

The Hanukkah Bush: Ethical Implications in the Clinical Management of Intersex

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As a young child of a conservative, but unobservant, Jewish household, I viewed Christmas as being about the large, aromatic firs and spruces adorning my friends' apartments, decorated with dazzling ornaments and surrounded by a profusion of foil-wrapped packages. Hanukkah, by contrast, was embodied in our home by only a small menorah on our window sill. Is it any wonder that I begged, pleaded, and cajoled my parents for a Christmas tree? Wisely, they would not relent.

Soon I discovered that the parents of some Jewish friends had instituted a custom of "Hanukkah bushes," which, to any honest observer, were clearly Christmas trees in drag. Seeing one for the first time it felt fake, hollow, half of something but all of nothing. My friends' parents, uncomfortable about their minority status, had been co-opted by the overwhelming pressure to make life "easier" for their children by diluting their heritage while assimilating to the dominant culture.

With the benefit of hindsight, I am glad my parents did not yield to such pressure even as I regret they did not do more to educate me about my roots. Having now learned the history of my religion I have discovered all that is rich and precious about Hanukkah, dissipating any desire for

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a Christmas tree. My "Hanukkah bush" friends, by contrast, derive no such meaning from the Festival of Lights, but at the same time feel like frauds if they lay claim to actual Christmas trees. Did their parents' response to societal pressure, though well-intentioned to help these children "fit in," simply leave my friends incapable of functioning comfortably in either world? Can the same be said of doctors who importune parents to manage their intersex children with surgery and secrets?

I might mention, as a footnote to this parable, that the population of Jews in the world is no larger than the population of intersex persons. Thus, I suppose it is fortunate that pediatric endocrinologists are not the stewards of the world's religions, because with the same rationale they use to support surgery and secrecy in managing intersex—that is, that it is unfair to leave children's ambiguous genitals in their natural state, or even openly acknowledge to them that they are intersexed, because this will render them outcasts to the majority of society—these doctors might argue that it is unfair to obligate children to live with a religion shared by only a tiny fraction of the world's population. As a practical matter, of course, religious tolerance is an accepted norm in our society, whereas doctors perceive something inherently intolerable about intersex.

Intersex is a subject near and dear to my heart (and other parts of my anatomy). But it is also

my personal history inflected by the burden of having lived almost all of my 40 years with the shame, secrecy, and isolation that are an inevitable byproduct of how my case was managed by the medical profession.

I have complete Androgen Insensitivity Syndrome (AIS), which is characterized by XY chromosomes and testes, but a complete inability, due to an androgen receptor defect, of the body to respond to the testosterone produced by the testes. Unable to virilize, my body, by preordination, simply developed along a female path. In my case, this was discovered 10 days after my birth, when my pediatrician noticed a swelling in my groin, suggesting a hernia. Exploratory surgery performed at two weeks revealed the presence of what seemed to be a testis. When the lab report confirmed this, my parents were told that it was medically necessary for them to consent to immediate gonadectomy. Lacking any better insight, they of course gave their consent.

In fact, there was no urgent medical necessity; my testes could have remained safely intact until puberty, at which time they should have been removed to prevent any risk of cancer. But I strongly suspect that there were pressing "psychological" necessities for their removal in infancy: (1) my doctors' desire to rid me of any vestige of a male anatomy and render my body "congruent"; (2) the equal desire to avoid the need at puberty to explain the nature of the surgery that would have to be performed, raising questions the doctors did not want to have to answer; and (3) shards of a superstitious fear that, despite what medicine knew in 1958 about "testicular feminization" (as it was then called), I might somehow virilize if my troublesome gonads were left intact.

Unlike Hanukkah, where my parents were sufficiently inculcated with the traditions of their religion to inoculate them against the pressure to conform to the dominant messages surrounding them, my parents are not, alas, intersexed, and so to learn the "culture" of what this meant to their child they had to rely on doctors to translate the language and meaning of words such as

"chromosomes" and "gonads" and "pseudohermaphrodite." Unfortunately, like most doctors even today, my doctors were steeped in a tradition that viewed intersexuality as a tragedy—a mistake of nature to be corrected, to the maximum extent possible, by medicine. This culture had been handed down to them without any concern for the long-term outcome of the recipients of such treatment protocols. Thus, they became self-appointed tour guides to a foreign country when they themselves had not bothered to ever communicate with the natives.

My experience over the past three years assisting families affected by AIS informs me that the most critical variable to achieving a better outcome for intersex patients is not surgical management followed up with platitudes and half-truths, but instead is the provision of resources for parents to be thoroughly educated about what intersex is, and to work through any anxiety or guilt they feel about having an intersex child. When parents are able to communicate their comfort and acceptance, the child's self-esteem can develop from a solid foundation. When parents are, by contrast, apprehensive, fearful, or ignorant about intersex, their child is left to flounder in a sea of confusion without support. Regrettably medicine has seen fit to "correct" what is between the child's legs while offering limited educational assistance and psychological support to either the child or her/his family.

Indeed, the sole instruction my parents received from my endocrinologists was one of "damage control," calculated to confirm a solid image that I was their daughter in the same breath that doctors enjoined them that they should not disclose my true diagnosis to anyone, least of all me. While informing my parents that I was "just like a normal female," my doctors offered no suggestions other than fabrication about how they should help me cope with the reality of having XY chromosomes and testes while lacking ovaries, a uterus, fallopian tubes, or fertility.

Fortuitously, my surgeon failed to diagnose that I have a vagina incapable of intromission; had he done so he likely would have suggested

vaginoplasty, a procedure that continues to be recommended in childhood to this day, despite its nearly 80 percent failure rate when performed prior to adolescence. Had I had been born with more ambiguous looking genitals, the solution offered would have been more surgery, most likely to make my genitals appear "female," even at the expense of diminishing sexual sensation. Cultural imperative, masquerading as medical necessity, would have made such additional surgeries inevitable.

I spent my adolescence filled with shame, though I was never told the true details of my diagnosis. My trauma was needlessly compounded by my doctor's stony silence while examining me, and his asking me to lie naked on an examining table so that teams of interns and residents could inspect my genitals. Such experiences themselves, far more than the true facts I later learned about the nature of AIS, instilled a sense of freakishness that I have only recently shaken. It is, however, disheartening to hear that similar treatment of intersex adolescents continues to this day.

Ultimately, I unearthed the truth about having AIS in a medical school library when I was 20 by researching the possible causes for my primary amenorrhea and lack of pubic hair. It is disorienting when you have always considered yourself female to learn that you have XY chromosomes and once had testes. It is equally disorienting when you have always considered yourself loved and cared for to discover that your parents and doctors have lied and left you to your own devices to discover this truth.

I appreciate that because I am 40 years old my treatment protocol was a product of 1960s thinking. I am frightened, however, that as we approach the turn of the millennium conventional medical treatment continues to endorse a nearly identical protocol. Doctors continue to debate the patient's right to know the truth, seemingly oblivious to the idea that they do not "own" the patient's medical information. This conspiracy of silence stems from the same root as the continuing protocol to surgically alter inter-

sex infants' anatomies—an inability to see intersex as anything other than shameful and pathologic. This, in turn, is communicated to the parents, whom I believe would be far less traumatized by the reality of intersex if they weren't receiving such negative cues from doctors.

Regrettably doctors fail to offer appropriate psychological support to parents or even communicate that the capacity to give and receive love is a function of the size of one's heart, not the size or appearance of one's genitals. Yet this capacity for healthy relationships is threatened at best, and more typically destroyed altogether, through the toxic mixture of silence and surgery which is offered up as the only "solution" to the child's intersex "problem."

In the aftermath of such surgery, doctors behave as though the "problem" has been cured ("you used to be intersexed but we fixed it")—as though being intersexed were an historic detail of the patient's life. Unfortunately, this too is communicated to the parents, who, in turn, assume that there is no need to offer their child a safe place to mourn and grieve what has occurred, or to help their child ascribe meaning to being intersexed. Often the parents are sufficiently uncomfortable and guilt-ridden about the whole affair that they are highly motivated to accept the doctor's revisionist history of the child's intersex state. Thus, the child has endured a personal holocaust while having to remain mute.

I believe, based upon my experiences overseeing the U.S. branch of the AIS Support Group, attending 10 AIS Support Group meetings in the U.S. and the U.K., and getting to know more than 100 intersex people, ranging in age from two months to 73 years, that under the best of circumstances learning the truth about being intersexed can be temporarily traumatic. But not knowing the truth culminates in experiences that are almost universally tragic. With limited inaccurate information, and in the face of an overarching sense of shame, the mind conjures a parade of horrors far worse than any truth. Indeed, of the more than 60 women with AIS whom I personally know, I have not heard of a

single instance where someone has reported that it was worse to know the truth than to live with lies.

Fortunately, many pediatric endocrinologists are endorsing the approach of truthful disclosure at the same time that they are revisiting the wisdom of surgical management of intersex. Apart from the ethical implications of a protocol rooted in dissimulation, the paradigm of deceit is, quite simply, shortsighted. The reports of women affiliated with the AIS Support Group reveal that patients are driven to learn what it is about themselves that seems to cause a palpable silence whenever they are examined by doctors or broach the subject of their childhood/adolescent gonadectomies. To that end, some members of our support group became expert in reading their medical charts upside down, while others inspected their files when their doctors momentarily left the examining room.

But there are even more unusual, and often painful, ways this information is obtained. Some members report the "dreaded" information spilling out in the heat of arguments with stepparents or siblings. One woman in our U.K. group literally discovered she had AIS by buying a house. She applied for a mortgage which required that she provide proof of good health. To do so she had to sign a medical release. She had never been told she had AIS—just that she had an "ovarian" problem and couldn't have children, but that this had no bearing on her health. She innocently signed the release. A few weeks later her mortgage company called her and said "Everything is fine but we need to know what this 'androgen insensitivity' thing is all about."

It is important to note that the significance of truth-telling has increased with the advent of intersex support groups, such as the AIS Support Group, the Intersex Society of North America, and the Coalition for Intersex Support Advocacy

and Education. These support groups provide a culture for intersexuals as well as validation of feelings; they offer enormous psychological relief for parents of intersex children, as well as intersex adolescents and adults.

To illustrate, in the case of AIS, many parents are understandably concerned about how they will communicate to their daughters that they have XY chromosomes; these parents are typically uncomfortable about this fact themselves. However, at a recent meeting of the AIS Support Group our members decided to take a photograph with the adult women with AIS, and the fathers of children with AIS, forming "Y's" with their arms while the mothers of such children crossed their arms to form "X's." The ability to defuse tension about "the chromosome thing" quite visibly allowed these parents to feel more comfortable and accepting of the entire issue.

Perhaps it is fitting that I have used a holiday theme in this article. For it was the day after Christmas in 1994 when I first discovered, while researching in a medical school library, that an AIS Support Group had recently been founded in the U.K. No gift I will receive in this lifetime will ever be as precious to me as discovering that information. My subsequent involvement with the support group has, remarkably, allowed me to view having AIS as a blessing—after all, if I didn't have AIS I would not have developed into the woman I believe God and nature intended me to be. This was certainly not the outcome my doctors would have predicted on a chilly September day when they removed my gonads and implored my parents never to tell me the truth. The miracle of life, however, is that we can evolve; I hope, in this holiday season, that this same miracle can touch those who will be privileged to care for the intersex children born while this article was being read.