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The influence of psychosocial and sexual wellbeing on quality of life in women with differences of sexual development

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ABSTRACT

Background: Previous research indicating that women with differences of sexual development (DSD), namely women with Turner syndrome (TS), women with congenital adrenal hyperplasia (CAH), and women with XY-DSD, have an impaired psychosocial and sexual well-being and quality of life (QOL), was often limited by small samples and inadequate control groups (CGs). Only few studies analysed which psychosocial and sexual factors influence QOL in women with DSD and no study so far has examined whether the DSD-condition itself and the diagnostic group to which they belong moderate this influence.
Methods: We compared 301 women with TS, 221 women with CAH and 142 women with XY-DSD with 603 non-DSD women regarding depression, anxiety, self-esteem, attention deficit hyperactivity disorder, autism, social participation, body acceptance, relationship status, sexual satisfaction and QOL. Furthermore, we investigated the influence of psychosocial and sexual well-being on QOL within and between diagnostic groups and examined whether the DSD-condition moderates the influence of psychosocial and sexual well-being on QOL.
Results: Women with DSD reported average psychosocial well-being and QOL; only women with CAH reported an impaired physical QOL. However, women with DSD were less satisfied with their body and had less often a partner than women in the CG. Women with CAH and XY-DSD were less satisfied with their sex life compared to women in the CG. Across groups, better health and lower depression scores predicted better QOL, whereas higher self-esteem especially predicted better QOL in women with DSD. The presence of DSD moderated the influence of psychosocial and sexual well-being on QOL, however, the specific diagnosis group mainly moderated the influence on physical QOL.
Conclusion: We have learned that body and sexual satisfaction need further attention in women with DSD. To optimize their QOL, psychosocial well-being should be taken in account. The improvement of self-esteem seems particularly relevant for women with DSD, as this helps coping with having a variant of sexual development.

1. Introduction

The term "differences of sex development" (DSD) comprises a heterogenous group of diagnoses in which the genetic, the gonadal, and the genital sex do not coincide. For women, these DSD diagnoses include (a) Turner syndrome (TS), a partial or complete monosomy X, (b) congenital adrenal hyperplasia (CAH) which is marked by an overproduction of androgens, and (c) women with XY-DSD who have either a disorder of gonadal development or a disorder of in androgen synthesis or action [1].

These syndromes lead to different, well-studied, physical symptoms. For TS, the most prominent symptoms are short stature and gonadal

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failure, which, unless treated with estrogen replacement, inhibits puberty and causes infertility in 95% of young girls with TS [2]. Similarly, women with CAH tend to have a small stature and, depending on severity, virilized genitalia as well as an insufficient aldosterone production that can lead to salt wasting and adrenal crisis [3]. Women with XY-DSD are typically taller than women of the general population. Women with an androgen insensitivity syndrome have female or ambiguous external genitalia and male internal genital organs. Women with pure gonadal dysgenesis have both female genitalia as well as a vagina and a uterus, but no functioning ovaries [4].

Besides physical deviations, studies indicate that women with DSD also suffer from an impaired psychosocial and sexual well-being as well as an impaired quality of life (QOL). In their review targeting the mental health of individuals with DSD, Bohet, et al. (2019) conclude that women with CAH and an XY-karyotype have a higher risk for depression and anxiety and report more interpersonal difficulties. For women with TS, a recent review also found a higher prevalence and severeness of depressive symptoms [5]. Moreover, some studies imply that women with DSD experience more often attention deficits and autistic mannerisms [6,7].

However de Vries et al. [8], only found females with XY-DSD with partial androgenization to be more anxious and only females with CAH to be more depressed. Other studies found no reduced psychosocial well-being at all in women with DSD [7,9,10].

As might be expected, individuals with DSD were also found to be less satisfied with their gender-specific body parts and to have lower self-esteem [11–13]. Furthermore, women with DSD are less likely to have a partner and often tend to isolate themselves [11,14,15]. Accordingly, women with DSD reported to have less sexual experience and to be less satisfied with their sexual life [10,11,16].

QOL can be defined "as an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, and their relationship to salient features of their environment" [17]. Concerning this construct in women with DSD, research is scarce and often inconsistent. However, a review of 13 studies indicates women with TS to have an impaired QOL [18]. Studies of women with other forms of DSD suggests a reduced to similar QOL to the general public [19,20].

In women with TS, satisfaction with height and breast development were found to influence the QOL positively [21], whereas another study observed that height did not influence QOL and otological difficulties had a negative impact on QOL [22]. For women with CAH, one study found older age, hirsutism and hypertension to reduce global QOL, whereas the degree of virilization influenced the physical QOL negatively and the psychological QOL decreased with increasing age at genital surgery [23]. Moreover, Han, et al. [24] found the body mass index (BMI) to negatively predict QOL in women with CAH. Overall, however, only very few studies examined *psychosocial* predictors for QOL in women with DSD. One of those was carried out by Amaral et al. (2015b) who found general age, positive feelings, spirituality and religion, personal beliefs and the sexual life to significantly influence QOL, measured by the WHOQOL-BREF, in adults with DSD.

Previous research examining the psychosocial well-being and QOL in women with DSD suffered from various limitations. First, preceding studies showed inconsistent results and were limited by small sample sizes or the absence of a proper control group. Therefore, it remains unclear to which degree the psychosocial/ sexual well-being and QOL is reduced in women with DSD. Second, only very few studies analysed which psychosocial and -sexual factors influence the QOL in women with DSD. As a systematic review studying QOL in rare diseases found that disease-relating factors mostly just predict physical QOL whereas psychosocial factors strongly impact all QOL-dimensions [25], such analyses are greatly needed. Third, no study so far has examined whether the specific DSD-condition moderates the influence of psychosocial and -sexual well-being on QOL which would help determine whether diagnosis-specific interventions are needed.

This study aims at overcoming those limitations. First, we will compare the psychosocial- and sexual wellbeing and QOL of a large sample of women with TS, CAH and XY-karyotype to a female control group (CG). Second, we will analyse which psychosocial and sexual variables influence QOL in these three patient groups (PGs) and the CG. Third, this study will be the first to examine whether the DSD-diagnosis group moderates the influence of psychosocial and sexual wellbeing on QOL.

2. Methods

2.1. Study design

Patient data was collected within the collaborative international European study "dsd-LIFE". This study recruited individuals with DSD aged ≥16 years in 14 study centers in Germany ($n = 4$), France ($n = 4$), the Netherlands ($n = 2$), Poland ($n = 2$), Sweden ($n = 1$) and United Kingdom ($n = 1$) between February 2014 and September 2015. The study centers recruited present and past patients via letters, e-mail, telephone or personal approach. A response rate of 36.1% was obtained (see Roehle et al., 2017). In addition, self-help groups were contacted and information was posted on the dsd-LIFE-website (www.dsd-life.eu). Ethical approval was given by all study centers. All participants had a DSD-diagnosis according to the Chicago Consensus Conference [1].

We included 301 individuals with TS, 221 individuals with CAH, and 142 individuals with XY-DSD who identified themselves as women in this study. One-hundred-and-fifty of the women with TS had a monosomy, 31 had mosaics, 59 had isochromosomes, 19 had deletions, 16 had a polyploidy, 12 had ring material and 14 were unknown or not classified. Regarding women with congenital adrenal hyperplasia, 109 had the salt-wasting type, 65 had the simple virilization type, 33 were non-classical and three were not classified. Nine women had other forms of CAH. Regarding XY-DSD, 20 women had a complete and 12 a partial gonadal dysgenesis, three women had ovotesticular DSD, 69 had a complete and 17 had a partial androgen insensitivity, and 21 women had other forms of XY-DSD. See Röhle et al. [26] for further information on diagnostic subcategories. The kind and number of surgeries the individuals of the dsd-LIFE-cohort experienced are described by Rapp et al. [27]. Individuals identifying as male or not male or female were excluded from this analysis.

The study included a medical interview and examination in the recruitment centers and a patient reported outcome (PRO) questionnaire that was filled out online. Upon request, a paper-pencil version was provided. The PRO consisted of standardized questionnaires and short questions assessing sociodemographic details (including age, height, weight, relationship status, social participation, health, sexual satisfaction, and years of education) and was offered in the language of the country the participant lived in. Theoretical and methodological details of the study have been described elsewhere [26].

An age-matched control group consisting of 603 women was recruited via the online panel survey "Norstat" (https://norstat.de) in Germany between March 16th and March 25th of 2020. Demographic details can be found in Table 1. Participants in the CG filled out a web-based questionnaire designed via SoSci Survey [28] corresponding the PRO. Participants gave informed consent to have their de-identified data used for research purposes.

2.2. Measures

2.2.1. Hospital anxiety and depression scale (HADS [29])

The HADS comprises the dimensions "depression" and "anxiety" which are both determined by seven items with a four-point Likert scale from 0 (e.g. "Definitely") to 3 (e.g. "Not at all"). Higher total scores

Table 1
Sociodemographic data of the control and patient groups.

	TG	CAHG	XYG	CG
Age	$M = 32.20$; $SD = 13.30$	$M = 30.10$; $SD = 10.90$	$M = 30.70$; $SD = 12.50$	$M = 31.70$; $SD = 12.30$
Age at diagnosis	$M = 10.50$; $SD = 9.19$	$M = 4.33$; $SD = 9.40$	$M = 10.30$; $SD = 8.91$	– –
Height	$M = 153.00$; $SD = 7.01$	$M = 161.00$; $SD = 7.80$	$M = 174.00$; $SD = 7.18$	$M = 167.00$; $SD = 6.61$
Country				
• Germany	$n = 43$ (14.29%)	$n = 91$ (41.18%)	$n = 38$ (26.76%)	$n = 603$ (100%)
• France	$n = 116$ (38.54%)	$n = 62$ (28.05%)	$n = 29$ (20.42%)	–
• Netherlands	$n = 82$ (27.24%)	$n = 24$ (10.86%)	$n = 42$ (29.58%)	–
• Sweden	$n = 46$ (15.28%)	$n = 11$ (4.98%)	$n = 8$ (5.63%)	–
• Great Britain	$n = 11$ (3.65%)	$n = 19$ (8.60%)	$n = 3$ (2.11%)	–
• Poland	$n = 3$ (1.00%)	$n = 14$ (6.33%)	$n = 22$ (15.49%)	–
Number of years of education	$M = 14.10$; $SD = 4.02$	$M = 13.70$; $SD = 3.88$	$M = 14.30$; $SD = 4.48$	$M = 13.70$; $SD = 3.15$
Health	$M = 3.73$; $SD = 0.67$	$M = 3.70$; $SD = 0.86$	$M = 3.81$; $SD = 0.89$	$M = 3.65$; $SD = 0.84$
Any longstanding illness (other than DSD)?				
• Yes	$n = 137$ (48.58%)	$n = 114$ (54.03%)	$n = 47$ (33.57%)	$n = 299$ (49.59%)
• No	$n = 136$ (48.23%)	$n = 92$ (43.60%)	$n = 86$ (61 .43%)	$n = 268$ (44.44%)
• I don't know	$n = 9$ (3.19%)	$n = 5$ (2.37%)	$n = 7$ (5.00%)	$n = 36$ (5.97%)
Type of health problem				
• physical	$n = 95$ (69.34%)	$n = 84$ (73.68%)	$n = 29$ (61.70%)	$n = 147$ (45.51%)
• mental	$n = 14$ (10.22%)	$n = 9$ (7.89%)	$n = 4$ (8.51%)	$n = 88$ (27.24%)
• both	$n = 21$ (15.33%)	$n = 11$ (9.65%)	$n = 7$ (14.89%)	$n = 71$ (21.98%)
• I don't know	$n = 7$ (5.11%)	$n = 10$ (8.77%)	$n = 7$ (14.89%)	$n = 17$ (5.26%)
Sexual orientation				
• Hetero	$n = 193$ (64.12%)	$n = 112$ (50.68%)	$n = 86$ (60.56%)	n.a.
• Nonhetero	$n = 79$ (26.25%)	$n = 95$ (42.99%)	$n = 50$ (35.21%)	n.a.
• No answer	$n = 29$ (9.63%)	$n = 14$ (6.33%)	$n = 6$ (4.23%)	n.a.

indicate a greater impairment.

2.2.2. Autism spectrum quotient (AQ10 [30])

The AQ10 is a 10-item questionnaire that screens for autistic symptoms on a four-point Likert scale, although only one point per item gets awarded, e.g., 1 for slightly/definitely agree, 0 for slightly/definitely disagree. Higher total scores indicate more autistic mannerisms.

2.2.3. Adult ADHD self-report (ASRS-v1.1 [31])

The ASRS-*v1.1* consists of six items to be answered on a five-point Likert scale from 0 ("Never") to 4 ("Very often"). Higher total scores represent a higher risk of having Attention Deficit and Hyperactivity Disorders.

2.2.4. Rosenberg self-esteem scale (RSES [32])

The RSES comprises ten items to be answered on a four-point Likert scale from 0 ("Strongly disagree") to 3 ("Strongly agree"), whereby higher total scores represent higher self-esteem.

2.2.5. Body image scale (BI-1 [33])

The BI-1 is a 30-item questionnaire that inquires the satisfcation with different body parts on a five-point Likert scale from 1 ("Very satisfied") to 5 ("Very dissatisfied"). Higher scores imply a greater dissatisfaction with the corresponding body parts. We only included the items regarding the dissatisfaction with height, weight, vagina and clitoris in this study.

2.2.6. WHOQOL-BREF [34]

The WHOQOL-BREF consists of 26 items to be answered on a five-point Likert scale from 1 (e.g. "Not at all") to 5 (e.g. "Extremely") that comprise the dimensions "global QOL", "physical QOL", "psychological QOL", "social QOL", and "environmental QOL". The environmental QOL-dimension asks for example how safe and healthy the participant's environment is and how available the information they need is in their day-to-day life. Higher total scores represent a greater QOL.

2.3. Analysis

The complete analysis was conducted in R [35]. To compare the psychosocial and sexual wellbeing as well as the QOL between the different PGs and the CG, we carried out multiple Bonferroni corrected analyses of variance with Tukey post-hoc tests. We tested variance equality across groups with Levene-tests beforehand, and whenever the assumption of variance equality was violated, we used Welch's analyses of variance with Welch's Bonferroni corrected post-hoc *t*-tests. To compare the binary discret variables "Do you have a current relationship" and "Have you ever had sex" we used χ^2-tests.

Before building multiple regression models for each group in order to evaluate the influence of psychosocial and sexual wellbeing on QOL, we centred all quantitative independent and dependent variables. Then, we established a multiple regression model for each group by starting with an "empty" model with no input variable but an intercept and then conducting a stepwise bidirectional elimination procedure [36] based on the *p*-criterion ($\alpha = 0.05$). The stepwise selection procedure for multiple predictors was executed with the "olsrr"-package [37].

Subsequently, we conducted the moderation analysis in the following way: for each PG, each regression model containing a specific QOL-dimension as the dependent variable and the respective selected predictors was extended by including the remaining PGs and the CG as dummy-coded predictors (thereby determining the original PG as the reference group) and all the interaction-terms of these dummy variables with all selected predictors. A significant regression-coefficient of an interaction-term suggests that the multiple regression weight of the predictor on the QOL-dimension is different for the PG represented in the interaction-term to the weight of the predictor for the original PG that serves as the reference group. Since the moderation analyses were exploratory, no Bonferroni-correction was carried out. Hence, a great number of interactions turned significant which is why only interactions with $\alpha < 0.01$ are reported in the results section. Before the selection procedure for the (group-specific) multiple regressions and the moderation-analysis, outliers were excluded. Changes in the position of addition and significance of predictors that hereby occurred will be reported. Outliers were determined by Bonferoni Outlier Tests [38].

To further corroborate differences between multiple regression weights between groups we conducted model comparisons. For that purpose, we took each estimated moderated regression model (that contains a specific QOL-dimension as the dependent variable, and a specific group as a reference group for which the predictors were selected) and estimated a comparison regression-model in which the regression weights of the interaction-terms are restricted to zero. A likelihood ratio-test between the original moderated regression-model and the restricted model delivers an overall-test for the moderation: the null-hypothesis states that all multiple regression weights of predictors for each dummy-coded reference group are equal to the multiple regression weights for the reference group. The alternative hypothesis states that at least one multiple regression weight is different for at least one comparison group compared to the reference group. Each likelihood-ratio test was computed a second time with a dataset

containing only the three PGs. These tests specifically check whether differences in the multiple regression weights exist between the PGs, whereas the former procedure will suggest rejecting the null hypothesis if predictors contribute differently to QOL only in the CG compared to the PGs.

3. Results

3.1. Psychosocial and sexual wellbeing and QOL in women with and without DSD

Table 2 displays the descriptive statistics and Table 3 shows the results of the univariate ANOVAs containing variables with equal variances. After Bonferroni correction, significant differences between the groups in these ANOVAs were only found for social participation and physical QOL. Subsequent Tukey post-Hoc-tests showed the CG (2.23 ± 0.89) to have a lower social participation than the PGs (minimum across groups in CAHG 2.51 ± 0.93, $p < .001$). Moreover, the group of women with CAH (CAHG; 68.10 ± 18.90) had a significantly more impaired physical QOL than the CG (73.30 ± 16.80, $p < .001$) and the group of XY-women with XY-DSD (XYG; 73.90 ± 17.90, $p = .01$). Regarding the environmental dimension, the XYG (75.60 ± 15.10, $p = .002$), the group of women with TS (73.90 ± 12.90, $p = .01$) and the CAHG (74.10 ± 15.70, $p = .02$) reported a significantly higher QOL than the CG (70.60 ± 15.00).

For the variables with unequal variances, Bonferroni corrected Welch-ANOVAs were conducted. Significant differences between the groups existed for all variables except for dissatisfaction with weight (see Table 4). Welch's Bonferroni corrected post-hoc *t*-tests showed the CG (5.73 ± 4.11) to be more depressed than the PGs (maximum across groups in CAHG 4.34 ± 3.55, $p < .001$). In addition, we found the CG (1.76 ± 1.56) to have higher ADHD-scores than the PGs (maximum across groups in XYG 0.83 ± 1.15, $p < .001$). Moreover, the CAHG (20.70 ± 6.08) reported a higher self-esteem than the CG (19.10 ± 6.80, $p = .01$) and the TG (19.00 ± 5.62, $p = .02$). Regarding their vagina, the XYG (2.82 ± 1.22) was less satisfied than the CG (2.40 ± 1.01, $p < .001$) and the TG (2.46 ± 0.82, $p = .005$). The CAHG (2.63 ± 1.15) was also less satisfied with their vagina than the CG ($p = .04$). Regarding their clitoris, the CG (2.24 ± 0.91) was significantly more satisfied than the XYG (2.58 ± 1.08, $p = .001$), the TG (2.49 ± 0.79, $p = .003$) and the

Table 2
Means and standard deviations of all dependent and independent variables by group.

Variables	TG	CAHG	XYG	CG
Independent				
Depression	$M = 3.67$; $SD = 2.87$	$M = 4.34$; $SD = 3.55$	$M = 4.19$; $SD = 3.82$	$M = 5.73$; $SD = 4.11$
Anxiety	$M = 6.89$; $SD = 3.69$	$M = 6.94$; $SD = 4.04$	$M = 7.26$; $SD = 4.36$	$M = 7.44$; $SD = 3.93$
Self-esteem	$M = 19.00$; $SD = 5.62$	$M = 20.70$; $SD = 6.08$	$M = 20.50$; $SD = 6.24$	$M = 19.10$; $SD = 6.80$
Autism	$M = 3.22$; $SD = 2.02$	$M = 3.16$; $SD = 1.93$	$M = 2.86$; $SD = 1.91$	$M = 3.43$; $SD = 1.93$
ADHD	$M = 0.61$; $SD = 1.01$	$M = 0.69$; $SD = 1.14$	$M = 0.83$; $SD = 1.15$	$M = 1.76$; $SD = 1.56$
Social participation	$M = 2.61$; $SD = 0.82$	$M = 2.51$; $SD = 0.93$	$M = 2.70$; $SD = 0.92$	$M = 2.23$; $SD = 0.89$
Dissatisfaction with vagina	$M = 2.46$; $SD = 0.82$	$M = 2.63$; $SD = 1.15$	$M = 2.82$; $SD = 1.22$	$M = 2.40$; $SD = 1.01$
Dissatisfaction with clitoris	$M = 2.49$; $SD = 0.79$	$M = 2.65$; $SD = 1.12$	$M = 2.58$; $SD = 1.08$	$M = 2.24$; $SD = 0.91$
Dissatisfaction with breasts	$M = 2.77$; $SD = 1.13$	$M = 2.68$; $SD = 1.26$	$M = 2.70$; $SD = 1.29$	$M = 2.71$; $SD = 1.19$
Dissatisfaction with weight	$M = 3.14$; $SD = 1.16$	M = 3.25; SD = 1.26	M = 2.92; SD = 1.31	M = 3.00; SD = 1.27
Dissatisfaction with height	$M = 2.96$; $SD = 1.09$	$M = 2.56$; $SD = 1.17$	$M = 2.05$; $SD = 1.02$	$M = 2.20$; $SD = 0.98$
Do you have a current relationship?				
• Yes	$n = 133$ (47.84%)	$n = 91$ (43.54%)	$n = 65$ (46.74%)	$n = 370$ (61.36%)
• No	$n = 145$ (52.16%)	$n = 118$ (56.46%)	$n = 74$ (53.24%)	$n = 233$ (38.64%)
Have you ever had sex?				
• Yes	$n = 170$ (61.15%)	$n = 143$ (68.10%)	$n = 97$ (69.78%)	$n = 505$ (84.31%)
• No	$n = 108$ (38.85%)	$n = 67$ (31.90%)	$n = 42$ (30.22%)	$n = 94$ (15.69%)
Age at first sex	$M = 20.80$; $SD = 5.28$	$M = 18.80$; $SD = 4.72$	$M = 19.10$; $SD = 4.03$	$M = 17.00$; $SD = 3.34$
Sexual satisfaction	$M = 3.20$; $SD = 1.00$	$M = 3.12$; $SD = 1.18$	$M = 2.89$; $SD = 1.16$	$M = 3.39$; $SD = 1.19$
Years of education	$M = 14.10$; $SD = 4.02$	$M = 13.70$; $SD = 3.88$	$M = 14.30$; $SD = 4.48$	$M = 13.80$; $SD = 3.73$
Dependent				
Global QOL	$M = 67.60$; $SD = 17.40$	$M = 68.80$; $SD = 21.70$	$M = 70.20$; $SD = 21.50$	$M = 65.80$; $SD = 19.40$
Physical QOL	$M = 71.50$; $SD = 16.80$	$M = 68.10$; $SD = 18.90$	$M = 73.90$; $SD = 17.90$	$M = 73.30$; $SD = 16.80$
Psychological QOL	$M = 63.70$; $SD = 16.10$	$M = 65.60$; $SD = 18.40$	$M = 64.30$; $SD = 19.70$	$M = 63.30$; $SD = 18.50$
Social QOL	$M = 65.90$; $SD = 18.60$	$M = 64.80$; $SD = 20.50$	$M = 61.80$; $SD = 20.20$	$M = 64.40$; $SD = 20.90$
Environmental QOL	$M = 73.90$; $SD = 12.90$	$M = 74.10$; $SD = 15.70$	$M = 75.60$; $SD = 15.10$	$M = 70.60$; $SD = 15.00$

Table 3
Results of the ANOVAs with equal variances.

Variable	*Df*	*SS*	*MS*	*F*	*p*
Anxiety					
Between groups	3	78	25.94	1.67	1
Within groups	1230	19142.00	15.56		
Autism					
Between groups	3	42	14.01	3.70	.230
Within groups	1225	4644.00	3.79		
Dissatisfaction with breasts					
Between groups	3	1.2	0.39	0.27	1
Within groups	1198	1722.20	1.44		
Social participation					
Between groups	3	44.8	14.94	19.15	<.001***
Within groups	1225	955.90	0.78		
Global QOL					
Between groups	3	3115	1038.40	2.69	.898
Within groups	1234	476040.00	385.80		
Physical QOL					
Between groups	3	4897	1632.00	5.44	.020*
Within groups	1233	369848	300.00		
Psychological QOL					
Between groups	3	849	283.00	0.86	1
Within groups	1234	404985	328.20		
Social QOL					
Between groups	3	1586	528.80	1.29	1
Within groups	1233	506766	411.00		
Environmental QOL					
Between groups	3	4647	1549.00	7.200	<.001***
Within groups	1233	265318	215.20		

Note. *$p < .05$, **$p < .01$, ***$p < .001$.

Table 4
Results of the Welch-ANOVAs.

	df1	df2	F	p
Depression	3	445.91	225.93	<.001***
ADHD	3	463.02	267.53	<.001***
Self-esteem	3	446.17	225.31	<.027*
Dissatisfaction with vagina	3	404.06	225.84	<.013*
Dissatisfaction with clitoris	3	398.18	211.55	<.001***
Dissatisfaction with height	3	414.75	238.51	<.001***
Dissatisfaction with weight	3	422.21	223.03	<.584
Relationship status	3	428.000	210.0000.	<.001***
Ever sex	3	403.07	221.41	<.001***
Age at first sex	3	228.37	220.91	<.001***
Sexual satisfaction	3	228.10	430.99	<.001***

Note. *p < .05, **p < .01, ***p < .001.

CAHG (2.65 ± 1.12, $p < .001$). Regarding their height, the TG (2.96 ± 1.09) was significantly less satisfied than the other groups (maximum across groups in CAHG 2.56 ± 1.17, $p < .001$). The CAHG was also less satisfied with their height than the CG (2.20 ± 0.98, $p < .001$) and the XYG (2.05 ± 1.02, $p < .001$).

On average, the CG (17.00 ± 3.34) was significantly younger than the PGs during their first sexual contact (minimum across groups in CAHG 18.80 ± 4.72, $p < .001$). Moreover, the CG (3.39 ± 1.19) was significantly more satisfied with their sexual life than the CAHG (3.12 ± 1.18, $p = .02$) and the XYG (2.89 ± 1.16, $p < .001$).

χ^2-tests showed that significant differences existed between groups regarding the variables "Do you have a current relationship" and "Have you ever had sex". The CG (0.61 ± 0.49) had significantly more often a partner than the TG (0.48 ± 0.5, $\chi^2(1) = 13.64$, $p < .001$), the CAHG (0.44 ± 0.50, $\chi^2(1) = 19.36$, $p < .001$) and the XYG (0.47 ± 0.50, $\chi^2(1) = 9.33$, $p = .002$). Moreover, significantly more women of the CG (0.84 ± 0.36) have already had an intimate sexual contact than women of the TG (0.61 ± 0.49, $\chi^2(1) = 56.13$, $p < .001$), the CAHG (0.68 ± 0.47, $\chi^2(1) = 24.63$, $p < .001$) and the XYG (0.70 ± 0.46, $\chi^2(1) = 14.88$, $p < .001$).

3.2. Multiple regressions

The selected predictors for all groups and all dimensions of QOL with their order of selection and their regression coefficients are shown in Table 5. The variable "age at first sexual intercourse" was not used as a potential predictor for the multiple regressions, as this would have excluded all participants who did not have sexual intercourse yet.

For global QOL, good health was the best predictor in all models, followed by low depression in the models of the CG, TG, and CAHG. Moreover, anxiety negatively predicted global QOL for the CG, the TG, and the XYG. Self-esteem predicted global QOL in all PGs. For the regression model of the XYG predicting global QOL "dissatisfaction with clitoris" was excluded because of a curvilinear relationship (identified via scatter-plot). The adjusted coefficient of determination amounted $R^2_{adj} = 0.55$ for the CG, $R^2_{adj} = 0.57$ for the TG, $R^2_{adj} = 0.66$ for the CAHG and $R^2_{adj} = 0.72$ for the XYG.

For physical QOL, good health and low depression rates were the best predictors. Low scores regarding ADHD and anxiety as well as young age positively influenced physical QOL in two of the models. The adjusted coefficient of determination amounted $R^2_{adj} = 0.59$ in the CG, $R^2_{ad\ j} = 0.49$ in the TG, $R^2_{adj} = 0.51$ in the CAHG and $R^2_{adj} = 0.64$ in the XYG.

The best predictors for psychological QOL were high self-esteem and low depression. Good health, low rates of ADHD, and satisfaction with weight and vagina influenced psychological QOL in two of the models. The adjusted coefficient of determination amounted $R^2_{adj} = 0.76$ in the CG, $R^2_{adj} = 0.70$ in the TG, $R^2_{adj} = 0.73$ in the CAHG and $R^2_{adj} = 0.77$ in the XYG.

Sexual satisfaction was one of the best predictors for social QOL in all groups. Low depression and having a partner were significant predictors for social QOL in the CG, CAHG and XYG. Moreover, high self-esteem predicted social QOL in all PGs but not in the CG. The adjusted coefficient of determination amounted $R^2_{adj} = 0.57$ in the CG, $R^2_{adj} = 0.48$ in the TG, $R^2_{adj} = 0.55$ in the CAHG and $R^2_{adj} = 0.63$ in the XYG.

Good health and low depression belonged to the strongest predictors of environmental QOL in all models. High self-esteem predicted environmental QOL in all PGs. Low anxiety influenced environmental QOL in the CG, TG and CAHG. The adjusted coefficient of determination amounted $R^2_{adj} = 0.41$ in the CG, $R^2_{adj} = 0.36$ in the TG, $R^2_{adj} = 0.46$ in the CAHG and $R^2_{adj} = 0.52$ in the XYG.

3.3. Moderation analyses

For the moderation analysis of the CAHG predicting global QOL, the VIF-test showed a risk for multicollinearity regarding the variables "diagnosis group" (VIF = 23.52) and "diagnosis group*height" (VIF = 23.62). Since the removing of predictors often leads to more problems than the multicollinearity itself [39], all variables were kept. In this model height had a stronger impact on global QOL in the CAHG ($\beta = 0.02$) than in the CG ($\beta = 0.0$, $p = .003$). For the moderation model explaining global QOL with the CG, TG and XYG as reference, no moderations with $\alpha < 0.01$ were found.

The moderation analysis of the CG explaining physical QOL showed a significant moderation regarding "dissatisfaction with height". In the CG, this variable influenced physical QOL negatively ($\beta = -0.11$), whereas it had a positive influence in the TG ($\beta = 0.06$, $p = .002$). For the moderation analysis predicting physical QOL and using the CAHG as reference, "height" had a significantly stronger influence in the CAHG on physical QOL ($\beta = 0.03$) than it had in the CG ($\beta = 0$, $p < .001$), the TG ($\beta = 0.0$, $p < .001$) and the XYG ($\beta = -0.02$, $p < .001$). No moderations with $\alpha < 0.01$ were found for the moderation analysis of the TG and XYG explaining physical QOL.

For the moderation analysis predicting psychological QOL with CG as reference, self-esteem had a significantly smaller impact in the CG ($\beta = 0.30$) than in the TG ($\beta = 0.46$, $p = .004$) and the CAHG ($\beta = 0.48$, $p = .006$). In accordance with this, the moderation analysis predicting psychological QOL and using TG as reference showed self-esteem to have a bigger impact in the TG ($\beta = 0.52$) than in the CG ($\beta = 0.36$, $p = .003$). Another significant moderation was shown in this analysis for "ADHD" ($p = .003$); in the TG, this variable had a negative impact ($\beta = -0.14$), whereas in the CAHG, the effect was positive ($\beta = 0.06$). However, the actual correlation between ADHD and psychological QOL was also negative in the CAHG ($r = -0.24$), although not significant after Bonferroni correction and smaller than the significant correlation in the TG ($r = -0.41$). For the moderation analysis predicting psychological QOL and using CAHG as a reference, a higher age at diagnosis had a negative impact in the CAHG ($\beta = -0.02$), whereas no impact was found in the TG ($\beta = 0$, $p = .001$). No moderations with $\alpha < 0.01$ were found for the moderation analysis of the XYG explaining psychological QOL.

When using the TG as a reference to explain social QOL, age had a significantly stronger impact in the TG ($\beta = -0.01$) than in the CG ($\beta = 0$, $p = .004$). No moderations with $\alpha < 0.01$ were found for the moderation analysis predicting social QOL and using the CG, the CAHG or the XYG as a reference.

When predicting environmental QOL, the moderation analysis using the CG as a reference showed health to have a significantly smaller impact in the CG ($\beta = 0.13$) than in the TG ($\beta = 0.36$, $p = .002$). However, the dissatisfaction with height had a significantly greater effect in the CG ($\beta = -0.16$) than in the XYG ($\beta = 0.07$, $p = .008$). No significant moderations were found for the moderation analysis predicting social QOL and using the TG, the CAHG and the XYG as a reference. All results of the moderation analyses can be found in the Supplement.

3.4. Model comparison

Please see Table 6 for details of the model comparisons. The model referencing TG and containing moderators explained global QOL significantly better than the model without moderators. For the remaining reference groups the addition of moderators did not lead to a significantly better prediction of global QOL. For physical QOL, all models containing moderators had a significant better model fit than the models without moderators. Only the model referencing the XYG, when the dataset with only PGs was used, did not improve. When using the CG- and PGs-including dataset, the addition of moderators resulted in a significantly better explanation of psychological QOL for all reference groups, but not for the model including all groups. When using the dataset containing only data of the PGs, only for the CAH-reference group the addition of moderators led to a significantly better model fit. The addition of moderators predicted social QOL significantly better in the reference groups CAHG and XYG, when using data of the CG and PGs. For all remaining models, the addition of moderators did not offer a significant advantage. When using data of the CG and PGs, all models with moderators proved to explain environmental QOL significantly

Table 5
Results of the multiple regressions for QOL with selected factors by group.

		CG		TG		CAHG		XYG	
		P.	β	P.	β	P.	β	P.	β
Global QOL	Health	1	-.48***	1	-.43***	1	-.53***	1	-.51***
	Depression	2	-.21***	2	-.21***	2	-.17*		
	Dissatisfaction with height	3	-.08**						
	Social participation	4	-.08**			6	-.13*		
	Anxiety	5	-.11**	6	-.14**			3	-.17**
	Age	6	-.01**	5	-.01***				
	Relationship status	7	-.14*	8	-.22*				
	Self-esteem			3	-.07	7	-.13*	2	-.24***
	Sexual satisfaction			4	-.06			5	-.10*
	Dissatisfaction with breasts			7	-.12**	5	-.12*		
	Height					3	-.16***		
	Age at diagnosis					4	-.08		
	Ever sex					8	-.09		
	BMI							4	-.02*
Physical QOL	health	1	-.43***	1	-.47***	1	-.43***	2	-.29***
	Depression	2	-.23***	2	-.16**	2	-.24***	1	-.35***
	ADHD	3	-.12***	3	-.16**				
	Autism	4	-.11***						
	Dissatisfaction with height	5	-.11***						
	Age	6	-.09*	4	-.13**				
	Anxiety	7	-.08			4	-.19**	3	-.20**
	Dissatisfaction with breasts	8	-.07*						
	Self-esteem	9	-.07	6	-.12*				
	Height					3	-.22***	4	-.01
Psychological QOL	Depression	1	-.31***	2	-.24***	2	-.26***	2	-.38***
	Self-esteem	2	-.32***	1	-.49***	1	-.46***	1	-.48***
	Health	3	-.14***			4	-.19***		
	Anxiety	4	-.14***						
	Dissatisfaction with breasts	5	-.07**					3	-.09
	Social participation	6	-.08**					5	-.08
	Dissatisfaction with weight	7	-.08**			5	-.09*		
	ADHD	8	-.07**	5	-.11**				
	Dissatisfaction with vagina	9	-.09**	3	-.14***				
	Dissatisfaction with clitoris	10	-.08**						
	Sexual satisfaction			4	-.11**				
	Dissatisfaction with height			6	-.12**				
	Age at diagnosis					3	-.18***		
	Relationship status							4	-.08
Social QOL	Sexual satisfaction	1	-.46***	1	-.42***	1	-.37***	2	-.34***
	Depression	2	-.28***			2	-.22**	1	-.23**
	Relationship status	3	-.14***			5	-.17**	4	-.17
	Social participation	4	-.12***	4	-.15**	4	-.13*	7	-.15*
	Dissatisfaction with weight	5	-.07*	5	-.09				
	Anxiety	6	-.08*	6	-.13*				
	Self-esteem			2	-.21***	3	-.21**	3	-.21*
	Age			3	-.20***				
	Dissatisfaction with breasts			7	-.10*				
	ADHD					6	-.11*		
	Health					7	-.11		
	Dissatisfaction with vagina							5	-.18**
	Age at diagnosis							6	-.01
Environmental QOL	Depression	1	-.30***	1	-.15*	1	-.22**	1	-.18
	Anxiety	2	-.20***	4	-.18**	4	-.17*		
	Health	3	-.13***	2	-.29***	2	-.23***	3	-.21**
	Dissatisfaction with height	4	-.14***						
	Autism	5	-.02*						
	ADHD	6	-.07						
	Social participation	7	-.06						
	Dissatisfaction with clitoris	8	-.06						
	Self-esteem			3	-.20**	3	-.18*	2	-.38***
	Age			5	-.09				
	Dissatisfaction with breasts					5	-.11	4	-.08
	Height							5	.19**
	Age at diagnosis							6	-.13*

Note. "β" represent unstandardized regression coefficients. "P." describes the position of addition to the model. *$p < .05$, **$p < .01$, ***$p < .001$. If outliers were included, the variable "Ever sex" would not have been included in the model explaining global QOL. However, the variable "Sexual satisfaction" would have been included as a significant predictor explaining physical QOL in the CAHG. Moreover, the position of addition of "Anxiety" and "self-esteem" would have been the other way around for environmental QOL in the CAHG.

Table 6
Model comparisons via likelihood ratio tests. The general model contains the interaction-terms of the predictors of a given model with the dummy-variables referring to groups. In the restricted model the regression weights of the interaction-terms are restricted to zero. For each QOL-variable the analysis is once conducted with a dataset containing the PGs and the CG and once with a dataset containing only the PGs.

Dependent variable	Data set and reference group	*df*	*F*	*P*
Global QOL	Dataset with CG and PGs			
	Reference: CG	24	1.05	<.393
	Reference: TG	32	1.73	<.008**
	Reference: CAHG	26	1.61	<.028
	Reference: XYG	21	1.27	<.1800
	Dataset with PGs			
	Reference: TG	22	1.38	<.124
	Reference: CAHG	18	1.28	<.193
	Reference: XYG	14	0.64	<.835
Physical QOL	Dataset with CG and PGs			
	Reference: CG	30	3.96	<.001***
	Reference: TG	18	7.63	<.001***
	Reference: CAHG	15	5.80	<.001***
	Reference: XYG	18	3.26	<.001***
	Dataset with PGs			
	Reference: TG	12	2.50	<.003**
	Reference: CAHG	10	3.85	<.001***
	Reference: XYG	12	1.77	<.052
Psychological QOL	Dataset with CG and PGs			
	Reference: CG	33	2.44	<.001***
	Reference: TG	27	3.06	<.001***
	Reference: CAHG	17	2.65	<.001***
	Reference: XYG	18	3.37	<.001***
	Dataset with PGs			
	Reference: TG	18	1.12	<.327
	Reference: CAHG	12	2.03	<.020*
	Reference: XYG	12	0.47	<.932
Social QOL	Dataset with CG and PGs			
	Reference: CG	21	1.01	<.448
	Reference: TG	24	1.43	<.083
	Reference: CAHG	24	1.75	<.014*
	Reference: XYG	29	1.67	<.015*
	Dataset with PGs			
	Reference: TG	16	1.17	<.284
	Reference: CAHG	16	1.04	<.413
	Reference: XYG	20	1.0000	<.469
Environmental QOL	Dataset with CG and PGs			
	Reference: CG	27	1.52	<.043*
	Reference: TG	18	1.64	<.043*
	Reference: CAHG	18	1.99	<.008**
	Reference: XYG	20	1.70	<.027*
	Dataset with PGs			
	Reference: TG	12	0.71	<.739
	Reference: CAHG	12	0.65	<.795
	Reference: XYG	12	0.96	<.485

Note. $^{*}p < .05$, $^{**}p < .01$, $^{***}p < .001$.

better than the models without moderators. This, however, is not the case when using only the data of the PGs.

Note that some regression coefficients have a counter-intuitive sign (e.g., for the regression model of the CG predicting physical QOL, the regression coefficient of "dissatisfaction with breasts" was positive). This is often observed in large regression models when the predictors are correlated, and hence, confounded to a certain extend [40]. This problem can best be addressed with confirmatory modelling and remains an issue for future research. It shall be mentioned that the binary correlations of the respective predictors with the criterions are reversed, i.e., as one would expect from a theoretical perspective.

4. Discussion

4.1. Psychosocial/ sexual well-being and QOL in women with and without DSD

Improving QOL is one main goal when treating women with DSD. Therefore, it is necessary to know in which areas they are restrained and what factors influence their QOL to which extent. In this study, women with DSD were found to be less depressed, have less symptoms of ADHD, and to have a better social participation than the CG. Women with CAH were found to have higher self-esteem than women in the CG and TG. No differences were found regarding anxiety and autism. These results indicate that women with DSD who are treated in tertiary centers experience good psychosocial well-being. This contrasts previous research that indicated women with DSD to have a lowered psychosocial well-being (e.g. Refs. [5,41]), even when using the same patient data and comparing it to European reference data [8,42]. These prior studies were often limited by improper control groups, i.e., groups that did not match the PGs' age distribution or were taken from a very specific sample. However, one should also consider the increased depression- and ADHD-scores as well as the decreased social participation rates of the CG to be a result of a biased control group. The CG was questioned from the 16th to 25th of May 2020. During this time, social distancing was recommended in Germany due to the COVID-19 pandemic. Reduced social contacts and fear of infection might in turn have led to an increase in symptoms of depression and anxiety. In line with this, Bäuerle et al. [43] found increased rates of generalized anxiety, depression and psychological distress when examining 15,000 people during the lockdown in Germany. However, the question regarding social participation asked how often one takes part in social activities *compared to other people of their age*, which is not expected to be significantly different among peers. It is also unlikely that the pandemic led to an increase in ADHD-symptoms in the CG. Although further research is needed to determine *why* CAHG has a higher self-esteem than the TG; this result is congruent with previous studies that indicated that women with TS, but not with CAH, have low self-esteem [44–46].

Regarding body satisfaction, the CG was more satisfied with their vagina than the CAHG and more satisfied with their vagina and clitoris than XY-women. Within the PGs, XY-women were less satisfied with their vagina than the TG and less satisfied with their clitoris than the TG and CAHG. Moreover, the CG and XYG were more pleased with their height than the CAHG and TG, whereby the latter was even less satisfied with their height than the CAHG. These results are congruent to the research of Nordenskjold et al. [47] and Köhler et al. [48] who found women with CAH and XY-chromosomes to be dissatisfied with their genitals and to the study of Lever et al. [49] who found smaller women to be less satisfied with their height than taller women.

Regarding love life, the results showed the PGs to be less often in a relationship and to have sex less often and later in life than the CG. Moreover, the CG was more satisfied with their sex life than the CAHG and women with XY-DSD. These results resonate with previous research that found fewer women with DSD to have a partner and to be content with their sex life (e.g., Refs. [11,16]). Potential explanations might be that women with DSD have a lower desire for sex or partnership or that these women experience shame because of their body. Moreover, pain during penetration or an impaired sensibility of the genitals might further reduce sexual pleasure for women with DSD [10]. Future work is needed to examine whether psychological interventions could help women with DSD gain more sexual pleasure.

Regarding the global, social or psychological QOL, no group differences emerged in this study. All PGs had a better environmental QOL than the CG. These results implicate that with good treatment, women with DSD can reach satisfactory QOL. This is congruent with the review by Amaral et al. [19] who found inconsistent results regarding the QOL of patients with DSD, but a generally more adequate QOL for patients who were treated in tertiary centers. However, the CAHG was found to have a worse physical QOL than the CG and XYG, which might result from the subgroup of salt-wasting CAH whose risk of hypovolemia is an additional burden [3].

4.2. The influence of psychosocial- and sexual wellbeing on QOL

In all groups, health was one of the best predictors for global, physical, and environmental QOL, whereas low depression scores were good predictors for physical, psychological, and environmental QOL. High self-esteem had an outstanding influence on the psychological QOL in all groups. Moreover, across PGs, self-esteem predicted the global, social, and environmental QOL. A high sexual satisfaction influenced social QOL in all groups. These results are congruent with the research of Rapp et al. (2018), who identified health as the strongest predictor for QOL in the PG samples of the current study. Similarly Amaral et al. [50] reported a positive influence of health, positive feelings, and a fulfilled sexual life on QOL in adults with DSD.

The striking influence of depression can be attributed to the diverse set of impairing symptoms as well as cognitive biases and therefore overgeneralized negative appraisal of QOL. A sensible intervention to detect mood changes could be done via the two-question screening for depression [51] every three months with all patients and offer psychological support when needed.

The positive effect of self-esteem on psychological QOL can be explained by its protective effect when dealing with critical life incidents [52]. Interestingly self-esteem only influenced the global, social, and environmental QOL in the PGs but not the CG.

All predictors combined explained between 36 and 77% of the variance in all regression models. This underlines the significance of psychosocial and sexual wellbeing influencing QOL and emphasizes the importance of integrating those aspects when treating women with DSD. Strikingly, physical predictors such as height and BMI only had a small if any influence on QOL in women with DSD.

4.3. Moderation of the DSD-diagnosis on the influence of psychosocial and sexual wellbeing on QOL

In this study, for the CAHG height had a significantly more positive effect on global QOL than in the CG and a more positive effect on the physical QOL than in the CG. Women with CAH, who were generally significantly smaller than women in the CG and the XYG, seem to experience their height as more impairing than women with average height do. However, it remains unclear why this effect did not emerge for the TG who are on average even smaller than the CAHG. For the CG, dissatisfaction with height had a significantly stronger influence on physical QOL than in the TG and a significantly greater influence on environmental QOL than in the XYG. For those patient groups, other factors seem far more relevant to gain a satisfactory QOL.

Multiple regression analysis showed self-esteem to be more often a predictor for QOL in the PGs than in the CG. The moderation analyses could verify that indeed self-esteem had a bigger impact on psychological QOL in the TG and CAHG than in the CG. When using a significance level of $\alpha < 0.05$, self-esteem moreover predicted psychological and environmental QOL better in the XYG and had a greater influence on social QOL for all PGs than in the CG. Furthermore, self-esteem predicted environmental QOL better for the TG than the CG. In light of these results, a higher self-esteem might help coping with a chronic disease and minority stress. This could particularly be the case for syndromes which are associated with feelings of shame, such as DSD. The finding that self-esteem seems to be more crucial for the QOL of women with than without DSD is especially relevant since a majority of previous studies found the self-esteem in women with DSD to be impaired and improving self-esteem could strengthen resilience and has potentially fewer side effects than most physical interventions. Moreover, the improvement of self-esteem could also positively affect other psychosocial predictors, e.g., social engagement and body satisfaction. Van de Grift et al. [13] already found an association between body embarrassment and self-esteem in the same patient cohort the present study uses.

Our analyses reveal further moderator effects regarding the health of the participants. For the TG, health had a greater influence on environmental QOL than for the CG. When applying a significance level of $\alpha < 0.05$, health was a better predictor for physical QOL in the TG and a better predictor for social QOL in the CAHG than in the CG. One potential explanation for this finding is that women with DSD who state to have a bad health might be significantly more impaired than the CG with the same narrative.

Moreover, age was a better negative predictor for social QOL in the TG than in the CG. This could be explained by the fact that with increasing age, women with TS become more aware of differences to women without DSD who can more easily start a family and find a partner.

4.4. Model comparisons

Noteworthy differences between the explanation models of the three PGs only exist for physical QOL. Therefore, new scientific insights regarding QOL-predictors in one of the PGs can, with the exception of physical QoL, probably be transferred to the other two. With regard to the moderator analysis, the particular role of physical QoL could be traced back to the influence of health and (satisfaction with) height.

Between all PGs and the CG, major discrepancies were found for the models explaining physical and psychological QOL, whereas smaller discrepancies emerged for the models explaining environmental QOL. Compared to the CG, the magnitude of the predictors' influence explaining global QOL was significantly different for the TG, whereas the magnitude of the predictors' influence explaining social QOL was significantly different for the XYG and CAHG. Therefore, one cannot assume that psychosocial and sexual wellbeing explains QOL in the same way for women with and without DSD. Apart from physical QOL, this seems especially the case for psychological QOL. For this QOL-dimension, moderation analyses showed that the main difference between women with and without DSD seems to be caused by the significantly greater impact of self-esteem in women with DSD.

4.5. Limitations

To the best of our knowledge, this study is the most extensive investigation of psychosocial and sexual predictors for QOL in women with DSD and the first to examine whether the different DSD-diagnoses in women moderate the influence of psychosocial and sexual well-being on QOL. However, our study has three major limitations: First, it is possible that patients with serious health problems declined to participate which might have led to an overestimation of the psychosocial well-being and QOL in women with DSD. Second, the CG and PGs were recruited at different time periods. As the CG was recruited at the beginning of the COVID-19-pandemic, this might have led to increased rates of depression and anxiety. Comparisons of those two constructs therefore have to be considered with caution. . Third, the CG, unlike the PGs, was only recruited in Germany. It is likely that patients from different countries will have had different cultural experiences. However, our analyses did not reveal that the country the patients lived in significantly influenced their psychosocial well-being or quality of life. We do recommend future research with control group data from other countries to confirm our results.

4.6. Conclusion

In conclusion, this study suggests that the psychosocial well-being and QOL of women who are treated in a tertiary center has mostly levelled up to that of the general population. However, the sexual well-being and the body satisfaction are still impaired in women with DSD. The QOL in women with DSD is best predicted by a good health, low depression, and high self-esteem. For all but the physical dimension, women with TS, CAH, and with XY-DSD are very similar in the selection and magnitude of factors influencing QOL. They may thus be helped by similar counselling which may call for expert centers that are open to

these various groups. However, the existence of a DSD-diagnosis moderates the influence of psychosocial and sexual wellbeing on QOL. Especially self-esteem seems to be more important in women with DSD. Therefore, this study shows that it is still necessary to improve treatment regarding the psychosexual wellbeing and body satisfaction in women with DSD. To optimize the QOL in women with DSD, the enhancement of psychosocial and sexual wellbeing should be implemented in the treatment plan. Compared to the general population, for women with DSD, the improvement of self-esteem should have even greater priority which could be addressed by means of DSD-specific self-esteem trainings.

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Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Appendix A. Supplementary data

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