

Psychological Distress in People with Intersex Conditions

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OBJECTIVE: It was hypothesised that people with intersex conditions would have a higher level of psychological distress than the general population.

STUDY DESIGN: The presence of psychological distress was investigated in 52 people who had been diagnosed with intersex conditions and recruited via specialist medical centres and support groups. Assessment was quantitative using a standardised psychological questionnaire (Brief Symptom Inventory).

OUTCOME: People with intersex conditions had more psychological difficulties than non-patients, but fewer than psychiatric outpatients. Approximately 41% of the sample reached the criteria for psychological caseness. Particular difficulties were found in the interpersonal areas of difficulty trusting others, feelings of inferiority and anger.

CONCLUSION: These findings are discussed in relation to the cultural and medical experiences of people with intersex conditions. Health care management should include: clear, honest information provision; ongoing support; opportunities to talk and awareness raising.

Key Words: Intersex, Androgen Insensitivity Syndrome, Congenital Adrenal Hyperplasia, Gonadal Dysgenesis, 5 alpha reductase deficiency, Brief Symptom Inventory, psychological.

In line with a current focus on re-consideration and re-evaluation of medical practices¹ and the increasing emphasis on evidence-based healthcare, there has been a recent and welcome recognition of the need for research pertaining to the psychological wellbeing of people affected by intersex conditions.

To date, the research has been mixed in its methodological rigour and its conclusions about the extent of psychological distress in this population. There are studies suggesting that psychological disorders are not an inevitable consequence of intersex: for example, a survey-based (N=14) study concluded that neither PAIS (Partial Androgen Insensitivity Syndrome) nor CAIS (Complete Androgen Insensitivity Syndrome) are necessarily associated with reduced psychological wellbeing². Further publications argued that women with CAIS did not differ from controls on any measure of psychological well-being³ and had satisfactory medical, surgical, and psychosexual outcomes⁴.

Other studies suggest that psychological disturbance is a more common occurrence. Female adolescents with CAH (Congenital Adrenal Hyperplasia) can achieve relatively good adjustment in personality functioning with optimum treatment, although ambivalence in gender identity often remains a significant issue⁵. A further study of adults with CAH argued that participants scored lower in social competence, expressing a more negative self-image⁶. They were more afraid to engage in partnerships, more likely to be unmarried than controls and significant impairments were found with regard to body image and attitudes towards sexuality. In addition, women with CAH (N=19) were found to be less sexually experienced, had more sexual problems and reported less satisfaction with the frequency of sexual opportunities than diabetic controls⁷. The authors concluded that the contribution of psychological factors were 'at least as great as that of medical/surgical factors' (p479).

One long-term study argued that 'severe general psychopathology' was evident in 39% of intersexed children studied, with early counselling appearing to provide a protective effect⁸. The psychological disorders included depression, anxiety, sexual problems and 'oppositional defiant disorder'. Subsequently though, this study has been criticised regarding its protocol and treatment methods^{9, 10}. In a further study, the authors found that a diagnosis of AIS is associated with shock, grief, anger and shame for both parents and adult patients¹¹.

Mental health problems in people with AIS have also been described in personal accounts¹². Recent qualitative research led to a theory that the fear of a negative reaction from others may be a major contributing factor to psychological problems¹³. Patient groups assert that much of their trauma is generated by the healthcare system itself, for example, stating that the primary problem is a 'lack of true communication'¹⁴ (p. 363).

Due to the expanding evidence of an increased incidence of psychological problems in people with intersex conditions, there is a view that psychologists should contribute to the evaluation of treatments¹⁵ and that there should be long-term psychological input for this population¹⁶. This process is hindered by the limited availability of research to guide such service development¹⁴.

The current paper goes beyond the scope of previous research in several ways. Participants were recruited from multiple sources, including several hospital clinics and a United Kingdom support group. To date, there has been no research with this range of recruitment sources and consequent generalisability. Adopting a quantitative methodology ensured that substantial numbers could be recruited including participants with a range of intersex conditions, enabling the findings and recommendations to apply to a broader population than has previously been the case. Ethical clearance was sought and obtained from Local Research Ethics Committees representing LTH NHS Trust and UCH NHS Trust.

Materials and methods

Participants were accessed from both medical [University College Hospitals (Obstetrician/ Gynaecologist and a Paediatric Urologist) and Leeds Teaching Hospitals (Obstetrician/ Gynaecologist and a Clinical Geneticist)] and a support group source (Androgen Insensitivity Support Group UK). All participants from medical sources were registered with one or more of the identified clinicians and were selected by the consultant as having been diagnosed with an intersex condition. Some participants were simultaneously registered with more than one of the consultants and to prevent duplication cross-referencing was carried out. All but one of the consultants approached for collaboration in the research agreed to take part. All identified patients were sent an opt-in letter and information sheet by their consultant. Patients who consented to being contacted by a researcher were sent a questionnaire pack containing an information sheet, a postage-paid return envelope, the Brief Symptom Inventory¹⁷ and a list of support groups. A reminder letter was sent a month later if necessary. All those recruited through hospitals also had a letter sent to their GP with notification of their consent to being approached by researchers. Recruitment of support group members was carried out during a presentation of the research at the organisation's annual conference and questionnaire packs were made available for the duration. It was not possible to medically verify diagnostic criteria of these participants and it is likely that some support group members had also received packs via their medical clinic. In case of this they were advised that they should only fill out one of the questionnaires (from either source).

All data was returned to LTH. The questionnaire responses were anonymous, with coding to allow for identification of the recruitment source and the participant's own accepted gender. Feedback of the results was prepared for all those involved; individual participants, local research ethics committees, hospital and support group collaborators.

Results

The majority of participants were recruited through hospital clinics following an approach by their consultant (Table 1).

Table 1	The proportion of participants recruited via each source		
Source of recruitment	Number of people approached	Number of participants	% response rate
Hospital Clinics (UCH and LTH)	166	42	25
Support groups	Members informed but no direct approaches.	10	N/A

Participants were demographically and clinically diverse (Table 2).

Table 2 Additional biographical information indicated by the participants

Factor	Subcategories	Frequency	%
Diagnosis	CAIS		38
	PAIS		12
	CAH		30
	Gonadal Dysgenesis		6
	5 alpha reductase deficiency		4
	Don't know		2
	Other		8
Identified	Male	4	8
Gender	Female	47	90
	Intersex	1	2
	Age Groups	18-24	15
	25-30	9	17
	31-35	5	10
	36-40	4	8
	41-45	3	6
	46-50	7	14
	51-55	4	8
	56-60	3	6
	61-65	2	4
	65-70	0	0
Relationship Status	Not in relationship	21	40
	In relationship	10	19
	Cohabiting	7	13
	Married	9	17
	Widowed	1	2
	Divorced	2	4
	Separated	0	0
	Not specified	2	4
Hormone treatment	Yes	40	77
	No	12	23
Surgery	Yes	45	87
	No	7	13
Support Group membership	Yes	25	48
	No	27	52

To find out the extent of psychological distress present in the sample the BSI global indices were calculated¹⁸ and compared to available normative data for nonpatients and psychiatric outpatients¹⁷.

Table 3 BSI global indices compared to normative data. The figures in parentheses indicate the standard deviation.

Index	Participants (N=52)	Nonpatients (N=974)	Psychiatric outpatients (N=1002)
Global Severity Index (GSI)	0.92 (0.69)	0.30 (0.31) p≤0.001***	1.32 (0.72) p≤0.001***
Positive Symptom Total (PST)	23.998 (12.58)	11.45 (9.20) p≤0.001***	30.80 (11.63) p≤0.001***
Positive Symptom Distress Index (PSDI)	1.88 (0.71)	1.29 (0.40) p≤0.001***	2.14 (0.61) p=0.013*

(*p≤0.05, **p≤0.01, ***p≤0.001)

The results show that people with intersex conditions scored significantly higher than nonpatients on all global indices of the BSI, but significantly lower than psychiatric outpatients.

The proportion of the study sample meeting BSI criteria for caseness (ie experiencing clinical levels of psychological distress) was 41%, compared to 10% of adult non-patients¹⁷ and 23.8% of cancer patients¹⁸.

The profile of scores on the nine symptom dimensions of the BSI was calculated and compared to (how?) normative data¹⁷(Table 4).

Table 4 Mean scores of the sample compared with normative data on the nine symptom dimensions.

Symptom dimensions	People with intersex conditions	Adult nonpatients (SD)	Adult psychiatric outpatients (SD)
Somatisation	0.59 (0.64)	0.29 (0.40) p=0.02*	0.83 (0.79) p=0.014*
Obsessive-Compulsive	1.00 (0.86)	0.43 (0.48) p≤0.001***	1.57 (1.00) p≤0.001***
Interpersonal Sensitivity	1.45 (0.97)	0.32 (0.48) p≤0.001***	1.58 (1.05) p=0.353
Depression	1.11 (0.93)	0.28 (0.46) p≤0.001***	1.80 (1.08) p≤0.001***
Anxiety	0.90 (0.95)	0.35 (0.45) p≤0.001***	1.70 (1.00) p≤0.001***
Hostility	0.92 (1.09)	0.35 (0.42) p≤0.001***	1.16 (0.93) p=0.137
Phobic Anxiety	0.62 (0.82)	0.17 (0.36) p≤0.001***	0.86 (0.88) p=0.048*
Paranoid Ideation	1.00 (0.88)	0.34 (0.45) p≤0.000***	1.14 (0.95) p=0.297
Psychoticism	0.81 (0.69)	0.15 (0.30) p≤0.001***	1.19 (0.87) p≤0.001***

*p≤0.05; **p≤0.01; ***p≤0.001.

For most dimensions, scores were significantly higher than those of non-patients and significantly lower than those of psychiatric outpatients. However for the dimensions of interpersonal sensitivity (M=1.45), hostility (M=0.92) and paranoid ideation (M=1.00), the scores of people with intersex conditions were not significantly different from those of psychiatric outpatients.

Age, hormone treatments, and support group membership were not related to any of the BSI global indices. However, those who had not had surgery (M=2.37) were found to be experiencing greater distress [PSDI ?? (p=0.042)] as a result of psychological difficulties than those who had undergone surgery (M=1.79).

Discussion

People with intersex conditions have higher levels of psychological distress than nonpatients, with a significantly higher proportion reaching the criteria for clinical levels of psychological distress

(41%) than either nonpatients or cancer patients. Further exploration of the profile of psychological difficulties shows that people with intersex conditions report particular difficulties in the areas of ‘interpersonal sensitivity’, ‘hostility’ and ‘paranoid ideation’. These psychological dimensions all contain a substantial relational component.

Although some previous studies have found no evidence of impaired psychological wellbeing or reduced incidence of stable sexual relationships³, the present study findings are consistent with a substantial proportion of the literature, much of which also contains some indication of problems in relational domains. This includes suggestions of problems in long-term social interaction and negative self-image among people with CAH⁵, reduced satisfaction with sexual opportunities⁷ and difficulties for both patients and families following a diagnosis of AIS¹¹.

Current interpersonal findings centre on anger (‘Hostility’), feelings of inferiority in comparison with others (‘Interpersonal Sensitivity’) and difficulty trusting others (‘Paranoid Ideation’). The psychiatric terminology can be considered unhelpful for the purposes of interpretation because some descriptions make judgements about the legitimacy of the experience [e.g. paranoid ideation as a ‘disordered mode of thinking’¹⁷ (p9) rather than as a direct consequence of others’ prejudiced behaviour]. This assumption may represent a naïve view of external reality in the case of stigmatised individuals (also noted in assessment of people with learning disabilities¹⁹). Whilst this does not diminish the importance of the elevated scores, it is important to consider in the fuller context of the situation

The interpersonal difficulties that are evident can be viewed in the context of how people with intersex conditions, as a group, have been treated by others. The most striking theme in the intersex literature^{12, 20, 14, 21} is of the historical treatment by the medical profession. Certainly, it is difficult to ignore the powerful criticism from intersex activists of the approaches taken by health care professionals¹. It seems likely that this may have unwittingly served to exacerbate these negative comparisons. Narratives of people with intersex conditions have conveyed “an internalisation of stigma derived from an ongoing and alienating medical focus on genital difference and ‘inadequacy’”²¹ (p62). Genital surgery with the explicit aim of reducing feelings of difference has often been experienced as emphasising a sense of alienation by suggesting to a person that they were unacceptable as they were. As a consequence they have sought out others who are like them, in order to challenge medical tales of the rarity of their situation and to gain understanding from others. A sense of self that is separate from the stigma of medicalisation and gender binarism is believed to be important in the process of adapting²¹.

Anger can be seen as an understandable, perhaps inevitable, consequence of such treatment. It may actually be a healthy response. There is a proportion of the literature indicating the expression of anger as a positive step for people with intersex conditions both individually and as a group. As mentioned, the medical profession have been the target of a great deal of anger and this has provided considerable momentum for change. Preves²¹ talks of the importance for many intersex people of externalising dissatisfaction with their bodies and themselves and refocusing it on the source of that

shame, such as their treatment at the hands of the medical profession. This allows for a level of demedicalisation of their identities and increased pride and greater understanding and acceptance of themselves.

All treatment of people with intersex condition should be carried out with reference to the emotional and interpersonal experiences of particular salience for this group. The following recommendations are made on basis of this.

Ongoing support: Relationship difficulties observed in the current study highlight the importance of a consistent, trusting relationship with health professionals, allowing more control in decisions about what would be useful.

Clear information giving: People with intersex conditions should be given honest information, provided by spoken and written means at a comfortable pace. This will allow reasonable adaptation and understanding by intersexuals and, where appropriate, their families. Ideally this should be with the involvement of a multi-disciplinary team.

Opportunities to talk: People should be given the opportunity to talk about the issues involved. The evidence suggests that there are a variety of settings appropriate for this, including routine medical appointments, support group meetings and specialist referral to psychology or counselling.

Listening to anger: Health professionals need to be able to listen to people's anger and not respond defensively. It is important to acknowledge where treatment may not have been optimal and accept responsibility where appropriate.

Sensitivity with language: Health professionals should try and avoid language and actions that may exacerbate feelings of inadequacy of people with intersex people in comparison to others. An openness of communication and relationship would be useful in negotiating this in individual 'doctor-patient' relationships. Along these lines the use of the terms 'typical', 'usual' or 'most frequent' rather than 'normal' is recommended²².

Increased awareness of intersex: Increased awareness of the issues of intersex conditions can only help reduce the secrecy and isolation that have been the experience of many.

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