# Sexual Function and Fertility of Women with Classic Bladder Exstrophy and Continent Urinary Diversion

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**Abbreviations and Acronyms**

BE = bladder exstrophy
CUD = continent UD
FSFI = Female Sexual Function Index
POP = pelvic organ prolapse
UD = urinary diversion

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**Purpose:** We evaluated the outcome in female patients with classic bladder exstrophy and continent urinary diversion for sexual function and fertility.

**Materials and Methods:** We reviewed the medical records of female exstrophy patients who underwent continent urinary diversion in our department between 1969 and 2014. Patients were invited for followup examination and asked to complete questionnaires relating to sexual function, social integration and maternity.

**Results:** Of 38 eligible patients 29 (response rate 76%) with a followup of 22.3 years were included in study. Primary continent urinary diversion was done in 62% of patients and 38% underwent secondary continent urinary diversion after failed reconstruction of the exstrophic bladder. Sexual function as measured by the Female Sexual Function Index was only little affected in all domains except desire. Mean total Female Sexual Function Index score was 28.4 of a possible 36. Of the women 31% were classified as at risk for sexual dysfunction, 72% had a stable relationship, 41% were married and 31% had completed higher education. The incidence of pelvic organ prolapse requiring surgical repair was 38%. A total of 16 healthy children were conceived by 12 patients. The pregnancy rate after primary continent urinary diversion was higher than after secondary diversion.

**Conclusions:** The sexuality and fertility of female patients with exstrophy after continent urinary diversion appears to be comparable with those in previously reported series of patients in whom the bladder was preserved. Management of sexual function, gynecologic pathologies and fertility should be an active part of long-term followup.

**Key Words:** bladder exstrophy, urinary diversion, pelvic organ prolapse, sexuality, fertility

Bladder exstrophy is one of the most complex congenital anomalies of the genitourinary tract. The majority of exstrophy patients undergo multiple reconstructive surgeries and have persistent problems with respect to urinary continence and sexual function. In females a spectrum of genital anomalies such as short vagina, narrow introitus, bifid clitoris, divergent labia, diminutive mons pubis and pelvic floor defects may negatively affect sexuality, fertility and psychological well-being.

The surgical management of BE has fundamentally changed in the last decades. Whereas the removal of the bladder plate and primary UD



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was abandoned at most centers in the 1970s, it was used as a primary option in our department until 10 years ago. Today staged repair of BE is the standard management and is generally accepted to give good functional and cosmetic results.[1]

However, secondary CUD may become necessary in a subset of patients with exstrophy in whom all attempts to establish a continent storage organ and protect the upper urinary tract have failed.[2] Moreover, primary CUD may be an acceptable alternative in parts of the world where there is a lack of expertise in exstrophy repair and management of its complications.[3]

Newer surgical concepts of exstrophy repair, comprising closure of the bony pelvis and genital reconstruction, are believed to result in better outcomes in relation to the cosmetic appearance of the external genitalia, sexual function and fertility compared to those achieved by primary cystectomy and CUD. However, studies that have addressed this hypothesis are scarce and methodologically flawed by the small number of patients who were old enough for adult review and the lack of uniform assessment criteria.

The aim of our study was to evaluate the outcome of female patients with classic BE and CUD for sexual function, fertility and gynecologic-obstetric complications, and discuss the clinical significance of the findings.

## PATIENTS AND METHODS

The medical records of patients treated in our department for classical BE between 1969 and 2014 were reviewed and female patients with CUD were identified. CUD was performed as a primary procedure, including removal of the bladder, or as a secondary procedure in referred patients in whom previous attempts at reconstructing the exstrophic bladder had failed. The most common type of primary UD was continent anal diversion via ureterosigmoidostomy until 1993 and thereafter by its modification, the sigma-rectum pouch (Mainz pouch II).[4] Continent cutaneous diversion using an ileocecal pouch (Mainz pouch I) was offered mostly to patients with multiple failed previous reconstructive procedures in the pelvis.[5]

After obtaining ethics review board approval patients were contacted, invited for a structured followup examination and asked to complete questionnaires relating to social integration, sexual function, including FSFI, and pregnancy. FSFI is a 19-item questionnaire that was developed as a brief multidimensional self-report instrument to assess the key dimensions of sexual function in women. It is psychometrically sound and easy to administer, and has demonstrated ability to discriminate between clinical and nonclinical populations.[6] The level of satisfaction with the functional and cosmetic outcome of genital reconstruction was assessed using an unvalidated questionnaire (supplementary Appendix, http://jurology.com/). All patients included in study consented to participate and returned complete questionnaires by mail or at followup.

Statistical analysis was performed using MedCalc (http://www.medcalc.com/). Mean questionnaire scores were compared with normative data reported by Rosen et al[6] using the t-test. The chi-square test was used to compare proportions.

## RESULTS

In our departmental databases we identified 46 patients older than 16 years with classic BE in whom CUD was performed at our institution. Eight of these women were excluded from study because of death in 2 and or loss to followup in 6. Of the 38 eligible patients 29 (76%) consented to participate in the study and completed the questionnaires and followup examinations.

Mean patient age was 38 years (range 22 to 61). Continent cutaneous and continent anal UD was performed in 13 (45%) and 16 patients (55%), respectively. Of the patients 62% had undergone primary CUD and 38% were treated with CUD after failed reconstruction of the exstrophic bladder. The mean total number of surgical procedures was 8.3 (range 2 to 25) and the mean number of genital surgeries was 2.2 (range 1 to 6). Seven patients (24%) had undergone pelvic osteotomy or pelvic ring adaptation by traction bandage. Mean followup was 22.3 years (range 2 to 45).

### Education Level and Partnership Formation

Nine patients (31%) had attained higher education, including 5 who had completed postgraduate programs. A total of 25 patients (86%) were in paid employment, 73% lived in a stable partnership and 41% were married (supplementary table 1, http://jurology.com/).

### Sexual Function

Of the patients 44% were satisfied with the cosmetic appearance and 62% were satisfied with the functional outcome of genital reconstruction as measured by a nonvalidated questionnaire. A total of 26 women (90%) were sexually active and reported having regular intercourse. The mean total FSFI score of sexually active women was 28.4. Sexual function, defined as a total FSFI score greater 26.55, was normal in 69% of women whereas 31% were classified as at risk for sexual dysfunction.[7] Subscale scores were not significantly lower compared to reference scores of a standardized population except for sexual desire (table 1).[6] None of the patients had severe sexual dysfunction according to FSFI criteria (table 2).[8] Of 26 sexually active women 19 (73%) stated that they were