

Introduction to the special edition of *African Urology* regarding the Second Annual Bladder Exstrophy Workshop

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Successful management of the exstrophy-epispadias complex (EEC) remains a challenge even in high-income countries. Multiple efforts have been made to impart the lessons learnt in managing EEC to the surgical community, children, and their families in low- to middle-income countries. Many of these efforts have resulted in individual patients receiving surgical management from various teams that travel to the location and perform procedures based on their experience. However, EEC is a condition that requires life-long medical management.

The prevalence of EEC in Africa is difficult to ascertain. Anecdotal data suggests a large population of children and adults may remain untreated, which can lead to significant social stigma and isolation, added to the inevitable medical comorbidities, such as chronic renal insufficiency, when the condition is left un- or under-treated. This may significantly influence the lives of the affected individuals and their families.

The modern staged repair of exstrophy (MSRE) was pioneered by Dr. Robert Jeffs at the Johns Hopkins Hospital in the late 1970s. This approach to exstrophy surgery was continuously and iteratively improved by Drs. John Gearhart (who focused on soft tissue modifications) and Paul Sponseller (who refined the indications for and approach to pelvic osteotomies). While not the only strategy for the management of EEC, this approach can be learnt and implemented in different geographic and institutional environments with good potential for a successful outcome. Therefore, together with the anaesthesia and nursing teams at Johns Hopkins Hospital, a successful, reproducible strategy has been developed to manage EEC. Translating this strategy to the African continent remains a challenge, partly due to the limited exposure of paediatric surgeons to the staged repair technique and existing knowledge gaps in exstrophy-specific medical and nursing care.

A single, well-accepted, reproducible paradigm for exstrophy management, which can be instituted initially at one centre and then diffused to the community over time, will provide a more sustainable strategy for this life-long condition. This is the mission and premise of the effort at Uro Care Hospital in Kampala, Uganda. Dr. Stephen

Watya and the team at Uro Care have graciously accepted the role of being the initial centre for learning and innovation in EEC, hoping that the lessons learnt can be translated to other parts of Uganda, Eastern Africa, and perhaps the entire continent. The initial mission focuses on teaching the surgical and postoperative strategies for epispadias and bladder exstrophy. Cloacal exstrophy is a multi-organ condition requiring greater specialised care and is not part of the mission at this time.

Even today, complex surgical care for EEC sometimes requires patients in parts of Africa to travel to other countries for their surgical care. This approach has several disadvantages, including significant financial hardship, lost parent(s) productivity, and a lack of continuity in their care (with only one aspect addressed for each episode abroad). The Association for the Bladder Exstrophy Community (A-BE-C) in the United States, under the leadership of Ms. Pamela Artigas, has committed to supporting efforts to bring this care paradigm to the children of Africa, similar to the support that the community currently provide on the Indian subcontinent.

This effort will likely succeed in Uganda because of the educated, dedicated cadre of medical professionals eager and willing to learn and innovate to meet the local community's needs. A focus of this ongoing effort in Uganda is to educate this remarkable group of individuals in MSRE. The understanding is that many of them will take the basic concepts learnt and invent novel ways to manage this complex entity to function in their unique hospital settings to provide life-long care for the children in Africa with EEC.

The primary goal of this ongoing effort is to teach preoperative and postoperative care in addition to hands-on surgical techniques and expertise to Ugandan nurses, physicians, and surgeons. Consequently, they can take up the long-term challenge of caring for children with EEC in Uganda. The workshop included a series of didactic lectures presented by the invited guests from the United States. In this special edition of *African Urology*, we present these lectures in manuscript form. The topics are intentionally broad and meant to serve as a starting point for the novice student and as a reference for the experienced surgeon who wishes to learn

more about or refresh their knowledge of this unique condition. Specifically, the reader will find practical articles covering a range of exstrophy topics, including:

- pathophysiology;
- embryology;
- epidemiology;
- pre-, intra-, and postoperative anaesthesia and pain management;
- exstrophy specific nursing considerations,
- orthopaedic considerations;
- MSRE surgical closure overview;

- operating theatre preparation;
- supporting child development in a hospitalised, immobilised patient; and
- what it is like to live with bladder exstrophy.

Taken together, we hope this special edition will serve as a bladder exstrophy reference to some extent for the journal's readers.

Lastly, please note that all patient photographs in this special edition of *African Urology* have been obtained with and used only after patient consent. No identifying patient information is contained in any photographs.