



Ethical Problems in Intersex Treatment

by Alice Dreger

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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 intersexuals 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 intersexuals 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 intersexuals 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 hypospadiac 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 intersexuals 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. Intersexuals 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 intersexuals report that the very treatments designed to prevent them from feeling like shameful freaks are in fact causing them to feel that way.



Introducing the Liaison Committee

by Howard Brody

Center for Ethics & Humanities in the Life Sciences

The masthead of this issue includes a new group of people— the Liaison Committee of the Center for Ethics and Humanities. I want to explain why we formed this committee and why we want all faculty and students on the campus to know about it.

The Center is administratively “housed” in the College of Human Medicine, but it relates to a grand total of eight deans and colleges. So how does a small unit, with very busy faculty and staff, effectively “relate” to that network?

We tried to do this in the past with an annual written report and occasional personal meetings between the Center’s director and the various deans. However, our intensive review of the Center two years ago found the deans to be very supportive of the Center, but also relatively unaware of what we do on a day-to-day basis.

Dean Abbett of Human Medicine suggested we could do better if we appointed one faculty member from each college to be the conduit of information between the Center and that college’s dean. So the idea for the Liaison Committee was born.

The role of the Liaison Committee is TWO-WAY communication. About 2-3 times a year, we will convene the Committee and report comprehensively on the activities of the Center. We expect each member will meet with his or her dean to report on behalf of the Center exactly what we are doing that involves their college. Ideally deans will thus be better informed and more able to support our activities.

But it is also the job of the Committee to critique the work of the Center and indicate where we could or should be doing more in collaboration with the various colleges. Therefore, any faculty who has ideas about how the Center could better support any of their work should get these ideas to their college’s liaison person.

We hope the Liaison Committee will make the Center more efficient and enhance our ability to serve the entire University community. Ideas on how to do this better are always welcome.

Shirley Bordinat-Johnson
College of Osteopathic Medicine
Howard Brody
College of Human Medicine
Lynne Goldstein
College of Social Sciences
Sharon King
College of Nursing
James Miller
College of Natural Science

Elizabeth Price
Detroit College of Law
Tess Tavormina
College of Arts and Letters
Tom Tomlinson
College of Arts and Letters
Peter Vinten-Johansen
College of Arts and Letters



Medical Ethics Course on the Web

by **Scot Yoder**

Center for Ethics & Humanities in the Life Sciences

Michigan State University is pleased to announce **Issues in Health Care Ethics**, a new distance-learning course designed for institutional ethics committee members. This is a pilot course which will test the feasibility of a distance-learning based health care ethics certificate program.

Issues in Health Care Ethics is a survey course of the major issues pertinent to the work of institutional ethics committees. Topics include refusal of treatment; informed consent; treatment limitations for incompetent patients; advanced directives; assisted suicide and euthanasia; allocation of limited resources; ethical issues in cost-containment systems; ethical issues in perinatal care; and others. The goal of the course is to insure that every participant is familiar with the vocabulary, basic reasoning, and key texts regarding central issues in health care ethics.

Ordinarily, in order to receive such training you would have to enroll in a traditional health care ethics course taught on campus or attend an intensive 3-5 day training course. For many people working on institutional ethics committees time, scheduling, or distance conflicts make an on-campus course impossible. Even those who manage to attend one of the short intensive training courses miss opportunities to develop the advanced skills in ethical analysis and argument that only time and practice can foster. In short, many ethics committee members are left to get their training entirely on the job or on their own.

To overcome these logistical obstacles **Issues in Health Care Ethics** will be run entirely on the World Wide Web. This provides the following advantages:

Distance is no longer an obstacle. Participants need never come to campus. The only physical requirement is that they have convenient access to a computer equipped with a web browser like Netscape or Internet Explorer.

Participants have more control over their schedule. The course will follow a schedule organized around weekly topics and assignments, but participants may do their work in the morning, afternoon, or evening — whatever fits their home and work schedule.

In addition to these advantages **Issues in Health Care Ethics** offers the opportunity to interact with different faculty members in the Center, like Howard Brody, Judith Andre and Leonard Fleck. While there will be a primary course instructor, faculty members from the Center will participate in the course on a regular basis, contributing in their particular areas of expertise. We are even investigating the possibility of having “visiting” preceptors from other parts of the country!

The course will be offered in the Spring 1998 Semester (January 14 through May 8). The cost will be \$648. To be eligible you must have completed at least a bachelor's degree and be either

employed by a health care institution or associated with an ethics committee. In order to ensure more personalized attention enrollment is limited to 20 participants.

You can preview the course online at http://iphh.cal.msu.edu/web_ethics/preview/al390_frm2.htm. For more information or to receive enrollment instructions contact:

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News and Announcements

Scot Yoder joins the Center Faculty as a Visiting Instructor for the 1997/98 academic year. Scot, who has been the editor of the Medical Humanities Report since 1995, is a doctoral candidate in philosophy at MSU. In addition to editorial and teaching duties he will be the primary developer and instructor for the web-based course in health care ethics described in this issue.

Jessica Berg left the Center this Summer to become Section Director, Professionalism at the American Medical Association's Institute for Ethics in Chicago.

Judith Andre has two articles in the current *Journal of Clinical Ethics*: "Speaking Truth to Employers" and "The Goals of Ethics Consultation: Toward Clarity, Utility, and Fidelity."

Judith Andre's "The Week of November 7: Bioethics as a Practice" appears in *Philosophy of Medicine and Bioethics*, Ron Carson and Chester Burns, editors (Boston: Kluwer Academic Publishers 1997), 153-172.

Len Fleck was a consultant to The Hastings Center Project "Genetic Dilemmas in Primary Care: An Educational Program" in July.

Judith Andre gave a brown-bag presentation on confidentiality at the University of Michigan Medical School, August 27.

In September **Len Fleck** presented "Genetics, Ethics, and Reproductive Decisionmaking: Why Community Dialogue?" at the First Annual Bioethics Conference of the Michigan State Medical Society at Mackinac, MI.

Len Fleck spoke at the Ninth Annual Medical Ethics Conference of the Colorado Springs Osteopathic Foundation in October. His presentation was titled "Corporate, Competitive, and Caring: Conceptual Confabulation in Health Care Today."

Len Fleck spoke at the Kleit Symposium of the National Kidney Foundation on October 10 in Mishawaka, IN. His presentation was titled "Withdrawing and Withholding Dialysis: Ethical Issues."

Len Fleck will speak on "Just Caring: Ethics, Genetics, and Cancer" at the Great Lakes Cancer Nursing Conference in Novi, MI. on October 21.

On October 29 **Tom Tomlinson** will lead "Ethical Issues in Organ Donation and Transplantation", a seminar sponsored by Life Connection of Ohio, Dayton, OH.

The Center will be represented well at the upcoming joint meeting of the American Association of Bioethics, the Society for Bioethics Consultation, and the Society for Health and Human Values. Presentations by Center Faculty and Adjunct Faculty include:

Judith Andre (with Todd Chambers): "The Language of Bioethics as a Pidgin"

Jessica Berg: "Uneasy Bedfellows -- Integrating Law and Biomedical Ethics."

Libby Bogdan-Lovis: "Midwifery Meets Managed Care: The Search for Effective Models of Professional Cooperation and Consumer Choice"

Douglas Brown: "Euthanasia and Newborns in Holland" and "The Boomsma Case: An Update on Boundaries for the Practice of Euthanasia in Holland" (**Howard Brody**, co-author/presenter)

Michael Fetters: "A Theoretical Framework for Family Autonomy"

Harriet Squire: "Rewriting Literature: An Analysis of Medical Student Writing Assignments" and "How Beginning Medical Students Depict the Doctor-Patient Relationship: An Analysis of Students' Creative Projects"

Tom Tomlinson (with Alvin Moss, M.D.): "Progress in Setting Limits on the Inappropriate Use of Life Support: A Report on Dialysis"

Scot Yoder: "Rethinking Professional Expertise"

Alice Dreger will chair a session entitled, "Listening to Hermaphrodites: Historical and Ethical Problems in the Medical Treatment of Intersexuality."