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'You have all those emotions inside that you cannot show because of what they will cause': Disclosing the absence of one's uterus and vagina

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ABSTRACT

This article examines young women's experiences of telling others that they have no uterus and no, or a so-called small, vagina – a condition labelled 'congenital absence of uterus and vagina', which falls within the larger category of 'atypical' sex development. Our aim is to investigate how affective dissonances such as fear and frustration are expressed in young women's narratives about letting others know about their 'atypical' sex development, and how these women narrate desired steps to recognition. By drawing on feminist writings on the performativity of affects or emotions, we examine what affective dissonances accomplish within three identified narratives: how affective dissonances may contribute to the women's positioning of themselves vis-à-vis other individuals and how affective dissonances can imply a strengthening and/or questioning of norms about female embodiment and heterosexuality. This allows us to tease out how routes for questioning of these norms become available through the three narratives that together form a storyline of coming out about a congenital absence of a uterus and vagina in the Swedish context. Furthermore, by demonstrating how others' responses shape the women – their understandings of their own bodies, their envisaged future disclosures and their relations – our analysis highlights the multifaceted intersubjective and in other ways relational, affective and temporal dimensions of coming out about one's 'atypical' sex development.

1. Introduction

Sweden has been 'hailed as a "global leader"' in the area of sex education (Sherlock, 2012:338), and openness and tolerance have been described as characteristic features of Swedish discourses on sexuality in general and teenage sexuality in particular (Edgardh, 2002; Forsberg, 2001). Scholars have also qualified such descriptions: while openness characterises these discourses, they rest, predominantly, on heteronormative perspectives and assumptions (Ambjörnsson, 2005; Martinsson and Esaiasson, 2007; Röndahl et al., 2006). Furthermore, even though openness and tolerance characterise some discourses on (hetero) sexuality in Sweden, this need not imply that openness and tolerance also mark talk about sexed bodily variations such as 'atypical' sex development, also labelled 'disorders of sex development' (DSD) or 'intersex'.

This article offers an analysis of Swedish women's narratives about letting others know about their 'atypical' sex development, and specifically about their congenital absence of a uterus and vagina. What it is like to tell others about one's 'atypical' sex development and its meaning can depend on prevailing norms concerning female embodiment and heterosexuality within one's sociocultural context, and on one's self-understanding, including expectations and dreams about the future. Such norms and expectations are brought to the fore in this article, in which we consider women's accounts of coming out as young heterosexual women with 'atypical' sex development and of connecting with others. In doing so, we make use of feminist writings on the performativity of affects or emotions, that is, what affects or emotions *do* (Ahmed, 2004; Hemmings, 2012), and we specifically draw on Clare Hemmings' (2012) notion of *affective dissonances,* which include anger, frustration, or desire for a connection that is not there.

Our aim is to investigate how affective dissonances such as fear and frustration are expressed in the women's narratives about

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letting partners, family, friends, and individuals with similar experiences know about their condition, and how they describe how they would want to become recognized as unique individuals. We explore what the expressed affective dissonances accomplish within the narratives: how they contribute to the women's positioning of themselves vis-à-vis other individuals whom they talk about, and how the affective dissonances can imply a strengthening and/or questioning of norms about female embodiment and heterosexuality.

The article contributes to the larger field of research on coming out (see, e.g, Plummer, 1995; Ridge and Ziebland, 2012), by discussing the specificity of coming out about a sex development which differs from that which the women themselves had expected. Furthermore, we examine a variety of emotional responses that the women describe having themselves encountered or experienced, and explore what these narrations accomplish in terms of resistance and questioning. In doing so, it becomes possible to take into consideration the women's potential resentment towards the idea of coming out, and to acknowledge 'outing' as being not confined to a single event in time but an ongoing process (Orne, 2011).

1.1. The case of Sweden: contextualizing the interviewees' narratives

The bodily and sexual changes that most often occur in female bodies in adolescence such as menstruation, transformations of figure and appearance and new dimensions and intensity of sexual desires are often associated with and shaped by numerous social connotations and images of 'womanhood' (Flaake, 2005). Adolescence is thus typically pictured as a period of transition marked by negotiation (Flaake, 2005). The embodied shifts of adolescence are also often confined to the private, personal, and individual realm, and they may involve both the pleasure of a new status and feelings of loss and ambiguity (Oinas, 2001).

The secrecy, intimacy, and privacy that have been found to signify female adolescence also recur in Swedish studies (Brantelid et al., 2013; Rembeck and Hermansson, 2008). At the same time, openness and tolerance have been thought to characterise Swedish discourses on sexuality, and particularly on teenage sexuality (Forsberg, 2001; Sherlock, 2012). The Kinsey Institute has described Swedes as 'having a liberal and permissive attitude towards sexual relations and intercourse' (Francoeur and Noonan, 2004:985). Similarly, a country report from the Alan Guttmacher Institute states that a 'notably open attitude to sexual matters is a feature of Swedish society' and that sexuality is perceived as 'positive, a source of pleasure and togetherness, so that talking about it is both proper and important' (Danielsson et al., 2001:17).

This brings to light how openness may be found in some areas and not others: openness, the same report states, mainly concerns the 'explicit presentation of facts about the appearance and functions of the genital organs, psychosexual development, sexual intercourse, masturbation, pregnancy, infertility, contraceptives and STDs' (Danielsson et al., 2001:17). 'Atypical' sex development is not included in this list of topics.

1.2. Categorizations and critical examinations

The congenital absence of a uterus and vagina falls within the medical umbrella term of atypical sex development. Within medicine, atypical sex development has also been labelled 'disorders of sex development' (DSD), which is defined as 'congenital conditions in which development of chromosomal, gonadal, or anatomic sex is atypical' (Lee et al., 2006:488). For some, the DSD term has been understood to contribute to the normalisation of these conditions making them conditions like any other (Feder, 2009). Others, however, argue for other ways to make use of the DSD acronym that underline difference rather than disorder, such as divergence of sex development (Reis, 2007), divergences of sex development (Schweizer et al., 2014), diverse sex development (Liao and Simmonds, 2014) and differences of sex development (Tamar-Mattis et al., 2014). Still others prefer the term intersex (Holmes, 2011), and the terminology debate is ongoing (Liao and Roen, 2014).

Academic examinations of conditions of DSD or intersex with a Swedish angle are limited, in particular examinations focusing on individuals' lived experiences (see, however, Alm, 2010; Guntram, 2013b; Zeiler and Guntram, 2014; Lundberg et al., 2016). Internationally, however, scholars have investigated parents' experiences of having a child with a condition categorized as DSD or intersex, as well as lived experiences of individuals with such conditions, and have critically examined the disciplining effects of medical treatment (Guntram, 2013a; Holmes, 2008; Karkazis, 2008; Kessler, 1998; Roen, 2008; Zeiler and Wickström, 2009).

1.3. Emotions, affective dissonances, and critique of norms

A large number of scholars have examined affects or emotions (e.g. Massumi, 2002; Sedgwick, 2003; Wetherell, 2012), some focusing especially on their performativity – what affects and emotions *do* (Ahmed, 2004; Hemmings, 2012). In this article, we draw on research in which individuals are understood as being shaped and reshaped by, and as shaping others in, emotional encounters – when emotions are expressed between the self and others. Here, emotions are understood to work performatively in interactions between bodily subjects, through body language and speech, as well as in written texts. Such performative work is discussed, for example, in Sara Ahmed's (2004:93) examination of disgust, where she shows how the utterance 'That's disgusting!' relies on previous norms and conventions of speech while concurrently generating the disgusting object or event that it names. To call something or someone disgusting, or to respond with an utterance such as 'yuck', may imply construing or positioning that thing or person as disgusting. Consequently, expressed emotions may result in differentiations between bodily subjects that make some stand out as disgusting, some as loveable, and others as fearful – to give a few examples. Through such differentiations, emotions expressed between subjects can make individuals stand out as legitimate, or illegitimate, objects of disgust, love, or fear (Ahmed, 2004:191), and some lives as more or less liveable than others (Butler, 2004). An examination of how the self and others are talked about and of how subjects, in narratives, express emotions (to certain audiences) and position themselves through their accounts of others' emotions, can shed light upon what emotions can accomplish within narratives.

When Hemmings (2012:147) discusses emotions, she proposes that the concept of affective solidarity can help in understanding modes of engagement with others and with one's surroundings that start from *affective dissonances* – such as frustration, anger, and the desire for a connection that is not yet there. Experiences of dissonance may cause an individual to become oriented towards others who narrate the world differently, who suggest change, or who value 'different ways of knowing and different knowledges' (Hemmings, 2012:157). In light of this, affective dissonances, as well as the affective solidarity that might result from them, can be understood as a basis for connecting to others which is not founded on identity or group characteristics or on presumptions about how the other feels, but on feeling that something is 'amiss in how one is recognized, feeling an ill fit with social descriptions, feeling undervalued, feeling that same sense in considering others' (Hemmings, 2012:150).