Ethical Problems in Intersex Treatment

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When they hear the word “hermaphrodite,” many people find their minds conjuring up an image of a mythical creature whose body poetically combines the male and the female. But, as soon becomes apparent when one looks at the situation in the U.S. today, hermaphroditism is not an imaginary status for humankind, and dominant medical approaches do not construct the hermaphroditic body as poetic. This essay briefly explores the basics of human hermaphroditism and some of the ethical problems I see as being inherent in the dominant treatment protocols.

What is hermaphroditism or intersexuality?
Implicit in the question “What is hermaphroditism?” is a much more difficult question: “What are the necessary or essential sex organs of the female and of the male, such that the combination of those essential organs in a single body would constitute a hermaphroditic state?” Scientists and medical doctors (not to mention poets and lawyers) have been struggling with this problem for centuries, and I do not propose to solve it here. In fact, after having studied the history of biomedical treatments of human hermaphroditism, I am convinced that — while there are indeed generalizable differences between most so-identified women and men — any strict claim about the essential natures of femalehood and malehood will necessarily depend as much on social politics as science. (I explore this idea in depth in my forthcoming book, Hermaphrodites and the Medical Invention of Sex, Harvard Univ. Press, 1998.)

Although I think strict definitions of sexual nature are socially constructed, I think it a clear fact that some people are born with something other than the set of organs usually considered to be the “standard female” or the “standard male” type. That is, some people are born with what are called “ambiguous” genitalia. Some have phalluses which look half-way between penises and clitorises, or like neither. Some appear to have both a penis and a vagina. Some seem to have a scrotum, no testicles, and a vagina. This isn’t all that surprising when you consider that female and male sexual anatomy share common developmental pathways. Sexual “ambiguity” can, of course, extend beyond the genitals, if you define sex in the common ways. Internal organs can be “mixed up” too, and some men appear to have breasts or little facial hair, while some women are practically bearded or flat-chested.

The current medical taxonomy for human hermaphroditism, which dates back to the late-nineteenth century, developed in response to a complex convergence of Victorian scientific and social concerns. That taxonomy divides hermaphroditisms into three kinds: true, female pseudo, and male pseudo. Under this scheme, the true hermaphrodite is the person who is born with both ovarian and testicular tissue; the female pseudo-hermaphrodite has only ovarian tissue but exhibits notable anatomical “masculinization;” the male pseudo-hermaphrodite has only testicular tissue but exhibits notable anatomical “feminization.” Present-day definitions sometimes also mention that female-pseudos have no Y chromosomes and male-pseudos do, but
that kind of added chromosomal criteria fails to account for “true hermaphrodites,” most but not all of whom exhibit a supposedly-“feminine” XX chromosomal combination. Generally the nosology is still based on gonadal tissue.

Types of “male pseudo-hermaphroditism” include androgen insensitivity syndrome (AIS) and 5-alpha-reductase (5-AR) deficiency. AIS women are born with testes but can develop pre- and post-natally to look quite feminine. By contrast, 5-AR children are born looking mostly feminine but at puberty develop along a strikingly masculine pathway. Types of “female pseudo-hermaphroditism” include congenital adrenal hyperplasia (CAH) in which “female” fetuses experience external “masculinization” because of exposure to high levels of androgens. Hermaphroditism can be dramatic enough that the “ambiguity” may not be noticed until puberty or even later. Complete-AIS (CAIS) girls are sometimes not diagnosed until they fail to menstruate, and some CAH children have been raised as undoubted males until they started menstruating.

Medical textbooks usually classify only these few particular conditions under the heading of “hermaphroditism,” but in practice a much wider variety are treated as “intersex” (sexually ambiguous) states. For example, Turner’s Syndrome and Klinefelter’s Syndrome as well as hypospadias (where the urethra exits somewhere other than the tip of the penis) and enlarged clitorises are often referred to and treated by specialists essentially as intersex cases.

How common is “ambiguous” sex? That obviously depends on where you draw the acceptable limits of malehood and femalehood. How big does a clitoris have to be before it should count as “ambiguous”? Again, answers to these questions are, I believe, historical (specific to time and place), not ontological. I can report that independent sources indicate that roughly 1 in 1,500 to 1 in 2,000 births in the U.S. today are of a child whose sex falls into serious question.

What are the dominant treatment protocols?

As sociological research into this field mounts, we are finding that the treatment of intersexed children in this country varies widely. There is, nonetheless, a consistent narrative about intersexed children and their treatment in the expert medical literature, a literature in the past authored mostly by psychologist John Money, and today authored mostly by pediatric urologists. That narrative sounds basically like this:

“The birth of a child with unusual-looking genitalia is a psycho-social emergency. That is because successful gender identity — as a straight and unambiguous man or woman — depends on convincing looking genitals. If we don’t ‘fix’ the anatomy of an intersexed child, the child, the parents, and their associates are going to have doubts about the child’s gender identity, and the child will wind up with an unsuccessful gender identity. That is, the child may wind up homosexual, conflicted, and so on. Penises are the key to malehood; therefore XY children born with ‘repairable’ penises should be assigned the male gender and have their penises (and other parts) fixed to look right as soon as possible. But XY children born with ‘unrepairable, unacceptable’ penises (including those with a stretched length of less than 2.5 cm.) should be assigned the female gender and constructed to look like girls. (Testes are removed; vaginas built; and so on.) By contrast, reproductive potential is extremely important to femalehood, and females should never have sizable, erectile phalluses. Therefore, XX children should be assigned [construct a penis].” Again, the foundational assumption is that all this construction must be done early because gender identity is set early and depends absolutely on right-looking genitals.

The narrative often continues this way: “Parents are understandably traumatized to learn that their child’s sex is unclear. Therefore, we the physicians must decide on the child’s sex within 48-hours of birth, and until that time, we must tell the parents that it is not the child’s sex that is
in doubt, it is only the physicians who are in doubt. (Avoid terms like ‘hermaphrodite’ or ‘intersex.’) We should tell parents the child indeed has a sex, male or female, but that the sex just looks blurry. We will figure out the ‘real’ [assigned] sex and ‘return’ the child to that ‘real’ sex via surgical and hormonal treatments. Referring parents or intersexuels to support groups is a bad idea because it would only increase gender confusion.”

What are the ethical problems here?

Feminist researchers and intersex activists articulate a number of problems with this approach. I list a few of them here. These problems become apparent when we perform three tasks: (1) consider the treatment of intersexuality as a social-scientific historical phenomenon, one that shares features with the history of biomedical treatments of women and homosexuals; (2) compare the treatment of intersexuality to generally-accepted standards in medicine and medical ethics; (3) listen to adult intersexuels talk about their experiences. Because of space limitations, I only touch the surface of possible discussions here:

(A) Construction of gender: Feminist and “queer” theorists including intersexuels are disturbed that an elite group of physicians feels it in their power to decide what counts as the “acceptable” limits of gender. Should homosexuality, for example, be seen as a failure of medicine or parenting, as the present treatments imply? Why can’t girls have large, erectile clitorises? Clearly gay people and women with big clitorises tend to be subversive of strict gender roles, but should social conservatism about gender roles necessarily dictate pediatric intersex treatment? To use an extreme comparison, the anatomy of “interracial” children is subversive of “racial” divisions, and interracial children may suffer the consequences of this, but we don’t solve racial tensions by “fixing” interracial children surgically. Moreover, gender identity is not necessarily dependent on genital anatomy. We know this from feminists, gay people, and transgendered people. We also know this because a study of boys with very small penises — “micropenis” boys raised as boys and shown support and honesty — showed that men can have small penises and still turn out with socially-standardized male gender identities.

(B) More questions of whether intersexuality should be constructed as “abnormal”: If “unusual” sex anatomies are fairly common, why should (so many of the) variations be treated as seriously, tragically abnormal? Compare: the rate of cystic fibrosis is about 1 in 2,000 for “Caucasian” newborns; the rate of medically “unacceptable” genitalia in newborns is significantly higher. At least 1 in 2,000 newborn’s sex is seriously unclear, but many more have “masculinized” or “feminized” genitalia according to stricter clinical definitions. There is also a question here of what “standard” (or average) genitals really are, statistically speaking. One study showed that 45% of 500 randomly-sampled men displayed technically hypospadic penises. Are definitions of genital normality extremely and peculiarly strict among surgeons? This much is clear: ambiguous genitalia are not a disease in any metabolic sense, though they may signal an underlying metabolic danger. As Suzanne Kessler has noted, intersexuality does not threaten the patient’s life; it threatens the patient’s culture.

(C) Sexist asymmetries in treatment: XY children have their fertility surgically negated via removal of the testes if their phalluses are small, but in XX children, potential fertility is seen as defining, almost sacred. Why is “female” fertility more valued than “male”? (XY children with small penises are often, but not always, infertile.) Similarly, why is so much demanded of penises, and so little of vaginas? Surgically “acceptable” penises have to become erect and flaccid at appropriate times, have sensation, have the urethral opening in just the right place, and so on. Meanwhile, vaginas are treated as “holes,” as mere spaces big enough to accept penises. Surgically-reconstructed vaginas need not be sensitive or self-lubricating to count as
“acceptable” to surgeons. I would argue (radically) that patients should be allowed some say in what counts as a “successful” surgical outcome.

(D) Ethnocentric asymmetries in treatment: In the U.S., African-heritage girls are now protected from “mutilating” genital conformity customs by federal law, but girls born here with big clitorises are subjected to strict genital conformity rules. Anti-female-genital-mutilation legislation makes it clear that a girl cannot get African-style conformity surgery even if she asks for it; girls born with “big” clitorises are subjected to genital-conformity rules without their consent and at the risk of their sexual pleasure.

(E) Withholding of information from patients and parents: Apparently in many clinical treatments of intersexed children, parents consent to particular surgical and hormonal treatments but are not aware that they are also implicitly consenting to Money’s largely unproved (or even disproved?) anatomically-strict psycho-social theory of gender identity formation. More troubling still, a disturbing number of intersexed report that their doctors have consciously withheld the truth of their diagnoses from them, because their doctors have assumed that the patients “couldn’t handle the truth.” Indeed, ethicists’ pleas to the contrary, intersex clinicians continue periodically to publish advice to colleagues to withhold medical information from intersexed patients. This is not just ethically problematic, it is bad medicine: AIS women have suffered early-onset osteoporosis because they stopped taking important medications in response to growing distrust of their obviously-lying physicians.

(F) Pediatric autonomy – an oxymoron?: Two pervasive problems in pediatric care are the questions of what parents should be able to decide medically on behalf of their children, and how much children should be told about their conditions (regardless of their parents’ wishes). Intersexual activists argue that no one but an intersexed person should have the right to consent to essentially “cosmetic” surgeries which carry serious risks. They also argue that, even if the surgeries worked every time (which they certainly don’t) — meaning that there were no loss of sexual pleasure and no complications — even then intersexed people should have the right to keep the genitals with which they were born. Intersexed also argue that intersexed children and adults have the right to be referred to psychologists and support groups (especially since this is allegedly a “psycho-social problem”), and that they have the right not to be deceived when they ask for information.

Conclusion

Intersex clinicians to whom these challenges are addressed often retreat to what I call the technological fallacy, that is, the mistaken belief that improved treatment technologies (e.g., better surgical techniques) will eliminate these dilemmas. Historically technologies have increased rather than decreased ethical dilemmas — and there is more at issue here than scar tissue from unperfected surgeries. Clearly involved parties need to have a deep and frank conversation about intersexuality and its medical treatment, especially since many intersexed report that the very treatments designed to prevent them from feeling like shameful freaks are in fact causing them to feel that way.