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Annastasia Ediati [a b], Achmad Zulfa Juniarto [b], Erwin Birnie [c], Stenvert L. S. Drop [d], Sultana M. H. Faradz [b] & Arianne B. Dessens [d]

[a] Department of Clinical Psychology, Faculty of Psychology, Diponegoro University

[b] Department of Human Genetics, Center for Biomedical Research, Diponegoro University

[c] Institute of Health Policy and Management, Erasmus University, Rotterdam

[d] Department of Paediatrics, Division of Endocrinology, Erasmus University Medical Center

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Annastasia Ediati
Department of Clinical Psychology, Faculty of Psychology, and Department of Human Genetics, Center for Biomedical Research, Faculty of Medicine, Diponegoro University

Achmad Zulfa Juniarto
Department of Human Genetics, Center for Biomedical Research, Faculty of Medicine, Diponegoro University

Erwin Birnie
Institute of Health Policy and Management, Erasmus University Rotterdam

Stenvert L. S. Drop
Department of Paediatrics, Division of Endocrinology, Erasmus University Medical Center

Sultana M. H. Faradz
Department of Human Genetics, Center for Biomedical Research, Faculty of Medicine, Diponegoro University

Arianne B. Dessens
Department of Paediatrics, Division of Endocrinology, Erasmus University Medical Center

In Indonesia, disorders of sex development (DSDs) are not well recognized and medical care for affected individuals is scarce. Consequently, many patients live with ambiguous genitalia and appearance. We compared reported outcomes on body image, sexual functioning, and sexual orientation of 39 adults with DSDs (aged 18 to 41) and 39 healthy controls matched for gender, age, and residential setting (urban, suburban, rural). Differences in gender and treatment status (treated or untreated) were also explored. On body image, adults with DSDs reported dissatisfaction with sex-related body parts. Compared to the matched controls, women with DSDs reported greater sexual distress, and men with DSDs reported lower erectile and ejaculation frequencies, and more dissatisfaction with sexual life but not with sexual desire and activities. Men with DSDs who had undergone genital surgery reported higher erectile and ejaculation frequencies than untreated men. More women than men in the DSDs group reported a nonexclusive heterosexual orientation. DSDs and infertility had a great impact on sexuality. Fear of ostracism complicated DSD acceptance. Findings were compared to those of Western studies. Based on these results, education about DSDs and their psychosexual consequences may help reduce the sexual distress and problems in adults with DSDs and improve quality of life.

The management of disorders of sex development (DSDs) in Indonesia faces significant barriers. In addition to the lack of diagnostic facilities, DSD conditions are also not well recognized among the Indonesian population, including the majority of health care providers. Anomalies of the genital tract are often considered abnormal

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Correspondence should be addressed to Annastasia Ediati, Department of Clinical Psychology, Faculty of Psychology, Diponegoro University, Jl Prof Sudharto SH, Tembalang, Semarang 50275, Indonesia. E-mail: aediati@yahoo.com

and shameful, leading to secrecy, social isolation, and stigmatization (Warne & Raza, 2008).

The most recently held consensus statements for clinical practices in DSDs favor preventing an ambiguous body appearance by giving hormonal treatments; removing gonads of individuals with 46,XY karyotype raised as females who are at risk for developing gonadal malignancies; and performing genital surgery (Joint LWPES/ESPE CAH Working Group, 2002; Hughes, Houk, Ahmed, Lee, & LWPES1/ESPE2 Consensus Group, 2006). Although still subject to debate (Köhler et al., 2012; Minto, Liao, Woodhouse, Ransley, & Creighton, 2003), these consensus statements also recommend early surgical correction of moderate to severely deviant genitalia. It is assumed that prevention of an ambiguous body and surgical correction will prevent social stigmatization and facilitate psychological adaptation to the assigned gender and sexual intercourse in adulthood (Carmichael & Alderson, 2004). Studies on psychosexual functioning have been initiated among patients with DSDs who are living as either men or women. Impaired body image, problems in establishing romantic relationships, and difficulties with sexual functioning have been reported among patients with different diagnoses of DSDs (Bouvattier, Mignot, Lefèvre, Morel, & Bougnères, 2006; Crouch, Liao, Woodhouse, Conway, & Creighton, 2008; Gastaud et al., 2007; Kojima et al., 2009; Migeon et al., 2002; Minto, Liao, Conway, & Creighton, 2003; Szarras-Czapnik, Lew-Starowicz, & Zucker, 2007; Wisniewski et al., 2000).

Before entrance, many Indonesian patients with DSDs never receive medical assistance and, consequently, are raised with ambiguous genitalia and bodies for many years. In 1989, a multidisciplinary team was set up in collaboration between Dr. Kariadi Hospital and the Faculty of Medicine at Diponegoro University (FMDU) to provide diagnostic and medical care for these patients. The team was often confronted with psychosocial and psychosexual problems related to DSDs. In collaboration with the Erasmus University Medical Center Rotterdam, a multidisciplinary study on the clinical diagnosis and treatment options for Indonesian patients with DSDs was initiated (Juniarto et al., 2012). As part of that study, we investigated body image and psychosexual functioning among Indonesian adults with DSDs who entered medical treatment late in life. Although genital ambiguity was often recognized at birth or body ambiguity developed in childhood or in adolescence, medical help seeking was delayed for many years as patients, parents, and local health workers were ignorant about possibilities for medical help. So the majority of our patients had not received medical treatment for their DSD conditions before they entered our hospital in adolescence or adulthood. We therefore were able to study the course of development and impact on the psychosexual and psychosocial aspects of patients for whom medical treatment for DSDs were absent for most of their lives.

Method

Study Design

The study was granted ethical approval by the board of the ethical commission at Faculty of Medicine, Diponegoro University. This was a cross-sectional study comparing body image and psychosexual functioning between patients with DSDs and their matched controls. All patients were managed clinically by the Sexual Adjustment Team at Dr. Kariadi Hospital.

Participants

Of 54 patients aged 18 or older who were diagnosed with DSDs (Juniarto et al., 2012), 5 patients could not be contacted due to invalid contact information and 10 patients refused to participate without giving explanation. Thus the study sample was composed of the remaining 39 patients, ages 18 to 41, diagnosed with DSDs, who were living as men or women (Table 1). Under Indonesian national law, legal gender assignment is obligatory, and a third gender designation is impossible. All patients had normal intellectual functioning.

The matched control group consisted of 18 healthy women and 21 healthy men matched for age (with maximum age disparity of 3 years), gender, and residential settings (urban, suburban, or rural).

For the purpose of assessing psychometric properties of the measures that were utilized, a Web-based survey was set up to involve a large group of Indonesian adults. This Web-based group included 377 healthy adults who volunteered to respond to this survey.

Instruments and Procedures

Translation and adaptation of the measures. In addition to qualitative data obtained from interviews, we evaluated the issues and concerns of participants in the areas of body image and psychosexual functioning with established measures. Because no validated Indonesian measures for psychosexual functioning were available, we utilized Western measures that had been used in comparable studies on sexuality: the Female Sexual Functioning Index (FSFI; Rosen et al., 2000; Gastaud et al., 2007), the Female Sexual Distress Scale–Revised (FSDS-R; DeRogatis, Clayton, Lewis-D'Agostino, Wunderlich, & Fu, 2008), the Body Image Scale (BIS; Lindgren & Pauly, 1975), and the Male Sexual Health Questionnaire (MSHQ; Rosen et al., 2004). Backward translation of these instruments into Indonesian language (Bahasa Indonesia) was conducted by a certified translator (UvA Talen, n.d.). Prior to implementation, the researcher (AE) and a Dutch anthropologist who specializes in research on sexuality in Indonesia and has a good understanding of Bahasa Indonesia and English reviewed the Indonesian translations. The instruments' original scoring procedures were applied.

Table 1. *Clinical Characteristics and Treatment History of Patients With Disorders of Sex Development*

Subject	Karyotype	Diagnosis	Age (in Years)		Type of Treatments Received
			At First Visit*	At Study Visit	
Living as women ($n = 18$)					
P01	46,XX	Congenital adrenal hyperplasia[a]	11	19	Clitorodectomy, age 16; HRT, age 16
P02	46,XX	Congenital adrenal hyperplasia[a]	33	36	Clitoral reduction, age 34; HRT, age 36
P03	46,XX	Congenital adrenal hyperplasia[a]	16	18	Clitoral reduction, age 7; HRT, age 8
P04	46,XY	Androgen action disorder[b]	16	18	Gonadectomy, age 16; HRT, age 17
P05	46,XY	Androgen action disorder[b]	12	18	None
P06	46,XY	Androgen action disorder[b]	20	24	None
P07	46,XY	Androgen action disorder[b]	19	19	None
P08	46,XY	Gonadal dysgenesis[c]	13	18	Gonadectomy, age 10; HRT, age 14
P09	46,XY	Gonadal dysgenesis[c]	39	39	None
P10	46,XY	Gonadal dysgenesis[c]	27	27	None
P11	46,XY	Gonadal dysgenesis[c]	23	23	None
P12	46,XY	Gonadal dysgenesis[c]	19	19	None
P13	45X (99%)/46,XX,iXq	Gonadal dysgenesis[c]	25	29	HRT, age 23; HRT (different types), age 30
P14	46,XidicY	Gonadal dysgenesis[c]	20	20	None
P15	46,Xi (X)(q10)(85%)/45,X (15%)	Gonadal dysgenesis[c]	20	20	None
P16	46,XY (73%)/45,X (27%)	Gonadal dysgenesis[c]	19	19	None
P17	46,X i(X)(q10)(24%)/45,X (76%)	Gonadal dysgenesis[c]	18	18	None
P18	46,XX	Other[d]	15	19	None
Living as men ($n = 21$)					
P19	46,XX	Congenital adrenal hyperplasia[a]	17	22	None
P20	46,XX	Congenital adrenal hyperplasia[a]	24	24	None
P21	46,XX	Gonadal dysgenesis[c]	10	18	Received treatment at age 7 months and 7 years in other clinics; detailed information about the treatment was not available
P22	46,XY	Androgen action disorder[b]/PAIS	26	31	Gynecomasty correction and chorda correction, age 24; hypospadia correction, age 26
P23	46,XY	Androgen action disorder[b]/PAIS	16	20	Gynecomasty reduction, chordectomy, and hypospadia corrections, ages 14 and 15
P24	46,XY	Androgen action disorder[b]/PAIS	12	18	Hypospadia correction, age 15
P25	46,XY	Androgen action disorder[b]	23	26	Gynecomasty correction, chordectomy, hypospadia correction, age 23
P26	46,XY	Androgen action disorder[b]	11	18	None
P27	46,XY	Androgen action disorder[b]	27	27	None
P28	46,XY	Androgen action disorder[b]	23	23	None
P29	46,XY	Gonadal dysgenesis[c]	14	19	Gonadectomy, age 14
P30	46,XY	Gonadal dysgenesis[c]	21	21	Chordectomy, age 11

(*Continued*)

Table 1. *Continued*

Subject	Karyotype	Diagnosis	Age (in Years)		Type of Treatments Received
			At First Visit*	At Study Visit	
P31	46,XY	Gonadal dysgenesis[c]	14	21	None
P32	46,XY	Gonadal dysgenesis[c]	41	41	None
P33	46,XY	Gonadal dysgenesis[c]	26	26	None
P34	46,XY	Unknown undermasculinization[e]	14	19	Chordectomy, age 15; urethroplasty, age 19
P35	46,XY	Unknown undermasculinization[e]	15	20	Hypospadia correction, age 5
P36	46,XY	Unknown undermasculinization[e]	15	20	Penis bend (twice) and hypospadia corrections, ages 13, 15, 16
P37	46,XY	Unknown undermasculinization[e]	15	18	Chordectomy, age 15; urethroplasty, age 16
P38	46,XY	Unknown undermasculinization[e]	29	29	Chordectomy, age 22 (in other clinic)
P39	46,XY	Unknown undermasculinization[e]	17	20	None

Note. Men and women with disorders of sex development were assessed according to the gender in which they were living at the time of study. DSD = disorder of sex development; hCG = human chorionic gonadotropin; HRT = hormone replacement therapy; PAIS = partial androgen insensitivity syndrome.

*First-time visit for medical treatment at the Sexual Adjustment Team (Dr. Kariadi Hospital–FMDU).

[a]46,XX congenital adrenal hyperplasia confirmed CYP 21 mutation in all patients.

[b]46,XY disorder of sex development and undervirilization. Androgen receptor gene mutations were confirmed in four men diagnosed with PAIS but not in the remaining patients. All subjects in this group had a normal hormonal testicular function with unilaterally/bilaterally undescended testes. Androgen action is presumed not to be fully effective. Their clinical and biochemical presentation was close to those of subjects with a mutation in the androgen receptor with elevated serum levels of luteinizing hormone, testosterone, and anti-Müllerian hormone, but the androgen receptor mutation could not be demonstrated.

[c]This group included ten patients with 46,XY karyotype (five men, five women), one man with 46,XX karyotype, and five women with sex chromosome abnormalities. All subjects had a normal hormonal testicular function with unilaterally/bilaterally undescended testes. Androgen action was presumed to be fully effective. Their clinical and biochemical presentation was close to those of subjects with a mutation in the androgen receptor. Serum levels of luteinizing hormone and follicle-stimulating hormone were elevated, but levels of testosterone, anti-Müllerian hormone, and inhibin were low for age, and there was no diminished serum testosterone response to hCG.

[d]46,XX DSD and cloacal malformation with genital ambiguity.

[e]46,XY and undervirilization. No cause for undermasculinization could be identified. Serum hormone values and response to hCG were all normal for age.

All measures were piloted prior to the study. This pilot indicated that the questionnaires were best administered orally to clarify subjects' understanding of the questions prior to giving their responses, particularly if subjects were unfamiliar with self-report questionnaires or had limited education.

Sociodemographic characteristics. Participants were asked about their age, gender, residential status, region of residence, religion, ethnicity, highest completed education level, marital status, and employment.

Body image. The Body Image Scale (BIS) measures the degree of satisfaction with body parts (Lindgren & Pauly, 1975). This scale consists of 30 items measuring the degree of satisfaction with different body parts, with a 5-point scale response options ranging from 1 (*Very satisfied*) to 5 (*Very dissatisfied*). The BIS originally consisted of three domains: primary sex characteristics, secondary sex characteristics, and so-called neutral body parts that are hormonally unresponsive, for example, eyes, hair (Lindgren & Pauly, 1975).

Female sexual distress. The Female Sexual Distress Scale–Revised (FSDS-R) measures frequency of sexual distress in women (DeRogatis et al., 2008). It consists of 13 items with a 5-point rating scale for response mode, including 0 (*Never*), 1 (*Seldom*), 2 (*Sometimes*), 3 (*Often*), and 4 (*Always*). The Cronbach's alpha of the original FSDS-R is .86.

Female sexual functioning. The Female Sexual Functioning Index (FSFI) measures sexual functioning in women who have been sexually active in the past four weeks (Rosen et al., 2000). It consists of 19 items with a 5- or 6-point response mode measuring different aspects of sexual functioning in sexually active women. Rosen and colleagues (2000) reported that the FSFI consists of six domains of female sexual functioning: sexual desire, sexual arousal, lubrication, orgasm, satisfaction, and sexual pain. These domains demonstrated good internal reliability (Cronbach's alphas $>.90$ for all subscales) and good test-retest reliability (test-retest reliability scores ranged from .79 to .88). A section of the FSFI can be applied to women who have not been sexually active in the past four weeks; the number of items that can be applied is limited to sexual desire (item 1 and 2) and satisfaction with overall sexual life (item 16) (Meyer-Bahlburg & Dolezal, 2007). The combined results of the FSFI and FSDS-R allow for the diagnosis of one or more sexual dysfunction(s) according to the *Diagnostic and Statistical Manual of Mental Disorders*, Fourth Edition, Text Revision (DSM-IV-TR; American Psychiatric Association, 2000). A FSFI score of less than 26.55 combined with a FSDS-R score of greater than 11 implies the existence of at least one sexual dysfunction according to the DSM-IV-TR (Rosen et al., 2000).

Male sexual functioning. The Male Sexual Health Questionnaire (MSHQ) assesses male sexual functioning. It consists of 25 items with a 5-point response mode. The original English version of the MSHQ has three domains of sexual function: ejaculation, erection, and sexual satisfaction. High degrees of internal consistency and test-retest reliability of those domains were reported: Cronbach's alpha $= .81$, Pearson's $r = .86$ for erection; Cronbach's alpha $= .90$, Pearson's $r = .87$ for ejaculation; Cronbach's alpha $= .90$, Pearson's $r = .88$ for sexual satisfaction (Rosen et al., 2004).

Sexual orientation. The Kinsey Rating Scale on adult sexual orientation measures sexual orientation using a 7-point rating scale ranging from *Exclusively homosexual* to *Exclusively heterosexual* (Kinsey, Pomeroy, & Martin, 1948, 1953) in sexual attraction, sexual relationships, romantic fantasy, erotic fantasy, and self-identification. To enable a proper statistical analysis, one option of response (*No experience*) was added. Subsequently, the subjects' responses were recoded into four categories: *Exclusively homosexual* (1), *Exclusively heterosexual* (2), *Nonexclusive orientation* (3), and *No experience* (4) (Zucker et al., 1996). We present subjects' response on each item. The concepts of heterosexuality and homosexuality were used in this study in accordance with the presented gender, not the chromosomal sex. In Indonesia, the term *homosexuality* is unfamiliar and often misunderstood or perceived negatively by the general population. Therefore, we applied the terms of *man to man* or *woman to woman* or *same sex* to refer to homosexuality or homosexual individuals. The interviewer began assessing subjects' experiences of their first love, dating, and sexual activities with the opposite gender then asked about the possibility of having similar experiences (imagery or behavior) with persons of the same sex.

Procedures

Data were collected between March 2007 and May 2011. Following diagnostic procedures confirming the diagnosis of DSDs (Juniarto et al., 2012), patients were invited to participate. Verbal and written study information was provided by a physician (AZJ). After a patient agreed to participate and had given written consent, an appointment for a psychological assessment was made. This assessment was performed at the hospital in all cases except one, in which the patient asked to have the assessment done at home. The psychological assessment was conducted by a clinical psychologist (AE) who had been trained to deliver the applied measures and to conduct interviews with patients with DSDs. A small gift or reimbursement of transportation and

a meal were provided for their participation. Men and women with DSDs were interviewed according to the gender in which they lived at the time of the study.

Initially, the study design aimed to include siblings as matched controls, but this was not feasible in terms of the demographic matching and secrecy surrounding DSD conditions within families. The researcher (AE) subsequently recruited participant controls who matched the demographics of the participants with DSDs in terms of residential status, gender, and age (matching factors). The researcher informed the matched control subjects about the study but said only that they were being asked to participate in a study on psychosexual development in adults carried out by the Faculty of Psychology of the Diponegoro University in Semarang to protect the study participants from being identified as patients with DSDs by their matched controls. After they received study information, the control subjects were invited to join the study. After giving written consent, matched control subjects followed procedures similar to the patient group. A small gift was provided for their participation. All matched control subjects requested that their assessments be conducted at home.

Regarding the Web-based survey that was set up to assess the psychometric properties of the instruments that were utilized, we sent an e-mail invitation to several mailing lists for Indonesian adults. Recipients were encouraged to forward the e-mail invitation to other adults in their contact lists. The study aim, principal investigator, affiliation, time estimated for completion of the measures, and confidentiality assurance were provided on the welcome Web page prior to participation. The survey was conducted within a period of four weeks. Sociodemographic data, such as occupation and educational level, showed that the Web-based control group differed substantially from the patient and matched control groups with respect to socioeconomic status and education; the Web-based control subjects came from well-to-do families (e.g., university graduates with well-paying jobs), whereas most patient and matched control subjects came from poor families. This sociodemographic difference affected results. Data from the Web-based controls were not presented for the targeted comparisons but were used to validate the measures only.

Statistical Analysis

Construct validity was explored using principal component analysis (PCA) with varimax rotation and Kaiser normalization. Instrument reliability was evaluated as internal consistency with Cronbach's alpha as the outcome measure. We report the optimal model for the Indonesian data, even when that model deviated from the original Western model. Only responses without missing data were used in the statistical analyses. Differences in continuous data between groups were compared using the Mann-Whitney U-test. Differences in categorical data were compared using Fisher's Exact test. Differences were considered significant at $p < .05$ (two-sided). Because of the small number of patients (Table 1), comparison among diagnostic subgroups was impossible.

Results

Participants

Table 2 shows participants' sociodemographic characteristics. The matched control and patient groups were not significantly different except in marital status. There were no significant differences between treated and untreated patients. However, untreated patients tended to be older than treated patients when they first visited our hospital.

Reliability and Validity of the Measures

As mentioned in the Method section, the validity and reliability of measures applied in this study were obtained using data from the Web controls. The results of reliability and validity analyses are presented in Table 3. The Indonesian versions of the instruments had good psychometric properties, and the components generated from these analyses were relevant to the constructs assessed in the original measures. The BIS comprised one component similar to the original version; the FSDS-R comprised one component similar to the original model but also facilitated a two-component model to assess cognitive and affective components of sexual distress. In the FSFI, items measuring frequency and difficulties in lubrication and orgasm are loaded separately. Similarly, in the MSHQ, items measuring frequency and difficulties in erection and ejaculation functioning are loaded separately. A few minor differences with the original versions are addressed in Table 3.

Body Image

In general views on the body (Table 4), men with DSDs did not differ significantly from the men in the matched control group; yet there was a trend toward significance in women with DSDs, who reported greater dissatisfaction with their bodies than did the women in the matched control group. However, as demonstrated in Table 5, patients with DSDs generally experienced greater dissatisfaction with their genitalia and other sex-related body parts than did controls. Significant differences were reported, particularly regarding ovaries/uterus, breasts, and vagina (in women) and penis, scrotum, and testes (in men). There were no differences between treated and untreated men and women (Tables 4 and 5). Almost all patients had ambiguous genitalia and ambiguous sex-related body parts, such as underdeveloped breasts, low-pitched voices in women, and sparse facial hair in men.

Table 2. *Sociodemographic Characteristics of Study Participants*

Sociodemographic Characteristics	Adults with DSDs ($n = 39$)	Matched Controls ($n = 39$)	p^a	Treated Patients ($n = 18$)	Untreated Patients ($n = 21$)	p^b
Age of visit (in year)	$M \pm SD$	$M \pm SD$		$M \pm SD$	$M \pm SD$	
At first admission	19.9 ± 7.3	—	.09	18.0 ± 6.6	21.5 ± 7.6	.09
At study visit	22.6 ± 5.9	23.3 ± 4.7		22.0 ± 5.5	23.1 ± 6.3	.31
	n (%)	*n* (%)		*n* (%)	*n* (%)	
Gender						
Male	21 (53.8)	21 (53.8)	.99	12 (66.7)	9 (42.9)	.20
Female	18 (46.2)	18 (46.2)		6 (33.3)	12 (57.1)	
Residential settings						
Rural	18 (46.2)	18 (46.2)	.99	7 (38.9)	11 (52.4)	.54
Suburban	13 (33.3)	13 (33.3)		6 (33.3)	7 (33.3)	
Urban	8 (20.5)	8 (20.5)		5 (27.8)	3 (14.3)	
Residence/province						
Central Java	32 (82.1)	37 (94.9)	.23	14 (77.8)	18 (85.7)	.47
Other provinces in Java	4 (10.3)	1 (2.6)		3 (16.7)	1 (4.8)	
Outside Java island	3 (7.7)	1 (2.6)		1 (5.6)	2 (9.5)	
Ethnicity						
Javanese	35 (89.7)	38 (97.4)	.36	15 (83.3)	20 (95.2)	.32
Non-Javanese	4 (10.3)	1 (2.6)		3 (16.7)	1 (4.8)	
Religion						
Islam	38 (97.4)	32 (82.1)	.05	18 (100.0)	20 (95.2)	.99
Other	1 (2.6)	7 (17.9)		0	1 (4.8)	
Marital status						
Men						
Married	3 (14.3)	21 (100)	<.001	2 (16.7)	1 (11.1)	.99
Never married	18 (85.7)	0		10 (83.3)	8 (88.9)	
Women						
Married	1 (5.6)	18 (100)	<.001	1 (16.7)	0	.33
Never married	17 (94.4)	0		5 (83.3)	12 (100)	
Educational level*						
Men						
Illiterate	2 (9.5)	1 (4.8)	.55	0	2 (22.2)	.08
Elementary school	2 (9.5)	2 (9.5)		2 (16.7)	0	
High school	16 (76.2)	14 (66.7)		10 (83.3)	6 (66.7)	
Higher education	1 (4.8)	4 (19.0)		0	1 (11.1)	
Women						
Illiterate	2 (11.1)	0	.52	1 (16.7)	1 (8.3)	.71
Elementary school	1 (5.6)	0		0	1 (8.3)	
High school	12 (66.7)	14 (77.8)		5 (83.3)	7 (58.3)	
Higher education	3 (16.7)	4 (22.2)		0	3 (25.0)	
Occupation						
Men						
Unemployed	8 (38.1)	1 (4.8)	.06	5 (41.7)	3 (33.3)	.92
Labor	7 (33.3)	9 (42.9)		3 (25.0)	4 (44.4)	
Self-employed	3 (14.3)	4 (19.0)		2 (16.7)	1 (11.1)	
Staff	3 (14.3)	7 (33.3)		2 (16.7)	1 (11.1)	
Women						
Unemployed	5 (27.8)	10 (55.6)	.14	3 (50.0)	7 (58.3)	.54
Labor	1 (5.6)	1 (5.6)		1 (16.7)	0	
Self-employed	4 (22.2)	0		0	0	
Staff	8 (44.4)	7 (38.9)		2 (33.3)	5 (41.7)	

Note. DSD = disorder of sex development. Men and women with DSDs were assessed according to the gender in which they were living at the time of the study.

*The highest completed education level.

[a]Comparison between the study group and the matched control group.

[b]Comparison between the treated and the untreated groups of adults with DSDs.

Table 3. *Results of Principal Component Analysis and Reliability Analysis*

Measures (Indonesian Version)	*N*	*N* of Components (% of total variance explained)	Components and Item Distributions	Cronbach's α
Body Image Scale (BIS)				
Woman version[a]	161	1 (53.4)	General body image (all items)	.97
			Sex-related body parts: items 6, 9, 14, 22, 24	.86
Man version[a]	82	1 (66.7)	General body image (all items)	.98
			Sex-related body parts: items 6, 9, 14, 18, 22, 27	.93
Female Sexual Distress Scale—Revised (FSDS-R)[b]	185	2 (55.1)	Affective sexual distress (items 1, 2, 3, 4, 5, 11, 12)	.91
			Cognitive sexual distress (items 6, 7, 8, 9, 10, 13)	.85
			Overall sexual distress (all items)	.93
Female Sexual Functioning Index (FSFI)[c]	94	6 (66.7)	Sexual desire (items 1, 2)	.79
			Arousal/lubrication frequency (items 3, 4, 5, 6, 7, 9)	.81
			Difficulty in lubrication and orgasm (items 8, 10, 12)	.90
			Orgasm frequency and pleasure (items 11, 13)	.69
			Satisfaction with sexual life (items 14, 15, 16)	.91
			Pain (items 17, 18, 19)	.89
Male Sexual Health Questionnaire (MSHQ)[d]	41	4 (53.8)	Erection and ejaculation frequency (items 1, 2, 3, 5, 6, 7, 11, 21)	.77
			Erection and ejaculation dysfunction (items 4, 8, 9, 10, 12, 20, 24)	.58
			Satisfaction with sexual life (items 13–18)	.89
			Sexual desire & activity (19, 22, 23, 25)	.61
Kinsey Rating Scale of Adult Sexual Orientation[e]	210 (142 women; 68 men)	1 (96.6)	All items	.99

[a]The BIS was originally developed for assessing body image in transgender persons. Three domains of sexual characteristics were measured in the original scale: primary, secondary, and neutral (hormonally unresponsive). The test-retest reliability of the original BIS showed good consistency (Lindgren & Pauly, 1975). Our findings correspond to one component of general body image. As disorders of sex development conditions might impact body image, in this study we included primary sexual characteristics for further comparison analysis after evaluating internal consistency.
[b]Originally, the FSDS-R consisted of one component measuring overall sexual distress using a total score. The Cronbach's alpha of the original scale was .86 (DeRogatis et al., 2008). Our findings demonstrated two components of sexual distress: cognitive and affective components of sexual distress. In this study, we included overall sexual distress for further comparison analysis after evaluating internal consistency.
[c]The Cronbach's alphas of the original FSFI scales were as follows: Desire: $\alpha = .92$; Arousal: .95; Lubrication: $\alpha = .96$; Orgasm: $\alpha = .96$; Sexual Satisfaction: $\alpha = .89$; Pain: $\alpha = .94$ (Rosen et al., 2000). In our study, items measuring frequency and difficulties in lubrication and orgasm were loaded on two different components. Due to lack of sexual activity and absence of a partner during the past four weeks, we applied items of sexual desire (items 1 and 2) and satisfaction with overall sexual life (item 16) for further analysis.
[d]The Cronbach's alphas of the original MSHQ scales were as follows: Erection: $\alpha = .81$; Ejaculation: $\alpha = .90$; Sexual Satisfaction: $\alpha = .90$ (Rosen et al., 2004). In our study, items measuring frequency and difficulties in erection and ejaculation functioning were loaded on two different components.
[e]Statistical analysis using sum score was inapplicable because the majority of patients reported lack of sexual experiences. Subsequently, a comparison analysis was performed on each item.

Sexual Functioning

Table 6 summarizes the findings on sexual functioning across groups.

Female sexual functioning (FSFI). In line with marital status (Table 2), only one woman with a DSD reported that she had been sexually active in the past four weeks, whereas all matched control women reported they had been sexually active during that period. Women with DSDs reported no differences from the matched control women in terms of sexual desire. They reported less

Table 4. *Body Image Scale: Global Score of Body Image Across Groups*

Subjects	Adults with DSDs	Matched Controls	p^a	Treated Patients	Untreated Patients	p^b
Women	$n = 18$	$n = 18$	.06	$n = 6$	$n = 12$	.99
	3 (2–3)	2 (1–3)		2.5 (2–3)	3 (2–3)	
Men	$n = 21$	$n = 21$	.59	$n = 12$	$n = 9$	.29
	2 (1–3)	3 (1–3)		3 (1–3)	2 (1–3)	

Note. DSD = disorder of sex development. Data are presented in median and range. A higher value indicates greater dissatisfaction with the body parts. The Mann-Whitney U-test was applied. Men and women with DSDs were assessed according to the gender in which they were living at the time of the study. A 5-point response mode was applied: *Very satisfied* (1), *Satisfied* (2), *Neutral* (3), *Dissatisfied* (4), and *Very dissatisfied* (5). Adopted from the Body Image Scale (BIS) from Lindgren and Pauly (1975).
[a]Comparison between the study group and the matched control group.
[b]Comparison between the treated and the untreated group of patients with DSDs.

Table 5. *Body Image Scale: Dissatisfaction and Satisfaction With Sex-Related Body Parts*

Sex-Related Body Parts	Dissatisfaction		Satisfaction		
	Adults with DSDs	Match Controls	Adults with DSDs	Match Controls	*p*
Women	*n* = 18	*n* = 18	*n* = 18	*n* = 18	
Ovaries/uterus	7 (38.9)	0	4 (22.2)	16 (88.9)	< .001
Breasts	6 (33.4)	0	6 (33.3)	14 (77.8)	.02
Voice	4 (22.3)	0	9 (50.0)	13 (72.2)	.37
Vagina	4 (22.2)	0	7 (38.9)	15 (83.4)	.05
Clitoris	2 (11.1)	0	7 (38.9)	13 (72.2)	.11
Men	*n* = 21	*n* = 21	*n* = 21	*n* = 21	
Penis	17 (81.0)	0	1 (4.8)	14 (66.7)	< .001
Scrotum	12 (57.2)	0	6 (28.6)	10 (47.6)	< .001
Testes	10 (47.6)	0	5 (23.8)	10 (47.6)	.004
Facial hair	4 (19.0)	2 (9.5)	8 (38.1)	6 (28.6)	.62
Body hair	3 (14.3)	1 (4.8)	10 (47.6)	8 (28.1)	.40
Breasts	4 (19.1)	0	10 (47.6)	10 (47.6)	.30

Note. DSD = disorder of sex development. Data are presented as *n* (%). Dissatisfaction responses included all "dissatisfied" and "very dissatisfied" responses on the Body Image Scale (BIS); satisfaction responses included all "satisfied" and "very satisfied" responses. The Fisher's Exact test was applied.

satisfaction with their overall sexual lives than control women did. In response to the item measuring satisfaction with the overall sex life, only two (11.1%) women with DSDs reported being satisfied compared to 88.9% of matched control women. Treated and untreated women with DSDs did not differ in sexual desire or satisfaction with sexual life.

Female sexual distress (FSDS-R). Women with DSDs reported greater affective and cognitive sexual distress than did matched control women; 72% of women with DSDs reported sexual distress (above the cutoff point of 11%), whereas among matched control women this percentage was 11% ($p < .001$). No differences in sexual distress were found between treated and untreated women with DSDs, although the median values of the FSDS-R exceed the cutoff score (Table 6).

Male sexual functioning (MSHQ). Men with DSDs reported lower frequencies of erections and ejaculations and less satisfaction with their sex lives than matched control men did, but they did not report better functioning

Table 6. *Sexual Functioning Across Groups (Data on FSFI, FSDS-R, and MSHQ)*

Measures	Adults with Disorders of Sex Development *Mdn* (min-max)	Matched Controls *Mdn* (min-max)	*p*[e]	Treated Patients *Mdn* (min-max)	Untreated Patients *Mdn* (min-max)	*p*[f]
FSFI[a]	*n* = 18	*n* = 18		*n* = 6	*n* = 12	
Sexual desire (sum of items 1 and 2)	4 (2–8)	5.5 (3–8)	.13	4 (2–8)	4 (2–8)	.79
Satisfaction with sexual life (item 16)	0 (0–5)	5 (2–5)	<.001	0 (0–5)	0 (0–0)	.09
FSDS-R[b]						
Overall sexual distress	19.5 (0–49)	2 (0–21)	<.001	15.5 (0–30)	20 (0–49)	.42
Affective sexual distress[c]	12.9 (0–30.4)	0 (0–15.2)	<.001	10.5 (0–15.2)	12.9 (0–30.4)	.39
Cognitive sexual distress	8 (0–24)	1 (0–8)	<.001	9 (0–17)	8 (0–24)	.73
MSHQ[d]	*n* = 21	*n* = 21		*n* = 12	*n* = 9	
Erection and ejaculation frequency[a]	32 (13–40)	37 (26–40)	.03	36.5 (18–40)	31 (13–38)	.05
Erection and ejaculation dysfunction[d]	27 (15–31)	29 (24–31)	.33	27 (15–31)	27 (15–31)	.51
Satisfaction with sexual life[a]	18 (13–27)	24 (17–30)	<.001	18 (13–27)	18 (14–24)	.85
Sexual desire and activity[a]	11 (9–20)	13 (8–17)	.54	11 (9–15)	12 (9–20)	.92

Note. Men and women with disorders of sex development were assessed according to the gender in which they were living at the time of study. FSFI = Female Sexual Functioning Index; FSDS-R = Female Sexual Distress Scale—Revised; MSHQ = Male Sexual Health Questionnaire.

[a]Consists of 19 items with 5- or 6-point response mode. Score range: 0–5 or 1–5. A higher value indicates better sexual functioning.

[b]Consists of 13 items with a 5-point response mode: *Never* (0), *Seldom* (1), *Sometimes* (2), *Often* (3), and *Always* (4). A higher value indicates greater sexual distress.

[c]Sum scores multiplied by 1.17 for equal comparison to cognitive-related distress.

[d]Consists of 25 items with a 5- and 6-point response mode. Score range: 0–5 or 1–5. A higher value indicates better sexual functioning, except in Erection and Ejaculation Dysfunction, where a higher value indicates a higher degree of sexual dysfunction.

[e]Comparison between the study group and the matched control group.

[f]Comparison between the treated and the untreated groups of patients with disorders of sex development.

Table 7. *Response Distribution on the Kinsey Rating Scale of Sexual Orientation*

Items and Response Categories	Adults with Disorders of Sex Development	Matched Controls	p^a	Treated Patients	Untreated Patients	p^b
Living as women	$n=18$	$n=18$		$n=6$	$n=12$	
1. Falling in love	*n* (%)	*n* (%)		*n* (%)	*n* (%)	
Exclusively homosexual	2 (11.1)	0	.04	0	2 (16.7)	.85
Exclusively heterosexual	13 (72.2)	18 (100.0)		5 (83.3)	8 (66.7)	
Nonexclusive orientation	1 (5.6)	0		0	1 (8.3)	
No experience	2 (11.1)	0		1 (16.7)	1 (8.3)	
2. Sexual relationships						
Exclusively homosexual	1 (5.6)	0	<.001	0	1 (8.3)	.99
Exclusively heterosexual	3 (16.7)	15 (83.3)		1 (16.7)	2 (16.7)	
Nonexclusive orientation	0	0		0	0	
No experience	14 (77.8)	3 (16.7)		5 (83.3)	9 (75.0)	
3. Romantic fantasy						
Exclusively homosexual	2 (11.1)	0	.17	0	2 (16.7)	.64
Exclusively heterosexual	11 (61.1)	16 (88.9)		5 (83.3)	6 (50.0)	
Nonexclusive orientation	1 (5.6)	0		0	1 (8.3)	
No experience	4 (22.2)	2 (11.1)		1 (16.7)	3 (25.0)	
4. Erotic fantasy						
Exclusively homosexual	2 (11.1)	0	.11	0	2 (16.70	.87
Exclusively heterosexual	10 (55.6)	16 (88.9)		4 (66.7)	6 (50.0)	
Nonexclusive orientation	1 (5.6)	0		0	1 (8.3)	
No experience	5 (27.8)	2 (11.1)		2 (33.3)	3 (25.0)	
5. Self identification						
Exclusively homosexual	0	0	.49	0	0	.99
Exclusively heterosexual	16 (88.9)	18 (100.0)		6 (100)	10 (83.3)	
Nonexclusive orientation	1 (5.6)	0		0	1 (8.3)	
No experience	1 (5.6)	0		0	1 (8.3)	
Living as men	$n=21$	*n=21*		$n=12$	$n=9$	
1. Falling in love						
Exclusively homosexual	0	0	.11	0	0	.99
Exclusively heterosexual	20 (95.2)	17 (81.0)		11 (91.7)	9 (100.0)	
Nonexclusive orientation	0	4 (19.0)		0	0	
No experience	1 (4.8)	0		1 (8.3)	0	
2. Sexual relationships						
Exclusively homosexual	0	0	.28	0	0	.99
Exclusively heterosexual	14 (66.7)	17 (81.0)		8 (66.7)	6 (66.7)	
Nonexclusive orientation	0	1 (4.8)		0	0	
No experience	7 (33.3)	3 (14.3)		4 (33.3)	3 (33.3)	
3. Romantic fantasy						
Exclusively homosexual	0	0	.23	0	0	–
Exclusively heterosexual	21 (100.0)	18 (85.7)		12 (100.0)	9 (100.0)	
Nonexclusive orientation	0	1 (4.8)		0	0	
No experience	0	2 (9.5)		0	0	
4. Erotic fantasy						
Exclusively homosexual	0	0	.99	0	0	.99
Exclusively heterosexual	20 (95.2)	20 (95.2)		11 (91.7)	9 (100.0)	
Nonexclusive orientation	0	0		0	0	
No experience	1 (4.8)	1 (4.8)		1 (8.3)	0	
5. Self identification						
Exclusively homosexual	0	0	.99	0	0	.17
Exclusively heterosexual	19 (90.5)	20 (95.2)		12 (100.0)	7 (77.8)	
Nonexclusive orientation	2 (9.5)	1 (4.8)		0	2 (22.2)	
No experience	0	0		0	0	

Note. Men and women with disorders of sex development were assessed according to the gender in which they were living at the time of study. Initially, a 7-point scale of response mode was applied, ranging from *Exclusively homosexual* to *Exclusively heterosexual*. However, sum scores could not be obtained due to participants' lack of sexual experiences. To enable a proper statistical analysis, participant responses were categorized into four groups: *Exclusively homosexual, Exclusively heterosexual, Nonexclusive orientation*, and *No experience*.

[a]Comparison between the patient and the matched control groups.

[b]Comparison between the treated and the untreated groups of patients with disorders of sex development. Fisher's Exact test was applied.

in erections and ejaculations, lower sexual desire, or less sexual activity (Table 6). Men with DSDs who had received treatment reported higher frequencies of erections and ejaculations than untreated men with DSDs; however, they did not report better functioning in erections and ejaculations, greater satisfaction with their sex lives, higher sexual desire, or more sexual activity than untreated men with DSDs did. Two out

of four married men with DSDs reported an inability to penetrate. This made them feel less capable of satisfying their wives.

Sexual relationships. A total of 16 women and 20 men with DSDs reported that they had been "in love." For this subgroup, 14 women (77.7%) and 7 men (35%) had never had romantic relationships (Table 7). During the interviews with patients, it appeared that fear of rejection by a partner due to infertility was the major reason they did not pursue romantic relationships. Women with DSDs also appeared to be emotionally sensitive and preferred to delay or refuse to engage in romantic relationships to avoid the possibility of a partner's rejection. One woman and three men with DSDs had preferred to end their dating relationships without disclosing their infertility. Three married men with DSDs noted the importance of family support in helping them live with DSDs and disclosed infertility to their spouses. Their spouses verbalized acceptance of their DSD. Another man with DSDs had intended to marry a single woman and instead married a widow with children from her previous marriage. This helped him reduce his anxiety that he would not be able to satisfy his spouse because of his inability to penetrate and to make her pregnant. When one married woman with DSDs, who received emotional support from parents and siblings, finally disclosed her infertility to her husband the result was divorce—after she declined his request for polygamy.

Sexual Orientation

Table 7 shows that more patients than controls had no sexual experience: 9 patients (23.1%) reported they had never had romantic/erotic fantasies, and 21 patients (53.8%) never engaged in sexual relations because they considered it sinful or taboo. Generally, more women with DSDs reported nonexclusive or exclusive homosexual orientation than matched control women with respect to falling in love and sexual relationships. In contrast, men with DSDs were similar to the matched control men with respect to their sexual orientation, favoring an exclusively heterosexual focus.

All four patients with 46,XX karyotype and congenital adrenal hyperplasia (CAH) reported exclusively heterosexual orientations: two patients with 46,XX karyotype and CAH living as men reported they felt sexually attracted to women only; two patients with 46,XX karyotype and CAH living as women reported they felt sexually attracted to men only. Nonexclusive heterosexual orientation was reported by 6 of 14 untreated patients with the 46,XY karyotype, living as men or women. Among these patients, one man with an androgen action disorder and one man with gonadal dysgenesis identified as nonexclusive heterosexual but did not report any nonexclusive heterosexual fantasies or behaviors. Both men concluded that their sexual identification could not be exclusively heterosexual because of their DSD condition. Four of nine women with 46,XY karyotype (two women with androgen action disorder, two women with gonadal dysgenesis) reported varying degrees of nonexclusively heterosexual fantasies or behaviors but identified as exclusively heterosexual.

Discussion

We studied psychosexual functioning among Indonesian adults with DSDs who had been identified and treated late in life. These patients had been raised and continued to live with ambiguous bodies and encountered barriers to seeking a mate and marrying—which, in Indonesia, is a major step toward being respected as an adult and acquiring full independence, particularly for women. Concerns about these psychosocial issues of gender and sexuality presented to the health care professionals on the Sexual Adjustment Team at Dr. Kariadi Hospital—FMDU gave rise to the study. Our major aim was to quantify these psychosexual problems in patients with DSDs and compare them to control subjects. To our knowledge, this is the first such study performed in Indonesia.

Body Image, Sexual Distress, and Sexual Functioning

Results on body image revealed that patients with DSDs, untreated or treated late in life, were dissatisfied with their sex-related body parts but not with their bodies in general. These results suggest that body ambiguity causes considerable distress in adults affected with DSDs. Early diagnosis and treatment may decrease body ambiguity during puberty and thus prevent these psychosocial consequences and improve quality of life. As stated in the consensus statement (Hughes et al., 2006), treatment of DSDs includes the entire diagnostic process; education for parents about diagnosis and treatment possibilities, surgical and hormonal; and facilitating parents and/or adult patients in making decisions with respect to whether to undergo treatment that they consider best for the individual with the DSD. Educating health care practitioners and raising public awareness of DSDs as a medical condition are essential steps toward improving the social functioning and quality of life of patients with DSDs.

Most women with DSDs had never been involved in a romantic relationship. They also reported having greater sexual distress, having fewer sexual experiences, and feeling less satisfied with their sex lives than control women. Low libido and lack of initiatives to seek a partner despite social expectancy to do so, and fear of social consequences due to infertility, probably lowered their satisfaction with their sex lives. The qualitative interviews indicated that body ambiguity induced negative thoughts and feelings in women with DSDs. Studies in Western women with DSDs also have found

problems relating to sexual desire, sexual arousal, and entering partner relationships (Gastaud et al., 2007; Köhler et al., 2012).

Treated and untreated women with DSDs reported sexual distress. The interview data suggested that their DSDs conditions and related infertility were related to this sexual distress. Fear of disclosure and possible negative consequences of disclosure on their social position (e.g., divorce or polygamy) prevented these women from entering romantic relationships. One significant consequence of this was a failure to meet the social expectation of marriage, which caused substantial distress. Western studies on psychosexual functioning in women with DSDs have also reported low desire and lack of sexual experiences, among other problems in sexual functioning (Gastaud et al., 2007; Minto, Liao, Woodhouse, et al., 2003; Szarras-Czapnik et al., 2007). These women also felt reluctant to enter sexual relationships because of the need for disclosure of their DSD condition and uncertainty about partner response, which could include outright rejection. In contrast, Western societies are less collectively driven than Indonesian society is and thus there is less pressure to marry and have children.

Previous studies reported increased erectile functioning and more frequent ejaculations among men with DSDs who had received treatment, for example, in those who underwent hypospadia corrections (Bouvattier et al., 2006; Kojima et al., 2009; Migeon et al., 2002). In our study, men with DSDs who had received hypospadia corrections reported better erectile functioning and more ejaculation than untreated men did. As we had no data on genital and sexual functioning before surgery, we had to rely on patients' self-reports. In comparison to their matched controls, men with DSDs reported lower frequencies of erection and ejaculation, but this did not influence their sexual desire and activity.

Sexual Relationships

In Indonesia, sexual relationships are legal only within marriage; premarital sex is socially unacceptable and regarded as sinful from a religious perspective. Although premarital sex does occur, as suggested by our Web-based study, very limited or no sexual experience was reported by patients with DSDs. These findings differ from prior studies reporting marital and premarital sexual experiences in men and women with DSDs (Gastaud et al., 2007; Kojima et al., 2009), indicating that culture plays a significant role in sexual behavior in individuals with DSDs.

Our study group included more men than women in established, romantic relationships. There are two explanations for this. First, men and women may use different strategies to cope with DSDs. Women with DSDs appear to be more emotionally sensitive and tend to avoid the risks of social rejection by delaying or not engaging in romantic relationships. Men with DSDs also experience distress but are more willing to enter into these types of relationships. Second, women are more subject to blame than men in terms of infertility. Pregnancy undoubtedly indicates female fertility; however, the absence of pregnancy was more often regarded as the impact of female infertility rather than male infertility. As procreation is a major reason for marriage among Indonesians, in the case of infertility, particularly among Muslims, men have more options than women: to divorce and marry another woman or to engage in polygamy. No one will blame an infertile man because he obeys the social demand to procreate and he is allowed to do so by his religious values. He might receive sympathy for being unfortunate not to have children after several marriages. His infertility remains undisclosed unless he intends to reveal it through fertility tests.

Infertility due to DSDs makes life much harder for adults. The fear of rejection leads to an unwillingness to disclose DSDs and related infertility, even among family. As a consequence, patients deal with their sadness alone. Their lack of incentive to seek a partner is often not understood, even by their own relatives who pressure them to get married and have children. Facilitating disclosure, family support, and more realistic expectations may reduce this sense of isolation, psychological distress, and level of acceptance for both patient and family. Four men in this study reported this type of family support; however, few women in the study experienced this, and one woman faced divorce when she disclosed her DSD. This may explain why men with DSDs in this study were more willing to take initiatives to seek romantic partners than did the women with DSDs.

Sexual Orientation

Two out of 20 men with DSDs identified themselves as nonexclusively heterosexual. They thought having a DSD was abnormal and therefore their sexual orientation should not be similar to people without a DSD. Nonexclusive heterosexual orientation was higher among women with DSDs than among the matched controls. Similar findings have been reported in Western studies of women with 46,XX karyotype and CAH and patients with 46,XY karyotype and partial action of and sensitivity for androgens, stressing the importance of prenatal action of androgens (Köhler et al., 2012; Meyer-Bahlburg, Dolezal, Baker, & New, 2008; Nordenstrom et al., 2010). Women with DSDs who reported various degrees of nonexclusively heterosexual orientation in fantasy or behavior did not identify themselves as nonexclusive heterosexually oriented, possibly to conform to socially acceptable norms and attitudes. This indicates that social influences are important in reporting sexual orientation among patients with DSDs living in a collectively driven society. Unfortunately, lack of published data disallows any comparison of our findings on sexual orientation to similar studies in Asian patients with DSDs or data

on homosexuality or bisexuality among the Indonesian population.

Treated and Untreated Groups Comparison

Comparison between treated and untreated groups of patients did not reveal any differences in reported (dis)satisfaction with their body parts, sexual distress, and main aspects of sexual functioning.

Despite early detection of ambiguous genitalia, for all but five patients medical help was delayed for many years as patients, parents, and medical help were not aware that medical treatment was available. Both treated and untreated groups of patients entered our medical service in adolescence or adulthood. Prior to entering our medical service, six patients had received some medical help, but proper diagnostic procedures and sufficient education on DSDs had not been conveyed. From studies on hypospadia repair, we know there is an optimal time window for treatment; corrections performed in early childhood give better urinary and sexual functioning than surgery performed after transition into adolescence (Woodhouse & Christie, 2005). The absence of differences between treated and untreated patients found in this study may be related to the fact that treatment started late. We assume that psychosexual problems such as dissatisfaction or shame for ambiguous genitals may gradually develop prior to adolescence but may intensify in puberty when the body tends to develop into an ambiguous state, visible to everyone, and making the affected person vulnerable to stigmatization. Because we could not test the impact of early treatment in childhood on psychosexual development among our patients, we are not able to assess effects of early treatment on sexual functioning and quality of life yet, but we hope we will be able to study this in the future.

Study Limitations

Prior to the study, locally validated instruments were unavailable. We performed an exploratory study first by utilizing Indonesian translations of existing instruments developed in Western countries. We were aware that application of Western measures could lead to different types of methodological problems, and we found solutions to these problems so that we could reach our goal to gain insight in psychosexual problems in late-treated Indonesian patients with DSDs. First, we carried out a pilot study to find out the applicability of the measures. We then noted that it would be better to apply questionnaires orally to avoid misunderstandings caused by illiteracy or unfamiliarity with Bahasa Indonesia. Second, we compared the patient data with those of matched controls, and finally we applied a Web-based survey of a large group of healthy Indonesians to carry out reliability analyses and scale construction in the Indonesian population. Our analysis showed that the Indonesian translations had many similarities with the original measures and also had good psychometric properties. Therefore, we assumed that it was valid to apply the questionnaires in our study. However, it is true that the Web-based participants differed from the patient and matched control groups in socioeconomic status; these group differences may limit the applicability of the validity and reliability measures to the experimental subjects.

Another limitation is that this study included different DSD diagnoses with a small number of patients in each diagnostic group. This kept us from performing a more detailed comparison between patients with 46,XX karyotype and CAH or 46,XY karyotype and androgen insensitivity syndrome (AIS) or gonadal dysgenesis (GD) who had been raised as different genders. *Disorders of sex development* is an umbrella term for many different anomalies that cover a large variety of underlying biological mechanisms leading to specific types of conditions. Part of the psychological distress is probably related to the specific, underlying biological mechanism of each type of DSD, so that in studies with small groups of patients only those psychological problems that are most significant and shared by patients in all diagnostic groups will appear.

Our patients had never received medical attention—or had received little medical attention—before they entered our hospital. We therefore were able to explore psychosocial and psychosexual problems faced by patients with DSDs whose bodies and minds had developed with little or no influence from medical treatments for DSDs throughout most of their lives. In the past 20 years, it has become clear that many patients with DSDs experience psychosocial and psychosexual problems that need to be addressed. Often early medical treatment has been pointed out as a source of these psychosexual problems, and some activist groups ask for delay of all childhood treatments not needed for survival. Our findings demonstrate that psychosexual problems are also present in patients who did not receive treatment and that there are many similarities with the psychosexual and psychosocial problems faced by Indonesian untreated patients and Western treated patients. These similarities in experienced psychosexual and psychosocial problems indicate that the problems are related to DSDs themselves rather than to the initiation of early medical treatment. We think the psychosocial problems with which Indonesian patients have to deal are large, due to a lack of understanding about DSDs, particularly in the community, which complicates patients' ability to cope with body ambiguity. Improvement can be reached by early diagnosis followed by comprehensive education for the parents on the diagnosis and treatment possibilities, both hormonal and surgical, so that the patient and/or parents will be able to make informed choices (Warne & Raza, 2008). The child's wishes need to be taken into account as soon as the child is able to become involved

in medical decision making. Medical treatment of DSDs is complex and should be performed only by experienced, specialized, multidisciplinary teams.

Conclusion

Having a DSD condition, being infertile, and fearing rejection caused significant distress, particularly among women. A nonexclusively heterosexual orientation in sexual attraction was more likely reported among adults with DSDs than by their matched controls. Late-treated patients experienced similar problems to untreated patients. Health practitioners should be aware of the social implications of reduced infertility and sexual functioning among adults with DSDs. Genetic counseling, patient education, and psychological counseling may provide support for patients and caregivers to discuss sexual problems and strategies for coping with conditions, ultimately facilitating greater acceptance. We recommend that primary health care providers identify patients with DSDs early in life and refer them to a specialized multidisciplinary team so adequate intervention can be provided.

As the majority of our patients had never received medical attention before they entered our hospital, we were able to study the course of development without medical treatment for the DSDs and its impact on the psychosexual and psychosocial aspects of persons with DSDs. By studying psychosexual functioning in untreated or late-treated patients, we were able to explore the problems faced by patients with DSDs whose bodies and minds developed with little or no medical interventions for their DSDs throughout most of their lives.

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