Measuring Participation Outcomes in Individuals with Communication Disorders

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- NIH planning grant “Developing a Scale of Communication Participation;” PI Yorkston
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- NIH R03 (Measuring communicative participation in adults with communication disorders): PI Baylor
- National Institute on Disability and Rehabilitation Research (NIDRR), National Rehabilitation Research and Training Center on Multiple Sclerosis: PI Kraft
Our Team

- Psychometry
  - Dagmar Amtmann
  - Alyssa Bamer
  - Jiseon Kim
- Speech-Language Pathology
  - Tanya Eadie
  - Lena Hartelius
  - Megan McAuliffe
  - Robert Miller
  - Michael Burns
- OT
  - Brian Dudgeon
  - Jean Deitz
I still meet rehabilitation professionals who believe that people can put their lives on hold until they have recovered.

A focus on participation challenges us to find ways for people to do the things that they need to do while they recover.

Participation itself, may foster this recovery because it brings focus to motivation, competency, and self-efficacy, all of which are psychologic concepts that are known to support growth and thus plasticity.
“If intervention does not address the social aspects of communication, it may succeed in the narrow setting of the therapy room, but fail to bring about important changes in the lives of people with motor speech disorders.”

Yorkston, Beukelman, Strand & Hakel, 2010
Origins of the Project

ICF

Theoretical Framework & Definition

PROMIS Initiative

Approaches to Measurement

Communicative Participation Item Bank
NIH PROMIS

- Patient Reported Outcomes Measurement Information System
- Started in 2004
- Mission: use measurement science to create a state-of-the-art assessment system for self-reported health, e.g. fatigue, pain interference, self-efficacy
- Website: NIHpromis.org
Health Condition

ICF Framework

Impairment
- e.g. respiration for speech

Activity Limitation
- Changes in speech intelligibility

Participation Restriction
- Restrictions in involvement in life situations

Personal Factors

Environmental Factors
Communicative participation: 
Involvement in life situations where knowledge, information, ideas or feelings are exchanged.
Interaction of Person, Task & Environment

- What the person can do
- What the person wants to do
- What the person has the opportunity to do
- What the person is not prevented from doing by the environment.

Mallinson and Hammel, 2010
- Reframing the question to move from ability to involvement (Mallinson and Hammel, 2010)

- Choice and control may be more important than performance (Mallinson and Hammel, 2010)

- Success as defined by the individual – not some ‘normative standard as to what participation should be.’ (Brown et al., 2004; Law, 2002)
Identify construct

Write and revise items

Qualitative item review

Psychometric analyses (IRT)

Item bank

Current Models

Literature Review

Professional Experience

Insider’s View

Item Bank Development

Computerized Adaptive Testing (CAT)

Targeted short forms

Disseminate and USE!
<table>
<thead>
<tr>
<th>Construct</th>
<th>Item Development</th>
<th>Psychometric Testing</th>
<th>Item Bank</th>
</tr>
</thead>
<tbody>
<tr>
<td>Existing scales</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Qualitative interviews of people with disorders</td>
<td></td>
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<tr>
<td>Focus group of rehab professionals</td>
<td></td>
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<tr>
<td>For coverage, conceptual models of roles &amp; responsibilities</td>
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<tr>
<td>Items universal to community dwelling adults</td>
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<tr>
<td>Construct</td>
<td>Item Development</td>
<td>Psychometric Testing</td>
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<tr>
<td>Burden of Stroke Scale (BOSS)</td>
<td>Stroke</td>
<td>Difficulty communicating</td>
<td>7/15</td>
</tr>
<tr>
<td>ASHA Quality of Communication Life (QCL)</td>
<td>General communication disorders</td>
<td>Difficulty communicating</td>
<td>8/19</td>
</tr>
<tr>
<td>Voice Handicap Index (VHI)</td>
<td>Voice disorders</td>
<td>Frequency of interference</td>
<td>7/30</td>
</tr>
<tr>
<td>Voice-Related Quality of Life (V-RQOL)</td>
<td>Voice disorders</td>
<td>Degree of interference</td>
<td>3/10</td>
</tr>
<tr>
<td>Voice Symptom Scale (VoiSS)</td>
<td>Voice disorders</td>
<td>Frequency of interference</td>
<td>4/30</td>
</tr>
<tr>
<td>Voice Activity and Participation Profile (VAPP)</td>
<td>Voice disorders</td>
<td>Frequency and degree of interference</td>
<td>5/28</td>
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</table>

Eadie et al, 2006
<table>
<thead>
<tr>
<th>Construct</th>
<th>Item Development</th>
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</thead>
<tbody>
<tr>
<td>Candidate Items Characteristics</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>▪ Low level of NA</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>▪ Represent a single factor</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>▪ A range of difficulty</td>
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<tr>
<td>▪ Ask about a single issue</td>
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<td>▪ Are unambiguous</td>
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<td>▪ Fit the mathematical model</td>
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</table>
**Decisions**

- Appropriate for community-dwelling adults
- Variety of life domains (home, work, leisure, community, personal relationships...)
- Range of communication disorders
- Focus on speech communication
- Ask about overall satisfaction for a global rating of participation (then the clinician’s task is to dig deeper in the clinical interview)
Examples of candidate items:

- ...having a casual conversation with someone you do not know well
- ...communicating in situations where there is a small group of people
- ...talking with people you live with about things that need to get done around the house
- ...making a phone call to schedule a personal appointment (dentist, haircut)
Cognitive Interviews: A qualitative approach to evaluating sources of response error in survey questionnaires. What cognitive processes are used to answer questions?
1. What does the question mean to the respondent?
2. How well does the respondent recall information to answer the question?
3. How does the respondent choose from the response options?
(Willis, 2005)
Interviews

- 13 Spasmodic dysphonia
- 12 Stroke
- 7 Parkinson’s disease
- 7 Multiple sclerosis
- 3 Laryngectomy
- 1 ALS
- 1 Stuttering

Baylor et al, 2011
From Cognitive Interview

- **Item:** Does your condition interfere with *using the telephone*?
  - **Problem:** Not enough context
  - **Modification:** Add multiple items specifying communication partner, purpose, & so on.

- **Item:** Does your condition interfere with *using humor in a conversation*?
  - **Problem:** Double-barreled items
  - **Modification:** Split into two items:
    1. Telling a funny story or joke
    2. Making a witty or funny comment
Problem: “Offensive” or unappealing wording

Items: “Yelling to someone outside”
   “Jumping into a conversation”

Modification:
   “Calling out to get someone’s attention”
   “Getting a turn in a fast-moving conversation”
## Selecting a Response

- What are you doing? (Diversity)
- How often? (Frequency)
- How much? (Intensity)
- With whom? (Social network)
- How difficult? (Performance ability)
- What assistance? (AT or people)

See King et al, 2004
Global Satisfaction

- Comfort
  - Ease
  - Confidence
- Success of outcome
  - Function is achieved
  - A connection is made
- Personal meaning
  - Personal preferences
  - Comparison with the past
  - Thinking about one’s own communication

Yorkston et al, 2007
How satisfied are you using the telephone?

Does your condition interfere with using the telephone?
Sample early CPIB item:

Does your condition interfere with making a phone call for household business?

Score

___ Not at all 4
___ A little 3
___ Quite a bit 2
___ A lot 1
___ Extremely 0
<table>
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</table>

- **Classical Test Theory (CTT)**
  - How most of our instruments have been developed
  - Observed score = True Score + Error

- **Item Response Theory (IRT)**
  - “Modern measurement theory”
  - Person score derived from mathematical relationship between item characteristics and person response to the item
Item Response Theory

- Measures a Latent Trait
- Takes what it knows about:
  - Characteristics of the items
  - Way people answer those item
- Makes an estimate of a person’s level of the trait being measured
Advantages of a Logit Scale

- Approximates equal intervals
- Allows mathematical operations
- Provides a common metric for equating across instruments
- Removed dependence on specific items or reference groups for interpretation
Normal Ogive Curve
(Item Characteristic Curve)

Theta: Interference with Comm. Participation

Probability of rating high interference
Normal Ogive Curve
(Item Characteristic Curve)

Probability

Hard Task

Easy Task

Interference Level

Little Extreme

Trait Level (Logits)

Response Odds
<table>
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<tr>
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</tr>
</thead>
</table>

**Original Response Categories**

___ Not at all  
___ A little  
___ Quite a bit  
___ A bit  
___ A lot  
___ Extremely
Logits (item difficulty centered at 0)

Probability of endorsing category:
- Not at all
- A little
- Quite a bit
- A lot
- Extremely

Construct Development Testing Bank

Original Response Category Curves
Logits (item difficulty centered at 0)

Probability of endorsing category

Revised Response Category Curves

Psychometric Testing
<table>
<thead>
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</tr>
</thead>
</table>

Does your condition interfere with making a phone call for household business?

___ Not at all
___ A little
___ Quite a bit
___ Very much
Key IRT Assumptions

- Essential or sufficient unidimensionality
- Model Fit
- Local independence of items
  - Subsets of items are not correlated beyond the single construct that they measure
  - Additional evidence of no confounding variables
Evidence of Sufficient Unidimensionality
Item with Poor Fit

Being polite
Locally Dependent Group of Items:

- Calling out to someone far away to get their attention
- Saying something to get someone’s attention
- Having conversation in noisy place
- Communicating with someone who is not paying attention to you
- Talking to someone who cannot see you
- Asking a familiar doctor or healthcare provider questions
1. Identify construct
   - Current Models
   - Literature Review
   - Professional Experience
   - Insider’s View

2. Write and revise items

3. Qualitative item review

4. Psychometric analyses (IRT)

5. Item bank

6. Computerized Adaptive Testing (CAT)
   - Targeted short forms

7. Disseminate and USE!
From Candidate Items to Item Bank

- Adequate measurement range  
  (Select items with appropriate information function)

- Minimize bias across populations  
  (Select items with minimal differential item function –DIF)
Differential Item Function

Original vs Purified Theta - Beta Change .05

Theta Adjusted for DIF vs Original Theta
<table>
<thead>
<tr>
<th>Construct</th>
<th>Item Development</th>
<th>Psychometric Testing</th>
<th>Item Bank</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>No DIF</td>
<td>Insufficient #'s</td>
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<td>Populations</td>
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<td></td>
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<td>176</td>
<td>215</td>
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<td>119</td>
<td>99</td>
<td>218</td>
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<tr>
<td>HNCA</td>
<td>121</td>
<td>76</td>
<td>197</td>
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<tr>
<td>ALS</td>
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<tr>
<td>Total</td>
<td>320</td>
<td>380</td>
<td>700</td>
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## CPIB 10-Item General Short Form Scoring Table

<table>
<thead>
<tr>
<th>Summary</th>
<th>Theta</th>
<th>T score</th>
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<td>-2.58</td>
<td>24.20</td>
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<tr>
<td>1</td>
<td>-2.18</td>
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<tr>
<td>2</td>
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<td>5</td>
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<td>16</td>
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<td>0.27</td>
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<td>21</td>
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<td>22</td>
<td>0.53</td>
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<td>23</td>
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<td>57.80</td>
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<td>60.60</td>
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<td>28</td>
<td>1.42</td>
<td>64.20</td>
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<td>29</td>
<td>1.67</td>
<td>66.70</td>
</tr>
<tr>
<td>30</td>
<td>2.10</td>
<td>71.00</td>
</tr>
</tbody>
</table>
Future Directions

- CAT scoring
Item Bank & Computer Adaptive Testing

Questionnaire with a wide range - but low precision

Questionnaire with a high precision - but small range
Item Bank & Computer Adaptive Testing

2. Question

Questionnaire with a high precision - AND a wide range

3. Question

high interference

low interference
Computerized Adaptive Testing (CAT)

More difficult situations

- Communicating in a large group of people
- Giving someone detailed information
- Talking with a clerk in a store about a problem with a bill or purchase
- Making a phone call to get information
- Having a long conversation with someone you know about a book, movie, etc.
- Having a conversation while riding in a car
- Sharing personal feelings with people close to you
- Ordering a meal in a restaurant
- Sharing your opinion with family and friends
- Greeting someone you know at a social gathering
- Answering a question from a doctor you know
- Comforting a friend or family member

Less difficult situations

- 46 CPIB items
- +3
- -3
Future Directions

- CAT scoring
- What things are associated with CPIB?
Regression Analysis

Model predicts 48.7% of variance
Baylor et al, 2010

Demographics
- Age
- Education
- Gender
- Duration of MS
- Employment

Social Support MSPSS

Communicative Participation

Symptoms
- Mobility EDSS
- Depression CESD
- Fatigue MFIS
- Pain
- Problems Thinking
- Slurred Speech
- Vision
Regression Analysis

Model predicts 48.7% of variance
Baylor et al, 2010

Demographics
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Communicative Participation

Symptoms
- Mobility EDSS
- Depression CESD
- Fatigue MFIS
- Pain
- Problems Thinking
- Slurred Speech
- Vision

Regression Coefficients:
- Fatigue MFIS: $r^2 = 0.393$
- Depression CESD: $r^2 = 0.314$
- Problems Thinking: $r^2 = 0.287$
- Slurred Speech: $r^2 = 0.224$
- Mobility EDSS: $r^2 = 0.10$
- Pain: $r^2 = 0.09$
- Vision: $r^2 = 0.079$
- Social Support MSPSS: $r^2 = 0.065$
- Employment: $r^2 = 0.065$

Model predicts 48.7% of variance.
CAT scoring
What things are associated with CPIB?
More populations, e.g. aphasia
Cultural & Language translations
Is it sensitive to change
How much does it need to change to be meaningful?
Lessons Learned

- There’s no better way is highlight your limited understanding of something than to try to measure it.
- Team research is need
  - People with communication disorder
  - Qualitative researchers
  - Quantitative researchers
- We are not finished yet
References


References

References


