

Medical Management of Intersexuality and Marginalization of Non-Normative Gender Identities

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Overview of this presentation

- What is intersexuality? The gender binary and its outliers
- Rationale and Objectives of this study
- Review of literature
 - Normative construction of gender identity
 - Medical practice and Intersexuality
 - Psychiatric classification of intersexuality
- Methodology



- Findings from interviews with medical practitioners
 - Doctors' understanding of sex/gender
 - Immutability of chromosomes as immutability of biological sex
 - Decision-making on gender of rearing and surgical intervention

- Discussion
 - Feminism and Intersexuality
 - The consent conundrum
 - Intersexuality and the law

- Conclusion



INTRODUCTION

- What is intersexuality?
- The Gender Binary
- Feminist conceptualization of *gender* as the socially constructed counterpart of sex



The Intersex Society of North America lists the following intersex conditions/variations:

- 5-alpha reductase deficiency
- Androgen Insensitivity Syndrome (AIS)
- Aphallia
- Clitoromegaly (large clitoris)
- Congenital Adrenal Hyperplasia (CAH)
- Gonadal dysgenesis (partial & complete)
- Hypospadias
- Klinefelter Syndrome
- Micropenis
- Mosaicism involving sex chromosomes
- MRKH (Mullerian agenesis; vaginal agenesis; congenital absence of vagina)
- Ovo-testes (formerly called "true hermaphroditism")
- Partial Androgen Insensitivity Syndrome (PAIS)
- Progestin Induced Virilization
- Swyer Syndrome and Turner Syndrome

(From: <http://www.isna.org/faq/conditions>)



Rationale

- Social ostracism, limitation of individual agency and infringement of bodily integrity
- Role of medical science in construction of gender norms
- Interplay of societal and scientific perspectives on *normal sexual appearance*



Objectives

- To study how normative gender gets constructed in medical discourse by focusing on case management of intersex infants
- To bring out social and cultural assumptions underpinning medical decision-making on the above
- To highlight the ways in which these practices reiterate the marginalized status of gender non-conforming bodies



Review of Literature

- Intersexuality and the normative construction of gender identity
 - Perceived coincidence of chromosomes and anatomy
 - Frequency of occurrence of intersexuality in the population: estimated to be between 1 in 500 to 1 in 1500 (Dreger 1998)
 - Meaning that we give to bodies is socio-culturally mediated
- Medical practice and Intersexuality
 - John/Joan case: The "optimum gender of rearing" model developed by Money and Ehrhardt of Johns Hopkins University in 1972
 - Failure of this experiment was seen as a blow to the social constructionist side of the argument



○ Psychiatric classification of Intersexuality

- Diagnostic and Statistical Manual of Mental Disorders IV-TR (APA 2000) at the time of data collection, included Intersex under Gender Identity Disorders Not Otherwise Specified.
- The DSM -V (2013) now defines Intersex as a specifier for Gender Dysphoria, renaming it as Disorders of Sexual Development)
- The intent behind this revision of categorization was to reduce stigma, but Kraus (2015), echoing concerns raised by Tamar-Martiss (2011) contend that this purpose would be better served by removing Intersex altogether from the DSM.



Methodology

- Field of the study
- Snowball sampling
- Sample: 8
 - Paediatric surgeon: 1
 - Paediatric endocrinologist: 2
 - Urologist: 1
 - Obstetrician/Gynaecologist: 1
 - Psychiatrist: 3
- Semi-structured interview
- Qualitative Data Analysis



Findings

- Doctors' understanding of sex/gender:
 - Conflation of categories of sex and gender
 - Assumption of Heteronormativity
 - Stereotypical notions of gendered behaviour and roles
- Immutability of chromosomes as immutability of biological sex:
 - Permeability of hormones and power of surgery to refashion genitalia, vis-a-vis the inalterability of chromosomal structure
 - However, stability of chromosomal sex in terms of congruence with gender identity is questioned by dissonance with gender development in adolescence, as is seen in case of Androgen Insensitivity Syndrome



- Decision-making on gender assignment and surgery:
 - Need for early decision
 - Greater reliance on chromosomal sex compared to any other factor
 - This is followed by genitoplasty in infancy and hormonal therapy in adolescence
 - Preservation of reproductive function, especially in girls. When gender *male* is assigned, appearance of genitalia is given greater weight, though reliance on chromosomes remains the same



Discussion

○ Feminism and Intersexuality:

- Perspectives from Feminist Science Studies (Emily Martin 1991) bring out how the biological understanding of sex itself is gendered.
- Questioning of the two-sex norm and its reiteration through medical categorization and treatment of intersexuality
- Intersexuality as a point of entry to revisit feminist methodology through breaking the analogical positing of sex/gender with nature/culture and studying the overlaps between the categories



○ The consent conundrum:

- Decision-making on assignment of gender should not automatically amount to surgery (ISNA)
- Intersex not exceptional among cases of medical/surgical intervention to make healthy bodies socially acceptable (Dreger 2006)
- Current model of treatment described as 'experimental' (Ford 2001) as outcomes cannot be predicted with certainty.
- Non-recognition of intersexuality as a legitimate and socially acceptable way of being.



○ Intersexuality and the law:

- Indian context- sexual minorities have resorted to the law for recognition of rights, albeit with mixed results.
- No law in the Indian context takes into account concerns of intersex individuals, especially with regard to consent of parents to genitoplasty
- Diminishing of agency of intersex individuals to live in accordance with the gender identity of their preference in adult life.



Conclusion

- While intersexuality remains deeply entrenched in the medical model, it is difficult to constitute it as an identity group
- Compulsions of heteronormative reproduction are at the root of approaching intersexuality through the medical model
- In view of limited options before parents of intersex children, decision-making should take place with greater openness, and without its being treated as a matter of medical emergency
- Future direction: Need to incorporate narratives of intersex individuals



References

American Psychiatric Association. Homosexuality and Sexual Orientation Disturbance: Proposed Change in DSM-II, 6th Printing, Page 44. Position Statement, Arlington: American Psychiatric Association, 1973.

- Diagnostic and Statistical Manual of Mental Disorders-IV-Text Revision. Washington DC: American Psychiatric Association, 2000.

- Diagnostic and Statistical Manual of Mental Disorders-V. Arlington: American Psychiatric Publishing, 2013

Butler, Judith. "Sex and gender in Simone de Beauvoir's Second Sex." Yale French Studies 72, 1986: 35-49.

- Bodies That Matter: On the Discursive Limits of Sex. New York and London: Routledge, 1993.

- Gender trouble: Feminism and the Subversion of Identity. New York: Routledge, 1990

Chase, Cheryl. "Hermaphrodites with Attitude: Mapping the Emergence of Intersex Political Activism." GLQ: A Journal of Lesbian and Gay Studies 4(2), 1998:189-211.



Diamond, Milton. "Sexual identity and sexual orientation in children with traumatized or ambiguous genitalia." *Journal of Sex Research* Vol. 34, No. 2, 1997: 199-211.

Dreger, Alice Domurat. "'Ambiguous Sex'—or Ambivalent Medicine?: Ethical Issues in the Treatment of Intersexuality." *Hastings Center Report* 28, No. 3, 1998: 24-35.
- "Intersex and human rights: the long view." In *Ethics and Intersex*, Springer: Netherlands, 2006, 73-86.

Dreger, Alice, and April Herndon. "Progress and Politics in the Intersex rights movement." *GLQ: A Journal of Lesbian and Gay Studies* 15: 2, 2009.

Fausto-Sterling, Anne. "The five sexes." *The Sciences* 33, No. 2, 1993: 20-24.

Ford, Kishka-Kamari. "'First, Do No Harm': The Fiction of Legal Parental Consent to Genital Normalizing Surgery on Intersexed Infants." *Yale Law and Policy Review* 19:2, 2001: 469-488.

Kessler, Susan. "The Medical Construction of Gender: Case Management of Intersexed Infants." In *Women, Science and Technology: A Reader in Feminist Science Studies*, by Mary, et al Wyer. Routledge, 2001.



- Kraus, Cynthia. "Classifying intersex in DSM-5: Critical reflections on gender dysphoria." *Archives of Sexual Behavior* Vol. 44, No. 5, 2015: 1147-1163.
- Kohler, et al. "Satisfaction with Genital Surgery and Sexual Life of Adults with XY Disorders of Sex Development: Results from the German Clinical Evaluation Study." *Journal of Clinical Endocrinology and Metabolism* 97 (2), 2012: 577-588.
- Martin, Emily. "The Egg and the Sperm: How Science has Constructed a Romance Based on Stereotypical Male-Female Roles." *Signs* Vol. 16, No. 3, 1991: 485-501.
- Menon, Nivedita. *Seeing like a Feminist*. New Delhi: Zubaan and Penguin, 2012.
- National Legal Services Authority v. Union of India & Ors. [Writ Petition (Civil) No. 400 of 2012]. Supreme Court of India: 2014
- Diamond, Milton. "Sexual identity and sexual orientation in children with traumatized or ambiguous genitalia." *Journal of Sex Research* Vol. 34, No. 2, 1997: 199-211.
- Mitra, Payoshini. "Play Like a Girl, Woman." *Feminists India*. August 29, 2012.
<http://feministsindia.com/play-like-a-girl-woman/> (last accessed April 18, 2016).



Sapolsky, Robert. "The Trouble with Testosterone: Will boys just be boys?" In *The Gendered Society Reader*, edited by M.S. Kimmel. New York: Oxford University Press, 2000.

Tamar-Mattis, Anne. "Leave Intersex out of the DSM-V." *Bioethics Forum*. June 17, 2011
<http://www.thehastingscenter.org/Bioethicsforum/Post.aspx?id=5406> (last accessed April 18, 2016).

The National Commission for Protection of Child Rights. "Citizen's Charter of the National Commission for Protection of Child Rights." www.ncpcr.gov.in. January 2013.
http://www.ncpcr.gov.in/view_file.php?fid=8 (last accessed April 18, 2016).

Warnke, Georgia. "Intersexuality and the Categories of Sex." *Hypatia* 16, no. 3 (2001).

Wiederkehr, Stefan. "'We shall never know the exact number of men who have competed in the Olympics posing as women': Sport, gender verification and the Cold War." *The International Journal of the History of Sport* 26, no. 4, 2009: 556-572.



THANK YOU!

