

# Learning to assist women born with atypical genitalia: journey through ignorance, taboo and dilemma

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**Abstract** *This aim of this article is to increase awareness of the psychological aspects of a range of conditions associated with atypical development of the reproductive-genital system. In highlighting some of clients' experiences with how atypical genitalia is managed, useful parallels can be drawn for other services.*

*Many clients report being distressed by previous non-disclosure of crucial aspects of their condition by medical practitioners or non-discussion of the implications. Current concerns often relate to having to discuss atypical genitalia with sexual partners. Psychological formulation of the women's difficulties must take account of dominant ways of conceptualizing sex and sexuality in our society. Within a feminist-discursive framework, psychotherapeutic interventions can be helpful in a number of ways. Psycho-educational efforts can help to further increase clients' expertise about their conditions and, thereby, increase control of decisions relating to treatment and to disclosure. However, information delivery would need to draw on alternative and subordinated discourses. Psychological therapy offers opportunities to further explore meanings of different aspects of the condition and to challenge notions of normalcy. Where such support is offered in a group format, it provides additional opportunities for making available different interpretations and solutions, and for reducing isolation.*

*Far from being an obscure area in medicine, management of conditions associated with atypical genitalia starkly exposes pervasive notions of 'normal' sexuality that underpin research and practice in many areas of health and illness, and as such should concern health professionals in general.*

**Keywords:** Ambiguous genitalia, intersex, psychology, feminist therapy, women's health.

## Background

'So, what's it like being a man living in a woman's body?'

In 1995, I was referred a client still shocked by being asked the above question some years before. The junior doctor who had posed the question at a routine medical

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appointment was unaware of the fact that Gloria's 'intersex' diagnosis was a well-kept secret from her. The question triggered a series of events culminating in her discovery that she had a 46XY karyotype, that she had had her testes, not ovaries, removed, that she had been born without a uterus and a smaller than average vagina, for which she had had reconstruction surgery without her knowledge.

A number of genetic conditions can disrupt gonadal and genital differentiation and development *in utero*. Where the gonads, genitalia and karyotype are neither 'all male' nor 'all female', the condition is classified as 'intersex' (see Hughes, 2002). However, parts of the external or internal genitalia could also be non-normative in the sense of being under-developed, rather than 'ambiguous' and this is not always associated with conditions classified as intersex. The various conditions are too numerous to describe here, interested readers can consult Balen *et al.* (2003). Some of these conditions are also associated with other medical problems (e.g. endocrine deficiencies, absence of a kidney) which may or may not be life threatening. I have chosen not to limit this article to work in intersex because similar psychological issues apply to atypical genital development, whether or not the condition is currently classified as intersex.

The condition may be diagnosed at any age. Where the external genitalia appear ambiguous (e.g. the clitoris is sufficiently enlarged to appear like a small penis or the labia are sufficiently fused to give a scrotal appearance), diagnosis of the underlying conditions is often made in infancy. Where the external genitalia look normative but the internal genitalia are not (e.g. absent or small vagina, and/or uterus, presence of testes), the underlying condition may not be identified until adolescence, e.g. following investigations for primary amenorrhea. 'Feminizing' surgery may be carried out at any age, and these might include removal or reduction of the external clitoris (the visible part) or enlargement of the vagina. Where testes are present, gonadectomy is routinely carried out, often due to a sizable risk of cancer.

Potential psychological costs associated with these techniques and the attendant scrutinizing of the genitals for monitoring purposes would be hard to quantify and as far as I know no attempt has been made to do so. Criticisms levied at the medical profession in recent years have focused more on the withholding of diagnostic information, non-consensual surgery, the absence of follow-up evaluations and inadequate psychological support (e.g. Anonymous, 1994; Simmonds, 2003).

It is now recognized that the best care is multidisciplinary and incorporating service user views. This article describes a developing psychological service for adult women. The service is the clinical psychology arm of the Middlesex Clinic ([www.uclh.org/services/reprodev](http://www.uclh.org/services/reprodev)), a multi-disciplinary centre of referral in the UK. There are several reasons for disseminating this experience. It is important for health professionals to be more informed about the existence of atypical reproductive-genital development, how it is managed and what the implications are. Although there are many references to the need for psychological-therapeutic input, the content of such input has not been articulated in any detail. Furthermore, very little direct information is available in the mainstream literature to conceptualize psychological practice in this field. It will become clear that the usual focus on functional variables, such as stress and coping that arise from the individualism in rational objective theories in health care psychology (Stam, 2000) is not enough. It has been important to also draw on feminist-discursive psychology in order to make sense of client difficulties. However, such analyses often give little consideration to how best to assist women with difficulties in practice in the here and now. Being caught between different theoretical

frameworks is something that is shared by practitioners in women's health in general, so all the more important to encourage discussion.

Controversies in management of ambiguous genitalia are historical and complex, and currently channelled in the surgical sexing of ambiguous genitalia in infancy and childhood. A detailed exposition of the debate can be found in Kessler (1998). My focus here is to offer a succinct account of clinical issues for adult women that are of direct relevance to readers of JRIP. Suffice it to say, however, that problems relating to sexuality and medical strategies for managing such problems cannot be understood without reference to social discourses.

I will focus on two areas of patient concern that are inter-related—compromised sexuality and anxiety relating to self-disclosure. I will make use of select extracts of therapeutic dialogues<sup>1</sup> to illustrate these concerns. To ensure anonymity I have removed all diagnostic, demographic or any other identifiable information. Threading through patient narratives of past experiences are allusions to ignorance, taboo and dilemma, which I believe are also shared by the helpers. In the latter sections, I will describe the range of psychological interventions that have been adapted for this service and also their limitations.

### **From imposed ignorance to dilemmatic knowledge**

By far the most often recurring theme in clients' accounts concerns past secrecy surrounding their diagnosis. These accounts parallel published lay accounts (e.g. Anonymous, 1994) and are especially common for women with an XY karyotype. Many clients recall frustrated attempts at finding information. Where information was given, there were usually few opportunities for discussion. Despite lack of formal information, sources have been identified independently. First of all, the women's own bodily events had informed them of their difference quite early on, for instance, one woman told me "[...] all the normal female development, menstruation and all that didn't take place [...]. I didn't have the words or the language in those days [...]." Other people's behaviour, often characterized by silence or curiosity or both, was also 'informative'. This woman continued, "I remember being paraded in a lecture, they'd been discussing it and then the door opened and I was put in front of them [...]."

Most individuals claim to have tried to find out more from health professionals, but often without much success – some felt that they had been fobbed off, while some received what we now know to be inaccurate information. One woman said, "I can't remember my GP's exact words but it's like 'don't make trouble'." Another told me, "Imagine being told when you are 14 that you can never have sex". Whilst in hospital recovering from her gonadectomy, a nurse said to a woman when she came to: "You'll never get pregnant, so lie back and enjoy it!" These reports may not reflect what had been said, just what was remembered.

Few people pressed hard for information for fear of upsetting others. Some clients have described upsetting family members when they as much as hinted at the subject, and some have not tried, believing that the family would not be able to cope with a discussion. One woman told me, "My parents couldn't discuss it. My father would have walked out of the room". Two women told of their mother's reactions: 'She would just burst into tears' and "All she would say is that she's been through hell".

Feeling ignorant and at the same time unable to break the taboo have meant that

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<sup>1</sup>Key to notation: [...] = text omitted; (text) = inserted by author for clarification.

many people have ‘muddled through’ the years. As one woman explained, “We (she and her family) didn’t know, so we didn’t know what to discuss”. She went on to say, “It was my boyfriend’s mother who (later) said ‘Look you got to do something about it (periods not having started by mid-twenties)’.” Although the muddling through was to last for decades for some, many remember stumbling upon pieces of information, for example from seeing someone on a television programme describing similar symptoms. Women have reported feeling confused by the different bits of information from various sources. This woman’s example is particularly poignant: “I learned a name for it – testes – but I knew about the (XY) chromosomes when I was 16 [...]. Even then, I thought when I was 25 I had a hysterectomy (laughs) [...].”

There are examples of successful requests, much later, in gaining information. For example, a woman told me, “Fifteen years ago (then approximately aged 40) I saw a doctor. He was very forthright. I had the maturity to accept what he said then. He was blunt, he gave me the whole story that I never had before.” When individuals find out about the truth, one of the first questions they ask is invariably to do with whether their parents had also been kept in the dark or whether their parents had known, but had withheld information from them. A vague memory offered by a woman with XY karyotype: “I remember my father used to get very angry when he saw me play football (considered a male sport), I was eleven [...] so, he knew something.” Another woman complained angrily, “Well, they’re (parents are) both dead so I’ll never know (what parents knew).” It is impossible to assess to what extent these difficulties have defined family relationships. As intersex activist, Cheryl Chase, said in an interview that “The whole family is distorted and unusual” (Hegarty, 2000). One client has recently attempted at a dialogue with her family as an experiment. Her feedback to me was ‘Well we had our weekend, I organised it, and I did, you know, I tried. Nothing happened [...]’. When I asked how it was that “nothing happened”, she responded, “Well, they just talked about other things”.

Clients have expressed a sense of betrayal at having been lied to and at the lack of opportunity to determine their own treatments. As one woman said, “I didn’t even know what was done to me [...] It was like a brick wall between me and my GP. We avoided the subject.” Another similarly protested, ‘It shouldn’t be one person’s decision, the doctor who operated on me, that was his choice, his decision, and his fault.’ Clinicians who are target of these latent protestations had no doubt believed it better for the patient not to know. Without the benefit of hindsight they were ignorant of the negative consequences of withholding information and taking unilateral control of clinical management.

Now with full diagnostic and treatment knowledge, the responsibility for disclosure to others has been transferred to patients. However, many of my clients do not feel in control of decisions relating to disclosure, which are invariably experienced as dilemmatic. One of the most frequently asked questions in clinic is whether to tell – whom, when, what and how. A number of clients have not disclosed about their condition to spouses or long-term partners, more have withheld at least some information. Non-communication in the past might inadvertently have reinforced the message of unspeakable shame. Disclosure to new partners is seen as risky even for women who have ‘successfully’ disclosed to previous partners. Having to explain about atypical genitalia to potential partners is often viewed as the most daunting task for those not in relationships. It is frequently cited as a reason for not seeking relationships.

### Normal sexuality, doing intercourse

Whereas a woman has the choice not to disclose to others about atypical genitalia, when it comes to sexual partners this becomes much more difficult. Thus, issues of sexuality and communication are bound together. The two most common concerns are whether the genitals look different and whether it is possible to 'have sex'. As for the wider culture, 'sex' is linguistically and conceptually conflated with intercourse (Boyle *et al.*, in press).

What makes disclosure a salient issue is that surgical fixing of the genitalia is less effective than previously imagined. Recent reviews suggest that the cosmetic and gynaecological outcomes of genital surgery are considerably poorer than previously estimated (Creighton, 2001). Surgery carried out in infancy and childhood is inevitably repeated in adolescence and/or later. With repeat procedures, scarring and loss of sensation are common. Many women, now that they are systematically asked, report a range of sexual difficulties (Boyle *et al.*, in press; May *et al.*, 1996; Minto *et al.*, 2003). Research reports concur with clinical experience.

I have heard very few clients spontaneously allude to pleasure as a reason for engaging or wishing to engage in sexual activities. Wishing for, but not looking forward to 'sex' is not unusual. It is as if vaginal intercourse accomplishes something important, but also represents high risk. It is not unusual for the women to terminate social interaction fairly early on to avoid having to give explanations or risk humiliation in case intercourse was to ensue – as if they could have no control over this. Fear and avoidance may well be related to past experience of not being in control of bodily experiences in clinical contexts. I have also noticed that women who are sexually-orientated towards men are more likely to express feeling anxious than those who identify themselves as lesbian or bisexual.

For those who are not sexually active, a situation of high stakes and high return means that some women are preoccupied with thoughts about relationships, whilst at the same time withdraw from opportunities. I have met women who have been in this perpetual state of conflict for years. Not engaging in sexual intimacy, but not wanting to raise suspicion about her condition, a young woman told me how she actively disguised sexual inactivity: "You just laugh it off [...], like they're always saying "Go on, tell us about your last shag" (laughs)." When I asked how she responded, she said, "Well I just said "Oh I don't talk about things like that'."

For those who have not taken any risk to discover that physical intimacy need not be perfect or follow a certain script, idealized notions about relationships are maintained and the psychological barriers further heightened. Whilst in potentially intimate encounters, some of the women describe spectating their own performance and their partners' reactions, thus problems can be self-fulfilling. Hardly any client reports experience of personal humiliation during sexual encounters, many more report suffering pain and discomfort. For instance, one woman told me, "Sex (intercourse with ex-husband) was always painful, I got very bruised you know."

Just as hardly any woman alludes to pleasure as reason for engaging in sex, hardly any woman who exclusively prefer male partners appears to have considered non-penetrative sexual activities as valid forms of sexual expression. The centralizing of intercourse is problematic for women in general and particularly for this client group. Vaginal intercourse might always be uncomfortable for some women, but at the same time it is almost regarded as the Holy Grail, perhaps for its imagined power to transform the individual from perceived deviance to normalcy. This somewhat magical

view of 'being able to have sex like a normal woman', coupled with negative self-evaluation and a sense of non-entitlement, effectively removes the opportunity for any form of sexual expression for some of the women.

### **Addressing the problems**

The relative absence of therapy literature to assist this client group has meant that I have had to adapt knowledge and skills developed in other women's health services to try and meet the needs of this client group. The tentative and evolving clinical activities are briefly discussed in this section.

#### *Sensitive delivery of information*

In order for patients to have greater control of their consultation and treatment, they need to become more expert about their own condition and attendant difficulties. However, in health care settings, patient information tends only to focus on medical (diagnostic and treatment) knowledge. Any of the following information delivered in a clinical language can be shocking: non-typical external genitalia, absent vagina, absent menstruation, infertility, karyotype, heredity, lifelong medication or devalued appearance characteristics, such as hirsutism, weight gain and short stature. Responsible disclosure means that patients and significant others are not left to contemplate the implications without support. A psycho-educational approach towards responsible information delivery is very much needed, using richer vocabularies and drawing on alternative discourses aimed not only to increase medical knowledge, but also to address the social, emotional and sexual aspects.

#### *Consultations for individuals and/or significant others*

Within the health service, therapy tends to be brief and the current service is no exception. With some clients there is an explicit agenda for the consultation process, such as management of self-disclosure, decision-making regarding (more) genital surgery or relationship difficulties. At other times, however, the conversations are more exploratory.

I avoid fixing my conversations with clients and families to therapeutic brands, and instead operate along the lines of 'technical eclecticism' outlined in Erskine *et al.* (2003). However, several characteristics are fairly predictable in my conversations with the women. First, I mostly begin the first session by inviting the person(s) to set an agenda. Secondly, given the historical conditions that have contributed to these women's difficulties, I believe that it is important to offer clients time to tell their stories. For those who have suffered losses (e.g. having to live with scarred genitals), it is particularly important to acknowledge their distress, and to support them as they grieve for their losses and consider the implications. Thirdly, an important role as a feminist therapist is to assist the women in developing a more questioning attitude towards dominant discourses of sex and sexuality, to deconstruct their assumed position of deviance. Fourthly, the task of facilitating clients' connections with their resourcefulness is often an important aspect of consultation. New and more enabling narratives may be developed in conversation, but I believe it is important to also perform them, to generate new life experiences that can, in turn, formulate preferred identities and inform a different kind of self-storying. Where relevant, I would negotiate practical tasks between sessions that might involve keeping a diary, reading a

particular book, conversing with a significant other, re-kindling a hobby or, indeed, eating well or taking up exercise. Lastly, given the problems of past secrecy, I routinely address psychological reports to clients in letter format to maximize openness.

Often, the younger patient finds it difficult to take on board all the complex information – infertility can be hard to process for a 17-year-old. However, the anxiety amongst parents is only too obvious. Parents and partners also need the opportunity to express their reactions, to share their concerns and to discuss how they could access support for themselves, as well as ways of supporting their daughter or partner.

#### *Group work*

Group work has been shown to significantly reduce psychological distress in the reproductive medicine context (Hunter & Liao, 1995; Liao *et al.*, 2000). Reduction in psychological distress has also been reported for a seven-session group intervention specifically for women with condition-associated atypical genitalia (Weijenborg & Ter Kuile, 2000). Currently group work is carried out for clients who have had some individual sessions, but express the wish to maintain contact with the service. Although this group that meets once a month was developed initially to compensate for the lack of resource for longer-term individual therapy, the group has shown itself to be useful in ways that individual therapy cannot be. It allows the participants to share common concerns, and makes available to each participant different interpretations and alternative solutions. Most of all, participants have made available to each other diverse identities and positions, thereby effectively deconstructing notions of normalcy.

#### *Developing less invasive treatments*

In our multi-disciplinary clinic, vaginal dilation, rather than surgery is favoured as the first line approach for increasing vaginal volume for those who seek this help. However, although dilation does not have the same risks as surgery and is not irreversible, it is nevertheless important to make this service as 'women-centred' as possible. A protocol for vaginal dilation treatment has been developed jointly with gynaecologists and nurses, whereby clients who have been prescribed dilation treatment will have the opportunity to have broader discussions of sexual practices. Whereas discussion of genital surgery has in the past typically (if not exclusively) emphasized functionality of female genitals as passive receptacle for the penis, within the current service, female desire, arousal and choices are emphasized.

Dilation requires ongoing effort for slow progress, thus adherence is variable even for those who have actively opted into treatment. Methods incorporating motivational interviewing, goal setting and self-monitoring are useful for encouraging progress and sustaining effort. Clear instructions and the teaching of relaxation exercises are provided. Participants are also encouraged to do further reading, and to continue to discuss aspects of female sexuality in their own contexts and review personal preferences.

#### *Working with the team*

Psychological perspectives are integrated in multi-disciplinary clinical management through joint consultations, case discussions, and audit and research projects with colleagues in gynaecology, endocrinology, urology and nursing. These activities

provide all of us with opportunities to learn from each other and to learn to function as a team. Psychologists can also usefully contribute to medical research. Recent multi-disciplinary research projects have directly influenced the clinical advice that is now offered to patients and families. For example, projects have clarified some of the limitations in gynaecological, psychological and sexual outcomes for genital surgery (Minto *et al.*, 2003), information that directly informs clinical practice.

#### *Liaising with lay support forums*

Lay support forums sometimes request clinicians' presence at their meetings. This is an important obligation for clinicians working in this field. Where possible, contribution is made towards support groups' effort to produce information and self-help material for their members.

#### *Psychological research*

More research is needed to address gaps of psychological knowledge in living with atypical genitalia. However, researchers have the responsibility to strike a balance between repeated gazing at the small populations and tangible achievements for those populations. Participant-centred psychological research might, for example, include projects that investigate family members' relationships to the condition in question, factors that can affect personal adjustment, the effectiveness of psychological interventions in this field, the impact of genetic testing on family relationships, the psychological effects of medical treatment and so on. Research that is closely knitted with client concerns will hopefully contribute to changes in the culture of intersex services in future.

### **Limitations of psychological approaches**

Psychology service users are amongst those who are experiencing difficulties; thus, I stand to miss other stories. I have certainly met patients who told me how they had come to lead fulfilling lives with no professional psychological support. Some say that they have had to overcome their difficulties without support, but wish they had had the choice, others have not felt the need for such support. Thus, psychological input should not be viewed as a necessity for this client group or any other.

For patients in difficulty or distress, many are aware that their problems are related to the way in which 'normality' is defined in society. As one woman said, the medical condition was for her 'not a physical condition', but 'to do with your identity', whilst another made reference to 'the order of society' and 'how you work out where you fit in'. An awareness of the way that distress is socially mediated, however, does not come with an ability to change society and many women feel compelled to make choices believed to lead to female normativity. Whilst these may seem like difficult paths to follow, patient choice must be respected and supported. It is well to remember that therapy privileges individual solution in the here and now, not possible social change in the distant future. Nevertheless, an imaginative awareness of dominant discourses of sex and sexuality can guide interventions aimed to construct experiences that are not entirely dictated by dominant culture.

Difficulties arise in evaluating interventions that are informed by feminist-discursive psychology. It would be more politically expedient to define goals in relation to categorization of clients' internal states (anxiety and depression 'caseness') or

abstract functional variables (e.g. ‘coping with stress’) (Stam, 2000). However, this acceptance will involve relocating the problem back in the person, and will profoundly influence our transactions with client and system. To negotiate our task in terms of clients’ life histories that are subject to complex social hierarchies is to introduce discomfort, and interventions at individual and systemic levels that aim towards co-creation of new discursive possibilities are marginalized, with relatively little state resources for development, implementation and evaluation. This remains an area of ignorance in psychology and a concern for those of us whose practice is influenced by discursive psychology.

### Summary

Clients differ in physical presentation, developmental history and psychological outlook, and not everyone born with atypical genitalia report appreciable difficulties. However, a range of problems are reported by those who seek psychological input including feelings of betrayal, negative self-appraisal, anticipatory and experienced sexual difficulties, and a sense of disconnectedness from others, sometimes including the immediate family. Since there is relatively little information on therapeutic services for people with atypical genitalia, it has been necessary to transfer experiences in other areas of reproductive psychology and integrate these with feminist-discursive analyses to interpret client experiences, to formulate interventions, and to refine these by tuning into diverse opinions and contradictions, taking into account resource availability.

Whilst it is never good enough to say “if only we can change society”, work in this field does require exposing and questioning societal mandates relating to sexuality. Different means for assisting clients to contextualize their problems have been discussed. The specific problems identified in this article may not be generalizable to other clinical contexts. However, other clinical services are similarly underpinned by shared cultural values and assumptions, e.g. that physical and psychological capacities for penis–vagina intercourse are prerequisites for being man or woman. Such values disadvantage many patient populations, not to mention women and men in the general population. Atypical genitalia are not obscure clinical phenomena with little generality for other fields. On the contrary, management of atypical genitalia very importantly exposes ideological influences in research and practice in many fields and disciplines. It should not be regarded as something best left to a handful of experts, rather what should concern us all.

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