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Changes in levels of parental distress after their child with atypical genitalia undergoes genitoplasty

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Summary

Background

The birth of a child with a disorder of sex development (DSD) and atypical genitalia can be traumatizing and isolating for families. Parents of children with DSD are at risk for increased levels of psychological distress, including depression, anxiety, illness uncertainty (IU), post-traumatic stress symptoms (PTSS), and impairments in quality of life (QOL). Our previous report indicated that although the majority of parents of children with atypical genitalia were coping well prior to the child's genitoplasty, approximately 25% of them reported experiencing some type of psychological distress.

Objective

The current study sought to examine the trajectory of parental psychological distress prior to, and 6 months after their child underwent genitoplasty.

Methods

Parents were recruited as part of an ongoing, prospective, multi-site study involving 10 pediatric hospitals with specialized care for children with atypical genitalia. Results from 49 parents (27 mothers, 22 fathers) of 28 children (17 female sex of rearing, 11 male sex of rearing) born with atypical genitalia (Prader rating of 3–5 in 46,XX DSD or by a Quigley rating of 3–6 in 46,XY DSD or 45,XO/46,XY) were included in the study.

Results

There were no significant changes in level of depressive or anxious symptoms or quality of life between baseline and 6-month post-operative follow-up, although mothers continued to report significantly higher levels of depressive symptoms than fathers, and as a group, these parents reported lower QOL than published norms. The level of PTSS significantly decreased for all parents, suggesting that parents may have come through the acute stress phase associated with their child's diagnosis. Finally, while there were no significant changes in IU over the time period, the level of IU for parents of boys actually increased, while parents of girls reported no change (Figure).

Conclusion

Six months after their child has undergone genitoplasty, the majority of parents report minimal levels of psychological distress. However, a subset of these parents continue to experience significant distress related to their child's diagnosis. Specifically, parents of boys appear to be at increased risk for difficulties, which may be related to either the lack of clinical diagnosis for almost half of these children or the necessity of two-stage surgeries for the majority of them. We will continue collecting data on these families to better understand the trajectory of these adjustment variables.

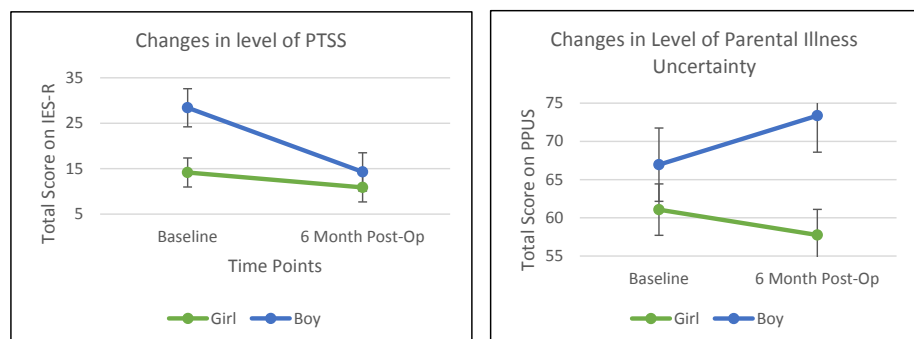


Figure 1 Graphs of significant changes.

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Introduction

A disorder or difference of sex development (DSD) is a congenital condition in which the chromosomal, gonadal, and anatomic sex is atypical [1]. The birth of a baby with DSD that involves atypical genitalia challenges societal beliefs about gender and “normalcy,” and can be shocking and traumatizing for families [2,3]. Parents of affected children are faced with long-term decisions such as choosing a sex of rearing and whether their child should undergo genital surgery and gonadectomy. There may be uncertainty surrounding the need for hormone replacement therapy and fertility potential later in life, which have implications for the child’s long-term quality-of-life and emotional health. The emotional health of parents is increasingly recognized as an important consideration in interdisciplinary care for DSD, as symptoms of depression, anxiety, post-traumatic stress (PTSS), and illness uncertainty (IU) are commonly reported by a subset of parents of these children [4–7].

The decision about whether or not a child with atypical genitalia should undergo early cosmetic genitoplasty is controversial, with some patient and family advocacy groups in favor of delaying surgery [8,9], whereas others support early genitoplasty [10]. Importantly, the presence of psychological distress in parents of children with genital atypia can affect the parents’ ability to fully understand their child’s diagnosis and to incorporate medical information into important decisions, especially those involving surgery [11].

Our group is currently involved in an ongoing, prospective, multi-center study that assesses medical and surgical outcomes of genitoplasty while also examining the psychological functioning of parents of children born with atypical genitalia as they progress through the experience of raising their child. Our recent report of psychosocial functioning in parents of young children with moderate to severe genital atypia prior to genitoplasty indicated that the majority of parents were functioning well. However, a small, but significant percentage reported elevated levels of psychological distress [12]. Specifically, 18% and 25% of parents reported significant levels of depressive and anxious symptoms, respectively. Levels of PTSS in this sample of parents were comparable with parents of children with cystic fibrosis and pediatric cancer [7,13], while levels of IU were comparable with parents of children with type 1 diabetes mellitus [14].

The aim of the current study is to begin studying the trajectory of parental distress so we can identify specific types of distress or patient groups that would most benefit from early intervention. The current report extends our previous findings by including psychosocial data from the first follow-up time point, the 6-month visit, as data collected on surgical outcomes are presented elsewhere [15].

Materials and methods

Participants

Baseline data for the initial 51 parents who were recruited from 10 pediatric hospitals around the country with

multidisciplinary treatment for children with DSD and/or genital atypia have been reported previously [12]. The current sample represents 49 of these parents who completed the 6-month follow-up time point at the time of manuscript submission. Parents were eligible to participate if they had a child who: 1) was younger than 24 months of age at enrollment; 2) was born with atypical genitalia, as defined by a Prader rating of 3–5 in 46,XX DSD or Quigley rating of 3–6 in 46,XY DSD or 45,XO/46,XY; and 3) had not undergone previous genital surgery. Exclusion criteria were: 1) infants and children with malformations of organ systems other than urogenital; and 2) families with limited comprehension of either English or Spanish.

Materials

Parents completed an investigator-created demographic form including questions about the child’s age, sex of rearing, and diagnosis. Additionally, parental information included parent age, sex, marital status, race/ethnicity, and annual family income.

Level of depressive symptoms was assessed with the Beck Depression Inventory – 2nd Edition (BDI-II) [16]. The BDI-II is a 21-item, self-report measure in which symptoms of depression are rated on a scale from 0 to 3, with higher scores indicative of higher levels of depressive symptoms. These scores can be categorized as minimal (0–13), mild (14–19), moderate (20–28), and severe (29–63).

The Beck Anxiety Inventory (BAI) assessed anxious symptomatology [17]. The BAI is a well-validated, 20-item measure of anxious symptoms in adults. Participants rate the degree to which they were bothered by symptoms of anxiety on a scale from 0 (not at all) to 3 (severely). Higher scores are indicative of more anxious symptoms and these scores can be categorized into minimal (0–9), mild (10–16), moderate (17–29), and severe (30–63).

Parental IU was assessed with the Parental Perceptions of Uncertainty Scale (PPUS) [18]. The PPUS is a valid and reliable measure that is often used for parents of children with a chronic medical condition. The PPUS includes 31 items, which are rated on a 5-point Likert scale of “strongly agree” to “strongly disagree.” Higher scores on the PPUS are indicative of more IU.

The presence of PTSS was assessed using the Impact of Event Scale – Revised (IES-R) [19]. The IES-R is a 22-item measure with responses ranging from “not at all” to “extremely,” with higher scores indicative of increased PTSS. A cut-off score of 33 indicates a clinically significant level of PTSS.

The Short Form Health Survey (SF-36) is a self-report measure of quality of life (QOL) [20]. The SF-36 includes 36 items rated on a 5-point Likert scale, with higher scores indicative of better QOL. The items are summed to create two summary scores reflecting QOL related to physical and mental health. A cut-off score of 42 on the mental health scale is suggestive of clinically significant psychiatric distress.

Procedures

After receiving Institutional Review Board (IRB) approval, parents were recruited by study staff as previously

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