



Emotional and behavioral functioning in children with bladder exstrophy—epispadias complex: A developmental perspective



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Received 4 January 2013; accepted 18 July 2013 Available online 17 August 2013

KEYWORDS

Urinary bladder; Bladder exstrophy; Children; Adolescents; Emotional and behavioral functioning **Abstract** Objective: To evaluate the emotional and behavioral functioning of children with bladder exstrophy—epispadias complex (BEEC), taking into account developmental and gender considerations. This study also sought to overcome methodological limitations of previous studies evaluating psychological well-being of children with BEEC.

Methods: Eighty-six children were consecutively evaluated using the parent report version of the Behavior Assessment System for Children during visits to a multidisciplinary urology clinic. Results: Results indicated normative emotional and behavioral functioning across the sample. However, there was a significant effect of age, such that older children consistently had worse internalizing symptoms and adaptive functioning. Males tended to have more externalizing problems as they aged, and also tended to have lower levels of adaptive functioning but this was independent of age. The level of psychological impairment was unrelated to the specific type of BEEC, and was also unrelated to whether or not the patient had undergone continence surgery.

Conclusion: Children with BEEC have a greater likelihood of experiencing a wide range of emotional and behavioral problems as they reach adolescence. These findings point to the need to prevent potential psychological distress by intervening with these children before they become clinically impaired.

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The physical challenges associated with bladder exstro-phy—epispadias complex (BEEC) are well known; however, the emotional/behavioral aspects are not yet fully appreciated. There are a number of possible psychological implications of the congenital anomaly and the associated surgical interventions and prolonged incontinence. For example, prolonged incontinence may have a negative impact on social functioning and self-esteem [1]. In an effort to optimize treatment outcomes, the physical and emotional well-being of the BEEC patient must be better understood.

Previous research examining the emotional and behavioral functioning of youth with BEEC has produced mixed results. Some findings suggest that affected children generally have good psychological functioning [2,3] and an overall quality of life comparable with normative benchmarks [2]. However, others have found internalizing diagnoses (i.e., anxiety and depression) and symptoms particularly common [4–8]. In the absence of anxiety and depression, acting out behaviors and poor school adjustment have also been reported [9]. In short, conclusions about psychological and behavioral functioning in children with BEEC have been ambiguous. Discrepant findings might, in part, be understood in the context of a developmental perspective which accounts for the role of age and gender in psychological functioning.

The incidence, manifestations, and etiology of psychological problems in young people are often influenced by developmental considerations; however, few studies have directly examined the role played by developmental factors in the expression of psychological distress in young people with BEEC [10]. Yet, there is some preliminary support for the notion that some of the negative psychological outcomes associated with BEEC may be moderated by age [4,9]. Taken together, these findings would suggest that young people with BEEC may have differential psychological outcomes as development unfolds. However, we are unaware of any study that has systematically examined how the behavioral and emotional correlates of BEEC are moderated by age across the full developmental spectrum.

While there are very few studies that have considered the role of age in the psychological outcomes in children with BEEC, there have been even fewer attempts to determine whether there is a differential influence on psychological wellbeing depending on gender (in the present study, the term "gender" is used to describe the distinction between males and females, while recognizing that there are social and biological determinants of the term). Although the role of gender has rarely been examined in research concerning BEEC, some studies have shown that older males tend to have greater internalizing problems, notably suicidal ideation [8], and lower quality of life [11]. However, we are unaware of any studies that have examined whether the developmental trajectory of children with BEEC is different for males versus females.

As noted, few studies have considered how age and/or gender may moderate the psychological outcomes associated with BEEC. However, methodological limitations could also be related to some of the differences in the findings that are reported across studies. These limitations included small sample sizes, given that bladder exstrophy is a rare

disorder, and measurement of psychological functioning. Whereas some studies utilized objective or standardized measures [2,4], other studies have relied more heavily on methods (i.e., clinical interviews or self-developed questionnaires) with limited psychometric properties or used methods that do not allow for a comparison to normative benchmarks [8,11]. Given the methodological limitations associated with the relevant research to date, it is important to include sound instrumentation and representative sampling methods when examining the overall level of behavioral and emotional problems displayed by children with BEFC.

Of the aforementioned studies, some have described the type of bladder exstrophy and continence status of patients in their samples; however, they did not formally examine whether these variables were related to psychological functioning [11]. There is evidence suggesting greater deficits in psychological functioning in those who were incontinent versus those who were continent [4]; at the same time, other researchers have reported that children who achieved continence after age 4 had more acting out problems [9]. However a recent study found no significant association between continence status and health related quality of life after controlling for factors such as age, gender, maternal education, catheterization status, and number of surgeries [12]. While those with cloacal exstrophy may have lower levels of adaptive functioning compared with those with other forms of bladder exstrophy [9], there is little research concerning whether the type of BEEC predicts psychological impairment. In particular, there is no evidence whether less complicated forms of BEEC (i.e., epispadias and classic bladder exstrophy) are associated with a differential psychological outcome. While there is very limited research concerning the relationship between the level of medical severity and psychological impairment, there is no research specifically examining whether gender or age moderates this relationship.

It was hypothesized that children with BEEC would have higher levels of psychopathology compared with normative samples. It was also hypothesized that older children with BEEC would have increasing emotional and behavioral impairment, especially with respect to externalizing problems (i.e., hyperactivity, aggression, conduct problems), internalizing problems (i.e., anxiety, depression somatization), and adaptive skills (i.e., adaptability, social skills, leadership, activities of daily living, functional communication). Given previous findings that show differentially higher levels of adaptation and psychological functioning depending on gender, it was also hypothesized that males and females would show different psychological adjustment; in particular, we expect males to display greater problems with emotional and behavioral functioning compared with females. Additionally, given the epidemiological findings that denote differential levels of psychopathology among males and females as development unfolds [10], it was hypothesized that there would be an interactive effect of age and gender in predicting the levels of internalizing problems, externalizing problems, and adaptive functioning found in children with BEEC. Finally, it was hypothesized that continence surgery and type of bladder exstrophy would be related to differential levels of

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