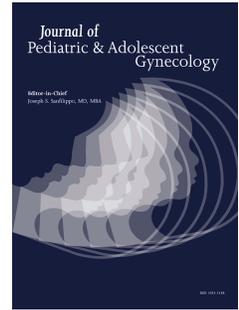


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Vaginal construction and treatment providers' experiences: a qualitative analysis

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## **Vaginal construction and treatment providers' experiences: a qualitative analysis**

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**Abstract**

Objective: To investigate specialist clinicians' experiences of treating vaginal agenesis.

Design: Semi-structured interviews.

Setting: 12 hospitals in Sweden and the UK.

Sample: 32 health professionals connected to multidisciplinary teams including medical specialists and psychologists.

Methods: Theoretical thematic analysis of recorded verbatim data.

Results: The gynecologist and psychologist interviewees share certain observations including the importance of psychological readiness for and appropriate timing of treatment. Three overlapping themes are identified in our theoretical analysis of the MDT clinicians' talk: 1) The stigma of vaginal agenesis and the pressure to be 'normal' can lead patients to minimize the time, effort, physical discomfort and emotional cost inherent in treatment. 2) Under pressure, treatment may be presented to patients with insufficient attention to the potential psychological impact of the language used. Furthermore, the opportunity to question what is 'normal' in sex is generally not taken up. It can be challenging to help the women to transcend their medicalized experiences to come to experiencing their bodies as sexual and enjoyable. 3) The reality of treatment demands, which is not always adequately processed prior to treatment, can lead to discontinuation with treatment and even disengagement with services.

Conclusions: Whilst the MDT clinicians in this study emphasized the importance of psychological input in vaginal construction, such input may need to proactively question social norms about how women's genital should appear and function. Furthermore, rather than steering patients (back) to treatment, the entire MDT could more explicitly question social norms and help the women to do the same. By shifting the definition of success from anatomy to personal agency, the clinical focus is transformed from treatment to women.

Keywords: Intersex, differences of sex development (DSD), vaginal agenesis, vaginal anomalies, vaginoplasty, dilation, female sexuality, critical psychology, medicalisation.

ACCEPTED MANUSCRIPT

## Introduction

Vaginal construction via surgery and/or dilation is a standard gynecological response to vaginal agenesis associated with complete androgen insensitivity syndrome (CAIS) and Mayer-Rokitansky-Küster-Hauser (MRKH) syndrome, two diagnoses categorized within the ‘disorders of development’ (DSD) nomenclature.<sup>1</sup> Specialists in Pediatric and Adolescent Gynecology (PAG) are most likely to be tasked with vaginal construction for CAIS and MRKH.<sup>2</sup>

PAG specialists are aware of the pressure to meet patients’ expectations to normalize their vaginas. However, research suggests that some women may remain sexually inhibited for years after their surgical construction and, when they finally attempt sexual intercourse, their experience is characterised by anxiety and discomfort.<sup>3</sup> A troubling if familiar clinical scenario is when a woman requests further surgery because she “still” feels abnormal or is unable to “have sex” despite an anatomically successful result.

Non-surgical dilation is currently the first line approach for vaginal agenesis in several European countries including the UK. Although dilation is not irrevocable and evidence suggests that it has the same potential to help women to achieve the vaginal patency that they desire whilst avoiding surgery,<sup>4</sup> dilation can be challenging in other ways. A familiar scenario that may seem puzzling to PAG specialists is when a woman deemed highly suitable for dilation does not sustain a regular regime and/or discontinue with treatment altogether. Previous studies suggest that the reasons for not dilating despite having expressed a wish to may include insufficient knowledge of how to use the dilators and lack of preparation for the effort and discomfort involved.<sup>5,6</sup> Some women have reported that ironically, the act of dilating actually reminded them of the difference that they had sought to eliminate.<sup>6</sup> To better understand the complexities in treatment processes, it is useful to look to psychological research.

Many women approach vaginal construction with the widely held assumptions that all women have a vagina of certain dimensions and that all women engage in vaginal sex.<sup>3</sup> Psychologists have highlighted the negative psychological impact of such assumptions. Research shows that emotional and sexual wellness are compromised for women with CAIS<sup>6,7</sup> and MRKH.<sup>8</sup> They suggest that the pressure to conform to the rigid norms relating to size and function can lead to a sense of aversion about the genitals and sex and diminish capacity for sexual enjoyment.<sup>3</sup> Despite this, many women on a dilation program avoid processing the emotional effects of

vaginal agenesis with psychologists.<sup>9</sup> Prompted by mixed clinical observations and research findings, the current research aimed to further clarify how DSD clinicians in multidisciplinary teams (MDTs) approach vaginal construction and understand and negotiate the challenges that are reported in previous research.

## Method

The current study is part of a larger project investigating the clinical management of DSD in Scotland, England, Norway, and Sweden (SENS) (refs removed for anonymity). The SENS project involves interviews and focus groups with clinicians, affected young people, parents, and a general population sample, with a focus on how the various participants make sense of current clinical practices, terminology, and ways of coping in the event of a DSD diagnosis, or other instances where sex development is not typical. The present study draws from 32 health professionals who were sampled via a snowball sampling method. Health professionals were included in the study if they were working within, or in close relationship to, multi-disciplinary teams (MDT) for children, adolescents and adults with DSD. The participants were recruited from 12 different hospitals in Sweden and the UK. The purpose of sampling internationally was to provide anonymity for participants, and to access a large enough sample, not to develop a comparative study.

The first author, an academic psychologist, carried out the semi-structured interviews which were audio-recorded, transcribed in full. The research participants' identities were known only to the interviewer; the rest of the research team was blinded to the gender, age and location of the participants. A theoretical thematic analysis<sup>10</sup> was used to work with the data. This means that (i) data were coded according to the themes arising during the interviews, (ii) excerpts focusing on psychological aspects of vaginal agenesis, vaginal construction, and vaginal dilation were identified for more detailed analysis, (iii) existing research literature was consulted to identify any themes that resonated with the present data analysis, (iv) theoretical understandings from critical psychology were used to provide a framework for the analysis. The 32 participants included 7 psychologists, 13 surgical specialists (gynecologists, urologists, and pediatric surgeons), 9 non-surgical specialists (endocrinologists and geneticists), and 3 nurse specialists. Most participants had many years of experience in working with DSD and many also had research expertise relating to DSD. The focus of the

present report is on data from experienced psychologists and surgeons with specialist knowledge of vaginal agenesis and interventions.

## Results

Before presenting the theoretical thematic analysis of the interview data, the first part of the Results section identifies the key psychologically relevant observations made by gynecologists and psychologists about vaginal agenesis and construction in interview:

- Readiness for talking about genital differences and for undergoing genital examinations is a key part of the process of vaginal construction.
- There is no point in starting a dilation program until the woman concerned is psychologically ready. For example, when the request for vaginal construction comes from a sexual partner, then the timing and reasoning are wrong.
- Some girls and young women seen by the specialists are sufficiently distressed that the outcome of their vaginal construction can be expected to be seriously compromised. For example, treatment and outcome expectations are so high that they are unattainable leading the patient to give up on treatment.

The psychologist interviewees offered further elaborations on the shared observations above:

- When grappling with the difficult feelings around bodily differences, it is common for girls and women to express a wish to be 'normal' and to seek medical interventions that might help them attain a 'normal' body rather than come to terms with being different
- There is often a sense of denial and shame: young women want to conceal the bodily difference from friends and partners for fear of being emotionally overwhelmed by facing the reality.

The following theoretical thematic analysis is presented under three headings: Bodily norms and stigma, Communication approaches, and Engaging women in healthcare. Example data excerpts are offered for each of them and focused upon the theoretical analysis and implications. These three headings reflect concerns frequently alluded to by the interviewees

and identified above. They are organized chronologically in relation to a woman's process of engagement with health services.

### ***Bodily norms and stigma***

Prior to entering the clinic, most women have already been affected by social norms about the body and bodily functions. According to normative understandings, the vagina signifies womanhood.<sup>11</sup> Gynecological and psychological specialists have described the devastating psychological impact for women with vaginal agenesis. Gynecologists in the present study similarly stated that "I think the women I meet as patients, if they haven't got a vagina, they don't feel like a woman" and "part of our role is managing that stigma." A systematic review of psychological implications of vaginal agenesis associated with MRKH, lead its authors to conclude that adjusting to this diagnosis is a "traumatic process" leading women "to question their identity as women and to experience a sense of confusion ... [giving] rise to ... negative self-beliefs, with many women seeing themselves as defective, inferior, or unlovable."<sup>12</sup> In other words, women and girls may lose a sense of who they are, or feel unable to lay claim to being female.

The identity threat, negative self-beliefs and strong emotions lead smoothly to the demand: *fix my body*. This means that, as a result of normative pressure, women might be seeking a physical solution to avoid an emotionally difficult problem. As one psychologist said:

*some patients I think come wanting [vaginal construction] because they just feel they should have [...] a vagina, they are a girl therefore they should have one or potentially [...] this might help me feel more like the girl I think everyone thinks I think I should feel like [laughs]... so if I had a vagina that would help [...] there is a sense of everyone else has got one [...] so if you could just fix my body*

The norm-related concerns described above are (1) that a girl *should* have a vagina (of a certain size), (2) that having a vagina makes one feel more like a girl, (3) that people expect a girl to feel like a girl, and (4) that all other girls have vaginas and feel like girls. While the desire for vaginal construction is an understandable response to these pressures, treatment does not make the pressure disappear. Clinicians have pointed to the flaw in the assumption that a change to vaginal size alone can help a woman to bear the emotional weight of these normative pressures: "*Many patients view the creation of a vagina as a solution to attaining*

*'normality'. The adoption of a surgical approach would seem to fulfill this wish ... However, normality is not achieved through anatomic surgical correction alone."* <sup>13</sup>

It has been argued that medical interventions for normalcy can ironically steer people further away from feeling 'normal'.<sup>14</sup> In previous research, some women reflected after their vaginoplasty that having to dilate served as "a continual reminder of difference".<sup>3,6</sup> Some reported that vaginal construction had made intercourse physically possible but not pleasurable,<sup>3,15</sup> and that being penetrated by a penis could feel like "a dead weight" inside.<sup>3</sup> The fact that some women have less than ideal experiences of their constructed vagina points to the need for very careful communication about what could be expected from treatment, including potential advantages and disadvantages.<sup>6</sup> We can also explore what goes on in doctor-patient communications to learn more about why elective invasive operations are performed in spite of the evidence that they do not always achieve the projected psychological outcomes."

### ***Communication approaches***

When women are in the clinical setting, they are strongly affected by language that health professionals use. The way that an idea is presented influences whether that idea is rejected or taken up. For example, a vignette study of parental consent to childhood genital surgery in DSD showed that adults exposed to a medicalised presentation of an elective intervention are three times more likely to express a wish for the intervention for their child, compared to people exposed to a de-medicalised presentation.<sup>16</sup> In the present study, gynaecologists were clearly aware of the sensitivity of talking with young women about vaginal construction. This sensitivity to language and timing is reflected in statements like: "They're often not at an age [...] where they actually want to engage with how their vagina works, so you can say, 'This is something that [...] you might want to be interested in the future, and I'll help you with it if you want me to' [...] and then you just need to wait" (Gynaecologist).

In the following excerpt, however, a psychologist draws attention to the language that is sometimes used to introduce an "offer" of vaginal construction, making it clear that this is an elective procedure:

*in terms of language, [...] I say to the girls and families [...], When a surgeon tells you the treatment that you need, what they mean is, "what we can offer you." [...] most*

*commonly they say, “So what we can do for you is.” [...] I’m always saying it’s a different language, this is elective, this is your decision*

The point made here is that there is an important difference between telling a woman what treatments the team can provide and telling her that she needs treatment. It is possible to emphasise that it is entirely up to her to decide now, later or never without affecting her access to the expert input of the team. The phrasing ‘this is what you need’ constructs an ideal body and positions the patient’s body as lacking by comparison. This could add pressure on the patient to take up the intervention particularly if it resonates with her experience of gender norms described above, and may steer away from considering all options including no treatment in the present. In de-centering the intervention, the patient is constructed as a free agent with genuine choices about whether, to what extent, and when they might engage medical intervention as a means to address the emotional pressure created by normative expectations about bodies. A de-medicalized presentation would begin by affirming what is already possible for the woman and situate vaginal construction as an elective and non-urgent intervention within a much wider spectrum of possibilities.

### ***Engaging women in healthcare***

Women going through treatment for vaginal agenesis can face challenges that lead to disengagement. In the following excerpt, a medical specialist describes a young woman who is avoiding contact with the hospital following vaginoplasty:

*We have a young lady [...] who’s refusing to dilate [...] she’s put herself through all the surgery and she’s refusing to dilate and saying that everything’s wrong down below and, but won’t come to clinic. [...] [the psychologist is] trying to engage with this young lady ... the psychologist will go out and meet them at home if they don’t want to come into hospital. ... we try everything we can to keep them engaged and to get, to understand why they won’t engage, that’s what psychologists do (Surgeon)*

The difficulty described by this medical specialist resonates with previous psychological research examining difficult emotions that lead women to discontinue treatment or avoid medical contact.<sup>5</sup> Given the contradictions between treatment process (medical) and outcome (sexual), tension and frustration is understandable.

Rather than framing the woman's discontinuation with medical contact as 'non-compliance', it might help to develop a more nuanced understanding of what is the woman's own sense of a good outcome, which is not necessarily the same as a good outcome as defined clinically. Health professionals may define a good outcome as the woman re-engaging with dilation and demonstrating that her vaginal opening is maintained at the intended size. However, as noted above, these outcomes do not always lead to sexual esteem and satisfaction. On the other hand, a woman might experience genital pleasure regardless of genital dimensions and choose to stop dilating and withdraw from further medicalizing contact. Such an outcome may be understood as a failure by her clinician but not by herself.

Psychological research shows that women with vaginal agenesis struggle to transcend the pathology-based to sensuality-based experiences of their genitals.<sup>3,5,15</sup> Psychologists in the present study also explained that they often work with women to mitigate the effects of medicalisation: "some of the (psychological) work [...] is about being able to separate out that very medical [aspect] and a more [...] sexual ... concept" and acknowledging that this can be "a difficult transition" especially "if people have had [...] lots of examinations."

For vaginal construction to be worthwhile for a woman, she will need to resolve the conflicted experience of her vagina as deficient and in pain, and her desire for her genitals to be a source of pleasure and satisfaction. It is precisely at this point of negotiating emotions and meanings where psychological input can make the difference between clinical outcomes that are satisfactory versus unsatisfactory from women's perspectives. Changes to how a woman with vaginal agenesis experiences her genitalia require transformation at the level of meaning and interpretation.<sup>17</sup> This requires skillful integration of gynaecological and psychological expertise to shift the definition of clinical outcome from anatomy to genital appreciation and sexual wellness. This may in turn involve reworking the language and process to move away from the fantasy of vaginal construction is an emotional bypass to 'normality'.

## **Discussion**

This research uniquely includes medical specialists' and psychologists' reflections on what psychologists currently do in MDTs.<sup>18</sup> The results and interpretations complement previous findings but also highlight, more compellingly and cogently than before, the implications for collaboration between gynaecologists and psychologists in vaginal construction. By taking a

critical and rigorous approach to examine healthcare providers' reflections about their experiences in vaginal construction for vaginal agenesis, we have identified issues that have significant implications that may also be relevant for acquired vaginal anomalies, e.g. vaginal construction after cancer treatment.

The issues identified relate to normative pressure, communication, and engagement. The clinical implications are succinctly summarized below:

A) Normative pressure: Clinicians are aware that women with vaginal agenesis often seek vaginal construction under normative pressure. Being emotionally burdened by pressure may seem like a strong motivating factor in starting treatment but is not necessarily a key factor in sustaining treatment or predicting good treatment outcomes.

B) Communication: Under pressure and in the face of patient distress, it might seem reasonable to offer treatment right away. However, the language used to discuss genital differences and their treatments can influence treatment process and outcome greatly. Certain ways of talking about bodily difference can imply a 'need' for treatment, which can increase the emotional burden of normative pressure. It may be more helpful to avoid medicalizing vocabularies when discussing bodily and sexual matters. So doing introduces broader factors other than vaginal size and genital intercourse to impact the women's self-understandings and opens the door for questioning what is 'normal' in sex.<sup>3</sup> Psychologists can help patients to re-interpret what is said in medical consultation but may have a better chance of success if all MDT members adopt a language that positively acknowledges diversity in sexual expression.

C) Engagement: When a woman embarks on treatment and then discovers that the process is too emotionally and physically challenging for her, she may discontinue treatment or disengage from services completely. In such a situation, it is worth the team reflecting on how normative pressure and communication might have led to this eventuality and how treatment success could be re-defined in light of the woman's action. A shift in team orientation away from anatomical outcomes toward personal agency is worth debating, in vaginal construction and perhaps other elective surgical and nonsurgical interventions in DSD more broadly.<sup>19</sup>

Rather than focusing on steering patients back to treatment, a more thorough involvement of psychological input throughout could be used to ensure that A (normative pressure) and B (communication) are addressed, thereby reducing the problem of C (engagement).

## **Conclusion**

Existing research shows on-going challenges in vaginal construction, including treatment outcomes that are unsatisfactory from the points of view of the women concerned. The present study is a psychological analysis of health professionals' talk about their work to support women with vaginal agenesis. The findings point to tangible, psychologically-informed ways to overcome some of the practice challenges.

Vaginal construction is a deeply emotional journey where the psychological work of addressing normative pressure is a crucial part of clinical intervention to promote care users' capacity for emotional and sexual wellness. While our clinician interviewees recognize that psychological clinicians play an important role in vaginal construction, the present analysis further emphasizes two points. First of all, MDTs would need to proactively question social norms about how women's genitals should appear and function. Secondly, and complementing the first suggestion, MDTs need to actively transform the clinical focus from treatment to women.

## **Limitations**

The qualitative method used, and the decision to sample across three national contexts, ensures that the findings are to some extent generalizable across locations. However, future research across national contexts could usefully examine cultural differences in terms of health care system, professional training, and the level of social pressure to conform to shared assumptions of genital appearances and functions.

**Disclosure of interest**

None.

**Contribution to authorship**

K.R. conceptualised the study, collected and analysed the data and wrote the paper; S.C. contributed to the study protocol and the development of the manuscript; P.H. contributed to the study design and development of the manuscript; L.L. contributed to the study design, recruitment of participants and wrote the paper. All authors had access to the data and take responsibility for the integrity of the data.

**Details of ethics approval**

The study was approved by NHS National Research Ethics Service (reference: 11/LO/0384) and University of Surrey Ethics Committee (reference: EC/2011/68/FAHS).

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