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Continence outcomes following reconstructive lower urinary tract surgery in incontinent adults and adolescents previously operated in childhood for exstrophy/epispadias complex

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Summary

Purpose
To describe the presentation and outcome of surgical management strategies applied to the adolescent and adult patient population (age >14 years) with bladder exstrophy/epispadias complex (BEEC) who presented with persistent incontinence even after previous numerous surgeries at our institution.

Methods
A retrospective review of the electronic medical records of patients with BEEC managed from January 1998 to December 2022 was undertaken. Patients aged >14 years at presentation, with detailed medical records were selected. Of these, we identified patients who underwent surgical intervention for incontinence primarily. Data on presenting symptoms, clinical findings, previous and present surgical intervention, post-operative complications, secondary procedures and follow-up periods were recorded. Data on continence was collected in the form of clean intermittent catherization (CIC) or voiding frequency, dry intervals and diaper usage. Subjective assessment of continence was assessed by a cross sectional survey using the International Consultation on Incontinence modular Questionnaire Urinary Incontinence (ICIQ-UI) short form. A patient was considered socially continent if he or she could perform normal activities without fear of urinary leak.

Results
A total of 27 (16 male and 11 female) patients of BEEC, aged 14 years and above who underwent surgical intervention for persistent incontinence in adolescence or adulthood following previous repairs over this 24-year period were identified and their records reviewed. Median age of presentation was 21 years (IQR, 14–25.8) and they had undergone a median of 4 surgeries prior to presentation (range, 2–10). Three patients had already been augmented with bowel along with a Mitrofanoff channel. The median follow-up was 42 months (range, 24–117). Regarding continence outcomes, at last follow-up, only one patient was volitionally voiding to completion, with the rest doing CIC through Mitrofanoff channel or by perurethral route with nearly 60 % (14/24) having a dry interval of 90 min. After excluding 3 patients who underwent incontinent urinary diversion, 17/24 (71.7 %) patients had no need for diapers and only 5/24 (21 %) had severe persistence urinary incontinence based on ICIQ UI scores. More importantly, 16/24 (67 %) of the patients in our cohort group were socially continent.

Conclusions
BEEC is difficult to manage, especially in resource-poor settings and some children reach adolescence and remain incontinent. However, with careful pre-operative assessment and exact surgical precision, a decent level of social continence can be expected, even in these patients presenting late in adulthood.

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Introduction

Exstrophy epispadias is a rare congenital disorder with an incidence of 1:10,000—1:50,000 [1]. Conventional treatment options include staged reconstruction or a single-stage approach, both of which are attempted soon after birth [2]. With modern techniques of lower urinary tract reconstruction, patients born with bladder exstrophy and incontinent epispadias can expect a high rate of urinary continence with controlled urethral voiding [3,4]. However, due to various reasons, not all patients who undergo surgery in childhood remain continent and especially in developing and underdeveloped countries many of these patients can enter adolescence and adulthood in diapers due to persistent incontinence [1—10]. There is no consensus on the ideal approach in this situation. Though the need for urinary diversion for ongoing incontinence in this group is uncommon, but becomes necessary for selected patients in whom repeated surgery has not rendered them dry; with persistence, they may then lead a full and productive life [6,7,10]. This paper examines the presentation, management, and outcome of definitive reconstruction in 24 patients who entered adolescence or early adulthood with persistent urinary incontinence, and also reports on the complications encountered.

Materials and methods

A retrospective review of the electronic medical records of patients with exstrophy epispadias complex managed in two high volume canters from January 1998 to December 2022 was undertaken. Patients aged 14 years or more at presentation with detailed medical records were identified and their records scrutinized. We excluded patients who presented to us for the first time in adulthood and patients of cloacal exstrophy or incontinent epispadias who had undergone reconstruction. Thirty-six patients of bladder exstrophy—epispadias complex aged >14 years presented to our institution over this 24-year period, out of which 4 patients presented for the first time and 32 had undergone previous intervention. Excluding two patients who presented for reasons other than incontinence, namely stomal stenosis and ureteric obstruction, a total of 30 (19 male and 11 female) patients who presented primarily with persistent incontinence into adolescence or adulthood following previous repairs were identified and their records reviewed. Among these 30 patients, three patients had refused further intervention for incontinence and 27 of them underwent further reconstruction for managing incontinence which constituted our study group (Fig. 1). Data on presenting symptoms, clinical findings, previous and present surgical intervention, post-operative complications, secondary procedures and follow-up periods were recorded in this cohort of 27 patients.

Patients were evaluated preoperatively with a detailed history and clinical examination. In patients who were doing CIC or voiding, bladder diaries or CIC diaries were scrutinized. The voiding diaries or CIC diaries are a crucial part of the preoperative assessment which helps us in understanding the true severity of incontinence and leakage and gives us an idea about the functional bladder capacities. Clinical examination usually revealed a spectrum of presentations ranging from a completely broken-down repair with exposed bladder plate to just a suprapubic fistula to a well reconstructed abdomen with persistent urethral leak alone. In males apart from the short penis, we assessed for persistent epispadias or even hypospadias in those with ventralized urethras and residual dorsal chordee also. Females were assessed for vaginal stenosis and prolapse of pelvic organs due to a lax pelvic floor.

Routine blood and urine investigations with plain X-rays of the pelvis and ultrasound examination of the abdomen were performed. Serum creatinine and GFR estimation was done to assess renal function and identify those unfortunate patients whose kidneys have already been damaged. Imaging in the form of an ultrasound was done to see for upper tract changes as most of them have undergone

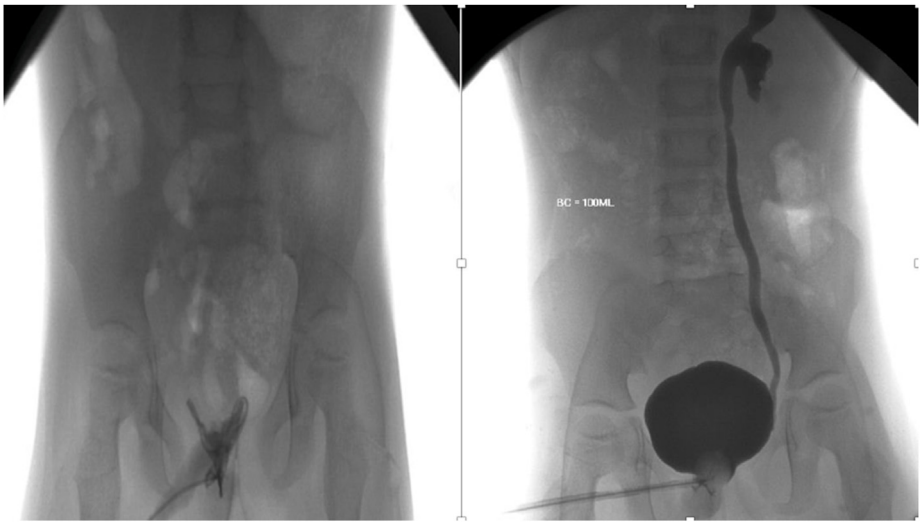


Fig. 1 Voiding cystourethrogram in one of the study patients showing **A.** Bladder not filling due to an incompetent outlet **B.** Bladder filling possible in the same patient following tugging of an inflated Foleys balloon against the incompetent outlet showing a capacity of 100 ml and vesicoureteral reflux on left side.

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reimplantation and hence there is always a possibility of a recurrent reflux or obstruction. A voiding cystourethrogram (VCUG) were done to know the status of the bladder and the bladder outlet. In situations where there is a weak bladder outlet, the practice of tugging the inflated Foleys balloon to close the bladder neck helped in getting the actual bladder volume and reflux status (Fig. 1). Diuretic renogram using ethylene cysteine scan was done in patients having associated obstructive upper tract changes to know function and drainage. Urodynamic studies were done to further document a poorly compliant bladder or an incompetent bladder outlet as this has a bearing on the management. Cystoscopy and examination under anesthesia were performed in more complicated cases, especially to assess the bladder capacity and competence of the bladder neck. Random bladder biopsies were performed, if cystoscopy showed any suspicious areas.

Once evaluation was complete, the reason for incontinence was identified which can be either due to incomplete emptying due to difficulty in catheterizing, small capacity bladder or and/or weak outlet and a management plan was drawn which included all the available surgical options ranging from bladder outlet procedure with or without augmentation to bladder neck transection to permanent urinary diversion.

Following this comes the most important step of discussion with the patients about these management options available. This needs a thorough open discussion where the aspirations of the young adult and the realistically feasible surgical options that the surgeon can provide are brought to the table, with the ultimate aim of coming to a consensus on identifying the best possible management options available to the particular patient in question. It has to be emphasized here that each patient is unique and on the part of the surgeon, tendency to generalize should be avoided and the options should be tailored to each patient based on their specific socioeconomic and educational backgrounds.

Regarding the surgical procedures, in patients with a normal creatinine and an incompetent outlet with a small bladder, our preference was a redo bladder neck reconstruction by a modified Young Dees technique with bladder augmentation with a Mitrofanoff channel which we offered as a first choice. Adjunctive procedures like an autologous sling or colposuspension were offered if the patient continued to leak after a redo BNR. Patients who were very particular about being dry, were counselled for a bladder neck transection with a Mitrofanoff channel. Patients who had a leak due to incomplete evacuation due to difficulty in catheterizing the Mitrofanoff channel were offered a Mitrofanoff revision. In patients with already elevated creatinine, we explained the need for incontinent diversion after excision of the bladder plate in the form of an ileal conduit or a ureterostomy. A definite plan for reconstruction or diversion was made after discussing the pros and cons of each option with the patient.

Post-operatively in patients who had their bladder plate preserved, Perurethral Catheters were removed at 3 weeks (in whom BNR was done) and at 6 weeks a cystogram was done through the Mitrofanoff channel to assess the augmented bladder capacities based on which the CIC schedule was formulated for each patient.

Postoperative follow-up included assessment of daytime and nocturnal continence, bladder emptying, serum biochemistry and ultrasound examination of the kidneys and bladder.

Data on continence was collected in the form of dry intervals between voids or catheterizations and diaper usage. Over the years, we realized that instead of focusing on dry intervals only, we need to emphasize more on the subjective assessment of incontinence from patients themselves. Since 2018, we have been using the International Consultation on Incontinence modular Questionnaire Urinary Incontinence (ICIQ-UI) short form (Supplementary Fig. 1), with score range of 0—21 to assess the subjective severity of incontinence. For the purpose of the study, we did a cross sectional survey and contacted all the patients in the cohort telephonically to know their latest ICIQ scores.

In ours study we placed emphasis on social continence which is more relevant to the patient's quality of life. A patient was considered socially continent if he or she could perform normal activities without fear of urinary leak (which we assessed using the ICIQ SF questionnaire). Patients with score <5 to question 3 of the ICS SF questionnaires were considered to be socially continent.

Results

The demographic profile of the cohort of 27 patients is shown in Table 1. Three patients had already been augmented with bowel along with a Mitrofanoff channel. Of the 27 patients, 24 had already undergone a bladder neck reconstruction (BNR) previously for continence (group A) and 3 were yet to undergo a BNR (group B). The details of all surgical procedures in this cohort are shown in Fig. 2. Immediate postoperative complications that were encountered was wound infection in 5 patients, febrile UTI in 2 and subacute intestinal obstruction which was conservatively managed in 2 patients.

Except one patient who was lost to follow up after 3 months, a minimum follow-up of 6 months was available for rest 27 patients. The overall median follow-up was 42 months (IQR:24—117) [48 months (IQR: 24—114) in group A and 24 months (IQR:15—42) in group B].

In the redo BNR group, two patients (one male and female) continued to have significant incontinence post redo BNR, the cause being a urethrovaginal fistula in the female which was successfully managed with fistula closure, however the other male patient needed a bladder neck closure (BNC) with a Mitrofanoff channel ultimately, for continence. In addition, three patients had difficulty in doing CIC and needed additional procedures in the form of a Mitrofanoff channel, Mitrofanoff stomal revision and a meatoplasty respectively. Apart from the secondary continence procedures, additional secondary procedures in the form of caesarean section for pregnancy, stone procedure (PCNL, URSL) and vaginoplasty, prolapse repair were needed in 5 patients. In the diversion group, one patient developed bilateral renal stone disease requiring bilateral percutaneous stone removal.

For assessment of continence, after exclusion of 3 patients who had undergone permanent diversion after

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Table 1 Demographic characteristics of patient cohort who underwent intervention for incontinence following exstrophy repair in childhood.

	n (total patients = 27)
Gender	
Male	**16**
Female	**11**
Median age at presentation in years median, (IQR)	**21 (15,27)**
Mean age at first surgery, months median, (IQR)	**6 (1,10)**
Initial operative concept	
Single-stage	**2**
Staged	**25**
No of previous surgeries, median (IQR)	**4 (3,7)**
Clinical examination findings	
• Completely broken down repair with exposed bladder plate	**3**
• Suprapubic/penopubic fistula with urethral breakdown	**6**
• Well reconstructed abdomen with urethral leak	**18**
Present continence mechanism	
Per urethral	**24**
Mitrofanoff	**3**
Imaging	
Upper tracts	
Normal	**25**
Dilated	**2**
Serum creatinine, median (IQR)	**0.71(0.6,1.0)**
Location	
Urban	**18**
Semi urban	**3**
Rural	**6**
Education level	
Secondary school level	**8**
High school diploma	**11**
Graduate	**8**
Occupation	
Attending high school	**7**
Studies in college	**1**
Unemployed	**3**
Self-employed	**3**
Unskilled employee	**8**
Skilled professional	**5**
Marital status	
Unmarried	**15**
Married	**11**
Divorced	**01**

cystectomy, we analyzed the remaining 24 patients who had their bladder plate preserved. At last follow up, only one patient was volitionally voiding to completion, with the rest 23 doing CIC through Mitrofanoff channel or by perurethral route.

Unlike the traditional objective definition of continence that has often been used in previous studies, which is a dry interval of minimum 3 h or more between voids or catheterizations, we used a criterion of 90 min in our study. Based on our experience, 90 min was the minimum duration that we expected in the immediate post-operative period and this duration tend to increase over time with increase in augmented bladder volumes. As some of our patients had a shorter follow-up, it was more logical to use 90 min as the cut-off in our study. Fig. 3A shows the dry intervals range in the cohort.

With respect to diaper usage, 17/24 (71.7 %) patients did not need diapers as shown in Fig. 3B. Three patients needed $\leq$2 diapers per day and four patients needed >2 diapers per day.

We were able to contact all 24 patients for the cross-sectional survey using the ICIQ questionnaire. The median time to the questionnaire survey following the last surgical intervention for incontinence was 94 months (IQR:46—138). With regards to the ICIQ scores, only 21 % (5/24) had severe persistence urinary incontinence based on ICIQ UI scores (Fig. 3C). Based on our criteria of social continence, we had 67 % (16/24) of the patients who were socially continent and were able to live a life without much interference by urine leak.

Discussion

Over the years the long-term outcomes in children born with exstrophy has tremendously improved thanks to the efforts of doyens of pediatric urology. Unfortunately, inspite of such rapid advances and improvements in the management of this disorder, we do tend to see children who grow into adolescence and adulthood with persisting incontinence [5—10]. This is especially a problem in developing countries, where due to the lack of proper transition services of these children to adulthood, these children tend to disappear from the follow up of pediatric surgeons/urologist who had managed them initially and end up with adult urologist who may not have the expertise to manage such a rare and complex disorder [6—10]. Unfortunately, literature on management of this group of patients has been very sparse, with most papers focusing on primary adult repairs and have offered diversion as the only option in most of these patients [6—10]. In this paper, we have tried to highlight management of this particular group of children who have now grown into adulthood with persisting incontinence with special emphasis on bladder preservation strategies.

The reasons for these children growing up into adolescence without attaining continence are many ranging from poor accessibility to medical resources, to ignorance on availability of resources and sometime even misinformation that continence will develop over time as they grow up [6]. While adolescence is a period of drastic change in the child's hormonal and social milieu the added challenged of persisting incontinence makes the life of these children miserable and leads to adjustment issues. Adding to this is the lack of availability of expertise in managing such a complex problem in the form of a trained transitional or adult reconstructive urologist who have had adequate exposure to congenital conditions.

By the time these young adults finally reach a surgeon with expertise, many of them have undergone multiple

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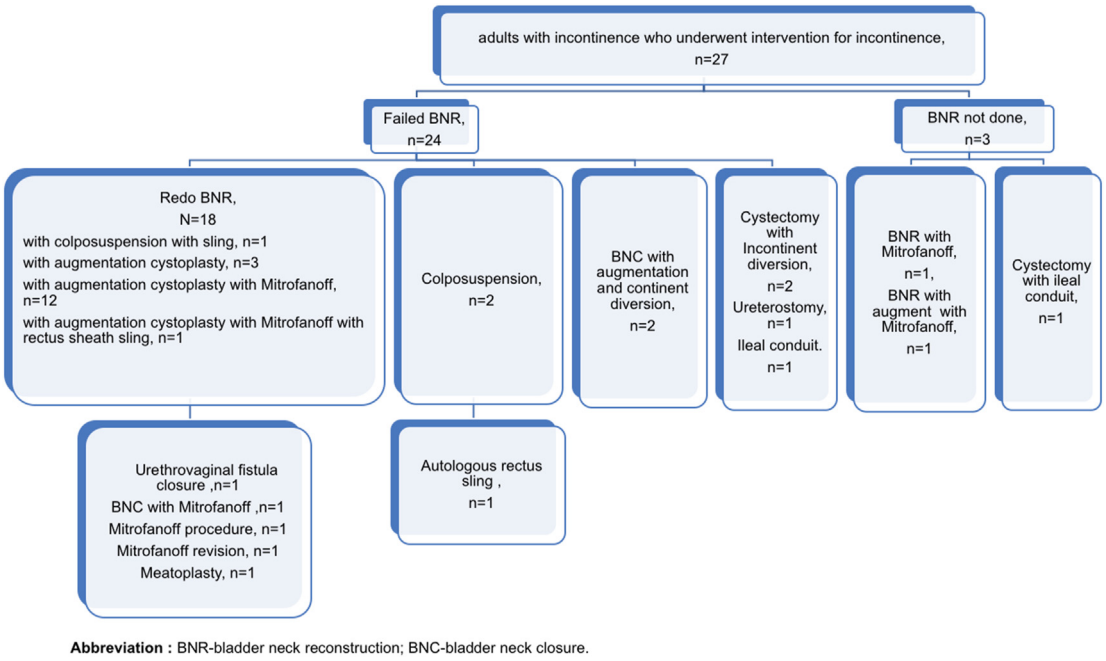


Fig. 2 Flow chart showing different surgical management options used in cohort of adolescent and adults of bladder exstrophy/epispadias complex with persistent incontinence.

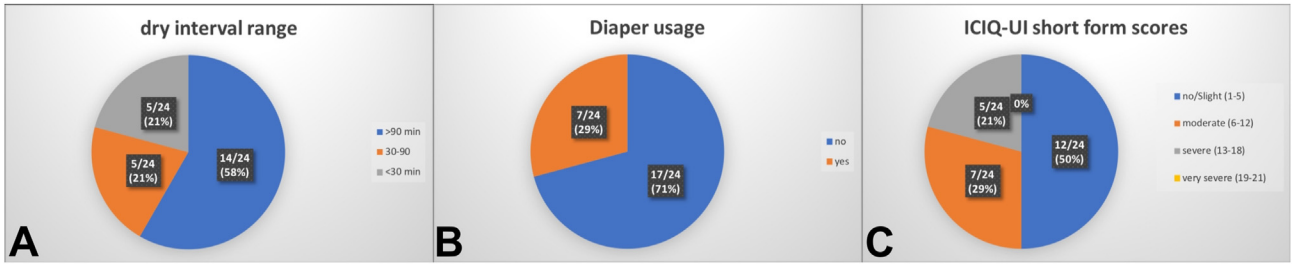


Fig. 3 Pie chart showing A. Dry interval ranges in the operated cohort at last follow up **B.** Diaper usage at last follow up and **C.** ICIQ UI short form score ranges in the cohort in cross sectional survey.

procedures which may adversely affect the quality of available tissue for creating any anti incontinence mechanism. In our patient cohort too, our patients had undergone a median of 4 surgeries before presenting to us and a majority had undergone some form of BNR (16/24, 71 %) before presenting to us. Some patients unfortunately may end up in chronic kidney disease also due to a poorly compliant bladder lading to damage to the upper tracts. This makes it very challenging for the treating surgeon to address the continence issues and it needs experience and even ingenuity on the part of operating surgeon to come up with management plans to address the incontinence as these need to be individualized to each patient. We had two patients who presented with chronic kidney disease and ultimately needed an ileal conduit and an ureterostomy respectively.

Among the procedures that were commonly needed in most of our adult patients were an augmentation with a bladder neck reconstruction with a continent stoma which was needed in 16/24 of patients. Most of these patients had some form of bladder neck tightening initially, which had failed. As is evident in our study, augmentation becomes necessary in nearly all of our patients as most of the remaining bladder wall will be used up for the BNR and because of the same reason, the addition of a continent stoma becomes imperative so as to allow effective emptying of the augmented bladder. This is in accordance with the observation of Burki et al. whose series on redo BNR in children where augmentation is necessary in nearly all patients [11]. We have a low threshold to augment in our patients as a bladder outlet procedure without augmentation makes the patients prone for upper tract changes and also decreases the chance of continence as shown by Grimsby et al. [12].

Continence outcomes following bladder neck reconstruction in the exstrophy population has been described mostly in children [11—17]. Our results following redo BNR is similar to that of Burki et al. who had addressed persistent incontinence following BNR as part of exstrophy repair in children. Similar to their study we observed that

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volitional voiding is very rare in this cohort of patients and majority of these patients will need CIC through Mitrofanoff for continence [11]. Nearly 70 percent of patients in our cohort were dry which is similar to the observation of Burki et al. and Gearhart et al. who had 60 % and 70 % of patients dry following redo BNR [11,17].

However, in a few patients a formal bladder neck reconstruction can still fail, in these situations' additional measures like colposuspension in females or an autologous rectus sheath sling may be needed [18,19]. An important reason we resorted to additional adjunct measures for continence was that though most of the patients were not averse to using a continent stoma, almost all of them were reluctant to consent to an irreversible option of a bladder neck closure. This shows that inspite of the fact that their perurethral passage is practically not used for voiding, taking a radical step of closing it permanently to achieve complete continence is something that most young adults don't prefer even at the risk of having some a little amount of incontinence. Also, we believe that in many of these patient's urethral pop-off can be beneficial in avoiding over distension of the augmented bladder and thereby decreasing the risk of spontaneous perforation which can be a real risk in patients following bladder neck closure.

Our study is especially unique, as to our knowledge it's the first study to assess outcomes of repeat BNR and adjunct procedures in adolescent and adults' patients. The fact that most patients achieved a reasonable level of social continence with this procedure shows that even when patients present in adulthood following previous bladder outlet procedure in childhood, if reasonable amount of local bladder tissues is available then a formal bladder neck reconstruction should be attempted and a hasty decision to bladder neck closure should not be taken.

An often-overlooked factor that need to be looked into these patients who present with leak following lower tract continence surgery is the adequacy of emptying when they are doing CIC as sometimes incomplete emptying or difficulty in emptying through the Mitrofanoff can lead to constant residual urine which leads to leakage. This was evident in our series too where 3 patients needed procedures to address the emptying by a Mitrofanoff addition or revision and meatoplasty as shown in Fig. 1.

Urinary diversion is a last resort that we use in patients where every attempt at maintaining the natural urethral pathway has failed due to multiple previous surgeries that preclude any form of effective bladder outlet procedure or the patient is very particular about being completely dry [6,7,19]. This usually necessitates a formal bladder neck closure with a continent diversion. Care has to be taken that these patients are educated and explained about the need for proper follow up to assess the upper tracts and strict adherence to CIC schedules. In our series, we needed bladder neck closure in three patients who were quite fed up with the need for diapers and wanted to be completely dry. In cases where there is not much bladder at all for a closure, an excision of the bladder plate with an incontinent diversion in the form of a ileal conduit becomes necessary, as was the case in three patients in our series.

All these procedures being major reconstructive interventions the possibility of complications both short-term and long-term are always there and patients have to be explained the need for long term follow to identify long term complications. Some of the early complications we encountered were mainly infective complications and bowel complication like subacute obstruction. The risk of late complications in any series of complex reconstructive operations on the urinary tract is always a concern, and vigilance from the patient/caregiver, as well as rigidly structured follow-up, are of great importance. The median follow-up period in the present series was 42 months, and hence comment on long-term complications cannot be made but the long-term complication rate might be expected to increase with the overall time from surgery.

Apart from the retrospective nature of the study, one of the main limitations of the present study is, due to the short follow-up of these patients as already mentioned, the long-term outcomes cannot be commented upon. Also, we have not commented on the other outcome aspects like genital satisfaction, sexual, fertility outcomes and overall quality of life which are also important aspects to be considered in this cohort.

Conclusions

Successful management of exstrophy epispadias complex requires a low-pressure bladder, healthy upper tracts, and a functioning continence mechanism. However, a number of children reach adolescence and remain incontinent. Our study of this select group of adolescent and adults with ongoing incontinence following failed exstrophy repairs has shown that with persistence and creativity, even in the scenario of a previously failed BNR, these patients can be made socially continent, thus proving that a reliable alternative exists without resorting to cystectomy with permanent urinary diversion.

Declaration of generative AI and AI-assisted technologies in the writing process

No AI tool was used in the preparation of the manuscript.

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Conflict of interest

None.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.jpurol.2025.05.008.

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