



dsd-LIFE ABSTRACT FOR THE GENERAL PUBLIC

Title

Fertility outcome and information on fertility issues in individuals with different forms of disorders of sex development: findings from the dsd-LIFE study

Authors

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What did we want to know?

Disorders of sex development (DSD) often affect the ability to have biological children. We wanted to know to what extent patients with different forms of DSD live in relationships and have children (biological, adopted, or step-children), and if assisted reproductive technologies (ART) had been available and used by them. Further, we enquired if the patients had received information about their fertility and if they were satisfied with how fertility issues were explained and discussed by the clinicians.

What did we do?

We have asked 1039 persons with different DSD conditions about fertility issues. The presence of gonads (testes and ovaries) and uterus was established on the basis of ultrasonography and information about gonadectomy (removal of testes and ovaries) from medical charts and patient-reported data. The study was performed in 6 European countries (Germany, France, the Netherlands, Poland, Sweden and Great Britain).

What were the main results?

In the total cohort, mean age was 32 years, 33% lived with a partner, but only 14% reported having at least one child, including 7% with ART and 4% adopted. Only 3.5% of the total cohort had been able to reproduce without ART, most frequently women with congenital adrenal hyperplasia, and only 0.7% of participants with other diagnoses. Of the participants, 72% had received information on fertility, but 17% were not satisfied with the information.

What does this mean?

Fertility is significantly reduced in all types of DSD and the situation differs considerably between the diagnostic groups. It means that treatment needs to be individualized. Fertility potential should be assessed individually during adolescence and in adulthood. This should be based on presence of testes or ovaries, their hormonal function, sperm/egg production and anatomical possibilities. Not all patients with DSD are optimally informed about their fertility potential. Yet, all patients with DSD have the right to be fully informed on their fertility status and possibilities of fertility treatment. In providing this information age and educational background need to be considered. The care should be individualized and the new possibilities

of reproductive medicine should be incorporated. In order to achieve this, a multidisciplinary team approach is necessary.

Reference:

Słowikowska-Hilczer J, Hirschberg AL, Claahsen-van der Grinten H, Reisch N, Bouvattier C, Thyen U, Cohen Kettenis P, Roehle R, Köhler B, Nordenström A; dsd-LIFE Group. Fertility outcome and information on fertility issues in individuals with different forms of disorders of sex development: findings from the dsd-LIFE study. *Fertil Steril*. 2017 Nov;108(5):822-831. doi: 10.1016/j.fertnstert.2017.08.013. Epub 2017 Sep 15.