

Gender dysphoria and gender change in disorders of sex development. Impacts on early surgery indication.

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The dsd-LIFE Study is a multicentric European study on the outcome of surgical, hormonal therapy and psychological intervention in disorders of sex development (DSD). The aim of this publication is to assess gender change and gender dysphoria with a cross-sectional study in 14 different centers with 1,040 participants.

Gender assignment is realized at birth solely based on the appearance of the external genitalia. The authors discuss how sometimes that may not be congruent to how one identifies oneself gender, and some of its implications. When a significant psychological distress is present, a diagnosis of gender dysphoria is made. For some people that develop the opposite gender identity (transgender), to be socially accepted as a person of the other gender might suffice, but others might need health care.

Many factors might influence the expressed gender through life, and the exposure to androgens pre- and postnatal has been shown to have a role on male behavior, which is significant for DSD treatment, particularly with 46,XY children. This study includes a variety of diagnosis, Turner and Klinefelter syndromes, congenital adrenal hyperplasia (CAH) and XY DSD.

Participants should be at least 16 years old, have a confirmed DSD diagnosis and consent to participate. They had a medical clinical interview and filled patient-report outcome (PRO) questionnaires, and clinical retrospective data were collected. Of the 3,217 invited, 1,040 (36.1%) were included.

The PRO questionnaires included the Rosenberg Self-Esteem Scale and a shortened version of the Utrecht Gender Dysphoria Scale. Both male and female versions were offered to the participant to choose the most appropriate.

Patients were organized in 6 main groups based on their current gender and kind of diagnosis and 47 (5.1%) of them had a gender change, but most of them, 36, had it done before puberty, probably based on clinical decision. Only 9 (8 in some XY group and 1 in the CAH group) had a postpubertal (probably a patient decision) change. The highest incidence of patient-initiated gender change was seen in the XY group, with androgen effect. Of 78 male-raised individuals, 2 (2.6%) changed gender, as opposed to 5 of 58 (8.6%) of the female-raised individuals. Eighteen individuals were not in the main groups (5 CAH), and 5 of them had a postpubertal change, so a total of 14 (1.3%) had a gender change.

Compared to a control group, only 5 individuals of the main group (3 Turner, 1 Klinefelter, 1 CAH) had a GD score higher than 3 SD above the mean. The ones that changed gender probably had GD before the transition.

Depending on the source of info (clinical interview or PRO), gender variance or non-binary gender expression rate was from 12 (1%) to 27 (2.6%). They had lower self-esteem, more anxiety and depression, and more gender dysphoria when compared to the gender-typical group. This later was below the GD found in non DSD gender

identity clinics. When considering partnership and sexuality there was no significant difference when comparing both groups scores.

Only 1% (3% if Turner and Klinefelter are excluded) DSD patients sought gender change after puberty, a low number, even if higher than what is found in the general population (up to 0.7%). Of the patients that had gender change during early childhood (since 2006 the age of 18 months is seen as an upper limit) without the patient input, only 1 transitioned back. As expected, the female to male change rate was higher in the XY group exposed to androgens, but the incidence of gender changes in the 5-a-RD-2 and 17-b-HSD-3 individuals was way lower than the literature reports, probably because in western societies (as the ones where the study was done), one can more freely accept a gender role that is different from the one assigned at birth. The presence of the DSD itself may cause some confusion and discomfort, even in individuals that have no desire whatsoever to change gender or role. Results also show that people in the gender fluid group had more gender related distress, anxiety and lower self-esteem, but lower than non DSD individuals seeking gender identity clinics.

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The surgical treatment of DSDs has evolved through the decades, from a simple anatomical adequacy of the external genitalia to the gender assigned at birth (as seen with the clitoris resection surgeries), to techniques concerned with sexual function and satisfaction as described by Passerini-Glazel¹. Recently there is concern in allowing future anatomic reversibility, as proposed by Pippi-Salle², but the feasibility of this approach has yet to be shown. Moving in the same direction, those decisions were taken from a single physician to a multi-disciplinary team with involvement of the parents³.

The dsd-LIFE study helps in shedding some light and numbers on a very controversial topic that has been contaminated by political, ideological and sexual orientation issues. Some activist movements, as interACT (<https://interactadvocates.org/>), pleas for a ban on all DSD patients surgeries until they can provide an informed consent, while others as CARES (<https://www.caresfoundation.org/>), fight to preserve CAH patient and parental right. Meanwhile bills like California SB-201⁴ are being passed. As the dsd-LIFE study shows that all different diagnosis do not have the same outcome and probably should be assessed in different ways.

References

1. Passerini-Glazel G. A new 1-stage procedure for clitorovaginoplasty in severely masculinized female pseudohermaphrodites. *J Urol* 1989;142:565-8.
2. Pippi Salle JL, Braga LP, Macedo N, Rosito N, and Bagli D. Corporeal sparing dismembered clitoroplasty: an alternative technique for feminizing genitoplasty. *Journal of Urology*, vol. 178, no. 4, pp. 1796-1801, 2007.
3. Douglas G, Axelrad ME, Brandt ML, Crabtree E, Dietrich JE, French S, Gunn S, Karaviti L, Lopez ME, Macias CG, McCullough LB, Suresh D, Sutton VR. Consensus in guidelines for evaluation of DSD by the Texas Children's Hospital Multidisciplinary Gender Medicine Team. *Int J Pediatr Endocrinol*. 2010;2010:1-17.
4. Leginfo.legislature.ca.gov. (2019). Bill Text - SB-201 Medical procedures: treatment or intervention: sex characteristics of a minor. [online] Available at: https://leginfo.legislature.ca.gov/faces/billTextClient.xhtml?bill_id=201920200SB201 [Accessed 5 Mar. 2019].