Sexual Function in Patients Operated on for Bladder Exstrophy and Epispadias

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Purpose: Bladder exstrophy and epispadias complex is a rare congenital malformation that may have detrimental effects on sexual function. We evaluated sexual function of patients with bladder exstrophy and epispadias complex using validated questionnaires and compared the results with age matched controls.

Materials and Methods: Patients with bladder exstrophy and epispadias complex treated between 1956 and 1992 were identified from our hospital operative database. A total of 63 patients were mailed questionnaires up to 3 times, resulting in 32 replies (51%). Men were mailed the International Index of Erectile Function-15 questionnaire and women were mailed the Female Sexual Function Index questionnaire, and all patients were asked auxiliary questions regarding children, satisfaction with external genitalia and urinary continence.

Results: There were no differences in sexual function between sexually active men with bladder exstrophy and epispadias complex and age matched controls on different erectile function domain scores according to the International Index of Erectile Function-15 questionnaire. The Female Sexual Function Index questionnaire among women yielded comparable results on different domain scores, except for median total score, which was higher in patients (33.6, IQR 29.4 to 34.9) than in controls (30.1, IQR 26.4 to 32.4, $p = 0.049$), suggesting better sexual function in patients with bladder exstrophy and epispadias complex. A greater proportion of patients with bladder exstrophy and epispadias complex had not become sexually active, compared to controls (35% vs 11%, $p = 0.008$). Patients with bladder exstrophy and epispadias complex were less likely to have children than controls (22% vs 45%, $p = 0.021$).

Conclusions: Men and women with bladder exstrophy and epispadias complex had good long-term outcomes on erectile and general sexual function tests. However, there is a likelihood that these individuals start their sexual life later than the general population, and fewer have children compared to controls.

Key Words: bladder exstrophy; epispadias; bladder exstrophy and epispadias complex; sexual dysfunction, physiological

Abbreviations and Acronyms

BE = bladder exstrophy

EEC = bladder exstrophy and epispadias complex

EHS = Erection Hardness Score

FSFI = Female Sexual Function Index

IIEF = International Index of Erectile Function

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Study received a priori approval of hospital district of Helsinki and Uusimaa ethics committee, and conforms to the principles of the 1975 Declaration of Helsinki.

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BLADDER exstrophy and epispadias complex is a severe congenital malformation that affects the external genitalia and may have detrimental effects on sexual function. The majority of patients with bladder exstrophy and epispadias complex undergo multiple surgeries, and their body image may be impaired.[1] The primary objectives of surgical repair have been the maintenance of urinary continence with preserved renal function, as well as cosmetically and functionally acceptable genitalia. There are

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multiple factors that may have negative effects on sexual function, such as short size or abnormal shape of the penis, tight vaginal introitus, low lying uterus, unsatisfactory scarring of the external genitalia or lower abdomen, abnormal shape of the bony pelvis, retrograde ejaculation, cryptorchidism or bothersome urinary incontinence.[2,3] The data on long-term outcomes in patients with bladder exstrophy and epispadias complex are scarce, and conflicting reports have been published describing findings ranging from marked erectile dysfunction to fair results regarding sexual function.[4,5]

We evaluated whether sexual function is impaired in men and women with EEC compared to age matched controls. We also evaluated whether unsatisfactory genitalia or urinary incontinence has an impact on sexual function.

PATIENTS AND METHODS

Patients with EEC treated between 1956 and 1992 were identified from the hospital operative database. The ethics committee of the hospital district of Helsinki and Uusimaa approved this study a priori, and the study conforms to the principles of the 1975 Declaration of Helsinki.

A total of 68 patients were identified, of whom 4 had died and 1 had an unknown address. The remaining 41 males and 22 females were mailed questionnaires up to 3 times, resulting in 32 replies (51%). Demographic data, surgical history and renal function are presented in table 1. No patient required dialysis for renal insufficiency, and the recorded serum creatinine values were collected from late adolescence to adulthood. Patient characteristics were comparable among responders and nonresponders.

Sexual function was evaluated in males with the IIEF-15 questionnaire and in females with the FSFI questionnaire.[6,7] Penile tumescence was evaluated with a modified EHS instrument.[8] Patients were asked, "How would you rate the hardness of your erection?" Possible answers included 1) the penis is larger but not hard, 2) the penis is somewhat hard but not rigid, 3) the penis is hard but not fully rigid, and 4) the penis is completely hard and fully rigid.

The IIEF-15 is a validated tool for assessing erectile function, orgasmic function, sexual desire, intercourse satisfaction and overall satisfaction during the preceding 4 weeks. The results of 21 responders were compared to 63 age matched controls from a population based sample of male twins and their brothers.[9] Scores higher than 25 indicate normal erectile function, and scores of 22 to 25 indicate mild dysfunction.[10] In this study erectile function was considered satisfactory if the IIEF score was 22 or greater.

The FSFI is a validated 19-item questionnaire for assessing 6 domains of female sexual function (desire, arousal, lubrication, orgasm, satisfaction and pain) during the preceding 4 weeks. The results of 11 responders were compared to 3 age matched controls per responder from a population based sample of female twins and their sisters.[11] For the FSFI questionnaire the range between minimum and maximum total score is 1.2 to 36, and a total FSFI score of less than 26.55 is considered abnormal.[12]

Whether and when the patient had started sexual life and number of offspring were also elicited in a controlled manner. In addition, all patients were asked auxiliary questions regarding offspring, satisfaction with the external genitals and urinary continence. Possible answers to the question, "Do you have children?" included 1) yes (biological), number, 2) yes (adopted), number and 3) no. Possible answers to the question, "Are you satisfied with the appearance of your external genitalia?" were 1) fully satisfied, 2) fairly satisfied, 3) reasonably satisfied, 4) fairly dissatisfied and 5) fully dissatisfied. Patients were considered to be satisfied if they selected the options fully, fairly or reasonably satisfied. Patients were also asked "Do you have urinary incontinence?" and the magnitude of incontinence, with options including "droplets," "gurgle" and "need for diapers."

The results of the IIEF-15 and FSFI scales are expressed as median and IQR. The Mann-Whitney U test was used to compare continuous variables and the Fisher exact test was used to compare categorical variables (StatView® 5.0.1 software program). A p value of less than 0.05 was considered significant.

Table 1. *Patient characteristics*

	Responders	Nonresponders
No. gender:		
M	21	20
F	11	10
Mean ± SD age (yrs)	30 ± 10	39 ± 14
No. diagnosis:		
Epispadias	13	11
BE	19	19
Median μmol/l serum creatinine (IQR)	67 (63–75)	61 (56–69)
Median general anesthesias (IQR)	18.5 (13–24)	13 (10–16)
Median cystoscopies (IQR)	9.5 (8–13)	10 (9–12)

RESULTS

When all patients with EEC were pooled together and compared to age matched controls, 15 of 33 patients (45%) and 43 of 96 controls (45%) had similar sexual activity during the preceding 4 weeks ($p = 1.0$). However, a greater proportion of individuals with EEC (8 of 23, 35%) had not become sexually active compared to controls (10 of 94, 11%, $p = 0.008$). Patients with EEC were also less likely to have children (7 of 32, 22%) than the control population (39 of 86, 45%, $p = 0.021$).

Erectile Function in Men with EEC

Male patients and controls were asked whether they had ever engaged in or attempted intercourse. Six of 21 men with EEC (29%) and 10 of 61 controls (16%) had not started their sexual life ($p = 0.337$). Sexually active male patients and controls had started their sexual life at a median age of 20 and 18 years, respectively ($p = 0.104$). The proportion of sexually active individuals during the preceding 4 weeks