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Nursing care of the bladder exstrophy patient: after primary closure

MA Eldridge

Johns Hopkins Hospital, Brady Urological Institute, Johns Hopkins School of Medicine, United States of America

Corresponding author, email: meldrid3@jhmi.edu

Bladder exstrophy (BE) is a rare congenital anomaly affecting the bladder and urinary tract. Data from the International Clearinghouse for Birth Defects Monitoring Systems and the United States' Healthcare Cost and Utilization Project Nationwide Inpatient Sample estimate the incidence of BE to be 3.3 in 100 000 live births. Two series have reported a 5 : 1 to 6 : 1 male-to-female ratio of exstrophy births. BE care requires specialised surgical intervention, and surgical outcomes are optimised by the thorough and transparent caregiver and patient preparation, experienced exstrophy nursing care, and exstrophy-specific social and emotional support of patients and families. This manuscript will describe the specific nursing assessments and care types undertaken in this endeavour during the February 2023 Exstrophy Workshop held at Uro Care Hospital in Kampala, Uganda.

Keywords: external fixator pin site care, postoperative nursing care, bladder exstrophy

Family preparation

Primary bladder closure requires intense and specialised care of the child and family, which should begin with sincere congratulations to the family on the birth of their child. An exstrophy support team should be available and should include a paediatric orthopaedic surgeon, paediatric anaesthesiologist, social workers, nurses with a particular interest in bladder exstrophy (BE), and a child psychiatrist with expertise and experience in genital anomalies.[1] Given the extensive nature of the bladder exstrophy-epispadias complex (BEEC), families are often overwhelmed by the defect and fears over its current and future health and socialisation implications. It is important to celebrate the gift of their child's life and reassure the family that their child's BE is limited to the bladder and urinary tract and does not impact the child's intelligence or ability to live a happy and productive life.

Appropriate medical care is, of course, imperative to that goal, and it should be explained to parents that BE care is a staged approach and will require several surgical interventions throughout childhood (Table I). It should be made clear that additional surgeries do not indicate a problem but are part of the staged repair process. They are both expected and necessary to achieve urinary continence and preserve renal health. It is also paramount to support parents as they often grieve the loss of normalcy and adjust to the idea and reality of having a child with special medical needs. The importance of emotional support for families cannot be overemphasised, and openly praising parents for their strength and love for their child can benefit their adjustment period and at each point of contact with the medical team.

Nursing management of the immobilised patient

BE treatment begins with the surgical closure of the bladder and anterior abdominal wall. Closure of the bladder in the first week of life can be accomplished, in some cases, without an osteotomy. However, beyond this initial short window of time, bladder closure is typically best supported with an anterior iliac osteotomy with external fixation and immobilisation for 4–6 weeks. This surgical approach was utilised for the four primary closures done during the joint A-BE-C- and Johns Hopkins Exstrophy-Epispadias Workshop undertaken at Uro Care Hospital in Kampala, Uganda, in February 2023.

Nursing care after primary bladder closure requires comprehensive paediatric nursing skills and specialised skills in assessing and managing the specific and nuanced postoperative needs related to both orthopaedic and urologic surgical interventions. These include frequent assessments and adjustments of the cardiovascular, musculoskeletal, respiratory, gastrointestinal, genitourinary, and integumentary systems. In the days and weeks following primary bladder closure, nursing care is intense and focused on cardiovascular and respiratory stability while minimising wound tension through safe immobilisation. Frequent assessments can minimise the risk of wound dehiscence/bladder prolapse, thus supporting a successful long-term closure result.

If the pelvic diastasis is > 4 cm, or if any uncertainty exists about the mobility of the pubic bones, a pelvic osteotomy is performed.[2] To support the osteotomy and closure result, external fixation with immobilisation is maintained for 4–6 weeks following surgery. This approach minimises tension on the abdominal closure, decreasing the risk of postoperative bladder prolapse through the abdominal wall. Immobilisation can be accomplished through Bryant's traction in newborns, Buck's traction in older infants and children, or casting of the bilateral lower extremities, including an immobiliser bar.

In the cohort of patients treated at Uro Care in February 2023, bilateral lower extremity casting with an immobiliser bar was utilised. It should be noted that the surgeons from our institution strongly prefer external fixation, as they believe it provides superior immobilisation; unfortunately, external fixation was not possible for various reasons in February 2023. Casts were placed mid-upper thigh to ankles with a wooden immobiliser bar set in the plaster. Nursing needs with such immobilisation focus on assessing the

Table I: Points for consideration in the initial evaluation and postoperative care of bladder exstrophy patients needing primary bladder closure

1. BE is very stressful for the patient's parents. The entire care team, including nurses, should:
   - Provide psychosocial support to the family
   - Stress that BE is isolated to the genitourinary system and that their child will not have an intellectual or major physical disability
   - Remind parents that BE is a life-long condition that will require multiple procedures
2. Nursing care immediately following a BE primary closure is intensive and requires a 1 : 1 nurse-to-patient ratio for up to 72 hours postoperatively. This is justified because the nurse needs to monitor and optimise sedation, perform frequent pin site care, observe and troubleshoot urinary drainage tube malfunction, and more.
3. A nurse should monitor the child for adequate pain control and sedation and signs of bladder spasm.
   Inadequate sedation is noted if the patient:
   - Is not easily consolable
   - Is rocking side to side or pushing their hips up

   If this occurs, the anaesthesiologist should be notified to increase the sedatives.
   Bladder spasms are noted when the patient:
   - Arches their back
   - Tries to bring their knees to their chest
   - Cries inconsolably despite having all other needs met

   If this occurs, the anaesthesiologist should be notified to increase sedation and anti-bladder spasm medicine.
4. Daily pulmonary physiotherapy to encourage coughing and promote clearing of pulmonary mucus is important for these patients because they will be immobilised in a supine position for 4–6 weeks.
5. The nurse should observe for significant abdominal distension, which can increase abdominal pressure and stress the surgical site/bladder closure.
   To minimise abdominal distension, consider:
   - Nasogastric tube (NGT) decompression of the stomach until bowel sounds and flatus returns
   - Starting oral feeds with small 20–30 ml boluses given via a NGT, which is then clamped and the residual gastric fluid checked after two hours; little residual indicates excellent gastric emptying and the return of bowel function
6. Stool softeners should begin when oral feeding starts and continue until hospital discharge.
7. When pelvic osteotomies are performed, and external fixation is used for postoperative immobilisation, the pin site care:
   - Goal is to keep the exit sites of the pins clean and dry
   - Should occur at least twice daily with a normal saline solution until pins are removed 4–6 weeks postoperatively
   - Is done sterilely by rolling a moistened sterile cotton swab around the pin site, thus removing accumulated blood
8. External fixator pins:
   - Are kept open to air, which prevents skin maceration and actually decreases infection risk
   - Can be surrounded by a 2 × 2-inch gauze if copious leakage occurs immediately postoperatively
   - May have an associated infection if cloudy, purulent drainage occurs; in this case, the cleaning solution should be 50% normal saline and 50% hydrogen peroxide
9. Urinary drainage tubes must be checked very frequently to ensure patency. Poor drainage could lead to urine leaks or other complications.
   A significant decrease in fluid output could indicate either:
   - A twisted or kinked drainage tube that must be rectified immediately
   - A drainage tube that is clogged with debris, which can be corrected by sterilely flushing the tube with 5 ml (ureteral drains) or 10–15 ml (suprapubic bladder drain) of normal saline

integument at each of the four cast edges (bilateral upper thighs and bilateral ankles). Padding and waterproofing materials were applied over rough plaster edges, and patient oedema was monitored every two hours to ensure that the cast did not become too tight. Pedal pulses were monitored at least every two hours, and patients were encouraged to wiggle their toes and ankles to reduce deep vein thrombosis (DVT) risk.

Patients were moved for diaper changes, skin assessments, and epidural site care with a team of nurses to minimise patient movement at the hip during such manoeuvres. Patients were maintained on air mattresses with skin assessments every 2–4 hours, linen changes for any moisture, application of barrier creams and use of pressure-relieving modalities such as heel pads. Maintaining skin integrity in a paediatric patient immobilised for 4–6 weeks is a unique and critical aspect of recovery and infection prevention.

Sedation management and intravenous access

Immobilisation of the paediatric patient is complex and requires significant sedation to achieve. To carry this out safely and effectively, nurses must frequently monitor the sedation level and optimise this through communication with the anaesthesia team and using PRN (as needed) medications. In addition, nurses must continuously evaluate the epidural site and peripheral intravenous (IV) site patency. In this cohort of patients, we experienced difficulty in maintaining peripheral IVs due to intermittent (rather than continuous) infusions coupled with the irritating effects of diazepam on peripheral veins.

Central line access carries additional infection risks but is preferred to obviate the need for repeated peripheral sticks and to maintain appropriate access for the timely delivery of all medications. Further, excessive crying increases intra-abdominal pressure, putting tension on the suture line. Keeping the baby content during the postoperative period is challenging for the parents and nurses. Parents are encouraged to stay with the child throughout the hospitalisation to promote parent-child bonding and comfort.[3]

Respiratory nursing considerations/management

Respiratory optimisation is another important aspect of nursing care for the immobilised postoperative patient. Preventing atelectasis and pneumonia secondary to prolonged supine positioning and decreased ventilation is paramount. Pulmonary toileting includes incentive spirometry and aggressive chest physiotherapy and should be initiated as early in the postoperative course as possible.

Formal incentive spirometry is only sometimes practical for young children and was not available for this cohort of patients. Therefore, alternate means of optimised spirometry were improvised using gloves taped to 60 ml catheter-tipped syringes, mouth-blowing party favours, and, in the case of a particularly cooperative five-year-old female, painting her nails one by one and having her blow on each until dry. While labour-intensive to encourage such spirometry, the importance of such care cannot be overstated. In addition, chest physiotherapy was undertaken at least once a shift starting POD #1 (postoperative day one) and continued for the entire 4–6 weeks of immobilisation.

Gastrointestinal/feeding management

Gastrointestinal assessment and management is another essential aspect of nursing care in the postoperative primary bladder closure patient. This includes using a NGT to manage gastric secretions while awaiting the return of bowel sounds, flatulence, and eventually bowel movements in the days following surgery; NPO (nothing by mouth) status is maintained until adequate return of bowel function is achieved. During this time, the patient is maintained with adequate IV hydration.

Moreover, mothers still breastfeeding must be counselled and assisted in pumping their breast milk to maintain production until the child's gastrointestinal system is ready to begin oral intake. This is critical to optimise the mother's comfort and preserve the child's most reliable and best nutritional resource for the future. Additionally, it is optimal for the patient's health and recovery and has significant economic advantages for the family once discharged home. When oral intake is initiated, it should be undertaken slowly and in small amounts (i.e. 20–30 ml) through the NGT, followed by clamping the tube and checking for residuals after a two-hour interval.

Throughout the postoperative course, great attention is given to abdominal girth. Abdominal distension increases abdominal pressure, increasing tension on the soft tissue wound closure and could lead to wound dehiscence. Oral feeds are halted or delayed if feeds are not well tolerated, abdominal distention increases, or high residuals are found following two-hour clamping intervals. Feeds typically begin 4–7 days postoperatively. However, the risk of postoperative ileus is high, especially in infants under one year of age whose gastrointestinal systems are not fully matured.

Premature feeding can increase the risk of postoperative ileus. Therefore, feeding initiation should be conservatively and carefully considered, and it should be delayed if there are no bowel sounds or flatus. In such cases, hydration should be maintained via IV infusion when possible. In rare cases when all IV access is lost, an alternate approach to hydration must quickly be established. We experienced this situation with a two-month-old male patient whose hydration was maintained via NGT with D5 lactated ringers 5 ml every 30 minutes until we were able to gain IV access once again.

Once oral intake is established and well tolerated, oral laxatives should be started to maintain very soft stools. This is typically achieved using an osmotic laxative such as Movicol 0.8–1.8 g/kg/24 h mixed in 120–240 ml non-carbonated/non-dairy liquid. The ideal efficacy of Movicol is typically achieved when ingested within 60 minutes of mixing the solution. If stool consistency is hard, severe straining during bowel movements increases pressure on the bladder and abdominal wall closure, which could lead to wound dehiscence and bladder prolapse and increase the risk of rectal prolapse.

Pin site care

External fixation following bilateral osteotomy is an effective modality to immobilise the pelvis and reduce tension on the healing abdominal incision. This is the preferred modality of immobilisation at our institution. External fixation requires careful nursing attention to positioning, padding of the bed for comfort, and, most importantly, pin site care and observation. The goal of pin site care is to keep the exit sites of the pins clean, dry, and free from dried blood. In the 1–2 week period following primary closure with osteotomies, the fixator pin sites are prone to oozing blood and require proper site care twice a day.

Although the tissue immediately surrounding the pins is raw, orthopaedic surgeons must take great care to maintain excellent skin integrity beyond the pin site. The nursing team further supports this by leaving the sites open to air rather than applying dressings, which become saturated and potentially harbour bacteria. In addition, capturing blood and fluid from the pin sites into an occlusive dressing actually poses a greater risk to intact, healthy tissue in the hip and pelvic regions through extended skin exposure to excess moisture. Also, changing occlusive dressings twice daily creates friction and trauma to the skin that can lead to the breakdown of previously healthy tissue. If oozing from the pin sites is significant in the first few postoperative days, an excellent management method is using a 2 × 2-inch split gauze placed lightly around the pins at the skin level and changed as needed for saturation/soiling.

Pin site care is performed twice daily and should be undertaken with sterile cotton swabs wet with normal saline. Each pin typically requires 2–3 swabs for proper cleaning. The swab is set at the base of the pin at the skin level and gently twisted between the thumb and forefinger while moving around the diameter of the pin until there is no remaining sterile surface on the swab. If there is significant blood or crusting at the site, up to three swabs per pin may be required to cleanse adequately. In cases of extreme crusting at the pin site, the nurse can wet a gauze with normal saline and place it around the pin for 5–10 minutes to soften the old, crusted blood before proceeding with pin site care.

Should any signs or symptoms of possible infection arise at the site, such as yellow exudate/pus or erythema of surrounding tissue, the orthopaedic surgeon and/or paediatric urologist should be notified, and the pin site care solution should be changed to 50% normal saline and 50% hydrogen peroxide. Hydrogen peroxide is only employed when there is a concern for possible skin site infection. It is only utilised at half strength, as full-strength hydrogen peroxide can be caustic to the healthy integument.

Usually, normal saline is used for pin site care throughout the hospitalisation until pin removal is complete. Nursing care at the time of pin and external fixation removal is essential. The family must be prepared, the child and caregiver supported, and the orthopaedic team must collaborate to optimally time pre-removal antibiotics and pain medications before removal. Diligent wound care and site checks continue following pin removal until proper healing is achieved and the patient is ready for discharge.

Urinary drainage tube management

During primary bladder closure, surgeons place a suprapubic tube (SPT) as well as bilateral ureteral stents to maintain continual urine drainage and bladder decompression during the 4–6-week healing period. These drainage tubes are brought to the skin's surface at

the approximate location of a typically located umbilicus. Each tube is attached to an individual drainage bag, and each stent and SPT are labelled on the tube a few inches distal to the externalisation site and its corresponding collection bag.

Bags should remain on the bed at the level of the bladder to decrease fluid and pressure changes, which can lead to significant bladder spasms. Bags should be secured on the child's lower extremity casts or traction device before lifting the patient for diaper changes, epidural site care, and integument checks. This ensures that the bags remain at the level of the bladder even during these times of necessary movement. Each drainage bag should be emptied, measured, and documented every two hours during the first postoperative week and then every four hours until urology intentionally removes the tubes before discharge.

While total urine output is paramount, recording each individual urine drainage source specifically allows the team to monitor for concerning decreases in drainage. Typically, there is very little drainage from the SPT during the first week, and the stents drain most of the urine. As the ureters' swelling decreases, the ureteral stents drain less, and the drainage from the SPT increases. Nursing staff must observe the SPT and stents' exit site for urine leakage/drainage.

Should leakage occur, the paediatric urology team must be notified, and gauze should be set on the exit site to absorb excess urine and keep the site and surrounding tissues as dry as possible. In addition, the gauze pads can be weighed and figured into the total urine output. If stents or the SPT drain well and then drop off significantly, the tubing should be carefully assessed and untwisted or unkinked if necessary to optimise drainage. If there is no twisting or other obvious source of urine flow obstruction, the offending tube can be gently flushed. In this circumstance, the paediatric urology surgeon should be notified and the situation discussed before proceeding with a stent or SPT flush.

Flushing of urinary drainage tubes should be undertaken in a sterile manner. The drainage tube is disconnected from its drainage bag using sterile gloves, and the drainage tube port is swabbed with an antiseptic, such as an alcohol prep pad. A syringe with 5 ml of normal saline should then be attached to the port and gently and slowly flushed over approximately 1–2 minutes. If there is significant resistance with flushing or if leakage is noted at the stent/SPT exit site, the nurse should call the surgeon before proceeding. If the flush proceeds smoothly and without concern, the tubing and port can again be sterilely swabbed with antiseptic and reattached. The flush amount should be documented and accounted for in the record to subtract from the total urine output at the next scheduled drain and urine measurement.

Maintaining the patency of the tubes and monitoring for adequate urine output is critical. While this varies by age, urine output should be at least 1 ml/kg/h in infants and small children.[4] Should the child's urine output decrease suddenly and significantly, especially if it falls below this guideline, paediatric urology should be notified.

Conclusion

BE is a rare congenital anomaly that requires multiple staged surgeries to optimise renal and bladder health and achieve urinary continence. As defined by continence, a successful primary closure is one of the most critical factors for long-term success. Therefore, surgical intervention by expert paediatric urologists and orthopaedic surgeons, trained specifically in exstrophy care, is critical to optimise patient outcomes. However, the surgical intervention must be succeeded by expert nursing staff trained and experienced in the specifics of BE patients and their postoperative needs and risks.

The training program undertaken in Uganda is unique because it is aimed at sustainability with a plan for both didactic and hands-on teaching and transfer of expertise to Ugandan healthcare professionals. These professionals will take over independent care of Ugandan BE patients in 5–8 years. This programme trains surgeons, nurses, and social workers to optimise each skill set and reinforces the team approach to exstrophy care. A high-functioning team with excellent communication and respect for individual areas of expertise is imperative to optimise patient outcomes. This model has been in place for many years at the Johns Hopkins Hospital. Nonetheless, it is an iterative process that requires adjustments as we learn from each patient treated. We will continue to work with our excellent Ugandan colleagues to tailor the training programme over time to meet the needs of the environment, the Ugandan medical team, and, most importantly, the BE patients of East Africa.

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Conflict of interest

The author declares no conflict of interest.

Ethical approval

This submission follows the principles laid down by the Responsible Research Publication Position Statements developed at the Second World Conference on Research Integrity in Singapore in 2010. This manuscript is exempt from Institutional Review Board approval because it did not involve human subjects.

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