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

Anat Segev-Becker MD, Roi Jacobson MA, Ronnie Stein MD, Ori Eyal MD, Asaf Oren MD, Anita Schachedt-Davidov MD, Galit Israeli MD, Yael Lebenthal MD, Naomi Weintrob MD

Dana-Dwek Children’s Hospital, Adrenals and HPA Axis

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)

• 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

<table>
<thead>
<tr>
<th></th>
<th>NCCAH</th>
<th>Control</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Feeling as a woman</td>
<td>Median IQR</td>
<td>Median IQR</td>
<td>R</td>
<td>P</td>
</tr>
<tr>
<td>Feeling as a man</td>
<td>4</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Sometimes feeling as a man and sometimes feeling as a woman</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Feeling as neither gender</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Satisfied being a woman</td>
<td>4</td>
<td>4</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Feeling as a woman</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Dissatisfied with the female body</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Feeling as the other sex</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Not feeling much in common with women</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Not feeling much in common with men</td>
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<td>4</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Being attracted to men</td>
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<td>4</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Being attracted to women</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Having fantasies about men</td>
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<td>5</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>Having fantasies about women</td>
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<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Past sexual relations with men</td>
<td>4</td>
<td>4</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Past sexual relations with women</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

Table: NCCAH vs. controls

First falling in love with: 0.02*

First sexual experience with: 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.