WHOSE LIFE IS IT ANYWAY?
Measuring Meaningful Outcomes for Children with Severe Disabilities

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Agenda
1. Introductions and Overview
2. QOL & HRQL
3. Framework of Patient Priorities
4. Q & A
5. Break
6. CPCHILD Questionnaire
7. Open Forum Q & A

Learning Objectives of Workshop
1. Define concepts of QOL and HRQL
2. Challenges in measurement of QOL & HRQL
   1. What to measure?
   2. How to measure?
   3. How to evaluate a measure
3. Developing and validating a measure
   – The CPCHILD
4. Discuss application, scoring & interpretation of the CPCHILD
MEET JACK
12 year old twin with CP
• Walks with canes at home
• Uses walker at school & in the community
• Parents proud that he is not using a wheelchair
• Less active over the last year due to:
  • fatigue
  • knee pain

MEET JILL
12 yr old girl with CP (GMFCS V)
• Non verbal
• Seizures under control
• Fed by g-tube
• Recently hospitalized for pneumonia
• Incontinent
• Full time wheelchair user
• Totally dependent: ADLs
• Adduction contracture
• Bilateral Hip Dislocations
• Reduced sitting tolerance

Goals of Medicine

• Practice of medicine
  – Obligation to relieve or prevent (health-related) human “suffering”
  – Promote health and well being
Conceptualization of Health

• Health: “a state of complete physical, mental and social well being, and not merely the absence of disease” – WHO

• Newer paradigm
  – full complexity of health
  – incorporating the human experience
  – recognizing individual rights and empowerment

Evidence Based Medicine

“....the conscientious, explicit, and judicious use of the current best evidence in making decisions about the care of individual patients” (Sackett)

EBM integrates:
1. Best available external evidence from systematic research
2. Individual clinical expertise
   – Proficiency and judgment acquired from Clinical Experience and Clinical Practice
3. Patient preferences

Evolution of Patient-Centered Care

• Growing interest in patients’ perspectives

• Outcomes research movement
  “to sort out what works in medicine and to learn how to make clinical decisions that reflect more truly the needs and wants of the individual patients” [Wennberg, 1990].

• The effectiveness of interventions should be judged using meaningful outcome measures that reflect the goals and expectations of individual patients.
Patient-Centered Outcomes

- Function
- Patient Satisfaction
- Quality of Life (QOL)
- Health Related Quality of Life (HRQL)

International Classification of Function, Disability and Health (ICF)

What contributes to your quality of life?
### Factors Contributing to Quality of Life

- Family life
- Social life
- Work life
- Health
- Food & drink
- Mobility
- Independence
- Sport & recreation
- Arts & culture
- Education
- Technology
- Financial security
- Home
- Neighbourhood
- Government
- Civic life & services
- Safety & security
- Personal/civil rights
- Justice
- Economy
- Climate/Environment
- Geography

### Quality of Life

“Individual’s perceptions of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards and concerns”

(WHO, QOL Group 1994)
Health Related Quality of Life?

- Health related factors that contribute towards the goodness and meaning of life, and how one perceives one’s ability to fulfill certain roles

- Health Related Quality of Life (HRQL)
  - What’s good for health may not always be good for QOL!
  - What’s good for QOL may not always be healthy!

Why is this Important for CP?

Impact of Cerebral Palsy

- Lifelong
- Child
- Parent / Caregiver
- Family
- Healthcare system
- Society in general
- What really matters?

What does Jack Want?

- Less active over the last year: fatigue and knee pain
- Feels excluded; especially during summer
  - Lots of time doing therapy or exercises
  - Would rather be out with friends
  - Friends at sleep over summer camps
  - Twin brother plays hockey and soccer
- Self conscious about using braces at school
- Wants to get rid of knee pain and keep up with friends
WHAT DOES JILL WANT?
“Unlike beauty, which rests in the eye of the beholder, quality of life is inherently an attribute of the reporter”
- Gill and Feinstein, 1994

HRQL in Cerebral Palsy: Challenges

• QOL: Personal, dynamic & contextual
  – It can change over time and circumstances

• Whose life is it anyway?
  – Patient’s perspective not accessible
    • What does (would) Jill want?
  – Parents’ perspective: Proxy
    • Perceived child’s quality of life
    • Perceived burden (ease) of care
    • Caregiver’s own quality of life

“No one asks me what might make life better for all of us.”
Parent of child with severe cerebral palsy
Challenges in the Measurement of HRQL in Children

- What domains to measure?
- Who defines the domains to measure?
- Whose perspective?
  - Child’s/Youth’s or Caregiver
- Group or individual data?
- Cross Cultural relevance?
- Developmental changes?
  - Cognition
  - Communication
  - Autonomy

Challenges: Proxy Report vs Self Report

- If HRQL is an individual’s perception, self-report essential
- Young children - parent proxy
  - Children’s cognitive immaturity
  - Limited social experience
  - Continued dependency
- Both parent proxy & child self report are collected

Proxy Report vs Self Report: Concordance

- Systematic review of 14 studies (Eiser, 2001)
  - Level of agreement between parents and children appeared to depend on the domain.
  - Good agreement (>0.5) between parents and children for domains reflecting physical activity, functioning and symptoms
  - Poor agreement (<0.30) for domains which reflected more social or emotional HRQL issues.
- Proxies and children may not agree about many issues, both perspectives are (equally) valid.
Why is this important?

- Fuller understanding of patients’ condition
- Communication with patients
- Clinical decision making
- Evaluation of response to treatments
- Outcome most meaningful to patients
- Primary outcome measure in clinical trials
- Ethical, Humanitarian & Economic

Quality of Life

- “Individual’s perceptions of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards and concerns” (WHO, QOL Group 1994)

- Framework of Patient Priorities
The Phenomenology of Parental Priorities in Childhood Disability:
Concerns, Needs and Expectations of Parents of Children with Severe CP

Unni Narayanan, MBBS, Msc, FRCSC
Laurie DeOliveira, BA, MSW, RSW
David Nicholas, RSW, PhD
Shannon Weir, BSc, (MSc)
Beverley Antle, MSW, PhD

Determining Priorities

• What are parents’ experiences of caring for a child with severe CP?
  – Gain deeper understanding of their priorities including their concerns, needs, desires and expectations
  – Gain insight that will inform decisions about interventions to improve quality of life for the child, family, and caregiver

Methods

• Qualitative methods
  – Participant observation
  – Interviews
  – Reflective journal writing
  – Photography

• Phenomenological approach (Heidegger)
  – Contextualizing parental experiences within a Social Model of Disability perspective
  – Lived experience
  – Meaning, Intentions, and Motivations
**Analysis: Phenomenological Approach**

- Interview transcripts analyzed by multi-disciplinary team
- Identified themes emerging from the interviews & photographs (coded using NVIVO)
- Synthesized to identify
  - Structure of the caregivers’ experiences
  - Specific concerns, needs, desires, and expectations
  - Relationship to QOL

**Purposeful Sample: n = 12**

- Age: 8 -18+: Mean age: 13.3
- GMFCS level IV & V
- Boys and girls
- Single and 2 parent
- Siblings (yes/no)
- Socioeconomic spectrum
- Urban, suburban, rural
- Dwelling type: House/Apartment/Townhouse
- Time of day/week
- School or holiday
- All Seasons: Full Winter, Spring, Summer, Fall

**Living / Caring for a Child with Severe Disabilities:**

- Identified Domains: Promoters (+) & Barriers (-)
  1. Child Factors
  2. Parental Health
  3. Parenting & Family Life
  4. Supports & Services
  5. Attitudes, Outlook, Feelings
  6. Coping Strategies
  7. Environment
  8. Life Events (The Wild Card)
Quality of Life

Parent QoL

Child QoL

Promoters (+ve) vs. Barriers (-ve)

1. Child Health
2. Parental Health
3. Parenting / Family Life
4. Support
5. Coping Strategies
6. Attitudes/Outlook/Feelings
7. Environment
8. Wild Card

Convergent or Divergent

Living / Caring for a Child with Severe Disabilities: Domain Interactions

SEVERE CP: MULTIPLE CO-MORBIDITIES

- Seizures
- Cognitive impairment
- Visual impairment
- Hearing impairment
- Non-verbal
- Drooling
- Swallowing difficulties
- Aspiration (pneumonia)
- Gastroesophageal reflux
- G-tube/GJ tube feeding
- Malnutrition
- Constipation
- Incontinence
- Contractures
- Deformities (trunk & limb)
Major Interventions

Multiple medical co-morbidities
Neurosurgical Procedures
• Hypertonia
Orthopaedic Procedures
• Hip dislocation
• Scoliosis
• Joint contractures

Major interventions
• Resource intensive &/or expensive
• Significant complication rate

LET’S MEET JILL AGAIN

12 yr old girl with CP (GMFCS V)
• Non verbal
• Seizures under control
• Fed by g-tube
• Recently hospitalized for pneumonia
• Incontinent
• Full time wheelchair user
• Totally dependent: ADLs
• Adduction contracture
• Bilateral Hip Dislocations
• Reduced sitting tolerance

JILL’S PROBLEMS

• GMFCS level V
  – Seizures under control
  – Fed by g-tube
  – Episodes of vomiting/ reflux?
  – Recently hospitalized for pneumonia
  – Incontinent
  – Full time wheelchair user
  – Reliant on carer for ADLs
• Sleeping poorly at night
  – Needs constant repositioning
• Single mother finding it difficult to
  – Clean, bathe and diaper her
  – Move her about and transport her
• Jill loves to swim & be taken for walks
  – Local public pool only open in the summer
  – Minimal snow removal services in the neighbourhood
Goals of Interventions

What’s important?
• Relieve or prevent pain
• Facilitate caregiving
• Preserve or improve health
• Preserve or improve quality of life

What do we measure?
• Spasticity
• Range of motion
• Radiographs

What do we need?
• A measure that incorporates what’s important.

The Imperative

A reliable, valid and responsive (sensitive to change) measure of HRQL* in children with severe cerebral palsy to evaluate the effectiveness of interventions in these children

* Comfort
* Ease of caregiving
* Health status/well being
* Quality of life

New Condition Specific Measure:
Item Generation

• Deriving the items from:
  – Caregivers: Interviews
  – Health-care professionals: Surveys
  – Review of other instruments

• Multiple iterations with caregivers
  – 37 items
  – Additional Caregiver specific items
### Caregiver Priorities & Child Health Index of Life with Disabilities (CPCHILD©)

- **The CPCHILD© questionnaire**

- 37 items across 6 domains

- **Scoring**
  - Standardized scores: From 0 to 100
  - Total Score + 6 domain scores

### The CPCHILD© QUESTIONNAIRE

<table>
<thead>
<tr>
<th>DOMAINS (6)</th>
<th>No. of Items (37)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Personal Care &amp; Activities of Daily Living</td>
<td>9</td>
</tr>
<tr>
<td>2. Positioning, Transferring &amp; Mobility</td>
<td>8</td>
</tr>
<tr>
<td>3. Comfort, Emotions &amp; Behaviour</td>
<td>9</td>
</tr>
<tr>
<td>4. Communication &amp; Social Interaction</td>
<td>7</td>
</tr>
<tr>
<td>5. Health</td>
<td>3</td>
</tr>
<tr>
<td>6. Quality of Life</td>
<td>1</td>
</tr>
</tbody>
</table>

7. Importance of each item: Contribution to child's QOL

### Personal Care & Activities of Daily Living

Consider how each of the following activities is *usually* performed by/for your child.

Rate how difficult each of these activities were in the past 2 weeks, and choose the level of assistance that was required to help your child perform these activities.

- Magnitude of difficulty of accomplishing each caregiving task
  - 7 point scale: Impossible (0) — No Problem at all (6)

- Level of assistance required to accomplish task
  - 4 point scale: Total assistance (0) — Independent (3)

- Full Range of Scores for each Item: 0 to 9
During the past 2 weeks, how often did your child experience pain or discomfort?

<table>
<thead>
<tr>
<th>Frequency</th>
<th>Every day</th>
<th>Very often</th>
<th>Fairly often</th>
<th>A few times</th>
<th>Once or twice</th>
<th>None of the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>Score</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
</tbody>
</table>

During transfers or position changes?

- Frequency of discomfort
  6 point ordinal scale: Every day (0) — None of the time (5)
- Intensity of discomfort
  3 point ordinal scale: Severe (0), Moderate (1), Mild (2) None (2)
- Full Range of Scores for each item: 0 to 7

**Importance of CPCHILD Items**

- Section 7 of questionnaire
- Caregivers rated the importance of each item’s contribution to their child’s overall quality of life
- Ordinal rating scale: 0 to 5
  - 0: Least important
  - 5: Most important

**Caregiver Rating of Importance of Items to Child’s QOL**

- Content validity by caregivers
  - Important items retained
  - Less important items may be dropped
- Variation in importance between items
  - Justification for weighting items?
- Variation in importance of items between caregivers
  - Caregiver specific weighted index (?)
- Identify caregiver priorities
  - Influence decision making and guide intervention
Caregiver Rating of Importance of Items

Do these items contribute to HRQOL?

<table>
<thead>
<tr>
<th>Importance of Item</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Most Important</td>
<td>5</td>
</tr>
<tr>
<td>Very Important</td>
<td>4</td>
</tr>
<tr>
<td>Fairly Important</td>
<td>3</td>
</tr>
<tr>
<td>Slightly Important</td>
<td>2</td>
</tr>
<tr>
<td>Not Very Important</td>
<td>1</td>
</tr>
<tr>
<td>Least Important</td>
<td>0</td>
</tr>
</tbody>
</table>

Validation Methods

- Pilot tested
- Participants:
  - Purposeful sample
  - Primary caregivers (n=77) of children (5 to 18 years) with cerebral palsy categorized by the GMFCS level
- Setting:
  - Tertiary children’s hospital
  - Children's rehabilitation centre

Results: CPCHILD Scores (0 - 100)

<table>
<thead>
<tr>
<th>GMFCS IV</th>
<th>GMFCS V</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean: 44.5</td>
<td>Mean: 59.3</td>
</tr>
<tr>
<td>Range: 24.2 to 81.5</td>
<td>Range: 35 to 93</td>
</tr>
<tr>
<td>Std Dev: 19.3</td>
<td>Std Dev: 13.2</td>
</tr>
<tr>
<td>n = 11</td>
<td>n = 41</td>
</tr>
<tr>
<td>Age = 13.2 (9 - 18)</td>
<td>Age = 13.6 (8 - 18)</td>
</tr>
</tbody>
</table>

p = 0.005
Distribution of CPCHILD Scores (0 – 100)

- Mean (SD): 50.63 (13.04)
- Range: 19.12 - 80.01

CPCHILD – Construct Validity

- Construct validity examines the logical relations that should exist between a measure and characteristics of patients and patient groups

**Hypotheses**

1. CPCHILD scores for non-ambulatory patients (GMFCS IV & V) would be significantly higher than for ambulatory patients (GMFCS I, II, & III)

2. CPCHILD scores would increase (worsen) with GMFCS level (eg. V > IV > III)

CPCHILD Scores: GMFCS I - V

<table>
<thead>
<tr>
<th>GMFCS Level</th>
<th>AMBULATORY CP</th>
<th>NON-AMBULATORY CP</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>34.4 (13.8)</td>
<td>61.2 (22.2)</td>
</tr>
<tr>
<td>II</td>
<td>44.3 (15.7)</td>
<td>71.3 (23.1)</td>
</tr>
<tr>
<td>III</td>
<td>56.3 (21.1)</td>
<td>83.3 (19.3)</td>
</tr>
<tr>
<td>IV</td>
<td>69.0 (18.2)</td>
<td>96.3 (12.3)</td>
</tr>
<tr>
<td>V</td>
<td>82.5 (17.3)</td>
<td>100.0 (0.0)</td>
</tr>
</tbody>
</table>

Mean CPCHILD (SD): 22(13.8), 38(22.2), 23(15.7), 44.3(19.3), 56.3(21.1), 69.0(18.2), 82.5(17.3), 100.0(0.0)

n = 12, 3, 10, 11, 41

F = 25.38; p < 0.001
Test - Retest (Intra-Rater) Reliability

- Test – retest 2 weeks apart
- Mean (absolute) difference: 4.1 points (SD 3.2)
  - Range of (absolute) difference: 0 to 11 points
- ICC total score: 0.94  (95% CI: 0.90 - 0.97)
- ICC domain scores: 0.78 to 0.92

Conclusions: Initial Validation

- CPCHILD: reliable/valid disease-specific measure
  - Health status & Well being
  - Functional limitations
  - Ease of care giving
- Caregivers’ perspective of children with severe CP (GMFCS levels IV & V)
  - Narayanan et al, Dev Med Child Neurol Oct 2006

Revision of the CPCHILD

- CPCHILD underwent revisions based on
  - Concurrent caregiver feedback on individual items
  - Caregivers’ rating of Importance of each items (Section 7)
  - Survey of healthcare professionals in Ontario
- Less important items were deleted/modified
- Wording of some items revised
- Format of CPCHILD was revised
- Scoring was reversed in keeping with conventional measures of HRQL
  - From (0) Worst to (100) Best
  - Total Score + 6 domain scores
Validation of Revised CPCHILD

- Validation study of the revised CPCHILD questionnaire repeated
  - Reliability
  - Validity

- Does it measure HRQL?

Methods

- CPCHILD administered to Caregivers of
  - 67 children with CP (GMFCS I-V)
  - 17 children temporarily disabled due to trauma
  - 6 to 18 years old

- Caregivers of children with severe CP (GMFCS IV & V; n = 38) were also given
  - PEDI (Caregiver assistance module)
  - Child Health Questionnaire (PF-28)
  - Repeat of CPCHILD 2 weeks after first

Demographics

<table>
<thead>
<tr>
<th>Group</th>
<th>Ambulatory CP (n=29)</th>
<th>Non-ambulatory CP (n=38)</th>
<th>Trauma (n=17)</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex</td>
<td>11 girls (41%)</td>
<td>14 girls (37%)</td>
<td>7 girls (41%)</td>
<td>0.95</td>
</tr>
<tr>
<td>Age</td>
<td>8.3 yrs (SD=2.8)</td>
<td>9.5 yrs (SD=4.0)</td>
<td>10.2 yrs (SD=2.9)</td>
<td>0.14</td>
</tr>
<tr>
<td>Caregiver Sex</td>
<td>25 women (93%)</td>
<td>34 women (89%)</td>
<td>14 women (82%)</td>
<td>0.76</td>
</tr>
<tr>
<td>Caregiver Age</td>
<td>41.0 (SD=5.9)</td>
<td>41.8 (SD=10.5)</td>
<td>41.7 (SD=7.3)</td>
<td>0.93</td>
</tr>
</tbody>
</table>

*Groups did not differ significantly in terms of demographics
*X2 test for categorical data, ANOVA for continuous data
Reliability

- Tested in GMFCS IV & V level only (n = 38)
- Test-retest Reliability (2 weeks apart)
  - Mean Absolute differences: 5.9 (SD 4.0)
  - Range of (absolute) differences: 0.5 to 14.1
  - ICC for the total score: 0.85 (95% CI 0.68-0.93)
  - ICC for domain scores: 0.63 to 0.87
- Internal Consistency
  - Cronbach’s alpha for domain scores: 0.74 to 0.93

Construct Validity – GMFCS Level

- Mean CPCHILD scores decreased with increasing GMFCS (p<0.001)

<table>
<thead>
<tr>
<th>AMBULATORY CP</th>
<th>NON-AMBULATORY CP</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean CPCHILD Score</td>
<td>Mean CPCHILD Score</td>
</tr>
<tr>
<td>I</td>
<td>II</td>
</tr>
<tr>
<td>mean</td>
<td>84.4</td>
</tr>
<tr>
<td>SD</td>
<td>12.8</td>
</tr>
<tr>
<td>n</td>
<td>12</td>
</tr>
</tbody>
</table>

Construct Validity – Groups

As hypothesized, mean CPCHILD scores were
- lowest for children with Non-ambulatory CP,
- higher for children temporarily disabled due to Traumas, and
- highest for children with Ambulatory CP (p<0.001)

<table>
<thead>
<tr>
<th>Ambulatory CP</th>
<th>Non-ambulatory CP</th>
<th>Trauma</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean CPCHILD Score</td>
<td>Mean CPCHILD Score</td>
<td>Mean CPCHILD Score</td>
</tr>
<tr>
<td>I, II, III</td>
<td>I, II</td>
<td>I</td>
</tr>
<tr>
<td>mean</td>
<td>79.9</td>
<td>62.4</td>
</tr>
<tr>
<td>SD</td>
<td>14.7</td>
<td>12.6</td>
</tr>
<tr>
<td>n</td>
<td>29</td>
<td>38</td>
</tr>
</tbody>
</table>
Convergent Validity – CHQ (PF28)

- 13/38 (30%) CHQs could not be analyzed
  - Too many missing data (inappropriate questions)
- Caregivers reported that questions were "too high level" and "not applicable"

Of those CHQs that could be analyzed
- CPCHILD scores demonstrated positive and significant Spearman’s rank coefficients with the CHQ (a generic measure of HRQL)

<table>
<thead>
<tr>
<th>CHQ (n=25)</th>
<th>Total Score</th>
<th>Physical health</th>
<th>Psychosocial health</th>
</tr>
</thead>
<tbody>
<tr>
<td>CPCHILD</td>
<td>R = 0.62</td>
<td>R = 0.52</td>
<td></td>
</tr>
</tbody>
</table>

Convergent Validity – PEDI

- CPCHILD scores: Positive and significant Spearman’s rank coefficients with the PEDI (measure of function)
- Correlations were high between sections that seemed to be measuring similar health concepts*

<table>
<thead>
<tr>
<th>PEDI (n=38)</th>
<th>CPCHILD</th>
<th>Self-care</th>
<th>Mobility</th>
<th>Social function</th>
</tr>
</thead>
<tbody>
<tr>
<td>Personal Care</td>
<td>0.45*</td>
<td>0.52</td>
<td>0.29</td>
<td></td>
</tr>
<tr>
<td>Positioning Transferring and Mobility</td>
<td>0.51</td>
<td>0.61*</td>
<td>0.30</td>
<td></td>
</tr>
<tr>
<td>Communication and Social Interaction</td>
<td>0.43</td>
<td>0.45</td>
<td>0.71*</td>
<td></td>
</tr>
<tr>
<td>Total Score</td>
<td>0.61</td>
<td>0.62</td>
<td>0.52</td>
<td></td>
</tr>
</tbody>
</table>

Convergent Validity: CPCHILD & PedsQL

Spearman correlations between the CPCHILD and PedsQL

<table>
<thead>
<tr>
<th>Questionnaire Domains</th>
<th>PedsQL (CP Specific Module)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Daily Activities</td>
</tr>
<tr>
<td>Personal Care &amp; ADLs</td>
<td>-0.09</td>
</tr>
<tr>
<td>Positioning, Transfers, &amp; Mobility</td>
<td>0.116</td>
</tr>
<tr>
<td>Comfort &amp; Emotions</td>
<td>0.26*</td>
</tr>
<tr>
<td>Communication &amp; Social Interaction</td>
<td>0.27*</td>
</tr>
<tr>
<td>Health</td>
<td>0.38**</td>
</tr>
<tr>
<td>Overall Quality of Life</td>
<td>0.14</td>
</tr>
</tbody>
</table>

* p < 0.05; ** p < 0.01
**Distribution of CPCHILD Scores (0 – 100)**

- Mean (SD): 50.63 (13.04)
- Range: 19.12 - 80.01

**Distribution of PedsQL Scores (0 – 100)**

**PedsQL Generic Core**
- Mean (SD; Range): 44.28 (20.22; 0.00 - 96.65)

**PedsQL™ CP Module**
- Mean (SD; Range): 27.02 (18.33; 0.00 - 85.71)

**Floor Effects of HUI - 2 & 3**

- HUI2: p < 0.001
- HUI3: p < 0.001
Results: Mean Importance Ratings

- Mean importance rating all items: 3.63 (SD=0.54)
- No items were rated below 2.0 (slightly important)
- Importance ratings of revised items increased
Variation In Domain Importance Ratings
1. Comfort & Emotions
2. Communication & Social Interaction
3. Personal Care & ADLs
4. Positioning, Transferring & Mobility

\( p < 0.01 \)

- No significant correlations between domain importance ratings and corresponding domain scores

Non-ambulatory versus ambulatory CP

Scoring: Weighted vs Unweighted
- Total CPCHILD scores calculated
  - Equal weighting of all items
  - Differential weighting by mean importance rating
- No significant difference in total scores
  - \( r = 0.99 \) (\( p < 0.001 \)).
Does the CPCHILD Measure HRQL?

- Correlations with generic HRQL measures
  - CHQ & PEDI
  - (HUI, PedsQL)
  - Convergent validity of the CPCHILD

- Caregivers’ Importance Ratings
  - Items are important contributors to HRQL
  - Face & content validity for the items in the CPCHILD

Conclusions: Revised CPCHILD

- CPCHILD is a reliable/valid disease-specific measure
  - Health status & Well being
  - Functional limitations
  - Ease of care giving for children with severe (non-ambulatory) cerebral palsy (GMFCS IV & V)

- Items of the CPCHILD are important to the quality of life of children with cerebral palsy

- Item-specific weighting contributes little to the scoring of the CPCHILD (apart from added complexity)

- Caregivers’ importance ratings may be useful to identify priorities for clinical or surgical interventions.

Conclusions

- CPCHILD: reliable/valid disease-specific measure
  - Health status & Well being
  - Functional limitations
  - Ease of care giving

- Caregivers’ perspective of children with severe CP (GMFCS levels IV & V)
Conclusions

- Item-specific weighting contributes little to the scoring of the CPCHILD (apart from added complexity).
- Caregivers’ importance ratings may be useful to identify priorities for clinical or surgical interventions.

Clinical Relevance

- What is the relative contribution of various co-morbid conditions to the HRQL of children with severe (non-ambulant) CP as measured by the CPCHILD questionnaire?
- Specific emphasis on musculoskeletal conditions
  - Lower extremity contractures
  - Hip pathology
  - Spinal deformity
- Hypothesis: children with one or more co-morbid conditions would have lower CPCHILD scores

DEMOGRAPHICS

<table>
<thead>
<tr>
<th></th>
<th>Participants (n=161)</th>
<th>Non-Participatio (n=28)</th>
<th>Difference (p value)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child Age</td>
<td>12y,2m (SD:3y,10m)</td>
<td>12y,5m (SD:3y7m)</td>
<td>0.746</td>
</tr>
<tr>
<td>Child Sex</td>
<td>60% boys (97/161)</td>
<td>64% boys (18/28)</td>
<td>0.699</td>
</tr>
<tr>
<td>Caregiver Age</td>
<td>44y,0m (SD:7y,11m)</td>
<td>45y,2m (SD:5y,11m)</td>
<td>0.683</td>
</tr>
<tr>
<td>Caregiver Sex</td>
<td>87% women (140/161)</td>
<td>86% women (24/28)</td>
<td>0.746</td>
</tr>
<tr>
<td>GMFCS Level</td>
<td>70% level V (112/161)</td>
<td>57% level V (16/28)</td>
<td>0.215</td>
</tr>
<tr>
<td>CPCHILD Score (Range: 0 - 100)</td>
<td>Mean: 48.7</td>
<td>- -</td>
<td>--</td>
</tr>
</tbody>
</table>

Participants did not differ significantly from non-participants on demographics or clinical status.
COMORBID STATUS (n = 161)

- Lower extremity contractures: 106 (66%)
- Hip pathology: 93 (58%)
- Scoliosis (18°– 100°): 84 (51%)
- ITB pump: 20 (12%)
- G-tube or GJ tube: 64 (40%)
- Seizures: 84 (52%)

UNIVARIATE ANALYSIS

<table>
<thead>
<tr>
<th>Predictor</th>
<th>β</th>
<th>R-Sq (adj)</th>
<th>P Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>GMFCS Level</td>
<td>-14.5</td>
<td>19.8%</td>
<td>&lt; 0.001</td>
</tr>
<tr>
<td>Feeding Method</td>
<td>-6.04</td>
<td>18.1%</td>
<td>&lt; 0.001</td>
</tr>
<tr>
<td>Hip Pathology</td>
<td>-5.66</td>
<td>15.8%</td>
<td>&lt; 0.001</td>
</tr>
<tr>
<td>Seizure Status</td>
<td>-7.56</td>
<td>11.2%</td>
<td>&lt; 0.001</td>
</tr>
<tr>
<td>ITB Pump</td>
<td>-8.99</td>
<td>3.4%</td>
<td>0.014</td>
</tr>
<tr>
<td>Scoliosis</td>
<td>-1.68</td>
<td>1.8%</td>
<td>0.057</td>
</tr>
<tr>
<td>Contractures</td>
<td>-4.68</td>
<td>1.5%</td>
<td>0.073</td>
</tr>
</tbody>
</table>

- CPCHILD© scores decreased with worse co-morbidity
- Further evidence of construct validity for the CPCHILD

EFFECT OF HIP PATHOLOGY

- Box plots of total CPCHILD© scores (medians) by hip pathology
### MULTIVARIATE ANALYSIS

<table>
<thead>
<tr>
<th>Predictor</th>
<th>β</th>
<th>95%CI</th>
<th>P Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>GMFCS Level</td>
<td>-6.68</td>
<td>-11.46 to -1.89</td>
<td>0.007</td>
</tr>
<tr>
<td>Hip Pathology</td>
<td>-4.09</td>
<td>-5.96 to -2.22</td>
<td>&lt; 0.001</td>
</tr>
<tr>
<td>Feeding Method</td>
<td>-3.60</td>
<td>-5.60 to -1.61</td>
<td>&lt; 0.001</td>
</tr>
<tr>
<td>Seizure Status</td>
<td>-4.54</td>
<td>-7.49 to -1.59</td>
<td>0.003</td>
</tr>
</tbody>
</table>

- 43% of variance of the CPCHILD scores explained by the
  - GMFCS level
  - Increasing hip pathology
  - Method of feeding
  - Presence and control of seizures
- Factors other than the selected co-morbid conditions contribute to the CPCHILD scores.

### CONCLUSIONS

- Co-morbid conditions have an impact on the health status, well being & caregiving of children with severe CP
- Includes some musculoskeletal conditions
  - Hip pathology: significant impact
  - Scoliosis (up to 100º): small impact in this sample
  - Lower extremity contractures: minimal impact

### VALIDATES DEFINITION OF CP

“Cerebral palsy describes a group of permanent disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain.

The motor disorders are often accompanied by disturbances of sensation, perception, cognition, communication and behaviour, by epilepsy, and by secondary musculoskeletal problems.”

Report on Definition and Classification, 2006

**Responsiveness**

- Prospective longitudinal cohort studies
- Selected cohorts (pre and post)
  - Intrathecal baclofen pump
  - G – Tube / GJ - Tube feeding
  - Nissen Fundoplication
  - Spinal fusion for scoliosis
  - Hip reconstruction

**Study Question**

Is the CPCHILD responsive (sensitive to change) following spinal fusion?

- Pre – Post difference
  - Paired t-test or repeated measures ANOVA
- Standardized Response Mean
  - Ratio of Mean Change to the standard deviation of that change
- Correlation with external verification

**STUDY DESIGN**

- Prospective longitudinal cohort study
  - HARMS Study Group
- Operative Group
- Control group: Non-operative
  - Asymptomatic (Managed by reactive strategy)
  - Those who declined surgery
- Outcome Measures
  - CPCHILD
- Measurement
  - At baseline (within 4 weeks prior to surgery)
  - 6 months & 12 months after surgery
### Baseline CPCHILD SCORES (0 – 100)

<table>
<thead>
<tr>
<th>Domain</th>
<th>OG: N = 120</th>
<th>NOG: N = 36</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Personal Care &amp; Activities of Daily Living</td>
<td>39.5 (15.0)</td>
<td>38.5 (17.3)</td>
</tr>
<tr>
<td></td>
<td>(0.0 to 85.2)</td>
<td>(0 – 82.7)</td>
</tr>
<tr>
<td>2. Positioning, Transfers &amp; Mobility</td>
<td>34.3 (16.7)</td>
<td>41.6 (16.7)</td>
</tr>
<tr>
<td></td>
<td>(0 to 75)</td>
<td>(13.9 – 91.7)</td>
</tr>
<tr>
<td>3. Comfort &amp; Emotions &amp; Behaviour</td>
<td>72.7 (21.5)</td>
<td>83.0 (17.0)</td>
</tr>
<tr>
<td></td>
<td>(16.3 to 100)</td>
<td>(34.9 – 100)</td>
</tr>
<tr>
<td>4. Communication &amp; Social Interaction</td>
<td>54.2 (29.3)</td>
<td>64.7 (23.6)</td>
</tr>
<tr>
<td></td>
<td>(0 – 100)</td>
<td>(14.3 – 100)</td>
</tr>
<tr>
<td>5. Health</td>
<td>56.4 (29.3)</td>
<td>69.1 (20.6)</td>
</tr>
<tr>
<td></td>
<td>(13.3 to 100)</td>
<td>(20 – 100)</td>
</tr>
<tr>
<td>6. Overall QoL</td>
<td>60.2 (24.4)</td>
<td>65.1 (24.6)</td>
</tr>
<tr>
<td></td>
<td>(0 to 100)</td>
<td>(20 – 100)</td>
</tr>
<tr>
<td>Total Score</td>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
</tr>
<tr>
<td></td>
<td>50.9 (14.7)</td>
<td>57.7 (12.8)</td>
</tr>
<tr>
<td></td>
<td>(Range)</td>
<td>(Range)</td>
</tr>
<tr>
<td></td>
<td>[17.9 to 83.6]</td>
<td>[29.2 – 90.0]</td>
</tr>
</tbody>
</table>

The Op Group had lower domain (5 to 13 points lower) and total (7 points lower) than the Non-Op control group.

### Pre – Post 12 Months Op vs Non-Op

<table>
<thead>
<tr>
<th>Domain</th>
<th>Operative Mean of Diff.</th>
<th>Non-Op Mean of Diff.</th>
<th>P Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Personal Care &amp; ADLs</td>
<td>4.3</td>
<td>0.5</td>
<td>NS</td>
</tr>
<tr>
<td>Positioning, Transfers &amp; Mobility</td>
<td>9.7</td>
<td>-5.5</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Comfort, Emotions &amp; Behaviour</td>
<td>4.5</td>
<td>17.0</td>
<td>NS</td>
</tr>
<tr>
<td>Communication &amp; Social Interaction</td>
<td>2.0</td>
<td>-7.8</td>
<td>&lt;0.05</td>
</tr>
<tr>
<td>Health</td>
<td>6.5</td>
<td>2.9</td>
<td>NS</td>
</tr>
<tr>
<td>Overall QoL</td>
<td>9.1</td>
<td>6.5</td>
<td>NS</td>
</tr>
<tr>
<td>Total Score</td>
<td>5.4</td>
<td>-5.5</td>
<td>&lt;0.01</td>
</tr>
</tbody>
</table>

### Responsiveness: SRM

Standardized Response Mean /Effect Size is used to gauge the responsiveness of scales to clinical change.

SRM = Mean Change Score (follow-up - baseline)

Standard deviation of the Change score

SRM > 0.8 is considered large.
**3 Possible Outcomes of Spine Surgery**

1. + ve change overall / some
2. - ve change overall / some
3. No change
   - Intervention did not work
   - Instrument is not sensitive to change
   - Intervention is prophylactic
   - Need for independent external verification of outcome

**External Verification (N = 47):**

**12 Month Post Op**

*“Since surgery my child’s overall QOL/Comfort/Caregiving/Health has:”*

<table>
<thead>
<tr>
<th>QOL</th>
<th>Comfort</th>
<th>Ease of Care</th>
<th>Health</th>
</tr>
</thead>
<tbody>
<tr>
<td>Deteriorated a lot</td>
<td>2</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Deteriorated a little</td>
<td>2</td>
<td>4</td>
<td>7</td>
</tr>
<tr>
<td>No noticeable difference yet</td>
<td>2</td>
<td>3</td>
<td>11</td>
</tr>
<tr>
<td>Improved a little</td>
<td>7</td>
<td>10</td>
<td>8</td>
</tr>
<tr>
<td>Improved a lot</td>
<td>34</td>
<td>29</td>
<td>20</td>
</tr>
</tbody>
</table>

- There were moderately positive correlations \((R = 0.2 – 0.37)\) between the changes in the CPCHILD domain scores and the external criteria ratings.

**Summary**

- At 6 and 12 months after surgery there is significant improvement in Total and some domain scores of the CPCHILD.
- In the non-operative (control group) CPCHILD scores either remained stable or deteriorated in some domains over 12 months
- The CPCHILD is sensitive to change following scoliosis surgery
Are we helping children with severe CP by reconstructing their hips?

**Methods**
- Observational prospective cohort study
- Hypothesis: Compared with children who did not undergo surgery, children who had hip reconstructive surgery for hip instability will benefit from the procedure as measured by changes in their CPCHILD scores

**Study Method**
- **Inclusion criteria (n = 40)**
  - Children with Cerebral Palsy 4 - 18 yrs
  - Non-ambulant Cerebral Palsy: GMFCS IV & V
  - Hip Instability: Migration Percentage > 40%
- **Exclusion criteria: previous surgery for hip instability**
- **Treatment Group:** Surgery for hip instability: N = 20
- **Control Group:** Waiting for or declined surgery: N = 20
- **Outcome measure:** CPCHILD questionnaire
  - 3 months, 6 months and 12 months
  - Secondary measure: Radiographic measures
- **Analysis:** (Repeated Measures) Analysis of Variance
  - Compare the change in CPCHILD scores (from baseline)
  - At 3, 6 and 12 months

**Results: Baseline Characteristics**

<table>
<thead>
<tr>
<th></th>
<th>Cases (n=20)</th>
<th>Controls (n=20)</th>
<th>P Value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Child Age (Mean)</strong></td>
<td>9.6 yrs (4.2)</td>
<td>10.5 yrs (3.3)</td>
<td>0.48</td>
</tr>
<tr>
<td><strong>Child Sex</strong></td>
<td>9 boys (45%) 11 girls (55%)</td>
<td>11 boys (55%) 9 girls (45%)</td>
<td>0.41</td>
</tr>
<tr>
<td><strong>GMFCS</strong></td>
<td>13 Level V (65%)</td>
<td>16 Level V (80%)</td>
<td>0.10</td>
</tr>
<tr>
<td><strong>Caregiver Age (Mean)</strong></td>
<td>42.3 yrs (7.4)</td>
<td>44.1 yrs (6.9)</td>
<td>0.43</td>
</tr>
<tr>
<td><strong>Caregiver Sex</strong></td>
<td>2 men (10%) 18 women (90%)</td>
<td>4 men (20%) 16 women (80%)</td>
<td>0.37</td>
</tr>
<tr>
<td><strong>CPCHILD© Total</strong></td>
<td>46.8 (14.6)</td>
<td>46.5 (10.3)</td>
<td>0.93</td>
</tr>
</tbody>
</table>
Differences in CPCHILD© Scores:
Baseline to 12 Months

<table>
<thead>
<tr>
<th>CPCHILD© Domain</th>
<th>Cases (n=20)</th>
<th>Controls (n=20)</th>
<th>P Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>CPCHILD Total Score</td>
<td>12.4 (13.0)</td>
<td>1.9 (7.7)</td>
<td>0.004</td>
</tr>
<tr>
<td>Personal Care/ADLs</td>
<td>15.1 (10.5)</td>
<td>1.5 (11.6)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Positioning, Transferring &amp; Mobility</td>
<td>9.8 (12.4)</td>
<td>2.3 (11.0)</td>
<td>0.05</td>
</tr>
<tr>
<td>Comfort &amp; Emotions</td>
<td>18.4 (26.0)</td>
<td>3.1 (15.4)</td>
<td>0.03</td>
</tr>
<tr>
<td>Communication &amp; Social Interaction</td>
<td>8.2 (18.9)</td>
<td>-1.4 (17.5)</td>
<td>0.11</td>
</tr>
<tr>
<td>Health</td>
<td>2.3 (12.8)</td>
<td>4.0 (15.8)</td>
<td>0.72</td>
</tr>
<tr>
<td>Overall Quality of Life</td>
<td>11.1 (26.8)</td>
<td>-1.1 (22.6)</td>
<td>0.15</td>
</tr>
</tbody>
</table>

* At 12 months from baseline, CPCHILD© total and domain scores improved significantly in cases and changed little or worsened in controls

Change in CPCHILD Total Score

Change in CPCHILD Domain Score
Personal Care & ADLs
Change in CPCHILD Domain Score
Positioning, Transfers & Mobility

Change in CPCHILD Domain Score
Comfort, Emotions & Behaviour

Standardized Response Mean & Effect Size

- **SRM**: 0.95
  - Range: 0.18 to 1.44

- **ES**: 1.32
  - Range: 0.16 to 1.32

<table>
<thead>
<tr>
<th>CPCHILD® Domain</th>
<th>SRM</th>
<th>ES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Score</td>
<td>0.95</td>
<td>1.32</td>
</tr>
<tr>
<td>Personal Care/ADLs</td>
<td>1.44</td>
<td>0.67</td>
</tr>
<tr>
<td>Positioning, Transferring &amp; Mobility</td>
<td>0.79</td>
<td>0.68</td>
</tr>
<tr>
<td>Comfort &amp; Emotions</td>
<td>0.71</td>
<td>0.36</td>
</tr>
<tr>
<td>Communication &amp; Social Interaction</td>
<td>0.43</td>
<td>0.16</td>
</tr>
<tr>
<td>Health</td>
<td>0.18</td>
<td>0.42</td>
</tr>
<tr>
<td>Overall Quality of Life</td>
<td>0.42</td>
<td>0.85</td>
</tr>
</tbody>
</table>
KEY FINDINGS

- The CPCHILD total and domain scores improved by 8% to 18% in the operated group
- CPCHILD scores remained stable or deteriorated in the control group over 12 months
- CPCHILD is sensitive to change after hip surgery
- First comparative study to provide such evidence using a validated outcome measure meaningful to patients and parents

International Multi-centre Study

- Generalizability
- Confirmatory factor analysis
- Responsiveness: Longitudinal Studies
  - Intrathecal baclofen
  - G – Tube / GJ - Tube feeding/Nissen Fundoplication
  - Spinal fusion
  - Hip reconstruction
  - Botulinum toxin injection
  - Natural History
- Canada, US, UK, Australia, New Zealand
- Translation/Back Translation/Cultural Adaptation/Validation
  - German, Dutch, Norwegian, Portuguese (Brazilian)
  - French, Spanish, Polish, Korean

Other Work

- Compare Parent vs Professional Caregiver perspective
- Parent vs Patient perspective (when possible)
- Testing the CPCHILD in other patient populations
  - Traumatic Brain Injury
  - SMA
  - Muscular Dystrophy
  - Spina Bifida
- Association between the QOL of the parent/caregiver and CPCHILD scores?
  - Concurrent administration of SF-36
  - Significant association between caregivers' self reported mental summary scores and their children's CPCHILD scores
How About Jack?

- Less active over the last year: fatigue and knee pain
- Feels excluded: especially during summer
  - Lots of time doing therapy or exercises
  - Would rather be out with friends
  - Friends at sleep over summer camps
  - Twin brother plays hockey and soccer
- Self conscious about using braces at school
- Wants to get rid of knee pain and keep up with friends

GOALS OF TREATMENT: AMBULATORY CP

- After intervention the child walks differently, but does the child walk “better”?
- Defining “better”
  - Body structure & function: Impairments
  - Activities & Participation
- Outcomes meaningful to patients & parents
  - Reduction of Pain
  - Improve Mobility: Walk longer distances
  - More physically active
  - Participation in sports/recreational activity
  - Improve the Appearance of gait
  - Improve fitness & endurance: Less tired
  - Better stability / Less tripping / Fewer falls

Gait Outcomes Assessment List (GOAL)

- Condition specific measure
- Based on patient and parental priorities & goals for gait interventions
- 48 items across 6 Domains
  - ADLs & Independence
  - Gait function & Mobility
  - Comfort & Endurance
  - Sports & Recreation
  - Gait Appearance
  - Body image/Self-esteem
Gait Outcomes Assessment List (GOAL)

**Activities of Daily Living & Independence**

Consider how you usually perform each of the following activities.

1) Rate how easy or difficult each of these activities was for you to perform in the past 2 weeks; AND
2) Choose how much assistance you required to help you perform these activities; AND
3) Select how important a goal improvement in each of the following is for you.

**TOTAL MODERATE**

<table>
<thead>
<tr>
<th>Level</th>
<th>Assistance</th>
<th>Goal</th>
<th>Importance</th>
</tr>
</thead>
<tbody>
<tr>
<td>None at all</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Minimal</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Substantial</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Extensive</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Complete</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
</tbody>
</table>

**Outcomes**

Consider how often you experienced each of these in the past 2 weeks; AND

1) Choose how severe the pain or discomfort was; AND
2) Select how important a goal improvement in each of the following is for you.

**SEVERE MODERATE MILD NONE**

<table>
<thead>
<tr>
<th>Intensity</th>
<th>Goal</th>
<th>Importance</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Mild</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Moderate</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Severe</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

**Pain or Discomfort / Fatigue**

Consider each of the following items.

1) Rate how often you experienced each of these in the past 2 weeks; AND
2) Choose how much assistance you required to help you perform these activities; AND
3) Select how important a goal improvement in each of the following is for you.

**During the past 2 weeks**

<table>
<thead>
<tr>
<th>Frequency</th>
<th>Goal</th>
<th>Importance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Every Day</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Very Often</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Often</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Fairly Often</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>A Few Times</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>None of the Time</td>
<td>5</td>
<td>6</td>
</tr>
</tbody>
</table>

The CPCHILD Team

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Further Information - CPCHILD

- www.sickkids.ca/cpchild
  - Can download questionnaires and manual
  - www.sickkids.ca/Research/CPCHILD-Questionnaire/CPChild-Questionnaire.html

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Thank You