

Adult patients treated for bladder exstrophy at a young age: What are their current demands?

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ABSTRACT

Introduction: Bladder exstrophy-epispadias complex is a rare condition that necessitates numerous surgical procedures during a patient's youth to achieve adequate urine storage and continence. This study aimed to identify the specific needs and functional challenges faced by adults who underwent pediatric bladder exstrophy reconstructions and assessing the management of these issues in an adult population.

Methods: A retrospective chart review was conducted for all bladder exstrophy complex patients who underwent surgery at a young age and were subsequently referred to our center between 2005 and 2020. Inclusion criteria included patients with cloacal or classical bladder

KEY MESSAGES

- Adults with bladder exstrophy arrive at adult facilities with various urinary reconstruction types.
- Their primary concerns are frequently related to continence or catheterization issues.
- Most patients who have achieved satisfactory functional outcomes perform self-catheterization using a continent cutaneous channel and have either a continent pouch or an augmented bladder.
- Transitional urology is of paramount importance in optimizing the care of bladder exstrophy patients.

exstrophy older than 18 years. We recorded the reasons for referral, management of contemporary complaints, types of past and present urinary reconstructions, and their current functional status.

Results: The study included 38 patients. The primary reasons for referral were incontinence (39%) and catheterization difficulties (24%). Management typically involved partial or complete surgical revision of their urinary reservoir, occasionally combined with a bladder neck procedure. Ultimately, only three patients continued to experience incontinence, while none reported catheterization issues after they underwent treatment at our center. Long-term exstrophy-related reconstruction complications included urinary tract infections (39%), stones (29%), stenosis (24%), fistulas (13%), chronic renal disease (16%), metabolic abnormalities (3%), and cancer (3%).

Conclusions: Adults who previously underwent bladder exstrophy reconstruction exhibit a wide range of urologic reconstructions. Their needs often revolve around continence and catheterization concerns. Most patients with satisfactory functional outcomes perform self-catheterization through a continent cutaneous channel and have either a continent pouch or an augmented bladder.

INTRODUCTION

Bladder exstrophy–epispadias complex (BEEC) constitutes a rare spectrum of anterior midline defects with variable expressions, involving the urinary tract, abdominal wall, musculoskeletal system, genitalia, and occasionally the intestinal system. From a urological perspective, the anomalies within this spectrum span from distal epispadias to cloacal exstrophy¹. The estimated incidence of BEEC ranges between 0.3 and 2.2 cases per 100,000 live births in Europe².

The management of BEEC often necessitates multiple surgical interventions to attain continence, sexual function, and satisfactory aesthetic outcomes for the abdominal and genital regions. Surgical correction for BEEC presents one of the most challenging situations in pediatric urology, and the principles guiding these procedures have evolved significantly over the years³. For instance, in the past, ureterosigmoidostomy was the preferred method for urinary diversion, whereas in contemporary practice, single or multiple staged approaches for native bladder closure are preferred. Contemporary care predominantly involves primary bladder closure (PBC) in newborns, followed by epispadias repairs and bladder neck reconstruction in subsequent years. Some practitioners now combine these into a single one-stage procedure within the first few months of life^{4,5}. Unfortunately, the success rate of these early procedures is limited, and a substantial number of children and young adults will require additional surgeries to achieve adequate bladder capacity, continence, and sexual function [6]. Consequently, adult urologists may encounter patients who underwent multiple surgeries during their youth, resulting in heterogeneous reconstruction configurations and diverse clinical presentations.

Given the paucity of literature on the management of adult patients who previously underwent BEEC surgery, our study aims to identify the most frequent functional deficits and requests among these individuals referred to our center. Additionally, we seek to describe the management options for these issues and their associated outcomes. Furthermore, we explored the complications associated with long-standing BEEC reconstruction.

METHODS

We conducted a retrospective review of bladder-epispadias exstrophy complexes patients who were referred to our center between 2005 and 2020. Our center is a tertiary adult urological facility renowned for its high volume of referrals in the fields of neurourology, reconstructive urology, and functional urology. Inclusion criteria encompassed previously operated cloacal and classic bladder exstrophy patients who were older than 18 years when referred to our center. All types of urological reconstructions were taken into consideration. Exclusion criteria involved patients with variant diagnoses, isolated epispadias cases, and those lacking sufficient details to classify their current or past reconstruction situations.

We meticulously examined medical records to identify patients and establish baseline characteristics, including demographic information and operative history related to urological reconstruction (excluding endoscopic procedures, isolated ureteral stent surgeries, and non-reconstructive surgeries). We also documented the continence mechanisms at the time of referral. Urological reconstruction types were categorized into the following groups: heterotopic pouch (HP), augmented cystoplasty associated with cutaneous continent derivation (AC-CCD), primary bladder closure only (PBC), urinary conduits, and ureterosigmoidostomy internal diversion (U-sig) procedures. When applicable, we also documented the bladder neck (BN) status, distinguishing between open bladder neck surgical reconstructions (including lengthening procedures like the Young-Dees-Leadbetter or the Pippi Salle), bladder neck closure (BNC), or bladder neck suspension (BNS).

Within the charts, we recorded the reason for referral, such as simple follow-up (including the transition from pediatric to adult care), incontinence or catheterization issues, and other urological problems, including recurrent infections, stone formation, cancer, and upper urinary tract deterioration. Continence status was determined based on patient reports, meticulously documented in the medical records.

Lastly, we documented the final reconstruction type and continence mechanism after their management at our center, along with their urological outcomes. These final functional outcomes encompassed micturition methods, continence status and sexual function.

RESULTS

A total of 38 patients met our inclusion criteria and were included in our study. Classic bladder exstrophy accounted for the majority (92%), while cloacal exstrophy accounted for the remaining (8%). Detailed patient characteristics, reasons for referral, and the nature of their

urinary reconstructions at the time of referral are presented in Table 1. Specific needs or problems, categorized according to their initial reconstruction types, are illustrated in Figure 1.

Management

Specific management strategies for patients' initial complaints are presented in Table 2. The post-management urological reconstruction types are illustrated in Figure 2.

Functional outcomes and complications

Functional outcomes were assessed after a mean follow-up period of 121 months. Micturition mode and continence function are reported in Table 3. All complications related to the urinary reconstruction type are presented in Table 4.

Internal diversion

Of the five initial U-Sig patients, only one maintained this type of urinary diversion due to severe chronic renal disease and comorbidities that precluded further surgical intervention. His continence status was satisfactory. Unique complications for U-sig patients included digestive adenocarcinoma (1/5) and severe metabolic abnormalities (2/5). Multiple severe infections (3/5), defined as more than three febrile infections in a year, were also frequent in this group.

Incontinent external diversion

At the last follow-up, seven out of nine patients with a urinary conduit still maintained this diversion. These patients were older (mean age of 61 years), and the majority (5/9) had grade 3 chronic renal disease at the time of referral. Following management, two patients with initial U-Sig were converted to an ileal conduit. Conduits were predominantly associated with recurrent and severe infections (7/11), complex renal stones (5/11), renal function degradation (5/11), and ureter-to-conduit stenosis (8/11).

Continent external diversion

Bladder augmentation with or without BNC

At the last follow-up, all 14 initial AC-CCD patients continued with this bladder management configuration. Among the five patients referred for urethral incontinence, two underwent a BNC, two received a BNS, and one declined the implantation of an artificial urinary sphincter (AUS). Continence rate was 100% for BNC, and 50% with BNS. Overall, 13 out of 16 (81%) final AC-CCD patients reported a satisfactory continence status. Failures included the one who refused the AUS, one BNS procedure failure, and one CCD leakage after a partial Mitrofanoff revision for stenosis. The occurrence of bladder stones was only associated with AC-CCD combined with BNC procedures (2/7). Otherwise, the major complication was CCD stenosis occurrence (7/14).

PBC without augmentation

All patients without AC at the initial presentation (7) were incontinent. Four of them declined surgery and maintained spontaneous urethral voiding and incontinence. All were female patients with a mean age of 35 years and had a PBC with bladder neck surgical reconstruction during

their early years. Unfortunately, the reasons for refusal were not documented in the chart. The other three patients underwent either AC-CCD (2) or an HP (1) and were continent at the last follow-up.

HP

Among the three patients with an HP configuration at presentation, two were referred for a pouch-to-vagina and pouch-to-native-urethra fistula, which were managed by fistula repair in addition to a pouch revision in one patient. At the last follow-up, seven out of eight (88%) final HP patients were dry, and one (12%) experienced CCD leakage.

DISCUSSION

Many patients with BEEC undergo extensive surgeries in their youth, with up to 70% requiring bladder augmentation or urine diversion, and approximately 60% needing additional BN procedures before adulthood⁷. Although short-term continence success rates are high (around 80-90%), long-term continence is less likely to be sustained, with only 40% of BEEC adults achieving perineal dryness⁸. In our study, the most common adult concern related to pediatric BEEC reconstruction was incontinence, affecting 39% (15/38) of our patients. We must, however, account for the obvious selection bias. Indeed, as our center specializes in reconstructive and functional urology, it will mainly attract referrals for bladder and urethral dysfunction. Despite this, we can however outline that all patients with PBC and BN reconstruction as the sole continence procedure were incontinent when referred to our center, while only 5/14 (36%) of those with AC at the time of referral experienced this issue. In these two groups, incontinence complaints were managed at our center by ensuring adequate bladder capacity, bladder neck manipulation, or creating a heterotopic continent pouch, with an overall success rate of 84%. Previous reports suggest that HP, AC with BN closure, AC with BN reconstruction, and PBC with BN reconstruction are more likely to result in long-term dryness^{9,10}. However, the optimal incontinence management should consider factors such as the severity of incontinence, the number and type of previous bladder procedures, and the patient's capacity and willingness for self-catheterization. Bladder conservation is feasible in most cases, but for those with a urinary conduit or ureterosigmoidostomy seeking an alternative continent system, HP with CCD appears to be the preferred option.

Excluding conduits and U-Sig, only 14% (4/28) of our patients maintained spontaneous urethral micturition, while the rest used a CCD for bladder emptying. This aligns with previous findings that only 15-25% of BEEC reconstructed patients can void normally via the urethra in the long term, with most relying on self-catheterization^{10,11}. Surgical procedures and bladder neck and urethral surgeries can lead to bladder fibrosis, detrusor decompensation, and obstructive voiding. Indeed, the multitude of surgical procedures may lead to bladder fibrosis with later detrusor decompensation while the bladder neck and urethral surgery may cause obstructive voiding that led to emptying failure^{8,12}. CCD creation may be needed after BNC to address urethral incontinence, HP creation or unsuitable urethra. CCD issues experienced by our

patient are the same as in the general population, including leakage and stenosis. Those complications are reported to occur in about 1/3 of cutaneous catheterize channels in the long run^{13,14}.

Sexual function outcomes were unfortunately not reported in our study due to multiple reasons, including the infrequent availability of such data in the patient charts, the absence of referrals for this specific issue to our center, and, when mentioned, the lack of standardized or validated questionnaires for evaluation. Furthermore, a striking omission was the virtual absence of mentions concerning female sexual function within our patient charts, despite it being a prevalent and well-documented issue in individuals affected by BEEC, irrespective of their gender^{15,16}. This underreporting could be attributed to several factors, including a lack of knowledge regarding its management, practitioner bias where other issues like continence are perceived as more important, and the potential patients' reticence to raise concerns about this sensitive topic. Another notable gap in our study was the omission of quality-of-life reports using easily available validated questionnaires. This oversight highlights the necessity of standardizing BEEC patient management, which, in turn, would facilitate a more comprehensive assessment of their well-being.

These observations underscore the importance of standardization in healthcare practices, such as implementing screening questions for sexual function, to alleviate patient hesitance in addressing these vital aspects of their well-being. Healthcare providers must recognize that a holistic approach to patient care includes addressing not only physical but also psychosocial aspects to ensure comprehensive and patient-centered management in BEEC cases. The lack of such assessments in our specialized center, both in terms of quality of life and sexual function, should prompt us to reflect on the opportunities for optimizing patient care within our center. Comprehensive and standardized evaluations, including these aspects, can significantly enhance the overall quality of care provided to individuals with BEEC.

Long-standing urinary tract reconstructions may be associated with intercurrent diseases. U-Sig, followed by conduits, had more severe complications, including renal deterioration, complex renal stones, electrolyte disturbances, and urinary diversion-associated neoplasia, which is consistent with previous reports^{17,18}. In this sense, U-Sig should not be considered an adequate urinary diversion option, and if conversion to another diversion type is not possible, close follow-up is mandatory. Ileal conduit should be a last resort when self-catheterization is not feasible, while continent diversions such as AC-CCD and HP should be considered preferable options as they allow for satisfactory continence outcomes without significant higher complication rate.

Conducting appropriate and precise studies on this specific population presents challenges due to the necessity of waiting decades to judge the true long-term implications of these surgeries. Therefore, because of its far retrospective aspect, data collection is arduous and imprecise, as seen in this study. Monitoring BEEC patients as they age into early adulthood is crucial for understanding the impacts of urinary reconstruction and their sustainability over time.

The development of effective pediatric-to-adult transitional programs is thus essential to decrease complications related to poor urological follow-up. These programs could facilitate the identification of procedures that are not sustainable into adulthood and optimize the initial surgical management of BEEC patients. Longer adult cohort patient follow-up is also mandatory to determine the performance of surgical management over the long term. This reinforces the need for structured transitional urology programs to obtain more complete data and draw more precise conclusions about the functional outcomes and complication rates of long-term pediatric reconstructions for BEEC.

CONCLUSIONS

Adults who have undergone bladder exstrophy repair in childhood may present with a wide range of bladder and bladder neck reconstructions in adulthood. Their complaints are often associated with continence or catheterization issues. In our cohort, most adult patients achieved satisfactory functional outcomes using a CCD in conjunction with either a continent pouch or an augmented bladder. Additional procedures such as bladder neck suspension, closure, or lengthening may be needed to achieve adequate urethral continence. This study focuses on the experiences of our adult urology center in managing long-term complications of bladder exstrophy in a carefully selected group of patients. It also emphasizes the importance of referring BEEC patients to specialized adult centers as they transition into adulthood as well as underlining the need for more standardized and comprehensive follow-up.

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FIGURES AND TABLES

Figure 1. Patients’ requests associated with their urinary reconstruction type at the time of referral.

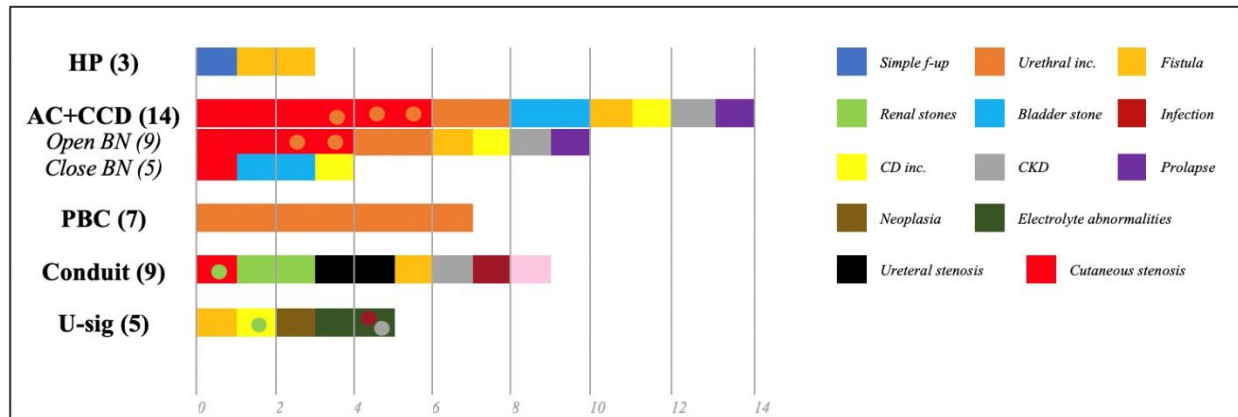


Figure 2. Patients’ urinary reconstruction type after management

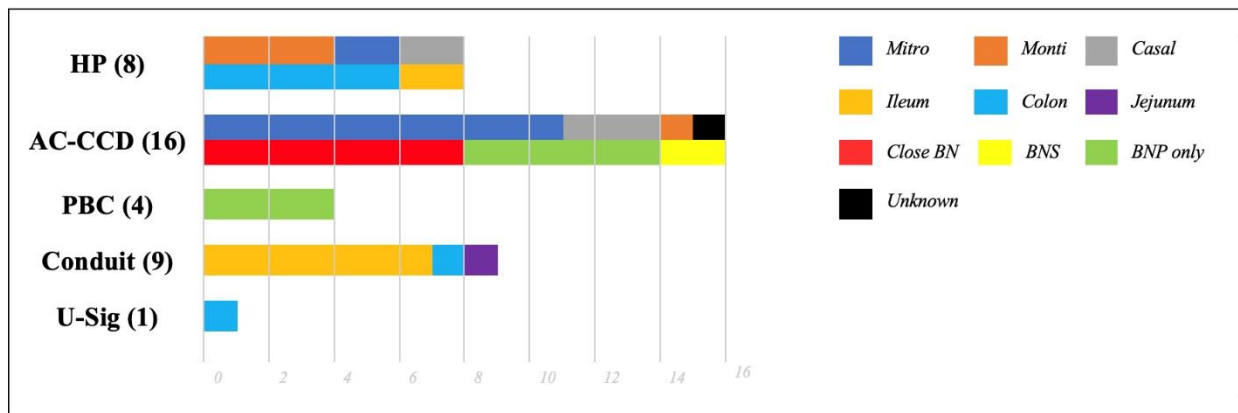


Table 1. Patients' demographics and requests at the time of reference	
Mean age at the reference (range), y	32 (20–62)
Mean age at last follow-up (range), y	44 (23–72)
Mean followup (range), m	121 (0–396)
Sex, n (%)	
Women	17 (45)
Men	21 (55)
Type of BEEC, n (%)	
Classic exstrophy	35 (92)
Cloacal exstrophy	3 (8)
Total number of past reconstructive surgery, n (%)	
<5	8
5–10	17
11–20	4
> 20	4
Unknown	5
Mean (range)	9 (2–25)
Initial urinary reconstruction status, n (%)	
HP	3 (8)
AC-CCD	14 (37)
Primary bladder closure only	7 (18)
Conduit	9 (24)
U-Sig	5 (13)
Initial bladder neck status (n=21)	
Open, n (%)	16 (76)
Lengthening procedure, n	16
ACT, n	1
Closed, n (%)	5 (24)
Initial requests, n (%)	
Simple followup	1
Incontinence	15 (39)
Catheterization issues	9 (24)
Fistula	5 (13)
Electrolyte abnormalities	2 (5)
Stones	5 (13)
Infection	3 (8)
Upper tract deterioration	3 (8)

AC-CCD: augmented cystoplasty + cutaneous continent derivation; ACT: pro-ACT™ paraurethral balloon; BEEC: bladder exstrophy-epispadias complex; HP: heterotopic pouch; m: month; U-sig: ureterosigmoidostomy internal diversion; y: year.

Table 2. Management of patients' initial complains according to their reconstruction type at time of referral			
Urinary reconstruction type at the time of referral	Reason for referral	Urinary reconstruction type after management	Management
U-Sig (5)	Electrolyte abnormalities and CKD	U-Sig (1)	No surgery, nephrology F/U
	Uretero-sigmoid anastomosis ADK Electrolyte abnormalities	Conduit (2)	Colectomy + ileal conduit (1) Ileal conduit alone (1)
	Anal leaking and UTI Uro-enteric fistula	HP (2)	HP creation (2)
Urinary conduit (9)	1- Uro-enteric fistula 2- Ureteral stenosis (2) 3- Cutaneous stenosis + stone (1) 4- Renal stones (2) 5- CKD	Conduit (7)	1,2,5- Creation of a new ileal conduit (4) 3-Partial conduit revision (1) 4- Stone management only (2)
	UTI Desire for continence	HP (2)	HP creation (2)
PBC + BN reconstruction (7)	Urethral incontinence for all	No change (4)	Patient refusal for AC-CCD and BN procedures (3) Lost in F/U (1)
		HP (1)	HP creation (1)
		AC-CCD (2)	AC-CCD creation (2): - With BN closure (1) - Without BN procedure (1)
AC-CCD (14) <i>Close BN (5)</i> <i>ACT (1)</i>	1- CKD (1) 2- Prolapse (1) 3- Uro-vaginal fistula (1) 4- Urethral incontinence (5) 5- CCD incontinence (1) 6- Bladder stone (2) 7- CCD stenosis (6)	AC-CCD (14) <i>Close BN (7)</i> <i>BNS (2)</i>	1- Transplant 2- Promontofixation 3- Fistula repair 4- BNS (2), BNC +AC (1), BNC alone (1), Patient refusal for AUS (1) 5- Partial CCD revision + AC 6- Percutaneous (1) and per-CCD (1) lithotripsy 7- Partial (2) and complete (4) CCD revision
HP (3)	1- HP-urethral fistula 2- HP-vaginal fistula 3- Simple F/U	HP (3)	1,2- Fistula repair (2) and complete HP revision (1) 3- F/U

AC-CCD: augmented cystoplasty + cutaneous continent derivation; ACT: pro-ACT™ paraurethral balloon; ADK: adenocarcinoma; AUS: artificial urinary sphincter; BN: bladder neck; BNC: bladder neck closure; BNS: bladder neck sling; CKD: chronic kidney disease; F/U: followup; HP: heterotopic pouch; PBC: primary bladder closure; U-sig: ureterosigmoidostomy internal diversion; UTI: urinary tract infection.

Table 3. Functional status after management at our center according to the urinary reconstruction type		
A) Micturition mode		
KT via CCD, n	24 (8 HP, 16 AC-CCD)	
Spontaneous voiding, n	4 (4 PBC)	
Other, n	10 (1 U-Sig, 9 Conduits)	
B) Contenance status		
Actual reconstruction	Yes	No
Total (excluding conduit)	21	8
HP (8)	7	1
AC-CCD (16)	13	3
BNC (8)	8	0
BNS (2)	0	2 (1 via the CCD)
Without BN procedure (6)	5	1
PBC (4)	-	4
U-Sig (1)	1	-

AC-CCD: augmented cystoplasty + cutaneous continent derivation; BNC: bladder neck closure; BNS: bladder neck sling; HP: heterotopic pouch; KT: catheterization; PBC: primary bladder closure only; U-Sig: ureterosigmoidostomy.

Table 4. Overall complications				
Complication, n (%)	HP	AC-CCD	Conduit	U-Sig
Infection, 15 (39)				
Multiple (>3)	–	5	4	3
Severe	–	–	3	-
Stone, 11 (29)				
Complex renal	–	1	5	2
Bladder	–	2	–	–
inconnu	–	1	–	–
Stenosis, 9 (24)				
Cutaneous	–	7 (Mitro)	1	–
Ureteral	–	–	3	–
CKD, 6 (16)				

Adults who underwent pediatric bladder exstrophy reconstructions

Stage 2	–	–	1	–
Stage 3–4	–	1	4	–
Fistula, 5 (13)				
Uro-enteric	–	–	1	1
Gyneco	1	1	–	–
Uro-uro	–	–	–	–
Other				
Metabolic abnormality	–	–	–	2
ADK	–	–	–	1

AC-CCD: augmented cystoplasty + cutaneous continent derivation; ADK: adenocarcinoma;
 CKD: chronic kidney disease; HP: heterotopic pouch; Mitro: Mitrofanoff; U-Sig:
 ureterosigmoidostomy.

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