

# Gender Identity, Sexual Orientation and Quality of Life in Women with Nonclassic Congenital Adrenal Hyperplasia

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## BACKGROUND

Females with the more severe salt-wasting form of congenital adrenal hyperplasia (CAH) reportedly have a higher frequency of atypical gender identity, non-heterosexual fantasies and sexual relationships, and cross-gender role behavior.

Comparable data and quality of life (QoL) measures among those with the milder, more prevalent form, the non-classic CAH (NCCAH), are scarce.

## OBJECTIVES

- To assess health-related QoL, gender identity, gender role, and sexual orientation in women with NCCAH

## PARTICIPANTS & METHODS

**Setting:** The Pediatric Endocrinology Clinic in Dana-Dwek Children's Hospital is a referral center for children, adolescents and young adults with adrenal hyperplasia.

**Recruitment:** Routine visit to the outpatient clinic between April 2015 and March 2017

**Study group:** 38 NCCAH females (median age 34 years, range:18-44)

**Control group:** 62 age-matched healthy female volunteers, hospital employees and their friends and family members (median age 30 years, range: 20-40)

**Questionnaire-based study:** validated Hebrew versions, completed anonymously

### Outcome measures:

- Sociodemographic parameters, habitual behavior, lifestyle preferences and medical history
- World Health Organization QoL questionnaire (4 domains): physical health, psychological health, social relationships, and social environment
- Multi-Gender Identity Questionnaire (multi-GIQ)
- Sexuality Questionnaire

*In relation to gender role - male-dominant occupation was defined when no more than 10% of females worked in the profession according to data from the Central Bureau of Statistics in Israel*

## RESULTS

### Sociodemographic parameters:

- marital status, number of children, educational level, unemployment rates and income were similar for both groups

### Quality of Life questionnaire:

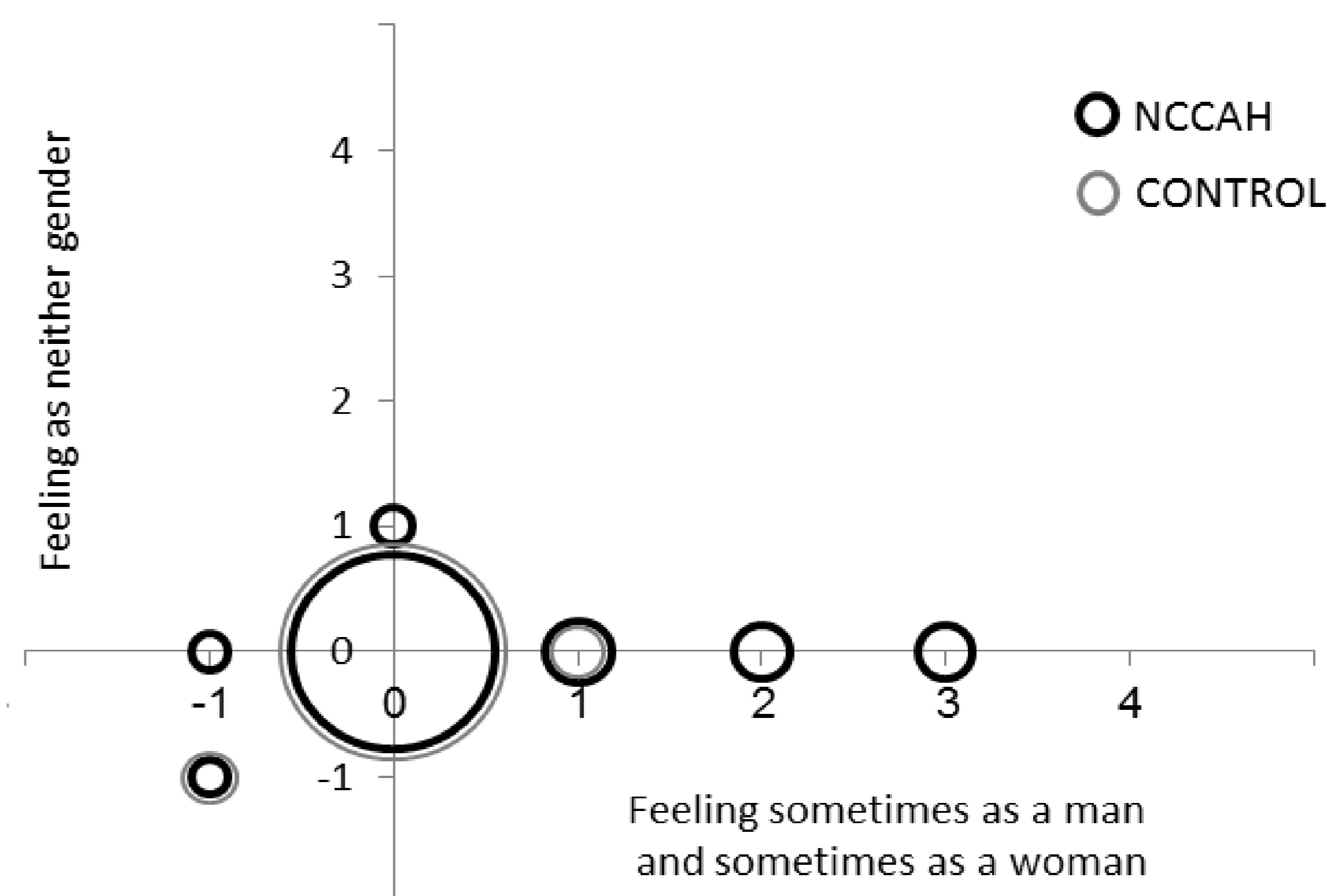
- No group differences were found in any of the domains, despite the facts that:
  - The NCCAH group reported more condition-related symptoms than the control group ( $P < 0.001$ ):
    - Hirsutism, menstrual irregularities, acne [18/37 (48.6%) vs. 3/59 (5.1%)]
    - Infertility [6/37 (16.2%) vs. 0%]
    - Asymptomatic [13/37 (35.2%) vs. 56/59 (94.9%)]
  - As expected, Glucocorticoid use was reported only in the NCCAH group [16/36 (44.4%),  $P < 0.001$ ]
- There was no difference in the rate of male-dominant occupations (1/31 vs. 4/56 among NCCAH and controls respectively,  $P = 0.65$ )

### Multi-Gender Identity Questionnaire (multi-GIQ)

- The two groups were highly similar on most measures
- Only a few of the participants in each group reported non-binary or queer-like feelings (e.g., feeling as both genders, feeling as neither gender)

## RESULTS (continued)

- However, "sometimes-feeling-as-a-man" and "sometimes-feeling-as-a-woman" were more frequently reported in the NCCAH group compared to the controls [7/38 (18.4%) vs 3/62 (4.8%), respectively,  $P = 0.02$ ] (see figure)



Measures from the multi-gender scale identity and sexuality questionnaires in NCCAH vs. controls

	NCCAH		CONTROL		U	P
	Median	IQR	Median	IQR		
Feeling as a woman	4	0	4	0	1053.5	0.66
Feeling as a man	0	0	0	0	675.00	0.15
<b>Sometimes feeling as a man and sometimes feeling as a woman</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>2673.5</b>	<b>0.02*</b>
Feeling as neither gender	0	0	0	0	1062.0	0.21
Satisfied being a woman	4	0	4	0	1012.50	0.70
Wishing to be a man	0	0	0	0	575.00	0.78
Dissatisfied with the female body	0	0	0	0	851.5	0.87
Wishing to have the body of the "other" sex	0	0	0	0	1026.00	0.18
Not feeling much in common with women	0	1	0	1	1056.50	0.63
Not feeling much in common with men	2	4	2	2	776.00	0.74
Being attracted to men	4	.40	4	.80	1015.00	0.69
Being attracted to women	0	.80	0	.80	1061.00	0.92
Having fantasies about men	4	.50	4	.25	1053.50	0.84
Having fantasies about women	0	1	0	1	1025.50	0.65
Past sexual relations with men	4	0	4	0	896.5	0.13
Past sexual relations with women	0	0	0	0	868.50	0.12
					Fisher's exact	P

### First falling in love with

First sexual experience with

**0.02\***

0.56

\*Comparison is significant ( $P < 0.05$ ) after false discovery rate adjustment.

†Hebrew is a gender-based language. Abbreviations: CAH, congenital adrenal hyperplasia; IQR, interquartile range

## Sexuality

- The two groups were highly similar on most measures
- The majority of participants in reported high levels of sexual attraction and sexual and romantic relations with men
- However, more NCCAH women reported first falling in love with a woman (11.1% vs 0%,  $P = 0.02$ )

## CONCLUSION

- Adult females with NCCAH are similar to healthy women in QoL and the majority of measures of gender identity, gender role, and sexuality.
- The subtle differences that emerged in the current study might suggest a continuum of the impact of androgens on feelings and behaviors from normal levels (controls) to mildly elevated (NCCAH) levels to the highly elevated levels in the classic forms of CAH.

