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Alderson, J., Madill, A. and Balen, A. (2004) Fear of devaluation : understanding the experience of intersexed women with androgen insensitivity syndrome. *British Journal of Health Psychology*, 9 (1). pp. 81-100. ISSN 1359-107X

<https://doi.org/10.1348/135910704322778740>

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Published paper

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ACKNOWLEDGEMENTS

We are very grateful to the women who participated in this research. We also thank contributors to the AISSG-UK and USA email discussion circle.

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ABSTRACT

Objectives

We aim to provide an understanding of the psychological sequela of Androgen Insensitivity Syndrome (AIS) in phenotypic females in order to begin to inform psychosocial health care services.

Design

Eight adult women with AIS were recruited through United Kingdom-Androgen Insensitivity Syndrome Support Group (UK-AISSG). Data was collected via two semi-structured interviews with each woman.

Methods

Transcripts were analysed using grounded theory and a conceptual model was developed which suggests a way of understanding the AIS DISTRESS experienced by our participants.

Results

The pivotal concept is a woman's FEAR OF DEVALUATION. This is connected to her level of ADAPTATION and perception of having a COMPROMISED WOMANHOOD. These, in turn, are related to her MEDICAL MANAGEMENT and involvement with others (SUPPORT GROUP and TALKING ABOUT AIS).

Conclusions

Participants showed a clear preference for open communication about their condition and we recommend sensitive, pacing of information in order to allow young women and their family to make informed decisions about treatment and a realistic adaptation to life with AIS.

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Fear of devaluation: Understanding the experience of intersexed women with
Androgen Insensitivity Syndrome

Androgen Insensitivity Syndrome (AIS) is one of a group of intersex states where a person's genital, gonadal, or chromosomal characteristics are neither all 'female' nor all 'male' (Kessler, 1998). AIS is one of the most common intersex disorders and subsumes the largest group of XY women; people with a female phenotype (apparent gender) and XY karyotype (chromosomal pattern usually associated with males). It has been estimated that female carriers have a 25% chance of bearing an affected 46XY child (Slijper, Frets, Boehmer, Drop & Niermeijer, 2000), however some cases arise as spontaneous mutations. AIS comprises two androgen resistance syndromes; Complete Androgen Insensitivity Syndrome (CAIS) and Partial Androgen Insensitivity Syndrome (PAIS). Estimated incidence of AIS has ranged from 1 in 41,000 to 1 in 99,000 births (Boehmer, Brüggewirth, van Assendelft, Otten, Verleun-Mooijman, Niermeijer, Brunner, Rouwé, Waelkens, Oostdijk, Kleijer, van der Kwast, de Vroede, & Drop, 2001).

With AIS, female internal sex structures do not develop although female secondary sex characteristics, such as breasts and female external genitalia, do occur. Typically, CAIS women have a normal vulva, clitoris, and introitus (vaginal opening) with a short or dimple vagina. At puberty, breast development occurs but pubic and axillary (under-arm) hair remains absent. Girls and women with PAIS commonly show ambiguous secondary sex characteristics, such as an enlarged clitoris, and have some pubic hair growth. In both CAIS and PAIS, hands and feet may be large and height is usually above female average (Wisniewski, Migeon, Meyer-Bahlburg, Gearhart, Berkovitz, Brown & Money, 2001). AIS often remains undetected until

adolescence when girls present with primary amenorrhoea (a failure to begin to menstruate) (Dewhurst, 1971). Sometimes AIS is diagnosed during early childhood when a feature such as testes is noticed, often due to the presentation of inguinal hernia (the displacement and protrusion of a testis through the wall of the groin canal). Occasionally a girl's XY karyotype is discovered following chromosomal tests for unrelated reasons. Often PAIS presents at birth with variable genital ambiguity and, when detected in infancy, a decision is made regarding the gender assignment of the child. Dependent upon a range of factors, including the grade of sensitivity to androgens, some people with PAIS are reared as girls and others as boys.

The long-standing aim of the medical management of intersexuality has been to encourage good psychological adjustment and the preservation of sexual function via the promotion of unambiguous gender identity (Creighton & Minto, 2002). John Money and his colleagues in the 1950's and 1960's proposed and developed the dominant psychological theory used to guide treatment of children born with ambiguous genitalia. (Money, Hampson & Hampson, 1955, 1957). Money suggested that socialisation exerts a decisive role in the development of gender identity. He proposed that, in the sex assignment or reassignment of neonates and babies, there is latitude of choice in gender as psychosexual identity is as yet undifferentiated. It follows that sex assignment and subsequent rearing can direct the course of gender differentiation. This paradigm gives precedence to the role of nurture over nature in the development of a gender identity as it is suggested that "genetic, hormonal or other prenatal determinates do not exercise a gross, inevitable predisposing effect" (Money, 1975, p.609). Clinical implementation of the theory that the patient's gender identity would be disturbed by parental ambiguity regarding assigned gender demanded secrecy about aspects of medical management. However, the practice of

maintaining secrecy has been argued to reinforce feelings of stigma and shame for those with intersex conditions (Preves, 1998). Moreover, it has precluded the opportunity for individuals to explore concerns about their condition and has hampered the development of theory and practice of medical and psychological care in this area.

Interviews with expert US clinicians in the mid-1990s revealed that surgical intervention still followed Money's principles, but there was a new belief that patients should be informed about their situation with age-appropriate explanations (Kessler, 1998). However, the practice of full or limited truth telling during the medical treatment of intersex conditions, such as AIS, is still debated. Edmonds (1989) gave advice to be guarded with the expressed intention of promoting a positive psychological response in parents and child. A similar position is evident in a more recent paediatric and adolescent gynaecology text which states sex should be determined and remain unequivocal (Dramusic & Ratnam, 1998). Fryer (1998) suggests that a limited explanation might be acceptable in childhood, but recommends a full explanation of AIS in adolescence. Similarly, when a diagnosis of AIS is made in infancy, Goodall (1991) recommends telling truth in stages over a period of years in line with the child's ability to understand.

There have been calls for retrospective outcome studies of the medical management of intersex conditions and, in response, a UK group have conducted a study of genital surgery outcomes in female intersex patients (Minto, Liao, Woodhouse, Ransley & Creighton, 2002). Some authors have recommended that psychologists contribute to the evaluation of treatments (Kipnis & Diamond, 1998; Wilson & Reiner, 1998) and there is an emerging opinion that psychological disciplines should be involved in the provision of health care to this population (Fryer,

1998; Howe, 1998; Schober, 2001; Wilson & Reiner, 1998). Recent publications regarding medical management of AIS are increasingly likely to recommend consideration of psychological factors and the inclusion of clinicians with psychotherapeutic skills (e.g., Fryer, 1998; Warne, 1998), although research evidence on which to base psychological management of intersex conditions is sparse (Sutton & Whittaker, 1998).

A survey of fourteen AIS respondents aged 16 years and above concluded that neither CAIS nor PAIS is necessarily associated with reduced psychological wellbeing (Hines, Ahmed, Fane, & Hughes, 1998). In addition, a long-term medical follow-up of 14 patients with CAIS, of whom 80% had received counselling, concluded that the women had “generally satisfactory medical, surgical and psychosocial outcomes” (Wisniewski, Migeon, Meyer-Bahlburg, Gearhart, Berkovitz, Brown, & Money, 2001). However, the literature is not always this positive.

In one long-term psychological evaluation of intersex patients (aged 4-26 years), five CAIS patients were diagnosed with psychological disorder including depression, anxiety, sexual problems, and ‘oppositional defiant disorder’. Moreover, one PAIS patient was diagnosed as having depression, sexual problems, gender identity disorder, and deviant gender role (Slijper, Drop, Molenaar, & De Munick Keizer-Schrama, 1998). A thematic content analysis of in-depth interviews with a large group of intersexed adults suggested that medical treatment in order to sex patients is experienced by them as degrading and shaming (Preves, 1998). Follow-up research by Slijper, Frets, Boehmer, Drop and Niermeijert (2000) found that parents and adult patients experienced lasting emotional reactions to diagnosis of AIS including shock, grief, anger, and shame. Moreover, a small number of personal accounts of the mental health problems of women with AIS are available (e.g.,

Anonymous, 1994) and case reports of psychological therapy conducted with women with AIS give additional indications as to the range of psychological problems experienced (e.g., Sutton, 1990, 1998). The Androgen Insensitivity Support Group (AISSG) also provides information to clinicians that suggests many women affected by AIS have suffered psychological problems (AISSG, 1998, 1999, 2000). Hence, the emerging literature on the psychological impact of intersex conditions suggests that patients continue to report psychological problems despite having received sex confirming medical treatment.

The design and delivery of healthcare services for intersex patients and their family are based upon the prevention of a pathological response to the diagnosis and effects of the condition. However, one view is that much of the trauma experienced is generated by the health care system itself with Wilson and Reiner (1998) suggesting that the primary problem is “lack of true communication” (p.363). Similarly, Kipnis and Diamond (1998) reviewed the management of intersex conditions and recommended “that efforts be made to undo the effects of past deception by physicians” (p.406) and argued that, without knowledge of their medical condition, individuals cannot “make a realistic appraisal and act accordingly” (p.407).

As a number of authors have pointed out, the methods of managing intersexuality are based upon hypotheses that have not been tested and, despite increasing anecdotal and clinical knowledge, there remains little research to guide psychosocial services for people affected by intersex conditions. Research on medical and psychological outcomes is ongoing and it is difficult to interpret inconsistent or preliminary findings. In many studies the number of individuals with specific diagnosis is small and studies often group individuals with different diagnosis. This together with differing assessment methods, medical and personal histories make only

the most tentative interpretations possible. Psychometric measures are currently being developed for use with children which should improve the validity and generalisability of future outcome studies and, in time, allow meta analyses (Meyer-Balhbarg, Sandberg, Dolezal & Yager, 1994; Meyer-Balhbarg, Sandberg, Yager, Dolezal & Ehrhardt, 1994).

In order to study one group of intersexed people in detail, we decided to limit our research to XY women and to AIS as the most common condition within that group. Three volunteers with CAIS, three with PAIS, and two who were unsure about whether their AIS was complete or partial were selected to take part. The complete and partial forms of AIS pose different challenges and it has been suggested that the two have different psycho-developmental trajectories (Zucker, 1999). The decision to group these two forms of AIS was made on the grounds that women with both CAIS and PAIS will be seen at the same service and the primary aim of the study was to inform the provision of such services. In addition, women with AIS strongly identify as a group and so, rather than appear divisive, we wanted this study to provide information on the needs of the group as a whole.

Qualitative methodology aimed at theory development is particularly relevant when there is little research from which to formulate hypotheses for testing. A qualitative approach was also consistent with our collection of data via participant interviews. Interviews were appropriate to our focus on participant experience but were also used as the organisation from which the participants were recruited (Androgen Insensitivity Syndrome Support Group-United Kingdom) advised that their members would be reluctant to take part in questionnaire-based research because it was deemed too impersonal. Grounded theory (Glaser & Strauss, 1967) was selected as the method of analysis as it provides a rigorous approach to developing a

conceptual understanding of textual data and aims to formulate a theory of the phenomenon under study.

METHOD

Ethical Approval

This study was approved by the Ethics Committee of the Leeds Teaching Hospitals Trust and had the official support of the AISSG-UK.

Researchers

The primary researcher, JA is a phenotypic female Chartered Clinical Psychologist working, in part, in developmental gynaecology which includes referrals of people with intersex conditions. This research was supervised by AM who is a phenotypic female academic psychologist and experienced qualitative researcher. AB is a phenotypic male Consultant Gynaecologist and Obstetrician, Sub-specialist in Reproductive Medicine. The authors have not established their own karyotype, nor are they aware of any relative or friend being intersexed.

Participants

Eight women participated in the main study (table 1). All were recruited via UK-AISSG media or through contact with AA at a group meeting. For ethical reasons participants were over 17 years old and were members of UK-AISSG, so had access to this support network. In order to avoid overlaps in professional and research contact, volunteers were excluded if they were patients of the department for which AA worked

----table 1 about here----

Theoretical sampling was used to choose eight participants from the 16 volunteers. Theoretical sampling is a form of sequential recruitment. Having analysed material from an initial participant, each subsequent participant is selected on the basis that

they are likely to provide information that will fill gaps in the developing theory, allow the exploration of differential experiences, or potentially challenge and test evolving conceptualisations (Strauss & Corbin, 1990). All participants were Caucasian and heterosexual, although these facts were not known before interview. All were established as women or girls before diagnosis and had been given a gonadectomy and hormone replacement therapy (HRT). None knew their karyotype until adulthood, although one was raised knowing about most aspects of her AIS. Three had CAIS, three PAIS, and two were unsure about whether their AIS was complete or partial. Five had consulted a psychotherapist or had been diagnosed as suffering with a psychological disorder perceived by the participant to have occurred in relation to her AIS.

Data Collection

A semi-structured interviewed schedule was developed from 30 short, anonymised autobiographies of women with AIS belonging to an e-mail circle. This was supplied with the consent of all contributors and did not include participants in our main study. A thematic analysis highlighted the following areas: pre-diagnosis knowledge, process of diagnosis, medical and parental management of information regarding AIS and disclosure to the affected individual, infertility, medical management, comparison and difference, relationships, and psychological distress and recovery. Questions were devised to elicit discussion of these areas but the schedule did not preclude exploration of additional topics. The schedule was piloted with a volunteer who provided positive feedback on the interview content and style. On reviewing the pilot, it was decided to conduct a second interview with each participant in order to ask tailor-made follow-up questions (Hollway & Jefferson, 2000) and to check early interpretations of the data (Stiles, 1993). Informed consent was obtained from all

participants and interviews took place at their home except one that was held in a private room at a conference centre. Interviews ranged from 45-90 minutes. The time between the two interviews ranged from 3-14 days, except for one participant whose illness meant delaying the second interview for seven months. A medical secretary with extensive experience of handling sensitive clinical material transcribed the audio-recordings.

Analytic Procedure

First, 'meaning units' (MUs) were identified defined as a portion of text expressing one concept relevant to the topic of study. MUs about the same phenomenon were collected into a category that was awarded a descriptive label. For example, the quote; *"I suppose it was the periods thing really because, I suppose at about that age my friends were starting, some of them, so I suppose it might have been that"* was considered a MU and placed in a category labelled 'Age relevant loss'. Category content and labels were refined in an iterative process as the coding continued and analysis of subsequent transcripts built on the coding that had already been developed. Particular care was given to identifying MUs which seemed to contradict the direction of coding so that the analysis did not overly simplify the participants' meanings.

Second, when the initial coding was complete, categories were clustered together at a higher level of abstraction. For example, categories 'Age/stage', 'Influenced distress', 'Mood effects', and 'Personal life on coping' were clustered under a higher-order category labelled 'Distress mitigated' as this captured their similarity at a more abstract level of meaning. Third, the relationships between higher-order categories were established. This was aided by reviewing memos that had been written throughout the analysis (Glaser, 1978). The conceptualisation of a relationship between higher-order categories led to the establishment of a theme. For example,

‘Sense of self’, ‘Comparison and difference’, ‘Gender’, and ‘Self-image’ were related and formed a central theme of the analysis: ‘Compromised womanhood’.

RESULTS

Our participants experienced variable levels of distress, characterised by fear of being devalued by others, in response to AIS. The woman’s view of herself, her relationships, the medical management of her condition, and her contact with other people affected by AIS could foster or mitigate this fear and, in turn, her level of AIS-related distress. In this section we first establish the presence of the theme AIS DISTRESS then explore a possible source of distress in COMPROMISED WOMANHOOD. The analysis suggests that FEAR OF DEVALUATION is developed from COMPROMISED WOMANHOOD and is influential in the way the participants talk about themselves and AIS (TALKING ABOUT AIS). Two major influences are presented; (i) the impact of medical investigations and treatments for AIS (MEDICAL MANAGEMENT), and (ii) the effects of making contact with others with the same condition (SUPPORT GROUP). Finally, in the theme ADAPTATION, we explore the participants’ process of adjusting to AIS

Theme 1: AIS DISTRESS

All participants experienced some level of distress related to AIS; *“It just makes me feel angry that people are so ignorant [about AIS], I suppose because it does, it still hurts”* (L). This distress often intruded on their lives; *“Every time I see a reflection of myself it’s almost as if it’s a reminder of the AIS”* (F). It could be intensified or offset by the preoccupations of a certain age. For example, Marie’s initial distress was limited by her priorities at adolescence; *“I cried for about a day and then just got on with life really, it wasn’t all that relevant at that age”*. However, Pauline felt the

impact of her infertility most keenly when she married; *“I’ve got no brothers or sisters, I’ve had no children either, so I’m loosing out all round now”*.

Theme 2: COMPROMISED WOMANHOOD

A possible source of AIS-related distress is captured in the theme COMPROMISED WOMANHOOD. Women with AIS may compare their bodies and their lives with those of other women; *“my sister was like overtaking me, I just thought ‘This is not right surely’”*(R). As with Rachel, their comparisons often resulted in feeling different in ways that were, on the whole, perceived by them as negative. For example, one of the most salient features of the experience of AIS was infertility and Barbara felt this added to her perceived devaluation of her life; *“I spent most of my life in a society which er rated reproduction and conventional marriage and family etc. as being the norm, so I didn’t conform to the norm”*. Looking feminine was discussed in positive terms whereas a masculine appearance was very distressing for the participants who saw themselves in this way; *“I was quite muscular and I felt that I looked quite masculine, and you know, I just felt that I looked awful”* (B). Fiona’s comments underline the implication of these threats to womanhood; *“It does help me to think that I’ve never responded to testosterone and in some ways that makes me less male and that’s what, that’s what I cling to”*.

Theme 3: FEAR OF DEVALUATION

This theme describes the women’s anticipation that others may hold them in low esteem as a result of AIS, an anticipation that, in part, may be influenced by the participants’ own feelings of COMPROMISED WOMANHOOD. The language used indicated their own, sometimes harsh, view of their condition. For example, Barbara referred to AIS as *“an unfortunate twist of nature”* and Kathryn described having had testes as *“the News of the World part”*. Five used the word ‘freak’ when talking about

themselves, or how others might view them, and the fear of being devalued was crystallised for many in the potential of being seen as a lower-value partner; *“I think ‘Oh God I can’t have babies, no one will ever marry me’”* (M), and many spoke in strong terms about their fear of rejection; *“If someone was to go ‘Oh God’, you know, revulsion, instant rejection, you know I think I would find that quite hard to cope with”* (K). Hence, many of the women had a freakish image of themselves which contributed to their fear that others might reject them.

Theme 4: TALKING ABOUT AIS

This theme conceptualises the way the participants’ relationship with others may be influenced by the women’s own response to AIS, particularly her FEAR OF DEVALUATION, which itself may be related to her level of ADAPTATION to her condition. The theme is labelled ‘TALKING ABOUT AIS’ because, as AIS is rarely obvious to others, our participants’ experience of making verbal disclosures was a strong feature of their accounts. The influence of FEAR OF DEVALUATION can be seen in what the women said about how, and why, they felt anxious before speaking to people about AIS and also how, and whom, they chose to tell. There are many facets to TALKING ABOUT AIS so description of this theme is relatively detailed.

Some feared the impact on their friendships of talking about AIS; *“I am putting all this burden on them, this kind of heavy stuff, they’re going to think I’m a bit odd”* (L). Hence, they used strategies to reduce the perceived risks, e.g., limiting the amount of information revealed; *“She knows I can’t have children and she knows I haven’t got a womb and I think she knows I take hormones as well so I don’t quite know whether she would need to know any more than that really”* (R), and Marie mentioned her practice of putting *“a good shine on things”*. FEAR OF DEVALUATION also meant that some felt they inadvertently colluded with the lack

of openness about, and acceptance of, their condition. For example, Lisa's fear of people's response made her "*change testes to ovaries*" during some conversations.

FEAR OF DEVALUATION was influential on the participants' anticipation of their partner's reaction on learning about AIS and affected the way they discussed the condition with them. The women might explain their infertility, lack of pubic hair, or short vagina without making a full disclosure; "*I just sort of didn't tell him much of the story. I just said 'Oh no I had deformities with my insides so they have taken my bits out'*" (M). Some perceived their fear as detrimental to their relationships. For example, Pauline said AIS "*actually ruined my marriage*", however she did not refer to her husband's response to AIS, but rather to the way her feelings about herself had prevented her from enjoying their relationship.

Participants were motivated to talk about AIS to their parents via a desire for empathy and understanding; "*I thought that they didn't understand how awful, and that was where part of the anger was, because I think they just belittled it*" (F). However, five experienced difficulty talking openly within the family, even where sisters were both diagnosed with AIS; "*Within a year of my diagnosis she knew hers but we didn't talk about it at all em which I feel is a shame*" (K). This difficulty may have been caused, in part, by the participant's FEAR OF DEVALUATION; "*My major thing was just to know how they felt about me after they found out*" (F). In particular, there appeared to be a complex relationship between some participants and family 'carriers'; XX women who have been diagnosed as carrying an androgen receptor defect. Some believed that their mother felt guilty because they may have passed on AIS to their child; "*Because you know mum feels guilty then you don't like talking about it with her because you know you are just causing her to feel guilty even more*" (L). On the other hand, some felt that their sisters secretly, or openly, blamed

them for bringing AIS into their lives; *“Every time she can she uses it to throw back in my face”* (C). Such issues may stem from the perception that AIS impacts negatively on other family members, for example parents; *“When Professor [] told me before I was fourteen that I’d never have children, my mother just broke down and cried”* (P), and siblings considering prenatal testing for AIS; *“I think I will always say terminate it”*(F).

Participants perceived there to be potential risks to disclosure yet all but one offered examples of other people giving positive responses on learning about AIS; *“They had a really good understanding of it, and were really fantastic about it”* (B). One aspect of a positive response was that the listener did not change their view of the woman; *“If anyone was to see me differently to how they saw me before, then it says more about them than me, but em just having to deal with that would be [...] the end of a friendship”* (K). However, participants often wanted people to be able to accept them and their condition without understanding it fully and some preferred not to be asked questions; *“didn’t question me at all...she seemed to accept it without hesitation”* (P).

Five reflected on being discussed in their absence, which provided further information about how they may have tried to minimise the risk of being devalued. Some accepted that members of their family talk about aspects of their condition, for example parents informing siblings; *“I think she told them that I couldn’t have children”* (R). There was no hint that the women felt threatened in circumstances where the family relationship was close, possibly as they did not fear being devalued by those particular people. However, they were less happy being talked about where the relationship was more peripheral. For example Kathryn stated that she would not like her father’s new partner to *“know the full details”* and that she would only be

likely to discuss AIS with her if *“I liked them and got on with them”*. Many participants also indicated that they would prefer to explain the condition themselves, rather than being talked about *“Because you’re not in control of the way it’s being told”* (L); *“I suppose its like me not being in control of the situation”* (K). The importance of being in control may be that they can then use strategies to limit the possibility of being devalued.

Feelings of isolation were not always prevented despite others knowing about the woman’s AIS. For example, Lisa described how her friends who knew about her condition still did not think about its consequences in the way she did; *“It will be little things and you find yourself thinking – but they won’t see it, but for you its always there... it means that again you’re kind of secluded in your own thoughts a lot of the time”*. Isolation could also be self-imposed due to negative feelings about AIS and, perhaps, the fear of being devalued; *“I didn’t allow my self to get close to them and em because it was this massive thing and I couldn’t bear anyone to find out so I, so I deliberately I suppose really built and kept that difference between me and them”* (F).

Some had a firm desire to be honest about their AIS and wanted to resist any pressure to ‘cover-up’, an act which some saw as dishonest; *“If I didn’t tell them I would have to tell lies, which I don’t want to do really”* (M). Others talked about covering-up; *“I said to mum ‘Don’t tell them. Tell them I’m going in for a cyst removal or something.’ I just wanted to be normal”* (R). Participants also offered other reasons for this. Fiona, for example, said; *“Because its such a big massive private thing”*, and some were influenced by having had a bad reaction to their disclosure in the past. Such explanations suggest that the women’s FEAR OF DEVALUATION was influential in their decision to be more or less open about AIS.

However, over all, most participants felt that the most positive response they could make to their AIS was honest disclosure.

Theme 5: MEDICAL MANAGEMENT

This theme concerns the participants' experience of assessment, investigations, and interventions resulting from their AIS including the manner in which they were treated, the advice they and their parents received, and the participants' psychological response. As with TALKING ABOUT AIS, this is a complex theme with many aspects.

The most distressing aspects of medical interventions appeared related to psychological aspects of physical treatments. Few were prepared for the discomfort of a demonstration of vaginal dilators and the need for the treatment itself was not always discussed; *"it was just 'Aaah!' Excruciating, I mean it wasn't so much the physical discomfort as the... you know I'm 17, I'm lying like this [indicates legs open], you know with someone sticking a glass tube up my hole, sorry up my vagina. You know, the complete surreal-ness of it all was – you know, it just didn't make any sense"* (K). In fact, none of the participants who were given vaginal dilators in their teens were able to use them appropriately. Some of the women taking HRT felt that their doctors had underestimated the psycho-biological impact; *"I thought that I was not coping with my work and was suffering from some sort of stress related to work. [...] But I didn't twig that it was possibly after taking three months of HRT"* (B). For some, a psychological discomfort led to poor adherence; *"I went through a stage of not taking my HRT, just because I felt that it was strange and I wanted to be normal"* (C), and, despite having taken HRT for years, some still had unanswered questions regarding this aspect of their medical management.

Consultations with medical staff appear to have been vitally important and influential upon the participant's view of herself, and feelings about treatment, but were often experienced as interpersonally difficult, embarrassing, or awkward; *"they were talking to me but not looking at me, there was no contact at all"* (P). Moreover, consultations often resulted in distress or left the participant puzzled. For example, Kathryn remembered her doctor saying 'Don't try to join an Olympic team' and puzzled about this remark for years; *"I mean I don't know why she said that, I mean maybe she was, maybe it was just a flippant remark"*.

All but one talked about secrecy within their MEDICAL MANAGEMENT which included a range of limited information giving, omission of information, and explicit directions to other professionals to keep the diagnosis from her; *"That's where the diagnostic side of it started. And from then on it was kept a complete and utter secret from me, exactly what condition I had"* (B). One woman considered her doctors had acted to protect her feelings; *"I suppose they didn't want to suddenly put the fear in me that I might be some sort of freak of nature"* (R). However, on the whole, withholding of information was perceived negatively; *"what I did feel angry about was the secrecy"* (B).

A number felt that they had not received adequate information about their condition or its MEDICAL MANAGEMENT as Pauline's harrowing account indicates; *"They made me be naked in a room and take pictures of me, and they took pieces off the skin and left me two marks on each arm and nobody said to me why they were doing it"*. Many sought information themselves by talking to doctors or by doing some form of private research although, at certain times, the search for further information was avoided; *"I knew there was something they weren't telling me and I was frightened to push too far"* (F). This suggests that, while the participants may

have wanted more information than they received, they also needed to play a part in regulating the information in terms of the amount and the pace.

There appeared to be commonalities in the way that doctors told the participants about their AIS. It was usual for the condition to remain unnamed; *“She said ‘you’ve got a medical condition’”* (M). Words describing female anatomy were often substituted for those that sounded like they pertained to a male body and the risk of cancer was routinely given as the reason for surgery; *“All they were told was that my ovaries had gone septic and if I didn’t have them removed it could lead to cancer”* (C). The participants emphasised that the way in which they first learned about their condition was of lasting importance and influenced the way they went on to talk about AIS with others; *“You know how much longevity words have in your own head, and how you were first told”* (L). Two were unhappy with the way they were told and were concerned not to mirror it. For example, when Marie talked about telling friends she said; *“I wouldn’t like say, ‘Right’ sit down I’m going to tell you something’”*. The timing of information-giving was also important but the impact varied between participants. Two felt that being diagnosed in late adolescence had caused them difficulties, for example in relation to academic performance. However, another felt this was positive in that the changes in her body with treatment took place when she was changing her routine and many of her friends.

Many reported difficulties communicating with health professionals. Sometimes this was because she had not understood something her doctor had tried to discuss; *“She did mention about XY chromosomes but it didn’t mean anything at all”* (K). Communication could be handicapped by the patient’s limited medical vocabulary as in Lisa’s experience of explaining her absence of a womb to a radiologist; *“You know I can only explain it the way I explain it to myself”*. However, at other times, the

communication problem was situated with the health professional. For example, six believed their doctors had purposefully used language to create a barrier to the truth about their condition; “*I understand I had testes but am I genetically male or female?*” and he kept saying, ‘*phenotypically you’re female*’” (F).

Each participant discussed the relationship they have had with medical staff. Many described positive aspects of the relationship, for example liking a doctor’s business-like manner; “*He’s very brusque and sort of, sort of quite an old fashioned doctor really which I quite like actually*” (R). On the other hand, a positive relationship could be built from making the woman feel special; “*I really very much felt that I was a special patient because I got to choose my operation date*” (M). Less comfortable relationships could be based on poor rapport; “*He’s got almost a patronising air as if to say em ‘There, there’, you know*” (L), or where the woman felt relatively powerless; “*I had requested time to go through my records in their possession and I went armed with a list of questions, but she didn’t actually let me look at the letters or the paperwork, she sort of gave me edited answers from across the desk*” (B). Overall there appears to be no style of doctor-patient relationship that can provide a model which suited all participants.

So far, the theme MEDICAL MANAGEMENT, has described participants’ experiences with health services. To conclude this section we review the participants’ ideas about improving health services for woman with AIS.

They cautioned against the over-use of examinations and seemed to want doctors to be open with patients about their diagnosis and the nature of investigations and treatments; “*If my doctor had been a bit more open about it I probably wouldn’t be so afraid of going to see him*” (C). However, they highlighted the importance of timing; “*I think I could have dealt with the truth if it was said to me in bite size*

portions at the time” (B), although there were some differences of opinion here; *“Being told bits monthly makes you think its almost worse than it is, or especially not being told at all, you know it kind of puts it as this big thing in your mind when maybe it wouldn’t be if you were told straight”* (L). Finally, some suggested that psychological support would have been useful; *“I would have liked the opportunity or you know, counselling (I would have freaked out if it was called counselling), or just somebody to speak to”* (K).

Theme 6: AIS SUPPORT GROUP

All the participants in the main study were members of the UK arm of the AIS Support Group. The level of involvement with the group varied, but each had been to one or more of the biannual group meetings and they all received the group’s biannual newsletter. When talking about their first or subsequent AISSG meetings, the participants expressed something of the intensity of the feelings they experienced; *“I literally opened my mouth and burst into tears”* (L). Some indicated that experiencing such feelings in the setting of the support group was valuable; *“I think that was the only time when I was allowed to get emotional about it because all the other times it was either me feeling sorry for the doctor, you know, not talking about it with my mother”* (K). However, talking about their experiences could at times be painful and challenging. For example, Lisa described her reaction to her mother’s contribution to meetings; *“I feel quite proud but also I wish we could have had this conversation before without all of these people”* (L).

For many, the support group was experienced as potentially empowering; *“I saw the young kids who have got exactly the same as me today and they know what’s going on with their lives, they’re getting married, everything”* (P). They valued the opportunity to speak openly about their AIS; *“You can start talking about the most*

intimate things em without any pretence, no sort of pussyfooting around” (B), although this was not universal; *“I haven’t really felt able to share anything with them yet” (F).* However, the intimacy between the participants appears to have been largely specific to the subject of AIS. Moreover, some were aware of the possible impact of their words on others and so, at times, were not completely open; *“I was thinking, ‘well you know I can’t really go and complain too much about my experiences because there have been so many people who have had a really horrible time’” (M).*

Within the theme COMPROMISED WOMANHOOD, it was indicated that the participants compared themselves with other women and felt that they were different. The participants also compared themselves with the other women with AIS whom they had met as a result of the support group. The impression that the participants gave, overall, was that their fellow group members were more attractive than they had feared they would be and not conspicuously different from other women; *“I was looking around this room and wondering you know, who are these people and have they all got AIS and why are they here – it was very difficult to work out who was who” (B).* A prominent mode of comparison was an estimation of the other member’s experience, distress, or coping with respect to their own; *“It sounds really selfish, it’s a relief to know that someone else is going through the same shit that you are” (L).* However, as Lisa’s quote implies, this did not appear to contradict the participants’ feelings of ‘sameness’ although some also recognised differences; *“They are all quite assertive and I haven’t been able to articulate my own feelings to myself” (F).*

Most indicated that membership of UK-AISSG could be emotionally taxing as a result of learning more about their condition and themselves; *“I really feel for people who are coming to them [meetings] for the first time, because the first one, you know, I sat crying the whole way through” (K).* In addition, when some members benefited

from support, sympathy, or concern this could have some cost for others. For example, Rachel remembered one member talk about her current situation and feeling *“I was, quite, you know, worried for her really”*. However, the participants appeared to find their support of others generally rewarding and considered it their responsibility to be positive in order to support other women with AIS; *“I have this sort of em this need to think that I can make things better for young girls going through it”* (F).

Theme 7: ADAPTATION

The final theme of the analysis, ADAPTATION, captures the way in which participants talked about their process of adjusting to AIS. FEAR OF DEVALUATION was present in the suspicion and confusion felt before a full understanding of AIS was achieved. However, without support, knowledge did not always mitigate this fear or, necessarily, promote adjustment. ADAPTATION to AIS DISTRESS, and a reduced feeling of COMPROMISED WOMANHOOD, was influenced by the quality and appropriateness of MEDICAL MANAGEMENT, experience of the SUPPORT GROUP, and TALKING ABOUT AIS with others.

There was a phase in each participant’s life when she had only a partial awareness of her condition; *“When I was about 10 or 11 I sort of half suspected something was amiss, em, and certainly by the time I was 12,13,14 I was pretty sure that something was amiss”* (B). Four mentioned a phase when they had been told something about their condition but did not have a full understanding; *“My friend had a doctor friend and I phoned her and she spoke to me and said briefly what it was but it left me feeling even more anxious”* (P). This phase, before being told about AIS, was the basis of making sense of their condition later; *“I used to think it was because they were checking if the hernias wouldn’t come back”* (M). They felt that they

learned the truth about their condition only when they were given its name and had many of their questions answered. Two learned about AIS from a television programme, one saw an article in a magazine, and a fourth accidentally saw something in her medical notes that lead her to ask her doctor questions. Learning more about AIS was seen as positive by the women who spoke about this; *When I found out I immediately rushed around saying 'look what I've got, you know, I'm happy this is good, this is excellent'* (C).

The practical and emotional support enjoyed by participants appears to have been provided by friends and family. For example, Marie talked about the support she received from her partner; *"He saw me at my absolute worst, he had a high level of patience with me"*. However, this was not universal and Fiona said of her parents; *"I thought they weren't being supportive of me in difficult times"*. Health services occasionally provided support but rarely of a formal nature; *"But the emotional side of it then, who's going to address it? The GP can't answer it for you they don't have time for it in their seven minutes"* (K).

The final aspect of the theme ADAPTATION relates to the process of coping with AIS. Participants drew upon strategies such as active sense-making which included searching in their family histories for other women who had possibly suffered with AIS and Barbara had *"decided to create for myself, because I was different to everybody else, my own workshop manual"*. Another strategy was to have a sense of oneself as not having been altered by AIS; *"I don't think I'm psychologically, would have been any different had I, well actually I suppose I might have done different things in life if I hadn't got it, but I don't think it would have changed me dramatically in any way"* (R). Drawing on personal strength was also important and Claire indicated that her openness and willingness to talk had helped

keep her from needing further psychotherapy; *“If there’s a problem someone hears about it I don’t bottle up or anything”*. However, within the coping process the participants could continue to experience ambivalence and confusion while being aware that their acceptance of their AIS was developing; *“I feel at ease with myself now, I wouldn’t say I’ve done it all alone, as I said it was a process and I can say how I feel now, whether that’s part of getting older or whether its because I fully know, accept and understand about myself, the AIS part of myself, I don’t know”* (K).

DISCUSSION

The aim of this study is to provide an understanding of the psychological sequela of AIS in phenotypic females in order to begin to inform the requirements for psychosocial health care services. The analysis suggests a way of understanding the AIS DISTRESS experienced by the participants. The pivotal concept is a woman’s FEAR OF DEVALUATION. This is connected to both her perception of having a COMPROMISED WOMANHOOD and level of ADAPTATION. These, in turn, are related to her MEDICAL MANAGEMENT and involvement with others (SUPPORT GROUP and TALKING ABOUT AIS).

Our study suggests that some level of psychological distress is likely to be expressed by a woman with AIS and can occur before she has even acquired information about her condition. For instance, some participants talked of being concerned that something about their body was not right before they had seen a healthcare professional, knew they had a medical problem, or had received a diagnosis. In addition, when a woman discovers she has AIS, she may need to reconsider some of her assumptions and expectations about her life. For example, pertinent to some of our participants was the disappointment of not being able to bear children. Infertility can become central to a person’s identity (Olshansky, 1996) and,

in the present study, contributed to participants' sense of COMPROMISED WOMANHOOD. Similarly, Sandelowski and Pollock (1986) describe a sense of 'otherness' in relation to infertile women's feelings of being left out, misunderstood, and defective. It may be that within the range of interventions and support offered to women with AIS, too little is aimed at promoting adaptation to the aspect of infertility resulting from their condition.

Medical management of people with intersex conditions is aimed at maximising their psychological wellbeing and physical health and most medical texts recommend a management approach that lies somewhere between withholding all information about diagnosis and 'true communication' (Dramusic & Ratnam, 1998; Edmonds, 1989; Fryer, 1998). However, participants in this study are testimony to the recent opinion that it is difficult to prevent XY women from eventually learning their diagnosis as five of the eight participants had made their own investigations, including the reading of medical textbooks (Kipnis & Diamond, 1998; Wilson & Reiner, 1998). Moreover, there is no evidence that withholding diagnostic information about an intersex condition will prevent ambiguous rearing, gender confusion, or emotional distress (Wilson & Reiner, 1998).

Our participants had a female phenotype and were successful in female roles, but all had at some point questioned their gender; half of them before they had been told their diagnosis. Participants who had experienced some concern about their gender before diagnosis had been prompted to question their gender for different reasons. One made assumptions due to her virilised genitals (PAIS), one felt extremely tomboyish (CAIS), another had been mistaken for a boy during childhood and had ruminated on this in light of her feelings of difference (specific AIS diagnosis unknown), and the fourth said that feeling more like a boy than a girl had made her

wonder about her sex and gender (PAIS). Hence, secrecy about karyotype does not guarantee unequivocal gender identity. It can also be argued that stable gender identity is not synonymous with, or necessary for, psychological wellbeing as, despite questioning their gender, most participants functioned throughout much of their lives without psychological disorder. Rather, AIS related distress was experienced by many as a result of medical interventions alongside a sense of the duplicity of doctors, health care staff, and sometimes parents.

Preves (1998) reached a similar conclusion, suggesting that gender assignment or sex enhancement treatments and secrecy regarding the medical histories of intersexed people can instil the very distress that medical intervention aims to prevent or alleviate. The simple binary delineation of sex is part of the wider context in which the identity of intersexed people is problematised and can create anxiety that they may not achieve utmost success in their (self or medically) assigned sex. For many it is the prescription of a sex or gender that is resisted. The Intersex Society of North America (A USA peer support and lobbying group) campaigns against the enforced identification of intersexed people as male or female and some people consider their gender to be neither male nor female but intersexed, while others within the same organisation are happy to be defined by their chromosomal pattern and gender role, e.g. XY women (Devore, 1999; Schober, 2001).

True communication implies an attitude of honesty and openness about AIS, with information imparted effectively (Wilson & Reiner, 1998). However, most participants felt their doctors had deliberately evaded their requests for information. Another problem was doctors' use of euphemisms as this could be experienced by some patients as patronising and as suggesting that the woman would not be expected to understand or face the reality of AIS. Rather than an attempt to soften the impact of

diagnosis and understanding of the condition via the use of euphemisms, other interventions such as the availability of psychological support might be considered. Many also experienced the commonly described phenomenon that patients are able to retain little of the information imparted by the doctor during a consultation (Pickersgill & Owen, 1992). A further problematic aspect of communication was the doctor's sensitivity to words that might feel demeaning or dehumanising to a woman with AIS and have the potential to increase her sense of COMPROMISED WOMANHOOD. This is consistent with Fryer (1998) who advises care over the choice of language used, being particularly mindful of the patient's gender.

Sensitive telling incorporates age-related pacing of information and it is well accepted that onset of a health condition, or its implications, is likely to impact the tasks of a child or adolescent's developmental stage (Edwards & Davis, 1997; Wallander & Varni, 1998). Many diagnoses of AIS are made in adolescence and surgery, or discussion of surgery, usually takes place at this age. Adolescence is believed to be a particularly difficult time at which to cope with a health condition as it can increase reliance on parents when the young person is seeking more independence (Edwards & Davis, 1997). Moreover, adolescents often have difficulty adhering to self-administered procedures. To compound this, the use of HRT can be perceived by a young woman as a phenomenon of middle age and therefore inappropriate for a person their age, and greater discussion of possible physical and psychological side-effects appears necessary.

Recommendations for open communication between parents and children, doctors and parents, and doctors and patients can be found in research on protective factors against poor adaptation with regard to a variety of medical conditions (e.g., Beresford, 1994; Bradford, 1997; Eiser, 1993). Similarly, our research suggests that

when a woman with AIS is given information about her condition she can begin to make sense of how it impacts her and to make appropriate adjustments. Certainly, many of our participants suffered as a result of not being able to appraise their situation, for example by limiting unduly their personal relationships, going without available treatments or, indeed, being unaware of the elective nature of some procedures. Most appeared to undergo a process of accepting their AIS only after receiving full information and appropriate support, and research suggests that both may be necessary for efficient adaptation (e.g., Edwards & Davis, 1997). The clinical implication of this is that parents should be encouraged to be open with their daughter about her AIS, its effects, and treatment. However, this can only be possible if doctors extend the same openness to parents.

Family approaches to the psychological management of chronic health conditions are increasing in their application (John & Bradford, 1991; Munson, 1986; Wallander, Varni, Babani, Banis & Wilcox, 1989). In line with Slijper et al. (2000), our study indicates that parents have their own adjustments to make in relation to AIS echoing research which suggests that feelings of guilt, especially in the case of congenital conditions, can increase distress within the family (Hunfeld, Wladimiroff, Passchier, Venema-Van Uden, Frets, & Verhage, 1993). Parents may experience psychological reactions such as FEAR OF DEVALUATION of themselves or their child and are surely influenced by the way the condition is discussed and treated within the medical environment. However, parents are also well placed to limit the level of distress experienced by their daughter and additional parent focussed support, such as genetic counselling, may be advisory, especially for mothers and other female relatives who are, or may be, carriers of AIS (Slijper et al., 2000).

Participants indicated that, although their doctors usually provided adequate medical care, many of their emotional needs had gone unmet and their questions left unanswered. It seems that the medical and the psychological management of AIS cannot be separated and that medical interventions must be provided with consideration of their emotional impact. This substantiates the need for the involvement of psychologically skilled staff. Many interventions require careful discussion and the consideration of consent beyond the scope of a medical consultation. This is, in part, due to the irreversible nature of many of the elective procedures but also because certain treatments rely heavily on patient adherence. In addition, some medical treatment outcomes need to be evaluated on psychological variables such as gender identity, sexual satisfaction, and social confidence. A further source of information and emotional support are support groups and our participants highlighted the potential benefit of making contact with others with this diagnosis (see also Edwards & Davis, 1997). Moreover, many authors suggest that support groups are of particular value when a condition is rare (Edwards & Davis, 1997; Liao, Abramson & Corp, 2000; Nettles, 1995). However, according to the present research, involvement is likely to engender powerful feelings and, although a level of emotional intimacy may be experienced, this is sometimes limited to discussion of subjects related to the shared condition.

Our participants cannot represent every experience of women with AIS. All were recruited from AISSG-UK that does not include people with AIS who have not been diagnosed, nor whose diagnosis is known by doctors but not by the woman herself. Moreover, women with a diagnosis of AIS who do not want to know more, or who are not interested in meeting others with the same condition, are unlikely to be represented amongst the support group membership. Acting as some balance to these

limitations, we sought diversity within our participant group and we obtained retrospective accounts of experiences prior to diagnosis and whilst the participants had limited knowledge of AIS. The commonality of support group membership introduced the risk that the participants may report a support group agenda (Wiersma, 1988), however this did not appear to be the case. Three of the women said that they did not identify with what they perceived to be the view of the group. Six indicated that they had not talked as openly before and that taking part in the research had enabled them to learn things about themselves of which they had not previously been aware. For example, one woman realised just how much she regretted having been unable to talk with her mother. AIS accounts for the majority of cases of XY women, but there are a number of other intersex conditions that produce a female phenotype with XY karyotype and it may be that the current research can be generalised to the clinical management of such conditions. Many aspects of our study may also be generalisable to conditions affecting XX women that necessitate similar treatments to those offered to women with AIS.

Our findings concur with previous authors that the approach to the medical management of AIS is influential in the aetiology of AIS distress (Preves, 1998; Schober, 2001). With the proposal that medical management should be provided in an atmosphere of openness with the incorporation of specialist psychological services, the need to evaluate the effectiveness of this new approach is clear. The value of meeting others with the same condition was highlighted and it would be useful to investigate further the role performed by support groups. More research into the most appropriate way to provide psychological services for the parents and family of people affected by AIS would be beneficial.

Our overall conclusion is that XY women with AIS experience distress that results from associated losses, continued medical involvement, and the attitudes and responses of others. These can instil FEAR OF DEVALUATION through a sense of having a COMPROMISED WOMANHOOD. However, our participants showed a clear preference for open communication about their condition and we recommend sensitive pacing of information in order to allow young women and their family to make informed decisions about treatment and a realistic adaptation to life with AIS.

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| Pseudonym | Age (yrs) | Diagnosis | Support Group Involvement |
|------------------|------------------|------------------|--------------------------------------|
| Lisa | 20 | CAIS | High |
| Marie | 21 | Not confirmed | Minimal |
| Claire | 22 | PAIS | Minimal |
| Kathryn | 33 | CAIS | High |
| Fiona | 33 | Not confirmed | Moderate |
| Rachel | 34 | PAIS | Minimal |
| Barbara | 52 | PAIS | High |
| Pauline | 54 | CAIS | Moderate |

Table 1: Description of participants