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Moving Intersex/DSD Rights and Care Forward: Lay Understandings of Common Dilemmas

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Abstract

When sex characteristics develop in ways that do not conform to binary models, dilemmas arise regarding how to understand the situation and what terminology to use to describe it. While current medical nomenclature suggests that it should be understood as a disorder of sex development (DSD) prompting medical responses, many describe intersex as a human variation in sexed embodiment that should be protected under discrimination laws. These opposing perspectives suggest different principles to employ in responding to dilemmas about gender assignment, early genital surgery and full disclosure of medical information. In this discursive psychological study, we explore how lay people, without prior knowledge or experience of intersex/DSD, make sense of these dilemmas and the underpinning discourses giving rise to how they talk about these situations. By using the discursive framework of ideological dilemmas, we analyse how people make sense of sex and gender (as binary or non-binary), how they deal with difference (as problematic or not), and how they understand who is in a position to make decisions in such situations. We conclude that engaging with dilemmas in-depth is more constructive than favouring one principle over others in moving social science research, reflexive clinical practice, and wider political debates on intersex/DSD forward.

Keywords: intersex, disorders of sex development (DSD), human rights, ideological dilemmas, health care, legislation

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Different terms are used to refer to anatomical, chromosomal and hormonal sex characteristics that do not conform to binary models. Medical professionals typically use *disorders of sex development (DSD)*, a term suggested at a medical consensus meeting in 2006 (Lee, Houk, Ahmed, & Hughes, 2006). Human rights advocates, researchers in the social sciences and humanities and many people with personal experience use *intersex*, a term reclaimed by intersex communities during the 1990s (Roen & Pasterski, 2014). Variations in sex characteristics can be dilemmatic for medical professionals, family members and others who wish to promote the wellbeing of the people concerned (Lee et al., 2016).

Many studies have focused on the experiences of people affected by intersex/DSD (e.g., Alderson, Madill, & Balen, 2004; Davis, 2015; Ediaty et al., 2017; Engberg, Möller, Hagenfeldt, Nordenskjöld, & Frisén, 2016; Ernst et al., 2016; Karkazis, 2008; Lundberg, Roen, Hirschberg, & Frisén, 2016; Meyer-Bahlburg, Khuri, Reyes-Portillo, & New, 2017; Preves, 2003; Roen, 2019; Sanders, Carter, & Lwin, 2015; Sanders, Edwards, & Keegan, 2017; Schweizer, Brunner, Gedrose, Handford, & Richter-Appelt, 2017). Such studies show that common sense understandings of sex, gender and “normality” frame patients’ and families’ sense making (Alderson et al., 2004; Gough, Weyman, Alderson, Butler, & Stoner, 2008; Karkazis, 2008), as well as that of medical professionals themselves (Dreger, 1998; Kessler, 1990). Whilst, very few studies have examined lay people, lay people’s sense making is important for two reasons. First, medical intervention is typically presented as facilitating living a “normal life” without stigma in relationships with others. However, very little is known about lay people’s general attitudes or thoughts regarding sex characteristics classified as intersex or DSD. Human rights advocates argue that if lay understandings underpin decisions to intervene surgically on infants’ genitals, then perceptions, not bodies, need to be the target of intervention (The Council of Europe Commissioner for Human Rights, 2015; United Nations Human Rights Council, 2013). Second, intersex/DSD can be experienced in any family without prior knowledge or experience of intersex/DSD (Kessler, 1998; Liao & Simmonds, 2014). We need to know more about the different kinds of understandings that lay people might bring to a clinical situation where information on intersex/DSD is communicated to them as families and patients, in order for health professionals to support informed decision-making (Lundberg, Lindström, Roen, & Hegarty, 2017; Pasterski, Mastroyannopoulou, Wright, Zucker, & Hughes, 2014).

Accordingly, this paper aims to explore how lay people, without any prior knowledge or personal experiences of intersex/DSD, make sense of common dilemmatic situations; namely, the dilemmas presented by choices about *gender assignment*, *early genital surgery* and *full disclosure of medical information*. We use the discursive framework of *ideological dilemmas* (Billig, Condor, Edwards, & Gane, 1988), to explore the underpinning discourses that give rise to lay people’s sense making of these situations. Our research question is: *What discourses do lay people draw on to make sense of the dilemmas that arise when they are being told that they, or a family member, have sex characteristics that can be described as intersex/DSD?*

Below, we introduce some bodily variations typically classified as intersex or DSD. We also present current perspectives on intersex and DSD respectively to situate the three dilemmas under investigation. We next describe how the discursive framework of ideological dilemmas informs the data analysis, and then we present our methods and findings.

Examples of Bodily Variations Classified as Intersex or DSD

Naturally occurring bodily variations that are not considered to be typical female or male sex characteristics are found in 0.3% to 2% of the population (Blackless et al., 2000; Lee et al., 2006).

From a medical perspective, DSD is an overarching term for several “congenital conditions” (Lee et al., 2006, p. e488) which are defined in terms of chromosomal configurations. The most common variation is Congenital Adrenal Hyperplasia (CAH). There are various types of CAH, which affect the function of the adrenal glands, of which one involves cortisol and aldosterone imbalances that typically need to be treated with medication. For children with 46,XX-chromosomes and CAH, the hormonal imbalance, which includes higher than average levels of androgens, might also affect sex characteristics. This involves, for example, developing a larger than average

clitoris and/or fused labia. When a child is born with CAH, dilemmas of gender assignment and early surgical intervention might arise (Lee et al., 2006).

Another medical diagnosis is Complete Androgen Insensitivity Syndrome (CAIS). CAIS is often diagnosed during adolescence. A person with CAIS is insensitive to androgens but has XY-chromosomes and gonads with testicular tissue. Sex characteristics such as external genitals and breasts develop in ways that are considered typically female. Clinical dilemmas about whether, and how, to disclose this information to the patient herself have been discussed for decades. Today, the consensus is to give information to the patient (Lee et al., 2006), but this does not routinely happen in practice and has not always been the standard approach (Karkazis, 2008; Roen, 2015).

Dilemmas and Principles: Medical and Political Perspectives

Until the 1990s, the standard medical protocol on intersex recommended consistent normalizing genital surgery, gender-consistent rearing, and non-disclosure of medical information to patients (Money & Ehrhardt, 1972; Natarajan, 1996). This protocol was effectively politicized by the *Intersex Society of North America (ISNA)* and other groups in the 1990s. These groups engaged in confrontational tactics, reclaimed the term *intersex* and demanded that harmful medical interventions should stop (Davis, 2015). Since then, many have continued to argue for the importance of human rights and the de-medicalization of intersex/DSD, but activism has also diversified to various forms of collaboration with medical professionals (Davis, 2015; Karkazis, 2008).

In response to the failures of the medical paradigm, new medical guidelines were drafted in 2006 by several paediatric medical authorities and some intersex advocates (Lee et al., 2006). This 2006 “consensus statement” reviewed the scientific literature, suggested new medical nomenclature, outlined medical guidelines and, suggested future studies. Dilemmas identified in the statement centred on *gender assignment*, *early surgery* and *full disclosure of medical information*. A recent global update on DSD identified the first two of these three dilemmas as persisting (Lee et al., 2016).

Currently, most commentators agree that physical and psychosocial wellbeing for people with experiences of intersex/DSD is a priority (Lee et al., 2016; Wiesemann, Ude-Koeller, Sinnecker, & Thyen, 2010). However, the means of achieving these goals remains dilemmatic. Medical guidelines foreground and promote genetic understandings of specific diagnoses and outcome studies in the hope of reducing uncertainty about optimal treatment (Lee et al., 2016). In policy-oriented contexts, ethicists and human rights advocates argue for the importance of legislation to curtail medical intervention, sometimes conceptualising people with experiences of intersex/DSD as a group entitled to human rights protection along with other minorities (The European Union Fundamental Rights Agency, 2015). Recent attempts to bring these diverse frameworks together (Lee et al., 2006; Lee et al., 2016) indicate the large differences between understandings in medicine and the law (see discussions in e.g., Delimata et al., 2018; Lundberg, 2017). Below, we sketch the key dilemmas that are inherent in current medical and human rights-perspectives.

Dilemmas of Gender Assignment

One principle implicit in the consensus statement (Lee et al., 2006) and the global update ten years later (Lee et al., 2016) was that every child should be assigned a gender within a binary scheme (i.e., as either a girl or boy). However, medical evidence only supports certain gender assignment in some cases and some researchers argue that there are no valid methods of predicting gender identity of children within this binary scheme (Byne et al.,

2012; Diamond & Garland, 2014). Others further note that gender needs to be approached via multidimensional models (Liao, Audi, Magritte, Meyer-Bahlburg, & Quigley, 2012).

From a medical perspective, the answer to the dilemma of gender assignment is to conduct more research on gender identity outcomes, drawing on a binary scheme, in relation to specific diagnoses. It is hoped that such evidence can assist parents and multi-disciplinary teams to make research-informed decisions on gender assignment. However, health professionals and parents are also encouraged to continually re-assess gender identity to assist reassignment if needed. Many critics argue, that decision-makers do not consider multidimensional aspects of gender or non-binary gender options explicitly in weighing up the costs and benefits of different treatments (even though some research reports suggest that people with experiences of intersex/DSD might later identify beyond a binary scheme, see e.g., Schweizer, Brunner, Handford, & Richter-Appelt, 2014). Some countries now recognize a third legal gender category that could be used to delay assignment as “female” or “male” (The Council of Europe Commissioner for Human Rights, 2015; The European Union Fundamental Rights Agency, 2015). However, some argue that a third legal category risks worsening stigmatization (Travis, 2015). Thus the literature suggests that, when making gender assignments, people may draw upon common sense understandings that remain within, or move beyond gender binary schemes.

Dilemmas of Early Surgery

A second dilemma centres on elective genital surgery on infants. Calls for a moratorium on elective genital surgery on infants have been issued since the 1990s (Diamond & Sigmundson, 1997). The 2006 consensus statement acknowledged that the purported psychological benefits of early normalizing surgery has never been evidenced, the risks of surgery have been under-acknowledged, and surgical outcomes remain uncertain in many cases (Lee et al., 2006). However, the consensus statement suggested that specific types of surgery might be carried out including clitoral surgery “in cases of severe virilization” (Lee et al., 2006, p. e491). The medical approach to this dilemma is to provide parents with decision-making powers, and to invest in long-term research on the effects of such surgery. Medical approaches often privilege function and fertility potential over cosmetic outcomes.

Ethico-legal commentators have argued that gender assignment seems to demand irreversible early surgery and that parents might feel unable to refuse consent to such interventions (The Council of Europe Commissioner for Human Rights, 2015; Tamar-Mattis, 2013). Not all children grow up to identify with the gender they were assigned, and irreversible surgery in infancy to mutate intersex/DSD traits could also remove tissue that a child might want later. Elective genital surgery early in life is criticized in human rights arenas because it violates the right to bodily integrity and individual autonomy; risks inflicting pain; refuses people health, sexual and reproductive rights; and may be degrading (The Council of Europe Commissioner for Human Rights, 2015; The European Union Fundamental Rights Agency, 2015; Tamar-Mattis, 2013; United Nations Human Rights Council, 2013).

Dilemmas of Full Disclosure of Medical Information

Third, in the consensus statement the authors suggested that the “process of disclosure concerning facts about karyotype, gonadal status, and prospects for future fertility is a collaborative, on-going action that requires a flexible individual-based approach. It should be planned with the parents from the time of diagnosis” (Lee et al., 2006, p. e493). Even though there is no current debate about the principle of disclosure, a dilemma persists around how and when disclosure should happen. Once again, medical consensus leaves this dilemma with parents.

Human rights documents have also highlighted the right to full information, access to medical notes and full involvement in medical decision-making (The European Union Fundamental Rights Agency, 2015; Tamar-Mattis, 2013). Accordingly, parents (who are usually lay people) are placed in a situation where they must interpret a complex and unexpected reality about their child quickly, make sense of the situation, and make decisions in the best interests of their children. Here, parents must avoid later accusations that they have withheld information from their child, therefore curtailing the child's ability to be involved in subsequent medical decision-making. Parental rights and the corresponding legal frameworks for involving children in medical decision-making vary considerably between countries (The European Union Fundamental Rights Agency, 2015; Tamar-Mattis, 2013), but the principle remains that being informed about one's body and healthcare are fundamental from the point of view of agency, empowerment, and rights.

Attempts to Integrate Medical and Legal Principles

Principles highlighted in ethical guidelines to be used in medicine include the importance of fostering wellbeing (Wiesemann et al., 2010), minimising physical and psycho-social risks, preserving fertility and promoting capacity for sexual relationships (Gillam, Hewitt, & Warne, 2010), and maintaining an open future that allows growing children the best chance of exercising agency in the future (Gillam et al., 2010; Kon, 2015). Achieving consensus about a hierarchy among these values is difficult. However, Wiesemann et al. (2010) state that psychological and social support of the family and child are more important than physical normalization. Gillam et al. (2010) suggest respecting the wishes and beliefs of parents above other matters. In this context, empirical studies of how lay people make sense of these dilemmas in practice have particular value in order to understand the difficulties people must overcome to express their wishes and beliefs in these dilemmatic situations. We situate our own study in this developing field next.

Empirical Findings: Moving From Principles to Practices

Since the 1990s, several studies have investigated whether, and how, the principles outlined above are materialized in practice. Despite the suggestion to do surgery only "in severe cases", research suggests that these principles have had little effect on the total number of surgeries being performed (Creighton, Michala, Mushtaq, & Yaron, 2014; Pasterski, Prentice, & Hughes, 2010), raising the question of whether the decision-making that leads to medical interventions has, or has not, changed substantially since the 2006 consensus statement.

Studies on how decision-making, particularly in relation to *early surgery* and *gender assignment*, has been experienced by affected parents have shown that decision-making is less straightforward than medical guidelines suggest (Karkazis, 2008), but also that many parents trust health professionals' recommendations (Sanders, Carter, & Goodacre, 2008; Zeiler & Wickstrom, 2009). Parental coping is also affected by how information is presented to parents (Duguid et al., 2007; Freda, Dicé, Auricchio, Salerno, & Valerio, 2015; Pasterski et al., 2014; Zeiler & Wickstrom, 2009). The manner in which information is communicated has implications for how parents understand sex and gender and how they make sense of their child's body, the potential delay in gender assignment and the perceived need for medical interventions (Crissman et al., 2011; Freda et al., 2015; Gough et al., 2008; Sanders et al., 2008; Zeiler & Wickstrom, 2009). As gender assignment seems to imply early genital surgery from the point of view of many people, parents might need support and additional time to disentangle these two unexpected dilemmas (Roen, 2019; Sanders et al., 2008; Zeiler & Wickstrom, 2009).

Experiences of *disclosure of medical information* have not been studied to the same extent. Studies have shown, however, that many parents consider it crucial to share information with their children (Dayner, Lee, & Houk,

2004), but challenging to do so (Freda et al., 2015; Lundberg et al., 2017). One study reported that young people with intersex/DSD had concerns about the process of receiving information (Sanders & Carter, 2015). Some researchers advocate for fuller disclosure (Sanders et al., 2015; Slijper, Frets, Boehmer, Drop, & Niermeijer, 2000). In sum, these studies suggest that parents who are entrusted with medical decision-making navigate a very difficult and unfamiliar set of choices, often under conditions of emotional distress.

Other Intersex/DSD-Studies With Lay People

Parents of children with experiences of intersex/DSD often voice concerns about how lay people in their lives – extended family, babysitters, neighbours, friends – will make sense of their child’s situation when they learn about it (e.g., Sanders, Carter, & Goodacre, 2012). A few studies show how lay people might approach these dilemmas. Kessler (1998) showed that lay people have wider standards for what counts as “normal genitalia” than medical professionals do. Kessler (1998) asked young adults if they would have wanted their parents to agree to surgery if they had been born with genitals considered atypical, or if they would choose such surgery for their own hypothetical children. Participants were much more likely to express a wish for surgical interventions for their own hypothetical children than for themselves.

Streuli, Vayena, Cavicchia-Balmer, and Huber (2013) asked participants to imagine being a parent and to consider whether or not to consent to surgery on behalf of an imagined child. When medicalized language was used to explain the child’s development, 77% of the participants said they would opt for early surgery for the child. In contrast, when non-medicalized language was used, only 34% said they would opt for surgery. Irrespective of condition or decision, all participants thought that their decisions had very little to do with the information given and more to do with their own attitudes and values. These results suggest that people may form retrospective impressions of what influenced their decision-making behaviours, thus overestimating prior values and underestimating the situational effects of framing information with certain underpinning understandings. These studies argue for the importance of knowing more about the values and understandings that underpin sense making about such dilemmas. We draw on the *ideological dilemmas* approach here to achieve this goal.

Ideological Dilemmas: Exploring Dilemmas in Depth

We take a discursive approach by drawing on the insights provided by the theoretical framework of ideological dilemmas (Billig et al., 1988). The definition of a dilemma as “a choice between two (or, loosely, several) alternatives which are or appear equally unfavourable” suggested by Billig et al. (1988, p. 9) is well-suited to the current context. Indeed, this framework has already been used in the intersex/DSD-literature by Boyle, Smith, and Liao (2005) who explored how adult women understood surgical procedures as dilemmatic.

By using ideological dilemmas, we are taking a *synthetic* approach to discourse (Wetherell & Edley, 1999). Such an approach assumes that the socio-cultural context is intertwined with the opinions or values that individuals express. Accordingly, “attention is directed not to the individual thinker [...] but to those aspects of socially shared beliefs [including moral values, social representations and discourses] which give rise to the dilemmatic thinking of individuals” (Billig et al., 1988, p. 8). Intersex/DSD researchers have often noted that popular gendered and heteronormative discourses typically underpin reasoning about these dilemmas (Boyle et al., 2005; Roen, 2008).

The framework of ideological dilemmas provides specific guidance on how to analyse the dilemmatic aspects of sense making. Billig et al. (1988) note that a researcher exploring ways of making sense of dilemmatic situations should expect to see differences in the values and discourses that are emphasised in the same situation for dif-

ferent people, as well as differences in what people judge as more or less important in the same situation. In order to study these conflicts, researchers should analyse “themes and counter-themes” (Billig et al., 1988, p. 21) in talk. In their study on adult women, Boyle et al. (2005) found that before the intervention, most participants hoped that surgery would help them feel less different and enable them to have a “normal” sexual relationship. After treatment, however, most women considered surgery a “failure to resolve the problems for which it was sought” and instead, “realized that post-operative procedures would be a continual reminder of difference” (Boyle et al., 2005, p. 579). Ours is the first study to take this promising approach to the study of how lay people, without any knowledge or experience of intersex/DSD, make sense of key dilemmas relating to *gender assignment*, *early genital surgery* and *full disclosure of medical information*.

Method

Design

This study is part of an international research project called SENS (Scotland, England, Norway and Sweden) exploring psychosocial aspects of intersex/DSD. The project includes qualitative data generated with health professionals, young people with personal experiences of intersex/DSD, parents of children with intersex/DSD as well as lay people without prior knowledge or experiences of intersex/DSD. This specific study is based on qualitative data from focus groups with lay people.

Participants and Procedure

Ten focus groups, with three to five participants in each group, were conducted in England (four groups, 16 participants) and Scandinavia (six groups, 25 participants). Eight focus groups took place at University campuses, and two were conducted in participants’ homes. Locations were chosen out of convenience and in accordance with participants’ wishes. All 41 participants (31 women and 10 men) were recruited via advertisements on social media or via local universities. Prospective participants were carefully screened with a brief questionnaire, asking whether they or somebody they knew had experienced variations in sex characteristics, and whether they had worked with the topic professionally or heard about it during their educations. People reporting previous experience and knowledge of intersex/DSD were excluded from participation in this specific study. In order to assess a variety of viewpoints, groups of participants with potentially varying perspectives were recruited; two groups of parents (aged: 32-47, $M = 36.4$), six groups of university students (aged: 19-39, $M = 21.9$), and two groups of clinical psychologists in training (aged: 22-33, $M = 28.5$).

The focus group guide aimed to maximise active dialogue between participants, such that the opinions expressed in collective talk could be the object of analysis. The session started with a presentation of the project and a question about what participants think clinicians do (and should do) when a child is born with atypical sex features (discussion one). After the introduction, two vignettes were presented highlighting dilemmas that are unresolved within the current consensus on healthcare (Lee et al., 2006; Lee et al., 2016). The first vignette resembled a situation used by Kessler (1998). Here, the participants were invited to reflect on a situation where a child is born with a larger than average clitoris and in which health professionals offer hormonal treatment as well as surgical reduction of the clitoris. Half of the groups were prompted to imagine that they were the parent of this child. The other groups were prompted to imagine that this had happened to them (discussion two). The second vignette dealt with disclosure of medical information. Participants were invited to imagine a teenage girl who had not

started having periods yet. Her parents had taken her to a doctor who had conducted several tests. When health professionals received the results, they contacted the parents to tell them that the girl had XY-chromosomes, testicles and no uterus. The question in this scenario was whether the participants would like the girl to know this information, and in that case, how they would like her to be told (where, when and by whom). Half of the groups were prompted to imagine that they were the parent of the girl and to consider whether, and how, they would tell their daughter about this. The other half of the groups were supposed to imagine themselves being this girl (discussion three).

The focus groups lasted from 80 to 121 minutes ($M = 98.5$). Each participant was compensated with approximately £10. The focus group sessions were audio-recorded, transcribed and anonymized. In this process, all participants were assigned a code consisting of a participant number (e.g. P1) and the number of the focus group (e.g. FG1) for the purpose of anonymized data reporting.

Ethics

The research ethics committee at the University of Surrey (No: EC/2013/86/FAHS) and the Norwegian Centre for Research Data (35028/3/KH) approved the study. Before the focus groups were convened, participants were given verbal information about the study and were promised confidentiality and the right to withdraw from the study at any time. The participants gave written consent before the discussion started. After the session, participants were provided with information about how they could access results from the study and resources for further information about intersex/DSD.

Data Analysis

The analysis was conducted in two steps. First, the entire dataset was coded descriptively according to thematic analysis (step one and two as outlined by Braun & Clarke, 2006) using NVivo software (version 11 for Mac, by QSR International). The second author developed a code list in collaboration with the first author and coded four of the Scandinavian focus groups. The first author coded the rest of the focus groups with the help of a research assistant. Following Braun and Clarke's (2006) thematic analysis steps three and four, the data within each discussion were analysed in relation to how participants mobilised principles and values, as they argued for one response to the dilemma over others.

As part of this initial analysis, potential systematic differences between focus groups, such as parents versus students versus clinical psychologists in training as well as UK-based groups versus Scandinavian groups, were explored. However, the most evident differences that appeared were *within* groups. There were also fewer systematic differences between being asked to imagine a child or to think of themselves than suggested by Kessler (1998) because participants shifted perspectives spontaneously during the discussions. Because this stage of the analysis did not show systematic differences, we do not report differences between groups.

The second step drew from Braun and Clarke's (2006) theoretically-focused approach by building on the discursive framework of ideological dilemmas (Billig et al., 1988). Here, the dilemmas identified by participants were explored in depth for "themes and counter-themes" (Billig et al., 1988, p. 21). This step was less descriptive and more interpretative (Braun & Clarke, 2006) and was undertaken by the first and second authors. Rather than summarizing the decisions participants said they would make, we analysed the discourses and counter-discourses that underpinned participants' decisions. We understand these discourses to explain how people make sense of the dilemmas and why some responses to the dilemmas seem more intelligible than others. After drafting the initial findings, all

authors discussed the content before we finalized the analysis. At this final stage, all Scandinavian quotes were translated to English.

Findings

The initial thematic analysis showed that all groups identified dilemmatic aspects of *gender assignment*, *early surgery* and *full disclosure*. Some argued that gender assignment should be done as early as possible whilst others argued that it should be left open. Some were in favour of early surgery and others opposed it. Most agreed that full information should be given to the patient, but a few participants were resistant to this. Most groups drew on principles and arguments that are evident in the medical and the human rights literature on intersex/DSD.

The secondary analysis yielded three overarching themes concerning how participants were: (i) *making sense of sex and gender*, (ii) *dealing with difference*, and (iii) *making decisions*, which were evident in relation to all dilemmas. To be comprehensive, we use the specific dilemmas to structure the rest of this section. We describe discourses and counter-discourses as they relate to each dilemma. Table 1 shows the dilemmas, the dilemmatic responses that participants suggested, and the overarching themes and discourses that relate to each dilemma.

Table 1

Summary of Dilemmas, Themes, and Underpinning Discourses

Dilemma	Responses	Themes with underpinning discourses
Gender assignment	Assigning gender or leaving it open	<i>Making sense of sex and gender</i> Binary or non-binary Biological trait or personal identity In need of assistance or unfolding from within
Early genital surgery	In favour of or against early surgery	<i>Dealing with difference</i> Difference as problematic or not Erasing or affirming difference
Full disclosure	In favour of or resistant to giving full information	<i>Making decisions</i> Parents versus health professionals Individuals versus parents Individuals versus health professionals

Gender Assignment

In relation to the dilemma of assigning a gender to a child, the ideas evident among many groups can be summarized by focus group eight:

2: I, it seems like there's three sort of options. That either you pick male [...], you pick female or you don't pick anything. And if, [...] you don't pick anything, then there's a definite kind of... uhm, feeling of exclusion from society, [3: Mm] cause society isn't set up to have a trans or a nonlabel [3: Yeah] at that age. [...], you could pick male, and that could be right, and you could pick female, that could be right, or it could be wrong. [1: Yeah] So there'll be a proportion of people whose gender you've assigned is right, [1: Yeah] but a proportion of people whose gender you've assigned is wrong. And you don't do the non-assignment

because it's, the world isn't set up that way.[...]. [3:Yeah; 4: It's like a fifty-fifty chance] Yes, [...] it kinda feels like that!

3: and is it fairer to assign somebody the wrong gender and allow them the choice themselves to change later on, [2: Mm] or would it be fairer to just bring up a child without a gender. [...]

2: Mm. And then what experience [...], does not having any gender [...] for so long have on your..decision to choose [...] one or the other, or [...] on your [...] general upbringing (FG8)

The responses discussed were whether to *assign a gender early*, with the risk of getting it wrong, *or wait* until the child could identify themselves (thus potentially facing some years of uncertainty). In line with clinical guidelines (Lee et al., 2006), many participants preferred to assign a gender both to help parents cope and because they presumed it would be easier for the child. As highlighted in our data and in human rights documents (The European Union Fundamental Rights Agency, 2015), a problem in the gender assigning process is that “there are no more categories than two” (FG4P3), this limiting the choice to ‘female’ or ‘male’. However, participants also suggested that if the child grows up failing to identify with their assigned gender, they should be assisted to have their gender reassigned (also explicit in Lee et al., 2006).

Others argued that the only people who can decide what gender to be assigned are the individuals themselves by “find[ing] their own identities” (FG5P1). This echoes human rights arguments (e.g., The Council of Europe Commissioner for Human Rights, 2015; Diamond & Garland, 2014). These participants thought that assigning a gender early was too risky and suggested that assignment should be left open. These participants confirmed that it is “hard to bring someone up gender neutral” (FG5P3) or without an assigned gender, but that there are other ways of coping with such a situation; particularly with “psychological counselling” (participants in e.g. FG5), with support from your “network” (participants in e.g. FG10) and more gender neutral attitudes in society (participants in e.g. FG3 and FG10).

Making Sense of Sex and Gender

The dilemma of gender assignment prompted participants to draw on a variety of discourses and counter-discourses through which sex and gender come to make sense. These include sex and gender *as binary or non-binary*, *as a biological trait or a matter of personal identity*, and *as something that needs assistance or unfolds from within*.

Binary or non-binary — A key tension in the discussions, as it is among experts (Kessler, 1998; Lee et al., 2006), is the understanding of sex and gender as binary or non-binary concepts. Some participants suggested assignation as a girl or a boy because that is “normal” (e.g. FG1P1) and is presumed to offer psychological and social benefits (e.g. FG2). Others were aware that people might identify “between” (FG3P3) gender categories or “with a third category” (FG10P4), leading them to think that leaving gender assignment open was correct and ethical. Binary understandings of sex and gender have been both reasserted (Lee et al., 2006) and criticised (Kessler, 1998) by experts.

Biological trait or personal identity — Discussions also revolved around the question of whether sex and gender are fundamentally matters of biology or of personal identity. More than half of the participants said that there must be biomarkers to follow, such as chromosomes or hormones, when reasoning about these cases:

2: I think you would really have to trace back to the chromosomes, cause that's like definitely telling you what gender they are. [1: Yeah] So, yeah, the genetic testing thing, I think that would be the best idea.

3: To be knowing better. So at least they know... they know what they are (FG6)

Participants suggested that these markers and results on outcomes from similar cases could be used to make “a best guess” (FG7P1), or choose what “fits best” (FG1P3, FG3P2). This idea accords with the research ambition to “find a biomarker of gender identity” (Lee et al., 2016, p. 11), which Griffiths (2018) has recently critiqued as *genetic futurism*. This biological perspective on sex and gender assumes that there is a “true sex” located in the individual, and has been critiqued as a social representation (e.g., Liao et al., 2012). Many participants were, however, not sure that biomarkers could be used to determine a child’s future gender identity, mostly because people might identify with a gender incongruent with their biology (e.g. FG1P3). These ideas were underpinned by understandings of gender as an aspect of personal identity, that can only develop by allowing a person to grow up and express what they feel and “[y]ou could tell them like: ‘Which one do you feel like you want to be?’” (FG5P1). This accords with how gender identity has been understood in several important legal cases (e.g., Travis, 2015).

In need of assistance or unfolding from within — Finally, participants were concerned with whether sex and gender are in need of assistance or simply unfold from within over time. Consistent with brain organisation theories (discussed in Liao et al., 2012), many participants understood biomarkers as determinants of gender identity, but often the same participants also highlighted the importance of gender roles and rearing:

3: At least the hope that just by giving the label and just deciding at birth, that that person can then go on and identify as that gender and just be brought up with those roles. [...]

2: Because it's easier to be assigned [3: Yeah] a definite category. And I guess it's a hope that you, you've assigned them...

1: the right category

3: Yeah [2: At that stage.] Or that... just assigned that category and bringing a child up in that category will make them identify [with the category] (FG8)

From this perspective, gender needs to be continuously assisted to form properly, consistent with the earlier criticised guidelines (e.g., Money & Ehrhardt, 1972). Similar ideas led some participants to argue for early surgery, in order to make “what [biologically] is there stronger” (FG1P3). Normalizing surgery could also help caregivers to approach the child appropriately and assist the socialisation of the child:

Yes, it is, something about that, that makes me think that if you decide early that this is a girl, for example, and then you will approach this baby through what we have, what we know are critical phases, as a girl. That this might lead to this person becoming a girl, or that this particular person will understand herself as a girl (FG1P3)

The opinions expressed also suggested that it is not only the biomarkers, but knowledge about them, that is causative of gender identity. Accordingly, several participants were concerned about giving young women information about “boy parts” (FG2P4) (i.e. gonads with testicular tissue and XY chromosomes) because it could potentially interfere with their gender identity development (e.g. FG4P3; FG4P4; FG8P4).

Those who argued in favour of leaving gender assignment open until the child could contribute to the decision-making process, seemed to suggest that gender identity comes from within and unfolds over time (that it may be a kind of embodied becoming described in e.g., Roen, 2009). These participants seem to suggest that identity is mostly dependent on an internal process, which can only become evident for others when you can ask the child

what they think and feel (e.g. FG5P1; FG7P1). From this perspective, a gender-neutral upbringing would let children explore their identities without pressure (discussed in e.g. FG10). Some argued that if people are content with themselves, knowing about biomarkers that seem inconsistent with their identity would not necessarily affect their wellbeing (discussed by e.g. FG9).

Early Surgery

Consistent with ethical guidelines (Wiesemann et al., 2010), participants suggested that the child's wellbeing should be considered most important in any decision regarding early genital surgery: "I guess I'd want to make the best-informed decision on the basis of health as opposed to anything aesthetic" (FG8P2). Several participants said they would have wanted their parents to agree to surgery for them, or would choose surgery for their child, consistent with literature that provides evidence of these preferences (reviewed in Creighton, Chernausek, Romao, Ransley, & Salle, 2012):

I think I would have said yes to do it right away. [...] if my doctor had said to me that "it is too big, we can remove it". Of course without any risks, if there is any talk about, well, any risks to the child's health [...], then it is a very different kind of issue, but if it is a safe intervention, recommended by the doctor or at least presented as "yes, this can be done and it will remove something that is medically understood as abnormal" [4: Mhm] Not just something that looks strange in a way, but that the doctor considers abnormal, I think I would have done it (FG3P2)

Many argued for surgery in order to look "normal"; an outcome assumed to promote psychological and sexual wellbeing, e.g. by being "content with oneself" (FG4P5) and able to "dare to get... a partner" (FG2P2). Researchers repeatedly point to the lack of empirical evidence for the assumption that surgery promotes wellbeing (Roen, 2019). Early surgery was also described as beneficial because the child might not remember what had happened (e.g. FG3P2). Several of these arguments resonate with the former, discredited, clinical guidelines (Money & Ehrhardt, 1972). However, participants repeatedly argued that they would only do surgery if it was "without risk" (e.g. FG3P2), if early surgery was likely to be more successful than later surgery (e.g. FG1P1), or if the clitoris was "very prominent" (e.g. FG4P4). Because evidence confirming that surgical procedures are safe is lacking (Lee et al., 2016), these qualifications effectively rule out early surgery.

Echoing Kessler's (1998) findings, almost half of the participants opposed early surgery:

No, I would have been [...] concerned [...] about my daughter's sexual health. It almost sounds like mutilation to... to do such an intervention [...] What could the positive effects be of that? It might stop her from feeling abnormal... Erm, and [having a larger clitoris] might make her feel different, but then you have to deal with that, when it becomes a problem and make sure she is accepted, because you cannot help how you have been born (FG2P4)

Arguments against surgery included: the risk of "potential damage" (e.g. FG10P4), "pain" (e.g. FG6P3) and failure to resolve the issue (e.g. FG2P2) (similar to the concerns raised by e.g., Liao, Wood, & Creighton, 2015). Participants (e.g. in FG10) also noted that surgery is irreversible and that doing it would violate the child's right to self-determination and bodily integrity (highlighted by e.g., United Nations Human Rights Council, 2013). Many suggested other, non-surgical, ways to deal with situations where looking different might be a challenge, such as counselling (also highlighted by e.g., Liao et al., 2015). Whether arguing for or against surgery, some participants talked about the potential for regretting any decision (e.g. discussions in FG7; FG10): "whatever decision I make,

if I choose surgery or not [...] [the child] might be grateful or feel resentment” (FG10P4). The risk of regret is discussed in ethical guidelines outlining principles for DSD-care (Gillam et al., 2010).

Dealing With Difference

During discussions of the early surgery dilemma, research participants drew on a variety of discourses and counter-discourses to make sense of, and to deal with, difference. These include framing *difference as problematic or not*, and considering whether it makes most sense to *erase or affirm difference* in such situations.

Difference as problematic or not — Key to this discussion are the questions of what constitutes difference and whether or not difference is problematic. Many participants said that their decision to do early surgery would depend on the size of the clitoris: “it is really, erm, I think it is about limits” (FG3P2). Several suggested their own “limits” as to what could be considered a difference that might be a problem for wellbeing, such as “clearly visible” (FG8P3), “double the normal size” and “protruding beyond the labia” (FG4P4), “look like a penis” (FG4P3, FG4P5, FG6P3, FG7P5, FG9P1) or when “it starts to signal something else” (FG7P5). The problem of establishing criteria for bodily normality based on anatomy alone has been critically discussed by Kessler (1998).

Several participants did not think that being different, or having a larger clitoris, was a problem. Some argued that many people might not even notice this difference (e.g. FG7P1) (a claim supported by some research; Dodds et al., 2008), and those that did might still be content and do well (e.g. FG5P3). Some suggested that having a larger clitoris might even “be beneficial” in intimate relationships (e.g. FG10P2). Finally, some said (e.g. FG7; FG10) that most people are different in one way or another, suggesting it is “normal to be different” (also evident in e.g., Guntram, 2013). These findings highlight that whilst medical guidelines suggest that surgery is justified when specific criteria are met, what is understood as difference, and whether difference implies a problem, is socially constructed and negotiable (a concern also expressed by e.g., Kessler, 1998).

Erasing or affirming difference — Participants argued for early surgery primarily with the belief that it would erase difference. This argument is in tension with the arguments about affirming difference. Many said that they would like, or would like their child, to feel “normal” and they imagined this would be possible to achieve by assigning a gender and surgically removing any physical differences:

But then your child's got to be, is, it is the normality thing, isn't it, to grow up thinking that you're different [...] it's awful for children, really, 'cause children... seem to just want to be like everybody else (FG7P5)

I would have been so [...] happy if they had just... done it [...] And I think that once you are more aware of such things... or... when you start thinking about such things [...] in puberty or when you start... talking... about it with others [...] or start to understand how others look, and... everyone else is, looks totally different compared to you, I think it would have been, erm, a thousand times more confusing then, compared to how puberty already... was. [...] I think it had... erm... probably created many situations that had been really... erm... that hadn't had to happen. It would have been, like, really challenging to... you would have felt a lot more, or I had felt a lot more of... that I am different and strange, instead of just fixing it [when I was a child] (FG1P2)

“Normality” was sometimes valued more than naturally occurring bodily features, individuality, genital sensitivity or autonomy in decision-making.

Many participants questioned whether surgery could “fix” difference or make things “normal” (as showed in Boyle et al., 2005). Participants mentioned problems like “scarring” (e.g. FG10P2), “pain” (e.g. FG6P3), need of “repeated surgery” (e.g. FG9P2), “loss of sensitivity” (e.g. FG6P1), removing tissue a person might want later (e.g. FG1P3), and still feeling different because surgery was needed in the first place (e.g. FG1P2). All these points support the argument against early surgery and resonate with the work of some clinician-researchers (e.g. Boyle et al., 2005; Liao et al., 2015). Instead of erasing difference, many argued that difference should be affirmed. In accordance with some commentators (e.g. Liao & Roen, 2014), participants suggested strategies such as having a supportive environment (e.g. FG5; FG10), where parents could talk with their children (e.g. FG3; FG9); strategies to handle challenging situations such as swimming pools or locker rooms (e.g. FG5); offering counselling to the parents as well as the child (e.g. FG2, FG10), and opportunities to meet people with similar experiences (e.g. FG9; FG10). Surgery was considered by some as reifying societal ideals and failing to address the underlying problem:

I think it is really unfortunate. Because it... it is rooted in our culture and our focus on having... a specific... a kind of ideal body. And in a way, we are starting to craft... the child's appearance on cosmetic grounds from birth, and I think that is very problematic for the child. And especially because the child is dependent on a trusting relationship to its parents, then it might feel that [1: Yes] the parents have tried to change the child... in agreement with an ideal model, from the beginning. And that would damage... I think that damages your self-image more than it would help you (FG3P5)

A good life therefore did not necessarily involve conforming to societal norms, but did involve feeling comfortable and being accepted by your parents.

Full Disclosure

When discussing whether, and how, parents or health professionals should tell a girl with XY-chromosomes about her situation, most participants supported full disclosure to the girl concerned:

I would have wanted to know. Because I might have started to wonder, because if you are 16 years old [...] I think you know more than what your parents think [...] and you could look for anything on social media today and so on. So I might have had an idea that it... Maybe these strange ideas that it was cancer or something [...] and if it is cancer, then I would like to know at once. And I think I would have liked to know from [...] the doctor (FG2P5)

The person in the imagined scenario was understood to have a “right to know” (FG1P3) and to be able to make informed choices about her treatment, which echoes the current consensus (Lee et al., 2006). While some participants thought it would feel safer to have the information delivered by their parents, most wanted it delivered either by a health professional or by both parties at once. Many said the fact about “not being able to bear children” (e.g. FG10P1) was the most important information to disclose. Several participants also said that the young person should know about their chromosomes and gonads (e.g. FG7P1; FG10P4) but disclosing this information might need to take place over time (as suggested by Lee et al., 2016).

Some participants expressed ambivalence about providing full information:

You are already, [at that age] you are extremely concerned with “How is everyone else?” so if you, if I learned that “No, you have some boy parts inside of you” [3: Mhm] I am not sure if I had made sense of that information really... I might have understood that as “Oh, there is something wrong with me” [3: Yes; 2: Mhm] [...] I would not have been mature enough at that stage [to understand] (FG4P4)

As suggested here, some considered young people to not yet be mature enough to take in such information or make decisions about their bodies. Others argued that information might cause worry and that not knowing, until they were “19 or 20” (e.g. FG10P3), would protect younger people from unnecessary suffering. These participants were especially concerned with information about chromosomes and gonads (e.g. FG4P4), which echoes now questioned perspectives within clinical literature (Natarajan, 1996). In response, many participants argued that it would be ethically wrong and illegal to withhold information (in accordance with e.g., Tamar-Mattis, 2013). The vast majority agreed, however, that this “is not an easy conversation to have” (FG1P3).

Making Decisions

During discussions about the disclosure dilemma, participants drew on various discourses relating to the question of who is in a position to make decisions. This involved negotiations of who has enough expertise to give information, to make informed choices, and to take responsibility for the decisions made. Discourses and counter-discourses presented different stakeholders as having dilemmatic positions in relation to each other. These included *parents versus health professionals*, *individuals versus parents* and *individuals versus health professionals*.

Parents versus health professionals — The challenge of positioning health professionals in relation to parents was evident in relation to both the gender assignment dilemma and the full disclosure dilemma. Many considered health professionals to have expertise, such as knowledge, experience and available technology, that would enable them to know best what to do and say:

I wouldn't wanna be told by mom or my dad, really. I think I probably wanna be told by a professional to understand properly what's going on, cause I think if my parents were to tell me it might come out differently, it might come out more emotionally [1 & 2: Yeah] I probably wouldn't even understand what's going on. (FG6P3)

Parents were described as emotionally affected and unable to explain medical information well, whereas health professionals were described as neutral and experienced in talking about these situations. From this perspective health professionals come to occupy the best position from which to advocate for the child's best interests:

I think for a large part it is the health professional themselves, because I'm, like, I'm assuming that they obviously dealt with such cases like before and they may done, they have more experience regarding the outcomes and how the things have turned out so, they would kind of be like experts as such, to give advice on this. I think parents should definitely have an output... But, and, and, sorry, but initially I think they have to rely on the professionals to guide them (FG5P1)

However, some participants questioned the expertise of health professionals in talking to young people, arguing that health professionals are also led by cultural ideals and “prejudices in decision making” (FG3P5). They suggested that it might feel much better to get this information at home from people you trust, rather than at a hospital from someone you have never met before (e.g. FG10P1). From this perspective, parents were seen as the best advocates for the child, because parents know their child better and know what to say and when (discussed in e.g. FG7). This emphasis on trust and personal knowledge rather than clinical detachment is consistent with the legal norm in many countries that positions parents as the best representatives of their child's best interests (The European Union Fundamental Rights Agency, 2015).

Individuals versus parents — Secondly, participants negotiated how the individual should be positioned in relation to parents (also discussed by e.g., Tamar-Mattis, 2013). Most agreed that the young person should get full disclosure

from a health professional to allow for informed decisions about their own body. This was accompanied by an idea that parents should support the decision-making process, whatever decision the young person makes. Some, however, noted that some situations could be more dilemmatic than that:

What can be problematic is [...] if you say “I will be open and let my child decide” but then the child makes a decision that you feel is bad... For example if you think that your child should be able to be the way it is, and then your child says “I will never have a relationship [...] because my sex life does not work [4: Mhm] and I want to do this surgery”. [...] I would have thought [...] “my child should not have to feel this way” [...] And then I might say no, even though, I from the beginning said that the [...] child should be able to decide (FG3P2)

The dilemmas created by a child making decisions that the parent does not support, was resolved for some by the suggestion that children should always be encouraged to wait until they are 18 years old before doing any interventions. In contrast, others argued that parents might agree to “fix it with surgery, fix it [with] medication, [so] everything's getting back to normal” (FG8P4), against the child's later wishes. Their responses support the need for structures to ensure the young person's right to self-determination is protected regardless of any decisions parents might want to make on their children's behalf.

A wish to protect the young person from feeling different was also evident in the dilemmas of *gender assignment* and *early surgery*, as discussed above. In addition to discourses that suggest that “normality” is better for wellbeing, such wishes can be interpreted as underpinned by social representations of children as vulnerable to harm (Roen, 2008); discourses which can also remove agency from the child and locate it within the parents:

I think, as a parent, you are responsible for the child till quite a long time so either way I think if you get it done the first year, it is best for the baby, for both of you whereas if it is much later then, you know, these questions of: “What sort of age? Are they ready?” They don't know what's best for them sometimes more then what parents do. (FG5P2)

As suggested by this participant, doing surgery early can be a way of dealing with the messy dilemmas of vulnerability by knowing what is best, whilst agency and responsibility become more and more salient as the child grows older. Some participants suggested that the solution to all dilemmas in relation to the child-parent relationship (e.g. if later conflicts arise because the child thinks that parents have made incorrect decisions), was “open communication” (FG1P3) about everything: “It is not really that problematic...what kind of decisions you make, but what can become problematic is the way you follow [or do not follow] things up [with the child]” (FG3P5).

Individuals versus health professionals — A final challenge was how to position the child or individual in relation to health professionals. With regard to gender assignment, people who understood sex and gender as something biological also trusted medical doctors to make decisions because of their expertise. In contrast, those suggesting that gender is a personal identity argued that only individuals themselves can decide what gender to be assigned:

Maybe one should not be that rigid and think, because even those who are biologically girls or boys do not necessarily feel like that themselves. [...] There are instances where very young children express that they want to identify with a gender that is not their biological one (FG1P3)

In accordance with human rights claims (e.g., [The Council of Europe Commissioner for Human Rights, 2015](#); [Travis, 2015](#); [Wiesemann et al., 2010](#)), these participants emphasised the importance of individual agency and integrity (e.g. discussion in FG10).

Discussion

The present study contributes to the acknowledged gap in the research literature regarding what lay people in general think about sex characteristics classified as intersex/DSD or how they would respond to hearing about intersex/DSD, as a parent or a patient. The present study also contributes to knowledge that can improve how information about intersex/DSD is communicated to parents and patients within healthcare. By having more detailed understandings of how lay people approach the dilemmas of *gender assignment*, *early surgery* and *disclosure of medical information*, health professionals could better support people's sense making in these situations.

All of the focus groups in the present study identified dilemmas relating to *gender assignment*, *early surgery* and *full disclosure*. While many participants opted for a principle of assigning a gender early on the grounds that assignment would be beneficial for the child, some argued that, in principle, it should be left open. Some argued in favour of doing surgery early (as long as it did not involve any substantial risks), but most participants argued against doing such interventions. Finally, most participants argued in favour of providing young people with full information about their bodies, but some were hesitant about full disclosure. These results show that lay people voice many of the principles that are drawn on by health professionals, ethicists and human rights advocates who address the same dilemmas. However, the secondary analysis revealed underpinning understandings concerning how participants were *making sense of sex and gender*, *dealing with difference*, and who they understood to be in a legitimate position to *make decisions*. Below, we discuss how these results can be used to improve clinical practice and inform wider societal debates on intersex/DSD and human rights.

Addressing Underpinning Understandings in Clinical Practice

Clearly people can and do draw on very different discourses and counter-discourses of *sex and gender*, *difference* and *decision-making* to make sense of intersex/DSD-related dilemmas. Underpinning our participants' sense making of these dilemmas, there seem to be very different approaches to stigma. Social psychologists have written about framing stigma as something to be concealed, minimized and altered, versus constructing it as a creative basis for collective identity and pride (Goffman, 1963; Tajfel, 1978). Such collective responses can have positive implications for health outcomes among members of stigmatized groups (Jetten, Haslam, & Haslam, 2012; Meyer, 2003), and for decision-making about medical interventions on stigmatized traits (Fernández, Branscombe, Gómez, & Morales, 2012). In the past, researchers have suggested that the term "intersex" afforded a means of making intersex characteristics a basis for a collective social identity (Preves, 2003). However, the re-medicalization of intersex characteristics as "disorders of sex development" has responded to and interrupted that trajectory (Davis, 2015). The lay people studied here appear to be on the horns of a dilemma about whether to consider less typical sex characteristics as something to be minimized or celebrated, and accordingly how much to support young people's engagement with open futures (Kon, 2015) in which they might enjoy self-determination and play a role in medical decision-making.

Similarly, prospective patients and families might draw on very different values and discourses that can affect how they make sense of medical information and how they make medical decisions. Having more knowledge of the diverse understandings that patients might bring to consultations puts health professionals in a better position to empower patients and their families to fully participate in decision-making in uncertain situations about unfamiliar topics. The present study bridges the gap between experiments showing how framing affects sense making (e.g.,

Hegarty, Smith, & Bogan-Carey, 2019; Streuli et al., 2013) and studies highlighting the sense making needs that parents report retrospectively after medical decisions have been made (e.g., Sanders et al., 2008).

Having a knowledge base of this kind is especially important because guidelines, legislation and policy also resolve dilemmas by giving precedence to certain principles over others; for example, by prioritizing self-determination over parental rights. Just as Billig et al. (1988) note that prioritising one principle does not solve a dilemma and does not make the de-prioritised principles disappear, our findings also suggest that solely presenting a principle would only provide a shallow solution. Our findings suggest that in clinical cases where early genital surgery is discussed as a possibility, parents who (also) value “normality”, or understand gender identity development as requiring assistance, might not prioritize bodily integrity because they conceptualize their child’s intersex/DSD characteristics as traits to be erased rather than as integral parts of their child’s distinct personhood that should be affirmed.

Davis (2015) has suggested that an important axis of difference in the lives of people with intersex/DSD concerns how these dilemmas between medical and social discourses are lived out. Based on her interviews, she concluded that those who have challenged the medical consensus have more difficult relations with parents but often less dilemmatic relationships with their own embodiment. In contrast, those who have accepted medicalization have better relationships with their parents but more difficult relations with their own embodiment. Her work, along with ours, suggests how lay people might set in motion chains of events that lead their children down particular paths. By explicitly addressing the impact of underpinning discourses, health professionals may be able to equip patients and families with reflexive tools that help them better make sense of intersex/DSD. Billig et al. (1988) emphasize that people neither passively resolve dilemmas nor easily stand outside of them. By engaging with underpinning discourses in depth, patients, parents and health professionals may be able to actively choose some values over others, rather than simply acting according to taken-for-granted understandings, and investing blind hope in ‘open communication’ as many of our participants did.

Informing Discussions on Intersex/DSD and Human Rights

These findings can also be used as tools to reflect on taken-for-granted discourses underpinning research and policies. Our findings show that using principles, including human rights principles, to solve dilemmas will only provide incomplete solutions. For example, even though many participants thought that young people have a right to know information about their embodiment, in accordance with legislation and guidelines, some still found it acceptable to keep some information from young people in an attempt to protect them from suffering. Accordingly, even if health professionals and human rights advocates agree on which principles to prioritize in a given clinical dilemma, diverse values and underpinning discourses may still affect the kinds of lives that people live out in this contested and increasingly politicized area. Instead of ethics based on principles, other kinds of ethics – such as ethics of care or embodied ethics (Feder, 2014) – may need to be even more explicitly discussed in relation to intersex/DSD.

Limitations

This study is based on a small convenience sample of participants, who were mainly recruited via universities, which will have affected the perspectives presented. In addition, even though studying lay people might be important to understand which underpinning discourses people might bring into a dilemmatic situation, imagining being in

these situations will never fully capture how one might actually react in such a situation (evident in e.g., Lundberg, Hegarty, & Roen, 2018). This needs to be considered in any discussions on transferability.

Conclusion

The findings of this study suggest that lay people easily identify the dilemmas of *gender assignment*, *early surgery* and *full disclosure* in relation to intersex/DSD. Our study also shows how various discourses underpin the responses of lay people to these dilemmas. These discourses concerned how participants were *making sense of sex and gender*, *dealing with difference*, and who they understood to be in a legitimate position to *make decisions*. These findings are important in several ways. The first relates to the ongoing use of normalizing interventions in response to health professionals' and parents' concerns about how lay people in the child's life might react to bodily difference. Our findings show that there is not just *one way* of making sense of these dilemmas among lay people. Addressing the available discourses explicitly might assist parents and affected individuals to use those discursive frameworks to communicate with others. Addressing these discourses on a societal level might also be key to raising awareness in the general public. The second importance relates to the point that most patients and families who find themselves in a situation where they are being told that they or their child have sex characteristics classified as intersex or DSD, do not have any prior knowledge of intersex/DSD. Our results suggest that health professionals need to attend to the very different ways that parents might make sense of this information, and also provide parents with counter-discourses when needed. Third, addressing the (counter-)discourses underpinning specific ways of making sense of these dilemmas is important both in healthcare and in human rights contexts. We conclude that engaging with dilemmas in-depth is more constructive than favouring one principle over others in moving social science research, reflexive clinical practice, and wider political debates on intersex/DSD forward.

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Competing Interests

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