Health Related Quality of Life in Patients with Bladder Exstrophy: A Call for Targeted Interventions

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Purpose: Research on health related quality of life in patients with bladder exstrophy has demonstrated mixed results compared to population samples. Few studies have had a comparison group with a urological disorder and none correlated body image to health related quality of life. We compared health related quality of life in patients with bladder exstrophy to that in patients with kidney stones and correlated body image to health related quality of life in the bladder exstrophy population.

Materials and Methods: Participants included 24 patients with kidney stones and 24 with bladder exstrophy. Patient age was 8 to 25 years. Participants completed the PedsQL (Pediatric Quality of Life Inventory) and the 25-item multiple choice UBIQ (Urological Body Image Questionnaire), which was created for the current study.

Results: Compared to patients with kidney stones those with bladder exstrophy indicated significantly higher scores on physical functioning ($p = 0.0005$) and overall health related quality of life ($p = 0.02$) in the 8 to 17-year-old cohort. When health related quality of life was compared to body image in patients with bladder exstrophy, lower social scores were associated with those who worried about friends finding out about the condition ($p = 0.01$) and about having romantic relationships ($p = 0.003$). Lower social ($p = 0.006$) and emotional ($p = 0.009$) functioning scores were associated with patients who thought that they were less likely to have romantic relationships.

Conclusions: The finding that patients with bladder exstrophy had a better physical functioning score than those with kidney stones is not surprising, given the morbidity of active stone disease. The negative correlations with body image in the bladder exstrophy population may be due to the possibility of others discovering the condition and the perceived likelihood of not having romantic relationships.

Key Words: bladder exstrophy, nephrolithiasis, quality of life, body image, questionnaires

Abbreviations and Acronyms

BE = bladder exstrophy
BI = body image
HRQOL = health related QOL
KS = kidney stones
QOL = quality of life

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BLADDER exstrophy is a rare, complex congenital anomaly characterized by failure of lower abdominal wall closure, bladder eversion and exposure, an epispadiac urethra and pelvic bone widening.[1] Despite advances in medicine studies of HRQOL in patients with other chronic medical conditions have shown decreased HRQOL compared to healthy individuals.[2,3] However, studies of HRQOL in patients with BE have

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demonstrated mixed results compared to normative populations.

In a survey of adults with BE Wittmeyer et al found that those with BE had a significantly lower QOL score on the SF-36® health and physical functioning domains compared to normative population scores.[4] In contrast, Schaeffer et al found no significant difference in HRQOL when comparing a population of adolescents with BE to 2 generic population samples.[5] To our knowledge no study has compared BE to another urological condition. Medical conditions affecting the urological system may be more stigmatizing than nonurological conditions. Specifically, the stigma associated with urinary incontinence and frequency is well established in the literature.[6,7] By comparing 2 urological conditions we sought to determine whether impaired HRQOL is a product of a urological condition in general or whether it is specific to a certain disorder.

Our first aim was to compare HRQOL in individuals with BE to those with KS. Patients with KS were chosen as the comparison group since they share the diagnosis of a urological condition and yet do not have the abdominal and genital scarring or incontinence that may be associated with BE. When comparing them to the general population, Bensalah et al found lower HRQOL scores in adults with KS in 5 SF-36 domains.[8] In line with these findings, due to the acute nature of KS and associated pain we expected patients with KS to have lower physical but similar or better emotional and social functioning scores than patients with BE due to the increased stigma associated with BE.

Our second aim was to correlate BI findings with QOL in patients with BE. Impaired BI due to abdominal and genital scarring is of particular concern in patients with BE. Specifically, the impact of BI on sexual relationships was discussed by Wilson et al.[9] We previously reported comparisons between the BE and KS populations.[10] The negative correlations to BI may be a driving force that inversely impacts aspects of HRQOL in patients with BE. We hypothesized that poorer BI indicators may negatively impact the HRQOL domains of social and emotional functioning.

MATERIALS AND METHODS

Patient Samples

Bladder exstrophy. After receiving institutional review board approval we reviewed the records of all 8 to 25-year-old patients with BE seen at the department of urology at our hospital since 1986. We identified 83 patients. After excluding 2 patients due to death, 10 due to limited English proficiency and 4 due to other medical conditions we sent a cover letter explaining the study to the remaining 67 eligible participants. We could not contact 33 patients (49%) due to a lack of current contact information or no response after leaving 2 voicemail messages. Nine of the remaining 34 patients, including 4 males, refused participation, citing disinterest. The 25 individuals who agreed to participate were sent surveys via mail or e-mail. Of this group 22 individuals were later telephoned at a convenient time to complete all surveys, of whom 2 completed the surveys via e-mail and 1 was lost to followup.

Kidney stones. All 8 to 25-year-old patients with KS seen at our stone clinic from May 2011 to February 2012 were screened for participation. Patients with limited English proficiency, a history of open operation or another medical condition were excluded from analysis. We approached 28 patients, of whom 2 refused participation due to disinterest and 26 were scheduled for questionnaire completion by telephone. We interviewed 23 by telephone, 1 returned the survey via mail and 2 were lost to followup.

The combined sample included 48 patients who participated in the study, that is 24 with BE, representing 71% of those contacted (17 males), and 24 with KS, representing 86% of those contacted (8 males) (table 1). Parental consent was obtained for all patients younger than 18 years.

Survey Instruments

Participants completed PedsQL[11] and UBIQ. PedsQL is a validated HRQOL measure that assesses 4 generic core scales, including physical, emotional, social and work/school functioning. A more detailed description of UBIQ was previously published.[6]

Statistical Methods

PedsQL scores were compared between the BE and KS groups using the independent sample t-test. The correlation between PedsQL scores and UBIQ ordinal variables was calculated using the Spearman correlation. The correlation between PedsQL scores and UBIQ binary variables were calculated using the nonparametric

Table 1. *Characteristics of 24 male and 24 female patients*

	BE	KS	p Value
Yrs age (No. male):			0.36
8–12	10 (7)	6 (4)	
13–25	14 (10)	18 (4)	
No. male	17	8	0.02
No. female	7	16	
No. race:			0.23
White	21	24	
Black	1	0	
Other	2	0	
No. successful initial closure (%)	23 (96)	Not applicable	—
No. bladder neck reconstruction (%):	14 (58)	0	—
Age 8–12 yrs	6		
Age 13+ yrs	8		
No. augmentation (%):	9 (38)	0	—
Age 8–12 years	3		
Age 13+ years	6		
No. clean intermittent catheterization (%):	13 (54)	0	—
Age 8–12 yrs stoma	4		
Age 8–12 yrs urethra	3		
Age 13+ yrs stoma	6		