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Original Studies

Intersex Conditions in Children and Adolescents: Surgical, Ethical, and Legal Considerations

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Abstract. *Introduction:* Approximately one in 2000 children globally is born with an intersex condition. There is unfortunately a relative paucity of data on the choices and the surgical and psychosocial outcomes in patients who undergo genital surgery for intersex conditions and ambiguous genitalia, especially in developing countries. Specialists in these and other countries, where patient follow-up is generally poor, are faced with the daunting task of offering the appropriate medical and surgical management, in the absence of guidelines or recommendations.

Surgical considerations: A surgical procedure in these patients sometimes involves clitoral recession, reduction, vaginoplasty, and gonadectomy. The best surgical outcome is likely to be achieved with a multidisciplinary surgical team; however, the choice of surgery and appropriate timing remains controversial. Some authors have suggested delaying surgery until the child becomes competent to make his/her own decisions.

Legal/Ethical Considerations: All procedures should conform to an ethical code of practice and be in the interest of the child. Exhaustive counseling of all parties and informed consent is of paramount importance, as is adherence to laws that protect the rights of the child as outlined in respective constitutions.

Recommendations: Recommendations in this article, which have been put together from the combined input of three departments, are broad-based. They emphasize the need for extensive counseling, informed consent, adherence to ethical and legal norms, a multidisciplinary input and a shift away from a paternalistic approach.

Key Words. Ambiguous genitalia—Genitoplasty—Decision making—Ethical practice

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Introduction

The management of intersex conditions frequently poses a challenge to gynecologists and pediatric surgeons in many countries. These conditions can broadly be defined as imperfect sexual differentiation into male or female.[1] Although surgery for intersex conditions and ambiguous genitalia has been well documented in medical literature, there has, until recently, been a relative paucity of data in both scholarly and lay media on the long-term outcome of affected individuals who undergo 'corrective' genitoplasty. The difficult social and personal adjustments faced by those who undergo gender re-assignment surgery is sometimes highlighted in the media, rather than in medical literature. The following compelling news story is one such example[2]:

> "A botched circumcision left David badly mutilated. His parents were then counseled to turn David into a girl. David had to be castrated, have surgical reconstruction, and be given female hormones and psychological conditioning. David became Brenda. The family was not identified in those early years, but David himself finally went public a few years ago. In his book, 'As Nature Made Him,' David revealed that far from enjoying dresses and dolls, he preferred boy's clothes, growing into a confused, rebellious adolescent. David revealed his mother tried to kill herself and he made at least 3 suicide bids before his final successful attempt. A month before his 16th birthday, he began to attempt to rebuild his life, undergoing the first of a series of operations to remove his breasts and create a penis. He later met and married a woman and adopted her 3 children, but the legacy haunted the family. David became morose. He lost his job and separated from his wife. David committed suicide in Winnipeg, Canada, where he had grown up." [Adapted with permission from the Daily News, courtesy Daily Mail].

Unlike in developing countries, the medical profession in the westernized countries is confronted by the

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critical voices of intersex and feminist consumer groups, further compelling doctors to conform to an ethical code of practice when embarking on surgery for ambiguous genitalia.[3] However, while considering the various entities that define human sexuality, many specialists are still more likely to make a decision on the choice of gender reassignment based on the predominant appearance of the external genitalia and the ease with which successful surgery can be performed. To this end, it is probable that most surgeons are more likely to opt for feminizing genitoplasty and female sex of rearing. In the USA and most western European societies, a female sex of rearing is the more likely clinical recommendation to parents.[4] However, in Africa, particularly South Africa, where a disproportionately high incidence of true hermaphrodites is seen among the South African black population, these recommendations may differ.[5]

Surgical Procedures

The two essential elements of feminizing genitoplasty are *clitoral* reduction/ recession and *vaginoplasty*.[6]

With greater acknowledgment of the vital role of the clitoris in female sexual function, *clitorectomy*—the removal of both the corpora and the glans—is no longer undertaken in the UK.[4] While the operation of clitoral shaft resection with preservation of the glans on its neurovascular bundle seems logical, and is probably an advance on total clitorectomy or clitoral recession, there is no evidence that the retained glans functions well in sexual/orgasmic terms.[6] Sexual function could actually be compromised by clitoral surgery, with higher rates of non-sensuality and inability to achieve orgasm.[4]

The ease with which *vaginoplasty* can be performed is related largely to the length of the common urogenital sinus. Pena et al have emphasized the appreciation of the intimate relations between the rectum and urinary tract, total urogenital mobilization, and an appreciation of associated Mullerian anomalies for improved surgical outcome.[7] Surgery can be performed early in life, but revision at puberty should be anticipated in some cases.[8,9] The few long-term studies currently available suggest that the majority of girls will require some, and often major, revisional surgery for vaginal or introital stenosis in adolescence.[9,10] Since there is no obvious benefit for vaginoplasty in the very young girl, it seems feasible option to delay it, until evidence from future research shows benefit. For later vaginal lengthening, various methods of self dilatation are available, and vaginal dilatation with acrylic moulds results in good outcome.[11] For the replacement of a completely absent vagina, colovaginoplasty has been reported with good results by some authors.[12]

The timing of *gonadectomy* remains controversial. Arguments that cite the potential for malignant change as reason for early gonadectomy are sometimes counterbalanced by the possibility of better bone maturation and body development in the presence of endogenous sex steroids. There are three possible options: (1) early gonadectomy, particularly if they are contained in the hernial sac, or if there are parental concerns over malignant change, or difficulty in accepting female phenotype while testicular tissue if present; (2) late gonadectomy performed as soon as puberty has been completed; (3) no gonadectomy at all in patients who are as well informed as possible about the risks of malignant change. Follow-up of such individuals would need to be assiduous and long term.[6]

In the undervirilized genetic male, follow-up studies by Reilly and Woodhouse on adult males with micropenis (dorsal penile length at least 2.5 standard deviations smaller than mean penis size) have shown surprisingly good outcomes in terms of sexual function.[13] Accordingly, whether the assignment of such individuals to the female gender by surgery should be done needs thorough consideration and therefore should only be undertaken with considerable caution and following full multidisciplinary investigation and counseling, with due consideration given to the sex of rearing where appropriate.

Defining Sex and Sexuality

Arguably, an emphasis on feminizing genitoplasty alone might fall short in considering a holistic definition of gender, inclusive of rearing, psychological and social concepts of human sexuality. Debates on this issue are shaped by the continuing issue of whether sexual identity is a biological phenomenon, determined by the genes and the anatomy, or whether it is constructed in society or culture. The former adopts a more ‘essentialist’ stance, and views sexuality as given by nature and therefore fixed and unalterable. The latter sees sexuality being organized through the regulative discourses of modern societies. This view will naturally support reconstructions and reinventions of sexuality and explore the questions posed by those living with intersex conditions about the existence of a third kind of gender, i.e. understanding subjects in terms of personal preference and self determination, and not simply defining gender as genital function on the basis of the ability to have sexual intercourse, a Freudian concept.

The birth of a universal prescription for intersex surgery is therefore unlikely, leaving gynecologists and surgeons without sustainable guidelines. Feminizing genitoplasty still remains a common management for intersex infants in the developed world because of

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