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

Cortney Wolfe-Christensen^{a,b}, Amy B. Wisniewski^a, Alexandria J. Mullins^c, Kristy J. Reyes^a, Paul Austin^d, Laurence Baskin^e, Kerlly Bernabé^f, Earl Cheng^g, Allyson Fried^h, Dominic Frimberger^a, Denise Galan^f, Lynette Gonzalez^e, Saul Greenfield^h, Thomas Kolonⁱ, Bradley Kropp^a, Yegappan Lakshmanan^b, Sabrina Meyer^h, Theresa Meyer^g, Natalie J. Nokoff^j, Blake Palmer^a, Dix Poppas^f, Alethea Paradis^d, Elizabeth Yerkes^g, and Larry L. Mullins^c

^aUniversity of Oklahoma Health Sciences Center, Oklahoma City, OK, USA

^bChildren's Hospital of Michigan, Detroit, MI, USA

^cOklahoma State University, Stillwater, OK, USA

^dSt. Louis Children's Hospital, St. Louis, MO, USA

^eUniversity of California San Francisco Medical Center, San Francisco, CA, USA

^fNew York Presbyterian Hospital/Weill Cornell Medicine, New York, NY, USA

^gLurie Children's Hospital of Chicago, Chicago, IL, USA

^hWomen and Children's Hospital of Buffalo, Buffalo, NY, USA

ⁱChildren's Hospital of Philadelphia, Philadelphia, PA, USA

^jChildren's Hospital Colorado, Aurora, CO, USA

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.

Correspondence to: C. Wolfe-Christensen, Cook Children's Medical Center, 801 7th Ave, Fort Worth, TX 76104, USA, cortney.wolfe@cookchildrens.org (C. Wolfe-Christensen).

Conflict of interest

Dr. Paul Austin - Pediatric advisory group & clinical investigator for Allergan and Dr. Dix Poppas - Co-founder of Promethean Surgical Devices, Inc. No other conflicts of interest.

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 followup, 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.

Keywords

Disorder of sex development; Intersex; Psychosocial; Parents; Psychological distress; Atypical genitals

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 described by Suorsa et al. [12]. The data collection time points for the current report involve a baseline assessment (pre-genitoplasty) and a 6-month post-operative assessment. Parents will be compensated \$50 on completion of the 5-year study period.

Statistical analyses

Analyses were conducted using SPSS version 23. First, statistically chosen covariates were identified using independent *t* tests to compare mothers and fathers on baseline levels of depressive symptoms, anxious symptoms, IU, PTSS, and QOL. Next, repeated measures analyses of covariance (ANCOVA) were used to examine changes in levels of depressive and anxious symptoms and QOL for all parents, while controlling for parent sex. Changes in the other levels of psychological distress (IU, PTSS) were examined using paired *t* tests. To determine whether there were differences in parental distress based on the child’s sex of rearing, mixed design ANCOVAs and ANOVAs were conducted, with child sex of rearing entered as a between-subjects variable.

Results

A total of 49 parents (27 mothers and 22 fathers) of 28 children with genital atypia (17 female sex of rearing, 11 male sex of rearing) who underwent genitoplasty were included in the current analyses. The children ranged in age from 6 to 23 months old ($M = 10.01 \pm 5.57$)

at the baseline assessment (Diagnostic information in Table 1 and parent characteristics in Table 2.).

Prior to their child undergoing genitoplasty, mothers reported significantly higher levels of depressive symptoms and anxious symptoms than fathers ($p = 0.02$; $p = 0.004$, respectively). They also reported lower QOL related to mental health ($p = 0.01$). However, mothers and fathers did not significantly differ on levels of IU or PTSS prior to surgery. As such, parental sex was utilized as a covariate in the subsequent analyses [12].

Depressive symptoms

Repeated measures analyses of covariance (ANCOVA) revealed an overall non-significant decrease in level of depressive symptoms for all parents ($p > 0.05$). Notably, at the 6-month follow-up, mothers continued to have a significantly higher level of depressive symptoms than fathers ($p = 0.03$). Additionally, at the 6-month follow-up, 12 parents (27.3%; 12/44) reported minimal to severe levels of depression, with four (9.09%; 4/44) falling in the moderate to severe ranges. Compared with baseline, there was a slight, but not significant, decrease in the number of parents reporting clinical levels of depressive symptoms (Table 3). Results of a mixed ANCOVA revealed that for depressive symptoms, an effect of child sex trended towards significance, such that parents of boys reported higher levels of depressive symptoms than parents of girls ($p = 0.06$).

Anxiety symptoms

Repeated measures analysis of covariance (ANCOVA) revealed an overall, non-significant decrease in level of anxious symptoms for all parents ($p > 0.05$). At the 6-month follow-up, mothers and fathers no longer significantly differed on level of anxiety. Additionally, at the 6-month follow-up, 17 parents (37.0%; 17/46) reported minimal to severe levels of anxiety, with 11 (23.9%; 11/46) falling in the moderate to severe ranges. More parents reported minimal anxiety compared with baseline, although this was not a significant increase. Results of a mixed ANCOVA revealed that for anxious symptoms, parents of boys and girls were not significantly different from each other ($p > 0.05$).

Illness uncertainty

A paired t test revealed no significant changes in level of IU between baseline and 6-month follow-up ($p > .05$). Examination of the means revealed that IU actually slightly increased between baseline and 6-month follow-up. A mixed ANOVA revealed a main effect of child sex ($p = 0.027$), with parents of boys reporting significantly more uncertainty than parents of girls. Examination of the means revealed that parents of boys showed an increase in level of IU, while parents of girls showed no change (summary Figure).

Post-traumatic stress symptoms

Paired t tests revealed a significant decrease in level of PTSS for all parents ($p = 0.004$). At the 6-month follow-up, six parents (13.6%; 6/44) reported clinically significant levels of PTSS, in comparison with eight parents at baseline. A mixed ANOVA revealed a significant PTSS $\times$ Child Sex interaction, such that while all parents improved, the change in level of

PTSS was more significant for parents of boys than parents of girls ($p = 0.03$) (summary Figure).

Quality of life outcomes

Repeated measures analysis of covariance (ANCOVA) revealed no significant changes in QOL related to either mental or physical health ($p > 0.05$). Twenty-two percent of parents ($N = 11$) reported a significant negative effect on QOL related to their mental health. This is comparable with 25% of parents who reported clinically significant difficulties at baseline. Additionally, mean scores on 7 of 8 of the QOL subscales continue to be lower than published norms.

Discussion

Most parents of children with a DSD and genital atypia continue to cope well, in terms of psychological distress, 6 months after their child's surgery. However, there is a subset of parents (approximately 25%) who report experiencing significant levels of a range of psychological symptoms. These data suggest that for some parents, neither time nor genitoplasty for their child, is sufficient in ameliorating their distress, underscoring the need for interventions aimed at helping parents to cope with their child's diagnosis. Importantly, as a group, the parents' level of PTSS decreased significantly between the baseline and 6-month follow-up visits, suggesting that parents have passed through the acute stress phase that may be associated with their child's diagnosis.

We have previously reported that parents of under-masculinized boys with a DSD have significantly higher levels of depressive symptoms than parents of over-masculinized girls [21]. Additionally, mothers of these boys perceived their children to be significantly more vulnerable than girls with DSD including atypical genitalia [22]. Findings from the current study support our previous reports that parents of boys born with genital atypia are at increased risk of experiencing psychological distress. When compared with parents of girls, parents of boys continued to experience higher levels of depression at the 6-month follow-up time point. However, even more concerning than the elevated level of depression, is the indication that not only do parents of boys have higher levels of illness uncertainty at baseline than parents of girls, but their level of uncertainty appears to increase over time. It should be noted that our surgical data indicated that while the girls received a one-stage genitoplasty, a significant number of the boys received a planned two-stage procedure [15]. Increased uncertainty in parents of boys may result from their children not yet completing their genitoplasty. Additionally, in our sample, two-thirds of the patients with a 46,XY karyotype did not have a clinical diagnosis, which could certainly affect the level of parental distress, especially illness uncertainty. We will also continue to follow this cohort to see if surgical complications are related to illness uncertainty or other measures of distress.

Across a range of pediatric health conditions, increased levels of parental uncertainty have been linked to numerous negative psychosocial outcomes, such as increases in psychological distress, specifically depression and anxiety in parents, in addition to poor adjustment outcomes in their children [14,23]. Although the experience of parenting a child with a DSD may be similar to parenting children with other medical diagnoses, parents of children with

DSD face unique circumstances as well. For example, the rarity of DSD diagnoses can leave parents feeling confused and isolated, as most parents do not have knowledge of sexual differentiation processes nor the abnormalities that can occur with these processes at various stages of prenatal development [24]. Additionally, qualitative studies of these parents have revealed an overwhelming fear of being stigmatized because of their child's medical condition. This stigma can result in parents being unable to seek social support from close friends and family [25].

Findings from the current study may be more generalizable as data are prospective and are collected from pediatric hospitals with specialized multidisciplinary care for DSD and genital atypia around the county. Previously, most studies on parents of these children have been retrospective and cross-sectional in nature, often precluding researchers from identifying temporal relationships between levels of parental distress and diagnosis and/or treatment-related variables. However, these findings should also be interpreted in light of weaknesses, including a potential sampling bias. The majority of the parents in our sample are Caucasian, are living with their child's biological parent, and have high educational attainment and income. It is possible that this may limit the generalizability of the findings to other racial and/or ethnic groups or to parents of lower socioeconomic status. The study would benefit from including a larger proportion of parents who elect not to have their child undergo early genitoplasty. At this time, the number of parents enrolled in our study who have not elected for surgery is extremely low (approximately 5%), which inhibits our ability to statistically compare the surgery and non-surgery groups. Hopefully, ongoing data collection process will result in the recruitment of more parents who choose not to pursue surgery, at least before their child is 2 years of age. Finally, the absence of a control group in this study precludes us from being able to identify specific patterns of distress that are unique to parents of children with genital atypia. However, the results from this study represent the first step in understanding how this understudied population of parents is coping in light of current medical practice.

Conclusions

While the majority of parents report minimal levels of psychological distress 6 months after their child undergoes genitoplasty, a subset report experiencing difficulties. Some aspects of distress, such as PTSS, appear to significantly decrease over time. However, neither time nor the decision to pursue surgery for their child is sufficient to improve the majority of parents' distress. Consistent with previous research, parents of boys born with atypical genitalia appear to be the group most at risk for psychological difficulties and are likely the group that would benefit most from psychosocial interventions.

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Figure.
Graphs of significant changes.

Table 1

Children's clinical characteristics.

Karyotype	Diagnosis	<i>n</i>	Sex of rearing
46,XX	CAH	16	16 F, 0 M
46,XY	PGD	1	1M
	PAIS	2	1 F, 1 M
	Unknown	8	0 F, 8M
45,XO/46,XY	MGD	1	1M

Table 2

Parents' demographics.

Parent sex (<i>N</i> = 45)	27 F, 22 M
Parent age (M ± SD; range)	33.43 ± 7.16; 21–61 years
Race/ethnicity	
Caucasian (not Hispanic)	59.2% (<i>N</i> = 29)
Caucasian (Hispanic)	12.2% (<i>N</i> = 6)
African American	10.2% (<i>N</i> = 5)
Asian/Pacific Islander	8.2% (<i>N</i> = 4)
Multi-racial	2.0% (<i>N</i> = 1)
Other (Hispanic)	8.2% (<i>N</i> = 4)
Living with child's other parent	93.9% Yes (<i>N</i> = 46)
Education level	
High school diploma/GED	16.3% (<i>N</i> = 8)
Some college	16.3% (<i>N</i> = 8)
Associate's degree (2 year)	6.1% (<i>N</i> = 3)
Bachelor's degree (4 year)	34.7% (<i>N</i> = 17)
Some graduate school	8.2% (<i>N</i> = 4)
Graduate degree	18.4% (<i>N</i> = 9)
Annual household income	
<\$30,000	24.5% (<i>N</i> = 12)
\$30,000–\$59,999	20.4% (<i>N</i> = 10)
\$60,000–\$89,999	12.2% (<i>N</i> = 6)
\$90,000	42.9% (<i>N</i> = 21)

Table 3Psychological distress variables (M $\pm$ SE).

Distress	Baseline	6-month follow-up	<i>p</i> -Value
Depressive symptoms	9.49 $\pm$ 1.5	8.55 $\pm$ 1.35	>0.05
Anxious symptoms	9.00 $\pm$ 1.38	7.83 $\pm$ 1.54	>0.05
Illness uncertainty	63.45 $\pm$ 2.67	64.06 $\pm$ 3.30	>0.05
PTSS	19.93 $\pm$ 2.95	12.26 $\pm$ 2.26	0.003
QOL – physical health	55.74 $\pm$ 0.96	56.2 $\pm$ 0.75	>0.05
QOL – mental health	46.38 $\pm$ 1.77	47.38 $\pm$ 1.82	>0.05

PTSS = post-traumatic stress symptoms; QOL = quality of life.