

## An Initial Evaluation of Pelvic Floor Function and Quality of Life of Bladder Exstrophy Patients After Ureterosigmoidostomy

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Classic bladder exstrophy is characterized by displaced pelvic floor musculature and significant skeletal and genitourinary defects. A paucity of data exist evaluating long-term pelvic floor function in exstrophy patients after ureterosigmoidostomy. This study is an initial attempt to evaluate the prevalence of urofecal incontinence, pelvic organ prolapse, and overall quality of life in patients who have had ureterosigmoidostomies. Fifty-two individuals who underwent ureterosigmoidostomy between 1937 and 1990 were identified through the Ureterosigmoidostomy Association and the Johns Hopkins bladder exstrophy database and mailed questionnaires approved by the Institutional Review Board (Johns Hopkins). Data were analyzed with SigmaStat 3.0 (SPSS, Inc., Chicago, IL). Eighty-three percent of the subjects responded, with a mean age of 44.4 years (range, 14–73 years) and mean of 40.9 years (range, 14–65 years) after ureterosigmoidostomy. Prevalence of daily urinary and fecal incontinence was 48% (n = 20) and 26% (n = 11), respectively, whereas the prevalence of weekly combined urofecal incontinence was 63% (n = 27). The incidence of pelvic organ prolapse in this cohort was 48% (n = 20). In these patients, a significant risk of urofecal incontinence and pelvic organ prolapse exists. Long-term follow-up studies are needed to understand the role of pelvic floor musculature in this complex birth defect. (J GASTROINTEST SURG 2006;10:473–477) © 2006 The Society for Surgery of the Alimentary Tract

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Bladder exstrophy is a major congenital birth defect involving the abdominal wall from the umbilicus to the tip of the urethra. The pelvic bones are separated, and the bladder lies externally between the two pubic rami. The urinary sphincters are absent. This abnormality is seen in 1 in 40,000 newborns.<sup>1</sup> Ureterosigmoidostomy is a surgical procedure historically used in the treatment of bladder exstrophy, where the ureters are inserted into the taenia of the sigmoid colon in a nonrefluxing manner. The use of the sigmoid colon allows the patient to maintain continence and evacuate urine through the anus, thus eliminating the need for a cutaneous urinary diversion or catheterizable abdominal stoma. This procedure is typically done in patients where the

native bladder is not amenable to reconstruction. Ureterosigmoidostomy is associated with a preserved body image and improved quality of life.<sup>2</sup> However, many long-term effects from this procedure, including pyelonephritic renal damage, nephrolithiasis, and neoplasia have been reported. What is unknown regarding ureterosigmoidostomy is long-term pelvic floor function, including urofecal incontinence. The purpose of this study was to evaluate this function in a cohort of patients with a longstanding ureterosigmoidostomy. Currently, to our knowledge, no studies exist evaluating the quality of life and long-term pelvic floor outcomes of adult ureterosigmoidostomy patients in the United States.

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## MATERIAL AND METHODS

After approval by the Institutional Review Board (Johns Hopkins), patients who were members of the Ureterosigmoidostomy Association or had a documented ureterosigmoidostomy in the institutionally approved Johns Hopkins exstrophy database were sent a four-page questionnaire. This questionnaire contained a modified version of the commonly used Fecal Incontinence Severity Index. The identical questionnaire was also available on a secure website. Reminder e-mails and letters were sent to patients 3 weeks after the initial mailing. Data were analyzed with SigmaStat 3.0 (SPSS, Inc., Chicago-IL). Continuous variables were calculated as mean  $\pm$  standard deviation. Categorical variables were summarized as percent. Multiple logistic regressions were used to investigate relationships between sex, uterine prolapse, and fecal incontinence. *T* tests were used to compare means of categorical variables. All statistical analyses were performed with SigmaStat 3.0 (SPSS, Inc.). All *P* values are two-sided and considered significant at  $P \leq 0.05$ . Results were assessed from returned questionnaires 1 month after the initial mailing.

## RESULTS

Fifty-two questionnaires were mailed to participants, and 83% ( $n = 43$ ) were returned either by mail or online. The respondents had a mean and median age of 44.4 and 43.5 years, respectively (Table 1). The number of male and female respondents was nearly equivalent ( $n = 22$  and  $n = 21$ , respectively). Over 90% ( $n = 39$ ) of respondents underwent ureterosigmoidostomy for bladder exstrophy. The mean and median number of years after ureterosigmoidostomy was 40.9 and 42 years, respectively, with a range of 14–65 years. Eighty-four percent of respondents ( $n = 36$ ) were married, and

this was distributed equally among men and women. Fifty-five percent of female respondents had children, with a mean parity of 1.85 live births. Overall, 53.8% of all respondents reported the frequency of sexual activity was as much as he or she desired; however, 77.2% ( $n = 17$ ) of women and 71.4% ( $n = 16$ ) of men had been sexually active within the past month.

In patients who have undergone ureterosigmoidostomy, incontinence frequently results in the loss of stool and urine. We have termed this situation as urofecal incontinence. Urofecal incontinence was present in 56% ( $n = 24$ ) of respondents. Half of all male respondents experienced urofecal incontinence (11/22), as did 62% (13/21) of female respondents (OR 1.79; 95% CI, 0.52–6.10). When frequency of incontinence was assessed, we found the prevalence of overall daily urinary incontinence was 48% ( $n = 20$ ). The prevalence of daily overall fecal incontinence was 26% ( $n = 11$ ), whereas the prevalence of overall weekly combined urofecal incontinence was 63% ( $n = 27$ ).

Age was not independently associated with urofecal incontinence (Fig. 1). However, when adjusted for age greater than 40, men were 70% more likely to be continent than women were. Women greater than 40 years of age were 45% more likely to have urofecal incontinence than their younger counterparts were (OR, 1.45). Women who did not have urofecal incontinence had a higher parity than women with urofecal incontinence did, but this was not statistically significant. The incidence of pelvic organ prolapse in this cohort of patients was 48% ( $n = 20$ ). There was no significant difference in urofecal incontinence or pelvic organ prolapse with respect to gender. In our study, 50% (10/20) of patients with uterine prolapse also experienced urofecal incontinence. However, 30% without uterine prolapse also experienced incontinence (Fig. 2). In addition, 40% of female survey respondents did not answer the question. Only four respondents reported a history of hysterectomy. Of those, two experienced urofecal incontinence.

Despite the above findings, 86% ( $n = 37$ ) of respondents were pleased with the results of their surgery and did not wish to have additional diversion surgery (Fig. 3). However, despite the fact that respondents were generally happy with their results after ureterosigmoidostomy, 90% ( $n = 39$ ) of all respondents needed additional surgery for their genitourinary disorder. When comparing male and female respondents, 77.8% ( $n = 17$ ) of men and 100% ( $n = 43$ ) of women had undergone additional surgery ( $P = 0.06$ ). Overall, 1.4% ( $n = 6$ ) of respondents stated that they would consider another form

**Table 1.** Patient characteristics

	Male (n = 22)	Female (n = 21)
Age	48.5 (range 33–73)	40.1 (range 14–67)
Years with ureterosigmoidostomy	45	36.7
Mean		
Marital status (%)	18 (82)	17 (81)
Respondents with children (%)	n/a	14 (63.6)
Mean parity	n/a	1.85

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