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

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**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 exstrophy–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 BEEC.

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

psychological functioning; in addition, we examined whether age or gender moderates the psychological impact of the respective medical presentation.

## Materials and methods

### Measures

The Behavior Assessment System for Children (BASC) [13] is a nationally standardized instrument involving a multisource and multidimensional assessment system including separate report measures that are derived from self, parent, and teacher respondents. In the current study, the BASC-Parent Report Scale (BASC-PRS) was used to assess adaptive and problem behaviors in children at one of three age levels: preschool (2–5 years), child (6–11 years), adolescent (12–18 years). The preschool version has 134 items, the child version has 160 items, and the adolescent version has 150 items. All items are rated on a 4-point frequency scale, ranging from 0 (“never”) to 3 (“almost always”). Parent rating composite scores of externalizing problems (including hyperactivity, aggression, and conduct problems), internalizing problems (including anxiety, depression, and somatization), and adaptive skills (including adaptability, social skills, leadership, activities of daily living, and functional communication) were used in this study. Higher scores on internalizing and externalizing scales indicate worse functioning, whereas lower scores on adaptive scales indicate worse functioning. The BASC manual provides compelling evidence of the respective scales’ sampling methods in addition to the convergent and discriminant validity of the parent report version of the instrument. The BASC was standardized according to age on a nationally represented sample of children and yields T-scores (mean = 50, SD = 10). Scores above a T-score of 60 on the externalizing and internalizing scales are at the 85th percentile and over this level are considered ‘at risk’; similarly, adaptive scales with a T-score of 40 are at the 15th percentile and below this level would indicate ‘at risk’ levels of maladaptive adaptive functioning. Scores above a T-score of 70 on the externalizing and internalizing scales are at the 98th percentile and over this level are considered ‘clinically significant’; similarly, adaptive scales with a T-score of 30 are at the 2nd percentile and below this level would indicate ‘clinically significant’ levels of maladaptive adaptive functioning.

### Procedures

Data for this study were obtained through chart review of patients’ medical records who were seen through a multidisciplinary pediatric urology clinic. This clinic employs an interdisciplinary care model which integrates the expertise of a pediatric urologist, a pediatric nurse practitioner, a pediatric behavioral psychologist, a clinic nurse, and a certified child life specialist. Care includes ongoing education and management focusing on constipation management, pelvic floor optimization through EMG animation biofeedback, timed voiding and hydration, and ongoing behavioral assessment and management. Parents were asked to complete BASC measures to assess for emotional and behavioral issues that may be impacting psychological

status, physical health, and medical adherence. We obtained institutional review board approval for this study.

### Data analyses

Descriptive statistics were initially calculated across the composite scores of the BASC. Next, Pearson correlation analyses were calculated to determine the relationship among study variables. A series of multiple regressions were used to identify the unique relationship of gender, age, continence surgery, and bladder exstrophy type in predicting the respective BASC composite scores, and also to examine the interactive effects of these predictor variables on the composite indices. A power analysis was conducted and results indicated that a minimum of 76 patients would be required to detect a medium effect size.

### Results

As only two females had cloacal exstrophy, they were dropped from the study. Patient population included 86 (53 male and 33 female) consecutive referrals, ranging in age from 3 to 16 years old ( $M = 7.97$ ,  $SD = 3.02$ ). Patients’ races/ethnicities included 77 White, 2 Black, 2 Asian, 1 Indian, and 4 Other, as reported in medical records. A total of 61 patients had classic bladder exstrophy and 25 had epispadias. Sixty-four patients were evaluated prior to their continence procedure and 22 were evaluated post surgery. Caregivers who completed BASC measures on these children included 65 mothers, 19 fathers, 1 grandmother, and 1 stepmother.

Table 1 reports the descriptive statistics of parent ratings on the BASC. All score means across BASC composite

**Table 1** Descriptive statistics of parent ratings on Behavior Assessment System for Children (BASC) composite scores (bold) and subscales, including mean T-scores, SDs, minimums, and maximums.

	Mean	SD	Minimum	Maximum
Hyperactivity	49.66	9.40	34	76
Aggression	48.32	8.72	36	77
Conduct problems	48.82	8.37	34	76
<b>Externalizing problems</b>	48.64	8.71	36	76
Anxiety	50.71	9.67	36	85
Depression	50.35	10.15	30	83
Somatization	49.82	9.31	35	74
<b>Internalizing problems</b>	50.26	9.47	29	77
Adaptability <sup>a</sup>	51.36	10.10	17	69
Social skills <sup>a</sup>	51.07	9.81	34	73
Leadership <sup>a</sup>	52.05	9.69	25	73
Activities of daily living <sup>a</sup>	47.88	10.66	12	71
Functional communication <sup>a</sup>	51.88	9.85	23	68
<b>Adaptive skills<sup>a</sup></b>	51.14	9.89	24	72

<sup>a</sup> Lower scores indicate greater deficits in functioning.

**Table 2** Mean T-scores, SDs, and percentage in the at-risk clinical range (T-score > 60 for internalizing and externalizing and T-score < 40 for adaptive) and clinically impaired (T-score > 70 for internalizing and externalizing and T-score < 30 for adaptive) on BASC composite scores across age ranges.

Age	N	Externalizing problems				Internalizing problems				Adaptive skills <sup>a</sup>			
		Mean	SD	% At-risk	% Clinical	Mean	SD	% At-risk	% Clinical	Mean	SD	% At-risk	% Clinical
3–5	25	46.12	7.46	4	0	46.96	8.96	12	0	54.28	9.61	8	0
6–7	30	47.93	6.30	4	0	48.79	9.60	14	4	53.60	8.25	7	0
8–11	19	50.53	10.27	16	11	51.74	6.39	5	0	47.26	9.48	26	5
12–16	12	52.58	11.90	25	8	58.33	10.16	33	16	44.58	10.81	33	8

<sup>a</sup> Lower scores indicate greater deficits in functioning.

scores of maladaptive functioning (i.e., internalizing and externalizing problems) and subscales were in the normative range (i.e.,  $\leq$ T-score of 60). Likewise, the mean scores of all indices of adaptive functioning were also in the average range (i.e., a T-score between 40 and 60). Table 2 reports the descriptive statistics for parent ratings on the BASC composite scores by age range and denotes a clear trend of increasing elevated externalizing and internalizing scores with advancing age; likewise there was a similar trend of more impaired adaptive functioning as development unfolds.

Table 3 reports the correlations between age, gender (females = 0; males = 1), continence surgery (pre-surgery = 0; post surgery = 1), type of BEEC (epispadias = 0; classic bladder exstrophy = 1) and parent ratings on BASC composite scores of externalizing problems, internalizing problems, and adaptive skills. Whereas males were more likely than females to experience poor adaptive functioning, gender was unrelated to other aspects of psychological impairment. In contrast, older children reliably displayed more internalizing and externalizing impairment as well as poorer adaptive functioning. Although the type of BEEC did not have a significant relationship to the respective indices of psychological impairment, individuals that had undergone continence surgery were more likely to experience higher levels of internalizing problems. Interestingly, continence surgery was also more likely to be associated with females and older age.

Following guidelines on testing moderator models [14], a series of hierarchical linear regression analyses were conducted to test for the unique and interaction effects of age,

gender, exstrophy type, and continence surgery status in predicting the level of internalizing and externalizing symptoms, and the level of adaptive functioning. To control for potential collinearity effects and test moderation effects with continuous variables, age was centered at the mean (mean = 8) prior to the creation of cross-product terms [15]. In the first step, age, gender, exstrophy type, and continence surgery status were simultaneously entered. In order to test whether the respective predictor variables interacted to predict psychological and adaptive impairment, a series of two-way interaction terms were independently entered in the second step.

There were no interaction effects in predicting adaptive functioning or internalizing problems; however, there were significant main effects (Table 4). Accordingly, older individuals and males were both independently associated with poorer adaptive functioning. As noted previously, the univariate findings would suggest that age and continence surgery tended to predict more internalizing problems. However, when all predictor terms were controlled, age clearly had a positive and independent relationship with internalizing problems whereas continence surgery did not. Finally, there was a significant interaction effect between age and gender in predicting externalizing problems ( $R^2$  change = .057,  $p < .05$ ;  $B = 1.48$ ,  $SE = .64$ ,  $\beta = .43$ ); in addition, the simple slope for age was significant for males ( $t = 3.53$ ;  $p > .001$ ), but not significant for females ( $t = -.40$ ;  $p = .69$ ). Whereas males tended to have more externalizing problems as they aged, the overall levels of externalizing problems of females were at normative levels and stable across development.

**Table 3** Correlations of age, gender, continence surgery (pre/post surgery), bladder exstrophy type (epispadias/classic bladder exstrophy), and parent ratings on BASC composite scores.

	1.	2.	3.	4.	5.	6.	7.
1. Gender	1						
2. Age	.03	1					
3. Continence surgery	-.25**	.35***	1				
4. Bladder exstrophy type	.13	.09	-.04	1			
5. Externalizing problems	.15	.28***	.09	.09	1		
6. Internalizing problems	-.15	.42****	.32***	-.04	.45****	1	
7. Adaptive skills	-.22**	-.37****	-.08	-.01	-.67****	-.52****	1

\* $p < .10$ , \*\* $p < .05$ , \*\*\* $p < .01$ , \*\*\*\* $p < .001$ .

**Table 4** Multiple regression analyses of gender, age, continence surgery (pre/post surgery), bladder exstrophy type (epispatias/classic bladder exstrophy) in predicting parent ratings on BASC composite scores.<sup>a</sup>

	Externalizing problems			Internalizing problems			Adaptive skills		
	B	SE	$\beta$	B	SE	$\beta$	B	SE	$\beta$
Gender	2.52	2.00	.14	-2.14	1.99	-.11	-4.26	2.13	-.21**
Age	.74	.33	.26**	1.15	.33	.37***	-1.22	.36	-.37***
Surgery	.71	2.34	.04	3.47	2.36	.16	.05	2.52	.002
BE type	.99	2.04	.05	-1.18	2.06	-.06	.98	2.20	.05

\* $p < .10$ , \*\* $p < .05$ , \*\*\* $p < .01$ , \*\*\*\* $p < .001$ .

<sup>a</sup> Beta coefficients ( $\beta$ ) are standardized coefficients computed when you standardize the dependent variables (Externalizing, Internalizing, and Adaptive Skills) and each of the independent variables (Gender, Age, Continence Surgery, and Bladder Exstrophy Type).

## Discussion

When considered together, the results showed that patients with BEEC had normative levels of emotional and behavioral functioning when compared with same aged peers. However, important differences were uncovered when considering the roles of age and gender. Indeed, the level of impaired functioning almost uniformly increased with age. In particular, internalizing symptoms (including depression, anxiety, and somatization) and adaptive skills (including social skills, leadership, activities of daily living) worsened over the course of development, such that older children had higher levels of impairment than younger children. It is worth noting that, independent of developmental considerations, main effects would suggest that males were inclined to have more adaptive impairment than females; however, in other instances, the harsher outcomes associated with developmental considerations were moderated by gender. For example, younger males and females of all ages did not display many externalizing symptoms; however, as they age, only males exhibited increasing levels of externalizing problems (i.e., aggression, conduct, and hyperactivity). Finally, previous studies would suggest that factors associated with continence predicted negative psychological functioning [4,9]; however, the current study would suggest that the apparent relationship between continence surgery and internalizing symptoms may reflect the higher incidence of older children having undergone continence surgery, and it is because they are older, and not continence surgery by itself, that places such individuals at higher risk for internalizing distress.

Few studies have specifically examined variations in the psychological and behavioral characteristics of children with BEEC as a function of age or gender. Support for decreased functioning in children with BEEC in the areas of adaptive skills and externalizing problems across development has been noted in previous studies [9]; however, for the most part, the role of development has largely been ignored in the available research examining the psychological implications of BEEC. Although few studies have examined the gender differences in individuals with BEEC, our findings are consistent with some of the prior research, which denotes impairment in social functioning among boys with BEEC [11]. However, we know of no other study that

has specifically examined whether age and gender interacted to predict psychological outcomes in young people with BEEC.

The notion that children with BEEC experience increasing psychological and adaptive impairment converges with emerging trends found in research that examines how normal developmental processes influence the potency of some of the risk factors that contribute to emotional and behavioral problems in children. For example, prevalence of internalizing symptoms, including depression, increases throughout development [16]. As adolescence emerges, formal operational thinking is realized, and there is an increasing capacity to take the perspective of others and to entertain a range of future outcomes. Coinciding with these cognitive transformations, the focus in young people's lives becomes more peer based and their social environment becomes more influential and has a larger impact on functioning [17]. Children with BEEC may be confronted with lifelong challenges associated with disclosure to peers, coping with physical abnormalities, repeated surgeries, and adherence to invasive medical regimens. However, the salience of these sources of stress may increase as they approach adolescence and are increasingly able to understand how others might view them and the future psychosocial implications of their medical condition. Thus, the combination of normal developmental transformations and the medical complications of BEEC may contribute to increasing vulnerability for anxiety and depression. Although this conceptualization is consistent with well-established psychosocial and developmental tenets, future research should better understand the specific risk factors that are instrumental in increasing vulnerability and the role of normal development in moderating these risk factors.

## Limitations

Although the current study addressed many of the methodological limitations associated with previous studies, there are several limitations that need to be addressed in future research. Although this study had a larger sample size compared with most previous studies with children with BEEC, we were not able to obtain equal representation across developmental levels. In addition, because this was a retrospective chart review, we did not have access to

some demographic variables such as socioeconomic status, and therefore do not know how these variables may moderate our results. We also did not obtain information on continence status at time of psychological evaluation, so, instead, we used continence surgery as a proxy for continence status. Although the BASC allowed for comparisons with a nationally represented benchmark, we did not compare patients with children with other chronic medical problems or who presented at medical clinics with more benign medical presentations (e.g., well child visits). Therefore, it is unclear whether the current findings are different from what might be found with other children who are seen in medical clinics or who experience chronic medical conditions. Finally, although the current study addressed most of the methodological pitfalls that often limit the causal influences that can be gleaned from cross-sectional studies [18], future investigations should incorporate a longitudinal design within a developmental framework.

There are number implications for the direction of future studies. In particular, we did not have a sufficient sampling of patients with cloacal exstrophy to examine whether there was a differential psychological outcome for these patients. Also, future studies should examine the psychological outcomes and the role that age at continence surgery and severity of disease play in children's emotional and behavioral functioning. Understanding these factors will help to drive better, more informed psychological intervention. In addition, it will be important to examine mediators, such as social and adaptive functioning, in explaining the relationship between having bladder exstrophy and increased psychopathology. Also, it is necessary to examine different perspectives on children's emotional and behavioral functioning, including the reports from multiple raters (i.e., teacher and self-reports). Finally, it would be important to evaluate parents' own coping, distress, and psychopathology in relation to their children's functioning.

## Conclusion

Results from this study may lend support to the need to prevent potential worsening of psychological distress by intervening with these children before they become clinically impaired. Through screening children at an early age, one may be able to identify emotional and behavioral issues that do not necessarily impact functioning at a young age, but may become increasingly detrimental to a child as they mature. Our results suggest that it is important for these youth to have regular contact with a pediatric psychologist as a standard of care.

## Conflict of interest/funding

None.

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