

# INTERSEX IN THE AGE OF QUEER BIOETHICS: Recommendations on the Fundamentals of Ovarioepididymectomy Interventions for Intersex Youth

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## ABSTRACT

Queer Bioethics and the inventory of its potential populations include a wide range of queer subjects: lesbian parents, HIV-positive gay and bisexuals, transgender youth, and non-cisgendered individuals, to name a few. With the ethical dilemmas and ethical duties couched inside of a Queer Bioethics in mind, this article will consider one of the field's most enduring citizens: the intersex child. More specifically, the figure of the intersex child with ovarioepididymectomy non-normativity will be scrutinized on ethical and clinical planes – a major aspect of queer bioethics is, after all, clinical ethics for queer populations. Ovarioepididymectomy conditions will be covered at length; we discuss different variations in addition to narrowing the topic to those with 46,XX and ambiguous genitalia, specifically those 75% diagnosed under the age of 20, and speak on issues related to this population. We will also briefly discuss the population of the 20% diagnosed under the age of 5 years old. Interventions will be discussed in all realms of intersex conditions – specifically ovarioepididymectomy. We will conclude with a principlist approach to ethical topics such as autonomy, beneficence, and non-maleficence, weighing these principles equally and ultimately erring on the side of autonomy within pediatric ethics where possible.

## ABSTRAKTI

Queer-bioeettistä tarkastelua voi soveltaa joukkoon erilaisia queer-positioita: esimerkiksi lesbovanhempiin, HIV-positiivisiin homo- ja bi-miehiin, transsukupuolisiin nuoriin ja sukupuoleltaan moninaiisiin henkilöihin. Tässä artikkelissa tarkastelemme intersukupuolisen lapsen positioita eettisten ongelmien ja velvollisuuksien keskiössä queer-bioeettisesti orientoituneesta näkökulmasta. Intersukupuolisuuden muodoista keskitymme ovarioepididymektiseen epänormatiivisuuteen, jota käsittelemme sekä eettisellä että kliinisellä tasolla – onhan eräs queer-bioetiikan tarkoituksista luoda queer-väestöt kattavaa eettistä ohjeistusta lääketieteen kliiniseen työhön. Aluksi tarkastelemme ovarioepididymektisuuden eri muotoja. Seuraavaksi keskitymme intersukupuolisuuden 46,XX-muotoihin, joissa henkilön sukupuoli on ulkoisten sukuelinten perusteella epäselvä. Keskitymme erityisesti kysymyksiin, jotka koskevat 75 % intersukupuolisista henkilöistä, jotka saavat diagnoosin alle kaksikymmentävuotiaana. Sivuumme myös ongelmia, jotka koskevat sitä 20 % henkilöistä, jotka diagnosoidaan viisivuotiaana. Tarkastelemme intersukupuolisuuteen – ja erityisesti ovarioepididymektisuuteen – liittyviä käytänteitä. Lopuksi esitämme autonomian, hyvän tekemisen ja pahan tekemisen periaatteisiin nojaavan eettisen tarkastelun mallin sekä punnitsemme näitä periaatteita suhteessa intersukupuolisuuden kliiniseen hoito-työhön. Päädyimme suositamaan autonomiaa lastenlääketieteen etiikan ohjenuoraksi silloin, kun se on mahdollista.

## Introduction

The realm of queer bioethics has had many citizens in its history. Some premiere examples of citizenship include the trans individual in the reproductive suite; the HIV-positive MSM (man who has sex with men) in the blood donation center; the lesbian couple seeking equal visitation rights in the hospital; and the gender-non-cis<sup>1</sup> person seeking lexiconographical inclusion in matters of clinical sensitivity. But, perhaps, one of queer bioethics' first and most enduring citizens has been the intersex child (Wahlert and Fiester 2011). Though bioethics in general has been slow to uptake the issue of intersexuality, queer bioethics – a young field that has emerged just within the last decade – has paid attention to the concerns of intersex individuals from its outset. In doing so, queer bioethics has emphasized the importance of good clinical ethics for intersex people, in keeping with its broader commitment to assessing the ethics of clinical care for queer populations.

The label intersex refers to a variety of conditions in which the sexual and other gendered anatomy does not match the typical characteristics of a traditionally defined cisgender male or female body. The chances of an individual being born with an intersex condition are roughly somewhere between 1 in 1500 births to 1 in 2000 births (ISNA 2008) depending on one's definition within the category of intersex spectrum conditions. Within these percentages, we find many different intersex conditions with some showing anatomical presentations of ambiguous/non-normative genitalia and others showing typical external genitalia. Some show normal male/female sex organs while others have a mix of sexual reproductive organs. Due to the elasticity in terminological requirements for intersex

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<sup>1</sup> In this paper, we use the terms “gender-non-cis” and “non-cisgendered” interchangeably, as both are used in the relevant literature.

conditions, the corresponding shift in protections demands that the subject needs to be continually discussed and addressed in queer bioethical circles.

In accordance with the need to continually discuss the topic of intersex, we would like to revisit the old/young queer bioethics figure of the intersex child. To do so, we turn to the Queer Bioethics Inventory, articulated by Lance Wahlert and Autumn Fiester in a 2014 special issue of the *Hastings Center Report* titled “LGBT Bioethics: Visibility, Disparities, and Dialogue.” The inventory is a list of questions to be used when analyzing bioethical cases; they guide us to appropriately address the needs and vulnerabilities of LGBTQ persons, particularly in the clinic. If the Queer Bioethics Inventory asks us to consider – in combination with recent queer theory and disability theory – the value and the subjectivity of non-normative, non-cisgendered bodies and anatomies, then a most savvy queer bioethics also tasks us to review the clinically normative ways in which intersex children and intersex bodies continue to be inappropriately objectified as urgently in need of “fixing.” (Wahlert and Fiester 2014, 57). In this paper, we explore the topic of intersex with this mandate from the Queer Bioethics Inventory in mind. Our aim is to question the standard-of-care for intersex children in the United States – particularly those with ovotesticular conditions – while addressing and drawing upon the foundational understandings of intersex in bioethical discourse.

We begin by providing an overview of intersex conditions to introduce the reader to the range of anatomical/genetic variations falling under the umbrella of intersex. We then discuss the clinical and bioethical history of intersexuality with commentary from well-known historians such as Alice Dreger and Elizabeth Reis and clinicians such as John Money. In the last stages of our argument, we pay special attention to the condition of ovotestes, which occurs in 2–10% of all intersex conditions (New and Simpson 2011). As with all spectrum disorders, there is value in discussing



IMAGE: Ami Koiranen: Kontrolli, nro 1.

the particular features and vulnerabilities of a specific condition. For example, the needs of individuals on either end of the autism spectrum vary greatly, as do those of someone with severe rheumatoid arthritis and another with mild osteoarthritis. Focusing on ovotestes also allows us to demonstrate the relevancy of our discussion of the history and prevalence of intersexuality by grounding it in a specific example. Ovotestes will be covered in length, with reference to different variations of as well as narrowing the topic to those with 46,XX and ambiguous genitalia. We focus specifically on the 75% diagnosed under the age of 20 and speak on issues related to this population. We will also briefly discuss the 20% diagnosed under the age of 5 (Dayal and O’Hern 2017). Interventions will be discussed specifically in the case of ovotestes, but we draw conclusions relevant in all types of intersex conditions. We conclude with a principlist approach to the clinical management of intersexuality, weighing the principles of autonomy, beneficence, and non-maleficence equally.

### Background and Overview on Intersex Conditions

Intersex conditions, known as Disorders of Sexual Development (DSD) to many within the medical profession, occur when an individual shows sexual or somatic discrepancies across the internal and/or external anatomical divide. The major different intersex conditions are as follows: 5-alpha reductase, Androgen Insensitivity Syndrome (AIS), Aphallia, Clitoromegaly (large clitoris), Congenital Adrenal Hyperplasia (CAH), Hypospadias, Klinefelter Syndrome, Micropenis, Mayer-Rokitansky-Küster-Hauser Syndrome (MRKH), Progestin Induced Virilization, Swyer Syndrome, and Turner Syndrome (ISNA 2008). This list is not exhaustive, but includes the most common intersex diagnoses, which are discussed below in order to give the reader a general understanding of the associated characteristics and treatment decisions.

*5-alpha reductase deficiency* is a condition defined by a lack of production of the hormone known as dihydrotestosterone (DHT). During puberty, people with 5-alpha reductase deficiency will develop some male secondary sex characteristics,

including increased muscle mass, height, and deepening of the voice, while the penis and scrotum grow larger (Genetics Home Reference 2017). Unlike most men, people with this condition tend not to develop significant facial or body hair and are usually infertile (Genetics Home Reference 2017). Those with this condition who identify as male can receive testosterone supplements as well as DHT supplements.

*Androgen Insensitivity Syndrome* (AIS) is a condition in which an XY individual is resistant to the effects of androgens (male hormones). Individuals with partial AIS typically display both male and female characteristics (Genetics Home Reference 2016). People with complete AIS (CAIS) have external female sex characteristics but do not have a uterus, meaning that they do not menstruate and are infertile. Most people with CAIS are raised as and identify as female (Genetics Home Reference 2016). They have undescended testes, which are sometimes removed as they carry a small risk of becoming cancerous later in life (Genetics Home Reference 2016). Hormonal therapy, in the form of estrogen replacement for those identifying as female, is also frequently recommended (MedlinePlus 2016).

*Aphallia* is a congenital condition in which the penis or clitoris is absent. The classical treatment for aphallia involves female gender assignment with initial feminizing genitoplasty for infants and vaginoplasty (construction of a vagina) performed later in life (Gupta and Gupta 2008). Hormonal therapy, started around the time of puberty and continued throughout life, is another component of the traditional treatment of this condition (Gupta and Gupta 2008).

*Clitoromegaly* describes the condition of an abnormally large clitoris. It is frequently caused by Congenital Adrenal Hyperplasia (CAH, discussed below) (Kaefer and Rink 2017). In moderate to severe cases, clitoroplasty (reduction of the clitoris) and vaginoplasty is often performed (Kaefer and Rink 2017).

*Congenital Adrenal Hyperplasia* (CAH) is a group of genetic disorders in which hormone production from the adrenal glands is diminished. There are two major types of CAH: Classic and Nonclassic (Mayo Clinic 2017). Classic CAH is usually discovered in infancy. Affected males have normal appearing genitalia, while females usually present with genitalia that is neither stereotypically male nor stereotypical female. Some of these affected female babies will undergo genital surgery to create normal-appearing genitalia, often necessitating further cosmetic surgery later in life (Mayo Clinic 2017). People with Classic CAH are frequently prescribed hormone replacement medications (Mayo Clinic 2017). Nonclassic CAH is milder, usually not discovered until childhood or early adulthood, and may or may not require hormone therapy (Mayo Clinic 2017).

*Hypospadias* is a congenital condition whereby the urethra opening is located on the underside of the penis instead of the tip. Surgery is usually performed during infancy to normalize the penis' appearance (Mayo Clinic 2016).

*Klinefelter Syndrome* (also called XXY syndrome) is a chromosomal condition affecting male physical and cognitive development. It is usually caused by the presence of an additional X chromosome, hence the name XXY syndrome (Genetics Home Reference 2017). The genes on the additional X chromosome interfere with normal male sexual development (Genetics Home Reference 2017). A reduction in testosterone in Klinefelter patients can lead to delayed/incomplete puberty, infertility, reduced facial and body hair and gynecomastia (breast enlargement) (Genetics Home Reference 2017). Individuals with Klinefelter syndrome often have delayed speech and language development along with other learning disabilities (Genetics Home Reference 2017). Treatments may include testosterone replacement, breast tissue removal, speech and physical therapy, educational evaluation and support, fertility treatment, and psychological counseling (Mayo Clinic 2016).

*Micropenis* is an abnormally small penis. It usually occurs as a consequence of other disorders, particularly hormonal conditions (Stanford Children's Health, accessed 2018). For some patients with micropenis, hormonal therapy is recommended to stimulate penile growth (Stanford Children's Health, accessed 2018). If this therapy is unsuccessful, surgery may be considered (Hatipoğlu and Kurtoğlu 2013).

*Mayer-Rokitansky-Küster-Hauser Syndrome*, abbreviated as MRKH and also known as Müllerian agenesis or vaginal agenesis, is a congenital condition affecting the female reproductive system. People with MRKH usually have normal ovaries and fallopian tubes, but a uterus and vagina that are absent or underdeveloped (Genetics Home Reference 2017). MRKH patients have typical external genitalia. Treatment options include doing nothing or using dilators and/or vaginoplasty surgery to create a vagina (Center for Young Women's Health 2017).

*Progestin Induced Virilization* is a condition where a genetically female (XX) fetus has prenatal exposure to exogenous androgens, most commonly progestin. Individuals with this condition present with a variety of external genitalia, ranging from "female with larger clitoris" to "male with no testes" (ISNA 2008). Feminizing genital surgery is often performed, although individuals born with genitalia sufficiently virilized to be considered fairly stereotypically male are often raised as boys (ISNA 2008).

*Swyer Syndrome* is also known as XY gonadal dysgenesis. This is a condition where an individual is born without functional gonads (NIH Genetic and Rare Diseases Information Center 2016). Individuals with Swyer Syndrome have typical female genitalia, uterus, and fallopian tubes, are usually raised as girls, and tend to have a female gender identity (NIH Genetic and Rare Diseases Information Center 2016). Swyer Syndrome patients often receive hormone replacement therapy and undergo surgical removal of "residual gonadal tissue called streak gonads" that can become

cancerous (NIH Genetic and Rare Diseases Information Center 2016).

*Turner Syndrome* is a genetic condition affecting females caused by the absence of or structural alteration to one of the two X chromosomes. Turner Syndrome can lead to reduced height, "failure to start puberty, infertility, heart defects, certain learning disabilities and social adjustment problems" (Mayo Clinic 2017). Turner Syndrome requires lifelong management including estrogen and growth hormone replacement and other therapies targeted to a patient's individual symptoms (Mayo Clinic 2017).

Many of the conditions above are treated with hormonal therapy and genital surgery. As we shall discuss further below, cosmetic surgery aimed at normalizing atypical genitalia is controversial and ethically questionable, particularly when performed on infants. Many intersex advocates call for refraining from immediate intervention and allowing the individual to make their own decision about surgery later in life.

## Intersex in the History of Medicine

In her book *Bodies in Doubt: An American History of Intersex*, Elizabeth Reis (2012) analyzes the changing definitions, perceptions, and medical management of intersex individuals in the US. To begin, she thinks about the question of what it means to be human. To be human, she writes, is to be "culturally gendered" and "physically sexed" as a man or a woman (Reis 2012, ix). Bodies that cannot be neatly categorized as male or female – i.e. those that are intersexed – challenge the classical understanding of the term 'human.' Historically, intersex has largely been seen as a problem and an issue that needs to be 'fixed.' Concurrently, interventions – primarily surgical – are at the forefront for all those individuals involved in care for the intersex person; for example, the doctor(s), the psychologist,

the geneticist, the family, the individual that has the intersex condition. Looking back at the history of intersex enables us to understand the traditions and beliefs that still impact how we approach intersex care today. In this section, and the one that follows, we seek to answer the question: Has medical ethics (in particular) and medical history (more largely) been friend or foe to those with intersex conditions?

Among the most instrumental changes that have occurred in the medical treatment of intersex are related to terminology. In the past, intersex individuals were called hermaphrodites. Many doctors and lay people, however, believed that “hermaphroditism, as it was then defined, did not exist in the human species” (Reis 2012, xi). The Greek mythological figure of Hermaphroditus, from whom the term ‘hermaphrodite’ is derived, found no counterparts in the human world. But saying that hermaphrodites did not exist encouraged doctors and laypeople to insist on two and only two sexes, when “not all bodies fit precisely into discrete male and female categories” (Reis 2012, xi). This mindset led to primarily doctors but also to other individuals, spending time determining the ‘true sex’ of intersex people. We see this in the case of Thomas(ine) Hall, the first person with ambiguous genitalia recorded in early America. In 1629, Hall was brought to court after appearing in female clothing. Hall was subjected to several investigations of his/her genitalia, but the court could not decide to which sex s/he truly belonged. The absence of such a conclusion meant “Hall would have to live as a public freak and laughing stock” (Reis 2012, 4).

In mid-eighteenth century, hermaphrodites were known as preternatural creatures (often labeled as ‘monstrosities’) within the medical marketplace. James Parsons, a British author of a 1741 medical text on the non-existence of hermaphrodites, lamented “the sorry fate that befell those deemed more monstrous than human” (Reis 2012, 6). Despite his conviction that hermaphrodites did not exist, his empathy for those labeled as

such led to the following recommendation: “predominancy of sex ought to be regarded; but if the sexes seem equal the choice is left to the hermaphrodite” (Greenhill and Schmitz 1939, 125–126). Parsons’ view that hermaphrodites should choose for themselves was uncommon among the practitioners that succeeded him in the nineteenth century.

By the late nineteenth century, which historian Alice Dreger has called the “Age of Gonads,” biomedical professionals in Europe and the US “groped around looking for stable and non-overlapping definitions of ‘male,’ ‘female,’ and ‘true hermaphrodite’” (Dreger 1998b, 346). In a decision made possible by the rise of gynecology and medical advancement/specialization more generally, American and European practitioners endorsed the idea that “the anatomical nature of the gonads (as ovarian or testicular) alone should determine a subject’s ‘true sex,’ no matter how confusing or mixed his or her other parts” (Dreger 1998b, 347). Even now, in the twenty-first century, we still see physicians deciding the sex of the intersex child. Overall, whether doctors asserted or denied hermaphrodites’ reality, they tried to determine each patient’s true, singular sex with certainty, even though the bodies they saw manifested ambiguity. “‘Undecided’ was the one medical conclusion physicians refused to reach” (Reis 2012, 23).

Currently considered derogatory, the term “hermaphrodite” is rarely used in contemporary medical practice. Today, intersex conditions are referred to as disorders of sexual development (DSD), though Reis advocates for using ‘divergence’ and others have adopted ‘difference’ to reject the view of intersexed bodies as disordered (Human Rights Watch 2017; American Pediatrics Association 2016, Reis 2012). On the other hand, Ellen Feder (2009, 225) contends that terms like ‘difference’ and ‘variation’ do not “permit appreciation of the genuine health challenges faced by many individuals with intersex conditions,” arguing that using ‘disorder’ need not mean we view the intersex individual as disordered. In

short, the terminology used to describe intersex conditions is still a matter of contention, but has evolved considerably since the “Age of Gonads.”

Another aspect that has changed considerably over time is the attitude of physicians towards intersexuality. Intersex individuals were first looked upon in the nineteenth-century as “willingly deceptive” and “insincere,” while later physicians looked empathetically upon their intersex patients (Reis 2012, 153). As we shall address in more depth in the next section, the initial instinct for twentieth century physicians, many of whom were driven out of this sense of empathy, was typically to correct the ‘problem’ of intersex. The use of the term ‘corrective’ (or others like it) is extremely controversial in intersex healthcare practice, but also understandable coming from a physician’s point of view. If physicians are ethically encouraged to provide care and do no harm, corrections for those that are gender atypical can be read as a challenge to the self-directed humanity of the individual.

## Intersex in Recent History of Ethics

In the mid-twentieth century, we move into what Dreger (1998b, 348) calls the “Age of Surgery,” driven by the work of John Money and his colleagues at Johns Hopkins. Clinical psychologist John Money (1921–2006) specialized in sexology and was an early advocate for the study of sexual identity and the biology of gender. Highly esteemed by LGBT persons in the 1970s for his efforts on behalf of trans individuals seeking gender affirmation surgery (then called sexual reassignment surgery), he was also an early advocate for LGBT rights. Money founded the Gender Identity Clinic at John Hopkins University in 1966. He was profoundly influential in establishing the standard of care (SOC) for intersex individuals (Human Rights Watch 2017). Until the late 1990s, the SOC for intersex people

with atypical genitalia was to intervene through cosmetic surgery as soon as the infant was born. Even now, a large percentage of physicians in the US prefer this option to alleviate trauma on the family – not singularly the intersex child (Human Rights Watch 2017). We might call this the Money Model. Ethicists, particularly in the last few decades, have questioned this model, asking: What would it hurt or who would it harm if an infant had ambiguous genitalia and we waited to intervene until the child could have a say and consent?

A well-known case that Money was involved in is known as the case of Joan/John, where a circumcision went wrong for a male infant and the parents were told they should allow Money to alter the child’s genitalia and gender to female. The parents agreed, and a ‘sex-change’ operation was performed on him, a process that involved clinical castration and other genital surgery when he was a baby, followed by a 12-year program of social, mental and hormonal conditioning to make the transformation take hold in his psyche. The case was reported as an unqualified success, and he became one of the most famous (though unnamed) patients in the annals of modern medicine.” Born John, the child was raised as Joan. (Colapinto 1997, 55.) Milton Diamond and Keith Sigmundson later interviewed John, who later identified as male after learning the truth about his medical history. During the interview, he stated, “It was like brainwashing, I’d give just about anything to go to a hypnotist to black out my whole past. Because it’s torture. What they did to you in the body is sometimes not near as bad as what they did to you in the mind – with the psychological warfare in your head.” (Colapinto 1997, 57.) Diamond and Sigmundson published an article about the Joan/John case in the March 1997 edition of the *Annals of Pediatric and Adolescent Medicine*, challenging the case’s “unqualified success” and setting off a fierce debate about the practice of sexual reassignment (and the secrecy and hormonal therapy that accompanied it) for individuals with ambiguous genitalia. (Ibid.)

Despite the fact that John's atypical genitalia were the result of a botched medical procedure rather than a congenital intersex variation, his case is a major one in the history of intersexuality. Looking back on it provides a launching point from which to consider what *not* to do when treating intersex patients, a process aided by Sigmundson and Diamond – a child psychiatrist and renowned sexologist, respectively – with their publication of the Joan/John case. According to John Colapinto, who wrote about the case for the Rolling Stone Magazine:

[Sigmundson and Diamond's] paper, powerful as it was as anecdotal evidence of the neurobiological basis of sexuality, was also a clear warning to physicians about the dangers of sexual reassignment – and not just for children like John, who are born with normal genitals. Diamond argued that the procedure is equally misguided for intersexual newborns, since physicians have no way of knowing in which direction, male or female, the infant's gender identity has differentiated. To stream such children, surgically, into one sex or the other, Diamond argued, is guesswork that consigns a large percent of them to lives tortured as [John's]. (Colapinto 1997, 57.)

Further support for a neurobiological basis of gender – as opposed to the purely social model espoused by Money – came from Bill Reiner, a child psychiatrist and former pediatric urologist who wrote an editorial in support of Milton and Diamond's paper (Colapinto 1997). In a study launched in June 1995 at the Johns Hopkins medical center, Reiner followed the lives of sixteen people with reassigned gender, focusing on sex genetic males born without penises who underwent castration and were subsequently raised as girls. By the time Reiner wrote his editorial, all six girls were “closer to males than females in attitudes and behavior” and two “spontaneously (without being told of their XY male chromosome status) switched back to being boys” (Colapinto 1997, 58). In recounting the children's unequivocal assertion that they were in fact boys, Reiner

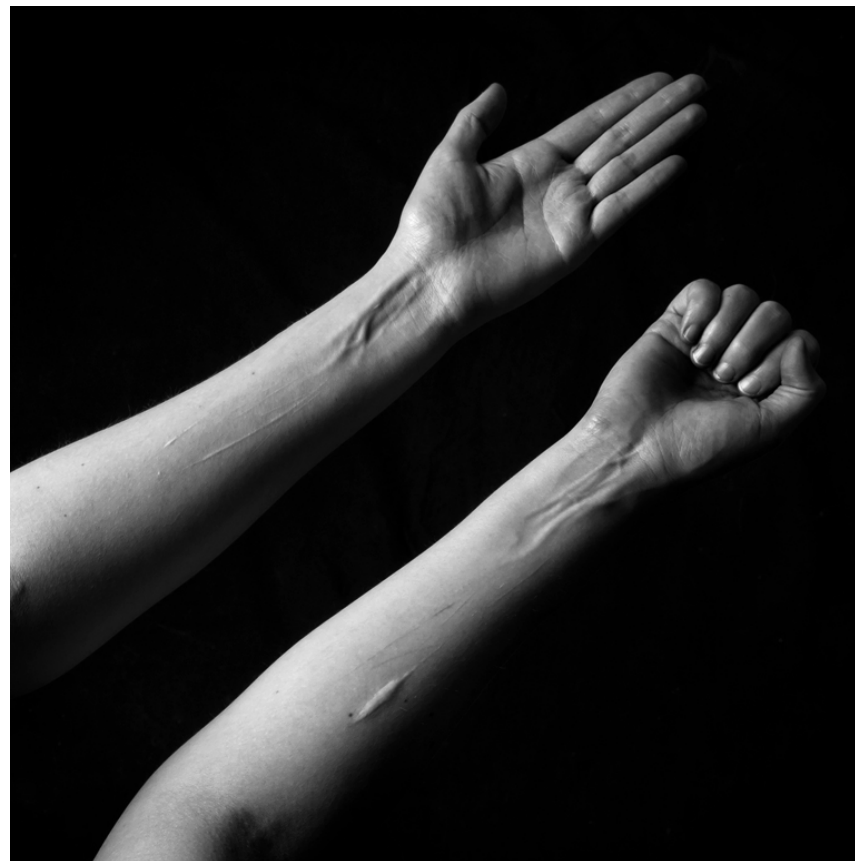


IMAGE: Ami Koiranen: Kehon muisti, nro 2.

pointed “to the parallel between the children [he studied] and Joan Thiessen, who also ‘knew,’ against all evidence to the contrary, that she was a he” (Colapinto 1997, 59).

The case of Joan/John, then, began to raise serious doubts about the ethical and scientific foundation of the Money Model. It is possible to give Money the benefit of the doubt and assume that he believed he was acting in the patient's best interests – indeed, the vast majority of genital



surgeries performed on intersex individuals were done under the reasoning that such procedures would prevent confusion, ridicule and psychological trauma later in life (Dreger 1998b). Ironically, the testimonials from the many intersex people that told their stories beginning in the late 1990s show that they frequently experienced such confusion, ridicule, and trauma as a *result* of the medical treatment of their atypical genitalia (Dreger 1998a). In the absence of data supporting the fact that such surgeries are beneficial, it is necessary to ask if they can be considered ethically sound. In other words, is it possible to justify performing sexual reassignment through cosmetic surgery and hormonal treatments without the patient's knowledge and consent (the Money Model)? We, along with Diamond and Alice Dreger, suggest that it is not. Cases like that of Joan/John should make us take one step back, and consider how to honor the gender of the individual regardless of whether they have ambiguous genitalia or other intersexual features.

Alice Dreger has been perhaps the academy's fiercest advocate supporting those with intersex conditions. In her article "Ambiguous Sex—or Ambivalent Medicine? Ethical Issues in the Treatment of Intersexuality," she questions the ethical foundation of dominant treatment protocols for intersex children. She states that, "Many parents, especially those unfamiliar with sex development, are bothered by their children's intersexed genitals and receptive to offers of 'normalizing' medical treatments. Many also actively seek guidance about gender assignment and parenting practices." (Dreger 1998a, 27). She goes on to describe how the common procedure in the United States is to normalize the child's genitalia and follow-up with years of hormonal therapies and psychological counseling – in other words, the Money Model. The continual problem is that the gender lies in the hands of the physicians rather than the child. If there is no life-saving medical necessity to intervene, then is there any real reason not to let the child decide about their gendered and anatomical future at an appropriate

age? What that appropriate age might be, of course, is an important ethical question that we address in more detail later.

Dreger urges the adoption of an ethically pragmatic as well as an ethically sensitive approach to the dilemma of intersex youth. She urges us to examine two features: "One is that intersexual must not be subjected to different ethical standards from other people simply because they are intersexed and second being that because the experiences and advice of adult intersexuals must be solicited and taken into consideration" (Dreger 1998a, 34). In collaboration with the Intersex Society of North America (ISNA), Dreger offers a chart that shows two paradigms of intersex treatment: a *concealment-centered model* and a *patient-centered model*. Using these models, she addresses the question of whether intersexed genitals (and by extension intersexed persons) are a medical problem. Her answers to this question, according to each paradigm, are as follows:

– *The concealment-centered model*: "Yes. Untreated intersex is highly likely to result in depression, suicide, and possibly 'homosexual' orientation. Intersexed genitals must be 'normalized' to whatever extent possible if these problems are to be avoided."

– *The patient-centered model*: "No. Intersexed genitals are not a medical problem. They may signal an underlying metabolic concern, but they themselves are not diseased; they just look different. Metabolic concerns should be treated medically, but intersexed genitals are not in need of medical treatment. There is no evidence for the concealment paradigm, and there is evidence to the contrary." (Dreger ISNA 2008.)

As Dreger demonstrates, the *concealment-centered model* aims to treat parents' psychological distress caused by the birth of an intersex child by 'fixing' the problem using "surgical, hormonal and other technologies" (Dreger and ISNA 2008). Instead, the *patient-centered model* advocates for

providing comprehensive psychosocial support and “as much information as they can handle. True medical problems (like urinary infections and metabolic disorders) should be treated medically, but all non-essential treatments should wait until the person with an intersex condition can consent to them.” (Dreger & ISNA 2008.)

From looking at these two models ethically, we contend that the *patient-centered model* is the best course of action. When physicians take an oath for their patients to do no harm they must commit to that value. Allowing the patient to have a choice in regards to their genitalia and gender reinforces how vital their physiological well-being is attached to their corporeal selfhood. In a 2004 article titled, “Health Care Professionals and Intersex Conditions” we see the patient-centered approach endorsed by a multidisciplinary group convened by the Hastings Center. They highlight the lack of physiologic and psychosocial justification for treating intersexuality with early surgery and subsequent drug/hormonal treatments, noting that the initial “surgeries may beget more operations in order to correct problems arising from those performed previously” while drugs may “further alter the child’s appearance and/or mood, again without the individual’s consent or sufficient rationale” (Frader et al. 2004, 426-427). They conclude that “[a]vailable data do not provide adequate reasons for using surgery in most cases before the child has the developmental capacity to participate in decision making” (Frader et al. 2004, 427). Although this article is evidence of a shift towards a patient-centered treatment model, we still see surgeries on infants with intersex conditions. A recent report by Human Rights Watch and interACT, an advocacy organization for intersex youth, argues that “there have been changes in practice in recent years, with many doctors advising against surgery on infants and young children. But even so, surgery continues to be practiced on children with atypical sex characteristics too young to participate in the decision” (Human Rights Watch 2017). Thus, the

*concealment-centered model* still persists, leading to the need to continue examining the ethics of intersex interventions. In turning the case of ovotestes in the next section, we hope to respond to that need by examining one of the least common intersex variations.

### Case Example: The Ethics of Interventions for Ovotestes

As stated in the introduction, we choose to focus on ovotestes both to demonstrate the relevance of our preceding discussion of ethics and history and to shed light on the specifics of one of the intersex spectrum disorders. Ovotestes occurs in 2–10% of all intersex conditions. It is one of the rarest of all intersex conditions; it has an approximate incidence of less than 1/20,000. More than 500 affected individuals have been reported (Vilain 2016). Individuals with ovotesticular conditions are born with ovarian as well as testicular tissue. Some have the chromosomal make up of 46,XX and some 46,XY, with 46,XY being the rarer of the two (Simpson 2011). For a useful overview of different variations of chromosomal complements, gender of rearing, and gonadal tissue distributions, see the chart widely available in Joe Leigh Simpson’s 2011 article titled “True Hermaphroditism.”

While many different variations exist in ovotesticular intersex diagnoses, we are going to focus on the most common: 46,XX with ambiguous genitalia. While professional recommendations for diagnosis and prognosis for this condition vary, we turn to Dayal and O’Hern (2017) who write:

Ovotestes are the most frequent gonad present (60%), followed by the ovary and then the testis (9%). The ovotestis tends to be anatomically located in an ovarian position, in the labioscrotal fold, in the inguinal canal, or at the internal inguinal ring. Ovaries, when

found, can occupy the normal abdominal position, although they may occasionally be found at the internal inguinal ring. Interestingly, ovaries occur more commonly on the left side than the right. The reason for this predilection is unknown. Testes are usually found in the scrotum, although they can be found at any level along the path of embryonic descent from abdomen to scrotum, frequently presenting as inguinal hernias. (Dayal and O'Hern 2017)

About 20% of ovotesticular disorders are diagnosed under the age of 5 (Dayal and O'Hern 2017). Given the prognosis of an individual with ovotesticular disorder, there is no immediate need to intervene in these cases. Gonadal tumors with a potential for malignancy only occur in 2.6% in all cases of ovotesticular disorder (Dayal and O'Hern 2017), an incidence that does not justify the need for immediate surgical intervention.

As discussed previously, surgery was historically the first intervention in intersex cases and became the standard of care beginning in the 1960s. Partially due to many individuals coming forward later in life and stating they wished they had been given the choice to choose their gender and anatomical features, surgery has come to a pause at many places. When surgery was performed, decisions about gender assignment and whether to construct a penis or a vagina were based exclusively on the surgeon's ability to 'successfully' create one or the other. We see this approach in the 1988 article from Luks et al., titled "Early Gender Assignment in True Hermaphroditism." According to the authors, "Predilection for the female gender is based primarily on the ability to reconstruct a functionally satisfactory genital anatomy. [...] Gender assignment can be based on the development of external genitalia alone" (Luks et al. 1988, 1122). In another article titled "Surgical Treatment of Intersex disorders" from 1995, we see a similar conclusion: "The basis of surgical treatment of intersex disorders is not to coordinate the phenotype and the genotype, but rather to form the external genital organs which will be of the appropriate

appearance and which will allow functional sexuality. It is much easier to create a vagina as a passive organ than an erectile phallus with sufficient dimension. Therefore, the authors suggest that most such infants be reared as females." (Krstić et al. 1995, 1273.) In other words, Krstić et al. and Luks et al. subscribe to the harsh doctrine euphemistically invoked by many surgeons who treat intersex conditions: 'It is easier to dig a hole than build a pole.'

In contrast, we argue that medical professionals should not choose the gender of an infant with an ovotesticular condition (or other intersex variation) gender due to the fact that the genitalia appear more male or female or whether a penis or vagina is possible to create surgically. In support, according to another leading source: "The patient and family must be provided with psychological support. Other treatments primarily involve hormone replacement. The need for and timing of surgical treatment is complex, depending on sex assignment and gonadal configuration. Management needs to balance the risks and benefits of gonadectomy and reconstructive surgery" (Ahmed et al. 2014). The Intersex Society of North America (2008) similarly emphasizes waiting to do gender reassignment surgery until the individual can consent to the procedure themselves. Dreger's patient-centered model also advocates for waiting to perform surgery, assigning gender at birth after hormonal, diagnostic, and genetic tests have been done and the parents have had the chance to speak with other parents of intersex children. The recommendation to assign a male or female gender is justified "because assigning an 'intersexed' gender would unnecessarily traumatize the child" (Dreger and ISNA 2008). All involved must remember, however, that the gender assigned to an ovotesticular infant "as with assignment of *any* infant, is preliminary" (Dreger and ISNA 2008). The baby may develop a different gender identity later in life, and we should consider, as we do below, how best to support youth with ovotesticular conditions as they go through this process.

It is necessary to address the needs of youth with ovotesticular disorders, as 75% of those diagnosed are under the age of 20. On a national level in the United States, we can learn from Germany, which passed a law in 2013 raising public awareness about intersexuality and legally recognizing intersex people. They recommend not performing surgery unless medically necessary and letting parents leave the gender on the child's birth certificate blank (Fong 2014). In the spirit of best and most humane care in domestic medicine, American pediatricians should follow the same guidelines and practice. Parents could still follow Dreger's guidelines and assign their infant a gender, but leave that section of the birth certificate blank in order to allow their child to affirm or reject their birth gender later in life. In the clinic, providers should strive to be honest and respectful in their interactions with young people with ovotestes (and intersex youth more generally); they should give full information, letting go of the secrecy of the past. A major question that remains is the proper timing of interventions, particularly the appropriate age of consent for irreversible medical/surgical treatments.

Sufficiently parallel to be useful in answering the question of consent are the cases of transgender youth consenting to hormonal and surgical interventions for sexual reassignment. In doing so, it is important to acknowledge Dreger and April Herndon's (2009, 213) warning that "intersex experiences and advocacy may become muddled, co-opted, or misguided in the conflation of transgender and intersex". We do *not* argue that intersex and transgender are synonymous; they possess different etiologies and differ in other important ways. Nevertheless, Dreger and Herndon (2009, 213) contend that "there are also reasons for intersex and trans advocates to unite". So too, for clinicians treating intersex and transgender youth. Indeed, the Human Rights Watch report (2017) states that some practitioners draw on insights from transgender care when dealing with intersex patients and their families. In terms of who is old

enough, the ethics of intersex and transgender body modifications bear striking similarities to the long historical questions surrounding age-of-consent laws related to neighboring fields in youth health such as sexual activity, reproductive choice, and preventative health care. Although there is not an exact age set in stone for consent, one approach (of course, if medically acceptable) is to wait until the age of majority, which is 18 in most but not all jurisdictions. But increasingly we are allowing and seeing teenagers and pre-pubescent youth capable of (and perhaps urgently ready for) self-consent – always when their parents/guardians are in support, and often when not.

The motivations for intersex and transgender care are the same: to affirm the young person's gender identity and help them realize psychological and physical wellbeing. In a recent *New York Times* article titled "Hannah Is a Girl: Doctors Finally Treat Her Like One," Jack Turban states:

Over the past few years, it has become clear that if we support these children in their transgender identities instead of trying to change them, they thrive instead of struggling with anxiety and depression. Hannah is using a puberty-blocking implant and getting ready to embark on the path of developing a female body by starting estrogen. Ten years ago most doctors would have called this malpractice. New data has now made it the protocol for thousands of American children. (Turban 2017.)

Hannah underwent a social transition at the age of 10, meaning she started dressing like a girl and changed her name. Stories like hers are reasonably common; transgender people are happier when they are empowered to live according to their gender identity. While guidelines for transgender care express caution about jumping into gender affirming surgery for early adolescents, or adolescents at all, they emphasize giving the child the free choice to express who they feel they truly are (Human Rights Watch

2017). We should strive to give intersex children and adolescents a similar amount of free choice.

The long-term health effect for intersex, trans, and non-cis gender youth who are not provided pre-adult autonomy is striking. Suicide rates and depression are extremely high for transgender youth and so too for those intersex individuals who feel they have been wronged by unwanted or unasked-for corporeal alterations (John of the Joan/John case eventually committed suicide). The *New York Times* article goes on to state, “Once transgender youth hit puberty, their gender identity is unlikely to change. At that point, doctors often consider medical interventions (Turban 2017). They usually begin with a puberty blocker, which accomplishes two goals: allow the adolescent to spend more time exploring their gender nonconformity and prevent the development of irreversible secondary sex characteristics (Human Rights Watch 2017). The effects of such blockers are fully reversible (Human Rights Watch 2017). When the adolescent is older, practitioners may initiate cross-sex hormones like estrogen or testosterone, the effects of which are partially reversible (Human Rights Watch 2017). Finally, irreversible gender-affirming surgery often follows in young adulthood (Turban 2017).

Though it depends on the specifics of the intersex variation (and, of course, the individual’s gender identity), the treatment stages for many intersex conditions are similar to those described above for transgender youth. Intersex individuals should be under the same guidelines and moral principles as those for transgender youths – which (as previously stated) often and rightfully follow the elasticity of age-of-consent protocols for sexual activity, reproductive choice, and minor-status autonomy. While we do not endorse a specific age of consent for irreversible cosmetic surgery in intersex individuals – it is a difficult ethical question that requires more analysis elsewhere – we enthusiastically support promoting the autonomy of intersex youth. Given the complexities of the categories of gender, sex,

bodily anomaly, and maturity for youth, any bioethical recommendation for intersex children that does not allow for the possibility of honoring a best, self-directed future body and self is intellectually naïve at best and ethically scandalous at worst.

## Ethical Principlism and Intersex Interventions

In the preceding section, we discussed the ethics of treating ovotestes in the clinic, responding to queer bioethics’ call for doing good clinical ethics for intersex people. We now extend our discussion of queer clinical ethics by briefly taking a principlist approach to intersex interventions. Whatever side one takes on the matter of medical interventions for DSD, no one argues that intersex youth should be traumatized by their medical treatments. Likewise, few argue that surgery should *never* be performed on intersex bodies. The disagreements are over *when* and under *whose* request. And the supremacy of the intersex child (his/her/their autonomy) should, in our opinion, always supersede the dilemma of parental comfort/discomfort of the child’s somatic and gendered status. Better avenues to rectify the Money Model would be counseling for parents, child, and healthcare providers. Better avenues for a child born with an intersex condition would be to embrace the child’s individual “healthiness” – rather than the child’s normality/abnormality.

The classic bioethical principles to consider are respect for autonomy, justice, non-maleficence, and beneficence (Beauchamp and Childress 2001). Justice is a “group of norms for distributing benefits, risks, and costs fairly” (Beauchamp and Childress 2001, 342). Though it could reasonably and importantly be used in regards to insurance coverage for intersex interventions, autonomy, beneficence and non-maleficence are the most pertinent principles to consider for our purposes. The practice of delaying surgery on intersex infants/young children and instead providing

counseling is supported by the principle of non-maleficence (do no harm) and beneficence (do good); the available data and narratives from intersex individuals suggest that this approach avoids the harms of early surgery and promotes good by addressing psychosocial discomfort in an appropriate manner. In regards to autonomy, the canonical bioethics literature states:

For a person to be autonomous in the sense of directing her own life in accordance with her own desires and values. This approach has primarily focused on what criteria must be met for a person's desires and values to be her 'own' in the sense required for her to be autonomous with respect to them, rather than to be alienated from them or else merely possessing them agentially, as a small child might possess her desires. (Taylor 2015.)

Of course, the age variable complicates intersex issues, and is an area for future discussion. Nevertheless, we believe the principle of autonomy for the intersex child holds the supreme value in this bioethical argument – over familial strife, parental trauma, or the expectations of gender-normativity at an earliest (or any) age.

In closing, we gesture to the well-known chart entitled Making Ethical Decisions about Surgical Interventions Tool Applied to Gender Ambiguity in the Infant. The chart, created by Lathrop et al (2013) and published in their article “Ethical Decision-Making in the Dilemma of the Intersex Infant” is not an exhaustive tool, but a wise and helpful one as we maneuver the field of queer bioethics for one of its first and most vulnerable citizens: the intersex child. It outlines a series of steps to go through after the birth of an intersex infant – a roadmap for making an ethical decision about gender assignment surgery.

As the chart mentions, parents often experience strong emotions of fear, shame, and shock when they learn their newborn is intersex. One major

area for future work is considering how best to support parents through these emotions so they can reach a medically and ethically appropriate decision. Which support services are most useful – social workers? Psychologists? Other parents of intersex children? Similarly, we should consider the nuances of providing medical care to intersex individuals throughout their lives. How should health care professionals conduct conversations with intersex people and their families? And as we have asked in several instances in this paper, at what point should intersex adolescents be able to consent to gender affirming surgery? These questions are evidence of the opportunity for further research and scholarship in the regards to the treatment of intersex individuals in the clinic. For its part, this paper has provided a rich overview of the current scholarship on intersexuality and addressed the particulars of one of the rarest intersex variations: ovotesticular disorders. As with all other intersex individuals, people with ovotestes should be granted autonomy over their bodies, including delaying surgery until they are old enough to pursue or reject it for themselves. Only when we uphold the rights of intersex people to bodily integrity and self-determination are we fully living up to the ideals of queer bioethics.

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