Reported Health

Physical Health
- Symptoms
- Function

Mental Health
- Affect
- Behavior
- Cognition

Social Health
- Relationships
- Function
PROMIS Current (2012)

**Physical Health**

**ADULT**
- Pain Behavior
- Pain Interference
- Fatigue
- Sleep Disturbance
- Sleep-related Impairment
- Physical Function
- Sexual Function

**PEDIATRIC/PARENT PROXY**
- Pain Interference
- Fatigue
- Upper Extremity
- Mobility
- Asthma Impact
There is a need to validate PROMIS measures in clinical populations

**PROMIS Pediatric Mobility Item Bank** – 23 items developed in sample of typically developing children

- **Mobility CAT**
  - administers at least 5 items, up to 12 items
  - Default critical standard error of 0.4

- **Mobility Short Form**
  - 8 Items
  - Kratz, Slavin, Mulcahey, Jette, Tulsky, & Haley (under review) An Examination of the PROMIS® Pediatric Instruments to Assess Mobility in Children with Cerebral Palsy
PROMIS Validation in CP

- 82 children ages 8-19 (M = 12.70 years); 48% male
- Concurrent validity – correlations with (1) self-report, (4) parent-report, and (3) performance-based measures of mobility
- Known-groups validity based on GMFCS

<table>
<thead>
<tr>
<th>GMFCS</th>
<th>Description of Function</th>
<th>Sample</th>
</tr>
</thead>
<tbody>
<tr>
<td>Level I</td>
<td>Walks without limitations</td>
<td>33 (39.8%)</td>
</tr>
<tr>
<td>Level II</td>
<td>Walks with limitations</td>
<td>32 (38.6%)</td>
</tr>
<tr>
<td>Level III</td>
<td>Walks using a handheld mobility device</td>
<td>14 (16.9%)</td>
</tr>
<tr>
<td>Level IV</td>
<td>Self-mobility with limitations; may use power wheelchair</td>
<td>2 (2.4%)</td>
</tr>
<tr>
<td>Level V</td>
<td>Transported in a manual wheelchair</td>
<td>1 (1.2%)</td>
</tr>
</tbody>
</table>
### PROMIS Validation Efforts in CP

#### Pearson Bivariate Correlations

<table>
<thead>
<tr>
<th></th>
<th>Child Self-Report</th>
<th>Parent-Reported</th>
<th>Performance-Based (Examiner-Administered)</th>
</tr>
</thead>
<tbody>
<tr>
<td>2. PROMIS Mobility CAT</td>
<td>.88**</td>
<td>.52**</td>
<td>-.30**</td>
</tr>
<tr>
<td>3. PedsQL Move</td>
<td>.58**</td>
<td>.60**</td>
<td>.39**</td>
</tr>
<tr>
<td>4. PODCI mobility</td>
<td>.90**</td>
<td>.90**</td>
<td>-.16</td>
</tr>
<tr>
<td>5. PODCI Sports</td>
<td>.52**</td>
<td>.48**</td>
<td>.21</td>
</tr>
<tr>
<td>6. FAQ</td>
<td>.60**</td>
<td>.54**</td>
<td>.19</td>
</tr>
<tr>
<td>7. CP-CAT LE</td>
<td></td>
<td>.54**</td>
<td>.39**</td>
</tr>
</tbody>
</table>

#### Concurrent Validity

- Short Form demonstrated small to moderate correlations with comparison measures.
- CAT correlations with comparison measures were weaker than expected, and no correlation with performance-based measures was found.
### Known Groups Validity

- **All** measures (including the PROMIS Short Form) discriminated between groups of children with CP with different levels of functioning.
- PROMIS Mobility CAT did not.
The PROMIS Mobility Short Form seems to function well...

Why doesn’t the PROMIS Mobility CAT show good validity in CP?

Look at how the CAT administered items
## PROMIS Mobility Items

<table>
<thead>
<tr>
<th>Items, arranged from highest to lowest mobility difficulty</th>
<th>Format*</th>
</tr>
</thead>
<tbody>
<tr>
<td>I could run a mile</td>
<td>CAT Only</td>
</tr>
<tr>
<td><strong>I could do sports and other exercise that kids my age could do</strong></td>
<td>Both CAT/SF</td>
</tr>
<tr>
<td>I have been physically able to do the activities I enjoy most</td>
<td>Both CAT/SF</td>
</tr>
<tr>
<td>I could ride a bike</td>
<td>CAT Only</td>
</tr>
<tr>
<td>I could keep up when I played with other kids</td>
<td>Both CAT/SF</td>
</tr>
<tr>
<td>I could walk more than one block</td>
<td>CAT Only</td>
</tr>
<tr>
<td>I could walk up stairs without holding on to anything</td>
<td>Both CAT/SF</td>
</tr>
<tr>
<td>I could stand on my tiptoes</td>
<td>Both CAT/SF</td>
</tr>
<tr>
<td>I could stand up by myself</td>
<td>Both CAT/SF</td>
</tr>
<tr>
<td>I could get up from the floor</td>
<td>Both CAT/SF</td>
</tr>
<tr>
<td>I could walk across the room</td>
<td>CAT Only</td>
</tr>
<tr>
<td>I could move my legs</td>
<td>Both CAT/SF</td>
</tr>
<tr>
<td>I could carry my books in a backpack</td>
<td>CAT Only</td>
</tr>
<tr>
<td>I could get down on my hands and knees without holding on to something</td>
<td>CAT Only</td>
</tr>
<tr>
<td>I could get in and out of a car</td>
<td>Not Administered</td>
</tr>
<tr>
<td>I could get into bed by myself</td>
<td>Not Administered</td>
</tr>
<tr>
<td>I could bend over to pick something up</td>
<td>CAT Only</td>
</tr>
<tr>
<td>I used a wheelchair to get around</td>
<td>Not Administered</td>
</tr>
<tr>
<td>I used a walker, cane, or crutches to get around</td>
<td>Not Administered</td>
</tr>
<tr>
<td>I could go up one step</td>
<td>Not Administered</td>
</tr>
<tr>
<td>I could get up from a regular toilet</td>
<td>Not Administered</td>
</tr>
<tr>
<td>I could turn my head all the way to the side</td>
<td>Not Administered</td>
</tr>
<tr>
<td>I could get out of bed by myself</td>
<td>CAT Only</td>
</tr>
</tbody>
</table>
Some Possibilities:

- Adjust CAT rules
  - Increase number of items administered.
  - Lower standard error stopping rule so additional items are administered.
- Collect CP-specific data and develop *new* item calibrations.
- Incorporate strategies to expose children using mobility devices to appropriate items.
  - Screening question
  - Custom Short Form
Recommendations to Researchers

- **Use PROMIS!**
  - Consider using thoughtfully-constructed Short Forms.
  - When using CATs, consider adjusting stopping rules.
  - Consider collaborating with someone who understands how PROMIS works.
Ongoing and Future Work

**Ongoing:**
- Replication and extension of validity findings in a larger sample of young adults (ages 14-25 years) with CP.
- Examination of other PROMIS instruments (fatigue, pain interference) in the same validation sample.

**Future:**
- Cognitive interviewing of participants with CP when completing PROMIS measures.
- Development of a PROMIS parent proxy measure applicable to children age 0-5 years old.
Thank You

alkratz@umich.edu

www.nihpromis.org

www.assessmentcenter.net