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Intersex Treatment as Standard Medical Practice, or, How Wrong I Was

By Alice Domurat Dreger

In 1998 I published an article in the Hastings Center Report criticizing the standard of care for the treatment of intersex.1 (Intersex is the general term used for a variety of conditions under which a person is born with something other than standard male or standard female anatomy.) I ended that article by arguing that the treatment of intersex was unlike anything else in modern-day medicine, that it looked like what George Annas had termed “monster ethics”—the treatment of supposedly “deformed” children by means that would otherwise be considered unethical.2 Back in 1998, I thought the standard treatment of intersex was so morally outrageous that, once exposed, it would quickly change. I was particularly struck by three components of intersex treatment that seemed to me extraordinary and morally specious. First, textbooks and journal articles instructed practitioners to lie to their intersex patients and to withhold information from them about their conditions. Second, otherwise healthy children were being subjected to procedures that risked sexual sensation, fertility, continence, health, and life simply because those children didn’t fit social norms. The third problem was the total lack of evidence—indeed, the total lack of interest in evidence—that the system of treatment was producing the good results intended.

After I published this article and the related book,3 many academic ethicists, journalists, and activists quickly agreed that the “concealment-centered” model of care for intersex was fundamentally flawed and needed changing. But the reaction among the medical establishment has been notably slower. Only now are some major medical centers starting to employ openly the reform model of treatment advocated by the Intersex Society of North America, an advocacy and policy organization devoted to improving the social and medical treatment of people born with atypical sex anatomies (an organization on whose board I have served since 1998). Only now are some medical students starting to learn something very different from what they learned in 1998 about how to understand and treat intersex. Indeed, it appears that in most medical centers and schools intersex is still treated according to a concealment-centered

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model that recommends clinicians withhold or misrepresent critical information and surgically alter children’s healthy genitals to calm parents. I’m often asked why intersex medicine hasn’t changed, and nowadays I think that the reason must be because, in spite of what I thought in 1998, the treatment of intersex actually looks a lot like other realms of modern medicine. The core components of the treatment of intersex didn’t—and doesn’t—shock most of the folks treating intersex because it is in fact pretty familiar. I have come to realize that when I started work to change the medical treatment of intersex I was really naïve about medicine. As a consequence, nowadays as I pursue intersex scholarship and activism, I no longer feel (as I did in 1998) like I am exposing a dark and tiny corner of medicine. Today I feel like I’m trying to shove the world’s biggest elephant when my feet are covered in soap.

How is the “standard of care” of intersex treatment like the rest of medicine? Consider first the issue of lying to patients and withholding information. In 1995 the Canadian Medical Association awarded a medical student a prize for an article arguing that practitioners had an ethical duty to deceive patients with Androgen Insensitivity Syndrome (AIS—an intersex condition) about the nature of their conditions. The logic was that the patients would needlessly suffer from knowing the truth about their intersex condition. In most of medicine today practitioners would never think it their ethical duty to lie and withhold critical medical information; indeed most would see their duty as the opposite. But I’ve come to realize that, at least in pediatric care of serious medical conditions, it is still often the case that practitioners withhold critical information from patients and parents under the guise of bearing the burden of knowledge for them. Sometimes the information withheld is about well-established and well-respected patient advocacy groups who would provide an alternative perspective on treatment options (often available at rival institutions), sometimes the information is about how little is known about outcomes for recommended options, and sometimes it is about how much difference it makes which surgeon you engage for a particular procedure.

A lot of the choice of what to reveal falls under the guise of “clinical judgment,” and I think in 1998 I had a simplistic idea of what might constitute “informing” in advance of obtaining consent. I’ve come to realize how often the ways lines are drawn by clinicians—
lines cutting off patients and families from information that some might consider critical—shade well into paternalism.⁴ And all over medicine there is great and problematic variation in how much doctors are willing to reveal about their own uncertainties. Often, uncertainty seems to serve as an excuse for paternalism rather than the critique of it that it could be.

What, then, about this issue of changing otherwise-healthy patients to fix social norms? Isn’t that unusual in medicine? Hardly. It happens to the great majority of boys born in this country when they get circumcised, when children with questionable diagnoses of ADD or ADHD are put on powerful stimulants, and when children who are simply short are put on growth hormones. This isn’t a simple case of parents acting as tyrants to their children. Since becoming a parent in 2000, I’ve realized how much I underestimated the parental (and sometimes pediatric-paternalist) desire to “normalize” children, a desire that is clearly a manifestation of the visceral—almost savage—desire to protect. Whereas I used to think that this push to “normalization” signaled a rejection of the “abnormal” child, I am now more inclined to think that the push is better seen as a paradoxical loving acceptance of the child. The parent (and pediatric surgeon) sees the child as essentially perfect, and wants the often-cloddish and boorish world to see the same, so she “reconstructs” the child to normality or perfection. In 1998, when, thanks to Art Frank’s work,⁵ I recognized the mythology of calling intersex surgeries “reconstructive,” I think I failed to understand how much parents and surgeons believed in the restitution narrative they spoke.

In that sense, I think I failed also to see what Adrienne Asch does in “Distracted by Disability,”⁶ namely the conflicted position of the physician approaching the congenitally or chronically “disabled” patient. How is it that a surgeon can truly accept the whole child born with an unusual anatomy—including the “deformed” anatomy which will very likely persist and form a critical aspect of that person’s identity—and also seek to “rescue” her from it? In 1998 I thought doctors treating intersex had put themselves in a contradictory position—wanting to help patients while unintentionally hurting them. Now I realize what I am calling them to is a much more contradictory position. How could they put down their tools of “correction” when in their minds that would signal abandoning the child, rather than accepting her? More generally put, I think I misunderstood to what extent intervention is the primary means of demonstrating caring for many clinicians, patients, and family members.

So here’s where I used to wish the evidence would save us. Here’s where I thought, in 1998, that we could all look at the treatment of intersex and say, “My word, they’re trimming phalluses and withholding information and building vaginas out of colons in infants with no evidence that it produces the desired results of a healthy patient!” But then slowly I realized what Howard Brody, Aron Sousa (my partner, a philosophical internist), and Libby Bogdan-Lovis were saying to me: we don’t have evidence for most of what happens in medicine. The treatment of intersex isn’t the exception; it’s the rule. Tradition and storytelling trump evidence—they trump even the desire for evidence much of the time in medical practice.

The question of evidence, though, is one place where there’s been progress in the treatment of intersex. Some clinicians—most notably the pediatric surgeon Ian Aaronson, who founded the North American Task Force on Intersex—are finally trying to get good data on what’s happened to people who were treated with the “concealment” model. In the UK,
there's been model leadership in this field by the gynecologists Sarah Creighton and Catherine Minto. But most clinicians treating intersex continue to believe whatever evidence we have doesn't apply to them, because their surgeries are better, their gender assignments more sensible, their patients obviously happy. They don't think the evidence will matter that much.

And part of me thinks they're right, but for the wrong reason. They think their surgeries are better than the ones now being evidenced to have resulted in poor outcomes, so the evidence doesn't matter. I think the evidence about which kind of clitoroplasty leaves more sensation won't matter much because, in the end, it's just wrong to cut healthy tissue off a girl's clitoris without her explicit informed consent. About this, my mind hasn't changed! I do think new follow-up studies will be useful for doing best-guess gender assignments in cases of intersex—they may help us understand which gender to assign preliminarily in various cases of partial AIS, for example—but all the evidence in the world in favor of the "effectiveness" of a treatment doesn't make it ethical.

So I end up realizing that what I'm looking for in medicine today—at least around the treatment of children born with socially-challenging anatomies—is a radical change. I'm no longer looking to bring the treatment of intersex into line with other forms of medicine. It's frighteningly close to that already. Instead, what I'm wishing for—what I hope I'm starting to work towards—is a radical medicine that recognizes and actively confronts the oppressive nature of social anatomical norms and questions the use of medicine to uphold, and even advance, particularly oppressive norms. In this vision, we would not ban or abandon all "normalizing" procedures. But doctors and nurses and social workers who work with these families would begin engaging in a conscious dialogue on the meaning of anatomy and the implications of "normalizing" procedures.

I suggest this vision today because of what I've learned from individuals and families who have lived through various kinds of treatment protocols. What I find almost universal among them is the story of how liberating it was for them to realize fully the political nature of their oppression and the complex ways that love is played out under oppression. As a historian, I shouldn't be surprised. Medicine historically sanctioned the oppression of women, blacks, lesbian women and gay men, and people with cancer and AIDS. (Barron Lerner's excellent book on the history of breast cancer activism reads like a primer for intersex activism.) Part of the liberation of these groups involved a rejection of the more oppressive forms of medicine and science once thought (by some) simply beneficent. Part of the liberation involved medical professionals joining in the struggle for reform. The best thing is, if history holds true to these analogies, intersex activism may well improve other realms of medical care.

On a final reflective note, only recently have I learned how very lucky I am to be at Michigan State University doing this work. Perhaps my biggest stash of naiveté in 1998 consisted in thinking I could have pursued this work anywhere. I now understand MSU—particularly the Center for Ethics and Lyman Briggs—to be a uniquely safe and supportive environment for the work I have done as a scholar who is also an activist with a long learning curve.

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Endnotes
3 Alice Domurat Dreger, Hermaphrodites and the Medical Invention of Sex (Harvard University Press, 1998).
4 I'm indebted to Joel Fader of Northwestern University for educating me on this from the point of view of a pediatrician-ethicist.
Changing One’s Mind

In her lead article for this issue, Alice Dreger describes changing her mind. *InkLinks* contributors below describe changing their own. Two found that policies they had endorsed brought about unexpected, even shocking, consequences. For the third writer the catalyst was a new intellectual perspective combined with practical knowledge (of Oregon’s rationing strategy). Fittingly, the last essayist describes changing his mind about the very nature of moral inquiry and its role in complex real life difficulties. Practical ethics, he argues, is not a matter of applying moral knowledge, but of developing it.

*InkLinks* is a regular column giving voice to readers: their research, their scholarship, their thoughts, and their activities. We welcome your contribution.

—JA

A Pediatrician: “Court-Ordered Transfusion Caused this Child to be Shunned”

In my early practice, I felt strongly that adults had a right to refuse treatment on religious grounds, but I did not support this for children. While I still hold this view in part, my involvement with Michael, an adolescent with sickle cell disease who was a Jehovah’s Witness, convinced me to modify my position.

When Michael was 16 years old his parents adamantly refused blood transfusion. As is standard practice, we sought and obtained a court order to give him a transfusion anyway. I cared for Michael again when he was 19. At that time his anemia was such that he had chest pain even when walking to the bathroom. In discussing the possibility of another transfusion, I learned that his previous transfusion had marked him as “contaminated” within the JW community, and that any illness or problem that he had was ascribed to “bad blood.” He was shunned by his community and suffered significantly from the isolation and rejection. Since Michael was now 19, he was allowed to refuse transfusion and died because of it.

I learned through this case that there is always a risk of unintended consequences in overriding a patient’s wishes, and that beneficence must be weighed against nonmaleficence when trying to decide how to use our authority with pediatric patients—and with anyone who lacks full capacity to make their own decisions.

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A Bioethicist: “Sex Selection had Shocking Consequences”

Until quite recently, the developing fetus was completely hidden until the moment of birth. In the 1970s, a cytogenetic test was introduced that began to yield some clues about the features of the fetus midway through the pregnancy. The test provided a chromosomal picture - or karyotype - of fetal cells. This test was offered to women who, because of advanced maternal age or family history, were at risk for having a child with Down syndrome or with health problems brought on by chromosomal irregularity. Now there was the opportunity to find out if the developing fetus had the normal chromosome number of 46 and to know if the chromosomes contained the correct amount of genetic material.

But that same chromosomal picture could also reveal something else: the sex of the fetus. If there were two X chromosomes, the fetus was a girl; if, instead, there was an X and (Continued on next page)
a Y chromosome, the fetus was a boy. An ethical question arose: Should parents be allowed to use genetic testing solely to select the sex of their offspring? Like many others at that time, I reasoned that though I was uncomfortable with this particular use of genetic testing, more harm would be done by erecting barriers that would interfere with a woman’s right to terminate a pregnancy during the first two trimesters for whatever reasons that seemed significant to her. To do anything to restrict her choice would weaken the recent and still-fragile Roe v. Wade decision of the U.S. Supreme Court.

And like others, I have since changed my mind. Why? Because over the years, we have begun to see the effects of sex selection. Not unexpectedly, it has most often been used to select against female fetuses. As a result, sex selection has supported and deepened biases in cultures in which women are already devalued. Statistics from countries such as India have revealed shocking deviations from the usual nearly even balance of males and females at birth. There is a take-home lesson for our own culture where biases may be less visible. Allowing sex selection marginalizes and devalues women. This is too high a price. On occasion, there may be valid medical reasons for considering sex selection. However, unless medical reasons apply, I no longer believe that employing genetic technologies for the purpose of sex selection is acceptable.

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A Philosopher: “I Came to Understand Fairness Differently.”

In the early 90’s I helped review a nonprofit insurance company’s policies about covering organ transplantation. At the time I concluded that as a matter of justice it should not be covered. I reasoned that expensive treatments that benefit a relatively small number of people should take second place to basic health care, which was becoming so expensive that millions of people were uninsured.

Several things have led me to moderate my view. First, the failure of health care reform in the mid 90’s meant that our system would remain economically an open system. Thus, there can be no guarantee that money saved by denying organ transplants will make basic health care more accessible. Second, I have come to think of health care justice differently, in terms of the procedures used to arrive at decisions rather than the content of those decisions. My changed perspective was influenced by the work of people such as Len Fleck and Norman Daniels, and by the way health care rationing was done in Oregon. If fair decision-making procedures are employed it is possible to arrive at different, equally fair, ways to allocate health care resources. Shortly after our task force made its recommendations, a survey showed that the company’s enrollees would rather forego coverage for basic and preventative care than eliminate coverage for organ transplants. I still think that such a decision would be unwise, but I no longer believe it would be unfair.

Scot Yoder, Ph.D.
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A Philosopher: “I Needed a New Way to Conduct Moral Inquiry”

As I taught “moral problems in medicine” courses, I gradually recognized a need for a new way to conduct moral inquiry. Textbooks in this new field began with brief summaries of established moral theories that competed with one another for supremacy. Students were invited to employ these theories in the investigation of specific problems (physician-assisted suicide, genetic engineering, and so on) even though the theories were not consistent with one another. Morality was regarded as a kind of possession: a principle, set of principles, or procedure for becoming fair-minded; a set of the proper intuitions, etc., to be “taken with us” when we deal with particular problems.

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Center News & Announcements

Tom Tomlinson presented “Thinking about Ethics,” ANR Week Horse Program “Horse show ethics: how do you place?” Michigan State University (March 1, 2003).


Congratulations to the MSU “Snowflakes”: Peter Vinten-Johansen (History), Howard Brody (CEHLS/Family Practice), Nigel Paneth (Epidemiology), Stephen Rachman (English/American Studies) and Michael Rip (Epidemiology). Their book, Cholera, Chloroform, and the Science of Medicine: A Life of John Snow has been released by Oxford University Press.

Len Fleck gave a keynote address titled “Just Caring: the Moral/Political Challenges of Health Reform and Health Care Rationing” for the Kansas Health Ethics Ninth Annual Conference “Ethical Dilemmas of Health Care Access and Affordability” in Wichita, KS (March 14 and 15, 2003).

To introduce this new (pragmatic, instrumentalist) approach I wrote and utilized in class a short textbook. Moral inquiry was no longer to be regarded as choosing and justifying a moral course of action. Instead, it is the initiation of new and realistic proposals about how to respond to a morally problematic situation. My classroom experiment was, I am relatively certain, not very successful. Creative inquiry is hard work! The predominant culture of moral inquiry takes for granted that the participants already possess the knowledge needed to work out a successful “moral” solution. When inquirers learn that problems about treating or terminating, or working out an adequate health care system, are indeed problems to which we do not now have successful responses, they are stymied and frustrated. It is far easier to debate which of two conflicting choices is really “moral” than to try to construct practical solutions satisfactory to everyone concerned.

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Coming Events

The 2003 Medical Ethics Resource Network (MERN) Annual Meeting
“Suffering, Palliation & End of Life: Ethical, Spiritual and Cultural Challenges”
Date: May 9, 2003
Location: Kellogg Center, Michigan State University, East Lansing, MI

Intensive Bioethics Course
“Medical Ethics for The 21st Century”
Dates: June 19-21, 2003
Location: Kellogg Center, Michigan State University, East Lansing, MI
Offering both ‘Basic’ and ‘Advanced’ Courses

For more information about either conference, including registration and agenda materials, please visit the MERN website at: http://www.mern.org/, or contact Jan Holmes (Jan.Holmes@ht.msu.edu).

For CME information, as well as other Center activities, please visit our website at http://www.bioethics.msu.edu/.