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%)
- Acceptable complication and revision rates

Introduction

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

Introduction

- Some require reconstruction for medical indications:
  - Upper tract deterioration
  - Skin breakdown
  - Improved institutional care
- In many reconstruction is predicated on assumption that quality of life is improved
- Scant data to support this assumption

Literature Review

- Medline search: 1966 to present
- Searched for papers relating to quality of life and surgery for urologic diseases in pediatric urology
- 184 citations retrieved

Literature Review

- 139 (76%) did not apply a quantitative measure for quality of life
- 10 (5%) applied a non-validated quality of life measure
- 4 (2%) applied a validated HRQoL measure

Literature Review

- 2 authors applied a validated measure in a survey of children with renal failure
- 1 author used a 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

- Evidence supporting using lower urinary tract reconstruction to improve quality of life in MM patients does not exist

Methods

- Ethics approved retrospective cohort design
- Mail out, mail back survey

Methods: Study Group

- 36 consecutive MM patients who underwent lower urinary tract reconstruction
- Procedure:
  - Intestinal cystoplasty (100%)
  - Mitrofanoff (89%)
  - Bladder neck surgery (53%)
    - Burch (15)
    - Sling (3)
    - Closure (1)
  - Continent cecostomy (33%)

Methods: Controls

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

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)
  - Questions tailored depending on previous GI/GU surgeries
- Nurse interview
- Chart review
- Acceptable urinary continence defined as no need for diapers/pads for ≥ 3 hrs

	Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(1) With regard to your bladder function, you are always dry.	1	2	3	4	5
(2) With regard to your bowel function, you are always clean between bowel movements.	1	2	3	4	5
(3) You do not have bladder accidents, therefore pull ups or attends are not necessary.	1	2	3	4	5
(4) You do not have bowel accidents, therefore pull ups or attends are not necessary.	1	2	3	4	5
(5) The mitrofanoff has significantly improved your hygiene and social confidence.	1	2	3	4	5
(6) The mitrofanoff has improved your level of independence.	1	2	3	4	5
(7) Your mitroffanof is significantly better than previous medical management.	1	2	3	4	5
(8) Overall, you are satisfied with your mitrofanoff.	1	2	3	4	5
(9) You would recommend the mitrofanoff procedure to other patients.	1	2	3	4	5
(10) The cecostomy has significantly improved your hygiene and social confidence.	1	2	3	4	5
(11) Your cecostomy is significantly better than previous medical management.	1	2	3	4	5
(12) Overall, you are satisfied with your cecostomy.	1	2	3	4	5
(13) You would recommend the cecostomy procedure to other patients.	1	2	3	4	5

Sample Size Justification

- Sample size calculations were done for both versions
- Sizes required to detect 15% difference in mean HRQoL (at 80% power, 5% two-tailed significance level):
- Child version – 12 cases, 24 controls
- Adolescent version – 20 cases, 40 controls

Results

- Response rates (overall 86%)
  - Child study: 12/12 (100%)
  - Adolescent study: 20/24 (83%)
  - Child control: 19/22 (86%)
  - Adolescent control: 33/40 (83%)
- Age, parental marital status, ambulatory status, lesion level, and shunt status all perfectly matched

Results

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

78% of reconstructed cases dry $\geq$ 3 hours between CIC

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

Conclusion

- Reconstructed cases have same HRQOL as controls

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
- Other disease specific measures of HRQoL need to be developed to assess interventions for other common urologic conditions