

EMPIRICAL STUDIES



Understanding sexual health concerns among adolescents and young adults with differences of sex development: a qualitative study

Line Merete Mediå ^{a,b}, Solrun Sigurdardottir ^c, Lena Fauske ^{d,e} and Anne Waehre ^{f,g}

^aWomen and Children's Division, Centre for Rare Disorders, Oslo University Hospital, Oslo, Norway; ^bDepartment of Interdisciplinary Health Sciences, Institute of Health and Society, University of Oslo, Oslo, Norway; ^cDepartment of Oncology, Norwegian Radium Hospital, Oslo University Hospital, Oslo, Norway; ^dDepartment of Child and Adolescent Psychiatry, Oslo University Hospital and Institute of Clinical Medicine, Oslo, Norway; ^eDivision of Endocrinology, Boston Children's Hospital, Boston, MA, USA; ^fDepartment of Pediatrics, Harvard Medical School, Boston, MA, USA

ABSTRACT

Purpose: Differences of sex development (DSD) are congenital conditions that involve variations in individuals' sex chromosomes, genes, external and/or internal genitalia, hormones, and/or secondary sex characteristics. This study sought to elucidate the experiences of adolescents and young adults living with DSD by focusing on their experiences of intimacy and sexual health.

Methods: An interpretative phenomenological research design was adopted. Semi-structured qualitative interviews were conducted with 11 Norwegian adolescents and young adults aged 16–26 years who had five different DSD conditions. The interview findings were analysed by means of a reflexive thematic analysis.

Results: The participants reported feeling different, both in terms of how their body functioned and how their body looked. Lack of knowledge increased this feeling of differentness. Moreover, lack of everyday language with which to talk about intimacy and sexual concerns resulted in the participants feeling stigma. Anticipating stigmatization and lacking everyday language complicated the participants' communication regarding their DSD and sexual health.

Conclusions: The sexual experiences of adolescents and young adults with DSD are diverse. Fear of stigmatization and lack of everyday language complicate communication with healthcare professionals and others. Understanding their unique needs is crucial to helping individuals achieve good sexual health.

ARTICLE HISTORY

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KEYWORDS

Disorders of sex development; differences of sex development; intersex; sexual health; stigma; communication

Introduction

Differences of sex development (DSD) represent a heterogeneous group of congenital conditions that cause the development of the genitals, hormones, and/or chromosomes to differ from traditional conceptions of male and female bodies (Lee et al., 2016). As a group, DSD have an estimated incidence of 1:4500 births (Sax, 2002). A DSD may become evident at birth or during childhood, adolescence, or adulthood, depending on the specific condition and its severity. Different DSD aetiologies, treatments, and individual experiences may affect individuals' sexual health (Amaral et al., 2015; Wisniewski et al., 2019). In fact, adolescents and adults with DSD have highlighted sexual aversion and lack of arousal as the most common problems experienced (Hughes et al., 2006). WHO defines sexual health as "a state of physical, emotional, mental and social well-being in relation to sexuality" (World Health Organization [WHO], 2015, p. 5). The WHO definition is quite broad. More specifically, sexual health may also concern gender identity, sexual orientation,

eroticism, pleasure, intimacy, and reproduction (Graugaard, 2017). In 2006, a consensus statement was published in an effort to improve the management of individuals with DSD (Hughes et al., 2006). The statement offered suggestions for improving individuals' sexual health, including a focus on interpersonal relationships, referral to sex therapy, avoidance of unnecessary medical photography and/or genital examination, access to mental health professionals, and assessment of sexual health (Hughes et al., 2006). An update to the statement was published in 2016, which highlighted the role of psychoeducation in reducing anxiety related to sexual and romantic relations (Lee et al., 2016).

The body of literature concerning the sexual health of individuals with DSD has grown in recent years, although it remains both limited and characterized by contradictory results (Wisniewski et al., 2019). Some quantitative studies involving individuals with different DSD reported the participants to exhibit overall satisfaction with their sexual health (Engberg et al., 2022; Schönbucher et al.,

CONTACT Line Merete Mediå  lmedi@ous-hf.no  Centre for rare disorders, Oslo University Hospital (Rikshospitalet), Postboks 4950 Nydalen, Oslo 0424, Norway

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Sexual Health Concerns 2nd Edition

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