Parent-child discrepancy on reports of quality of life and physical function in youth with spinal cord injury

Prepared by: Kathy Zebracki, Ph.D., Ashley Moss, B.A., Erin Kelly, Ph.D., Heather Russell, Ph.D., M.J. Mulcahey, Ph.D., and the Pediatric Committee of the American Spinal Injury Association

Date: July/ August 2012

CLINICAL SCENARIO: A spinal cord injury (SCI) and its management may place a substantial burden on the youth and family’s daily activities, physical functioning, and overall well-being. Moreover, youth are at an increased risk for experiencing emotional distress (e.g., anxiety, depressive symptoms), restricted participation in activities, and school absenteeism. These areas of functioning reflect components of multidimensional construct of health-related quality of life (HRQOL). Assessment of HRQOL is an essential aspect of clinical care, both to understand the impact of the SCI on the youth as well as to identify areas of difficulty that may be addressed through medical or psychosocial intervention. When possible, youth self-report of perceived physical functioning and HRQOL is preferred; however, in cases when youth are unable to report their perceptions due to factors such as developmental level, verbal limitations, and cognitive functioning, parent-report is relied upon as a proxy.

FOCUSED CLINICAL QUESTION: How does parent report compare to child report when assessing outcomes of physical functioning and quality of life in children and adolescents with a SCI?

CLINICAL BOTTOM LINE: There is a lack of empirical data showing that parental reports of their child’s perceived physical functioning and HRQOL are an accurate assessment.

SUMMARY of Search, ‘Best’ Evidence’ appraised, and Key Findings: 2 articles met inclusion criteria and helped answer clinical question best:


- Agreement on HRQOL between youth and parents is moderate at best; youth consistently rated their HRQOL as better than their parents.


- Children rated their HRQOL better than parents did for physical, social, emotional and school functioning; however, only differences between reporters for physical and social functioning were statistically significant.
- Intraclass correlation coefficients revealed excellent agreement on emotional functioning and good agreement for physical, social, and school functioning.

Limitation of this CAT: This critically appraised topic has not been peer-reviewed another independent person/ scientist.

SEARCH STRATEGY:

Terms used to guide Search Strategy:
- Patient/Client Group: Youth with spinal cord injury, ages birth to 18
• Intervention (or Assessment): Parent and self-report of HRQOL and physical function
• Comparison: Parent versus youth self-report on HRQOL and physical function
• Outcome(s): To assess parent and youth agreement on youth's HRQOL and physical function

<table>
<thead>
<tr>
<th>Databases and sites searched</th>
<th>Search Terms</th>
<th>Limits used</th>
</tr>
</thead>
<tbody>
<tr>
<td>• PubMed/</td>
<td>• Spinal cord injury</td>
<td>• English language</td>
</tr>
<tr>
<td>• Medline</td>
<td>• Quality of life</td>
<td>• Peer-reviewed</td>
</tr>
<tr>
<td>• PsychInfo</td>
<td>• Physical function/ functioning</td>
<td>• Ages 0-18 years</td>
</tr>
<tr>
<td>• Cinahl</td>
<td>• Child</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Adolescent</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Pediatric</td>
<td></td>
</tr>
</tbody>
</table>

INCLUSION and EXCLUSION CRITERIA

• Inclusion: Peer-reviewed papers on youth ages 0-18 years with a spinal cord injury assessing HRQOL and/or physical functioning from both youth and parent reports
• Exclusion: Non-English language papers, studies that did not have both youth and parent reports, non-peer reviewed publications, abstracts, and theses/ dissertations

BEST EVIDENCE
The following papers were identified as the ‘best’ evidence and selected for critical appraisal. 
Reasons for selecting these studies were: These two papers represent the only peer-reviewed studies, to date, examining parent-child discrepancies in reporting of HRQOL and physical functioning.

SUMMARY OF BEST EVIDENCE

**Health related quality of life after pediatric spinal cord injury.** (Garma et al., 2011)

**Objective:** To describe health-related quality of life (HRQOL) among youth with spinal cord injury (SCI), examine agreement between child and caregiver report HRQOL, investigate relationships between HRQOL and demographic, injury and psychological variables.

**Methods:** Caregivers and youth with SCI completed a pediatric HRQOL measure and mental health measures; injury information was gathered from medical records.

**Results:** One hundred and ninety-seven youth with SCI and their caregivers participated. HRQOL was associated with current age, age at injury, level of injury and child and caregiver anxiety/depression. Child mental health significantly predicted child-report HRQOL ($p < .001, f^2 = 1.07$), whereas child ($p < .001, f^2 = 0.098$) and caregiver ($p < .001, f^2 = 0.277$) mental health both significantly predicted caregiver-report HRQOL. Agreement between child-report and caregiver-report was moderate at best, with youth rating their HRQOL as better than their caregivers.

**Conclusion:** Mental health of youth and caregivers is critical to HRQOL in pediatric SCI. Interventions to optimize psychological adjustment should be provided to both caregivers and youth.

**Quality of life in children with spinal cord injury.** (Oladeji et al., 2007)

**Purpose:** To compare reports of the child’s quality of life (QOL) between children with spinal cord injury (SCI) and their parents using the Pediatric Quality of Life 4.0 Generic Scales (PedsQL), and assess agreement between parent and child responses. To examine the influence of level of injury on QOL and internal consistency reliability of the PedsQL in pediatric SCI.

**Methods:** Twenty-eight children (17 male children and 11 female children) between five and 13 years and their parents completed the PedsQL.
Results: Children rated their QOL better than their parents; however, there was good to excellent parent-child agreement. No differences were noted between children with tetraplegia and paraplegia. Low internal consistency reliability was obtained for various domains.

Conclusions: In addition to using summary scores, specific ratings may raise important points for clinical decision-making. Results on internal consistency reliability suggest the need for condition-specific questionnaires for children with SCI.

IMPLICATIONS FOR PRACTICE, EDUCATION and FUTURE RESEARCH

Practice:
- It is important to consider both parent and youth reports on HRQOL and physical functioning; differences observed may be clinically relevant and a target for intervention

Education:
- Clinicians and researchers should aim to obtain youth self-report on HRQOL and physical functioning. When this is not possible, due to factors such as developmental level or cognitive functioning, it is important to recognize that parental perspectives while important may not be a true representation of the youth’s perspective.

Research:
- Researchers should aim to obtain information from several reporters (e.g., youth, parent, and teachers) regarding constructs such as HRQOL and perceived physical functioning. Discrepancies among reporters should be examined as they may be a source of conflict and/or a target for intervention.