

Atypical Sex Development

Perspectives of Laypeople

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Master of philosophy in psychology

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Abstract

The purpose of this study has been to research lay perspectives of atypical sex development: the understandings of people without experience or knowledge of the topic from before. Atypical sex development can be understood as development that differs from what is categorized as typically male or typically female. How to understand, conceptualize and manage atypical sex development has been subject to debate for decades. Research and practice concerning atypical sex development involves many disciplines, among them psychology. The present study is undertaken from a societal psychological standpoint. The overarching research question guiding the study is: *“How do people with no experience of atypical sex development talk about and understand atypical sex development?”* To answer the research question, four focus groups with a total of 18 participants were conducted. The majority of participants were students at the University of Oslo. The data material was analyzed through combining the framework of ideological dilemmas (Billig et al., 1988) and thematic analysis. Two ideological dilemmas were developed in the analysis: “Being different: normality versus individuality” and “Decision-making: agency versus expertise”. I argue that these dilemmas frame the participants’ talk and understandings of atypical sex development. Presented with theories of gender identity, participants wanted several kinds of information, including biological, psychological and cultural, but with emphasis on psychological. Asked to evaluate the terms “Disorders of Sex Development” and “Intersex”, participants found them both problematic. The research contributes to current debates in the field, for example regarding early genital surgery and regarding terminology.

Keywords: atypical sex development, disorders of sex development, intersex, ideological dilemmas

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Introduction

Most people take chromosomes, gonads and anatomy associated with sex for granted: either you are male and have XY chromosomes, testes and a penis, or you are female and have XX chromosomes, ovaries, labia, clitoris and a vagina. For some of us though, these sex characteristics develop atypically or combine in unusual ways.

Commonly used terms to describe such development are *Disorders of Sex Development* (DSD) and *Intersex* (Holmes, 2011). Due to controversy related to both of these terms, the term *atypical sex development* will be used in this study to denote development that differs from what is categorized as typically male or typically female. Atypical sex development is an umbrella term encompassing many greatly varying conditions, having in common that they are understood as related to sex characteristics (e.g., Consortium on Disorders of Sex Development, 2006; Lee, Houk, Ahmed, & Hughes, 2006).

Atypical sex development is often discovered at birth due to atypical external genitalia like a large clitoris and fused labia, or a very small penis (Ahmed et al., 2011; Brinkmann, Schuetzmann, & Richter-Appelt, 2007; Wisniewski, Chernausek, & Kropp, 2012). Sometimes it can be detected in utero (Speiser, 2010). Other times atypical sex development is identified when puberty does not follow the usual path (Ahmed et al., 2011), for example if menstruation does not start (Brinkmann et al., 2007). A study of the medical literature on atypical sex development from 1955 until approximately 2000 concluded that the best estimation of frequency might be close to 2% (Blackless et al., 2000). Even when using lower estimations, atypical sex development is more common than Down syndrome or albinism (Hester, 2004).

Preves (2003) writes that “the occurrence of physical sexual variation is a given. How to respond to that variation is not” (p. 11). Decisions about how to respond to atypical sex development are contingent on how it is understood. Atypical sex development has been, and arguably still is, understood as developmental errors from the biological categories of male and female. Based on the idea that typical sex and gender is desirable, the response to physical sexual variation has generally been to surgically or medically alter atypically sexed bodies to fit better with the categories of male and female (Kessler, 1998; Roen, 2008, 2009). Such altering can for example involve surgical interventions aimed at making atypical genitalia in newborns look more typical.

Management of atypical sex development, especially concerning medical and surgical interventions, has been subject to excessive debate. One alternative to understanding atypical sex development as errors is to see it as part of natural variation (e.g., Fausto-Sterling, 2000;

Preves, 2002). In this perspective, the decision to perform ‘normalizing’ surgery may seem less reasonable. Through years of research and activism, the perspectives of doctors, psychologists, parents and people experiencing atypical sex development have been fairly well documented (e.g., Brinkmann et al. 2007; Chase, 1998b; Duguid et al., 2007; Schober, 1998). The perspective of laypeople has also been investigated, in pioneering research by Suzanne Kessler (1998). What there is still little knowledge of is the *process* of how lay understandings come to be.

Building on Kessler’s work, the current research project is aiming for expansion of the scientific knowledge of laypeople’s view, through examining the process of forming understandings of atypical sex development. This study is conducted in relation to a Ph.D.-project on atypical sex development conducted by Tove Lundberg, Department of Psychology at the University of Oslo. Our studies are part of a cluster of international projects focusing on atypical sex development involving researchers and clinicians from Sweden, Norway and the U.K. Lundberg and I have carried out similar focus groups in England, Sweden and Norway. The current study has used focus groups with participants unfamiliar with the topic to generate data on the lay perspective of atypical sex development.

The understandings of people without specific experiences with atypical sex development are important, both because they may inform other perspectives by providing basis for comparison, and because there are made assumptions by health professionals within the field of what laypeople think, without this being scientifically examined. For example, one Norwegian pediatric surgeon has stated that “The long clitoris is embarrassing, and it is not good for the girls when they grow up and others see this” (Hanger, 2008, my translation). This claim seems to be based on an assumption of atypically sexed bodies as socially unacceptable, an assumption not grounded in empirical evidence. Though the surgeon’s understanding cannot be assumed representative for the medical perspective in general, it illustrates the relevance of knowledge about how laypeople understand atypical sex development.

Knowing more about laypeople’s view of atypical sex development might also open up for new insights and alternative understandings. This could benefit people experiencing atypical sex development, their families and friends, as well as professionals working with the subject. Expanding the knowledge of sex and gender diversity can also be valuable for people not directly involved with atypical sex development, as sex and gender are important concepts in most cultures, affecting everyone.

Thesis structure

In the subsequent chapter I will elaborate on how atypical sex development has been and is understood, focusing especially on research within the fields of psychology and medicine. Further, I will describe my theoretical approach to investigating this topic, presenting the premises guiding the research process and ending with the research questions. Description of ethical and epistemological basis will then precede the chapter on methodology, in which I will describe methodological choices in and procedure for generation and analysis of data. Results will be presented and discussed, before ending the thesis with a general discussion and concluding remarks.

Atypical sex development

Common forms of atypical sex development

Two of the most common ways atypical sex development occurs are in Congenital Adrenal Hyperplasia (CAH) and Androgen Insensitivity Syndrome (AIS) (Alderson, Madill, & Balen, 2004; Wisniewski et al., 2012). CAH and the Partial form of AIS (PAIS) are commonly associated with atypical genitalia, often termed ambiguous (e.g., Hughes, (2008).

CAH involve hormone production in utero that can lead to atypical genitals, and often there is a life-threatening problem with salt wasting (Jordan-Young, 2012; Wisniewski et al., 2012). Infants with CAH therefore often need hormone replacement to cope with hormone production. In addition, atypical genitals resulting from CAH have often been performed surgery on, to make them look more typical (Creighton, 2006), something that is central to current debates in the field (Karkazis, 2008).

AIS can be either partial (PAIS) or complete (CAIS). The present research will concentrate on CAIS. People with CAIS have XY chromosomes, as typical of males, but are completely unable to respond to androgens (Alderson et al., 2004; Wisniewski et al., 2012). Therefore people with CAIS experience a typically female development, except for the internal sex organs that consist of testes instead of female typical ovaries (Alderson et al., 2004; Diamond & Watson, 2004; Wisniewski et al., 2012). It is recommended to remove the internal testes to prevent later malignancy (Lee, Houk, Ahmed, & Hughes, 2006).

Management of atypical sex development

Before the 1950s, the main focus for dealing with atypical sex development was on physical consequences, not psychological (Fausto-Sterling, 2000). A paradigm shift came

with the psychologist John Money and his colleagues (Karkazis, 2008; Reis, 2009). Money expanded the number of physical characteristics to be considered when managing atypical sex development, and emphasized the importance of psychological aspects, for example introducing the concept of gender-identity/role (Karkazis, 2008). The protocol put forth by Money and colleagues “has remained the basis for much contemporary thinking about treatment interventions” (Karkazis, 2008, p. 48).

Central to the theory presented by Money and his colleagues is the assumption that consistency between gender identity and physical sex is necessary for healthy psychological development (Kessler, 1998; Reis, 2009). The theory postulated that psychological gender do not become fixed until a child is about two years, so if one were to alter the body to look typically male or female before this time, the child would grow up to identify as the chosen gender, given that the environment consistently treats the child according to the assigned gender (Fausto-Sterling, 2000). The main evidence for the theory was the John/Joan-case where a newborn boy, whose penis was accidentally amputated, was surgically altered to look like a typical girl (Kessler, 1998; Reis, 2009). Not having a penis or having an inadequate penis was seen as detrimental for a male gender identity, and because it was deemed easier to surgically “create” normative female genitals, common practice became to operate most children with atypical genitalia to be girls (Dreger & Herndon, 2009; Kessler, 1998). The work of Money and colleagues inspired a medical practice where infants with atypical genitalia were systematically operated upon according to whether it would be surgically easier to make their genitals look typically male or typically female (Karkazis, 2008; Kessler, 1998).

The case of John/Joan was for a long time “cited as proof of the plasticity of gender” (Kessler, 1998, p. 6), but in 1997 Diamond and Sigmundson published an article revealing that the sex reassignment had not been successful and had caused much unhappiness for David Reimer, the person behind the pseudonym. This knowledge has had impact on the management of atypical sex development. Sex and gender are no longer understood as changeable in the way Money and colleagues suggested (Lee et al., 2006). However, the idea that physical sex is dimorphic (male/female) and that it is necessary to have consistency between gender identity and physical sex is still central to clinical practice concerning atypical sex development (Roen, 2008).

Kessler (1990, 1998) and Fausto-Sterling (1993) were among the first scholars to criticize the medical practice inspired by Money and colleagues. In relation to Fausto-Sterling's article, Cheryl Chase (aka Bo Laurent) announced the formation of the Intersex

Society of North America (ISNA) (Chase, 1998a; Dreger & Herndon, 2009). ISNA offered peer-support and challenged the medical protocol, especially concerning genital surgery performed on infants (Karkazis, 2008; Kessler, 1998). The activism importantly led by ISNA “were informed by principles of feminism (particularly the right to speak for oneself and critiques of sexism), gay and lesbian rights (particularly critiques of heterosexism and homophobia), and patients’ rights (especially regarding autonomy, informed consent, and truth telling)” (Dreger & Herndon, 2009, p. 204).

In 2007 ISNA transformed into the Accord Alliance, and are now working in collaboration with medical and psychological professionals (Spurgas, 2009). The work of critical scholars and activists has been important in problematizing decision-making regarding management of atypical sex development, and in forming the situation of today.

Following an International Consensus Conference on Intersex in Chicago in 2005, a consensus statement on standards for optimal investigation and management of atypical sex development was published in 2006 (Lee et al., 2006; Hughes, Houk, Ahmed, & Lee, 2006). This conference was attended by fifty experts, primarily in medical fields, and two intersex activists (Lee et al., 2006; Spurgas, 2009). More specific guidelines have also been published, for example a UK guidance (Ahmed et al., 2011) and a clinical guidance by the Accord Alliance (Consortium on Disorders of Sex Development, 2006).

The guidelines developed through the Consensus Conference are based on the understanding of male and female as the only “real” sexes and genders, and of physical dimorphism as necessary. Such understandings emphasize categorization of people with atypical sex development as male or female (Lee et al., 2006), and may encourage subsequent surgical and medical interventions to “normalize” the atypical body (Roen, 2008). Normalizing surgery, e.g. reduction of large clitorises, is still practiced today, but subject to great debate and controversy.

Decision-making related to management of atypical sex development, for example regarding whether to perform interventions and which interventions to perform, is a difficult issue. Since the beginning of the debates regarding management of atypical sex development, the focus has turned from providing parents and individuals with restricted or no information about the situation (Sytsma, 2006) to emphasizing patient-centered care (Consortium on Disorders of Sex Development, 2006) and encouraging parents’ participation in the decision-making process (Lee et al., 2006). Still, there are several problems related to decisions about atypical sex development. For example, parents of infants with atypical genitalia may not perceive normalizing surgery as part of a decision-making process, but instead as obviously

necessary (Crissman et al., 2011). In relation to this, neither parents nor health professionals are necessarily aware of the impact the communicator of information has on the decision being made by parents (Streuli, Vayena, Cavicchia-Balmer & Huber, 2013). Also, Kessler's (1998) point that decisions are made based on "shared cultural values that are unstated, perhaps even unconscious" (p. 25) is still valid. Concerning the basis on which decisions are made and the cultural values involved, knowledge about laypeople's view can be informative.

When comparing the views of parents and college students, without specific experience with sex development issues, with medical professionals, Kessler's (1998) research indicated that laypeople could be more accepting of atypical sex characteristics than doctors/physicians. Concerning the size of penises and clitorises at birth, doctors define the acceptable range for penises as between 2,5 and 4,5 centimeters and the acceptable range for clitoral size as between 0,2 and 0,9 centimeters. College students, in contrast, expected acceptable penis and clitoris size in centimeters respectively to be 2,1-3,6 and 0,9-1,9 (Kessler, 1998). 35 percent also allowed for overlap between smallest acceptable penis and largest acceptable clitoris (Kessler, 1998). Putting the importance of genitals in perspective, the women respondents were more likely to want surgery to large ears, a large nose or large breasts than to reduce a large clitoris (Kessler, 1998). Such knowledge is important when discussing and evaluating the possible ways of understanding and managing atypical sex development. What there is still little knowledge of is the process of how these understandings come to be. In order to research this, the approach of ideological dilemmas developed by Billig, Condor, Edwards, Gane, Middleton, & Radley (1988), which focuses on the preconditions of decision-making, may be a useful framework.

Ideological dilemmas

The approach of ideological dilemmas emphasizes the preconditions for decision-making (Billig et al., 1988). According to the authors, these preconditions are dominated by ideology, and more specifically by *ideological dilemmas*. I am going to use this approach as a framework for examining the lay perspective on atypical sex development.

Billig et al. (1988) criticize the way most psychological studies treat dilemmas. They claim that the dilemma itself is often taken for granted and the dilemmatic situation is reduced to its bare minimum. By focusing purely on the choices being made, and minimizing the social nature and content of dilemmatic situations, the "great moral and ideological

complexities of the original dilemmas” (Billig et al., 1998, p. 12) missing in much psychological research.

Billig et al. (1988) argue that the traditional conceptualization of ideology lacks recognition of the dilemmatic nature of thought. They oppose the image of the decision-making individual as primarily thinking and acting based on a coherent value system in order to achieve cognitive balance. Instead, they propose an image of the thinker as an argumentative debater, shaped by dilemmatic ideology, rather than an individual blindly following ideological dictates. The material enabling such argumentative thought is common sense; “the sense commonly shared by a community” (Billig et al., 1988, p. 13).

Common sense involves the assumed agreement of which positions, opinions, beliefs etc. are commonly sensible and which are commonly affronts (Billig, 1987). Beliefs that involve moral prescriptions can be classified as values. “Ideologically produced dilemmatic thinking arises when two valued themes of an ideology conflict, and these dilemmatic elements can spill over into a full-scale dilemma, when a choice has to be made” (Billig et al. 1988, p. 66). Situations concerning atypical sex development, where decisions have to be made, can be said to constitute such ‘full-scale dilemmas’.

Expressions of common sense often take the form of maxims or proverbs, and for every common sense statement there is often a counter statement. For example, the sayings “Opposites attract” and “Birds of a feather flock together” convey contrary meanings, but are both commonsensical. Though opposites, the two can concurrently be true in given contexts and to certain extents. Billig et al. (1988) postulate that this dilemmatic quality is characteristic of common sense. Without dilemmas, there could be no deliberation, argumentation or thought (Billig et al., 1988). Given this position, the dilemmas of common sense are important issues of investigations for researchers wanting to examine the process of how people deliberate and reason.

Billig et al. (1988) re-analyzed data from prior research on diverse topics, and found them to be full of ideological dilemmas. They proposed that “above all, the dilemmatic aspects can give rise to actual dilemmas in which choices have to be made” (Billig et al., 1988, p. 144). The current analysis has approached this the other way around: starting with dilemmatic situations where choices have to be made, and examined whether the talk about the phenomenon in question was ideologically dilemmatic.

The approach of ideological dilemmas can be a resourceful contribution to the discussion of problems, dilemmas and questions related to atypical sex development. Acknowledging the dilemmatic quality of ordinary and expert thought could open up for new

discussions, for example of whether the search for a right and unambiguous way of understanding atypical sex development is useful.

Research questions

The overarching research question guiding the study is: *How do people with no experience of atypical sex development talk about and understand atypical sex development?* This research question is approached through using focus groups consisting of people without experience of atypical sex development for generating data material, and the framework of ideological dilemmas for analyzing the talk and understandings in the data material.

Based on the ideological framework and emphasis of decision-making process, three more specific research questions are:

Can their talk and understanding be interpreted as ideologically dilemmatic, and if so, how?

What kind of values and beliefs are involved in the talk and understandings?

What consequences might the talk and understandings have for decisions?

Epistemology, macro-ethics, and reflexivity

Epistemological questions concern the nature of knowledge (Guba & Lincoln, 1994). What exists to be known something about? How this can be known? What is the relationship between the knowledge, the researcher and the researched? Epistemological questions and ethics in research will be addressed jointly in the next section, the issues being understood as interrelated.

The current study is based on a social constructionist stance. Social constructionism cannot be exhaustively defined, but there are some key assumptions common for most social constructionist positions (Burr, 1995): “a critical stance towards taken-for granted knowledge” (p. 3), recognition of historical and cultural specificity, seeing social processes and interactions as crucial for producing and sustaining knowledge, and focus on the relationship between knowledge and action. Perhaps underlying all of the assumptions is the rejection of the idea that social sciences can produce objective knowledge. ‘Truth’ is understood as knowledge that is collectively accepted, rather than objective observations (Burr, 1995). This does not mean that obtainable knowledge is worthless or untrue, but that it is wrong to believe “that scientific method can be detached completely from controversy, either scientific or ideological, and, as extreme rationalists would say, is the only way to truth” (Billig et al., 1988, p. 150)

The assumptions listed above about the nature of knowledge provide the epistemological basis for this thesis. Firstly, common sense understandings, shared knowledge that is taken for granted (e.g. gender as dichotomous), are explicitly in focus. The research venture is undertaken recognizing that the results produced are situated in a specific cultural and historical context. This for example means being grounded in a privileged western culture, and a particular age of medical technology. Historical, cultural and subjective influences are understood as imperative in making knowledge about people meaningful and useful. Social constructionism involves seeing knowledge as constructed between people, and importantly so through everyday practices (Burr, 1995). I view the research at hand as a meeting point between previous theories, my experience and the participants' understandings. There is also an underlying assumption of this study that understandings and talk are importantly affecting possibilities for actions: different ways of conceptualizing atypical sex development may invite different courses of medical management. Seeing the knowledge being produced as linked to social action in this way can be related to what Brinkmann and Kvale (2005) define as macro-ethics: ethics concerning how the knowledge produced through the research may affect other people and the larger society or culture.

Brinkmann and Kvale (2005) use consumer research aiming for manipulation of potential buyers as an example of how research may be ethically conspicuous on a macro-level. Another example of how research may be macro-ethically wrong is provided by Brown (1997), who criticizes research on intellectual differences between people of different skin color for legitimizing racist discourse and weakening social support for people of color. Analogous to this, the present research project could be defined as ethically corrupt if there was a goal of imprinting in the readers a certain understanding of atypical sex development implying a certain form of management or if it could lead to a discriminating discourse. The goal of this research is to open up for new understandings and more options for choice, based on the idea that this may hinder manipulation and promote possibilities for better-informed individual choice.

The language used in the thesis has also been thought through in order to be as sensitive as possible, and not to promote discriminating discourse. One example of this is the avoidance of the commonly used terms "Disorders of Sex Development (DSD)" and "Intersex", because the first is seen by some as "undeniably pathologizing" (Clune-Taylor, 2010, p. 154), while the latter is seen as potentially pejorative and confusing by others (e.g., Lee et al. 2006).

In contrast to macro-ethics, the ethical concerns related to how the participants and their contributions are treated, including the relationship between the researcher and the researched, can be defined as micro-ethics (Brinkmann & Kvale, 2005). Important elements to micro-ethics are:

...to obtain the subjects' consent to participate in the research, to secure their confidentiality, to inform them about the character of the research and of their right to withdraw at any time, to avoid harmful consequences for the subjects, and to consider the researcher's role (Brinkmann & Kvale, 2005, p. 167)

For the moment I will concentrate on the researcher's role, and discuss the other elements when presenting the methodology in the next chapter.

My understanding of the researcher's role is that of an actively partaking constructor of knowledge, for example in contrast to that of a detached expert optimizing objectivity. In line with what Toma (2000) describes as subjective and interpretative researchers, I do not believe in a single reality or truth open for discovery by researchers, and I see my person as inseparable from the data production and analysis. The presence of the researcher in the research is not a necessary evil, but an important condition leading to good qualitative data when combined with methodological rigor (Toma, 2000). With this perspective in mind I have tried to strike a balance between not eliminating my person from the text and not putting myself at the center of the text.

Contemplation about the researcher's role involves reflexivity. Willig (2008) defines reflexivity as "more than acknowledging personal 'biases'; reflexivity invites us to think about how our own reactions to the research context and the data actually make possible certain insights and understandings" (p. 18).

I categorize myself as a person with typical sex development and typical gender identity for that sex. Writing a thesis on a topic that I do not have firsthand information about has not been unproblematic. I have among other questions struggled with the feeling that I have no "right" to write about a topic that is not part of my embodied life. Conflicting with this is my desire to write about a theme that generally is given little focus, a genuine interest in exploring alternative understandings of sex and gender, and the belief that it is important for people categorized as a majority to take an active interest in understanding and exploring minority perspectives. As such, my role in this research venture is ideologically dilemmatic as well, characterized by competing values.

In the research situation, it is likely that my role as a psychological researcher affected the focus group discussions. Streuli et al. (2013) found that participants' judgments were prominently and significantly affected by whether information about atypical sex development is provided by medical experts or psychological experts. When hypothetically deciding whether to perform sex assigning surgery on their infant with atypical genitalia, 66% opted for surgery after watching a medicalized information video in contrast to 23% choosing that option after watching a demedicalized video (Streuli et al., 2013). In light of this research, it is probable that the focus group discussions would have been importantly different if moderated by a medical student rather than a psychology student.

Methodology

In this chapter I will describe how and argue for why the focus group method was used to produce knowledge of the everyday perspective on atypical sex development.

Qualitative research

When Kessler (1998) examined the everyday perspective, the methodology was first and foremost quantitative, examining the decisions laypeople made and comparing them to those of physicians'. One of the findings of Kessler was that college students were likely to opt for early normalizing surgery in the hypothetical situation of having a newborn with atypical genitalia. Though reasoning behind the choices were reported to some extent, e.g. "not wanting their child to feel out of place in society" (Kessler, 1998, p. 103), the process leading up to a decision is largely unexamined. For the purpose of studying the preconditions of choice, and the meanings involved in this, a qualitative approach is needed.

Central to qualitative research is the orientation towards process as compared to outcome, and interest in meaning making and experience (Willig, 2008). In the current study I am using the approach of ideological dilemmas to produce knowledge on the process of decision-making in relation to atypical sex development, and the social meaning making and experience involved in this. According to Barbour (2007) focus groups "excel at providing insights to process rather than outcome" (p. 30).

The focus group method

The focus group method is a method for collection of qualitative data, where people are brought together in order to have a group discussion focused on the topic of investigation (Wilkinson, 2008). The researcher moderates (i.e. keeps focused) a more or less free

discussion among the participants on the topic in question. Most focus groups lasts from one to two hours (Morgan, 1997).

The number of participants, the degree of moderator involvement, and the number and specificity of questions in focus groups may vary according to research purpose and resources (Morgan, 1997). For example, a focus group can start with the moderator initiating the discussion with only one broad question, and intervene minimally with group interactions. A different focus group design could concentrate the discussion on three broad questions, with additional questions the moderator asks if the participants don't touch upon the content of these otherwise, i.e. intervene if certain subjects are not discussed.

Morgan (1997) suggests a rule of thumb of six to ten focus group participants. A disadvantage of small group size is "the risk of being less productive because they are so sensitive to the dynamics among the individual participants" (Morgan, 1997, p. 42). The best use of small groups is for researching in detail each person's reactions. Comparably, large groups can involve small conversations among some of the participants, and more people talking at the same time (Morgan, 1997). Large groups are more often difficult to moderate (Morgan, 1997).

High level of moderator involvement is "especially when there is a strong, preexisting agenda for the research" (Morgan, 1997, p. 39). For exploratory research less moderator involvement may be more fruitful (Morgan, 1997). Connected to the degree of moderator involvement is the specificity of the questions or topic to be discussed, highly moderated groups often involve a more structured focus group guide (Morgan, 1997). The focus group guide should be devised to balance the focus of the researcher and the discussion of the participants (Morgan, 1997).

Choice of method. Knowledge about "the everyday view" of atypical sex development could also have been produced through use of other methods, for example interviews or observational methods.

Observational methods could have been useful for producing data on ideological dilemmas. Billig et al. (1988) used data from observation research in their analysis, but observation would not have provided the same emphasis on atypical sex development that the focus group method facilitates. The focus group method allows for secure focus on the topic at hand, through researcher moderating of the group discussion.

Compared to interviews, focus groups more closely resemble everyday conversations and discussions (Wilkinson, 2008). This adds to the ecological validity of the research. Another way the focus group differs from interview methods is the importance of the

interaction between participants and the data being produced (Willig, 2008). Though interviews also involve social interactions between the interviewer and the interviewee, the focus group method invites interactions that are more equal concerning status and roles than that of the interview (Wilkinson, 1998). This provides a different social quality to focus group data from that of data developed in interviews.

The focus group method produces data on “the *process* of collaborative sense-making: *how* views are constructed, expressed, defended and (sometimes) modified” (Wilkinson, 2008, p.189, my emphasis). Focus groups may therefore provide not only the content, the “what”, but also the “how” of everyday talk and understandings. The setting of the focus group allows for elements of talk and understanding to emerge that are more difficult to cultivate in other research situations, such as joking, storytelling and persuasion (Wilkinson, 2008). These characteristics, along with contradictions, tensions and use of qualifications, are highly relevant for the approach of ideological dilemmas, since they signify dilemmatic thought (Billig et al. 1988).

Frith (2000) argues that:

focus groups are ideal for exploratory research in areas where little is known, not simply because they allow for the generation of ideas and the development of hypotheses to be tested, but because through the interplay between participants researchers are able to get a sense of the contested nature of particular issues, the strength with which particular views are held, and to observe the ways in which these views are rationalised and defended. (p. 291).

This fits well with the purposes of this study, since little is known of the process involved in forming the everyday perspective on atypical sex development. The current study could serve as a pilot project, providing basis for further studies, both qualitative and quantitative.

Talking about genitals and sexed embodiment can be seen as sensitive topics, and possibly difficult to discuss in a group of strangers, especially when they have been asked to participate because of their lack of knowledge about the subject matter. Contrary to this plausible assumption, focus groups have been documented to be a very suitable method for researching sensitive topics (Farquhar & Das, 1999; Frith, 2000; Morgan, 1998; Wilkinson, 2008), dependent on the research question being asked (Farquhar & Das, 1999). One main reason for this may be the creation of a safe space (Farquhar & Das, 1999), where the presence of others encourages talk about own experiences (Frith, 2000).

Procedure

Recruitment. The purpose of this project is to examine the ways laypeople talk about and understand atypical sex development, not to map the attitudes of a general population. A representative sample is therefore not needed, and the participants were recruited through convenience sampling.

The main criterion for participation was not to be familiar with the topic. If the participants had known about the discourses of for example intersex activists or pediatric surgeons working with atypical sex development, that would likely have affected their understandings, and probably defeated the purpose of getting information about lay perspectives. Other requirements for participation were to speak fluent Norwegian, and to be able to attend at one of the designated times.

Based on a general rule of thumb, projects using the focus group method should comprise of three to five groups, because this amount in most cases ensures saturation (Morgan, 1997). I planned to conduct four focus groups. The aim was to have four or five participants in each group, attempting to strike a balance between the advantages and disadvantages both large and small groups. This would allow enough time for each participant to talk, while still maximizing the methods' advantage of producing data on processes of social sense-making. More participants and/or groups would also have required more resources. Sixteen to twenty participants therefore seemed like a sensible number, considering the time and resource frame of the project.

Participants were recruited from the University of Oslo (UiO), through face-to-face contact in lecture breaks, e-mails and posters. Through recruitment in lecture breaks I got the names and e-mail addresses of 28 persons who were interested in participating in the project. After the primary face-to-face contact I kept in touch with the potential participants via e-mail. They were given information about the project and what participation would involve, included that they would be compensated with 100NOK (see appendix 2).

Those interested in participating were asked to answer some questions to help them think about potential experience of atypical sex development before they made any commitment to participate (see appendix 6). This was done in order to make sure that they did not have prior knowledge or any experiences of the issue. Five out of the initial 28 did not respond to the emails. Three persons were excluded from participation because their answers implied that they had knowledge or experience of the topic from before. Four persons could not attend any of the scheduled times. Two of the participants scheduled to participate in the first focus group cancelled the same day, and I did not manage to fill their places in the

group. This encouraged me to over-recruit participants to the remaining groups in order to secure at least four participants to each discussion. New participants were recruited via posters on campus and e-mail via a listserv at the Department of Psychology. Twelve people were recruited in this manner.

In the remaining groups, six persons cancelled before their scheduled group. Three gave no reason, for the other three something more important came up. One person did not show up nor give any notice. Three people who wanted to attend the last focus group were turned down. One person because they did not have the skills in Norwegian that was required to be in the group, and two because the group was already full.

Though there were common problems like no-shows and cancellations, all the planned focus groups took place on the appointed time. The first group consisted of three participants, and the rest of the groups consisted of five participants. None withdrew during the focus groups. All in all, out of the forty people who had indicated interest in participation, sixteen cancelled or did not respond and six were excluded. Thus, 18 participants took part of the study.

Participants. The groups were homogenous in that they consisted mainly of young students, the majority (12 participants) studying psychology. Of those not studying psychology, one works as a psychologist and five are students within social sciences, humanities or neuroscience. Sixteen were or had been students at the University of Oslo, two had studied at other Norwegian universities. The participants' ages ranged from 19 to 39 (mean= 21.94 year, median = 21,5, mode = 19).

Eleven identified as women and seven identified as men. The first group consisted only of women. Two groups consisted of three women and two men, and one of three men and two women. The participants generally did not seem to know each other beforehand, though they were not asked specifically to report this. It is possible that while not knowing each other well, a few participants had a nodding acquaintance.

Focus groups. When I joined the project, my supervisor Tove Lundberg had developed a focus group guide in English. Since we were going to conduct comparable focus groups, I translated this guide into Norwegian. Some slight changes were done in the process of translation to make sure that the Norwegian wording did not sound awkward when read out loud. To create an informal environment for the group discussion, something that was seen as an advantage in producing lay understandings, it is essential that questions be asked in a conversational manner that is comfortable for the moderator (Krueger, 1998).

A pilot group was conducted to test the Norwegian focus group guide. The participants were friends and acquaintances of Lundberg and me, and I acted as moderator with assistance from Lundberg. This provided opportunity for familiarization with the guide, testing of the time frame, discovering of unclear formulations, etc. It was also useful for evaluating whether saturation was reached with the fourth group. The pilot group was not audio taped and is not included in the data material.

The focus groups took place at the Department of Psychology, University of Oslo. Each group lasted nearly two hours. The participants were offered refreshments, and we made small talk until everybody had arrived. Before starting the focus group the participants read and signed the consent sheet (see appendix 3) and were given information about the research and the discussion. Participants' right to withdraw at any point was repeated. Confidentiality was emphasized, and we decided on some ground rules for the discussion, for example not interrupting others during the discussion.

The guide includes probes and follow-up questions, in order to ensure that that relevant themes already set by the researchers were covered, and a degree of consistency in the themes discussed in each group. There are also reminders for the researcher to ask for and encourage questions, to make sure that everybody understands the issue in question and to ensure participants that what they have to say is important.

The focus group discussions consisted of four main parts: 1) opening questions, 2) two vignettes with clinical dilemmas, 3) discussion of terms/words and 4) evaluation of gender identity theories. All questions and activities relate to issues that currently are debated, for example whether or not to surgically reduce a large clitoris. This focuses the discussion on issues that are especially challenging in practice and where this research might provide insights relevant to clinical thinking.

The opening questions are meant to elicit participants' immediate understandings of atypical sex development. They addressed what they think health professionals do when they discover that a child has atypical sex development, what they think should be done, and whether they have heard about this issue before. This part of the discussion forms an important part of the data material since it gives information about which understandings might be readily accessible when people hear about atypical sex development for the first time. It also provided participants with an opportunity to relate any other experiences to the topic. The introductory questions can be seen as a mix of what Krueger (1998) defines as introductory questions and transition questions. They introduce the topic for the discussion, and "allows participants to tell about how they see or understand the phenomenon under

investigation” (p. 24), while opening up for the key questions and making “connection between participant and topic” (p. 25). As well as producing important data, the opening questions are vital in laying the foundation for the rest of the discussion.

Following the opening questions the participants are presented with two vignettes depicting hypothetical situations where decision-making related to atypical sex development is central. Participants are asked to imagine themselves or their child in a situation where atypical sex development is evident. They are then asked to discuss how they would act and make decisions in this situation. These hypothetical clinical dilemmas are similar to actual clinical situations experienced by parents and patients, related to the forms of atypical sex development described before: Congenital Adrenal Hyperplasia and Complete Androgen Insensitivity Syndrome.

The first vignette concerns a newborn girl having an adrenal malfunction and a visible clitoris, common for girls with Congenital Adrenal Hyperplasia (CAH). The decisions that might be relevant involve whether or not to use medicines to stabilize the adrenal gland function, and whether or not to surgically reduce the size of the clitoris.

The second vignette concerns a teenage girl who has not started menstruating and has discovered a lump near her groin. The vignette reveals that the girl has XY chromosomes and an internal testicle, common for girls with Complete Androgen Insensitivity Syndrome (CAIS). The issues that need to be addressed here are whether or not to disclose the information to the girl and, if so, how to do that. The emphasis is on the process of decision-making, rather than the decisions being made.

All groups are presented both vignettes, but two of the groups were asked to imagine themselves in the first situation and their child in the second, and the other two groups the other way around. This was done in order to open up for possible differences between understandings when imagining oneself versus one’s child in a specific situation. Suzanne Kessler (1998) found that such differences in position could importantly influence the decision-making, in that people typically opted for performing normalizing surgery on their child, but not on themselves.

What concepts to use in research, clinical practice and everyday life when talking about atypical sex development have been subject to great debate. It is therefore interesting to investigate everyday understandings of the most used concepts. Two of the most commonly used and hotly debated terms are “intersex” and “disorders of sex development”. After discussing the vignettes, the participants are presented with these terms and asked for their opinion of them. They are also encouraged to think of new, and potentially preferable, terms.

In the final part of the focus group discussion, the participants are presented with three theories of gender identity: a hormonal theory, a psychological theory and a cultural theory. The first one centers on hormones as the most important factor for understanding gender identity, saying that hormones act on the body and brain from before birth, usually leading one to feel, and look, like a man or like a woman. The second theory focuses on subjective well-being, saying that having a typical body is not necessary to feel comfortable about one's gender, it is more about how one relates to norms and pressure to conform. The last theory highlights cultural differences in rules for gender, and says that the definition of what makes someone a woman or a man is different in different cultures.

They are given a card for each of these theories, and asked to arrange them according to how useful they think it would be for a young girl experiencing atypical sex development. That is, in order for the girl to understand her situation and give it meaning. Ranking of the cards is done individually, before having a group discussion about thoughts of the theories.

At the end of the focus group session, all that has been discussed is shortly summarized. Participants are asked for questions and comments. Information needed in order to transfer compensation is collected, as well as demographical information about gender, age and study program/job title. Participants are given an information sheet thanking them for their participation (see appendix 5). The sheet provides information about relevant web sites for learning more about atypical sex development, as well as researcher contact information in case questions come up later on.

Transcription. To get familiar with the data I listened to all the recordings before I began to transcribe. Using the software HyperTRANSCRIBE I transcribed all interviews myself. This provided consistency, but also required a lot of work. Not having done focus groups before, I was not quite prepared for how long time this part of the research process would take. The transcriptions mimicked the audio recordings closely, including hesitations, stuttering and intonation, but dialects were written in the most used official written standard of Norwegian. Not including dialect variations enabled me to better anonymize the participants, as well as writing faster, without compromising the meaning of what was said. While transcribing thoughts and reflections relevant for coding and analysis later on was written down as analytic memos. Preliminary codes were also recorded.

Analysis

The framework and fundament of the analysis in this project is the approach of ideological dilemmas, inspired by the work of Billig et al. (1988). Billig et al. (1988) applied

the approach of ideological dilemmas to data that were collected without this framework in mind. They wanted to show that ideological dilemmas permeate all kinds of talk, and are essential for many topics. In comparison, I went through the whole research process with analytic approach of ideological dilemmas in mind.

Though Billig et al. (1988) describe the importance of ideological dilemmas, what the dilemmas can look like, and what kinds of discursive elements especially imply them, their work is not that of a methodological guide for analysis. Several methods for analyzing qualitative data could possibly have been used, but I have chosen to do a primarily thematic analysis.

The analytic process involved looking for important themes, just like regular thematic analysis, but at the same time looking for ways in which these themes included contrary thoughts indicating ideological dilemmas. “The presence of contrary themes in discussions is revealed by the use of qualifications” (Billig et al., 1988, p. 144). The analysis therefore proceeded comparably to typical thematic analysis, but with special attention to use of qualifications. Braun and Clarke (2006) are often credited with giving the most thorough description of thematic analysis for use in psychological research, a method that is widely used, but often poorly demarcated.

Braun and Clarke (2006) describe six phases of thematic analysis. The first involves familiarization with data, including transcribing, reading and initial ideas. In the second phase the researcher begins the coding process by creatively, though systematically, coding interesting items in the data set. The third phase entails searching for potential themes, while the fourth engages in reviewing the themes, by for example seeing whether the themes work in relation to the codes and the entire data set. Then, in the fifth phase the researcher needs to define, refine and name the different themes, and ensure that they refine what general story the analysis promotes. The final phase concerns the producing of the report, involving the selection of extracts, relating the analysis to literature and the research question, and finally to produce the scholarly report.

Though the stages demarcated by Braun and Clarke (2006) constitute very useful guidelines, “the distinctions between different stages of the analysis is conceptual for the most part” (Howitt, 2013, p. 182). The analytic process has been continuous throughout the current research process, involving looping back and forth between the stages, as typical of qualitative studies (Richards, 2005). Such nonlinear development of the analysis is not a weakness, but rather a sign of analytic effort and constant improvement of the analysis (Howitt, 2013).

The first important analytic steps in this project were undertaken during the focus group sessions, through reflections about and interpretation of what the participants said and did. For example, I early on got the impression that the concept of “normality” would be important in the analysis of the data, since the theme was brought up as important in all groups. I also paid attention to whether the participants’ talk seemed to be dilemmatic or not. Through transcription of the spoken records I wrote down analytic memos about the data set. These included my thoughts and questions, and ideas for possible common sense understandings, themes and contrary themes in the participants’ talk. This process familiarized me with the data to a great detail, and I got a feeling of the data material as a whole. This process continued through the coding phase.

The data material was coded using the software program HyperRESEARCH. Computer aided coding is especially helpful for data management when dealing with large amounts of data (Howitt, 2013), as was the case for this project. When coding the data material I read and reread the transcripts, marking passages of text according to what the participants focused on in their talk. Because I am interested in social understandings, not for example individual opinions, the level of analysis is the group. Hence, individual voices are important insofar as they represent socially shared understandings.

Primarily using a bottom up-approach to coding (Braun & Clarke, 2006), I started by coding the first part of all the transcripts, where the opening questions are discussed. After coding the first part of all four groups, I went through the first group again with the codes created in the last three at hand. Then the second group was recoded with the codes created when coding group three and four. Lastly, group three was reread and recoded with the codes made during the work with group four. This way of coding and recoding was used with the rest of the transcripts. Thus, all transcripts were coded with the same codebook. I started the coding of each of the four main parts of the data material (introductory questions, vignettes, terms, and theories) with a new group each time. This was done in order to avoid the possibility of one group getting more acute attention than others.

After initially creating many codes, over 400, I revised the codebook and ended up with 111 codes. Knowledge of the literature on atypical sex development and on ideological dilemmas affected the codes that were developed, but I related to the data material as openly as possible. Codes that were understood to refer to the same concepts were collapsed, and codes that were unimportant to the research question were deleted. It also became evident that some codes were the reverse of others, and these were collapsed into one code with two poles.

During the coding phase I became aware of how vast the data material actually was. In order to make the data more manageable for analysis I decided to leave out the two last parts of the focus group discussions, concerning terms and theories, from the thematic analysis. Since these parts of the data also provide information relevant to current discussions, they will be presented briefly before the results from the thematic analysis.

Browsing through the coded material, I began to develop themes that best captured the participants' talk and understandings of atypical sex development, and the ideological dilemmas involved in these. I used lists, mind maps and manual sorting of pieces of paper to explore how all the elements may best be put together in order to form overarching ideological dilemmas. The tentative themes were tested against the transcripts to ensure that they were representative of the data material, by going through the data and my preliminary themes and seeing whether they fitted within the candidates for final dilemmas.

At this stage of the analysis process, I started to write about quite a few tentative ideological dilemmas that had been developed through combining codes. Through writing about these dilemmas and discussing them with my supervisor, it was possible to see the interconnections between them and how many of them referred to different sides of the same superior dilemmas. After reviewing and refining the initial themes and dilemmas, that is: "identifying the 'essence' of what each theme is about (as well as the themes overall) and determining what aspect of the data each theme captures" (Braun & Clarke, 2006, p. 92), two overarching ideological dilemmas were decided upon: "Being different: normality versus individuality" and "Decision-making: agency versus expertise".

In line with Braun and Clarke's (2006) recommendation the excerpts and quotes used in the presentation of results have been chosen because of their ability to capture the essence of the points being made. The data have been translated quite literally, with mind to their informational content and demonstration of dilemmatic ideology rather than how natural they sound in English. Filler words like "then", "so" and "like", and stuttering were deleted to make the quotes easier to read. In Norwegian, the word for gender and for sex is the same, "kjønn". When the participants have used this word, I have quoted it as "gender/sex", because of the dual meaning.

Micro-ethics

The present study has gotten ethical approval by the Norwegian Social Science Data Services (NSD), received the 9th of September 2013 (see appendix 1). However, as Kvale (2008) points out: "ethical issues go through the entire process of an interview investigation"

(p. 24). Before performing the focus groups, some of the most important tasks related to ethical conduct were to devise an informed consent form and information sheets (see appendix 2, 3 and 5). Data material was stored on encrypted memory sticks. Only my supervisor and me had access to the data material. Contact list and consent forms were safely stored in a locked cupboard.

The participants received a sheet with information about the project through email. This was formulated in order to give the information about the project and participating in it that was needed to be able to give truly informed consent, but not so much that it prepared the participants on the subjects they were going to discuss. I wanted them to be fully aware of what they consented to without preparing mentally to discuss the issues, since I wanted their spontaneous thoughts and understandings.

When giving informed consent (see appendix 3), the participants signed that they would not disclose any information about the focus group that could identify other participants. This measure was taken to minimize the risk that they would jeopardize each others' confidentiality. This is something I could not thoroughly control, and illustrates how research is dependent on trust. It also exemplifies that "most of the ethical issues in focus groups flow from relationships" (Morgan, 1998, p. 85).

Monetary compensation can pose ethical problems. The participants in this study were awarded 100NOK each, as an expression of gratitude for their time and effort in contributing to the research. Though payments help with recruitment, it is not always appropriate, especially with vulnerable groups (Barbour, 2007). As to the participants in this study, they were not likely to be disadvantaged in relation to socio-economic status, and hence it was reasoned that 100NOK would not be a large enough amount to make people participate purely for the sake of earning money.

Power relations are important to consider when doing qualitative research (Kvale & Brinkmann, 2005). The researcher most often holds most of the power, for example by having "the scientific competence and the right to pose questions and set the agenda" (Brinkmann, 2007, p. 129). Compared to interviews, the focus group researcher's "power and influence is reduced, because she has much less power and influence over a group" (Wilkinson, 1998, p. 114). The more equal power relationship between researcher and researched can give the participants more opportunity to control the discussion, something that can pose a problem for keeping focus, but also be positive though making the experience more enjoyable for the participants (Wilkinson, 1998).

It was not deemed likely that the participants would have negative consequences due to participating, since they were not considered vulnerable. Instead, acquiring better knowledge of the process of research, as well as learning about a topic they knew little of from before, can be seen as benefits from participation. The positive responses from the participants after the sessions support this assumption.

Results and discussion

In this chapter I will describe and discuss the results of the study. Firstly, the results regarding the terms “Disorders of Sex Development” and “Intersex”, and theories of gender identity will be presented, then the results from the thematic analysis using the framework of ideological dilemmas are presented.

Two ideological dilemmas were developed in the analysis: “Being different: normality versus individuality” and “Decision-making: agency versus expertise”. The sides of the dilemmas represent contrary values conflicting in the talk and understandings of the themes. The first dilemma concerns how the contrary values of normality and individuality form the understanding of atypical sex development as a way of being different. The latter dilemma concerns the importance of the conflicting values of expertise and agency in forming the understanding of decisions and choices related to experiencing atypical sex development. The analysis can be seen as consisting of two steps; firstly examining the understanding of the phenomenon, and then examining the understanding of decision-making related to the phenomenon.

The two dilemmas represent both what the participants were interested in discussing, and what I saw as most interesting and relevant based on the existing literature, and current discussions on how to conceptualize and manage atypical sex development.

Terms and theories

As described in the methodology chapter, part of the focus group discussions dealt with the naming of atypical sex development, and with theories of gender identity. During the research process, it became evident that the data material was too vast for me to examine all of it in great detail. The introductory questions and the part of the data material dealing with hypothetical clinical dilemmas were therefore prioritized. Because the discussions of terms and theories of gender identity also provide information highly relevant to current discussions in the field, they will be described shortly here.

Disorders of sex development and intersex. When being presented with the term

disorders of sex development, the participants generally perceived it as negatively loaded.

Quote 1: Participant 1, group C

But I maybe think that, fair enough that it is abnormal, but as soon as it is a ‘disorder’, the word disorder, it is not positive. At all. It’s okay, you can be abnormal, you can be unique, you can be special, and that is a nice thing, but if you are disordered [...] do you have a disorder then you have...in my ears there is nothing positive in that.

The participants typically saw it as problematic to name something as a “disorder”, even if it was meant as purely descriptive. One participant saw nothing wrong with the term.

The opinions of the term “intersex” were more diverse. More were positive towards the term “intersex,” but generally this term was not greatly favored either. Some changed from beginning out positive towards “intersex” to talking more negatively about the term. Others changed their understanding the other way around. Intersex was often understood as meaning that one identified as something in between male and female.

Quote 2: group B

Participant 4: [DSD has] more negative focus, I think, than intersex. It is in a way just a new, like, male, female, intersex

Participant 5: Yes, but I really think that it, intersex is more like “I don’t know if I am entirely boy or girl, so therefore I am a neuter”, in a way

It could be argued that the necessity of having an umbrella term for all kinds of atypical sex development springs from a dichotomous gender/sex system; “othering” certain types of development. The understandings in the focus group discussions seemed to generally favor more specific terms.

Quote 3: Participant 4, group B

the common term in a way becomes a bit unnecessary, maybe I want skip saying that I have a sex disorder. (5: Mhm) Because what, what does that tell us, kind of. Just that you are abnormal. (5: Mhm) Then I would rather say that for example “I don’t have ovaries. I don’t menstruation. I...” Right?

It is important to note that it is not clear cut how people understand these terms, and perhaps that both of the terms are ideologically dilemmatic in their own right. The results presented here support voices critical of the term “disorders of sex development”, like Reis (2009), but also those seeing the term “intersex” as potentially misleading (e.g. Lee et al., 2006).

Theories of gender identity. 14 of the participants rated the psychological theory as most important, out of these nine rated the hormonal theory second. This might not be surprising, seeing as most of the participants were psychology students. Two rated the hormonal theory as primary and two the cultural theory as primary. Two of these four were not psychology students. In total, only one participant rated the psychological theory last, giving primacy to the hormonal theory. Most participants argued that all of the theories were relevant, and many described them as complementary.

These results support the 2006 guidelines recommendation of multidisciplinary approach, and suggest that people would like to get different kinds of information, including biological, psychological and cultural. The following section presents the results from the main analysis, results that may add to the information available.

Being different: normality vs. individuality

When presenting the topic of atypical sex development to people that had no knowledge of it from before, it was deemed necessary to talk about it as divergence from what is thought of as typical sex development. The focus group discussions to a great extent came to revolve around the notion of “being different”. This will therefore be the focus for this part of the analysis.

The participants used both the words introduced by me (“atypical”, “different”), and others (“abnormal”, “unusual”, “special”, “unique”) to talk about atypical sex development as a way of being different. Central to the discussions of “being different” were the values of normality and individuality.

Normality as a value. Normality was a dominant theme in all of the focus group discussions. The concept was most often used comparably to the dictionary definition “conforming to a standard; usual, typical, or expected” (“normal” n.d.). Participants used the words “normal” and “abnormal”, as well as phrases implying normality, like “ordinary” and “everybody/nobody else...”. Being normal was often assumed to be good and desirable.

Quote 4: Participant 2, group B

...one may not dare to get a [boy-/girlfriend] and such, because one knows that one is a bit abnormal. And, like, when you are like young, it is difficult anyway, or, it is frightening with [boy-/girlfriends] and everything like that. And I can just imagine that it is extra bad if one feels abnormal

Quote 5: Participant 5, group D

if it is something that really bothers (...), that it becomes abnormal, that she feels that she in a way isn't content, because there is that, it is also quite important and it is, have become, yes, they have very much in the media about all that, that one should be content with oneself and (3: Mhm, 4: Yes) one, one does not want to be abnormal when one is in puberty, right

The quotes above exemplify how normality often was talked about in the focus groups. Participant 2 talks about being and feeling normal. The assumption that normality is preferable underlies the argument that abnormality will negatively impact the individual. It is taken for granted *why* being or feeling abnormal would make close relationships more difficult. The generalization participant 5 makes when saying “one does not want to be abnormal” suggests that this knowledge is part of common sense.

By being implicitly or explicitly endorsed as a goal to achieve, normality is not

merely a term used to describe what is common, but a value prescribing how it is desirable to be. This value can be considered common sense, since it is often socially taken for granted.

Individuality as a value. Individuality was another dominant theme in the discussions. The Oxford Dictionary of English defines individuality as “the quality or character of a particular person or thing that distinguishes them from others of the same kind, especially when strongly marked”. In the current analysis, this definition is combined with Billig et al.s definition of individualism as a “moral prescription to appreciate the rights and liberty of the individual” (1988, p. 126). The concept of individuality as used in this analysis emphasize appreciation of individual variation, and the moral prescription that individuals should have the right and liberty to determine and express their own distinguishable quality or character. Thus, individuality can be understood as a value.

The words “individual” and “individuality” were seldom used in the focus group, but other phrases I consider representing the value of individuality, for example “the person”, “identity”, “yourself”, were often used. The quotes below illustrate how individuality was recognized in the focus groups.

Quote 6: Participant 3, group D

We are different. And that's totally okay. That it isn't any stress if somebody has a large clitoris or large labia majora or whatever, like.

Quote 7: Participant 5, group A

a person with this [atypical sex] development should, should get these conversations with a therapist (2: Mhm) where they focus on recognition (1: Mhm) of the individual, and talk about where, where the value of the human being lies. And talk about that these gender categories are only socially constructed to us, to make society function. Boy wardrobes and girl wardrobes and the whole thing, kind of. And it does not necessarily have something to do with...it need not have anything with your identity to do then, necessarily...or your dignity.

In these quotes it is emphasized that difference is ok, and that norms for gender/sex need not determine ones identity or dignity. This kind of talk can be seen as expressions of the value of individuality. Individual variation is presented as something that should be accepted, not normalized.

Negotiating between the values of normality and individuality can be difficult. The desire to live up to what is considered normal may conflict with the desire to live out one's individuality. Because they involve moral beliefs that are part of common sense (Billig et al., 1988), normality and individuality can be defined as ideological issues. The focus group participants' talk and understandings of atypical sex development were shaped by the value of normality and the value of individuality in a way that is ideologically dilemmatic.

Normality and individuality as ideologically dilemmatic. One of the situations the focus group participants were asked to imagine themselves in was that they had been born as

a girl with a larger than average clitoris. In this situation, the doctors offered surgical reduction of the clitoris. The question to be discussed was what the participants would have wanted their parents to do in this situation. The excerpt below is from one of the discussions of that question.

Quote 8, group A

Participant 2: Perhaps, as a parent that feels, that drama maybe feels a bit different [...] if you sit and think “Yeah, do we now really just make a cosmetic decision for our child?” But, at the same time then, many parents would want [...] that their child would, not be the norm, but in a way not be born with any

Participant 4: Be different

Participant 2: Yes, and some, yeah, all children are different, but they, like, don’t want it [the child] to have any unnecessary disadvantages then, or inconveniences, to them.

This excerpt shows how the assertion of normality as desirable conflicted with the acknowledgement of individual variation in the participants’ discussions. Participant 2 implied that many parents would want their child to be a certain way, but qualifies this by disclaiming that they desire for the child to “be the norm”. This can be interpreted as based on the value of individuality, since the implication involves the value judgment that it is wrong to compel a child to fit a norm. Participant 4 upholds the value of normality by suggesting that the parents do not want their child to “be different”. This was partially accepted by participant 2, who agreed, but qualified the agreement by emphasizing individual variation (“all children are different”). This is qualified in turn, through hinting at the assumption that too much difference, or some specific kinds of difference, would negatively impact the individual (“unnecessary disadvantages then, or inconveniences”).

Use of qualification is one of the indicators of dilemmatic ideology (Billig et al., 1988). This exchange shows the tension between normality and individuality in the participants’ talk about difference. It also exemplifies how this was part of common sense, seeing as the participants used generic terms and generalizations like “if *you* sit and think”, “many parents”, “all children” (Condor & Gibson, 2007). The dilemma of normality versus individuality can be compared discursively to the tension between prejudice and tolerance that Billig et al. (1988) write about.

Billig et al. (1988) describe how tolerance is proclaimed, before being followed by a prejudiced qualification, for example in the form of “I’m not racist, but...”. Such remarks show the awareness of the common sense understanding of prejudice as morally inappropriate, and deflect potential accusations of this common sense not being recognized (Billig et al., 1988). Comparably, in quote 8 awareness of the value of individual variance is proclaimed, before qualifying this statement leaning on the value of normality (“all children

are different, but...”). The moral inappropriateness of forcing individuals to fit a certain norm is recognized, before placing importance on the possible disadvantages with not fitting the norm.

The contrary themes of ideological dilemmas are not necessarily expressed with equal force (Billig et al., 1988). In quote 8, normality seems to be given most weight. This weighting is reversed in the quote below, where the participant relates how she would have talked to her child about having atypical genitalia.

Quote 9: Participant 2, group D

To like try to explain her a bit that (...) you are not completely like everybody else there, but that, that does not matter. In a way. It, it is completely ok not to be like everybody else and, because there are many others who have this (...) too.

Using the expression “everybody else” often has the effect of procuring an image of everybody but the person in question being a certain way, in this case having typical genitalia. It is interesting to note the conflict of the image of “everybody else” with the assertion that “many others” also differ from what is normal, claims that are logically incompatible. This illustrates how thinking and arguing is contradictory.

In the quote, the value of normality is acknowledged first, before being qualified with the value of individuality (“you are not completely like everybody else there, *but* that, that does not matter”). This is based on the same common sense values as the quote 8, but with reverse prioritizing. If the awareness of the value of normality were not present, there would be no need to qualify the assertions of variation as neutral or positive, and there would be no dilemma. Through the use of qualification, the opinion that it is ok for an individual to be different from what is normal can be asserted without being accused of unawareness of the common sense that normality is desirable. By weighting the sides of the dilemma differently, different images of the individual experiencing atypical sex development are produced.

Abnormal or unique? There are many possible ways to talk about and understand the individual experiencing atypical sex development. The preconditions for decisions related to atypical sex development are shaped by the values of normality and individuality, and importantly so through affecting what kind of image is conveyed of the atypically sexed individual. This section will concentrate on two kinds of images that were present in the focus group discussions, formed by the dilemma of normality versus individuality: the abnormal and weird individual, and unique and special individual.

One way of talking about atypical sex development was as causing individuals to see themselves and be seen by others as abnormal and weird. Such an image is illustrated in the quote below.

Quote 10: Participant 2, group C

I would have felt much more [...] that I am different and weird, than if one just...fixed it like, and then one is a girl

The quote demonstrates how the participants understood the relationship between body and identity as intertwined. The atypical body appearance also implies something about the person's identity and self ("I *am* different and weird"). Gender/sex was most often talked about as something one *is* or *has*, in contrast to for example seeing gender/sex as a social accomplishment (Kessler & McKenna, 1978). This emphasizes the importance of the body as integrated part of self and identity, especially so if sex/gender is understood as something you *are*. The connection between physical development and identity is demonstrated further in the following quote. The situation being discussed is discovering as a teenage girl that you have XY sex chromosomes and an internal testicle.

Quote 11: Participant 4, group B

if I then got to know that "No, you have some, like, boyparts in you" I don't know if I would have managed to understand that quite correctly, I would maybe just have perceived it as "Oh, there is something wrong with me, there is something seriously wrong with me" I would not have understood, because I am, would not have been mature enough at that stage to like "girls can be boys, and boys can be girls, and it is not always as clear a division between that as it can seem like", but, so if they should explain me this thing, then they had to at least start with, like, an introduction that "It is not always so that girls are just girls and boys are just boys, and when the body develops there can happen some differences", and if, at once the parents had said "Then there can happen mistakes, something wrong, and something abnormal", had they used those words, then I think I right away had, in a way, seen it as if it is me as a person who is mistaken and wrong

This quote illustrates how understanding the body as abnormal is connected to understanding the person as abnormal. It also hints to the importance of words and concepts that are used to understand the situation for the individual ("mistakes, something wrong, and something abnormal, had they used those words"). The ideological dilemma of normality and individuality can be used to understand the image created in this kind of talk. When saying "I don't know if I would have managed to understand that quite correctly, I would maybe just have perceived it as 'Oh, there is something wrong with me'", the participant implicitly argues that understanding atypical sex development as "something wrong" is not quite correct. Not conforming to what is defined as normal is portrayed as very difficult, with serious implications for the person's identity. Seeing oneself as "mistaken and wrong" is perceived as an imminent danger. Individual variation is valued to some extent, but succumbs to the value of fitting within the norm.

A contrary focus was on the individual's right to identify differently from what is defined as normal.

Quote 12: group B

Participant 5: ...it could be that a person who has an atypical sex development, like, think that that is (1: Yes) that person,

Participant 1: That's just it

Participant 5: and want to be just like [s/he] is, even if.. (4: Mhm) it is a bit doubtful then, probably one wants to go into a like..[sex/gender]role, but (2: Yes), or I don't know, but I imagine so.

The participants quoted above emphasize the individual's right to define and embody their own identity. There is a struggle between the assertion of this, and of the assumption that most people would want a role considered more normal, ending up with an uncertain position ("I don't know, but I imagine so"). In a more positive view of an identity as different, the individual experiencing atypical sex development can be framed as a unique and special individual rather than an abnormal one, as illustrated by the quote below.

Quote 13: Participant 3, group D

We are all unique in our own way. So why not [...] that it [atypical sex development] is a way of being unique. It is not abnormal, it is just a way of being.

This way of understanding the atypically sexed individual was not very widespread, and seldom taken for granted, but in some way or other the image was present in all focus groups. Preves (2003) argues that acknowledging one's difference to self and others is part of the process of demedicalizing atypical sex development and ending stigma.

In this picture, atypical sex development is only one of many ways of being different, and that difference may be embraced rather than minimized. The desire to fit within what is commonly understood as normal is downplayed, and diversity emphasized as part of being human. Rather than adapting the difference to fit the "rule" for what is considered normal, the concept of normality becomes widened to include difference in this kind of understanding.

Dichotomous understandings. One of the common sense notions that can be seen as a "rule" for what is normal is the concept of dichotomous gender/sex. The idea that there are only two sexes, male and female, is deeply embedded in Western culture (Fausto-Sterling, 1993). The sex dichotomy relies on "an understanding of sexual difference grounded in biological understandings of an incontrovertible, materially encoded absolute separability and distinctness between 'the sexes'" (Malatino, 2009, p. 79). Paralleling the distinction between male and female biological sex is the distinction between two correspondent genders, referring to the "psychological, social, and cultural aspects of maleness and femaleness" (Kessler & McKenna, 1978, p. 7). In general, the dichotomy of sex and gender was basic to the focus group discussions, male and female being understood as the two ways of being normally sexed and gendered. However, the idea that gender identity and physical sex

possibly did not match, and acknowledgement of such experiences, was commonly available. The quote below illustrates how this “mismatch” was talked about, and possibly derived from reports in media.

Quote 14: Participant 1, group A

Now a little while ago, it was an article about he who became, in a way, a national hero because he had felt like a boy. All life had appearance like a girl (2: Yes), but felt like a boy.

This is an example of how certain forms of individual variations were recognized within a dichotomous understanding of sex and gender, and possibly even celebrated (“national hero”). Such an understanding aligns with Kessler’s (1998) argument that transgenderism (non-matching male or female sex and identity) can be accepted within a dichotomous gender system, while atypical sex development may “call the whole system into question” (Kessler, 1998, p. 5). By stressing the importance of matching sexed body and gendered identity, transgender goals may contribute to upholding the gender/sex dichotomy (Preves, 2003). The maintenance of the male/female binary is evident in the often taken for granted assumption in the focus groups that medical and surgical interventions aimed at sex change was desirable and necessary in transgender cases, as exemplified in the quote below.

Quote 15: Participant 1, group C

if it had turned out that I would have felt more like a boy, er, and that had been very important to me, then would I then rather...go through a sex [change] operation...when I became so sure that it was wrong to be a girl that I could know it myself

Though the gender/sex dichotomy importantly influenced the discussions, it was not always taken for granted that this categorization was necessary. There were both propositions of a third gender/sex category, and of conceptualizing gender/sex more fluidly, like participant 5 in quote 7.

Quote 16: Participant 3, group C

one should perhaps, then, had some or other external category then, so that they who are a place between a boy and girl [...] can...put them in temporarily, so they may rather then, when the child grows up, see what they identify themselves like. It is probably a bit healthy for the rest of society as well, not...having so [...] marked distinction between how we treat boys and girls.

Quote 17: Participant 5, group D

Haven’t there come like, I don’t quite know, [...] this is just something I’ve read like by change once, but [there] are like some countries who have come up with new, it is not only male and female, it is also like an X, or something like that?

Neither the third category option nor the idea of gender/sex categories were proposed for the participants by me. Hence, the results imply that alternatives to strictly dichotomous understandings can be available for laypeople.

Herdt (1996) describes the emphasis on gender/sex dichotomy to reproduction as “a paradigm of science and society” (p. 25), and proposes that the general belief underlying the

dichotomy is that “sex and/or gender exist for reproduction of individuals and species” (p. 26). In this perspective, the fundament of the gender/sex dichotomy is an understanding of reproductive capabilities as crucial.

Reproduction. The fundamental importance of reproduction was present in the focus group discussions. When the participants were informed that the girl with XY chromosomes and an internal testicle was infertile, this was understood as the major problem and often the other issues they had been discussing were seen as trivial in comparison.

Quote 18: group D

Participant 4: I have grown up as a girl and imagined a future there, and then you find out that you cannot have children and that you have, yes, X and Y chromosomes. That changes your whole life then. And what you can do. [...]

Participant 2: With that information, then I would definitely say that treatment should happen with a psychologist, or someone who are [experts] in this field, because now, now I cannot have children...As a teenage girl to learn that you can never have children...That can be pretty hard.

Participant 5: That one is hard.

Participant 2: So now it is almost not the treatment that is most important, just now it is perhaps most important to get over that I can never have children

Not having the possibility for biological children was generally understood as a great restriction to leading a normal life, but it was mentioned both that individuals do not necessarily want children and that adoption is an alternative.

In addition to being understood as very important for the individual, reproductive organs were often understood as defining sex. This fits well with the medical practice of emphasizing “reproductive anatomy, and the child’s potential for future fertility” (Wisniewski et al., 2012, p. 14) when determining gender and sex (see e.g. Diseth, 2008; Lee et al. 2006).

Quote 19: group D

Participant 4: [...] So, reproductively you have one, you have one sex then. Yes (3: Hm)

Participant 2: I just think we speak very much about reproduction. There are many who don’t want children. (3: Mhm) Is it *that* that should categorize us? If we can reproduce as this or that sex? Not to feel like, there are many who are, yes, [hermaphroditic] (3: Mhm) and who actually want to be that. Who want to have

Participant 4: No, but it is at least something objective one can [pinpoint] Yes. (2: Mhm.) And of course you decide for yourself how you want..yes (5: Mhm) how you want to live your life, as long as it does not affect others. [...]

Participant 3: But when we don’t have more categories than two... (2: Mhm) it is difficult if one then is one, is in a mans body and feel like a woman, then one doesn’t have any category to put oneself in. to have one’s own personal identity

Quote 19 shows how reproduction was lifted up as the objective factor distinguishing male and female from each other, but also how this was contested (“is it *that* that should categorize

us?”). Participant 2 and participant 3 struggle with fitting identities different from the norm into the dichotomy. They talk about valuing individual difference (“to have your own personal identity”), but are formed by dichotomous understanding of gender/sex (“this or that sex”, “we don’t have more categories than two”).

If genitals are seen as denoting reproductive capability, the importance of reproduction may explain why genitals are seen as critical for gender/sex.

Genitals. Genitals were importantly present in the focus group discussions, and some of the questions the participants found most difficult related to operations on genitals. The issue of early genital surgery “lies at the center of current controversies” (Karkazis, 2008, p. 4). Genitals not conforming to the stereotypical idea of male and female external genitalia was one of the topics of discussion where the values of normality and individuality were especially evident.

In the excerpt below, the participants have been asked to imagine learning that their teenage daughter is experiencing atypical sex development. The specific matter they were discussing was the possibility of lengthening/widening a smaller than average vagina.

Quote 20: group D

Moderator: What about that, widening of the vagina, what do you think about that? Do you think that is something she would have done, or why and why not?

Participant 1: I would think that...if one feels like a girl, [one] would like to do that, unless it is very risky and...yes, harmful, I do think that, or, I don’t know how much it matters...

Participant 2: Yes, it probably depends [...] from person to person, how much like practical importance it has, but I think like...it’s probably a bit like one, like we talked about earlier, that like, if one is a girl or a woman, then one wants to, yes, be able to have sex like everybody else and, in a way, be normal then. I think. So, if it is something that has a particular importance and it is something one can see or feel the difference of, then I think I would have done it myself, yes.

Participant 3: Yes, if it could make her feel more established in her chosen gender role, then...absolutely. I can imagine that it affects self image and such then, when you start to have sexual relationships and such, that you want to look normal, and it would perhaps help on the self image as well that you feel more like a girl when you see, feel yourself that you look like a girl, and then you perceive yourself and others treat you more like a girl maybe, I don’t know.

The excerpt illustrates how people assume that there is a normal way of looking and being (“have sex like everybody else and, in a way, be normal”, “you want to look normal”, “that you look like a girl”), that it is desirable and positive to achieve (“one wants to”, “you want to look normal, and it would perhaps help on the self image”). The use of generic terms as “you” and “one” might imply that the value of normality is embedded in common sense (Condor & Gibson, 2007), while the presence of qualifications (“I don’t know”, “perhaps”,

“it probably depends”) hints to dilemmatic thought. Using concepts like “from person to person” can be seen as acknowledgment of individual variation, while the emphasis on identity, self image, etc. reflect a concern for the individual’s liberty to be comfortable in their own skin.

In addition to being seen as an obstacle towards looking and being normal, a small vagina is also seen to impair the ability to have what is presumed to be normal sex (“sex like everybody else”). Not being able to have pain free penis-in-vagina intercourse was often taken for granted as restricting normality. Braun (2000) asserts that “heterosexist arguments, comments, questions and so on are seductive, seemingly natural and do not need to be accounted for by the speaker” (p. 137) because they are part of common sense. However, counter arguments were raised against such assumptions. One comment was that the person in question could be lesbian, another that a male sexual partner could have a small penis.

In contrast to the case where a small vagina was seen as impairing physical capability of sexual intercourse, the case with the large clitoris was sometimes seen as socially impairing the possibility for close relationships and sex.

Quote 21: Participant 1, group C

If they had not undertaken the operation [to reduce the clitoral size], then I would have more understanding for a person [boy/-girlfriend] that not quite can accept that

Though negative social implications of a clitoris not perceived as within the normal range were of concern, the risk for reduced clitoral sensitivity was generally perceived as a much bigger problem in the discussions.

Quote 22: group A

Participant 3: But then one must, or, I am wondering a bit about, I don’t know if it has any effect, but, yes, one becomes similar cosmetically, but imagine if it in a way prevents sensation or gives reduced sensation in clitoris (2: Mhm) that is... (5: Mhm) I think would be much worse than to have a bit too big clitoris

Participant 2: Yes, that is probably..

Participant 4: Yes, that is true!

Participant 2: That is true

The understanding that a large clitoris need not be a problem was prevalent in the discussions. One participant’s initial reaction to the concept of surgically reducing a large clitoris was “That clitoris is big, what does, does that have something to say for anything?”, while another framed it as “possibly a plus even, for the sex life later”. Such lay understandings are relevant to know about because there is placed great focus on the possibility for social stigma related to atypical genitals, and medical interventions aimed at reducing such stigma through normalizing the genitals (Preves, 2003). Implicit in the concern

for social stigma is the assumption that people in general will not accept atypical genitals. The possibility these results hint at, that this assumption is not necessarily correct, is worth further discussion and research.

Linking preconditions and decisions. The previous sections have outlined how understandings of atypical sex development are shaped by the values of normality and individuality. Before going on to describe and discuss the next dilemma, the link between the preconditioning values and decisions will be further explored.

Exemplified in quote X, valuing normality (e.g. “you want to look normal”), relying on gender/sex dichotomy (e.g. “if one is a girl or a woman”), and understanding difference as abnormality seem to be connected to wanting to perform normalizing interventions (e.g. “I think I would have done it [the surgery] myself”). Such interventions were sometimes talked about as fixing or correcting a fault. This parallels what Karkazis (2008) describes as biomedicine’s practice of treating “the body and its parts as appropriate sites of intervention“ (p. 5), and encouraging the changing physical reality in order to fit human ideals for this reality.

Contrary to valuing normality highly, valuing individuality and expression of self can be linked to preference for postponement of interventions until individuals can choose for themselves. In the excerpt below, the participants are discussing what motives should underlie the decision of whether to operate on a child with atypical genitals.

Quote 23: group A

Participant 1: I don’t think I, I think that I would have wanted to get medicine, but not have surgery, had I been a child. Also, because of what you talked about, that about (sighs) that it affects the self-esteem, and I am thinking that I would have wanted that my parents would teach me to be proud of myself no matter how I looked, or what I had, no matter what that unusualness or abnormality should arise, or whatever it might be. So that I would learn to be proud of myself with what I had, and that I instead later could make the choice if it was something I wanted to change.

[...]

Participant 4: Yes, but at the same time the risk of [...] if we compare undertaking the surgery early and undertaking surgery, perhaps choose, let the choice be open then. Right? Then the risk attached to developing psychological, in a way, issues then, with that difference, I think is bigger if one choose not to operate, because then one has to, I am thinking the opposite of what you [participant 1] are saying, then one need to in a way learn to manage this difference and such, right. And if you never have had... So I actually think that I would have wanted this operation [as an infant], because then I would never have to take a position in relation to it at all, and (2: Mhm) would just be presented with it, and then I would not have to learn to be, then, different in that aspect, because that, in a way, that problem would then come (2: Mhm) later, and [...] both to be different in itself, and having to ask oneself the question “Should I take that operation?” are to quite big, (1: Mhm, 2: Mhm) questions, and if you never are

presented with the problem at all, then it is obviously not something you need to relate to. And that spares the child of some...

Participant 2: Discomfort (4: Yes) Or...

Participant 4: Something like that. Something in that direction.

Participant 5: That's a good point, because no matter if you take the surgery or not, the child may angle this [...] "Why did you not do this for me?" or "Why did you do this to me?" That phase for the child would come no matter what, then.

Participant 1: But I am thinking that it in a way is better if you answer..., or if the parents answer that "Yes, [we] undertook that surgery because we thought it was best for you to feel normal", then the child could take that two ways, that it could either think "Ok, so you wanted me perfect, like society is", but it could also think that "That was good because then I am spared of feeling different", but at the same time I think that it is very good for the parents to be able to say that you are good the way you are, no matter what, in a way. I have met bully victims who were bullied from first to eight grade, who feel great now because the parents were very good at saying that "It is not you who are the problem, it is them" (4: Hm) And then I think that no matter what they get bullied over or denounced for or feel different for, then the parents have a very strong role in being able to, yes, help so that it does not become a problem then.

Participant 5: I think that that was a good point. And perhaps, like, part of the solution would be that, right. It does not really matter which of the choices one makes, but what matters is the follow-up.

This excerpt quite explicitly demonstrates the tension between normality and individuality in the participants' talk ("the child could take that two ways, that it could either think "Ok, so you wanted me perfect, like society is", but it could also think that "That was good because then I am spared of feeling different"). Participant 4 argues that the potential difficulty related to being different is the most important threat to the child's welfare. Participant 1 on the other hand, argues against medical interventions aimed at normalizing the atypically developing body, on the basis that difference can be accepted and/or appreciated ("be proud of myself", "you are good the way you are, no matter what"). The desire to be normal and the assumption of interventions as good were questioned. In this perspective, interventions can be understood as damaging rather than fixing. It seems to make intuitively sense that abnormality needs interventions to be fixed or bettered, while uniqueness could be damaged through interventions. The view of interventions as damaging can also be connected to the concern for damage to genital sensitivity. Participant 5 demonstrates a rare approach: downplaying the importance of the choice, and instead stressing the handling of whichever choice that is made.

Contrary to the focus on handling the consequences demonstrated by participant 5, many participants focused on avoiding difficulty, like participant 4 ("if you never are presented with the problem at all, then it is obviously not something you need to relate to").

The use of the word “obviously” suggests that the possibility of avoiding difficulty is part of common sense (Condor & Gibson, 2007). This way of talking about and understanding difficulty construct it as an undesirable aspect of living that it is morally right to minimize or eliminate. Alternatively, difficulty can be constructed as a valuable and necessary part of living.

Quote 24: Participant 1, group B

I think I am like fundamentally in disagreement with the mentality that one should spare children and youth of like any difficulty they may experience [...] In many other cultures it is so that even if one have difficulties, one is not necessarily unhappy, or it could...It [difficulty] has value in itself

There seem to be links between understanding atypical sex development as abnormality or uniqueness, interventions as fixing or damaging, and difficulty as something that should be avoided or tackled. Common for most understandings were that the welfare of the individual was the main focus, though there were expressed some concerns as to societal implications as well. As cited in quote 16, it was suggested that it might be healthy for society to loosen the strict rules for gender. Other concerns for societal consequences were also voiced.

Quote 25: group A

Participant 5: Maybe one negative is that it [genital surgery] puts, in a way, a completely wrong...It puts the whole medical practice in a totally wrong direction, that it is much more about cosmetics, more and more about cosmetics

Participant 4: Plus that you contribute further to this idea of, in a way, the ideal and the perfect then. Right? You support it.

The quotes above show how participants understood the consequences of management of atypical sex development as relevant not only to the people experiencing it firsthand, but also to society as a whole. This insight demonstrates the link between individual experience and the larger culture this life and experience is part of.

Decision-making: agency vs. expertise

As described in the methodology chapter, participants were asked to discuss and relate themselves to difficult judgments and decisions, for example through imagining themselves or their child experiencing atypical sex development. Much of the basis for the focus group discussions thus concerned decisions and choices related to atypical sex development.

When discussing decision-making, the participants’ understandings were characterized by the values of agency and expertise. *Expertise* can be defined as involving “a great deal of knowledge or skill in a particular area” (“expertise” n.d.). Expertise will in this analysis be used about knowledge that is seen as more correct or true than other kinds of knowledge, and experts as people that are expected to hold such knowledge. Regarding the

talk and understandings of expertise in the data material in this study, scientific knowledge in medicine and psychology were considered major sources of expertise.

Another important theme regarding decision-making is agency. *Agency* can be defined as “the freedom of individuals human being to make choices and to act on these choices in ways that make a difference in their lives” (Martin, Sugarman, & Thompson, 2003, p. 1). In this discussion agency especially concern choices regarding own health and welfare, for example surgical and medical interventions.

In the excerpt below, participants are discussing interventions aimed at altering congenital physical differences related to atypical sex development.

Quote 26: group B

Participant 3: I think it is an extremely big mistake. (4: Yes) If one shall alter such things without, in a way, the person themselves [...] choose it

Participant 4: No, because they cannot do that when they are born

Participant 5: No

Participant 3: No, exactly. So...

Moderator: You have touched upon it, but what do you think doctors and other experts *should* do when they discover that a child has atypical sex development? [...]

Participant 3: I don't think they should do anything. Think they should just leave it as it is.

Participant 4: Yes, I am a bit like...I think, I imagine that if they have a situation where they either are uncertain of sex, or see some other fault, then they try to intervene (2: Mhm) and try to make it become, function as good as possible either as girl or as boy. And I, I maybe see that as what I feel they should do. They should seek the advice of experts in the field, with mind to later development. Because to grow up as abnormal...

Participant 5: Yes, that is not good.

Participant 2: Not good

Participant 3 describes doing interventions as “an extremely big mistake”, unless it is the person in question that chooses this themselves. This assertion can be interpreted as meaning that the agency to choose for oneself is highly valuable. In contrast, participant 4 lifts up the value of expertise by speaking in favor of intervening based on advice from “experts in the field”. This understanding frames following experts advice as something one should do. The excerpt illustrates how participants in the current study endorsed both agency and expertise as moral goals to achieve, goals that may conflict in laying preconditions for how decisions should be made. Because they are seen as prescriptive goals, the concepts can be defined as values.

On the one hand, the participants argued that decisions about body and self should be up to the individual. Having the possibility to make decisions about and choose for oneself was understood as inherently valuable. The value of agency can be related to the value of

individuality described earlier, because the individual should have the right and liberty to choose. On the other hand, making a correct or right choice was also highly valued in the focus group discussions. In this perspective, a good decision is a good decision whoever made it, and expertise can be understood as pivotal to making good decisions. The dilemma of agency versus expertise can hence be understood as the dilemma between ideals of making one's *own* choice and of making the *correct* choice.

Agency and expertise are both interdependent and conflicting. It can be argued that if individuals are to have genuine and informed possibility to choose, they need information about their options from somewhere, something that often involves expertise. Getting expert information could make some choices easier to make and others harder, something that possibly could impede agency. For example, Hester (2004) argues that “the rhetoric of pathology fundamentally constrains the autonomy and freedom of the parents and patients by denying the natural state of the patient [with atypical sex development] its social and physiological legitimacy” (p. 39).

The recommendation for practice concerning atypical sex development today is to have patient-centered care, where for example it is advised that some surgery is postponed until the patient can participate in the decision-making (Consortium on Disorders of Sex Development, 2006). Lee et al. (2006) list the essentiality of “open communication with patients and families” (p. 490), and the encouragement of participation in decision-making, as one of the points in providing optimal care. The encouragement of patients and families’ participation can be interpreted as implying that the starting point for decision-making is the professionals’ expertise, while the agency of those experiencing atypical sex development is encouraged. The need to encourage agency might suggest that this value has the weakest position. Because of the conflicting relationship between the values of agency and expertise, the preconditions for decisions related to atypical sex development are ideologically dilemmatic.

Important in all of the focus group discussions was reliance on science for provision of expert information. Scientific testing and empirical evidence were generally understood as sources of expert information.

Testing. Testing of biological variables, such as sex chromosomes and hormonal levels, was suggested in relation to determining whether a child with atypical sex development is male or female. Assessing behavior was also suggested for this purpose. In the excerpt below, participants discuss what doctors should do when discovering that a child experiences atypical sex development.

Quote 27, group C

Participant 2: [...] I think that...with some one could maybe see it in, like, more thorough tests. [...] that it might be clear with...that one maybe is girl or boy on the inside, or like DNA and XY chromosomes, and yes. I am thinking that...yes, it is probably not all, or in many situations some of them would probably give a bit more clear answer, or in most situations one would perhaps biologically incline to the one or the other sex. [...] I think then, that one should choose, if it is something that indicates more on the one or other side. Really...

[...]

Participant 1: Yes, because if it is possible to test it [...] There have been some tests of...boys usually choose more masculine toys [...] If one could do such kinds [of tests], if there are other kinds of tests one can do. To see what it is most, or if one can test something, I don't know when it becomes testosterone in the blood or what there is most of. But if one cannot do that, that is what is harder I think [...] Because, if one first chooses, then it becomes hard as well, if it is wrong, it is really like a gamble.

The excerpt above demonstrates how the testing was perceived as a way acquiring information appropriate to base decisions on. The concept of utilizing scientific tests in order to establish male or female gender/sex can be related to the previously described gender/sex dichotomy. When combining the value of expertise with the belief that there only are two 'real sexes', tests to establish "real sex" seem relevant in order to make the right choice between male and female. Concern for the risk of 'making the wrong choice', as in the last part of the excerpt above, was recurrent in the discussions.

If it is taken for granted that female and male are categories with truly discrete biological differences, physical attributes that are not typical of these categories (e.g. atypical genitals) may lead people to understand this as unclear or ambiguous. According to Preves (2003) "genital ambiguity is presented as 'hiding' an underlying sex, yet to be 'discovered' by the physicians" (p. 54). Going back to quote 26, an understanding of atypical sex development as causing uncertainty about gender/sex, or as a fault can be detected in the talk of participant 4: "I imagine that if they have a situation where they either are uncertain of sex, or see some other fault, then they try to intervene (2: Mhm) and try to make it become, function as good as possible either as girl or as boy." This understanding aligns with the recommended management of atypical sex development, where gender assignment as male or female is high priority (Lee et al., 2006). Quote 26 also illustrate how the value of expertise is connected to dealing with uncertainty; here it is the expert, not the parents or individual, that is understood as having the solution to the uncertainty.

Empirical evidence. In quote 28 below, the participants respond to a question of what they think doctors would like as result from making decisions concerning atypical sex development in a child.

Quote 28: group D

Participant 4: No, I think they just...have kept up to date [scientifically] in that field, and recommend what is most safe and [scientifically] reasonable. [...] looked at which consequences, and looked at studies and such, and then come with recommendations on based on that

Participant 3: I think they want categories to place the kid in. Man or woman, or boy or girl. That they would like to have that. I think.

Participant 5: Yes, I also think so. That they maybe are, may want it a bit categorized, but also that they look some at what has been done earlier, when a person, this isn't something that is new to them. So, some persons are born with this or that then, so they see like "Yes, ok, we did this a year ago", for example, so "Ok, then we perhaps suggest doing the same thing again" or like, yes, or look at prior experiences then.

The excerpt illustrates the trust given to empirical evidence and the people conveying this knowledge. It also illustrates how the value of expertise might fall short when there is little empirical knowledge to build decisions on. For example, there is "significant lack of objective medical and/or quality of life data on long-term outcome with or without genitoplasty in any DSD condition." (Streuli et al., 2013, p. 1958). The quote from participant 3 in the excerpt above can be interpreted as critique of the taken for grantedness of categorization. Participant 5 agrees with both of the other participants, and attempts to strike a balance between the understandings. In the quote below, categorization is put in relation to prejudice.

Quote 29: Participant 5, group A

I also think that, unfortunately, there are underlying prejudices behind the doctors decisions. Where there is a need to pressure the child into a category, either boy or girl.

This quote does not necessarily mean that expertise is devalued, but it suggests an understanding of expertise as subject to prejudice similar to other kinds of knowledge. The use of the word "unfortunately" can suggest that the ideal of the objective expert is valued, but that it is necessary to nuance this view in the meeting point between ideals and reality. Use of phrases like "placing the child" and "pressure the child" can be understood as skepticism towards restricting individuals' agency to determine own categorization and identification.

Even though the role of medical professionals was problematized, as in the previous quote, doctors and other professionals were generally seen as representing scientific expertise and having the necessary experience of atypical sex development.

The medical professional. "The doctor" was generally talked about as the person with medical expertise that the individual experiencing atypical sex development and their parents got information from and collaborated with when making decisions about medical interventions. Doctors were often taken for granted as trustworthy and legitimate authorities

and sources of knowledge.

Quote 30: Participant 2, group A

But I have to quite honestly say that if I had been parent in this situation, then I probably would have done it. I think I had said yes to doing it right away. If a doctor, if my doctor had said to me that something was too big, we can remove it. Without, yes, of course, without risk then, if one starts to talk about “yes, there is a certain risk for health and such”, then it is a totally different question, but if it is, in a way, a harmless operation, that the doctor recommends or at least presents that “Yes, this exists” and it would remove something that in medical terms is abnormal. Not just that looks funny in a way, but that doctors think is abnormal, then I think I would have done it

Participant 2 talked about how information and advice provided by the doctor would be crucial for the decision of whether to operate on their child “that the doctor *recommends* or at least *presents*”). The only major obstruction to perform an operation that the doctor suggests is the risk to life and health, which is presented as common sense (“*of course*, without risk”).

The doctor is understood as more knowledgeable than the parents and the patient, legitimately able to decide what is abnormal and not, and the value of expertise encourages following the doctor’s advice. This illustrates the need for awareness of cultural influences on understandings and decisions, for example through critically examining common sense, since the medical and other professionals’ understandings also are influenced by values and beliefs. As Frank (2004) writes: “Information always requires interpretation in order to be acted upon, and even the most accurate, appropriate information will be interpreted within dominant cultural paradigms” (p. 25).

While the appreciation of medical professionals’ knowledge was widespread, it was not endorsed that the doctors should be the ones making the decision. The final decision was to be made by either the individual or the parents, informed by experts.

Quote 31: Participant 2, group D

...what they should do, ideally, would have been that, I think, when doctors find this out [that the child develops atypically], inform parents, and [...] then it should perhaps be up to the child. That is, if this does not have any physical afflictions connected to it, that it won’t make urinating hard or any such functions complicated, then I don’t quite see the reason to do an intervention so early, because it will not trouble the child so early.

Quote 32: Participant 1, group B

Then doctors or the state or whatever must accept...accept them, there are many things they don’t accept. Shall this, like, be one of the things they accept or not, that the parents choose, then.

This can be seen as springing from the value of agency, both for the individual and for the family. In the excerpt below the same participant cited in quote 30 argues against enlarging a small vagina through dilation or surgery. Like in quote 30, the participant was asked to imagine being presented with the option of an intervention by medical professionals.

Quote 33: Participant 2, group A

If my child is now in adolescence, then I would perhaps simply want that my child would make, participate in making, maybe just making that choice themselves. Or perhaps postpone making the choice, because, I imagine that this has to do with sex, probably, and what would then be possible and what would be easy and what would be hard. And that is a very personal choice that I would not feel comfortable with making for my child.

By emphasizing the value of individual agency rather than the value of expertise, the participant relates differently to the decision-making process. He does not want to change what the experts suggest to be abnormal without this being a conscious choice made by the person whose body would be subject to intervention. The assumption underlying this kind of talk is that there is an inherent value in choosing, and that certain personal choices should only be made by the individual they concern. The value of expertise hence becomes less important than the value of agency.

There could be several reasons for the different prioritizing of values in the two cases. For example, it could be that agency is a more salient value when talking about a teenager than a baby. There was a slight tendency towards this in the focus groups in this study, though agency also was present in the talk about the baby with CAH. In order to say something more specific about the link between values and positions, further research, perhaps more quantitatively oriented, would be needed. It could be that visibility affects how the sides in the dilemma are weighted. It could be that visible difference (e.g. large clitoris) is understood as more dramatic than difference that is not evident at first glance (e.g. small vagina).

Freedom to vs. freedom from. Billig et al. (1988) make a distinction between the values of having freedom to do something, and having freedom from external pressure. I will use the concept to refer to a slightly different distinction, one between *freedom to* decide and *freedom from* decisions. If making the objectively right choice, rather than making one's own choice, is understood as the primary concern, not having to make a decision can be seen as a form of freedom. Contrarily, if one first and foremost values the individual's right to choose, and especially if one does not believe in there being a correct decision, freedom to choose is highly valued.

The excerpt below shows how participants talked about having the freedom to choose for oneself contra being free from having to choose.

Quote 34: Participant 4, group A

I am thinking as well that if one chooses not to take that operation, then... The parents will then say to the child "We did not choose to perform the operation" and then the child is left with a feeling either of like "[My] parents let me choose, that is nice" or, but on the other side, it may also think "[My] parents just did nothing. My parents couldn't be bothered to do something for me, and now I have to do, now I am left with this responsibility and problem

then”

The quote exemplifies how agency may be liberating (“let me choose”) and a burden (“I am left with this responsibility and problem”), and implies that the concept of freedom is not free from dilemmatic tension either. This kind of talk and understanding implies that not performing interventions is a choice of “doing nothing”, while intervening constitutes a choice. This can be contrasted to one understanding that was expressed right at the end of the first focus group.

Quote 35: Participant 2, group C

One does take a decision, it is a decision to choose not to do anything about it [the large clitoris] too, and then [I] think that, yes, then they [the parents] have taken quite a big decision by not doing something, because then one is like, involuntarily then, a pioneer for this third [gender/sex] then. And that, yes, should one not be able to choose that as well, [for oneself]?

This quote demonstrates how not performing interventions was seen as a choice, and possibly a more invasive choice than doing so. Participant 2 draws upon the value of agency, and the understanding can be interpreted as advocating the freedom from being atypical or abnormal. This illustrates how complicated the dilemma of agency versus expertise can be.

General discussion

The results presented before show how the everyday understandings of atypical sex development and of the decisions related to this topic are ideologically dilemmatic. In line with Billig et al. (1988), the ideology involved in these understandings is not understood as consisting of separate images or values, but as intertwined and formed by conflicting counter-values. Especially important is it to recognize that there *are* decision-making processes involved in management of atypical sex development, something that isn’t necessarily obvious (Streuli et al., 2013).

Participants in the present study understood atypical sex development as a way of “being different”, and this difference was understood through the contrary values of normality and individuality. The contrary values of agency and expertise shaped the participants’ understandings of decisions related to atypical sex development. The ideological dilemmas of normality vs. individuality and of agency vs. expertise form preconditions for decisions that might need to be made in atypical sex development issues.

The approach of ideological dilemmas provides opportunity to analyze and contemplate about the beliefs and values involved in the process of forming the understandings that precondition choices and decisions. The results from this research support Karkazis’ (2008) claim that atypical sex development is framed as abnormal, but

adds to the picture that “normality” is not free from contradiction, but part of ideologically dilemmatic understandings. The results of this study also show that people without much experience with the topic are able to frame atypical sex development differently by drawing upon the value of individuality.

When highlighting normality as a value rather than taking it for granted as description of reality, one can better consider how it affects one’s understanding of a phenomenon, and how one wants to relate to this value. It is possible through the approach of ideological dilemmas to analyze how the common sense beliefs “that every individual *must* be either ‘male’ or ‘female’, and that it is essential to determine which” (Billig et al., 1988, p. 128) are importantly based upon and upholding the value of normality. Knowing about how values affects thinking in such ways may be useful for considering consciously whether one wants to subscribe to the value or challenge it. Understanding how people’s ideas of what is normal and not is also essential to good medical practice (Karkazis, 2010). Hence, both laypeople and experts need to reflect on the impact of values like normality on their understandings, and decisions based on these. Through making “invisible” common sense values evident, the approach of ideological dilemmas may be used to illuminate alternative values and alternative understandings.

Awareness of alternative values, and that neither thinking nor decision-making is a straight-forward process, could be beneficial for making better-informed choices. For example, the results presented before imply that putting emphasis on the value of individuality can make interventions on a child’s body seem less reasonable than if normality is highly valued. Streuli et al. (2013) found “a strong relationship between the desire for normality plus unambiguous genitalia” (p. 1957) and whether information was provided by an endocrinologist or a psychologist. Being able to reflect actively on which values one wants to prioritize, instead of commonsensically taking them for granted, can be seen as empowering because one may be aware of processes like those Streuli et al. (2013) documented.

Being conscious of how one is striking a balance between the two values may also make it easier to explain one’s understandings and decisions to oneself and to others. To be able to actively direct focus to certain common sense values may also provide an opportunity to change focus in discussions about choices. For example, if a parent is very concerned about the possibility of their child being bullied because of their atypically sexed appearance, a professional may shift the focus of the discussion by pointing out the values of agency and individuality. This way, the discussion between parent and professional may avoid fixating

on only one value and the implications of this, and better explore alternative understandings. Such a process could possibly help in avoiding a situation where the parent would come to prioritize the values differently later and regret the choice based on the dominant value.

Highlighting common sense assumptions and the values and belief inherent in these, can provide basis for reevaluation of arguments. The approach of ideological dilemmas could serve as a tool for how to scrutinize own and others assumptions. Arguments for or against intervening on a baby with atypical genitals based on degree of risk for harm and potential for benefit may sound intuitively persuasive and logical. Though analyzing such arguments as preconditioned by negotiation between the values of expertise and agency, it is possible to see that there may be a conflict between the ideal of making the correct decision and the ideal of giving people the power to choose for themselves.

Argumentation with emphasis on risks opens up for discussions about whether or not interventions should be performed based on information about benefits and harms, but it does not open up for discussion of the underlying ideology of intervening. If medical interventions are taken for granted as basically good by both laypeople and experts, it makes it difficult to discuss ethical issues other than the potential risks. Highlighting the values involved in thinking and arguing can therefore open up for alternative discussions.

The results from this study imply that people do not necessarily see choices about matters like surgery as purely individual, but reflect about the implications such decisions may have on society and culture. This hints to recognition of an understanding that “the personal is communal” (Frank, 2004, p. 26), something that goes both ways. The communal, or cultural, is also part of the personal. Reflecting upon this may open up for discussions about whether it is the individual that should adapt to society or the other way around. For example, it can be argued that instead of normalizing atypical sex development to fit with society’s conventions, societal conventions can be normalized to fit with atypical sex development. One small, but important, step towards this may be to raise public awareness of the fact that sex development is not as easily divided into two routes as one may think.

Opening up for new discussions might open up for new understandings and possibilities for choice. The motive of the guidelines for management of atypical sex development (Lee et al., 2006) is to outline optimal management. The approach of ideological dilemmas could be used to move focus away from defining ‘correct’ answers on how atypical sex development should be understood and managed, and deemphasize the idea of “a single ethically correct progression from the wrong way to the right way to treat intersex” (Morland, 2009, p. 191). Instead, there could be acknowledgement of and

engagement with the ideological dilemmas involved in understandings and practice related to atypical sex development. This may also contribute to making it possible to “recognize that bodies and diseases are not there to be solved” (Frank, 2004, p. 26).

Related to the ideal of finding the best way of managing atypical sex development is the seemingly unanimous perception of uncertainty, especially regarding gender/sex, as negative. Lee et al. (2006) claim that “Initial gender uncertainty is unsettling and stressful for families” (p. 491). The approach of ideological dilemmas may be useful for dealing with uncertainty by providing insight to how all understandings are influenced by contrary themes, and hence seldom unambiguous and possible to eliminate all uncertainty from.

Further research

The participants in this study were primarily psychology students. It would be interesting to conduct further research on lay perspectives involving participants from other populations, for example examining whether the same dilemmas dominate or if there might be other important dilemmas in laypeople’s perspectives on atypical sex development.

In addition, it would be interesting to use the approach of ideological dilemmas in further research on the perspectives of people with experience of or scientific knowledge of atypical sex development. Further research could also explore in more detail how the knowledge of values involved in understanding atypical sex development might be used in practice.

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Appendixes

Appendix 1: NSD approval

Norsk samfunnsvitenskapelig datatjeneste AS
NORWEGIAN SOCIAL SCIENCE DATA SERVICES



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Vår dato: 02.09.2013

Vår ref:35028 / 3 / KH

Deres dato:

Deres ref:

TILBAKEMELDING PÅ MELDING OM BEHANDLING AV PERSONOPPLYSNINGER

Vi viser til melding om behandling av personopplysninger, mottatt 23.07.2013. All nødvendig informasjon om prosjektet forelå i sin helhet 29.08.2013. Meldingen gjelder prosjektet:

35028	<i>Atypical sex development - the everyday view</i>
Behandlingsansvarlig	Universitetet i Oslo, ved institusjonens øverste leder
Daglig ansvarlig	Tove Lundberg
Student	Ingrid Dønåsen

Personvernombudet har vurdert prosjektet og finner at behandlingen av personopplysninger er meldepliktig i henhold til personopplysningsloven § 31. Behandlingen tilfredsstiller kravene i personopplysningsloven.

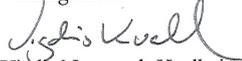
Personvernombudets vurdering forutsetter at prosjektet gjennomføres i tråd med opplysningene gitt i melde skjemaet, korrespondanse med ombudet, ombudets kommentarer samt personopplysningsloven og helseregisterloven med forskrifter. Behandlingen av personopplysninger kan settes i gang.

Det gjøres oppmerksom på at det skal gis ny melding dersom behandlingen endres i forhold til de opplysninger som ligger til grunn for personvernombudets vurdering. Endringsmeldinger gis via et eget skjema <http://www.nsd.uib.no/personvern/meldeplikt/skjema.html>. Det skal også gis melding etter tre år dersom prosjektet fortsatt pågår. Meldinger skal skje skriftlig til ombudet.

Personvernombudet har lagt ut opplysninger om prosjektet i en offentlig database, <http://pvo.nsd.no/prosjekt>.

Personvernombudet vil ved prosjektets avslutning, 31.05.2014, rette en henvendelse angående status for behandlingen av personopplysninger.

Vennlig hilsen


Vigdis Namtvedt Kvalheim


Kjersti Haugstvedt

Kjersti Haugstvedt tlf: 55 58 29 53
Vedlegg: Prosjektvurdering
Kopi: Ingrid Dønåsen, Bentsebrugata 27A, 0469 OSLO

Avdelingskontorer / District Offices:

OSLO: NSD, Universitetet i Oslo, Postboks 1055 Blindern, 0316 Oslo. Tel. +47-22 85 52 11 nsd@uio.no
TRONDHEIM: NSD, Norges teknisk-naturvitenskapelige universitet, 7491 Trondheim. Tel. +47-73 59 19 07. kyrre.svarva@svt.ntnu.no
TROMSØ: NSD, SVF, Universitetet i Tromsø, 9037 Tromsø. Tel. +47-77 64 43 36. nsdmaa@sv.uit.no

Appendix 2: Pre-participation information sheet

Forskning på utypisk kjønnsutvikling Informasjon til deltakere

Om meg

Jeg heter Ingrid Dønåsen og er student på Psykologisk Institutt ved Universitetet i Oslo. Studien du blir spurt om å delta i er mitt masterprosjekt om utypisk kjønnsutvikling. Prosjektet er en del av et større internasjonalt prosjekt om kjønnsutvikling.

Bakgrunn og formål

Det tas som regel for gitt at mennesker kan ha to kjønn: mann eller kvinne. Vi forbinder menn og kvinner med ulike kropper og ulik biologi, men ikke alle barn som blir født passer inn i det vi tenker på som typisk kvinnelig eller typisk mannlig. For eksempel kan man ha kjønnsorganer som er annerledes eller man kan ha kromosomer som ikke er vanlig for ens kjønn. Noen kan være forskjellig fra fødselen av, andre utvikler seg annerledes i puberteten.

Mesteparten av forskningen på kjønnsutvikling fokuserer på perspektivet til helsepersonell, og det er behov for mer kunnskap om dagligdags tenking rundt kropp og utvikling. For å bidra til økt kunnskap på dette feltet vil jeg undersøke perspektivene til mennesker uten erfaring med utypisk kjønnsutvikling. Dette er grunnen til at du blir spurt om å delta.

Hvem kan delta?

Alle som er uten erfaring med utypisk kjønnsutvikling kan delta i studien. Dersom du er interessert, men usikker på om du vil delta kan du også ta kontakt. Jeg svarer veldig gjerne på spørsmål om forskningen.

Metode

For å få frem forskjellige forståelser av utypisk kjønnsutvikling vil fokusgrupper være metoden i studien. En fokusgruppe vil bestå av rundt fem personer og vare i omtrent 90 minutter og vil finne sted på Psykologisk Institutt eller annet avtalt sted på Universitetet i Oslo.

I disse gruppene vil deltakerne bli stilt forskjellige typer spørsmål og bedt om å dele tanker om temaet, noe som innebærer å vurdere situasjoner, begreper og teorier som blir presentert. For eksempel får man beskrevet en situasjon knyttet til utypisk kjønnsutvikling og blir bedt om å forestille seg selv i denne situasjonen og snakke om hvordan man ville tenke og føle. Det finnes ingen fasit på hvordan problemstillingene bør løses, så det er ingen riktige eller gale svar. Jeg er interessert i dine tanker, ideer og perspektiver.

Hva skjer med informasjonen du gir?

Alle personopplysninger vil bli behandlet konfidensielt. Jeg vil gjøre alt jeg kan for å anonymisere og holde privat det som deles i fokusgruppen. Alle deltakere må også skrive under på at de ikke vil dele informasjon fra gruppen som kan identifisere andre deltakere.

For å kunne skrive ned nøyaktig hva som blir sagt vil det bli gjort lydopptak av fokusgruppediskusjonen. Informasjonen som samles inn vil bli brukt i min masteroppgave, og potensielt i en vitenskapelig artikkel. Lydopptaket og transkriptet vil lagres sikkert på Universitetet i Oslo. Kun jeg og min veileder vil ha tilgang til disse. Da jeg har fått skrevet ned alt som sies i lydopptakene, vil opptakene slettes. Navn og annen identifiserende informasjon vil ikke brukes i transkriptet. Det er mulig at du selv kan kjenne igjen sitater eller beskrivelser i den ferdige masteroppgaven, men det skal ikke være mulig for andre å gjenkjenne deg som deltaker i studien.

Prosjektet skal etter planen avsluttes mai 2014. De anonymiserte transkriptene vil lagres også etter dette for å kunne brukes i en vitenskapelig artikkel.

Frivillig deltakelse

Det er frivillig å delta i studien, og du kan når som helst trekke ditt samtykke uten å oppgi noen grunn. Du har rett til å trekke deg både før og under fokusgruppen, da er det bare å gi meg beskjed.

Studien er meldt til Personvernombudet for forskning, Norsk samfunnsvitenskapelig datatjeneste AS.

Dersom du ønsker å delta eller har spørsmål til studien, ta kontakt på:

e-post: ingrid.donasen@gmail.com
eller telefon: 48096499

Spørsmål kan også sendes til min veileder Tove Lundberg på:
e-post: tove.lundberg@psykologi.uio.no

Vennlig hilsen
Ingrid Dønåsen
Masterstudent i kultur- og samfunnspsykologi ved UiO

Appendix 3: Informed consent

Samtykkeskjema

Deltakelse i fokusgruppe om temaet ”utypisk kjønnsutvikling” høst 2013.

Tittel på prosjekt: Atypical sex development – the everyday view

Forskning utført av Ingrid Dønåsen og Tove Lundberg.

Jeg bekrefter med dette at jeg har (kryss av):

- lest og forstått informasjonen i informasjonsskrivet jeg har fått om studien, og mulighet til å stille spørsmål
- fått nok tid til å vurdere om jeg vil være med i studien eller ikke
- forstått at min deltakelse er frivillig og at jeg kan trekke meg når som helst før og under fokusgruppen, uten å oppgi grunn
- forstått at forskerne vil gjøre alt de kan for å holde all informasjon privat, og jeg lover å overholde reglene vi setter for fokusgruppa, samt ikke fortelle andre informasjon som kan brukes for å identifisere andre deltakere.

Jeg ønsker å delta i prosjektet

Deltakers navn
(blokkbokstaver)

Dato

Signatur

Forskers navn
(blokkbokstaver)

Dato

Signatur

Kommentarer eller tanker i løpet av prosjektet

Dersom du har kommentarer, noe du er bekymret for eller andre tanker kan du diskutere dette med Ingrid Dønåsen (student) eller Tove Lundberg (veileder). Hvis det er noe du ønsker å klage på, enten det gjelder tilnærming, behandling eller andre ting, kan du ta kontakt med Tove Lundberg, ved UiO. Vennligst referer til tittelen på prosjektet oppgitt i dette skjemaet.

Appendix 4: Focus group guide

FOKUSGRUPPEGUIDE

Denne guiden er beregnet for fokusgrupper med 4-5 deltakere.

Introduksjon

Velkommen, og takk for at dere vil delta i denne fokusgruppa

Introdusere meg og mitt prosjekt

- Ingrid, 24 år, master i kultur- og samfunnspsykologi
- Masteroppgave om utypisk kjønnsutvikling
 - o Hva tenker ”vanlige folk” om dette? Til forskjell fra leger og psykologer
- Min masteroppgave er en del av et internasjonalt prosjekt om kjønnsutvikling, som min veileder Tove Lundberg og flere andre forskere jobber med.
- Dataene fra denne fokusgruppa kommer til å bli brukt i min masteroppgave, og de kan bli brukt i en vitenskapelig artikkel/forskningsrapport.

Informasjon om fokusgruppa

- Den vil vare i omtrent en og en halv time
- Jeg kommer til å gjøre lydopptak, kanskje notere noen ting, og senere skrive ned det som blir sagt til en tekst (transkript). Da jeg har fått skrevet ned alt kommer jeg til å slette lydopptakene.
- Navn og andre ting som kan identifisere dere blir sletta fra transkriptene, så det kommer ikke til å være mulig å finne ut hvem dere er ut i fra dem
- Dere har rett til å trekke dere fra fokusgruppa når som helst uten å oppgi grunn. Hvis du trekker deg underveis, så kommer jeg til å ta med det du har sagt frem til da, og selvsagt anonymisere det.
- Alt som sies her vil bli behandlet så konfidensielt som mulig.
- Kun jeg og veilederen min vil ha tilgang til transkriptene.
- Det blir umulig for meg å love konfidensialitet på vegne av dere, men jeg håper at dere ikke vil fortelle andre om fokusgruppa på en måte som kan identifisere de andre deltakerne og at dere vil respektere de reglene vi setter for gruppa.
- Har dere noen forslag til regler?
 - o Jeg foreslår at vi lar én snakke om gangen, både av respekt for den som snakker og fordi det gjør jobben min med å høre og skrive ned det som blir sagt så mye lettere.
- Hvis det skulle komme frem noe som tyder på at en av dere står i noen form for fare, så kan det være jeg må bryte konfidensialiteten og kontakte noen som kan gi passende hjelp.
- Etter fokusgruppa kommer vi til å ha en liten diskusjon om hvordan det var å delta og eventuelle tanker dere sitter igjen med.
- Da vil jeg også sjekke at alt som ble sagt føles greit for dere.
- Dere må også fylle ut et honorarskjema, slik at jeg kan få overført pengene til dere.
- Bare forsyn dere fra det på bordet, og gi meg et tegn hvis dere trenger pause for å gå på do eller noe.

- Jeg kommer til å stille spørsmålene, men ikke svare på dem. Jeg vil at dere skal diskutere med hverandre de tingene jeg tar opp.
- Spørsmålene som jeg stiller har ingen riktige eller gale svar. Det kan hende dere blir uenige om ting, og det er helt greit. Før vi begynner med problemstillingene vil jeg fortelle litt mer om temaet.

Introduksjon

- Mange mennesker blir født med en form for fysisk ulikhet sammenliknet med andre, noe som kan gjelde både utseendemessig og hvordan ting i kroppen fungerer.
- Når et barn blir født er som regel det første spørsmålet foreldrene får: ”er det en gutt eller en jente?”.
- Men noen ganger kan man ikke se dette med en gang, noe som er en del av det jeg kaller ”utypisk kjønnsutvikling”. Andre former for utypisk kjønnsutvikling kan for eksempel vise seg i puberteten.
- Jeg bruker begrepet ”utypisk kjønnsutvikling” fordi det handler om kjønnsorganer (feks eggledere eller testikler), hormoner, kromosomer og så videre som ikke er vanlige.
- Hva tror dere leger og andre eksperter gjør når de oppdager at et barn har utypisk kjønnsutvikling?
- Hva synes dere de burde gjøre?
- Har dere hørt om dette fra før av? (I så fall,) hvor har du hørt om det?

Probes (introduseres hvis temaene/spørsmålene ikke nevnes)

- *Hva slags intervensjoner/behandling/håndtering?*
- *Hvem bestemmer?*
- *Hva tror dere leger og andre profesjonelle ønsker som resultat?*
- *(Dersom deltakerne refererer til kultur, gå videre med dette – hva betyr det?)*
- *Veldig bra start, nå vil jeg gi dere noen problemstillinger som jeg vil at dere skal vurdere og diskutere sammen, uten at jeg er med i diskusjonen. Ok? Det er fint om jeg kan lese ferdig bakgrunnen for spørsmålet først, og hvis noe er uklart, så er det bare å stille spørsmål da jeg har lest ferdig. Ok?*

Følgende spørsmål omhandler dilemmaer som er uløste i dagens konsensus for behandling. Vignett 1 og 2 er oppdelt. 1a og 2a gis til halvparten av gruppene, 1b og 2b til resten.

Vignett 1a – CAH og tidlig intervensjon (som barn)

- Det første jeg vil at det dere skal gjøre er å forestille dere at da du ble født (*hvis gutter: at du ble født som jente*), la både foreldrene dine og helsepersonellet merke til at klitorisen din var ganske synlig.
 - o Altså at du ble født med en større klitoris enn de fleste andre jenter.
- Helsepersonellet oppdaget også at binyrene dine (kjertel på nyrene) produserte hormoner som kunne påvirke helsen din negativt, noe som hang sammen med grunnen til at klitorisen din var større enn vanlig. De tilbød derfor behandling med medisin for å holde binyrenes funksjon stabil.
- De tilbød også å redusere klitorisen din gjennom operasjon, for å gjøre den mindre synlig.
- Er alle med på hva det er snakk om så langt?

- Ok. Det jeg vil at dere skal gjøre da, er å se for dere denne situasjonen, og tenke over:
 - o Hva ville du at foreldrene dine skulle ha valgt å gjøre da de ble tilbudt disse behandlingsmulighetene (medisin og operasjon) for å endre på kroppen din?
 - o Snakk med hverandre om dette, og diskuter spørsmålene uten at jeg er involvert.
 - o Dette er en vanskelig situasjon, som få foreldre er forberedt på å møte.
 - o Folk kan ha ulike tanker om hva som er mest riktig å gjøre her.
 - o Jeg vil at dere skal tenke på hva DU hadde villet at DINE foreldre skulle gjort.
 - o Jeg er veldig interessert i alles mening om dette.
 - o Dere kan stille meg spørsmål hvis dere har noen, så vil jeg svare så godt jeg kan.

Probes (introduseres senere i diskusjonen hvis de ikke nevnes)

- *Hva ville være avgjørende for om du velger operasjon eller ikke?*
- *Hva skulle til for at du ville at foreldrene dine skulle valgt operasjon (feks størrelsesmessig)?*
- *Det kan være både positive og negative utfall av operasjonen, kan dere tenke dere noen effekter?*
 - o *Et eksempel på positivt resultat kan være at man ikke blir flau over klitorisen når den er mindre synlig.*
 - o *Eksempler på negativt resultat kan være at man trenger flere operasjoner, får arrdannelse og mister følsomhet.*
- *Hvis foreldrene dine hadde valgt å ikke operere, hva kunne effektene vært?*
 - o *Kan du tenke deg situasjoner der dette kunne bli problematisk, fordi kroppen din kunne være synlig for andre (for eksempel bading, gym)?*
 - o *Hvordan tror du du hadde taklet disse situasjonene?*
 - o *Kan du tenke deg situasjoner der det kunne bli problematisk med tanke på forhold og sex? Hvordan da?*
- *Hvis foreldrene dine hadde valgt å operere, hva kunne effektene av det vært?*
 - o *Kan du tenke deg situasjoner der det kunne bli problematisk med tanke på forhold og sex? Hvordan da?*

Oppmuntre spørsmål

- *Det er et veldig godt spørsmål, og dere kommer sikkert på mange gode spørsmål*
- *Folk har ofte den typen spørsmål om dette, så skriv gjerne ned alle spørsmålene dere kommer på, så tar vi en runde med dem etterpå.*

Vignett 2a – informere datter med AIS (som forelder)

- Ok, da skal jeg be dere forestille dere en annen situasjon.
- Nå vil jeg at dere skal se for dere at du er forelder til en tenåringsjente.
- Hun er blitt så gammel at dere hadde forventet at hun skulle begynne å menstruere, men det gjør hun ikke.
- I tillegg oppdager dere at hun har noe som ser ut som brokk (en slags klump) nederst på magen.
- På grunn av dette drar dere til legen, som gjør forskjellige tester.
- Etter noen dager drar du som forelder alene til legen og får svar på testene, uten at datteren din er med.
- Du får da vite at datteren din har XY-kromosomer, og at det som virket som brokk (den lille klumpen på magen) er en indre testikkel.
- Er alle med på scenarioet så langt? Ok.

- Da vil jeg at dere skal diskutere disse spørsmålene:
 - o Vil du at datteren din skal vite om XY-kromosomene og den indre testikkelen?
 - o (I så fall), hvordan vil du at hun skal få vite det?
 - o Igjen, så vil dere sannsynligvis ha ulike synspunkter på dette, men se for deg at du er forelder og snakk med hverandre om hvordan DERE ville håndtert denne situasjonen og hva DERE ville gjort.
 - o Det er fortsatt bare å stille meg faktaspørsmål hvis dere har noen.

Probes (introduseres senere i diskusjonen hvis de ikke nevnes)

- *XY er kjønnskromosomene som er typisk for menn.*
- *Dette betyr at hun ikke kommer til å kunne få barn*
 - o *Har ikke livmor eller eggstokker*
- *Hun kan ha en kortere vagina enn andre jenter*
- *Ellers er kroppen hennes som en typisk jente*
- *Intervensjoner som er vanlige å tilby er hormonbehandling og operasjon for fjerning av indre testikkel/testikler*
- *Hvis hun har en kort vagina er det mulig å bruke et instrument for å utvide den. Denne settes inn i vagina og utvides slik at den strekker vevet. Det er også mulig hun blir tilbudt kirurgi for å forsøke å gjøre vaginaen lenger.*
- *Du og legene sliter med hva, når og hvordan*
 - o *Hvordan ville du likt å få dette forklart til deg?*
 - o *Hvilke ord ville du brukt for å forklare det til datteren din?*

Oppmuntre spørsmål

- *Det er et veldig godt spørsmål, og dere kommer sikkert på mange gode spørsmål*
- *Folk har ofte den typen spørsmål om dette, så skriv gjerne ned alle spørsmålene dere kommer på, så tar vi en runde med dem etterpå.*

Vignett 1b – CAH og tidlig intervensjon (som forelder)

- Det første jeg vil at det dere skal gjøre er å forestille dere at du nylig ble forelder til en datter.
- Både du og helsepersonellet la umiddelbart merke til at klitorisen til datteren din var ganske synlig.
 - o Altså at hun ble født med en større klitoris enn de fleste andre jenter.
- Helsepersonellet oppdaget også at binyrene (kjertel på nyrene) til datteren din produserte hormoner som kunne påvirke helsen hennes negativt, noe som henger sammen med grunnen til at klitorisen hennes er større enn vanlig. De tilbød behandling med medisin for å holde binyrenes funksjon stabil.
- De tilbød også å redusere klitorisen hennes gjennom operasjon, for å gjøre den mindre synlig.
- Er alle med på hva det er snakk om så langt?
- Ok. Det jeg vil at dere skal gjøre da, er å se for dere denne situasjonen, og diskutere disse spørsmålene:
 - o Hva ville du som forelder valgt å gjøre da du ble tilbudt disse behandlingsmulighetene (medisin og operasjon) for å gjøre endringer på kroppen til datteren din?
 - o Snakk med hverandre om dette og diskuter spørsmålene uten at jeg er involvert.
 - o Dette er en vanskelig situasjon, som få foreldre er forberedt på å møte.

- Folk kan ha ulike tanker om hva som er mest riktig å gjøre her.
- Jeg vil at dere skal tenke på hva du tror DU ville gjort som forelder.
- Jeg er veldig interessert i alles mening om dette.
- Dere kan stille meg spørsmål hvis dere har noen, så vil jeg svare så godt jeg kan.

Probes (introduseres senere i diskusjonen hvis de ikke nevnes)

- *Hva ville være avgjørende for om du velger operasjon eller ikke?*
- *Hva skulle til for at du ville valgt operasjon (feks størrelsesmessig)?*
- *Det kan være både positive og negative utfall av operasjonen, kan dere tenke dere noen effekter?*
 - *Et eksempel på positivt resultat kan være at man ikke blir flau over klitorisen når den er mindre synlig.*
 - *Eksempler på negativt resultat kan være at man trenger flere operasjoner, får arrdannelse og mister følsomhet.*
- *Hvis du hadde valgt at datteren din ikke skulle opereres, hva kunne effektene av det vært?*
 - *Kan du tenke deg situasjoner der dette kunne bli problematisk, fordi kroppen hennes kunne være synlig for andre (for eksempel bading, gym)?*
 - *Hvordan tror du du og datteren din hadde taklet disse situasjonene?*
 - *Kan du tenke deg situasjoner der det kunne bli problematisk med tanke på forhold og sex? Hvordan da?*
- *Hvis du hadde valgt at datteren din skulle opereres, hva kunne effektene av det vært?*
 - *Kan du tenke deg situasjoner der det kunne bli problematisk med tanke på forhold og sex? Hvordan da?*

Oppmuntre spørsmål

- *Det er et veldig godt spørsmål, og dere kommer sikkert på mange gode spørsmål*
- *Folk har ofte den typen spørsmål om dette, så skriv gjerne ned alle spørsmålene dere kommer på, så tar vi en runde med dem etterpå.*

Vignett 2b – informeres om AIS (som barn)

- Ok, da skal jeg be dere forestille dere en annen situasjon.
- Nå vil jeg at dere skal se for dere at du en tenåringsjente, og at du har blitt så gammel at du hadde forventet å begynne å menstruere, men det gjør du ikke.
- I tillegg har du nylig oppdaget at du har noe som likner brokk (en slags klump) nederst på magen.
- På grunn av dette drar du og foreldrene dine til legen, som gjør forskjellige tester.
- Du har ikke fått vite resultatet av testene ennå.
- Det legene har funnet ut er at du har XY-kromosomer og at det som virket som brokk (klumpen nederst på magen) er en indre testikkel.
- Legene har fortalt dette til foreldrene dine, men de har ikke sagt noe til deg ennå.
- Er alle med på scenarioet så langt? Ok.
- Da vil jeg at dere skal forestille dere denne situasjonen, og vurdere to spørsmål:
 - Vil du få denne informasjonen?
 - (I så fall,) hvordan vil du få den?
- Igjen, så vil dere sannsynligvis ha ulike synspunkter på dette, men se for deg at det er deg dette hender og snakk med hverandre om hvordan DERE ville foretrukket denne situasjonen.
- Tenk litt og snakk med hverandre uten at jeg er involvert i diskusjonen.

- Det er fortsatt bare å stille meg faktaspørsmål hvis dere har noen.

Probes (introduseres senere i diskusjonen hvis de ikke nevnes)

- *XY er kjønnskromosomene som er typisk for menn.*
- *Dette betyr at du ikke kommer til å kunne få barn*
 - o *Har ikke livmor eller eggstokker*
- *Du kan ha en kortere vagina enn andre jenter*
- *Ellers er kroppen din som en typisk jente*
- *Intervensjoner som er vanlige å tilby er hormonbehandling og operasjon for fjerning av indre testikkel/testikler*
- *Hvis du har en kort vagina er det mulig å bruke et instrument for å utvide den. Denne settes inn i vagina og utvides slik at den strekker vevet. Det er også mulig du blir tilbudt kirurgi for å forsøke å gjøre vaginaen lenger.*
- *Foreldrene dine og legene sliter med hva, når og hvordan de skal fortelle deg om dette.*
 - o *Hvordan ville du fått dette forklart for deg?*
 - o *Hvilke ord ville du at de skulle ha brukt?*

Oppmuntre spørsmål

- *Det er et veldig godt spørsmål, og dere kommer sikkert på mange gode spørsmål*
- *Folk har ofte den typen spørsmål om dette, så skriv gjerne ned alle spørsmålene dere kommer på, så tar vi en runde med dem etterpå.*

Betegnelser/navn og definisjoner

- Dere har akkurat vurdert to situasjoner, en med en jente som har en synlig klitoris, den andre med en jente som har XY-kromosomer og en indre testikkel.
- Dette er situasjoner som noen mennesker opplever.
- Ofte må de finne en måte å snakke om dette på, for å kunne snakke om hvem de er og hva de har opplevd.
- Det jeg vil vi skal snakke om nå er hvilke ord man kan bruke for å snakke om dette.
- Prøv å være kreative, og se for dere at dere må snakke om det å være i denne situasjonen.
- Jeg skal gi dere to hovedbetegnelser, men dere kan finne på så mange andre som dere vil.

Vis kort med betegnelser/ev. Skriv de to betegnelse øverst på et ark

- Èn av hovedbetegnelse er ”intersex”. For eksempel kan man da si ”jeg er intersex fordi jeg er en kvinne med XY-kromosomer”.
- Forstyrrelser i kjønnsutviklingen/uklare kjønnskarakteristika/disorders of sex development (DSD) er en annen betegnelse. For eksempel kan man da si ”jeg har en kjønnsutviklingsforstyrrelse, siden jeg er en kvinne med XY-kromosomer”. Eventuelt ”jeg har en DSD , siden jeg er en kvinne med XY-kromosomer
- Jeg er interessert i å høre om hva dere synes om disse betegnelse, og om dere kan tenke ut noen andre betegnelser, som kunne passet bedre til å beskrive disse situasjonene.
- Diskuter dette mellom dere. Jeg blir ikke med i diskusjonen, men dere kan stille meg faktaspørsmål hvis dere har det.

Probes (ved behov)

- *Finnes det, eller kan vi finne på, andre ord enn disse to for å beskrive det samme?*
- *Hvorfor ”forstyrrelser i kjønnsutviklingen” (DSD)?*
 - *Brukes ofte av medisinere og helsepersonell fordi de trenger å kategorisere forskjellige tilstander med liknende uttrykk inn i en betegnelse, for å kunne gi diagnose og behandling. Situasjonene vi har snakket om har til felles at de handler om kjønnsutvikling.*
 - *Noen foretrekker ”forstyrrelser i kjønnsutviklingen” (DSD) fordi de synes det er en presis beskrivelse av situasjonen.*
 - *Noen foretrekker ”forstyrrelser i kjønnsutviklingen” (DSD) fordi de synes det beskriver at det handler om deler av kroppen, ikke om personen som helhet.*
 - *Noen liker ikke ”forstyrrelser i kjønnsutviklingen” (DSD), men vil heller bruke spesifikke diagnoser*
- *Hvorfor intersex?*
 - *Intersex brukes av mange fordi det ikke er et medisinsk begrep.*
 - *Noen liker begrepet intersex fordi det ikke er sykdomsrelatert*
 - *Noen synes dette er et veldig unorsk begrep, har dere noen forslag til bedre norske begreper?*
 - *Noen bruker intersex fordi de identifiserer seg som intersex/med begrepet.*
 - *Ved å bruke intersex-begrepet kan man føle at man er del av en gruppe, med liknende opplevelser og erfaringer, noe som kan gi en følelse av felles identitet (fellesskap).*

Teorier om kjønnsidentitet

- Som jeg har forklart erfarer noen at kroppen utvikler seg på disse måtene.
- Mange forskere er interessert i hvordan vi identifiserer og føler oss som kvinner og menn, altså kjønnsidentitet.
- Kjønnsidentitet har blitt mye diskutert i forskningen på utypisk kjønnsutvikling.
- Det jeg vil gjøre nå er å presentere tre teorier for dere, og at dere skal vurdere hvor nyttige disse teoriene kan være for en ung kvinne med en kropp som utviklet seg utypisk (for hennes kjønn).

- Den første teorien fokuserer på hormoner.
- I følge denne teorien den måten du føler deg på nå, som mann eller kvinne, ”programmert” av hormoner som påvirket hjernen og kroppen din før du ble født.
- Disse hormonene påvirket også kjønnsutviklingen din i puberteten.
- Dette betyr at hormonene som påvirket hvordan kroppen din utviklet seg også kan påvirke kjønnsidentitet senere.
- Forskjeller i hormonpåvirkning kan dermed også ha konsekvenser for kjønnsidentitet.
 - Denne teorien kan vi kalle ”hormon-teorien”.

- En annen teori fokuserer mer på velvære.
- Når man sammenlikner seg med andre kvinner eller andre menn kan man føle at man er typisk eller at man ikke er det.
- De fleste føler også mer eller mindre press til å passe inn/oppfylle normene for menn eller kvinner.
- I følge denne teorien kan mennesker med utypiske kropper og kjønn føle seg vel med seg selv og være lykkelige, så lenge de ikke føler for mye press til å være som andre kvinner eller menn.
 - Denne teorien kan vi kalle ”den psykologiske teorien”.

- Den siste teorien fokuserer på kultur og sier at det vi kaller en mann og det vi kaller en kvinne er litt vilkårlig.
- Så, i vår kultur sier vi at mennesker med XY-kromosomer og testikler er menn, mens folk med XX-kromosomer og eggstokker er kvinner.
- Men i andre kulturer er det andre regler som bestemmer hva som gjør deg til en mann eller en kvinne.
- Noen kulturer har også en tredje kjønnskategori.
- I følge denne teorien virker mennesker med utypisk kjønnsutvikling uvanlige fordi de ikke passer inn i våre kulturelle regler for kjønn, men de kunne passet bedre inn i et annet kulturelt system.
 - o Denne teorien kan vi kalle ”den kulturelle teorien”.
- De tre teoriene jeg vil at dere skal vurdere er altså:
 - o ”Hormon-teorien”, som sier at hormoner påvirker kroppen og hjernen før man blir født på en måte som vanligvis gjør at man føler seg som (og se ut som) en mann eller en kvinne.
 - o ”Den psykologiske teorien”, som sier at det å ha en typisk kropp ikke er nødvendig for å være komfortabel med kjønn, det handler mer om hvordan man forholder seg til normer og press til å passe inn.
 - o ”Den kulturelle teorien”, som sier at definisjonen av mann og kvinne er ulikt i forskjellige kulturer.

Del ut lapper med teoriene

- Det jeg vil dere skal gjøre nå, er å forestille deg at du skal snakke med en jente med en kropp som har utviklet seg utypisk.
- Du har lyst til å si noe som kan hjelpe henne med å forstå og gi mening til situasjonen sin.
- Dette skal dere gjøre hver for dere, uten å se på eller snakke med de andre i gruppa.
- Tenk på de tre teoriene, og tenk på jenta med utypisk kjønnsutvikling.
- Hvilken teori tror dere vil være mest nyttig for at hun skal forstå situasjonen sin?
- Ranger teoriene ut i fra hvor nyttig du mener de vil være, den mest nyttige som nummer 1, den nest beste som nummer 2 og den minst hjelpsomme teorien som nummer 3.
- Skriv nummeret på lappen og legg dem opp-ned.

Vent på at alle får rangert lappene sine

- Har alle rangert lappene sine? Flott!
- Da vil jeg at dere skal snakke med hverandre om hvordan dere har rangert dem.
- Hvorfor mener du at én teori er mer eller mindre viktig?
- Dere kan også her ha veldig forskjellige meninger om og perspektiver på dette, men jeg er interessert i alles mening.
- Igjen så er det bare å stille spørsmål, hvis dere har noen.

Probes

- *Hva tror dere hun trenger fra en teori?*
 - o *Hva vil hjelpe henne gi mening til sin opplevelse?*
- *Hvilken del av denne teorien tror du ville være spesielt hjelpsom for henne?*
- *Hvorfor mener du denne delen av teorien vil være nyttig?*

- *Mer spesifikt hva tror du hun ville få ut av den teorien sammenliknet med de andre?*
- *Er det noe hun trenger som hun ikke ville få ut av denne teorien?*
- *Er det noe hun ikke får ut av noen av disse teoriene?*
- *Hva ville dere sagt til en person som fortalte dere at hen var intersex eller hadde en DSD?*

Avslutning

- Oppsummere hovedpunkter
- Be deltakerne om å stille spørsmål.
- Spør deltakerne om hvordan det var å være med på fokusgruppa (si at det kan hjelpe meg videre).
- Si at jeg forstår om det har vært utfordrende og vanskelig, men at de virkelig har bidratt til forskningen
- Dele ut informasjonsskriv og si at hvis de lurer på noe i etterkant står det der hvor de kan finne mer informasjon
- Få alle til å fylle ut honorarskjema
- Takke igjen for deltakelsen
- Forhøre om fremtidig kontakt, spesielt hvis deltakerne vil ha tilbakemelding om hvordan forskningen går.

Appendix 5: Post-participation information sheet

INFORMASJON TIL DELTAKERE I FOKUSGRUPPER OM UTYPISK KJØNNSUTVIKLING

Tusen takk for at du deltok i denne forskningen! Jeg er veldig glad for at du ville være med i fokusgruppa! Prosjektet vil forhåpentligvis være med på øke kunnskapen om dagligdags tenkning om kropp og utvikling generelt, og om utypisk kjønnsutvikling spesielt.

Hvor kan jeg få mer informasjon om utypisk kjønnsutvikling?

Landsforeningen for lesbiske, homofile, bifile og transpersoner i Oslo Akershus (LLH OA) har startet opp siden intersex.no der du kan finne informasjon og linker til andre ressursider.

For informasjon spesifikt om de formene for utypisk kjønnsutvikling vi har snakket om (CAH og AIS) kan livingwithcah.com og aissg.com være spesielt nyttige sider.

Hva vil informasjonen jeg har gitt brukes til?

Det som ble sagt i fokusgruppene vil bli skrevet om til tekst. Disse tekstene vil danne grunnlaget for min masteroppgave og potensielt en vitenskapelig artikkel.

Hva skjer fremover?

Når masteroppgaven er innlevert vil den være tilgjengelig for alle ved UiO på duo.uio.no. Dersom du ønsker å lese den ferdige oppgaven og ikke har tilgang til DUO kan du gi meg beskjed om dette så kan jeg sørge for at du får et eksemplar.

Dersom du har spørsmål i etterkant kan du kontakte meg på ingrid.donasen@gmail.com

Igjen, tusen takk for deltakelsen!
Ingrid Dønåsen

Appendix 6: Questions about experience with atypical sex development

Spørsmål om erfaring med kjønnsutvikling

Kjønnsutvikling refererer til utviklingen av kroppsdelene som er knyttet til kjønn. Det inkluderer vanligvis kjønnsorganer, testikler, eggstokker, kromosomer (XX og XY), samt hormonnivåer. Å erfare utypisk kjønnsutvikling kan bety at en eller flere av disse kroppsdelene utvikles på en annerledes måte enn det som er vanlig.

1. Har du erfart noen eller flere av disse situasjonene?
 - a. At kjønnsorganene dine er eller var annerledes sammenliknet med andre, og at dette er noe du og foreldrene dine har vært i kontakt med helsepersonell i forbindelse med.
 - b. At du har annerledes kromosomsammensetning enn de fleste andre av ditt kjønn
 - c. At utviklingen av dine testikler eller eggstokker har vært annerledes sammenliknet med andre og at dette er noe du eller foreldrene dine har vært i kontakt med helsepersonell i forbindelse med.
 - d. At du har eller har hatt problemer med hormonnivåer, noe som innebærer/innebar at du må/måtte ta medisiner med eller knyttet til kjønns hormoner for at kroppen din skal fungere optimalt.
2. Har, så vidt du vet, noen i din familie eller andre du kjenner opplevd noe av det som ble nevnt i spm 1a-d?
3. Har du noen gang jobbet i en setting der du møtte mennesker med kjønnsutviklingsproblematikk eller på annen måte jobbet med kjønnsutviklingsproblematikk?
4. Har du noen gang skrevet en oppgave eller gjort annet skolearbeid om kjønnsutviklingsproblematikk?