



dsd-LIFE ABSTRACT FOR THE GENERAL PUBLIC

Title

Disorders or Differences of Sex Development? Views of Affected Individuals on DSD Terminology

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What did we want to know?

A decade ago, the “Consensus Group on management of intersex condition” proposed Disorders of Sex Development (short DSD) as new umbrella term for conditions in which sex development is atypical. This Group wanted the new term to be sensitive to the concerns of individuals having these conditions. Yet, although their aim was to replace older, more stigmatizing, wording people have criticized the new term as well.

We wanted to know how individuals with DSD, who were treated in clinics from six European countries, think about a number of terms meant to describe their condition.

What did we do?

We initiated a study in 14 European medical centers (in France, Germany Poland, the Netherlands, United Kingdom, and Sweden). We asked 1040 persons (717 female identifying and 311 male identifying persons, and 12 persons identifying with another gender) with medically confirmed diagnoses for their opinion about the preferred terms.

What were the main results?

Overall, a large majority of participants (69%) reported that the term Disorder of Sex Development applies to their condition or that they feel neutral about this term. Most did not prefer other terms that are medically neutral. In general, they preferred terms that are specific to their physical condition.

What does that mean ?

We found that using the term Disorder of Sex Development is not perceived (or viewed) as insensitive to feelings of most patients. Thus, it should not be given up. Differences of Sex Development was suggested as an alternative umbrella term. We recommend that clinicians, when communicating with their patients, ask what their patients prefer.