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Pediatric Outcome Measures in Neurorehabilitation

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Disclosures

I do receive an honorarium for presenting this course. I do not receive any compensation from any manufacturer or vendor.
Objectives

After this course, participants will be able to:

- Recognize appropriate measures for pediatric assessment in neurorehabilitation.
- Differentiate qualities of various measures and identify their utility in practice.
- List resources for finding different outcome measures.

Practice Survey

- Pediatrics?
- Adults?
- Acute care/ In-patient hospital?
- Out-patient clinic?
- Students?
Do you...

- Use standardized measures?
- Use clinical observations?
- Use the same measures over time?
- Look at the psychometrics of a test before you use it?

Why do we measure?

- To obtain information about individual
- To establish a baseline of performance
- To measure progress
- To predict future performance
- To identify or measure specific traits of behaviors
But...

- Lack of accessible, valid, and reliable tools in pOT
- Therapists resort to making their own tools, parent report
- Standard measures objectify clinical judgments

Chesson et al. (2006) and McBurney (2000)

Responsible Service Delivery

- We have a responsibility to make sure our patients are benefitting from treatment and we are using resources appropriately.
- If you don’t document it, it didn’t happen.
- Make evidence-based, data-driven decisions
Data-Driven Decision Making

- Identify participation challenges and goals
- Describe current level
- Identify factors affecting participation
- Conduct assessment
- Identify strengths and barriers
- Generate hypothesis
- Design intervention
- Identify outcomes
- Conduct intervention
- Collect, display, and analyze data
- Monitor progress

Schaaf, 2015
What do we measure?

- Impairments
- Function
- Behaviors

International Classification of Functioning and Disability – Children and Youth (ICF-CY)

World Health Organization (2007)
ICF-CY
Ex: Teaching typing to pt. w/CP

- Body Function/Structure: anatomical parts of the body and their physiological functions of body systems
  - Abnormal tone, joint deformity, decreased strength and coordination, cognitive impairment
- Impairments: problems in body function and structure
  - Decreased strength and coordination
- Activity: execution of a task or action
  - Difficulty learning keyboarding skills
- Participation: involvement in a life situation
  - Difficulty communicating and engaging in school activities

World Health Organization (2007)

How do we measure?

Objective: Performance Based
- Standard assessment
  - Manual Muscle Test
- Quantitative measurement
  - Limb length
  - HR/Blood pressure

Subjective: Patient/Proxy Report
- Clinical observation
  - Developmental Checklist
- Survey/Questionnaire
  - PEDI
  - COPM
Evaluating a tool’s psychometrics

- Reliability
- Validity

For your patient

Reliability

- Is the test stable? Can scores be reproduced?
- Sample Specific
- Interrater: Do multiple raters get the same result?
- Test-retest: Is the test consistent from time to time?
Validity

- Does it measure what it is supposed to measure?
- Is it sensitive to change?
- Construct: Does the test measure the skill it is intended to evaluate? Does it have content to measure the range of the skill?
- Criterion: Does the test measure as well as another established instrument?

Challenges in measurement

- Capacity vs capability
- Reliability of child and instrument
  - Patient Reported Outcomes
- Burden on therapist
- Development vs disease
Capacity vs. Capability

- Capacity is the highest achievable level
- Capability is what the child typically does in their environment

Reliability of child and instrument

- Measuring a moment in time
- Consider child’s willingness and ability to participate
- Is there a learning effect to the test?
Patient Reported Outcomes

- Questionnaire or assessment where data comes directly from patient without interpretation from clinician
- Child/Proxy
  - Cognitive ability
  - Attention
  - Insight/Bias

Problems with PRO items

- Vague
- Complex
- Medical jargon
- Familiarity with item
- Interpretation based on self
- Inability to describe differences between response choices
Is this child sort of like you?

"No, because she only has four fingers."

Rebok, Riley, Forrest, et al., Quality of Life Research, 2001
Is this child sort of like you?
“No, because she only has four fingers.”

Could you be friends with this child?

“Yes, I could like someone with only four fingers.”
Spinal Cord Independence Measure III

- Observational tool to measure functional progress and to be sensitive to clinically modest changes
- Capacity
- Often used by interview
- 19 items in 3 domains
  - Self-care
  - Respiration and sphincter management
  - Mobility
- Weight for clinical relevance

Catz et al., 2001; Itzovitch et al., 2007

SCIM III Psychometrics

- Inter-rater Reliability: Adequate to excellent on individual items and subscales to total score
- Internal consistency: Excellent
- Construct validity: Excellent correlation to FIM scores
- Responsiveness: More sensitive than FIM (26%), better for mid-range injuries

Bluvstein et al., 2011; Catz et al., 1997
SCIM III-Self Report

- Developed to reduce time, effort, and burden
- Wording of the 19 items was adapted to include personal pronouns and avoid technical terms
- Complex items were broken down

Fekete et al., 2013

SCIM III: Respiration

0. Requires tracheal tube (TT) and permanent or intermittent assisted ventilation (IAV)
2. Breathes independently with TT; requires oxygen, much assistance in coughing or TT management
4. Breathes independently with TT; requires little assistance in coughing or TT management
6. Breathes independently without TT; requires oxygen, much assistance in coughing, a mask (e.g., peep) or IAV (bipap)
8. Breathes independently without TT; requires little assistance or stimulation for coughing
10. Breathes independently without assistance or device
SCIM-SR: Breathing

- I need a respiratory (tracheal) tube...
  1) as well as permanent or from time to time assisted ventilation.
  2) as well as extra oxygen and a lot of assistance in coughing or respiratory tube management.
  3) as well as little assistance in coughing or respiratory tube management.
- I do not need a respiratory (tracheal) tube...
  4) but I need extra oxygen or a lot of assistance in coughing or a mask (e.g., PEEP) or assisted ventilation from time to time (e.g., BIPAP).
  5) and only little assistance or stimulation for coughing.
  6) and can breathe and cough independently without any assistance or adaptive devices.

SCIM III vs. SCIM-SR

- SCIM-SR correlates with SCIM-III (r=0.87; CI=0.82-0.91)
- Mean and median values of SCIM III were lower than SCIM-SR, especially in mobility
- Recommend use of SCIM-SR in outpatient/community setting and SCIM III in hospital

Fekete et al., 2013
SCIM-SR in Children

- Cognitive testing
- Every item and response scale required revision

PRO Items

- Written clearly without jargon (ex: external drainage instrument vs. diaper)
- Use preambles to prime patient and set expectations (ex: answer based only based on the section of arm/hand being asked about)
- Low cognitive burden, easy to understand
- Clear and consistent

Good Information Comes From Good Questions
Burden on therapist

- Time
- Cost
- Training
- Utility in documentation

Development vs. Disease

- Has the child’s condition impacted their ability to meet developmental milestones?
- Are you measuring recovery from disease/condition or deviation from normal development?
- Ex: In SCI
  - Peabody Developmental Motor Scale (PDMS)
  - Pediatric Neurorecovery Scale (pNRS)
Selecting an outcome measure

- What do I want to measure?
- What are the limits of the patient?
- What are my limits?
- Is the test valid for my patient?
- Do I need more than one?

Item Response Theory (IRT)

- Paradigm for the design, analysis, and scoring of tests measuring abilities, attitudes, or other variables.
- Items in pool are selected to cover the continuum of skills.
- It does not assume that each item is equally difficult.
- Forms the platform for more efficient testing.
Computer Adaptive Tests (CATs)

- Computer-based assessment that adjusts to the patient’s level of function.
- Individualized measure selects set of items from calibrated pool to best measure patient’s ability
- Patients will only get questions appropriate for them
  - Won’t get all questions
  - May not get the same questions each time
- Good for global function/participation, not individual skill. Ex: PEDI-CAT

Sample CAT Items: Manual Mobility

- I can push my manual wheelchair all day in school
- I can push my manual wheelchair on grass outside
  - I can push my manual wheelchair on mulch or gravel outside, like at a playground
- In my manual wheelchair, I can pop a wheelie
- I can push my manual wheelchair down a curb
- I can push my manual wheelchair up a curb
- In a wheelie position, I can push my manual wheelchair
- In my manual wheelchair, I can go down the stairs
- In my manual wheelchair, I can go up the stairs
Short Forms

- Include carefully selected items from calibrated banks, usually 8-10
- Paper and pencil
- Show good correlation with CAT scores

Sample Battery for 4yo SCI

**Body Functions/Structure**
- Height
- Weight

**Impairment**
- Manual Muscle Test
- Range of Motion

**Activity**
- WeeFIM
- Peabody Developmental Motor Scale

**Participation**
- Pediatric Evaluation Disability Inventory (CAT)
- COPM
### Examples of UE Outcome Measures by ICF Level

#### Body Structure/Function
- Limb Length
- Forearm Circumference
- Blood Pressure
- Heart Rate

#### Impairment
- ROM
- MMT
- Grip/pinch strength with dynamometer
- Sensory Testing

### Examples of UE Outcome Measures by ICF Level

#### Activity
- Quality of Upper Extremity Skills Test
- Bruininks-Oseretsky Test of Motor Proficiency 2nd Ed
- Fugl-Meyer Upper Extremity Assessment
- pNRS
- Box and Blocks Test
- 9-Hole Peg Test
- WeeFIM/SCIM

#### Participation
- Pediatric Evaluation of Disability Index
- Canadian Occupational Performance Measure
- Children’s Assessment of Participation and Enjoyment
- Stroke Impact Scale (SIS)
- Motor Activity Log (MAL)
Limb length measurement

- Track growth, muscle hypertrophy
- Length: Follow segments between anatomical landmarks
  - Acromion to olecranon
  - Olecranon to ulnar styloid
  - Ulnar styloid to tip of middle finger
- Circumference
  - Midpoint of brachium and antebrachium
  - Use joints as control for muscle gain/loss
- Validated in leg

NeuroRecovery Scale (NRS)

- Adapted from the Adult NRS
- Classifies functional performance of mobility tasks according to normal, pre-injury capabilities
- No compensation or assistance
- 7 overground tasks (sit, sit-up, reverse sit-up, trunk extension, sit-to-stand, and walk)
- 4 treadmill tasks (stand retraining, stand adaptability, step retraining, and step adaptability)
- 30-45 minutes to administer

Behman et al., 2012
<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
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<tbody>
<tr>
<td>1A</td>
<td>Unable to maintain proper posture of trunk.</td>
<td>1B</td>
</tr>
<tr>
<td>2A</td>
<td>Able to both attain sitting with appropriate posture of trunk and position of pelvis and maintain this for approximately one minute.</td>
<td>2B</td>
</tr>
<tr>
<td>3A</td>
<td>Same as 2C and forward and lateral/lean &lt;5 inches and return to proper sitting posture with inappropriate kinematics of the scapula, shoulder, elbow, wrist and fingers (full UE).</td>
<td>3B</td>
</tr>
<tr>
<td>4A</td>
<td>Able to attain and maintain appropriate sitting posture indefinitely. Able to forward and lateral reach/lean &gt;10 inches &amp; return to appropriate sitting posture appropriate kinematics of the elbow, inappropriate kinematics of the scapula, shoulder, wrist and finger flexors.</td>
<td>4B</td>
</tr>
</tbody>
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**NRS Psychometrics**
- Good interrater reliability, better with more experience
- Discriminant validity demonstrated
- Able to discriminate categories of patients better than the ISNCSCI

NeuroRecovery Network, 2014
Pediatric NRS

- Ages 1-12yrs
- Includes developmental items
- Includes UE items
- Initial validation completed

Photos compliments of Dr. Behman; Ardolino et al, under review
Canadian Occupational Performance Measure

- 5-step semi-structured interview
- Focuses on identifying activities within each performance domain that the client wants, needs, or is expected to perform
- Rate the performance and satisfaction for top 5 activities
- The patient and therapist create goals for therapeutic interventions.
- Caregiver/proxy may respond on the patient’s behalf
- Pediatric and multicultural versions available
- Designed for use with any diagnosis
- Available for purchase from CAOT

COPM Psychometrics

- Validated in Stroke, COPD, Pain, Cerebral Palsy, Traumatic Brain Injury, Parkinson's Disease, Arthritis, Ankylosing Spondylitis
- Excellent test-retest and interrater reliability
- Score changes of more than 2 are clinically significant

Law et al., 2005
Building your toolbox

Rehab Measures Database

http://www.rehabmeasures.org/default.aspx

- Database of almost 300 instruments
- Provides quick, easy to understand information including descriptions of population, content, administration/scoring instructions & psychometric properties
- Provides citations to PubMed abstracts
Patient Reported Outcomes Measurement Information System

www.nihpromis.org

- System of measures of patient-reported health status
- Data provides patient-reported information on effect of therapy & better understanding of how treatments affect what patients can do as well as their experiences

NINDS Common Data Elements

http://www.commondataelements.ninds.nih.gov

- Purpose: to standardize the collection of investigational data in order to facilitate comparison of results across studies and more effectively aggregate into significant metadata results.
- Outlines data standards and provides accompanying tools (ex: case report forms, references, etc.) to help investigators and research teams collect and record standardized clinical data.
- Instruments across ICF continuum
- Summarizes Psychometrics
- CDEs are developed by working groups convened by the NINDS, consisting of national and international experts
- Diagnoses: Spinal cord injury, Traumatic brain injury, Epilepsy, Stroke, Parkinson’s disease, Friedreich’s ataxia, Multiple sclerosis, Huntington’s disease, Amyotrophic lateral sclerosis, Headache, Mitochondrial disease, Neuromuscular disorders (MD, SMA)
NIH Toolbox

- http://www.nihtoolbox.org/Pages/default.aspx
- Set of brief measures assessing cognitive, emotional, motor and sensory function from ages 3 to 85
- The website includes material requirements, administration instructions, and scoring manual for each of the tests across the four domains.
- No-disease specific scoring and interpretation data is available. Normative data is to be published soon, per the website.
- Toolbox measures are accessed through the Assessment Center, a free, online data collection tool that enables researchers to create study-specific websites for capturing participant data securely online.
- Sample items:
  - Cognitive: Flanker Inhibitory Control and Attention Test, Picture Vocabulary Test
  - Emotional: Perceived Stress CAT, Self-Efficacy Survey
  - Motor: 9-Hole Peg Test, 2-Minute Walk Test
  - Sensory: Visual Acuity Test, Words in Noise Test

NeuroQOL

http://www.neuroqol.org/Pages/default.aspx

- Set of self-report measures that assesses the health-related quality of life (HRQOL) of adults and children with neurological disorders.
- Comprised of item banks and scales that evaluate symptoms, concerns, and issues that are relevant across disorders - along with measures that assess areas most relevant for specific patient populations.
- Neuro-Qol is intended for use in clinical trials, observational research, comparative effectiveness research, and population surveys.
- Available as short from PDFs or as CATs through the Assessment Center.
SCIRE Project

- http://www.scireproject.com/outcome-measures

- Core set of psychometrically validated and recommended measures for use in SCI clinical practice.
- Summary information on each measure for clinical use and measurement properties.
- Information for administration and scoring, or if unavailable, a purchase link from the creators of the measure.

Books

- Rehabilitation Outcome Measures by Emma K. Stokes
- Occupational Therapy Assessment Tools: An Annotated Index by edited by Ina Elfant Asher
- Measures for Children with Developmental Disability: An ICF-CY approach by Annette Majnemer
Keys to successful assessment

- What do I want to measure?
- How do I want to measure?
- Is that appropriate for my patient?
- How will I use this information?

Questions