



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

J Morrell, S Secord, AE MacNeily

Division of Pediatric Urology

University of British Columbia

Vancouver BC Canada

Objective

- To determine whether lower urinary tract reconstruction in meningocele (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 exstrophy 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

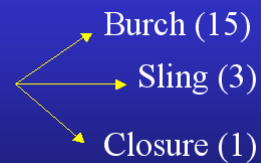
- ERB approval
- Retrospective cohort design
- Mail out, mail back survey

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%)



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)

Parkin et al: Quality of life Research: Vol 6 1997 123-132

Survey Instrument: HRQoL

- 44+ item questionnaire

Quality of life domains
Social
Emotional
Intellectual
Financial
Medical
Independence
Environmental
Physical
Recreational
Vocational

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

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

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