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## Understanding sexual health concerns among adolescents and young adults with differences of sex development: a qualitative study

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### ABSTRACT

**Purpose:** Differences of sex development (DSD) are congenital conditions that involve variations in individuals' sex chromosomes, genes, external and/or internal genitalia, hormones, and/or secondary sex characteristics. This study sought to elucidate the experiences of adolescents and young adults living with DSD by focusing on their experiences of intimacy and sexual health.

**Methods:** An interpretative phenomenological research design was adopted. Semi-structured qualitative interviews were conducted with 11 Norwegian adolescents and young adults aged 16–26 years who had five different DSD conditions. The interview findings were analysed by means of a reflexive thematic analysis.

**Results:** The participants reported feeling different, both in terms of how their body functioned and how their body looked. Lack of knowledge increased this feeling of differentness. Moreover, lack of everyday language with which to talk about intimacy and sexual concerns resulted in the participants feeling stigma. Anticipating stigmatization and lacking everyday language complicated the participants' communication regarding their DSD and sexual health.

**Conclusions:** The sexual experiences of adolescents and young adults with DSD are diverse. Fear of stigmatization and lack of everyday language complicate communication with healthcare professionals and others. Understanding their unique needs is crucial to helping individuals achieve good sexual health.

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Disorders of sex development; differences of sex development; intersex; sexual health; stigma; communication


## Introduction

Differences of sex development (DSD) represent a heterogeneous group of congenital conditions that cause the development of the genitals, hormones, and/or chromosomes to differ from traditional conceptions of male and female bodies (Lee et al., 2016). As a group, DSD have an estimated incidence of 1:4500 births (Sax, 2002). A DSD may become evident at birth or during childhood, adolescence, or adulthood, depending on the specific condition and its severity. Different DSD aetiologies, treatments, and individual experiences may affect individuals' sexual health (Amaral et al., 2015; Wisniewski et al., 2019). In fact, adolescents and adults with DSD have highlighted sexual aversion and lack of arousal as the most common problems experienced (Hughes et al., 2006). WHO defines sexual health as "a state of physical, emotional, mental and social well-being in relation to sexuality" (World Health Organization [WHO], 2015, p. 5). The WHO definition is quite broad. More specifically, sexual health may also concerns gender identity, sexual orientation,

eroticism, pleasure, intimacy, and reproduction (Graugaard, 2017). In 2006, a consensus statement was published in an effort to improve the management of individuals with DSD (Hughes et al., 2006). The statement offered suggestions for improving individuals' sexual health, including a focus on interpersonal relationships, referral to sex therapy, avoidance of unnecessary medical photography and/or genital examination, access to mental health professionals, and assessment of sexual health (Hughes et al., 2006). An update to the statement was published in 2016, which highlighted the role of psychoeducation in reducing anxiety related to sexual and romantic relations (Lee et al., 2016).

The body of literature concerning the sexual health of individuals with DSD has grown in recent years, although it remains both limited and characterized by contradictory results (Wisniewski et al., 2019). Some quantitative studies involving individuals with different DSD reported the participants to exhibit overall satisfaction with their sexual health (Engberg et al., 2022; Schönbucher et al.,

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2008), whereas other quantitative studies found that DSD had a negative impact on participants' emotional and sexual well-being (Liao et al., 2011; van de Grift et al., 2022). A meta-ethnography of 16 qualitative studies concerning DSD suggested sexual health to be negatively related to DSD and, consequently, quality of life (Sani et al., 2019). The medical consequences of DSD (type and severity), psychological experiences of treatment (e.g., distress, anxiety), and reactions from others (e.g., stigma) have all been found to have a negative influence on sexual health (Meyer-Bahlburg et al., 2018; Wisniewski et al., 2019). Furthermore, the surgical management of DSD has been determined to be associated with both positive and negative consequences with regard to individuals' sexual health (Sani et al., 2019).

Over the past decade, there has been an increased focus on the relation between sexual health and both physical and emotional health (Graugaard, 2017; Rew, 2006; WHO, 2015). It has been established that adolescents and young adults (AYA) with a positive perception of their body and good knowledge of sexuality often exhibit better physical and psychological health when compared with AYA who lack knowledge and personal control over what happens to their body (Callens et al., 2021; Rew, 2006). However, only a limited number of studies have investigated sexual health among an AYA population with DSD. Thus, the present study sought to increase the understanding of the experiences of AYA with DSD by focusing on their experiences of intimacy and sexual health in a broad sense, and let the data and the analytical process guide the focus of this study.

## Methods

### Design

We sought to understand the lived experiences of AYA with DSD and so applied an explorative qualitative research design that was epistemologically grounded in the hermeneutic phenomenological tradition (Kvale & Brinkmann, 2009). Hermeneutic phenomenology focuses on the first-person perspective as experienced by the individual themselves as well as on how the researcher interprets meaning based on their professional knowledge (Giacomini, 2010). More specifically, the interpretation is based on both the participant's and the researcher's preunderstandings, as well as on the research context, and it develops throughout the entire research process (Giacomini, 2010). To capture the experiences of AYA living with DSD, interviews were conducted to collect data. In addition, to ensure affected individuals and public involvement, a reference group of AYA (three females and

one male) with personal experiences of living with four different DSD was established.

### Recruitment and participants

This study was conducted in Norway. The recruitment period ran from August 2020 to June 2021, and the study included two out of three subgroups of DSD: 46,XY DSD and 46,XX DSD. The inclusion of DSD conditions was based on the classification from Hughes et al. (2006) and Cools et al. (2018), including e.g., Mayer-Rokitansky-Küster-Hauser syndrome (MRKH) and proximal hypospadias. The exclusion criteria were AYA with sex chromosome DSD. We chose to include different DSD conditions and all genders in order to elucidate the similarities and differences between the diagnoses among AYA with DSD aged 16–26 years.

We aimed to capture AYA with verified diagnosis of DSD by recruiting participants from the two multidisciplinary DSD teams based at Oslo University Hospital and Haukeland University Hospital and the Center for Rare Disorders at the Oslo University Hospital, Norway. Consequently, we did not aim to include individuals with DSD from a community sample and the perspectives of human rights defenders or activists were not explored in this study.

Thirteen individuals signed the consent form and were subsequently contacted by telephone to arrange a time and place for the interview. One individual had a sex chromosome diagnosis and was excluded, whereas one individual did not attend the scheduled interview. The recruitment size was smaller than expected and the enrollment was time consuming due to several issues. The researchers did not approach AYA directly and had to rely on clinicians for recruitment. In addition, participants were recruited during the COVID-19 pandemic and AYA might thus have cancelled the clinical follow-ups.

The information gathered about diagnoses and treatments was based on the participants' own reporting. The participants reported five different conditions: congenital adrenal hyperplasia (CAH), proximal hypospadias and/or complex syndromic structural associations of male genital development, Mayer-Rokitansky-Küster-Hauser syndrome (MRKH), Swyer syndrome, and complete androgen insensitivity syndrome (CAIS). Table 1 presents brief descriptions of the five conditions.

The 11 participants differed in terms of their gender, age (range: 16–20 years [ $n=5$ ] and 21–26 years [ $n=6$ ]; mean age: 20.3 years), time of diagnosis (at birth/infancy [ $n=6$ ], puberty/early adolescence [ $n=5$ ], and number of surgeries. Most participants had an ethnicity originated in the country where the study was conducted. All participants identified with

**Table I.** Brief descriptions of the represented conditions.

Diagnosis	Brief description	Reference
Congenital adrenal hyperplasia (CAH)	CAH affects both males and females. Persons born with CAH lack an enzyme that the body needs to produce cortisol and aldosterone, two vital hormones. Consequently, the body produces more testosterone than required. For females, this may result in genital variations, such as larger than typical clitoris and a closed vaginal opening. Persons diagnosed with CAH require lifelong medication to stabilize their hormone levels.	Witchel (2017)
Mayer-Rokitansky-Küster-Hauser syndrome (MRKH)	MRKH only affects females. The ovaries and external genitals are normal, and females with MRKH develop breasts and pubic hair. However, females born with MRKH have a uterus, cervix, and upper vagina that has not developed as expected. Consequently, they do not start to menstruate and cannot become pregnant. Penetrating intercourse might be difficult due to a shorter vagina.	Herlin et al. (2020)
Swyer syndrome	Females with Swyer syndrome have a female phenotype. They have a uterus, vagina, and fallopian tubes. The gonads have not developed as expected and produce no hormones. They have a 46,XY karyotype and do not menstruate. Females with Swyer syndrome cannot have genetic children, although pregnancy may be feasible through egg donation. Early prophylactic removal of the streak gonads is discussed due to the risk of developing gonadal malignancy. Hormonal therapy is required.	Michala and Creighton (2010)
Complete androgen insensitivity syndrome (CAIS)	Individuals with CAIS exhibit hormonal resistance to androgens, which results in a female phenotype with a 46,XY karyotype and testes that produce androgens (testosterone). Consequently, females with CAIS have an absent uterus, shorter vagina, are infertile, and do not menstruate. Prophylactic removal of the gonads (testis) is considered due to the risk of developing gonadal malignancy. Hormonal replacement therapy is offered.	Grymowicz et al. (2021)
Hypospadia, severe form	Hypospadia only affects males. It affects the development of the penis. The types of hypospadias range from the urethral opening appearing nearer the tip of the penis or nearer the scrotum. The testis may be affected.	Kumar and Cherian (2022)

the assigned sex at birth (male or female), no one identified themselves as non-binary. Table 2 presents participants' gender, age and diagnosis. Six of the female participants had 46,XX DSD. Of these, three females were diagnosed before the age of two years. The other three were diagnosed later in childhood and adolescence (age range: 7–16 years). Five of the 46,XX females reported having undergone a primary surgery to the genitalia or removal of the inner genital structures (either before two years of age, at a pre-pubertal age, or during puberty). Three had undergone additional genital surgeries later in childhood or adolescence, and two had plans for further surgeries in the near future. In addition, five participants took glucocorticoid replacement therapy.

The 46,XY female group comprised two females with different diagnoses. They were both diagnosed in adolescence and had undergone surgical removal of gonads (gonadectomy), uterine rests, vaginal dilations, and/or surgical incision. Both 46,XY females had received information about the use of vaginal dilators. In addition, they both took sex steroid replacement therapy.

The three male participants all had proximal hypospadias and/or complex syndromic structural associations of male genital development. Furthermore, they

had associated congenital anomalies (e.g., skeletal, kidney, gastrointestinal tract) and were diagnosed within the first two years of life. They had undergone surgeries to the genitalia within the first two years of life. One male had undergone three surgeries in adolescence, while another was waiting for reconstructive genital surgery. The third male reported needing a hypospadias correction. The male participants are referred to as XY males in this study.

Seven participants had sexual experiences with a partner and eight participants were or had been in romantic relationships. Most participants reported that they had been in love. Seven participants reported sexual attraction to a person of the opposite sex. Two of them had also thought about sexual relations with a person of the same sex, although they identified themselves as heterosexual. Three participants reported sexual attraction to the same sex, whereas one participant reported not yet knowing to whom the person was attracted to.

All the participants had received medical follow-ups prior to turning 18 years old. None of them had received a multidisciplinary follow-up after the age of 18 years. Three participants had received psychological treatment as adults. All participants diagnosed in childhood

**Table II.** Sample characteristics.

	Total (n = 11)	Male (n = 3)	Female (n = 8)
Age range (mean)	16–26 (20.4)	16–23 (20.6)	16–26 (20.3)
46,XX DSD female			
CAH (n)	5	-	5
MRKH (n)	1	-	1
46,XY DSD female			
CAIS (n)	1	-	1
Swyer syndrome (n)	1	-	1
46,XY DSD male			
Hypospadias or structural associations of external genitalia (n)	3	3	-

Note: DSD = differences of sex development, CAH = congenital adrenal hypoplasia, MRKH = Mayer-Rokitansky-Küster-Hauser syndrome, CAIS = complete androgen insensitivity syndrome.

had received follow-up from a multidisciplinary team including a child and adolescent psychiatrist until the age of 18. Few participants talked about psychological support from a sexologist, endocrinologist or gynaecologist during adulthood. Participants diagnosed after 18 years old had not received psychological support on a regular basis from clinicians.

### **Data collection**

The semi-structured interviews were conducted by the first author between October 2020 and June 2021. The dates and locations for the interviews were decided in collaboration with the participants. Due to restrictions necessitated by the COVID-19 pandemic, five interviews took place via video conferencing and one interview by telephone. Moreover, five interviews were conducted on a face-to-face basis, either in the participant's home ( $n=2$ ) or at University Hospital ( $n=3$ ). The interviews lasted between 35 and 123 minutes (mean: 63 minutes). All the interviews were audio recorded using a Zoom H2n Handy Recorder and then transcribed verbatim by the first author and a research assistant. The participants were de-identified in the interview transcripts.

The questions used in the interview guide were discussed by the research team and clarified in meetings with the reference group to ensure that topics were relevant and comprehensible (Tracy, 2010). The participants were asked open-ended questions covering a wide range of themes, including romantic relationships, satisfaction with surgical/medical/psychological treatment, information received since diagnosis, and disclosure. The participants were encouraged to describe their experiences in their own words, and follow-up questions were used to prompt them to elaborate on relevant issues or to offer examples to illuminate their stories (Kvale & Brinkmann, 2009). After each interview, the participants could make additional comments or ask questions to ensure their experiences of the relevant theme were understood. In addition, the first author wrote a short reflexive summary with the aim of capturing impressions not easily captured on audio recordings, such as changes in moods, body language, and facial expression.

### **Data analysis**

The data were analysed in accordance with the principles of reflexive thematic analysis, as described by Braun and Clarke (2006, 2019). This method was chosen because a reflexive thematic analysis is recognized as a suitable method for identifying patterns of meaning across datasets as well as divergence within data (e.g., between diagnoses, age at the time of diagnosis, gender) (Braun & Clarke, 2019). To

ensure the credibility of the findings, the authors double-coded a subset of interviews (50%) (Levitt et al., 2018). They began by familiarizing themselves with the data through reading and listening to each interview several times in order to gain an impression of the participants' experiences. The first author coded (and recoded) each interview inductively by hand on the basis of the participants' own words. Consequently, codes regarding sexual health were generated. Next, the researchers searched for categories, similarities, and divergences in the data. This step involved questions focusing on what the participants were telling about their sexual health, what was important to them, and how they were describing issues with intimacy and fertility.

Finally, all the authors agreed to the codes and themes that represented the findings. Engaging professionals with a variety of background in the research group was important to analyse and interpret themes from different perspectives and to ensure that the process was not misinterpreted (Tracy, 2010). This helped us to view the transcripts, interpretations, and results in different ways, to question each other's preunderstandings, and to gain a more in-depth understanding of the phenomena under study, thereby strengthening confirmability (Shenton, 2004). Throughout the entire process of analysis, the researchers regularly returned to the original data to check the themes and quotes and ensure that the meanings had not been lost during either interpretation or translation. The questions regarding sexual health were open-ended with the aim to let the participants guide the direction of this sensitive topic.

The reflexive summaries written after the interviews also formed part of the analysis. To elucidate each theme, the researchers identified a selection of illustrative quotes, which were slightly revised to improve their readability, as suggested by Kvale and Brinkmann (2009). All the quotes from the interviews were translated from Norwegian into English by the first author. To ensure rigour of the study the Consolidated Criteria for Reporting Qualitative Studies (COREQ) was followed (Tong et al., 2007), the checklist is available as supplementary material.

### **Ethical considerations**

This study was conducted in accordance with the principles of the Declaration of Helsinki. All the protocols and methods were approved by the Norwegian Regional Committee for Medical Research Ethics in South-Eastern Norway (approval number 79,444) as well as by the Data Protection Officer at Oslo University Hospital (approval number 7,000,898). Due to the sensitive nature of the topics discussed, each participant was offered a follow-up conversation after their interview. Two participants wanted a follow up



conversation, and a referral to eligible health care personnel was arranged for.

When writing the results of this study, an arbitrary name was assigned to each participant to ensure their confidentiality. Moreover, the participants' age was dichotomized into groups of 16–20 years and 21–26 years for the purpose of de-identification. The same approach was adopted in relation to their medical conditions, which were organized into three groups: XX, females, XY, females, and XY, males.

## Results

### *Themes regarding sexual health*

Three themes regarding sexual health described the experiences of the participating AYA with DSD, namely the importance of being “normal,” communication, and prospects of fertility.

#### *The importance of being “normal”*

The analysis generated subthemes wherein normalcy became relevant and described the effect on sexual health of “a body that is functionally different” and “a body with genitals that look different.”

Two-thirds of the participants reported having had sexual experiences with a partner. They described sex and, in particular, intimacy as problematic to the extent of affecting their everyday lives. The female participants talked more about this topic than the male participants. The participants described how being functionally different influenced their sex life, for example, requiring preparation such as dilating the vagina, experiencing sex as painful, or feeling the need for genital surgery. Nora had difficulty with intercourse due to having a short and narrow vagina. She had wondered whether it would be better to date girls than boys: “I wasn't really able to have sex. Maybe I decided, that... Maybe I should like girls instead, because I struggled so much with dilating” (XY, female, 21–26 years).

Furthermore, two-thirds of the participants had undergone both invasive and non-invasive genital procedures. The operations involved constructive or reconstructive feminizing and masculinizing surgeries of the genitalia and/or urethra, or the construction of a neovaginal opening. Self-dilation therapy was often necessary for the maintenance of a functional vagina. In this regard, Ellida explained that vaginal dilation prevented her from being impulsive when it came to meeting a partner and having sex: “Yes, it [sex] is kind of problematic, because ... I need to kind of do preparations like vaginal dilatation such a long

time in advance... In a way, it kind of ruins the whole experience” (XX, female, 16–20 years).

For the female participants, experiencing their first menstruation, or the lack thereof, was described as characterizing an especially vulnerable period of life and representing a situation where their bodily function differed from that of their peers in a concrete way. Several participants explained that not starting menstruating at the same time as their peers was something they had learned to live with and found less problematic than what they felt clinicians expected them to feel. Agnes started her period earlier than her peers. Her doctor put her on hormones to postpone puberty, which resulted in side effects such as weight gain. Agnes related the following:

I could easily have learned to live with it [menstruation]. Instead of just pushing it away and putting me on that hormonal shot [...] It would have been better if someone could just have told me why I got my period early and explained how I could live with it. (XX, female, 16–20 years)

One of the female participants who had not started menstruating due to having a hormonal imbalance also did not problematize the issue: “I don't need to have menstruation, because I'm not going to have children anyway” (Rebekka, XX, female, 16–20 years). However, Nora, a young woman who required a medical examination due to amenorrhoea, talked about feeling abnormal: “Then I started wondering why ... why everybody had started their period, except me ... We used to talk about that person who got it so late and I started thinking, “Oh my god, am I that person?” (XY, female, 21–26 years).

In addition to having genitals that required “improvements” to be like those of others and function like they were supposed to, as well as having a body that did not menstruate like it should, the participants' sexual debut was an experience that seemed to significantly rely on society's norms regarding how to “be” a sexual partner. The participants did not seem to describe their first sexual experience as being related to their own pleasure and satisfaction. Rather, the question of whether or not it was considered a good experience appeared to be dependent on their partner's reactions. Nora had difficulty with dilation and did not have sex until she had undergone dilation in narcosis. When asked about how her first sexual experience went, she responded: “It went well ... it did ... we met two to three months after the surgery... it wasn't, kind of ... he didn't notice anything, so it wasn't a problem” (XY, female, 21–26 years). Another young woman described her sexual debut in the following way:

The first time anyone was going to see me naked ... Like in a sexual context, then... Well, it was really in

the dark and it all went very well. He didn't sense or feel anything different about me [...]. It was actually a good first time. (Agnes, XX, female, 16–20 years)

The normal appearance of the genitalia was important for some participants (CAH, XY, males). Having genitals that looked more “normal” was something all these participants wanted to achieve through surgery. Indeed, some were willing to pay for it if necessary (such surgery is normally covered by public health-care in Norway). “That sucked, because I would like to have nice looking genitals. Everybody wants that. And it means a lot to me as an adolescent, not having a regular partner. [...] I hope that I can get the surgery I want” (Agnes, XX, female, 16–20 years). Sex was described as problematic by the male and female participants who reported having genitals that were visibly different from the norm, which resulted in them expending a lot of mental resources on feeling different. Despite this, several participants described that when they had intercourse, it was unproblematic. They explained that this was because of the partner's response, which wasn't described as negative, as mentioned above.

Some participants did not differentiate between appearance and function. Instead, they talked about the two as being dependent on each other, with appearance being more important than function. Agnes experienced reduced clitoral sensation. She was not pleased with the appearance of her genital and had recently undergone corrective surgery. She explained: “Because if the appearance had been, like perfect, I don't think I would have had such an issue with the functionality” (XX, female, 16–20 years).

### Communication

Communicating about sexual health became an issue when the participants “lacked knowledge about their bodily differences and/or “lacked everyday language.”

Not knowing why their body was different led to feelings of insecurity that affected the participants' sexual relationships. Thomas expressed having little knowledge about his DSD. He was unsure whether he had actually had an operation during childhood. He wanted to talk with doctors about the appearance of his penis but felt embarrassed about addressing the issue. He felt insecure in intimate relationships and avoided answering questions from partners: “Because I wasn't sure why [my penis looked different], I didn't have any answers as to why it looked different. [...] So I didn't say anything. [...] I kind of didn't know what to say” (XY, male, 21–26 years). By contrast, Henrik reported having regular discussions with his doctor and his mother about his DSD. Even though he acknowledged that adolescence was a particularly vulnerable period for a male whose penis looked different from the norm, he had the following to say

about being intimate with a girl: “The more times you face it, the more confident you become that ... You know what? It is not that important at all really” (XY, male, 21–26 years).

A difference was observed among the participants in terms of how they expressed their experiences with sexual intimacy. Several reported lacking everyday language with which to talk about intimacy and wishing that clinicians routinely initiated sexual health counselling.

It is difficult to express oneself ... correctly ... [...] just talking about it [the condition] with a partner. Because I usually don't talk about it, so it kind of... [...]. And I was never prepared for how I could talk about it with others, so it is maybe an area where I am a bit unsecure. (Ellida, XX, female, 16–20 years)

Talking about private and intimate parts of the body appeared to be difficult, especially for the youngest participants. Some participants used words such as “thing” when talking about their genitals, thereby indicating a reluctance to use medical terms and/or a lack of everyday language.

Four participants had not had sexual experience with a partner and two of them had never been in a stable romantic relationship. Moreover, they gave the impression that they were unwilling to talk about sexual intimacy during their interview. In fact, their answers to the question regarding their thoughts about future intimacy were experienced by the interviewer as both guarded and dismissive.

### Prospects of fertility

Having a body that may potentially have problems conceiving a child represented a significant experience reported by all the female participants. Three female participants reported being unable to have biological children and stated that they had accepted it. Having other important interests in life and considering alternative ways of being a mother, such as adoption or egg donation, were reported as reasons for the acceptance of infertility. However, the acceptance of infertility was not always as easy as it first appeared, as illustrated by Nora's ambivalent feelings concerning this theme when the interviewer asked her if fertility was something she thought about: “No, not really... Sometimes, when I lie in bed maybe, alone. Maybe I think a little bit about it. I can get a little sweaty ... or kind of get... almost like a panic attack. I can get that” (XY, female, 21–26 years). For her part, Aurelia indicated that acceptance might become more difficult as she gets older: “and over the last year, the wish for my own children has increased, but I haven't been sad about it, because I have thought since I was 15 that ‘well, it is just how it is” (XY, female, 16–20 years). All the participants for whom this was an issue reported talking to a partner

about possible or certain infertility to be difficult. In addition, the participants described the disclosure of fertility issues to become more relevant and also more difficult as they got older.

One-third of the participants (all females) were unsure about their prospects of fertility. A lack of information or discrepancies in the information provided to them were experienced as a significant strain. Susannah related being initially told that she could not conceive a child, although she was later informed that she had a good chance of fertility. She described a long journey to receiving accurate and adequate information after not being taken seriously regarding fertility issues: "It actually took six years from the time I started requesting information until I was taken seriously! Because I was then old enough to be considered a possible parent" (XX,female, 21–26 years).

None of the male participants reported thinking about their future fertility, nor did any of them problematize the issue, although the oldest male participant did talk about his prospects of having a family when he was older.

## Discussion

This study sought to develop an in-depth understanding of the experiences of AYA with DSD by focusing on their experiences of intimacy and sexual health. The key findings of the study revealed that the participants who were sexually active described intimacy and sex as being problematic in terms of both their genital functioning and their genital appearance. Furthermore, having limited knowledge about their condition and lacking everyday language affected the participants' feelings of differentness, which combined with their feelings of stigma. The female participants expressed ambivalent feelings regarding infertility, which influenced their decision to discuss the topic with their partner.

The participants in this study were clearly engaged in an ongoing process of finding acceptance and trying to understand their sexual health needs. Some reported sexual well-being while others reported having no sexual experience with a partner, which confirmed sex and intimacy to be highly individual amongst AYA with DSD. Ongoing functional difficulties (penis/vagina) and atypical genitalia were described as factors contributing to the feeling of not being normal. The related functional difficulties included a reduced sex drive, short and/or narrow vagina, penis dysfunction (e.g., due to curvature), and hormonal imbalances due to medication or DSD symptomatology. These findings are in line with previous studies showing that painful intercourse and dissatisfaction with genital function can have a negative effect on sexual health (Köhler et al., 2012).

Having genitals that appeared more "normal" was a topic raised by all the participants in this study that affected their genital development (most XX,DSD females and XY,DSD males). Genital surgery can help to promote a feeling of normalcy in some individuals with DSD (Boyle et al., 2005). Normalization has previously been identified as a common coping strategy among individuals living with multiple conditions (Sanderson et al., 2011). In fact, one of the six distinct normality typologies proposed by Sanderson et al. (2011) is "struggling for normality, presenting a normal life whatever the cost." In this study, the participants expended a lot of mental resources on feeling different and emphasized how striving for normalization entailed adjustments. Some were even willing to pay for a chance at normalcy. An individual's experience of their deviant appearance and the disruption to their bodily identity are both influenced by cultural norms concerning how a normal and attractive body should appear (Eagly et al., 1991; Toombs, 1995). Given their key role in shaping how individuals feel about themselves, appearance and body satisfaction likely represent the most important contributing factors to self-esteem (Thompson & Kent, 2001). Individuals with a visible difference may experience problems in their social life (Tiggemann, 2001). Moreover, it is challenging to reveal a deviant appearance to others because it can result in negative reactions from others and discrimination. Some of the participants in this study indicated genital appearance to be more important than function.

The AYA who participated in this study described applying the coping strategies of hiding or not revealing their DSD condition to friends and sexual partners. As individuals with DSD have a concealable condition, they might experience being stigmatized when compared with traditional conceptions of "normal" male and female bodies. This might lead to them anticipating stigma if their condition became known, thereby resulting in concealment (Quinn & Chaudoir, 2015). A prior study on DSD determined dissatisfaction with sex life to be associated with traumatic sexual experiences, stigma, and social anxiety (Wisniewski et al., 2019). Other studies on DSD have found that sexual health is associated with the physical condition itself, use of medication, mental health history, body image, gender, age, psychological support, culture, and social media (Hegde et al., 2022; Meyer-Bahlburg et al., 2018; Wisniewski et al., 2019).

Leder (2022) emphasized how dealing with an ill and impaired body requires the application of different strategies during the healing process. He referred to some healing strategies as being intended to "free oneself from the body" (e.g., *ignoring, refusing*) and presented others as being designed to "embrace the body" (e.g., *accepting, befriending*). These strategies were clearly apparent among the AYA with DSD who participated



in our study. For example, some participants described how their sexual well-being depended on their partner's response and explained how *ignoring* bodily problems and focusing more on strengths (e.g., a positive or neutral reaction from a partner) made sex appear less threatening. In addition, despite the negative feelings associated with being infertile, the female participants seemed to be moving forward in life, which indicated that they were *refusing* "to give in to the body as a controlling factor in their social, emotional or professional lives," as described by Leder (2022, p. 142). In this study, the female participants who were infertile or had problems with menstruation used strategies for acceptance. Nora's description of her tension captured the struggle involved in *accepting* reality: "Maybe I think a little bit about it ... almost like a panic attack." Moreover, *befriending* entails an attitude of bodily care best illustrated by Henrik, who initially felt vulnerable in relationships because his penis looked different but decided "It is not that important at all really."

### **Need for information clarity**

The findings of recent studies have suggested that healthcare professionals remain reluctant to talk about sexual issues to AYA with DSD (Callens et al., 2021; Wisniewski et al., 2019). Most participants in this study expressed the need for individualized information and consultation concerning fertility and future parenthood, potential treatment options, and sexual functioning. This study also found that AYA need everyday language with which to communicate about their DSD condition to healthcare professionals. A critical review of the literature regarding the psychological well-being of those with DSD found that if healthcare professionals use only medical terminology, it leads to affected individuals believing that they can only talk to medical professionals (Roen, 2019). Uncertainties about genital surgery and fertility were reported to be burdensome in the present study, especially when accompanied by inconclusive information. Thus, clear communication is particularly important when AYA require healthcare support for the emotional challenging they experience.

Recent studies have focused on fertility issues among AYA with DSD (Corona et al., 2022; Papadakis et al., 2021). For instance, Corona et al. (2022) revealed how support from family, clarity of information, and support from individuals with similar diagnoses were all important factors when dealing with fertility issues. Fertility was an important issue for the female participants in the present study, who reported experiencing inconsistent information and feeling that their concerns were not taken seriously or prioritized. Several participants focused on alternative routes to parenthood such as adoption or surrogacy. However, the male participants in this study did not share

experiences of fertility. This might be because fertility was not addressed as an issue during consultations, because they lacked information about potential difficulties, or because they were not willing to share information due to their young age. A prior study reported lower fertility and less satisfaction with sex life in males with severe form of hypospadias when compared with control groups (Örtqvist et al., 2017). Fertility is shown to be dependent on the type and severity of the condition, frequency in partnership, and postoperative complications of genital surgery (Asklund et al., 2010; Skarin Nordenvall et al., 2020; Örtqvist et al., 2017).

### **Clinical implications**

Heterogeneity is a key feature of DSD. Indeed, most participants in this study emphasized the importance of receiving individualized medical information and consultation. Since the publication of the first consensus statement on DSD in 2006 (Hughes et al., 2006), the importance of full disclosure of medical information to individuals with DSD has been emphasized. This change in the approach to medical consultation has presented opportunities to broadly discuss healthcare needs with parents, children, and AYA with DSD (Brennan et al., 2012; Roen, 2019; Wisniewski et al., 2019). Based on the present findings, further understanding is required regarding sexual well-being and different aspects to think about in those with DSD from the clinical perspective. Today, healthcare professionals need to initiate conversations about sexual health and sensitive issues, and they need to become better at letting AYA know that it is fine to talk about sex. Moreover, healthcare professionals need to stress to AYA with DSD that their problems are not rare, irrelevant, or untreatable. Among the most challenging issues for the female participants in this study were their prospects of fertility, early menstruation, or absence of menstruation. The participants also raised concerns about acceptance among healthcare professionals and the provision of information about genital surgical treatments. In general, the participants expressed positive views about potential cosmetic surgery as part of the treatment plan for a "normal" genital appearance. None of them had experienced any "disapproving gaze" or negative remarks from healthcare professionals, although the emotional reactions stemming from having a functionally and/or visibly different body might lead to feeling different or not "normal".

### **Strengths and limitations**

In this study, the researchers attempted to recruit a heterogeneous sample from two multidisciplinary clinics at two university hospitals and in collaboration

with a national competence centre related to DSD situated at one of the hospitals. The sample size is considered adequate for a qualitative phenomenological study. The diversity of diagnoses might limit the transferability of the findings. However, the explorative and qualitative nature of the study gave rich and nuanced data that represented universal life experiences. As such, the findings may have utility in similar situations and across contexts (Shenton, 2004). However, findings should be interpreted with caution due to the heterogeneous nature of participants (Braun & Clarke, 2019). Further, even though an interpretive phenomenological approach gives an insight in the lived experiences of AYA with DSD, other possible phenomena related to sexual health might be revealed in other cohorts. Future studies may look to expand the present findings to other settings and to include experiences of patient advocacy groups or activists. In terms of dependability and trustworthiness, the findings of this study are reinforced by the transparency of the analysis (Shenton, 2004).

A limitation of the study is that the interviews did not cover sexual activity in detail (e.g., frequency, type of activity, partner's gender). This is because the participants guided the direction of the interview. As some AYA may be unwilling to talk about detailed activity unsolicited, researchers could facilitate for those who wanted to elaborate on this in more detail when ethically appropriate, thorough preparation of the participants in the initial information conversations or in the invitation letter.

## Conclusion

The findings of this study provide an in-depth understanding of the experiences of AYA with DSD regarding sexual health and well-being. Three major themes emerged in this study, namely the importance of being "normal," communication, and prospects of fertility. The sexual experiences of AYA with DSD are diverse and likely culturally dependent. The process of finding acceptance occurs outside of and beyond medical settings, although the understanding of AYA with regard to sexual well-being remains focused on medical or surgical treatments. Fear of stigmatization and lack of everyday language has the potential to both complicate communication with healthcare professionals and others. Clinicians may consider to begin by enabling AYA with DSD to express themselves with respect to their unique healthcare needs and to voice their own perspective on sexual well-being. Fertility/infertility issues concerned the female participants in this study, who felt that healthcare professionals do not sufficiently acknowledge such concerns. This finding suggests that clinicians need to find a way to talk to AYA of both genders about fertility.

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## Authors' contributions

LM contributed to the conceptualization, recruitment of participants, methodology, interviewing, analysis, writing-original draft, and writing-review/editing.

SS contributed to the conceptualization, methodology, analysis, writing-original draft, writing-review/editing, and writing the application for funding (Foundation DAM).

LF contributed to the conceptualization, methodology, interviewing, analysis, writing-original draft, and writing-review/editing.

AW contributed to the conceptualization, recruitment of participants, methodology, analysis, writing-original draft, writing-review/editing, and writing the application for funding (Foundation DAM).

All authors read and approved the final manuscript. All of the co-authors approved the submission of this work for publication.

## Data availability statement

Given the qualitative nature of this study, the generated datasets are not publicly available due to participant confidentiality issues.

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