Quality of Life Perspectives in Children with Cerebral Palsy

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Introduction

• Focus is on results of 2 studies.
• Examining QoL perceptions among school-age children with cerebral palsy and their typically developing peers.
• Part of a larger study of social integration of children with disabilities.
Definition of Quality of Life

• WHO 1997 definition:
  – “individuals’ perception 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.”

• NIH PROMIS Steering Committee (2009) opted to retain the WHO QoL framework of physical, mental and social health.
Topics of Interest of the Two Studies

1. The feasibility of utilizing a modified self-generated child-reported quality of life instrument with children, from ages 6-12, with and without cerebral palsy.

2. To generate information about differing perspectives (child-reported vs. parent-proxy reports) and differing domains (predetermined vs. self-generated) on QoL of school-age children with and without cerebral palsy.
Hypotheses of Study One

1. Children, ages 6-12 years, will be able to self-generate QoL domains using a modified Schedule for the Evaluation of Individual Quality of Life-Direct Weight (SEIQoL-DW) procedure;

2. Group difference in SEIQoL-DW Total Index Score will not be statistically significant; and

3. Group differences in frequency, ranking and status of domains will not be statistically significant.
Method: Sample

- \( n = 101 \) school-age children, 6-12 years
- 41 children with cerebral palsy (CP)
- 60 typically developing (TD) children
Method: Sample

*Inclusion/Exclusion Criteria for all children*

- IQ 70 or greater
- Functional oral communication skills
- Public or Private schooling
- Absence of current psychiatric diagnosis
- Absence of any recent medication changes that could affect cognition
Method: Sample

*Inclusion/Exclusion Criteria for children with CP*

- Only a history of congenital CP with no history of post-neonatal acquired brain injury (i.e., traumatic brain injury, stroke, encephalitis, or injury secondary to status epilepticus)
Method: Sample

Inclusion/Exclusion Criteria for TD children

- No history of cognitive, functional, or physical impairments, no special education certification, and no diagnosis of CP.
Method: Sample

<table>
<thead>
<tr>
<th></th>
<th><strong>Cerebral Palsy</strong> (CP)</th>
<th><strong>Typically Developing</strong> (TD)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>n</strong></td>
<td>41</td>
<td>60</td>
</tr>
<tr>
<td><strong>Age (years)</strong></td>
<td>8.8 (1.8)</td>
<td>8.9 (1.7)</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>27</td>
<td>30</td>
</tr>
<tr>
<td>Female</td>
<td>14</td>
<td>30</td>
</tr>
<tr>
<td><strong>Seizure History</strong></td>
<td>27% positive**</td>
<td>0% positive**</td>
</tr>
<tr>
<td><strong>Birth weight (grams)</strong></td>
<td>2113.72 (1097.68)**</td>
<td>3468.56 (513.0)</td>
</tr>
<tr>
<td><strong>Gestation (weeks)</strong></td>
<td>30.6 (6.4)**</td>
<td>37.7 (1.1) **</td>
</tr>
</tbody>
</table>

GMFCS levels as follows: Level 1 (5), Level II (1), Level III (17), Level IV (5), Level V (1) and 12 children classified as having no restrictions and no limitations.
Instrument: SEI-QoL-DW modified

- Semi-structured interview QoL instrument by which individuals identify domains or importance.

- Three Stages
  - **Stage 1** – nominate 5 domains of importance
  - **Stage 2** – Rate the domains
  - **Stage 3** – Rank the domains
Results of Study One

• 11 quality of life domains were self-identified:
  – Family
  – Friends
  – Pets
  – Hobbies
  – Physical Play
  – Physical Health/Physical Needs
  – School/Education
  – Religion
  – Electronics/Entertainment
  – Travel
  – Other
Five Most Frequently Generated Domains

<table>
<thead>
<tr>
<th>Category</th>
<th>CP</th>
<th>TD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family</td>
<td>0.8</td>
<td>0.9</td>
</tr>
<tr>
<td>Physical Play</td>
<td>0.9</td>
<td>0.8</td>
</tr>
<tr>
<td>Friends</td>
<td>0.7</td>
<td>0.8</td>
</tr>
<tr>
<td>Electronics</td>
<td>0.6</td>
<td>0.7</td>
</tr>
<tr>
<td>Hobbies</td>
<td>0.5</td>
<td>0.6</td>
</tr>
</tbody>
</table>
Statistically Significant Difference in SEIQoL Frequency Domains
For Physical Health/Physical Needs Domain
• Group difference in SEIQoL-DW Total Index was not significantly different and there were no statistically significant group differences in satisfaction ratings.

• There were no statistically significant associations between GMFCS and the SEIQoL-DW in the CP group.
Study Two “Differing Perspectives”

Questions

1. What are the associations between predetermined and self-generated QoL domains in school-age children with CP and their typically developing (TD) peers?

2. What is the concordance between child-rated QoL and parent ratings of the child’s HRQoL in children with and without CP?
Study Two: Instruments & Method

- Kinder Lebensqualitätsfragebogen (KINDL) (Ravens-Sieberer & Bullinger, 1998),
- Child Health Questionnaire (CHQ) (Landgraf, Abetz, & Ware, 1996), and
- SEIQoL-DW modified.
RESULTS
Means & SD for SEIQoL, KINDL, CHQ

*CP
**TD
*p < .05  **p < .01
Statistically Significant Means & SD for KINDL Psychological Scale – Individual Items

*CP

**TD

*p<.05  **p<.01
Statistically Significant Means & SD for KINDL Physical Scale – Individual Items

*p<.05  **p<.01
Pearson Bivariate Correlations
Child Self-generated, Self-reports with Child Predetermined, Self-reports

<table>
<thead>
<tr>
<th>TD</th>
<th>CP</th>
</tr>
</thead>
<tbody>
<tr>
<td>KINDL Total</td>
<td>KINDL Total</td>
</tr>
<tr>
<td>KINDL Physical</td>
<td>KINDL Physical</td>
</tr>
<tr>
<td>KINDL Psychological</td>
<td>KINDL Psychological</td>
</tr>
<tr>
<td>KINDL Functional</td>
<td>KINDL Functional</td>
</tr>
<tr>
<td>KINDL Social</td>
<td>KINDL Social</td>
</tr>
</tbody>
</table>

SEIQoL Total Score

* p<.05  **p<.01
Pearson Bivariate Correlations

*Parent-Proxy Predetermined with Child, Predetermined and Child, Self-generated*

- KINDL Total
- CHQ Physical
- CHQ Psychosocial
- KINDL Functional
- KINDL Social
- KINDL Psychological
- KINDL Physical
- SEIQoL Total

* * p<.05   ** p<.01
• Which raises the interesting possibility that parents of children with cerebral palsy may not be aware of the extent to which these children experience non-observable feelings of stress.
• And, it leads to the possibility that these psychological symptoms may be erroneously identified as symptoms ascribed to the condition of cerebral palsy which may be termed “neurodevelopmental diagnostic over-shadowing” or an example of “hidden morbidity” as described by Varni, Burwinkel and others in 2005.
Conclusion

• Children, ages 6-12 years, can self-generate dimensions of importance to their quality of life based on experience and developmental stage.

• Children with the unique health condition of cerebral palsy self-generate a list physical and social dimensions of importance that are not radical differences from their typically developing peers.
Conclusion

• Both children and parent perspectives and expectations should be assessed as complementary views rather than opposing or confirmatory views.
Conclusion

• Broader assessment of children with cerebral palsy may need to be considered beyond the motor and physical functional abilities to include the less obvious psychological and emotional comorbidities that impact a child’s quality of life.