



The Ethical Implications of Intersex Surgery

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Background Information

Intersex is an umbrella term used for people born with variations of chromosomes, hormones, and/or sex characteristics that do not correspond with the gender binary (male or female). In some cases, intersex can easily be identified by external sex characteristics at birth. In other cases, intersex babies may have external genitalia that fit typical male or female bodies, but have malformed, different, or no internal genitalia.¹⁰ Hence, intersex bodies can be discovered at birth, during puberty, or even adulthood. Because of this, there has been an unclear consensus on the diagnosis of intersex.¹ It is important to note that intersex relates only to an individual’s biological sex characteristics and not their sexual orientation or gender identity. In the 20th century, medical sex “normalizing” procedures were introduced to the treatment of intersex people. Upon this introduction, intersex people were subject to surgeries and hormonal therapies in attempts to “normalize” ambiguous genitalia and establish a gender at birth.⁹ Over time, it was shown that these medical interventions had negative, even fatal consequences in children.⁶ This has resulted in a societal failure to recognize intersex people in daily life, subjecting them to alienation, physical, and psychological trauma.

History

- 1930s-1940s: Surgeries were performed on intersex individuals to allow one’s “true sex” to emerge with a focus on intersex adults¹¹
- 1950s: Psychologist John Money from Johns Hopkins University proposes intersex surgeries should be completed within the first 18 months of life as he believed gender identity was malleable during this period.⁵
- 1960s: Intersex care shifts its focus toward caring for infants rather than adults.¹¹
- 1993: Cheryl Chase founds the Intersex Society of North America (ISNA) in response to the public criticism of gender reassignment surgeries by intersex individuals¹³
- 2013: The United Nations Special Rapporteur on Torture condemns the completion of unnecessary surgeries on intersex children¹¹
- 2017: Three former US Surgeon-General’s call for an end to medically unnecessary surgeries on intersex children noting that the research to date does not support cosmetic infant genitoplasty

Scientific Considerations

Development of Reproductive Organs

- The differentiation between male and females happens early in gestation, occurring around nine weeks. Around this time, the gonads either change into testes or ovaries
- The default pathway of differentiation is referred to as feminization, where the gonads turn into ovaries.
- In order to divert from the default pathway of feminization and get male development, the SRY, which encodes for testes, needs to present and two processes need to occur.
 - **Defeminization:** This process prevents the development of a female reproductive tract
 - **Masculinization:** The result is a penis, scrotum, epididymis, and vas deferens, but also a male brain.
- Each of these processes is governed by the hormonal milieu secreted from the testes. Masculinization is due mostly to a large impulse of testosterone, while defeminization is due to a few other hormones, such as estradiol. Both processes are necessary to get us anything other than females.
- Sometimes masculinization and defeminization do not work as intended, and the result is intersex, such as Androgen Insensitivity Syndrome⁴

Harmful Physical Effects	Harmful Psychological Effects
<ul style="list-style-type: none">• Loss of sexual sensation, scarring, severed nerves and ongoing pain• Incontinence• Reduced bone density• Increased BMI and blood pressure²	<ul style="list-style-type: none">• Feelings of continued dread and horror• Avoidance of seeking professional healthcare later on in life• Gender Identity Disorder• Depressive mood disorders and anxiety²

Ethical Considerations

Informed Consent

- Parents of intersex children consent to surgeries based on guidance from medical professionals³
- Medical professionals do not always inform parents that their child may not identify with the gender assigned during surgery³
- Based on the rhetoric of medical professionals, surgery is presented as the default plan of action to parents rather than an option⁵
- Without informed consent, surgical intervention can be recognized as physical battery of the child or infant.
- Downplaying alternate outcomes of the surgery raises concerns of whether parents are truly giving informed consent because they do not understand the potential risks of consenting to this procedure

Principle of Nonmaleficence

- Studies conducted by the 2017 Council of Europe’s Committee on Bioethics regarding intersex surgery have yet to find any quality data confirming its safety and benefits for affected children.
- Adult intersex patients have reported evidence of “genital dysfunction, scarring, loss of sexual feeling, loss of fertility, chronic pain, and the wrong gender assignment—with irreversible excision of genital and gonadal tissues” as a result of genital surgery in their infancy or young childhood. Due to the negligence of their physicians, these patients were subjected to unnecessary and irreversible surgery.¹²
- Acting in the “patient’s best interest” is nearly impossible because there is no objective scale to accurately determine each individual patient’s best interest as they mature.¹⁴ Physicians cannot ensure that a decision as permanent as genital reassignment surgery will have a favorable outcome for an infant or child post-puberty.
- If an intersex infant or child rejects the sex that they were surgically assigned, they may face a lifetime of pain and psychological suffering.
- The performance of medically unnecessary intersex surgery violates the principle of nonmaleficence because the patient is put at high and unreasonable risk of physical harm and the psychological pain associated with rejecting the sex assigned to them.

Principle of Autonomy

- The United States is the only member of the UN that has not ratified the Convention on the Rights of the Child (CRC)
- The CRC endorses the idea that states should “ensure that no-one is subjected to unnecessary medical or surgical treatment during infancy or childhood, guarantee bodily integrity, autonomy and self-determination to children concerned, and provide families with intersex children with adequate counselling and support.”
- Dangerous and irreversible intersex surgeries violate a person’s s right to autonomy over their own future¹²
- The child should be respected as a member of the decision making process because even young children, from the age of 6 or 7, can begin to express preferences, understand biological processes, and reflect on their identity¹⁴

Differential virilization of the external genitalia using the staging system of Prader, from normal female (left) to normal male (right). Sagittal (upper panel) and perineal (lower panel) views shown.

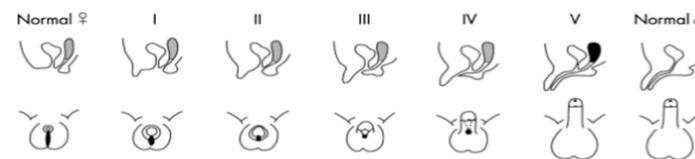


Figure from Davies K. (2016). Disorders of Sex Development-Ambiguous Genitalia. *Journal of pediatric nursing*, 31(4), 463–466.

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Case Study

Wendy, a mother of twins, was expecting to have twin girls. She had selected names for her twins but after giving birth, Wendy was told to reevaluate her choice of names by her physician. The physician was unsure if one of the newborns was a boy or girl. Blood tests showed that one of the twins had XY chromosomes with ambiguous external genitalia. While the baby was in the NICU and the baby’s survival was uncertain, Wendy was approached by surgeons to operate on the baby for genital reassignment surgery. Since leaving the hospital with her child, Wendy was repeatedly urged to allow surgeons to operate and transform her child into a “normal girl”, which would be an easier surgery, or a “real man”, who could eventually “stand up and pee”.

After attending an intersex surgery conference to learn more about her child’s condition, Wendy opted to not have surgery performed on her child. In making this decision about her genetically male son, Wendy rationalized, “I don’t want to do something that can’t be undone.” The child, known as Stephen, shared that he sits down to urinate, but he has never faced any bullying or harrasment from peers as a result of being intersex. Wendy reported that because Stephen has such good health, she avoids taking him to any medical appointments unless it is an emergency. Both Wendy and Stephen dread going to doctor appointments because they are still urged to consider surgery, even though Stephen is comfortable in his body. Wendy and Stephen fear that they will be pressured to undergo a medically unnecessary surgery if they pursue routine medical care.¹⁴

Guidelines and Recommendations

Surgery for intersex infants should be delayed until individuals can decide for themselves in all cases except those where it is medically necessary. Due to high risk of harm against intersex people, further guidelines are suggested:

- 1) Intersex surgery should only be performed when there is strong evidence it is beneficial and not harmful.
- 2) Intersex surgery should only be performed in cases of medical necessity.
- 3) Intersex surgery should normally be delayed until the intersex person is able to assent to treatment or decide against it.
- 4) Conventional ethical requirements regarding truth-telling apply equally to intersex children as they do to anyone else.
- 5) If physicians or parents think surgery is in the best interest of the child, the burden of proof lies with them.

Recommendations for Health Care Providers

- Physicians should interact with patients who speak about their experiences at medical conferences. This is a way for patient advocates to communicate with physicians and give them a better understanding of the outcomes of intersex surgery post-puberty as adults.
- Open communication with families and promote acceptance of individual development
- Avoid emotionally-driven decisions and delay non-urgent decisions until psychological counseling has been given. Promote participation of trained peers in the decision-making process.
- Establishment and integration of multidisciplinary “DSD Teams” in hospital settings to advocate on behalf of the intersex child’s rights The rights of intersex people not to undergo medical intervention for social and cultural reasons must be recognized. Thus, the development of rights-based clinical pathways and intersex-led advocacy and support groups must be prioritized.⁷
- Reporting of intersex surgeries in the U.S is highly unregulated, so there should be policy for hospitals to report this in their databases.

Recommendations for Parents

- Biological: When explaining the condition to children, emphasize that it is a naturally occurring variation.
- Medical: Explain sex and gender as non-binary concepts and in the context of sex determination and differentiation. Furthermore, provide precise information on the specific conditions, including information regarding vital, functional and elective medical interventions, while emphasizing risk and benefits, and offer alternatives to provide patients with choices that respect their autonomy.
- Gender-Related: The parents should put forward gender contentedness as the ultimate goal. They should encourage self-expression of the developing child and allow them to modify their social gender role throughout development.⁷