Subjective Quality of Life for Youth with Spina Bifida

Presented by Karen Lowry (Study Collaborator) for Janette McDougall and Virginia Wright (Study Investigators)
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Subjective Quality of Life for Youth with Spina Bifida

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• Does not intend to discuss commercial products or services.

• Does not intend to discuss non-FDA approved uses of products/providers of services.
Background

• This analysis is part of a larger study examining quality of life for youth with various chronic health conditions (McDougall et al., 2016)

• Funded by: **Canadian Institutes of Health Research**

• **Across 8 children’s treatment centres in Ontario, Canada** (London, Toronto, Ottawa, Sudbury, Chatham-Kent, Windsor, Kingston, Simcoe York)
Introduction

• Research into quality of life (QOL) for persons with spina bifida has focused mainly on **health-related QOL** (HRQOL), including health in **physical, mental, and social domains** (Barf et al., 2007, Barf et al., 2010)

• **Few studies** have examined **life satisfaction** or **overall subjective QOL** (SQOL) for individuals with SB, especially children and youth with SB (Barf et al., 2010, Sawin et al., 2002)

• Research indicates **cognitive functioning** is associated with SQOL for young adults with SB and hydrocephalus (Barf et al., 2010)
  • No known studies have examined the relationship between cognitive functioning and SQOL for **children and youth** with SB
Objectives

• This research explored the SQOL of youth with SB by:
  • comparing SQOL mean scores of youth with SB to scores of youth with other chronic conditions;
  • comparing youth SQOL mean scores as reported by youth themselves to those reported by one of their parents;
  • looking at cognitive as well as physical functioning as factors related to youths’ SQOL, controlling for youth age, gender, and household income
Study Participants

• 36 youth with SB (presence of hydrocephalus not known)

• Between 11-17 years of age (14 on average)

• 25 (69%) female

• Parent participants primarily birth mothers (92%)
Study Methods

• Questionnaires were administered to youth and their primary caregiver shortly after admission to the study.

• Each youth took part in a face-to-face interview (30-60 minutes).

• The parent questionnaire (30-60 minutes) was self-completed at the same time and place as the youth interview, but in a separate room.
Measures

• **Outcome (Subjective Quality of Life)**
  • Student Life Satisfaction Scale (SLSS) - Abbreviated Version (Huebner, 1991)
    • Parent report and youth self-report - domain-free overall life assessment
    • 5 items using 6-point rating scale from 1 = strongly disagree to 6 = strongly agree
      • My life is going well (My child’s life is going well)
      • My life is just right
      • I have a good life
      • I have what I want in life
      • My life is better than most kids
Measures

- **Functioning**
  - Child and Adolescent Factors Inventory (Bedell, 2004)
    - Parent report
  - **Cognitive Impairment** - 4 items using 3-point rating scale from 1 = little problem to 3 = big problem
    - Paying attention or concentrating
    - Remembering people, places, directions
    - Problem solving or judgment
    - Understanding or learning a new thing
Measures

• **Functioning**
  • Child and Adolescent Factors Inventory (Bedell, 2004)
    • Parent report
  • **Physical Impairment** - 2 items using 3-point rating scale from 1 = little problem to 3 = big problem
    • Movement (balance, coordination, muscle tone)
    • Strength or energy level (e.g., weakness or fatigue)
Analyses

• Analysis of variance examined mean differences in SQOL scores among youth with different conditions

• A *t*-test assessed mean differences in youth and parent scores for youth SQOL

• Multivariate linear regression identified correlates of youth SQOL


Findings

<table>
<thead>
<tr>
<th>Condition</th>
<th>N</th>
<th>M</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spina Bifida</td>
<td>36</td>
<td>24.75</td>
<td>4.55</td>
</tr>
<tr>
<td>Acquired Brain Injury</td>
<td>59</td>
<td>24.66</td>
<td>4.73</td>
</tr>
<tr>
<td>Communication Disorder</td>
<td>40</td>
<td>25.97</td>
<td>4.07</td>
</tr>
<tr>
<td>Autism Spectrum Disorder</td>
<td>36</td>
<td>24.80</td>
<td>4.71</td>
</tr>
<tr>
<td>Cerebral Palsy</td>
<td>151</td>
<td>25.41</td>
<td>4.63</td>
</tr>
<tr>
<td>Developmental Delay</td>
<td>28</td>
<td>26.71</td>
<td>2.67</td>
</tr>
<tr>
<td>Amputation</td>
<td>18</td>
<td>27.06</td>
<td>2.21</td>
</tr>
<tr>
<td>Other</td>
<td>64</td>
<td>24.84</td>
<td>4.87</td>
</tr>
</tbody>
</table>

\[ F = 1.35, p = 0.22 \text{ (n.s.)} \] 432 | 25.32 | 4.48

QOL by Condition
Findings

- Quality of Life Scores - SLSS

<table>
<thead>
<tr>
<th>Participant</th>
<th>M</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Youth</td>
<td>24.59</td>
<td>4.62</td>
</tr>
<tr>
<td></td>
<td>(out of 30 points)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(4.9/6, Moderately agree)</td>
<td></td>
</tr>
<tr>
<td>Parent/Primary Caregiver</td>
<td>21.94</td>
<td>4.67</td>
</tr>
<tr>
<td></td>
<td>(4.3/6, Mildly to moderately agree)</td>
<td></td>
</tr>
</tbody>
</table>

$t = 2.97, p < 0.01$
## Findings

Factors Related to SQOL

<table>
<thead>
<tr>
<th>Factor</th>
<th>B</th>
<th>t</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cognitive Impairment</td>
<td>-0.61</td>
<td>-3.36**</td>
</tr>
<tr>
<td>Physical Impairment</td>
<td>0.30</td>
<td>1.70</td>
</tr>
<tr>
<td>Gender</td>
<td>0.32</td>
<td>1.91</td>
</tr>
<tr>
<td>Age</td>
<td>0.06</td>
<td>0.34</td>
</tr>
<tr>
<td>Household Income</td>
<td>-0.02</td>
<td>-0.10</td>
</tr>
</tbody>
</table>

*p < 0.05; **p < 0.01

F=2.84; p < 0.05
Implications

• Given that, on average, youth with SB ‘moderately agree’ their life is going well, and 31% score below that average, it would be beneficial to routinely assess SQOL to identify youth at risk for low SQOL.

• It is essential to assess youth perspectives of their SQOL, but also useful to assess parent perspectives of youth SQOL, as each offers unique insights.

• Greater cognitive impairment was associated with lower QOL.
  • This finding requires further study with larger samples that inquire about presence of hydrocephalus, but indicates that it would be worthwhile to assess cognitive functioning of youth with SB in addition to medical status and physical functioning as part of care and outcome research.
Questions/Comments?

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To access QOL Study webpage:
http://www.tvcc.on.ca/qol.htm
References


