Published in final edited form as:

J Urol. 2012 November ; 188(5): 1924–1929. doi:10.1016/j.juro.2012.07.014.

Health Related Quality of Life in Adolescents with Bladder Exstrophy-Epispadias as Measured by the Child Health Questionnaire-Child Form 87

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Abstract

Purpose—We determined health related quality of life as reported by adolescents with bladder exstrophy or epispadias using a validated generic instrument.

Materials and Methods—Adolescents age 11 to 18 years with bladder exstrophy or epispadias (57) completed a validated, generic, health related quality of life instrument, the CHQ-CF87 (Child Health Questionnaire-Child Form 87). Urinary incontinence, catheterization status, and medical and surgical history data were also obtained. Mean summary scores and 95% CIs for each subdomain of the CHQ-CF87 were calculated, and descriptively compared to 2 population based samples. In our sample health related quality of life outcomes by continence status were compared using univariate and multivariate analysis. However, this analysis was limited by a small sample size.

Results—Mean age of the 49 patients with bladder exstrophy and the 8 with epispadias was 14.3 years, 67% were male and 81% were Caucasian. There were 31 participants who reported incontinence and the median number of lifetime surgeries was 9. The exstrophy population scored well in all subdomains of the instrument when descriptively compared to 2 large samples of adolescent populations. In our sample incontinent patients had lower scores by multivariate analysis in 7 of 10 domains and better scores in 3 of 10 domains, although these differences were not statistically significant.

Conclusions—Adolescents with bladder exstrophy and epispadias reported relatively good scores on the CHQ-CF87 when descriptively compared to other reference populations. This

finding suggests that these children adapt well to the challenges of their condition. Analysis of the association of incontinence with health related quality of life was limited by the small sample size.

Keywords

quality of life; bladder exstrophy; epispadias; adolescent

Bladder exstrophy-epispadias is a rare (incidence of 2.15/100,000 live births)¹ midline closure defect in which a child's lower abdominal musculature, bones and bladder fail to form normally. The effects of a child's exstrophy condition, multiple surgeries in the first decade of life and incontinence on health related quality of life are not well understood. From a psychosocial perspective, many studies have demonstrated that patients with exstrophy have significant psychosexual dysfunction and prevalent anxiety disorders.^{2–4} Nonetheless, children with exstrophy appear to achieve success in school and professional activities.^{4,5}

The WHO broadly defines health as a “state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.”⁶ HRQOL instruments can be used by health care providers to measure the effects of illness and its treatment on the overall well-being of their patients. Generic quality of life instruments (such as the Child Health Questionnaire™) are designed to assess QOL regardless of the underlying disease and allow for comparison of outcomes across disease states. Disease specific QOL instruments (eg the Childhood Asthma Questionnaire) address how a particular medical problem affects an individual's QOL.

The generic CHQ-CF87 has been used to study children with chronic medical and surgical conditions. For example, children with some chronic medical conditions such as diabetes and those born with low birth weight in general report a quality of life similar to that of normal adolescents.^{7,8} However, adolescents who have undergone liver transplantation and are subjected to daily immunosuppression reported overall worse quality of life than the general population.⁹

HRQOL has been under studied in the exstrophy population, with few prospectively collected studies using validated instruments. Many of the studies reporting QOL in bladder exstrophy are limited in that they are retrospective studies, use nonvalidated or physician directed questionnaires, and have small sample sizes.^{10,11} Wittmeyer et al recently used the generic SF-36 to assess 25 French adult patients with exstrophy, and found their QOL scores lower than the norms in general health perception and physical activity, but otherwise comparable to those of normal adults.¹² In a second study using the SF-36 Jochault-Ritz et al found French adolescent patients with exstrophy to have superior QOL scores compared to adult and child patients with exstrophy as well as the general population.¹³ Our prior study of parent-proxy reported generic HRQOL in the adolescent exstrophy population also showed that HRQOL is no worse than the norms in most areas.¹⁴ However, parent and child perspectives of HRQOL may differ, particularly relating to social or emotional HRQOL.¹⁵

Urinary incontinence is a potentially debilitating condition that affects physical and emotional well-being. Women with stress urinary incontinence report worse HRQOL than

continent women.^{16,17} The impact of lifelong urinary incontinence on HRQOL in children is not well understood. An important difference between children born with incontinence and adults with acquired incontinence is that children have always lived with their condition. Studies in the spina bifida population have not suggested a difference in quality of life between incontinent and continent adolescents.^{18,19} To our knowledge there have been no studies using validated generic or incontinence specific instruments to study the effect of incontinence on HRQOL in the adolescent exstrophy population. Therefore, a secondary aim of this study was to determine the association of incontinence status and HRQOL in this select population.

We measured child self-reported HRQOL using a validated, generic HRQOL instrument, the Child Health Questionnaire-Child Form 87, in adolescents with BEEC. We present the results using the same instrument from 2 large samples of different populations for descriptive comparison to our population. We also explore the association of continence status and HRQOL scores in adolescents with exstrophy.

METHODS

Study Population

Potentially eligible participants were identified at a tertiary referral pediatric urology clinic and through query of an institutional exstrophy database. Inclusion criteria were age 11 to 18 years, diagnosis of bladder exstrophy, bladder exstrophy variant or epispadias, and ability to read English at least at a 4th grade level. Foster children, wards of the state and children with other diagnoses (such as spina bifida, cloacal exstrophy or Hinman syndrome) were excluded from analysis. Institutional review board approval was obtained for the study.

Data Collection and Clinical Variables

Baseline demographics and medical history were obtained by structured interview with the parent and review of the medical record. A structured interview was used to obtain child reported incontinence and catheterization status. Incontinence was defined as any self-reported urinary leakage. A surgery was defined as any surgical procedure requiring anesthesia. The CHQ-CF87, a generic HRQOL instrument, was administered to participants to complete in the clinic or at home.

The Child Health Questionnaire-Child Form 87

The Child Health Questionnaire is a set of generic quality of life instruments designed for children 5 to 18 years old.²⁰ There are separate parent forms and an 87-item child form designed for adolescents age 10 to 17 years which was used in this study. The CHQ-CF87 includes 10 multi-item scales and 2 single-item questions. Individual questions in the multi-item scales can be summed and transformed to a 0 to 100 score, with higher scores representing better quality of life. The single-item questions were not included in this analysis.

Statistical Analysis

Stata® 10 (2007) statistical software was used for all analyses. Baseline characteristics were determined for the study sample. The 10 outcome variables were the scores obtained for each scale score of the CHQ-CF87 and from these, 95% CIs for the population means were constructed. Comparison of demographic variables between continent and incontinent participants were made using Pearson's chi-square and Fisher's exact tests where applicable. Incontinence was defined as a child reporting any urinary leakage.

Two population based samples using the CHQ-CF87 are presented for comparison. The study by Raat et al consisted of 444 elementary and middle school children from Rotterdam, The Netherlands, with a mean age of 12.8 years and 50.5% male.²¹ The study by Landgraf and Abetz included 232 middle school children from a suburban school district in the United States.²² The majority of this American sample was African-American, with a mean age of 13 years and 42% male. Direct statistical comparisons between these population samples and our exstrophy sample are restricted by the different ethnic, cultural and socioeconomic makeup of these populations, all factors that have been shown to affect HRQOL.^{23–26} However, these are the only published results of large samples and are presented to provide a reference of how select general populations have scored using this instrument.

As an exploratory analysis to assess the impact of incontinence on quality of life, univariable and multivariable linear regression models were also developed. We controlled for variables that may affect HRQOL in children including age, gender and, as a surrogate for socioeconomic status, maternal education.²⁷ We also adjusted for clinical variables including the total number of lifetime surgeries and catheterization status. We used robust variance estimates to account for potential model misspecification.^{28,29} Power calculations were based on the Mental Health Scale on which we hypothesized scores would be worse in our population compared to the general population. Assuming that a clinically meaningful difference would be half the standard deviation of the population based sample³⁰ and that continent children would have a mean QOL similar to the Dutch mean value of 78.2, there was 47% power to detect a 6.5-point difference between continent and incontinent children.

RESULTS

Study Population

Between January 2006 and December 2009, 87 patients were identified from clinic visits or an institutional bladder exstrophy database, underwent formal screening and were eligible for the study. Of these patients 72 completed the consent process. Of these 72, 57 participants completed CHQ-CF87 questionnaires and were the subjects of this study. Nonrespondents were defined as those who refused to participate, did not complete the consent process or failed to return the CHQ-CF87 after consenting to the study. When we compared the characteristics of the 30 nonrespondents and the 57 respondents, there were no significant differences in age, gender, race, underlying diagnosis, number of surgeries or urinary incontinence.

The characteristics of the sample are shown in table 1. Median participant age was 14 years (range 11 to 18), 38 (67%) were male and 47 (81%) were Caucasian. Bladder exstrophy was

the primary diagnosis in 49 (86%) and epispadias in 8 (14%). In addition, 1 patient had a skin covered bladder exstrophy variant. The median number of lifetime surgeries was 9 (range 3 to 26), with 46% of participants having between 8 and 12 surgeries. There were 31 participants (54%) who reported that they currently leak urine and 32 (56%) who perform intermittent catheterization. A total of 41 (72%) mothers reported at least a college education, which suggests a generally high socioeconomic status for the study population.

Comparison to Reference Samples

Table 2 shows the CHQ-CF87 scale means and associated 95% CIs based on the study sample and 2 reference samples. Compared to the Dutch sample, the exstrophy sample appears to score well in nearly all domains, but the mean General Health Perceptions and the mean Mental Health scores in the exstrophy sample were worse. However, these differences may not represent clinically meaningful differences. The exstrophy sample scored no worse than the American sample in most subdomains, and had better scores in the Physical Functioning, Role Functioning-Emotional, Role Functioning-Behavioral, Role Functioning-Physical and the Behavior scales.

Pertinent CHQ-CF87 questions addressing a child's General Health Perception include, "I seem to be less healthy than other children," "I worry more about my health than other people my age" and "I expect that I will have a very healthy life." Questions addressing a child's mental health include responses (ranging from all of the time to none of the time) about how much of the time, during the last 4 weeks, a child felt like crying, acted nervous, felt lonely or acted cheerful. Clinically meaningful differences signifying worse QOL would require the children with exstrophy to score approximately half a standard deviation lower or higher than a given reference population in these 2 domains,³⁰ which equates to a 6.5 to 8-point difference.

Comparison of Incontinent to Continent Participants

An exploratory analysis was performed to determine the effect of incontinence on each CHQ-CF87 subdomain after controlling for age, gender, catheterization status, maternal education and number of surgeries (table 3). In the adjusted analysis incontinence was associated with lower HRQOL scores in 7 of 10 domains and higher HRQOL scores in 3 of 10 domains, although these results failed to reach statistical significance. However, with a larger sample size we may be able to detect a true difference in HRQOL based on continence status.

DISCUSSION

In this study of self-reported HRQOL among adolescents with BEEC, the exstrophy population in general scored well. Our sample had a General Health score and a Mental Health score that were marginally worse than those of the Dutch reference sample, but most likely not representative of clinically meaningful differences. Moreover HRQOL was at least as good as the Dutch sample in all other domains, and was no worse or better than the American sample in all subdomains.

These findings concur with other studies of HRQOL in adolescents with exstrophy. Jochault-Ritz et al used a validated generic HRQOL instrument, the SF-36, to assess 18 adolescent children with bladder exstrophy.¹³ Like many generic HRQOL instruments, the SF-36 includes subdomains analogous to those of the CHQ-CF87. Similar to the present study, these authors reported no difference in QOL scores in most subdomains, and superior scores in the Physical Functioning, Bodily Pain and Role Emotional domains compared to the French general population. We previously reported results using the Child Health Questionnaire-Parent Form 50 to understand parent reported QOL in the same BEEC sample as the current study.¹⁴ Although parents responded that the physical and psychosocial adaptation of their children to their disease was not different than that of healthy peers, nonetheless they reported that their children's general health was worse than that of normal children. Using a different generic HRQOL instrument, the Child Health and Illness Profile-Adolescent Edition, children with bladder exstrophy (37) and spina bifida (10) had significantly worse scores in the domain measuring biomedical states of poor health, which is similar to the General Health domain.³¹

One might suppose that children with chronic disease have poor self-confidence, which could limit interactions with friends, and hinder schoolwork as well as personal and academic achievement. However, this current report suggests that adolescents with BEEC actually seem to have good self-esteem and few limitations in performing schoolwork or activities with friends as a result of emotional or behavioral problems compared to 2 other select populations of children.^{21,22} In general these findings concur with those of other studies showing good adaptation and high achievement in the exstrophy population.^{4,5}

The exploratory analysis did not reveal a significant association between exstrophy associated incontinence and decreased quality of life as measured by the CHQ-CF87, which may be due to the small sample size and limited power to detect even clinically meaningful differences. It is notable that in the spina bifida population MacNeily et al showed that despite improvement in urinary incontinence, HRQOL was unchanged in 26 patients.¹⁹ Similarly Lemelle et al used a French generic QOL instrument, the Vécu et Santé Perçue, to study adult and adolescent patients with spina bifida, and did not find an association between urinary incontinence and HRQOL.¹⁸ Although based on relatively small samples, these reports suggest urinary incontinence in the spina bifida population may not adversely affect HRQOL. With time our study population will increase in size and permit a more rigorous analysis to determine if the same association exists in exstrophy associated incontinence.

The study has several limitations, including the select patient population and small sample size. The exstrophy population at this institution included patients and families who are often self-referred, and are highly motivated and involved in improving their condition. Our relatively small sample size decreased our ability to identify small differences between continent and incontinent subgroups in our sample. Specifically the underpowered nature of our secondary analysis meant that there could be a difference in quality of life between incontinent and continent children with exstrophy that was not detected. In addition, it is possible that the CHQ-CF87 was not sensitive to the effects of bladder exstrophy on HRQOL. Finally, this study is limited in that statistical comparison to a population based

norm was not available. The 2 available population based samples presented here were neither age nor gender matched, and had a different ethnic, cultural and socioeconomic composition than our sample, which are factors reported to be associated with HRQOL outcomes. Therefore, direct statistical comparison would be prone to confounding. Despite these limitations, this study is the largest on HRQOL in exstrophy-epispadias using a generic, child self-reported validated instrument, the CHQ-CF87. The findings suggest that children with bladder exstrophy adapt well to their condition.

CONCLUSIONS

Adolescents with bladder exstrophy and epispadias reported relatively high scores on the CHQ-CF87. When descriptively compared to 2 large samples of different populations, the exstrophy population appears to have similar HRQOL scores overall. This suggests that these children adapt well to the challenges of their condition. Our sample size was too small to detect or rule out any differences in HRQOL by continence status.

Acknowledgments

Supported by NIH/NIDDK T32DK007552 (AJS), NIH/NIDDK U01OK066174 and K24KD078737 (SLF), and 1K23DK078671 (JLD).

Andre Hackman provided assistance with data management and Sarah Smith assisted with report preparation.

Abbreviations and Acronyms

BEEC	bladder epispadias-exstrophy complex
HRQOL	health related quality of life
QOL	quality of life

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Table 1

Baseline patient characteristics

	Overall	Incontinent	Continent	p Value [*]
No. pts (%)	57	31 (46)	26 (54)	
Pt age:				
Median (SD)	14 (1.9)	13 (2.0)	14.5 (1.8)	0.55
Range	11–18	11–18	11–18	
No. gender (%):				
M	38 (67)	20 (65)	18 (69)	0.71
F	19 (33)	11 (35)	8 (31)	
No. race (%):				
White	47 (81)	26 (84)	21 (80)	1.0
Other	10 (19)	5 (16)	5 (20)	
No. diagnosis (%):				
Bladder exstrophy [†]	49 (86)	24 (77)	25 (96)	0.06
Epispadias	8 (14)	7 (23)	1 (4)	
No. maternal education (%):				
College or professional degree	41 (72)	23 (74)	18 (69)	0.68
Other	16 (28)	8 (26)	8 (31)	
Lifetime surgeries:				
Median (SD)	9 (4.9)	9 (5.0)	10 (4.8)	0.45
Range	3–26	3–26	5–21	
No. surgeries (%):				
3–7	18 (32)	9 (29)	9 (35)	0.60
8–12	26 (46)	16 (52)	10 (38)	
Greater than 12	13 (23)	6 (19)	7 (27)	
No. catheterize (%):				
Yes	32 (56)	10 (32)	22 (85)	30.001
No	25 (44)	21 (68)	4 (15)	
No. catheter location (%):				
Stoma	27 (84)	7 (70)	20 (91)	0.29
Urethra	5 (16)	3 (30)	2 (9)	

^{*} Student's t test was used for continuous variables and the chi-square or Fisher's exact test was used for categorical variables.

[†] One patient had a skin covered exstrophy variant.

Table 2

Child reported QOL in exstrophy compared to population based samples

	Mean Exstrophy Sample (95% CI)	Mean Raat et al Population Sample (95% CI) ²¹	Mean Landgraf and Abetz Population Sample (95% CI) ²²
Physical Functioning	97.1 (95.5–98.8)	96.8 (96.2–97.3)	88.8 (87.0–90.6)
Role Functioning-Emotional	96.9 (94.8–99.0)	92.3 (90.7–93.9)	85.9 (83.2–88.6)
Role Functioning-Behavioral	97.7 (95.8–99.6)	91.4 (90.1–92.7)	86.5 (83.8–89.3)
Role Functioning-Physical	96.7 (94.1–99.2)	96.5 (95.4–97.6)	88.3 (85.6–91.0)
Bodily Pain	77.0 (71.9–82.1)	78.2 (76.4–80.0)	74.4 (71.4–77.3)
Behavior	81.6 (78.2–85.0)	83.6 (82.6–84.6)	76.6 (74.7–78.5)
Mental Health	74.8 (71.3–78.2)	78.2 (77.0–79.4)	72.7 (70.6–74.8)
Self-Esteem	84.8 (81.3–88.3)	75.4 (74.2–76.6)	81.8 (79.8–83.9)
General Health	69.9 (65.4–74.4)	74.6 (73.1–76.1)	66.4 (64.5–68.3)
Family Activities *	86.3 (82.2–90.4)	—	—

* No Family Activities mean and SD score given in Raat et al or Landgraf and Abetz samples.

Table 3

Unadjusted and adjusted differences in HRQOL comparing incontinent to continent patients with exstrophy

CHQ-CF87 Scale	Unadjusted Estimated Difference in HRQOL (95% CI)*	p Value	Adjusted [†] Estimated Difference in HRQOL (95% CI)*	p Value
General Health	4.3 (–4.9, 13.6)	0.35	–2.3 (–11.1, 6.5)	0.60
Physical Functioning	1.3 (–2.1, 4.7)	0.45	0.91 (–2.1, 4.0)	0.55
Role Functioning-Emotional	3.7 (–0.78, 8.17)	0.10	3.7 (–0.3, 7.7)	0.07
Role Functioning-Behavioral	–1.9 (–5.6, 1.7)	0.29	–4.8 (–10.4, 0.88)	0.10
Role Functioning-Physical	3.3 (–2.1, 8.7)	0.22	2.4 (–3.0, 7.9)	0.37
Bodily Pain	–1.2 (–11.9, 9.4)	0.82	–4.6 (–15.2, 6.0)	0.39
Behavior	3.1 (–3.9, 10.1)	0.38	–1.2 (–9.30, 6.9)	0.76
Mental Health	1.6 (–5.6, 8.9)	0.65	–3.3 (–11.0, 4.4)	0.39
Self-Esteem	2.1 (–5.3, 9.4)	0.58	–3.9 (–10.8, 3.1)	0.27
Family Activities	3.7 (–4.7, 12.2)	0.38	–1.2 (–10.7, 8.3)	0.80

* For the interpretation of difference, a negative difference implies that incontinent children have a worse quality of life.

[†] Adjusted for age, gender, maternal education, catheterization status and number of surgeries.