

Changing attitudes to sex assignment in intersex

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INTRODUCTION

The recent upsurge of interest in intersex is shown by a proliferation of media reports (<http://www.ahn.org>, accessed August 2003), medical discussions [1,2], social and psychological analyses [3], ethical debates [4], and historical accounts [5]. The situation is complex and confusing. Many clinicians are puzzled by the intense criticism of their well-meaning and skilful work. Some experts advocate the same policies but with improved techniques, whilst others urge a thorough re-examination of every aspect of infant sex assignment. This review is an attempt to bring together the key perspectives of the debate, drawing attention to research evidence and methodological issues, and the theoretical premise.

INTERSEX

Intersex conditions occur when there is a defect in the process of sexual development and differentiation, leading to the birth of an individual with a blend of both male and female internal and/or external genitalia. The mode and age of presentation are variable [7]. Where the external genitalia are ambiguous, e.g. congenital adrenal hyperplasia (CAH), or partial androgen insensitivity syndrome, or where there is discordance between the phenotype at birth and the karyotype on amniocentesis (e.g. complete androgen insensitivity syndrome, CAIS), the diagnosis is usually made at birth. The condition is also diagnosed after the presentation of precocious puberty in childhood (e.g. CAH) or virilization in a girl at puberty (e.g. testosterone biosynthetic defects). Alternatively, a teenage girl may present with primary amenorrhoea and be found to have an XY karyotype (e.g. CAIS).

As this review specifically addresses sex assignment, which tends to take place in

infancy or early childhood, the focus will be on conditions associated with the early presentation of ambiguous genitalia.

HISTORICAL PERSPECTIVE

The existence of people who are neither 'all male' nor 'all female' has long been recognized in many societies and, with the advent of scientific medicine in European societies in the 19th century, effort has been directed at determining the 'true sex' of such individuals [5]. Taxonomy was a new and exciting intellectual activity, and cases of 'doubtful sex' were a challenge to science and medicine. According to Dreger [5], factors then accepted as indicative of true sex included appearance of the head, timbre of voice, lack of breast development, presence of penis and absence of periods. Personality traits were also considered important demarcators of sex, e.g. bravery was considered a male attribute, and modesty female. Likewise, 'true males' were thought to desire only 'true females' and vice versa. In contrast to today, the role of surgery then was to confirm a hermaphroditic diagnosis rather than to change or reinforce the 'true sex'.

MODERN MANAGEMENT

Since 1950s and 1960s, intersex management has been dominated by what became known as the 'optimal gender policy' developed by a group of psychologists in the USA [7]. These experts proposed that all infants are gender neutral at birth and that gender development (the process of identifying oneself as male or female) occurs by interaction with the environment, processes that rely on the appearance of the genitalia. Acceptance of this theory led automatically to the alignment of genital appearance by surgical means to the assigned sex of rearing. Furthermore, parents and child must be left in no doubt of the assigned sex as the true sex and parents have thus been advised to withhold diagnostic details from the child [4].

Whilst the recommendation of sex of rearing does take results of clinical investigations into

account, the decision has been largely influenced by the supposition that the construction of a 'functional' vagina (i.e. capable of receiving a penis) is technically more feasible than that of a 'functional' penis (i.e. capable of erection and penetration). Surgeons generally favour female assignment [8] which may comprise one or more of the following: removal of some of the clitoris or phallus to reduce its size, construction of a vagina or opening the vaginal introitus, and fashioning of the labia.

As patients have tended not to be fully informed of their condition and cannot therefore be recruited into research studies with full consent, and as this approach has generally been accepted as obvious, the collection of longitudinal data has been less than rigorous; thus follow-up reports have tended to be based on a few frequently cited cases using problematic methods [4]. More than that, the widespread practice of surgical sex assignment has meant that few nonsurgically assigned patients have been available for comparison. Whilst there is much to learn from adult volunteers, recent studies have been criticised, on the grounds that clinic samples and members of patient support groups may bias results towards a negative outcome. Because intersex conditions are relatively rare, large multicentre and longitudinal studies have been referred to as the 'gold standard'. However, such studies require major funding on a national (in the case of some conditions international) scale, and obviously the necessary commitment and collaboration from all involved health professionals on a long-term basis. Calls for a national database have also prompted concerns about data protection and confidentiality.

Whilst the evidence base for and against surgical sex assignment is in stalemate, recent research and analysis has nevertheless introduced doubt into standard practice. Service users can access the diverse expert opinions with increasing ease through the Internet. Surgeons may not be able to suspend for much longer the reality of the challenges posed by different groups and continue their usual practice unabated.

A QUESTION OF SIZE

Newborn penile size charts were first used in the 1960s and any child with a penis of stretched length of <2.5 cm was likely to be assigned as female regardless of the underlying diagnosis [9]. In such cases the penis would be removed with the testes and the child would undergo vaginal reconstructive surgery either as an infant or later in life. This was considered preferable to male sex assignment because of the poor outcome of penile reconstructive surgery. Many reconstructive techniques used in the past may produce a penis with an acceptable appearance when not erect, but the capacity for erection and penetration is usually poor. Recent advances in tissue engineering indicate a possibility of growing penile tissue. The corpus cavernosum is the most difficult part of the penis to reconstruct, as it has complex functions, but researchers have grown varying lengths of rabbit corpus cavernosum in the laboratory [10]. If this technique works in humans, penile enlargement will be possible for XY males with aphallia and micropenis.

Technical advances may cast doubt on the current leaning towards female sex assignment in boys with absent or underdeveloped penis but, were it not the case, clinicians would still need to show that assignment of these boys to female is better than leaving them as boys. In Western societies, a large penis in men obeys contemporary fashion rules and it can be surmised that having a micropenis would put boys and men at risk of psychological difficulties. However, this is far from deciding that these boys are better off, however defined, growing up as girls. Indeed, small studies with men with micropenis have failed to find the predicted high levels of sexuality-related emotional and behavioural disturbance [11]. It has been asked whether the re-assignment of boys with micro or absent penis to girls constitutes cultural practice or evidence-based medicine [12].

SURGICAL SEX ASSIGNMENT: COSMESIS

Vaginoplasty has been considered an integral part of feminizing genitoplasty and is common during the first 1–2 years of life, even though the child is not expected to menstruate for a further ≈ 10 years (if she has

a uterus) or to be sexually active. Given that there are no available data to suggest early infant vaginoplasty has a better long-term anatomical, cosmetic and functional outcome than later delayed surgery, vaginoplasty in infancy is then chiefly to create a reassuring appearance for significant adults. We know of no study that has assessed the patient's satisfaction with the resulting appearance of her surgery. However, studies based on ratings by medical doctors have reported unsatisfactory or poor cosmetic results in 28–46% of patients. The most commonly identified anatomical problem after surgery is vaginal stenosis, reported in 36–100% of women [13]. This leads to a frequent need for repeat surgery in adolescence even if the original procedure had been planned as a 'one-stage' process. We are unsure to what extent parents opting for vaginal surgery in their infant daughter appreciate that a one-off surgical fix to 'normalise' genital appearance now looks unlikely.

SURGICAL SEX ASSIGNMENT: SEXUAL FUNCTION

Women with CAH report more sexual difficulties than their counterparts without CAH and than women with other chronic medical conditions. Dittman *et al.* [14] assessed 34 female patients with CAH and compared them to 14 unaffected women. The former were less likely to have experienced sexual activity with male partners, whilst over half of the sample of women with CAH in the report by May *et al.* [15], most of whom had had genital surgery, reported current pain with intercourse and considerable anxiety about sex. It is of course difficult to determine the relative contributions of physical and psychological factors in sexual difficulties, especially in women with CAH [16].

More recently, women with ambiguous genitals who had undergone feminizing genital surgery were compared with women who had ambiguous genitalia with no surgery [17]. Overall sexual function scores were poor in both groups when compared with a standard UK population of women. Those who had undergone clitoral surgery were significantly less likely to report experience of orgasm than those who had not had surgery. Subsequent research using objective testing of genital sensory thresholds in a pilot sample of women with CAH found that those who

had undergone clitoral surgery had marked differences from normative values [18]. Sensory input from the genitals is a contributory factor for female arousal and sexual pleasure and could be altered adversely by clitoral surgery.

Thus far the only known function of the clitoris is erotic pleasure. Recent work on the neuroanatomy of the human fetal clitoris showed an extensive network of nerves surrounding the tunica with many perforating branches entering the dorsal aspect of the corporeal body and glans [19], making it clear that any incision to the clitoral glans, corpora or hood could risk damage to the dense innervation. Past confidence amongst paediatric surgeons in unimpaired sexual function after clitoral surgery seems no longer tenable [20].

The importance of evaluating childhood and adult genital surgery has received greater recognition in recent years, but psychologists have also drawn attention to the question of how such an evaluation should be made. Women have reported not feeling able to discuss sexual matters with their doctors [15], so an absence of complaints in medical records or in consultations may not mean that sexual experience is positive [4]. In a detailed interview study of adult intersex women, experiences relating to elective vaginoplasty in adulthood were extremely complex [21]. Experiences shifted across stages of help-seeking, from contemplation of surgery to after intervention. The authors argued that, given the motivation is complex and outcome expectancy largely psychological (e.g. to be more comfortable in social situations), surgery needs to show a positive effect in psychological and mechanical terms.

Clinicians have also drawn attention to the importance in re-examining information given to parents and patients about sex assignment surgery in infancy and childhood [22], and to genital surgery in adulthood [21]. Psychologists have raised the important issue of how such information is communicated. It has been suggested that clinicians are best to avoid a panicked insistence that, without question, 'something must be done', that they discuss the possibility that the desired genital appearance even if achievable (and even if those involved willingly risk physical damage to achieve this) may not realise for parent or patient their gender aspirations [21].

PSYCHOLOGICAL WELL-BEING

Hurtig and Rosenthal [23] noted from their case work that female adolescents with CAH who have received early and adequate medical and psychological care achieve relatively positive 'personality functioning', although the authors also predicted future problems with gender identity. However, Kuhnle and Bullinger [24] reported mixed results of reduced social competence and poorer body image, but also a lesser tendency towards 'depressive coping' than in a control group. Another source of information comes from intersex adults who have been more outspoken about their personal experiences, and who have articulated reasons for their distress (Intersex Society of North America, ISNA; <http://www.isna.org>). Lay criticism has targeted the poor communication of diagnostic and treatment information, absent or inadequate follow-on health monitoring, humiliating encounters with health professionals, poor treatment outcome, and inadequate psychological support [4,25]. It is impossible to verify how representative are patients who experience significant psychological difficulties, but it is undeniable that a proportion of patients have voiced some very serious concerns.

If the psychological impact of surgical sex assignment on the developing patient cannot be agreed upon, we are even less sure of the impact on parental anxiety, even though this has often been cited as a major reason for feminizing genitoplasty in childhood [26]. It has been noted that there is no evidence to suggest that surgical sexing actually mitigates parental anxiety or doubt over the sex of the child [8]. Far from 'normalizing' the child and relieving parental anxiety, many intersex adults report growing up in a family environment characterized by shame, confusion, lack of discussion and private distress [25]. Many also report overwhelming sexual and indeed social anxiety as well as identity issues.

Some psychologists have questioned how clinicians could be so sure that the physically traumatizing procedures, and the repeated intrusive examinations that they necessitate before and afterward, are less psychologically traumatizing for the young patient than the 'presumed catastrophe of nonintervention' [27]. In that sense, it is ironic that a delay in surgical feminization has been referred to as 'cruel' [28]. Furthermore, it has been indicated

that the unquestioned insistence that 'something must be done' about the child might negatively influence parental feelings and attitudes, that questions must be raised as to how these perceptions and emotions might affect the child's identity development and overall psychological well-being [27]. In other words, might such attitudes in themselves communicate the very freakishness that surgery tries to 'cure'?

Equally, it cannot be assumed that in leaving the genitals unaltered the child will have few problems. On the contrary, it can be surmised that intersex children and adults, like all those perceived as 'different', are at risk of psychological problems. But surgery is not the only answer to social intolerance. In the case of intersex, it may not be the best option for every patient. Feminizing surgery, at any age, does not necessarily protect patients from having to confront their difference [15,21].

ANATOMY AS SEXUALITY

It is assumed that in 'normalising' the genitals, psychological and sexual development will likewise be normalized [29]. This, psychologists have argued, exposes a leap of faith in a tight relationship between anatomy, identity development and psychological well-being [4,12].

The extent to which gender development arises specifically from the genital anatomy is far from clear. The most well known reports of gender re-assignment and subsequent gender development are based on two boys who were re-assigned as girls after penile damage when young. In the case hailed as the proof of modern management protocol [30], although feminine gender development was claimed, the individual has since re-assigned himself and is now living as a heterosexual man [31]. In the other case, the boy who was reassigned as a girl now identifies herself as a bisexual woman, apparently with no evidence of gender dysphoria [32]. Boys born with no penis or with a micropenis who have been assigned as girls also seem to have variable gender outcomes. Some clinical reports suggest that these individuals experience problems in developing a female identity [33], whilst others find outcomes similar to those for girls with CAH, i.e. increased likelihood of masculine play style but no less likely to develop a female core-gender identity [34].

It is no wonder that this area of research is confusing, with each investigator trying to tie the outcome to their favourite psychological theory, ignoring variables that do not interest them [12]. Many social, familial, educational and emotional factors can influence gender development. Chase (quoted by Hegarty [35]) describes families with an intersex child as 'distorted and unusual' and refers to 'all the trauma that intersexed children and their families experience'. That is, the 'degrading and shaming experience' of medical sexing [36], and patient care before and after can profoundly alter individual and family functioning. Thus although the biology of intersex conditions can influence sexuality, as intersex people have also been subjected to major developmental interference, their sexuality (normative or variant) can say little about the relative contributions of genetic, anatomical, hormonal or environmental influences [12].

Hines [16] argues that methods in this area need to be overhauled, but perhaps the investigative framework itself needs re-thinking. There are many and changing facets to human sexuality, including gender positioning (feeling as man or woman), sexual partner choice, and sexual activity, each representing a dynamic interplay of thoughts, emotions, sensations, behaviours and our subjective interpretation of them, framed by available language and shared cultural beliefs [12]. Unlike the sexual anatomy, human sexuality shifts as we navigate the social world. Take gender identification alone; a person may feel or indeed chooses to be more masculine or more feminine in different situations or as life progresses. Take sexual partner orientation for another example; a person may prefer sexual activity with different-gender persons yet engages in sexual fantasies of same-gender persons, and this could change. So, taking the human lifespan as a whole, the many aspects of sexuality are rarely (if ever) entirely congruent in a person. These ideas are not new, but they have been sidelined to preserve a sexually dimorphic ideology, that of two fixed, discrete but complementing sexes [12].

The very notion of a 'normal' sexuality that is universally verifiable is contentious, if not theoretically and empirically problematic [12]. Whereas these perspectives have not influenced medical practice in the past, they will become highly relevant in intersex management, not least because service users

can access alternative viewpoints with increasing ease.

FURTHER COMPLICATIONS: FERTILITY CONSIDERATIONS

The ability to reproduce has been a major factor in sex assignment. In some conditions the decision seems relatively simple, e.g. women with CAH are able to conceive and bear children, although their fertility potential depends on good steroid control. Fertility potential is seen as an overwhelming benefit and even very virilized girls of Prader stage 5 are assigned to a female sex of rearing.

Fertility considerations for the XY woman are complex. Women with pure gonadal dysgenesis (Swyers syndrome) have a normally formed Müllerian system. They can conceive with ovum donation and *in vitro* fertilization. There have been several case reports of pregnancies successfully carried to term in this group of women [40]. XY babies with ambiguous genitals are usually assigned female as it has been assumed that they are infertile whether male or female. However, with the increasing development of fertility techniques this is no longer the case. The advent of intracytoplasmic sperm injection (ICSI) in 1992 led to pregnancies even in the presence of oligo- or even azoospermia [38]. ICSI involves injecting a single sperm into the oocyte, and bypasses all natural hurdles which may prevent abnormal sperm from participating in fertilization. Spermatozoa can be aspirated from the testis or epididymis and can be used fresh or cryopreserved for later use. There have been cases reported of successful pregnancies in conditions previously labelled as infertile. For example, 5 α -reductase-deficient men have previously been considered infertile. They have a low sperm volume with high viscosity, and oligo- or azoospermia associated with undescended testes and the sequelae of multiple genital operations. However, pregnancies have been reported in this group both spontaneously and using fertility techniques such as intrauterine insemination and ICSI [39].

The development of techniques like ICSI have rendered the situation in, e.g. CAIS, even more complex. Potentially, sperm could be aspirated from a CAIS testes and used to fertilize an ovum, which could then be carried by a surrogate mother. The moral and ethical implications of this are hard to untangle and

there are no reported cases. It is currently difficult to offer helpful advice, although delaying gonadectomy until adolescence where appropriate at least allows the patient a voice in this discussion.

THE FUTURE OF SEX ASSIGNMENT

Genital ambiguity has always existed, *but* the current policy for its management is historically recent, made possible by the advent of genital surgical techniques [4]. There has been criticism of what we now know to be standard intersex management for some time, but critics had little impact and the 'optimal' gender policy went on to become the only gender policy. Dissent has gathered momentum in recent years because of the voice of adult intersex women. In the light of medical and psychological uncertainties, patient dissatisfaction and ethical considerations. Kipnis and Diamond [1], while advocating infant sex assignment, have argued for a moratorium on nonconsensual genital surgery until more supporting evidence becomes available. That is, children are assigned a sex of rearing without the irreversible genital procedure(s). However, most clinicians continue to recommend and practise genital sexing on infants and young children [40,41].

It is true that current clinicians have access to improved investigative techniques to help them in decision making. The advent of noninvasive imaging such as ultrasonography and MRI offer detailed information on the structure of internal organs. Biochemical and hormonal studies also offer more specific information. Molecular genetics have advanced enormously and in many conditions the specific gene defect can be identified [42]. These changes have resulted in improved understanding of aetiology of intersex conditions. But just because genital ambiguity has genetic and physiological correlates, like all anatomical characteristics, does not in itself make it a disease awaiting medical alteration. Rather, the extent to which this particular set of anatomical features is considered unacceptable relates to gender mandates of that culture, at that time [12]. The extent to which health professionals have a role in the lives of people with nonstandard genital characteristics may have to be negotiated in future, rather than taken for granted as in the past.

The formation of lay forums (ISNA) has enabled those with first-hand experience to campaign for changes in clinical practice. The ISNA argues that parental distress should not be treated by surgery on the child, and that all children should be assigned as a boy or girl without surgery. Many intersex people around the world vehemently condemn infant genital surgery, especially that which is used just to make the child look more female, i.e. for cosmetic purposes to reassure others. Chase likened infant genital sexing to female genital mutilation and to castration, claiming that the difference is political (quoted in [35]).

Most parents would want to assign sex; it is mainly the timing of irreversible surgery that is being questioned. Given the uncertainties it would seem reasonable to consider a case-by-case exploration of assignment to a sex of rearing without irreversible infant and childhood surgery. However, it is unlikely that this would mean the end of genital surgery for intersex. There will always be parents who choose surgery for their children despite full information about potential risks. Older children and adult patients can contribute to decision-making and may opt for genital surgery. However, a more realistic appraisal of the benefits and risks, a stronger sense of personal control, and a collaborative relationship, are likely to lead to improved patient satisfaction and reduced risk of concomitant psychological distress.

CONCLUSIONS

If surgical sex assignment and genital surgery in intersex are increasingly challenged now, it is not the good intentions of surgeons that are called into question. Rather, like patients and parents, clinicians are likewise driven by a cultural mandate. Thus, assisted by a simplistic psychology of sexual development, each clinician becomes attached to their favoured regimens and anything outside it feels experimental and unethical [8]. This makes any debate emotive and problematic, with those holding onto one set of logic refusing to consider or wilfully misinterpret others' viewpoints. For example, recent cautioning about adverse effects of clitoral surgery [17] has been mischievously misrepresented as advocating a third sex [28]. Far from it; those who advocate caution and debate are well aware that currently only two sexes are on offer, that intersex people and families will invariably choose one or the

other, and that the role of service providers is not to engineer social change but to solve problems [27]. However, what many experts say is that in view of the lack of consensus amongst medical practitioners, social and psychological analyses, ethical critique, and strong reservations from at least some recipients of the standard approach, a re-examination of the situation is long overdue. In particular, a greater commitment to case-by-case exploration of assignment to a tentative sex of rearing and at delaying irreversible genital surgery ought to be given more consideration, with rationalized psychological backup, professional and/or lay, that is appropriate to the circumstances of patient and family.

If this sounds experimental, sex assignment by genital surgery also represents an experiment involving invasive, risky and irreversible intervention. We are unsure how the absence of rigorous evaluation of the intended outcome could ever have been justified in interventions with such grave consequences, but overconfidence in the past has left the current generation of clinicians and patients floundering with uncertainties. Research in recent years and expected changes in reproductive technology and tissue engineering make clinical management more uncertain than ever. The clinician's choice is stark; to share the diverse opinions with patients and parents and assist them to develop their own responses, or pretend to certainty and intervene before they learn what questions to ask.

Above all, patients, parents, practitioners and scholars in many disciplines are also experts in intersex. Future consensual statements must include service user, legal and ethical representation, as well as input from experts in sexual development and overall psychological and family functioning. It is not for the medical profession itself to decide behind closed doors on behalf of society how to seal the fate of persons with nonstandard genitals.

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Abbreviations: CAH, congenital adrenal hyperplasia; CAIS, complete androgen insensitivity syndrome; ISNA, Intersex Society of North America; ICSI, intracytoplasmic sperm injection.