

"Differently normal" and "normally different": Negotiations of female embodiment in womens accounts of atypical sex development

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“Differently normal” and “Normally different”: Negotiations of sexed embodiment in women’s accounts of ‘atypical’ sex development

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Keywords

Normality, negotiation, diagnosis, sexed embodiment, atypical sex development, qualitative analysis, young women, Sweden

Research highlights

- There is limited knowledge about facing atypical sex development as a young woman.

- The article explores how such women negotiate sexed embodiment.
- It shows how they use a “differently normal” and a “normally different” strategy.
- Doing so, they focus on bodily features that they *do* have to construe normalcy.
- Finally, it highlights the complex role of diagnosis in such negotiations.

Abstract

During recent decades numerous feminist scholars have scrutinized the two-sex model and questioned its status in Western societies and medicine. Along the same line, increased attention has been paid to individuals' experiences of atypical sex development, also known as intersex or 'disorders of sex development' (DSD). Yet research on individuals' experiences of finding out about their atypical sex development in adolescence has been scarce. Against this backdrop, the present article analyses 23 in-depth interviews with women who in their teens found out about their atypical sex development. The interviews were conducted during 2009–2012 and the interviewees were all Swedish. Drawing on feminist research on female embodiment and social scientific studies on diagnosis, I examine how the women make sense of their bodies and situations. First, I aim to explore how the women construe normality as they negotiate sexed embodiment. Second, I aim to investigate how the divergent manners in which these negotiations are expressed can be further understood via the women's different access to a diagnosis.

Through a thematic and interpretative analysis, I outline two negotiation strategies: the "differently normal" and the "normally different" strategy. In the former, the women present themselves as just slightly different from 'normal' women. In the latter, they stress that everyone is different in some manner and thereby claim normalcy. The analysis reveals that access to diagnosis corresponds to the ways in which the women present themselves as "differently normal" and "normally different", thus shedding light on the complex role of diagnosis in their negotiations of sexed embodiment. It also reveals that the women make use of what they *do* have and how alignments with and work on norms interplay as normality is construed.

Introduction

Since the eighteenth century, the two-sex model, i.e. the notion of two dichotomous sexes, has been dominant in Western culture (Laqueur, 1990), and during recent decades, several feminist scholars have addressed its supremacy (e.g. Fausto-Sterling, 2000). In line with these critical

examinations, increased attention has been paid to individuals' experiences of atypical sex development, that is, conditions that are medically defined as congenital conditions in which development of chromosomal, gonadal or anatomic sex is atypical, also known as 'disorders of sex development' (DSD) (Lee, Houk, Ahmed, & Hughes, 2006). These studies have commonly concerned individuals diagnosed and treated at birth and parental experiences of having a child with unclear sex (e.g. Dreger, 1999; Karkazis, 2008; Preves, 2003; Zeiler & Wickstrom, 2009). Little attention, however, has been paid to experiences of finding out about and having treatment for atypical sex development in adolescence (see however Boyle, Smith, & Liao, 2005; Holt & Slade, 2003; [self-reference removed]).

Against this backdrop, the larger project of which the present article is a part involves women who have found out about their atypical sex development in their teens. Concentrating on how these women make sense of their development, the project aims to explore reinforcement and questioning of female bodily norms ([self-references removed]). The purpose of the article is more specifically to explore these individuals' negotiations of sexed embodiment. How is normality construed in such negotiations? How can the divergent manners in which these negotiations are expressed be further understood via accounts that reflect the women's access to medical labels and diagnosis?

Below I present an analysis of 23 interviews that identifies two strategies by which the women negotiate sexed embodiment and construe normality: the "differently normal" and the "normally different" strategy. In the former, the women present their bodies as just slightly different from 'normal' ones by drawing on medical discourses. In the latter, they stress that everyone is different, that it thus is normal to be different, and underscore the positive aspects of their particular difference. I also examine their accounts about raising awareness and claiming shared identities and suggest that the diverging access to a diagnosis that these accounts reveal sheds light on how the women have come to use the strategies. Finally, I discuss how alignments

with and work on norms interplay as normality is construed (c.f. Winance, 2007) and the complex role of diagnosis in the women's negotiations of sexed embodiment.

Out of the 23 interviewees, thirteen have been diagnosed with Turner's syndrome, henceforth referred to as the Turner group. The remaining ten have found out that they do not have a uterus and no, or only a 'small', vagina. These ten women share the same symptoms, but only seven of them refer to Mayer-Rokitansky-Küster-Hauser (MRKH) syndrome, and out of these only three say that they have been given this diagnosis by a physician. The remaining three have no medical label or name. Owing to their shared symptoms, these interviewees are henceforth referred to as the uterine/vaginal absence (UVA) group. Although both Turner's syndrome and MRKH are included in "DSD" and intersex, none of the interviewees uses such terms and the majority is not aware that their condition is included in such categories. This is, however, not particularly surprising given the limited discussions of DSD and intersex in the Swedish context.

Female embodiment, normality and diagnosis: theoretical vantage-points

Two research fields are particularly relevant to this article. First, it relates to the extensive feminist research on sexed embodiment and femininity. While some scholars have taken their vantage point in queer and feminist phenomenology in order to explore sexed embodiment and experiences of the body (e.g. Ahmed, 2006; Young, 2005) others have attended to discourses of femininity (e.g. Wilkinson & Kitzinger, 1995) and women's narratives regarding e.g. menstruation (Burrows & Johnson, 2005) and infertility (Throsby, 2004). Within these fields scholars have critically examined the notion that there are two clearly distinguishable and dichotomous sexes and the influence of medicine in (Western) understandings of femininity and female embodiment. As Braun and Wilkinson (2005, p. 510) point out, the link between genitals and gendered identity "...seems to constitute a basic, every day, taken-for granted common sense, in

society, medical practice, and psychology”. Consequently, a ‘woman’ is commonly categorized as a person with a uterus, two ovaries and a vagina and who has the capacity to gestate, menstruate and conceive (Fausto-Sterling, 2000; Kessler & McKenna, 1985; Martin, 2001). The symbolic meaning of ovaries and uteri in female gender identity is more specifically addressed by Jane Elson. Exploring women’s experiences of hysterectomies, Elson (2003, p. 765) outlines an “elaborate hormonal hierarchy” with ovaries at the top and indicates that ovaries bear greater symbolic meaning than uteri when it comes to gender identity. The cultural categorizations of ‘women’ and notions of ‘normal’ female embodiment that this body of research reveal form the backdrop of my interviewees’ negotiations of sexed embodiment. Hence, I do not view notions of ‘normality’ as objective concepts, but as interactively constructed and shaped categories.

Notions of normality are also central concerns in sociological research on the complexity of diagnosis, which forms my second vantage point. Through diagnosis, societal norms are expressed and ‘normal’ experiences are distinguished from those calling for treatment (for overviews see Jutel, 2009; Lupton, 1994). Exploring notions of disability, Winance (2007) argues that while these normalization processes have long been considered to involve alignment with norms (e.g., Goffman, 1990), new views are emerging in which normalization is seen to involve work on the norm. Moreover, representing a “specific step in, and enabling factor of, medicalization”, a diagnosis may be both stigmatizing and regulatory (Jutel, 2009, p. 285). Its descriptive character and emphasis on pathology may create “problem saturated identities” (Gillman, Heyman, & Swain, 2000, p. 403). However, a diagnosis may also provide comfort, facilitate identification and make support networks accessible, and may legitimize and validate the individual’s experiences and complaints in medical as well as in other settings (Lillrank, 2003; Reid, Ewan, & Lowy, 1991; Wray, Markovic, & Manderson, 2007). It may allow affected persons to tell their stories, exchange information and offer hope, encouragement and advice to one

another (Fleischman, 1999). I situate my analysis in the latter strand, as I explore how access to a diagnosis shapes negotiations of sexed embodiment.

Data and Methods

Interviewees and interviews

The overall aim of the project, i.e. to explore how women make sense of atypical sex development, made in-depth interviews an appropriate method for data collection. However, before turning to the interviews, I will describe the interviewees.

Because of the rareness of the conditions and symptoms investigated and the lack of public forums in the Swedish context, the recruitment process was characterized by opportunity. As mentioned above, 13 interviewees had Turner's syndrome, which occurs in 1/2500 women as a result of a total or partial absence of one of the X chromosomes. Medically these women present a short stature, dysfunctional gonads, cardiac and renal malformations and otological problems. They most commonly undergo hormone treatment in order increase their height and to induce pubertal development, but owing to their dysfunctional ovaries most women with Turner's syndrome cannot conceive (Sheaffer, Lange & Bondy, 2008).

In the Turner group, nine interviewees were recruited through the Swedish Turner Association, three through blogs and one through a specialist clinic. All of them were given written information about the project, its focus on Turner's syndrome, and what it meant to take part in an interview. Five of these interviews were conducted between 2009 and 2010 and eight at the end of 2011 and beginning of 2012. The women were 18–35 years old at the time of the interview and were all Swedish. Two had been diagnosed in the age range 4–5, nine in the age range 8–12 and two in the age range 13–15. The large span in age ranges (regarding both age of diagnosis and age at the time of the interview) resulted from initial difficulties in recruiting interviewees, which called for broadened inclusion criteria. Nevertheless, the structure and

content of the interviews with the two women diagnosed before adolescence did not stand out from the rest.

The ten interviewees in the UVA group, those who had discovered that they did not have a uterus and no or only a small vagina, had all had medical examinations confirming the absence. The majority of these women referred to the MRKH syndrome, which in medicine is described as a congenital absence of the uterus and of the entire or parts of the vagina, and is found in about 1/4000–1/10,000 females (ACOG, 2002). The women affected cannot menstruate or conceive and may have difficulty performing vaginal penetration. Moreover, because MRKH does not affect genes and ovaries, pubertal development as regards breasts and the external genitalia (such as the clitoris and labia) is ‘normal’ (Morgan & Quint, 2006). These symptoms were also present among the three women who did not use the MRKH label. Because there have been no successful uterus transplantations in terms of pregnancies to date (Brännström, Diaz-Garcia, Hanafy, Olausson, & Tzakis, 2012), treatment is limited to the creation of a “neo-vagina”, either through surgery or by stretching the vaginal dimple using dilators (Edmonds, 2003). These procedures can be painful and both physically and emotionally challenging ([self-reference removed]).

In the UVA group, five interviewees were recruited through specialist clinics, four through blogs and one through an advertisement. They were given the same written information about the project as the women with Turner’s syndrome. When distributed to women who themselves mentioned MRKH when writing about their condition on the Internet, the letter referred to MRKH. The rest received letters that did not focus on a specific diagnose, but on atypical sex development in general. These interviews were conducted during 2009 and 2010. The women were 20–26 years old at the time of the interview, had discovered their symptoms when they were 15–18 and were all Swedish.

The study followed the ethical guidelines of the Swedish Research Council (Vetenskapsrådet, 2002) and was approved by the regional ethical board. The interviewees were informed that personal information and answers would be treated confidentially and that they could end the interview whenever they liked. They were also given contact information to a psychotherapist. All participants gave their oral and written informed consent to participate and to being recorded during the interviews.

The interviews followed a semi-structured interview guide with questions designed to encourage the interviewees to talk about their experiences. Twenty-two interviews were conducted face-to-face and one over the phone, as the interviewee was living abroad at the time. Each interview lasted approximately an hour and a half; they were all recorded and were transcribed verbatim. In the transcripts all names were replaced by pseudonyms: names beginning with T for the women in the Turner group, and names beginning with M for the women in the UVA group, as the majority of these women used the “MRKH” label.

Analysis

The analysis of the transcribed interviews was thematic and interpretative (Kvale, 1996; MacPhail & Campbell, 2001). It focused on the women’s experiences, paying close attention to how they talked about their lives and their bodies. I treat these accounts as *interpretative autobiographies* (Kitzinger & Willmott, 2002), which implies that the analysis centred on the women’s experiences and how they made sense of their body and situation. Moreover, in order to avoid fragmenting the data into ‘snippets’ (Riessman, 2008, p. 12), the analysis revolved around overarching patterns and extensive excerpts.

The analysis involved two stages. In the first stage, I read each interview in detail, paying close attention to the interviewees’ beliefs about female bodies and highlighting sections that explicitly or implicitly concerned normality or difference. These sections were then compared across the interviews to identify major themes, similarities and divergences. By doing so, I

identified two strategies used by the women to negotiate sexed embodiment: the “differently normal” and the “normally different” strategy. In the second stage, I looked at how these two strategies were expressed by the interviewees. While doing this I noted certain differences between the women with regard to how they distinguished themselves from others and how they justified and motivated such distinctions (Taylor & Bogdan, 1998). To further understand these differences, I read the interviews once more, this time focusing on how the women labelled their condition. During this reading, I found that the women’s accounts about raising awareness and sharing collective identities provided explanations for the different manners in which they applied the strategies, particularly because these accounts revealed the women’s different access to a diagnosis.

Before turning to the results, the context, i.e. research interview, in which the interviewees’ negotiations took place, requires mentioning. By asking the women to tell me about their experiences of ‘atypical’ sex development, I was implicitly asking them to negotiate sexed embodiment. This request for meaning-making may position the potential interviewees’ experiences, lives and bodies as phenomena that call for a specific exploration, which in turn may, although unintentionally, construct interviewees as ‘others’ in relation to the researcher (Fine, 1994, p. 72). In light of this, I found it of great importance to reflect on my role as an interviewer throughout the project and to strive to create an open and emphatic interview situation in which the interviewees could tell their stories and express their views. Moreover, in order to provide a reflexive stance vis-à-vis my role as an analyst, the methods and results were discussed in different academic contexts.

Results

In the following I first present each of the identified strategies, focusing particularly on the different manners in which the women adopted them. Second I seek to further understand these differences. By examining the women’s accounts about raising awareness and interacting with

others who share similar conditions or symptoms, I reveal certain divergences as regards the two groups' access to a diagnosis and their ability to talk about and label their bodies and situations. And this in turn, I argue, provides an explanation for the different manners in which the two strategies are employed.

Differently normal: just another kind of normal

Using the “differently normal” strategy, the women present themselves as a different “kind” of normal. They emphasize that are just like any other women and normalize their conditions' impact on their experience of sexed embodiment with reference to the possibilities of medicine and their conversations with doctors. This medical focus is not surprising, in that the women's encounters with the medical profession and experiences of treatment were a theme covered by the interview guide. What I find interesting, however, is the varying focus among the women.

When the *Turner women* use the differently normal strategy, they typically highlight the various medical interventions available to make their bodies more like everyone else's and they underscore their satisfaction with treatment results. For example, Tanja says that “research has come so far that I feel I can have good treatment and have kind of the same quality of life as everybody else”. Some of them do point out that treatment can be difficult at times, but these women nevertheless also stress that the outcome has been good. Specifically, the Turner women underscore the importance of treatment resulting in menstruation. Teresa, for example, says that the absence of ovaries did not make her feel less like a woman, but that puberty, including menstruation, were of greater significance.

I've kind of always felt that ... [... marks a pause or hesitation] I'm a real woman still [i.e., although her ovaries have been removed]. (*Interviewer*: Yes) On the other hand, one doctor told me that all this about puberty — that was when I asked whether I could go without it ... how can I put it [sighs] ... but entering puberty's

really a very important part (*Int: Mmm*) of feeling like a woman (*Int: Mmm*) and to have a regular period every month, and I feel ... I feel that's more important (*Int: Mmm*) than ... a more important part of feeling like a woman (*Int: Mmm*) than whether or not you have ovaries. Because it's more ... mmm. (*Int: Mmm*) I think it's got to do with that... you know... how you feel — at least that's the way it was for me (*Int: Yes*), and that was what my doctor said too: “It's very important that you have the treatment, that you enter puberty, because ...” well... (*Int: Mmm*) And if I hadn't I don't think I'd have felt as much like a woman. (*Int: No*) But the fact that I don't have ovaries, I really don't think ... no. (*Int: No*)

While Teresa seems to have reflected on whether she “could go without” puberty, she still emphasizes that puberty and especially menstruation are of importance if one wishes to “feel like” a woman. She furthermore validates this perspective by referring to her doctor's description of the importance of treatment in relation to puberty. This way of presenting menstruation, and especially its cyclic feature, as being more pivotal for feeling like a woman than, for example, the presence of ovaries or chromosomes, is a recurrent pattern among the Turner women. By emphasizing the potentials of treatment, they can present themselves as just slightly different from the norm.

Moreover, the Turner women highlight similarities between their own hormonal treatment and the hormonal contraceptives that “everyone” uses. For example, one woman says that she only takes “ordinary hormone pills, oestrogen” and that this is “kind of like the pill”. Another woman says that her medication is pretty much like “the pill”, and explains that “the package looks almost the same”. A similar pattern is found when these women talk about pregnancy and fertility. Although the majority of them state that infertility has been the most negative consequences of their condition, they make sure to point out one can have children in various

ways. They stress the potential of egg donation and IVF, interventions that five of the interviewees have undergone, but also consider adoption as an option. By equating puberty-inducing hormonal treatment with hormonal contraception and pointing out that one can have children in various ways, they align with notions of ‘normal’ female embodiment.

Treatment is a recurrent topic among the *UVA women* as well. However, these women to a greater extent stress the physical and emotional strains and difficulties caused by dilation treatment (see also [self-references removed]). Moreover, they do not draw on treatment when employing the differently normal strategy but emphasize that they are just missing *some* “female” parts. For example, Miriam says that “the uterus is completely missing and a small part of the vagina, about two thirds or something like that, is missing too. But except for that, everything’s intact. So it’s basically just that.” Like the Turner women, physical features are also mentioned here as central to feeling like a woman, but the potential of medical tests that can confirm your sex is in focus. Michaela provides an example of this when telling about how her sex was confirmed:

And I know, right at the beginning I had a few thoughts, I suppose — not that many, I think — ... but about ... I think especially that before all the chromosome tests and all that had been done ... that ... “Wait a minute, OK ... how much of a woman am I?” (*Int:* Mmm) and “How ... how ... how can I relate to this in some way?” but then ... I think for me it made it a lot easier in some way that all the chromosome tests were very neutral – or ordinary [laughs] (*Int:* Mmm) and showed [laughing] that I really was a woman in every sense and all that. (*Int:* Mmm) And because you have ... ovaries and hormones and all those things work this wasn’t something I thought about that much afterwards — a bit in the beginning, I suppose, but then it settled: (*Int:* Mmm) “Yeah, OK, there’s just one piece of the

puzzle missing” — yeah, like that (*Int: Mmm*). Eee ... which in a sense has some consequences but ... I didn’t ... I’d say I could let it go quite a lot after that. (*Int: Mmm*.) And that was nice anyhow (*Int: Mmm*). So you didn’t have to think about it.

Michaela underscores the significance of medical tests by explaining that things became easier for her in part when the test turned out to be “ordinary” and showed very clearly that she “was a woman in every sense”. Because of the tests and their results, she did not have to pay further attention to sex categorization and the socially engendered norms that distinguish a woman and a female body. They brought credibility to Michaela’s interpretation that there is “just one piece of the puzzle missing”. Thus, here sex is viewed as being distinguished by several biological aspects that together form a larger puzzle. However, in this puzzle chromosomes seem to have a specifically central role, as they are seen to confirm your sex; as long as you have the “right” chromosomes you can still be missing another piece without losing the overall picture of the puzzle. This way of according particular significance to chromosomes, ovaries and hormones while de-emphasizing the significance of the absent womb and vagina in female embodiment constitutes a recurrent pattern in the UVA group. Another example of this is provided by Monica when she tells about how her doctor informed her of her absent uterus and vagina

“...she [the doctor] meticulously stressed that ‘You are a woman, there is no question about that and you do have ovaries and there is nothing wrong with your hormones or that kind of thing, so you are a woman, you’re only missing this particular part’. So she very carefully explained that there was no strange chromosome mix or anything like that.”

In Monica’s account, certain significance is given to ovaries, hormones and chromosomes. By testing these one can assess whether one is a woman. Once again sex is presented as constituted

by several “parts”, out of which Monica just happens to be missing one. Hence, with reference to the doctor’s explanation, Monica can present her body as just slightly different from a ‘normal’ female body.

Using the differently normal strategy, the women – in light of their particular condition and symptoms – negotiate their understanding of sexed embodiment. As the Turner group refer to medical treatment as that which makes one feel like a woman, they also signal the cultural significance of menstruation (Martin, 2001). In contrast, UVA group refer to medical tests to support their interpretation of how to distinguish a ‘woman’ and their claim to belong within this category and thus underscore the cultural connections between chromosomes, hormones and gender identity (c.f Elson, 2003). In both cases, however, medical discourse enables the women to underscore the significance of the bodily features that they *do* have and thus to present themselves as differently normal.

Normally different: presenting variety as normality

Adopting the second strategy, the women stress the normalcy of difference. This involves the women emphasizing that everyone is different in some way — it is normal to be different, that is — and that difference makes you unique. Instead of presenting their bodies as just slightly different from what is considered ‘normal’, as was found in the first strategy, here the women re-evaluate the meaning of ‘normal’ and the value of difference.

The *Turner women* recurrently state that everyone is different in their interviews, saying for example that “in some way everyone has some strange thing going on”, that not everyone is “cast in the same mould” and that there are many different diseases and illnesses. However, when doing so they typically also highlight that their condition makes them somewhat special. For example, Tilda says she believes that “if you’ve got Turner’s syndrome you’re, to my mind, a very special woman, one who’s really strong, and you’re ... a very grand person ... and you shouldn’t have any doubt about that.” Tina supports the uniqueness of the condition by describing how

friends seem to find her condition interesting; they thought her syringes were “kind of cool” and “a bit special”, and she believes they “found it exciting”. She also talks about being able to “shine in class” because she learned about chromosomes before her classmates did.

I sort of got to know a bit earlier [about chromosomes] than my friends (*Int:* Oh, right). I mean, I knew how chromosomes were divided into pairs and about sex chromosomes and that (*Int:* Mmm). So it’s mostly been that you’ve been able to shine in class (*Int:* [laughs]) and sort of [when the teacher asked] “What’s the name of the male chromosome pair?” (*Int:* Mmm) [I’ve replied] “Oh, XY” and kind of like that — like that. But then I’ve also talked to my biology teachers and explained, like told them (*Int:* Mmm). And they’ve gone like “Oh! Cool!” and kind of thought that it’s been a bit exciting.

Tina indicates that her condition has not only made her more knowledgeable than her friends, but that it is also somewhat ‘cool’, which she further underscores by describing her teachers’ reactions. By presenting difference as normal, it not only becomes possible for the women to present their condition as normal, but also to distinguish themselves from those who have not experienced an atypical sex development, and this in a positive sense.

The *UVA women* also construe normality in terms of variety. Maria, for example, says that in “one way or other everyone’s different”, yet they can still be categorized as male or female. Monica tells about how she has compared her absent uterus and vagina with the absence of other organs, saying that it is “no stranger than being born with only one lung or only one kidney or whatever”. Likewise, Miriam says that it is quite common that people do not have all “the parts” that you expect them to have: “you might be missing an arm or some organ, that’s not uncommon”. Although some of the UVA women do indeed say that they find that their difference makes them special, this is not the main focus when they talk about the positive

aspects. Instead they stress positive physical consequences regarding contraceptives and menstruation. While they would like to feel what it is like to menstruate or be pregnant ([self-reference removed]), they stress that it is nice not having to care about menstruation and unwanted pregnancies. Below Michelle describes the absence of menstruation in terms of relief.

Int: And if ... I don't know, but I'm just thinking that when others, when your friends talk about the pill and periods and whatever (*Michelle:* Yeah...), how ... — do you remember something of that, what it felt like?

M: You know, I ... in some way I kind of feel it's pretty nice not having a period (*Int:* Mmm). You know [laughs] (*Int:* Mmm?), if you're allowed to say so, I think it's kind of a relief, in that sense. Eee ... not having all that ... and not having to be on the pill and that — yeah that's really nice! (*Int:* Mmm) Kind of, I feel right now — and that's what I felt before too, I'd say — that it's pretty nice.

Michelle illustrates that the positive consequences not mainly concern the ways in which differences can be used in interaction with others, but practical benefits. Yet although Michelle describes the absence as “pretty nice”, she also points out the potential controversial aspect of interpreting menstruation in this way. This is indicated when Michelle laughingly wonders “if you're allowed to say so”, thus implying that menstruation is something one ‘should’ want and ‘should’ find significant. The socio-cultural norms that the remark reflects are more explicitly spelled out by Maya. In her view, the uterus is an important part of being a woman, because it is required to experience pregnancy and menstruation and “all those things that make you a woman”. While these women tell of the great chock in finding out about the absence and the emotional and physical difficulties that it has resulted in (see also [self-reference removed]) they nevertheless, like the Turner women, emphasize the many ways in which it is possible to become a parent.

In the second strategy, women in both groups are found to underscore the commonality of difference and the positive aspects of their particular difference. While these positive features in the Turner group are related to uniqueness and to becoming more knowledgeable, UVA women frame the benefits in practical terms by focusing on not having to care about periods and contraceptives. By doing so they not only underscore the significance and substantiality of difference (cf. James, 1993), but also manage to distinguish themselves from more ‘ordinary’ others.

The meaning of diagnosis in negotiations of sexed embodiment

In the above, I have examined how the interviewees negotiate sexed embodiment using the differently normal and the normally different strategy. While both strategies are used by both groups, they are nevertheless, as shown above, applied in different ways: the Turner women put greater emphasis on the potential treatment and uniqueness, while the UVA women stress the potential of medical tests and practical benefits. In the following I address how these divergences connect to the women’s different access to a diagnosis, which becomes particularly clear in their descriptions of their possibilities to raise awareness and claim a collective identity.

Not only did the Turner women stress that they had gained more knowledge because of their condition, they also emphasized the importance of raising others’ awareness about bodily variety. Tanja, for example, explains that throughout her life she has been aware that bodies do not always develop as one might expect, and therefore it has been important to her to make others aware of diversity and of her condition. These women describe having explicitly engaged in this task by blogging, organizing lectures and talking to friends about their condition. In these accounts, the meaning accorded to having a label for one’s condition is evident. For example, Tilda explains that it has been good to have an “explanation” for why she “is the way she is”, for example when she once talked about her short stature and her late puberty in class. In her account, a diagnosis facilitates disclosure in that it allows one to put atypical sex development

into words. Teresa also exemplifies the meaning of a diagnosis when stating that it was ‘enormously liberating’ to receive it.

Teresa: Because when I eventually found out what it was, then it felt so nice because then I kind of knew that...well, it’s not me as a person that there’s something wrong with, but it [the atypical sex development] is actually caused by something (*Int:* Mmm) and that I’m not the one causing it (*Int:* Right). And that gave me a lot...it has given me...it made me a lot stronger and increased my self-confidence (*Int:* Mmm), to know what it is.

Int: You mean the diagnosis achieved that?

Teresa: Yes. That’s really important, because I believe it is important (*Int:* Mmm. Mmm...) ‘Cause when you know what it is you can also do something about it.

In Teresa’s case, the diagnosis enabled her to stop blaming herself for her atypical development, and this increased her self-confidence. Moreover, the label made treatment accessible; in Teresa’s words it made it possible to “do something about it”.

Moreover, the Turner women’s access to a diagnosis is made clear when they talk about “us” and “we” with reference to “Turner women”. This may partly be explained by the fact that the majority of these interviewees were recruited through the Swedish Turner Association. Yet the participants who were not active in the association or who were not members also spoke of “Turner women” and positioned themselves as belonging to this group. Several of the interviewees have also been in touch with other women with Turner’s syndrome. Thea, for example, says such encounters have been “wonderful”, it feels as if you belong to a “family” and you recognize a lot in one another.

In these accounts, a diagnosis represents a disclosure resource that enables the women to present their condition as medically manageable when adopting the differently normal strategy. That is, with a medical label comes the possibility of medical intervention. Likewise, access to a diagnosis enables a focus on uniqueness and knowledge when one adopts the normally different strategy. Having a name for your condition makes a shared identity and a sense of belonging available, which in turn allows these women to stress uniqueness rather than deviance in their interactions with others.

The *UVA women* likewise underscore that they have become more aware of bodily variation, but in comparison with the Turner women, they express difficulties when it comes to raising awareness. They stress the sensitive nature of disclosing information about their bodies to others and the silence surrounding such bodies (see also [self reference removed]). Maria explains that she finds it “difficult to place your condition in a context if you don’t have a context to place it in, or if there’s no room for this condition in society”. She would like to “learn something from all this” and help others in the future, but this is hard when “you don’t know anything about others [with the same condition]”.

The majority of the UVA women connect the difficulties they have encountered as regards finding information and other women who share the same symptoms with their lack of a label for the condition. Magdalena describes how she has been “using all different kinds of weird combinations” when Googling and describes what it felt like when she eventually came across some information about MRKH.

And then you just felt “But this is me! This is what it’s got to be!” Because that’s exactly the picture I’ve got of myself (*Int:* Mmm). But I feel, too, that if there’s a name for it, why didn’t they tell me right away? (*Int:* Would you have wanted that?) Yeah ... you know, it would’ve probably made it easier if you felt that “Yeah, but this

is who I am”, kind of. And ... I really don’t know why, but I suppose it would’ve been easier just knowing. That there’s a name. I thought I was kind of the only person in the entire world, that’s pretty much what it felt like, when you were so cut off and you didn’t know anything and nobody said anything. And then suddenly it turns out that there *is* information available (*Int:* Mmm) — a *bit*, anyway. And that there’s a name! (*Int:* Mmm) And ... that in fact it affects one in 5000 — just knowing that, that I’m not all alone!

The consequences of not being able to name your condition and the opportunities that a name creates are highlighted in this example. In particular it reveals the meaning of having a diagnosis in identity formation, as the information made her realize that “this is who I am” and that she is not “the only person in the entire world” who has this. Like Magdalena, many of the UVA women point out that a name allows one to recognize oneself and one’s condition. By signalling that one is not likely to be the only one affected it can provide a collective identity.

In contrast to the Turner women, the UVA women’s accounts highlight the difficulties of not having a label for one’s condition. The challenges that the lack of a name results in are reflected in their employment of the two strategies. First, with limited information and support available, knowledge about treatment options and the expected results of treatment was not accessible for these women. In light of this, their focus on medical tests rather than medical treatment makes sense. Treatment is not presented as having the potential to create a ‘normal’ body and a distinguishable sex, but instead the focus is on how to confirm one’s sex through medical tests. Second, this seems to imply greater efforts than required in the Turner women’s negotiations, as it involved re-interpreting the categorization of female bodies and re-evaluating which bodily features makes one feel like a woman.

Moreover, the difficulties that the UVA women associate with not having a name for their condition offer insights into their use of the normally different strategy. Without the resources that a name is said to make available, it is not surprising that they did not focus on their interactions with others to the same extent as the Turner women did when using this strategy. Yet the practical benefits, i.e. not having to use contraceptives or care about menstruation, could still be drawn on to claim that variation is normal and that their symptoms, in some respects, are positive.

Together the women's accounts concerning collective identities and raising awareness reveal that a diagnosis represents a resource in the women's negotiations of sexed embodiment as well as in disclosure and when seeking support. This confirms that a diagnosis is not to be understood only as a source of stigmatization and medicalization, but may also function as a starting point for sense-making (Jutel & Nettleton, 2011), and that it, as such, can be welcomed and requested by affected individuals (Fleischman, 1999; Gillman et al., 2000).

Concluding discussion

While medicine in general and diagnosis in particular may have both stigmatizing and regulating effects (Goffman, 1990; Jutel & Nettleton, 2011; Lupton, 1994), the present analysis shows how individuals can make use of the "language of medicine" (Mishler cited in Brown, 2000, p. 82) instead of being restricted by it. It underscores that the value of a diagnosis lies not only in its prognostic capacity (Brown, 2000) and confirms that a diagnosis may facilitate identification, make support networks accessible (Lillrank, 2003; Reid, Ewan, & Lowy, 1991; Wray, Markovic, & Manderson, 2007) and allow affected persons to tell their stories (Fleischman, 1999). However, the above analysis moreover provides insights into the complex role of diagnosis in negotiations of sexed embodiment.). It reveals that access to diagnosis corresponds to the ways in which the women present themselves as "differently normal" and "normally different" while also adding

knowledge from two groups of women whose conditions and experiences have received little previous.

Furthermore, the analysis shows that the women when employing the two strategies neither dismiss the two-sex system nor embrace the categories of intersex/DSD. Rather, they attempt to expand norms regarding ‘normal’ female bodies and organs by focusing on what they *do* have. For example, the Turner women emphasize menstruation and de-emphasize chromosomes, while the UVA women emphasize chromosomes and more often de-emphasize menstruation. This stands in contrast to the hormonal hierarchy outlined by Elson (2003), in which ovaries are placed at the top and thus given greater significance than other ‘typically’ female features for distinguishing sexed embodiment. By using the “different normal” and “normally different” strategy, the women in the present study are shown to instead re-interpret and re-define notions of such hierarchies in light of their specific sexed embodiment.

Finally, In her analysis of normalization processes, Winance (2007, p. 634) wonders how we can, by working on norms

“...build a society which includes different people whilst at the same time ‘normalising’ them?’ or, to put it another way, how can we build a society made of people who are ‘normally different’ or ‘differently normal’.”

In correspondence to Winance (2007) the above analysis shows how two groups of women, whose bodies are considered ‘atypical’, attempt to make sense of and space for their sexed embodiment by using a “differently normal” and “normally different” strategy. However, it also reveals that this involves both alignment with and work on norms. In the differently normal strategy, the Turner women aligned with norms about the role of menstruation in female embodiment, whereas the UVA women rather worked on such norms when they re-evaluated and de-emphasized the significance of having a uterus and vagina. In the normally different strategy, both groups challenged the notion of ‘normality’ as an objective category by

underscoring the normalcy of variety. The Turner women's emphasis on their uniqueness, in particular, could be read as work on such notions of normality. While the UVA women also worked on norms concerning the value of menstruation when they emphasized the practical benefits of their absent organs, they concurrently aligned with the same as they also signalled the importance of menstruation to female embodiment. Hence, the above analysis reveals an interplay between alignments with and work on norms of sexed embodiment and categorizations of what is required to "feel like a woman". In this interplay it becomes possible for the women to present themselves as "differently normal" and "normally different" and thus re-evaluate understandings of the collective in which they are included.

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