Quality of Life in Adolescent Girls With Polycystic Ovary Syndrome

Maria E. Trent, MD, MPH; Michael Rich, MD, MPH; S. Bryn Austin, ScD; Catherine M. Gordon, MD, MSc

Objectives: To examine health-related quality of life (HRQL) in adolescents with polycystic ovary syndrome (PCOS), compared with healthy adolescents, and to determine whether clinically observed or self-perceived severity of illness affects their HRQL.

Design and Setting: Cross-sectional study of female adolescents conducted at an urban, hospital-based adolescent medicine clinical practice.

Participants: Ninety-seven adolescent patients with PCOS and 186 healthy patients who were seen for care between October 15, 1999, and March 2, 2001.

Main Outcome Measures: Health-related quality-of-life scores as determined by the Child Health Questionnaire–Child Self-Report Form.

Results: Adolescents with PCOS scored lower on subscales measuring general health perceptions, physical functioning, general behavior, and limitations in family activities because of illness. Patients scored higher on the change in health in the last year subscale, and most had been diagnosed and initiated treatment for PCOS in the last year. Patients who had higher self-perceived severity of illness also scored lower on the general health perceptions subscale, but clinical severity was not associated with differences in HRQL.

Conclusions: Adolescents with PCOS experience lower HRQL compared with healthy adolescents. Polycystic ovary syndrome and perceived severity of illness negatively affect HRQL in adolescents. This study suggests a need to develop interventions to reduce the distress that patients with PCOS may face as adolescents and young adults.

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POLYCYSTIC OVARY syndrome (PCOS) occurs in 5% to 10% of women, making it one of the most common endocrine disorders.1,2 The syndrome represents a range of clinical presentations, with variable degrees of severity and physical findings. Common clinical findings of the disorder include irregular menstrual cycles, hirsutism, acne, acanthosis nigricans, obesity, and infertility.3

Polycystic ovary syndrome has a significant effect on adult women, resulting in diminished quality of life, altered feminine identity, and dysfunction in the family and work environment.4-6 Adolescent patients with PCOS, who are at the height of identity development and awareness of body image, may have a more significant disturbance in quality of life. However, no research to date, to our knowledge, has examined the relationship of PCOS to health-related quality of life (HRQL) in adolescent girls. Anecdotal evidence from clinical practice with this age group suggests that the disorder can disrupt their quality of life. The aims of this study were to examine HRQL in adolescents with PCOS, compared with healthy adolescents, and to determine whether clinically assessed or self-perceived severity of illness affects HRQL.

DESCRIPTION OF THE SAMPLE

Four hundred thirteen adolescents who had scheduled medical appointments were asked if they would be willing to participate in the study. The refusal rate among all girls asked to participate in the study was 7.3% (n=8) among the PCOS group and 26.4% (n=69) among the healthy comparison group. The most common reason for refusal was lack of time.

Two hundred ninety-three patients were recruited, of whom 283 met all eligibility criteria for inclusion in the study. The mean±SD age of all participants was 16.9±2.3 years. There were no significant...
PARTICIPANTS AND METHODS

Participants were recruited from an urban, hospital-based adolescent medicine practice providing primary and specialty health care, including reproductive endocrinology and pediatric and adolescent gynecology. This cross-sectional study used a confidential, 30-minute HRQL instrument and a general health history questionnaire, administered at the end of a clinic visit. Data collection occurred between October 15, 1999, and March 2, 2001. Each adolescent provided informed consent to participate in the study. The Committee on Clinical Investigation at Children’s Hospital Boston approved the study protocol. Parental consent was waived because of the confidential nature of many of the visits. Participants were mailed $10 in compensation for their time.

Inclusion criteria for PCOS participants were age 13 to 22 years, with a diagnosis of PCOS as exemplified by hyperandrogenism (clinical or laboratory diagnosis) and menstrual irregularity. Adolescents with PCOS were recruited from the primary care practice and referral base. Healthy female adolescents presenting for routine or sports physicals, routine gynecologic care, contraceptive management, or follow-up of a minor medical issue were recruited as comparisons, if they were age 13 to 22 years and did not meet the exclusion criteria outlined in the next paragraph. Although most healthy participants were from the primary care practice, young women referred for routine gynecologic care and contraception were also recruited for the study.

Exclusion criteria for all participants included: (1) a diagnosis of hyperprolactinemia, nonclassical 21-hydroxylase deficiency, or evidence of an androgen-secreting tumor or intersex state; (2) language or cognitive difficulties preventing reliable completion of the questionnaire; or (3) a chronic or acute illness unrelated to PCOS that could potentially affect the participant’s quality of life. Patients who were pregnant or were having a medical or mental health crisis at the time of the visit were also excluded from participation. Demographic factors, such as race/ethnicity, insurance status as a proxy for socioeconomic status, and age, were considered to ensure that participants in both groups were representative of our adolescent medicine practice. Blocking was used to oversample certain race/ethnicity groups and to increase statistical power to compare across race/ethnicity groups.

DEMOGRAPHIC VARIABLES

Data were collected on demographic variables, including age, grade in school, and self-defined race/ethnicity. Insurance status was obtained from the computerized scheduling system after patients had been recruited for the study. Clinical variables obtained from the health care provider at the time of the visit included Ferriman-Gallwey (FG) score as a measure of hirsutism, global acne (GA) score, weight, and height. Body mass index (BMI) was calculated as weight in kilograms divided by the square of height in meters. Pretreatment hormonal values for dehydroepiandrosterone sulfate and free and total testosterone were collected on PCOS participants. As a part of the general health–history questionnaire, information was collected on timing and irregularity of menstrual cycles; perceived acne, body hair, and weight status; medications and procedures used; and behavior risks.

Continued on next page

differences between the PCOS and healthy groups with regard to race/ethnicity, age, or insurance status (Table 1). One hundred one patients with PCOS were enrolled in the study, and 4 were later excluded because they did not meet all eligibility criteria. One hundred ninety-two healthy participants were enrolled in the study, and 6 were later excluded because they did not meet all eligibility criteria.

CLINICAL VARIABLES

The mean BMI and FG and GA scores were higher for the patient group (Table 2). The mean age at diagnosis of PCOS was 15.1 years, and 51 (60%) of the 85 patients had been diagnosed within the last year. Eighty-three percent (70/84) of the patients had elevated free testosterone, 47% (42/89) had elevated total testosterone, and 29% (24/84) had elevated dehydroepiandrosterone sulfate levels before initiation of treatment.

PCOS STATUS AS A PREDICTOR OF QUALITY OF LIFE

Compared with healthy adolescents, participants with PCOS scored 0.3 points higher on the change in health in the last year subscale, 7.7 points lower on the general health perceptions subscale, 2.9 points lower on the behavior subscale, 4.1 points lower on the physical functioning subscale, and 6.0 points lower on the family activities subscale. The patients showed a trend toward lower mean scores on the mental health subscale, but this difference was marginally significant (Table 3).

SEVERITY OF ILLNESS

The mean FG and GA scores, BMI, and free testosterone among the PCOS group increased in a stepwise fashion with mild, moderate, and severe PCOS, supporting the rationale of the summary measure for clinical severity (Figure). There were, however, no significant differ-

Table 1. Demographics*

<table>
<thead>
<tr>
<th>Factor</th>
<th>PCOS (n = 97)</th>
<th>Healthy (n = 188)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean age, y</td>
<td>16.9</td>
<td>17.0</td>
</tr>
<tr>
<td>Mean age at PCOS diagnosis, y</td>
<td>15.2</td>
<td>N/A</td>
</tr>
<tr>
<td>Refusal rate, %</td>
<td>7.3</td>
<td>26.4</td>
</tr>
<tr>
<td>Ethnicity, %</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hispanic</td>
<td>21</td>
<td>18</td>
</tr>
<tr>
<td>Black</td>
<td>20</td>
<td>30</td>
</tr>
<tr>
<td>White</td>
<td>49</td>
<td>43</td>
</tr>
<tr>
<td>Other</td>
<td>10</td>
<td>8.5</td>
</tr>
</tbody>
</table>

*PCOS indicates polycystic ovary syndrome; N/A, not applicable.
HRQL MEASURES

The Child Health Questionnaire—Child Self-Report Form (CHQ-CF87) is a self-report questionnaire that was developed and validated at the Health Institute of the New England Medical Center, Boston.11 The tool consists of 12 summarized subscales and is designed to measure the physical and psychosocial health of adolescents. The subscales include the following summary measures: (1) change in health in the last year, (2) role/social emotional, (3) role/social behavioral, (4) bodily pain, (5) behavior, (6) mental health, (7) self-esteem, (8) general health perceptions, (9) family activities, (10) family cohesion, (11) physical functioning, and (12) role/social physical.

The items on the CHQ-CF87 are scored from 0 to 100, except for the change in health in the last year and family cohesion variables, which are scored from 1 to 5. Higher scores on these variables indicate health improvement in the last year and better family cohesion, respectively. Higher scores on all other variables indicate better quality of life. This instrument has a record of reliability and validity for evaluating aspects of health that are pertinent across age, gender, health condition, and socioeconomic status in adolescents.12

SEVERITY OF ILLNESS

Clinical severity of illness was a composite of the FG and GA scores and BMI. An FG score of 8 or higher,8 a GA score greater than 0,9 and a BMI of 30 or higher13,14 were used as diagnostic criteria for the clinical factors. Each participant was given 1 point for each clinical factor present and a score of 0 to 3 based on the presence or absence of each of the clinical factors, creating mild (0-1 point), moderate (2 points), and severe (3 points) categories.

Table 2. Differences in Clinical Variables and Age Between Patients With Polycystic Ovary Syndrome (PCOS) and Healthy Peers

<table>
<thead>
<tr>
<th>Variable</th>
<th>PCOS</th>
<th>Healthy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Body mass index, kg/m²</td>
<td>31.7 ± 8.4</td>
<td>23.5 ± 4.2</td>
</tr>
<tr>
<td>Ferriman-Gallwey score</td>
<td>13.5 ± 9.2</td>
<td>2.7 ± 4.8</td>
</tr>
<tr>
<td>Global acne score</td>
<td>4.4 ± 4.7</td>
<td>1.8 ± 3.2</td>
</tr>
<tr>
<td>Age, y</td>
<td>16.9 ± 2.0</td>
<td>17.0 ± 2.4</td>
</tr>
</tbody>
</table>

*Data are given as mean ± SD.

ences in HRQL outcomes among patients in the mild, moderate, and severe clinical severity categories.

Patient scores for perceived severity of PCOS ranged only in the mild to moderate categories. Controlling for race/ethnicity, patients with perceived moderate severity scored 7.9 points lower on general health perceptions than those with mild disease (β, 7.9; SE β, 3.6; P<.03).

COMMENT

This study demonstrates that adolescents with PCOS had lower HRQL scores on the CHQ-CF87 than healthy comparisons in the areas of general health perceptions, physical functioning, behavior, and family activities. Most participants in this study perceived their illness to be mild, despite the finding that 69% (67/97) had moderate (n=35) to severe (n=32) clinical severity scores. In terms of patients’ ability to cope with PCOS, it was encouraging that they perceived their severity of illness as mild or moderate. Compared with the clinical assessment, their perception of illness severity correlated more directly with their quality of life with PCOS.

The absence of a direct relationship between clinical severity of illness and quality of life may be explained by several reasons: (1) clinical severity of illness may not be associated with quality of life, (2) there may be an unmeasured confounder, or (3) there was not enough power to detect a difference between groups.

These results must be interpreted in light of acknowledged limitations. Not every patient who was eligible participated in the study, and there were different rates of participation between the PCOS (93%) and healthy (74%) samples. It is unknown whether patients who did not return for their appointments or who were not asked to participate by health care providers were comparable to those who were enrolled. It is possible that participants who had PCOS but did not have menstrual abnormalities significant enough to merit clinical evaluation may have been included in the healthy group. However, this would bias the study results toward the null hypothesis.
Finally, this is a cross-sectional study, and causality cannot be inferred from the associations found.

Health-related quality of life is a critical outcome measure for any patient, but it may be particularly important for adolescents and young adults with chronic conditions who must cope with and manage their condition for extended periods. It has been used as a key outcome measure in pediatric studies of chronic renal disease, asthma, allergic rhinitis, cystic fibrosis, and childhood cancers. Although clinical criteria measure the magnitude of physiologic dysfunction, they do not capture the physical, emotional, and social effects on the lives of those who live with the disease. This is supported by our finding that the patient’s perception rather than the clinician’s assessment of PCOS is more relevant to HRQL. Clinicians who serve adolescents and young adults should know that factors other than treatment of disease affect HRQL. As a result, HRQL is an increasingly important outcome measure in child, adolescent, and young adult health.

The social predicaments and developmental tasks that all adolescents face may mediate a patient’s ability to cope with PCOS, as adolescent girls look to their peers for validation. For example, although a girl may have acne secondary to her PCOS, she may not perceive herself as being different from her peers, given that acne is common in adolescence. Obesity is also increasingly common among adolescent girls without PCOS. Individual factors or a combination of factors, including the milieu of adolescence, may therefore mediate the quality-of-life experience of patients with PCOS in this age group.

This study supports the hypothesis that adolescents with PCOS experience lower quality of life compared with healthy adolescents. Most important, it is the patient’s perceived rather than the clinician’s assessed severity of illness that negatively affects quality of life. This study suggests potential areas of investigation and intervention in the field of adolescent PCOS. Patients noted a greater change in their overall health in the last year compared with their healthy peers, which suggests a positive role of medical intervention in their lives. Health services research that examines the timing of diagnosis and initiation of treatment, variability in treatment approaches, and patient–health care provider communication may also be instrumental in understanding the long-term health and quality-of-life outcomes in adolescents with PCOS. This study also suggests the need to develop supportive interventions that address quality-of-life issues to reduce the distress that patients with PCOS may face as adolescents and young adults.

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We thank the members of the Divisions of Adolescent/Young Adult Medicine and Gynecology at Children’s Hospital Boston for their role in patient recruitment. In addition, we thank S. Jean Emans, MD, for her input on this project, Jeanne Landgraf, MA, for her guidance in analyzing the CHQ-

### Table 3. Mean Quality-of-Life Scores on Child Health Questionnaire–Child Form 87 and Differences as Determined by Linear Regression Models

<table>
<thead>
<tr>
<th>Model</th>
<th>Subscale</th>
<th>Polycystic Ovary Syndrome</th>
<th>Healthy</th>
<th>β</th>
<th>SE β</th>
<th>P Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Change in health in the last year</td>
<td>2.8 ± 1.1</td>
<td>2.5 ± 1.0</td>
<td>0.3</td>
<td>0.1</td>
<td>.04</td>
</tr>
<tr>
<td>2</td>
<td>General health perceptions</td>
<td>68.6 ± 16.1</td>
<td>76.3 ± 15.3</td>
<td>-7.7</td>
<td>2.0</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>3†</td>
<td>Physical functioning</td>
<td>91.2 ± 12.2</td>
<td>94.8 ± 7.8</td>
<td>-4.1</td>
<td>1.2</td>
<td>.001</td>
</tr>
<tr>
<td>4†</td>
<td>Mental health</td>
<td>66.5 ± 16.9</td>
<td>70.3 ± 14.3</td>
<td>-3.8</td>
<td>2.1</td>
<td>.07</td>
</tr>
<tr>
<td>5†</td>
<td>Family activities</td>
<td>77.2 ± 21.3</td>
<td>81.8 ± 18.9</td>
<td>-6.0</td>
<td>2.7</td>
<td>.03</td>
</tr>
<tr>
<td>6</td>
<td>Behavior</td>
<td>93.9 ± 12.7</td>
<td>94.8 ± 11.7</td>
<td>-2.9</td>
<td>1.4</td>
<td>.04</td>
</tr>
<tr>
<td>7†</td>
<td>Role/social emotional</td>
<td>87.3 ± 19.8</td>
<td>88.7 ± 18.5</td>
<td>-1.4</td>
<td>2.4</td>
<td>.57</td>
</tr>
<tr>
<td>8‡</td>
<td>Role/social behavioral</td>
<td>93.8 ± 12.7</td>
<td>94.8 ± 11.7</td>
<td>-1.3</td>
<td>1.6</td>
<td>.43</td>
</tr>
<tr>
<td>9</td>
<td>Bodily pain</td>
<td>70.4 ± 19.5</td>
<td>73.4 ± 19.2</td>
<td>-2.9</td>
<td>2.4</td>
<td>.23</td>
</tr>
<tr>
<td>10‡</td>
<td>Self-esteem</td>
<td>73.9 ± 14.8</td>
<td>77.7 ± 15.3</td>
<td>-3.1</td>
<td>2.5</td>
<td>.19</td>
</tr>
<tr>
<td>11§</td>
<td>Role/social physical</td>
<td>94.3 ± 13.6</td>
<td>97.0 ± 10.7</td>
<td>-2.3</td>
<td>1.6</td>
<td>.15</td>
</tr>
<tr>
<td>12</td>
<td>Family cohesion</td>
<td>61.2 ± 29.0</td>
<td>65.2 ± 24.9</td>
<td>-4.1</td>
<td>3.8</td>
<td>.28</td>
</tr>
</tbody>
</table>

*Data are given as mean ± SD unless otherwise indicated. †Controlled for ethnicity. ‡Controlled for ethnicity and insurance status. §Controlled for insurance status.

Stepwise increase in mean body mass index (BMI), Ferriman-Gallwey (FG) score, global acne (GA) score, and free testosterone (FT) (in picograms per milliliter) for mild, moderate, and severe clinical severity levels among patients with polycystic ovary syndrome.

We thank the members of the Divisions of Adolescent/Young Adult Medicine and Gynecology at Children’s Hospital Boston for their role in patient recruitment. In addition, we thank S. Jean Emans, MD, for her input on this project, Jeanne Landgraf, MA, for her guidance in analyzing the CHQ-

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Polycystic ovary syndrome has considerable effects on the lives of adult women; however, to our knowledge, research has not previously investigated the potential effects on the health-related quality of life of adolescents with this illness. This study examined health-related quality of life in patients in this age group with PCOS compared with healthy peers. It demonstrates that PCOS and higher self-perceived severity of illness negatively affect quality of life in these patients. This study also provides direction toward potential areas of investigation and intervention in the field of adolescent PCOS, aimed at reduction of the significant quality-of-life disturbance these patients may face as adolescents and young adults.

REFERENCES