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Psychological Adjustment of Parents of Children Born with Atypical Genitalia 1 Year after Genitoplasty

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Abstract

Purpose: We examined the psychological adjustment of parents of children born with moderate to severe genital atypia 12 months after their child underwent genitoplasty.

Materials and Methods: Parents were recruited longitudinally from a multicenter collaboration of 10 pediatric hospitals with specialty care for children with disorders/differences of sex development and/or congenital adrenal hyperplasia. Parents completed measures of depressive and anxious symptoms, illness uncertainty, quality of life, posttraumatic stress and decisional regret.

Results: Compared to levels of distress at baseline (before genitoplasty) and 6 months after genitoplasty, data from 25 mothers and 20 fathers indicated significant improvements in all psychological distress variables. However, a subset of parents continued endorsing clinically

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Study received institutional review board approval.

relevant distress. Some level of decisional regret was endorsed by 28% of parents, although the specific decision that caused regret was not specified.

Conclusions: Overall the majority of parents were coping well 1 year after their child underwent genitoplasty. Level of decisional regret was related to having a bachelor's level of education, increased levels of illness uncertainty preoperatively and persistent illness uncertainty at 12 months after genitoplasty but was unrelated to postoperative complications.

Keywords

disorders of sex development; genitalia; parents; gender identity; adjustment disorders

Disorders or differences of sex development are congenital conditions in which chromosomal, gonadal and anatomical sex are discordant.¹ Parents of young children with disorders or differences of sex development are confronted with decisions regarding gender of rearing for their child and whether to proceed with surgical interventions such as genitoplasty and gonadectomy. The long-term implications of these decisions, coupled with ongoing medical management, may contribute to health related stressors for families. Emerging data suggest that the birth of a child with atypical genitalia secondary to a disorder or difference of sex development or congenital adrenal hyperplasia places parents at increased risk for psychological distress across multiple domains, including depression, anxiety, illness uncertainty, posttraumatic stress symptoms and impaired quality of life.^{2,3}

Information regarding long-term parental adjustment following the diagnosis of a congenital anomaly in their child is limited and is not specific to the challenges of parenting a child with a DSD.⁴ Increased maternal depressive and anxiety symptoms have been observed for years after a child has been diagnosed with congenital malformations.⁵ Similar patterns of persistent distress are also noted in parents of children who have been successfully treated for cancer.^{6,7} Parents of children with chronic medical conditions are also at risk for increased levels of IU, defined as the inability to determine the meaning of illness related events that occurs when the parent does not understand all of the information or is unable to predict outcomes.

As part of an ongoing, prospective, multicenter study assessing medical, surgical and psychological outcomes of children and families affected by genital atypia, we are following psychological functioning in parents who are raising children born with moderate to severe genital ambiguity. We previously reported psychological outcomes before and 6 months after genitoplasty.^{2,3} Those results indicated that approximately 25% of parents had increased depressive and anxious symptoms at baseline that persisted after genitoplasty.

We examined the trajectory (12 months post-operatively) of parental distress following genitoplasty in children and the role of decisional regret in these parents. Our findings will inform early intervention protocols by identifying parent groups at greatest risk for persistent distress and exploring distress symptoms through time.

MATERIALS AND METHODS

Participants

Parents were recruited from 10 pediatric hospitals around the country with multidisciplinary treatment programs for children with DSDs and/or congenital adrenal hyperplasia. Parents were eligible to participate if their child 1) was younger than 24 months at baseline enrollment, 2) was born with atypical genitalia as defined by a Prader rating of 3 to 5 in 46,XX DSD or a Quigley rating of 3 to 6 in 46,XY DSD or 45,XO/46,XY mosaicism and 3) had not previously undergone genital surgery. Exclusion criteria were 1) presence of urogenital anomalies plus malformations of other organ systems and 2) limited comprehension by the family of English or Spanish.

Materials

Parents completed an investigator created demographic form including questions regarding their child concerning age, birth date, gender of rearing and diagnosis. Parent information included age, gender, marital status, race/ethnicity, education level and yearly family income.

Depressive symptoms were assessed using the Beck Depression Inventory, 2nd edition.⁸ The Beck Anxiety Inventory assessed anxious symptomatology,⁹ and parental IU was measured with the Parental Perceptions of Uncertainty Scale.¹⁰ The presence of PTSS was assessed using the Impact of Event Scale-Revised.¹¹ The SF-36® Health Survey is a self-report measure of QOL.¹² Further information on these measures was published previously in the baseline and 6-month followup articles.^{2,3}

For the 1-year post-genitoplasty followup we also examined parental decisional regret. The Decisional Regret Scale is a self-report measure of distress or remorse following a health care decision.¹³ The scale includes 5 items that are rated on a 5-point Likert scale, with higher scores indicative of more decisional regret. Other researchers have published DR categories of 0 = “none,” 1 to 25 = “mild” and 26 to 100 “moderate to severe” in parents of children undergoing distal hypospadias repair.¹⁴

Procedures

After receiving institutional review board approval parents were recruited as described previously.³ Parents were eligible to participate regardless of their decision to proceed with genitoplasty. For parents who pursued genitoplasty for their child the data collection points involved baseline assessment (preoperative for families electing genitoplasty), and 6-month and 1-year followup evaluations.

Descriptive statistics were calculated to identify the demographic characteristics of the sample. Repeated measures ANOVA were used to examine the changes in level of parental distress between the baseline, 6-month and 12-month visits. Parental gender was previously identified as a statistically chosen covariate.³ For these variables ANCOVA was used. Additionally mixed models were used to examine differences in distress between mothers and fathers, differences based on assigned gender of rearing in the child, and differences

between parents whose children did and did not have postoperative complications. Finally, levels of DR at the 12-month postoperative point were compared to other measures of psychological distress and to previously published DR data in similar parental populations.

RESULTS

A total of 45 parents of 26 children completed the 12-month postoperative followup (see table). Nearly all children (25, 96.2%) underwent genitoplasty. For subsequent analyses only parents of children who underwent surgery were included.

Depressive Symptoms

Results revealed a significant decrease in depressive symptoms between baseline and 12-month followup visits ($p = 0.021$, fig. 1). At 12-month followup only 6 parents (14.0%) reported clinically meaningful symptoms of depression, with 4 (9.3%) scoring in the moderate to severe range.

Anxious Symptoms

Anxious symptoms significantly decreased between baseline and 12-month followup ($p = 0.001$, fig. 2). At 12 months after genitoplasty 5 parents (11.6%) reported minimal to moderate levels of anxiety.

Posttraumatic Stress, Illness Uncertainty and QOL Outcomes

Level of PTSS continued significantly decreasing between baseline and 12-month followup assessments ($p < 0.001$, fig. 3). One parent (2.4%) reported clinically significant PTSS at 12-month followup. IU significantly decreased between baseline and 12-month followup ($p = 0.044$, fig. 4). Parental mental health QOL significantly improved between baseline and 12-month followup ($p = 0.043$, fig. 5) but physical QOL remained unchanged.

Gender Effects

At 12 months after genitoplasty mothers continued to report more depressive symptoms than fathers ($p = 0.010$), with none of the fathers reporting even mild symptoms. Mothers and fathers did not differ significantly on any other measure of distress. Comparisons of parents based on assigned gender of rearing of their child showed nonsignificant findings for all distress variables such that at 12 months after genitoplasty child gender of rearing did not affect level of parental distress.

Postoperative Complications

Postoperative complication rates were 13% for females and 25% for males with planned 1-stage procedures and 50% for males with planned 2-stage procedures.¹⁵ Parents of children with and without postoperative complications were compared, and no significant differences emerged between the groups on any of the distress variables.

Decisional Regret

At 12 months after genitoplasty 12 parents (27.9%) reported some level of DR, with 9 (20.9%) in the mild range and 3 (7.0%) in the moderate to severe range. Parents in the current sample reported significantly lower DR than parents whose children underwent distal hypospadias repair ($p < 0.001$ and $p < 0.023$, fig. 6), despite the children undergoing more complex genital surgery.^{14,16} Based on a study by Ghidini et al,¹⁴ exploratory ANOVA was used to compare educational groups (bachelor's degree vs lower and higher education) regarding level of DR. Results demonstrated a significant between group effect ($p = 0.007$), such that parents with a bachelor's degree reported significantly higher levels of DR than those in the lower and higher education groups at 1-year followup (fig. 7).

Examination of the relationships between baseline levels of distress and future DR revealed that after controlling for surgical complications increased levels of DR at 12 months following genitoplasty were related to higher baseline levels of IU ($p = 0.013$), suggesting that parents who reported higher IU at baseline are at increased risk for future DR. Comparisons of differences in level of distress between the DR groups (none vs mild vs moderate to severe) at 12 months after genitoplasty showed no significant differences except for level of uncertainty ($p = 0.023$), with post hoc comparisons demonstrating differences between the group with no DR and the moderate to severe DR group ($p = 0.037$).

Summary of Clinically Increased Symptoms

At 12 months after genitoplasty 34 parents (79.1%) were in the "normal" range on all 4 measures, while 3 (7.0%) reported clinically increased symptoms on only 1 scale, 4 (9.3%) on 2 scales and 3 (4.7%) on 3 scales. No parent reported clinically increased levels of distress on all 4 measures.

DISCUSSION

Psychological Distress Symptoms

At 1 year following genitoplasty the majority of parents of children with a DSD, including genital atypia, exhibited adaptive psychological functioning (improvement in clinical distress in more than 1 domain). However, a subset of parents (21%) continued to endorse clinically relevant distress in domains of depression, anxiety, QOL and/or PTSS. These symptoms are consistent with or below prevalence rates for the United States adult population.¹⁷ The IU in this sample of parents diminished to levels similar to parents of children with diabetes after receiving an intervention targeting symptoms of uncertainty.¹⁸ The progressive resolution of depression, anxiety, IU and PTSS, and increase in QOL are consistent with resiliency models found elsewhere in the literature on parental coping with child illness and injury.^{19–21} Together these data strongly indicate that the parents of children affected by a DSD with atypical genitalia have generally passed the acute stress phase within 1 year of their child undergoing genitoplasty. It remains unknown whether this observed symptom resolution is specific to parents who elect genitoplasty or whether a similar pattern of adaptation is seen in parents whose children do not undergo surgery.

Gender Effects

We previously reported that mothers and fathers are affected differently when their child is diagnosed with atypical genitalia and when facing decisions regarding the option of genitoplasty.²⁰ One year after their child undergoes genitoplasty mothers continue to report increased levels of depressive symptoms compared to fathers. However, no differences are observed for anxiety, PTSS, IU or DR. This gender difference in depressive symptoms is consistent with base rate discrepancies in the general population and observations of parents of children with cancer.^{8,22,23} Although surgical literature has also linked levels of anxiety to gender, that pattern was not supported by our data.²⁴ Additionally 1 year after genitoplasty the previously observed effects of child gender on parental distress and IU resolved.²

Decisional Regret

While a minority of parents in the sample reported DR, the questions on this measure were broad and did not assess precisely which specific decisions parents regretted. Rates of DR did not increase after children underwent genitoplasty. When we compared our sample to parents of boys who underwent surgical repair for distal hypospadias, the parents in our series reported much lower levels of DR, although the surgical procedures were more complex.^{14,15} Reasons for this unexpected discrepancy require further exploration but may relate to perceived necessity of surgery, a tendency toward greater commitment to decisions for which one has already deeply invested or information and support received by the families during the decision making processes. Our data suggest that parents who report more IU before their child undergoes genitoplasty are at increased risk for DR at 1 year postoperatively. Additionally parents reporting moderate to severe DR 12 months after genitoplasty report a persistence of heightened IU in the year following the procedure. Although our data are correlational and causation cannot be inferred, this relationship supports further exploration into whether promoting better coping with IU at baseline results in less DR through time.

Consistent with the findings of Ghidini et al,¹⁴ but in contrast to the findings of Lorenzo et al,¹⁶ surgical complications were unrelated to DR and parents with intermediate education reported the most DR. This relationship between education attainment and decisional regret is not well explored in current literature and is not consistent across all patient populations.^{25,26} Among other medical populations attainment of college education has been associated with a greater propensity to seek health information from written sources^{27,28} but not to discuss that information with health care providers.²⁹ The protective factors (ie increased access, experience reading scientific texts, communication style) that may be enabling the post-graduate group of parents to avoid decisional regret is an area for further study.

Parents, particularly those who use health information sources other than their medical team, are likely to require support in understanding and weighing all the options. Additionally parents with lower educational attainment may require support to acquire information regarding treatment options and alternatives necessary for truly informed consent.

Strengths and Limitations

The prospective longitudinal design of this study allows researchers to identify temporal relationships between levels of parental distress and other treatment related variables. A major limitation of the current project is possible sampling bias. It is likely that external validity is affected since the majority of the parents in our sample are Caucasian, live with the other biological parent of their child, have at least a bachelor's degree and report a yearly income of \$90,000 or more. It is unclear how these findings may extend to other racial and/or ethnic groups or to parents of lower socioeconomic status. In addition, the measures are all self-reported, thus increasing risks of social desirability biases impacting data. Also, little is known about parents who elect not to have their child undergo genitoplasty because the sample (1 parent) is too small to statistically analyze. Finally, we do not have information on the specific surgical counseling and mental health intervention that occurred at each site.

Ongoing recruitment will aim to include parents of children who decline or delay genitoplasty until after their child is 2 years old. The absence of a control group limits our ability to identify precise patterns of distress that may be unique to parents of children with genital atypia compared to other medical conditions.

The results of this series represent a longitudinal contribution to the emerging body of literature examining coping in this under studied population of parents. We plan to continue following the psychological adjustment of this cohort of parents and patients as the children grow up. It is quite possible that levels of parental distress will change through time as the children face various developmental milestones and/or experience their own psychological distress.

CONCLUSIONS

The majority of parents reported progressive resolution of psychological distress 12 months after their child with atypical genitalia underwent genitoplasty. The explanation for these changes is unclear as it is likely that a combination of factors contribute to this improvement, including variables such as time since diagnosis, acceptance of diagnosis and surgical intervention. Nevertheless, parents reporting DR 12 months after genitoplasty are more likely to have a bachelor's degree, report increased psychological distress before their child undergoes surgery and endorse persistent IU 12 months after the procedure. Parents most at risk for persistent distress and DR could potentially be identified by brief psychological screening measures. Early interventions aimed at helping these parents cope with IU could possibly reduce DR through time.

Abbreviations and Acronyms

DR	decisional regret
DSD	disorder of sex development
IU	illness uncertainty

PTSS	posttraumatic stress symptoms
QOL	quality of life

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Figure 1.

Categories of severity of depressive symptoms. Post hoc comparisons reveal significant differences between baseline and 6-month followup ($p = 0.001$), and baseline and 12-month followup ($p = 0.012$). *Mod-Sev*, moderate to severe.

Figure 2.

Categories of severity of anxious symptoms. Post hoc comparisons show significant differences between all points (baseline to 6 months, $p = 0.031$; 6 months to 12 months, $p = 0.018$; baseline to 12 months, $p = 0.004$). *Mod-Sev*, moderate to severe.

Figure 3. Categories of severity of PTSS. Post hoc comparisons demonstrate significant differences between baseline and 6 months ($p = 0.001$), and baseline and 12-month followup ($p < 0.001$).

Figure 4. Level of illness uncertainty. Post hoc comparisons reveal significant differences between baseline and 12-month followup ($p = 0.022$). *PPUS*, Parent Perception of Uncertainty Scale.

Figure 5.
Categories of severity of QOL impairments

Figure 6.

Comparison of level of DR between current sample and other studies.^{14,16} *DRS*, Decisional Regret Scale.

Figure 7. Comparison of parental decisional regret based on level of education. *DRS*, Decisional Regret Scale.

Subject characteristics

No. parent gender/total No.:		
Female	25/45	
Male	20/45	
Mean $\pm$ SD parent age (range)	34.45 $\pm$ 6.92 Yrs	(24–63)
No. child gender/total No.:		
Female	14/25	
Male	11/25	
Mean $\pm$ SD child age (range)	25.82 $\pm$ 7.3 Mos	(17–41)
No. diagnosis (%):		
Congenital adrenal hyperplasia due to 14 (56) 21-hydroxylase deficiency		
46,XY DSD, unknown/unclassified	7	(28)
Mixed gonadal dysgenesis	2	(8)
Partial androgen insensitivity syndrome	1	(4)
Bilat anorchia	1	(4)
Mean $\pm$ SD 46,XX Prader rating (range)	3.35 $\pm$ 0.72	(3–5)
Mean $\pm$ SD 46,XY or 45,XO/46,XY Quigley rating (range)	3.86 $\pm$ 0.90	(3–5)
No. parent race/ethnicity (%):		
Caucasian (not Hispanic)	27	(60.0)
Caucasian (Hispanic)	6	(13.3)
African American	4	(8.9)
Asian/Pacific Islander	1	(2.2)
Multiracial	2	(4.4)
Other (Hispanic)	4	(8.8)
Not reported	1	(2.2)
No. parent living with other parent (%)	41	(91.1)
No. parent education level (%):		
High school diploma/GED	2	(4.4)
Some college	12	(26.7)
Associate's degree (2-yr)	2	(4.4)
Bachelor's degree (4-yr)	14	(31.1)
Some graduate school	3	(6.7)
Graduate degree	11	(24.4)
Not reported	1	(2.2)
No. annual household income/total No. (%):		
Less than \$30,000	5/44	(11.1)
\$30,000–\$59,999	7/44	(15.6)
\$60,000–\$89,999	8/44	(17.8)
\$90,000 or More	24/44	(53.3)