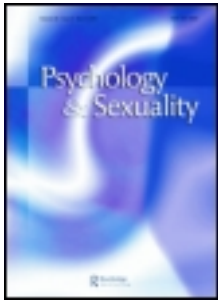


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Gender experience and satisfaction with gender allocation in adults with diverse intersex conditions (divergences of sex development, DSD)

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The aims of this mixed-methods study were to: (1) describe the gender experience and level of satisfaction with gender allocation of intersex persons and (2) explore the spectrum of their gender identities. Of the 69 participants with a number of divergences of sex development (DSD), gender allocation at birth was female in 83% and male in 17%. Seventy-five per cent were satisfied with gender allocation. As adults, 81% lived in the female gender role, 12% in the male role and 7% chose other roles. Nine per cent reported gender change or reallocation. Twenty-four per cent reported an inclusive 'mixed' two-gender identity, including both male and female elements, and 3% reported a neither female nor male gender identity. Twenty-six per cent were highly uncertain about belonging to a specific gender, 14% received increased transgender scores on the gender identity questionnaire (GIQ). The dichotomous categorisation of gender fails to capture the gender experiences of a significant proportion of our participants. Uncertainty of belonging to the female or male gender category as well as non-binary identifications highlight the need for alternative gender categories. A reconsideration of the medical approach towards intersexuality, which is currently based on a binary categorisation, is discussed.

Keywords: satisfaction with gender allocation; sex assignment; gender identity; gender role; DSD; intersex; psychosexual development

The concept of *gender* encompasses both a person's gender identity and their gender role. *Gender identity* refers to the subjective feeling of being male, female or indeed other. *Gender role* refers to the social role deemed appropriate for a given gender within society and in which a person outwardly lives. Our research reiterates the importance of taking sufficient account of individual experiences of gender in medical management. Our work is concerned with the interrelationships between gender role and gender identity – what we call *gender experience* – in adults with intersex conditions. It further explores each participant's narrative of perceived satisfaction with gender allocation.

In this paper, we differentiate between *gender allocation*, defined here as the social act of bestowing a gender role on a person, and *sex assignment*, which is intended to support a gender choice with regard to social role but includes physical alteration of the body. Furthermore, in this paper, 'DSD' is an acronym for '*divergences of sex development*' (Reis, 2007), rather than '*disorders of sex development*', as proposed in the consensus

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statement (Hughes, Houk, Ahmed, & Lee, 2006). The latter terminology is rejected because of its pathologising implications. We also choose to continue using the term *intersex*. Though criticised by the consensus group as imprecise, it continues to be accepted by a number of individuals, advocacy groups and clinicians as an umbrella term describing congenital conditions with an atypical somatosexual development.

We begin by identifying four problems in the medical literature regarding the gender experiences of people affected by DSD: (1) the conceptual restrictions imposed by the dichotomisation of gender; (2) the pathologising of non-binary gender expressions, (3) the enmeshing of decisions regarding social gender allocation and medical sex assignment and (4) neglect of the uncertainties surrounding adult gender identity trajectories for many DSD conditions.

Bodily experiences have been found to have a formative influence on a person's psychological development and identity experience (Breakey, 1997; Brunner, Prochnow, Schweizer, & Richter-Appelt, 2012; Freud, 1923). Our central assumption is that a person's experience of their intersex body is likely to be embedded in an atypical gender identity development trajectory that is located outside the binary categorisation. This view is supported by descriptions of the intersex experience of people with intersex bodies (Diamond, 1997; Garrels, 1998; Stoller, 1968) and by qualitative research (e.g. Preves, 2003). Together they question the appropriateness of either/or, male/female gender endpoints for people born with intersex conditions.

Recent research appears to suggest that the majority of intersex people see their experience of gender as being adequately represented by a binary model (DeVries, Doreleijers, & Cohen-Kettenis, 2007; Sobel & Imperato-McGinley, 2004; Zucker, 2006). People who do not align themselves unequivocally to either a male or a female gender or who show a more fluid gender identity are often pathologised as 'gender dysphoric' ('a strong feeling of dissatisfaction about oneself as male or female', DeVries et al., 2007, p. 345). Their fluid gender identity is often assumed to be indicative of impaired gender development (DeVries et al., 2007), whether or not this leads to a desire for or actual gender change.

The capacity to forecast adult gender identity is currently limited for a number of DSD conditions including congenital adrenal hyperplasia (CAH) (Dessens, Slijper, & Drop, 2005; Meyer-Bahlburg, Dolezal, Baker, Ehrhardt, & New, 2006), forms of gonadal dysgenesis (GD) (Szarras-Czapnik, Lew-Starowicz, & Zucker, 2007), androgen biosynthesis deficiencies (Cohen-Kettenis, 2005; Schweizer, Brunner, Schützmann, Schönbucher, & Richter-Appelt, 2009) and partial androgen insensitivity syndrome (PAIS) (DeVries et al., 2007). There are also case studies that question female gender assignment for all individuals with complete androgen insensitivity syndrome (CAIS) (Kulshreshtha et al., 2009; T'Sjoen et al., 2011). Gender dysphoria has been reported in both male- and female-allocated people with CAH, male- and female-reared persons with PAIS and female-allocated persons with androgen biosynthesis deficiencies (DeVries et al., 2007). Gender change has been documented for people with PAIS (Mazur, 2005; Meyer-Bahlburg, 2005), CAH (e.g. Dessens et al., 2005) and androgen biosynthesis deficiency (Cohen-Kettenis, 2005). Altogether, changes from female to male have been described more frequently than the reverse, the exception being people with PAIS. Despite these findings, it has repeatedly been argued that the gender assigned at birth is the best 'predictor' for adult gender identity and satisfaction with gender role (DeVries et al., 2007; Mazur, 2005). The possibility that neither the male nor the female gender alternative on its own constitute a suitable option has not been considered.

The consensus statement (Hughes et al., 2006) stipulates that all children with DSD should be assigned male or female after expert evaluation. It clearly favours female assignment for conditions such as CAIS and CAH. An exact diagnosis and prognosis

regarding future gender development are regarded as necessary preconditions for medical interventions. At the same time the difficulties in predicting gender identity outcomes have not been well addressed, and the consensus statement fails to challenge the problems associated with medical sexing based on the socially allocated gender. Medical interventions are to be based on the social gender allocation, ‘function’, and phenotypical appearance and age, rather than the specific diagnosis.

In terms of surgical sexing of ambiguous genitals, ‘function’ is to be prioritised over appearance. In the case of *female gender allocation*, surgery on the clitoris is only to be conducted in the case of severe virilisation. Operations for the construction of an artificial vagina and stretching of the vagina are not to be performed before adolescence (see Hughes et al., 2006, pp. 556–557). In the case of *male gender allocation*, the difficulties with penis-construction operations in adulthood are addressed (Hughes et al., 2006, p. 557). The removal of the gonads is also regarded from the point of view of social gender allocation: the ‘testes’ should if possible be removed before puberty, not only in the case of GD and female-allocated people with PAIS but also in the case of people with CAIS (Hughes et al., 2006, p. 557) because of the risk of degeneration. Gonadectomies are not recommended in the case of male-allocated people with PAIS (Hughes et al., 2006, p. 557). Surely the risk of developing gonadal tumours depends on the condition and position of the gonads (Hughes et al., 2006; Looijenga et al., 2010) and not on the social gender allocated. These inconsistencies betray a continued enmeshing of between social allocation of gender and medical sexing of the body. It is therefore important to explore the impact of what is clearly a continuation of the optimal gender paradigm (see Meyer-Bahlburg, 2004) on psychological well-being and authentic experiences of self (e.g. Kessler, 1998; Ozar, 2006; Stark, 2006).

The aims of this mixed-methods study were to: (1) describe the gender experience and satisfaction with gender allocation of intersex persons and (2) explore the spectrum of their gender identities, paying particular attention to those gender experiences that transcend the male/female dichotomy.

Method

This study is part of a larger research project on the quality of life and treatment experiences of adults with different intersex conditions which was conducted in 2002–2008 in Hamburg, Germany (for a more detailed description see Schönbucher et al., 2012; Schweizer et al., 2009). Ethical approval was granted by the medical association of Hamburg (German Research Foundation Ri 558/2-2). Data collection took place at the study centre. Data were collected using a comprehensive questionnaire with standardised scales and items as well as open questions inviting qualitative narratives. Participants were offered counselling after taking part. They gave their written informed consent to participate as well as permission to use their data confidentially for research purposes and publication. They also gave written permission that their physicians could be contacted regarding personal medical records.

Participants

Seventy-eight individuals participated in the study. A response rate could not be calculated due to the various means of data collection. The participants had heard about the study via their medical doctor (39%), the internet (30%), a support group (16%), the research group directly (10%) or their family (1%). 2/69 (3%) did not respond to this question.

Data from 69 persons whose DSD was confirmed by their medical files were included in the analyses. The age range was 16 to 60 years with a median of 32.00 years and a mean age of 33.01 years (SD = 10.44). Of the entire sample, 37/69 (54%) had completed high-school exams that qualify them for university entrance; 24/69 (35%) had completed 10 years of schooling (corresponding to the German ‘Realschulabschluss’) and 7/69 (10%) had completed 9 years of schooling (corresponding to the German ‘Hauptschulabschluss’). One person grew up in the Middle East, all other participants reported a European ethnic background: 64/69 (93%) grew up in Germany and 4/69 (6%) in the UK, Switzerland, and Austria.

45/69 participants (65%) had *XY-chromosomal conditions* (e.g. CAIS, PAIS and GD), 21/69 (30%) had *XX-chromosomal DSD* (i.e. different forms of CAH) and 3/69 (4%) *sex chromosome DSD* (i.e. 2 with mixed GD and 1 with ovotesticular DSD).

13/69 (19%) had CAIS and 12/69 (17%) had PAIS. 14/69 (20%) displayed different forms of GD, i.e. mixed (5/14), pure (4/14) and GD not specified [GD n.s.] (5/14). 7/69 (10%) had a form of androgen biosynthesis deficiency: 3/7 with 5-alpha-RD-2-deficiency, 4/7 with 17-beta-HSD-3-deficiency. 1/69 (1%) had Leydig-cell-hypoplasia (LH) and 1/69 (1%) ovotesticular DSD. 21/69 (30%) had different forms of CAH: 10/21 with CAH salt-wasting (CAH sw), 7/21 with CAH simple virilising (CAH sv), 4/21 with the non-classical CAH late onset (CAH lo).

Almost all participants reported medical treatment experiences in response to their intersex condition. Hormone therapy was carried out on 66/69 participants (96%). 44/69 (64%) were gonadectomised. Genital operations were performed on 38/69 (55%) including operations on the external genitals or on the urethra, as well as the construction of neovaginas and surgical dilatation of the vagina, with many repeat operations (for a more detailed presentation see Brinkmann, Schützmann, & Richter-Appelt, 2007; Schönbacher et al., 2012).

Measures

The instruments include the following single items, standardised scales and open questions.

The four-dimensional gender identity questionnaire (GIQ) (Eckloff, 2007)

All of the participants completed the GIQ by Eckloff (2007). This includes *female gender identity* (FGI) and *male gender identity* (MGI) scales in addition to a so-called *transgender identity* (TGI) scale and a *certainty of belonging to one specific gender* (CG) scale. These four dimensions were assessed on a 5-point Likert scale ranging from 1 (disagree) to 5 (fully agree). For an overview of the instrument’s characteristics see Schweizer et al. (2009) and Richter-Appelt, Discher, and Gedrose (2005).

Gender experience, gender allocation and change

Gender role today. Participants could choose between the categories ‘male’, ‘female’, ‘varies’, ‘third gender’ and ‘undecided’ to describe their current gender role.

Gender identity today. Participants were asked whether they agreed with the following statements: ‘Since early adulthood, I have experienced myself (a) as a woman, (b) as a man, (c) sometimes as a woman, sometimes as a man’. The latter will be referred to here as a ‘mixed’ two-gender identity.

Gender allocation at birth. Gender allocation at birth was assessed with the question ‘Which gender was allocated to you directly after birth?’.

Gender re-allocation, gender change, and change considerations. Gender reallocation and/or sex reassignment were assessed by means of the question ‘Were you at a later point in time allocated to a gender different to that which you had originally been allocated?’.¹ Furthermore, the participants were asked whether they had changed their gender according to their own wishes. The answer options were ‘yes’ or ‘no’. We also asked whether they had considered changing their gender, and if so at what age this occurred.

Mixed-methods assessment of satisfaction with gender allocation

Satisfaction with gender allocation was assessed by asking participants in a single item how satisfied they were with their allocated gender on a 5-point Likert scale ranging from 1 (very unsatisfied) to 5 (very satisfied). In addition, extra space was provided for an explanation of their choice. The resulting short narratives were evaluated qualitatively with a view to individual gender experience.

Data analysis

Data were analysed at individual and group levels. The answers to the open questions were examined according to the principles of Mayring’s qualitative content analysis (Mayring, 1990). The authors chose this approach as it is suitable for mixed-methods methodologies and allows the meaning units making up the qualitative categories to be displayed in a quantitative manner.

Frequencies were calculated for single items. For the GIQ, the mean scores on each gender identity scale were calculated and transformed into *z*-scores ($M = 0$, $SD = 1$) based on control groups of men and women without DSD (Eckloff, 2007). The calculation of *z*-scores is based on male control group data for the PAIS m and CAH m subgroups. For all other groups the female control group data were used. *Z*-scores $\geq |1.64|$ were considered as statistically higher or lower in comparison with the control group because 90% of the expected scores lie between -1.64 and $+1.64$ standard deviations.

Results

Table 1 is a summary of the participants’ reported gender experience, i.e. gender role and gender identity, as well as original genital appearance, gender allocation at birth, scores and narratives regarding satisfaction with their original gender role allocation and gender changes. Pseudonyms were chosen for each individual.

Genital appearance and gender allocation

Regarding *genital appearance*,² 37/69 (54%) were reported to have female-appearing genitalia (2/7 with CAH sv, 4/4 with CAH lo, 13/13 with CAIS, 3/12 with PAIS, 9/14 with GD, 1/1 with LH, 1/3 with 5- α -RD-2 and 4/4 with 17- β -HSD-3). Genital status after birth was declared male in only two cases (3%), both with CAH sw. 30/69 (43%) were reported to have ambiguous genitalia at birth: 13/17 (76%) of those with CAH sv or CAH sw, 9/12 (75%) of the participants with PAIS, 5/14 (36%) of those with GD, 2/7 (29%) of those with androgen biosynthesis deficiencies (i.e. 5- α -RD-2: 2/3) and 1/1 with ovotesticular DSD.

Table 1. Gender experience and satisfaction with gender allocation in adults with diverse intersex conditions ($n = 69$).

Nr	Pseudonym	Individual information			Current gender experience			Genital appearance, gender (re-)allocation, satisfaction with gender allocation, gender change			Gender reallocation/ gender change
		Age	Condition	Gender role (today)	Gender identity (today)	GIQ*	Genital appearance (birth)**	Gender allocation (birth)	Satisfaction with gender allocation/sex assignment	Satisfaction with gender allocation, gender change	
----- CAIS ($N = 13$) -----											
<i>I experience myself as . . .</i>											
<i>Scale-scores:</i>											
<i>z-score</i>											
<i>> II.64I</i>											
1	Hanna	24	CAIS	Female	Woman	FGI: $z = -4.53$ CG: $z = -3.34$	Female	Female	Moderate	—	—
2	Inga	25	CAIS	Female	Sometimes as woman, sometimes as man	FGI: $z = -4.06$ CG: $z = -4.49$	Female	Female	Moderate	'I don't want to be forced into a clear direction, I do sometimes have doubts about this allocation'	—
3	Jana	47	CAIS	Female	Woman	MGI: $z = 2.16$	Female	Female	Very	'I am a woman +'	—
4	Katja Lea	42	CAIS	Female	Woman	—	Female	Female	Very	'No doubts'	—
5		36	CAIS	Female	Woman	MGI: $z = 4.54$	Female	Female	Very	'I feel myself to be female'	—
6	Marie	38	CAIS	Female	Woman	—	Female	Female	Very	'I have never questioned my gender'	—
7	Nina	43	CAIS	Female	Sometimes as woman, sometimes as man	FGI: $z = -1.7$	Female	Female	Very	'Even though I have XY chromosomes, I could not imagine being a man'	—

8	Olga	46	CAIS	Female	Woman	—	Female	Female	Very	'I find the feminine nicer, women are cleverer and more holistic, and live closer to and in more harmony with creation. However, there are limitations with regard to the female role'	—	—
9	Petra	41	CAIS	Female	Woman	—	Female	Female	Very	—	—	—
10	Renate	32	CAIS	Female	Woman	CG: $z = -4.11$	Female	Female	Very	'I feel myself to be female'	—	—
11	Sara	43	CAIS	Female	Woman	—	Female	Female	Very	'Because for me it is consistent'	—	—
12	Tina	36	CAIS	Female	Woman	—	Female	Female	Very	—	—	—
13	Ute	30	CAIS	Female	Woman	—	Female	Female	Very	—	—	—
----- PAIS (N = 12) -----												
14	Xenia	46	PAIS f	Female	Woman	—	Female	Female	Very	'I feel profoundly like a woman, and I find the societal role of a man in many respects problematic'	—	—

(Continued)

Table 1. (Continued)

Nr	Pseudonym	Individual information			Current gender experience			Genital appearance, gender (re-)allocation, satisfaction with gender allocation, gender change			
		Age	Condition	Gender role (today)	Gender identity (today)	GIQ*	Genital appearance (birth)**	Gender allocation (birth)	Satisfaction with gender allocation/sex assignment	Gender reallocation/ gender change	
15	Yelda	43	PAIS f	Female	Sometimes as woman, sometimes as man	FGI: $z = -5.96$ MGI: $z = 3.75$ TGI: $z = 1.67$ CG: $z = -5.65$	Ambiguous	Female	Not at all	—	—
16	Zara	35	PAIS f	Female	Woman	FGI: $z = -3.58$ CG: $z = -2.57$	Female	Female	Moderate	'I am not an "XX-woman", but do not have a need to be a man'	—
17	Amelia	17	PAIS f	Female	Woman	—	Ambiguous	Female	Very	'I feel like a woman, and my appearance is therefore very suited to my sex/gender, I am treated like a woman by my fellow human beings (friends, etc.)'	—
18	Clara	27	PAIS f	Female	Woman	—	Female	Female	Very	'Because I'm a girl'	—
19	Dorothea	56	PAIS f	Female	Neither nor	FGI: $z = -5.94$	Ambiguous	male	Low	—	34 M → F
20	Gabriele	27	PAIS f	Female	Woman	CG: $z = -4.11$	Ambiguous	Female	Very	'Because I feel myself to be, and am, female'	—

21	Viktor	22	PAIS m	Male	Man	—	Ambiguous	Male	Fairly	'I actually feel really good'	—
22	Wolfgang	18	PAIS m	Male	Man	—	Ambiguous	Male	Moderate	'I have hypospadias'	—
23	Ben	45	PAIS m	Male	Man	FGI: $z = 2.9$	Ambiguous	Male	Fairly	'It works'	—
24	Erik	42	PAIS m	Male	Man	—	Ambiguous	Male	Very	'For me there was never cause for discussion about whether male or female; for as long as I can remember, I have felt clearly male, childhood, youth, adulthood'	—
25	Frank	24	PAIS m	Male	Man	FGI: $z = 3.41$ MGI: $z = -2.33$ TGI: $z = 2.73$	Ambiguous	Male	—	—	—
----- GD (N = 14) -----											
26	Gudrun	28	Pure GD	Undecided	Sometimes as woman, sometimes as man	FGI: $z = -3.58$ MGI: $z = 1.76$ TGI: $z = 2.32$ CG: $z = -2.57$	Female	Female	Moderate	'Sometimes I feel more like a woman than a man'	—
27	Heike	23	Pure GD	Female	Woman	—	Female	Female	Very	'Because I spent a happy childhood with it'	—
28	Isabelle	25	Pure GD	Female	Woman	—	Female	Female	Very	'Because that is how I feel'	—

(Continued)

Table 1. (Continued)

Nr	Pseudonym	Individual information			Current gender experience			Genital appearance, gender (re-)allocation, satisfaction with gender allocation, gender change			
		Age	Condition	Gender role (today)	Gender identity (today)	GIQ*	Genital appearance (birth)**	Gender allocation (birth)	Satisfaction with gender allocation/sex assignment	Gender reallocation/ gender change	
29	Josephine	24	Pure GD	Female	Woman	–	Female	Female	Very	'I feel myself to be a woman, even if in comparison with other women I certainly do see myself as a woman with special features. I do not yet know how much meaning the male in me has for me, but that it has meaning for me is something I am certain about'	–
30	Nicky	32	Pure GD	Third gender	Neither nor	FGI: $z = -6.89$ TGI: $z = 1.67$ CG: $z = -4.11$	Ambiguous	Female	Moderate	'I would rather live as that which I am, 'I have always identified myself as being female'	–
31	Louisa	33	Mixed GD	Female	Woman	–	Female	Female	Fairly		–

32	Martha	28	Mixed GD	Female	Sometimes as woman, sometimes as man	—	Ambiguous	Female	Fairly	'I feel good with it'	—
33	Nathalie	27	Mixed GD	Female	Woman	FGI: $z = -2.17$ MGI: $z = 2.16$	Female	Female	Very	'Because I don't feel male'	—
34	Patricia	30	Mixed GD	Female	Sometimes as woman, sometimes as man	—	Ambiguous	Female	Fairly	—	—
35	Ruth	31	N. s. GD	Female	Woman	—	Ambiguous	Female	Fairly	'It was the "most convenient decision" back then'	—
36	Stefanie	46	N. s. GD	Female	Sometimes as woman, sometimes as man	FGI: $z = -2.17$ TGI: $z = 2.11$	Female	Female	Moderate	'A feeling partly of forced transsexualisation was triggered by the operation, uncertainty'	—
37	Tanja	32	N. s. GD	Female	Woman	—	Female	Female	Very	'I feel very good as a woman, what else'	—
38	Ulrike	27	N. s. GD	Female	Woman	—	Ambiguous	Female	Fairly	'I am a woman!'	—
39	Vera	18	N. s. GD	Female	Woman	—	Female	Female	Fairly	—	—
40	Emily	31	5 α -RD-2	Female	Sometimes as woman, sometimes as man	Androgen biosynthesis deficiencies ($N = 7$) FGI: $z = -2.64$ MGI: $z = 1.76$ CG: $z = -1.80$	Female	Female	Fairly	'I live in the role of a woman and am just starting to discover my male elements. Gender is not so important'	—

(Continued)

Table 1. (Continued)

Nr	Pseudonym	Individual information			Current gender experience			Genital appearance, gender (re-)allocation, satisfaction with gender allocation, gender change				
		Age	Condition	Gender role (today)	Gender identity (today)	GIQ*	Genital appearance (birth)**	Gender allocation (birth)	Satisfaction with gender allocation/sex assignment	Gender reallocation/ gender change		
41	Fiona	32	5 α -RD-2	Female	Sometimes as woman, sometimes as man	FGI: $z = -2.64$ MGI: $z = 3.35$ TGI = 2.76 CG: $z = -2.5$	Ambiguous	Female	Moderate	'I could also well imagine living as a man'	—	—
42	Gina	36	5 α -RD-2	Female	Sometimes as woman, sometimes as man	—	Ambiguous	Female	Moderate	'Because I have the feeling that I belong to a third sex, whereby I am sometimes very satisfied, though right now I am having problems with my identity'	—	—
43	Anne	60	17 β -HSD-3	Female	Woman	FGI: $z = -4.06$ CG: $z = -5.65$	Female	Female	Low	'In hindsight a male allocation would perhaps have been better, but at the time the question did not arise'	—	—

44	Barbara	43	17 β -HSD-3	Female	Woman	—	Female	Female	Very	—	—	'Because until about the end of 1972/ beginning of 1973 I was doing fine with it'
45	Claudia	26	17 β -HSD-3	Female	Sometimes as woman, sometimes as man	MGI: $z = 3.75$ TGI: $z = 2.32$	Female	Female	Fairly	—	—	'I couldn't imagine being male, although I am not female either'
46	Daniela	48	17 β b-HSD-3	Female	Woman	—	Female	Female	Fairly	—	—	'Because I can imagine living in the male role even less'
----- LH ($N = 1$) -----												
47	Angela	37	LH	Female	Woman	—	Female	Female	Very	—	—	'I feel myself to be a woman'
----- Ovotest. DSD ($N = 1$) -----												
48	Luca	48	Ovotest. DSD	Third gender	Sometimes as woman, sometimes as man	FGI: $z = -6.89$ TGI: $z = 3.12$	Ambiguous	male	Not at all	42	M \rightarrow F	'It's all nonsense'
----- CAH sv ($N = 7$) -----												
49	Christa	23	CAH sv f	Female	Woman	—	Ambiguous	Female	Very	—	—	'I am a woman, feel like a woman, and am very satisfied'

(Continued)

Table 1. (Continued)

Nr	Pseudonym	Individual information			Current gender experience			Genital appearance, gender (re-)allocation, satisfaction with gender allocation, gender change			
		Age	Condition	Gender role (today)	Gender identity (today)	GIQ*	Genital appearance (birth)**	Gender allocation (birth)	Satisfaction with gender allocation/sex assignment	Gender reallocation/ gender change	
50	Dana	16	CAH sv f	Female	Sometimes as woman, sometimes as man	CG: $z = -2.95$	Ambiguous	Female	Very	—	—
51	Esther	18	CAH sv f	Female	Woman	FGI: $z = -1.86$ CG: $z = -2.57$	Female	Female	Very	—	—
52	Francesca	37	CAH sv f	Female	Woman	—	Ambiguous	Female	Very	'I am a woman!'	—
53	Ines	28	CAH sv f	Female	Woman	—	Female	Female	Very	'I like being a woman!'	—
54	Bernhard	43	CAH sv m	Male	Man	—	Ambiguous	Male	Very	'I have felt male from childhood onward → teen age → adulthood. I like women → feel attracted to them'	—
55	Martin	58	CAH sv m	Male	Sometimes as woman, sometimes as man	FGI: $z = 5.45$ MGI: $z = -5.39$ TGI: $z = 2.43$ CG: $z = -1.82$	Ambiguous	Female	Moderate	'It troubles me that I still have to struggle with my identity, it doesn't leave me in peace'	7*** F → M
56	Nora	33	CAH sv f	Female	Woman	CAH sw ($N = 10$)	Ambiguous	Female	Very	—	—
57	Olivia	21	CAH sv f	Female	Woman	FGI: $z = -3.11$	Ambiguous	Female	Very	'Why "because"?? I am what I am!'	—

58	Pina	20	CAH sw f	Female	Woman	—	Male	Male	Very	'I am unequivocally female, aren't I'	2	M → F
59	Ricarda	21	CAH sw f	Female	Woman	MGI: 1.76	Ambiguous	Male	—	—	1	M → F
60	Sandra	33	CAH sw f	Female	Woman	—	Ambiguous	Female	Very	'I have never thought about it until now'	—	—
61	Tamara	16	CAH sw f	Female	—	—	Ambiguous	Female	Very	—	—	—
62	Annika	24	CAH sw f	[Female]****	Woman	CG: z = -4.11	Ambiguous	Female	Fairly	—	—	—
63	Alex	26	CAH sw f	Third gender	Sometimes as woman, sometimes as man	FGI: z = -2.17 CG: z = -3.72	Ambiguous	Female	Low	'I can't identify with the behaviour of a classical woman'	—	—
64	Carsten	47	CAH sw m	Male	Woman	FGI: z = 5.96 MGI: z = -6.41 TGI: z = 4.56	Ambiguous	Male	Not at all	'I can't identify with it'	—***	—
65	Robin	40	CAH sw m	Third gender	Sometimes as woman, sometimes as man	CG: z = -5.61 FGI: z = 1.88 MGI: z = -3.35 CG: z = -4.47	Male	Male	Low	'The definition as female and the iatrogenic trauma connected with it destroys identity'	1	M → F 35 F → M
66	Diana	31	CAH lo	Female	Woman	CAH lo (N = 4)	Female	Female	Very	'I get along fine with it'	—	—
67	Ellen	28	CAH lo	Female	Woman	—	Female	Female	Very	'I was never anything other than "female"'	—	—

(Continued)

Table 1. (Continued)

Nr	Pseudonym	Individual information		Current gender experience			Genital appearance, gender (re-)allocation, satisfaction with gender allocation, gender change				
		Age	Condition	Gender role (today)	Gender identity (today)	GIQ*	Genital appearance (birth)**	Gender allocation (birth)	Satisfaction with gender allocation/sex assignment	Gender reallocation/ gender change	
68	Franka	38	CAH lo	Female	Woman	—	Female	Female	Very	'I am a woman'	—
69	Greta	27	CAH lo	Female	Woman	—	Female	Female	Very	—	—
Total		M = 33.01 (SD = 10.44)		Female: 56/69	Woman: 44/68	FGI (z < -1.64): 18/69	Female: 37/69	Female: 57/69	Very: 38/67		M → F: 5
N = 69		Md = 32 (16–60)		Male: 8/69 undecided: 1/69	Man: 6/68	FGI (z > 1.64): 5/69	Male: 2/69 Ambiguous: 30/69	Male: 12/69	Fairly: 12/67		F → M: 2
				Third gender: 4/69	Sometimes woman/man: 16/68****	MGI (z > 1.64): 9/69			Moderate: 10/67		
					Neither nor: 2/68	MGI (z < -1.64): 4/69			Low: 4/67		
						TGI (z > 1.64): 10/69			Not at all: 3/67		
						CG (z < -1.64): 18/69					

Notes: *GIQ = gender identity questionnaire (Eckloff, 2007), 4 scales: (1) FGI = female gender identity; (2) MGI = male gender identity; (3) TGI = transgender identity; (4) CG = certainty of belonging to a specific gender. Z-scores > 1.64 are presented in the table. If we set a higher cut-off at 1.96 or a lower cut-off at 1, the frequencies will change as follows:

FGI (z < -1.96): 16/69
 FGI (z > 1.96): 4/69 (only CAH m or PAIS m)
 MGI (z > 1.96): 6/69
 MGI (z < -1.96): 4/69 (only CAH m or PAIS m)
 TGI (z > 1.96): 8/69
 CG (z < -1.96): 16/69

**We used medical records and self-declarations to determine genital appearance at birth.

***These three participants had already or were still considering changing their gender.

****This person with CAH sw did not answer on current gender role. However, other answers in the questionnaire indicate that she is living in the female role.

*****We refer to a 'mixed' two-gender identity based on an experience of self as 'sometimes a woman, sometimes a man'.

The initial gender allocation after birth was female in 57/69 participants (83%) and male in 12 cases (17%). All those with female-appearing genitalia (see above, 37/69, 54%) were allocated a female gender role; those two with male-appearing genitalia were allocated a male role. Amongst the participants with ambiguous genitalia, 20/30 (67%) were allocated the female gender (3/7 PAIS f; 5/14 GD; 2/3 5-alpha-RD-2; 4/7 CAH sv and 6/10 CAH sw); 10/30 (33%) were allocated a male gender role (5/5 with PAIS m; 1/7 with PAIS f; 1/1 with ovotest. DSD; 1/7 with CAH sv; 2/10 with CAH sw).

Gender re-allocation and gender change

5/69 participants (7%) reported gender re-allocation in childhood: *Pina*, *Ricarda* and *Robin* who were diagnosed with CAH sw, *Martin* (with CAH sv) and *Luca*. *Pina*, *Ricarda* and *Robin* had previously been allocated a male gender and were reallocated to a female gender within their first year of life. *Robin* decided at the age of 35 to take on an intersex gender role. After an initial female gender allocation, *Martin* was allocated a male gender at the age of 7 years following medical advice because of signs of virilisation; he has been living in the male role ever since, though he reports gender identity difficulties. *Luca* reported a gender history with more than one gender change. In his/her first weeks of life s/he was allocated the female gender. Between 12 and 15 months s/he was reallocated the male gender and was then raised as a boy, remaining in the male role until the age of 42, when s/he decided to live in the female role. Finally, at the age of 43 *Luca* was informed for the first time about his/her full diagnosis and consequently decided to live in the female and the third gender.

Adult gender change was also reported by *Dorothea* (with PAIS), who changed from the initial male gender allocation to a female gender at the age of 34. *Gender change considerations* were voiced by 3/69 (4%): *Martin* (with CAH sv) had considered changing to the female role, as did *Carsten* (with CAH sw) (see Schweizer, Brinkmann, & Richter-Appelt, 2007). *Fiona* with 5-alpha-RD-2 had thought about changing to the male role (see Schweizer et al., 2009).

Gender experience today: gender role and gender identity

For a descriptive summary of the results of the whole group of participants ($n = 69$), see the bottom line of Table 1, which presents the frequencies in each category studied.

Regarding their *gender role today*, 56/69 participants (81%) live in the female role and 8/69 (12%) in the male role. 5/69 (7%) participants explicitly named a role not provided within the binary model: *Nicky* (with pure GD), *Luca* (with ovotesticular DSD), and *Alex* and *Robin* (both with CAH sw) reported living in a third gender. *Gudrun* (with pure GD) was undecided.

In the single-item assessment of *gender identity today*, 16/68 participants (24%) reported having a 'mixed' two-gender identity, that is 'sometimes as a woman, sometimes as a man'. They included participants from almost all subgroups: CAIS (2/13), PAIS f (1/7), GD (4/13), androgen biosynthesis deficiencies (4/7), ovotesticular DSD (1/1), CAH sv (2/7) and CAH sw (2/10). Gender identity 'as a woman' was chosen by 44/68 participants (65%); 6/68 participants (9%) with PAIS (5/5) and CAH sv (1/7) identified as men. 2/68 (3%), i.e. *Nicky* (GD) and *Dorothea* (PAIS f) chose 'neither nor' instead of the other three answer options. Thus, in total 18/68 participants (26%) did not comply with an unambiguous perception of self as either a man or a woman, but instead reported having 'mixed' two-gender or other identities.

Regarding the *gender identity assessed by the GIQ* compared with non-intersex women, 18/60 (30%) participants, i.e. not including the PAIS m and CAH m groups, scored markedly lower on the FGI scale; 9/60 (15%) scored markedly higher on the MGI scale. Compared with non-intersex men, 5/9 participants (56%) with PAIS m or CAH m scored markedly higher on the FGI scale; 4/9 (44%) scored markedly lower on the MGI scale. In comparison with either set of non-intersex men, in the case of PAIS m and CAH m, or non-intersex women, in the case of all other subgroups, 10/69 participants (14%) scored markedly higher on the TGI scale and 18/69 (26%) scored markedly lower on the certainty (CG) scale.

Gender narratives and satisfaction with gender role allocation (DSD subgroups)

A total of 67/69 participants (97%) reported on their level of satisfaction with their original gender allocation: 38/67 (57%) reported being very satisfied, 12/67 (18%) fairly satisfied and 10/67 (15%) moderately satisfied. However, 7/67 (10%) were dissatisfied, i.e. 4/67 (6%) were not satisfied and 3/67 (4%) were not satisfied at all.

The CAIS subgroup (N = 13)

Being female with(-out) doubt. The gender allocation of every participant with CAIS was female. 11/13 (85%) identified as women. 2/13 (15%) reported a 'mixed' two-gender identity. 11/13 (85%) reported a high level of satisfaction with their female allocation. All members of this group reported a female gender identity except for *Inga* and *Nina*, who reported a 'mixed' two-gender identity on the gender identity today item. In their narratives, *Marie* and *Katja* explained that they had never questioned their sex or gender. *Lea* and *Renate* stated that they 'feel female' and *Olga* described how she likes the feminine role, attributing to it positive qualities, e.g. of being 'nicer, more holistic', though also noting its limitations. Within this group of satisfied participants, 4/11 (36%) showed remarkable scores on the GIQ: *Nina*, who could not imagine being male despite having 'XY-chromosomes', nevertheless had a markedly low score on the FGI. *Lea* and *Jana* both showed markedly high scores on the MGI scale, while *Jana* also wrote that she is a 'woman +'. *Renate*, who like the others confirmed a female identity on the gender identity today item, showed markedly low scores on the certainty of belonging to one specific gender (CG) scale.

Hanna and *Inga*, 2/13 (15%), were only moderately satisfied with their female gender allocation. *Inga* pointed out that CAIS does not necessarily have to be associated with an unambiguous and doubt-free gender identity experience: 'I don't want to be forced into a clear direction, I do sometimes have doubts about this allocation'. They both also yielded markedly low FGI and CG scores, with *Inga* reporting a female and *Hanna* showing a 'mixed' two-gender identity.

The PAIS subgroup (N = 12)

Participants with PAIS are reported on separately according to their current gender role: as PAIS f in case of a current female role and PAIS m in the case of a current male role.

The PAIS f subgroup (N = 7): Feeling female, both or neither nor – but not male! 5/7 (71%) participants with PAIS living in the female gender role reported a female gender

identity, 1/7 (14%) reported a 'mixed' two-gender identity and 1/7 (14%) reported a 'neither nor' identity. There is a high level of variance in satisfaction with gender allocation, with 4/7 (57%) being satisfied, 1/7 (14%) being only moderately satisfied and 2/7 (29%) being dissatisfied. *Xenia*, *Amelia*, *Clara* and *Gabriele* reported a high level of satisfaction with their female gender allocation. *Gabriele* however scored markedly low on the CG scale. In their narratives these four emphasised a strong sense of female identity in terms of 'being' or 'feeling' female or 'as a girl'. *Amelia's* statement included three aspects on which her identity experience was based: feeling, appearance and social acceptance (being 'treated like a woman'). *Xenia* described her identity as a woman by referring to the male gender in a societal sense: She feels 'profoundly like a woman', because she sees the 'societal role of a man' as being 'problematic', however does not provide further details.

Zara was only moderately satisfied; she shows markedly low scores on the FGI and the CG scales. She also explained her answer with regard to the male category by referring to her chromosomal status ('I am not an "XX-woman" [. . .]'), which in her opinion was not reason enough to develop the 'need to be a man'.

Yelda and *Dorothea* both reported dissatisfaction with their original gender allocations, with the difference being that *Yelda* was allocated the female gender and *Dorothea* the male. Neither of them explained their answers. In the case of *Dorothea*, her low satisfaction with the original male allocation appears congruent with her decision to change gender from male to female at the age of 34. With regard to current gender identity, *Dorothea* reported herself as being 'neither nor', and on the GIQ she shows a markedly low FGI score. *Yelda*, also living in the female gender role, without having changed before, shows a 'mixed' two-gender identity and had remarkable *z*-scores on all four scales of the GIQ: markedly high MGI and TGI as well as extremely low FGI and CG scores.

The PAIS m subgroup (N = 5): (Dys-)function and male identity. All five of the PAIS m group reported their current gender identities as being male. Three were satisfied with the original male allocation. This satisfaction was associated with well-being by *Viktor*, and a clear male identification over time in *Erik's* experience of identity or with functionality ('it works') by *Ben*, with the latter leaving open whether this refers to physical or psychosocial functioning. *Ben* also has a high FGI score. *Frank* did not report on satisfaction but showed markedly increased FGI and TGI scores as well as a very low MGI score. Moderate satisfaction with male gender allocation was expressed by *Wolfgang* and attributed to physical dysfunction (hypospadias).

The GD subgroup (N = 14)

(Non-)binary individuality and female well-being including and excluding male parts. Of the participants with GD, 9/14 (64%) identified as women; 4/14 (29%) reported a 'mixed' two-gender identity and 1/14 (7%) a 'neither nor' identity. 11/14 (79%) reported being very or fairly satisfied with their female gender allocation and 3/14 (21%) reported being moderately satisfied. None expressed clear dissatisfaction.

Out of the group of satisfied participants, 9/11 reported a female identity. Two, *Martha* and *Patricia*, described a 'mixed' two-gender identity. Being highly or fairly satisfied was linked to narratives of positive well-being and feelings in relation to being female, such as feeling 'very good as a woman' (*Tanja*) or feeling 'good with it' (*Martha*). Satisfaction was further associated with expressions of congruence such as 'that is how I feel' (*Isabelle*), or 'I am a woman!' (*Ulrike*), and continuity, such as in the case of *Louisa*, who had 'always identified [her-]self as being female'. *Ruth* chose a more pragmatic explanation: the

female assignment was the ‘most convenient decision back then’. *Nathalie* argued within the parameters of the binary gender model, explaining that being satisfied derived from excluding the male alternative. Nonetheless, she also showed markedly high MGI and low scores despite her identification as a woman. *Josephine*, who was very satisfied, explained that she felt herself to be a woman ‘with special features’, acknowledging an inner male part. Reference to experiencing ‘a happy childhood’ with the allocated female gender was made by *Heike*, who was also very satisfied.

Moderate satisfaction in 3/14 (21%) participants with GD was accompanied by expressions of individuality and non-dichotomous gender identity. *Gudrun*, who was undecided on her current gender role, explained herself as sometimes feeling ‘more like a woman than a man’. *Nicky*, who lives in a third gender role, would ‘rather live as that which I am’. *Stefanie* referred to a feeling of ‘uncertainty’, also emphasising that medical treatment experience played a central role, resulting in ‘a feeling partly of forced transsexualisation’.³ All three also reported a ‘mixed’ two-gender or ‘neither nor’ gender identity, and remarkable scores on the GIQ, with low FGI and high TGI scores in all three, an extremely low feeling of femaleness in *Nicky*, and low certainty scores for *Gudrun* and *Nicky*, with *Gudrun* also showing markedly high MGI scores.

The androgen biosynthesis deficiency subgroup (N = 7)

From male to female – a wide and open gender spectrum. The 7 female-allocated participants were diagnosed with 5-alpha-RD-2 ($n = 3$) and 17-beta-HSD-3 ($n = 4$). Of this group, 4/7 (57%) were satisfied, 2/7 (29%) moderately satisfied, and 1/7 (14%) was dissatisfied with their female gender allocation. 3/7 (43%) identified as women; 4/7 (57%) reported a ‘mixed’ two-gender identity.

Satisfaction with female allocation was associated with narratives of well-being at least up to a certain point in time (*Barbara*). *Claudia* and *Daniela* refer to the male gender as not being an alternative. *Emily* clearly experiences herself as living in the ‘role of a woman’ while setting out to experience male aspects of herself against the background of a gender-relativising attitude. Both *Emily* and *Claudia* reported having a ‘mixed’ two-gender identity. Both showed markedly high MGI scores on the GIQ, with *Emily* scoring low on the FGI and CG scales. *Claudia* additionally reported high TGI scores.

For *Fiona*, moderate satisfaction with her female gender allocation was linked to openness regarding gender: She could ‘also well imagine living as a man’, which was also documented in her current considerations regarding gender change. *Gina* described a more fluctuating level of satisfaction, with identity problems at times as well as satisfaction in a third gender role at other times. While *Gina*’s scores on the GIQ were unremarkable, *Fiona* showed either higher or notably lower scores on all four scales when compared with non-intersex women. Both *Fiona* and *Gina* reported ‘mixed’ two-gender identities.

Anne, who was the only one explicitly dissatisfied with her female gender allocation, thought male allocation would have been more appropriate, but at the same time reported a FGI on the gender identity today item. Her FGI and CG scores were however extremely low. More detailed results for this particular group have been published elsewhere (Schweizer et al., 2009).

Participants with LH and ovotesticular DSD (N = 2)

Two extremes – unequivocal female and non-binary gender options. *Angela*, the only participant with LH, reports being very satisfied with her female allocation: ‘I feel myself to be a woman’, showing an unequivocal FGI and gender role.

Luca, the only participant with ovotesticular DSD and today living in a third gender role, reported being not at all satisfied with the original male allocation, arguing that it was 'all nonsense'. This statement is underlined by a 'mixed' two-gender identity and markedly low FGI and high TGI scores on the GIQ as well as a gender change from male to female as an adult.

The CAH subgroups (N = 21)

Participants with CAH are reported on separately according to their specific CAH diagnosis and gender allocation at birth. Within the group of participants with classical CAH (i.e. CAH sv and CAH sw, $n = 17$ with 1 answer of Tamara missing), 11/16 (69%) identified as women, 4/16 (25%) reported a 'mixed' two-gender identity and 1/16 (6%) a male gender identity. Within the non-classical group (with CAH lo), all 4 participants identified as women.

CAH sv subgroup (N = 7): Female and male, mixed and struggling identities. Satisfaction with female allocation was high in 5/6 (83%) of originally female-allocated participants with CAH sv. *Christa*, *Francesca* and *Ines* reported an unequivocal experience of female gender identity, which is supported by their narratives. *Ines* likes 'being a woman'. *Esther*, who also reported a female gender identity, nonetheless had a low certainty score on the GIQ; furthermore, *Esther* scored low on the FGI scale. *Dana* reported a 'mixed' two-gender identity.

Martin was only moderately satisfied with his original female gender allocation, which was followed by a re-allocation to the male gender at 7 years, explaining 'It troubles me that I still have to struggle with my identity, it doesn't leave me in peace'. He reports having a 'mixed' two-gender identity today with remarkable scores on all four GIQ scales: extremely high FGI and TGI scores and markedly low MGI and CG scores. In contrast, *Bernhard* is very satisfied with his original male allocation as it matches his male identity experience throughout childhood, adolescence and adulthood; to him it is also in line with his gynephile sexual orientation.

CAH sw subgroup (N = 10): Continuous, mixed and destroyed identities. Amongst the participants with CAH sw, 6/10 (60%) were originally female allocated. Of these, 5/6 (83%) were very or fairly satisfied and reported having a FGI, with the exception of *Tamara* who did not reply regarding current gender identity. *Sandra* stressed that she had not yet had any doubts about being female. *Olivia* wrote 'Why "because?" I am what I am'. Neither *Nora* nor *Annika* explained their satisfaction with female allocation any further, but *Nora* additionally had markedly low FGI scores and *Annika* had markedly low CG scores. *Alex*, living in a third gender role, was not satisfied with his/her original female gender allocation and explains her/his answer by referring to gender typical behaviour: 'I can't identify with the behavior of a classical woman'. S/he reported having a 'mixed' two-gender identity as well as markedly low FGI and CG scores.

4/10 (40%) participants with CAH sw were originally allocated a male gender after birth. *Ricarda* and *Pina* were reallocated the female gender in order to become girls at 1 and 2 years of age, respectively. Both identified as women. *Ricarda* also had a markedly high score on the MGI scale and did not respond to the satisfaction item. *Pina*, who was very satisfied with her original gender allocation, was probably referring to the reallocation at age 2 when she declared 'I am unequivocally female, aren't I'.

Carsten and *Robin* both reported dissatisfaction with their original male allocation. *Carsten*, who showed a clear-cut identification as a woman and extremely low MGI and

CG scores as well as extremely high FGI and TGI scores on the GIQ, simply explained: ‘I can’t identify with it [male allocation]’. His/her strong female gender identity development, ‘despite’ many medical sex-assigning interventions intended to underline the male gender role, has been published in a case study elsewhere (see Schweizer et al., 2007). *Robin* had high FGI scores as well as low MGI and CG scores. *Robin* was first allocated a female and then newly allocated a male gender before the age of one and lives in the third gender role today. S/he reported a ‘mixed’ two-gender identity and explained his/her dissatisfaction with his/her original gender allocation by writing: ‘The definition as female and the iatrogenic trauma connected with it destroys identity’.

In total, only 1/5 (20%) male-allocated participants with CAH sv and CAH sw, i.e. *Bernhard* (with CAH sv), reported high satisfaction with male allocation and developed a male gender identity.

CAH lo subgroup (N = 4): Unequivocal femaleness. All four with CAH lo reported gender identities as women and a very high satisfaction with female gender allocation at birth. Three of them explained their responses, with *Diana* ‘getting along fine with it’ and *Franka* writing: ‘I am a woman’. *Ellen* confirmed a stable gender identity experience by writing ‘I was never anything other than “female”’.

Discussion

This study aimed at tackling the problems of dichotomisation of gender experience and enmeshing of medical and social sexing in DSD management. The specific aims were (1) to describe the gender experience and level of satisfaction with gender allocation of intersex persons and (2) to explore the spectrum of their gender identities.

As suggested in previous reviews (DeVries et al., 2007), the majority of participants were assigned to the female gender and currently lived in the female gender role. Seventy-five per cent reported satisfaction with the gender allocated at birth, however there were differences between the diagnostic subgroups. Additionally, the male/female dichotomy was not applicable for over a quarter of the participants, who reported a ‘mixed’ two-gender identity, i.e. who experienced both male and female identification at different times, or preferred an identity that was ‘neither nor’. A ‘mixed’ two-gender identity was reported more than once in all diagnostic subgroups other than LH, most notably in the GD group (5/14) and androgen biosynthesis disorders group (4/7). Furthermore, 14% of the participants reported high TGI scores on the GIQ, suggesting a capacity for integrating both male and female aspects into their gender experiences.

In contrast to the predominant view in medical and psychological research on gender development in DSD (e.g. DeVries et al., 2007) we do not conclude that early sex assignment or gender allocation, either to the female or the male gender, is the ‘best predictor’ of later gender identity development: individual and ‘mixed’ two-gender identities as well as third and undecided gender roles have all been described by participants even though the majority were satisfied with their gender allocation. These findings clearly indicate the need for a conceptual separation of gender role and gender identity. Gender role could provide a framework for meeting the need to belong to established societal categories, while gender identity represents a space for internal, possibly private individual experiences.

The participants’ narratives suggest that a high level of satisfaction with gender allocation is associated with experiences of continuity and a congruent experience of self over time, which can be based on experiences of physical appearance and the capacity to experience oneself as being of a gender. Well-being, positive appraisal (‘liking’), social

feedback and confirmation of one's gender-related appearance, gender role and identity play an important role for a positive evaluation, as well as the absence of doubts. Somatic dysfunction appears to be related to dissatisfaction, as do the lack of identification with the allocated gender role and medical interventions.

The findings on gender identity measured by the four-dimensional GIQ support the notion of a wider, more inclusive gender spectrum instead of a one-dimensional dichotomous gender model. This type of spectrum of identities and gender roles beyond the gender binary was in particular demonstrated by those participants with GD, CAH sw and ovotesticular DSD, who had chosen neither a male nor a female gender role, but rather a third gender or an undecided gender role. These gender role decisions were partly reflected by the participants' gender identity narratives, for instance, by stressing their wish for individuality and authenticity such as wanting to 'live as that which I am' (*Nicky*, GD). Gender experience is also associated with condition-related medical interventions, resulting in identity-destroying 'iatrogenic trauma' (*Robin*, CAH) or 'forced transsexualisation' (*Stefanie*, GD).

Participants expressed a desire for more self-determination and flexibility, e.g. wanting to avoid being 'forced into a clear direction' (*Inga*, CAIS). These gender expressions were associated with dissatisfaction with original gender allocation and thus accord with Stark's (2006) argument that intersex people be allowed the right to an authentic and where relevant intersexual self. Some referred to an all-excluding 'neither nor' identity category, e.g. 'couldn't imagine being male, although I am not female either' (*Claudia*, 17-beta-HSD-3).

Some participants described DSD-specific identities similar to the notion of a 'mixed' two-gender identity: *Jana* (CAIS), for example, who both elaborated on her strong satisfaction with her female allocation ('I am a woman +') and also had remarkably high male identity markers (cf. MGI scale), and *Josephine* (GD), who described herself as a 'woman with special features', taking into account that the male inside her must have some meaning. These 'features' and the signifier '+' could be interpreted as 'modifiers', as described by Kessler (1998, p. 89), which are coupled with maleness or femaleness and express an extended gender identity experience.

While some participants distanced themselves from conventional gender expressions such as 'the behaviour of a classical woman' (*Alex*, CAH) or a 'XX-woman' (*Zara*, PAIS), the majority did refer to the male/female gender categories, even if some identify with one of these two genders because the other is less of an alternative (e.g. *Nathalie*, GD, and *Daniela*, 17-beta-HSD-3).

The remarkable findings regarding the uncertainty of belonging to a gender (CG scale of the GIQ) expressed by 26% of the participants need to be better understood. High uncertainty could be read as an indicator of gender dysphoria. Indeed gender dysphoria in terms of dissatisfaction with the current gender role (not identity) has been reported by *Carsten* while *Martin* (also both with CAH) expressed gender dysphoria in terms of identity struggles. However, the results also indicate that high levels of satisfaction with gender allocation can co-exist with high levels of uncertainty. We propose that uncertainty of belonging to a male or female gender might also point to the need for alternative categories: the gender dysphoria and gender identity problems in the studies reviewed by DeVries et al. (2007) could also be seen as a symptom of the lack of adequate identity categories for individuals with DSD. Language creates identity. Identity problems might therefore arise when society does not have suitable categories on offer. An 'intergenerational' category as proposed by Kessler (1998, p. 84) could be an option for those who feel they genuinely belong to a group of their own. In addition, the analyses of attitudes in the CAIS

group of participants demonstrate that a third gender category is desired by a considerable proportion (see Handford, Brunner, Schweizer, & Richter-Appelt, 2012).

Limitations and suggestions for further research

Since it has not been possible to relate gender experiences to medical experiences on the basis of the data to hand in the present paper, it is imperative that the interplay between gender and medical experiences continues to be studied. Furthermore, though the study began with the intention of inviting pluralities of gender experiences, the research process took place within a binary framework, e.g. for the purpose of categorising data.

Future research should aim at the following: an examination of the relationship between physical intersexuality and intergender experiences; a detailed exploration of specific gender experiences by means of both quantitative and qualitative methods; a methodology that allows for non-binary gender experiences in DSD research, and finally an examination of care providers' understanding of gender. This work needs to be informed by literatures outside an empiricist paradigm. Observations by Stoller (1968) and Diamond (1997) as well as qualitative analyses (e.g. Lang, 2006; Preves, 2003) have, for example, emphasised just how variable intersex gender experience is. Theoretical concepts for understanding intergender identity development are provided by queer and gender theory, as well as the field of psychoanalysis. With regard to its conception of early and unconscious body experience, the latter could make a valuable contribution towards a better understanding of psychosexual development in individuals with DSD (cf. Aron, 1994; Benjamin, 1994; Stoller, 1968; Williams, 2002). The bringing together of different hermeneutic approaches with empirical methods and experiences from research with other sexual minorities (see Mair, 2010; Roen, 2011) could further develop research on identities of people with DSD.

Conclusions

An important assumption in the 'optimal gender paradigm' (see Meyer-Bahlburg, 2004) was that an ambiguous body should be treated in order to achieve a clear sense of belonging to either the female or male gender. Our findings highlight the inadequacy of the dichotomous, one-dimensional male/female categorisation for the purpose of allowing an authentic sense of gender identity in individuals with DSD. Our research further suggests that treatment goals should be re-directed from 'successful' gender outcome in binary terms to psychological well-being regardless of feeling male, female, both or neither.

Though the consensus statement (Hughes et al., 2006) offers useful suggestions for clinical management, a fundamental weakness lies in its perpetuation of 'optimal-gender' thinking (e.g. 'successful gender assignment is dependent on this procedure [phalloplasty]') (Hughes et al., 2006, p. 557). Whilst prediction of adult gender identity remains illusive, social allocation of a gender to facilitate gender identity development should continue. However, non-emergency sex-assigning interventions should be the subject of much tighter scrutiny.

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Notes

1. Due to the nature of the German term 'Geschlecht' used in the original item, in which the meanings sex and gender are both subsumed, the question could also have been understood to mean: 'Were you at a later point in time assigned a different sex to that which you had originally been assigned?'
2. *Genital appearance at birth* was assessed by the participants' self-report and their medical records. The self-report was assessed by means of the items 'Were physical anomalies found to be present within 8 weeks after birth?' and 'What was the opinion concerning your genitals with regard to sex directly after birth?'. With regard to the latter item, the categories 'definitely female', 'more likely female', 'ambiguous', 'definitely male', 'more likely male' and 'other' were provided in the original version. The outcomes of these sources were summarised as 'female', 'male' or 'ambiguous'.
3. For details see Schönbucher et al. (2012): *Stefanie* reported having a gonadectomy at the age of 16.

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