



Introduction

Despite decades of its acceptance in healthcare, a plethora of intersex scholars have argued against Intersex Pediatric Surgery (IPS). Some scholars appeal to the empirical evidence that NIS is physiologically, psychosexually and bodily harmful. Others appeal to more traditional bioethical violations such as a lack of respect for autonomy. Aiming for optimal intersex neonate healthcare, my dissertation seeks to evaluate these arguments both for their philosophical plausibility and clinical recommendations. It is found that **the arguments are unanimously implausible**, and that their clinical recommendations are consequently inappropriate. Drawing on recent scholarship, **my dissertation offers a principle-based model of NIS' moral (im)permissibility, contextualized in a Beneficent Paternalist (BP) clinical framework for optimizing intersex neonatal family-directed, patient-centered care.**

Study Questions

What does "intersexuality" mean, and why medicalize "intersexuality" into Disorders/Differences of Sexual Development (DSD)? What are the conceptual and normative implications of this medicalization? Does our (medical) characterization of intersexuality entail surgical implications? Under what conditions is IPS morally (im)permissible?

Background

With a presence rate of **0.018%**, there are over forty known variations of "intersexuality", laid out in **six categories**:

1. XX, DSD (a form of virilizing congenital adrenal hyperplasia)
2. XY, DSD (abnormal testicular differentiation)
3. Sex Chromosome DSD (Turner and Klinefelter Syndrome)
4. XX or XY Disorder of Gonadal Development (sex reversal and ovotesticular disorder)
5. XY Persistent Mullerian Duct Syndrome (Mullerian structures)
6. Malformation Syndrome (urogenital anomalies/malformations, appearing as DSDs)

Disorders of Sexual Development ('DSDs') are largely caused by **Congenital Adrenal Hyperplasia (CAH), a rare (inherited) autosomal recessive disorder caused by the deficiency of one of the enzymes requisite to create specific hormones.** A DSD is thereby defined as:

Disorder of Sex Development (DSD) is a congenital condition of disordered gonadal sexual development based on a discordant chromosomal, genetic, gonadal and phenotypic/anatomical sex, involving abnormal and ambiguous (indiscernibly male or female) genitalia/genital anatomy.

Q: Does the language of "disorder" imply a need for surgical repair? Does it unnecessarily pathologize individuals who are born with a different sexual anatomy? Does the language of "disorder" mean that it is not evaluatively acceptable to not fit in with the sex binary of male/female?

Intersex Pediatric Surgery (IPS): For and Against

Arguments against IPS...

- (1) IPS is heteronormative, producing cisgendered futures and eradicating intersex
- (2) IPS is medically unnecessary, cosmetic, and genitally mutilating
- (3) IPS violates the right to bodily autonomy via lacking consent for elective cosmetic surgeries

Problems with arguments against IPS...

- (1) Generalizes cases which comes at the cost of individualized, patient-centred care
- (2) Conflates cosmetic and reconstructive surgery, and cases of difference with disorder
- (3) Relies on implausible philosophical theses, including social constructionism about human sexuality

What makes for a good approach to IPS?

Some criteria...

- (1) Consistent with **patient-centred, family-directed care**
- (2) **Refrains over-generalizations** which both compromises care as well as lacks the resources to anticipate future medical contingencies
- (3) Relies on **substantially defensible philosophical premises**, especially pertaining to inferences from medical terminology and data, as well as theories of human sexuality
- (4) Clearly accounts for the **wrong-making features of NIS** when it is morally impermissible
- (5) **Empowers Substitute Decision Makers (SDMs) of intersex children and multidisciplinary care teams** to make clinically effective choices which recognize evaluative differences

"...patients are **individual people** who happen to have a disease or disorder, rather than a person intertwined with or defined by the disorder..."

--V. Paterski & I.A. Hughes

Case Study

In Nora Neus' CNN story "She's 7 and was born intersex. Why her parents elected to let her grow up without surgical intervention", we read about Rosie Lohman, a seven-year-old (self-identified) girl who was born "intersex." Against Rosie's physician's recommendation, her parents refused genital surgery for her; instead, they opted to raise Rosie with her "intersex condition", allowing her to choose her own pronouns, gender identity and sexual orientation. Rosie's mother Stephani raised the following concerns about surgery: the surgeries can have devastating side effects e.g., loss of sexual function, psychological trauma and life-long pain. She also expressed distrust in Rosie's surgeon, citing feelings of "intimidation", being "overwhelmed" and "pressured". Rosie's father Eric cites that his reservations over the surgery were justified since the surgeon did not offer a compelling case for the "elective" (Eric's term) surgery. Like Stephani, Eric cited his experience of fear that the surgeon would perform the surgery (although the specific object of fear was ambiguously reported e.g., fear of the surgeon's suggestion of surgery or fear that they would perform the surgery without his/Stephani's consent). Though their reasons were both different, both Stephani and Eric agreed to not proceed with early surgery.

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Happy to send references,
discuss further, and
collaborate!

Commentary

It is clear that Neus' article highlights that the moral dimension of IPS is beyond argumentation for or against the surgery. It is a question of...

1. **Physician competence** e.g., pediatric urologists specializing in intersex care (certification post-2008)
2. **Reconciling modern medical beneficence with intersex persons' systematic medical distrust** - truth-telling and reconciliation
3. **Empowering families for intersex neonates** in our language, policies and frameworks for difficult decision-making
4. Addressing **the need to respect the position of multi-disciplinary care teams'** suggested treatment recommendations with the values, beliefs and morals of the families of the intersex neonate
5. **Admitting when evidence is lacking**, and when clinical expertise and ingenuity needs to be applied without medical certainty
6. Considering **the role of a clinical bioethicist** in an intersex neonate's care team: possible role might be to screen for any discriminatory attitudes, biases and mistaken normative judgements regarding intersex neonates and their futures