ILLNESS UNCERTAINTY, PERCEPTIONS OF COSMETIC APPEARANCE, AND POSTTRAUMATIC STRESS SYMPTOMS IN PARENTS OF CHILDREN WITH DISORDERS/DIFFERENCES OF SEX DEVELOPMENT

By

ALEXANDRIA JADE MULLINS

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Oklahoma State University

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Thesis Approved:

Dr. Larry Mullins

Thesis Adviser

Dr. John Chaney

Dr. R. Matthew Alderson

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Abstract: The current study examined illness uncertainty and parents' perceptions of the cosmetic appearance of their child's atypical genitalia as predictors of posttraumatic stress symptoms (PTSS) in parents of children with a newly diagnosed Disorder/Difference of Sex Development (DSD). Participants were 55 mothers and 41 fathers of 55 children with a DSD and atypical genitalia prior to undergoing genitoplasty. Parents were recruited within 6 months of their infant's diagnosis from 11 clinic sites specializing in the treatment of DSD. Results revealed that mothers reported significantly greater levels of PTSS than fathers. No differences existed between mothers' and fathers' levels of illness uncertainty or ratings of the cosmetic appearance of their child's atypical genitalia. Hierarchical regression revealed that illness uncertainty and cosmetic appearance ratings significantly predicted PTSS in mothers. Illness uncertainty was found to be a significant, positive, predictor of PTSS, independent of cosmetic appearance rating. The final model accounted for 27.2% of the variance associated with PTSS. Cosmetic appearance rating did not contribute unique variance, independent of illness uncertainty, to the final model. Such results indicate increased illness uncertainty to be significantly associated with elevated levels of PTSS for mothers of children with a newly diagnosed DSD. When developing clinical interventions for families of children with DSD, mothers' beliefs regarding their child's illness should be considered.

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CHAPTER I

INTRODUCTION

Disorders/Differences of sex development (DSD) is a catchall term that refers to a set of heterogeneous medical conditions involving discordance between chromosomal, phenotypic, and/or gonadal sex (Hughes, Houk, Ahmed, & Lee, 2006). DSDs are approximated to effect 1 out of every 4,500 children born (Hughes et al., 2006). Amongst other concerns, DSDs can affect the functionality and appearance of the genitalia, resulting in atypical or ambiguous genitalia at birth. Importantly, research has shown that such physical differences associated with congenital disorders, whether readily visible or hidden, are related to negative adjustment outcomes, particularly in parents who may feel guilt or shame regarding their child's condition (Holmbeck & Aspinall, 2015). Indeed, for parents of boy children with DSD, degree of genital malformation has been linked to higher rates of caregiver depression (Wolfe-Christensen et al., 2010). Furthermore, for individuals with a DSD, decreased satisfaction regarding the appearance of their genitalia is associated with negative outcomes as well (Oner et al., 2009).

When a child is born with a DSD and atypical genitalia, surgery may be necessary for normalization of the appearance of the genitalia and the preservation of fertility (Rangecroft, 2003). As such, parents of a child born with DSD must make complex medical decisions including gender assignment and incidence and timing of surgery for their child (Rangecroft, 2003). Deciding whether or not to choose surgery before a child can give assent is a notably difficult decision, with parents experiencing a considerable amount of stress surrounding their child's diagnosis (Wiesemann, Ude-Koeller, Sinnecker, & Thyen, 2010; Kirk et al., 2011; Brain

et al., 2010). In addition to such worries, parents report concerns regarding how to discuss their child's DSD with others and the potential stigma surrounding their child's condition as well (Duguid et al., 2007). Although parents of children with DSDs generally report relatively low overall levels of stigma compared to parents of children with another stigmatizing disorder (i.e., epilepsy), a subset of parents report moderate to high levels of perceived stigma surrounding their child's DSD diagnosis. In particular, parents indicate worrying most about future outcomes related to their child's condition and the stigma their child may face due to their condition (Rolsten, Gardner, Vilain, & Sandberg, 2015). Parents' concerns about their child's adjustment are warranted, as children and adolescents with a DSD are at increased risk of experiencing a host of negative psychosocial outcomes, including decreased health-related quality of life, impaired self-esteem and school functioning (Jurgensen et al., 2014), behavioral and emotional problems (Oner et al., 2009), and increased rates of gender dysphoria and dissatisfaction with their assigned gender compared to their peers without a DSD (Meyer-Bahlburg, 2011; Korte et al., 2008).

The stress and worry related to having a child diagnosed with a DSD appears to take a toll on parents. Mothers and fathers are at risk for elevated depressive and anxious symptoms, changes in parenting perceptions, such as increased perceived vulnerability (Wolfe-Christensen et al., 2012; Hullmann, Fedele, Wolfe-Christensen, Mullins, & Wisniewski, 2001; Kirk, et al., 2011), as well as decreased quality of life, and posttraumatic stress symptoms (PTSS; Pasterski, Mastroyannopoulou, Wright, Zucker, & Hughes, 2014; Suorsa et al., 2015). Specifically, parents of children with DSD seem to experience rates of PTSS at levels similar to those reported by parents of children with cancer (Pasterski et al., 2014; Suorsa et al., 2015). Pasterski and colleagues (2014) further reported that in a cross-sectional sample of parents of children with DSD 31% of mothers and 18% of fathers endorsed levels of PTSS indicative of posttraumatic stress disorder (PTSD). Similarly, Suorsa et al. (2015) found that in a small sample of parents with newly diagnosed DSD, approximately 15% of parents reported symptoms of PTSS that reached the clinical threshold.

The Medical Traumatic Stress Model proposed by Kazak and colleagues (2006) suggests that it is the interaction between the "objective nature of the event" and "subjective interpretation of the event" that leads an individual to characterize an experience, such as the diagnosis of illness, as being traumatic or not traumatic (Kazak et al., 2007). A diagnosis of a DSD is potentially life-altering for both children and parents. It can be argued that whether or not such a diagnosis will be perceived as a traumatic event for parents depends on subjective interpretations and individual factors related to the severity and trajectory of the disease. For parents of children with DSD, considerations may include degree of genital malformation, recommendations for gender assignment, need for surgical intervention, potential for fertility, and perceived social stigma (Hewitt & Warne, 2009). Parents of children with a DSD must navigate a multitude of illness-related factors when making medical decisions for their child, thus it is noteworthy that they indicate feeling dissatisfied with their knowledge about their child's DSD, particularly information regarding surgery and post-surgical care (Duguid et al., 2007). This is an important consideration, as Paterski et al. (2014) found that perception of confusion and disbelief were significant contributors to PTSS in parents of children with DSD. Additionally, it warrants noting that later surgical interventions for children with DSDs have been associated with poorer adjustment outcomes for parents (Crawford, Warne, Southwell, & Hutson, 2009). Arguably, it may be that the uncertainty associated with their child's condition and the anticipation of future outcomes influence untoward adjustment outcomes in parents of children with DSD. This is particularly important as research indicates that child and parent adjustment outcomes are related (Chaney & Mullins, 1997; Fedele et al., 2013; Lopez, Mullins, Wolfe-Christensen, & Bourdeau, 2008), so that suboptimal outcomes for parents predict poorer outcomes for children as well.

Illness Uncertainty

Within the pediatric and health psychology literature, the construct of illness uncertainty has been consistently associated with adjustment outcomes for both parents and children (Stewart & Mishel, 2000). The perception of illness uncertainty can be understood as the experience of an

illness-related event or situation in which a person is unable to assign value to the event or predict related outcomes (Mishel, 1981, 1983). To date, illness uncertainty has been shown to be a predictor of psychological distress in parents of children with a number of chronic health conditions, such as juvenile rheumatic disease (Fedele et al., 2011) and pediatric brain tumors (Fuemmeler et al., 2001). Further, there is evidence to support the link between maternal illness uncertainty and child depressive symptoms in children with chronic illnesses, indicating that increased levels of maternal uncertainty surrounding their child's diagnosis of a chronic illness may be a key predictor in the development of negative adjustment outcomes in children (Page et al., 2012). Illness uncertainty has also been associated with increased psychological distress in children and adolescents with type-1 diabetes (Hoff, Mullins, Chaney, Hartman, & Domek, 2002), and increased anxiety symptoms and PTSS in survivors of pediatric cancer, with evidence supporting illness uncertainty as a possible antecedent of PTSS (Lee, 2006; Santacroce, 2006). Notably, this relationship between illness uncertainty and PTSS is an important one as it may help to explain the risk factors contributing to the development of PTSD in parents of children with a chronic illness. Considering the many medical decisions parents of children with DSD face (e.g., gender assignment, surgical considerations, information disclosure and timing), illness uncertainty may be particularly salient in this population, although there is little research examining this construct.

Posttraumatic Stress

In summary, parents of children with chronic illnesses may be vulnerable to developing PTSS, particularly shortly after their child's diagnosis (Phipps, Long, Hudson, & Rai, 2005). For example, parents of children with cancer report greater PTSS compared to parents of healthy children (Kazak, 1998), tend to be specifically vulnerable to re-experiencing symptoms, and are more likely to experience PTSS than their ill children (Kazak et al., 2004). In a preliminary study of parents of children survivors of brain tumors, Fuemmeler, Mullins, and Marx (2001) reported that illness uncertainty was associated with increased PTSS and general psychological distress in

this sample as well. Additionally, Tackett et al. (2016) found that illness uncertainty was related to PTSS in parents of children with cancer. Such studies support a link between illness uncertainty and adjustment, particularly PTSS, in parents of children with a chronic illness. However, further investigation into the individual and environmental factors that may contribute to the development of PTSS in parents remains warranted, particularly for parents of children with DSD, for whom extant research is considerably lacking (Holmbeck & Aspinall, 2015).

Study Aims

Although DSDs can be conceptualized as a heterogeneous group of disorders that are highly uncertain in nature, no research to date has examined the parental experience of illness uncertainty and the development of subsequent psychosocial outcomes. Thus, the current study seeks to add to the literature by investigating the relationship between illness uncertainty and PTSS in parents of children diagnosed with a DSD. Specifically, the current study seeks to examine perceived illness uncertainty as a predictor of PTSS in parents. We hypothesized that illness uncertainty would be a significant predictor of PTSS in parents of children with DSDs, such that higher levels of perceived illness uncertainty would be associated with higher levels of PTSS. Additionally, we sought to explore the relationship between parental satisfaction with the appearance of their child's genitalia and PTSS, as previous studies indicate that patient satisfaction of genital appearance is related to negative psychosocial adjustment (Oner et al., 2009) and a greater degree of genital malformation is associated with poor psychosocial outcomes for parents (Wolfe-Christensen et al., 2010).

CHAPTER II

LITERATURE REVIEW

Disorders/Differences of Sex Development

The term Disorders/Differences of Sex Development (DSD) represents a set of medical conditions that involve discordance between chromosomal, phenotypic, and/or gonadal sex (Hughes, Houk, Ahmed, & Lee, 2006). These conditions affect approximately 1 out of every 4,500 children born (Hughes et al., 2006) and are comprised of highly complex, heterogeneous congenital conditions. DSDs range in degree of virilization and often affect the development and outward appearance of the genitalia though degree of genital ambiguity or malformation varies across disorders and cases.

For diagnostic purposes, DSDs are divided into three main categories, which are further broken down into more specific subcategories. The three umbrella categories are: 1) sex chromosome DSD, 2) 46,XY DSD, and 3) 46,XX DSD. Sex chromosome DSD consists of abnormal gonadal development due to abnormalities in numerical sex chromosomes. Examples of this type of DSD include 45,XX Turner and variants, 47,XXY Klinefelter and variants, 45X.46XY, mixed gonadal dysgenesis, and chromosomal ovotesticular DSD. Turner and Klinefelter syndrome make up the most common types of sex chromosome DSD. Next, 46,XY DSDs consist of disorders of testicular development and androgen synthesis, such as complete/partial gonadal dysgenesis and androgen synthesis defect. Lastly, 46,XX DSD consists

of congenital adrenal hyperplasia (CAH) and non CAH fetal androgen excess disorders. Examples include 21-OH definciency (CAH) and non CAH fetal androgen excess disorders. Examples include 21-OH definciency (CAH) and aromatase deficiency (non CAH). The most common form of DSD is 46XY DSD (Damiani, 2007; Ocal, 2011), and congenital adrenal hyperplasia and mixed gonadal dysgenesis are the most typical causes of genital ambiguity (Thyen, Lanz, Holterhus, Hiort, & Horm, 2006).

Treatment

Individuals with DSDs may undergo complex treatment regimens, including hormone therapy and the possibility of surgical intervention (Kim & Kim, 2012). Hormone therapy is used to replace hormones in individuals with DSD whose bodies can not create them and repress the secretion of hormones for individuals with DSD whose bodies create too much of a certain hormone. For example, without the replacement of cortisol and aldosterone, salt-wasting congenital adrenal hyperplasia would be a fatal condition for those affected (Warne, Grover, & Zajak, 2005a). Hormone therapy is also used during the adolescent years to stimulate the effects of puberty and secondary sexual characteristics and this treatment is often necessary for proper sexual development (Warne et al., 2005b). Importantly, individuals with certain types of DSD are at an increased risk for developing a type of malignant tumor called germ cell tumors, thus testicular biopsies are recommended at puberty for those at risk (Hughes et al., 2006).

For individuals with DSD and ambiguous genitalia, surgical interventions may also be necessary to preserve or maximize urinary, sexual, and reproductive functioning. Surgery may also be utilized to more accurately align the appearance of the outer genitalia with the assigned gender (Clayton et al, 2002). When surgery is necessary, it is recommended that it be conducted when the infant is between two and six months. This is due to evidence supporting superior cosmetic and medical outcomes, along with fewer long-term complications with the functioning

of the genitalia (Kass et al., 1996; Kim & Kim, 2012). It is thought that early interventions may reduce parental distress, the risk of being stigmatized by having a DSD, and the prevalence of gender dysphoria or confusion, as well as increase parent child attachment (Crawford, Warne, Southwell, & Hutson, 2009; Warne et al., 2005b). However, according to the Consensus Statement on Management of Intersex Disorders, the evidence to support these tenets is sparse (Hughes et al., 2006) and it should be noted that cosmetic alteration of the genitalia without child consent is controversial.

Psychosocial Outcomes in Individuals with DSD

Individuals with DSD are at increased risk of experiencing a host of negative psychosocial outcomes. The literature indicates that these individuals are at a higher likelihood to suffer from decreased health related quality of life (HRQOL) across the lifespan (Jurgensen et al., 2014; Johannsen, Ripa, Mortensen, & Main, 2006) and greater behavioral and emotional difficulties as children (Oner et al., 2009). Additionally, individuals with DSD tend to experience increased distress related to the physical and emotional effects of puberty (Schwiezer, Brunner, Schutzmann, Schönbucher, & Richeter-Appelt, 2009; Ebert, Scheuring, Schott, & Roesch, 2005) and higher rates of gender dyspohoria than the general population (Meyer-Bahlburg, 2011; Korte et al., 2008). Adolescents and young adults with DSD also report increased isolation (Hiort, et al., 2003) and decreased self-esteem and social support (Cohen-Kettenis & Pfäfflin, 2003). In a study by Slijper, Drop, Molenaar, & de Muinck Keizer-Schrama (1998) results indicate that adolescents with DSD may also be at a significantly increased risk for comorbid psychiatric diagnoses as well.

Quality of life is of particularly concern for individuals with DSD, as recent studies have shown an increased risk for lower quality of life outcomes (Jurgensen et al., 2014). Health Related Quality of Life (HRQoL) is a measure of psychosocial functioning, which encompasses

an individual's overall adjustment to having a medical disorder and receiving medical intervention (Schober, 1999). Due to the complex nature of DSD, treatment is multifaceted, consisting of surgery, hormonal treatments, and long-term follow-up care. This complex regimen along with psychosocial factors, such as the uncertainty and stigmatization associated with the disorder may place individuals with DSD at risk for lower quality of life (Johannsen et al., 2006). For example, Johannsen et al. (2006) found that in a sample of Danish women with DSD and healthy controls, women with DSD rated their quality of life significantly lower than the healthy controls. Additionally, study participants were significantly less likely to have a current relationship or be parenting children than healthy controls. Kuhnle & Bullinger (1997) reported similar findings; compared to healthy controls; finding that women with congenital adrenal hyperplasia (CAH) were more likely to be single and less likely to have children.

Jurgensen et al. (2014) reported that in a sample of German children with DSD, these children reported significantly lower HRQOL than their healthy counterparts when compared to reference data from non-affected children in the same age range. Specifically, the authors reported that children with DSD indicated lower HRQOL in the areas of self-esteem, physical wellbeing, and school functioning. Collectively, the results reported by Johannsen et al. (2006) and Jurgensen et al. (2014) about HRQOL in children and adults with DSD suggest that individuals with DSD are indeed suffering from psychological distress related to aspects of their DSD diagnosis. These results also reveal that further research is needed in these families to tease apart the distressing symptoms experienced and the factors contributing to them.

Other types of psychological adjustment outcomes have been assessed in this population as well, including behavioral and emotional outcomes. Oner et al. (2009) reported that female children with CAH had significantly greater behavioral and emotional difficulties than both matched peers with type one diabetes mellitus and healthy controls. Interestingly, patient outcomes, including both externalizing and emotional problems, were related to the child's

satisfaction with her genital appearance, the surgeon's rating of the degree of success of the procedure, and the child's mean testosterone levels. Oner et al. (2009) also reported that the degree to which the child exhibited these negative adjustment indicators was related to the degree of androgenization, satisfaction of the appearance of the genitalia, and the success of the surgery. Although this study was limited by its small sample size (n=28 females with CAH, n=28 patients with diabetes mellitus, n=28 healthy controls), results suggest an important empirical link between having DSD and exhibiting untoward adjustment outcomes other than impaired quality of life. Importantly, these results also support a relationship between adjustment outcomes and patient perception of cosmetic appearance and the severity of the disorder, indicating that along with the severity of the disorder, early surgical outcomes may later influence patient adjustment.

Additionally, youth with DSDs tend to experience increased distress related to the physical and emotional effects of puberty. Specifically, youths of pubertal age report feeling different than same-aged peers, questioning their assigned gender, and feeling increasingly isolated (Schwiezer et al., 2009; Ebert et al., 2005). In a mixed method retrospective study exploring gender and coping experiences in female adults with DSD, Schwiezer et al. (2009) found that all participants (n=7) reported psychological distress during puberty. This distress was reportedly due to their body virilizing unexpectedly. Participants reported worries about gender assignment, gender role, and that they would be perceived outwardly as a male despite identifying as a female. Participants reported feeling ashamed, insecure, depressed, lonely, and helpless during this period of their lives and some even reported contemplated suicide due to the negative feelings they had in association with the virilization of their bodies. Six out of seven participants reported limited to no social support and feeling as if they had no one with which they could discuss their experience.

In a separate a retrospective follow-up study Ebert et al. (2005) found that children and adolescents with a DSD known as exstrophy-epispadias complex (EEC) who underwent complete

functional repair of the genitalia reported generally low satisfaction with the appearance of their genitalia. Additionally, over half of the adolescents indicated anxiety about engaging in sexual activities. Specific to concerns about their own psychological adjustment, 93.9% of respondents in this study reported an interest in receiving psychological services. Additionally, diminished social support was also reported, with nearly 60% indicating that their peer contact was impacted by their EEC diagnosis and that they had few close relationships because of their DSD. Over one quarter of the participants reported that they hid their DSD from their peers and 16% of participants indicated that only their immediate family was aware of their DSD.

Further, individuals with DSD tend to experience higher rates of gender dysphoria, formerly known as gender identity disorder, or patient initiated gender reassignment than the general population (Meyer-Bahlburg, 2011). Gender dysphoria is defined by the Diagnostic and Statistical Manual of Mental Disorders- Fifth Edition (DSM-5) as the "distress that may accompany the incongruence between one's experienced or expressed gender and ones' assigned gender" (American Psychiatric Association, 2013, p. 451). Currently, the rate of gender dysphoria in the general population is reported as less than one percent (Korte et al., 2008; American Psychiatric Association, 2013, p. 454). For individuals diagnosed with DSD, this rate is recognized to range up to 35% and varies widely by condition (Meyer, 2011). Importantly, individuals with gender dysphoria are likely to suffer from comorbid psychiatric diagnoses, such as depressive disorders (Korte et al., 2008; Grossman & D'Augelli, 2007) placing individuals with DSD at an even higher risk for developing a psychiatric disorder.

Regardless of the presence of gender dysphoria, adolescents with DSD tend to be at higher risk for other negative psychosocial outcomes, including perceived isolation (Hiort et al., 2003), low self-esteem, decreased social support (Cohen-Kettenis & Pfäfflin, 2003) and comorbid psychiatric diagnoses (Slijper, Drop, Molenaar, & de Muinck Keizer-Schrama, 1998). However, it is important to note that findings vary, and some studies report that adolescents tend to adjust

well to their diagnoses with impairment being limited to sexual development and participation (e.g. Kleinemeier et al., 2010). For example, after examining psychological outcomes and psychosexual development in 60 adolescents with DSD and comparing this to reference data from a national survey, Kleinemeier and colleagues (2010) found no significant impairment in health-related quality of life or mental health status for adolescents with DSD. However, boys with DSD were significantly more likely to report negative body images related to primary sex characteristics while girls with DSD were significantly less likely to engage in developmentally appropriate sexual activities compared to their peers. Additionally, Schönbucher, Weber, & Landolt (2008) found that boys with hypospadias suffer from inhibited sexual behavior and negative perceptions of the cosmetic appearance of their genitalia. Though it is impossible to predict why adjustment outcomes for adolescents vary across research studies, outcomes may be influenced by methodological flaws, such as limited sample sizes due to the rarity of the disorder and sampling bias. Families with greater social economic standing may seek out more specialized care for their child, such as DSD clinics where they are more likely to approached for to participate in research. Such families may have greater access to psychological services and more skilled surgeons, thus influencing surgical outcomes.

Youth with DSD are not the only ones reporting negative psychosocial outcomes related to their disorders. Adults with DSD also report higher rates of psychological distress and self-harming behaviors (Schutzmann et al., 2009) and impaired sexual quality of life (Schönbucher, Schweizer, & Richter-Appelt, 2010) compared to their healthy counterparts. In a review of studies exaining sexual quality of life in persons with 46,XY DSD, Schönbucher et al. (2010) discovered that when compared to unaffected individuals, persons with 46,XY DSD reported feeling more insecure in both social and sexual situations, being less satisfied with their sexual functioning, cosmetic appearance of their genitalia, and overall sex life, and indicating having more sexual problems than their unaffected counterparts. Further, Schönbucher and associates

(2010) found increased rates of psychological distress in a sample of individual with various forms of DSD compared to a non-clinical norm population. Additionally, suicidal thoughts and self-harming behaviors were higher for individuals with DSD than the comparison sample. Rates of suicidal thoughts and self-harming behaviors were comparable to rates reported for women who have experienced physical or sexual trauma (Schönbucher et al., 2010). Although speculative, such results indicate that persons with DSD may be at a higher risk for negative psychosocial outcomes during adulthood than during childhood or adolescents (Berenbaum, 2006). It is possible that the more distressing issues associated with DSD, such as issues with lack of fertility, sexual dysfunction or dissatisfaction, and barriers these issues may pose in establishing romantic relationships, may not surface until later adolescents or adulthood. Thus, children and younger adolescents may be buffered at somewhat from confronting these issues related to their DSD diagnosis (Kleinemeier et al., 2010).

Psychosocial Outcomes for Parents

According to Jurgensen et al. (2014), parents of children with DSD report significantly lower "emotional well-being" than parents of unaffected children. Conversely, the researchers also found that parents of children with DSD reported better physical well-being than parents from the reference data. One of the most interesting findings from this study, however, relates to parent-child agreement on self-reported psychological dimensions. Parents tended to rate their child's emotional well-being and family quality of life as worse than their children's rating of their own well-being and family quality of life. Parents over-rated their child's perception of their physical wellbeing, self-esteem, and abilities in school. Such results indicate that parents may have very different perceptions related to their child's psychosocial adjustment, and one could speculate that this might lead to family unrest or psychological distress for the individuals within the family.

Interestingly, evidence suggests that in addition to degree of genital malformation, sex of rearing may be related to parent's psychological adjustment. Research indicates that for parents of boy children, their child's degree of genital malformation is related to their own levels of depressive and anxious symptoms (Wolfe-Christensen et al., 2012). Parents of children with DSD are particularly susceptible to displaying negative or maladaptive parenting practices during their child's infancy as well. Parents of infants and toddlers with DSD report experiencing higher rates of perceived vulnerability than parents of children with DSD in other developmental stages (Hullmann et al.. 2001). Sex of rearing may influence parenting practices as well, as parents of boy children with DSD are more likely to perceive their children as vulnerable compared to parents of girl children with DSD (Kirk et al., 2011). Additionally, Wolfe-Christensen, Fedele, Mullins, Lakshmanan, and Wisniewski (2014) reported that a positive relationship exists between parent-reported perceived child vulnerability and increased anxious symptoms in parents of children with DSD.

Though research examining gender differences related to parenting a child with DSD is mixed, previous findings hint that mothers and fathers may cope differently with having a child with DSD. Wolf-Christensen and colleagues (2014) reported findings that female caregivers of children with DSD report experiencing increased levels of anxious symptoms compared to their male counterparts. Alternatively, Suorsa et al. (2015) reported no significant differences between male and female caregivers of children with DSD; however, it should be noted that these finding are preliminary due to the small nature of the sample size. Suorsa et al. (2015) also stated that parents of children with DSD report significantly lower quality of life outcomes when compared to community norms.

In a study by Duguid et al. (2007), the authors found that 19% of parents of children with a newly diagnosed DSD exhibited clinically elevated stress related to their child's condition. Further, over 60% of parents indicated difficulties discussing their child's condition with family

and friends and had some concerns about potential stigma related to having a DSD. Rolsten et al. (2015) similarly reported that in a sample of parents of children with DSD that a subset of parents reported moderate to high levels of perceived stigma surrounding their child's DSD diagnosis. Particularly, parents seemed to worry most about future outcomes related to their child's condition and the stigma their child may face due to their condition. When considering the unpredictable nature of DSD (e.g., the potential for children to reject their assigned gender, the potential for sexual dysfunction, and problems with fertility) it is understandable that parents worry about their child's future outcomes and whether or not their child will face social difficulties related to their disorder. As the literature is mixed, more research is needed to investigate the relationship between having a child with DSD and exhibited untoward psychological adjustment. Additionally, research related to the effect parental adjustment on child adjustment within this disorder should take precedence.

Illness Uncertainty

One cognitive appraisal variable consistently with associated with psychological distress in parents of children diagnosed with chronic health condition is illness uncertainty. Illness uncertainty can be understood as the experience of or judgment about an illness-related event or situation in which a person is unable to assign value to or predict outcomes related to the event or situation (Mishel, 1981). Similarly, perceived parental illness uncertainty is characterized by the uncertainty a parent experiences surrounding a child's diagnosis of a chronic or life-threatening illness and can be defined as the parent's difficulty in assigning meaning to or predicting the outcomes of their child's illness (Mishel, 1983). Mishel (1981) hypothesized that parental illness uncertainty is comprised of four factors: 1) ambiguity, or the inability to discern the state of the illness or distinguish between treatments, 2) lack of information about the illness and its related treatments and side effects, 3) complexity of known information related to the illness and healthcare system, and 4) unpredictability surrounding the illness prognosis and the patient's

quality of life (Mishel, 1982, 1983; Santacroce, 2001). Of these four factors, ambiguity is thought to be the most general and possibly the most salient. When a child's illness is appraised as being ambiguous by a parent, this ambiguity generates perceived illness uncertainty (Mishel, 1983).

Within the pediatric and health psychology literature, illness uncertainty has been shown to be a predictor of psychological distress in parents of children with chronic illnesses, including juvenile rheumatic disease (JRD; Fedele et al., 2011) and pediatric brain tumor (Fuemeller, Mullins, & Marx, 2001) and children and adolescents with type-1 diabetes (Hoff, Mullins, Chaney, Hartman, & Domek, 2002). For example, Hoff and associates (2002) found that illness uncertainty was significantly associated with psychological distress and perceived control in a sample of adolescents with type 1 diabetes. Interestingly, the relationship between uncertainty and distress was noted to be direct and not impacted by the effect of perceived control, indicating the strong role uncertainty may play in childhood adjustment to a chronic illness. Fuemmeler et al. (2001) reported that increased illness uncertainty was associated with greater PTSS and general psychological distress in parents of children with pediatric brain tumor, and in a sample of youth with JRD and their parents Fedele and colleagues (2011) discovered illness uncertainty to be significantly related to both parent distress and child distress. For older youth an interaction between parental uncertainty and child distress was established, while for younger children an interaction between parental uncertainty and both youth distress and youth depressive symptomology was reported. Similarly, Page et al. (2012) reported that that in a sample of mother-child dyads of children with various chronic illnesses increased levels of maternal uncertainty surrounding their child's diagnosis of a chronic illness significantly predicted child depressive symptoms. This relationship was mediated by child uncertainty (Page et al., 2012). Such results indicate that parental illness uncertainty may not only effect outcomes, but additionally downstream child adjustment. Further, illness uncertainty is associated with increased anxiety symptoms and symptoms of posttraumatic stress (PTSS) in survivors of

pediatric cancer (Fuemeller et al., 2001) with evidence supporting illness uncertainty as a possible antecedent of PTSS (Lee, 2006; Santacroce, 2006).

Posttraumatic Stress Disorder

Posttraumatic Stress Disorder (PTSD) is a psychological disorder triggered by the exposure to a traumatic event, such as actual or threatened death, serious injury, or sexual assault (APA, 2014). In 1994, the APA constituted that the knowledge of a child's life-threatening illness should be considered a traumatic event (APA, 1994). Since this time, a body of research examining the relationship between PTSD and having a child with a chronic or life-threatening illness has emerged, and it has been shown that children with a chronic or life-threatening illness and their parents are indeed at risk for developing symptoms of posttraumatic stress (PTSS; e.g., Barakat et al., 1997; Phips, Long, Hudson, & Rai). For instance, this relationship has been documented in parents of children cancer as well as parents of children with DSD. Kazak (1998) documented that when compared to parents of healthy children, parents of children with cancer seem to be at an increased risk of developing Symptoms of Posttraumatic Stress (PTSS) and tend to be specifically vulnerable to developing the re-experiencing symptoms of PTSD. More recently, Pasterski and colleagues (2014) reported that parents of children with DSD seem be at increased risk of development posttraumatic stress disorder as well. The authors found that the development of PTSS in parents of children with DSD was significantly predicted by cognitive confusion. To measure cognitive confusion, parents were asked to rate on a 5-point Likert scale the extent to which they experienced confusion and disbelief related to their child's condition. Interestingly, the researchers did not find a relationship between PTSD and emotional response (i.e., the experience of shock, shame, anger, guilt, grief, and relief). Considering the limited knowledge related to rates of PTSS/PTSD in parents of children born with DSD and the little we know of how it may impact later psychosocial adjustment for both parents and children further research is warranted in this area.

Summary

DSD encompasses a broad set of medical conditions that involve discordance between chromosomal, phenotypic, and/or gonadal sex and affects approximately 1 out of every 4,500 children born (Hughes et al., 2006). Notably, DSDs often affect the development and outward appearance of the genitalia, though degree of genital ambiguity or malformation varies across disorders and cases. Due to the nature of DSD treatment regimens can be complex and variable, and may include hormone therapy and the possibility of surgical intervention (Kim & Kim, 2012), which may be necessary to preserve or maximize urinary, sexual, and reproductive functioning or to more accurately align the appearance of the outer genitalia with the assigned gender (Clayton et al, 2002). As such, surgery may be elected for cosmetic reasons as well as medical ones, and it is generally suggested that surgery be conducted when the infant is between two and six months of age (Kass et al., 1996; Kim & Kim, 2012). Understandably, the process of assigning gender and deciding whether or not to choose surgery before the child can give assent is a notably difficult decision, and research suggest that parents experience a considerable amount of stress (Wiesemann, Ude-Koeller, Sinnecker, & Thyen, 2010; Kirk et al., 2011).

Although the majority of children and their parents will likely adapt well to having a DSD, it seems that a significant subset of children and parents are vulnerable to experiencing psychological distress (Wolfe-Christensen et al., 2014, Paterski et al., 2014, Suorsa, et al., 2015; Jurgensen et al., 2014; Oner et al., 2009). Parents of children with DSD report increased depressive and anxious symptoms, changes in parenting perceptions (e.g., increased perceived vulnerability; Wolfe-Christensen et al., 2012; Hullmann et al., 2001; Kirk et al., 2011), decreased quality of life, and symptoms of posttraumatic stress (Pasterski et al., 2014; Soursa et al., 2015). Parents report worrying about future outcomes related to their child's condition, and, the stigma their child may face due to their condition, with a subset of parents reporting moderate to severe perceived stigma surrounding their child's DSD (Rolsten et al., 2015). Further, youth with DSD

report decreased health-related quality of life, lower self-esteem and school functioning (Jurgensen et al., 2014), behavioral and emotional problems (Oner et al., 2009), and increased rates of gender dysphoria and dissatisfaction with their assigned gender compared to their peers without a DSD (Meyer-Bahlburg, 2011; Korte et al., 2008).

Due to the psychosocial issues that arise after being diagnosed with a rare disorder such as a DSD, it has been argued that having access to psychosocial support is warranted for individuals with DSD and their families. However, the extant literature is short on data needed to inform the development of proper psychosocial support for these individuals ((Holmbeck & Aspinall, 2015; Schönbucher, Weber, & Landolt, 2008). Thus, the current study seeks to contribute to the literature by exploring the relationship between the experience of uncertainty and the development of PTSS in parents of children with DSD. Research suggests that illness uncertainty is a robust predictor of psychological distress in parents of children with chronic illnesses (Fedele et al., 2011; Fuemeller, Mullins, & Marx, 2001; Hoff et al., 2002). Further there is evidence to suggest that illness uncertainty may precede the development of PTSS/PTSD (Santacrose, 2003; Lee, 2006; Santacroce, 2006; Fuemmeler et al., 2001). Thus, the current study will examine illness uncertainty as a predictor of PTSS in parents of children with a newly diagnosed DSD. Additionally, due to research establishing a link between perceptions of the appearance of the genitalia and psychosocial outcomes in individuals with DSD and their parents, we will examine the role of satisfaction with the appearance of their child's genitalia in predicting PTSS in these parents as well. We hypothesize that both illness uncertainty and cosmetic appearance ratings will be significant predictors of PTSS, so that higher levels of perceived illness uncertainty and negative cosmetic ratings will be associated with higher levels of PTSS. The clinical implications of this study are that the knowledge gathered will inform the development of proper psychosocial interventions and support for families of children with newly diagnosed DSD.

CHAPTER III

METHODOLOGY

Participants

Participants were 55 mothers (M_{age} = 31.78 years, SD = 5.89) and 41 fathers (M_{age} = 35.06 years, SD = 7.37) of 55 children with a DSD and atypical genitalia prior to undergoing genitoplasty (M_{age} = 9.26 months, SD = 5.73). Parents were recruited within 6 months of their child's diagnosis from 11 clinic sites specializing in DSD care from around the US. Participants completed a demographic form and measures of illness uncertainty, perceived cosmetic appearance of their child's genitalia, and posttraumatic stress as part of a larger study assessing psychosocial factors related to a new DSD diagnosis. Descriptive statistics for parents and children are reported in Tables 1-3.

Procedures

As this study is part of a larger project examining psychosocial factors related to a parenting a child diagnosed with a DSD, Institutional Review Board approval has been obtained from the following participating institutions: Ann & Robert H. Lurie Children's Hospital of Chicago, Children's Hospital of Colorado, New York-Presbyterian/Weill Cornell Medical Center, University of California San Francisco Medical Center, University of Oklahoma Health Sciences Center, University of Washington Medical Center, and Woman and Children's Hospital of Buffalo. Parents of children with a new diagnosis of DSD were approached during regularly

scheduled DSD clinic appointments. Families were compensated for travel costs to the center, and will be compensated further after the completion of the 5-year longitudinal study.

Materials

Demographics form. The Demographics Form consists of items assessing parent-reported child gender, child age and date of birth, diagnosis, parent relationship to child, parent marital status, parent race/ethnicity, parent date of birth, and household income.

Illness uncertainty. The Parent Perception of Uncertainty Scale (PPUS; Mishel, 1983) is a 31-item self-report questionnaire that measures a parent's perception of illness-related uncertainty surrounding their child's health problem. Item responses are presented on a 5-point Likert-scale ranging from *Strongly Agree* to *Strongly Disagree*. Scores range from 31 to 155. Higher overall scores on the PPUS indicate higher levels of uncertainty. An example of an item on the PPUS is, "I am unsure if my child's illness is getting better or worse." The PPUS is a well-established measure of parental illness uncertainty in the area of childhood chronic illness, evidencing moderate to high coefficient alphas (α =.86 to .93; Mishel, 1997). Cronbach's alpha was .87 for mothers and .92 for fathers in this sample.

Cosmetic appearance. The Cosmetic Appearance Rating Scale is a 1-item, self-report, Likert-scale that assesses parent's satisfaction with their child's physical appearance. Specifically parents are asked to rate their satisfaction with the cosmetic appearance of their child's genitals. Answer items range from 1 (*satisfied*) to 4 (*dissatisfied*), with lower scores indicating greater satisfaction with appearance. To date no psychometric data is available for this measure, as it was developed by the advisory board, specifically for the current grant project.

Posttraumatic stress. The Impact of Events Scale-Revised (IES-R; Weiss & Marmar, 1997) is a 22-item, self-report measure widely used to assess posttraumatic stress symptoms. Respondents are asked to rate their feelings related to a potentially traumatic event, in this case

their child's diagnosis of DSD (e.g., "Any reminder brought back feeling about it") on a Likert-scale, ranging from *Not at All* to *Extremely*. Higher scores indicate an increased amount of posttraumatic stress symptoms. A total score of 33 or above on the IES-R has been established as indicating clinically significant PTSS (Pasterski et al., 2014). Using two separate standardization samples, Weiss and Marmar (1997) report coefficient alpha's ranging from .79 to .92 for the three subscales. For the current sample Cronbach's alpha was .95 for mothers and .93 for fathers.

Overview of Statistical Analyses

First, dependent samples *t*-tests were conducted to analyze group differences between mothers and fathers for the variables of interest (i.e., cosmetic appearance ratings, illness uncertainty, and PTSS). Secondly, bivariate correlations were independently conducted to explore the relationships between these variables for mothers and fathers. Next, demographic variables were explored as covariates for the final model via examination of bivariate correlations, independent samples t-tests, and Analysis of Variance (ANOVA). Hierarchical multiple regression was then used to assess perceived illness uncertainty and cosmetic appearance ratings of the child's genitalia as predictors of posttraumatic stress symptoms. Prior to conducting the hierarchical regression analysis, preliminary tests were employed to ensure no violation of the assumptions of normality, linearity, multicollinearity, and homoscedasticity occured. For this analysis bias-corrected bootstrapped resampling with replacement was used at the level of 5,000 draws. In hierarchical regression the independent variables (predictors) are entered in steps or blocks in a predetermined order based on theory. Parental cosmetic ratings of their child's genitalia were entered on step one of the model. By 'forcing' this variable onto step one, we examined its effect on the dependent variable, level of posttraumatic stress symptoms, independent of illness uncertainty. Next, illness uncertainty was entered on step two. Again, this allowed us to independently assess the variance predicted by each variable. R Square values were used to determine the percentage of variance accounted for by each step and by the model as a

whole. A significance value of .05 was used to determine statistical significance. Lastly, to better characterize our sample rates of mothers and fathers who would likely meet criteria for a diagnosis of PTSD were examined by utilizing a caseness cutoff score of 33 on the PTSS measure.

CHAPTER IV

RESULTS

Preliminary Analyses

There were no significant differences between cosmetic appearance ratings or levels of illness uncertainty between mothers and fathers. However, mothers reported significantly greater PTSS (M = 23.42, SD = 19.24) compared to fathers (M = 13.08, SD = 12.71). Due to this significant difference, bivariate correlations were conducted for mothers and fathers independently, and revealed significant relationship between the variables of interest for mothers, but not fathers. Thus, the remaining analyses were performed for mothers only. Bivariate correlations are presented in Tables 4-5. To assess for potential covariates of the model, we then examined relationships between the primary variables of interest and demographic variables for mothers (i.e., mother's age, child's age, degree of genital malformation via Quigley/Prader ratings, mother's level of education, and family income). None were significant. Next, potential group differences were examined via independent samples t-tests and ANOVA to further evaluate if covariates should be included in the final regression model. No significant differences existed for cosmetic ratings, levels of illness uncertainty, or PTSS for parent reported child gender of rearing (girl, boy, or unsure), karyotype (46,XY; 46,XX; 45,XO/46,XY; other), or mothers' race. As such, no additional covariates were included in the final statistical model. To further characterize our sample, the percentage of parents who would likely meet criteria for a diagnosis of PTSD

were examined. We found that 20% of mothers and 7.3% of fathers who completed the IES-R met or exceeded the cutoff score for a clinically significant level of PTSD symptoms.

Hierarchical Multiple Regression Analysis

Because preliminary analyses indicated no significant relationship between the variables of interest for fathers, hierarchical regression analysis was performed for mothers only. There were no violations of the assumptions of normality, linearity, multicollinearity, or homoscedasticity. For step one of the model, mothers rating of the cosmetic appearance of their child's genitalia was a significant predictor, accounting for 10% of the variance associated with PTSS, $F(1,44) = 4.85$, $p = .03$. Next, illness uncertainty was entered on step two. Step two significantly predicted PTSS and explained an additional 17.3% of the variance of PTSS, $F(1, 43) = 10.20$, $p = .03$. Step two of the model also revealed that cosmetic appearance rating did not contribute unique variance above and beyond illness uncertainty. Overall, the model was significant, explaining 27.2% of the variance in PTSS, $F(2,43) = 8.03$, $p = .001$, such that increased illness uncertainty was significantly associated with higher levels of PTSS. Results are presented in Table 6.

CHAPTER V

DISCUSSION

Study Review

The current study explored the relationship between parental illness uncertainty, cosmetic ratings of their child's atypical genitalia, and symptoms of posttraumatic stress (PTSS) in mothers of children with newly diagnosed Disorders/Differences of Sex Development (DSD). Hierarchical multiple regression analysis was conducted, with the final model accounted for 27.2% of the variance associated with PTSS in mothers. Illness uncertainty was the only significant contributor to the final model, accounting for 17.2% of the variance in PTSS when controlling for the effect of cosmetic appearance ratings on PTSS. We did not explore this relationship for fathers, as preliminary analyses revealed significant differences on levels of the outcome variable (i.e., PTSS) between mothers and fathers and no significant correlations between the primary variables of interest for fathers. Mothers and fathers did not differ on levels of illness uncertainty, nor did they differ on their ratings of the appearance of the child's genitalia.

Contemporary models of coping argue that adjustment outcomes are the product of multiple interrelated factors, including illness-specific variables, such as disease type, demographic variables, such as socioeconomic status, and interpersonal factors, such as attribution style (Kazak et al., 2006; Thompson & Gustafson, 1996). Our preliminary findings are consistent with such models and add to the accumulating evidence supporting the relationship between illness uncertainty and the development of untoward adjustment outcomes in

parents of children with chronic illnesses (Stewart & Mishel, 2000), including PTSS (Tackett et al., 2016). Indeed, it can be speculated that the uncertainty and ambiguity associated with having a child diagnosed with DSD may be associated with an increased likelihood for the development of PTSS in mothers.

Additionally, mother's increased negative perceptions of the appearance of their child's genitalia may cause parents to view their child's condition as more stigmatizing or severe, in turn leading to increased PTSS. This is consistent with previous research finding that a greater degree of under-masculinization in male children is related to increased distress in caregivers of children with DSD (Wolfe-Christensen et al., 2010). Further, our findings regarding elevated rates of PTSS in mothers of children with DSD compared to their child's fathers suggests that mothers may be particularly vulnerable to the development of PTSS. Using the established caseness cutoff score of 33 previously used in this population (Paterski et al., 2014), 20% of mothers met criteria for a likely diagnosis of PTSD compared to 7.3% of fathers. This is consistent with previous research assessing adjustment outcomes in parents of children with DSD that show mothers tend to report greater levels of PTSS (Pasterski et al., 2014) and anxious symptomology (Wolfe-Christensen et al., 2014) compared to their male counterparts. Wolfe-Christensen et al. (2014) hypothesized that for fathers of children with DSD, low levels of distress within the context of their child's condition may be due to fathers' use of disengagement to cope with their child's illness. Research supports this assumption, suggesting that men and women tend to utilize different coping styles when faced with a stressful life experience, such has having a child diagnosed with a chronic illness (Tamres, Janicki, & Helgeson, 2002; Mastroyannopoulou, Stallard, Lewis, & Lenton, 1997) and that adjustment is interrelated for mothers and fathers of children with chronic illnesses (Chaney & Mullins, 1997). For the current study, it may be speculated that fathers' disengagement, increases the burden of the child-rearing responsibilities (e.g., changing diapers, bathing) for mothers, and this increased exposure to the baby's atypical genitalia due to performing childcare tasks may inhibit mothers from adjusting to their child's

condition at the same rate as their child's father who has disengaged.

Clinical Implications

Due to the psychosocial issues that arise when being diagnosed with a rare condition, such as a DSD, it has been argued that having access to psychosocial support is warranted for individuals with DSDs and their families (Hughes et al., 2006). However, little research has been conducted to inform the development of proper psychosocial interventions and support for this population (Schönbucher, Weber, & Landolt, 2008). Although the majority of children and their parents will likely adapt well to having a DSD, it seems that a significant subset of children and parents are vulnerable to experiencing psychological distress (Wolfe-Christensen et al., 2014, Paterski et al., 2014, Soursa et al., 2015; Jurgensen et al., 2014; Oner et al., 2009) and our results support this assumption. Importantly, for families of children with DSD negative psychosocial outcomes in parents has been directly linked to parenting capacity variables (i.e., parenting stress, overprotection, and perceived vulnerabilities), particularly for parents of young children (Wolfe-Christensen et al., 2012). Such research indicates a strong need for readily accessible resources available to families of children with a newly diagnosed DSD shortly after birth to improve psychosocial trajectories for both children with DSDs and their families. To inform such clinical support and intervention, additional research is needed to investigate those factors that lead to suboptimal psychological adjustment post-diagnosis for youth with a DSD and their families. Future studies further examining the role of cognitive appraisal variables in the development of negative adjustment outcomes in this population are warranted to inform clinical development. Prospective longitudinal data, which has been a primary aim of our lab, is needed to better articulate the driving forces behind the development of PTSS in parents of children with DSD over time. Additionally, greater information regarding the role of illness uncertainty in the development of PTSS for mothers, as well as the resilience factors facilitating psychological adjustment in fathers is needed.

Conclusions and Future Research

In summary, mothers of children with a newly diagnosed DSD appear to be particularly vulnerable to PTSS compared to their children's fathers. Further, the degree of uncertainty may significantly contribute to the development of PTSS in mothers. Compared to other pediatric populations, research and clinical resources are lacking for individuals affected by DSDs and their families (Holmbeck & Aspinall, 2015) and greater research is needed to inform such resources. Our findings, although preliminary, contribute to the scientific knowledge examining psychosocial outcomes in parents of children with DSD; however, significant limitations exist. First, this paper reports only baseline adjustment outcomes for parents, thus we cannot speak to the directionality or trajectory of the relationship between parental illness uncertainty and PTSS for this sample. Additionally, results should be considered as preliminary considering the limited sample size and cross sectional nature of this study. Future studies could address these limitations through the use of longitudinal data collection methods and larger samples to better account for the multiple types of DSD.

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APPENDIX A. TABLES

Table 1. Descriptive Statistics for Mothers

	N	M (SD, Range)
Mother Age	41	31.78 years (5.89, 18-44)
Cosmetic Rating	55	2.58 (.994, 1-4)
Illness Uncertainty	49	64.59 (15.10, 33-99)
PTSS	46	23.42 (19.24, 0-70)
	N	**Percentage**
Education		
Some High School	1	1.8%
High School/GED	7	12.7%
Some College	10	18.2%
Associate's Degree	2	3.6%
Bachelor's Degree	15	27.3%
Graduate Degree	3	5.5%
Race		
African American	5	9.1%
White	33	60.0%
Asian/Pacific Islander	4	7.3%
Multi-Racial	4	7.3%
Other	4	7.3%
Income		
$0 - $4,999	1	1.8%
$5,000 - $9,999	2	3.6%
$10,000 - $14,999	3	5.5%
$15,000 - $19,999	2	3.6%
$20,000 - $29,999	8	14.5%
$30,000 - $39,999	5	9.1%
$40,000 - $49,999	3	5.5%
$50,000 - $59,999	2	3.6%
$60,000 - $69,999	1	1.8%
$70,000 - $79,999	2	3.6%
$80,000 - $89,999	0	0%
$90,000 - $99,999	5	9.1%
$1000,000 +	19	34.5%

Table 2. Descriptive Statistics for Fathers

	N	M (SD, Range)
Father Age	34	35.06 years (7.37, 21-61)
Cosmetic Rating	40	2.58 (.958, 1-4)
Illness Uncertainty	36	63.31 (14.68, 31-90)
PTSS	36	13.08 (12.71, 0-50)

Table 3. Descriptive Statistics for Children

	N	M (SD, Range)
Child Age	53	9.26 months (5.73, 1-24)
	N	**Percentage**
Karyotype		
46,XY	21	38.2%
46,XX	26	47.3%
45,XO/46,XY	3	5.5%
Other	2	3.6%
Gender		
Girl	30	54.5%
Boy	22	40.0%
Unsure	2	3.6%

Table 4. Bivariate Correlations for Mothers

	1	2	3	4	5	6	7	8
1. Cosmetic Rating								
2. Illness Uncertainty	.186							
3. PTSS	.303*	.467**						
4. Parent Age	-.292	.027	-.089					
5. Child Age	-.159	.080	.010	.174				
6. Quigley Rating	.030	.096	-.166	.442	-.301			
7. Prader Rating	.132	-.015	-.235	.076	.036	--		
8. Education	-.044	.164	.190	.646**	-.073	.311	-.256	
9. Income	.066	.145	.143	.423**	-.153	-.100	-.263	.589**

Table 5. Bivariate Correlations for Father

	1	2
1. Cosmetic Rating		
2. Illness Uncertainty	-.188	
3. PTSS	-.025	.086

Table 6. Results of Hierarchical Regression Analysis on PTSS

	b	SE B	β	*p*	R^2
Step 1					.099
Cosmetic Rating	5.781	2.625	.315	.033	
Step 2					
Cosmetic Rating	4.334	2.430	.236	.082	.272
Illness Uncertainty	.504	.158	.423	.003	

APPENDIX B. IRB APPROVAL

Oklahoma State University Institutional Review Board

Date:	Tuesday, October 22, 2013
IRB Application No	AS1361
Proposal Title:	Short Term Outcomes of Genitoplasty in DSD Study 3 - Psychosocial Outcomes of Caregivers of Children with Ambiguous Genitalia
Reviewed and Processed as:	Full Board

Status Recommended by Reviewer(s): Approved Protocol Expires: 10/21/2014

Principal Investigator(s):

Larry L. Mullins
116 North Murray
Stillwater, OK 74078

Elizabeth Molzon
116 N. Murray
Stillwater, OK 74078

The IRB application referenced above has been approved. It is the judgment of the reviewers that the rights and welfare of individuals who may be asked to participate in this study will be respected, and that the research will be conducted in a manner consistent with the IRB requirements as outlined in section 45 CFR 46.

☒ The final versions of any printed recruitment, consent and assent documents bearing the IRB approval stamp are attached to this letter. These are the versions that must be used during the study.

As Principal Investigator, it is your responsibility to do the following:

1. Conduct this study exactly as it has been approved. Any modifications to the research protocol must be submitted with the appropriate signatures for IRB approval. Protocol modifications requiring approval may include changes to the title, PI, advisor, funding status or sponsor, subject population composition or size, recruitment, inclusion/exclusion criteria, research site, research procedures and consent/assent process or forms.
2. Submit a request for continuation if the study extends beyond the approval period of one calendar year. This continuation must receive IRB review and approval before the research can continue.
3. Report any adverse events to the IRB Chair promptly. Adverse events are those which are unanticipated and impact the subjects during the course of this research; and
4. Notify the IRB office in writing when your research project is complete.

Please note that approved protocols are subject to monitoring by the IRB and that the IRB office has the authority to inspect research records associated with this protocol at any time. If you have questions about the IRB procedures or need any assistance from the Board, please contact Dawnett Watkins 219 Cordell North (phone: 405-744-5700, dawnett.watkins@okstate.edu).

Sincerely,

Shelia H. Kennison

Shelia Kennison, Chair
Institutional Review Board

VITA

Alexandria Jade Mullins

Candidate for the Degree of

Master of Science

Thesis: PERCEPTIONS OF COSMETIC APPEARANCE, ILLNESS UNCERTAINTY, AND POSTTRAUMATIC STRESS SYMPTOMS IN PARENTS OF CHILDREN WITH DISORDERS OF SEX DEVELOPMENT

Major Field: Clinical Psychology

Biographical:

Education:

Completed the requirements for the Master of Science/Arts in Clinical Psychology at Oklahoma State University, Stillwater, Oklahoma in July, 2016.

Completed the requirements for the Bachelor of Arts in Psychology at Oklahoma State University, Stillwater, OK in 2014.

Experience: Graduate Research Assistant and Study Coordinator, Pediatric Psychology and Health Lab, Department of Psychology, Oklahoma State University, Supervisor: Larry L. Mullins, Ph.D.

Senior Undergraduate Research Assistant, Health Promotion Science and Technology Lab, Department of Psychology, Oklahoma State University, Supervisor: Christopher Cushing, Ph.D.

Undergraduate Research Assistant, Health Psychology Lab, Department of Psychology, Oklahoma State University, Supervisor: Thad Leffingwell, Ph.D.

Professional Memberships: Psi-Chi, National Honors Society for Psychology, American Psychological Association, Student Affiliate, American Psychological Association, Division 54: Society of Pediatric Society, Student Affiliate, Oklahoma Psychological Association, Student Member