Is Delayed Primary Bladder Exstrophy Closure the New Norm? An Analysis of the Epic Cosmos Database

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OBJECTIVE To determine the age at primary bladder exstrophy (BE) closure from 2012 to 2023. We hypothesized that the median age at primary BE closure increased from within the first week of life to more delayed closure.

METHODS A retrospective, cross-sectional analysis was performed using the Epic Cosmos database. BE patients were identified using a combination of diagnostic and procedure codes. The use and timing of pelvic osteotomies, epispadias repairs, postoperative complications, and length of stay were also noted.

The primary outcome was the age at the primary BE closure. Delayed closures were defined as occurring > 7 days of life. Secondary outcomes included other surgical and postsurgical aspects (eg, concomitant epispadias repair and/or osteotomy, postoperative complications, and length of stay).

RESULTS One hundred forty-nine patients (77(52%) male) were identified as having a BE closure within the database. Of these, 10(7%) had an epispadias closure and 52(35%) had pelvic osteotomies coded within 2 days of their BE closure. The majority (44/52) (85%) of osteotomies occurred in patients whose BE closures were performed at > 7 days of age. In 4 of the first 5 years of the study, the median age at BE closure was within 1 week of birth. Conversely, in 6 of the last 7 years of the study, the median age at BE closure was ≥2 months of life.

CONCLUSION Data from Epic Cosmos hospitals suggest a shift from immediate postnatal to delayed primary BE closure between 2012 and 2023. Only one-third of patients underwent pelvic osteotomy synchronous with BE closure. UROLOGY 205: 196–203, 2025.

Bladder exstrophy (BE) is a rare and severe congenital anomaly of the genitourinary system, characterized by the incomplete closure of the lower abdominal wall during fetal development, resulting in the exposure of the bladder mucosa.[1-3] The incidence of BE ranges from approximately 1 in 20,000 to 1 in 50,000 live births.[4,5] The impact of BE on patients and healthcare systems is profound, presenting significant challenges due to its complexity, and the extensive surgical interventions required.[6]

Historically, the primary surgical closure of BE was performed within the first 72 hours of life, with delayed closures only reserved for patients with bladder templates considered too small for immediate postnatal closure.[3] Early closure was believed to promote early bladder cycling for optimal bladder growth and improve urinary continence,[7,8] and has the advantage of approximating the pubic bones without the use of osteotomies. However, with the development of bladder exstrophy consortia, delayed primary BE closure was required for practical reasons.[6,9,10] The team of BE experts was required to travel from different regions to convene for each BE closure.[6,9-12] Proponents of delayed BE closure suggested that additional benefits were achieved by permitting critical early parental bonding with their newborns.[7] Delaying surgery may be beneficial from an anesthetic safety perspective as well. Furthermore, studies indicate that the incidence of perioperative complications and surgery-related morbidity is higher in newborns than in older children, suggesting a potential safety advantage to delaying surgery until 3 to 4 months of age.[13,14]

Abbreviations: BE, Bladder exstrophy; NSQIPP, National Surgical Quality Improvement Program Pediatric; ICD, International Classification of Diseases; CPT, Current Procedural Terminology; UTI, Urinary tract infection; SSI, Surgical site infection; LOS, length of stay

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Ahn's investigation into the age at BE closure at 90 select institutions participating in the National Surgical Quality Improvement Program Pediatric (NSQIPP) suggested that over 70% of primary BE closures between 2012 and 2015 occurred after 72 hours of life.[15] This study is an important contribution to the exstrophy literature because, although there are a variety of single-institution or consortia-based studies showing a trend toward more delayed primary bladder closures,[6,9,10,16,17] it was the first to show a shift towards delayed primary BE closure across a wider sample of US-based pediatric hospitals.[15] However, this study is confined to just 3 years of data and to only 90 NSQIPP participating institutions. We sought to determine if this trend toward delayed closure is consistent across another very general sample of pediatric hospitals and over a wider timeframe.

This study aims to investigate trends in the age at primary BE closure from 2012 to 2023 utilizing the Epic Cosmos database. We hypothesized that the median age at primary BE closure increased from within the first week of life in 2012 to more delayed closure (ie, > 7 days) in 2023.

MATERIALS AND METHODS

Study Design and Setting

A retrospective, cross-sectional analysis was performed using the Epic Cosmos database, a de-identified dataset containing information from 246 million distinct patients extracted from 1415 participating Epic hospitals and over 32,500 clinics. It includes diverse inpatient and outpatient information such as medical diagnoses, procedures, and socio-demographic data. While individual patient record access is not available, Cosmos nevertheless facilitates tracking individual patients across participating Epic hospitals, supporting population health insights and general care decisions.[18] The study timeframe was from January 1, 2012, to December 31, 2023.

Participants

Patients diagnosed with BE were identified using a combination of current procedural terminology (CPT) procedure codes and International Classification of Diseases (ICD) diagnostic and procedure codes. Given the aim of the study, those with BE were only included if they also had a BE closure appear in their record. Specifically, a patient was included if they had a BE diagnostic code (ICD-9 code 753.5 and/or ICD-10 code Q64.10) *and* BE closure procedure codes (CPT code 51940 and/or ICD-9 procedure code 57.86 and/or ICD-10 procedure codes 0TQB0ZZ and 0TSB0ZZ). BE patients were excluded from analysis if they had any bowel surgery, colostomy, and/or ileostomy within the first month of life (presumed to have cloacal exstrophy), if there was no BE closure code, or if there was a diagnostic (ICD-9 [752.62] or −10 [Q64.0]) and/or procedure code (CPT 54380, 54385, and 54390) for epispadias without any BE code(s) (Table 1).

Variables and Data Sources

The primary outcome was the age in days at which primary BE closure was performed. Secondary outcomes included other surgical and postsurgical aspects. These include whether epispadias repair and/or a pelvic osteotomy occurred synchronously with BE closure. These adjunctive procedures were identified with procedure-specific CPT or ICD codes (Table 1). If a subject had 2 BE closure codes, the age in days at the first code was used. For analytic purposes, we considered an epispadias or pelvic osteotomy code appearing within +/- 2 days of the BE closure as occurring on the same day. (Table 1).

Demographic variables such as gender and race were also collected. Additional information collected included events during the index surgery hospitalization (epidural use, blood transfusion, duration of stay), wound or surgical site infection (SSI) occurring within 45 days post-surgery, post-surgery complications occurring within 6 months (limited to vesicocutaneous fistula, urethrocutaneous fistula, UTI, sepsis), bladder prolapse/cystocele occurring within 24 months post-surgery, and repeat BE closure surgery as an indicator of failure. These were identified using relevant codes and timeframes as detailed in Table 1.

Statistical Analysis

Continuous variables, including age at closure and length of stay, were summarized and are reported using median (Q1-Q3) in addition to their ranges. Categorical variables were summarized using counts (N) and percentages (%). Due to privacy constraints for small cohorts within the database, counts less than 11 are reported as "< 11" and corresponding percentages calculated accordingly. The distribution of the primary outcome (age at closure), stratified by year, was displayed using box-and-whisker plots. Given that 5 years had < 11 BE closures, comparative statistics would yield unstable estimates and were not performed. All statistical analyses were conducted using R Statistical Software (version 4.1; R Foundation for Statistical Computing, Vienna, Austria).

RESULTS

Between 2012 and 2023, 149 patients were identified as having BE and undergoing primary closure at 1715 hospitals participating in Epic Cosmos. Among these, 77 (52%) were male and 72 (48%) were female. A summary of patient demographics, including the racial and ethnic breakdown, is shown in Table 2.

The year with the greatest number of closures (n = 19) was 2019, whereas the fewest number of closures occurred in 2012, 2013, 2014, 2015, and 2020 (each with < 11 closures). Across the entire study period, the median (Q1-Q3) age at BE closure was 54 days

Table 1. List of International Classification of Diseases Ninth and 10th edition (ICD-9/ ICD-10) and current procedural terminology (CPT) codes used for inclusion and exclusion criteria and variables of interest.

Diagnosis/procedure	ICD-9	ICD-10	CPT	Time limit
Inclusion criteria				
Exstrophy of urinary bladder	753.5 57.86	Q64.10 Q64.11 Q64.19 0TQB0ZZ 0TSB0ZZ	51940	None
Exclusion criteria				
Cloacal exstrophy of urinary bladder	N/A	Q64.12		None
Epispadias (isolated)	752.62	Q64.0	54380, 54385, 54390	None
Colostomy	V44.3	Z93.3	44141 - 44143 - 44144 - 44146 - 44160 - 44188 - 44205 - 44206 - 44208 - 44320 - 44322 - 44340 - 44345 - 44346 - 44388 - 44390 - 44391 - 44392 - 44404 - 44604 - 44605 - 44626 - 45110 - 45126 - 45395 - 45563 - 45805 - 45825 - 50810 - 51597 - 57307 - 58240 - 88304 - 99505	Within the first month of life
Ileostomy	V44.2	Z93.2	44150 - 44151 - 44155 - 44156 - 44157 - 44158 - 44186 - 44187 - 44210 - 44211 - 44212 - 44310 - 44312 - 44314 - 44316 - 44385 - 44386 - 45113 - 45136 - 50825 -	Within the first month of life
Variables of interest				
Bladder exstrophy closure	57.86	0TQB0ZZ 0TSB0ZZ	51940	None
Epispadias closure			54390	None
Pelvic osteotomy		0QB20ZZ, 0QB23ZX, 0QB23ZZ, 0QB24ZX, 0QB24ZZ, 0QB3, 0QB30ZX, 0QB30ZZ:	27146 - 27147 - 27151 - 27156 - 27158.	Within 48 h of bladder exstrophy closure surgery
Other pelvic bone surgeries		*0Q820ZZ, 0Q830ZZ, 0QS20ZZ, 0QS30ZZ, 0QS304Z, 0QS204Z, 0QS305Z, 0QS205Z, 0QH305Z, 0QH205Z, 0QH335Z, 0QH235Z, 0QH204Z, 0QH304Z*		Within 48 h of bladder exstrophy closure surgery
Epidural use	03.90, 03.91, 03.92, 03.93, 99.29	3E0U3BZ, 3E0U3CZ, 3E0U3DZ	62320, 62321, 62322, 62323, 01991, 01992	During index surgery hospitalization
Blood transfusion	99.00, 99.01, 99.02, 99.03, 99.04	30233N1, 30243N1, 30233P1, 30243P1 < br > Dx: D62, R58, T81.11XA, T81.31XA	36430, 36440 < br > Products: P9010, P9016, P9021, P9022	During index surgery hospitalization
Dehiscence / Wound disruption	998.3, 998.30, 998.31, 998.32, 998.59, 998.83	T81.3XXA, T81.3XXD, T81.3XXS, T81.31XA, T81.31XD, T81.31XS, T81.32XA, T81.32XD, T81.32XS	13160, 12020, 12021, 15734, 15738, 49900, 12031–12057	Within 45 days after surgery

Table 1 (*Continued*)

Diagnosis/procedure	ICD-9	ICD-10	CPT	Time limit
Wound infection / SSI	998.5, 998.50, 998.51, 998.59, 996.66, 996.67, 590.3, 569.61	T81.4XXA, T81.4XXD, T81.4XXS, L08.9, T81.41XA, T81.41XD, T81.42XA, T81.42XD, T81.43XA, T81.43XD	Debridement: 11042–11047, 97597, 97598 < br > I&D: 10060, 10061, 10180	Within 45 days after surgery
Osteotomy-related complications	996.40, 996.41, 996.42, 996.43, 996.44	T84.010A, T84.020A, T84.030A, T84.7XXA, M96.6	20680, 27720	Within 45 days after surgery
Vesicocutaneous fistula	596.2	N32.2	51800	Within 6 months after surgery
Urethrocutaneous fistula	599.1	N36.0	53520, 53400	Within 6 months after surgery
Fistula due to genitourinary prosthetic device, implant, or graft	N/A	T83.79XA	N/A	Within 6 months after surgery
Postoperative fistula (NEC)	N/A	T81.83XA	N/A	Within 6 months after surgery
Urinary tract infection (UTI)	599.0, 996.64, 997.5, 599.81, 590.10, 590.80, 595.0	N39.0, T83.511A, T83.511D, T83.511S, T81.4XXA, T81.44XA, T83.598A, N30.00, N30.01, N30.90, N10	N/A	Within 6 months after surgery
Sepsis	038.9, 038.0, 038.11, 038.12, 038.2, 038.3, 038.42, 995.91, 995.92, 785.52	A41.9, A41.01, A41.02, A41.50, A41.51, A41.52, A41.89, R65.20, R65.21, T81.4XXA, T81.44XA, T81.44XD, T81.44XS, T81.12XA, T81.12XD, T81.12XS	N/A	Within 6 months after surgery
Bladder prolapse/cystocele	618.01, 618.02, 618.03, 618.04, 618.09	N81.1, N81.2, N81.3, N81.4	57240, 57260, 57265, 57267, 57280, 57282, 57283, 57285	Within 24 months after surgery

Table 2. Demographics of bladder exstrophy patients (N = 149).

Characteristic	Category	Patients N (%) Total = 149 (100%)
Race*		
	White	100 (67.1%)
	Black or African American	20 (13.4%)
	Other Race	11 (7.4%)
	Asian	< 10 (< 6.7%)
	Native Hawaiian or Other Pacific Islander	< 10 (< 6.7%)
	Multiracial	< 10 (< 6.7%)
	Unknown	< 10 (< 6.7%)
Ethnicity		
	Not Hispanic or Latino	117 (78.5%)
	Hispanic or Latino	21 (14.1%)
	Unspecified	11 (7.4%)

* Due to data privacy constraints for small cohorts, patient counts less than 10 are not specified

(4–132 days). Importantly, though, the range of closures was highly variable from 0 to 3647 days. Figure 1 displays the breakdown of age at closure for each year of the study. During 4 of the first 5 years of the study (2012-2016), the median age at BE closure was within 1 week of birth. However, in 6 of the last 7 years, the median age at BE closure was at least 2 months or older.

Fifty-two patients (35%) had pelvic orthopedic procedure codes appear together with BE closure. Notably, 85% (44/52) of pelvic osteotomies were in patients whose BE closures were performed more than 7 days after birth. However, only 47% (44/94) of patients with delayed closure actually had a pelvic osteotomy. Concomitant epispadias repair was coded in only 10 (7%) patients; simultaneous exstrophy closure and epispadias repair would indicate use of the complete primary repair of exstrophy (CPRE) or possibly the radical soft tissue mobilization (ie, (Kelly) repair, as opposed to the modern staged repair of exstrophy (MSRE).[19] The median length of stay (LOS) for the index BE closure hospitalization was 14.0 (7-32) days. The maximum LOS observed was 281 days. Epidural anesthesia was used in 12 patients (8.1%), and blood transfusion was required for 40 patients (26.8%) during the index hospitalization. Regarding postoperative complications and events, wound infection/SSI occurred in < 11 patients (< 7.4%), and UTIs were reported in 43 (28.9%) of patients. Any type of fistula was detected in 17 (11.4%) patients. This category comprised vesicocutaneous fistula, urethrocutaneous fistula, fistula due to genitourinary prosthetic device/implant/graft, and postoperative fistula. Vesicocutaneous fistula specifically occurred in 13 (8.7%) patients. Bladder prolapse was found in 37 (24.8%) patients. Repeat bladder exstrophy repair procedures were recorded for < 11 patients (< 7.4%).

DISCUSSION

The management and timing of BE closure remain subjects of debate among pediatric urologists.[7,16] Proponents

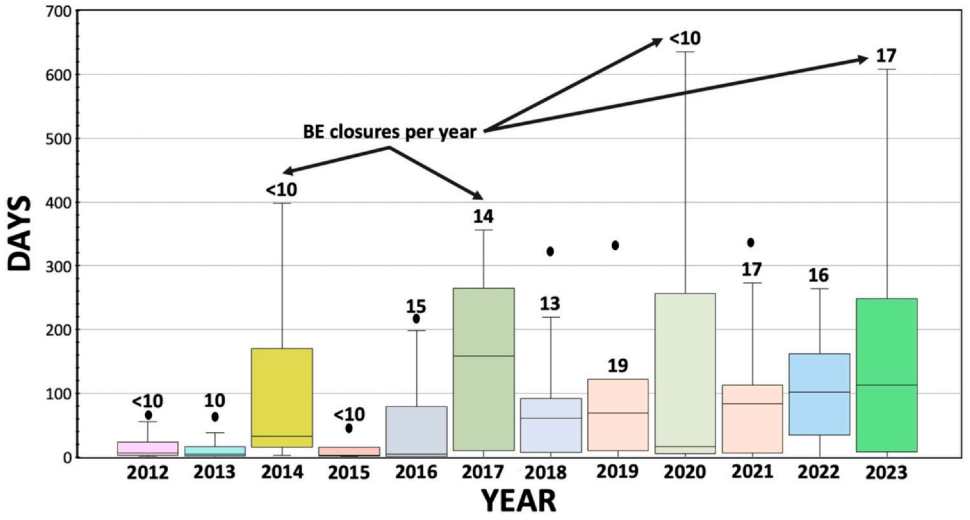

Figure 1. Box-and-Whisker plots demonstrating the age in days at primary bladder closure for each year of the study. Medians and 25th and 75th quartiles are represented, as are extreme outliers. The number of closures for any given year is shown above each bar.

of early or "immediate" postnatal closure (which is typically within 72 h of life) argue that it minimizes the risk of infection, facilitates better anatomical outcomes, promotes early bladder cycling, and obviates the need for pelvic osteotomies.[15,20] Conversely, advocates for BE closure beyond this early 72-hour window suggest that waiting allows for critical parent-child bonding, improved surgical planning, better patient physiology, and potentially fewer complications.[16,17,20] Comparative studies have yielded mixed results, with some indicating no significant difference in long-term outcomes between early and delayed closure, while others highlight benefits specific to each approach.[15,20] Our results are important because they indicate a shift towards delaying primary BE closure beyond the first week of life. Specifically, the median age at closure for the years 2012, 2013, and 2015 was within 1 week of birth; however, in the latter half of the study, the median age shifted well beyond 1 week to 3 months or later. Whatever the reason for the shift, we show that the historical teaching to close the exstrophic bladder in the first 72 hours of life is no longer the standard across a broad selection of pediatric hospitals in the United States. This shift necessitates further research to assess the implications of delaying surgery on patient outcomes.

Several factors may explain this shift away from the historical dogma to close all bladder exstrophy patients within the first 72 hours of life. One obvious reason is the advent of the multi-institutional exstrophy consortia, whose surgeons must delay surgery until the entire team can gather for initial bladder closure.[6,9,10,16,17] All of these reports come from bladder exstrophy centers of excellence and are not necessarily indicative of the broader practice patterns across North America. While only 2 of the multi-institutional collaboration hospitals contributed data to this EPIC Cosmos study and may have influenced these results, the practice patterns of these collaborative groups seem to have influenced the decision-making of the majority of exstrophy surgeons in our study with respect to the timing of initial closure. Our data support the only other study that evaluated the timing of closure at a wider breadth of pediatric hospitals.[15]

There are also other notable findings of this work. Even though there is a trend to more delayed closures, the use of pelvic osteotomies—which some exstrophy surgeons consider as an obligatory adjunct to delayed bladder closures—in only 47% of patients with a delayed closure is extremely low. One possible explanation for this alarmingly low rate of osteotomies could be a failure to select the appropriate codes to capture said procedures. However, our search criteria were very broad and specifically designed to capture the majority of patients who received this procedure. Future studies will have to confirm this finding and determine the contribution pelvic osteotomies have on patient morbidity and closure success rates. Similarly, the extremely low rate of epidural use was an unexpected finding. This could also be attributable to the under-coding, a preference for other regional anesthetic techniques that may not have been captured by our search criteria, or simply lack of awareness of the benefits of epidural catheters for postoperative pain control.

Many have shown that the success of the initial bladder closure is one of the most important factors that contribute to eventual voided urinary continence.[21-23] Therefore, this general sample of pediatric hospitals that do BE surgery can provide important insights into the success of primary closures (and eventual continence) occurring outside of the major exstrophy centers. Repeat BE closures occurred in an extremely small number of patients in this study (< 11 patients or < 7.4%), which, if true, represents incredible success with this extremely complex surgery. Failed initial bladder closures, however, are most likely much higher because this number does not account for patients with a failed BE closure who left the EPIC Cosmos system and sought care at a non-participating hospital. We propose that the bladder prolapse rate of 25% is more indicative of failed primary closure because bladder prolapse is considered by many to be a failed closure.[24,25] That is, nearly all with bladder prolapse will require a repeat closure. Accordingly, if the 25% bladder prolapse rate is considered a failed primary closure, these data are concerning, considering the high stakes and importance of the primary bladder closure.

Interestingly, the 10 epispadias repairs coded at the same time as the bladder closure is a very low number. If the capture of epispadias repairs is accurate, this suggests that most exstrophy repairs are staged repairs.

This study should be viewed in light of its limitations. Most notably, this study reports information from only 149 patients who received BE closures. This is an incredibly low number of subjects, considering the Epic Cosmos database contains millions of patient records. Several reasons could account for this discrepancy. First, even though we believe our coding strategy was appropriate and inclusive, the database could have systematically mis- or under-captured the appropriate codes. Another explanation, though, is that once the exstrophy condition is identified, parents could choose to leave the initial hospital and seek care at a hospital that does not contribute data to EPIC Cosmos. The administrative nature of the database also eliminates the ability to access operative reports and other patient-specific data to verify that the correct codes were used or perhaps erroneously excluded. This also eliminates the possibility to confirm details about outlier patients and reliably differentiate between specific surgical approaches such as CPRE and MSRE due to the granularity of administrative coding. Therefore, unfortunately, these data are insufficient to draw meaningful conclusions about the use of one surgical technique over another. Regardless of these limitations, these data are nevertheless important because they provide sufficient information to demonstrate at least the primary closure practice patterns across many North American hospitals and thus, are indicative of more general bladder exstrophy closure practices.

More general practice patterns are important because so much bladder exstrophy literature is dominated by single institution or consortia-based studies.

Future research should focus on multicenter prospective or survey-based studies to validate the findings of this study and provide a more comprehensive understanding of the long-term outcomes associated with different surgical approaches to BE. Comparative studies evaluating immediate versus delayed closure, incorporating standardized protocols for postoperative care and long-term follow-up, are necessary to determine the optimal timing and techniques for BE management.

CONCLUSION

In conclusion, the management of BE appears to be evolving, with a trend toward delaying the primary bladder closure. Overall, the rate of repeat closure, considered as an indicator of failure within this dataset, was low but the incidence of postoperative bladder prolapse—which occurred in 25% of patients—was very high. Importantly, only one-third of patients underwent pelvic osteotomy synchronous with BE closure. If osteotomies occurred, they were more likely to be in patients with delayed BE closures.

These findings underscore the evolving surgical approach to primary BE closure and emphasize the importance of further research to compare modern outcomes in bladder exstrophy management with those from earlier eras. Further research and long-term follow-up are necessary to determine the effects of delaying bladder closure on bladder growth, urinary continence, and other outcomes.

Ethical Approval

Institutional Review Board (IRB) approval was not required for this study due to the de-identified nature of the dataset.

Disclosures

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CRediT Authorship Contribution Statement

Kiarad Fendereski: Writing – review & editing, Writing – original draft, Visualization, Validation, Supervision, Software, Resources, Project administration, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Ranjiv I. Mathews:** Writing – review & editing, Writing – original draft, Visualization, Validation, Supervision, Project administration, Methodology, Investigation, Formal analysis, Conceptualization. **Anthony J. Schaeffer:** Writing – review & editing, Writing – original draft, Visualization, Validation, Supervision, Software, Resources, Project administration, Methodology, Investigation, Funding acquisition, Formal analysis, Data curation, Conceptualization.

Declaration of Competing Interest

The authors have no conflict of interest to declare.

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

The authors did not use generative AI or AI-assisted technologies in the development of this manuscript. Generative AI and AI-assisted technologies were NOT used in the preparation of this work.

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