

Ambivalent Ambiguity?

A study of how women with 'atypical' sex development make sense of female embodiment

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To the 23 women who let me share their stories.

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Linköping, 2014

LIST OF ARTICLES

Article I

Guntram L (2014) Creating, maintaining and questioning (hetero)relational normality in narratives about vaginal reconstruction. *Feminist Theory* 14 (1), 105–121

Article II

Guntram L and Zeiler K (under revision for European Journal of Women's Studies) '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

Article III

Guntram L (2014) Negotiations of normality and the meaning of a diagnosis: exploring women's experiences of 'atypical' pubertal development. *Social Science & Medicine* 98, 232–238

Article IV

Guntram L (submitted to *Social Science and Medicine*) Hooked on a feeling. Corporeal connectedness and relationality in infertility accounts.

INTRODUCTION

This is a bit different from finding out that you don't have two legs at the age of 17.

It has to do with having sex and sex categories and all that,
and that's very, very charged.

Charged in a way that a leg might not be.

‘Maria’¹

The idea that female and male sex are biologically defined as two, and only two, binary and separate entities has, according to Thomas Laqueur (1990), been deeply rooted in Western cultures since the eighteenth century.² In some interpretations of this ‘two-sex model’ genitals have been given a specifically central role, as it has come to be taken as a ‘truth’ that a female is a person with a vagina and a male is a person with a penis (Kessler and McKenna, 1985: 113)³, spelled out, for instance, in how the first assignment of an individual’s sex is based on genital inspection at, or before, birth (Braun and Wilkinson, 2005). The ‘pervasiveness’ of this understanding of biological sex, Toril Moi (1999: 12) wrote, can make whole classes of activities ‘endowed’ with sex as if every habit, gesture, and activity is sexualized and categorized as female or male, masculine or feminine. Furthermore, such sociocultural presumptions about the materiality of sexed bodies may result in precarious associations of gendered identity and sexed embodiment with specific body parts and processes (Butler, 2004; Fausto-Sterling, 2000a; Martin, 2001; Moi, 1999), so that wombs, vaginas, and ovaries, and menstruation, ovulation, and pregnancy become signifiers of female embodiment and womanhood (see, e.g., Braun and Wilkinson, 2005; Martin, 2001).

Now, in the light of these pervasive sociocultural associations between body parts and bodily processes, female embodiment, and womanhood in Western cultures, how may those women who do not have the organs and may not experience the processes that are seen to signify the female sex make sense of their embodiment? Attempting to provide answers to this question, this thesis explores

¹ Interviewee with uterine and vaginal agenesis.

² For contrasting accounts, see Park and Nye (1991) and Green (2010).

³ See also Garfinkel (1967).

narratives told by women, whose sex was not questioned or reassigned in infancy, but who have learned, commonly in adolescence, that their bodies develop in a way considered ‘atypical’ for the ‘female’ sex. Specifically, the women that this thesis revolves around have *either* found out that they have no uterus and no, or a so called small, vagina, a group of symptoms⁴ which I henceforth call uterus and vaginal agenesis (UVA), *or* they have found out that they have Turner syndrome (TS), which means that they do not have two X chromosomes, and have no or non-functioning ovaries.⁵ Both UVA and TS are medically categorized as ‘disorders of sex development’ (DSD), a concept deployed by some feminist and gender scholars and activists (see, e.g., Davis, 2014; Feder and Karkazis, 2008), while others argue for the use of the term ‘intersex’ (see, e.g., Holmes, 2011).

This compilation thesis aims to discern how women with UVA and TS make sense of their sexed embodiment, alone and in relation to others, and how norms and beliefs governing female embodiment can be reinforced and challenged in their narratives. From different angles the four articles that this thesis comprises examine how these women talk about their bodies, their situations, and their interactions with others. The first part of the thesis, the ‘kappa’, positions the study in relation to a general scientific problem and situates its four articles within a particular field of inquiry. It also serves to present and discuss the study’s methodological frameworks and research ethics. The second part of the thesis consists of the original articles. Now, before going into the more precise aims of my work, I will outline previous feminist examinations of the two-sex model and of female embodiment and then identify some especially perilous gaps in related research fields.

⁴ Since not all of these interviewees could refer to a specific medical label – some of them said that they had not been given one, and others said that they had not had the label that they used confirmed by a physician – it is uncertain whether these interviewees have the same medical diagnose, although they share the same symptoms. Therefore, I have chosen to use UVA when referring to these interviewees.

⁵ The interviewees with UVA have found out that they will not menstruate, that they cannot conceive, and that they might find vaginal penetration painful and difficult. The interviewees with TS have found out that they will not enter puberty if not given hormonal treatment and that they most likely will need egg donation in order to become pregnant.

FEMINIST EFFORTS TO CHALLENGE THE TWO-SEX MODEL

In several manners feminist scholars have scrutinized and challenged the pervasiveness of the two-sex model and its effects, particularly in medicine. In the 1970s the conceptualization of gender as a social category separate from the biological categorization of sex gained ground in these critical debates. The distinction between sex and gender, it was suggested, made it possible to highlight previous confluences of biological features of female bodies and sociocultural constructions of femininity, that were, for example, spelled out in the association of reproductive capacities and ‘normal’ womanhood (Malson and Swann, 2003). For instance, Gayle Rubin (1975: 179) argued that gender was the ‘socially imposed division of the sexes’ and deployed the term ‘sex/gender system’ to describe ‘a set of arrangements by which the biological raw material of human sex and procreation is shaped by human, social intervention’ (Rubin, 1975: 165). While Rubin, for example, held that feminism should aim to create a ‘genderless (though not sexless) society, in which one’s sexual anatomy is irrelevant to who one is, what one does, and with whom one makes love’ (Rubin, 1975: 204), this separation of ‘biological’ sex and ‘social’ gender did not necessarily result in a reconceptualization of the very definition and understanding of biological sex.⁶

In contrast, other feminist critique of the two-sex model more specifically addressed the very understanding of sex that formed the basis of the two-sex model (e.g. Butler, 1990, 1993, 2004; Heinämaa, 2012; Moi, 1999). Portraying sex as an ‘essence’, onto which ever-changing gender is inscribed, the separation of sex and gender, they held, reiterated inherent binary structures of the two-sex model. Instead, they suggested that both sex and gender should be understood as coherent, historical, and social phenomena. Judith Butler (1993), for example, opposed the idea that gender is a cultural construct imposed upon a given sex and argued instead that not only gender but also sex is a cultural construct. Sex, Butler (1993: 3) wrote, is not a ‘bodily given’ on which gender is imposed but a ‘cultural norm which governs that materialization of bodies’. Therefore, ‘sex’ cannot simply be understood as something that subjects *have* or as a static description of what subjects *are*. It is, rather, one of the multiple norms that make subjects viable and by which bodies become materialized, in other words, that which ‘qualifies a body for life within the domain of cultural intelligibility’ (Butler, 1993: 2). Furthermore, Butler (1990) showed, since female and male sex, and likewise the two genders

⁶ At times it also meant that the female body and, for instance, its ability to give birth and nourish children, was honoured and celebrated, inasmuch as the specificities of female bodies and femininity were seen as a means to fight the patriarchy (for an overview, see Gemzöe, 2002: 49–53).

(masculine/feminine), have been defined as each other's opposites, with desires directed towards each other, heterosexuality has been construed as imperative and obligatory. Along the same lines, other scholars demonstrated how the dominant Western discourse surrounding sexualities arranges sexual practices in an hierarchical system in which marital, reproductive sex acts are placed at the top (see, e.g., Jackson, 2008; Rubin, 1984; Smart, 1996). Consequently, as, for instance, Seidman (2005: 40) maintained, normative heterosexuality orders heterosexuality and homosexuality hierarchically, while also distinguishing 'hegemonic and subordinate forms of heterosexuality'.

Moi (1999) took another route as she questioned the poststructuralist use of 'sex' and 'gender', represented, for example, in Butler's work – a critique which also could be read as questioning the two-sex model. The poststructuralist reconceptualization, she asserted, preserved the previous division of sex and gender and could not sufficiently explain the experience and meaning of human sex difference, or create an understanding of what it means to be a woman or a man in a given society. Instead, Moi asserted, we must start our analysis of sex in experiencing, and situated, subjects and engage with the concept of lived experience (Moi, 1999: 114).

Likewise raising concerns about the very understanding of sex as by nature comprising given and binary categories, others took their point of departure particularly in the experiences of individuals whose bodies do not fit into either the male or the female category of the two-sex model, and the medical management of their bodies (Dreger, 1998; Fausto-Sterling, 2000a; Kessler, 1998).^{7,8} These scholars suggested that by making visible that which is perceived as 'abnormal' in certain times and contexts, those bodies that throughout history commonly have been labelled hermaphroditic make us see what has been taken for granted as unquestionably 'normal' when it comes to sex in specific times and contexts (Dreger, 1998). In the early 1990s Anne Fausto-Sterling made a provocative suggestion for how to challenge and reconceptualize contemporary Western notions of 'normally' and 'abnormally' sexed bodies, as she argued that five categories, at the least, ranging between female and male, should be considered as sexes in their own right (Fausto-Sterling, 1993: 21).⁹ Others, however, were not too

⁷ It is estimated that about 1.7% of all children born have bodies that do not 'fit' these categorizations on chromosomal, gonadal, genital, and/or phenotypic levels (Blackless et al., 2000).

⁸ Butler engaged with similar issues in 'Undoing gender' (2004).

⁹ Fausto-Sterling (1993) furthermore differentiated between those who possess both egg- and sperm-producing gonads, whom she labelled herms (a.k.a. hermaphrodites), those who have testes and some 'female' genital features but no ovaries, whom she labelled merms (a.k.a. known as male pseudohermaphrodites), and those who have ovaries and some 'male' genital features but no testes, whom she labelled ferms (a.k.a. female pseudohermaphrodites).

sure about this route. For instance, while Suzanne Kessler agreed that a validation of alternative genitals contributes to the validation of alternative sexes and as well may function to question of the privilege of the ‘female’ and ‘male’ binaries, she stressed that an introduction of five sexes still resulted in making genitals (although not only two kinds) signifiers of gender (Kessler, 1998: 90).

Instead, Kessler (1998: 131) argued that if the meanings of ‘male’ and ‘female’ genitals were seen not as fixed but constantly renegotiated, there would ultimately ‘just be women with large clitorises or fused labia or men with small penises or misshapen scrota – phenotypes with no particular clinical or identity meaning’ (Kessler, 1998: 90). Kessler’s call for decreased attention to genitals was later embraced by Fausto-Sterling (2000b), who nevertheless maintained that we are still far from an ideal world in which genital variations are just different phenotypes without specific meaning (Fausto-Sterling, 2000b: 22). Furthermore, Fausto-Sterling (2005) asserted, while Butler had argued for feminist inquiry to reclaim the term *sex* her examination did not specifically go into how sex and gender physically materialize in bodies. Biological accounts of human development can for sure not entirely explain the ‘emergence of lived and differently gendered realities’, Fausto-Sterling asserted, but we need to carefully recognize ‘the body as simultaneously composed of genes, hormones, cells, and organs – all of which influence health and behavior – and of culture and history’ (Fausto-Sterling, 2005: 1495).

Overall, these examinations of sexed bodies contributed to problematizing ideas of biological sex and sexed embodiment. They also contributed to conceiving of sex in terms of a continuous and malleable spectrum that reaches between two poles representing that which is understood as biologically typical for ‘females’ and ‘males’, respectively, and in which bodily variations blend imperceptibly into one another (Greenberg, 1999: 275; Hubbard, 1996; Dreger, cited in Hull, 2006: 55). Moreover, by shedding light on the medical treatment of those bodies that are not clearly located in either of the extreme ends, these examinations showed how the two-sex model, by reinforcing conceptions of ‘normal’ male and female bodies as having certain organs, functioned as a ‘truth’ taken for granted in Western medicine – resulting in medical examinations and interventions when those organs and features that were said to signify sex were not present or were considered ‘abnormal’.

FEMINIST EXPLORATIONS OF FEMALE EMBODIMENT

But first, what is a woman? “*Tota mulier in utero: she is a womb,*” some say.

(Beauvoir, 2010: 3)

Much feminist research has shown how body features such as uteri, ovaries, and vaginas, external genitals, genes and hormones have been understood and used as ‘emblems of difference’ (Bell and Apfel, 1995) to distinguish ‘woman’ from ‘man’ and differentiate between ‘women’, in contemporary Western societies, and it has been demonstrated how the absence of such ‘markers’ of sex has been seen to call for medical inquires and interventions (see, e.g., Holmes, 2008; Kessler, 1998; Roen, 2008). The identification of such meaning has, however, not meant that certain aspects of women’s sexed (reproductive) bodies have been conceived as natural, apolitical, and ahistorical (Malson and Swann, 2003). Instead, scholars have more commonly expressed the necessity of acknowledging the specificities of the sociohistorical contexts in which subjects are situated when conceptualizing women’s (and men’s) bodies and lived experiences of embodiment (see, e.g., Käll and Zeiler, 2014).

Feminist studies of female young women’s experiences of embodiment have shown how bodily and sexual changes that adolescent women are expected to experience, such as menstruation, transformations of the figure, and new dimensions and intensities of sexual desires, have been associated with and shaped by numerous social connotations and images of ‘womanhood’ (see, e.g., Flaake, 2005; Holland et al., 2004; Oinas, 2001). Conceptions of female embodiment that such work makes visible underscore meanings accorded to certain organs, bodily features, and capacities. With regard to meanings surrounding the vagina, Susan Bell and Roberta Apfel (1995: 5) noted that inasmuch as the vagina functions both as birth canal and place of sexual intercourse, it ‘has been the basis for fantasies, fears and contests between men and women for eons’. Others have demonstrated that although the vagina’s central part in the common-sense linking of genitals and gendered identity occasionally can be questioned in women’s talk about the vagina, the close relationship between the vagina and gendered identity is still commonly ‘discursively and interactionally reinscribed as the norm’ (Braun and Wilkinson, 2005: 518). This cultural significance of the vagina has also been brought out and been problematized in studies on transsexualism (e.g. Bremer, 2011), female genital

cosmetic surgery (FGCS) (Braun, 2005, 2009), and genital surgery for intersex individuals (e.g. Karkazis, 2008) and through such studies it becomes possible to articulate how the vagina's cultural significance intersects with Western dominant interpretations of penile–vaginal intercourse as 'real sex' in culture (see, e.g., Gavey et al., 1999; Jackson, 2008; McPhillips et al., 2001; Rubin, 1984).

Moreover, the significance accorded to the vagina in notions of female can be embodiment related to the often strong sociocultural meanings of menstruation and its association with female gender identity (e.g. Elson, 2002; Laws, 1990; Martin, 2001). While, on the one hand, often being pictured as something dirty, as a universal taboo, and even as a negative and traumatic experience, especially by white, Western middle-class girls (for an overview, see Burrows and Johnson, 2005) menstruation has, on the other hand, been seen as highlighting women's transition from girlhood to womanhood and as signifying a symbolic bond between women (see e.g., Delaney et al., 1988; Martin, 2001). As Natalie Angier (1999: 95) expressed it, not all women breed, but nearly all women bleed, or have bled, and therefore, there is 'no clearer rite of passage, no surer demarcation between childhood and adulthood, than menarche, the first period'.

Also providing insight into the cultural meanings of female embodiment are feminist explorations of ovaries and uteri. Exploring meanings accorded to both uteri and ovaries, Jean Elson (2003) argued that the ovaries carry specific symbolic meaning in identity gender formation because of their capacity to produce 'sex hormones'. Studying women's lived experiences of simple hysterectomy (surgical removal of the uterus) versus oophorectomy (surgical removal of one or both ovaries), Elson demonstrated how her interviewees especially accord symbolic value to knowing that their bodies are 'working' in the same ways as the bodies of ovulating women – that is, in the same way as the bodies of those women that the interviewees described as 'normal' (Elson, 2003: 760). This, Elson contended, reflects the cultural understanding of ovaries as the 'cultural signifiers of sex difference' and that ovaries, because of their hormonal production, thus are placed at the top of a socially constructed 'hormonal hierarchy' through which sexual difference can be understood (Elson, 2003: 765).

Nevertheless, because of the ever present sociocultural connections between womanhood and motherhood, uteri may acquire certain cultural significance through its childbearing potential (Beauvoir, 2010; Elson, 2003). The ways in which, for example pregnancy, birth, and motherhood have been viewed as 'normal', 'natural', and 'peak' experiences of women's lives have been problematized by many feminist scholars (Morse, 2000; Rich, 1995; Woollett and Boyle, 2000; Woollett and Marshall, 2000). For instance, the numerous feminist

examinations of individuals' experiences of voluntary and involuntary childlessness, which, often with a focus on individuals' engagement with assisted reproductive technologies (ART), tease out sociocultural norms about, for instance, genetic linkage and reproductive capacity and desire, at play in the shaping of interconnections between understandings of motherhood and womanhood in Western societies (Franklin, 1997; Kirkman, 2008; Peterson and Engwall, 2013; Throsby, 2004).

Now, this overview shows how dominant understandings of reproduction, (hetero)sexuality, and womanhood shape understandings of female embodiment in sometimes precarious manners, but indicates at the same time that such understandings can be renegotiated. Studying individuals' accounts of illness or the loss or 'divergence' of body parts, feminist and gender scholars have more specifically shown how identities and understandings of embodiment may have to be negotiated, in the light of prevailing norms of the context in which the individual is situated. Such studies have also shown how normative notions of sexed embodiment, sexuality, and sexual practice can be challenged in such accounts. In a study of women's experiences of vulvar pain Amy Kaler (2006) demonstrated how affected women rethink and redefine the core of womanhood by tying it to practices and behaviours other than heterosexual ones. Similarly, a study on women's experiences of polycystic ovarian syndrome (PCOS), a condition that may result in excessive hair growth, disturbed menstruation, and infertility, showed that resistance to the socially constructed notion of 'normal' women as being 'effortless, feminine, hair-free, 28-day cycle creatures' occasionally occurred, when the women talked about the 'freakishness' of their condition, which fundamentally challenged social constructions of womanhood and femininity (Kitzinger and Willmott, 2002: 359).

In the studies covered women, and men, are typically not seen as prisoners of their own sex, and gender identity is understood as a set of norms that are lived and transformed in the embodied practices of men and women (see McNay, 2000). Such norms, then, not only shape our understandings of female embodiment; they may also, especially when enacted through medical practices, materially shape bodies inasmuch as bodies, through medical interventions, often are altered to align with that which, for example, is considered statistically normal and/or ideal (see, e.g., Connell, 1999; Doyle, 2008; Dull and West, 1991; Sandell, 2001).

Some have argued that such shapings are to be conceived of as processes of domination and control through which female bodies are objectified (e.g. Bordo, 1997; Morgan, 1991) and that the recent celebration of agency when it comes to women's interactions with their bodies does not give sufficient attention to the

systematic constraints that women live under (Bordo, 1997).¹⁰ Others have suggested that women should be treated as ‘embodied subjects who think, act, and know through their bodies’ (Davis, 1997: 57) and that the female body should be seen a site of subversive practices, struggles for self-determination and empowerment (e.g. Davis, 1997; Fisher and Davis, 1993; Lorentzen, 2008; Meyers, 2002). However, material shapings of the body, motivated by specific norms, these scholars have asserted, should not simply be seen to resolve problems and provide liberation. The body rather represents a ‘site of contestation’ (Price and Shildrick, 1999) and material shapings of bodies may function as subversive practices that can enable individuals to renegotiate their relationships to their bodies and construct a different sense of self (Davis, 1995).

Overall, the feminist explorations of female embodiment that I have covered in the above feed into feminist theoretical problematizations of how dominant norms can be made visible and challenged. However, to formulate such critique of norms is commonly not an easy undertaking (Malmqvist and Zeiler, 2010). Clare Hemmings (2012), for example, discussed how restraining norms can be challenged through an examination of how affective dissonance, such as frustration or anger, which may occur when the subject faces the lives of others, can make the subject orient towards those who narrate the world in manners that differ from the dominant ones. Affective dissonance thus functions to connect us with, and express solidarity for, others – not on the basis of identity or group characteristics, or on presumptions about how the other feels – but on the basis of 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). Butler (2004: 4) similarly held that in order for subjects to act critically against bodily and gendered norms that govern idealized human anatomy, a collective capacity to articulate an ‘alternative minority version of norms and ideals’ is required. The interrogation of the terms by which life is constrained that such critical acts encompass does not necessarily involve a celebration of differences as such, but rather entails the establishment of different modes of living and more ‘inclusive conditions for sheltering and maintaining life’ (Butler, 2004: 4).

¹⁰ However, it should be noted that Bordo does suggest that, although the possibility to resist the pressure to conform might be a fantasy, it is still a precious one worth defending.

CONCERNS AND GAPS IN PREVIOUS RESEARCH

This chapter revolves around empirical research that concerns similar, or the same, symptoms and conditions as those explored in this thesis. First, I turn to studies that concern medical treatment and lived experiences of that which in contemporary debates often is referred to as ‘disorders of sex development’ or ‘intersex’. Second, I turn to the existing research pertaining to uterine and vaginal agenesis and Turner syndrome. In doing so, I furthermore specify the gaps in knowledge that I identify in each field, respectively.

PREVIOUS RESEARCH ON INTERSEX AND DISORDERS OF SEX DEVELOPMENT

In feminist and social scientific research on what commonly is referred to as intersex or DSD, and in which both UVA and TS commonly are included, three central concerns are of particular relevance to my project: discussions about the concepts of intersex and DSD, examinations of medical treatment protocols and practices, and studies on individuals’ experiences of living with intersex/DSD. These three main concerns are relevant for my project not only because they cover conditions and symptoms that are interlinked to UVA and TS, for example, through medical classifications such as DSD, but more importantly, because they expose gaps in the knowledge regarding specific conditions and experiences within the intersex/DSD field.

The first relevant concern is the ever present debate over nomenclature, among scholars and activists. For a long time the term *intersex* was deployed both by medical and feminist/social scientific scholars, as well as in public debates and activist discourses, to describe individuals whose bodies biologically deviate from the female and/or male sex. However, the meaning of the concept varied from one context to another. In medicine the term was at times used in a rather narrow manner, for example, to refer to those individuals whose bodies present both male *and* female characteristics on chromosomal, gonadal, or genital levels (see, e.g., Sax, 2002). In other settings the concept was used more broadly to describe any individual who ‘deviates from the Platonic ideal of physical dimorphism at the

chromosomal, genital, gonadal, or hormonal levels' (Blackless et al., 2000: 161), or used also to refer to an identity (Preves, 2003). In the escalating debates among physicians, researchers, and activists in the 1990s and 2000s over medical practices and sex assignment with regard to new born babies concerns were raised about these disparities as well as about the potential interpretation of 'intersexuality' as being a matter of sexual orientation. In the medical setting this resulted in the introduction of the DSD label when the first consensus statement on the management of intersex disorders was published in 2006 by the Lawson Wilkins Paediatric Endocrine Society and the European Society for Paediatric Endocrinology (Lee et al., 2006). The statement, which also included proposals for how to reorganize medical evaluations, care, and treatment, concluded that previously used labels such as 'intersex', 'pseudohermaphroditism', and 'hermaphroditism' were controversial and problematic, because they potentially were perceived by patients as pejorative and were confusing to both practitioners and parents. Instead, it was suggested that DSD should be used to describe 'congenital conditions in which development of chromosomal, gonadal, or anatomic sex is atypical' (Lee et al., 2006).

Whereas the DSD label soon was adopted in much medical research as well as in clinical contexts, internationally and in Sweden (Nordenström et al., 2008), nomenclature has continued to be a topic of debate within the activist movement and among scholars in feminist and queer studies. In the academic discussions some stress the benefits of keeping 'intersex' (Clune-Taylor, 2010; Holmes, 2011), arguing, for example, that, since activist history of the term intersex is crucial to many people, it would be politically harmful and of limited heuristic value to allow clinicians to replace it with a freshly pathologizing term, that is, DSD (Holmes, 2011: 407). Others argue, in contrast, that the term DSD makes it possible to transform intersex conditions from 'disorders like no other' to 'disorders like many others' (Feder and Karkazis, 2008). Yet others replace 'disorders' in 'DSD' with 'divergence' (Reis, 2007), or 'diverse' (Roen and Pasterski, 2014), to avoid the negative, medicalizing, and stigmatizing connotations that potentially are attached to 'disorder'. Likewise, it has been shown that there is a great range of ways to engage with the term DSD by those who knowingly are labelled by it – some arguing against it, others supporting it, and a few being indifferent to it (Davis, 2014).

These discussions about terminology become relevant to my project foremost in relation to my interviewees' limited usage and sometimes limited knowledge about that which I, in the light of this debate, henceforth call intersex/DSD and about the relationship between such concepts and their own conditions or

symptoms. In the light of these controversies it is possible to identify gaps in knowledge regarding the views of those individuals who sometimes unknowingly are labelled by such terminology, and the consequent need for further explorations of the meanings accorded to such labels by those being labelled, especially within the Swedish context.

The second central concern in previous research on intersex/DSD relevant to my project is that of critical examinations of medical treatment and in particular genital surgeries in infants. These medical practices have often been described as resting on theories presented by John Money and colleagues, which stipulated that sex assignment and sex of rearing 'predicated a hermaphrodite's adult gender role and sex orientation more accurately than did any aspect of h/her [sic] biological sex' (Fausto-Sterling, 2000a: 66). That is, if surgeons created the 'necessary' genitals and parents reared the child in accordance with the assigned sex, gender role (cultural gender norms) and gender identity (personal experience of identity) would fall into place (Kessler, 1998: 6; Money and Ehrhardt, 1972: 144). Although much medical research has continued to focus on psychosexual evaluations of sexual pleasure and gender assignment (see, e.g., Hines et al., 2004; Houk and Lee, 2012; Hughes, 2007; Lee and Houk, 2010; Meyer-Bahlburg, 2004; Sandberg et al., 2012; Slijper and Drop, 1998; Zucker et al., 2004), and assessments of surgical techniques (see, e.g., Conway et al., 2003; Lesma et al., 2014; Massanyi et al., 2013; van der Zwan et al., 2013; Zhang et al., 2013), an increased awareness of the complexity of DSD and the importance of multidimensional treatment approaches has been witnessed (see, e.g., Houk and Lee, 2012; Moshiri et al., 2012). In medical studies it has also, since the publication of the consensus statement, often been stressed that there is a push for postponing genital surgeries (Streuli et al., 2013).

Concomitantly, feminist and social scientific scholars have, with different aims and from different vantage points, prevailed in their scrutiny of these medical protocols and practices, predominantly with a focus on surgery involving infants and on parental decision-making. Such examinations show that parents may still tend to disfavour postponing genital surgery because of the pain and frustration that might result from thinking of one's child as 'in between' the two sexes and as not being 'in line' with the dominant notions of either female or male bodies, represented in the two-sex model (Zeiler and Wickstrom, 2009). Another possible interpretation, made in the U.S. context, is that parents' possibilities of imagining the child's future in any way other than in being in need of immediate surgical correction are obstructed by their guilt and shame and by their being discouraged from identifying with the child (Feder, 2006). These tendencies may not, however, mean that there are no openings for shifts in clinical practice which could make it

possible to reconceptualize the ‘atypically sexed child as a whole, agentic subject’ and of her/his embodiment as a process (Roen, 2008).¹¹ Local conditions of surgical care, for example, can, through their ramifications for the possibility of surgeons to meet the state-of-the art cosmetic standards for heteronormalizing genital surgery, create openings for changes in existing surgical practice and shifts in those frameworks that form the basis of the clinical management of intersex (Kraus, 2013). These problematizations of surgical interventions and the dominant focus on infants in them highlight the lack of, and need for, explorations and problematizations of genital surgeries and other forms of treatment introduced in puberty or adulthood, and in particular for examinations of the decision-making processes among affected individuals (see, however, Boyle et al., 2005; Holmes, 2008).

The third concern in studies on intersex/DSD relevant to my project revolves around individuals’ experiences of intersex/DSD and of medical treatments, and typically calls attention to the importance of considering individuals’ perspectives in the development of medical treatment protocols. Drawing on autoethnographical data, narratives from other members of the intersex movement, and fictional accounts, Morgan Holmes (2008) examined dominant narratives of intersex and offered counter narratives to the same in a cultural analysis which underscores the necessity of spelling out how categories such as ‘natural’, ‘normal’, and ‘healthy’ become conflated. Likewise providing first-person narratives of the day-to-day lives of intersexed people and their families, Dreger and others showed that ‘intersex’, on the one hand, does not constitute the entire individual and that the medical treatment of intersex, on the other hand, makes these narratives extraordinary (Dreger, 1999). Aiming to address the lack of research concerning the quality of life of intersex individuals¹² who have undergone medical intervention, Sharon E. Preves (2003) analysed interview data with the intention of exploring how the reworking of intersexed identity may transform stigma and shame into empowerment, pride, and potential activism.¹³ Individual and collective actions, Preves maintained, carry great potential to redefine sexual ambiguity in a more positive and empowering light, which may lead to increased social tolerance of sex and gender variability and changed clinical practice. Finally, in an analysis of the

¹¹ Studies of multidisciplinary medical teams managing these conditions furthermore point out that while there is still a lack of high-quality, multicentre, multidisciplinary research to prospectively monitor the long-term multiple outcomes of surgery and no surgery, individuals and families may, if given adequate information and guidance, find it possible to postpone elective interventions (Creighton et al., 2014).

¹² Defined by Preves (2003: 168) as individuals who have ambiguous genitalia, sexual organs, or sex chromosomes.

¹³ For a critical reading of Preves (2003), see Holmes (2008).

viewpoints of individuals with intersex diagnoses, their parents, and clinicians, Katrina Karkazis (2008) asserted that medicine should not be portrayed ‘as a batch of bad intentions fuelled by a desire to control people’ and demonstrated how it can be possible to understand why some people are labelled as intersex, and whom or what this label serves, in relation to frameworks other than biomedical ones.

While these studies provide valuable insights into the meanings that affected individuals assign to their bodies and to medical treatment, as well as implications of the same, individuals’ sense-making in relation to specificities of conditions or symptoms are rarely discussed. Furthermore, experiences of individuals with UVA and individuals with TS are seldom covered to any greater extent in these studies¹⁴ – a somewhat peculiar gap, given the inclusive take on intersex/DSD commonly deployed by feminist and social scientific scholars in the field.

Finally, before turning to previous research that more specifically concerns UVA and TS, something should be said about research on intersex/DSD in the Swedish context and about the even greater knowledge gap found here. In contrast to the – for my thesis – relevant, focal points of international research on intersex/DSD, Swedish research on intersex/DSD has predominantly concerned historical developments of, for example, views on hermaphroditism in Sweden (Bondestam, 2010) and definitions of intersex in state policies such as Swedish government official reports (SOU) and their implications (Alm, 2006; Edenheim, 2005). In a comparison of the Swedish and the American contexts regarding contemporary developments of intersex discourse and activist movements, Erika Alm (2010) furthermore identified a lack of feminist engagement in Swedish intersex discourse and discussed its implications for academic as well as activist agendas. Alm also noted the lack of examination of treatment practices and individuals’ narratives in the Swedish context, the limited public debate about medical procedures and media coverage of these individuals’ lived experiences in Sweden and that activist and patient organizations have only fairly recently formed – features that could be considered rather striking, given Sweden’s reputation for being a particularly open context with respect to matters such as sexuality and gender equality (see, e.g., Danielsson et al., 2001; Forsberg, 2001; Francoeur and Noonan, 2004; Sherlock, 2012).

¹⁴ Preves’s study includes individuals whose intersexuality either had been discovered in infancy or who learned about their intersexuality in puberty, but did not focus on potential specificities of the latter group. In her study 3% of the interviewees had TS, but because of the unclear total number of interviewees, the exact number of interviewees with Turner syndrome is difficult to estimate. My interpretation is that one of her interviewees had Turner syndrome. Karkazis’s study mainly focuses on individuals with androgen insensitivity syndrome, which involves a congenital absence of the uterus and the vagina but also the presence of XY chromosomes and ‘male’ gonads, and individuals with congenital adrenal hyperplasia (CAH) which may result in ambiguous genitalia. The volume edited by Dreger as well as Holmes’s study cover a range of condition, but the texts engage not specifically with TS or UVA.

PREVIOUS RESEARCH ON TURNER SYNDROME AND UTERINE AND VAGINAL AGENESIS

I demonstrated above that individuals' experiences of UVA and TS have sometimes been included in research focusing on intersex/DSD (see Holmes, 2008; Preves, 2003), but studies that use social scientific and feminist perspectives to address the particularities of these individuals' experiences are inexistent when it comes to TS, and scarce when it comes to UVA.

Examining the social, emotional, and psychological consequences of living with an 'incomplete' uterus and vagina, one study shows how affected women struggle to interpret their condition in a positive manner and to maintain a stable view of themselves, often by using dichotomous concepts such as ill–not ill, normal–abnormal, female–not female, and different–not different when describing their lives (Holt and Slade, 2003). This study also highlights the need for greater acknowledgement of the complexities of the condition in medical care settings, for example, through more patient-centred approaches and revised language use. Similarly, a study that addressed adult genital reconstruction, including those vaginal reconstructions that women with UVA often undergo, argued for revised care practices (Boyle et al., 2005). Examining the interviewees' statements about their decision to have vaginal surgery, this study showed that while the women at first perceived surgical interventions as ways to produce normality and femininity, these interventions later on became problematic. The interviewees described themselves as passive recipients of medical treatment, with no or limited opportunities to actively make choices about treatment. Neither did the results, in terms of normality and function, meet the women's expectations. This, the authors concluded, underscores the need for further discussions and examinations of the rationales that motivate adults with DSD to undergo genital surgery (Boyle et al., 2005).

In the psychological and medical fields there are however studies that focus specifically on UVA and TS, and those relevant to my project concern psychosocial and psychosexual assessments and treatment evaluations. Such psychosocial and psychosexual assessments have shown that not being able to conceive and feelings of not being fully and functional women are said to be the most troubling reactions among women with congenital absence of uterus and vagina, in medical literature also known as Mayer–Rokitansky–Küster–Hauser (MRKH) syndrome (Bean et al., 2009). It has also been demonstrated that the psychological health status of these women varies with personality, life situation, length of time passed since the

diagnosis or treatment, and levels of support from family and health providers (Morgan and Quint, 2006).

Furthermore, in medical evaluations of the results of vaginal reconstructions, which are meant to create a vagina or increase the size of a so called small vagina, a growing tendency to encourage the use of methods that only involve dilation instead of surgical procedures followed by post-operative dilation can be noted. The invasiveness of surgical interventions, and the lack of statistically significant differences regarding 'functional' success between non-surgical and surgical methods, are often described as motivating this shift (Callens et al., 2014). However, it has also been noted that success is distinguished in a range of ways in such evaluations (Liao et al., 2006). In some studies functional success is defined as 'satisfaction with sex', which also includes 'non-genital sex' (Callens et al., 2014), or by using the Female Sexual Functional Index (FSFI), which measures desire, arousal, lubrication, orgasm, satisfaction, and comfort (Kuhn et al., 2013; Morcel et al., 2013). Other studies focus on anatomical success, often defined in terms of the achievement of a vaginal length of 7 cm or more (for an overview, see Callens et al., 2014). In general, Lih-Mei Liao et al. (2006) asserted, definitions are notably vague; retrospective studies of vaginal dilation have reported a success rate up to 80%, yet rarely do they explore factors such as compliance and outcome.¹⁵ In contrast, their study identifies several barriers to dilation in terms of required time, privacy, pain and discomfort. Correspondingly, Catherine Minto et al. (2003) discussed the complexity of compliance in dilation treatment and showed that only one-third of the patients in their sample described dilation treatment as satisfactory.

Concerning Turner syndrome, psychological and medical studies have highlighted the implications of hormonal treatments, which are meant to increase height and induce puberty, for social relationships and sex life. Such studies have shown that a delayed induction of puberty may have long-lasting effects on sex life (Carel et al., 2006) and that, even though height and pubertal treatments result in what is considered 'normal' height and puberty induction at a 'normal' age, the women affected may still present psychological difficulties because of the treatment (Carel et al., 2005; van Pareren et al., 2005). It has also been reported that Canadian girls and young women with TS score significantly lower when measuring general, social, and appearance-related self-esteem, but do not differ from women without Turner Syndrome when it comes to performance-related self-esteem (Cragg and Lafreniere, 2010).

¹⁵ Karkazis (2008) similarly notes that women are not asked whether they find their sexual experiences pleasurable and in what kind of sexual activities they engage when vaginoplasty is evaluated.

Furthermore, a Swedish study showed that while women with TS do not report impaired psychological well-being or impaired perceived health in comparison to normative data, they do report experiencing social difficulties to a greater extent (Boman et al., 2001). The low psychological well-being among Swedish women with TS has furthermore been statistically correlated to lack of sex hormones during adult life, hearing impairment, higher age at diagnosis, and higher age at menarche or induced bleeding (Boman et al., 2004). Other studies, which assess the sex lives of women with TS, have shown that women with TS who have a partner report 'normal' overall sexual functioning, whereas those who do not have a partner typically report very low sexual functioning (Sheaffer et al., 2008). It has also been demonstrated that women with TS have their sexual debut later than the average Swedish population (Rolstad et al., 2007). Yet, it should be kept in mind that none of the studies on women with TS problematize the way in which health and well-being or sexual function is estimated.

These findings from psychological and medical studies on UVA and TS function, like those concerned within research on intersex/DSD that I outlined above, to bring out interesting gaps in knowledge, as, in light of these findings, it becomes clear that there is a need for further explorations of how individuals' with UVA and TS make sense of female embodiment and problematization of medical treatments. Now, let's turn to the particular aims and research questions of this thesis.

AIMS AND RESEARCH QUESTIONS

Against the backdrop sketched above, this thesis explores young women's narratives about finding out, as an adolescent, that one's body is developing in a way that is considered 'atypical' for female bodies, which might call into question that which previously perhaps has been taken for granted about pubertal development and about female embodiment. The overall aim of the thesis is to discern how these individuals make sense of their atypical sex development, alone and in relation to others, and how norms about female embodiment, may be problematized through these narratives.

More specifically, the thesis first aims to explore how specific bodily 'divergences' from what commonly is considered a 'typical' female embodiment are understood and negotiated, as affected individuals tell about their lives, bodies, and relations with others in the past, present and the future. I hence ask: *How do the interviewees make sense of their sexed embodiment and situation as they talk about finding out about, and living with, an 'atypical' sex development?*

Second, it aims to examine how these individuals position their sexed embodied selves in relation to others', in particular, in narratives that concern interactions with, and relations to, others. I hence ask: *How is sexed embodiment negotiated through such positionings?*

Thirdly, it aims to examine reinforcement of, and resistance to, dominant norms about female embodiment, heterosexuality practice, and in/fertility through the lens of these narratives. I hence ask: *What beliefs and norms about female embodiment, heterosexual practice and in/fertility do these narratives highlight, and how may such beliefs and norms become strengthened and/or challenged in them?*

In the following chapters I will describe and discuss materials and methods as well as research ethics and reflexivity. I will also summarize the four articles that the thesis consists of and provide a final discussion.

MATERIALS AND METHODS

Comprising a number of approaches and tools, qualitative methodologies often aim to tease out and understand the meanings people bring to certain phenomena (Denzin and Lincoln, 1994: 2). The data examined in this project were collected using in-depth interviews in which the interviewees narrated their experiences. Through narratives, individuals are able not only to recount and describe their experiences to a specific audience, but narrations also enables them to reinterpret and negotiate their relationships with the world and may thus be central in the formation of experiences (see, e.g., Frank, 1995; Riessman, 2008). When narratives are understood in this way, examinations of how individuals' make sense of their lived experiences inevitably involves explorations of stories (Hagen, 2013; Slatman and Widdershoven, 2010). By this, I do not mean to say that the narratives and accounts created in interviews provide unmediated access to the interviewees' experiences, but that they offer insights into how people perceive, understand, manage, and make sense of the phenomena in question within the realm of the research interview (see, e.g., Kvale, 1996). Hence, by studying people's stories about their experiences, collected, for example, through in-depth interviews, an 'objective' view of the phenomena of interest cannot and is, more importantly, not meant to be, obtained. Instead, such studies can offer knowledge about the perspectives of the interviewees and about sociocultural assumptions and norms that are expressed through their narrations (see also Hagen, 2013: 33ff). With this being said, I will in the following describe how interviewees were recruited and how interviews were conducted, transcribed, and analysed, as well as the problems I've faced and the insights I have gained throughout this process.

RECRUITMENT STRATEGIES AND CHALLENGES

In my initial design of the project I set out to talk to individuals who had learned that their bodies were not developing in the ways considered typical for the male or female sex, whose sex development had not been an issue prior to that, and who had experienced this period of life rather recently. I therefore began searching for individuals in the ages of 18–25 years who had learned about their 'atypical' sex

development in adolescence.¹⁶ Primarily I looked for individuals diagnosed with Klinefelter syndrome, Turner syndrome, androgen insensitivity syndrome (AIS), late-onset congenital adrenal hyperplasia (CAH), 5-alpha reductase deficiency, vaginal agenesis, or Mayer–Rokitansky–Küster–Hauser (MRKH) syndrome, since these are conditions that may be detected in adolescence (see Lee et al., 2006; Nordenström et al., 2008). A focus on these particular conditions also meant that I included both individuals who previously had assumed that their bodies would develop in a ‘typical’ male way and individuals who had assumed that they would develop in a ‘typical’ female way. Furthermore, I wanted to include individuals who had been in contact with the health care system and individuals who had not; individuals who had received a medical diagnosis and individuals who had not, but from their perspective considered their bodily development to be ‘atypical’ for their assigned sex; and individuals who had had medical treatment and individuals who had not.

An information letter about the project (see appendix A) was distributed through the websites, e-mail lists, and newsletters of the National Association for Congenital Adrenal Hyperplasia (CAH-föreningen), the Swedish Turner Association (Svenska Turner föreningen), Intersexuella i Sverige (INIS), local branches of the Swedish Federation for Lesbian, Gay, Bisexual and Transgender Rights (RFSL), and on the Nordic Internet community Quiser, as well as on pages that I created on Facebook.¹⁷ I also searched for personal blogs and websites using as keywords ‘intersex’, ‘intersexuality’, and ‘DSD’, as well as the diagnoses commonly included in these concepts, to find other possible ways to distribute my letter. Moreover, I asked the four centres in Sweden specializing in DSD, as well as clinicians focusing on any of the conditions mentioned above, to distribute the letter to potential interviewees among their patients. I requested that potential interviewees were to be given the information letter and that those who were interested should be asked to contact me.

I was soon made aware, however, that finding and recruiting young men with Klinefelter syndrome was a lot harder than I had anticipated. The specialist that I contacted said that these men rarely had continuous contact with the health care system and that the clinic currently did not have any patients in the ages that I was

¹⁶ The lower age limit was set in consideration of parental informed consent often being required for research, in Sweden, that involves participants younger than 18, especially if the research concerns information that is considered sensitive. Since I wanted to avoid being required to get parents’ informed consent, I chose to set the minimum age at 18. Informed consent is further considered as I discuss research ethics.

¹⁷ In Sweden the number of patient organizations targeting these individuals is limited, and the existing ones are quite small. Several of my interviewees expressed a great need for networks and underscored the importance of getting in touch with others and their desire to do so.

interested in. Neither was there at the moment any active patient organization targeting individuals with Klinefelter syndrome in Sweden specifically, and it was not possible for me to recruit any male interviewees through INIS, the Swedish support network for individuals with DSD. As a result, the aims of the project were revised so that the study involved individuals who had experienced a sex development considered ‘atypical’ for the female sex in their teens. I also learned that women with an ‘atypical’ sex development who have been diagnosed in adolescence often are referred to the general departments of obstetrics and gynaecology at the age of 18, and therefore, I got in touch with a number of plastic surgeons and gynaecologists specializing in this area.

Hence, whereas my initial sampling strategy was meant to be purposive in that it focused on achieving a varied sample as regarded diagnosis, treatment, and medical contacts (Creswell, 2007: 125), the recruitment difficulties resulted in my sampling strategy rather being based on opportunities and convenience. As a consequence of these difficulties I also revised my inclusion criteria so that the study would include women from 18 to 30 years of age. My search continued.

Now, as it turned out, one of my clinical contacts was able to put me in touch with a number of women who in their teens had found out that they did not have a uterus or a vagina (or only had parts of a vagina), and all but one of these were willing to take part in an interview. I had also got in touch with five women with TS who agreed to take part in an interview; three through blogs and two through the Swedish Turner Association. Still, to recruit individuals with other diagnoses continued to be a challenge, and I was running out of recruitment options. I decided to focus on finding more women with TS. I contacted the Turner Association once more, asking if they would consider sending my information letter directly to members who fit my inclusion criteria. As I had done in my contacts with clinicians, I underscored that I would not get any personal information about the association’s members, but that those interested would be asked to contact me. I was lucky – after having read and discussed my letter, the association board responded that they were happy to help me.

Things started to look better, but when the board reviewed their members’ present ages and ages at diagnosis, we realized that my inclusion criteria might still be too narrow. To avoid having these efforts result in no additional interviewees, I decided to include women between the ages of 25 and 35 who had been diagnosed in adolescence or in childhood, but not in infancy. The distribution of information letters from the Swedish Turner Association resulted in my recruiting seven interviewees in addition to those five that I already had conducted with women with TS. Around the same time, about three years after beginning my project, I also

got in touch with yet another clinician who had contacts with women who had been diagnosed with TS, and through whom I recruited one interviewee.

Hence, in the end I conducted 23 interviews in total. Out of the ten interviewees with UVA five were recruited through a clinician and four through blogs, and one contacted me after having read about the project on a website. Out of the 13 interviewees diagnosed with TS nine were recruited through the Swedish Turner Association, three through blogs, and one through a clinician.

To gather the amount of data on the basis of which I could be relatively sure that more data would not challenge the findings of the analysis in any major sense, in other words, to achieve saturation, I made some inevitable compromises in relation to the present circumstances. If these had not been made I would not have had enough interviews to make a sound analysis. But this does not, of course, mean that these compromises should be left unproblematized. My choice to enlarge the age span of potential interviewees upon realizing that I had to focus on women with UVA and women with TS was such an inevitable decision. Looking back at these endeavours I, moreover, recognize that it might have been easier to get access to a larger and more varied sample if I had invited clinicians to take part in the design of the project and to co-author articles. While I see the potentials of such collaborations and believe that they can be most interesting and fruitful, I did not consider them an option in this project, since they would have led to more extensive compromises on my part than were desirable. For example, my initial intent was to design the overall project so that it would capture a range of stories about experiences of bodily development considered ‘atypical’ for one’s own sex in puberty, including, hopefully, those stories and accounts that are not told or given space in a medical setting. A closer collaboration with medical professionals could have impeded my opportunities to capture such stories and accounts. This was also to be confirmed by many of the interviewees, as they stressed the value of getting an opportunity to tell their stories outside of medical settings and to someone who was not a medical professional.

Furthermore, even the level of cooperation that was present in the project probably had an impact on how my information letter was presented to and interpreted by potential interviewees. When it was distributed through clinics, individuals with few and/or bad experiences of the health care system were perhaps less inclined to read the letter and consider participating in the project. Neither could I control how the physicians treated the letter, for example, how and to whom it was distributed, or whether it was distributed at all. By this I do not mean to say that I’m not thankful to those who did help me distribute the letter; without their help I would not have been able to conduct as many interviews as I

did. I mean rather to highlight the fact that possible recruitment strategies, and the data that finally are collected, are shaped by compromises made as well as by relational and material circumstances.

Finally, the recruitment difficulties I encountered could also have been related to my decision to not describe my project as being about ‘intersex’ or DSD but as concerned with ‘atypical’ sex development. The reason for this was that I wanted to frame my project in a manner that individuals both with and without knowledge about intersex/DSD terminology could relate to. I was hesitant about the connotations of sexual orientation that ‘intersexual’¹⁸ could carry – a body that does not conform to any of the binary sex categories is not, in my view, a matter of sexual orientation, and I wanted to avoid using ‘DSD’, because it refers to ‘disorder’. Although I believe that replacing ‘disorder’ with ‘divergence’ or ‘diverse’ could be a fruitful route to reconceptualize medical terminology, I found that this was not as easy in the Swedish translation of contemporary terminology, where DSD is called ‘tillstånd med avvikande könsutveckling’ (Nordenström et al., 2008).¹⁹ Since I had help from clinics distribute information about their about the project, I was also concerned that using ‘DSD’ would cause the potential interviewees to associate my project with medical research and practice to a greater extent than if not doing so.

Given these considerations I decided to describe my project as being concerned with sex development considered ‘atypical’ for one’s sex, or with ‘atypical’ sex development.²⁰ Indeed, I acknowledge that these terms by no means are unproblematic or all encompassing. They might, for example, give the impression that there are ‘true’ and ‘stable’ sexes in relation to which an individual’s sex development can be considered ‘typical’ or ‘atypical’, and they might strengthen feelings of alienation if not deployed by those affected. Possibly, this phrasing might also have impeded my chances of finding individuals who do use labels such as intersex or DSD when describing their bodies and situation. These were not my intentions. Instead, I find that by using ‘atypical’ it was possible to avoid implying that such bodies are bad or sick, or require corrections, which a label such as ‘abnormal’²¹ perhaps would suggest. To use ‘atypical’ sex development instead of intersex or DSD seemed wise in the light of my interviewees’ general unawareness

¹⁸ ‘Intersexuell’ in Swedish.

¹⁹ Directly translated into English, this would read ‘conditions with divergent sex development’ (my translation).

²⁰ In Swedish I used “‘otypisk” könsutveckling” or ‘könsutveckling (eller pubertetsutveckling) som anses “otypisk” för det egna könet’.

²¹ ‘Onormal’ in Swedish.

about the relationship between their condition and intersex/DSD, but at the same time allowed me to underscore that I was specifically interested in how individuals made sense of those aspects of their condition that pertained to sex categorizations and female embodiment. Judging from my conversations with physicians and representatives from patient organizations, I'm inclined to believe that my recruitment difficulties had mainly not to do with these decisions about how to frame my project, but rather with the lack of networks through which to reach these individuals in the Swedish context.

INTERVIEWEES

The 23 interviewees that I recruited had all undergone a sex development considered 'atypical' for the female sex, either by themselves or by medical professionals. The ten women with UVA did not have a uterus and no, or a so called small, vagina, but did have two functioning X chromosomes and functioning ovaries. The 13 women with TS *did* have uteri and vaginas, but did not have two X chromosomes (or a Y chromosome) and either no ovaries or non-functioning ones. In the following I describe the interviewees in more detail.

INTERVIEWEES WITH UTERINE AND VAGINAL AGENESIS

The ten women with UVA were 20 to 26 years old at the time of the interviews and had learned about their congenital absence of the uterus and either the whole of, or parts of, the vagina when they were 15–18 years old. For most of them this was a complete surprise, and all but one said that they had not suspected that something would be different about their bodies until they did not start to menstruate in their teens.²² Commonly, they described the medical exams that followed as stressful and emotionally painful, and most of them said that they found the information about the absent uterus and vagina devastating and difficult to take in.

All of them had had gynaecological exams that confirmed the absence of uterus and vagina, but only seven used a specific diagnosis when talking about it. Those seven referred to MRKH syndrome, a condition estimated to occur in 1/4000–1/10 000 women (ACOG, 2002). However, only three of these said that they had been given this diagnosis by a doctor, and the other four had come to the conclusion that this must be what they had, through information they had got

²² The interviewee who said that she had suspected that something might be different about her body said that she had not mentioned this to anyone and that she had not sought medical advice until she realized that she was not getting her period. Prior to that, she said, she did not know how to bring it up.

online. The three interviewees who did not use the term MRKH said that they had not received a specific diagnosis or name for their condition and instead used descriptive terms such as ‘absence of uterus and vagina’. None of the ten interviewees used terms such as intersex, intersexuality, or DSD to describe their condition.²³ Eight of them said that they were unaware of such labels, and while the two who did relate the absence of uterus and vagina to such labels reflected on the potential value of feeling included in intersex terminology, they said that they did not feel that such terminology applied to their situation.

It was these variations in the interviewees’ use of diagnostic labels that led me to simply describe their symptoms when referring to their condition, that is, to use ‘uterine and vaginal agenesis’, instead of a specific diagnosis such as MRKH. However, while it is not certain that these women had the same diagnosis, they all described themselves as presenting the symptoms that are said to characterize MRKH. That is, a ‘normal’ female karyotype (46, XX), but the absence of fallopian tubes, uterus, and vagina, which results in an incapacity to menstruate and conceive, and in potential difficulties in performing vaginal penetration. Yet, since sex chromosomes, ovaries, and hormonal levels are not affected, external genitalia, pubertal growth, and ovulation are medically considered ‘normal’ (Alessandrescu et al., 1996; Lindenman et al., 1997; Morcel et al., 2007).²⁴

Commonly, and as was the case for my interviewees, MRKH is detected in adolescence as a result of absent menarche (ACOG, 2002). At the point when these interviews were conducted, there was no way to medically treat the absence of a uterus (for recent developments of live uterus transplantation see Brännström et al., 2014). However, an absent, or so called small, vagina could be ‘treated’, meaning that a neo-vaginal space can be created, either by surgery and post-operational dilation or simply by dilation. At the time of the interview 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. The ones who had been told to only use dilators were told that surgery was not necessary but that it could be considered later on if the women so wished.²⁵ All of them mentioned being told that the vagina could be enlarged by

²³ As I have made clear above this was not specified as a prerequisite in the selection of interviewees.

²⁴ A congenital absence of the uterus and vagina also occurs in individuals with androgen insensitivity syndrome (AIS). In addition, however, those individuals have an XY karyotype and may have undescended testes in their abdomen. This was not the case for any of my interviewees.

²⁵ As mentioned earlier it is, however, in the medical literature increasingly stressed that to avoid unnecessary pain and scarring, and because of postoperative contracture and persistent bloody and/or offensive discharge that can result from such procedures, and since vaginal dilation still has to be performed after surgery, dilation is preferred

having sex, which was equated with penile–vaginal penetration, and eight said they had had such sex. Commonly, and as was the case for my interviewees, vaginal reconstructions are undertaken in late adolescence (ACOG, 2002).

Sometimes it is furthermore stressed that because this is considered a ‘sensitive’ period in girls’ lives, and because of the physical efforts required, treatment needs to be provided and performed in the most gentle way and requires high surgical and technical competence as well as attentiveness to the patients’ individual situation (Frost-Arnér et al., 2004). Occasionally, the women in my study mentioned having been offered psychological counselling, but typically said that the content of the support did not match their needs or that the offer was made too early, at a time where they could not make the most of it or even wanted to talk about their bodies. Furthermore, all but one expressed the explicit wish to meet others in similar situations, but said that they had found it very hard to make such contacts.

As the interviewees talked about their lives, all mentioned previous, present, or future boyfriends. All but one said that they had had or presently had a male partner, and eight of the total ten said that they had had penile–vaginal penetration.²⁶ Out of those nine who had had or had a male partner, one had not told the partner about the absent uterus and vagina. Although all of the ten had told some family members and close friends, they typically said that they were not that open about it. For example, the two who blogged about their experiences did so anonymously, but all of the ten said that they would appreciate a greater awareness in society at large about bodily variety in general and about genital variety in particular.

INTERVIEWEES WITH TURNER SYNDROME

Turner syndrome occurs in about 1 out of 2500 women as a result of a total or partial absence of one of the X chromosomes. Individuals with TS may present with a short stature, dysfunctional gonads, cardiac and renal malformations, and otological problems (Carel et al., 2005, 2006). It is estimated that about 20% of these individuals are diagnosed when older than 12 years of age (Massa et al., 2005). This condition is, like UVA, included in the DSD label (Lee et al., 2006), but none of my interviewees used DSD, or intersex, when talking about their condition;

over surgical alternatives (Callens et al., 2014; Edmonds, 2003; Ismail-Pratt et al., 2007; Liao et al., 2006; Moen, 2000).

²⁶ A heterosexual orientation or experiences of specific sexual practices were not specified as prerequisites in the selection of interviewees.

neither did they relate their condition to such terms or express an awareness about their condition being covered by them.²⁷

The 13 interviewees in my study who had TS had learned about their condition at different stages of life. Two had been diagnosed at the ages of 4–5 years, nine at the ages of 8–12 and two at the ages of 13–15. They were also in different stages of life when they took part in the interviews, and their ages ranged between 18–35 years old. I anticipated that this wide range, particularly that of age of diagnosis, would result in rather great differences in respect of interview focus, which could present potential complications in the analysis. However, as it turned out, the structure and contents of the interviews with those women diagnosed before adolescence did not stand out from the rest in any remarkable sense; nor did the interviews with those older than 30 years.

Most of these interviewees recalled the doctors' appointments and examinations preceding their diagnosis, and typically they said that their parents had scheduled these appointments because they were worried about the interviewees' short stature. Some described these experiences as tiresome and sometimes stressful, and the majority talked of the relief they felt when the condition finally was discovered. None of these interviewees said that the diagnosis, to their knowledge, had been kept secret from them, and most of them described being told about its consequences as soon as, or shortly after, the condition had been discovered (cf. Sutton et al., 2006).

After being diagnosed, all of them had undergone hormone treatments meant to increase their height and introduce pubertal development, since these would not occur spontaneously because of the ovarian failure (see also Carel et al., 2005). Several interviewees described these treatments as sometimes confusing, as they made the body change rapidly, but as still desirable. They commonly stated that having the condition at times had been difficult when growing up, especially when they were made aware that their bodies were not developing in the same way and as early as the bodies of their peers, and when it came to disclosing the condition to present or future partners.²⁸ Out of the thirteen, ten said that they had or had had a partner (of whom all were male), and three said that they had not had a partner but talked about future male partners.²⁹

Furthermore, whereas these interviewees most often stressed that their condition had been manageable, the incapacity to become pregnant without

²⁷ As noted in relation to the interviewees with UVA, this was not a prerequisite in the selection of interviewees.

²⁸ Some of them also described being aware of the risk of cardiac problems, but did not mention having experienced any.

²⁹ Once again, to have, have had or envisage a male partner was not a prerequisite in the selection of interviewees.

medical intervention often resulting from the condition had been and was, for some, still a central concern, in particular in relation to partners (see also Sutton et al., 2005). Egg donation may involve substantial risks for women with TS, since it may cause hypertensive disorders, preeclampsia, and even life-threatening disorders (Hagman, Källén, et al., 2013; Hagman, Loft, et al., 2013). Yet, my interviewees rarely talked about such risks and were overall positive towards egg donation, but likewise towards adoption.³⁰ One interviewee mentioned that she had had her eggs frozen in early adolescence as a part of a research scheme, and five interviewees had had an egg donation. Out of these five, three had had one child, one had had two children, and one had not had any children.

INTERVIEWS

As mentioned above, I found in-depth interviews to be an appropriate method for gathering data in relation to the study's aims. The purpose of in-depth interviews, according to Kvale (1996: 187), is to describe and interpret themes in the interviewees' lived worlds. This does not mean that in-depth interviews permit researchers to 'dig out' the 'pure experiences' of interviewees, but rather the research interview is seen as a specific context for dialogue in which certain stories can take shape (cf. Riessman, 2008: 28). The interactions in a research interview are, in my view, to a large extent shaped and framed by the personal characteristics, such as gender, age, and body features, of the interviewer and of the interviewee and therefore research interviews can be said to create situated 'understandings grounded in specific interactional episodes' (Denzin and Lincoln, 1994: 353). Thus, a topic that stands out as particularly significant in one interview may reside in the background in another in the light of the specifics of a particular encounter and those taking part in it.

The use of interview data can, of course, be fruitfully combined with analyses of other kinds of data. My project could, for example, have combined an analysis of interview data with explorations of patient organizations' perspectives through examinations of websites and activities or of medical studies on UVA and TS. It could also have involved interviews with physicians, to capture medical discourses surrounding these particular conditions. However, in light of the identified knowledge gap regarding individuals' lived experiences of these conditions and

³⁰ It should be noted that egg donation is not allowed for lesbian and single women in Sweden since it is illegal to have in vitro fertilization (IVF) with donated egg and sperm in Sweden (SFS, 2006: 351; Zeiler and Malmquist, 2014). These women/couples may however apply for adoption.

their sense-making, and my wish to try to capture these individuals' stories as told in their own words, I decided that in-depth interviews with individuals who had experiences such an 'atypical' sex development were the most appropriate method for gathering data.

STRUCTURE AND FOCUS

I conducted all the interviews myself; those with the ten women with UVA and the first five with women with TS were conducted in 2009 and 2010, and the other eight interviews with women with TS at the end of 2011 and beginning of 2012. While the interviews differed from each other, depending, for instance, on the mood of the interviewer and the interviewee, I usually found that a rather high degree of rapport and openness was established and that the interviews were comprised of emotional and reflexive dialogues.

The interviewees chose the location of the interviews; most of them wanted to meet in their homes, but some preferred that I reserved a private room at the local library, which is available in most towns in Sweden, and others preferred to meet in my office. One interview was conducted over the phone, since this interviewee lived abroad at the time. While I at first thought that it would present certain difficulties to conduct the interview over phone, for example, in terms of establishing trust in the interview situation, my experience was rather that the level of rapport in this interview was high, which the interviewee also explicitly noted at the end of our conversation. This could, of course, have had to do with 'personal chemistry', but it also highlights the potential advantages of the physical distance in phone interviews in terms of, for instance, making topics that might be perceived as sensitive in a face-to-face situation easier to talk about. All interviews were recorded and on average they lasted for about one and a half hours, after which I wrote down notes and impressions from the meeting.

A semistructured interview guide formed the core of the interviews. The guide revolved around questions concerning what it had been like to find out about and live with an 'atypical' sex development from the interviewees' perspectives, including, for example, queries about the interviewees' encounters with medical professionals, their interactions with family, friends, and partners, and occasions when interviewees potentially had been reminded about the specifics of their development. The insights gained as the project progressed resulted in some revisions of the interview guide so that themes of certain interest were given more attention, and questions that, for example, appeared too abstract or complicated were modified. Generally, the themes and questions that I wanted to cover were ordered chronologically in the guide. I usually began the interview by asking the

interviewee to tell me how it all started and then moved forward to the present and the future. This did not mean that the interviews necessarily resulted in chronological descriptions; the interviewees' focus in their responses and my follow-up questions rather made our conversations move back and forth between different topics and phases in time, but it helped me to cover the areas of interest to me.

As I conducted the interviews some striking differences in their general structure occurred to me. In general, the women with UVA, who I came to interview first, did not seem to have any 'well-rehearsed' stories to present; often we moved rather rapidly between different topics, events, and periods, and did not always have a clear beginning, middle and end. Furthermore, at times I found these interviews emotionally challenging, and it often seemed that the interviewees found it somewhat hard to put their experience into words. The majority of the interviewees said that they had not talked with others about their condition to any great extent before the interview, but nevertheless often expressed a strong wish to tell me about their experiences. Viveka Adelswärd (1997) has noted that, whereas stories that have been told several times often involves coherent details and episodes, those told for the first time often need more support from the listener to become coherent. The efforts that were required from me as a researcher in these interviews, in terms of probing and follow-up questions, could thus be explained as resulting from the interviewees', and my own, lack of experience in talking about their specific experiences.

In contrast, the structure of the interviews with women with TS was different; they often had a clearer chronological structure and were also less emotionally laden. They also covered larger sections of time. We more often talked about the general courses of events, and the interviewees provided fewer detailed descriptions of specific occasions at specific points in time. These features could, if again, following Adelswärd (1997), be seen to relate to the interviewees' previous experiences of disclosures – most of these women had experience talking with others, outside the realm of family and close friends, about their condition, and these experiences could have enabled them to draw on 'prerehearsed' stories in their interviews. And, since these interviews were conducted at a later stage of the project, I was furthermore more 'rehearsed', which, of course, affected both the structure of the interviews and my experience of the same.

In accordance with the identified patterns in the interviews' structure I put greater focus on questions meant to capture the interviewees' interactions with others, as I found that such questioned could enable me to explore how the interviewees expressed dominant norms in their narratives. For example, I asked

the women to recall occasions or situations when they had been reminded about their condition and to describe interactions with family, friends, partners, and others, and how the women felt about and managed such interactions.

TRANSCRIBING AND TRANSLATING

I transcribed all recordings from the interviews. When transcribing sometimes messy talk from verbal interviews, researchers do not, Riessman (2008: 28) wrote, ‘stand outside in a neutral objective position, merely presenting “what was said”’. On the contrary, the researcher is very – and constantly – present in this process, through which spoken words, utterances, and gestures are transformed into a text suitable for the analysis we are about to undertake. Viewed in this manner, transcribing becomes an interpretative and analytic practice that rests upon the researcher’s theoretical vantage points (Bird, 2005; Lapadat and Lindsay, 1999).

There are a number of coexisting conventions on how to go about transcription in qualitative research (see, e.g., Lapadat and Lindsay, 1999). As my aim was to find out how individuals make sense of their ‘atypical’ sex development, I found that the level of transcription didn’t need the same amount of detail as required when performing, for example, a conversation analysis, but at the same time, I did not ‘clean up’ transcripts in the sense that I omitted grammatical errors, hesitations, and unstructured talk. Adopting a rather basic level of detail, I indicated pauses and hesitations, but not the exact length of them in seconds, and marked words that were difficult or impossible to distinguish. Emotional expressions such as laughter or crying were noted, which was important, as such expression facilitates the researcher’s distinguishing multiple dimensions of what has been said; for example, laughter that might indicate an ironic tone or extenuate the strength of an utterance (see also Adelswärd, 1996).³¹ In the excerpts used in the articles I replaced symbols that indicated these non-verbal utterances, such as * for laughter, with descriptions of the utterance in hard brackets [laughter] to make them easier to read.

When transcribing I also marked when I during the interview, for example, in a confirming or wondering tone, said ‘Hmm’, ‘No?’ or ‘Yes...?’. Such small remarks, made it possible to, for instance, see when what had been said was clear and made sense to both to me and the interviewee, or the surprise that I presented in the light of what had been said, as well as the way in which such small words helped the narrative to develop. I also indicated when we interrupted each other. If this was done with a short remark, I put the sentence or sentences in parentheses within the

³¹ See appendix B for the transcription guide.

account; if the interruption involved a longer stretch of talk, I marked it by placing it on a new line.

I transcribed all interviews myself, in parallel with conducting more interviews and beginning to analyse those transcribed. In contrast to the complaints from many researchers about transcription being the most boring and tiresome part of the qualitative research process, I find it rather rewarding (cf. Bird, 2005). As I listen, stop, write, rewind, stop, listen, stop, rewind, stop, correct, rewind, stop, listen at a lower speed, stop, add two words, stop, and so on, the interviews stays with me. In this continuous, physical process, the interview ‘sticks’ in my mind *and* to my body, as it makes the muscles around my eyes tense, my shoulders stiff, and my back sore. I view this as an interpretative act that familiarizes the researcher with the data and makes it possible for the researcher to recall, for example, non-spoken aspects of importance for understanding the interviewees’ stories. Transcription is thus not only a process by which what has been said is recaptured; it constitutes a part of the analytic process (Riessman, 2008).

The process of translating the excerpts for international publications is perhaps not as physically straining as that of transcribing, but may nevertheless certainly present a creative and analytic challenge. I conducted all interviews in Swedish, since it is both my and the interviewees’ native language. I also kept to the original Swedish texts as I conducted the analysis. This was important, because it enabled me to distinguish sentiments in specific accounts and recall the atmosphere of the interviews. The subsequent necessity of translating specific quotes and excerpts when publishing internationally does not, in my view, means that one should not publish in such fora, but it indeed highlights the importance of reflection upon what might be lost, and gained, in the process of translation. For instance, words that might be assumed to mean the ‘same’ thing might have specific connotations in the cultural context of the original language. The words chosen thus matters and also highlights the personal and interpretative dimensions of translations (Temple and Edwards, 2002).

When I translated excerpts, my main concerns were to make the translations as accurate as possible regarding their content, and to capture sentiments and expressions within them. Yet, despite extensive efforts, I do believe that certain aspects inevitably get lost in translation. In particular, idiomatic expressions may be difficult to capture, as well as those small words that appear over and over again in an interview and which cannot be easily translated, but which may make a great difference to the spirit of the text. Moreover, I found that when translating some accounts their ‘messiness’, which may be of great analytic significance in that it signals that there is no rehearsed story for the interviewee to draw on (cf.

Adelswärd, 1997), can get lost. I often found it particularly difficult to convey in translation those grammatical errors and hesitations that may indicate that a certain topic is hard for the interviewee or the interviewer to talk about. This does not mean that I turned ‘messy’ or incoherent quotes into ‘neatly’ ordered stories, but rather that I carefully tried to capture the sentiment without violating the grammar of English in a way that would make the quotes too ‘Swenglish’ or incomprehensible. To do so, I moved back and forth between the Swedish ‘original’ and the English translation when writing up the articles. I also sought advice from supervisors and colleagues, and those sections that I had found particularly difficult to translate were sent, in Swedish, to professional language reviewers, fluent in both English and Swedish, who proofread the final drafts of the articles. Thus, while the process of transcribing called attention to the complexities of teasing out the non-verbal information and sentiments in the interviews, the process of translating brought attention to the challenges of avoiding having the meanings of certain words and ways of talking become lost in translation. Furthermore, efforts made to handle such challenges contributed to strengthening credibility in the sense that they forced consideration of the ways in which to represent what the interviewees said.

ANALYSIS

The project’s analytic process was divided into two phases. The first phase began as the first interviews were transcribed in parallel with the conduct of additional interviews. In this phase passages of interest in relation to the aims and research questions of the study, but also issues that were surprising and unexpected, were highlighted. Aspects to which I wanted to give greater attention in subsequent interviews were also noted. These analytic steps were followed by a basic coding of each interview, in which important themes and narratives in regard to both content and structure were identified and labelled. These labels were then compiled into a ‘list of contents’ for each interview. By comparing these lists across interviews I could identify similarities and incongruences in the data in relation to, for example, the interviewees’ current age, their age at diagnosis, whether they described themselves as being used to talking about their condition or not, and their contacts with other individuals with similar conditions.

When I, as I described above, had conducted ten interviews with women with UVA and five with women with TS, the analysis concentrated on the women with UVA. I especially found it promising to further examine the narratives that these women provided in their interviews, despite the fact that these often were

presented without a clear beginning, middle, and end, and often were spread out in the interview. When later on I conducted another eight interviews with women with TS, the analysis focused more directly on important themes and contrasts that I previously had identified through my initial analysis of the first five interviews with women with TS, in relation to the ten interviews with women with UVA.

In the light of the initial analysis the more specific focus of the four articles that form the basis of this thesis took shape. In this process a narrative approach and a thematic approach were applied. While representing two separate ways to approach data, there are some particularly significant overlaps between them that should be spelled out. First, both of them fall within what Wilkinson (2000: 438) called ‘biographical’ research in the sense that they concern ‘people’s search for meaning and their attempt to make sense of their lives and identities’. Second, both approaches examine extended segments of texts rather than singular coding units in order to address individuals’ meaning making and to take into account how the specific cultural and local contexts of an interview shape both that which can and that which cannot be said. Third, both approaches recognize that, while in applying them it is not possible to obtain direct access to commonly held assumptions and dominant norms of the cultural context in question, such assumptions and norms can still be interpreted and analysed with the help of theoretical frameworks and previous research. This shared basis ties the analytic approaches of the articles together while at the same time allowing each article to explore specific dimensions of the data.

AN EXPERIENCE-CENTRED NARRATIVE APPROACH

To analyse the recurrent narratives that I identified when comparing ‘lists of contents’ created for each of the interviews with women with UVA, an experience-centred approach to narrative analysis was deployed. With theme rather than structure in focus, and by centring on individuals’ experiences rather than specific events, this approach seeks to capture how narrators organize experiences into sequential and meaningful stories³² (Squire, 2008). Narratives may thus concern events of the past, but can as well take a more flexible stance in regard to time, and may address more general experiences that are not necessarily temporally ordered as well as the present and the future. The approach thus acknowledges that narratives do not necessarily have a clear structure, in the sense of presenting a distinct beginning, middle, and end, and recognizes the process of identifying and

³² I use the term narrative and story interchangeably. However, stories are in some traditions seen as a specific kind of narrative, in comparison to, for example, habitual or hypothetical narratives (see Riessman, 2008: 6).

distinguishing narratives from one another within one interview as an interpretative one (see also Riessman, 2001). To identify narratives in the interviews and to distinguish them from one another I focused on recurrent patterns in the structure and content of the interviewees' attempts to order events and experiences in sequential and coherent manners. When trying to determine where the narratives began and ended, I paid specific attention to how one narrative could be disrupted by another and then be picked up again.

Furthermore, within this approach narratives are seen to comprise both first-person recountings and stories about others and about the cultural context in which the narrator is situated.³³ Therefore, an analysis of narratives may convey how subjects present and position themselves in relation to others within the cultural context in which they are situated (Lindemann-Nelson, 2001; Squire, 2008). As Riessman (2008: 105) poignantly put it, stories 'don't fall from the sky (or emerge from the innermost "self"); they are composed and received in contexts – interactional, historical, institutional, and discursive – to name a few'. Certain experiences, interests, realities, and identities are therefore privileged over others in the specific context that the research interview constitutes (Langellier, 2001). This means that I understand narratives as *performative*, that is, enacted in specific manners in relation to those listening, and thus, view narratives' structures and contents, as well as the meanings they express, as being shaped by the specific context in which they are told (Langellier and Peterson, 2004).

More specifically, in applying this approach to narrative analysis, I teased out how the interviewees, in their narratives, positioned themselves in relation to specific others (cf. Riessman, 2008: 106). Using positioning as an analytic tool in this manner did not imply that I viewed the interviewees' positioning as necessarily intentional, but rather I treated it as being constructed in relation to the specific context of the story (see Bamberg, 2004).

In practice this phase of the analytic process involved rereading the interviews while looking particularly for sections in which the women talked about relationships and interactions, and how they in such talk aligned with and contrasted themselves to others. I also paid close attention to how the interviewees used different implicit systems of values and assumptions about the world, that is, 'explanatory systems', as resources in their positioning and to bring coherency to their narratives (Adelswärd, 1997; Linde, 1986). In doing so, I could examine how the interviewees managed to juggle several, at times opposing, narratives

³³ In William Labov's definition a minimal narrative is constituted as 'a sequence of two clauses which are temporally ordered' (Labov 1972:369 cited in Patterson, 2008). Defined in this manner, a narrative is primarily seen as a text that functions to recapture and represent past events, taking limited account of context (Patterson, 2008).

simultaneously, and how they, when doing so, both reinforced and challenged culturally shared beliefs and norms (cf. Bamberg, 2004). These explorations of positioning also, and finally, involved examinations of what the interviewees' expressions emotions such as fear, frustration, and desire for connection with specific others, accomplished in their narratives, for example, in terms of differentiating between subjects (see, e.g., Ahmed, 2004; Butler, 2004; Hemmings, 2012).

AN INTERPRETATIVE THEMATIC APPROACH

When I more thoroughly analysed all of the 13 interviews with women with TS, my earlier impressions of differences in character between these interviews and those with women with UVA were strengthened. Intrigued by these differences, I decided to examine them across the entire data set, that is, including all the 23 interviews. When doing so, I found that certain themes rather than narratives spanned the two groups. To further explore these identified differences in structure and overarching themes, a broad analytic strategy was required, and I chose to use an interpretative thematic approach.

Thematic analysis has often been described as a tool employed in a range of qualitative approaches, but has also occasionally been distinguished as an analytic approach of its own (see, e.g., Braun and Clarke, 2006; Kitzinger and Willmott, 2002). First, and importantly, the application of this approach when analysing the entire data set enabled examinations of accounts that did not have a narrative structure (Kvale, 1996: 201). Furthermore, my deployment of this approach could more specifically be distinguished as 'contextualistic' in that it focused on how the interviewees' meaning-making is shaped by larger social contexts, while at the same time bearing in mind the material 'limits of reality', such as the materiality of bodies (cf. Braun and Clarke, 2006). Using this approach I thus, in line with Kitzinger and Willmott (2002: 351), treated the interviews as 'interpretative autobiographies', which meant that I did not attend to the 'locally specific' actions of our encounters in the research interviews per se, but rather to the understanding and sense-making that the interviewees presented in their accounts (Kitzinger and Willmott, 2002: 351).

Finally, the thematic approach was interpretative in the sense that it was not simply used for identifying and describing themes, but also for relating them to theoretical frameworks and previous research. By this, I do not mean that 'anything goes' when it comes to interpretation. The theoretical assumptions that form the basis of one's examinations must still be clearly spelled out, but there is flexibility in the ways that theoretical frameworks can be combined to shed light upon the data.

The interpretative feature of my thematic approach made it possible to bring out assumptions underpinning the identified themes, interconnections between such assumptions, and implications resulting from them (see Braun and Clarke, 2006). It did not, however, mean that I accommodated the analysis to a pre-existing ‘coding frame’ of theoretical concepts, but instead I identified themes as interesting on the basis of their significance and occurrence in the interviews.

In practice, my application of the thematic approach meant that I moved back and forth between general impressions and specific statements within and across interviews (see Kitzinger and Willmott, 2002). Focusing on the meaning and underlying assumptions of the identified themes, these readings concerned why a specific theme was talked about in a particular way and not in others, and what overall insights the identified themes provided about not only the interviewees’ sense-making but also the shared cultural beliefs and norms that they related to (cf. Braun and Clarke, 2006). In particular, I compared strategies used by the women to negotiate and account for normality, how they understood and distinguished themselves and their experiences, and how they justified and motivated such distinctions (see Taylor and Bogdan, 1998). The patterns generated through this process were then read against those circumstances of everyday life that the interviewees underscored as particularly significant. Furthermore, I made use of tools from narrative analysis as I examined ‘subjunctivizing’ strategies – that is, how they construed plots for what was happening to them and what might happen in the future (see Kirkman, 2002).

SOME FINAL REMARKS

Above, I have covered the ways that data were gathered and analysed, and described the choices and the decisions taken throughout the course of the project. Some final remarks regarding the project’s design and the analytic process are, however, in order. In correspondence with my aims and research questions, my study covered a rather small number of interviews. While my findings may not directly be generalized to all other women with UVA and TS, conclusions drawn from an analysis which presents ‘thick descriptions’ can, however, have a bearing on examinations of similar narratives or in related fields (see Bryman, 2008). Throughout the course of the project I have strived to present such descriptions when analysing the data. To corroborate my conclusions and tease out potential weaknesses of my analysis I have, moreover, presented and discussed its design and analysis in different academic contexts. By putting my work under such scrutiny and through the detailed account of the research process provided above, I hope

credibility of my analysis is strengthened and that the consistency of my project at large is brought out.

RESEARCH ETHICS

In this chapter I discuss research ethics and reflexivity, specifically in relation to the potential sensitivity of the phenomena of interest in my study.

The overall design and execution of the study followed guidelines formulated in the act concerning the 'Ethical Review of Research Involving Humans' (SFS, 2003: 460),³⁴ which covers communication of research aims, acquisition of informed consent from participants, participants' rights to refuse or terminate participation, confidentiality, and assessment of potential risks and benefits for participants as well as risks and benefits in a more general perspective generated by the research at hand.³⁵

Regarding communication of aims, the information letter distributed to potential interviewees described not only the aim of the project at large but also what participation in an interview involved (see appendix A). Furthermore, it emphasized that the interviewees were free to interrupt and/or terminate the interview and withdraw their consent whenever they liked, without having to explain their reasons for doing so. The letter also stated that all data would be handled confidentially, meaning that all personal information and names would be replaced by codes and that original transcripts and recordings would be kept in a safe at Linköping University. It was also stressed that the collected material would only be used for research purposes and that, if they wished, the interviewees would get a copy of the final publications resulting from the project. Those clinicians, patient organizations, and interviewees who distributed the letter to potential interviewees were informed that I was not to receive any information about potential interviewees, but that those who were interested should contact me, using the contact details specified in the letter.

Those women who contacted me and subsequently agreed to participate were given the same information once again at the time of the interview, both in writing and orally, as well as contact information for a psychotherapist whom the interviewees could contact if they wished to talk about their experience, or about

³⁴ The act stipulates that all research that employs a method which includes an apparent risk of injuring the research subject either physically or mentally, whether the work is experimental or theoretical, should undergo ethical vetting. The present project underwent ethical vetting and was approved in June 2009 (Linköping Regional Ethics Review Board, 2009).

³⁵ See also Hermerén (2011).

the interview, with someone other than the research group. They were also once again informed that both their consent forms and the lists linking specific individuals to key codes that would replace their names in the transcripts would be kept in a safe. Interviewees who had been recruited through clinicians were furthermore informed that their doctors would not have access to the original data but only to published articles (in which all names would be replaced by pseudonyms).

With regard to the guidelines about informed consent and termination of participation, all interviewees signed an informed consent form by which they confirmed that they had been given the information described above, and that they were aware that they could interrupt and/or end the interview whenever they wanted, without having to explain why, and by which they agreed to participation and to the interview being recorded. During the course of the study none of the interviewees chose to terminate their participation.

With respect to confidentiality, all documents with information that could identify the interviewees – the signed forms, original recordings, transcripts of interviews (one digital and one paper copy), lists with interviewees' names and corresponding codes, paper copies of e-mails – were kept in a safe. When analysing the interviews, and when presenting excerpts at seminars and conferences, only transcripts with pseudonyms were used. I have also throughout the course of the project restricted background information about the interviewees in publications and presentations in order to secure confidentiality. This was particularly important in order to avoid clinicians being able to identify their patients and representatives from patient organizations being able to identify members, in my study.

Finally, regarding assessment of risks and benefits for participants, research involving interviewees' personal narratives always carry the risk of making interviewees recall frightening and painful experiences and may thus threaten participants' integrity. Moreover, among the risk of research to be considered is the inherently hierarchical character of the relationship between researcher and 'researched', in which the situation and the area of interest are defined and interpreted by the researcher, and the researcher selects the manner of presentation and the audience for the results produced. On the other hand, research interviews can be beneficial for the interviewees in that these may present opportunities to talk about issues and experiences of the interviewees' choosing, with someone actively listening to what they have to say. They may provide a sense of purpose, self-acknowledgement, and validation (Kavanaugh and Ayres, 1998; Rosenthal, 2003), and even a therapeutic experience of disclosure and reflection about oneself,

which make previous fears (more) liveable (Corbin and Morse, 2003; Frank, 2007; Guillemin and Heggen, 2009).

The potential risks of this kind of research do not, in my view, mean that it should not be conducted, but they require that the researcher take measures throughout the research process to conduct the interviews in a way that increase the chances of it becoming a positive experience for the interviewees. This means that the researcher must carefully consider how to create an atmosphere in which the interviewee feels comfortable talking about such memories and experiences, but also feels free to express a desire not to talk about certain topics. I strived to give the interviews an open character by constructing a wide question that allowed the interviewees latitude to guide the course and focus of what we talked about, while at the same time asking follow-up questions that could support and facilitate their narration. In this undertaking my revisions of the interview guide were crucial in that they contributed to refining my questions and figuring out what could make the interview situation comfortable as possible, given that the topic of concern could be experienced as painful or difficult to talk about.

Also of note is that it could be argued that, as my analysis categorized interviewees according to medical labels, it might have reinforced precarious medical categorizations, and in doing so, restricted rather than facilitated individuals' opportunities to identify and create interconnections with others and failed to empower them. However, and importantly, since the interviewees themselves used medical diagnoses or descriptive terms when talking about their bodies and situations, I found that using the same labels was the best way to do justice to the ways in which the interviewees themselves talked about and described their bodies. Furthermore, many of the interviewees said that while they had felt nervous about participating they felt that the interview provided a space where they could talk about experiences and issues which they seldom discussed with others (the latter was especially the case among the interviewees with UVA). They said that they valued the project's focus on their perspectives and views, and that they believed the interview was a way to have their voices heard and possibly to help others, without having to disclose their names.

On a more general level the benefits of research concerned with personal narratives within under-researched areas, such as 'atypical' sex development, include an increased and deepened knowledge about how individuals make sense of the phenomena of interest. It is my belief that such examinations have the potential to contribute to an increased general awareness about 'atypical' sex development and, more specifically, to improved care practices that take the experiences of individuals into greater consideration. Furthermore, the researcher herself may also

benefit from the reflexive processes that this kind of research should involve in the sense that it ultimately may lead to new self-understanding and to the uncovering of values and assumptions previously taken for granted.

SENSITIVITY AND REFLEXIVITY

In the view of the ethical review board the research group should include supervisors with experience in doing *difficult* research interviews on *sensitive* topics with *vulnerable* persons.³⁶ [italics added]

(Linköping Regional Ethics Review Board, 2009)

The above quote not only presents one of the comments that I received from the regional ethics review board; it captures as well the reactions that I often have received when talking to people in general about my research. But then, what counts as a “difficult” research interview? What makes a topic sensitive? Who is considered vulnerable? And how may such understandings of interviewees risk positioning them in perilous manners? Along with the ethical considerations taken throughout the project these questions have informed my own reflexive process.

As my project progressed, the statement from the ethical review board bothered me. Indeed, I have often found the topic of my study difficult to approach and emotionally challenging – but what might it mean to distinguish certain interviews as difficult, certain topics as sensitive, and certain persons as vulnerable, even before the interviews have taken place? As I conducted the interviews, I found that such presuppositions could be ethically problematic insofar as they made me less reflexive about the assumptions that shaped my research design and about the co-construction taking place in the dialogue between me and the interviewees.

In response to these queries I found it fruitful to view sensitive topics as relationally constructed, which means that the sensitivity of a topic is understood to occur in relation to the personal views of the teller and the listener, and the cultural

³⁶ The original Swedish quotation reads, ‘Nämnden anser att forskargruppen bör knyta till sig handledare med erfarenhet av svåra forskningsintervjuer med sårbara personer kring känsliga frågor’ [my translation] (Linköping Regional Ethics Review Board, 2009).

and contextual circumstances in which they are situated (Hydén, 2008).³⁷ A topic is thus not sensitive *per se*, but *becomes* sensitive when culturally defined norms which shape the relationship are violated. While I at first had expected certain topics to be sensitive and had not fully acknowledged the practical implications of the relational dimensions of sensitivity, I was soon made fully aware of the complexity of what makes a topic sensitive. As I started to conduct the interviews, topics that I had expected to be difficult were sometimes not particularly hard for the interviewees to discuss, while topics that I had expected to require few specific measures on my part, in terms of probing, for example, at times required extensive work. Furthermore, a topic that was extremely emotionally laden in one interview could appear unproblematic in the next, and while most interviewees were very open to talking to me about their ‘atypical’ sex development – which is not particularly surprising given that they volunteered to participate in an interview – they at the same time recurrently expressed that their condition often had been a sensitive issue in interactions with close others, such as friends and family.

Especially, I found that, despite considering myself rather experienced in talking with young people about sexuality and sexual practice from my involvement in previous research projects, topics relating to sex and sexuality were less thoroughly covered in my interviews with women with TS than in those with women with UVA. The uneasiness and sometimes surprise that I noted among the interviewees with TS when I introduced questions concerning sex and sexuality made me, at times, shy away from such topics. Similarly, the unawareness of the inclusion of TS in DSD or intersex terminology and the trouble and confusion that such topics seemed to create made me hesitant to ask too much about this.

Overall, these features led me to make further efforts to create an open atmosphere and maintain an open attitude in the interviews, for example, by coming up with a range of alternative questions in the interview guide for me to draw on if the interview got stuck. I also paid close attention to the interviewees’ non-verbal reactions, and when they seemed uncomfortable, I reminded them that they were the ones deciding what felt okay to talk about and what did not.

The relational understanding of sensitivity furthermore led me to reflect upon my own body’s situatedness in the interviews and especially the relationship between my own and the interviewees’ bodies (see also Sandberg, 2011: 111ff). In the interviews bodily differences between me and the interviewees were usually not obvious. We were at about the same age and seemed to have about the same size in clothes, and although women with TS usually are shorter than the Swedish average

³⁷ For somewhat contrasting but still contextually oriented perspectives, see Johnson and Clarke (2003), Lee (1993), and Siber and Stanley (1988).

height for women, my 160 cm body did not stand in stark contrast to theirs – some of them were even taller than I. Still, I knew, and to me it seemed that the interviewees might have guessed, that at a visceral level our bodies differed. Although we did not talk about it, unless the interviewees specifically asked me, I felt that the presence of a uterus, a vagina, ovaries, and two X chromosomes in my body mattered in our interaction.

Research interviews are, in my view, to be considered as processes of co-construction – inasmuch as both the researcher and the one being researched shape what is being said – but the relationship between the researcher and the researched is at the same time inherently hierarchical (e.g. Alcoff, 2000; Fine, 1994; hooks, 1990; Wilkinson and Kitzinger, 1996). This means that interviews inevitably are shaped by the researcher's perspectives, for which the researcher's body not only may represent a vantage point but also may function to highlight differences and similarities that can increase and/or reduce the distance between the researcher and the researched. As a colleague of mine, a male professor in his mid-fifties commented, it would not have been possible for him to conduct the same interviews as I had, in terms of either the questions I had asked or how I had asked them. This feature highlights the importance of keeping a reflexive stance towards the relationship between the researcher and the researched and its unequal power relations. Scholars in, for example, disability studies (see, e.g., Bogdan, 2001; Stone and Priestley, 1996), feminist/gender studies (see, e.g., Bartky, 1990; Fawcett and Hearn, 2004; Fine, 1994; Krus, 2001; Wilkinson and Kitzinger, 1996), and post-colonial studies (see, e.g., Mattsson, 2009) have addressed whether their inquiries may contribute to, rather than alleviate, the marginalization and oppression of those to whom their interest is directed. But does this, then, mean that research is best done by someone as close and similar as possible to those who are being researched?

Linda Alcoff (1991) argued that, while it certainly is problematic to speak for others, the opposite, to only speak for oneself or for those groups of which one is a member, is not an alternative. If striving to create increased space for voices that are rarely heard, one should, Alcoff suggested, strive to create conditions that make possible dialogue and speaking *with* and *to* others, rather than *for* them, since this may facilitate the production of a 'counter-sentence' and may result in alternative narratives. The questions posed in the context of the research interview may then, as Marguerite La Caze (2008: 127) pointed out, represent 'a kind of admission that we do not already know the others' perspective' and allows us to express our respect for and interest in others. At the same time, such questions call for caution. As the researchers, through questions, demand to know perhaps not everything but

a lot about the other, yet often refuse to reveal themselves, questions may strengthen the asymmetric power relations between the researchers and those being researched.

Sustaining a reflexive stance towards these complexities has informed my understanding of the benefits and risks of my project, as formulated above, and shaped how I approached the interviewees. It has made me carefully consider the fine balance between questions that signal interest and respect and those which become intrusive, and in each interview explain and signal through my responses in our interactions that I was interested in listening to their stories and perspectives and that there were no 'right' or 'wrong' ways in which to answer my questions.

In this reflexive process I have also been made aware of the efforts required to counterbalance my emotional engagement and desire to give these women voice. Although my research may increase awareness and potentially provide tools for sense-making to be used by individuals with an 'atypical' sex development to articulate their experiences, my main aim has not been to give voice or tools but to investigate sense-making. I have had to stay constantly aware of and try to resist the possibility of uncritically valorizing their voices, and instead seriously listen to them and properly examine them (cf. Holmes, 2008: 64).

SUMMARY OF ARTICLES

This chapter provides an overview of each article, while its relation to the overall aims and the research questions are discussed in the next chapter. It should be noted that the order of the articles is not strictly chronological but is rather meant to capture the analytic progression in a coherent manner. In focus in the first and second articles are narratives about UVA, whereas the third and the fourth articles present an analysis of the entire data set.

ARTICLE I

Guntram L (2014) Creating, maintaining and questioning (hetero)relational normality in narratives about vaginal reconstruction. *Feminist Theory* 14 (1), 105–121.

Examining how the women with UVA make sense of the option to undergo vaginal reconstruction, of the (often surgical) intervention in their bodies that vaginal reconstruction involves, and of their ‘post-interventional’ situation, the general aim of the first article is to explore how these women draw on and challenge norms and beliefs about heterosexuality and bodies in their narratives about vaginal reconstruction. Doing so, the article presents an analysis of three treatment narratives.

The first of the three narratives concerns the interviewees’ decision-making with regard to treatments that involve surgical creation of a vagina, and post-operative dilation, or enlargement of a so called small vagina, with the use of dilators. Such treatments are, in the first narrative, presented as self-evident and unavoidable in the light of the women’s dissatisfaction with ‘the present state of affairs’ (i.e. not having a vagina or having one considered too small) and their wish to be ‘normal’ in the sense of being more like everyone else and having a body that ‘works’. An ideal (hetero)relational normality – that is, the enablement of a long-term relationship with a male partner, including ‘normal’ heterosexual practice, which in this narrative often centres around penile–vaginal penetration – here presented as desirable and as attainable only if one has a vagina.

The second narrative concerns how the women, despite the pain often inflicted, have continued to dilate the vagina in order to make it gain, and subsequently maintain, a ‘normal’ size, which will make ‘sex’ work. Moreover,

insofar as dilation can be substituted with penile–vaginal penetration, this ‘maintenance work’ not only comes to concern the women’s interactions with their own bodies, through their use of dilators, but as well their interactions with partners. Maintenance work thus strengthens norms and beliefs about required vaginal size and sexual practice and, since male partners come to play a central role in maintenance, it also reinforces beliefs and norms about the size and function of male genitals and assumptions about male partners’ sexual desires and expectations with regard to sexual practice.

However, while the body in the first narrative represents a site for modification, and in the second a site for maintenance, the third narrative presents yet a different aspect. In this narrative the women depict their decision to cease dilation and question the results of treatment. Usually, this does not mean that they explicitly dissociate from their previous treatment decisions, but rather, that their questioning lies in the way they underscore that they do not by any means like the maintenance work required. They point out that dilation is hard and that, although treatment is meant to create a ‘normal’ vagina, it may still be more difficult than was previously expected. Some of the women also occasionally – more explicitly – challenge the significance of vaginal size by underscoring that male partners do not seem to notice any difference. Those interviewees who have not had surgery likewise challenge the potential results of treatment. While they, on the one hand, describe penile–vaginal penetration as often being painful, on the other hand, they express their uncertainties regarding whether surgery would make things better. In either case, in this questioning the women reflect upon sexual practices, male partners’ expectations, medical possibilities of creating a vagina, and the specificities of their sexual subjectivities in a manner that enables them to reevaluate and expand understandings of (hetero)relational normality and position their bodies as sites for resistance.

My intention in this analysis is not to dismiss the interviewees’ treatment decisions (cf. Karkazis, 2008), but by examining the negotiations taking place in the interviewees’ narratives about vaginal reconstruction expand understandings of possible motives for bodily modification, which are especially important in relation to the unfortunate absence of discussion about this sort of vaginal reconstructions in relation to female genital cosmetic surgery (see, e.g., Braun, 2009; Tiefer, 2008) and in examinations of treatment of DSD (see, however, Boyle et al., 2005). In particular, I argue, the article spells out how the notion of ideal (hetero)relational normality, enacted through medical interventions, may shape the women’s bodily ways of being and interacting with others. The knowledge of the absence of a vagina gives rise, in the first and second narratives, to a desire and a felt need for

treatments that are aimed at creating a body that fits the ideal – which in turn informs understandings of ‘functioning’ bodies and ‘functioning’ sexual practice. In this manner sociocultural norms shape corporealities, when are enacted in medical treatment, and such corporeal shapings may in turn express and consolidate sociocultural norms. The ‘juggling’ of treatment narratives, brought out in the article, points to the complexity of living with vaginal agenesis and of undergoing vaginal reconstruction and highlights, in as it shows how sociocultural norms about female embodiment and heterosexual practice inform and feed into corporeal modifications and maintenance work. It also shows how understandings of female embodiment and heterosexual practice can be renegotiated and questioned in the light of the women’s management of their vaginas and their interactions with male partners.

ARTICLE II

Guntram L and Zeiler K (under revision for *European Journal of Women’s Studies*) ‘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.

The second article continues to explore narratives from the interviews with women with UVA, using an experience-centred approach to narrative analysis. In focus are the interviewees’ stories about disclosure and connecting with others. In exploring these, the article identifies three narratives that together form the interviewees’ larger storyline of coming out. The analysis of these narratives draws on feminist writings about the performativity of affects or emotions (Ahmed, 2004; Hemmings, 2012), in which individuals are understood as being shaped and reshaped by, and as shaping others, in emotional encounters. In particular, the article makes use of Clare Hemmings’s (2012) notion of affective dissonance as a way to understand how emotions may enable individuals to connect with others and articulate critique. The article’s specific aim is to investigate how fear and frustration are expressed and may function as affective dissonance in the interviewees’ narratives about letting others know that they have no uterus and no, or a so-called small, vagina. It also examines how the interviewees narrate desired steps to being recognized in relations with others. In focus are thus the accomplishments of emotions in the interviewees’ narratives – what emotions ‘do’ in terms of enabling the interviewees to position themselves vis-à-vis other individuals and of implying strengthening and/or questioning of norms about female embodiment and heterosexuality.

The first narrative concerns the women's fear of being rejected by former, present, and imagined male partners because of not being seen as 'real' women. Here, the ability to have 'sex', which the women, in line with the analysis of the first article, construe in terms of penile–vaginal intercourse, and to later in life become pregnant, stands out as signifying a 'real' woman who can be approached as a potential girlfriend by male partners. In this narrative it is furthermore the fear of being rejected should the women not live up to these expectations that represents an affective dissonance, insofar as this fear prompts disclosure. The fear furthermore functions to position the women as individuals who are not 'luring' anyone into a relationship. Such a positioning, the analysis demonstrate, can be interpreted as stemming from an 'experience of discomfort' (Hemmings, 2012: 158), since remaining in an undisclosed present is narrated as undesirable, and particularly so in relation to the discomfort that the women envisage they would encounter if they were to continue to conceal the information.

In contrast, the second narrative concerns the interviewees' expressed frustration over the pity of others – mainly female friends – and how certain emotional reactions can position the women's bodies and lives as 'unliveable'. In this narrative, the interviewees do not disregard the difficulties that the absent uterus and vagina has caused, but they repeatedly emphasize that they do not want to be pitied by others because of it. The analysis shows that others' responses can be interpreted as informed by heteronormative presumptions about the normality of heterosexuality, specific heterosexual practices, and the presence of specific body parts in bodies assigned a female sex, in the light of which it seems appropriate to respond by saying 'Poor you!' or 'Oh, I'm so sorry for you!' (see also Braun and Wilkinson, 2005; Dreger, 1999; Holmes, 2008). In this narrative it is, moreover, precisely the interviewees' frustration over such emotional reactions that creates an affective dissonance through which they succeed in their narrations in questioning the unwanted positioning that others' emotional responses encompass.

The third narrative concerns, instead, desirable responses which enable the women to describe themselves as being recognized either as individuals who can engage with others, just as they did before disclosing the absence of uterus and vagina, or which recognize their specific embodiment. The analysis show that the women, in their narrations about others' objections to their envisaging themselves as being rejected by male partners, and the absence of tears and pity in such responses, succeed in positioning themselves as *rejecting* rather than *rejectable*, and their lives as *liveable* rather than *pitiable*. Furthermore, as the women talk about their desire to connect with others who have similar experiences – connections which most of them have not yet experienced – they instead succeed in envisaging future

opportunities to imagine ‘different modes of living’ (Butler, 2004: 4) and achieve recognition of their specific sexed embodiment.

The article’s examination of the three narratives demonstrates that coming out about uterine and vaginal agenesis is a continuous processes, which is not confined to a single event in time (see also Orne, 2011; Rust, 1993), and which may not be simply cathartic but can be construed as inevitable and prompted in the light of an envisioned future pain. Furthermore, the storyline demonstrate 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, even in the allegedly open and tolerant Swedish context.

ARTICLE III

Guntram L (2014) Negotiations of normality and the meaning of a diagnosis: exploring women’s experiences of ‘atypical’ pubertal development. *Social Science & Medicine* 98, 232–238.

In contrast to the first and second articles, the third article examines the entire body of data. In this article a thematic analysis of how the interviewees make sense of female embodiment is presented. First, the article aims to explore how normality is construed in the interviewees’ negotiations of female embodiment. Second, it aims 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.

Against a backdrop of feminist and sociological writings that problematize sexed embodiment and investigate medicalization in terms of teasing out the complexities of diagnosis (e.g. Braun and Wilkinson, 2005; Burrows and Johnson, 2005; Elson, 2003; Jutel, 2009; Lillrank, 2003; Lupton, 1994; Martin, 2001; Wray et al., 2007), the article demonstrates how the interviewees deploy two negotiation strategies which are conceptualized as the ‘differently normal’ and the ‘normally different’ strategies. When deploying the first strategy, the interviewees present themselves as just a different ‘kind’ of normal, often by referring to medical treatments and examinations. Among the interviewees with TS, medical possibilities for treating their condition, and in particular, the ways in which treatment induces puberty, are especially drawn on in this strategy, as these interviewees stress that satisfactory treatment results make it possible to present oneself as just slightly different from that which is considered ‘normal’. While the interviewees with UVA do underscore, as also spelled out in the first article, that

they choose treatment in order to become more like ‘everyone else’, they do not to the same extent as the interviewees with TS present treatment as actually *making* their bodies ‘just slightly different’. Instead, in their deployment of the first strategy, they highlight how medical tests have asserted their sex by showing that they are simply ‘missing’ some ‘female’ parts. In both cases, however, references to medical terminology and practices enable the women to present themselves as ‘differently normal’.

Now, in the second strategy identified, the ‘normally different’ one, the women instead stress the normalcy of difference. By underscoring that everyone is different in some way, and that difference is that which makes an individual unique, they re-evaluate the very meaning of ‘normal’. When this strategy is deployed by the interviewees with TS, it is stressed that, since everyone is different in some way, it is ‘normal’ to be different and that the condition makes them somewhat special and unique. Among the women with UVA, normality is also construed in terms of variety, as they compare their absent organs with other conditions that might involve a congenital absence of another organ, such as a lung or a kidney. In this group the absence is, however, not so much presented as signifying that one is unique and special; rather, the practical consequences of the absent organs – such as not needing contraceptives or having to care about menstruation – are more often highlighted. Despite these differences in deployment, the ‘normally different’ strategy enables the interviewees to emphasize the significance of difference and, at times, distinguish themselves from others.

In the third part of the analysis the identified divergences in deployment of the two strategies are connected to the interviewees’ access to a diagnosis. By exploring the interviewees’ descriptions of their possibilities of raising awareness and claiming collective identities, it is shown how the diagnostic label can function as a resource in the women’s attempts to find others in similar situations to whom they can relate, as well as in their efforts to raise awareness about bodily variety. In doing this, the third article ties in to the second inasmuch as it continues to focus on the interviewees’ access to support and to sharing stories that are similar to their own. The third part of the third article shows that, without a diagnostic label, it seems that information as well as treatment becomes restricted – which in turn is shown to correspond to the differences identified in the interviewees’ deployment of the ‘differently normal’ strategy. Furthermore, with limited access to those resources to enable disclosure that a diagnosis may represent, it may become more challenging to present oneself as unique and special in the light of one’s condition than to stress positive practical consequences of the same.

By connecting the interviewees' access to diagnosis with the identified strategies, the article spell out the complexity of diagnostic labels by demonstrating how a such a label may provide the interviewees with a starting point for making new sense of female embodiment and not simply represent a force of stigmatization (see, e.g., Fleischman, 1999; Jutel and Nettleton, 2011). The article conclude that, while the two strategies identified do not involve a dismissal of the two-sex system, or an embrace of categorizations such as intersex and DSD, the negotiations that they comprise can still be read as attempts on the women's part to expand norms governing female embodiment. However, the women are doing so not by according significance to any specific features, but by pragmatically drawing on those features that they *do* have (cf. Elson, 2003). The two strategies thus enable the women to align *with* and work *on* norms about female embodiment, as they allow for the women to re-evaluate female embodiment the light of their specific experiences of sexed embodiment.

ARTICLE IV

Guntram L (submitted to *Social Science & Medicine*) Hooked on a feeling. Corporeal connectedness and relationality in infertility accounts.

The fourth article once again turn to the entire dataset, as it explores, through a thematic analysis, the interviewees' talk of infertility and, in particular, their accounts of their desire to experience what pregnancy 'feels like'.

The examination of the entire dataset and the analytic approach connects this article to the third one, but the fourth article does not explicitly compare the two groups. Instead, it explores accounts of infertility that span the material, in an attempt to nuance understandings of what infertility might mean to affected individuals. More specifically, the aim of this article is to discern how the interviewees emphasize embodied experiences as they make sense of their infertility, and how they, in the light of this, present 'solutions' to the same.

By making use of the rich research on infertility and assisted reproductive technologies (ART), the first part of the analysis presented in the article shows that the primacy that the interviewees accord to experiencing pregnancy is spelled out in three specific ways. First, the interviewees underscore their desire for certain corporeal sensations – to feel the foetal movements and experience the process of pregnancy. Second, they talk about the special corporeal connectedness to the foetus that pregnancy may provide; and third, they underscore that pregnancy may enable a specific relatedness to others who interact with the woman's pregnant

embodiment. Their preference for being pregnant, and therefore choosing ART over adoption, does thus not have to do with a wish to increase one's reproductive potential (Simpson, 2013) in the sense of 'spreading' one's genes, but still concerns a desire for corporeal connectedness and relatedness. The analysis suggests that in framing the primacy accorded to pregnancy in terms of connectedness, the women's accounts provide an alternative conception of relatedness that contrasts with the dominant focus on genetic linkage in Western conceptualizations of families (Haines, 2003) and the centrality of genetic linkage in the common understanding of what it means to have children of 'your own' (Brakman and Scholz, 2006).

The second part of the analysis concerns the interviewees' accounts about the present and the future and the manners in which they, in these accounts, talk about how to manage and potentially 'solve' their infertility. The solutions they present focus on medical interventions, and while most of the interviewees are positive towards alternatives that would not involve them being pregnant, such as adoption, most of them nevertheless construe medical intervention as not only the most preferable but also the easiest option. The article demonstrates how this is being done with reference to the primacy that the interviewees accord to experiencing pregnancy, spelled out in the first section of the analysis, and by outlining how the Swedish legal and economic circumstances in regard to IVF and adoption shape the interviewees' construal of solutions.

Finally, the last part of the article discusses how this analysis nuances understandings of the ways individuals make sense of, motivate, and manage infertility and ART. It suggests that the very specificities of the interviewees' infertility highlight the great variety in underlying reasons for infertility and the time of life when it may be detected. This, in turn, makes visible limitations of the common definition of infertility, that is, not being able to conceive after having tried to do so via sexual intercourse for at least a year (see Zegers-Hochschild et al., 2009), which matters for how infertility is understood as well as for the organization of medical care. Moreover, it is contended that while the analysis supports previous findings of how medical interventions are construed as the first option when individuals are faced with infertility (Hammons, 2008; van Balen et al., 1997), it furthermore identifies an alternative basis for this preference inasmuch as it shows that the interviewees' desire to feel what it is like to be pregnant is not primarily construed as a desire for genetic linkage (Brakman and Scholz, 2006). In focus in their infertility accounts is, rather, how pregnant embodiment becomes 'a site of relatedness-making' (Pashigian, 2009: 34) reachable through ART.

By this, the article do not mean to reduce women to wombs or to reinforce notions of pregnancy as the singular constituent of a maternal-foetal bond and as a central core of female embodiment and womanhood (see e.g. Bulbeck, 1998:11 in Morell, 2000: 316). Instead, it is suggested that by paying greater attention to corporeal and relational dimensions of individuals' accounts of their infertility experiences, understandings of biological relatedness can be expanded (cf. Pashigian, 2009), and stereotypes which picture women who use ART as unfulfilled, mad or desperate can be 'unpacked' (Letherby, 2002).

FINAL DISCUSSION

In the beginning of this thesis I asked how women, who in adolescence learned that they have an ‘atypical’ sex development, make sense of their sexed embodiment and situation alone and in relation to others.

In response to this question the first article showed that the absence of a vagina was made sense of in relation to a notion of an ideal (hetero)relational normality expressed through envisaged expectations of male partners and medical encounters, as narrated by the interviewees. In the light of this notion, vaginal reconstruction was construed as an ‘inevitable’ option which informed the women’s understandings of female embodiment and heterosexual practice and materially shaped their bodies. The second article approached the women’s sense-making from another angle, as it focused on how the women with UVA made sense of the absence of uterus and vagina with reference to others’ emotional reactions and responses to their bodies. It showed how the interviewees, by narrating what they felt and thought about such emotional responses – how they, for instance, feared them, or felt frustrated or supported by them – made sense of common understandings of what female embodiment was ‘supposed’ to encompass and of the specificities of their ‘atypical’ sex development.

Negotiations of female embodiment were further elaborated in the third article, in that it specifically identified a ‘differently normal’ strategy, by which it was underscored that one is ‘just slightly’ different from that which is considered normal, and a ‘normally different’ strategy, by which the normalcy of variety was underscored. The strategies were used to different extents and in different ways in the women’s negotiations of female embodiment; the majority used both strategies but on different occasions in the interviews, others used only the first and yet others used only the second strategy. Female embodiment becomes, the third article showed, ‘malleable’ in these negotiations in the sense that its meaning is constantly shifting on the basis of what one does have, in respect of ‘typically’ female body parts and processes, rather than on fixed meanings accorded to specific body parts. It also showed how hierarchical orderings of specific body parts and processes can be reinterpreted (cf. Elson, 2003).

In contrast to this general focus on negotiations of female embodiment in the third article, the fourth article more specifically addressed how the women made sense of the infertility that resulted from their ‘atypical’ sex development and their

futures in the light of it. This article spelled out how the women expressed their desire to experience corporeal and relational dimensions of pregnancy when making sense of infertility. In particular it showed how they related these dimensions to a provision of connectedness, not only with the child to be, but with others, through interactions with the women's pregnant embodiment. It also argued that in relation to this envisaged provision of connectedness the interviewees construed specific medical 'solutions' as preferable, and in the light of local circumstances and regulations with regard to IVF and adoption, furthermore presented such 'solutions' as the easiest option when envisaging their futures.

I moreover asked at the beginning of this thesis, how do these women position their embodied selves in relation to others, in particular, as they narrate their interactions with, and relations to, others? The first article responded to this question by demonstrating how women with UVA in their narrations about vaginal reconstruction positioned their embodied selves in relation to male partners. 'Through these positionings, the woman made sense of female embodiment and assumptions about what female bodies are supposed to 'do' in heterosexual practices. The article furthermore showed that these positionings mattered for how they made sense of male embodiment, assumptions about the function of male bodies in heterosexual practices, and the relationship between female and male embodiment. And, finally, the article showed that when narrating what life had been like after having ceased to dilate, or after having decided not to undergo vaginal reconstruction, the women were found to present themselves as individuals who refused to endure the pain that maintenance of a 'normal'-sized vagina inflicts, and who even challenged assumptions about male partners' expectations about vaginas that they previously had taken for granted.

The second article also showed how the women positioned themselves in relation to imagined male partners' expectations insofar as male partners' reactions formed the basis of the women's fear of being rejected. This fear of being rejected, were the women not to be seen as 'real' women by male partners, shaped their interactions since it prompted disclosure. However, the article also demonstrated that, as the women narrated their responses to undesired and desired reactions from others – such as pity and recognition – the women succeeded in positioning themselves as not being victims and their lives as not being 'unliveable' in relation to the lives of others.

Relatedly, while not focusing specifically on positionings enabled through narratives about intimate relationships, the third article demonstrated how the interviewees with UVA and those with TS positioned themselves on a more general level in relation to other women's bodies. In demonstrating how the interviewees

deployed the ‘differently normal’ and the ‘normally different’ strategies, the analysis teased out how the women related the specificities of their bodies to the bodies’ of ‘normal’ others – both by aligning themselves with statistically, and ideally ‘normal’, women, and by redefining ‘normal’ in terms of variety. In their deployment of the second strategy, in particular, the interviewees managed to position themselves as unique individuals whose experiences could contribute to raising awareness about bodily variation.

Finally, in the beginning of this thesis I asked how norms governing female embodiment, heterosexual practice, and in/fertility might be reinforced and resisted in the women’s sense-making. In response to this question I suggest that the women’s sense-making comprises a concomitant reinforcement and resistance of such norms as they are expressed, as I have discussed, through medical terminology with regard to treatment but also in the women’s interactions with others – medical professionals, partners, friends, and peers, to name a few.

The first article’s examination of narratives about vaginal reconstruction particularly demonstrated how the women expressed norms about female embodiment and heterosexual practice when making sense of their bodies and of medical treatment. More specifically, the article demonstrated that when such norms were expressed in the women’s narrations about envisaged expectations among male partners, medical encounters, and required dilation practices, it proved difficult for the women to imagine their ‘atypical’ sex bodied in any way other than calling for medical intervention (see also Feder, 2006; Zeiler and Wickstrom, 2009). However, as the women talked about ceasing dilation and narrated what life was like after having ceased dilation, or when narrating their doubts about having surgery in the future, the interviewees were able to reflect upon the actual ‘need’ for a vagina and the results of vaginal reconstruction. While these reflections did not involve a questioning of the very status of the presence of a vagina as a marker of female sex (Bell and Apfel, 1995) or of a hierarchical ordering of heterosexualities and heterosexual practices (Seidman, 2005: 40), they did allow the women to take a critical stance towards accepting restrictive norms about female embodiment and heterosexual practice, enacted through vaginal reconstructions, as ‘truths’ taken for granted.

Similar norms were found to be expressed in the interviewees’ narratives about disclosure to male partners and female friends examined in the second article. It demonstrated how norms about female embodiment and heterosexuality were enacted through envisaged rejections by male partners and in friends’ emotional reactions of pity, as they were described by the interviewees. However, when the women narrated such reactions to their bodies, dominant norms were not

simply reinforced. When narrating their own reactions to undesirable as well as desirable responses from others the women created vantage points from where they ultimately could challenge the ways others, through their emotional responses, positioned the women's lives as 'unliveable' (Ahmed, 2004; Butler, 2004). The repositionings that the women accomplished through such narrations, the article argued, could be interpreted as voicing critique toward the norms enacted in others' emotional responses to the women's bodies (cf. Butler, 2004).

The specific value that the interviewees accorded to their being able to label their symptoms, in order to renegotiate and ultimately question norms about female embodiment and raise awareness, was already indicated in the second article, but was even more clearly pointed out in the third. As this analysis demonstrated how the interviewees' access to diagnosis related to their deployment of the 'differently normal' strategy and the 'normally different' strategy, it was argued that medical terminology could not simply be interpreted as being experienced and functioning as a limitation in the women's sense-making. Instead, medical diagnosis could, as the women made use of it in their negotiations of female embodiment, be experienced and function as a resource – making it possible for them to both align with and work on those norms about female embodiment enacted in their interactions with others.

Finally, the fourth article brought out the interviewees' desire for the corporeal experience of pregnancy and their usage of medical 'solutions' as they envisaged their future, or looked back on how they had previously envisaged it. As such, it could be taken to reiterate the conflation of womanhood and motherhood, inasmuch as the desire to experience pregnancy could be interpreted as expressing a wish for 'normal' womanhood in terms of experiencing pregnancy, birth, and biological motherhood (cf. Morse, 2000; Rich, 1995; Woollett and Boyle, 2000; Woollett and Marshall, 2000). However, the article argued that the different corporeal dimensions of this desire instead contributed to expanding notions of biological relatedness and in that way that challenged Western assumptions about biological relatedness as a matter of genetic linkage. Thus, the body here becomes, as shown also in the first article's questioning of the need for and results of vaginal constructions, a site for contestation (Price and Shildrick, 1999), yet not of norms governing female embodiment but rather of norms which stipulate that genetic linkage is an assumed requirement for biological relatedness (cf. Becker, 2000; Brakman and Scholz, 2006).

A COMPLEX JUGGLING – CONCLUDING COMMENTS

To conclude, I suggest that when bringing the four articles together, this thesis shows that as the interviewees' made sense of their sexed embodiment and in doing so positioned their embodied selves in relation to others, norms and beliefs about female embodiment, heterosexual practice, and in/fertility – expressed and enacted specifically through medical encounters and close relationships – concomitantly were reinforced and resisted in a complex 'juggling'.

Through the articles' different angles on the women's sense-making, it was demonstrated how certain 'imaginaries', through which the women could construe their sexed embodiment and futures when faced with an 'atypical' sex development, were more easily accessed than others. In particular, as the articles highlighted, what became impossible and possible imaginaries in these negotiations were often connected to the ways in which norms about female embodiment, heterosexuality, and in/fertility were expressed, as the women talked about encounters with clinicians and interactions with others. However, when brought together, the articles also show how diagnostic labels became resources in the women's sense making. The thesis thereby feeds into previous critical examinations focusing on the medical treatment of individuals with 'atypical' sex development and contributes specifically with increased knowledge on how 'atypical' sex development is made sense of by affected individuals.

By this, I do not mean to imply that medical terminology such as diagnosis or treatment for 'atypical' sex development cannot be precarious, or that it should not be critically examined. But, I argue, this thesis underscores the importance of carefully considering and keeping together how norms about female embodiment, heterosexual practice, and in/fertility, enacted for example in medical terminology and practice, can be reinforced *and* resisted when individuals make sense of their 'atypical' sex development. By doing so, it is possible to tease out the complexities of the sense-making of these women, without positioning them either as 'duped' by medicine (see also Davis, 1995) or as responsible for challenging restrictive norms to a greater extent than any other individuals (see also Holmes, 2008).

Finally, from the articles I also draw the conclusion that, although the women in this 'juggling' seemed to retain a rather ambivalent stance towards their bodies' 'ambiguity', their stories still involved questioning. Whereas they, as they made sense of their sexed embodiment, did not seem to reject the very notion of sex being two, and only two, binary and separate entities (Laqueur, 1990), nor explicitly embrace the notion of a 'sex spectrum' (Fausto-Sterling, 1993; Greenberg, 1999;

Hubbard, 1996), their stories encompassed norm-critical potential precisely because they *expanded* rather than dismissed norms and beliefs about female embodiment, heterosexual practice, and in/fertility. This meant that, at least occasionally, the women were enabled to position their bodies as sites of contestation (Price and Shildrick, 1999) and make new sense of the specificities of their sexed embodiment. Hence, I suggest that, even when there might be few collective articulations of alternative norms available (cf. Butler, 2004), questioning, even if ever so implicit, is maintained through the interviewees' juggling of reinforcement and resistance in their sense-making.

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APPENDIX

A

Vill du vara med i ett forskningsprojekt om hur det är att leva med [diagnos/symtom]?

Det finns mycket lite kunskap om hur det är att i tonåren fått veta att man har [diagnos/symptom]. I det här forskningsprojektet vill vi därför ta del av dina erfarenheter, tankar och känslor om ditt liv och din situation i en intervju.

Om forskningsprojektet och forskargruppen

Projektets syfte är att bättre förstå hur det är att som tonåring få veta att man har [diagnos/symptom]. Det finns nästan ingen tidigare forskning om det. Vi vill fråga dig om hur du i tonåren upplevt och hur du nu upplever din situation. Vi vill också ta del av dina funderingar kring samhällseliga normer om hur kroppar ”ska” vara och se ut. Vår förhoppning är att den kunskap projektet ger ska leda till en ökad förståelse och ett förbättrat bemötande i vården liksom i samhället.

Projektgruppen består av Professor Stellan Welin, Docent Kristin Zeiler, Docent Karin Zetterqvist-Nelson och doktorand Lisa Guntram. Alla forskarna är verksamma vid Linköpings universitet. Projektet har också en referensgrupp som består av överläkare och Professor Barbro Wijma, Linköpings Universitetssjukhus, och leg. psykoterapeut Suzanna Boman, RFSU-kliniken. [Tillägg vid kontakt genom vården/patientförening: Vi har också kontakt med NN på [sjukhus/patientförening] och det är genom henne/honom som detta brev skickats ut till dig].

Om Ditt deltagande i forskningsprojektet

Vi vill fråga dig som är mellan 18-[max gränsen justerades under projektets gång] år om du vill delta i en intervju. I intervjun ber vi dig berätta om dina upplevelser, tankar och känslor kring ditt liv, din situation och din kropp. Hur är det att leva med [diagnos/symtom]? Hur ser din vardag och dina relationer till andra ut? Du väljer själv var och när intervjun ska genomföras.

Intervjun beräknas att ta ungefär en timme. Att delta i forskningsprojektet och i intervjun är frivilligt. Du kan när som helst avbryta ditt deltagande utan att du behöver motivera varför. Intervjun spelas in på band och skrivs sedan ned. Den nedskrivna intervjun görs anonym, det vill säga alla namn och andra uppgifter som kan identifiera dig byts ut mot en kod. Alla bandinspelningar och intervjuer kommer att förvaras inlåsta.

Om du vill är det möjligt att göra en uppföljande intervju då du kan berätta mer och förtydliga dina svar. Vi kan också träffas eller höras av på telefon för att tala igenom intervjun. Om du skulle vilja prata med någon utanför forskargruppen kan vi även hjälpa till att förmedla sådana kontakter. Intervjun genomförs av Lisa Guntram, doktorand vid Avdelningen för hälsa och samhälle, Institutionen för Medicin och Hälsa, Linköpings Universitet.



Vill Du ha mer information om projektet eller boka tid för en intervju?

Om du vill det, kontakta då Lisa Guntram med e-post: lisa.guntram@liu.se, eller på telefon 013-285823 eller 0736-515950. När och var intervjun ska genomföras väljer du själv. Om du inte vet någon bra plats kan vi ordna det.

Om du har några frågor om forskningsprojektet kontakta då Lisa Guntram eller någon annan av oss i forskargruppen.

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Alla forskarna är verksamma vid Linköpings universitet.

Forskningshuvudman: Linköpings universitet

APPENDIX

B

TRANSCRIPTION GUIDE

–	interruption, for example by another person
. . .	hesitation or unfinished sentence
-?	interrupted or unfinished question
word/words	word/words coinciding with laughter
“word”	recaptured utterance or quote
(word within parentheses)	difficult to distinguish the exact words/uncertain interpretation
(xx)	word impossible to distinguish
(xx xx)	several words impossible to distinguish
[word]	non-verbal aspects or clarifying comments, e.g. as regards context

Articles

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