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Beyond the Incision: Recognizing Disability in Exstrophy Epispadias Complex

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In an era where surgical advances have transformed the outlook for many congenital anomalies, bladder exstrophy remains an unpleasant reminder of the challenges that modern medicine has yet to fully overcome. It is not merely a defect—it is a lifelong condition that demands resilience, both from the child, caretakers, and the healthcare system around them. Despite centuries of evolving surgical strategies and interdisciplinary care, the outcomes for patients with exstrophy-epispadias complex (EEC) continue to be marked by uncertainty, limited functional restoration and a quality of life often compromised by incontinence, altered body image, and social isolation.

This editorial explores the multidimensional burden of EEC—not just from the lens of anatomical reconstruction, but through the lived realities of those born with it. It also calls for a critical reassessment of how we, as a medical community, classify disability and what it means to truly support those navigating this complex condition, especially in low-resource settings.

The first description of bladder exstrophy dates back to the 16th century [(1)]. Despite significant advances in surgical techniques in the 20th century, the management of this congenital anomaly remained a formidable challenge for much of history. Initially, the treatment was urinary diversion into the large intestine, but with time, surgeons began focusing on bladder closure and functional repair of the urethral sphincter. In recent years, bladder augmentation, which involves using intestine or stomach tissue to enlarge the small bladder, and clean intermittent catheterization (CIC), have become standard practices in many cases [(2)].

The goals of exstrophy surgery are clear: to restore bladder functionality, achieve urinary continence, enable normal sexual function, and improve cosmesis. Over the years, global pioneers such as Von Grafenberg, Pancoast, Wood, Maury, Trendelenburg, Young, Ansell, Jeffs, Duckett, and Kelly have laid the foundation for how we understand and manage this complex anomaly. In India, stalwarts like Karthikeya Varma, Veereshwar Bhatnagar, Sudipta Sen, Bharati Kulkarni, Shiv Narain Kureel, and many other dedicated pediatric surgeons have played an instrumental role in improving the lives of children born with bladder exstrophy.

And yet, despite these decades of tireless efforts, innovation, and surgical evolution, the challenges remain formidable. As noted in the leading pediatric surgery textbook by Holcomb and Ashcraft: “Even now, optimal management is elusive and surgical reconstruction may require multiple operations.” This statement is not just a reflection of medical complexity—it is a call to action. It highlights the ongoing need for research, multidisciplinary support, and most importantly, policy recognition to ensure that individuals living with exstrophy receive the comprehensive care, dignity, and rights they deserve.

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The Challenges in Exstrophy Bladder Surgery

Achieving normalcy remains an ultimate goal in the management of bladder exstrophy. The anomaly affects the body's most intricate and complex structures. Even with the best surgical teams and techniques, achieving true functional and anatomical normalcy is rare, and the desired outcomes are often only approached but never fully attained. In many cases, multiple surgeries are required to address the various issues of bladder function, continence, and external genital appearance. Each of these procedures comes with its own complications, and these surgeries can place a tremendous emotional and financial strain on the patient and their family.

A significant challenge in bladder exstrophy is the small size of the bladder, which is often incapable of holding adequate amounts of urine, leading to kidney damage over time. The high incidence of vesicoureteric reflux further complicates the situation, making urinary tract infections (UTIs) a constant concern and contributing to kidney deterioration. For many patients, bladder augmentation may be necessary, but this also brings with it risks and long-term complications [3].

One of the greatest challenges for individuals with exstrophy is continence. Achieving continence of urine is essential for a normal social existence. However, absolute continence remains an unlikely outcome in many cases, leaving individuals with a lifelong struggle to manage incontinence, which significantly impacts self-esteem and quality of life [4].

Impact on Genitalia and Sexual Function

For males affected by exstrophy, only 10% report being reasonably satisfied with the length of the penis, a result of the structural alterations caused by the anomaly. These concerns often lead to psychological distress, which can have a lasting impact on the individual's sexual function and overall self-esteem. The psychosexual impact can affect relationships and lead to sexual dysfunction, while suboptimal fertility outcomes are also a frequent concern [5]. Indeed, many individuals affected by bladder exstrophy face psychological issues related to their external genitalia and their ability to participate in reproductive activities.

Lifelong Care and Follow-up

The treatment for bladder exstrophy is not complete with the initial reconstructive surgeries. Patients must undergo lifelong care, which includes regular urine examinations, blood tests, scanning, functional evaluation of kidneys, and medications. Surgical interventions may still be necessary to address complications such as infection, stone formation, and vesicoureteric reflux. Urodynamic studies are often needed to assess bladder function. Long-term follow-up is essential to ensure the best possible quality of life for these patients [1,4]

Quality of Life and Disability Considerations

The Rights of Persons with Disabilities Act, 2016 defines a "person with disability" as one with a long-term physical, mental, intellectual, or sensory impairment which, in interaction with various barriers, hinders full and effective participation in society on an equal basis with others. By this definition, it is unacceptable that congenital anomalies such as the Exstrophy Epispadias Complex (EEC) remain unrecognized under this legislation.

Individuals born with EEC face significant lifelong challenges: persistent incontinence, repeated surgical interventions, altered genitalia, compromised sexual and reproductive health and psychological distress. These factors cumulatively restrict their social participation, limit educational and employment opportunities and place an enormous emotional and financial burden on families. In every sense, their condition meets the criteria for disability as laid out by the Act.

India is a signatory to the United Nations Convention on the Rights of Persons with Disabilities (2006)[6], which promotes the doctrines of non-discrimination, dignity, and inclusion. Failing to include conditions like EEC under the umbrella of disability rights not only contravenes the spirit of the Convention but also perpetuates exclusion in a society where legal recognition is a prerequisite for support.

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It is time we broaden our understanding of disability to include complex congenital anomalies such as Exstrophy Epispadias Complex, severe urological malformations, and major anorectal defects. Legislative amendments must be prioritized, and government support in the form of disability certification and monthly financial assistance should be instituted. This is not merely a legal necessity—it is a moral imperative to uphold the basic human rights and dignity of this overlooked patient population.

In conclusion, Exstrophy Epispadias Complex is more than a challenging surgical diagnosis—it is a lifelong condition with deep psychosocial, functional, and systemic implications. Despite advances in reconstructive techniques, patients continue to struggle with incontinence, compromised sexual function and a quality of life often at odds with societal expectations. These realities demand not just clinical excellence but structural compassion. Inclusion of such congenital anomalies under the Rights of Persons with Disabilities Act, 2016 is not merely a legislative correction—it is an ethical imperative. As medical professionals, we are not only healers but also advocates. By lending our voices to this cause, we help restore dignity to those who navigate this condition with resilience, often in silence. The time to act is now.

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