



dsd-LIFE ABSTRACT FOR THE GENERAL PUBLIC

Body Image and Self-Esteem in Disorders of Sex Development: A European Multicenter Study

Authors

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What did we want to know?

Disorders of Sex Development (DSD; also known as intersex or Differences of Sex Development) constitute of a group of conditions in which sex characteristics develop other than the typical male or female definitions. We were particularly interested in what the body image and self-esteem were in people with DSD. Also, associated factors as well as condition-specific areas of concern were studied.

What did we do?

In a European study, conducted in 14 expert clinics, 1040 individuals with DSD were recruited. Participants filled out questionnaires (on body image, self-esteem and other background characteristics) and underwent clinical examinations. We compared people with different diagnoses on their body image and self-esteem; also, we assessed whether factors such as openness, sexual satisfaction, and psychological problems were associated.

What were the main results?

Individuals with DSD scored less favorable compared with the reference values. As different DSD diagnoses implied different symptoms and treatments, body image and self-esteem issues showed some variation as well. Most negatively evaluated body areas included breasts and genitals. For individuals diagnosed with Turner Syndrome, issues often related to head and neck, and muscularity and posture-related body areas. For individuals with Congenital Adrenal Hyperplasia these areas included hair growth and hips. BMI and hormone therapy were associated with overall body image. Sexuality, embarrassment and openness were strongly connected with both body image and self-esteem as well.

What does this mean?

This study is the first study of this scale on this subject. Because of the large numbers of participants, we were able to compare between the DSD groups, but also to identify other significant factors. It is important for individuals with DSD as well as healthcare providers to know that body image and self-esteem are frequently less favorable in this group when

compared to reference values. Gaining this knowledge is of interest when developing affirmative healthcare services for this group. Professionals should focus more on sexuality, openness, embarrassment and on treating psychological issues, rather than focusing on medical treatments 'only'.

Reference:

van de Grift TC, Cohen-Kettenis PT, de Vries ALC, Kreukels BPC. Body image and self-esteem in disorders of sex development: A European multicenter study. *Health Psychol.* 2018 Apr;37(4):334-343. doi: 10.1037/hea0000600.