

PARENTS OF
INTERSEX
CHILDREN
AND THE
QUEST TO
LOCATE
A "TRUE SEX"

Intersexuality disturbs the Western notions of sex and gender because it questions the presumed naturalness of the two-sex system of biological sex. The medical management of the male and female body through surgical 'correction' of the genitals reflects the need to normalize and regulate intersexed bodies in order to maintain the idea that biological sex fits a system of binary opposition – male versus female. In 1972, sexologists John Money and Anke Ehrhardt proposed theories that sex and gender were specific categories. The *Gender Role Theory* emphasizes the physical attributes that are anatomically and physically determined and the psychological identification of the self as male or female, respectively.¹ Money posited that "children are psychosexually neutral at birth and can be molded into either gender, so long as the child's anatomy is altered to reflect the chosen gender at an early age and the people around the child treat the child as a member of the chosen gender."² However, the body's sex is too complex to be subjected to the limitations of a dichotomous relationship of male or female. Accordingly, Sharon E. Preves proposes that "distinctions regarding male and female bodies are on a continuum, rather than a dichotomy."³ Regardless of the theories on sexuality as a continuum, proposed by individuals such as Anne Fausto-Sterling and Preves, the practice of surgically altering the ambiguous genitalia of intersex infants as put forth by sexologists such as Money remains a standard.

Medical procedures, which maintained their validity largely because of Money's widely accepted *Gender Role Theory*, have resulted in many problems for intersexed individuals and their families. The surgeries have led intersexed individuals to feel ashamed, betrayed, angered, and alone as they age.⁴ These problems and issues begin at birth. As Samantha S. Uslan notes, "parents of intersex children [are] likely to consent to genital-normalizing surgeries given the medical procedures promoted, and what they believe is in their child's best interest."⁵ When parents are told about their child's ambiguous sex, their emotional reactions directly relate to the decisions made regarding the child's future.⁶ Due to the limited research in the area of parents of intersex children and normalizing surgery, I draw strongly upon Gough, et al. to address the rationale behind the actions of parents in deciding upon gender normalizing surgical procedures for their intersex children. In their research, Gough, et al. examine how parents of intersex children make sense of their child's uncertain status, considering how the prevailing assumptions about sex and gender proposed by Money and other sexologists influence the child's care, identity development, and future.⁷

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Analytical Summary

In their piece, *‘They Did Not Have a Word’: The Parental Quest to Locate a ‘True Sex’ for Their Intersex Children*, Gough, et al. investigate how parents of intersex infants make sense of the ambiguous genitalia of their children at birth through the use of qualitative, semi-structured interviews, and phenomenological analysis.⁸ The understandings and experiences of parents of children with ambiguous genitalia are under-researched.

Gough, et al. summarize the only two known studies on the subject. In their summary, the authors identify a number of ‘parent factors,’ which affect the natural development of the child. Factors such as the parents’ sense of shame and guilt communicated to their child as they age, their adaptation to the child’s health conditions, and their need to come to terms and accept the notion of intersex first in order to enable the further acceptance of the notion by their children.⁹

Gough, et al.’s qualitative methods in their semi-structured interviews enabled the parents’ meanings to be elicited, and allowed for rich, participant-centered accounts and feelings to be recorded.¹⁰ Eleven parental-individuals of eleven children with Congenital Adrenal Hyperplasia (a masculinising condition affecting external genitalia), pure gonadal dysgenesis, and other intersex diagnoses were interviewed. The parents were interviewed regarding their child’s medical records, the decisions made concerning their sex, and subsequent medical interventions. In addition, how the parents coped emotionally and their reactions regarding the events were examined to determine if there were any common themes in the responses.¹¹

Gough, et al. extract two themes expressed by all interview participants. The first, intersex, as an unfathomable ‘otherness.’ This concerns the parents’ difficulty in understanding ‘intersex’ and involved feelings of “confusion and disbelief, a profound absence of knowledge, and a lack of language with which to categorise (sic) their child’s (non-) status.”¹² It was noted that a sense of bewilderment and disturbance was felt among the majority where their natural ‘truth’—that all humans are either male or female—had been shattered.¹³ The uncertainty felt appeared to be the result of the discovery that the sex of their child was not obvious, but rather indistinct and veering from the ‘norm.’ In sum, parents of intersex children appeared to have had a failure in understanding and coping when confronted with a child of ambiguous sex.¹⁴

The second theme discovered was the struggle for parents to recover a ‘true sex’ in their intersex child.¹⁵ All the interviewees described a determined effort to define their child as either male or female. Furthermore, Gough et al. uncovered that “it seemed difficult for parents not to attri-

bute a sex to their child while status remained medically unresolved."¹⁶ Gough, et al. indicate that this determination portrayed a conscious effort by parents to adhere to the concept of the two-sex system, while also questioning their own beliefs about what constitutes sex.¹⁷

Gough, et al. cite that the very existence of intersex individuals "challenge[s] scientific-medical efforts at defining and diagnosing sex status" in individuals.¹⁸ Parents of intersex children are forced into a situation in which established conceptions of sex and gender, as promoted by the medical and scientific professionals, are radically unsettled. Gough, et al. suggested "a more fluid understanding of sex and gender [in both the medical and scientific fields, as well as society in general], would perhaps help parents cope with the initial impact of having an intersex baby."¹⁹ This understanding would, in turn, lead to appropriate support and better facilitate communication between parents and health professionals.

Critical Analysis

Gough, et al. seek to improve on the limited research on the parents of intersex children. Their study and analysis is a valuable contribution to the issues of parental emotions and reactions to the discovery of the ambiguous sex of their infant, as well as an analysis of how the two-sex system influences these reactions. This critical analysis will highlight the strengths and weaknesses of the Gough, et al. study by further elaborating on the information available regarding intersex children and the relationship with their parents.

Gough, et al. provide an excellent operational definition of what constitutes intersex conditions. Referencing works by Preves, they write that intersex children are "born with ambiguous genitalia, sexual organs or sex chromosomes."²⁰ For the purpose of the study, the authors describe intersex as "infants born with ambiguous genitalia [as] a key early indicator of intersex," and continue by addressing the various underlying conditions that cause ambiguous genitalia to occur in infants.²¹ The authors investigate how intersex has been addressed by medical literature, with a strong emphasis on the "appearance of the genitalia as normal, and being raised consistently as male or female [as being] necessary for a child to develop a clear gender identity and achieve psychological well-being."²²

They also address the perspectives of parents of intersex children, referencing the two studies which consider the experiences of parents of intersex children. The two studies cited by Gough, et al. are one by Slijper et al. (2000) and an unpublished thesis by Le Maréchal (2001), summa-

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rized and analyzed by Carmichael and Alderson (2004), which both focus solely on children born with Androgen Insensitivity Syndrome (AIS). The study by Gough, et al. encompassed a variety of diagnoses leading to ambiguous genitalia, rather than limiting research to a single diagnosis.²³

In order to expand upon the previous research done on parents of intersex children and to accurately measure the reactions of parents at the discovery of their child’s ambiguous genitalia, some limitations were purposely implicated in the study. In examining the impact of contemporary medical procedures, treatments, and services from the perspective of the parents, the authors used accounts from parents whose children were born between 2001 and 2006.²⁴

Following the eleven parent interviews, Gough, et al. develop two themes concerning the responses of parents. The first suggests an overarching theme pertaining to bewilderment and unease upon the detection of a ‘problem’ in the sex of their child. In the shattering of a basic, natural ‘truth’ upon the discovery of a ‘problem’ with their child’s sex, parents appeared to experience uncertainty in their understanding of sex and gender.²⁵ The experiences discussed reflect the idea that sex and gender are separate categories, where sex refers to the physical and gender to the psychological.²⁶ While being born with ambiguous sex organs disrupts a binary understanding of sex and gender, it is only disrupted due to the general medical consensus that intersex requires gender normalizing surgeries.²⁷ This general consensus, as well as the profound absence of knowledge on the parents’ behalfs regarding intersex, is addressed by Gough, et al. insofar that the breakdown in the comprehension of intersex extended to health professionals and the general public promotes the cultural dominance of the two-sex system.²⁸

The second theme suggests the parental struggle to recover a ‘true sex’ for the intersex child.²⁹ All parents interviewed “described a determined, if difficult, effort to secure an unequivocal sex category for their child as either male or female.”³⁰ Some parents actively reduced ambiguity in order to accept the circumstances “through the fulfillment of gender stereotypes.”³¹ In addressing the fulfillment of gender stereotypes by parents, Gough, et al. show that parents had to confront their understanding of the two-sex system. Gough, et al. further state that gender normalizing surgery was regarded as a solution to the anxiety experienced.³² By forcing the ‘normal’ to take precedence over the ‘natural’, parents further promoted gender stereotypes and the two-sex system to quell their perturbation given the child’s ambiguous sex and perceived implications.³³ The two themes developed by Gough, et al. attend to the shock encountered by many parents upon the discovery of ambiguous sex organs in

their child; an event that “radically unsettles established taken-for-granted conceptions of sex and gender and marks one’s child as ‘other.’”³⁴ Gough, et al. adequately promote that a greater understanding of sex and gender, on behalf of both parents and health professionals, would aid in coping strategies and support systems with regards to the initial impact of having an intersex child.³⁵ As “beliefs about gender affect what kinds of knowledge professionals produce about sex”, medical practitioners with greater appreciation and understanding of the emotional difficulties faced by parents would lead to better consent-based, collaborative health care models with regards to intersex children.³⁶

Gough, et al. also state that “the very existence of intersex individuals may challenge scientific-medical at defining and diagnosing sex status.”³⁷ While this statement may be interpreted as a negation of the existence of intersex individuals, the analysis put forth by Gough, et al. supports the notion put forward by Preves that distinctions between female and male bodies are actually on a continuum, rather than a dichotomy.³⁸ In addressing the continuum of distinctions of sex status, Gough, et al. conclude that while it may be difficult for all medical experts to subscribe to definite sex assignment criteria, health professionals should opt for an understanding of sex status that is defined and performed by taking in social, political, biological and environmental aspects.³⁹

Gough, et al.’s sample presented limits to their study. Their objective was to recruit mother-father pairs of parents whose children were born with ambiguous sex, “the final group included three couples, two mothers from partnerships where the father chose not to participate, and two single mothers.”⁴⁰ This limited sample size, as well as the lack of diversity – there were only three male participants in a sample of eleven – leaves something to be desired. Gough, et al. hypothesize that both fathers and mothers who chose to participate in the study are “likely to be those who were more open about how they felt” regarding the circumstances with regards to the circumstances they faced, and that those who opted out of the study may have done so because it may have been “too difficult to talk in depth about their feelings.”⁴¹ Given that one to two in every two thousand infants are born with ambiguous sex, Gough, et al. recommend further interviews with parents of children with a wider range of intersex conditions and a more diverse and representative sample of intersexed individuals.⁴² The ethnicity of participants also presented limitations. Of the eleven participants, eight were white British, one was British-Asian, one British-African, and one undisclosed.⁴³ Nonetheless, Gough, et al.’s sample was sufficient in that it enabled the development of core themes and similarities in the interview responses, allowing for findings to be

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applicable to similar situations with regards to the dynamic between parents and intersex children.⁴⁴

Gough, et al. acknowledge the lack of research in this field and indicate how future research could expand these preliminary findings.⁴⁵ Gough, et al. recommend that a longitudinal study would be crucial in examining “how parents’ struggles change over time, [and] may give insight into the points in time which are particularly difficult for parents.”⁴⁶ Gough, et al. acknowledge that the subject is controversial in that it bends the understanding of what sex and gender truly are, dismantling the historical and medical categories made for bodies that fit the norm and establishing those that do not as the ‘other.’⁴⁷

A question not addressed by Gough, et al. in their study is: how does one define an intersexual’s ‘true sex’? Gough, et al. mention the importance of external genitalia as an informal way of ‘telling’ sex, but the notion of ‘true sex’ is neither referred to in the interview questions nor in the in-depth analysis of the responses.⁴⁸ If an individual’s ‘true sex’ is defined by chromosomes, then the genital normalizing surgery deemed necessary by health professionals and parents has no effect on an individual’s ‘true sex’ because “surgery cannot change an individual’s chromosomes.”⁴⁹ Uslan argues that “if ‘true sex’ is based on whether or not an individual has the ability to bear or beget offspring, [...] then this too cannot be altered by surgery”, and once again, the surgery used to ease the anxiety experienced by parents does not provide an accurate definition for ‘true sex.’⁵⁰

As Gough, et al. note, “the notion that sex as well as gender is constructed and multifaceted leads to a necessary” reassessment of the terms.⁵¹ Sex and gender are generally viewed as binary opposites; the biological underpinnings of maleness and femaleness, and the social expression of the masculine or the feminine.⁵² These dichotomous depictions have led to medical procedures deeply entrenched in the notion of the *Gender Role Theory*, “whereby to successfully raise a child either male or female, their genitals must coincide with that identity.”⁵³ The surgical alteration of the genitals, in an effort to ease their development, as well as ease the anxiety experienced by parents, “appear to cause more problems than they solve.”⁵⁴

A more fluid understanding of intersex would allow parents to cope more easily with the psychosocial ‘trauma’ experienced by the discovery of their child as having ambiguous genitalia.⁵⁵ Furthermore, sexual variation is nothing to be ashamed of, and that feeling of shame and guilt would not be experienced by many intersex individuals, as well as their families, peers and support groups, if it were necessarily recast as normal.⁵⁶

Doctors, parents, and others have the ability to normalize sexual variation", by responding to it with a more fluid understanding.⁵⁷

"Anything that challenges the definition of girl and boy fuels our cultural anxiety around gender."⁵⁸ As previously discussed, these challenges radically unsettle established conceptions to the point where morals and beliefs are questioned, furthering anxiety.⁵⁹ Whether it is the parents, professionals, or peers, this anxiety permeates the fabrics of society, due to a lack of understanding and knowledge regarding intersex. Regardless of the limited information available concerning the reactions and feelings of parents regarding their children of ambiguous sex, Gough, et al. strove to further the understanding of why these anxieties arise, under what circumstances they are quelled, and what methods could be undertaken to cope with the anxiety experienced by parents.⁶⁰ Further research on parents of intersex children would lead to educating individuals and enable the transformation of the established two-sex system from one of binary opposite to one occurring on a continuum, showing that sexual anatomy is of a diverse and varied nature; one that must not be categorized.

Endnotes

¹ Anne Fausto-Sterling, Duelling Dualisms, in *Sex, Gender and Sexuality: The New Basics* 6–21, edited by Abby L. Ferber, Kimberly Holcomb, and Tre Wentling (Oxford: Oxford University Press, 2008), 7.

² Samantha S. Uslan, "What Parents Don't Know: Informed Consent, Marriage, and Genital-Normalizing Surgery on Intersex Children," *Indiana Law Journal* 85 no. 1 (January 2010): 302.

³ Sharon E. Preves, "Intersex Narratives: Gender, Medicine and Identity," in *Sex, Gender and Sexuality: The New Basics* 32–43, edited by Abby L. Ferber, Kimberly Holcomb, and Tre Wentling (Oxford: Oxford University Press, 2008), 33.

⁴ Stephen Kerry, "Intersex Individuals' Religiosity and their Journey to Wellbeing," *Journal of Gender Studies* 18, no. 3 (September 2009): 277–285.

⁵ Samantha S. Uslan, "What Parents Don't Know: Informed Consent, Marriage, and Genital-Normalizing Surgery on Intersex Children."

⁶ Brendan Gough, et al., "They did not have a word': The parental quest to locate a 'true sex' for their intersex children," *Psychology & Health* 23, no. 4 (May 2008): 493–507.

⁷ Ibid.

⁸ Ibid.

⁹ Ibid.

¹⁰ Ibid.

¹¹ Ibid.

¹² Ibid., 499.

¹³ Ibid.

¹⁴ Ibid.

¹⁵ Ibid.

¹⁶ Ibid., 501.

¹⁷ Ibid.

¹⁸ Ibid., 504.

¹⁹ Ibid.

²⁰ Ibid., 494.

²¹ Ibid.

²² Ibid.

²³ Ibid.

²⁴ Ibid.

²⁵ Ibid.

²⁶ Fausto-Sterling, "Duelling Dualisms."

²⁷ Preves, "Intersex Narratives."

²⁸ Gough et al., "They Did Not Have a Word," 493–507.

²⁹ Ibid.

³⁰ Ibid., 501.

³¹ Ibid., 502.

³² Ibid.

³³ Fausto-Sterling, "Duelling Dualisms."

³⁴ Gough et al., "They Did Not Have a Word," 504.

³⁵ Ibid.

³⁶ Fausto-Sterling, "Duelling Dualisms," 7.

³⁷ Gough et al., "They Did Not Have a Word." 504.

³⁸ Preves, "Intersex Narratives."

³⁹ Gough et al., "They Did Not Have a Word."

⁴⁰ Ibid., 497.

⁴¹ Ibid., 506.

⁴² Ibid.

⁴³ Ibid.

⁴⁴ Ibid.

⁴⁵ Ibid.

⁴⁶ Ibid.

⁴⁷ Preves, "Intersex Narratives."

⁴⁸ Ibid.

⁴⁹ Uslan, "What Parents Don't Know," 319.

⁵⁰ Ibid.

⁵¹ Gough et al., "They Did Not Have a Word," 505.

⁵² Fausto-Sterling, "Duelling Dualisms."

⁵³ Kerry, "Intersex Individuals' Religiosity and their Journey to Wellbeing," 278.

⁵⁴ Ibid.

⁵⁵ Ibid.

⁵⁶ Preves, "Intersex Narratives."

⁵⁷ Ibid., 41.

⁵⁸ Phyllis Burke, *Gender Shock: Exploding the Myths of Male and Female*, in *Sex, Gender and Sexuality: The New Basics* 255–262, edited by Abby L. Ferber, Kimberly Holcomb, and Tre Wentling (Oxford: Oxford University Press, 2008), 255.

⁵⁹ Gough, et al., "They Did Not Have a Word."

⁶⁰ Ibid.

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