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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.

## **Keywords**

Sweden; emotions; intersex; disorder of sex development (DSD); uterus; vagina; coming out; affective dissonance

## **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

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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, 2004; Martinsson & Esaiasson, 2007; Rödahl, Innala & Carlsson, 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 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

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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 & 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).

### **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, Nilvér & Alehagen, 2013; Rembeck & 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 & Noonan, 2004:985). Similarly, a country report from the Alan

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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, Rogala & Sundström, 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.

### **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, Houk, Ahmed & Hughes, 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, Brunner, Handford, & Richter-Appelt, 2014), diverse sex development (Liao & Simmonds, 2014) and differences of sex development (Tamar-Mattis, Baratz, Baratz-Dalke, & Karkazis, 2014). Still others prefer the term intersex (Holmes 2011), and the terminology debate is ongoing (Liao & 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 & Guntram, 2014; Lundberg, Roen, Hirschberg, & Frisén, available online). Internationally, however, scholars have investigated parents' experiences of having a child

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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).

### **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

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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).

Affective dissonances do not, however, automatically involve a move to affective solidarity. For Hemmings (2012:157), such a move requires that someone deem that which caused the dissonances (be it life conditions, specific situations, constraining norms or values) to be unacceptable. This may not be easy. If we come to live according to certain socioculturally shared norms or values on a taken-for-granted level of existence, we may enact them without even noting it. A critique of the norms and values requires that we first become reflectively aware of them – that we 'excorporate' them from our taken-for-granted bodily way of being – and this can be painful (Zeiler, 2013; Zeiler & Guntram, 2014). For Butler (2004:3), a critical relation to norms and values requires a 'capacity, invariably collective, to articulate an alternative minority version of norms or ideals', which enables the subject to act. This critique – an interrogation of the terms by which life is constrained – does not necessarily involve a celebration of differences, as such, but

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rather an establishment of different modes of living and of more 'inclusive conditions for sheltering and maintaining life' (Butler, 2004:4).

## **Research design and materials**

In this article we deploy a narrative approach to analyse in-depth interviews with women with a congenital absence of a uterus and vagina, in part or in its entirety. Narratives are, in our view, *means of human sense-making*, through which the narrator recaptures experiences and events in a manner which is – at least somewhat – sequential, coherent, and meaningful to the narrator (Squire 2008). We furthermore view narratives as *performative* in the sense that they are enacted in a specific manner in relation to those listening, and shaped in relation to the larger cultural and societal contexts within which they are told (Langellier & Peterson, 2004).

The design of the study followed Swedish research ethics guidelines (Hermerén 2011) and was approved by the regional ethics committee. Owing to the rarity of the condition and the lack of patient organizations and forums in Sweden, participant selection was carried out using convenience sampling. In total, ten interviewees were recruited through specialist clinics, websites, and blogs. All were informed about the aim and content of the interviews and that participants would not be given any compensation. They all gave their informed consent to participate.

All interviews were conducted in Swedish by the first author. They were on average 60 minutes long and followed an interview guide with general themes and open-ended questions. Primarily, the themes and questions covered the interviewees' encounters with medical professionals and interactions with family, friends, and partners, as well as occasions when the interviewees had had to pay attention to the specificity of their 'atypical' sex development. All interviews were recorded, and transcribed verbatim, and names were replaced by pseudonyms.

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Through our narrative approach, we explored how the interviewees, when narrating past, present, or imagined events or experiences that included themselves and others, presented and positioned themselves in relation to others (Riessman 2008). The analytic process was divided into three phases. In the first phase (conducted by the first author), transcripts were read several times and interesting, surprising and unexpected passages were highlighted. The focus was also on identifying narratives and distinguishing them from one another. To do so, recurrent patterns in the structure and content of the interviewees' attempts to order events and experiences in a sequential and coherent manner were highlighted and labelled. However, this does not mean that we viewed narratives as necessarily neatly presented, with a distinct beginning, middle, and end. Rather, we found the narratives in our material to be scattered across the interviews and that topics often intertwined. In order to determine where the narratives began and ended, specific attention was paid to the ways in which one narrative could be disrupted by another and then be picked up again later in the interview.

In the second phase (conducted by both authors), a basic coding was conducted and compiled into a 'list of contents' for each interview. By comparing the lists across interviews we identified similarities and incongruences in the data in terms of how the interviewees narrated occasions when letting others know about their condition and their encounters with other individuals with similar conditions, or lack thereof. Finally, in the third phase we focused particularly on what the interviewees' expressions of fear, frustration, and desire for connection with specific others accomplished in their narratives, in terms of differentiating between subjects and of aligning the interviewees with and separating them from others.

The interviewees were 20–26 years old at the time of the interview and were all Swedish. They all presented themselves as female although such categorization stood out as a topic requiring re-negotiation (see Zeiler & Guntram, 2014). When specifically asked about the terms DSD or

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intersex, none of the interviewees said that these were terms they used to describe their condition or themselves. Most of them said that they had not even heard of these terms, and they did not associate their occasional consciousness-raising activities (through blogs, etc.) with the intersex activist movement.

It should also be noted that while all interviewees reported having had medical examinations confirming that they had no uterus and no, or only a 'small', vagina, seven of them used the label Mayer–Rokitansky–Küster–Hauser (MRKH) syndrome, which occurs in about 1/5000 women (Edmonds, 2003), when describing their situation. The other three had no specific name for their condition.

In the interviews, the women most often talked about heterosexual relationships and sexual practices and all of them talked about having had, having, or envisaging having, male partners. In order to increase the size of the vagina and enable penetration, seven of the interviewees had had surgery and postoperative dilation, two had been advised to only use dilators, and one had been offered surgery but had turned the offer down and was not offered dilators. All of them had also been told that penetrative intercourse would dilate the vagina. Nine of them had or had had a boyfriend, and eight of the total ten said that they had had penile–vaginal penetration, but most of them said that they had found it physically and emotionally difficult to have penile–vaginal intercourse. Only one interviewee explicitly touched upon non-heterosexual relations and sexual practices. However, a heterosexual orientation or experiences of specific sexual practices were not specified as prerequisites in the selection of interviewees (see also Guntram, 2014).

## **Results**

### **The interviewees' coming out storyline**

The bodily changes that are often said to mark the transition from 'girlhood' to 'womanhood' (Flaake, 2005; Oinas, 2001) were recurrently drawn upon as the interviewees told of their

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experiences. They did not, however, reference these bodily changes as signs of such transition, but described how the absence of particular changes made them realize that their bodies were not developing in the expected manner. When describing what it was like to find out about their 'atypical' sex development, the interviewees talked about shock, disbelief, and distress. They emphasised that they had tried to imagine the worst, and yet, had never expected anything like this. Moreover, the majority of the interviewees had not talked at length about their experiences before taking part in the interview, but most of them had mentioned their condition, at least briefly, to a boyfriend, some close friends and/or close family. Sometimes they emphasised that there was no reason to tell others and that their bodies were nobody else's business, which could be interpreted as a resistance to discourses in which 'coming out' is seen as positive and productive. However, most of them said that their reluctance towards disclosure was associated with the difficulty of explaining something to others that they initially could hardly explain to themselves. Maria, for example, said that she would describe her condition as a great taboo. This, she explained, would make it very difficult when trying to explain it to someone else, because

...it is such an obvious thing that one should have a period, especially when you're in school, that that you're supposed to be in a certain way and that you're supposed to develop in a certain manner.

Against this background, we identified three narratives, which together form the women's wider coming out storyline.

### **A narrative about fear of rejection**

The first narrative tells of the women's fear of being rejected for not being seen as 'real' women by former, present, and imagined male partners, and this in light of specific norms about hetero-relationships and female embodiment. In this narrative, the women described themselves as dreading rejection and, as we will show later, as taking action to avoid it.

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Elsa, who had not yet had a boyfriend, exemplified this fear, saying that she was afraid that a future partner would think there was something 'wrong' with her – when she thought about the future she wondered 'whether anyone will ever want me'. As another example, Patricia said that she had thought about what characterises a 'real' woman. She said that people often reply 'mothers' if asked what comes to mind when they think about women, and then continued sarcastically, 'All due respect to chromosomes, but "a woman's task is to give birth to babies", that's what you've heard'. First and foremost, Patricia said, when it comes to telling a partner

...you're afraid that the person won't accept all of it or think that you're not a real girl. Perhaps be afraid that the person they're dating is someone, kind of. . . yeah, an androgynous person or something like that.

She continued on, explaining,

What if we take it [the relationship] to another level and I have to tell? . . . and I'll be dumped. That's the biggest fear, I should think, that someone would say, "Oh well, in that case you're not for me."

While Patricia underscored the significance of the uterus in others' understandings of 'real' women, Anna, another interviewee, implicitly signalled the specific significance of the vagina when she explained her decision to have vaginal surgery, by saying that it was 'not possible to have a boyfriend in the long run without, like having sex [here understood as penile–vaginal penetration] at all'. That is, without a vagina and a uterus, a relationship, which the interviewees understood as a heterosexual one, was considered impossible.

A deeper understanding of the association between uteri and vaginas and 'real' women found in the first narrative can be gained through studies on Swedish girls' construction of gender (Ambjörnsson, 2004; Bengs, 2000). To be considered mature and gain status in the girl community, in the context studied by Ambjörnsson (2004:117), one should have a 'just right' [in Swedish *lagom*] (hetero-) relationship and (hetero-) sex, meaning that one should not have too much sexual experience with too many partners, but equally should not be totally without sexual experience or

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a current or previous boyfriend. Applied to the first narrative, such a 'just right' heterosexual relationship seems not only to imply certain sexual practices but certain bodies; it requires a 'real' woman. In contrast to the focus on looks and appearance in previous research (Ambjörnsson, 2004; Bengs, 2000), other bodily characteristics such as the ability to have 'sex', here understood in terms of penile–vaginal intercourse, and to become pregnant later in life, stand out as distinctive of 'real' women in this narrative.

In relation to the value accorded to 'just right' heterosexual relationships, the fear of not being a 'real' woman can be seen in a new light. To not be a 'real' woman is not simply a matter of the absence of specific organs; it is about relationality. If one does not qualify as a 'real' woman in this particular sense, one may be dumped, and this belief can make the women disclose rather than conceal information about their bodies. The women all agreed that complete concealment was not an option. Elsa, for example, talked about being afraid that she would be 'luring someone into a relationship', if she did not tell. Ester, similarly, described wondering whether it was better to 'wait until you know it's serious and then be more hurt when he leaves you?' – adding, 'that's what you think will happen, that he'll leave you'. Hence, one 'should' tell before getting too involved, since worse than being rejected early on seems to be the prospect of being rejected later, when one is emotionally invested.

Ahmed suggested, drawing on Martin Heidegger, that fear involves anticipation of a future injury or pain that 'can, and yet in the end it may not' happen (Heidegger, quoted in Ahmed, 2004:65), and because of this, fear 'projects us from the present into a future' (Ahmed, 2004:65). Moreover, not encountering that which is feared does not necessarily mean that the fear is diminished or overcome. Rather, because the fearful can be *everywhere* but is not *here* at this moment, the self may seek to withdraw from the world and preserve the present (Ahmed, 2004). This focus on the temporality of fear is useful to shed further light on the women's fear of rejection.

None of the women talked about having experienced the rejection that they feared, yet all of them said they were afraid that they *would*. In this sense, the women's fear was not narrated as having been overcome. Still, and contrary to Ahmed's suggestion that fear may result in attempts to preserve the present, our interviewees' fear of what might happen in the future did not seem to make them want to preserve a present in which heterosexual relationships and sexual practices were avoided. To do so would not only imply living in a manner that went against cultural norms, such as those of 'just right' hetero-relationships, but was also counter to their wishes and hopes for the future, as expressed in the interviews. Neither, however, did the women seem to want to keep information about their bodies concealed. Instead – and especially, because, as they explained, one cannot go on too long without telling a potential partner – the women's considerations of disclosure involved confronting their fear. The even greater pain that would follow if they were to be rejected later on seemed to prompt them to face the potential pain caused by rejection through early disclosure. In other words, when being projected into the future, they sought to disclose in the present.

In the first narrative, fear is presented as calling for action. To the extent that it prompts disclosure this fear functions to position the women as individuals who are not, as Elsa poignantly put it, 'luring' anyone into a relationship. On the one hand, this repositioning can be interpreted as an 'experience of discomfort' (Hemmings, 2012:158), where remaining in an undisclosed present is considered undesirable. On the other, the discomfort that the repositioning involves is a future one that the women envisaged encountering if they concealed their condition.

### **A narrative about frustration over pity**

The second narrative revolves around the women's frustration over others' pity. Mainly it concerns their interactions with friends and reveals how others' reactions to their bodies involve a sometimes explicit positioning of their bodies and lives as 'unliveable'. Without disregarding the

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hardships the women have been through, this narrative concerns the ways in which they do *not* want others to respond to them. Jenny, for example, who had decided to only tell her closest family about her condition, explained that although she did not feel that her condition needed to be kept secret, at the same time she said that

Everyone doesn't need to know exactly everything about me ...kind of...the...more intimate...To me it felt important in some way to kind of...not be seen as different in that particular way.

The majority of the interviewees described others' pity at length, repeatedly emphasising that they did not want to be pitied. Veronica, for example, said that she had not told any of her friends just because 'the worst thing would be if they started to feel sorry for me', and because she was afraid that 'they'd make too big a deal out of it'. Anna more specifically talked about her experiences of family members and friends bursting into tears when being told about her uterus and vagina. At first, before she had told anyone, she said, she just wanted to shout out loud, 'Feel sorry for me! Comfort me!' But then, she had realized that 'they shouldn't feel sorry for me'. At that point, she did not feel like telling people any longer, because she 'noticed how others reacted and that they all just broke down'. The reluctance about disclosure in the light of others' reactions that Veronica and Anna described could indicate a general questioning of the idea that coming out means catharsis (cf. Preves, 2003).

However, the second narrative more specifically concerns how such emotional reactions position the women as *pitiable* and their lives as even being *unliveable*. The severity of the absence of a uterus and vagina, as gauged through reactions from friends and family, was particularly clear when Elsa told of the response she received from a classmate. When hearing that Elsa did not have a uterus or vagina, the girl's immediate reply was that if she herself had such a condition she would not want to live anymore. This was very difficult to hear, Elsa said. Similarly, Joanna explained that sometimes, when asked if she was born with a vagina, she said yes, precisely because

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of what others' responses told her about her life. She explained that you do not 'kind of want them to feel sorry for you because you can't have sex. It's such a big deal. . . they wouldn't be able to live without it'. Here, others' envisaged responses were avoided because of their performativity – how they positioned lives and bodies like the interviewees' as unliveable (see Butler, 2004).

These responses, predominantly from female friends, can also be read as being bound up with taken-for-granted assumptions about the importance of being able to experience certain heterosexual practices. If so, heteronormative presumptions about the normality of heterosexuality, specific heterosexual practices, and the presence of specific body parts in bodies assigned a female sex informs what qualify as 'appropriate' responses to the women's disclosure – such as saying 'Poor you! Oh, I'm so sorry for you!' (see also Holmes 2008). Furthermore, emotional responses such as pity that may signal the failure of the women's bodies to live up to the 'ideals' of female embodiment and heterosexual relationships, 'confirm the ideals in the first place' (Ahmed, 2004:109) and thus reinforce norms that stipulate which lives *do* count as liveable.

However, another excerpt from Joanna's interview brings out another performative dimension of such emotional responses in that it exemplifies how the women strive to resist being positioned as pitiable. Here, Joanna talks about what happened when at a party a female friend asked why she was playing so hard to get with men.

And then I said I found it a bit hard with blokes because I was born without a womb and that. . . And then I remember she just said, 'Ohhh, no! Poor you!!!' That's what makes it so hard to tell, because you just hear 'Oh, poor you!' – and you just go, 'No, it's not poor me!', kind of. Then you just kind of want to be on the same level as all other girls, kind of. You don't want to hear, 'But it is poor you, you're not like everyone else.'

In this excerpt, Joanna underscored that she finds comments such as 'Poor you!' difficult because of what they do to her as a subject – they position her as someone to feel sorry for, someone who is not on the same level as other girls. In contrast, Joanna emphasised that she does not feel sorry

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for herself, but that she seeks to present herself having a life that does not call for others' pity. The performative dimension of her friend's pity thus concerned how Joanna, when narrating precisely this pity, could reposition herself – for example, by underscoring that she wants to be on the same level as all other girls – and from this position request recognition and equality.

In this manner, the women's frustration with specific emotional reactions to their bodies formed an affective dissonance as they narrated it, from which the present circumstances could be questioned. In their narrations they opposed the view that their lives, in light of others' emotional reactions, were positioned as being 'pitiable' and countered the position accorded to them by others by claiming their lives were 'liveable'.

### **A narrative about accomplishing recognition**

In contrast to the focus on undesirable responses in the first and second narratives, the third narrative addresses desired ones. Specifically, it concerns how responses from close friends or other women who share their condition implied or could imply recognition of the women as individuals who could engage with others, just as before the disclosure, or recognition of their specific embodiment.

When talking about relations with close friends, responses in focus were those which enabled the women not to envisage themselves being rejected by male partners, as was described in the first narrative, but instead to position themselves as potential girlfriends. An excerpt in which Jessica talks about her friends coming to visit after she had found out about her condition illustrates how this was accomplished. Her friends had brought candy and spent the evening in Jessica's room, chatting and watching TV.

First they wanted to know what had happened, of course. And then we just talked as usual and I remember texting this guy [that she had just met the weekend before]. He was called Jim. And then I said, 'God, I'll never be able to go on seeing him, it won't work!' But then they [the friends]

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just said, 'Of course you can!' We talked a lot about those sorts of things, you know, and it was a bit like it always had been and that was nice.

The example indicates that what empowered Jessica in this interaction was the way in which her friends made it feel 'a bit like it always had been'. Jessica succeeded in stressing that news about the absence of uterus and vagina did not matter so much in this interaction – they still 'talked as usual'. Furthermore, as Jessica described her friends' objections when she raised concerns about Jim, she also positioned herself as someone who was still approachable as a potential girlfriend, regardless of the absent uterus and vagina. The absence of strong emotional expressions – of, for example, sadness or pity – on the part of others, and her friends' strong objections towards Jessica's doubts about continuing her relationship with Jim, can be seen to enable Jessica to express, in her narration, that something is amiss in the belief that she could not continue to date Jim (cf. Hemmings, 2012).

A similar example from Patricia's interview sheds further light upon how responses from friends can enable the women to question the absence of a uterus and vagina as a reason for not being viewed as 'real' women – and because of this, being rejected. While Patricia said that she 'of course is really worried' that men will not accept her as a woman because of her condition, she also described how these really good friends of hers said 'that if that was to happen he's not worth it' and 'if he's really interested he should accept what he's given'. She also said that they asked her what she would do if she were in the same situation as him. And, she added, 'you've got to think like this: "If blokes reason the same way I do, they'll accept it."' In Patricia's description, her friends' comments expressed recognition of her as someone worth having and through them she was enabled to position herself as someone who rejects those who disagree. Moreover, and in contrast to those responses filled with pity, these responses can be read as enabling a repositioning of male partners in that they signal that it is not just possible but even plausible that male partners,

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if they think like Patricia, would accept her condition and could recognize women like her as potential girlfriends.

Desired responses from female friends are hence those that do not communicate grief and shock – for instance, through tears and pregnant silences – or pity. Instead, the desired responses enable the women to position themselves as *rejecting* rather than *rejectable*, and their lives as *liveable* rather than *pitiabile*. Thus, desired responses can also be seen to provide vantage points for affective solidarity. That is, for solidarity through which individuals connect with each other, not on the basis of shared identities, group characteristics, or presumptions about how the other feels, but on the basis of feeling that something is 'amiss' and postulating that, for instance, certain life conditions, specific situations, and constraining norms or values are unacceptable (see Hemmings, 2012).

The interviewees also described another kind of desired response, whereby their specific embodiment is recognized as unique and as female. Joanna and Maria briefly talked about the importance of forming connections with others who share experiences of having a body which does not align with norms about female embodiment, such as those of transsexual individuals or 'individuals with intersex conditions'. However, all interviewees explicitly stressed that they longed for opportunities to meet other women who had neither a uterus nor a vagina, and who would know what it was *really* like, or they would at least like to have access to others' stories about such experiences.

Linda, for example, said she thought it would have been good to talk to someone who had gone through the same vaginal dilation treatment 'because it's difficult to imagine what it would be like. A broken leg, something more tangible, is something you can think about – you can reflect on those things, but this was hard to imagine'. Likewise, Ester said that she looked for information

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about her condition on the Internet because she wanted to 'know that I'm not completely alone' and to find others 'who have the same opinions as I do, and who live the same life as I do, maybe'.

As the women narrated this desire for specific connections with 'similar' others, they underscored that such connections potentially could enable them to envisage what life would be like without a uterus and a vagina. They also pointed to the value of being part of a collective in which others, as Ester put it, hold the same opinions as she does and perhaps live the same life as she. When the women talked about such connections, which they said they desired but which most of them had yet not experienced, it was not so much a recognition of them as potential girlfriends or 'would-be lovers' (Ahmed, 2004:145) in relation to male partners that was accomplished. Instead, what they accomplished as they narrated their desire for forming such collectives was to envisage future opportunities to imagine 'different modes of living' (Butler, 2004:4) and recognition of their specific sexed embodiment.

## **Concluding comments**

Through the three identified narratives, the above analysis has detailed what it can be like to 'come out' as a young Swedish heterosexual woman with a congenital absence of a uterus and vagina, when being unaware of, or unwilling to use, labels such as intersex or DSD. Furthermore, none of our interviewees presented themselves as a member of the intersex community or any other community based on shared experiences of 'atypical' sex development. For this reason, we cannot draw conclusions about the significance of such communities for disclosure, affirmation and recognition.

Instead, our analysis focuses on the accomplishments of affective dissonances: how disclosure may be prompted by fear of rejection while at other times also allowing for an implicit critique of norms despite limited access to collectives of individuals who share similar experiences.

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By teasing out 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 these women's outing.

The three identified narratives demonstrate disclosures which are not associated with catharsis (c.f. Preves, 2003) but that rather can be prompted by fear of rejection. The analysis shows how this fear may be aggravated by previously experienced or imagined responses of pity from others insofar as such responses express cultural norms about female embodiment and heterosexuality. The narratives are thus not temporally ordered within a neat storyline, but are concurrent, constantly feeding into and overlapping one another. In line with contemporary conceptualizations of coming out (e.g. Orne, 2011), we see this interplay between the narratives as indicating that the interviewees' outing represent neither a developmental trajectory nor an event confined to a single moment in time. Instead the narratives express, as put by Orne (2011:698), a complex, continual and contextual process of identity management in which the narrator is "never fully 'out' or 'closeted'".

Our analysis enriches explorations of such processes by showing that attention to affective dissonances in narrations of disclosure can bring out how experienced, or envisaged, emotional responses from others might prompt or obstruct disclosure and bring to light what experiences of affective dissonance may accomplish when narrated. It shows how the women, especially when narrating their frustration over others' pity, sought to reject the positions that such responses accorded to them. It also shows how the women, when narrating specific desired responses, told of how others helped them to challenge assumptions about female embodiment or how others could help them recognize the specificity of their embodiment. Such accomplishments were particularly noteworthy in the last narrative about achieving recognition, in which the women

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succeeded in questioning, even though their access to collectives of others who shared similar experiences and who could potentially articulate alternative norms was limited.

As a contribution to research on outing, these findings underscore the role of affective dissonances and affective solidarity in-between individuals in these narratives: how the expression and experience of pity, for example, unfold between individuals, and how the disclosing individual's experience is relationally formed. This implies a shift in focus from discussions of strategic outing as strategic because individuals "sense a variety of reasons to come out and 'stay in' that must be considered simultaneously and in conjunction with social context" (Orne, 2011:696) to how affective expressions can shape what gets to be perceived as desirable disclosure and bring to light intersubjective dimensions of self-understanding and agency, when someone discloses her atypical sexed embodiment.

The examined storyline also shows how norms and beliefs, as expressed in descriptions of actual or envisaged interactions and relations, make certain bodies and lives difficult to talk about and respond to. It demonstrates that provision of recognition, through others' responses, need not be understood as depending on shared experiences nor on the provision of an explicit critique of norms about female embodiment. In other words, responses which make repositioning possible can also offer solidarity even if not based on shared identities, group characteristics, or presumptions about how the other feels (Hemmings, 2012) or on an explicit collective critique of specific norms. What seems crucial, instead, is that responses enable the kind of distance that makes possible the articulation of alternative norms or ways of living, and this in ways that do not "celebrate difference as such but [...] establish more inclusive conditions for sheltering and maintaining life that resists models of assimilation" (Butler, 2004:4). In the light of our analysis, such articulation can be made possible by responses that express an affective solidarity in communicating that something is 'amiss' when the subject coming out is positioned as rejectable

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or pitiable. And while rarely implying an explicit critique of norms about female bodies or heterosexuality, the examined storyline nevertheless demonstrates, in emphasising the meaning of such responses, an implicit questioning of such norms.

Given the design of the study and that all but one interviewee had experience of heterosexual intimate relations and none identified as intersexual, we can only speculate about the role of shared social locations in receiving or achieving affective solidarity. To explore how such characteristics may help shape specific expressions of affective solidarity, for example, in interactions with teenage peers, would require a different research strategy. Nevertheless, we do note that in the examined narratives the role of homogeneity, in the sense of sharing experience of 'atypical' sexed development, seemed less important than relations over time with individuals who did express this solidarity.

Finally, our analysis have implications for care and support provided to individuals living with an 'atypical' sex development. First, by demonstrating that outing cannot be confined to a single event in time it indicates the urgency of considering distribution and availability of care and support over time (see also Guntram, 2013a). Second, our analysis highlights the importance of finding ways to support individuals with 'atypical' sex development in their attempts to challenge assumptions about female embodiment and gain recognition of the specificity of their embodiment. This, we suggest, would require efforts being made in educational programmes – in e.g. in medicine, nursing and midwifery – to increase care providers' knowledge about individuals' experiences of living with 'atypical' sex development. In addition, support meant to help individuals with 'atypical' sex development to challenge assumptions about female embodiment and gain recognition would benefit from raised public knowledge about DSD/intersex. This could for example be accomplished through increased information and discussion about bodily variations and 'atypical' sex development in schools' sex education and further engagement from

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actors such as the Swedish Association for Sexuality Education (RFSU). Such joint efforts, we believe, would contribute to making certain bodies and lives *less* difficult to talk about.

In light of the limited number of studies exploring the experiences of individuals living with a condition categorized as intersex/DSD while not being aware of, deploying, or identifying with such labels (see, however, Guntram, 2013b; Holt and Slade, 2003; Lundberg et al. available online), this article has provided a unique contribution to social scientific and feminist explorations of intersex/DSD conditions. Specifically, it has delineated a route for exploring how individuals who live with conditions labelled intersex/DSD – but do not present themselves as belonging to such communities – can gain recognition and has in doing so brought 'different modes of living' (Butler, 2004:4) with such conditions to the fore.

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