

Service users' experiences of obtaining and giving information about disorders of sex development

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Objective To quantify participants' experiences of obtaining and giving information about disorders of sex development (DSD).

Design Cross-sectional survey study that asked people about their current and past experiences relating to DSD disclosure.

Setting A large tertiary referral centre for DSD management in the UK.

Population One hundred of 126 people with a confirmed diagnosis of DSD who were invited to participate in the study formed the usable sample.

Methods All people who attended clinic for follow-up during the study period and members of a patient support group whose annual meeting fell within the study period were asked to complete the Middlesex Communication Survey.

Main outcome measures The Middlesex Communication Survey.

Results Younger participants were more likely to report having been appropriately informed about their diagnosis than older

people. Nearly half of the former had been fully informed about their diagnosis by age 15 years, compared with 0% of the older age group. In terms of information sharing, mothers were most likely to be the person with whom the participant had shared (almost/all) DSD information (74%), followed by current partners (71%). Information relating to genital surgery, presence of testes and clitoral anomalies were the least likely aspects to have been unambiguously shared with even the most informed person.

Conclusions Our results suggest that difficulties in obtaining DSD information from care providers were common, and that communication has improved for younger participants. The study also confirmed that many people with DSD continue to struggle with confiding, even in those closest to them, about aspects of their diagnosis. Care protocol needs to centralise psychological adaptation, which should also be a primary focus for future research.

Keywords Ambiguous genitalia, communication, disclosure, disorders of sex development, intersex, psychology.

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Introduction

Sex differentiation typically begins at about six weeks of embryonic life, and a sex-undifferentiated fetus gradually assumes the anatomical structures and appearance of what we think of as male or female. A number of genetic conditions, however, can disrupt the process, resulting in developmental outcomes that do not clearly correspond to one of the two mutually exclusive sex categories recognised by most postindustrial societies. That is to say, the usual markers of sex—gonads, genitalia and karyotype—are neither all male nor all female or not all typical.

Various terms have been applied to these conditions, including 'intersex'¹ and, further back in time,

'hermaphroditism'.² In a recent consensus statement, 'disorders of sex development' (DSD) was put forward as an umbrella term to denote a broader range of diagnoses, that is, to include all 'congenital conditions in which development of chromosomal, gonadal or anatomical sex is atypical'.³ All terms are potentially pejorative and, not surprisingly, this new term has been greeted with mixed reactions. It remains to be seen to what extent it will prevail.

Partly as a result of the bias towards female sex assignment,⁴ more women than men present with DSD in adult services. There are two main presentation scenarios. The first relates to adolescents or adults whose pubertal development has not occurred as expected. Having been born

with female-typical external genitalia, the underlying genetic condition often remains undetected, and many individuals do not come under paediatric management. These people may have a female-typical genetic karyotype (46XX) as in Mayer–Rokitansky–Kuster–Hauser syndrome, or a male-typical genetic karyotype (46XY) as in complete androgen insensitivity syndrome. The second presentation scenario concerns individuals who have come under paediatric management as the result of recognisable genital anomalies for which most would have had surgery in childhood. These people may have 46XX karyotype as in the case of congenital adrenal hyperplasia, or 46XY karyotype as in partial androgen insensitivity syndrome.

Total or partial concealment of diagnostic and treatment information from people with DSD used to be common practice, in the interest of psychological wellbeing.⁵ If medical information were offered, it might have been incomplete, and absence of opportunities for discussion might have been common.^{6–9} Personal^{6,7} and professional^{8,9} accounts documenting people's precarious fact-finding missions proliferate in professional and service-user literatures. Words like 'testes' and 'Y chromosome' may continue to be omitted by clinicians. By no means can health workers assume that the adults they see—at whatever age—have developed a firm grasp of all the relevant information.

For some time, questions have been raised by adults with DSD,¹⁰ clinicians¹¹ and scholars¹² regarding the ethical implications of such practices. Without full information and discussion, the notion of informed consent relating to investigation, treatment, genetic testing and research would have been seriously compromised. Importantly, the practice of concealment had compromised the opportunity for quality research into the physical and psychological impact of interventions, especially childhood genital surgery, in the immediate and longer term. The withholding of diagnostic information has also obstructed the development of peer and professional psychological support. Dissatisfaction and dissent culminated in a wave of publications in the 1990s, with some reflecting close collaboration between professional and service-user communities.¹³

The current study aimed to quantify some of the experiences of receiving and giving information about DSD that had been alluded to in medical and user literatures. The key research questions were the following. 1. How pervasive were difficulties in obtaining information about aspects of DSD? 2. Were younger people with DSD, whose care has presumably been less affected by the traditional practice of concealment, being informed at a younger age, compared with older people? 3. Did younger and older people with DSD differ in their evaluation of the appropriateness of professional communication about DSD? 4. Which aspects of DSD information were participants least likely to confide in others?

Methods

The study took place at a large tertiary referral centre for DSD management. The Middlesex Clinic (named after the former Middlesex Hospital in London where individual clinicians had historically attended small clusters of people with DSD) consists of physicians, surgeons, psychologists, nurses and researchers. Most people are either transferred from specialist paediatric services or referred from adult services that do not specialise in DSD management. The geographical location within a multicultural capital city means that some of these people are from overseas, and some may have had interventions that cannot be easily ascertained retrospectively or have been given information not congruent with current clinical observations and investigations. Exclusion criteria were: below the age of 16 years, new patients, unconfirmed DSD diagnosis, current acute psychiatric episode, learning disability, deemed unable to give informed consent by clinical staff.

Middlesex Communication Survey

The Middlesex Communication Survey was designed to quantify some of the communication difficulties identified in user narratives⁷ and clinical observations.⁹ Questions to elicit quantifiable information are presented in Appendix 1.

Recruitment

A trained assistant (H.G.) who was not a member of the clinical team invited all eligible people attending clinic during the study period to complete the Middlesex Communication Survey anonymously. An information sheet explained the purpose of the study; further clarification was offered as requested. Where possible, questionnaires were completed and collected during clinic; participants unable to finish were asked to return the questionnaire by post. Additional participants were approached opportunistically at a members meeting of the UK Androgen Insensitivity Syndrome Support Group.

Participants

A total of 126 individuals were invited to participate. Of these, four declined, 16 of the 122 questionnaires were not subsequently returned and six were not correctly completed or had large amounts of missing information. One hundred participants formed a usable sample (100/126, 80%). Of these, the largest diagnostic groups were androgen insensitivity syndrome (30), congenital adrenal hyperplasia (26) and Mayer–Rokitansky–Kuster–Hauser syndrome (18); the remaining participants comprised small clusters of people with a range of DSD diagnoses.

The mean age of the sample was 30.12 years ranging from 16 to 62 years. All but one participant completed the socio-demographic assessment, on which 80/99 self-identified as

white; 93/99 self-identified as female, 3/99 self-identified as intersex and 3/99 did not specify their gender; 70/99 reported having had further education; 85/99 were in full-time or part-time employment or full-time education; 43/99 were in stable relationships; 11/99 were parents.

Data analysis

Ninety-seven of the 100 participants gave their ages, and a median split at 27 years divided the sample into similar numbers of younger ($n = 49$) and older ($n = 48$) age groups for comparisons using chi-square test.

Results

Table 1 lists the proportions of the entire sample who considered themselves as having been (more or less) appropriately informed about applicable component aspects of DSD information. As a whole sample, participants were most likely to rate themselves as having been appropriately informed in relation to amenorrhoea and infertility, and least likely in relation to the presence of testes and a Y chromosome. Table 2 lists the proportions of participants aged below 27 years and aged 27 years or older that reported having learned about component aspects of DSD information by age 15. It is noteworthy that 0% of the older group had learned their full diagnosis by age 15, compared with 49% of the younger group. Using chi-square test, compared with participants aged 27 and above, patients <27 years of age were significantly more likely to have been informed at an earlier age about nearly all of the information components. Furthermore, participants <27 years of age were significantly more likely to express that they had been appropriately informed about the full diagnosis, and less likely to express the wish to have been informed earlier or differently; the pattern was reversed for participants aged 27 years or older ($P = 0.001$). Figure 1

Table 2. Percentages of younger and older participants having discovered component parts of DSD information by age 15 years

Information	<27 years (%)	27 years or older (%)	P value
Primary amenorrhoea	58	25	0.007
Infertility	50	25	0.022
Absent uterus	60	17	0.001
Absent ovaries	65	17	0.001
Lifelong estrogen	71	17	0.001
Vaginal anomalies	66	21	0.001
Clitoral anomalies	79	36	0.02
Genital surgery	67	40	0.58
Testes	77	4	0.001
XY karyotype	68	3	0.001

illustrates clear differences in age at which discovery of the full diagnosis had been made.

In terms of perceptions of parental knowledge of DSD, as shown in Table 3, the older group were almost three times more likely than the younger group to report that their parents had known and said little to them (59% versus 21%). In contrast, 41% of the younger group felt that their parents had had a lot of information which had been shared with them fully, compared with 0% of the older group.

The experience of stumbling upon information unintentionally was high for both groups—only 30% of the older and 41% of the younger groups reported having never done so. As indicated in Table 4, both groups were most likely to come upon DSD information incidentally through the mass media, followed by health professionals ‘spilling the beans’.

The proportions of participants who had shared DSD information with significant others are listed in Table 5. Mothers were the most likely group with whom participants

Table 1. Satisfaction with receiving component parts of DSD information

	No. for whom information was applicable	(More or less) appropriately informed (%)	Wish had been informed sooner/differently (%)	Wish never told (%)
Primary amenorrhoea	69	64	36	0
Infertility	81	63	37	0
Absent uterus	63	56	43	1
Absent ovaries	57	51	47	2
Lifelong estrogen	58	62	36	2
Vaginal anomalies	73	51	48	1
Clitoral anomalies	36	44	53	3
Genital surgery	55	47	49	4
Testes	44	25	73	2
Y chromosome	54	33	65	2

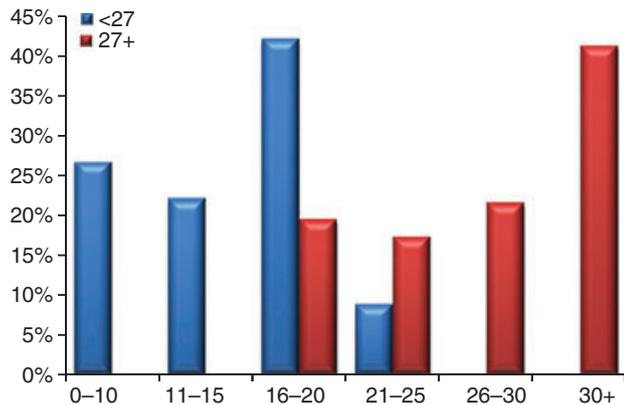


Figure 1. Age of discovery of full diagnosis for participants aged 27 years or above and participants aged <27 years.

Table 3. Younger and older patients' beliefs about parents' knowledge of DSD

	Age <27 years	Age 27 years or older
Parents knew and said hardly anything	20%	59%
Parents knew some things and told what little they knew	30%	32%
Parents knew more than what they told me	9%	9%
Parents knew a lot and shared it all with me	41%	0%

Table 4. Percentages of participants reported having stumbled on information by chance

	Age <27 years	Age 27 years or older
Never	41%	30%
Yes, through mass media	41%	44%
Yes, through health professionals	21%	33%
Yes, through family members	16%	7%

had shared (almost/) all DSD information (74%) followed by partners (71%; $n = 52$) and ex-partners (34%, $n = 62$). It is worth noting that over one-third of participants who had siblings with DSD reported having shared no or little information with these siblings (37%; $n = 24$).

Finally, participants answered the question as to how much does the one most knowledgeable person in their

Table 5. Disclosure/discussion about DSD

Discussed with:	(almost/ everything (%))	something (%)	(next to/ nothing (%))
Partner	71	13	16
Ex-partner(s)	34	37	29
Father	55	23	22
Mother	74	19	7
Sibling with DSD	63	0	37
Sibling without DSD	47	26	27
One or two friends	40	42	18
Several friends	16	31	53

Table 6. Proportions of participants who have disclosed about applicable aspects of DSD to the one most knowledgeable person outside professional and support forums

Aspects of DSD	Disclosed to the person who knows the most (%)
Primary amenorrhoea	91
Infertility	91
Absent uterus	87
Absent ovaries	88
Lifelong estrogen	86
Vaginal anomalies	82
Clitoral anomalies	75
Genital surgery	71
Testes	75
Y chromosome	85

personal life—outside clinics and support forums—know about applicable aspects of DSD. As seen in Table 6, the lowest percentage had shared information relating to genital surgery, the presence of testes, and clitoral anomalies.

Discussion

Various difficulties in obtaining and giving information about aspects of DSD have been identified in user narratives and qualitative analyses. This study represents the first attempt to quantify some of the experiences that had been alluded to. An important strength of the study was its large sample size based on a high response rate, though space does not permit the inclusion of verbatim material thereby limiting a more nuanced discussion.

In the field of DSD, negative experiences of communication with health professionals have often been marginalised as exceptional, affecting only a few adversarial individuals.¹⁴ This study, however, suggests that negative experiences of communication with health professionals

were far from exceptional for older age groups. The relatively high proportions of younger participants who had learned about their full diagnosis by mid-adolescence and who reported having been more or less appropriately informed suggest that this trend has changed in a positive direction.

In an age of patient-centred medicine, the inevitability of information giving is generally taken for granted. In any case, aided by the internet, information has been available for a long time. It was therefore not surprising to observe that a relatively large proportion of study participants had incidentally come across DSD information. If disclosure is left too late, there may be a danger of people with DSD self-diagnosing inaccurately without the opportunity for discussion with expert care providers. Not all people are able to articulate their wish to their doctors for more information and clarification. This could sometimes be mistaken for not wishing for or not being ready to process challenging sound bites. Notwithstanding the difficulties of gauging readiness, by mid-adolescence, most of the component information parts should probably have been shared with the majority of people with DSD. Postponement may not make it any easier for patient or doctor. It is worth bearing in mind that the challenges of communicating difficult information unambiguously are not unique to clinicians working in DSD; care providers in many specialties tacitly accept these difficulties as part of their professional role. It is however interesting to note that whereas communication training is accepted as routine for specialties like oncology, there is no formal acknowledgement in the medical and scientific literature that practitioners and researchers in DSD require any such support.

Younger participants of the current study were far more likely than older participants to perceive their parents as having been well informed and truthful with them about DSD. Even so, more than half of them did not express this belief. It is also noteworthy that a proportion of participants had not discussed DSD even with similarly affected siblings, confirming some of the family difficulties observed by researchers¹⁵ and familiar to health professionals working in the field. This study has identified considerable scope for improvement in psychological service provision for families.

People with DSD and their families may prefer complete honesty, but DSD information could pertain to any of the following: absent vagina and/or uterus and/or ovaries, ambiguous external genitalia, infertility, unusual karyotype, heredity, the necessity of lifelong medication, weight gain, hirsutism and short stature. Any of these information components could provoke strong emotional reactions. Skilful delivery of diagnostic and treatment information is of course key but, even so, these improvements may not in themselves alleviate the psychosocial

challenges posed by certain aspects of DSD. The current study suggests that a significant minority of adults struggle to confide even in stable partners about aspects of DSD. Social support is an important variable in coping and adaptation but this support is not available to those who are unable to confide even in those closest to them. Now that the move from secrecy to openness has been accepted in the professional sphere, focus could shift towards helping people with DSD make optimal decisions about self-disclosure.

In the professional literature, genital surgery is typically presented as an obvious solution.¹⁶ It is interesting that in this study, participants were least likely to have shared information unambiguously about their genital surgery with the one person in their personal life who was most knowledgeable about their DSD. This suggests that far from being a straightforward solution, genital surgery can itself be stigmatising and shaming.¹⁷ The centrality of surgical correction in care delivery may have inadvertently sidelined the development of quality care that targets psychological adaptation, and more commitment from service providers will be needed to make this a primary focus in clinical management. More investment in psychosocial research to improve knowledge of patient perspectives will help to educate and train health professionals to provide quality care,¹⁸ define short-term and long-term clinical outcomes and enable clinicians to methodically evaluate the impact of medical, surgical, social and psychological interventions.

Shame and fear of repercussions may continue to render personal communications about DSD too challenging for some individuals. So perhaps the most important collaboration between professional and user communities, ultimately, is a long-term social project to improve public understanding of DSD.

Conclusions

A considerable proportion of people with DSD reported a wish to have been informed about aspects of DSD sooner or differently, especially in the older age groups. Many more younger participants reported having been appropriately informed and at an earlier age, suggesting that at least some of the communication issues previously alluded to in service-user narratives have been addressed. This study also identified the potential for improvement in communications within families, and more investment in psychological support may be needed to assist families. The results also suggest that many people with DSD have difficulties in confiding even in close others about aspects of their diagnosis and treatment. Development of effective psychosocial support and collaborative research to identify factors that predict optimal adaptation should be a priority for multi-disciplinary teams in future.

Disclosure of interest

None.

Contribution to authorship

L-M.L. conceptualised the study, designed the questionnaire, supervised the research and data analysis and wrote the paper; H.G. was responsible for the data collection and processing and contributed to the manuscript; S.C. contributed to the study design, recruitment of participants and the manuscript; N.C. contributed to the study design, data analysis and the manuscript; G.C. contributed to the study design, recruitment of participants and the paper and supervised the data analysis. All authors had access to all of the data and take responsibility for the integrity of the data.

Details of ethics approval

The study was approved by the Joint UCL/UCLH Committee for Ethics in Human Research.

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Appendix 1. The Middlesex Communication Survey

1) Socio-demographic information

2) At what age did you find out for certain the following information?

	Age found out	Doesn't apply to me
I would never have periods	<input type="text"/>	<input type="checkbox"/>
I cannot have children naturally	<input type="text"/>	<input type="checkbox"/>
I was born without a (normal) womb	<input type="text"/>	<input type="checkbox"/>
I was born without (normal) ovaries	<input type="text"/>	<input type="checkbox"/>
I needed long-term oestrogen replacement	<input type="text"/>	<input type="checkbox"/>
I was born with problems of the vagina	<input type="text"/>	<input type="checkbox"/>
I was born with problems of the clitoris	<input type="text"/>	<input type="checkbox"/>
I had (may have) genital surgery	<input type="text"/>	<input type="checkbox"/>
I was born with testes	<input type="text"/>	<input type="checkbox"/>
I have XY chromosomes	<input type="text"/>	<input type="checkbox"/>
My full diagnosis as I now know it	<input type="text"/>	<input type="checkbox"/>

3) On which aspects of your condition have you been appropriately informed or wish you had been informed earlier or differently?

(Tick one box per line)

	I was more or less appropriately informed	I wish I was informed earlier or differently	I wish I was never informed of this	Doesn't apply to me
I would never have periods	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I could not have children naturally	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I was born without a (healthy) womb	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I was born without (healthy) ovaries	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I needed long-term oestrogen replacement	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I had (have) problems of the vagina	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I had (have) problems of the clitoris	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I had (may have) genital surgery	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I was born with testes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have XY chromosomes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My full diagnosis as I now know it	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

4) How much do you think your parents knew about your condition when you were a child or adolescent?

(Tick one box only)

- My parents knew and said hardly anything
- My parents knew some things and told me what little they knew
- My parents knew more than what they told me
- My parents knew a lot and shared it all with me

5) Have you ever stumbled upon information that got you thinking...?

(Tick as many boxes as applicable)

- No, never
- Yes, health professionals somehow spilled the beans
- Yes, family members/friends somehow spilled the beans
- Yes, through the media (e.g. TV, magazine, radio, internet)
- Yes, there was this instance (please specify):

6) How else – if at all - have you got/come across information?

(Tick as many boxes as applicable)

- I haven't needed to
- I wanted to but didn't
- I looked up books
- I looked up the internet
- I got information from support groups
- I got hold of my notes/records
- Other means of finding information (pls specify):

7) How much have you discussed your condition with the following people?

Please go through each item on the left column and tick one box on each line:

	(Almost) Everything	Something	Hardly anything	N/A
My current partner / date	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My ex-partner(s)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My father	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My mother	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Grown-up sibling(s) with same condition	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Grown-up sibling(s) without same condition	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A friend or two	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Several friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Others (please say who):	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

8) Apart from yourself, clinics and support group members, which person currently knows the MOST about your condition? (If no one knows anything at all, put *NO ONE*)

9) Which of the following aspects does he or she know?

	Yes	No	Not sure	Doesn't apply to me
I never had (won't have) periods	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I could not have children naturally	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I was born without a (healthy) womb	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I was born without (healthy) ovaries	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I needed long-term oestrogen replacement	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I had (have) problems of the vagina	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I had (have) problems of the clitoris	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I had (may have) genital surgery	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I was born with testes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have XY chromosomes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>