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First Adolescent Romantic and Sexual Experiences in Individuals With Differences of Sex Development/Intersex Conditions

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A B S T R A C T

Purpose: Adolescence is an important period for sexual development, including sexual debut. The purpose of this study was to assess first romantic and sexual experiences and debut age in individuals with differences of sex development (DSD/intersex) and compare these with age-matched and gender-matched population control values.
Methods: Questionnaire data on sociodemographic characteristics, romantic and sexual milestones (e.g., masturbation, dating), satisfaction with sexual life and sexual activity at follow-up, self-esteem, and feelings of femininity or masculinity were collected from 976 participants in Europe with a DSD condition. Participants were divided into six diagnostic subgroups based on their diagnostic classification: women with Turner syndrome, congenital adrenal hyperplasia, 46XY-DSD nonvirilized, and 46XY-DSD female partially virilized conditions and men with 46XY-DSD male or Klinefelter syndrome. Age-specific and gender-specific reference values were retrieved from a Dutch population sample.
Results: Individuals with DSD were less likely to reach each of the romantic and sexual milestones compared to their peers without these conditions and they were significantly older when reaching these milestones. Between clinical subgroups, individuals with Klinefelter were significantly older when reaching milestones and in the female groups and individuals with Turner were the least likely to reach milestones. Furthermore, a higher age when reaching several romantic and sexual milestones was correlated with lower self-esteem, lower satisfaction with sexual life, and lower sexual frequency at follow-up.
Discussion: Due to a difference in biopsychosocial context, individuals with DSD often experience a different and/or delayed sexual development during adolescence. Healthcare providers should be aware of these differences in adolescents with DSD and their sexual development to optimize affirmative counseling.

IMPLICATIONS AND CONTRIBUTION

Adolescence is a critical period for sexual maturation, an important biopsychosocial development. An insight into the sexual development, its biopsychosocial context, and its associations with psychosexual outcome measures is important for counseling individuals with DSD. Such counseling should aim to improve the psychosexual wellbeing of this group.

Conflicts of interest: The authors have no conflicts of interest to declare.

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Differences of sex development (DSD/intersex) encompass a group of various congenital conditions characterized by divergent chromosomal, gonadal, and/or genital sex development [1]. Some individuals prefer to denote these as intersex conditions and/or identify as intersex. As per the 2006 Chicago consensus statement, DSDs are categorized into several groups: chromosomal syndromes, including Turner syndrome (TS) and Klinefelter syndrome (KS); 46XY karyotype conditions, such as complete/partial androgen insensitivity syndrome, complete/partial gonadal dysgenesis, steroid synthesis errors, and severe hypospadias; and 46XX karyotype conditions, mainly congenital adrenal hyperplasia (CAH) [1,2]. DSDs are often diagnosed because of either the presence of ambiguous genitalia at birth or discovered after atypical physical development during puberty [1]. Some individuals with DSD may receive surgical interventions directed at gonads, internal reproductive anatomy, and/or external genitalia, sometimes in early childhood [3]. Moreover, some individuals with DSD may also require hormone replacement therapy (HRT) to induce puberty and/or secure sufficient gonadal function [4]. DSD symptoms, such as atypical sex anatomy or sex hormone levels and forthcoming medical treatments and/or psychosocial distress may have a significant impact on individuals' quality of life [5].

Sexual wellbeing, an essential part of quality of life, is a multidimensional concept and generally defined by physical, psychological, and sociocultural factors [6]. Definitions of this concept vary widely but can be generally be understood as "a state of physical, emotional, mental, and social wellbeing related to sexuality" in line with the World Health Organization definition [7]. Adolescence, a period in which changes in sexual attraction, desire, arousal, physical function, and behavior are experienced [8], is crucial for sexual development. In adolescents with DSD conditions, both biological and psychosocial factors may impact sexual development [9]. In general, timing of puberty influences sexuality onset [10,11], which may be delayed in individuals with DSD. Evidence suggests an association between prenatal exposure to androgens and the development of male-typical behavior and nonheterosexual orientation in females [9,12,13]. During adolescence, developmental differences between individuals with DSD and their peers without DSD variations can become more visible and may become more of a concern as the perceived pressure to conform to peers is typical at this stage in life [14]. Delayed or impaired pubertal development and atypical appearance can lead to psychological difficulties, including stress and low self-esteem [14], or even affect emotional and behavioral psychosexual development [15]. Learning how to accept and cope with a chronic condition during puberty can be challenging, especially when the condition has recently been diagnosed as with many individuals with DSD. Research on the sexual experience of adolescents with cerebral palsy reported a delay in gaining several romantic/sexual experiences [16]. Individuals with DSD may experience more difficulties in experimenting with and initiating sexual activities because of past genital surgeries, HRT, atypical physical appearance, low self-esteem, body dissatisfaction, and identity questions [17]. Several studies found that women with DSD have fewer sexual experiences during adolescence compared to their female peers without sex variations [14,18,19]. Pubertal development in women with TS may be postponed [20] and they tend to experience their first sexual intercourse and start a romantic relationship at a later age than female controls [18]. Adult women with CAH reported lower sexual functioning scores and were older at their sexual intercourse debut than their female peers [19]. Earlier research reported impaired sexual functioning and a high degree of social and sexual anxiety in persons with 46XY-DSD, suggesting they were less likely to engage in sexual contact with a partner and to be in a relationship [21]. No difference was found in debut age of masturbation between individuals with 46XY-DSD and female reference values, implying that masturbation, a solo sexual activity, was less likely to be influenced by these anxieties [21]. In men with KS there is evidence of delayed sexual development [22,23] and more sexual dysfunction, which may be linked to low testosterone levels [24].

Given the experiences that individuals with DSD variations may share, and the possible clinical implications for counseling and biopsychosocial treatments of adolescents with DSD, the purpose of the present study was to assess first romantic and sexual experiences (hereinafter referred to as milestones) and debut age in a large group of individuals with diverse DSD conditions in six European countries. Furthermore, we aimed to perform cross-condition and age/gender-matched control comparisons and associated data on romantic and sexual milestones with psychosexual outcome measures later in life.

Methods

Procedure

The dsd-LIFE study was a cross-sectional multicenter clinical evaluation study that took place in 14 specialized clinics in Europe. From February 2014 until September 2015, 3,217 individuals with various DSD diagnoses of 16 years and older were approached, of whom 1,040 participated in the study (36%) [2]. Data were collected through medical history taking, clinical report forms, a patient-reported outcome survey (PRO), and optional medical examinations. The PRO included standardized instruments and self-constructed items, for which iterative review was performed by patient support group representatives. All data were anonymized and reviewed at the Coordinating Centre for Clinical Studies at the Charité. Ethical approval was received at all participating centers and all participants provided informed consent. A comprehensive description of the study procedure can be found in Röhle et al. [2].

Participants

Participants were included based on a confirmed clinical and/or genetic DSD diagnosis and an age of 16 years or more. Exclusion criteria were incapability of giving consent or answering the questionnaires, being diagnosed with Mayer-Rokitansky-Küster-Hauser syndrome or nonendocrine urogenital malformations [2]. Participants with missing data for variables for the reaching of at least one romantic or sexual milestone were excluded. As a result, a total of 967 participants were included for the current analysis, of whom 670 identified as female, 285 as male, and 12 as other (e.g., inter, other gender). Participants were divided into six groups based on their diagnostic classification (for Turner, CAH, Klinefelter) and diagnostics classification combined with gender identity at time of the interview (F = female, M = male) and degree of virilization (nv = non virilized, pv = partially virilized) for those with 46XY-DSD, following previous studies [17,25,26], resulting in the following categories: Turner F, CAH F, 46XY-DSD F nv, 46XY-DSD F pv, 46XY-DSD M, and Klinefelter M. Participants who identified

their gender as other than female or male were grouped based on diagnosis with its most frequently expressed corresponding gender to reduce analytical complexity. Age-specific and gender-specific references for the outcome values were retrieved from a study in Dutch youth aged 16–24 years [27].

Measures

Sociodemographic characteristics. Data on age, diagnosis, age at diagnosis, and surgery of the sexual organs received (gonadectomy, clitoral surgery, vaginoplasty, hypospadias surgery, perinealplasty and labioplasty) were retrieved from medical history and clinical report forms. Education (low, medium, high, unknown), relationship status (partner yes/no), gender identity (female, male, open [not defined], inter [in between], other [e.g., 'human being']), and sexual orientation (androphilic, bisexual, gynephilic, other [e.g., asexual]) were collected from the PRO (multiple choice options) [2].

Romantic and sexual milestones. Questions on romantic and sexual milestones used were based on a questionnaire developed for an earlier study on CAH [28], which was based on the Dutch population study used as reference for this study [27]. Romantic and sexual milestones included the following: 'falling in love,' 'kissing with tongue,' 'dating,' 'masturbation,' 'romantic relationship,' 'genital caressing,' and 'oral sex/penetration'. For each milestone, individuals were asked if they ever experienced the milestone (yes/no) and at what age (in years).

Sexual life and satisfaction at follow-up. Data on several measures of sexual wellbeing at the time of participation were collected. Satisfaction with sexual life and sexual activity in the past 12 months was assessed by the following questions: "How satisfied are you with your sex life?" and "How satisfied are you with the frequency of your sex life?" Satisfaction was measured on a 5-point scale, from 1 (very dissatisfied) to 5 (very satisfied). These questions were also used in an earlier study on DSD [29]. Sexual activity in the past 12 months was assessed by the following question [17]: "How frequent was your sexual activity with a partner?" (I do not have sexual partner/NA, I had no sexual contact with my partner in the past 12 months/almost daily/1-2 times a week/1-2 times a month/1-2 times a year). Finally, participants were asked whether they had ever had difficulty initiating sexual contact, disliked sexual activities or had fear of sexual contact (yes/no), and whether they experienced distress from this (yes/no). These items were derived from an earlier study as well [21].

Self-esteem, feelings of femininity, or masculinity. The Rosenberg Self-Esteem Scale (RSES) was used to measure self-esteem [30]. Participants were asked to rate 10 statements on a scale from 0 (strongly agree) to 3 (strongly disagree). The RSES was reported as a sum score, where a higher score represented a higher overall self-esteem. In an earlier study in the same cohort, good psychometric reliability of the RSES was reported [31]. Experienced feelings of femininity or masculinity over the last 12 months were assessed for both psychological/emotional and physical feelings. Participants were asked how feminine or masculine they felt about their emotions and body. Answer options were scored on one of two 10-point scales (feminine/masculine), ranging from 1 (not feminine/masculine at all) to 10 (very feminine/masculine). These questions were constructed in an earlier study [2].

Statistical analysis

Some variables were recorded for the purpose of this analysis. The variable surgery of the sexual organs was recoded into yes/no based on the sum of all variables of the specific surgery (gonadectomy, clitoral surgery, vaginoplasty, hypospadias surgery, perinealplasty, and labioplasty), in line with an earlier study [32]. For experienced psychological and physical femininity/masculinity feelings, the mean score matching the gender identity of the participant was taken. If gender identity was other than female or male and participant answers contained both feminine and masculine feelings, the mean of the femininity and masculinity scores was calculated.

Sociodemographic characteristics were described using medians (25–75 IQR) for non-normally distributed parameters and frequencies (%). Continuous data were compared by Kruskal–Wallis tests, frequencies by Chi-squared tests, and frequencies with cell counts $n < 5$ were compared by the Monte Carlo exact test, effect sizes were measured with Cramer's *V*. The reaching of romantic and sexual milestones was subdivided per age group and DSD subgroup, described using frequencies (%), and compared to age-matched control values [27]. Debut ages per milestone were normally distributed and analyzed descriptively using means (standard deviation). Means of debut ages per milestone of participants with DSD were compared to control values using one-sample *t*-tests. Similarly, means of gender-specific DSD groups were compared with gender-matched control values. One-way analysis of variance was used to assess cross-condition comparisons per milestone. To examine the association between debut age of romantic and sexual milestones and psychosexual outcome measures, a correlation analysis was performed. Only participants who reached the particular romantic or sexual milestone were included for these analyses. All statistical analyses were performed with SPSS statistics, version 26. p values $< .05$ were considered statistically significant.

Results

Background characteristics

Among the 967 participants included for analysis, there were 298 participants diagnosed with TS, 214 with CAH, 104 with 46XY-DSD F nv, 64 with 46XY-DSD F pv, 83 with 46XY-DSD M, and 206 with KS. Participant characteristics are shown in Table 1. Participants in the 46-XY-DSD M group were the youngest at participation (median = 22 years) and least likely to be in a current relationship (28.9%), whereas participants in the Klinefelter group were the oldest (median = 38 years) and most likely to be in a relationship (65%). Participants with TS or KS were less likely to have undergone surgery of the sexual organs in comparison to the other groups (7% resp. 6.8%).

Romantic and sexual milestones

Reached milestones and debut age. Reached romantic and sexual milestones of all participants with DSD versus age-specific control values are displayed in Figure 1. Reached milestone frequencies subdivided by clinical DSD subgroups versus

Table 1
Sociodemographic characteristics by group

	Turner F (n = 298)	CAH F (n = 214)	46XY-DSD F nv (n = 104)	46XY-DSD F pv (n = 62)	46XY-DSD M (n = 83)	Klinefelter M (n = 206)	Test statistics
Age at diagnosis							
Median in years [25–75 IQR]	10 [5–14]	0 [0–3]	15 [11–16.5]	1 [0–12]	0 [0–1]	23 [15–32]	H(5) = 326,613, $p < .001$[a]
Age at participation							
Median in years [25–75 IQR]	29 [21–42.3]	29 [21–38]	27 [22–41]	26 [20.8–32]	22 [18–29]	38 [28–51]	H(5) = 91.960, $p < .001$[a]
Gender identity							
Female (%)	298 (100)	210 (98.1)	101 (97.1)	60 (96.8)	0	1 (0.5)	$p < .001$[b]
Male (%)	0	4 (1.9)	0	0	81 (97.6)	200 (97.1)	V = 0.496
Open (%)	0	0	1 (1)	1 (1.6)	0	3 (1.5)	
Inter (%)	0	0	1 (1)	1 (1.6)	2 (2.4)	2 (1)	
Other (%)	0	0	1 (1)	0	0	0	
Education							
Low (%)	45 (15.1)	40 (18.7)	11 (10.6)	11 (17.7)	25 (30.1)	59 (28.6)	$p < .001$[b]
Medium (%)	137 (46)	101 (47.2)	44 (42.3)	24 (38.7)	37 (44.6)	100 (48.5)	V = 0.141
High (%)	96 (32.2)	52 (24.3)	44 (42.3)	24 (38.7)	19 (22.9)	29 (14.1)	
Unknown (%)	20 (6.7)	21 (9.8)	5 (4.8)	3 (4.8)	2 (2.4)	18 (8.7)	
Relationship status partner (%)	140 (47.1)	94 (44.1)	48 (46.2)	32 (51.6)	24 (28.9)	134 (65.0)	X^2 (5) = 36.024, $p < .001$[c] V = 0.197
Sexual orientation (%)							
Androphilic	229 (78.7)	148 (70.1)	84 (84)	46 (75.4)	2 (2.5)	9 (4.5)	$p < .001$[b]
Bisexual	5 (1.7)	8 (3.8)	5 (5)	2 (3.3)	1 (1.3)	12 (6.1)	V = 0.466
Gynephilic	7 (2.4)	31 (14.7)	4 (4)	8 (13.1)	73 (92.4)	163 (82.3)	
Other	50 (17.2)	24 (11.4)	7(7)	5 (8.2)	3 (3.8)	14 (7.1)	
Surgery sexual organs (%)	21 (7)	153 (71.5)	81 (77.9)	58 (93.5)	78 (94)	14 (6.8)	X^2 (5) = 545,756 $p < .001$[c] V = 0.751

CAH = congenital adrenal hyperplasia; DSD = differences of sex development; F = female; M = male; nv = non virilized; pv = partially virilized.
[a] Kruskal–Wallis test.
[b] Monte Carlo exact test.
[c] Chi-squared test.

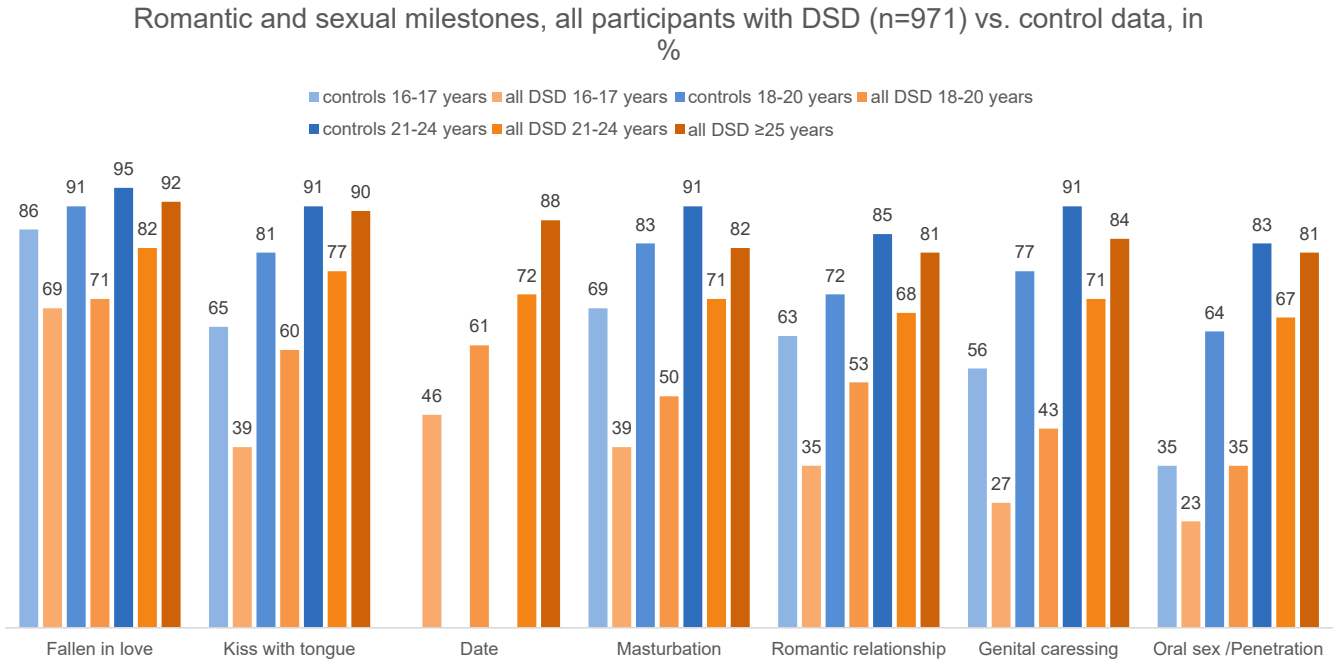

Figure 1. Reaching of romantic and sexual milestones frequency in % subdivided by age groups. DSD = differences of sex development. All DSD: 16–17 years (n = 83), 18–20 years (n = 130), 21–24 years (n = 129), and ≥ 25 years (n = 629).

age-specific control groups can be found in the Appendix (Figures A1–A6). There were no reference values on reaching the milestone 'dating' available. Every romantic and sexual milestone was reached by a majority of the study participants. Also, in older age groups more individuals had reached the milestones. Sexual milestones with a partner were less frequently reached than the more casual or solo ones. Figure 1 shows individuals with DSD were less likely to have reached each of the romantic and sexual milestones compared to the controls in all age groups. Even at the age of 25 years and more, individuals with DSD were less likely to have reached each of the romantic and sexual milestones compared to controls aged between 21 and 24 years. However, the difference generally decreased in older age groups. Table 2 shows sexual milestones and mean age at debut of all participants with DSD (total and subgroups) and controls. No control values were available for debut ages of 'falling in love,' 'dating,' and 'romantic relationship'. All participants with DSD together had a significantly higher debut age at every milestone compared with the control group. 'Genital caressing' was the milestone with the largest difference in debut age between individuals with DSD and controls (19.1 years vs. 16.2 years).

In the specific DSD subgroups, men with KS differed least with the control group in reaching romantic and sexual milestones. They were, however, significantly older than male controls and other DSD subgroups when reaching these. Furthermore, the KS subgroup consisted of the oldest participants. Despite a lesser overall reaching of all milestones, men with 46XY-DSD had no significant difference in debut age compared to their male controls. Men with 46XY-DSD and men with KS were more likely to masturbate compared to women with DSD. Women with TS and 46XY-DSD pv were least likely to masturbate. Debut ages for 'masturbation' were not different in all women with DSD compared with female controls. In the female groups, women with TS were less likely to reach all romantic and sexual milestones and they were significantly older when reaching many of the romantic and sexual milestones compared with their female controls and the other DSD subgroups.

Correlation between debut age of romantic and sexual milestones and other variables

Correlations between debut age of romantic and sexual milestones and satisfaction with sexual life and sexual activity at follow-up, occurrence of sexual problems, and self-esteem are shown in Table 3. Debut ages of romantic and sexual milestones involving a partner were negatively correlated with satisfaction with sexual life and sexual frequency, implying that a higher debut age was associated with lower sexual satisfaction and lower frequency. The sexual problems 'difficulty with initiating/seeking sexual contact' and 'fear of sex' were associated with a higher debut age of sexual milestones that involved a partner. Higher self-esteem was correlated with a younger age when falling in love for the first time or the first date. 'Falling in love' and 'dating' were negatively correlated with psychological and physical feelings of femininity/masculinity, meaning that a lower debut age was associated with feeling more feminine or more masculine psychologically and physically (i.e., in congruence with their experienced gender). Finally, none of the psychosexual outcome measures or sexual wellbeing measures were associated with reaching the solo sexual milestone 'masturbation'.

Discussion

In the present study, we examined first romantic and sexual experiences and debut age of individuals with various DSD conditions, performed cross-condition and age/gender-matched control comparisons, and associated these with psychosexual outcome measures later in life. Every romantic and sexual milestone was reached by the majority of individuals with DSD. However, each of the romantic and sexual milestones was less frequently reached in individuals with DSD compared to the reference values in every age group. In all DSD subgroups milestones with a partner were less often reached with increasing intimacy, similar to the control group. These results are consistent with studies showing fewer sexual experiences in adolescents with DSD [14,20,21,33]. As the normative pressure is significant during adolescence, and therefore feelings of not wanting to feel different from peers are emphasized, individuals

Table 2
Romantic and sexual milestones and age at debut per DSD subgroup, mean age in years (SD)

	Turner F (n = 298)[a]	CAH F (n = 214)[a]	46XY-DSD F nv (n = 104)[a]	46XY-DSD F pv (n = 62)[a]	46XY-DSD M (n = 83)[b]	Klinefelter M (n = 206)[b]	DSD all[c]	Control all[d]	Control F	Control M
Falling in love (n = 703)	16.2 (4.6)	16.0 (4.6)	14.7 (4.4)	15.9 (4.8)	14.4 (3.5)	16.6 (6.8)	**15.9 (5.2)***	-	-	-
Kiss with tongue (n = 640)	**17.6 (4.6)*****	**16.7 (4.6)*****	**16.0 (3.7)****	**16.5 (5.2)***	14.9 (4.3)	**19.1 (8.1)*****	**17.3 (5.7)*****	**15.4*****	14.6	15.8
Date (n = 627)	18.5 (4.8)	17.2 (4.1)	16.6 (3.2)	16.6 (3.4)	15.5 (2.3)	18.3 (6.1)	**17.6 (4.7)***	-	-	-
Masturbation (n = 453)	16.9 (5.9)	15.4 (4.9)	16.0 (6.0)	18.8 (6.1)	13.6 (2.5)	**15.0 (6.8)****	**15.6 (5.9)****	**14.4*****	16.2	13.3
Romantic relationship (n = 606)	19.3 (4.8)	18.4 (5.6)	18.2 (4.5)	18.1 (5.4)	17.1 (3.3)	20.0 (6.8)	**18.9 (5.5)***	-	-	-
Genital caressing (n = 572)	**19.9 (5.3)*****	**18.0 (4.1)*****	**18.2 (3.8)*****	**19 (4.6)*****	17.7 (4.3)	**20.2 (7.8)*****	**19.1 (5.6)****	**16.2*****	16.1	16.3
Oral sex/Penetration (n = 557)	**20.6 (5.4)*****	**18.9 (5.2)****	**18.8 (3.5)****	**19.6 (4.9)***	18.7 (3.6)	**21.1 (7.4)*****	**19.9 (5.7)****	**17.9*****	17.5	18.2

CAH = congenital adrenal hyperplasia; DSD = differences/disorders of sex development; F = female; M = male; nv = non virilized; pv = partially virilized.
Statistically significant differences in bold; *$p < .05$, **$p < .01$, ***$p < .001$.
[a] DSD female versus control female tested for significance.
[b] DSD male versus control male tested for significance.
[c] Differences between DSD subgroups tested for significance.
[d] DSD all versus control all tested for significance.

Table 3
Correlation romantic and sexual milestones and age at debut and psychosexual outcome measures at follow-up

Variables	Fallen in love (age)	Kiss with tongue (age)	Date (age)	Masturbation (age)	Romantic relationship (age)	Genital caressing (age)	Oral sex/ Penetration (age)
Satisfaction with sexual frequency	0.06	−0.06	−0.05	−0.05	−0.06	**−0.09***	**−0.09***
Satisfaction with sex life in general	0.03	**−0.10****	−0.07	−0.08	**−0.08***	**−0.11***	**−0.10***
Sexually active with partner (12 months)	0.05	−0.06	−0.04	−0.06	−0.02	−0.05	**−0.08***
Sex problem: difficulty initiating/seeking sexual contact (encounter)	0.03	**0.11****	**0.11****	0.04	**0.17*****	**0.17*****	**0.16****
Sex problem: dislike sex (encounter)	−0.02	0.01	0.01	0.04	−0.07	0.02	−0.02
Sex problem: fear sex (encounter)	−0.003	0.06	0.03	0.02	0.07	**0.09***	**0.11****
Self-esteem (RSES sum)	**−0.10***	−0.08	**−0.12****	−0.03	−0.07	**−0.09***	−0.08
Feminine/masculine psychologically	**−0.09***	−0.06	**−0.12****	−0.01	0.08	−0.04	−0.06
Feminine/masculine physically	**−0.09***	−0.05	**−0.11****	0.01	−0.07	−0.07	**−0.11***

RSES = Rosenberg Self-Esteem Scale.
Statistically significant differences in bold; *$p < .05$, **$p < .01$, ***$p < .001$.

with DSD could start to struggle more with their condition. Insecurity about physical appearance or genital anatomy or fear to tell a potential sexual partner about the DSD condition could lead to avoidance of sexual contact [14,15]. However, reduced sexual activity during adolescence and adulthood could be both a source and a result of sexual anxiety in individuals with DSD. Moreover, individuals with DSD were significantly older at their debuts of kissing with tongue, masturbation, genital caressing, and oral sex/penetration than their peers of the general population. Later sexual debut may not be problematic in itself; however, there could be experienced barriers for adolescents with DSD to engage in sexual activities. Early pubertal maturation has been associated with earlier and more advanced sexual behavior [11], while in individuals with DSD, development of secondary sex characteristics may be delayed or absent [4]. HRT can be needed to initiate pubertal development which may result in later sexual engagement as well [14]. Psychical differences between individuals with DSD and their peers can become more apparent during puberty and may suddenly become a source of concern [14]. These concerns of feeling different may result in anxiety and social isolation, which subsequently may lead to fewer opportunities to learn about sex from peers and to engage in sexual experimentation [34]. Dealing with a chronic condition during puberty could also be a reason for delayed sexual activity. Earlier research in adolescents with cerebral palsy reported higher debut ages of romantic and sexual activities with a partner as well [16]. Other research found that adolescents with more severe physical disabilities were less likely to have experienced sexual intercourse in early adulthood compared with those with less severe or without disabilities [35]. A last finding in the present study included that more men with DSD had reached the milestone masturbation compared to women with DSD, which is in line with gender differences observed in youth of the general population [27].

Individuals with a chromosomal variation, KS, and TS were significantly older than the controls when reaching each of the romantic and sexual milestones, with the exception of masturbation in individuals with KS [18,22]. Moreover, women with TS had the highest debut ages of all DSD subgroups. Delayed sexual debut in women with TS and men with KS compared to the general population is in line with earlier findings [18,23]. These delays could partly be explained by the neurobehavioral components associated with these syndromes. Men with KS tend to have more difficulty in psychosocial and interpersonal functioning [36] and women with TS are described to be more contact avoidant on average [18,37]. Another contributory cause to the delay in sexual experiences in women with TS may be postponed pubertal development [20]. A study reported that women with TS who had a spontaneous puberty onset had an earlier sexual debut [38]. A biological factor that could be of influence on delayed sexual development in men with KS can be a hypoactive sexual desire as a result of underlying hypogonadism [24]. Furthermore, men with 46XY-DSD were less likely to reach each of the milestones compared to the control group; however, there were no significant differences in debut age for these milestones. These findings could be (partly) explained by the fact that this group was the youngest group at participation. An earlier dsd-LIFE study already reported that men with 46XY-DSD had more difficulty initiating or seeking sexual contact in comparison to the other DSD subgroups [17]. In prior research, women with complete androgen insensitivity syndrome (CAIS; nonvirilized) were younger when experiencing first sexual intercourse than individuals with other 46XY-DSD conditions [21]. However, these women were less satisfied with their sexual life and more often express physical and psychological problems with it, whereas women with partial androgen insensitivity syndrome (partially virilized) were more often dissatisfied with their genitals [17]. A study on women with CAH emphasized the importance of supportive and satisfying relationships with partners [39]. Being involved in a romantic relationship with a trusted partner may provide adolescents with DSD with less fear of sexual contact and more experience in sexual activities. This shows the complex interplay of biopsychosocial and developmental factors in adolescents' sexual maturation and the many ways this can be influenced by having a DSD condition.

This study found that lower self-esteem was correlated with a higher debut age when falling in love or dating. Moreover, a higher debut age of romantic and sexual milestones with a partner was associated with lower satisfaction with sexual life and lower sexual frequency at follow-up. A previous study of the same cohort showed lower self-esteem across DSD clinical groups, which was strongly associated with lower body image [31]. Lower self-esteem may both be a cause and a result of later sexual debut and could be a contributory cause to lower sexual frequency and satisfaction later in life. Individuals who differ in age from their peers when experiencing sexual activities for the first time could feel isolated; this isolation may lead to less sexual experiences and possibly in lower sexual satisfaction [40]. A recent qualitative study on sexual health and wellbeing needs in healthcare of individuals with DSD showed the importance of

concise and comprehendible language in regard to sexual health questions [41]. Moreover, healthcare providers should regularly explore sexual wellbeing in young adults with DSD to help them when is needed [41]. Further qualitative research on first romantic and sexual experiences in individuals with DSD could be beneficial to provide more contexts to these findings. Furthermore, as individuals with DSD are subjected to different forms of interventions (hormonal, surgical, and psychological), it would be useful to see how these correlate with first romantic and sexual experiences.

Limitations

This study has several limitations. The reference values used were retrieved from a recent Dutch study [27] and compared to participant data from multiple countries in Europe. As sexual development is multifactorial, differences in culture could be a factor of relevance. Furthermore, there were differences in participation age between the DSD subgroups, and because age is of importance in reaching romantic and sexual milestones, this could have influenced the results.

Conclusion

During adolescence, a crucial period for sexual development, the biopsychosocial context of individuals with DSD is commonly different compared to the general young population. Adolescents with DSD reach less romantic and sexual experiences and experience a delay in romantic and sexual debut, which were associated with psychosexual difficulties later in life. Healthcare providers should be aware of these findings when counseling adolescents and adults with DSD to provide guidance in sexual development and support psychosexual wellbeing when appropriate.

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Supplementary Data

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