

# Sexual Life and Sexual Wellness in Individuals with Complete Androgen Insensitivity Syndrome (CAIS) and Mayer-Rokitansky-Küster-Hauser Syndrome (MRKHS)

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## ABSTRACT

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**Introduction.** Sexual wellness depends on a person's physical and psychological constitution. Complete Androgen Insensitivity Syndrome (CAIS) and Mayer-Rokitansky-Küster-Hauser Syndrome (MRKHS) can compromise sexual well-being.

**Aims.** To compare sexual well-being in CAIS and MRKHS using multiple measures: To assess sexual problems and perceived distress. To gain insight into participants' feelings of inadequacy in social and sexual situations, level of self-esteem and depression. To determine how these psychological factors relate to sexual (dys)function. To uncover what participants see as the source of their sexual problems.

**Methods.** Data were collected using a paper-and-pencil questionnaire. Eleven individuals with CAIS and 49 with MRKHS with/without neovagina treatment were included. Rates of sexual dysfunctions, overall sexual function, feelings of inadequacy in social and sexual situations, self-esteem and depression scores were calculated. Categorizations were used to identify critical cases. Correlations between psychological variables and sexual function were computed. Sexually active subjects were compared with sexually not active participants. A qualitative content analysis was carried out to explore causes of sexual problems.

**Main Outcome Measures.** An extended list of sexual problems based on the Diagnostic and Statistical Manual of Mental Disorders, 4th ed., text revision, by the American Psychiatric Association and related distress. Female Sexual Function Index (FSFI), German Questionnaire on Feelings of Inadequacy in Social and Sexual Situations (FUSS social scale, FUSS sexual scale), Rosenberg Self-Esteem Scale (RSE), Brief Symptom Inventory (BSI) subscale depression. Open question on alleged causes of sexual problems.

**Results.** The results point to a far-reaching lack of sexual confidence and sexual satisfaction in CAIS. In MRKHS apprehension in sexual situations is a source of distress, but sexual problems seem to be more focused on issues of vaginal functioning. MRKHS women report being satisfied with their sex life.

**Conclusion.** Different conditions can affect individuals in diagnosis-specific ways despite some shared clinical features. Professionals should adopt an interdisciplinary approach and provide custom-made care in order to promote sexual well-being in patients. Fliegner M, Krupp K, Brunner F, Rall K, Brucker SY, Briken P, and Richter-Appelt H. Sexual life and sexual wellness in individuals with Complete Androgen Insensitivity Syndrome (CAIS) and Mayer-Rokitansky-Küster-Hauser Syndrome (MRKHS). *J Sex Med* \*\*,\*\*,\*\*\_\*\*.

## Satisfaction with Genital Surgery and Sexual Life of Adults with XY Disorders of Sex Development: Results from the German Clinical Evaluation Study

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**Background:** Prenatal deficit of androgens or androgen action results in atypical genitalia in individuals with XY disorders of sex development (XY,DSD). XY,DSD include mainly disorders of gonadal development and testosterone synthesis and action. Previously, most XY,DSD individuals were assigned to the female sex. Constructive genital surgery allowing heterosexual intercourse, gonadectomy, and hormone therapy for feminization were often performed. However, outcome studies are scarce.

**Objective:** Our objective was evaluation of satisfaction with genital surgery and sexual life in adults with XY,DSD.

**Design and Methods:** We evaluated 57 individuals with XY,DSD from the German multicenter clinical evaluation study with a condition-specific questionnaire. The individuals were divided into subgroups reflecting the absence/presence of partial androgen effect or genital constructive surgery.

**Results:** Dissatisfaction with function of the surgical result (47.1%) and clitoral arousal (47.4%) was high in XY,DSD partially androgenized females after feminization surgery. Dissatisfaction with overall sex life (37.5%) and sexual anxieties (44.2%) were substantial in all XY,DSD individuals. Problems with desire (70.6%), arousal (52.9%), and dyspareunia (56.3%) were significant in XY,DSD complete females. 46,XY partially androgenized females reported significantly more often partners of female (9.1%) or both sexes (18.2%) and dyspareunia (56.5%) compared with controls. Individuals with complete androgen insensitivity syndrome stated significant problems with desire (81.8%), arousal (63.6%), and dyspareunia (70%).

**Conclusions:** Care should be improved in XY,DSD patients. Constructive genital surgery should be minimized and performed mainly in adolescence or adulthood with the patients' consent. Individuals with DSD and their families should be informed with sensibility about the condition. Multidisciplinary care with psychological and nonprofessional support (parents, peers, and patients' support groups) is mandatory from child to adulthood. (*J Clin Endocrinol Metab* 97: 577–588, 2012)