

# Intersex Management in the United States and Non-Western Cultures

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In Western nations, there is growing agreement about ethical approaches to clinical intersex management. At the same time, as Western-trained physicians increasingly encounter intersex patients in other parts of the world, new ethical tensions arise. Which cultural values are fair parameters for gender-assignment decision-making, particularly in cultural milieus where there is social and economic inequality between the sexes? How can physicians uphold universal bioethical principles while remaining

culturally sensitive? Physicians have a primary commitment to patient beneficence and universal human rights, requiring physicians to promote concordance between the child's assigned gender and his or her likely future gender identity. Ultimately, the potential patient distress posed by gender dysphoria fundamentally outweighs the influence of local cultural factors such as economics, gender politics, and homophobia.

## INTRODUCTION

We live in a sexually dimorphic reality, where one is required to choose either male or female when filling out everything from census questionnaires to voter registration forms. Likewise, medical records neatly report sex as male or female. Yet significantly many babies are born each year with ambiguous genitalia, an unclear sex assignment, or both, leading some to argue that gender is truly a continuum, not a binary. According to the Intersex Society of North America, 1 percent of babies physically differ from "standard male or female" (ISNA, "How Common Is Intersex?"), while 0.1 to 0.2 percent of babies require medical intervention and surgery to "normalize" their genital appearance (ISNA, "How Common Is Intersex?").

Such genital ambiguity can be caused by a variety of disorders of sex development, including congenital adrenal hyperplasia (CAH), androgen insensitivity syndrome, and 5-alpha-reductase deficiency. Congenital adrenal hyperplasia is characterized by increased production of androgens, resulting in the genital virilization of chromosomal females. Meanwhile, genotypic males with androgen insensitivity syndrome have cells that cannot respond to androgens, hindering the development of normal male genitalia and the later expression of male secondary sex characteristics during puberty. And in 5-alpha-reductase deficiency, genotypic males have difficulty converting testosterone to dihydrotestosterone (DHT). Because DHT is a more potent androgen than testosterone, this deficiency means that affected neonates are often born with ambiguous or feminized genitalia. However, at puberty increased testosterone levels may lead to sufficient generation of DHT to promote subsequent masculinization (PubMed Health, "Intersex").

For many of these intersex patients, complex decisions must be made to determine the appropriate gender of rearing and whether to pursue "corrective" genital surgery. Such decision-making raises ethical issues, including the roles of the various actors involved (physicians, parents, and

patients), as well as which parameters are appropriate to take into account during this process. Other ethical concerns include the patient's right to bodily integrity, informed consent, and disclosure of his or her intersex status.

In the United States and other Western nations, clinical management of intersex infants has evolved significantly over the past half century. Harsh critiques by adult intersex activists and an enhanced scientific understanding of gender-identity formation have contributed to a greater appreciation of the ethical issues involved in gender assignment. At the same time, as Western-trained physicians increasingly encounter intersex patients in other parts of the world, new ethical tensions arise. Which cultural values are fair parameters for gender-assignment decision-making, particularly in cultural milieus where there is social and economic inequality between the sexes? And how can physicians uphold universal bioethical principles while remaining culturally sensitive in such settings?

## INTERSEX MANAGEMENT IN THE UNITED STATES

According to historian Alice Dreger, for most of modern Western history intersex people were integrated into the general population, adopting either a male or a female identity in accordance with binary gender norms. They maintained their ambiguous genitalia without significant psychological harm or social stigma. However, by the late 1800s the mounting anxiety over homosexuality—"abnormal" sexual behavior—led physicians to pay increasing attention to "abnormal" genitalia and perform corrective surgeries; these included surgeries for enlarged clitorises and hypospadias (in which the urinary hole is in an abnormal location in males) (Dreger & Herndon, 2009).

Still, corrective surgeries did not become the medical norm until the 1950s, when Johns Hopkins psychologist John Money and colleagues developed the "optimum gender of rearing" model. This model posited that children were

born gender neutral and that gender identity was a result of upbringing rather than genetics or hormone exposure; thus, intersex children with an assigned sex and corrective surgery to match this assignment (before age 2) would successfully adopt this gender identity. Physicians largely determined the child's "true" sex with limited input or informed consent from parents; further, often the patient was never informed of having been born intersex, in order to limit possible psychological distress (Dreger & Herndon, 2009).

For several decades beginning in the 1950s, clinicians were biased toward female gender assignment, as it was easier to fashion a vagina than a "reasonably sized" penis. In other words, a primary value was placed on genital aesthetics and the ability functionally to penetrate or be penetrated (Dreger & Herndon, 2009). For a penis to count as functional, surgeons expected it to have the ability to become erect appropriately and be a conduit for urination and ejaculation. In contrast, surgeons at that time believed that a vagina merely needed to be a hole large enough to fit a penis, as it was not expected to be self-lubricating or sensitive to sexual stimulation. As a result, a large number of intersex infants were assigned female (Dreger, 1998), as "it's easier to make a hole than build a pole" (Gorman & Cole, 2004).

This bias toward female assignment is evidenced by the famous John/Joan case—Money's prototypical success story for the "optimum gender of rearing" model. Baby John, one of two identical twin boys, had his penis damaged during a botched circumcision, so Money and colleagues decided to transform John surgically into Joan. Joan was raised as a girl, and Money reported in the medical literature that the sex reassignment had been successful (Fausto-Sterling, 2000a). For example, in 1975 Money wrote that no one would ever suspect that Joan was born a boy: "Her boyish behavior is so normally that of an active little girl, and so clearly different by contrast from the boyish ways of her twin brother, that it offers nothing to stimulate one's conjectures" (Kipnis & Diamond, 1998). Money's work seemingly provided scientific evidence of the malleability of gender identity at a young age.

However, in the mid-1990s sexologist Milton Diamond followed up with Joan, and he discovered that Joan had in fact consistently identified as male since her youth. Joan preferred boys' toys, activities, and clothing, and at age 14 she decided to transition formally back to the male gender (Diamond & Sigmundson, 1997). The publication of Diamond's findings discredited the claimed success of Money's gender-reassignment protocol, in the process debunking the theory of gender neutrality and pliability at birth.

Around this time, adult intersex patients who had been subjected to sex-reassignment surgery as children began publicly to criticize the clinical management of their condition. This coincided with the burgeoning of the intersex activist movement, spurred by Cheryl Chase's 1993 founding of the Intersex Society of North America (ISNA) (Chase, 1998).

In her 1998 article "Hermaphrodites with Attitude," Chase recounts that as a teenager she realized she had no clitoris and was incapable of reaching orgasm, but she never understood why. After obtaining her medical records, Chase learned in her twenties that she was a "true hermaphrodite" (Chase, 1998) and had been raised as a boy for a year, until a clitorectomy was performed and she was reassigned as female. Along the way, Chase's doctors not only had failed to disclose her medical history to her, but had actively obstructed her efforts to obtain her own medical records. Chase relates her emotional turmoil upon discovering her intersex past: "To myself, I was a freak, incapable of loving or being loved, filled with shame about my status as a hermaphrodite and about my sexual dysfunction" (Chase, 1998).

As a result of the experiences of Chase and her allied intersex activists, the ISNA currently advocates complete disclosure to intersex patients, as well as gender assignment at birth *without* surgery. The ISNA explains, "Genital 'normalizing' surgery does not create or cement a gender identity; it just takes tissue away that the patient may want later" (ISNA, "What Does ISNA Recommend?"). The ISNA asserts that such surgery on young children causes irreversible damage and denies them agency regarding their own bodies. Instead, the ISNA believes that corrective surgery is permissible only once the child is old enough to decide with fully informed consent (ISNA, "What Does ISNA Recommend?").

Other writers maintain that intersex individuals should be able to legally proclaim a third, hermaphroditic, nonfemale/nonmale gender identity. On passports Australia permits individuals to label themselves "X," which stands for unspecified sex or intersex. And the Australian state of Victoria issues birth certificates with the sex listed as indeterminate/intersex (Meyer-Bahlburg et al., 2004).

While the ISNA claims to speak on behalf of the general intersex community, in reality intersex adults express a variety of opinions about appropriate clinical management policies. For example, in a 2004 study surveying 72 adult intersex patients in the eastern United States, 15 percent believed that a third gender category should be available to children with ambiguous genitalia. And 33 percent of those surveyed agreed that intersex children should not undergo corrective surgery before they are able to give fully informed consent. In contrast, 47 percent of respondents stated that in hindsight, they felt that their corrective genital surgery should have occurred during infancy. There is little agreement within the adult intersex community about the appropriate timing of surgery; this lack of consensus underscores the ethical uncertainty inherent in the medical management of intersex infants (Meyer-Bahlburg et al., 2004).

One of the most fraught ethical concerns centers on the rights of parents versus intersex children to make clinical decisions about genital corrective surgery. Because young children generally lack decision-making capacity, U.S. law recognizes the parental right to make medical decisions on their behalf. This parental agency assumes that parents

know their children best and will act in their best interests. However, in the case of intersex children, parents may not always be the best arbiters. For example, the existence of congenital birth defects (such as ambiguous genitalia) may hamper early parent-child bonding, and societal stigma and emotional distress may bias parents toward early corrective genital surgery (Lloyd, 2005).

Such parental medical decision-making rights are not absolute, and under the doctrine of *parens patriae* courts can intervene to prevent death or serious harm to the child. For example, most states restrict parents from sterilizing their children, as a person's right to make decisions concerning reproduction is constitutionally protected. Similarly, per 1996 Congressional legislation, parents are prohibited from consenting to female genital cutting of their daughters as part of cultural rituals. This law was passed under the auspices of protecting a child's right to bodily integrity. By extension, some argue that corrective gender-reassignment surgery in intersex children is likewise a violation of their bodily integrity and reproductive rights, particularly because the surgery may impair reproductive ability or sexual sensitivity (Lloyd, 2005). Historian Alice Dreger explains:

While it is easy to condemn the African practice of female genital mutilation as a barbaric custom that violates human rights, we should recognize that in the United States medicine's prevailing response to intersexuality is largely about genetic conformity and the "proper" roles of the sexes. Just as we find it necessary to protect the rights and well-being of African girls, we must now consider the hard questions of the rights and well-being of children born intersexed in the United States. (Dreger, 1998)

As a result, some camps have called for a complete moratorium on normalizing genital surgery in intersex children. Others maintain that enhanced parental informed consent is adequate; in other words, as long as physicians fully explain what "intersex" means, as well as various aspects of the surgery (alternatives, ethical issues, risks, and whether it's medically necessary), parents should make the ultimate call. And others have criticized such "all-or-nothing" approaches (Muckle, 2006). Instead, they call for the involvement of hospital ethics committees and consultants in bringing together physicians and parents to determine the best interests of the child, on a case-by-case basis (Muckle, 2006). While this approach represents a pragmatic middle road, the availability and utility of ethics consultants or committees, particularly ones with expertise in intersex issues, vary considerably among hospitals.

In addition to the charged issue of who should have decision-making agency, there is considerable ethical debate concerning the parameters and values within which it is ethically permissible to make such decisions. For example, should concerns such as potential societal stigma, shame, or bullying come into play? If keeping a child's genitalia ambiguous would impair child-parent bonding, is this an acceptable reason to pursue surgery? Or do parents have an ethical obligation to overcome their prejudice and care

for their child? What is the relative value of genital aesthetics, reproductive ability, phallic size (in men), ability to be penetrated (in women), and intact erotic sensation? And what are the potential risks that physicians and parents will choose the wrong gender assignment, given the limited scientific knowledge concerning gender-identity formation? Is surgery more acceptable for intersex conditions in which a majority of patients end up identifying as a common gender?

To grapple with the complexities of intersex clinical management, the Lawson Wilkins Pediatric Endocrine Society in the United States and the European Society for Pediatric Endocrinology organized the International Consensus Conference on Intersex. This conference included more than fifty international experts on intersex management and compiled their responses into a consensus statement, published in 2006 in *Pediatrics*, the official journal of the American Academy of Pediatrics (Lee, Houk, Ahmed, & Hughes, 2006).

The consensus statement strongly supports gender assignment as male or female, after a detailed examination of the baby by a multidisciplinary team of physicians. It emphasizes the importance of mental-health support from psychologists and psychiatrists, as well as the utility of support groups and medical ethicists. It also endorses complete medical disclosure to both parents and patients. And while the document supports parental decision-making rights, it maintains that patients should have input once they are "sufficiently developed for a psychological assessment of gender identity" (Lee et al., 2006). Accordingly, if a child experiences gender dysphoria and insists upon a gender transition, this desire should be respected. The goal of clinical management is not only gender assignment and normalized genital appearance, but also ensuring patient quality of life—which encompasses the ability to form intimate relationships, and sexual functioning and sensation. It follows, then, that clitoromegaly should result in surgical intervention only in cases of severe virilization; in such instances, surgery should prioritize preserving erectile ability and innervation of the clitoris, rather than strictly cosmetic normalization.

In contrast, in the United States, precedence was historically given to cosmetic correction, to limit stigma and teasing and facilitate improved parent-child bonding. The *Pediatrics* consensus statement debunks the scientific validity of this alleged enhanced bonding, and it charges medical staff to minimize shame and stigma, for example by taking photographs when patients are under anesthesia for a procedure (Lee et al., 2006).

For certain well-studied intersex conditions, the statement makes clear recommendations regarding the optimal gender of rearing. For example, it advises that markedly virilized 46,XX infants with CAH be reared as female, while an infant with a micropenis should be reared as male. It also notes that 100 percent of 46,XY complete androgen insensitivity syndrome babies assigned female in infancy maintain a female identity; for these patients, it recommends removal

of the testes to prevent malignancy (though this removal can be delayed until adolescence, as malignancy normally does not develop until at least age 14) (Lee et al., 2006).

While many of these recommendations are currently followed, in the clinical setting preserving female fertility is often given higher priority than preserving male fertility. Academics hypothesize that “this difference might be because physicians and parents believe that motherhood is more important to females than fatherhood is to males” (Diamond & Beh, 2008). It is ethically troubling that important clinical decisions are being made based on deep-seated societal gender-role assumptions. And while early disclosure to both parents and patients is now the norm, insufficient psychological counseling and support are still major problems (Diamond & Beh, 2008). This raises the question: is it truly beneficent for physicians to impart potentially psychologically damaging information without giving pediatric patients the tools to process it? The medical establishment has an ethical obligation both to practice disclosure and to help ameliorate any psychological trauma engendered by such disclosure.

#### INTERSEX MANAGEMENT IN NON-WESTERN CULTURES

Although there is growing agreement in the United States regarding the ethical values important in intersex management, it is less clear whether these principles are applicable in non-Western settings. Are “Western” bioethical values indeed fundamentally universal and thus viable in other cultural milieus, where social, political, and economic inequity between the sexes may influence clinical decision-making? How can physicians remain culturally sensitive without abandoning their commitment to informed consent, personal autonomy, bodily integrity, disclosure of medical information, and beneficence? And is it just to take into account extreme societal stigma/shame (including the potential for violence) during the sex-assignment decision-making process?

Physicians treating ethnic Indians living in Malaysia have observed the overriding influence of economic concerns in intersex management. Physician Ursula Kuhnle and colleagues noted that for Indians living in Malaysia, daughters present a major financial burden for the family, as they must pay a dowry; in contrast, sons increase the family’s wealth. For this reason, many Indian families “took off with their ambiguously born child” (Kuhnle & Krahl, 2002) after physicians suggested female sex assignment. Kuhnle and collaborators contrasted this with the behavior of Muslim Malay families, who usually did not object to female sex assignment—presumably due to the increased economic power and independence of Muslim Malay females (Kuhnle & Krahl, 2002).

Similarly, physicians working in India have reported that economic factors profoundly affect intersex clinical management. If a woman is unmarried or divorced, she may be unemployable and reduced to “wretched poverty because of the stigma attached to being single” (Warne & Bhatia, 2006). In other words, she will remain economically depen-

dent on her parents forever. In contrast, single men are able to find jobs and live independently. If an intersex child is raised as an infertile female who does not menstruate, she will not be able to find a husband; even if the family tries to hide her infertility, once the husband discovers the truth this provides grounds for immediate annulment (Warne & Bhatia, 2006).

A pediatric endocrinologist in northern India related how parents of intersex children consistently valued female fertility over sexual function. “These social considerations were ubiquitous, no matter what the religion of the patient” (Warne & Bhatia, 2006). During discussions with the doctor, the parents would typically offer arguments along the lines of: “Doctor, we will have to raise the baby in our society, not yours.” This physician reported that as a result, in India, parents rather than physicians assumed the main decision-making role during sex assignment (Warne & Bhatia, 2006).

Parents of intersex children in India often fear that their children will be kidnapped by the *hijras* if their intersex status becomes public. The *hijras* are males who adopt a female gender identity by having part or all of their genitals removed, in addition to dressing as female (Nanda, 1985). They live in groups apart from mainstream society and are generally stigmatized and viewed suspiciously. The *hijras* traditionally make a living by singing and dancing at public celebrations such as weddings, and they also often engage in prostitution with male customers (Warne & Bhatia, 2006). The public predominantly believes that *hijras* kidnap intersex infants to “claim” them, yet there is scant evidence to support this superstition. Still, on occasion the popular press prints allegations about *hijras* kidnapping young boys for sex or prostitution (Nanda, 1985).

Parents may worry that their intersex children will suffer societal discrimination if their condition becomes well known. Indian physicians explain that “this kind of discrimination is real . . . and occurs in village communities as well as in sophisticated city environments” (Warne & Raza, 2008). It is important to consider how such extreme parental fear may influence decision-making, especially with respect to the timing of corrective genital surgery that erases any outward sign of sexual abnormality.

Similarly, a 2012 report from Cairo, Egypt, found that economic motives drive a large percentage of families to choose the male gender. Specifically, 60.35 percent of intersex patients are reared as male, because “in Egyptian society, female infertility precludes marriage, which also affects employment prospects” (Shawky & Nour El-Din, 2012). And a 2011 study of intersex children in Port Harcourt, Nigeria, found that the societal importance of males makes it “difficult for parents to accept the fact that there [sic] male babies could be females” (Jaja, Yarhere, & Anochie, 2011). Instead of pursuing clinical intervention, many parents whisk away their children under the pretense that the problem is spiritual rather than medical (Jaja et al., 2011).

In Saudi Arabia the clinical management of intersex infants

is likewise influenced by the economic, social, and political benefits of being male. A strict segregation between the sexes is enforced, and women have limited visibility in public life. Women are not allowed to drive and must obtain the permission of a male sponsor to travel or engage in commerce. In public, they are required to cover themselves in floor-length cloaks and headscarves. Women are prohibited from appearing in court and are relegated to separate stores, restaurants, and offices within companies (Zoepf, 2010). And women gained the right to vote only as recently as September 2011, in part due to the pressure from Arab Spring uprisings (MacFarquhar, 2011).

A 1994 study attributed male gender preference in Saudi intersex management to such economic, social, and cultural factors. An intersex individual reared as an infertile female will be unable to find a husband, causing several social repercussions:

A woman who is not well-educated remains unemployed but in general males are always employed. An unmarried woman lives with her parents. . . . After a certain age, an unmarried woman loses considerable social status. . . . In this community where unmarried males and females are segregated, it is preferable to be an infertile male with an inadequate penis than to be an infertile female with primary amenorrhea and requiring estrogen substitution. (Taha, 1994)

A 20-year retrospective study by Dr. Nasir Al-Jurayyan in a pediatric endocrine clinic in Riyadh, Saudi Arabia, found a high incidence of congenital adrenal hyperplasia in genetic females (46,XX) with ambiguous genitalia, owing to high levels of consanguinity. Out of the 25 XX congenital adrenal hyperplasia patients originally assigned male due to extreme virilization, four (16 percent) refused reassignment to the female gender. In contrast, all of the 46,XY patients reared female accepted physician recommendations to be reassigned as male (Al-Jurayyan, 2010).

Dr. Al-Jurayyan's report relates that once the genital ambiguity is discovered, the clinical team discusses both medical details and the Islamic guidelines for sex reassignment (as promulgated by Saudi Wahhabi religious leaders) with the patient's family. The Wahhabi Islamic guidelines state:

Those who have both male and female organs need to be investigated and if the evidence is more into a male, it is then permissible to treat him medically (by hormones or surgery), to eliminate his ambiguity, and raise him male. If the evidence is more into a female, it is permissible to treat her medically (by hormones or surgery) to eliminate her ambiguity, and raise her as a female. (Al-Jurayyan, 2010)

In contrast, a sex-change operation performed on a "completely developed gender to the opposite sex" is always prohibited. Dr. Al-Jurayyan also conveys the tension between such Islamic religious guidelines and the reality of the "dominating role of male gender in the community," which predisposes families toward male gender assignment.

Al-Jurayyan asserts that such cultural concerns "should not overrule the Islamic Laws which should not be ignored and given a prime consideration" (Al-Jurayyan, 2010).

This preference for males is exemplified by a 1998 paper detailing the psychological aspects of Saudi intersex patients initially reared female; physicians noted the powerful familial pressure to reassign them as male. In one case, though the patient strongly identified as female, when physicians recommended against male reassignment the family members became so upset that they insisted upon prompt discharge from the hospital (Elsayed, Al-Maghraby, Hafeiz, & Tasha, 1998).

This societal male dominance also strongly affects the ease of adjustment to a different gender. Dr. Yasser Jamal, a Saudi surgeon who has performed more than 200 operations on intersex patients, explains that patients normally experience a smooth transition from female to male. In contrast, men often find it difficult to be reassigned as female, as "the restrictions of being female in Saudi Arabia [are] difficult to cope with" (Usher, 2004).

This complex situation for intersex individuals in a society where rights are tied to gender harkens back to the 1843 case of intersex Connecticut resident Levi Suydam. Suydam wanted to vote as a Whig in a close local election; however, only men held the right to vote. As a result, a physician was brought in to determine Suydam's gender. Upon seeing Suydam's phallus and testicles, the physician declared him a male entitled to the franchise—and the Whigs won the election by one vote. But a few days later the doctor discovered that Suydam menstruated regularly, though it's unclear whether at that point he lost his right to vote (Fausto-Sterling, 2000b). This American example sheds light on how cultural context can make gender identity and assignment politically loaded, particularly when rights are tied to sexual anatomy, as they are in Saudi Arabia.

Furthermore, while patient disclosure is a widely accepted norm in American intersex clinical management, some have argued that it may not be optimal in an environment where the family patriarch traditionally holds sole decision-making authority. For example, in 2003 the *Hastings Center Report* published a case study about a 13-year-old intersex boy from an unnamed Middle Eastern country. Though he was originally brought to the hospital for hypospadias, bleeding through the penis, and abnormal breast development, it was soon discovered that the boy was genetically XX and had a uterus and ovaries. He was diagnosed with congenital adrenal hyperplasia and required hysterectomy and oophorectomy (removal of the ovaries) in order to prevent bleeding through the penis (representing menstruation) (Diamond, Systma, Dreger, & Wilson, 2003).

The parents requested that all of the surgeries (for hypospadias, bilateral mastectomy, hysterectomy, oophorectomy, and nephrectomy for a nonfunctioning kidney) be performed at the same time without telling the child of his intersex condition or his female reproductive ability; in other

words, they wanted the patient to be completely left out of the decision-making process. Still, it is clear that the boy did support the mastectomy to “avoid teasing.” The case study also explains that the culture favors males, the parents would have a difficult time accepting their child as a female, and that the child might be at risk for physical harm or murder if he became homosexual. This case presents an ethical dilemma; the surgeon did not feel comfortable operating without the child’s consent, while the family maintained that the father should make this important decision without disclosure to the patient (Diamond et al., 2003).

The ethically contentious nature of this issue is highlighted by the three commentaries published in the *Hastings Center Report* alongside the original case. In his response, pediatric urologist David Diamond delineates the fundamental tension between the patient’s autonomy and the needs of his family. Diamond notes that a “family-centered model” supports the father’s right to make a decision, as it gives the smooth functioning of the family unit the biggest priority (versus the independence of its individual members). For instance, if the child’s reassignment to female would make it impossible for the family to return home due to societal prejudice, this reality should be a factor in decision-making (Diamond et al., 2003).

Meanwhile, ethicist Alice Dreger and pediatric endocrinologist Bruce Wilson vehemently attack the case study’s proposed nondisclosure to the intersex boy. They assert that intersex children have a right to be informed and make important decisions about their bodies, regardless of culture. In other words, children’s genitals are not “an acceptable locale for cultural relativism” (Diamond et al., 2003).

Dreger and Wilson also make an appeal to the pragmatic, explaining that disclosure is necessary given the ongoing nature of intersex clinical management, particularly endocrine management; such disclosure facilitates greater patient cooperation. Moreover, the authors note that this case presents a false sense of urgency about the need to fix the problem. In reality, halting puberty (and its attendant menstruation and breast development) through once-monthly leuprolide injections represents a reasonable way to delay decision-making until the child is mature enough to participate (Diamond et al., 2003). Still, this tactic might face cultural obstacles, such as limited access to hormones and public shame if it were discovered the child still had internal female anatomy.

It is due to this societal prejudice that ethicist Sharon Sytsma maintains that the physicians should accede to the parental request for surgery without disclosure. Sytsma writes that “not performing the surgery means the child will continue to be taunted and suffer almost certain disenfranchisement and rejection, and that he quite possibly will be murdered” (Diamond et al., 2003). However, Sytsma is conflating gender identity and sexual orientation; while the case report indicates that homosexuality is punishable by death, it is less clear if being intersex poses an equal risk of death.

Sytsma also contends that “changing the boy is certainly more within our power than changing his culture, and the surgeries will make it easier for him to thrive in that culture” (Diamond et al., 2003). This assertion presents an ethically slippery slope. In a race-conscious society where being white provides socioeconomic advantages, should we allow parents to have their young children’s skin bleached or Asian eyelids Anglicized? How is it ethical to surgically modify children’s bodies without their consent, on the basis of societal prejudice?

Sytsma goes further by recommending that the child remain male in order to ensure his heterosexuality in a homophobic culture. She draws on research indicating that XX individuals reared male with pre/perinatal and postnatal/pubertal elevated androgens are usually gynephilic. She also asserts that if surgery is not performed the “female hormones may incline him to be attracted to males” (Sytsma, 2006). According to Sytsma, then, the child should remain male because he is likely attracted to females; in addition, surgery should be undertaken to ensure that he does not develop an attraction to males (Sytsma, 2006). Sytsma’s contention is troubling in that it endorses gender assignment and genital surgery to reinforce societal norms concerning sexual orientation. And by performing this surgery, physicians are condoning the homophobia that spurred it in the first place. At what point does the medical establishment become a tool to blunt diversity of sexual orientation and undermine human rights?

In Iran homosexuality is a crime punishable by lashing or death; two gay teenagers were executed in 2005 in the Iranian city of Mashad (Fathi, 2007). To try to eliminate homosexuality from the country, Iran encourages homosexuals to undergo sex-change operations by heavily subsidizing them (Tait, 2007). Is it ethical for physicians to follow in Iran’s footsteps and use surgery to curb homosexuality? At what point does medical intervention stop prioritizing the patient’s best interests and become an agent of social engineering? And what is the distinction between “normalizing” genital appearance and “normalizing” sexual orientation to heterosexuality? Are they fundamentally ethically dissimilar, or is the latter more scandalous to Westerners because homosexuality is increasingly embraced in Western society?

## DISCUSSION

While the clinical management of intersex infants remains fraught with contentious ethical issues, in the United States there is growing agreement about ethical approaches to gender reassignment. The 2006 consensus statement in *Pediatrics* enumerates the important issues to take into account (such as patient quality of life, sexual functioning, and sensation), and it makes specific recommendations regarding the optimal sex of rearing for various intersex conditions; these guidelines are based largely on the predicted gender identity of the patient and the potential for future fertility. Moreover, the statement emphasizes that children who later experience persistent gender dysphoria should undergo psychological evaluation and be supported in transitioning to the desired gender (Lee et al., 2006). In

other words, the primary value is placed on a concordance between the child's gender assignment and internal gender identity—an important component of quality of life.

However, the 2006 consensus statement fails to take a stance on the myriad ethical issues that arise in the non-Western world, such as the appropriateness of taking into account the stark economic and political inequality between the sexes. In an increasingly globalized world, where Western physicians frequently work abroad and treat culturally diverse immigrants, such lack of globally conscious guidance is troubling. While some may argue that the field of bioethics itself is fundamentally "Western" (Ryan, 2004) and lacks "adequacy and credibility" (Ryan, 2004) abroad, the reality is that "Western" bioethical principles have been adopted globally through the work of the International Bioethics Committee (IBC) of the United Nations Educational, Scientific, and Cultural Organization (UNESCO). UNESCO's 2005 Universal Declaration of Bioethics and Human Rights, drafted by the IBC (UNESCO, "UNESCO's General Conference Adopts"), emphasizes maximizing benefit and minimizing harm (beneficence and nonmaleficence), patient autonomy, and informed consent (UNESCO, 2005). In this context of increasing interaction with the non-Western world, the 2006 consensus statement must be expanded to incorporate globally relevant concerns.

### Gender Assignment and Corrective Surgery

In an ideal world, infants with ambiguous genitalia and uncertain gender assignment would grow up in a third gender category, with the ability to decide later on a gender for themselves. However, in our imperfect world both rampant societal stigma and other pragmatic realities preclude such a path—necessitating timely gender assignment. Such gender assignment should be guided by comprehensive medical analysis and seek to conform to the child's likely future gender identity. For example, more than 90 percent of XX infants with CAH and all XY patients with complete androgen insensitivity syndrome who are assigned female in infancy continue to identify as female (Lee et al., 2006). Still, gender assignment should not necessarily include genital corrective surgery. Instead, physicians should discuss with parents the benefits of delaying surgery until the child is old enough to be a part of the decision-making process, particularly in cases where surgery may impair erotic sensation or fertility. Such a postponement helps preserve the child's fundamental right to bodily integrity.

However, in some cases corrective surgery in infancy may be in the child's best interest. For XX CAH patients with extreme external virilization (for example, typical male-appearing genitalia as opposed to mild clitoromegaly), it may be medically beneficial to undertake corrective surgery sooner rather than later. In this context, early surgery to feminize the genitalia and separate the vagina from the urethra may prevent medical complications as well as minimize psychological distress and gender dysphoria. Nevertheless, in these cases surgeons should be careful to preserve fertility and sexual sensation.

### Disclosure and Informed Consent

The 2003 *Hastings Center Report* case study broached the issue of disclosure and informed consent in a global setting. In this case, parents requested that a 13-year-old intersex boy undergo surgery to remove his internal female genitalia without informing him of his intersex condition. Thus, the clinical team faced two separate questions with ethical implications: should the child undergo surgery to align him with the male gender, and should the child be informed about his female genotype? (Diamond et al., 2003).

With respect to the latter question, it is imperative that physicians be open and honest with the patient. Dishonesty would only confuse the boy, destroy the integrity of the patient-physician relationship, and impede patient compliance; a patient who understands the importance of his medication regimen is more likely to follow through with it. While the child may be traumatized upon discovering his intersex condition, such distress can be limited by appropriate psychological and familial support. Patient disclosure is essential to ensure that paternalism does not go too far. Parents and physicians are empowered to act on the patient's behalf as long as the patient lacks decision-making capacity; however, as the patient grows older, he should be made aware of his medical history so that he can partake in his own medical decision-making.

Turning to the ethical question of whether parents can consent to surgery for their child, Diamond's *Hastings Center Report* case commentary argues that the family-centered model supports the father's right to make a decision; this model gives top priority to the well-being of the family unit as a whole (Diamond et al., 2003). However, this approach ignores that the physician's most important obligation is to the child. The child, not the parents, will be most intimately affected by any decisions that involve his gender assignment, genital appearance, fertility, and sexual sensation. This primary emphasis on the child's well-being is especially important in cases where the child is too young to speak in his own behalf; in such instances, enhanced parental education and informed consent, as well as the involvement of hospital ethics committees, are optimal to ensure that the parents are reaching decisions in line with the child's best interests.

### Globally Specific Parameters: Economics, Politics, and Homophobia

In many of the cases described, economic and political reasons were the chief motivators for intersex patients to maintain or adopt a male gender identity, even if it went against medical recommendations. However, physicians have a fundamental obligation to promote both human welfare and human rights, and they should not condone medical decision-making that legitimates societal prejudice or inequality between the sexes. Physicians have a primary obligation to ensure patient well-being as reflected by concordance between a patient's gender assignment and internal gender identity. Allowing cultural factors such as economics, politics, and homophobia to supersede this concordance unethically puts the child at risk for gender dysphoria. Gender dyspho-

ria often results in extreme distress and is associated with emotional and behavioral problems (Meyer et al., 2002).

Moreover, permitting the consideration of economics, politics, and homophobia would create a problematic slippery slope. For example, could a U.S. couple demand male gender assignment on the basis of the nation's gender pay gap—claiming that their child would be economically disadvantaged as a female? (Rampell, 2011). Similarly, could a U.S. couple demand male gender assignment based on the persistent underrepresentation of women in U.S. politics? (Lawless and Fox, 2012). And if intersex clinical decision-making taking into account extreme homophobia is permissible in Iran, what if a U.S. couple demands a heterosexual child, based on extensive bullying of gay teenagers (and resulting gay suicides) in the United States? (McKinley, 2010). What if U.S. parents argue that being heterosexual is in the patient's best interest, as otherwise he will be unable to marry in the states that prohibit gay marriage? Permitting economics, politics, and societal homophobia to shape clinical decision-making creates a dangerous precedent, and it turns the well-meaning physician into an agent enforcing perceived social norms.

Finally, making important medical decisions based on cultural factors is dangerously short-sighted. Cultures are fluid and societal conditions are constantly in flux, making the future largely unpredictable.

For example, though economic obstacles exist for women in India and Saudi Arabia, these countries are currently experiencing an increasing number of women in the workforce. The *Times of India* reports that "women in the IT workforce grew from 4.21 lakh in 2006 to 6.7 lakh in 2008" (one lakh equals 100,000) ("Caution: Women at work," 2011). And in Saudi Arabia, the government is now encouraging women to find work; this is in part motivated by its desire to decrease unemployment benefit payments. The Saudi government has been working with Glowork.net, a new work-recruiting site for women. The government has also been pushing through a program to feminize the workforce in certain settings, such as female lingerie stores (Hamdan, 2012). Saudi women have had trouble finding work in the past due to the strict segregation of the sexes, meaning that female workers must work in offices separate from their male colleagues; the cost of maintaining two offices thus provides disincentives for companies to hire women (Hamdan, 2012). To surmount this obstacle, Saudi Arabia is currently planning a new city exclusively for female workers, which is predicted to generate 5,000 jobs in the textile, pharmaceutical, and food-processing industries (Baker, 2012). In addition, the advent of the Internet and cloud-computing technology has allowed Saudi women increasingly to work for companies from home. This allows companies to maintain the strict separation of the sexes without having to take on the economic burden of two offices (Hamdan, 2012).

While women in Saudi Arabia continue to be deprived of many political rights, conditions are far from static. For example, in 2011 Saudi women gained the right to vote and run in

municipal elections (MacFarquhar, 2011), and Saudi women were permitted to compete in the Olympics for the first time at the 2012 London Summer Olympics. There, 16-year-old Wojdan Shaherkani, an athlete in judo, made history as the first female Saudi Olympic competitor (Addley, 2012). And while Saudi women still lack the right to drive, King Abdullah told foreign reporters that Saudi women will likely drive at some point in the future. In the meantime, Saudi activists continue to press for change. In October 2013 a few dozen Saudi women with driver's licenses from other countries got behind the wheel in protest. "We are looking for a normal way of life, for me to get into my car and do something as small as get myself a cappuccino or something as grand as taking my child to the emergency room," explained Saudi activist Madiha al-Ajroush (Hubbard, 2013).

The 2003 *Hastings Center Report* case probed the idea of using future sexual orientation as a clinical decision-making parameter in societies with extreme homophobia. Specifically, ethicist Sharon Sytsma advocated for solidifying the child's male gender identity through surgery, to ensure his heterosexuality in a homophobic culture (Sytsma, 2006). At first glance, Sytsma's argument might appear to be in the patient's best interest, especially in a country such as Iran where homosexuality is punishable by death. Still, it is ethically untenable for physicians to participate in sexual-orientation engineering. This is especially true given the troubling history of American clinical interventions to curb homosexuality, such as electroshock therapy, castration, lobotomies, hormone therapy (Swartz, 2011), and nausea-inducing drugs (James, 2011). And "reparative" therapy—psychological therapy intended to change sexual orientation—has been shown to cause significant emotional harm to patients, often inducing depression and suicide attempts (Associated Press, 2009). Furthermore, scientific knowledge about the specific genetic, biological, and environmental factors influencing sexual orientation is nebulous to begin with, making any kind of informed medical decision-making problematic (Langstrom, Rahman, Carlstrom, & Lichtenstein, 2010). All in all, then, attempts to manipulate sexual orientation in intersex patients are historically insensitive, an ethical abrogation of human rights, emotionally detrimental to the patient, and scientifically hazy.

In making her argument, Sytsma contends that "changing the boy is certainly more within our power than changing his culture, and the surgeries will make it easier for him to thrive in that culture" (Sytsma, 2006). However, the family and the patient retain the choice of moving to a more accepting social environment at a later date if the child indeed does identify as homosexual. Specifically, the United States (Bilefsky, 2011) and Great Britain ("Two Gay Men," 2010) grant asylum based on persecution due to sexual orientation, though the asylum process is often extremely long, arduous, and full of uncertainty (Bilefsky, 2011). It is myopic to allow ever-changing social conditions such as homophobia significantly to affect gender assignment and clinical decision-making. Attitudes toward homosexuality in the U.S. have drastically shifted in recent years. NORC/University of Chicago data indicate that in 1973, 69.7% of

polled adults believed homosexual relations were always wrong, and this number fell to 43.5% in 2010 (Smith, 2011). This public-opinion shift is exemplified by the U.S. Supreme Court's June 2013 ruling declaring the Defense of Marriage Act unconstitutional (Schwartz, 2013). While homosexuality remains socially stigmatized and often illegal in the Arab world, this attitude is not necessarily impervious to change. Brian Whitaker, a former Middle East editor of the *Guardian* and author of the book *Unspeakable Love: Gay and Lesbian Life in the Middle East*, explains:

Well, I still like to think that probably attitudes will change at some time in the not too distant future. I mean, I think you have to look at the way satellite TV and the Internet are affecting people in the region. They're getting information from outside the region that they wouldn't have had in the past, and I think gradually this is beginning to change attitudes, particular[ly] among the educated young people in some of the big cities. (CNN Transcripts, 2006)

## CONCLUSION

Physicians involved in intersex clinical management have a responsibility to respect patient autonomy, patient disclosure, and informed consent. They also have an ethical obligation to pursue the patient's best interests while promoting universal human rights. This obligation requires the physician to be concerned primarily with promoting concordance between the child's assigned gender and his or her likely future gender identity, in order to minimize the risk of gender dysphoria. Local cultural factors such as economics, politics, and homophobia simply have no place in clinical decision-making.

I thus embrace ethical universalism in intersex clinical management. While physicians must remain culturally sensitive to local values, such sensitivity cannot fundamentally impinge on universal truths and human rights. In undertaking ethical decision-making, physicians must balance the benefits and harms to the patient within the local milieu. In this case, the potential distress posed by gender dysphoria ultimately outweighs any local cultural benefits gained by being assigned a specific gender or sexual orientation.

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