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Quantified outcome for patients with bladder exstrophy

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Abstract *Aim:* Outcomes of bladder exstrophy patients were studied in numerical terms using scoring systems for continence and health-related quality of life (HRQOL), along with renal function, in short-term follow up.

Patients and methods: Patients who had undergone bladder-preserving exstrophy repairs, either staged or as a single procedure, and those who had been managed by bowel augmentation were included. Continence was assessed according to five variables (max. score 15) and HRQOL assessment was by means of a structured modified questionnaire scored on a Likert-scale model (max. score 150).

Results: A total of 39 patients were followed. Mean age was 8.3 years and mean follow up duration 3 years. Mean HRQOL score was 107.55 (83–133, SD ± 19.31). Mean continence score was 8.73 (6–11, SD ± 1.544).

Conclusions: Evaluation of bladder exstrophy outcomes should not be done merely by reporting the length of dry intervals. If performed in numerical terms as outlined in this series, patients across centres will be comparable over a common assessment protocol. Continence score achieved in this series was low in comparison to the literature due to the strict evaluation protocol.

Introduction

Bladder exstrophy is a difficult condition to manage. Even after multiple attempts at repair, the level of continence achieved is variable. The outcome of bladder exstrophy is measured in terms of continence, upper tract deterioration, health-related quality of life (HRQOL), satisfaction with genitalia reconstruction, sexual function and fertility

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[1]. Several studies have provided results of exstrophy treatment with regard to all or some of these factors across various age groups [2,3].

There are few studies published that have combined an HRQOL survey with continence and renal function. Lack of a common evaluation protocol makes it difficult to compare these series of patients. The importance of standardization for evaluation of continence and HRQOL in conditions like exstrophy has never been stressed in the literature. Different surgeons across the world report outcomes that are not comparable due to different variables being used and the subjective nature of evaluation. The aim of this paper was to present an objectivized standardized format for evaluation of outcomes of bladder exstrophy. The same format is used for patients of mutually non-exclusive groups (bladder-preserving exstrophy repairs and augmentation-based repairs) to report the results. The described protocol can be applied to any other group of patients, for comparison across series.

Patients and methods

This was a bidirectional study (5-year retrospective study conducted from July 2004 to June 2009 and 1-year prospective study from July 2009 to June 2010) involving two mutually non-exclusive groups of patients. Group I had undergone bladder-preserving exstrophy repairs either as a staged or single-stage procedure. Group II were patients who had been managed by bowel augmentation. Patients who had undergone repair outside our institute, those with less than 1-year of follow up, and those with incontinent epispadias were excluded.

The protocol followed for the management of bladder exstrophy was that patients presenting early with a pliable non-polypoidal bladder plate were subjected to bladder-preserving repair either as staged or single-stage surgery. Late on, when a subset of these patients demonstrated incontinence with minimal bladder growth, they were subjected to bladder augmentation.

At the beginning of the study, a scheme was developed under which the patients were evaluated. The various components of the scheme are depicted in Fig. 1. As can be seen, this is a three-dimensional system with two objectivized arms measuring HRQOL and continence. The third arm measures renal status in terms of dilatation, scars, reflux and pyelonephritis.

HRQOL or psychosocial assessment was done by means of a structured questionnaire as provided by KIDSCREEN-52 [4]. The questionnaire was modified to suit the study population. The modified questionnaire was not validated as there was no control group. The questions cover six dimensions representing various aspects of physical and psychosocial well being. These are: physical well being and participation in daily life activities, school environment and performance, participation in group activities, social support and relationship with peers, self perception and satisfaction with genitalia reconstruction, and psychological well being. The response was recorded on a Likert-scale model – never, seldom, sometimes, often, always – represented by a 1–5

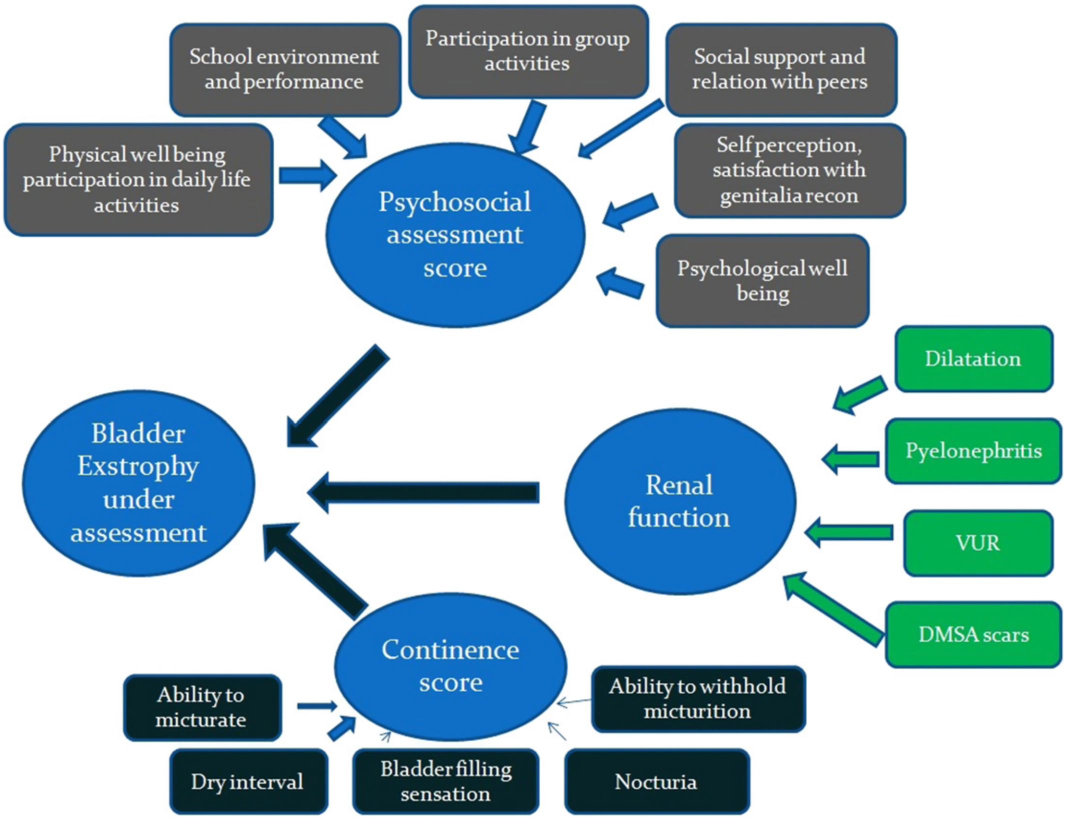

Figure 1 Scheme of assessment.