



Julie Alderson, Maia Thornton, Nicky Nicoll,
Julie Jones, Mars Skae, Elizabeth Crowne

Background and Method

Paediatric multi-professional management of Differences of Sex Development (DSD) / Variations of Sex Characteristics / Intersex, aims for good psychological health throughout life. Confident parent and child discussion of health and development is recommended^{1, 2}.

In a qualitative study using thematic analysis, we investigated contemporary family responses to clitoromegaly in girls with Congenital Adrenal Hyperplasia (CAH) following surgical and non-surgical management. We interviewed 27 parents of girls below age 16.

Discussion covered how parents felt, thought and what they did in relation to their daughter having a large clitoris (as part of ambiguous genitalia at birth). Parents also reflected Discussion on decisions made with clinicians about surgery.

Our analysis tracked which of the parents chose each management path:

1. **Surgical reduction of the clitoris**
2. **Surgery to hide the clitoris via alteration of the vulva (genitoplasty/concealment surgery)**
3. **No surgery on or around the clitoris.**

We explored how parents respond to their child's genital difference with and without, before and after surgery.



Results: Themes with Discussion and Clinical Implications

Ignorance is Bliss

Parents try to protect children by limiting discussion.

Parents who chose appearance altering surgery and those did not often avoided discussion concerning:

- Genital appearance at birth
- Current genital appearance
- Past medical or surgical intervention on appearance.

"We don't discuss it because obviously she doesn't know what's right. She doesn't know, she doesn't realise". (no surgery)

Parents aim to prevent their child's awareness and concerns whilst having high levels of anxiety and worry about:

- Other people's awareness of the girl's genital difference
- Possible future difficulties for their daughter.

CLINICAL IMPLICATION

Failure to foster a child's growing awareness and knowledge and of DSD is against consensus advice to advance an individual's understanding of her body via age-appropriate discussion through childhood³. **Parents' avoidance of talking about genital difference could prevent positive psychological adaptation during childhood.**

No Decision No Regrets

Parents view their decisions about surgery as uncontroversial.

Parents acknowledge their central role in multi-professional decisions about early genital surgery, yet they consistently report that the medical facts and professional advice point to **one clear best option** for their child⁴.

Parents take the guided path then carry the long term responsibility for the decision about early genital surgery.

"I felt that the medical profession as well were more or less saying, "you're gonna do it". (reduction surgery)

Strong professional guidance lets parents to believe in a simple and correct surgical option. Yet parents still feel a weight of responsibility for possible future problems.

CLINICAL IMPLICATION

The interplay between professional guidance and parental choice creates a false perception of parental responsibility of the clinical decision.

Psychological adaptation processes coupled with widespread practice of infant surgery means that parent-report measures in outcome studies will predominantly favour past or established management.

Genital Difference Remains

With or without appearance altering surgery, genital diversity is challenging for parents.

Parents have long-term concerns about the impact of genital difference across all three management paths.

Early surgery *aims* to ameliorate parental concern about genital difference. After surgery parents still worry about genital appearance, future interventions, and sexual relations.

"Its always bothering me actually; Like, is she going to think she's different herself, or when she's ready to have sex. Its running through my mind all the time". (concealment surgery)

CLINICAL IMPLICATION

Care focussed on childhood genital appearance is insufficient to resolve parental concern about atypical genitals. **Parent-focussed psychological care is necessary in surgical and non-surgical care pathways.**

Declaration: Julie Alderson is Chair of Trustees of the UK Charity *dstdfamilies*

¹Nordenström, A., & Thyen, U. (2014). Improving the communication of healthcare professionals with affected children and adolescents. In *Understanding Differences and Disorders of Sex Development (DSD)*, 27, 1113-127

²Lundberg, T., Lindström, A., Roen, K., & Hegarty, P. (2016). From knowing nothing to knowing what, how and now: Parents' experiences of caring for their children with congenital adrenal hyperplasia. *Journal of pediatric psychology*, 42(5), 520-529.

³Hughes, I. A., Houk, C., Ahmed, S. F., & Lee, P. A. (2006). LWPE consensus group; ESPE consensus group. Consensus statement on management of intersex disorders. *Arch Dis Child*, 91(7), 554-63.

⁴Gough, B., Weyman, N., Alderson, J., Butler, G., & Stoner, M. (2008) 'They did not have a word': The parental quest to locate a 'true sex' for their intersex children, *Psychology & Health*, 23:4, 493-507,

