

Adult Genital Surgery for Intersex: A Solution to What Problem?

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Abstract

The desirability of routine genital surgery for infants with ambiguous genitalia is increasingly debated. But there is less discussion about intersex adults who choose genital surgery, despite evidence suggesting that the results are often unsatisfactory. This study reports on how six women with intersex conditions decided to have feminizing genital surgery and how they evaluated the outcomes. The initial analysis highlighted a chronological transition from surgery as non-dilemmatic to surgery as a serious dilemma; a version of Foucauldian discourse analysis was then used to place the women's experiences in a cultural context. The implications for psychological involvement in services for women with intersex conditions are discussed.

Keywords

decision making, intersex, outcomes, surgery, women

THE TERM 'intersex' refers to a result of sexual differentiation and development problems in which a person's chromosomal, gonadal and/or genital characteristics cannot be unambiguously placed into our categories of male and female. Two conditions implicated in intersex outcomes are congenital adrenal hyperplasia (CAH) and androgen insensitivity syndrome (AIS). In the former, an enzyme abnormality results in a female (XX) foetus producing substantial amounts of androgens which masculinize the external genitalia to varying degrees. In AIS, an XY (male) foetus, with male gonads, produces normal amounts of androgens but lacks receptors to respond to them. The infant may have 'standard' female genitalia but without cervix, womb or ovaries (so that the condition may not be diagnosed until puberty) or may show varying degrees of masculinization of the genitals, depending on the degree of residual receptor or hormonal activity. Estimates vary, but Warne (1998) suggests that around 1/4500 live-born infants has a genital abnormality severe enough to make the immediate assignment of sex difficult.

It has been standard paediatric practice to recommend sex assignment to male or female, and then genital surgery for infants with ambiguous genitalia, with potential sexual function (erectile and penetrative potential of the phallus) a major consideration in the case of infants who might be sex-assigned as males, and fertility (presence of womb and ovaries) in the case of chromosomal females (Creighton, 2001). Because it is easier to construct a 'functional' vagina (i.e. capable of receiving a penis) than a 'functional' penis (i.e. capable of erection and penetration), surgeons have generally recommended female assignment where genital ambiguity is pronounced (Wilson & Reiner, 1998). Following sex assignment, parents have traditionally been advised to raise the child without ambiguity, which may mean that the child (and adult) receives limited information about their medical condition (Hegarty, 2000; Kessler, 2000; Wilson & Reiner, 1998). Infant surgery might be followed by further genital surgery in childhood, adolescence or adulthood, together with the administration of hormones to align the child's physical appearance to the assigned sex.

Very recently, these practices have been chal-

lenged not least through the 'coming of age' of those who had such interventions as children and, as adults, have spoken negatively of their experiences. Professionals have focused critically on reports of adults with intersex conditions choosing to change gender later in life (Meyer-Balhbarg, Gruen, & New, 1996; Reiner, 1996); on infant surgery; and on the fact that raising a child 'unambiguously' in line with the assigned sex has often meant that information has been withheld from children and adults, raising serious ethical issues, not least about consent to treatment (Fausto-Sterling, 2002; Kessler, 2000). It is also unlikely that children are not aware that they are different, given possibly evasive or incomplete answers to questions, frequent hospital visits, possible absence of menstruation, genital surgery and hormonal treatments (Wilson & Reiner, 1998).

There is, too, a lack of information on the outcomes of surgical sex assignment. Large-scale studies may remain impractical, but an increasing number of smaller-scale studies and case reports suggest that the outcomes of genital surgery, even using newer techniques, are problematic with repeat surgery usually needed after puberty if intercourse is to take place. Women also report scarring, loss of sexual sensation and pain on intercourse (Creighton, 2001; May, Boyle, & Grant, 1996; Minto, Liao, Woodhouse, Ransley, & Creighton, *in press*).

As a result of these concerns, a number of changes in the management of intersex have been suggested. Although there are disagreements on the desirability of sex assignment at birth, there is general agreement among those seeking changes in practice on the need to involve parents fully in decision making; to foster more open communication among parents, children and professionals; to stop viewing the birth of an infant with ambiguous genitalia as an 'emergency' (unless surgery is medically necessary) and as far as possible to delay genital and gonadal surgery until the person can give informed consent (Creighton, 2001; Kipnis & Diamond, 1998).

Rationale for the present study

Criticism of traditional management of intersex targets non-consensual genital surgery for infants and children. But there has been little discussion

of the issues raised when intersex adults choose genital surgery (e.g. vaginal construction or clitoral reduction), almost as if 'consensual' surgery removes the need for discussion. But the study of these adult choices is important because the cultural imperatives underlying infant sex assignment, particularly the male–female dichotomy and assumptions about what male and female genitals are *for*, are also likely to impinge on expert advice about adult surgery and on decisions to accept it. In addition, studies that show surgery outcomes to be problematic raise questions about the information patients receive, the decision-making process and criteria for 'success'. The present study is concerned with the experiences of women with intersex conditions who chose genital surgery as adults (and most adult surgery is carried out on women). The study focuses on decision making for surgery, the experience of surgery itself and perceived outcomes. More specific research questions will be discussed in the analysis section.

Method

Participants

Participants were recruited from a support group for women with intersex conditions following circulation of research information on the group's website and a brief presentation by one of the authors (SS). We had hoped to recruit women who had chosen not to have surgery, although we knew this would be difficult because of high rates of genital surgery. Of the six participants only one had not had genital surgery but had instead used vaginal dilators. We will return later to issues raised by the recruitment process.

The women had a variety of medical (intersex) conditions, including complete androgen insensitivity syndrome, although none of the women had CAH. However because we were interested in what the women had in common—an intersex diagnosis and atypical genitalia—and to protect their confidentiality, only group information about non-diagnostic characteristic is given in Table 1.¹

Materials

Interview schedule A semi-structured interview format was chosen to balance a structure imposed by the researchers with the need to

Table 1. Participant characteristics

<i>Non-diagnostic characteristics</i>	
Total	6
Age range	27–52
Age at surgery	19–43
Type of intervention	
Clitoridectomy	1
Vaginaplasty	4
Dilators only	1
Number of operations	
One	3 participants
Two	2 participants
Relationship status	
Divorced	1
With a male partner	2 (includes divorced participant)
Not in a relationship	4
Education	
To degree level	6

allow participants to speak about what was relevant to them. The schedule covered the women's initial decision making about surgery, their experience of surgery and the outcomes of surgery, particularly in relation to self-perception, forming intimate relationships and sexual activities.

Procedure

When ethical approvals had been obtained, women who expressed an interest in the research were given an information sheet and asked to sign a consent form; participants chose whether to be interviewed in their homes (4) or in a hospital psychology department (2). The interviews (carried out by SS) were recorded with participants' consent and took between 1.5 and two hours. The tapes were transcribed verbatim and all potentially identifying information removed from the transcript.

Analysis

Analytic methods

The interview transcripts were analysed using two methods: interpretative phenomenological analysis (IPA; Smith, 1996) and a version of Foucauldian discourse analysis. Because these methods may be seen as representing the

different epistemological traditions of realism and constructionism (although in the case of IPA, the distinction may be rather blurred; see Willig, 2001), we will discuss why this dual approach was chosen.

Our two major aims were to highlight patterns in the reported experience of intersex women who had chosen or not chosen genital surgery, and to consider the meanings of these experiences in a cultural and gendered context. IPA appeared to be the method of choice for our first aim, given its aim of conveying the quality of an individual's experience and the meanings they attach to it, while acknowledging that such experiences always involve interpretation (Smith, 1996). The strength of IPA may be its insistence on remaining with participants' accounts of their experiences and their meanings, but as Yardley (1997a) points out, we have no choice but to convey our experiences using cultural concepts and language. Willig (2001) similarly emphasizes the tensions between IPA's assumption of the representational validity of language and the possibility that language does not constitute the means of expressing our subjective experience but instead prescribes what we *can* think and feel. Willig has further argued that while IPA is able to generate rich descriptions of participants' experiences, it has not generally furthered our understanding of *why* such experiences take place or of the social, linguistic and material conditions that give rise to, and continue to shape them.

A form of discourse analysis was chosen to complement IPA because the latter's limitations are precisely in those areas focused on by discursive approaches which explicitly acknowledge the socially and linguistically mediated nature of human experience (Yardley, 1997a). Stam has also argued for more attention to discourse in health psychology, emphasizing that 'the activities [of those who provide and use biomedicine] are constituted discursively and an analysis of care-talk necessarily leads to a deconstruction of traditional categories of health care' (2000, p. 274).

A version of Foucauldian discourse analysis was therefore used here because of its particular concern with examining the relationships among the cultural availability of discursive resources, the social conditions which contribute to and are shaped by discursive resources and

the ideological and power relations which are reflected in and strengthened by the use of particular discourses. Foucauldian discourse analysis is also concerned with the potential relationships between discursive practice and the construction of individual desires, as well as with 'subject positions', i.e. possibilities for feeling and acting, made available or closed down by particular discourses.

The analytic approach adopted here has much in common with material discursive psychology (e.g. Ussher, 1997; Yardley, 1997b) and, like Yardley (1997a), we would argue for the usefulness of complementing a phenomenological perspective with some form of discourse analysis. The ways in which the two approaches were combined will be discussed later.

Analysis—process

Although different types of qualitative analysis ask different questions of and make different assumptions about the data, there is much procedural overlap because all analyses seek regularities or themes in people's accounts of events or experiences. We adopted here Taylor and Bogdan's description of themes as units obtained from patterns in, for example, 'conversation topics, vocabulary, recurring activities, meanings [and] feelings' (1984, p. 131). This type of analysis is central to IPA (Willig, 2001) and we therefore initially followed procedures outlined by Smith, Jarman and Osborn (1999) but noted that these overlap with those for discourse analysis (Parker, 1992). However, as we were concerned with the chronology of the women's experience in choosing, having and living with the outcomes of surgery, this sequence formed an overall framework for the analysis. In order to facilitate the integration of IPA and the Foucauldian discourse analysis, further specific questions were then posed of the thematically organized accounts of the women's experiences. The two parts of the analysis will be presented separately.

Results and discussion: IPA²

The superordinate theme identified was that of the transition from the relative absence to the marked presence of a dilemma. Thus, the three chronological periods—before surgery, the experience of surgery and post-surgery—were

characterized by a transition from experiencing surgery as largely non-dilemmatic to experiencing it as a serious dilemma. We are using 'dilemma' here in the sense discussed by Billig et al., who have argued that '[t]o experience a dilemma is to live out an opposition, so that one is divided upon it in the failure to achieve a resolution' (1988, p. 91). The transition process in the women's accounts, from relatively non-dilemmatic to dilemmatic thinking, is described below.

Before surgery: the absence of dilemma

The relative absence of dilemmatic thinking, or self-argumentation, in the women's experience of choosing genital surgery can be understood in terms of three constituent themes which characterized their accounts of this process: 'conferring normality'; 'conferring sexual and relationship entitlement'; and 'doctor knows best'.

Conferring normality The women spoke of their feelings of being 'outsiders', even of potentially being seen as 'monsters' or 'freaks', who had become skilled at concealing the physical and emotional effects of their medical condition. Surgery was then seen as a means of conferring 'insider' status or normality:

I felt as though I was on the outside, if you like. Maybe they would talk about the things they did and often I'd give it the big, old, 'Oh yea, you know, me too.' (P6)

I had also expected that the surgery would eliminate the [] I always hoped that the strong [] the desire for . . . a perfect female body which [] I'm *sure* a lot of women (laughs) *have*, I-I mean all our advertising is certainly geared towards it. And I expected that that would go away. (P3)

I expected that I would have an ordinary heterosexual relationship. That was, that was my expectation. (P2)

But as well as feeling normal and having 'ordinary' heterosexual relationships, the women also hoped that surgery would remove the need for questions and explanations:

. . . to find yourself in that intimate situation with [] a male partner [] and for them [] to

[] make some comment about the fact that you didn't have . . . you know, a vagina . . . it would open up this whole can of worms and you'd have to kind of explain things . . . I just couldn't handle it. (P5)

Well, if, if a guy went to [] to have full sex with me and he found out I was too short, there *would* be questions, I would have to explain *something*. I didn't even know [] myself [] what was wrong, you know. (P7)

These comments emphasize that it is not simply that the women feared having to explain their condition, but that they might not know what to say particularly as many had been given incomplete or misleading or no explanations when they were growing up.

Conferring sexual and relationship entitlement This second constituent theme was closely related to the previous theme of conferring normality. The women talked not only of feeling like outsiders, but of feeling *unentitled* to 'normal' relationships:

And if you've lived your whole life *knowing that* [] you know, that you—that the vagina's, like, one centimetre or whatever, um [] you know, you just, you just get this sort of fixation in your mind that you're not [] entitled, really, to have that sort of relationship. (P5)

This entitlement involved the assumption that a vagina is essential to heterosexual relationships: 'I would think it's really nice to be able to have a vagina before, or even, or *just, just to have a vagina* and then you would have a chance to have an intimate, committed relationship' (P7). The taken-for-granted connection between vaginas and relationships was also evident in doctors' reported consultations with the women: 'when the time comes you have surgery' and similar phrases implied that surgery would be necessary when the woman wanted to have an (assumed heterosexual) relationship. The idea of a vagina as a pre-condition of this was also strongly reinforced by the women's assumptions that men would 'scream'; 'freak out'; 'run off' or 'totally flip' when they discovered that the woman did not have a normal vagina.

Surgery thus had the strong appeal of a procedure which would confer normal femininity, rendering the women acceptable both to

themselves and future male sexual partners; it was seen as a means of escape from a situation where concerns about the inevitability of 'discovery' led all of the women either to end relationships with men at a very early stage or not to form them at all. Notably, the woman who chose not to have surgery (but later used dilators) did so partly because at that time she could not imagine 'finding anyone'.

Doctor knows best The third theme that contributed to the relatively non-dilemmatic nature of choosing surgery was 'doctor knows best'. A striking aspect of the women's accounts was the extent to which they recalled genital surgery being presented matter of factly, as generally unproblematic and desirable:

Well, he did explain that it, you know, it might make [] things look a little bit different . . . I did actually ask, I said, are there not any other options that could be tried? And he said that, you know, he thought this was the best one. (P5)

He said, these are the other alternatives, he said you *can* dilate, but you do it for months and months and—you start off tiny, it's a long drawn-out process, um, *the way* [] the way he described it at the time, left the impression to me that [] that wasn't the way to do it, that wasn't, that wasn't the way he'd recommend. (P7)

The combination of medical authority, the straightforward presentation of surgery and the consultation setting made it difficult to engage in detailed discussion of what surgery might or might not achieve:

I think part of it could have been, well, this doctor knows what to do best, as my doctor []. I was like, oh, you know best, you're the professional here, I'll, and I'll bow to your better judgement. (P6)

Whenever I used to see the doctor, there would always be at least eight white coats sitting behind me, you know, scribbling down notes, and that's not really a time that you can then sit there and say, 'is it going to affect my orgasms?' because I could just imagine, you know, all the eyes glancing at one another and you, you just don't do it. (P5)

But the subjugation of potentially dilemmatic aspects of surgery in the medical encounter was strongly reinforced by the women's own hopes for surgery, as we discussed earlier:

It's, it's, I'm sure they explained those things to me, it's just that I was [] *s-o* desperate at the time that explanations just went right on by. (P3)

You *want* some instant resolution [] so you're kind of prepared to put up with [] the sort of [] side-effects, because you think, you think the overwhelming benefits are going to be [] overwhelming [laughs]. (P5)

For both women and doctors, then, surgery appears as the taken-for-granted means of correcting what is held to be *the* obstacle (i.e. non-typical genitalia) to an active (hetero) sexual life or, as one woman put it, 'something you've got to do' (P7).

The experience of surgery: an emerging dilemma

Two themes were identified in women's accounts of the process of surgery, and of its immediate after-effects: 'just another fanny' and 'the imperfect results'.

Just another fanny This theme represents a pivotal point in tracing the emergence of dilemmatic thinking in the women's accounts because the experience of surgery marked a sharp divergence between the women's experience of surgery as a momentous event, and the routines of medical management:

I was seeing a doctor that was going to do, you know, examine me in a way that perhaps I'd been examined half a dozen times before, and, to me, it was a big deal, whereas to him, it was just another [] fanny [laughs], you know . . . and I really did feel as though, you know, we were all lined up like a cattle market. You know, they just come and have a quick look and a prod and a poke, and then go off again. (P6)

He didn't even examine me, he didn't, he just said, yea, I'll see you on the operating table . . . so, I just [] don't worry about it, I don't need to examine you now. (P7)

You just went and got it done, and you got on with it, and that was it [] go away. (P2)

It was perhaps at this point that the women began to see themselves more as passive recipients of medical management than as people who had made an active choice:

I just signed the consent form. I didn't have any information on, really, what he was going to do. How he was going to do it. I just sort of signed my name and that was it. [] I let him do what he wanted. (P2)

So I was like, yea, OK, if that's what needs to be done, that's what needs to be done. Um [] and then obviously I signed the consent form . . . (P6)

The imperfect results of surgery This theme bridges the immediate post-operative and the long-term outcomes of surgery and will be elaborated further in the next section. It was clear, however, that the short-term outcomes were often very different from those hoped for. One woman suffered severe post-operative infection; three experienced stenosis (closure) of the newly constructed vagina: ' . . . after the first operation, because that closed up [] really quickly . . . it just closed up so [] quickly. So that was a complete waste of time, really' (P5).

Another woman (P6) described the discrepancy between her doctor's description of the procedure as 'a bit painful . . . it's only the discomfort while we're stretching you' and the 'excruciating pain' she experienced post-operatively. She described the procedures as 'acts of violation'; other women described them as 'disfiguring' and 'stigmatizing', particularly ironic comments given the power previously invested in surgery to de-stigmatize.

Post-surgery: surgery as dilemma

Far from surgery being 'the end of it' as one woman had hoped, its dilemmatic aspects became increasingly salient. Two themes particularly reflect surgery's apparent failure to resolve the problems for which it was sought: surgery is not experienced as conferring 'normality' or satisfactory intimate relationships.

The women realized that post-operative procedures would be a continual reminder of difference:

Having to have [] *having to go* to a doctor every year for a physical, rather than [] the assumption that, OK, when the surgery's over that's all you get for a lifetime, you know? [] And I didn't know that I'd . . . have to dilate. (P3)

'Having to dilate'—often necessary to keep the constructed vagina open—was a process which some women found unpleasant (one described it as 'a nightmare'), as well as a reminder of difference. It was not clear whether the women had been told beforehand that regular dilation might be necessary; some claimed not to have known, others that they might not have 'heard' the information, so great was their desire for surgery. In either case, dilation was problematic:

I haven't been dilating, it's just painful . . . The first year I was very good at it [] but then, *after that* [] um, I think maybe, I got more sick about doing it . . . *I just worry that I'll progressively go worse and worse and eventually have to have an[other] operation.* (P7)

Nor did surgery make it easy to form intimate relationships; on the contrary, it made visible what had previously been masked:

I felt . . . like [] I hadn't learned all the social sort of skills that were needed to [] you know to-to establish a relationship and that maybe that was the main problem, and having a vagina wouldn't really help . . . there's more going on than just vaginal length. (P5)

But then I still, even though that [] part of the problem had been taken away, that, you know, penetrative sex could be possible, I still had all the other hang-ups, the shit that I was still carrying around. (P6)

All of the women still had difficulty in starting or continuing any (potentially) sexual relationship. These difficulties centred round two major pre-occupations: does it work? and, will I pass?

The women's concern over whether their altered genitals 'worked' meant that sexual encounters were seen as a test rather than an opportunity for pleasure:

Initially, you know, it probably took four years, three to four years, post-operatively, before I was really able to put it to the test. (P6)

It's like, everything is all a *test* you know, it's [] like with this second guy, I regarded the whole thing as, like, a test, you know, I was testing it all out sort of thing, to see if part A fitted into part B and stuff like that. (P5)

[Intercourse] was this [] big [] kind of thing that I had to cross [] that I was working to understand [] but it didn't feel earth-shattering to be able to do that to myself [use dilators]. I still thought that the big [] test will be intercourse. (P4)

And, because of the need to dilate to avoid closure of the vagina, for some women, this 'test' could become a regular part of their sexual relations:

As regards functioning [] um [] I-I've only tried it out on someone four or five times, but even then, when I did try it [] I think I was just too conscious about [] um, is it long enough, and have I dilated enough in the last two days to make it, make it the right size? (P7)

But as well as needing to 'test out' the size of their vaginas against the size of their partner's penis, the women faced the continuing threat of being 'found out', in spite of the fact that one of the reasons for having surgery had been to escape this threat:

The whole scenario [sexual intimacy] is so filled, filled with anxiety [] that, you know, I just can't relax [] because the whole, the whole thing has become associated with [pause] you know, being wrong or being found to be wrong, uh, you know, and not being adequately equipped . . . (P5)

I think a lot of the time I've been [] afraid to open up too much, or let them, let them see, or even feel, too much of my body in case they ask me about my scarring. (P7)

Even the woman who had had clitoral reduction and no vaginal surgery was not able to anticipate satisfactory sexual relationships because she had, so to speak, been found out by herself: '*Like I said*, people say they would—people wouldn't know, but I mean, I know [] and to me that's, that's enough. [] That is a stumbling block' (P2).

What these women know, of course, is not

simply that they have had genital surgery, but the reason for it—that they have an intersex condition whose implications in terms of self-perception and anticipated perception by others cannot, it seems, be negated by attempting to correct the most visible outward sign. However, the dilemma faced by the women after genital alteration was not simply that it had fulfilled few of the hopes invested in it, but that there seemed to be no alternative way of solving the problems for which it had been sought. Some of the women wondered if the outcomes would have been different if they had used only dilators rather than having surgery, with their dilemma being particularly strikingly conveyed by P5, who had had two vaginoplasties, choosing the second procedure because of its assumed technical superiority, but then asking herself whether it would not have been better just to have used dilators, while also saying that 'there's more going on than just vaginal length. It's like I haven't learned, sort of, how to relate to people properly or, uh, how to sustain a relationship.' But since the women had attributed most of their relationship difficulties to their non-typical genitalia, then the only possible solution appeared to be to standardize them, a solution which did not seem to work. For some of the women, meeting 'the right man' was seen as a way out of this seemingly insoluble problem; this idea was also present in May et al.'s (1996) study of women with CAH. But the fear of being 'found out' made it difficult to see how this meeting could take place.

We have used Billig et al.'s (1988) approach to everyday thinking as dilemmatic, as an 'analytic thread' (Taylor & Bogdan, 1984) linking the themes which characterized the women's accounts of choosing and living with genital alteration. We have suggested that for these women, the process involved a transition from relatively non-dilemmatic to explicitly dilemmatic thinking. It seemed to be at the point of surgery itself that dilemmas began to be explicitly formulated, while further, post-operative dilemmas were organized around the knowledge that a complete resolution of the previously defined difficulties did not occur. Post-operatively, some of the problems of bearing the condition became apparent, no longer obscured by the authoritative appeal of a mechanical solution.

A discursive approach

We argued earlier that phenomenological approaches were less able to account for why people's experiences took the form they did or why particular meanings were assigned to them. We also argued, with Stam (2000) and Yardley (1997a), for the relevance of a discursive approach that acknowledges both the material and the socially constructed nature of the body and experiences associated with it. In the next sections, we therefore present a brief analysis of the women's accounts from this perspective. The analysis focuses on key questions posed by Foucault (1972): what makes particular desires, or ways of talking about things, seem reasonable? How do they come to be taken for granted? The questions emphasize the point that any particular way of talking or desiring depends for its intelligibility on often unarticulated assumptions which reflect dominant (cultural) forms of making sense of the world in any given period (Sawicki, 1991). This relates to Billig's (1991) suggestion that our private thoughts have the structure of public arguments. Thus, if our personal thinking about an issue is relatively non-argumentative, we might expect an equal lack of public argument on the issue, or taken-for-granted assumptions about 'the way things are'. We will analyse here three aspects of the women's experience in order to highlight these points: (1) choosing potentially harmful genital surgery or dilation when it was unnecessary for either reproduction (none of the women could become pregnant) or sexual pleasure; (2) the relative lack of dilemmatic thinking in choosing surgery or dilation; and (3) the complete absence of talk of enhanced sexual pleasure or enjoyment as an explicit goal or outcome. The first two of these will be discussed together.

Choosing surgery and choice as non-dilemmatic

The women's choice of surgery (or dilation) and its relatively non-dilemmatic nature, can be at least partly understood with reference to two powerful, and powerfully related, discursive constructions: two fixed sexes and the linguistic and conceptual conflation of sex with intercourse.

Two fixed sexes The idea that there exist two sexes, one to each body, is so taken for granted

by us, so much not a subject of day-to-day argumentation, that it is extremely difficult to see the idea as constructed and contestable, rather than natural and immutable. Dreger (1998) and Foucault (1979) have focused on the late 19th and early 20th centuries—a time when the social order was especially threatened by war and by women's demands for the vote and a greater role in public life—as the beginning of the modern preoccupation with demarcating two sexes, biologically, socially and psychologically; at this time, the 'perverse' adult—the homosexual and the hermaphrodite—was a particular object of scrutiny given their obvious capacity to threaten a dichotomous division of the sexes. Dreger (1998) and Kessler and McKenna (1978) have argued that the historical importance attributed to outward and easily checked appearance, and the later development of surgical techniques for altering genitals, contributed to a shift during the 20th century from gonads to genitals as *the* signifier of gender and to the modern centrality of genital surgery in the demarcation of two sexes. Thus when the women in this study talk about being a freak or state bluntly 'you are a freak', they are expressing the fact that culturally they are not supposed to exist. The emphasis they place on the psychologically transformative power of genital surgery to make them feel 'more feminine' and a 'normal female' is therefore not surprising.

The conflation of sex with intercourse The women, however, did not choose surgery or dilation only to *feel* more womanly but also to enable them to *act* like women, to 'have sexual relationships' with men. That this should seem to require surgical or manual alteration of the genitals in women already very capable of sexual arousal and orgasm is made at least partly comprehensible by the strong discursive conflation of (hetero) sex and intercourse (Holland, Ramazanoğlu, Scott, Sharp, & Thompson, 1990; Sanders & Reinisch, 1999), a conflation evident in the women's accounts and reinforced by medical encounters in which it seemed to be taken for granted that the women would have surgery in order to 'have sexual relationships'.

The desire for surgery or dilation as *the* means to 'have sex' was, however, also dependent on the meanings of intercourse, with penetration

allowing you to 'be a woman' or being 'a yardstick of a womanly status'. Such meanings are cultural rather than purely personal. A further part of the linguistic, psychological and social importance placed on penis-vagina intercourse, however, depends on its power to signify heterosexuality; as some of the women in this study were well aware, surgical or manual alteration of the genitals in preparation for 'sex' implied a rejection of homosexuality.

The absence of pleasure talk

We noted earlier that the women did not talk of enhanced sexual enjoyment as a goal or outcome of genital surgery or dilation. On the contrary, there was explicit acknowledgement of *not* enjoying intercourse after surgery: 'To be honest, it was just like a dead weight [] inside, which sounds strange, but it was [] I, I don't know, I didn't know how [] I could get enjoyment from it' (P7). This lack of talk about enhanced sexual pleasure as a goal is also evident in surgical outcome studies (e.g. Azziz, Jones, & Rock, 1990; Azziz, Mulaikal, Migeon, Jones, & Rock, 1986) whose criteria for 'success' or 'normal sexual function' or 'fully satisfactory intercourse' do not include sexual enjoyment, but simply the woman's ability to accommodate a penis without pain or discomfort. Similarly, intercourse (like dilators) was presented to some of the women in this study as part of post-operative maintenance, as a way of keeping the vagina open, as one woman put it, 'for the biggest size [of penis]' (P7).

The de-emphasis of women's sexual pleasure might be explained by the potentially more important psychological meanings of possessing a vagina and having intercourse, which were discussed earlier. But the striking lack of pleasure talk in both the literature and from the women themselves, also needs to be understood in a cultural context which has generally privileged male sexual pleasure over female (Hollway, 1989; Maxwell & Boyle, 1995; Ramazanoğlu & Holland, 1993). And in Azziz et al.'s study, surgery was considered a 'partial success' even if the woman experienced discomfort during intercourse, provided this 'did not fully impair penetration' (1990, p. 24). Not surprisingly, then, the women in this study often conveyed the impression that although they expected to gain psychologically from surgery

or dilation, these procedures were also undertaken for imaginary future male partners who, it was assumed, would not accept a relationship which could not include vaginal intercourse.

Discussion

Methodological issues

All of the participants were recruited from a support group for women with intersex conditions; this may have produced a sample with more similar (and possibly negative) experiences than would have been the case had more varied recruitment methods been used. The sample was also small and none of the women had CAH. There are, however, several reasons for assuming that these factors may not significantly compromise the study's validity. First, we made no attempt to suggest an interest in negative experiences of surgery. Second, the women all spoke unprompted of differences of views and experiences within the group. Third, aspects of the women's experiences are corroborated by the most recent data on sexual function collected by medical practitioners (Minto, Liao, Conway, & Creighton, in press; Minto et al., in press). Lastly, the women's experiences not only made sense in terms of well-researched constructions of sexuality and gender, but their accounts of sexual and relationship problems following surgery were very similar to those reported by May et al. (1996) for women with CAH, all of whom had been recruited from medical records for a broader study of quality of life.

It is nevertheless important to extend research to larger samples. Barthold and Aaronson (2002), noting the sparse outcome data on genital surgery, have also called for research using 'objective criteria' to evaluate outcome. But it is important to be very cautious about 'objectivity', given the implicit assumptions that may inform criteria used for 'success'. We would also argue for the routine inclusion of methods that allow women to give their own accounts of outcomes.

The participants had also had surgery some years ago (from the mid-1970s to the mid-1990s) and while this allows the evaluation of longer-term outcomes, it might be argued that procedures have improved since then. Wilson and Reiner (1998) caution strongly against this

argument, given the lack of systematic evaluation of newer techniques and the lack of evidence that their results are superior (see also Creighton, 2001; Kessler, 2002). We were also unable to detect any clear differences in the accounts in terms of when the women had had surgery.

Clinical implications

The study has highlighted some of the 'dominant ways of making sense of the world' (Sawicki, 1991, p. 104), which appear to shape both the desire for genital surgery and its medical provision. These include the dichotomous construction of sex; the conflation of genitals and gender; and the conflation of heterosexual relationships with intercourse. When the psychological and behavioural ideals implied by these constructions cannot be achieved by material alterations to the genitals, then a serious dilemma ensues, whose only solution appears to be more of the same (further surgery or dilation) or a fantasy partner. Yet neither of these solutions arguably provides a basis for constructive psychological input either to women with intersex conditions or to the medical professionals involved in their care.

We would like to suggest several changes to practice, focusing first on the issue of informed consent. Clinical teams would need to (re-)consider what information to give women and how best to explore their understanding of its implications, as well as avoiding the usual presupposition that a vagina or clitoris of certain dimensions are pre-conditions of 'sex'. The possibility that surgery might damage the very thing that it tries to fix—appearance and 'normal' sexual function—must be entertained, as should the fact that surgery may not remove the possibility of having to give explanations to partners or bring about an ideal relationship.

Second, in direct work with women, a major aim would be to encourage more 'self-argumentation' at an early point rather than seeing surgery as the inevitable and only 'solution'. It is possible to increase personal control of social interaction in general, including disclosure situations, and to explore alternative avenues of satisfaction—sexual and non-sexual (Liao, in press). For women who do choose surgery or dilation, the priorities may be the management of their limitations and the development of

sexual relationships which focus on mutual pleasure rather than the 'testing' of surgically or mechanically altered genitals.

It is, finally, worth noting that the social, familial and medical secrecy which has surrounded intersex, together with the pursuit of surgical and mechanical solutions, has resulted in doctors, patients and their families having little vocabulary with which to discuss the condition and the experience of living with it beyond that of its most visible sign—the non-typical genitalia. It is no surprise, then, that the 'solution' of genital alteration should be so readily offered and accepted. Recent calls for more open discussion of alternatives to infant and child surgery, as well as a greater emphasis on psychological aspects of intersex, may help provide a future context in which it is possible to talk—and think—about intersex and its management with richer vocabularies and conceptual frameworks than has traditionally been the case.

Notes

1. Participants are numbered 2–7. No quotations are provided from P1, who volunteered for the research because she wished to talk about her experiences of intersex but surgery was not an issue for her or her doctors.
2. Key to transcript notation: [] = noticeable pause in speech; . . . = text omitted; [abc] = text inserted by authors for clarification; *abc* = said with emphasis.

References

- Azziz, R., Jones, H. W., & Rock, J. A. (1990). Androgen-insensitivity syndrome: Long-term results of surgical vaginal creation. *Journal of Gynecological Surgery*, 6, 23–26.
- Azziz, R., Mulaikal, R. M., Migeon, C. J., Jones, H. W., & Rock, J. A. (1986). Congenital adrenal hyperplasia: Long-term results following vaginal reconstruction. *Fertility and Sterility*, 46, 1011–1014.
- Barthold, J. S., & Aaronson, I. A. (2002). Editorial. *Dialogues in Pediatric Urology*, 25, 1–2.
- Billig, M. (1991). *Ideology and opinions*. London: Sage Publications.
- Billig, M., Condor, S., Edwards, D., Gane, M., Middleton, D., & Radley, A. (1988). *Ideological dilemmas: A social psychology of everyday thinking*. London: Sage Publications.
- Creighton, S. (2001). Surgery for intersex. *Journal of the Royal Society of Medicine*, 94, 218–220.

- Dreger, A. (1998). *Hermaphrodites and the medical invention of sex*. Boston, MA: Harvard University Press.
- Fausto-Sterling, A. (2002). Gender identification and assignment in intersex children. *Dialogues in Pediatric Urology*, 25, 4–5.
- Foucault, M. (1972). *The archaeology of knowledge*. London: Tavistock.
- Foucault, M. (1979). *The history of sexuality, vol. 1: An introduction*. London: Allen Lane.
- Hegarty, P. (2000). Intersex activism, feminism and psychology: Opening a dialogue on theory, research and clinical practice. *Feminism and Psychology*, 10, 117–132.
- Holland, J., Ramazanoğlu, C., Scott, S., Sharp, S., & Thompson, T. (1990). *Don't die of ignorance . . . I nearly died of embarrassment*. WRAP Paper 2. London: Tufnell Press.
- Hollway, W. (1989). *Subjectivity and method in psychology: Gender, meaning and science*. London: Sage Publications.
- Kessler, S. J. (2000). *Lessons from the intersexed*. New York: Rutgers University Press.
- Kessler, S. J. (2002). Questioning assumptions about gender assignment in cases of intersexuality. *Dialogues in Pediatric Urology*, 25, 3–4.
- Kessler, S., & McKenna, W. (1978). *Gender: An ethnomethodological approach*. Chicago, IL: University of Chicago Press.
- Kipnis, K., & Diamond, M. (1998). Pediatric ethics and the surgical assignment of sex. *Journal of Clinical Ethics*, 9, 398–410.
- Liao, L. M. (in press). Learning to assist women born with atypical genitalia: Journey through ignorance, taboo and dilemmas. *Journal of Reproductive and Infant Psychology*.
- Maxwell, C., & Boyle, M. (1995). Risky heterosexual practices amongst women over 30: Gender, power and long-term relationships. *AIDS Care*, 7, 277–293.
- May, B., Boyle, M., & Grant, D. (1996). A comparative study of sexual experiences: Women with diabetes and women with congenital adrenal hyperplasia due to 21-hydroxylase deficiency. *Journal of Health Psychology*, 1, 479–492.
- Meyer-Bahlburg, H. F. L., Gruen, R. S., & New, M. I. (1996). Gender change from female to male in classical congenital adrenal hyperplasia. *Hormones and Behavior*, 30, 319–332.
- Minto, C. L., Liao, L. M., Conway, G. S., & Creighton, S. M. (in press). Sexual function and complete androgen insensitivity syndrome. *Fertility and Sterility*.
- Minto, C. L., Liao, L. M., Woodhouse, C. R., Ransley, P., & Creighton, S.M. (in press). Adult outcomes of childhood clitoral surgery for ambiguous genitalia. *Lancet*.
- Parker, I. (1992). *Discourse dynamics: Critical analysis for social and individual psychology*. London: Routledge.
- Ramazanoğlu, C., & Holland, J. (1993). Women's sexuality and men's appropriation of desire. In C. Ramazanoğlu (Ed.), *Up against Foucault: Explorations of some tensions between Foucault and feminism* (pp. 239–264). London: Routledge.
- Reiner, W. G. (1996). Case study: Sex reassignment in a teenage girl. *Journal of the American Academy of Child and Adolescent Psychiatry*, 35, 799–803.
- Sanders, S. A., & Reinisch, J. M. (1999). Would you say you 'had sex' if . . . ? *Journal of the American Medical Association*, 281, 275–277.
- Sawicki, J. (1991). *Disciplining Foucault: Feminism, power and the body*. New York: Routledge.
- Smith, J. (1996). Beyond the divide between cognition and discourse: Using interpretative phenomenological analysis in health psychology. *Psychology and Health*, 11, 261–271.
- Smith, J. A., Jarman, M., & Osborn, M. (1999). Doing interpretative phenomenological analysis. In M. Murray & K. Chamberlain (Eds.), *Qualitative health psychology: Theories and methods* (pp. 218–40). London: Sage Publications.
- Stam, H. (2000). Theorizing health and illness: Functionalism, subjectivity and reflexivity. *Journal of Health Psychology*, 5, 273–283.
- Taylor, S., & Bogdan, R. (1984). *Introduction to qualitative research methods*, 2nd edn. New York: Wiley.
- Ussher, J. (Ed.). (1997). *Body talk: The material and discursive regulation of sexuality, madness and reproduction*. London: Routledge.
- Warne, G. (1998). Advances and challenges with intersex disorders. *Reproduction, Fertility and Development*, 10, 79–85.
- Willig, C. (2001). *Introducing qualitative research in psychology: Adventures in theory and method*. Buckingham: Open University Press.
- Wilson, B. E., & Reiner, W. G. (1998). Management of intersex: A shifting paradigm. *Journal of Clinical Ethics*, 9, 360–369.
- Yardley, L. (1997a). Introducing material-discursive approaches to health and illness. In L. Yardley (Ed.), *Material discourses of health and illness* (pp. 1–24). London: Routledge.
- Yardley, L. (Ed.). (1997b). *Material discourses of health and illness*. London: Routledge.