Assessing Health Related Benefit after Reconstruction for Urinary and Fecal Incontinence in Children: A Parental Perspective

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Purpose: We sought to evaluate health related benefit in children undergoing surgical reconstruction for urinary and fecal incontinence from a parental perspective.

Materials and Methods: A health related benefit instrument was mailed to the parents or guardians of 300 consecutive patients who had undergone reconstruction for urinary and/or fecal incontinence at our institution between 1997 and 2011. We assessed parent reported health related benefit using the validated Glasgow Children's Benefit Inventory and satisfaction with 6 supplemental questions. One-sample t-tests as well as exploratory univariate and multivariate linear regressions were performed for statistical analysis.

Results: Response rate was 40.0% at a mean of 5.5 years (range 0.6 to 13.8) after reconstruction. Spina bifida was the most common primary diagnosis (48 patients, 56.5%). Mean total Glasgow Children's Benefit Inventory score and subscores for each domain were positive, indicating an improved health related benefit after reconstruction (all $p < 0.0001$). Certain patients, possibly based on diagnosis and gender, may particularly benefit from reconstruction ($p \leq 0.04$). Parents believed that the bladder augmentation and/or urinary continent catheterizable channel most changed the life of their child but that achievement of stool continence was most important to themselves. Only 17 families (16.2%) required more than 1 month to become comfortable with catheterizations, and 69 patients (68.8%) required less care or no assistance with daily activities after reconstruction. Only 2 parents (1.9%) would be unwilling to consent to the procedure again.

Conclusions: We observed moderate parental satisfaction and parent reported improvement in health related quality of life for children undergoing surgical reconstruction for urinary and fecal incontinence.

Key Words: child, fecal incontinence, quality of life, spinal dysraphism, urinary incontinence

Abbreviations and Acronyms

GCBI = Glasgow Children's Benefit Inventory

HRB = health related benefit

HRQOL = health related quality of life

MACE = Malone antegrade continence enema

SB = spina bifida

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Study received institutional review board approval.

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Children with neurological diseases and congenital anomalies of the lower urinary tract often suffer from dysfunction of the lower urinary tract and/or bowel. The primary goal in managing these cases is prevention of urinary tract deterioration through an early functional evaluation, and aggressive institution of conservative measures such as clean intermittent catheterization and anticholinergic therapy. Urinary and fecal continence

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has also become an increasingly important goal with the improved survival of these children.

Some children fail a conservative approach and require surgical reconstruction for preservation of renal function and achievement of continence. It is often assumed that they experience health related benefit after reconstruction, including an improved health related quality of life. As defined by the World Health Organization, quality of life encompasses a subjective sense of well-being and perception of position in life in the context of individual culture and values, and in relation to goals, expectations, standards and concerns.[1] Those aspects related to disease and its treatment represent a construct called health related quality of life.[2]

Assessing HRQOL is essential for understanding the impact of chronic debilitating diseases, and improving counseling of children and their families before any intervention. Several series have investigated HRQOL in children undergoing surgical reconstruction for urinary and fecal incontinence, with equivocal results.[3–7] Other studies in children undergoing only MACE have been more promising and have revealed consistent improvement in HRQOL after reconstruction.[8–13]

We assessed HRB in children undergoing surgical reconstruction for urinary and fecal incontinence from a parental perspective, using the validated GCBI. Based on our experience, we hypothesized that parents would be highly satisfied and have a perceived improvement in HRQOL for their children.

MATERIALS AND METHODS

Study Cohort

After receiving approval from the institutional review board at Indiana University School of Medicine we performed a cross-sectional study on a consecutive series of 300 patients who had undergone reconstruction for urinary and/or fecal incontinence at our institution between 1997 and 2011. Patients were identified from an institutional database for inclusion in the study. Those with less than 6 months of elapsed time after reconstruction were excluded to ensure that their responses were not affected by the immediate postoperative course. Reconstruction for urinary and/or fecal incontinence was defined as any combination of bladder augmentation, urinary continent catheterizable channel and MACE. A letter explaining our study, consent form and HRB instrument were mailed to the families of these patients (supplementary Appendix, http://jurology.com/). The consent form and instrument were completed by the parents or guardians and returned in a preaddressed, postage paid envelope. Informed consent was required before becoming eligible for the study. Only completed instruments were included in the analysis.

Assessment of HRB

We evaluated HRB using the GCBI, a validated instrument for assessing a health related benefit after an intervention in children.[14] This instrument is generic and has been used after a wide variety of interventions, including pediatric urological procedures.[15,16] The GCBI is designed to be completed by a parent for a child of any age. The survey consists of 24 questions addressing the consequences of a specific intervention on various aspects of life. It encompasses 4 domains, ie emotion, physical health, learning and vitality. Each response is ranked on a 5-point Likert rating scale, with the central point being "no change" and the extremes being "much better" and "much worse." A total score is calculated by assigning a numerical value from -2 (much worse) to +2 (much better) for each response, adding all responses, dividing by the number of questions and multiplying by 50 to produce a score on a rating scale from -100 (maximum harm) to +100 (maximum benefit). The subscores for each domain are calculated in a similar fashion.[14]

We also included 6 supplemental questions in the instrument. These questions were designed to evaluate the relative importance of urinary and stool continence, willingness to consent to the procedure again as an indicator of decisional regret, comfort with catheterization and level of independence.

Statistical Analysis

Descriptive statistics were calculated for each response, as well as the total GCBI score and subscores for each domain. Mean total score and subscores were compared to a score of 0 (no change) and 50 (a little better) using a 1-sample t-test. Exploratory univariate and multivariate linear regression analyses were subsequently performed to identify any variables associated with the mean total GCBI score and subscores for each domain. Variables included gender, age at reconstruction (younger than 7 vs 7 years or older, based on mean age), elapsed time after reconstruction (less than 5 vs 5 or more years, based on mean elapsed time) and primary diagnosis of SB. A critical p value was defined as less than 0.05. All statistical analysis was performed using Stata®, version 10.1.

RESULTS

Of the 300 consecutive patients invited to participate the parents of 120 (40.0%) returned the instrument. A total of 13 patients were excluded due to incomplete responses and 2 were excluded due to insufficient elapsed time after reconstruction, resulting in 105 patients participating in the study (35%). Demographic information was unavailable in 20 patients (19.0%) due to their desire to remain anonymous and was not collected in patients who did not respond to the instrument. Mean age in the remaining patients was 7.3 years (range 1.9 to 19.9) at reconstruction and 13.0 years (4.0 to 21.3) at completion of the instrument. A total of 45 patients (53.0%) were male and SB was the most common primary diagnosis (table 1). Various combinations of procedures were indicated for the treatment of urinary and/or fecal incontinence (table 2). A combination of bladder augmentation, urinary continent