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**How young people talk about their variations in sex characteristics:
Making the topic of intersex talkable via sex education**

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ABSTRACT

Classrooms are important spaces for young people with variations in sex characteristics and for their classmates. Sex education can promote agency and well-being by helping young people make sense of their embodiment and form rewarding social relationships and by changing societal understandings about variations in sex characteristics. Realising this potential however may hinge on how sex education makes intersex (un)talkable. We draw on interviews with 22 young people on how and why they try to make their variation in sex characteristics talkable with others. By focusing on how they talk to others and why they do not talk to others, this research highlights how participants ‘fear rejection’ but need to talk to others about their variation in the process of ‘dealing with it’. Participants also struggle with ‘secrecy versus privacy’ and how to ‘communicate strategically.’ Findings acknowledge the emotional work required of people with variations in sex characteristics when making intersex talkable. The analysis points to the role of both talking and silence. We conclude by envisaging a norm-critical sex education that engages with the responsibilities of both talking and listening, shifting the burden away from individual young people with variations in sex characteristics and working towards more mutual social relationships.

Keywords: intersex, sexuality education, diverse sex development / DSD, communication, norm-critical

Introduction

Including intersex in sexuality education brings together two highly politicised questions. The first question is whether 'intersex' is best framed as a set of medical conditions or Disorders or Differences of Sex Development (DSD) (Lee et al. 2006, Lee et al. 2016), or whether intersex variations might be understood in a less medicalised way. Young people with variations in sex characteristics often experience paediatric healthcare that is the object of a globalised stand-off between medical and human rights bodies (Carpenter 2016, Davis 2015). Parties on both sides of this debate agree that promoting wellbeing for young people with variations in sex characteristics is important, but differ in opinions regarding the adequacy of current medical frameworks for promoting this (Lee et al. 2016, Ghattas 2015, Rubin 2017). The second question refers to the contested field of sex education itself. Sex education is mandatory in many countries, but its practices have been contested throughout its history (see e.g., Irvine 2004, Moran 2009)¹. Ideologies shape which school children should be taught what, how, when and by whom. Current educational practices are informed by conservative, liberal and feminist/postmodern discourses (Sherlock 2012, Jones 2011). Diverse theories have given rise to different didactic strategies to reach very different goals, whose effectiveness is not always evidenced (UNAIDS Inter-agency Task Team on Young People et al. 2006). Sex education is a messy business with or without consideration of intersex. Sex education classrooms are important spaces for youth with variations in sex characteristics as much as for their classmates (Enzendorfer and Haller 2020, Breu 2009), but classrooms have received far less attention than clinics in intersex studies.

The current research is situated in northern Europe, where liberal sex education aims to promote a positive and shame-free attitude to sexuality by emphasising sexual rights and sexual health. A liberal approach to sex education advocates giving young people information to enable informed and autonomous choices (McAvoy 2013). Similar goals concerning children's developing autonomy, such as the right of self-determination, have become central to human rights arguments against continued medical interventions on intersex traits (Carpenter, 2016). These concerns can be expanded however to consider autonomy over the use of language and terminology (Carpenter 2016, Breu 2009) and sexual and reproductive human rights (Kanem 2019). In other words, including the topic of intersex in sex education should promote something that both doctors and human rights advocates value: agency and well-being for young people with variations in sex characteristics in their everyday lives. This paper contributes to imagining such education by drawing on interviews with young people, attempting to do justice to the complexity of their voices and engaging sex education policy and practice with a mediated understanding of how young people experience and understand their own agency within and beyond sex education classrooms.

¹ Irvine (2004) and Moran (2009) examine the history of sex education in the 20th Century U.S. context.

Promoting visibility, awareness, agency and mutuality in sexuality education

Several calls have been made to include the topic of intersex in sexuality education in order to promote visibility and raise awareness (Breu 2009, Enzendorfer and Haller 2020, Koyama and Weasel 2002) and to counter the silence around variations in sex characteristics in an understanding that this silence is embedded in the culture into which children are socialised (Enzendorfer and Haller 2020, Breu 2009, Jones et al. 2016). This aligns with a more general argument that sex education should provide young people with correct and useful information about human sexuality (Aggleton and Campbell 2000). Two important goals of including intersex in sex education are: first, to recognise the existence of young people with variations in sex characteristics who may then feel that they are not alone (Breu 2009); and, second, to increase awareness and acceptance in students with no prior knowledge of variations in sex characteristics (Enzendorfer and Haller 2020). Achieving these goals could promote individual wellbeing and intervene in the social contexts in which children grow. It seems important to intervene on settings where fear of bullying from peers in school, combined with lack of awareness of variations, can make normalising forms of surgery appear necessary (Breu 2009).

Providing young people with sex education information is not straightforward, either generally (Aggleton and Campbell 2000, Allen 2004), or in specific relation to intersex (King 2016). Educating about intersex can be problematic in a number of ways such as when medicalised perspectives are foregrounded (Enzendorfer and Haller 2020) and when a voyeuristic or exoticising perspective is taken (Enzendorfer and Haller 2020, Koyama and Weasel 2002, Brömdal et al. 2017). It would also be problematic to use the topic of intersex only to deconstruct binary sex or to take an 'othering' approach that assumes people with intersex characteristics are not in the classroom (Koyama and Weasel 2002). For example, Brömdal et al. (2017) describe how a television programme with the intent of raising awareness of intersex variations can have stigmatising effects instead.

Because sex education should empower young people in their everyday lives (Allen 2005, Aggleton and Campbell 2000), theory and practice must come together in order for intersex-inclusive sex education to be successful (Koyama and Weasel (2002). 'Banking' information about sex in education, in which students receive information top-down to fill an assumed deficit in knowledge (Freire 1972) may not do the job of empowerment, not least because knowledge about sex is organised by actively produced silences (Sedgwick 2008, Foucault 1978), about women's sexual pleasure and LGBT identities (Fine 1988, Fine and McClelland 2006) for example. For a classroom to become a 'crucial public forum' (p. 103) that can enable self-determination and agency, silenced topics must become talkable (Breu 2009). Contexts where the hetero-, binary cis- and endonormativity that underpin sex education are not talkable are of particular concern. In these contexts, it may be difficult to broach the topic of intersex without activating a warning that some things are dangerous for young people to know about (Brömdal et al. 2017, Enzendorfer and Haller 2020, Jones et al. 2016).

McAvoy (2013) argues that education that goes beyond information-giving should engage with young people's understanding of themselves as subjective beings

living within social and normative contexts. Such education enables young people to recognise and criticise values, reject privileges and perceive moral obligations arising in relationships and interdependences with others. In other words, sex education cannot only be about individual empowerment, but must refer to the agency experienced through mutuality. This is consistent with suggestions that intersex-inclusive sex education should help students think about how they are implicated in relations of power (Brömdal et al. 2017) and how they and their lives are framed by stereotypical ideas about gender and sexuality (Breu 2009). Such sex education could conceptualise human life as a process of embodied becoming (Roen 2009), with the understanding that intersex variations are always possibilities for embodiment.

Making things ‘talkable’: young people’s (communication) needs

Making gender and sexuality talkable is part of becoming a sexual subject; it can involve making things intelligible to oneself in a normative context (Austin 2016) and being able to communicate with friends or partners (Montemurro, Bartasavich, and Wintermute 2015). Concerns and normative understandings become apparent when trying to make things ‘talkable’ both in everyday life and in research (Weeks 2011, Montemurro, Bartasavich, and Wintermute 2015). Not being able to talk about something can engender shame and a sense that something or someone, such as the self, is unintelligible due to being misaligned with conventional norms or understandings (e.g., Montemurro, Bartasavich, and Wintermute 2015).

The research described in this article engages the dynamic between what is talkable and what is not talkable in relation to sex characteristics. We understand that many people with variations in sex characteristics find communicating with others challenging, especially when it comes to talking to peers, such as friends and classmates and (potential) partners (Jones et al. 2016, Sani et al. 2019, Schweizer et al. 2017, Frank 2018, Liao et al. 2010, Engberg et al. 2016, Carroll et al. 2020). Some people fear being devalued (Alderson, Madill, and Balen 2004) or rejected (Ernst et al. 2016, Frank 2018, Guntram and Zeiler 2016) and some have experienced negative or unhelpful responses from others (Jones et al. 2016, Ernst et al. 2016, Malouf et al. 2010). These experiences have led some to avoid or limit relationships with others (Guth et al. 2006, MacKenzie, Huntington, and Gilmour 2009). However, others report having support and positive responses from other people (Ernst et al. 2016, MacKenzie, Huntington, and Gilmour 2009, Jones et al. 2016, Malouf et al. 2010, Davis and Wakefield 2017). Overall, a growing body of research points to the challenges and opportunities faced by young people with variations in sex characteristics in relation to talking about their variation. Such communication issues are precisely the kinds of everyday concerns that should be addressed in order for sex education to be effective (Skarpås 2010). Accordingly, we asked young people with variations in sex characteristics how and why they try to make their variation talkable with others, especially friends and partners.

Methods and Materials

Ethics and Participants

This study is part of the SENS research project, which involved interviews with clinicians, young people with variations in sex characteristics and parents. This research was titled SENS because it took place in Scotland, England, Norway and Sweden and focuses on how people make sense of variations in sex characteristics. The UK-based aspects of the research were approved by the National Research Ethics Services: NRES Committee London/West London (REC: 11/LL/0385); the Joint Research Office at University College London Hospitals (R&D Project ID: 11/0143) and the Ethics Committee at the University of Surrey (EC/2012/52/FAHS). The aspects of the research that took part in Sweden were approved by the Regional Ethics Committee in Stockholm (2008/1671-31/3). All participants were guided through the information sheet and the consent form, with the project subscribing to an ethics of care as well as of justice (Edwards and Mauthner 2012).

The study participants were 22 young people aged 15-26 years ($M = 21.6$) in Sweden ($n=10$) and the UK ($n=12$). All had been assigned female at birth and all but three identified exclusively as women. Participants reported their diagnoses as gonadal dysgenesis ($n=7$), androgen insensitivity syndrome (AIS, $n=6$), congenital adrenal hyperplasia (CAH $n = 5$), chromosomal mosaicism ($n=1$) and Mayer Rokitansky Küster Hauser Syndrome (MRKH, $n=1$). Six participants reported being in a relationship and 14 either reported they were single or did not indicate their relationship status.

Procedure

The first author conducted one-to-one in depth semi-structured interviews in places convenient to the participants. One participant preferred to be interviewed together with a parent. The interview guide addressed questions about life in general, social context, experiences and thoughts about health care and the future. During the interviews, follow-up questions were used to explore issues that young people considered important. Interviews were audio-recorded, transcribed and anonymised. Elsewhere, we have reported on other aspects of the interview data, such as the participants' experience receiving a medical diagnosis (Lundberg et al. 2016) and their preferences for terms to use when talking about their variations (Lundberg, Hegarty, and Roen 2018). Here, we report on how and why participants make their variation talkable with others.

Data Analysis

Data analysis occurred in two phases. The first author coded all interviews using inductive thematic analysis (steps 1-2 as outlined by Braun and Clarke 2006) aided by NVivo software (version 11 for Mac, by QSR International). The first author then developed a code list structured by *in vivo* codes that were later organised into overarching 'parent codes.' Data coded under the parent code 'To talk about it with

others’ were analysed by the third and the first author, applying steps 3 – 4 in thematic analysis (Braun & Clarke, 2006). The third author summarised what was being said in relation to communicating with others in the interviews conducted in English. Drawing on this analysis, the first author analysed the Swedish data. Throughout this process, the first and third author re-familiarised themselves with the interviews to make sure that all relevant data had been included. The draft results were discussed within the research team before themes were finalised.

Findings

The analysis is organised by four themes (see Table 1). First, telling others about one’s variation did not elicit positive feelings for all as, for some, it elicited ‘fear of rejection.’ Second, participants explained that they might need to talk to others about their variation as part of the process of ‘dealing with it.’ Telling others was also related to developing closeness with friends and partners, but was experienced as a burdensome obligation described in the theme ‘secrecy versus privacy.’ Finally, participants developed a range of strategies of navigating normative expectations to be able to talk about their variations described under the thematic heading ‘communicating strategically.’

Table 1.

Overview of themes

Themes
Fear of rejection: Worry in relation to friends and partners
Dealing with it: Relating to oneself with the help of others
Secrecy versus privacy: The obligation to tell others in order to be close
Communicating strategically: Navigating normative expectations

Fear of rejection: Worry in relation to friends and partners

Medical and human rights perspectives as to what is best for young people with variations in sex characteristics all acknowledge the risk of stigma. Some young people explained how their bodies made them feel not ‘normal,’ and expressed ‘a bit of a fear’ or ‘worry what other people are going to say’ because of their variation. They feared judgment from others because ‘people make snap judgements and perceptions so easily.’

For some, such worries were influenced by past negative experiences. One participant’s ex-boyfriend ‘freaked out a bit over it’ and ‘that’s made [her] a bit

cautious' about talking with others. Understandably, participants described wanting to be 'a normal teenager' in response to the threat of being stigmatised. Experiences such as not being able 'to become pregnant,' 'missing school,' not 'having periods' and 'wearing hormone patches' created situations in which privacy needed to be managed. Some described strategies to explain school absences and some pretended to have periods. Many feared that telling friends about their variation would risk social exclusion or gossip. One participant worried that being talked about behind her back might 'affect my relationships with people in general [...] I felt very paranoid the whole time. I just never felt comfortable.' Another participant was worried that, after telling friends, those friends would act and talk differently around her whilst she did not 'want it to kind of change their view.' These comments resonate with other research documenting the experience of stigma reported by women with congenital adrenal hyperplasia (CAH) (Meyer-Bahlburg et al. 2017).

The expectation of rejection is recognised within psychological literature and minority stress research (Frost 2011, Holman 2018) as presenting a significant challenge. In this study, telling (potential) partners was described as a central concern for most participants. Several participants feared rejection by partners and one who had just entered a new relationship explained that she was still 'just too nervous to have the conversation.' Another said that 'it is one of my most intense phobias, to be rejected [...] Or that they will think that I am weird and abnormal really.' Whilst telling (potential) partners was important, it was considered 'very, very difficult'. Disclosure seemed to be risky for participants.

Dealing with it: Relating to oneself with the help of others

Why might young people have a need to communicate about their variation if all they want is to be normal and for their relationships to be unchanged? Not all participants felt that they 'need to talk about it.' Some participants said that they 'never feel that different [...] compared to others' or 'early on decided that this should be only a part of my life and not all my life'. For other participants, however, talking with others can be part of the process of coming to terms with one's own embodiment. Many described the need to make their variations talkable particularly to get support in dealing with negative feelings and thoughts in relation to their sex characteristics.

Some had internalised very negative views, using strong language to refer to themselves as 'a freak-show,' or saying that 'if I saw myself as a commodity I'd be [...] a very rubbish one'. One said that having this variation was 'a scandal.' Others expressed being 'sad' about being different or spoke of handling their negative feelings by just avoiding talking about it or making it a 'blocked-off section' in their life. Despite having a range of positive and negative views of their own variation, some participants were aware that people with the same variation lived successful lives. However, participants' self-image was not necessarily enhanced by such positive role models.

Some participants described how struggles to accept themselves and openness about their variations had a mutual relationship with each other:

It is like there is a stop within me and I can't let anyone else in [...] I know that this is something I want. Yes, being close to someone and... But it is just that... I guess it is up here really, the psychological, to let someone in.

Participants' accounts suggest that a future without 'letting someone in' was not a very 'open' one. Some explained how 'the idea of ever marrying someone just seems like something that's never going to happen' and how they do not 'really get into [relationships] because I am a bit too fearful about it at the moment.' For some participants, closing down present and future relationships seemed to be the cost of non-disclosure.

While some participants felt inhibited talking to others, due to their negative view of themselves, others had formed friendships or romantic relationships despite their fears. Participants with positive relationships with others who were aware of their variation, described how they could turn to those close relationships when they needed support:

I have two friends that I usually talk with [...] when something feels hard or something like that. And then you usually call and you might be sad. And then 'yes, what are you sad about', 'Well, that thing you know, that thing' And then they just know what you mean.

One described how she and her partner both knew about, but avoided talking about, her variation, which was why they could have a positive relationship. Another said that 'it has been really hard to say it. But it has always gone very well [...] So, I guess I have been quite lucky there.' Another participant explained that: 'the more I tell my friends, the stronger I grow in having this [...] it has helped me grow.' This same participant mentioned that feeling accepted by friends and family contributed to her self-acceptance. Others said that self-acceptance was important for their well-being. One who was actively involved in an LGBT community described how that community as 'always very, very accepting' of her. Two participants with similar variations sought help together, sharing the process of finding out about their diagnoses.

Some participants described good relationships with parents and family members as providing the support they needed. However, many described talking to parents becoming less comfortable with growing independence: 'I was obviously at that age where I like I found it really hard to talk about things anyway with my mum and dad.' For others, it remained embarrassing or difficult to talk to parents or family members, leaving some feeling 'very much on my own.' In these situations, connecting with friends and partners might be an even more important source of support.

In sum, participants conceptualised coming to terms with their embodiment as something that they had to do alone or could only do in mutual relationships with supportive others. However, participants also found silences – from knowing partners and friends – to be important.

Secrecy versus privacy: The obligation to tell others in order to be close

In addition to talking in order to seek support, several participants said that they thought telling others honestly about their variation was an important part of having a close relationship. Most participants described situations in which talking about their variation had been important in getting closer to others. Participants experienced day-to-day situations, in friendships, where talking about their state of being would be

ordinary, such as when going through treatment or when they were struggling. One participant explained that if they became moody because of changes in medications, it felt good to tell friends who might then be forgiving if they lost their temper.

One participant had experienced a period of severe depression but said that a colleague of hers 'kept in contact basically [...] so I got to a point where I was quite comfortable and she's basically told me that it doesn't matter what I tell her, it's not gonna change the fact that we're friends.' Not all participants felt comfortable talking with friends and 'not talking' could be understood as problematic. One had lost friends because she often felt depressed and never opened up to them. She was afraid that other people might get the sense that 'I do not consider them important enough to tell them these things, but that is not the thing. It's my inner problems that make me unwilling to talk to them.' Some participants found they were in a no-win situation where they felt obliged to talk to others about their variations.

Friendships could bring about casual conversations about having and not having children. Several participants said that knowing about their own infertility was burdensome and was something their friends never had to think about. Participants described infertility as something important for others to know about. Some participants used infertility to open up talk about their variation naturally. One described a discussion with her friends about having kids in the future and said that 'when it came to my turn it was like, well if I had I'd have to adopt 'cause I can't have kids naturally.'

When beginning an intimate relationship, participants often felt stronger pressure to talk about their variation. One participant said that it would be very 'weird to keep, or I mean hide something like that away when you are in a relationship [...] when you are supposed to build some kind of trust' and another felt that not telling their partner invoked a feeling of 'going around carrying something that is a very, very huge part of me that they maybe should have known when "they chose me." One said that if 'it does turn into quite a serious relationship in the future, it's like, it's down to both of us [...] it would affect both of us.' Infertility, possible effects on sexual intimacy, making sex difficult and lower sexual desire were all mentioned as important reasons to tell a partner; important matters that a couple would need to talk about.

In related work, we have described how parents of young people with variations in sex characteristics work out when and how to talk about their children's variations (Lundberg et al. 2017). Similarly, young people themselves asked of their relationships, 'when is a good time?' and 'is it after a year or is it after two years or three years, or, you know, when they propose to you or just a week before you get married?' Several participants described talking to others as an obligation. One said that not having told a partner 'gnaws within you until you have said it basically [...] you feel like a hypocrite if you do not say it.' Another participant felt she was 'going in with this lie' in the relationship. This meant that while some participants understood that they were perhaps protecting their privacy rather than being secretive, social norms around openness and honesty meant that they 'can't ever go into a relationship with someone guilt free.' It appears that the requirement of talking to others about one's variation can become an emotional burden.

Communicating strategically: Navigating normative expectations

Some of the normative expectations talked about in detail were gendered. Participants gave examples of how societal norms regarding women, sexual intimacy, bodies and fertility impacted on them, influencing their attempts to communicate about their particular experience. Some explained that they needed to handle partners' normative and gendered understandings of women, as when a participant's partner expressed that 'every woman wants to be taken care of [...], men want a woman to have a baby with.' Concerns about telling others were exacerbated in strongly heteronormative communities where 'it's kind of very built around, [...] early marriage and having lots of kids.' One participant had experienced instances of university lecturers talking insensitively about infertility whilst assuming that no one present experienced it personally. Some participants described instances where they had expressed resistance to norms of womanhood or motherhood only to find that others reacted negatively, closing down the conversation. One participant elaborated on this, commenting: 'sometimes the reaction to the fact that, um, that I can't carry children makes me think, oh my god if they knew the other bit, what would they think about that?'

Normative understandings of binary and gendered embodiment also brought difficulties and these understandings were reified in school. As one participant explained:

I have XY chromosomes, [...] I just do not want anyone in any way to think that I have, that I am half man you know. And if you do not have enough information, you might easily believe that. Because that is what you still learn in school [...] And I absolutely do not want that.

Another person described how physical development was explained at school as 'a linear thing, it was boys develop this way, girls develop this way' during sex education. Another explained that when they talk to others it is like 'a whole new world' opens up for the people listening, a world that is not usually mentioned in school. Communicating strategically with others thus seems to be contextualised by the absent, or very limited and misleading, discussion of intersex characteristics in sex education. Media interventions were not always helpful in this context. One participant referred to a television show describing someone born with intersex characteristics in an unrealistic and problematic way and later experienced her colleagues discussing that particular show and 'talking about something [they] don't understand.' While the television show might have been intended to increase awareness, it only made her more cautious about talking with her colleagues about her own variation.

Participants showed awareness of how norms and ignorance structured their social worlds, prompting them to develop communication strategies such as 'choos[ing] my phrasing quite carefully,' and tending to 'leave out the medical diagnosis.' A strategic approach to information management was necessary because 'if I tell someone and then they go, [...] and Google it and then they read sort of stuff about the wrong thing, I don't want them to sort of be like, oh my god like what's

happening.’ One said ‘it is better to explain than people [Googling it] [...] then I can explain, that this is the way it is.’ In conversation you can ‘just drip feed... information, so little bits at a time.’ Others used humour as a communication strategy, ‘Cause it’s a lot easier, isn’t it, to make everything into a joke. [...] Like when people start to complain about their periods and stuff and so it’s like, make a joke about that.’

Several participants shared details very selectively using language such as ‘there was a problem when I was born,’ ‘I can’t carry children,’ or talked about some aspects of the variation, such as having cancerous gonads, but not other aspects. One described her strategy of ‘start[ing] off with what I consider the easy stuff for people to hear.’ Another said that talking about it once had made it easier for her the second time. She also found that it felt easier to talk with some people than with others.

Several participants also mentioned ways they did not want people to respond. They indicated that responses should not be negative, exoticizing or stigmatising, but neither overly conciliatory. Some participants explained the importance of having their feelings and experiences validated, whatever they might be.

Discussion

The aim of this study was to explore how and why young people with variations in sex characteristics try to make their variation talkable with others, especially friends and partners. The results indicate that there are several ways young people try to make their variation talkable, such as communicating strategically. There are also several reasons why they wanted to do this, such as getting support and developing close relationships. However, many did not talk to others because of a fear of rejection or needing to deal with normative or inaccurate expectations. Many also felt an obligation to talk to others in the context of building close relationships.

What do these findings tell sex education policy makers and practitioners? On the basis of our analysis, we suggest that the comments of the young people we interviewed point to three key directions for change.

First, by starting with the lived experiences and grounded insights of young people with variations in sex characteristics, we see that agency takes shape in relationships with friends and partners, as well as family, in larger cultural contexts. As psychologists, we understand that the ability to talk with others and to share information about oneself can be fundamental to psychosocial well-being (Roen 2019) and that development happens in an ecological context (Schweizer et al. 2017). Our findings resonate with others by showing that talking to others about variations in sex characteristics is framed by fear of rejection (e.g., Jones et al. 2016, Alderson, Madill, and Balen 2004, Sani et al. 2019, Guntram and Zeiler 2016), limited social understanding of intersex characteristics (Enzendorfer and Haller 2020, Breu 2009, Jones et al. 2016, The European Union Fundamental Rights Agency 2020, Liao 2003) and problematic understandings of gendered embodiment as binary (Brömdal et al. 2017, Guntram and Zeiler 2016). Some young people want to talk about their variation because they want to connect with others, derive support and talk about their future, including honest talk with partners (see also Ernst et al. 2016, Liao 2003). Participants described how others’ talk with and about them and how their embodiment impacted their own self-regard. These data are consistent with calls to research the stigma

associated with variations in sex characteristics as something akin to ‘minority stress’ that originates in social contexts and is not inherent in variation itself (Lee et al., 2016).

Second, rather than more information, young people with variations in sex characteristics seem to want respectful listening which can include the kind of silence that signals tacit recognition and gives another space. Factual information in sex education classes, in university lectures, in medical diagnostic terms and on Google were all described as making it harder to enact agency in particular social contexts. These data call not for a liberal approach to sex education focused on giving information, but a norm-critical one, built on feminist and postmodern thinking ‘examining different societal norms and how they affect people on an individual, group and societal level’ and learning ‘to notice and challenge the norms that frame what is considered “normal” and thus what is, unconsciously, understood as desirable’ (RFSU 2016, 23). Some might describe such a norm-critical approach as ‘confront[ing] the queerness of intersex’ (Breu 2016, 76), although this could be an uncomfortable framing for most people with variations in sex characteristics who do not identify with any notion of queerness.

Third, it was the taken-for-granted ideas about identity, embodiment, sexual practice, relationships and full disclosure that were referenced by the participants explicitly and assumed in this study. These are the norms that must be explored and deconstructed to enable mutual agency. What young people seem to be asking by way of norm-criticality is a re-alignment of norms about what is said and what goes without saying in conversations, so that the agency in both disclosing information and in withholding information are recognised. Accordingly, we advocate the use of norm-critical approaches to distinguish between different forms of silence. The untalkability of intersex that fear brings, is not the same silence as the one that occurs because your friend tacitly understands why you are upset or your partner understands what you do not want to talk about. Silence is part of the structure of the discourse of sex education, not the limit of that discourse (Foucault 1978, 27).

We agree that sexuality educators have a role to play (see Table 2) not only in providing information, but also in promoting certain kinds of agency by fostering autonomy and mutuality (McAvoy 2013) and we understand this to be related to achieving human rights for people with intersex variations (Kanem 2019, Breu 2009, Carpenter 2016).

From this norm-critical perspective, the critique of certain kinds of information including medical accounts, is not simply grounded in the understanding that those kinds of information are stigmatising or pathologising (Enzendorfer and Haller 2020, Koyama and Weasel 2002, Brömdal et al. 2017). Rather, the recognition that young people with variations in sex characteristics need others to mutually enact agency in support, means that sometimes the best thing others can do is to silently concede the floor in the conversation rather than speak the truth of an expert scientific discourse. Indeed, in relation to the theme “secrecy versus privacy”, the young people we interviewed were often undone by a norm of being truthful, which they experienced as an uncomfortable obligation to tell others, particularly in intimate relations. We are cautious about overvaluing disclosure in ways that might strengthen this norm and fail to take account of the fact that the norm of truthfulness asks more of young people with variations in sex characteristics than it is reasonable to ask. It is clear that young people with variations in sex characteristics are required to do a lot of emotional work

in mutual social relations by having to make their variation talkable. Norm-critical sexuality education that engages the responsibilities of talking and listening supportively with peers with variations in sex characteristics could shift this burden into mutual social relationships rather than finding it in the relationship between a body and a norm.

Table 2.

Implications for sex education policy-makers and practitioners

	Principles and understandings	Actions
Educational approaches	Information-giving approaches risk presenting medical discourse as truth and pathologising people with variations in sex characteristics. Norm-critical approaches open up questions about social norms relating to the sexed body and relationships.	Support students to think about bodily norms and variations in a way that questions presumed norms and normalises otherwise stigmatised variations
Talking and agency	Understand that any sex education class may include a young person who has a variation in sex characteristics and may chose not to talk about it. Prioritising youth agency in a sex education context specifically means prioritising the agency of young people with variations in sex characteristics.	Ensure that students have the choice to talk about, or not talk about, their own variation in sex characteristics, with both of these options being valid and respected.
Listening and mutuality	Understand that talking about variations in sex characteristics can create an emotional burden for some young people and opportunities for listening and mutuality may be at least as important as talking. The topic of intersex might best be considered in relationship and dialogue between people, not as a topic or phenomenon to be exoticised.	Find ways for young people in classrooms to listen to accounts of others and to reflect on how other people in the classroom might be affected by one's own comments and views.

Limitations

This qualitative study is based on a small convenience sample with participants who were all assigned female at birth, meaning that conclusions are limited in their application and relevance to other people and contexts. In interview, several participants talked on their own initiative about how future forms of sexuality education might develop and if we had asked more explicit questions about this, participants may have given more elaborate responses.

Conclusion

Young people make their variations talkable by communicating strategically. They do this in order to build and maintain relationships and to seek support. While being able to talk with others about one's own experience is important for psychological well-being, it is also important that young people are agentic in this process rather than feeling obliged to share personal details with others. Young people with variations in sex characteristics may best be met with respectful listening. In sex education, taking a norm critical approach can create space for the kind of talk that is neither medicalising nor exoticising and the kind of silence that communicates tacit recognition.

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