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Why do ‘we’ perform surgery on newborn intersexed children?

The phenomenology of the parental experience of having a child with intersex anatomies

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Abstract

Few parents-to-be consider that their child may be born with ambiguous sex, i.e. external and internal genitals, gonadal structures, sex chromosomes or hormone levels that are not typical only for one sex. Still, parents of a newborn child with ambiguous sex are expected to make a far-reaching decision for the child: should the child be operated upon so that it has either female or male genitals?

Surgeries on external genitals are most often not life-saving but aimed at creating genitals that are acceptable to the individual and society. The surgeries have been the target of criticism from patients’ organisations and researchers. Some patients who have had operations assert that the operations have created a sense of abnormality that was meant to be avoided. They describe how their sexual function and pleasure have been impaired. Criticisms have also been directed at the parents’ proxy consent and it has been suggested that surgeries should be postponed until the child can participate in the decision.

The aim of this article is to examine, phenomenologically, why parents decide to have their children undergo genital surgery in spite of the fact that there is most often no medical reason to do so. Drawing on phenomenological work by Maurice Merleau-Ponty, Simone de Beauvoir and Sara Ahmed, we examine parents’ frustration when their child’s sex is ambiguous and their

experiences of the practice of medical sex assignment. We also examine parental identity work when the child has been assigned a sex and the interaction between parents and medical professionals when parents make decisions regarding surgery on their child. Furthermore, we provide a critical perspective on the surgical practice.

Keywords: cultural norms, dys-appearance, intersex, parents' experiences, phenomenology of the body

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When parents are told that the sex of their newborn child is ambiguous, many of them find this frustrating or even almost unconceivable. It may be particularly difficult for them to accept the situation if they have not known, beforehand, that some children are born with external and internal genitals, gonadal structures, sex chromosomes and hormone levels that are not typical for one sex only. The incidence of so-called intersex conditions varies from 1.7 to 4% of all children depending on how the term ambiguous sex is used and on whether children whose ambiguous sex is discovered during puberty are included (Blackless et al 2000, Gough et al 2008).ⁱ Even if the lower figure above is used, this means that more children are born sexually ambiguous than with Down's syndrome (1 in 800-1000) in Europe and the USA (Hester 2004). Yet public awareness is less as regards the possibility of having a child with ambiguous sex than the possibility of having a child with Down's syndrome.

When a child is born with ambiguous sex, medical professionals state that a thorough assessment and decision regarding the child's sex is required as soon as possible (Lee et al 2006). In most cases, the reason for the emergency is not medical but social. Empirical research on this situation highlights parental bewilderment that the child's sex is ambiguous (Gough et al 2008). Parents suddenly realise that not all children are born as either a girl or a boy. What they previously took for granted, the division of humans into two sexes, i.e. the two-sex model, is shattered. Parents also articulate frustration vis-à-vis the medical professionals who do not know "what" the child is (Gough et al 2008:499, Bergström 2001:33).

Medical professionals agree internationally that genital surgery, if performed, should almost always be done in an early phase of the child's life (Lee et al 2006, Ritzen & Hagenfeldt 2003). They also emphasise that parents ask for early surgical intervention (Rebelo et al 2008, Linde 2006). In Sweden, medical professionals at the specialised Sex Disorder Syndrome Unit at one of the more prestigious large university hospitals state that almost all parents want their child to undergo surgery (Linde 2006). In many cases one operation is followed by others.

The surgery has been the target of criticism from patients' organisations and researchers. Some patients assert that the operations created a sense of abnormality that was meant to be avoided (Dreger 1998, Preves 2000). They describe how their sexual function and pleasure have been impaired (Kessler 1990, Hirsland 2003). Criticisms have also been directed at the parents' proxy consent. It has been suggested that surgery should be postponed until the child can participate in the decision (Dreger 1998, Kipnis & Diamond 1999).

The aim of this article is to examine, phenomenologically, parents' experiences of getting a child with ambiguous sex, the decision-making process regarding gender assignment and whether to let the child undergo genital surgery. We apply phenomenological perspectives (Merleau-Ponty [1945]1962,ⁱⁱ de Beauvoir [1949] 2003, Ahmed 2006, 2007) to previous empirical research on parents' experiences of this situation (Gough et al 2008, Feder 2006, Bergström 2001, Dreger 1998, Kessler 1990). This perspective has not previously been used in discussions of intersex, to our knowledge.ⁱⁱⁱ Parents' experiences, the ways parents come to think about, feel about, respond to the child's ambiguous sex and integrate it into their own lives, can give us insights into gender theoretical debates about sex, embodiment and sexuality. Furthermore, by exploring parents' decision-making in this specific medical context, we can better understand the intricate interplay between mainstream Western society's established gender norms, the doctor's task of judging between normal and abnormal, and parents' wish both to accept children as they are and to shape them in accordance with societal norms.

The article is divided into three sections. First, we present our phenomenological approach. Second, we phenomenologically examine parents' frustration when their child's sex is ambiguous and the parental identity work when the child has been assigned a sex. We explore how "normal" appearance and function of genitalia become a compulsory ground for socialisation. We also examine the interplay between parents and medical professionals when parents make decisions regarding surgery on their child. Third, we highlight the critical potential of this phenomenological approach, particularly in relation to surgical practices.

Intersex Conditions and Adult Patients' Experiences of Surgery

We use the term intersexed children as a synonym for children born with ambiguous sex. These are the terms preferred by patients' organisations. Nevertheless, medical professionals in pediatric endocrinology have agreed internationally to use the term "disorders of sex development" (referred to as DSD) for children and adolescents with gender-atypical development of chromosomes, gonads or anatomical sex (Lee et al 2006). DSD contains many different conditions from severe to mild ones, from those that make a child infertile to conditions that concern appearance. For example, an intersexed child may have a female genital appearance at birth, male chromosomes, undeveloped testicles and no uterus or ovaries (Slijper et al 2000), or be born with female chromosomes and with either male external genitalia or so-called virilized female genitalia. DSD is also used as a medical term for boys born with hypospadiac penises.^{iv}

For medical professionals, the reasons for genital surgeries on children with DSD are medical, functional and cosmetic (Lee et al 2006). Feminising surgeries such as clitoro- and vaginoplasty are done when the child is between 2 and 6 months and, later on in life, when the child is between 13 and 17 years old. Masculinising surgeries such as urethra- and phalloplasty are done between 6 and 18 months. Most children need a series of operations as well as supplementary procedures in puberty (Nordenström et al 2008). Long-term functional outcomes of genital reconstruction in infancy have proved disappointing (Thomas 2004). However, cosmetic surgeries, such as clitoridectomy, separation of the labia or reconstruction of the urethra, are thought to reduce parental distress and trauma, to help the child develop a gender identity, and to limit social humiliation for the child (Sanders 2007).

In 2006, a consensus conference that gathered medical professionals in the DSD field identified "a major shortfall in information about long-term outcome" in diagnosing and treating DSD (Lee et al 2006:e496). Gender identity, it was stated, is due to multiple determinants and it is not certain that the gender the child is assigned is also the one that she or he sees as hers or his as

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an adult (ibid.). Despite this acknowledgement, it is difficult to find statistics about how many children with intersex anatomies feel uncomfortable about, or want to change, their sex as adults. The shortfall in information about long-term outcomes makes it difficult to know how intersexed children, who are now adults, have experienced, interpreted and managed their situations. Some women who have chosen genital surgery for intersex conditions as adults found that surgery, which was supposed to fix appearance and sexual function, failed to solve the problems (Boyle et al 2005). Other women report that they “gained a better self-confidence and a new value as women” (Ekdal et al 2005). However, many adult patients with intersex syndromes state that their condition is unseen in society and is surrounded by shame and mystery-making (Hirsland 2003); that contact with medical services enhances feelings of uncertainty instead of facilitating understanding of the diagnosis (Holt & Slade 2003, Jürgensen et al 2006); and that medical professionals evade patients’ requests for information (Alderson et al 2004).

H-Embodiment, pPerception, oOrientation

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A phenomenological perspective on the body implies a focus on the self as an embodied and constantly meaning-making agent, on the lived basis of experience and on how the self, together with others, interprets, engages with and acts in this world of shared inhabitation (Merleau-Ponty 1962 [1945], Beauvoir 2003 [1949], Kruks 2006, Stawarska 2006). It allows us to analyse how parents, as individuals, “live” and “do” culture together with others.

Phenomenology starts with a Husserlian claim: consciousness is always directed towards something. This means that objects appear perceptually for us as objects “given” to consciousness, i.e. as objects that consciousness has in its view. Consciousness is also shaped by that (objects, other beings, the world) towards which it is turned. For Merleau-Ponty, Beauvoir and more recent phenomenologists of the body (Ahmed 2006, Kruks 2006), it is important to explore the role of the body in meaning-making. Through perception, we find ourselves always already immersed in meaning. Meaning-making is a social phenomenon, an intersubjective

enterprise.^v Nevertheless, our bodies make meaning-making possible and set certain constraints for our interpretations of others and the world. In this sense, the body is “the vehicle of being in the world” (Merleau-Ponty [1945]2006:94). We perceive and interpret the world and other beings through our bodies and we perceive and interpret our bodies through the world and other beings.

It is important to remember that the body, in these discussions, is never merely an object for others. It is someone’s lived reality and this someone exists neither as a thing nor as pure consciousness. Merleau-Ponty, Beauvoir and others seek to overcome the opposition between the body-as-lived-from-within and the body-as-object. The self as subject is always embodied and my body is never merely an object to me (Merleau-Ponty [1945] 2006:453, Beauvoir 1948). This idea also lies at the heart of the concept of the lived body. The lived body is an ambiguous mind-body unity that experiences and acts in a specific situation. It is our lived relationship to a world immersed in meaning, which we constantly interpret and make meaningful to ourselves, through interaction with others. The lived body is someone’s “grasp of the world” (Beauvoir 2003:36, 267).

To say that our lived bodies are our grasps of the world is to say that we do *not* first have perceptions that we interpret and then act on. It is also to say that we should not understand selves as isolated entities that relate to cultural norms. Selves, in this perspective, are always cultured beings for whom perception, interpretation and acts are closely interwoven. To say that our lived bodies are our grasps of the world is also to say that we perceive the world from particular points of view, from our “now” and “here.”

To perceive the world as a lived body indicates “direction rather than a primitive function” (Merleau-Ponty [1945]2006:13).^{vi} This is a thread that Sara Ahmed (2006) elaborates on. Ahmed emphasises that what we can perceive depends on how we are oriented. We must be near enough to something, and turned towards it, in order to see it, and though we can change our perspective on something, depending on our orientation towards the particular thing, we always have a perspective. Furthermore, in perceiving an object in a particular way, we position ourselves in a

certain way towards it or, if one so likes, the object orients us towards it. If we perceive an autumn-leaf as beautiful, we may want to get nearer to it; if we perceive our new-born child's ambiguous sex as unconceivable, we may want to change it so that it becomes conceivable.

Orientations matter for how we inhabit space, for our perception and apprehension of this world. It is important to note the close relationship between self, other and the world and the intersubjective dimension of perception, orientation and action. We are born into a world already inhabited and shaped by others. It is a world made familiar to us by others. The familiar is both that which is given to us, by others, and that "which in being given 'gives' the body the capacity to be oriented in this way or in that" (Ahmed 2006:7). The familiar is an effect of how others have already inhabited and continue to inhabit this world. How others have done and do so matter for the self's orientation.

When oriented, we typically start in the familiar, in the taken-for-granted. We will be differently oriented depending on what we take for granted. Depending on our orientation and on what is "in line" with our orientation, certain things (acts or ways of being or thinking) will be excluded for us. What is "reachable" for us will depend on how we are oriented. Furthermore, there is always a negotiation going on between the familiar and the unfamiliar. Depending on which way we turn, i.e. how we orient ourselves, we may extend the familiar. We may reach for "the 'just about' familiar" and by so doing extend it.

In Ahmed's vocabulary, to be oriented is to be in line:

We are "in line" when we face the direction that is already faced by others. Being "in line" allows bodies to extend into spaces that, as it were, have already taken shape. Such extensions could be redescribed as an extension of the body's reach ... the body gets directed in some ways more than others. (Ahmed 2006:15)

In this thinking, how we orient ourselves, which bearings we focus on and which direction we take, needs to be understood in the light of how others orient themselves and of the field of reachable and unreachable things in the world that is familiar to us. If we follow a line that others in our socio-cultural setting also follow, we may not notice that we follow a line.^{viii} The line disappears for us. Note also that lines depend on the repetition of certain patterns of thinking, of conventions and of norms – though, since these are taken for granted, we tend not to think about it – *and* they are created as a result of this repetition (Ahmed 2006).

The phenomenological concept of orientation, we suggest, allows us to understand why parents have their children undergo genital surgery and it provides us with a theoretical tool for a critical examination of this practice. Parental bewilderment and frustration when their child is born with ambiguous sex, and when professionals do not know what sex the child has, need to be understood against the background of a dualist conception of sex, which orients parents in certain ways and not others: i.e. certain ways of thinking are “reachable” whereas others are not.

Two more phenomenological concepts are noteworthy: the concepts of disappearance and dysappearance. When we inhabit the familiar, certain things – the familiar ones – disappear into the background (compare Husserl 1989:102, Leder 1990). This is also the case with our own bodies. When we are “at ease” in our bodies and the world, our bodies typically disappear from our attention. However, if we experience illness and dis-ease, this can result in a bodily dysappearance. Instead of disappearing in the background, the dysfunction body appears and comes into the foreground as something “‘bad,’ ‘hard,’ or ‘ill’” (Leder 1990:85).

For the dys-appearing body, the previously familiar self-body-world unity is broken. The dys-appearing body appears as alien. It is thematised; it is no longer the taken for granted “here” and “there” of the embodied self. Most analysis of dys-appearance focuses on how the lived body dis-appears and/or dys-appears for the subject, in this case the parent. However, we will use the concept of dys-appearance both in relation to the parents’ and the children’s lived bodies. This will be examined in more detail in the last part of the article.

III. Parental Experience in the Medical Practice of Sex Assignment and Surgery

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To be disoriented in the two-sex model landscape

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Many parents of children born with ambiguous genitals say that medical staff declared a specific sex of their child at birth but changed opinion some hours or days later (Kessler 1990, Bergström 2001). Others tell stories about different doctors having different opinions on their child's sex (ibid.). During this first state of uncertainty, parents learn that genitals may be ambiguous and that their child is a complex and difficult case. Whereas they previously considered the two-sex model as "true" and "familiar", this model is now questioned.^{viii} Since the model is not only a theoretical tool but also something that they live as gendered beings, their frustration is certainly understandable. Parents lose their orientation, because they are urged to question the way of understanding sex which they previously took for granted.

Many parents describe the realisation that doctors do not know the sex of their child as bewildering. As put by one father, "We were just confused obviously, what don't, why don't they know what he is?" (Gough et.al 2008:499). When doctors cannot say whether the child is a girl or a boy, on the basis of the examination of external genitals, this also results in a questioning of the idea that sex has primarily to do with genitals. Again, this can result in an experience of disorientation.

Very soon after the birth of a child, medical professionals start the process of biologically defining the child's sex, through a search for different marks on or in the body. This sex assignment process of chromosome tests, ultra-sounds, treatment with hormones and measurement of how the phallus has responded to hormones may take several months. During the process, the doctor's judgement as to the child's real sex may shift according to different criteria. In one example, a child was assigned female sex at birth. Later on, staff noted that the

child's genitals were somewhat unusual for girls and started to examine the baby. A chromosome test showed that the child had XY sex chromosomes, no womb and no ovaries. They then assumed that the child could be male. One of the doctors stated that if the baby's phallus responded to male hormones by growing, this was a criterion to designate the baby a boy. The baby did not respond in this way and they started to discuss the possibility of making the child a girl, which meant widening the vagina, removing the testicles and in puberty giving female hormones. Still later, however, they saw a reaction to the testosterone that the child had been given. The phallus had grown a little. This became the main criterion for designating the baby a boy. Nevertheless, the genitals needed surgeries to look like a boy's and more testosterone was given (Bergström 2001:42). The case shows how doctors sometimes speak about finding the real sex, but act as if they are searching for the most appropriate sex (cf. Dreger 1998). Parents' disorientation is deepened by these practices.

At this stage, parents seem to experience themselves as being in a liminal state of waiting for a result. It is as if they haven't had a child yet, because a child is supposed to be either a boy or a girl. One mother explained that she "just felt numb you know and, I didn't, I couldn't register with, with her anyway, 'cos I didn't even know what she was!" (Gough et al 2008:499). The parental experience of disorientation and numbness as long as the child has not been assigned either female or male sex indicates how strongly Western cultures presuppose a sex dimorphism. When parents do not know the sex of a newborn baby, some find it difficult to "reach" the baby. The child's genitals cannot disappear, for the parents, in the sense that a "typical" female or male newborn child's sex can. The child's ambiguous sex becomes the focus of the parents' worries.

It is noteworthy that although several tests are done, genital appearance turns out to be the decisive ground for decision. As one endocrinologist said: "Why do we do all these tests if in the end we're going to make the decision simply on the basis of the appearance of the genitalia?" (Kessler 1998:20). Let us explore why the focus is on external genital appearance at this stage of

the process. It seems that doctors are “in line” with certain prevailing socio-cultural ideas of what it means to be a sexual being, such as the idea that a penis needs to function in heterosexual penetrative sex and in standing urination. In this sense, parents and doctors are oriented not only in a two-sex model landscape where the sexes are supposed to be kept separated, but also in a landscape where certain ideas about how humans have sex are more reachable than others, and where certain norms of what qualify as satisfactory female or male genitals prevail. If the phallus is not big enough for the child to be considered male, if such a “good-size” penis cannot be created (Dreger 1998:183) or if it is not without doubt that the child’s body will masculinise in the teens, a common rule has been to assign the child a female sex (Dreger 1998, Ritzén 1987).^{ix} Furthermore, since the criteria for female genitals (i.e. being penetrable for a penis and not protruding) are surgically easier to obtain than the criteria for male genitals, more infants have been assigned female than male sex (Kessler 1990:21, Dreger 1998:183).

It seems, then, that it is more important that male genitals follow strict norms for appearance and function than that female genitals should do so. Female gender become the default gender: if the child’s genitals do not qualify as male, the child will be assigned female gender. On the one hand, this highlights that the female is still the “second sex” as Beauvoir put it (compare Bergström 2001). On the other hand, Beauvoir discusses how women have been more closely defined by their biological functions than men. In the case of sex assignment and genital surgery, it seems as if biological functions and aesthetics for male children are either considered as just as important as or, possibly, even more important than they are for female children.

Medical professionals say that when they are finding out the true sex of the child, they act according to cultural conceptions about genital appearance and penetrating sex. Nevertheless, even though such socio-cultural norms prevail, some parents question this focus on genitals. Such was the case when one father, whose child had XX chromosomes, was told that the child “would make a very nice boy” because of the child’s genitals. “In my mind,” he commented, the

chromosomes made the child a girl “irrespective of the appearance of the genitalia” (Gough et al 2008:502). Parents may hold on to the chromosome test results, even though doctors may shift their focus to appearances again.

Finally, it is worth remembering that the landscape that parents and medical professionals are oriented in is one in which more and more medical treatments are offered not only for medical reasons, but also for aesthetic reasons.^x

Identity ~~w~~Work and ~~r~~Reorientation

After a baby has been assigned a sex, parents have to perform identity work. While they have previously been told not to give a name to their baby or even to call it he or she, boy or girl (Bergström 2001:31, Kessler 1990:21), they are now asked to do so. This is often described as a relief (Bergström 2001:30, 48). Through assignment of the child’s sex, the new-born child becomes a human being, an individual. The liminal, insecure period is over. The identity work or the socialisation process with the child may start.

During the period of identity work, doctors tend to shift the focus from biological factors as a proof of the “real” gender, to gender as fluid and dependent on social factors (Kessler 1990:23). When asking two parents whether they have thought about a name for the child – who recently has been assigned male sex – and then hearing that they are considering calling their son Johan, the doctor says: “That is good. He must have a sterling boy’s name” (Bergström 2001:38, our translation). This highlights how medical professionals not only are oriented in a two-sex model, but also strengthen this orientation.

This is also evident when doctors “prepare” parents for what will come by giving them a diagnosis to tell others. “Tell them it was a malformation, say hypospadias”, one doctor says to help a family handle questions (Bergström 2001:48, our translation). When this is done, the focus is on the position of the urethra, even though this can be seen as quite a small part of the child’s “problem.” It is also noteworthy that parents and community are thought to construct the child’s

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gender. The child's gender identity, some medical professionals suggest, "will depend, ultimately, on how everybody treats your child and how your child is looking as a person" (Kessler 1990:24). Yet this communal gender identity work is not considered to be enough. This is evident when medical professionals such as Martin Ritzén and Kerstin Hagenfeldt (2003:1628) say that it is, "probably, most inappropriate" for a girl to have external genitals that may be mistaken for male genitals throughout her childhood. The psychosocial rearing of the child in line with the assigned sex is seen as more or less calling for surgery on the genitals.

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Though genital surgery seldom is necessary for the child's health (Kessler 1998:81)^{xi}, the medicalisation of ambiguous genitals has created intersex as a disorder of sex development that is seen as curable through surgeries (Lee et al 2006). The assumption that surgeries will enable the child's stable gender identity is born and fed in the interaction between biomedical understanding, cultural norms and everyday life. Parents worry about norms and the world in which their children are going to live. They worry that the children will be teased if their ambiguous sex is not surgically corrected. Choosing surgery for the child is often part of parents' effort to help the child be accepted in society. As an example, one mother explained her choice of surgeries like this:

The fact is that there are two sexes, there are boys and there are girls. Is it possible to not let our child have an identity and not know who he is? We did not consider it very much, to us it seemed natural. I don't think I can understand why one should not have the children undergo operation, those children I really feel sorry for. (Linde 2006)

The line of reasoning is noteworthy here: a sharp distinction is made between girls and boys, the sex of the child is thought to be what gives the child an identity and surgery is seen as a means to strengthen this identity. Though parents may lose their orientation during the testing period, this

disorientation is not used to question the idea of surgery. Instead, the norms of mainstream Western society are emphasised – and surgery is seen as a remedy.

The strength of the phenomenon of orientation can be highlighted by the example of perception, given by Maurice Merleau-Ponty. He describes what takes place when someone sees a room through a mirror that reflects it at an angle of 45 degrees to the vertical. The subject

at first sees the room “slantwise.” A man walking about in it seems to lean to one side as he goes. A piece of cardboard falling down the door-frame looks to be falling obliquely. The general effect is “queer.” ... After a few minutes a sudden change occurs: the wall, the man walking in the room, and the line in which the cardboard falls become vertical. (Merleau-Ponty 2002:289, also cited in Ahmed 2006)

A reorientation, one might say, takes place because of the body’s purposefulness. In order to be able to act, we “straighten” the slantwise perception. The queer effect is overcome in order to make action possible. This seems also to be what happens to parents of children with ambiguous sex. Initially, some of them articulate frustration and even shock (Gough et al 2008:499). They lose their bearings because they find themselves in a most unfamiliar situation where their conceptual framework all of a sudden appears slantwise. There is no sharp distinction between girls and boys. Biological sex is not only or primarily about genitals. At the same time, however, parents are also given ambiguous descriptions of how the sex of the child should be decided (Bergström 2001:43, Gough et al 2008:502). While waiting for the medical test results, parents are told that a number of different factors need to be taken into account when deliberating on which sex is the most appropriate (Bergström 2001:47). When the test results are given, and when medical professionals give their recommendation, this is described as a matter of finding out the “true” sex (Kessler 1998:30).

As a result of the whole process, some parents declare that they see things differently, as compared to before the birth of their child. Sex is much more “fluid” than they had previously thought to be the case. Some say they start to accept more diversity in being human; a richer variation in gender roles seems acceptable to them (Bergström 2001:58). Nevertheless, many parents have their children undergo surgery. While their perspective is, for a moment, “queered,” they nevertheless “straighten” it when they consider their own child’s situation. This “straightening process” is also encouraged by many medical professionals.

Vulnerable dDecision-mMaking: pProviding iInformation to pParents and the rRelevance of eEmbodied eExperience

In order to understand the conditions for parental decision-making in this context, we need to consider how and what information is presented. We need also to consider the power of orientation. After the first stage of bewilderment, parents express relief when they are referred to experts in a hospital specialising on the care of children born with ambiguous sex. They describe both how they trust the experts’ medical knowledge and how, during the liminal period, they are in the hands of experts. This can be exemplified by one parent who explained that “we felt that we were in good hands, that they really knew what they were talking about and had a sort of understanding of what we felt, that it was urgent to get an answer [as regards the child’s gender identity], and that they did everything they could” (Bergström 2001:66. Our translation).

The experience of having trust in the medical experts is important to understanding parents’ willingness to have their child undergo surgery. How experts orient themselves to the child’s intersex anatomies, i.e. how they talk and act, matters for the parents’ own orientations. It matters for whether surgery becomes an alternative more feasible than refusing it. For this reason, it is relevant that in medical literature, the genitals of intersexed children are referred to as a defect or deformity, atypical or malformed (Ritzen & Hagenfeldt 2008). Even though doctors do not use such vocabulary in front of the parents, they often present surgery as treatment for –

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and a solution to – the problem of the intersex condition. Empirical research show that the “no-surgery” alternative is not talked about as an alternative in the parent-medical professionals encounter (Sanders et al 2007, Kessler 1998). In Sanders et al’s study of parents’ experiences, only one out of ten parents had sought information outside the medical setting (Sanders et al 2007).

Parents trust medical expertise and often express a wish to know more about surgery, risks and side-effects. Some of them want to speak to parents who have had their children undergo surgeries several years ago. However, it seems difficult for them to get such information, and they may become worried at a later stage about what they have done. As one example, a mother who agreed to a series of surgeries on the doctors’ strong recommendation, has said that “at the time it seemed like the right thing to do, but I should have done more research then; by now I’ve talked to people who’ve had hypospadias repair, and they’ve gone through hell. It’s all about peeing standing up, but the body has ways of undoing these surgeries. He’s developed a leak... If I knew then what I know now...” (Feder 2006:203).^{xii}

When intersex conditions are presented and treated as emergencies, the focus is on sex assignment (either male or female) and not on surgical complications and side-effects. The fact that the condition, treated or not, may lead to gender confusion and influence quality of life in many ways is even more difficult for parents to get information about (cf. Feder 2006:193).

Let us, again, turn to the concept of orientation. From the moment of birth and through the process of sex assignment, parents lose their orientation, “recover” from this loss, and finally seem to find themselves in a situation where they see surgery as the final step in a long process of doing what is best for their child. Surgery is part of the identity work. Not letting one’s child undergo surgery becomes conceptualised as a way to make the child stand out and not be in line. In this line of reasoning, if parents do not have their child undergo surgery, they contribute to the child’s gender identity confusion.

When oriented, a person will see certain things and not others. As should now be clear, not only perception but also action depends on orientation: actions “depend” on the reachability of a

particular object. If certain acts are beyond our reach because of our orientation, we may not see that towards which we could have been directed. As parents, we may not see non-surgery as an act within our reach – because of how we are oriented. By choosing surgery for our children, however, we also reproduce certain lines and not others. This also has consequences for which acts become reachable for other parents’.

The Critical Potential of Phenomenology

Orientation is about how we find our way and how we come to feel at home. When we inhabit the familiar, familiar things disappear into background. In a related way, our body typically disappears from our attention when we are “at ease” in it and the world. In the case of the parental experiences discussed in this article, the child’s ambiguous sex can make the parents question the very understanding of sex that they had previously lived. If someone previously perceived her or his own and others’ biological sex as more or less equal to genitals and if this person perceived the distinction between female and male sex as a clear-cut one, she or he may no longer do so after the child’s birth.

Consider now the phenomenon of bodily dys-appearance. When the body is at ease, it disappears from the subject’s attention. She or he does not think about the body when dancing, driving a car or eating. If a woman, while dancing, feels an intense pain in her leg, this pain will draw her attention to the leg. She will no longer be able to dance and her leg will “appear” to her as painful. It “dys-appears” to her (see Leder 1990). The central idea here is that the pain in this particular body-part disrupts the harmony between self, others and the world. Consider another example. A tightrope walker is slowly walking on the tightrope, ten meters up in the air. His concentration is on a fixed spot on the other side of the space. However, if he for some reason should all of a sudden concentrate on the size of his feet, he will lose his balance. Again, a bodily dys-appearance has taken place.

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In the case of parents, the child's ambiguous sex disrupts the way they have thought about sex – and also about children as in a clear-cut manner either girls or boys. Parents' way of managing the ambiguous sex of their child as care-givers can be seen as a matter of “willing” the disappearance (and not the dys-appearance) of the child's sex, for the child, in the future.^{xiii}

In the case of surgery on children with intersex anatomies, the focus is directed at the child's ambiguous sex. Surgery is seen as a way to enable disappearance: through surgery, the child's sex comes into line with the two-sex model. It looks familiar. It can disappear into the background. For this reason, to try to “correct” the body of an intersexed child is to try to minimise the child's possible future frustration about being off line and experiencing bodily dys-appearance. The hope is to avoid the sense of abnormality that the child may experience if surgery is not performed.

However, and as noted by critics of this surgery, surgery may fail to achieve this goal. Surgery may result in genitals that do not function as desired. They may, as one example, lose sensitivity. This can result in bodily dys-appearance. If genitals feel numb or if they hurt, this may make them dys-appear to us. Our attention is drawn to these body-parts and they cannot disappear into the background. Furthermore, since one surgical operation is often followed by others through the child's life, these very encounters with medicine can make the child's body “stand out” as abnormal. Through medical treatment, the child's genitals are thematised as objects in need of treatment. Unintentionally, repeated medical treatment may hamper bodily disappearance in the sense that the child's sex is brought to the fore as something that needs to be checked and changed. This can become particularly clear in the case of children who have gone through vaginoplasty, who need daily vaginal dilation by a parent in order to prevent the new vagina from closing up. This may be traumatic for both the child and parent (Kessler 1998:59).

As a lived body, the intersexual child may experience dis-ease instead of bodily disappearance. This can be the case even where medical encounters do not include objectifying

perception, i.e. perception through which, for example, our genital body-parts are talked about as and/or taken to be (more or less) the most crucial aspect (or the whole) of our being.

Bodily dys-appearance can also take place in two other senses. Our bodies may dys-appear to us because of the way they appear to others and the way others react to them. The locker-room scenario is the typical case here. If someone's body appear as off-line (in the two sex model), and if others stare at this person's body, she or he may experience bodily dys-appearance. Her or his body appears as a hindrance to her or his way of engaging with others: it becomes a stumbling-block that does not disappear into the background. Furthermore, our bodies may also dys-appear to us because of the way we think they appear to others. The frustration for parents to make far-reaching decisions for their child is understandable; omitting to act may make the child's body dys-appear in front of others; deciding on surgery may make the child's body dys-appear for her- or himself.

The ~~v~~Violence of ~~p~~Perception

Merleau-Ponty does not develop a systematic account of ethics. Nevertheless, he believed that his phenomenology was consistent with certain moral commitments. We will end this article by outlining an ethical potential in the work of Merleau-Ponty and applying it to the context of parents' experience that surgery on their intersexed child is necessary.

When Merleau-Ponty discusses the phenomenon of perception, he emphasises its intersubjective dimension. No sooner, he notes, "has my gaze fallen upon a living body in the process of acting than the objects surrounding it immediately take on a fresh layer of significance: they are no longer simply what I myself would make of them, they are what this other pattern of behaviour is about to make of them" (Merleau-Ponty 2006:412). This certainly highlights the interplay between self and others in perception. What we perceive is not independent of others' perception, orientation and action. There is a potential for criticism in these very conditions of perception. Others may question or even shatter the image we have made of them and/or of

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what they perceive; we may question the image others have made of us and/or of what we perceive. Indeed, if the other is “really another, at a certain stage I must be surprised, disoriented” as a “result of the violent act which is perception itself” (Merleau-Ponty 2006:421). The act of perception is violent in the sense that it destroys the possibility of solipsism.

The violence of perception is part and parcel of all acts of perception.^{xiv} Nevertheless, though the violent act is always there, we may choose to put ourselves in situations where we are more or less exposed to this “violence.” The term violence may be provocative in this context; adult persons who have been born with intersex anatomies have certainly experienced the surgery that they have undergone as violent. However, the term is useful for what we want to say. Listening to the other’s story can be painful. It can be a violent experience. And, choosing to put oneself in such a situation – where one is likely to be exposed to this violence – can be an ethical enterprise.

The ethical potential lies in the attitude we take to this violent act of perception. We may choose to will this exposure to others’ stories, others’ way of perceiving and thinking, since this is what can help us question what we previously may have taken for granted.^{xv} Such questioning is often painful: it is in many ways psychologically easier for us to go on as we have previously done – to follow the dominant lines in our particular society.

If an ethical call can be derived from Merleau-Ponty’s work, it is that we should will the possibility of the violent act of perception. Indeed, this seems not to be that far-fetched since Merleau-Ponty (1964:40) emphasises the value of “establishing that communication with others and with ourselves for which our temporal structure gives us the opportunity and of which our liberty is only the rough outline.” This also implies a call for language and dialogue through which communication becomes enriched. We should will the possibility of questioning what we take for granted. This attitude may, indeed, enable a re-orientation or at least a nuanced reflection on the lines we repeat and why we repeat them.^{xvi} Such a reflection is possible, and possibly particularly so, when one is losing one’s orientation. When we lose our orientations and are in the process of

re-orientation, we may reach for that which is “just about reachable,” i.e. that which was previously not reachable because of how we were oriented but which we may now just about reach (given how we are now oriented).

Applied to the medical context of sex assignment and surgery, to will the possibility of questioning our perspective could imply that we start to listen to the experiences of those who have already undergone surgery (both those who are satisfied with surgery and those who are not). If their stories are brought forward, this can provide new perspectives that the medical profession may not have emphasised.

Conclusion

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In the two-sex model, a body in line is either male or female. A body between these categories is off line and to think of one's child as between male and female can be frustrating and painful. This can explain parents' eagerness to straighten the “slantwise” perception through sex assignment and often also through agreeing to surgery on their child, even though intersexuality itself questions the sex dimorphism that we take for granted. This can also explain some doctors' advice to parents not to tell anyone about the child's ambiguous sex, at least not until the child has been assigned a particular sex. However, the silence that surrounds the phenomenon of intersexuality, including the surgical solutions, results in secretiveness and invisibility (cf. Boyle et al 2005). Downs' syndrome on the contrary is well known to everybody and there is a vocabulary to discuss the condition and the experience of living with it. If intersexual phenomena were not associated with silence and shame,^{xvii} parents and doctors could possibly talk and think more freely about intersex, and thus be able to consider different possibilities and even alternatives to infant and child surgery.

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- ⁱ Gough et al (2008:494) include children whose ambiguous sex is discovered not only at birth, but also during puberty. This, they suggest, makes an incidence figure as high as 4% reasonable. Others such as Sax (2002) hold the number to be much smaller.
- ⁱⁱ Merleau-Ponty's theory of embodiment has been criticised by feminist philosophers for presupposing a generic body, which is male. However, we agree with feminist scholars such as Sonia Kruks (2006) that his theory of embodiment allows an analysis of multiple differences (including for example gender differences) even though he does not engage in such an analysis himself. Though Merleau-Ponty fails to attend to gendered ways of being-in-the-world, we think his theory can be developed in ways that do attend to differences in gender and sexuality.
- ⁱⁱⁱ However, for further phenomenological analysis of the phenomenon of incorporation and excorporation in relation to the birth of a child with intersex anatomies, see Malmqvist and Zeiler 2009.
- ^{iv} In hypospadias, the urethral opening is not located on the tip of the penis.
- ^v The "social is already there," as Merleau-Ponty puts it ([1945]2006:422).
- ^{vi} In other words, perception has not only to do with physical seeing but with how we are directed – oriented – in this world.
- ^{vii} These lines and perspectives are often most clearly distinguishable in retrospect or when questioned. As put by Merleau-Ponty, "we do not begin by knowing the perspective aspects of the thing; it is not mediated by our senses, our sensations or our perspectives; we go straight to it, and it is only in a secondary way that we become aware of the limits of our knowledge and of ourselves as knowing." Perspectives, then, are not only dynamic and intersubjectively created. They are also "invisible" when they orient us towards a certain person or situation. We do not see that which *makes* us see certain things and not others – our orientation – until it is questioned. For a discussion of how that with which we see "disappears" for us, see Leder 1990, Weiss 1992.
- ^{viii} However, the two-sex model does not exist in all cultures. In Polynesian societies a third gender, *fa'afafine*, exists alongside with the male and the female gender (Sua'ali'i 2001).
- ^{ix} It is worth remembering that when a German team of doctors screened a group of 500 men only 275 were considered "normal" according to the medical criteria for penile normality. Forty-five percent "displayed what intersex experts call 'hypospadias'" (Dreger 1998:188).
- ^x Cosmetic surgeries, for many different reasons, seem to be more common (Helström 2004), and women are especially the target of offers of surgeries (Sandström 2004). "Designer vaginas" are a growing phenomenon (Johnsdotter & Essén 2004). The body does not disappear so easily in this time of medicalisation.
- ^{xi} Some specific disorders need surgeries in order to alleviate health problems (Ritzén & Hagenfeldt 2003).
- ^{xii} As another example, one mother who let her son have three surgeries on his penis said: "I will explain to my child... I did the best I could with the information at hand. My son will know I am human, I

make mistakes, and I love him. Hopefully he will know I didn't intend harm but I was not informed" (Kessler 1990:91).

- ^{xiii} When parents experience the lived situation of having given birth to a child with intersex anatomies they not only bring with them previous perspectives on what having a child means – but also their future hopes for this child. In this way, the child's body may dys-appear *for them* here and now. It may also dys-appear for them and – in their fears – for the child in the future, even if at this early stage it does not dys-appear for the child. For another angle on the issue of how intersexed childrens' genitals are rendered "familiar" through surgery, see Morland (2005).
- ^{xiv} Please note that the violent act of perception need *not* result in the objectification of others; yet the violence of objectification can be a result of how the violent act of perception is used by the perceiver.
- ^{xv} Compare Andrews (2006). The parallel distinction to the one that we suggest here is present when Beauvoir distinguishes between natural/ontological freedom, freedom as a human life condition, and the will to freedom. To be moral, for Beauvoir, is to will oneself free and one can persist, though in vain, in not willing oneself free (Beauvoir 1948).
- ^{xvi} This should certainly not be interpreted as a matter of "blaming the victim" (in this case the parent). Since the individual is always part of a cultural context and since we do not see what we take for granted, this is instead a statement of how reflection can be enabled, also concerning what we take for granted.
- ^{xvii} For an interesting discussion of whether the use of the terminology DSD instead of intersex conditions can result in these conditions being seen as conditions "as many other conditions", see E.K. Feder (2009).

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