Lower Urinary Tract Reconstruction in Spina Bifida: Does it improve Health Related Quality of Life?

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Objective

• To determine whether lower urinary tract reconstruction in meningomyelocele (MM) patients improves health related quality of life (HRQoL)

• Definition of HRQoL: “...functional effect of an illness and its consequent therapy upon a patient, as perceived by the patient.”
Introduction

• Well established surgical approaches to incontinent MM patient
• High reported success rates (~90%)
• Established complication and revision rates

Introduction

• Reconstruction is a major undertaking
• Requirements:
  – Specialized surgical expertise
  – Significant operative times
  – Prolonged hospitalization
  – Motivated and compliant patient/family
  – Long term follow up
Introduction

• Reconstruction is predicated on assumption that quality of life is improved
• Scant data to support this assumption

Methods

Literature Review

• Medline search: 1966 to present
• Publications related to QOL and surgery for urologic diseases in pediatric urology
• 184 citations retrieved
Methods

Literature Review

- 139 (76%) no quantitative HRQoL measure
- 10 (5%) non-validated HRQoL measure
- 4 (2%) applied validated HRQoL measure

Methods

Literature Review

- 2 authors: validated measure in CRF
- 1 author: generic HRQoL survey to assess a small group of MM patients
- 1 author: assessed HRQoL in a small group of cloacal extrophy patients using a pediatric specific measure
Literature Review: The Bottom Line

- Good evidence that major lower urinary tract reconstruction improves QOL in MM patients lacking

Methods

- ERB approval
- Retrospective cohort design
- Mail out, mail back survey
Methods: Study Group

• 36 consecutive MM patients undergoing lower urinary tract reconstruction
• Mean follow-up: ~ 30 months
• Indications for surgery:
  – Incontinence
  – Upper tract deterioration failing conservative management

Methods: Study Group

• Procedure:
  – Intestinal cystoplasty (100%)
  – Mitrofanoff (89%)
  – Bladder neck surgery (53%)
  – Continent cecostomy (33%)

- Burch (15)
- Sling (3)
- Closure (1)
Methods: Controls

- Controls recruited from MM clinic database
- Matched 2:1 with study group patients
- Matched for:
  - Age
  - Level of lesion
  - Shunt status
  - Ambulatory status
  - Parental marital status

Sample Size Justification

- Powered to detect 15% difference in mean HRQoL
  (80% power, 5% two-tailed significance level)
Survey Instrument: HRQoL

• Age and MM disease specific discriminative measure of HRQoL
• One for children 5-12 yrs old, one for adolescents 13-20 yrs olds
• Previously validated for use by parents (child version, 5-12 yrs old) and patients (adolescent version, 13-20 yrs old)


Survey Instrument: HRQoL

• 44+ item questionnaire

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<th>Quality of life domains</th>
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Continence Assessment

• 13 item self-assessment scale (5 point Likert)
• Nurse interview
• Chart review
• Acceptable urinary continence: no diapers/pads for ≥ 3 hrs between CIC

Results

• Response rates (overall 89%)
  – Child study: 12/12 (100%)
  – Adolescent study: 20/24 (83%)
  – Child control: 19/22 (86%)
  – Adolescent control: 33/40 (83%)
Results

78% of reconstructed cases dry > 3 hours between CIC

No sig case:control difference in self-reported continence scores

<table>
<thead>
<tr>
<th>Series</th>
<th>Child (age 5-12 yrs)</th>
<th>Adolescent (age 13-20 yrs)</th>
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<td>mean HRQOL score (range)</td>
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<td>Parkin et al</td>
<td>168 +/- 24 (100-213) n=152</td>
<td>182 +/- 30 (98-225) n=89</td>
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<tr>
<td>Current cases</td>
<td>165 +/- 23 (122-200) n=12</td>
<td>190 +/- 23 (152-233) n=20</td>
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<td>Current controls</td>
<td>162 +/- 27 (104-198) n=19</td>
<td>192 +/- 26 (132-222) n=33</td>
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Conclusion

- Reconstructed cases have same HRQOL as controls
Discussion

Possible Interpretations

• Surgery does not improve HRQoL at all
• Surgery improves HRQoL up to that of controls
• Surgery only improves HRQoL in a subset
• Surgery only improves caregiver HRQoL
• Surgery only improves surgeon HRQoL

Discussion

• Impact of pediatric urological surgery on HRQoL warrants further study
• Disease specific measures of HRQoL need to be developed to assess interventions for other common Pediatric urologic conditions