



dsd-LIFE ABSTRACT FOR THE GENERAL PUBLIC

Title

Quality of health care in adolescents and adults with disorders/differences of sex development (DSD) in six European countries (dsd-LIFE)

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What did we want to know?

People with disorders/differences of sex development (DSD) may have health problems. Sometimes they have very different health care needs. We wanted to know how good the quality of care in the DSD health care centers is. We also wanted to find out whether the participants of the study were satisfied with the services.

What did we do?

We studied how 14 European medical centers in France, Germany, Poland, the Netherlands, United Kingdom, and Sweden provided care. We looked into aspects such as infrastructure of the center, whether the centers had multiprofessional teams and provided services like case management, health education, transition care and other aspects of care. We investigated the relationship of the quality of care and satisfaction with care in participants of the study with disorders/differences of sex development (DSD). We compared four different groups of people with DSD: 261 with Turner syndrome, 173 with Klinefelter syndrome, 190 with congenital adrenal hyperplasia and 257 with various types of XY-DSD. We measured *participant satisfaction* with care using questionnaires (CSQ-4 and YHC-SUN-SF).

What were the main results?

We found large differences between the infrastructure and the kind of care in the 14 centers. Not only were there differences between all centers of one country but there were also differences between centers caring for the same condition. In Germany and its four centers, we found the largest differences. Differences among the four French centers were smaller. In any case we found a relationship between the quality of care and satisfaction with services reported by the participants. People with good health status and fewer health problems were more satisfied with patient-centered care, doctors' behavior and how they received information. Participants with bad or very bad health statuses had lower scores on their global satisfaction with care.

What does that mean?

The findings show that participants appreciate having access to high quality and multidisciplinary care. The development and implementation of standards of care is an important task for harmonization of care across Europe.

Reference:

Thyen U, Ittermann T, Flessa S, Muehlan H, Birnbaum W, Rapp M, Marshall L, Szarras-Capnik M, Bouvattier C, Kreukels BPC, Nordenstroem A, Roehle R, Koehler B; dsd-LIFE group. Quality of health care in adolescents and adults with disorders/differences of sex development (DSD) in six European countries (dsd-LIFE). BMC Health Serv Res. 2018 Jul 5;18(1):527. Doi:10.1186/s12913-018-3342-0