



dsd-LIFE ABSTRACT FOR THE GENERAL PUBLIC

What are the hormone treatments and how satisfied are person with different DSD conditions with the treatment

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What did we want to know?

Most persons with disorders/differences of sex development (DSD) need life-long hormone therapies due to impairment of gonadal (gonads: testes and ovaries) and/or adrenal function. We wanted know which hormone treatments are applied in the different conditions and the patients' own views and satisfaction on their treatment.

What did we do?

We have asked persons with different DSD conditions and their physicians about the hormone treatments used and the patients' satisfaction with the treatment. As DSD conditions are rare the study was performed in 14 clinics in 6 European countries ((Germany, France, the Netherlands, Poland, Sweden and Great Britain).

What were the main results?

The questionnaire about hormone therapies was answered by 366 persons with Turner syndrome, XX gonadal dysgenesis or 45,X/46XY genes, 218 persons with Klinefelter syndrome, 6 males with XX chromosomes, 222 with XY DSD conditions, 21 with 45,X/46XY chromosomes, and 226 with congenital adrenal hyperplasia (CAH). A combination of bioidentical estrogens resembling the ones produced by the body and luteal hormones was applied by most persons (81%). Only a few individuals used a combined hormone replacement with a much more active estrogen which is normally used for contraception (19%). Many persons, 198, had testosterone treatment. Most took their hormone medication regularly and very few stopped the treatment (10% who were on oestrogens, 5% on testosterone). However, a considerable number was dissatisfied with the treatment mostly because of psychological side effects (20%). Persons with CAH very seldom stopped their glucocorticoid replacement. The majority of the participants wase satisfied with the information about the hormone treatment (75%) but fewer were satisfied with the information they had received about treatment options and side effects.

What does this mean?

More than 50% of the participants had hormone replacement and hormones were, for the most part, taken regularly. However, the hormone replacement therapies may be improved. This may be achieved by more focus on the individual's needs, views, and the timing of the treatment. In addition, the information for patients regarding the specific aim of the treatment as well as both long term and short-term hormonal effects and side effects should be more clear and given in a more comprehensive way.

Reference:

Nordenström A, Röhle R, Thyen U, Bouvattier C, Slowikowska-Hilczner J, Reisch N, Claahsen van der Grinten H, Brac de la Perriere A, Cohen-Kettenis PT, Köhler B; dsd-LIFE group. Hormone therapy and patient satisfaction with treatment, in a large cohort of diverse disorders of sex development. *Clin Endocrinol (Oxf)*. 2018 Mar;88(3):397-408. doi: 10.1111/cen.13518. Epub 2017 Dec 17.