Title: Pediatric Ethics and the Surgical Assignment of Sex

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Abstract

It has been standard pediatric practice to recommend surgery for infants with ambiguous genitalia or loss of the penis. The parents of these patients are told to raise them without ambiguity and, in consequence, many adults who have had these operations in infancy have never been candidly informed of their medical histories. This management approach, which can involve a reassignment of sex, has its basis in research done on hermaphrodites and a single set of identical twins originally tracked more than two decades ago. The current article reviews this practice and its epistemic foundations. It is argued that there should be a moratorium on such surgery; that the medical profession should complete comprehensive lookback studies to assess the outcomes of past interventions; and that efforts should be made to undo the effects of past deception.

CASE REPORT

In 1983, one of the authors of this study (KK) received a call from a pediatric surgeon to do a clinical ethics consultation following the birth of a full-term baby boy with multiple congenital anomalies. While other deficits will be described below, the surgeon was immediately concerned about the child's abnormally small penis: technically, a micropenis. Apprehensive about the possibility of the child being shamed in the boys' locker room -- psychosocial distress as he matured -- the pediatric surgeon was counseling immediate surgical reassignment as a girl. According to the surgeon's plan, the testes would be removed and the genitalia fashioned into a cosmetic vulva before the baby left the hospital. The parents would be instructed to raise the infant as an unambiguous girl. At about the age of 12, estrogens would be administered to stimulate the development of female secondary sex characteristics. Eventually doctors would create an artificial vagina. Although the resulting woman would be unable to bear children, the surgeon anticipated that prompt surgical attention would allow the infant to enjoy a better and more normal life as a female than would be possible for a male with a very small penis.

The boy's mother was livid with rage and bitterness. Having given birth only days earlier, her dreams of a perfect child had disintegrated into a nightmarish reality. Pronouns were failing her and she did not know what to say to relatives. Communication had broken down with the surgeon and she was unable to discuss reassignment with him much less consent to it. It fell to the ethics consultant to try to resolve the impasse by investigating the issues and making a recommendation. Research went in two directions: a survey of the literature on ambiguous genitalia and an inquiry into the medical condition of the infant. It was in the context of this case that the authors of the present article first began to work together: the philosopher-ethicist consulted with his colleague (MD) across the campus at the John A. Burns School of Medicine.

The literature review led immediately to the work of John Money, then a psychologist at the Gender Identity Clinic at The Johns Hopkins University. In a series of articles and a landmark 1972 book (Man & Woman, Boy & Girl)[1] Money described the case of a pair of identical male twins born in the 1960s. At the age of 7 months, the boys were scheduled for circumcision because of phimosis (a narrowing of the opening of the foreskin). An electrocautery knife used on one of the boys severely burned his penis, destroying it. A psychiatrist at the time expressed what one supposes was the conventional wisdom about the boys probable future: "He will be unable to consummate marriage or have normal heterosexual relations; he will have to recognize that he is incomplete, physically defective, and that he must live apart..." (Quoted in Colapinto.)[2]

Crushed by the loss, the parents learned of Money's work at Johns Hopkins and the early sex-change operations that were being done there. Following consultation, Money recommended to the parents that the boy be surgically reassigned and raised as a girl. Accordingly, at the age of 17 months, surgeons removed his testes and reshaped his scrotum to approximate a vulva. John, as he later became known in the literature, had become Joan, to be raised as a normal girl without any suspicion of early trauma.

Money's earlier research had convinced him that hermaphroditic children who appeared physiologically similar to each other could nonetheless develop into adults identifying and behaving either as men or as women.[3, 4] Inferring from this work that all infants are sexually neutral at birth and malleable during a window period that remains open until about 18 to 24 months when gender becomes fixed, Money concluded that social imprinting and learning were the key factors in psychosexual development: an account that was consistent with research in language acquisition. Finally, echoing Freud,[5, 6] Money surmised that the presence or absence of the penis was the critical anatomical factor. In a nutshell, the theory held that sexually neutral infants, both consciously and subconsciously, notice the presence or absence of a penis, observe the social distinctions between males and females, and characteristically comport with local standards of gender. Thus, given an unambiguous upbringing, normal behavior would follow perceived anatomy. While earlier reports

had described the reassignment of infants with ambiguous genitalia, the appearance of unambiguously male identical twins, one needing attention, offered an unparalleled opportunity to confirm the theory of sexual neutrality at birth.

The twins were evaluated regularly at Hopkins and, in a series of celebrated publications[1, 7, 8] Money described their psychosexual development to about the onset of puberty: the one surgically reassigned as a girl and the other identical twin, in effect, a control. Glowingly relating remarkable results, Money wrote in 1975: "No one . . . would . . . ever conjecture (that Joan was born a boy). Her 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."[8] Reported in professional publications and the national media,[9] Money's writings dramatically confirmed the plasticity of gender: an infant, born as an unambiguous male, had been surgically reassigned as female and successfully reared as a normal girl.

Drawing on Money's research and his theory of psychosexual development, pediatricians caring for infants with ambiguous genitalia inferred that genetic makeup and prenatal endocrinology could largely be ignored in the clinical assignment of sex. They reasoned that the penis had to be plainly absent or present from infancy on, and that these children had to be raised as girls or boys with no hint of abnormality. Accordingly pediatric surgeons would strive to benefit these patients by “normalizing” ambiguous genitalia: reducing enlarged clitorides (eliminating visible penis-like structures in babies assigned as females) and, because of the technical difficulty creating functional and cosmetically believable male genitals, refashioning anomalous male genitalia as female.

Well before the 1983 birth of the boy with micropenis, Money's published work had emerged as the epistemic foundation for the new pediatric standard of practice. Thus it was clear why the surgeon wanted to reassign the baby boy as a girl. Pediatric textbooks, then and now, characteristically recommend surgery when the size of the stretched penis is less than about 2.0 centimeters[10, 11, 12] or when the size of the clitoris is greater than about 1 centimeter.[13, 14] If surgical disambiguation could succeed with an infant born unambiguously male, it would -- it was thought -- surely benefit other babies with ambiguous genitalia. These medical interventions, done with parental consent, as soon after birth as possible, were taken as beneficial, like the pediatric correction of cleft palate. The hermaphrodite and twin studies, it was thought, provided evidence that surgery benefited children with ambiguous genitalia and that, eventually, as one would suppose for infants with cleft palate, they too would have reason to thank their parents and doctors for medical ministrations received as infants

While the literature supported the surgeon's 1983 recommendation, doubts arose following inquiry into other aspects of the boy's medical condition. There were other congenital anomalies. A second physician called attention to the boy's undeveloped eyes; the baby was blind. There was evidence of deafness and a probability of other central nervous system deficits the nature and extent of which had not yet been determined. Accordingly, the child was unlikely to experience locker-room derision and might even go through life without being conscious of gender. The ethics consultant concluded that surgery could not be expected to benefit this particular patient and recommended that reassignment be delayed indefinitely. The surgeon and the parents concurred and the procedure was not done.

While more can be said about this case, here we want to observe both the narrowness of the clinical vision -- the focus of attention initially did not extend above the pubis -- and the mechanical application of a standard of practice calling for surgical reassignment on the basis of micropenis. We will revisit these themes below.

THE FURTHER HISTORY OF JOHN/JOAN

Notwithstanding that Money's twin study had only a single experimental subject and a single control, his publications were nonetheless decisive in establishing what quickly became the standard of practice in pediatrics. As recently as April of 1996, the American Academy of Pediatrics (AAP) issued recommendations governing the Timing of Elective Surgery on the Genitalia of Male Children . . . :

> Research on children with ambiguous genitalia has shown that sexual identity is a function of social learning through differential responses of multiple individuals in the environment.[4-6] For example, children whose genetic sexes are not clearly reflected in external genitalia (i.e., hermaphroditism) can be raised successfully as members of either sex if the process begins before the age of 2 years. Therefore, a person's sexual body image is largely a function of socialization.[15]

The three works cited by the AAP in support of these findings list John Money as the lead author. No corroborating research is referenced. In fact, Money's theory and recommendations had been vigorously challenged in medical and scientific literature.[16, 17, 18, 19]

Suzanne Kessler has written: "Almost all of the published literature on intersexed infant case management has been written or co-written by one researcher, John Money. . . . Even though psychologists fiercely argue issues of gender identity and gender role development, doctors who treat intersexed infants seem untouched by those debates. . . . Why Money has been so single-handedly successful in promoting his ideas about gender is a question worthy of a separate substantial analysis."[20]

It is worthwhile to note that as early as 1966, medicine was coming to terms with transsexuals, individuals whose sexual self-identification is in opposition to their genital configuration and rearing.[21] Despite appropriate anatomy and socialization, the existence of these adults should have stimulated the AAP to question its acceptance that "sexual identity is a function of social learning."

It is conservatively estimated that 1 in 2000 newborns are found to have ambiguous external genitalia[22] that 100-200 pediatric surgical sex reassignments are performed in the United States annually, and that, globally, thousands of these procedures have been done since the initial publication of the twins case (estimate by Dr. William Reiner in Colapinto).[2] It is notable that, notwithstanding more than three decades of clinical experience with the surgical reassignment of infants, there have been no systematic large-scale studies done to assess the outcome of these procedures. (Some small scale reviews by Kessler,[20] Schober[23] and others will be discussed below;) It is

also notable that Money's narrative of the twins case ends before his subjects reach adolescence. In his last update, in 1978, Money writes: "Now prepubertal in age, the girl has . . . a feminine gender identity and role distinctly different from that of her brother.. . .The final and conclusive evidence awaits the appearance of romantic interest and erotic imagery."[24] This evidence never appears and John/Joan, like many of these patients, is "lost to follow-up."

While several recent developments have called into question the venerable basis for the standard of pediatric practice, perhaps the most dramatic has been the reopening of the John/Joan case. In 1994, one of the authors of this study (MD) located and interviewed the former research subject. A richer and more comprehensive picture has emerged of the childhood that loomed so prominently in the literature of the 1970s.[25]

In a nutshell, the child never was and never became a normal girl. Now in his thirties, having married a woman with three children, John lives as a man. He, his mother and brother now recall that Joan regularly rejected girls' toys, clothes and activities. His mother says that, despite an attractive female appearance, Joan's movements and speech "gave him away and the awkwardness and incongruities became apparent."[18] John's twin brother has said: "When I say there was nothing feminine about Joan, I mean there was *nothing* feminine. She talked about guy things, didn't give a crap about cleaning house, getting married, wearing makeup" (emphasis in original). At the age of six or seven, Joan told her brother she wanted to be a garbage man: "Easy job, good pay."[2] Despite the absence of a penis, Joan often stood to urinate. Other girls at school eventually barred her from their bathroom, threatening to kill her if she came in. Eventually she would use a back alley for urination.[25] Contrary to Money's earlier reports, Joan's behavior during childhood failed to be "so normally that of an active little girl."

Despite rearing as a girl, Joan dreamed of a future as a he-man type with a mustache and sports car. Although placed on estrogens at the age of 12, she often discarded the drugs, disliking how they made her feel. She was disturbed by her developing breasts. At one point she told her endocrinologist that she had suspected she was a boy since the second grade. She adamantly refused the surgery that would give her a vaginal opening and complained to her psychiatrist how she dreaded the trips to Johns Hopkins where people looked at her and showed her pictures of nude bodies. At the conclusion of her final visit in 1978, Joan told her mother she would kill herself if she had to go again. By 1980 Joan's relationship with her clinicians at Hopkins had reached impasse. "Do you want to be a girl or not?" her endocrinologist had demanded. "No!" replied Joan emphatically. At the age of 14, without knowing the history, she decided to cease living as a girl: Joan became John.[2, 25]

Following the transition, John's father, on the advice of a psychiatrist, revealed what had happened during infancy. Until that moment her parents and clinicians had tried to conceal all that was problematic about her gender, to give her the unambiguous rearing as a girl they were told to provide. Listening intently to his father tell the story of the botched circumcision and surgery, John experienced relief. A puzzling past began to make sense. At John's request, male hormones were subsequently administered, a mastectomy was performed, and surgeons eventually created a penis. John now takes satisfaction as a husband, father and breadwinner.

In retrospect, it seems clear that the surgical refashioning of infants' genitalia must be assessed during the adulthoods of those patients, after the sexual organs take on their distinctive importance in intimate and procreative relationships. To judge success by genital appearance and psychosexual development prior to puberty is to fall victim to narrowed vision.[26] When viewed comprehensively, the life of John/Joan undercuts both the standard of practice and the theory that children observe the distinction between male and female, and comport with local standards of gender. Though Joan learned all she was supposed to, her behavior nonetheless exhibited quintessential male elements and she failed to identify as female. Social imprinting did not occur. In the end, the medical intervention had added the insults of infertility, emotional trauma and ego loss to the injury of an accidental penectomy. Castration now necessitates a continuing regimen of male hormone replacement.

OTHER DEVELOPMENTS

The outcome of the John/Joan case has been observed with comparable patients. In a recent and ongoing study Reiner tracked six boys who had lost their penises in infancy and were being reared as girls. These children behaved more like boys than girls and, in two cases, not knowing they were XY, the children autonomously changed gender and assumed male roles.[27]Reiner has stated: "it would be wrong to say that these two children wished to be boys or felt they were boys in girls bodies: they believed they were boys." (Quoted in Colapinto.)[2]

Another significant development has been the emergence of the Intersex Society of North America (ISNA) and related advocacy and support groups. The ISNA membership includes adults who were surgically "normalized" as children, generally without being told, and other intersexuals who have not had surgery. Having attempted unsuccessfully to dialogue with medical organizations in the U.S., some intersexuals have taken to picketing hospitals and conferences.[28] Unlike those with surgically corrected cleft palates, intersex patients are condemning physicians for their surgeries and for withholding the truth about their medical condition and treatment. The John/Joan case, the Reiner study, the activist protests and other cases reported in the literature,[29, 30, 31] strongly suggest that pediatric reassignment may often be failing the thank you test for clinical beneficence,[32] and that these poor outcomes may not be isolated droplets of misfortune in a downpour of excellent results.

There is some research exploring what happens when infants do not receive surgery. One well known outcome study has been done on adult males with micropenis who have never been operated upon but would have been reassigned in infancy as females under the present standard of practice. Of 20 such males, 12 were postpubertal 17 to 43 years old. While 6 of these dozen admitted to having been teased about a small penis, all 20 patients “felt male,” were gynecophilic and all had erections and orgasms. Nine had sexual intercourse satisfactory to themselves and their partners; seven were married or cohabiting, and still others were sexually active. One

had become a father.[33] A separate paper reported success in helping men with very small penises who presented at a clinic for counseling. All were sexually functional. They and their partners were able to come to terms with their differences.[34] Contrary to conventional wisdom, it is not inevitable that such a man must "recognize that he is incomplete, physically defective, and that he must live apart."

The locker-room argument -- that an individual without a penis, would be subject to ridicule by peers -- has recently received attention. A pre-operative female-to-male transsexual has related showering routines that allow one to manage without embarrassment.[35]

A review of the literature has failed to turn up a single article on the hazards, psychosocial or otherwise, of having a large clitoris.[23] Most individuals are not aware that a size standard exists and, indeed, in some cases the parents were unaware of the presence of their daughters hypertrophied clitoris until clinicians pointed it out in the context of recommending surgery.[20] On the contrary, there are reports of such women and their sexual partners enjoying the configuration (personal cases of MD). For women who have had the surgery, some retain a capacity for orgasm[36, 37] while others complain about pain and insensitivity.[37, 38] Research has not] shown that any of the reduction procedures in use reliably preserves full erotic sensitivity to adulthood.

Finally, Kessler has polled adult men and women on their attitudes toward surgery in infancy.[20] Women were asked if they would want surgical correction had they been born with a clitoris of 1.0 to 2.5 centimeters. Ninety-three percent said they would have not wanted treatment unless the condition was life threatening and the surgery would not reduce pleasurable sensitivity. Over half of the women would not have wanted the surgery even if the condition were unattractive and made them feel uncomfortable; twelve percent of the women would not have wanted the surgery under any circumstance. Men were likewise asked whether they would want reassignment as a female had they been born with micropenis. Over half would not have wanted the reassignment under any condition. Almost all would have refused surgery if it reduced pleasurable sensitivity or orgasmic capability. The responses of Kessler's subjects are consistent with the reasonable view that the roles that procreative capacity and sexual pleasure play in intimate adult relationships are far more important than the normality of genital appearance, especially given that the unusual anatomy is almost always concealed. While the clinical and academic debate as to the rationale for such surgery continues[37, 39, 40] the pediatric standard of practice makes precisely the opposite ranking

SEX AND GENDER

The conceptual distinction between male and female persons (men/women, boys/girls, ladies/gentlemen, etc.) is standard cognitive equipment in culture, deeply implicated in self-identification and social ideology. Particularly in the West, it is taken for granted that humanity comes in two mutually exclusive sexes, that these are readily distinguishable at birth by the presence or absence of a penis which, in turn, signals a vast array of other permanent physiological and behavioral variations, both present and in the developmental future. Most of us check off the M or the F box and choose the corresponding clothing, hair removal patterns, rest rooms, careers, urination positions, intimate partners, and underarm deodorants.

Intersexuality -- biologically variant sexuality -- disturbs the conventional: both our institutional practices and our ways of thinking and behaving. Though we are typically educated to think in binary terms, there are common medical conditions that move human beings away from the male and female norms. In this context it is useful to sketch and explain some of the principle dimensions of "normality," both at the biological level (i.e., sexuality) and the psychosocial level (i.e., gender). We now sketch some complexities of sexual variation in the light of everyday concerns.

Locker-room appearance: At the biological surface is what we look like in the locker room: male or female? While typical male and female genitalia (and breast development) represent the familiar bimodal distribution, there is a full spectrum in between.

External Genitalia: The roots of sexual difference are to be found in embryology. It is a useful oversimplification to see baby girls as the default outcome of gestation, the developmental route that is taken unless androgenic hormones are present. For XY (male) embryos, a region on the Y chromosome induces the development of testes from undifferentiated gonadal tissue. The testes in turn produce virilizing androgens in sequences and quantities that can cause that which would otherwise become the labia majora to fuse into a scrotum, and cause that which would otherwise become the labia minora and clitoris to elongate and enlarge into a penis. In the absence of male hormones, which also inhibit feminization, the gonads become ovaries and the vagina and uterus develop.[41] Apart from differences in size and shape, common visible anatomical variations for XY males include hypospadias, where the penis is open at some location other than at the end; bifid (divided) scrotum; and undescended testicles. Conversely, an XX female may have an enlarged clitoris, an absent or shallow vagina, partially fused labia, and so on.[42] In sum, external genitalia can be typically male, typically female, or virtually anywhere in between. A very large clitoris and a very small penis may be indistinguishable except for the term used to describe them.

Functionality: There are three principle dimensions in which normal function can be assessed. The first takes into account the individual's ability to have sexual intercourse. Is there a functional penis or vagina? A second dimension takes into account erotic potential. It is common for genital surgery to compromise erotic sensitivity and, to that extent, the intimate relationships that depend upon it. The third dimension considers reproductive potential. Is it possible to become a genetic and/or gestational mother or a genetic father?

Gonads: It is possible to have both ovarian and testicular tissues: true hermaphrodites have both. Gonadal tissue may also be undifferentiated in an adult: neither testicular nor ovarian or it may be of unclear character and formation (mixed gonadal dysgenesis). And gonadal tissue may be completely absent.[42]

Endocrinology: This dimension calls attention to hormone levels, their timing, and the body's responsiveness to them. Among many variations, two common ones can serve as examples. A condition called congenital adrenal hyperplasia (CAH) causes some XX female fetuses to develop male-like external genitalia. Their adrenal glands produce large amounts of androgens, virilizing the fetus.[42] These children will sometimes menstruate through the phallus after puberty. A second condition called androgen insensitivity syndrome (AIS) causes XY male fetuses to develop female external genitalia. Their normal testes produce androgens but, because of a cellular abnormality that partially or completely inhibits response to the hormone, gestational development is unaffected and proceeds toward a female external morphology at birth.[43]

Genetics: In addition to the most common XX and XY karyotypes, there are also, for example, XO (Turners' syndrome, a sex chromosome missing), XXY (Klinefelter syndrome), XYY, XXXY, XXYY or XXXYY. Embryos can also develop with XX cells in one part of the body and XY or other type cells in another part (mosaicism).[44]

Central Nervous System: Hormones also organize the brain to bias an individual for future male-typical or female-typical behaviors. Laboratory experiments on mammals, for example, have elicited male behavior patterns in adult XX females after *in utero* exposure to androgens at critical stages of fetal development.[45, 46] Likewise, female behavior patterns have been promoted in XY male mammals by prenatal exposure to anti-androgens.[47] Analogous phenomena have been observed with humans. This type of research supports the view that prenatal endocrinology biases psychosexual development by affecting the central nervous system. Rather than having been born neutral, the androgen-rich ambiance in which John/Joan's brain developed probably accounts for her later masculine behavior and her suspicion, against the evidence, that she was really a boy.[41, 48]

Psychosocial Life: While it remains to be seen how deeply our gendered behavior is neurologically hard-wired, there are at least three aspects of it that deserve consideration. The first calls attention to one's *sexual identity*. How does one see oneself at the deepest level? In addition to female and male, some now self-identify as intersexed. The second calls attention to one's *gender role*. How does one present publicly in dress, speech, gesture and so on, as man or woman? And the third calls attention to *sexual orientation*. The condition of intersexuality precludes the application of terms like hetero- and homosexuality that conceive sexual desire, and its idealized object, in relation to the subject's sex. Instead, we reaffirm the recommendation to substitute the terms androphilic, gynecophilic, and ambiphilic.[30]

Because variation occurs independently at many of these levels, the total number of biological/psychosocial possibilities will be very large indeed. The study of intersexuality forces us far from the view that humanity comes in two mutually exclusive sexes, readily distinguishable at birth by the presence or absence of prominent external genitalia.

The discussion so far highlights four critical limitations in our capacity to manage intersexuality clinically. First, in the face of what to many is an astonishing variability, it appears impossible to draw any bright line that decisively and non-arbitrarily separates men and women. Second, even if there were such a procedure, parents lack the ability to engineer the psychosocial development of a target gender.[49] Third, we are unable to predict with confidence the gender that an intersexual newborn will settle into during adulthood. (Indeed, we are often enough mistaken even with anatomically typical infants.) And finally, given the deep and largely uncharted pervasiveness of the effects of being a typical male or female, it is unlikely that surgical reassignment will ever truly "normalize."

In the face of these four practical limitations, and the high probability that they will long endure, it may be time to accept that sex and gender have never been strictly binary; that, on the contrary, there have always been persons in between. In some cultures -- various American Indian tribes and societies in Africa and New Guinea for example -- there are societal categories for persons who are neither men nor women as we understand these terms.[50, 51] Intersexuality is common and understandable. Rather than an occasion for emergency surgery and concealment, the birth of a baby with ambiguous genitalia may be an occasion for medical, parental and social humility and reflection, perhaps even for celebration.

But, as Alice Dreger suggests,[52] the standard of practice represents, not humility at all, but a striking appropriation by doctors of the authority to use the arts of medicine to police the boundary between male and female in the defense of cultural norms. Whether this *hubris* is intentional or not, the surgical concealment of intersexuality lends support to those who take for granted that there are but two sexual configurations, each associated with a distinct gender and sexual preference. In making available routine procedures for reconciling deviant anatomy to cultural expectations, medicine vastly empowers the implementation of "normality" even, we would add, as it diminishes the value of difference.

Several commentators have observed the analogy between "normalizing" genital surgery and what has been called "female genital mutilation" as practiced on young girls in Islamic Africa. While both impose morbidity and loss of function in the course of conforming a child's genitalia to cultural expectations, medicine has been vocal in its condemnation of the latter even as it continues to recommend the former. We question whether physicians should ever sacrifice the organic functionality of any nonconsenting child -- Somali or American -- on the altar of cultural expectation.

THREE RECOMMENDATIONS

FIRST RECOMMENDATION: That there be a general moratorium on such surgery when it is done without the consent of the patient.

In arriving at this first recommendation, we do not appeal to the premise that normalizing surgery in infancy does more harm than good. As noted earlier, the large-scale studies that could confirm this have yet to be done. While only a skeptical premise is warranted -- i.e., that we do not now know that surgery does more good than harm -- it suffices nonetheless to justify a moratorium.

As a firm rule, doctors should never undertake surgery, especially without consent, unless there are disproportionate hazards associated with all of the other options: Above all, do no harm. The presumption has always to be against surgery unless two types of evidence are at hand. First, one needs to know that comparable patients generally do well after the surgery: such data are not at hand regarding the adult beneficiaries of these surgeries. And second, one needs to know that comparable patients generally do badly without the surgery. Since surgery is always harmful per se, it should never be done unless there is an expectation of ample compensating benefits. Because this evidence is lacking, the surgical assignment of sex remains an experimental procedure: one in which the results cannot be properly assessed until at least 20 years after the intervention.

Accordingly, it is not possible for a patient's parents to give informed consent to these procedures precisely because the medical profession has not systematically assessed what happens to the adults these infant patients become. Doctors can't tell parents what the long-term risks and benefits are because they haven't done the studies and don't know.

With the publication of the rest of the John/Joan story, and the additional research sketched above, the standard of practice appears to have lost the epistemic foundation it was earlier thought to have. And yet for some reason these operations continue despite the erosion of their justification. We recommend that all pediatric surgical assignments be suspended until these issues are resolved.

Two caveats: We are not arguing that medically justified surgical interventions be withheld. Many conditions -- bladder exstrophy, certain types of CAH -- are associated with risks of morbidity, mortality and loss of function. Such conditions should always be treated appropriately. And second, we are not suggesting that intersexual children be raised without gender. The choice of gender assignment should take into account the infant's condition, including its causes, and whatever is known about the prognosis.[53] The aim must be to raise infants in a way that will most probably turn out to be comfortable for the maturing child. But gender assignment has to be provisional, subject to revision by the intersexual child as he or she matures. Our objection is to the surgical assignment of sex, not to gender assignment per se.

SECOND RECOMMENDATION: That this moratorium not be lifted unless and until the medical profession completes comprehensive lookback studies and finds that the outcomes of past interventions have been positive.

In part, this recommendation emerges from sympathy with the view that early surgery may be medically indicated for some types of intersexuality. We need to know more, for example, about the high incidence of cancer in cases of mixed gonadal dysgenesis.

But a stronger justification flows from medical integrity: the profession's ethical commitment to learn as much as it can, even when it makes mistakes.[54, 55] Luckily, a 20-year double-blind prospective study is unnecessary. There are now many thousands of grown intersexuals who have and who have not had surgical and hormonal treatment. Retrospective outcome studies can now be done on these adults, uncovering the comparative effects of treatment and nontreatment. The willingness to subject its practices to honest scrutiny is part of what any profession owes to the community it serves, part of what makes the profession worthy of its community's trust.[56] Pediatrics has an obligation to assess the mature products of its handiwork.

Finally, these studies may be of significant benefit to intersexuals themselves. If the studies find these patients to be at risk for certain medical conditions, this information should be passed along so they can plan and act accordingly.

THIRD RECOMMENDATION: That efforts be made to undo the effects of past physician deception.

For years, pediatric surgeons have stressed the necessity of rearing post-surgical intersexual infants as unambiguous boys or girls. We do not question that. However, in implementing this approach, parents and clinicians have often concealed aspects of surgery and treatment from the child and excluded maturing children from medical management decisions. Joan Hampson, one of Money's early co-authors, has remarked: "Oddly, even in children old enough to have some opinion, in our experience it has been rare that they have been given any opportunity to express it."[57] This practice can take the form of a well-intentioned albeit deceptive conspiracy between family and clinicians and against the child.

Taking the long view, one might ask when, if ever, these former patients should be told of their medical histories. Should it be the intention, at infancy, that these patients never be told or, rather, is the mature or maturing patient entitled to know? There is no standard that the pediatrician advise parents to disclose when their child reaches puberty or adulthood or at any other time. Adults who have had these procedures in childhood are now presenting at clinics quite ignorant of their history.

This secrecy does damage to the patient. For success in deception entails that the adult patient not understand his or her medical condition. Just to the extent that these adults are misled, they cannot act rationally out of a realistic appraisal of their situation.

But a second objection proceeds from the observation that these cultivated illusions cannot be nurtured reliably and indefinitely. Often patients will discover their condition from an inadvertent family slip, community gossip or personal investigation into puzzling aspects of their lives. As these children mature into full adulthood and initiate independent clinical relationships, the web of deception will weaken, at least to the extent that the patient develops genuine relationships of trust and confidence with doctors. Unless the entire profession is complicit (thereby ruling out genuine relationships of trust and confidence), one must expect that the truth will emerge. And when it does, the patient will learn anyway what she or he was never supposed to have found out. (If the patient is going to find out anyway, surely it is better for the physician to initiate disclosure.) Even more disturbing than discovering the secret, the former patient will also discover that his or her deformity is unspeakably shameful in the minds of parents and physicians. Last, the former patient will learn that she or he has since childhood been systematically deceived by the very people who should have been the most trustworthy. These patients will often avoid physicians and become estranged from their parents. All this is damaging. Most of it is needless.

On a broader scale, it will not be only those patients who learn that physicians are willing to participate in deception. It will be the general community who come to know that doctors choreograph familial mendacity: this is what the former patients are saying.

We recommend that the medical profession find ways to own up to these adults, initiating disclosure of the medical histories doctors have helped to conceal from their former pediatric patients. In addition to the ethical obligation, clinicians may even have legal duties to warn their former patients when matters of importance are discovered.[58]

One final conjecture. It may well be that this lack of candor is at the root of the profession's failure to do the needed outcome studies, the reason why so many former patients are "lost to follow-up." For researchers cannot easily question former patients on the effects of surgery done in infancy when those same patients have never been informed of the surgery, let alone the reasons for it. Although our recommendations are threefold, they speak to a single complex problem. Parents cannot be informed of the expected outcome of the pediatric surgery because the adult outcome studies have not been done. And the adult outcome studies have not been done because these adults have not been informed of the surgery. We may have here an epistemic "black hole" that entraps parents, patients, and physicians in lies, secrets, and avoidable ignorance. While it will take intellectual integrity and professional courage for these pediatric practitioners to extricate themselves, we expect the profession will rise to this occasion.

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Should the parents choose the assignment of the sex to a newborn child and subject them to a life of surgery and doctor visits? There are 100 to 200 pediatric surgical reassignments every year. Many of these children are subjected to doctor visits for the rest of their childhood.Â Conditions That Qualify for Gender Reassignment: Over the past five decades, surgical interventions have been recommended as standard procedure for infants who are born with either ambiguous genitalia or who suffer from traumatic genital injury. Surgical advances in this century have made it possible for physicians to choose a gender for the child and then sculpt the appropriate genitalia. The ethics consultant concluded that surgery could not be expected to benefit this particular patient and recommended that reassignment be delayed indefinitely. The surgeon and the parents concurred and the procedure was not done.Â Because this evidence is lacking, the surgical assignment of sex remains an experimental procedure: one in which the results cannot be properly assessed until at least 20 years after the intervention. Accordingly, it is not possible for a patient's parents to give informed consent to these procedures precisely because the medical profession has not systematically assessed what happens to the adults these infant patients become. Pediatric Ethics and the Surgical Assignment of Sex. Because this evidence is lacking, the surgical assignment of sex remains an experimental procedure: one in which the results cannot be properly assessed until at least 20 years after the intervention. But gender assignment has to be provisional, subject to revision by the intersexual child as he or she matures.

While pediatric surgeries performed on children with ambiguous genitalia have been the topic of intense bioethical controversy, there has been almost no discussion to date of the ethics of the use of PGD to reduce the prevalence of these conditions. I suggest that PGD for those (...) conditions that involve serious medical risks for those born with them is morally permissible and that PGD for other â€œcosmeticâ€ variations in sexual anatomy is more defensible than might first appear.Â This article presents the Islamic bioethical deliberation on the issue of sex assignment surgery for infants with disorders of sex development or intersexed as a case study. The main objective of this study is to present a different approach in assessing a biomedical issue within the medium of the Maqasid al-Shariâ€™ah. Sex assignment (sometimes known as gender assignment) is the determination of an infant's sex at birth. In the majority of births, a relative, midwife, nurse or physician inspects the genitalia when the baby is delivered, and sex is assigned, without the expectation of ambiguity. Assignment may also be done prior to birth through prenatal sex discernment. Sex assignment at birth usually aligns with a child's anatomical sex and phenotype. The number of births where the baby does not fit into strict