Parent-child discrepancy on reports of health-related quality of life in youth with spinal cord injury

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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, some youth may face 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 the multidimensional construct of health-related quality of life (HRQOL). HRQOL describes an individual’s perception of the impact a medical condition has on his/her physical, psychological, and social well-being. 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 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 self-report when assessing HRQOL 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 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.
- Parent reports of their child’s HRQOL were better predicted by parent mental health than child mental health.

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Limitation of this CAT: This critically appraised topic has not been peer-reviewed by another independent person/ scientist.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

• **Comparison:** Parent versus youth self-report on HRQOL

• **Outcome(s):** To assess parent and youth agreement on youth’s HRQOL

### Search Methodology

**Databases and sites searched**

- PubMed/
- Medline
- PsychInfo
- Cinahl

**Search Terms**

- Spinal cord injury
- Quality of life
- Child
- Adolescent
- Pediatric

**Limits used**

- English language
- Peer-reviewed
- Ages 0-18 years

### INCLUSION and EXCLUSION CRITERIA

- **Inclusion:** Peer-reviewed papers on youth ages 0-18 years with a spinal cord injury assessing HRQOL from both youth and parent perspectives

- **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.

### 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, and 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 as 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 self-report on HRQOL in family centered care. Differences observed may be clinically relevant and target for intervention.
- In general, parents’ perception of their child’s HRQOL is lower than the youth’s self-report. Moreover, parental report of the child’s HRQOL is more strongly related to the parent’s emotional functioning than to the child’s, which illustrates a further area for support and intervention.

Education:
- Clinicians and researchers should aim to obtain both parent and youth self-report on HRQOL. When youth self-report 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. Discrepancies among reporters should be examined as they may be a source of conflict and/or a target for intervention.