



## “Differently normal” and “normally different”: Negotiations of female embodiment in women’s accounts of ‘atypical’ sex development



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### 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 female 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 shows 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 female 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.

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### 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 questioned 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; Guntram, 2013; Holt & Slade, 2003).

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 (see also Guntram, 2013; Zeiler & Guntram, 2014). The purpose of this article is more specifically to explore the interviewees’ negotiations of female embodiment. How is normality construed in such negotiations? And, how may 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 female embodiment and construe normality: the “differently normal” and the “normally different” strategy. In the former, the women present their bodies

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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 which 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 (cf. Winance, 2007) and the complex role of diagnosis in the women's negotiations of female embodiment.

Out of the 23 interviewees who took part, 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. Seven of them refer to the Mayer–Rokitansky–Küster–Hauser (MRKH) syndrome, yet 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 "agenesis" group. Although both Turner's syndrome and MRKH commonly are categorized as DSD or "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). However, in both strands 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 to my analysis. Furthermore, in the light of this I do not view 'normal' and '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).

### Data and methods

#### Interviewees and interviews

The overall aim of the project, 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 to 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 agenesis 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. Seven 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 characteristics 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),

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