

## ORIGINAL RESEARCH: EMPIRICAL RESEARCH – QUALITATIVE

# Young women with a disorder of sex development: learning to share information with health professionals, friends and intimate partners about bodily differences and infertility

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### Abstract

**Aim.** To understand the experiences of young women with a disorder of sex development when sharing information about their body with healthcare professionals, friends and intimate partners.

**Background.** Disorders of sex development are lifelong conditions that create bodily difference such as absence of reproductive organs which can impact on young women's fertility and sexual experiences.

**Design.** Interpretive phenomenological analysis with thirteen young women (14–19 years old) with a disorder of sex development.

**Methods.** The young women chose to participate in either a face-to-face semi-structured interview or to complete a paper diary between 2011–2012.

**Results.** A superordinate theme focusing on the meaning bodily differences held for these young women is presented through three themes: self-awareness and communicating this to others; actualizing intimacy; and expressing meaning of altered fertility to self or professionals or partners. During early adolescence, the young women were guarded and reticent about sharing personal information about their disorder of sex development but as they moved towards adulthood, some of the young women learnt to engage in conversations with more confidence. Frustrations about their bodily differences and the limitations of their bodies were talked about as factors which limited physical spontaneity, impacted on their perceived sexual fulfilment and challenged the development or sustainability of close friendships or intimate partnerships. The young women wanted empathic, sensitive support from knowledgeable health professionals to help them understand their bodies.

**Conclusion.** Attachment and a 'sense of being' were the concepts that were closely linked to the young women's development of a secure identity.

**Keywords:** adolescents, disorder of sex development, genital surgery, infertility, nursing

**Why is this research needed?**

- Fear of an adverse psychological response has meant that medical information has not always been disclosed to or shared with young women with disorders of sex development.
- Improved communication by healthcare professionals can help young women with disorders of sex development to understand their condition and explore how they may wish to safeguard or share their health information.
- Professionals have a responsibility to share all available information that a young woman with a disorder of sex development may find helpful.

**What are the key findings?**

- Young women with disorders of sex development may be 'on guard' about sharing personal information but over time, they learn to negotiate and navigate these conversations.
- As the young women move into adulthood and engage in friendships and intimate relationships, their responses to and the meanings they give to infertility change.
- For young women with a disorder of sex development, bodily intimacy may require planning which has an impact on their perceived expectation of sexual spontaneity in a relationship.

**How should the findings be used to influence practice?**

- Nurses have a core role in the multidisciplinary team to help young women with disorders of sex development to understand their disorder, so they can explain their condition to friends and partners.
- Nurses have a role in ensuring that young women with disorders of sex development transition to adult services with sufficient knowledge of their bodily functions and differences to help them to make informed decisions.

**Introduction**

Disorders of sex development (DSD) are lifelong conditions usually diagnosed at birth or during adolescence and may require lifelong management (Ahmed *et al.* 2011); other conditions such as bladder exstrophy also require young women to undergo genital surgeries in infancy and childhood (Baird 2011, Anderson *et al.* 2014). While sexuality is a core element of adolescent development, the focus is on typical bodies and physical sexual function (Murray *et al.* 2014),

and Stephenson and Meston (2010) note that bodily differences and the impact of individual beliefs and psychosocial factors are often overlooked (Stephenson & Meston 2010).

Parents of young women (considered here as aged 14–19 years) born with DSD will, during their daughter's infancy and childhood, enter into conversations with healthcare professionals about their daughter's genitalia, reproductive potential, sexuality and likely future intimacy (Wisniewski 2012). Parents have to try and translate this information into meaningful language to aid their daughter's understanding of her bodily difference, sex and fertility (Sanders *et al.* 2012).

**Background**

Erickson's (1995) theoretical model of psychosocial development includes sexuality and proposes that for adolescents to co-create intimacy rather than remain isolated, they have to overcome uncertainty around role confusion and establish their own personal identity. Personal identity develops and evolves over the life course and is influenced by self-esteem and early attachments (Bowlby 1988). Bartholomew and Horowitz (1991) note that thoughts about self and others are important components in attachment in adult relationships. While people are biologically driven to form attachments with others, they are influenced by learning, experiences and specific attachment styles (Overall *et al.* 2003). Romantic relationships can be a secure base from which people can explore life's challenges and opportunities (Hazan & Shaver 1990) and there are important links between attachment and intimacy (Collins & Freeney 2004). Intimacy is a set of interactions where innermost thoughts, feelings or experiences are disclosed in a close relationship where the partner responds to the disclosure in a way that makes the person feel validated, understood and cared for (Kohlenberg *et al.* 2009). These interactions can include verbal self-disclosure, intimate interactions and non-verbal expression such as physical intimacy.

There is very little relevant literature specific to the concerns of young women with DSD about intimacy, friendships and fertility. However, bladder exstrophy shares similarities to some DSD conditions and Anderson *et al.* (2014) notes that young people with bladder exstrophy report that variation in physical appearance and challenges to managing bodily functions affect the establishment and maintenance of close friendships and intimate partnerships. While some young women with DSD grow up with knowledge of their infertility (Lee *et al.* 2012), there is less evidence to suggest whether they chose to share or conceal this information. The infertility literature can help inform

professionals, but it is limited in its relevance to DSD as it is predominantly couple-oriented, assumes the context of an established relationship, focuses on the women's failure to conceive and the lived experiences of infertility and infertility treatments (Espie 2012). Furthermore, women who undergo fertility treatment generally have hopes for future fertility (Wirtberg *et al.* 2007) while women with certain DSD conditions will experience lifelong infertility.

Maslow's concepts of growth, safety and defence (Maslow 1968) may help nurses understand how the young women express or internalize bodily differences. For Maslow (1968) growth is intrinsic for a person to realize their identity. Life is the experience that sets a balance between an individual choosing to grow or not, dependent on their needs and the ways essential needs are fulfilled are as important as the needs themselves. From a phenomenological perspective, a person is a being for whom things have significance and growth is contextual in relation to the activities pursued; a person's interactions with encounters have individual meaning (Leonard 1994). Our human experience is one where meaningful relationships with self and people in the larger world are influenced by social factors. For young women with DSD the opportunity to grow may be curtailed by inhibitions about sharing explicit details of bodily differences and physical functions (e.g. amenorrhoea) with peers; repressing this growth can result in 'self-betrayal' (Maslow 1968). The very nature of living and experiencing the world of self-understanding, meanings and traditions (Benner 1994) means that only the individual knows the moment when the balance tips from the fear of going forward to a point of courage and growth (Maslow 1968).

This article focuses on the meaning of bodily difference for young women with DSD and the themes presented are from a wider study examining clinical conversations between young women who have DSD and their healthcare professionals.

## The study

### Aim

To understand the experiences of young women with a disorder of sex development when sharing information about their body with healthcare professionals, with friends and with intimate partners.

### Design

Interpretive phenomenological analysis (IPA) draws on ideography, phenomenology and hermeneutics thus generating the opportunity to focus on participants' unique under-

standings, how they make sense of their experiences, and giving consideration to the process of interpretation and reflection (Benner 1994). We were specifically interested in how the participants' self-knowledge changed and subsequently enabled or prevented them from talking to healthcare professionals, friends and partners about bodily differences. Thus, our choice of an IPA approach was relevant to help us gain insight into the worlds of our participants and how they made sense of their experiences.

### Rigour

Our approach to validating the study focused on including a small group of self-selecting young women with DSD. These young women were known to the lead researcher and together they formed an Advisory Group (AG). Our AG of four young women with DSD aged (16-20 years) led discussions with the lead researcher about possible research topics and helped to identify the research methods. The AG advised that methods should engage those who would not be uneasy with face-to-face contact and those who had not participated in the research previously: semi-structured interviews and written diaries were agreed as the data collection methods. The AG highlighted the potential sensitivity around discussing fertility, sexuality and gender issues with a researcher and said that using diaries might increase study participation. The AG advised that the focus of data collection should be on exploring the meanings associated with communicating about DSD and conversations about bodily difference. The topic guide for both the interview and diaries were developed, reviewed by the AG and amended consistent with their advice. The AG also contributed to the analysis of data.

### Sampling

Three healthcare teams providing services to young women with DSD based in the UK collaborated in the research. A clinical lead at each site agreed to be the local collaborator and sent out invitation packs to young women with DSD under their care who met the inclusion criteria (Table 1); up to ten study packs were sent from each site. Patient information, consent and assent forms and a brief questionnaire which sought to enquire if potential participants considered the research intrusive or potentially upsetting were included in the invitation pack along with a return stamped addressed envelope.

### Data collection

Data were collected over a period of a year (2011-2012) using either non-directive, semi-structured, face-to-face

**Table 1** Inclusion and exclusion criteria.

Inclusion criteria	Exclusion criteria
<ul style="list-style-type: none"> <li>• All young women between and including the ages of 12-21 years born with a DSD condition (as defined by the Hughes <i>et al.</i> 2006).</li> <li>• Either able to give informed consent or to provide assent (with parental consent if &lt;16 years).</li> <li>• Living in the United Kingdom during the study.</li> <li>• Diagnosed with DSD for longer than three months.</li> </ul>	<ul style="list-style-type: none"> <li>• Healthcare professional with responsibility for the care of the young person considered it inappropriate for the young person to be approached to participate in the study.</li> <li>• Young person who met the inclusion criteria, but who was acutely unwell or had a life threatening condition at the time of recruitment as determined by the medical teams managing their care.</li> </ul>

interviews or semi-structured diaries. Although diaries are not commonly used in IPA (Smith *et al.* 2009), other studies have adopted such methods [e.g. when researching body image in pregnancy (Johnson *et al.* 2004) and eating disorders (Mulveen & Hepworth 2006)]. While we acknowledge that these different modalities would shape the way that the young women shared their experiences, we felt that allowing them different ways of participating was appropriate.

At the start of the interview and when introducing the diary, it was made clear that the researcher was interested in the young women's conversations about themselves with healthcare professionals, friends and partners. For participants who chose to use the diary, their diary was mailed with a request for it to be returned within 6 months of posting. Both the interview schedule and structured diary retained a level of flexibility to allow the young people to shape and define the information they provided.

### Ethics

Ethical approval was given by the lead National Health Service (NHS) Ethics Committee. Site specific approval was granted from collaborating trusts and the NHS Research Scotland Co-coordinating Centre and adopted by NIHR study (UKCRN ID 10400).

### Analysis

Interpretive Phenomenological Analysis (IPA) generates understanding through the detailed examination of live indi-

vidual experiences (Smith *et al.* 2009). The meanings that participants may ascribe to an event or experience are integral to IPA but are accessed through the process of interpretation (Biggerstaff 2012). IPA in this study focuses on understanding young women's experiences of sharing information about their condition with others. All interview and diary data were transcribed, anonymized and imported into Atlas.ti version 5. The transcripts, field notes and audio-recordings of the interviews were subjected to in-depth review, with the spotlight transferring between the main participant statements and the lead researcher's interpretations of the meaning of these statements. Interview and diary transcripts were analysed as single cases in the order they were collected. Each transcript was analysed to identify the emerging and embedded themes (Langdridge 2007); the aim being to tease out the significance of themes, interpret broader meanings, define the essence of the superordinate themes and to clarify the supporting themes. Throughout the analysis the lead researcher continued to reflect on the interpretive nature of the process and was challenged by both the research team and the AG. Any taken-for-granted misunderstandings (Benner 1994) were illuminated and challenged by the AG. Transparency in analysis is evident in the progression of interpretation to the final themes and in the use of the participants' own words to illustrate the narrative summaries.

## Findings

### Descriptive summary of participants

Fourteen young women with DSD (aged 14-19 years) of the 30 who were invited agreed to participate; one young woman chose not to be interviewed when she became unwell. The young women who participated had the following diagnoses: female XY ( $n = 3$ ); cloacal anomaly ( $n = 4$ ); syndromic such as vaginal atresia ( $n = 4$ ) and abnormal androgen action DSD conditions such as congenital adrenal hyperplasia ( $n = 3$ ). Seven young women were interviewed, while six chose to complete the diary over a period of 1-5 months. Three young women used the diary structure as an aid when writing their thoughts, emotions and experiences, two completed some of the structured sections and one returned a diary of her own design. All the young women have been given pseudonyms.

### The meaning of bodily difference: Self-awareness and communicating this to others

Some of the young women were uncertain about how they had or how they could in the future gather facts about their

bodies. They believed this uncertainty limited their ability to define who they were and interact with the external world. For many, their knowledge about their condition was largely dependent on explanations from their parents. They were aware that while knowledge could be upsetting it might also help reduce their anxiety, satisfy curiosity and promote growth. When information had not been shared with them, which they interpreted was to reduce their anxiety, some participants reported uncertainty about what their bodies were capable of, which in turn increased their difficulty in talking about themselves with others. Several young women who did not have a uterus (resulting in amenorrhea) recalled that they would have valued being able to enter into conversations confidently with their peers about menstruation. They reported that since periods are a part of growing up there was an expectation they should know about them since they are a normal event for women, as Carla explained: 'females get periods but I didn't know the sort of information you might want to know what goes on, what to expect, what happens how you manage them.' Furthermore, knowing where to source information about themselves was not always sufficient; several young women reported needing confidence to be able ask professionals as Carla explained, "you need courage to do that, ask them about vaginas and stuff like that, it's an embarrassing sort of thing". A few participants explained that they might never feel safe or confident enough to confide any information about personal aspects of themselves with anyone; the risk was too great, as Brenda explained, "I'd never tell friends exactly what it is. I've told them bits but nothing too big that they could spread it around". Containing personal information gave her a level of confidence and control in her ability to minimize future intrusive encounters and to maintain her integrity. Conversely, three of the young women described positive experiences that followed sharing their story with others. Harriet, who described herself as a confident person, reflected on the acceptance she experienced when she shared her story with her classmates when she was younger:

It was in primary school, I wouldn't have done it in high school not talking about me like that. But everyone was pally, pally so I did a project about my condition, it's in the attic still I think. Everyone treated me the same afterwards. . .yes it felt good to do it, they weren't nosey about it afterwards

Sharing information within a partnership was considered by a few of the young women to be more difficult than talking to professionals or friends. In these situations the young women appraised their own bodies and worried that others might view them less positively as a result of their

difference. The young women who had not yet had a partner talked about this as an anxiety. Evelyn spoke about how the prospect of having to talk about herself with a partner 'makes me worry about having boyfriends and stuff', furthermore she was not sure how to develop her own confidence to have a relationship in the future. For those who had partners, resolving the dilemma of sharing intimate or personal information had taken the strength of character as evidenced by the emotions that were conveyed when they spoke about their experiences. Florence talked in detail about how she learnt to talk about herself, she reflected that in her mid-adolescence, she had spent a long time avoiding potentially intimate situations as she was worried about disclosure. She described how she negotiated telling her boyfriend and became very animated and a little tearful when talking about trust in the context of her relationship:

Oh it took a while [to tell him]. Soon after I met him he went away, so I said to my friend with whom I'm really close, I was like - 'What am I going to do?'...It was quite hard and I was like - 'Oh how is he going to take it, is he just going to run off or is he going to sit and listen and try to figure out?', but it eventually came out, in a roundabout way. I thought he was just going to be... unsure but he was so interested. I didn't expect him to be so interested because he asked me all these questions

The motivation to tell partners was balanced against the risk of the partner ending the relationship. The young women also worried about the consequences of having shared their story as they were concerned that their partner's curiosity would mean future in-depth discussions that they were not always ready to have. Florence described how conversations about her condition were navigated in her relationship:

Sometimes we talk about it but it's not something I speak about on a regular basis. We hardly ever, talk about it and if we do it's not like a proper conversation, it's a bit weird. . .Sometimes I talk about it and sometimes I don't really want to talk about it. He respects that, he doesn't judge me or anything so it's alright

Friendships and partnerships were described as important aspects of everyday life with the young women accepting that having a partner could result in intimacy.

### **The meaning of bodily difference: Actualizing intimacy**

Intimacy was described as both physical and emotional. The physical aspects were explained as holding hands, kissing, touching and, for a few of the young women, sex. Emotional intimacy focused on feeling loved and wanted by

their partner. Several of the young women had not entered into intimate relationships with either male or female partners. Two spoke about same sex partnerships and intimate relationships; three spoke about their experience of sex with male partners. Two young women were uncertain if they could have penetrative sexual relationships, while one was certain she could not since she had refused vaginal surgery for what she described as ‘one opening’. Three young women were worried that their reconstructive vaginal surgery would result in painful intercourse. Grace talked about her hope for a long-term relationship and how difficult, yet important, this was for her:

It’s hard for people like me to get a steady functional intimate relationship. Because if you think about it you’ve got your medical problems to explain for one and a lot of people these days are only out for one thing [sex] and you can’t just tell everyone that you can’t, things get round too fast. You have got to be careful. Everyone says you can have a decent life without a relationship, I don’t think that’s true. I’m sure there is, [someone like me] somewhere out there but I wouldn’t even speak to them about it all, because it’s just too awkward

Grace felt the risk of anecdotes being shared about her was very real; she alluded to having to be competent at judging others before feeling safe enough to disclose information about herself. However, for those already with a partner, the hoped for sexual spontaneity did not always happen, which was frustrating as Harriet struggled to explain:

In some ways yes, I’d like to be like all my mates... they are all doing it after a month but I don’t know, I’m not jealous, I’m far from jealous [about boyfriends] I’m just jealous of them having sex. I have been seeing someone for ages now and I’ve not been able to do anything with him do you know what I mean? He’s like – I’m not bothered. But it bothers me that he’s got to wait so long.. it’s twelve months we’ve been together now...I’m sure it’s not normal

For some young women, vaginally penetrative intercourse was not possible; this then had an impact on their belief about themselves as a potential sexual partner. For Harriet, this challenge resulted in a renewed motivation to continue with vaginal dilation that previously she had only undertaken intermittently since she felt it ‘didn’t work’. Intimate relationships had the capacity to provide strong emotional attachments for these young women and to fulfil their need to be cared for and loved by others and to give love in return. For the young women, finding a comfortable level of physical intimacy was an important part of their lives; some had achieved this, for others it was something they aspired to achieve.

### The meaning of bodily difference: Expressing meaning of altered fertility to self or professionals or partners

Altered fertility included the impact of previous reconstructive genital surgeries, the absence of a uterus, no periods and the possibility that getting pregnant could be hard because of the daily need for medication or poor medication compliance during early adolescence. One young woman, Joanne, expected that she could easily fall pregnant despite her complex surgery for cloaca and she was actively trying and having unprotected sexual intercourse with different partners. Many participants talked about the need to gain personal control over their body and its potential performance and limitations in intimate situations. Carla reflected on her uncertainty about her own fertility, as without a uterus, she knew she could not carry her own baby. However, she was hopeful that she could use a surrogate:

I think ‘worry’ is like off and on when you are thinking of certain stuff, like when my sister was having a baby. I love kids and I was always like – oh I want a baby and then you are like – but can I? Then it’s like alright I’ll just adopt, sort of thing I just won’t deal with it at all, I’ll cut it out and say – oh it’s ok I’ll just adopt sort of thing

Although a couple of the young women spoke about growing up knowing they could not have children, it became clear that initially this knowing was superficial and that a sense of realization dawned as they came to better understand their own body. Harriet talked about how her mother had made sure she knew she could not have children although she did not recall specifics about the conversation:

It was a while ago and to be fair it didn’t bother me as much as I thought it would. I didn’t have periods still [when she told me] and then I was thinking back to when I was younger, people were saying – ‘can you have kids?’ I was like – ‘yes’. ‘Do you have periods?’ No! So then you just get it, I knew, I just knew in the end I wouldn’t be able to have them

Two young women spoke about never wanting children and one was worried she might pass her condition on to her child if she could have children. A few young women discussed adoption as a solution to altered fertility but this was not explored in detail; perhaps reflecting their sense that there was no real urgency to think about this in their immediate future. Humour was described by a couple of the young women as a strategy they used when talking about infertility with their peers, in an attempt to not let their friends ‘feel sorry’ or ‘be sad’ for them. For the two young women in same sex relationships, infertility was only

mentioned briefly in the context of their partner possibly being able to carry a pregnancy. Two young women recalled comments from professionals for example; 'no one would guess you dilated' as unhelpful comments. While conversations of surrogacy briefly gave a sense of optimism, the young women considered that having time to adjust to what infertility meant for them, as a person was important and could be missed by professionals.

## Discussion

Learning to understand and anticipate the risks associated with sharing aspects of their bodily difference and keeping themselves safe were integral to the lives and experiences of the young women in this study. Keeping the core aspect of bodily difference or infertility private until they understood the risk in publicizing this information aligns with Maslow's (1968) concept of safety. When they chose to disclose such information, they had considered risk, safety and the benefits of sharing. The benefits included the opportunity to further define themselves and 'facilitate their growth towards mastery' (Maslow 1968, p. 49). In the context of this study, our interpretation of mastery focuses on how they developed their insight and their physical and emotional comfort in sharing information. Developing a vocabulary that was personally meaningful and which they could use with professionals and adapt when talking to friends and partners was part of their 'growth towards mastery'.

During adolescence, all young women are faced with managing peer relationships, understanding gender roles and negotiating transitions in many areas of their lives (Slater *et al.* 2001) to move towards a sense of being. In some senses, the 'sense of being' (Maslow 1968) is similar for young women with DSD and their peers without a DSD. It can be argued that the body of a young woman with DSD – as a human body – is perhaps not radically different since it is a vehicle that provides the material for subjectivity, thought, emotion and language all of which are essential in creating meaning from experience (Cromby & Nightingale 1999). However, while the inner nature of young women with DSD inevitably shares some characteristics with other young women, such as the desire for a relationship, some features are unique to them as a group and to them individually. As the young women in our study undertook the work of trying to define their sense of identity, there were times when appreciating their bodily difference (Satinsky *et al.* 2012) and learning to value themselves despite their functional differences was very difficult. Some of the uncertainty, insecurity and confusion they expressed about who they are and how they fit in friendship groups and society relates to

their development of personal identity (Erickson 1995) and there was a sense that better communication could have supported this development. The young women reflected on the frustrations they had in respect of communication with health professionals. As their bodily difference or infertility could not be cured, they said that health professionals should be prepared to have ongoing conversations with them especially during the key stages of development. They acknowledged these conversations might be 'difficult' and would need to be underpinned by empathy.

The concerns the young women expressed about their desire for intimacy can be seen to be linked to the wider concept of attachment and as Collins and Freeney (2004) found, relationships that frequently satisfy the desire for intimacy lead to more secure attachments between partners. Many of the young women wanted to be able to confidently share the essence of who they were with others to feel secure in a relationship. A few of the young women were not ready to do this or actively shied away from exploring relationships. Maslow (1968) suggests that if the capacities to be loved or to give love are unused, this may diminish the ability for the self to grow. Our findings show that having a DSD created additional challenges to those that commonly confront young women as they mature and work to strengthen their personal identity. The young women coped with these challenges by being guarded about their bodily difference. Over time and as a result of safe friendships and positive experiences, many of the young women were able to control the degree to which they allowed their DSD to define them.

Most people, including adolescents, actively seek human companionship (Biordi & Nicholson 2009) and friendships since both can offer an anchor to community and culture. Belonging involves a sense of relatedness to other people and it is deemed to be fundamental to social well-being (Biordi & Nicholson 2009); this was the case for the young women in our study who talked of wanting to achieve safe and secure friendships or relationships. Some of the young women guarded personal information as a form of self-preservation to protect themselves from the potential hostility or bullying they anticipated they might encounter from others. This notion of guarding information has resonance with practices of transgendered young people in work by Goodrich (2012) and Baiocco *et al.* 2012 and is also seen in Anderson *et al.*'s (2014) findings on concealment reported by patients with bladder exstrophy. Disclosing information was considered risky due to inability to retract this information once it was in the public domain.

Bodies are intimate places where nature and culture meet (Cromby & Nightingale 1999) and differences from the

norm raises curiosity from people in peer groups and the wider community. There were times the young women were frustrated and angry that their body did not function in the ways they 'just wanted it to'. Spontaneously entering into intimate relationships with the same sort of abandonment they perceived occurred with their peers was a desire for at least two young women. Although they did not condone the risk-taking behaviours that their friends reported, they felt cheated that they did not have similar choices. Maslow (1968) proposes that learning about our strengths and limitations and by meeting challenges, failing and experiencing hardship creates the opportunity for growth. This was the case for a few of the young women who had had intimate relationships. While failure to achieve the sexual intimacy had been physically and emotionally painful for a couple of the young women, the respect and thoughtfulness of their partners had enabled these young women to remain positive about their futures.

### Limitations

The use of two methods to collect the young women's experiences will inevitably have shaped these data as the young women using the diary had the opportunity to amend and remove entries and to participate at their own pace and had more control than in even the best managed interview situation. While the advisory team participated in the research process and gave advice and engaged in early data analysis it was difficult to sustain their engagement since the research spanned a year and during this time their lives moved on. There was a lack of ethnic diversity in our participant population and this needs to be given consideration in future study design.

### Conclusion

Findings from this study suggest ways both individual professionals and DSD multidisciplinary teams could focus on trying to better understand the essential needs of young women with DSD and how they can be fulfilled. Health professionals should not assume that the young women they are caring for are knowledgeable about their condition, confident about talking about issues of concern or have a vocabulary that helps them to explain their differences to friends and partners. Nurses should be offering the young women they care for sensitive information, education and support tailored to their individual needs and developmental stage. Nurses should facilitate conversation with and between young women with DSD for them to explore any frustrations

and uncertainties; this could reduce anxiety and isolation. Encouraging young women with DSD to access the sort of support their friends may be using (e.g. school counsellors) could help normalize their engagement with health services.

Health professionals need to consider taken-for-granted assumptions, such as those relating to sexual intimacy; some of the young women felt that health professionals assumed they would be in heterosexual relationships while some were in same sex relationships. The development of attachment, intimacy and identity are inextricably linked. Health professionals should acknowledge the impact that bodily difference has on young women's ability to build a secure identity and adjust to the meaning bodily differences have to them and the impact of their infertility.

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### Conflict of interest

No conflict of interest has been declared by the authors.

### Author contributions

All authors have agreed on the final version and meet at least one of the following criteria [recommended by the ICMJE (<http://www.icmje.org/recommendations/>)]:

- substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data;
- drafting the article or revising it critically for important intellectual content.



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