Quality of Life, Psychosocial Well-Being, and Sexual Satisfaction in Women with Polycystic Ovary Syndrome

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Polycystic ovary syndrome (PCOS) is a common endocrine disorder characterized by chronic anovulation and hyperandrogenism. PCOS is one of the leading causes of infertility and manifests with hirsutism, acne, and obesity. To investigate its impact on health-related quality of life and sexuality, 50 women with PCOS and 50 controls were evaluated with standardized questionnaires (36-item short-form health survey, symptom checklist revised, and life satisfaction questionnaire). The impact of hirsutism, obesity, and infertility was assessed using five-point rating scales, and sexual satisfaction was analyzed with visual analog scales. Patients showed greater psychological disturbances on the symptom checklist revised dimensions, obsessive-compulsive, interpersonal sensitivity, depression, anxiety, aggression, and psychoticism,

along with a lower degree of life satisfaction in the life satisfaction questionnaire scales health, self, and sex. Health-related quality of life measured with the 36-item short-form health survey revealed significantly decreased scores for physical role function, bodily pain, vitality, social function, emotional role function, and mental health in patients with PCOS. Although patients had the same partner status and frequency of sexual intercourse, they were significantly less satisfied with their sex life and found themselves less attractive. Most of the differences were not affected by correction for body weight. In conclusion, PCOS causes a major reduction in the quality of life and severely limits sexual satisfaction. (J Clin Endocrinol Metab 88: 5801–5807, 2003)

OLYCYSTIC OVARY SYNDROME (PCOS) is a common endocrine disorder characterized by chronic anovulation and hyperandrogenism. The prevalence among women of reproductive age is at least 5% (1, 2). Its pathophysiology, most likely a combination of genetic disposition and environmental factors, is not completely understood (3, 4). PCOS is one of the leading causes of infertility and also characterized by hirsutism, cystic acne, seborrhea, hair loss, and obesity (5, 6). A significant proportion of patients with PCOS have been found to suffer from defective insulin secretion and insulin resistance, as documented in U.S. cohorts (5) and German cohorts (our unpublished data). Accordingly, patients with PCOS may be expected to have a higher morbidity and mortality from the sequelae of the metabolic syndrome (type 2 diabetes mellitus, obesity, hypertension, lipid disorders, atherosclerosis). However, although the existing data support an acceleration of the development of an adverse cardiovascular risk profile (7, 8) and even subclinical signs of atherosclerosis (9), it is unclear whether PCOS lowers the age of clinical presentation because a large retrospective study has shown no difference in mortality from cardiovascular events (10), and prospective studies with a sufficient sample size and follow-up have not been done (11).

Many aspects of the disorder can very conceivably cause a significant amount of emotional stress (12). Changes in

Abbreviations: BMI, Body mass index; FLZ, Fragebogen zur Lebenszufriedenheit (questionnaire on life satisfaction); GSI, Global Severity Index; HRQL, health-related quality of life; PCOS, polycystic ovary syndrome; PSDI, Positive Symptom Distress Index; PST, Positive Symptom Total; SCL-90-R, symptom checklist revised; SF-36, 36-item shortform health survey; VAS, visual analog scale.

appearance, irregular or absent menstrual periods, difficulties conceiving, and possibly disturbances in sexual attitudes and behavior can result in psychological distress and may also influence the feminine identity of patients with PCOS (13). Accumulating evidence on the long-term health risks associated with PCOS (e.g. diabetes mellitus) may also have a negative impact on psychosocial well-being. Indeed, the diagnosis of PCOS has been found to be associated with feelings of frustration and anxiety (14). In adolescents with PCOS, a negative impact on various aspects of health-related quality of life (HRQL), including limitations in physical functioning, general behavior, and family activities, has been found (15). In 1998 a self-administrated quality-of-life-questionnaire (PCOSQ) for women with PCOS was published by Cronin et al. (16), but results of its use have not been published. We now present an investigation of the impact of PCOS on psychosocial and emotional functioning, HRQL, and sexual satisfaction in a German patient sample compared with an age-matched healthy control sample.

Subjects and Methods

Subject recruitment

Patients were recruited from the outpatient clinics of the Division of Endocrinology, Department of Medicine at the University of Essen, based on referrals from gynecologists in the surrounding area or patients attracted by the clinic's home page. Based on the criteria derived from the 1990 National Institutes of Health conference (3), diagnosis of PCOS was established when either oligomenorrhea (cycles lasting longer than 35 d) or amenorrhea (absence of menstrual cycles in the past 6 months) and either clinical signs of hyperandrogenism [hirsutism with a Ferriman/Gallwey score of more than 7 (17) or obvious acne] or an elevated total testosterone (normal range < 2.0 nmol/liter) were found, and other

pituitary, adrenal, or ovarian diseases could be excluded. All recruited women were required to be otherwise healthy. Age-matched healthy controls were recruited from a health screening program for employees instituted at the University of Essen. Exclusion criteria for controls included any known medical condition or psychological disorder, ir regular periods, or hormonal disturbances. This was verified by personal interview, physical examination, and measurement of hormone parameters including LH, FSH, estradiol, total testosterone, TSH, free $\rm T_4$, and cortisol. All hormone parameters were determined on an automated chemiluminescence assay system (Centaur, Bayer Vital, Fernwald, Germany) with an intraassay variation of less than 5% and an interassay variation of less than 8%. The study protocol was approved by the Ethics Committee of the University of Essen. All participants gave written informed consent before entering the study, and all questionnaires were made anonymous before evaluation.

Instruments and measures

Quality of life, psychosocial well-being, and sexuality of patients with PCOS and controls were assessed with three standardized, validated questionnaires: Psychological disturbances were assessed with the German version of the symptom checklist revised (SCL-90-R) (18), which quantifies psychological distress on the dimensions of somatization, obsessive-compulsive, interpersonal sensitivity, depression, anxiety, aggression, phobia, paranoid ideation, and psychoticism as well as on three global scales, namely the Global Severity Index (GSI), the Positive Symptom Distress Index (PSDI), and the Positive Symptom Total (PST) (19). HRQL was assessed with the German version of the 36-item short-form health survey (SF-36) (20). This widely used and validated instrument contains a total of eight subscales, namely physical function, physical role function, bodily pain, general health, vitality, social function, emotional role function, and mental health (21, 22). Summed data from the subscales are transformed into a 0- to 100-point scale. In addition, the subscales are combined to yield physical function and mental health as two summary health status measures. Subjects further completed the Fragebogen zur Lebenszufriedenheit (questions on life satisfaction) (FLZ), which is a questionnaire assessing satisfaction with various aspects of life on a total of 10 scales, namely health, work and profession, finances, leisure activities, marriage and relationship, relationship to children, self, sexuality, friends and relatives, and living conditions (23, 24). However, the scale relationship to children was omitted from analyses because only a small proportion of participants had children.

In addition to these standardized instruments, a questionnaire was constructed addressing several PCOS-specific issues: On a five-point rating scale (not at all, a little, average, more than average, and very much), participants rated the impact of excess body hair, obesity, and infertility. On the same scale, they rated their satisfaction with outer appearance. Sexual satisfaction was assessed using a 100-mm visual analog scale (VAS) ranging from not at all at the 0-mm mark to very much at the 100-mm mark. Included were items regarding the impact of hirsutism on sexuality and the ability to make social contacts, the

importance of a satisfying sex life, own satisfaction with their sex life during the past month, satisfaction of the partner with their sex life, sexual thoughts and fantasies during the past month, frequency of pain during sexual intercourse, the feeling of being sexually attractive, and the feeling that their partner finds them sexually attractive. Women were instructed to place a mark at the point that best corresponded with their feelings. In this context, there were also items documenting the partnership situation of the subjects, including information about marital status as well as number and duration of relationships. The frequency of sexual intercourse during the past month was also recorded. All patients completed the questionnaires without linguistic or cognitive difficulties.

Data analysis

The SCL-90-R, SF-36, and FLZ were scored and analyzed according to the published guidelines (18, 20, 23). For VAS scales, the distance from 0 mm to the patient's mark was measured. For statistical comparisons of the two groups, independent-samples Student's t tests were computed using the Statistical Package for the Social Sciences (SPSS, Inc., Chicago, IL) statistical software package (25). To take the effect of body weight into account, secondary covariance analyses with body mass index (BMI) as the covariate were carried out. For group comparisons of sociodemographic sample characteristics, Fisher's exact tests for analysis of frequency distributions was used. Pearson's r was computed for correlations. The α -level for statistical significance was set at 0.05. In the initial analysis, no adjustments were made for multiple comparisons, but the effect of α -correction using Bonferroni's method to control for type I error is indicated. Here, a more conservative α -level was applied, which was calculated based on the number of scales in each questionnaire (i.e. rather than applying an alpha of 0.05 for accepting statistical significance, 0.05 was divided by the number of scales in each questionnaire) (26). Data are presented as mean \pm sp.

Results

Participants

A total of 50 women with PCOS and 50 aged-matched, healthy women were recruited. The majority of patients with PCOS were referred to our clinic by their gynecologist. A few patients with PCOS initiated contact based on information posted on the clinic's home page. Patients with PCOS and healthy controls did not differ in sociodemographic variables, including age, family status, education, and employment (Table 1). In addition, the majority of individuals in both groups did not smoke, drank alcohol infrequently, and rated their general health as being good or very good. Fifty-four percent of patients with PCOS (controls 32%) were clin-

TABLE 1. Sociodemographic and health symptom characteristics in women with PCOS and controls

	PCOS (n = 50)	Controls $(n = 50)$	P
Age [mean (SD)]	28.4 (5.0)	29.9 (5.7)	NS
$BMI [(kg/m^2, mean (SD)]$	30.1 (9.8)	24.4 (5.3)	< 0.001
Elevated BMI [>25 kg/m ² , % (n)]	54 (27)	22 (11)	< 0.001
College degree (German "Abitur") [% (n)]	36 (18)	48 (24)	NS
Family status			
Married [% (n)]	42 (21)	38 (19)	NS
Divorced [% (n)]	2(1)	6 (3)	NS
Single [% (n)]	46 (23)	54 (27)	NS
With children [% (n)]	20 (10)	30 (15)	NS
Have had a sexual partner for >2 months [% (n)]	66 (34)	76 (38)	NS
Unfulfilled wish to conceive [% (n)]	42 (21)	6 (3)	< 0.001
Full-time job [% (n)]	52 (26)	46 (23)	NS
Part-time job [% (n)]	10 (5)	20 (10)	NS
General health rated good or very good [% (n)]	72 (36)	86 (43)	NS
Nonsmoker [% (n)]	74 (37)	58 (29)	NS
Drink no or little alcohol [% (n)]	96 (48)	84 (42)	NS

ically obese (BMI $\geq 25 \text{ kg/m}^2$), corresponding to an elevated mean BMI of 30.1 ± 9.8 in affected women (controls 24.4 ± 5.4). Furthermore, a significantly greater proportion of patients with PCOS reported to currently have an unfulfilled wish to conceive a child (PCOS 42%, controls 6%). This difference was very likely to be related to a selection bias/self-selection for specialized medical treatment because 30% of patients were referred specifically because of infertility problems, and almost all patients had previously been diagnosed with PCOS and thus aware of potential infertility problems. The diagnosis of PCOS had been established an average of 37.9 ± 47.0 months before the patients took the survey. As expected, parameters characteristic for PCOS were elevated in affected women, with a mean hirsutism score (17) of 12 \pm 5 (controls 3 \pm 2), a mean LH:FSH ratio of 2.7 \pm 1.2 (controls 1.3 \pm 0.6), and a mean serum testosterone of 2.7 ± 0.9 nmol/liter (controls 1.1 ± 0.6).

HRQL, life satisfaction, and psychological disturbances

HRQL, life satisfaction, and psychological disturbances in patients with PCOS and healthy controls were evaluated with a survey containing general questions on PCOS-specific issues and three standardized questionnaires (SCL-90-R, SF-36, and FLZ). Patients with PCOS reported that the disorder negatively affected various aspects of their life, including family life (40.0%), professional activities (27.5%), leisure activities (29.5%), and physical fitness (23.6%).

Evaluation of psychological disturbances with the SCL-90-R revealed significantly higher scores on the dimensions of obsessive-compulsive, interpersonal sensitivity, depression, aggression, and psychoticism in patients with PCOS (Fig. 1), whereas healthy controls scored within the normative population means for all scales. Accordingly, patients' scores were significantly elevated on two of the questionnaire's three global indices, namely the GSI [PCOS $0.72 \pm$ 0.65; controls 0.42 \pm 0.44 (mean \pm sp; P < 0.01)] and the PSDI

[PCOS 1.6 \pm 0.64; controls 1.3 \pm 0.37 (mean \pm sp; P < 0.05)], corresponding to an increase in patients with PCOS by about 1 sp above the norms' means for all scales as well as for the global indices. Following alpha adjustment for multiple comparisons according to the conservative Bonferroni method (corrected alpha for accepting statistical significance: 0.05/ 12 = 0.0042), group differences in the dimensions of obsessive-compulsive (P < 0.002), interpersonal sensitivity (P <0.002), and depression (P < 0.002) remained statistically significant.

Patients with PCOS reported significantly lower HRQL, measured with the German version of the SF-36 (20). Compared with controls, women with PCOS had significantly decreased scores, indicating lower quality of life, on the scales of physical role function [PCOS 71 \pm 37; controls 90 \pm 21 (mean \pm sp)], bodily pain [PCOS 73 \pm 30; controls 85 \pm 26 (mean \pm sp)], vitality [PCOS 43 \pm 20; controls 60 \pm 20 (mean \pm sp)], social function [PCOS 66 \pm 30; controls 80 \pm 27 (mean \pm sp)], emotional role function [PCOS 49 \pm 44; controls 87 ± 27 (mean \pm sp)], and mental health [PCOS 53 \pm 20; controls 70 ± 18 (mean \pm sp)] (Fig. 2). In contrast, no significant differences were found for the scales of physical function and general health. Based on a corrected alpha for multiple comparisons (adjusted alpha for accepting statistical significance: 0.05/8 = 0.0063), group comparisons remained significant for physical role function (P < 0.003), vitality (P < 0.0001), emotional role function (P < 0.0001), and mental health (P < 0.0001).

Analysis of the FLZ life satisfaction questionnaire showed that women with PCOS reported significantly lower satisfaction in the areas of health [PCOS 31 \pm 9; controls 37 \pm 8 $(\text{mean} \pm \text{sd})$, self [PCOS 34 ± 8; controls 39 ± 6 (mean ± sd)], and sex [PCOS 30 \pm 9; controls 37 \pm 8 (mean \pm sp)], compared with controls (Fig. 3). In contrast, the patient and control groups did not differ significantly in the scales of work and profession, finances, leisure activities, marriage and relationship, friends and relatives, and living conditions.

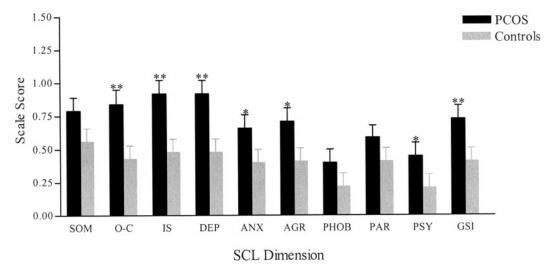
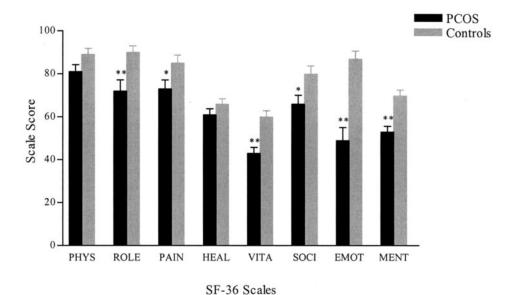
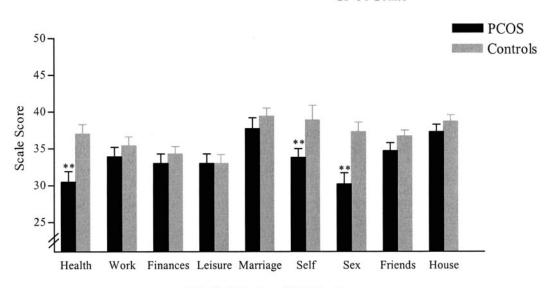


Fig. 1. Psychological disturbances measured by the German version of the SCL-90-R in women with PCOS, compared with controls. Patients had significantly higher scores, indicating greater psychological disturbances, on the dimensions of obsessive-compulsive (O-C: **, P < 0.01), interpersonal sensitivity (IS: **, P < 0.01), depression (DEP: **, P < 0.01), aggression (AGR: *, P < 0.05), and psychoticism (PSY: *, P < 0.05) as well as on the GSI (**, P < 0.01). No group differences were found for the scales of somatization (SOM), anxiety (ANX), phobia (PHOB), and paranoid ideation (PAR). All data are presented as mean + sd.

Fig. 2. HRQL measured with the German version of the SF-36 in women with PCOS and healthy controls. Patients reported significantly lower quality of life on the scales of physical role function (ROLE: **, P < 0.001), bodily pain (PAIN: *, P < 0.05), vitality (VITA: **, P < 0.001), social function (SOCI: *, P < 0.05), emotional role function (EMOT: **, P < 0.0001), and mental health (MENT: **, P < 0.0001). No group differences were found for the scales of physical function (PHYS) and general health (HEAL). All data are presented as mean + SD.





Life Satisfaction (FLZ) Scales

Fig. 3. Life satisfaction measured with the FLZ questionnaire. Women with PCOS had significantly lower scores on the scales of health, self, and sex (**, P < 0.001), indicating less satisfaction in these areas. All data are presented as mean + SD.

The alpha adjustment for multiple comparisons (adjusted alpha: 0.05/9 = 0.0056) did not affect the FLZ questionnaire results because all comparisons had an alpha level of P < 0.001.

Sexual satisfaction and sexual self-worth

As one important area of quality of life, sexual satisfaction was assessed in patients and controls with a questionnaire using VASs (Table 2). The majority of women in both groups currently had a sexual partner (patients: 66%, controls: 76%), with similar numbers of patients and controls being married (42% vs. 38%) or single (46% vs. 54%). Patients with PCOS and controls did not differ in the frequency of sexual intercourse or sexual thoughts and fantasies during the past month (Table 2). In addition, the groups rated a satisfying sex life as equally important. However, women with PCOS were sig-

nificantly less satisfied with their sex life and found themselves significantly less sexually attractive. Responses regarding sexual satisfaction and the feeling of being sexually attractive were significantly correlated in both patients with PCOS (r = 0.51, P < 0.001) and controls (r = 0.63, P < 0.001). Compared with the healthy control women, patients with PCOS further felt that their partners were significantly less satisfied with their sex life and that their partner found them significantly less sexually attractive. Finally, women with PCOS believed to a significantly greater extent than controls that their excessive body hair negatively affects their sexuality and that their outer appearance makes it difficult to form social contacts (Table 2). Using an adjusted alpha level to control for inflation of type I error (adjusted P 0.05/9 =0.056) did not affect the reported results (all P < 0.001) except for the VAS scales addressing the partners' assessment of

TABLE 2. Frequency of sexual intercourse, sexual self-worth, and sexual satisfaction in women with PCOS and controls

	PCOS(n = 50)	Controls $(n = 50)$	P
Frequency of sexual intercourse during the past 4 wk			
0 times [% (n)]	26 (13)	22 (11)	NS
1–5 times [% (n)]	30 (15)	26 (13)	NS
5–10 times % [(n)]	18 (9)	22 (11)	NS
>10 times [% (n)]	2(1)	10 (5)	NS
During the past 4 wk ^a			
How satisfied were you with your sex life?	41.3 (33.4)	73.8 (27.4)	< 0.001
How many sexual thoughts and fantasies did you have?	47.7 (25.8)	58.0 (28.7)	NS
How important is a satisfying sex life for you?	76.3 (22.0)	76.3 (24.1)	NS
In general			
Do you find yourself sexually attractive?	37.4 (27.1)	58.5 (29.3)	< 0.001
How sexually attractive does your partner find you?	57.7 (25.7)	71.6 (26.7)	< 0.05
How satisfied is your partner with the sex life?	50.6 (31.5)	74.8 (24.9)	< 0.001
How much does excessive body hair impact your sexuality?	45.8 (26.2)	12.2 (33.3)	< 0.00
How often do you experience pain during intercourse?	20.8 (22.5)	15.8 (23.8)	NS
Does your appearance make it difficult to make social contacts?	28.4 (31.7)	12.7(24.5)	< 0.05

NS, Not significant.

sexual attraction (P < 0.02) and the impact of outer appearance on the difficulties to form social contacts (P < 0.05).

Effects of obesity

To take the potentially confounding effects of obesity into account, secondary covariance analyses were carried out using BMI as the covariate. Having controlled for group differences in obesity with this procedure, the following group comparisons remained statistically significant: Patients with PCOS reported significantly lower HRQL, measured with the SF-36, on the scales of physical role function (P < 0.01), vitality (P < 0.01), emotional role function (P < 0.001), and mental health (P < 0.05). In the FLZ life satisfaction guestionnaire, patients demonstrated significantly lower satisfaction in the areas of health (P < 0.05), self (P < 0.01), and sex (P < 0.01). With regard to psychological disturbances, measured with the SCL-90-R, patients had significantly higher scores, indicating greater disturbances, in the dimensions of obsessive-compulsive (P < 0.05), interpersonal sensitivity (P < 0.05), depression (P < 0.05), and psychoticism (P < 0.05). However, after controlling for BMI, no differences between groups were found for the SCL-90-R's three global indices (i.e. the GSI, PSDI, PST).

In contrast, BMI had no impact on the VASs addressing sexual satisfaction: Both obese and nonobese women with PCOS reported being significantly less satisfied with their sex life in the past month (P < 0.001), finding themselves significantly less sexually attractive (P < 0.05), believing their partner to be significantly less satisfied with their sex life (*P* < 0.001), and reporting that excessive body hair affected their sexuality (P < 0.001). BMI also had no significant effect on the frequency of sexual intercourse or sexual thoughts and fantasies.

Discussion

PCOS is among the most common endocrine disorders of premenopausal women. Accompanying clinical symptoms and long-term complications affect various aspects of their quality of life. Because PCOS often manifests at an age when

finding a partner, sexual activity, and marriage are important, its cosmetic and psychosexual implications are thought to cause profound emotional distress in affected women (12). The three most bothersome symptoms commonly reported by affected women are excess hair growth, irregular or absent menstruation, and infertility (13). As a result, patients with PCOS expressed feeling different from other women and less feminine (13). Accordingly, a psychometric evaluation by Sonino et al. (27) revealed more anxiety and psychotic symptoms at Kellner's Symptom Rating Test and significantly higher social fears assessed with Marks' Social Situations Questionnaire in hirsute women, compared with healthy nonhirsute controls, whereas no differences in depression, somatization, anger/hostility, and cognitive symptoms were found. Almost all women associate negative emotions of frustration, anxiety, and, to a lesser extent, sadness with PCOS, although the self-reported knowledge level for the disorder is high (14).

Although an early study on married women coping with infertility using the Institute for Personality and Ability Testing (IPAT) Anxiety Scale, the IPAT Depression Scale, the Tennessee Self-Concept Scale, and the Internal-External Scale found no emotional maladjustment (28), recent studies on adolescent girls with PCOS using the Child Health Questionnaire-Child Self-Report Form reported a 3.4 times increased concern about their ability to become pregnant (29). Girls with PCOS also had a 2.8 times reduced likelihood to have sexual intercourse than healthy subjects, although the mean age at initiation of sexual intercourse among sexually active girls was not significantly different between the two groups, and the severity of PCOS and the worry about fertility were not associated with odds of being sexually active (29). Furthermore, limitations in general health perceptions, physical functioning, general behavior, and family activities have been found in adolescents with PCOS (15). Two case report studies have reported an association of an increased psychiatric morbidity in patients with PCOS, implying an etiology of monoamine imbalances (30) or elevations of LH and androgens (31) because monoamine oxidase inhibitor

^a Assessed with 100-mm visual analog scales (minimum, not at all = 0 mm; maximum, very much/very often = 100 mm); data shown as mean ± SD in millimeters.

antidepressants and clomiphene citrate, respectively, ameliorated the psychiatric illness.

We have now evaluated HRQL, life satisfaction, and sexuality in adult patients with PCOS with a comprehensive combination of standardized questionnaires and a collection of questions designed to specifically evaluate characteristics of PCOS. The comparison of healthy controls and patients with PCOS revealed no differences in sociodemographic variables, the FLZ's dimensions for work, finances, leisure activities, marriage, friends, and living conditions. The differences in quality of life and sexuality in the two groups thus appear to be health related rather than dependent on the social situation or living conditions of affected women. Furthermore, because the SF-36's dimensions on general health were also similar in the two groups, PCOS-specific factors must be responsible for the pronounced reduction in HRQL and sexuality reported here.

Psychological disturbances, evaluated with the SCL-90-R, are considered to be an important factor influencing quality of life. Women with PCOS reported greater psychological disturbances, compared with controls, with significantly elevated global indices (GSI, PSDI, and PST), designed to measure the overall psychological distress and the intensity of symptoms. Secondary analyses controlling for BMI revealed that some of the reported group differences in the SCL-90-R's scales were attributable to obesity rather than PCOS. However, even after statistically controlling for BMI, patients with PCOS had significantly greater scores in the dimensions of obsessive-compulsive, interpersonal sensitivity, depression, and psychoticism. These problems in socioemotional wellbeing, particularly symptoms of depression, could very conceivably contribute to an exacerbation of the effects of medical illness. The FLZ demonstrated disease-specific restrictions in the scales of health, self, and sex. Thus, in patients with PCOS, disease-related changes in appearance, irregular or absent menstrual periods, and infertility appear to have a considerable effect on quality of life.

In addition to limitations in emotional well-being, quality of life, and life satisfaction, the diagnosis of PCOS clearly has a negative impact on sexual self-worth and sexual satisfaction, which deserves more attention in clinical practice and research. Although PCOS and control groups were comparable regarding partner status, frequency of sexual intercourse, and sexual thoughts and fantasies, patients with PCOS were significantly less satisfied with their sex life and reported on their impression that their partners were less satisfied, too. In addition, women with PCOS found themselves significantly less sexually attractive, which was significantly associated with the feeling of sexual satisfaction. Disease-related changes in appearance, particularly hirsutism, acne, and obesity, hormonal disturbances, fear of infertility, and psychological distress may contribute to these negative effects on sexual satisfaction and sexual self-worth, possibly by affecting self-esteem and female identity. Although it remains to be determined which of the accompanying clinical symptom(s) of PCOS accounts for the present results, obesity was clearly not the only determinant because statistical control for elevated BMI left the results virtually unchanged.

It should be noted that the interpretation of the current

data on frequency of sexual intercourse is limited by the fact that a proportion of participants had no sexual partner and that not all aspects of sexuality were analyzed. Therefore, further work is needed to characterize sexual functions in women with PCOS more precisely, including sexual activity that does not involve intercourse (e.g. masturbation frequency) and to take into account the quality of sexual experiences (e.g. sexual arousal, ability to reach orgasm). It is further important to point out that the present results may not apply to the entire PCOS population. Thirty percent of patients in this study were referred from their gynecologist due to infertility problems, and all patients had previously been diagnosed with PCOS, and thus aware of at least some of the implications of their condition. Therefore, a selection bias and/or effects of self-selection for specialized treatment are likely to have affected the results. This is illustrated by the fact that the percentages of women currently wishing to conceive a child were significantly different between the groups even though they were well matched regarding age, education, and socioeconomic status. Hence, generalizability of the present results is limited because affected women were more likely to be concerned about their medical condition and its long-term consequences.

In conclusion, the present study documents the pronounced psychological and psychosocial problems affecting HRQL of patients with PCOS. Although an effective medical treatment aimed at improving PCOS-related symptoms (especially hirsutism, obesity, menstrual irregularity, and infertility) will also reduce psychological distress and improve sexual self-worth, consideration of both the medical and psychological situation with the availability of an additional psychological counseling and participation in a PCOS self-help group are likely to further improve life satisfaction and coping of affected women.

Acknowledgments

We are grateful to Drs. W. Behring van Halteren, T. Eriz, A. Fechtig, U. H. Gerhold, C. Helligrath, A. Huster-Sinemillioglu, K. T. Joachim, R. Kimmig, A. Kucharczik, J. Lipowski, M. Massing, U. Partenheimer-Schiffer, S. Rösle, C. Schröer, H.-J. Stangier, S. Tauber, L. Tharandt, and H. Weydandt for referring the patients. We thank the nursing staff of the outpatient clinics of the Department of Medicine at the University of Essen for expert patient care.

Received April 1, 2003. Accepted August 24, 2003.

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References

- Knochenhauer ES, Key TJ, Kahsar-Miller M, Waggoner W, Boots LR, Azziz R 1998 Prevalence of the polycystic ovary syndrome in unselected black and white women of the southeastern United States: a prospective study. J Clin Endocrinol Metab 83:3078–3082
- Asuncion M, Calvo RM, San Millan JL, Sancho J, Avila S, Escobar-Morreale HF 2000 A prospective study of the prevalence of the polycystic ovary syndrome in unselected Caucasian women from Spain. J Clin Endocrinol Metab 85:2434–2438
- Dunaif A, Thomas A 2001 Current concepts in the polycystic ovary syndrome. Annu Rev Med 52:401–419
- Legro RS, Strauss JF 2002 Molecular progress in infertility: polycystic ovary syndrome. Fertil Steril 78:569–576
- Venkatesan AM, Dunaif A, Corbould A 2001 Insulin resistance in polycystic ovary syndrome: progress and paradoxes. Recent Prog Horm Res 56:295–308

- 6. Hahn S, Bering van Halteren W, Kimmig R, Mann K, Gärtner R, Janssen OE 2003 Diagnostic procedures in polycystic ovary syndrome. J Lab Med 27:53–59
- Talbott EO, Zborowski JV, Sutton-Tyrrell K, McHugh-Pemu KP, Guzick DS 2001 Cardiovascular risk in women with polycystic ovary syndrome. Obstet Gynecol Clin North Am 28:111-133, vii.
- 8. Legro RS 2002 Polycystic ovary syndrome. Long term sequelae and management. Minerva Ginecol 54:97-114
- Christian RC, Dumesic DA, Behrenbeck T, Oberg AL, Sheedy PF, Fitzpatrick LA 2003 Prevalence and predictors of coronary artery calcification in women with polycystic ovary syndrome. J Clin Endocrinol Metab 88:2562-2568
- 10. Wild S, Pierpoint T, McKeigue P, Jacobs H 2000 Cardiovascular disease in women with polycystic ovary syndrome at long-term follow-up: a retrospective cohort study. Clin Endocrinol (Oxf) 52:595-600
- Legro RS 2003 Polycystic ovary syndrome and cardiovascular disease: a premature association? Endocr Rev 24:302-312
- 12. Eggers S, Kirchengast S 2001 The polycystic ovary syndrome—a medical condition but also an important psychosocial problem. Coll Anthropol 25:
- 13. Kitzinger C, Willmott J 2002 'The thief of womanhood': women's experience of polycystic ovarian syndrome. Soc Sci Med 54:349-361
- 14. Sills ES, Perloe M, Tucker MJ, Kaplan CR, Genton MG, Schattman GL 2001 Diagnostic and treatment characteristics of polycystic ovary syndrome: descriptive measurements of patient perception and awareness from 657 confidential self-reports. BMC Womens Health 1:3
- 15. Trent ME, Rich M, Austin SB, Gordon CM 2002 Quality of life in adolescent girls with polycystic ovary syndrome. Arch Pediatr Adolesc Med 156:556-560
- Cronin L, Guyatt G, Griffith L, Wong E, Azziz R, Futterweit W, Cook D, Dunaif A 1998 Development of a health-related quality-of-life questionnaire (PCOSQ) for women with polycystic ovary syndrome (PCOS). J Clin Endocrinol Metab 83:1976-1987
- 17. Ferriman D, Gallwey JD 1961 Clinical assessment of body hair growth in women. J Clin Endocrinol Metab 21:1440-1447
- 18. Schmitz N, Hartkamp N, Kiuse J, Franke GH, Reister G, Tress W 2000 The Symptom Check-List-90-R (SCL-90-R): a German validation study. Qual Life Res 9:185-193

- 19. Derogatis LR, Rickels K, Rock AF 1976 The SCL-90 and the MMPI: a step in the validation of a new self-report scale. Br J Psychiatry 128:280-289
- 20. Ware Jr JE, Gandek B, Kosinski M, Aaronson NK, Apolone G, Brazier J, Bullinger M, Kaasa S, Leplege A, Prieto L, Sullivan M, Thunedborg K 1998 The equivalence of SF-36 summary health scores estimated using standard and country-specific algorithms in 10 countries: results from the IQOLA Project. International Quality of Life Assessment. J Clin Epidemiol 51:1167-1170
- 21. Ware Jr JE, Sherbourne CD 1992 The MOS 36-item short-form health survey (SF-36), I. Conceptual framework and item selection, Med Care 30:473-483
- 22. McHorney CA, Ware JE, Jr., Raczek AE 1993 The MOS 36-Item Short-Form Health Survey (SF-36): II. Psychometric and clinical tests of validity in measuring physical and mental health constructs. Med Care 31:247-263
- 23. Henrich G, Herschbach P 2000 Questions on life satisfaction (FLZ)—a short questionnaire for assessing subjective quality of life. Eur J Psychol Assess 16:150-159
- 24. Goldbeck L, Schmitz TG 2001 Comparison of three generic questionnaires measuring quality of life in adolescents and adults with cystic fibrosis: the 36-item short form health survey, the quality of life profile for chronic diseases, and the questions on life satisfaction. Qual Life Res 10:23-36
- 25. Chambers M, Connor S, Diver M, McGonigle M 2002 Usability of multimedia technology to help caregivers prepare for a crisis. Telemed J E Health 8:343–347
- 26. Dunn OJ 1961 Multiple comparisons among means. J Am Stat Assoc 56:52-64
- 27. Sonino N, Fava GA, Mani E, Belluardo P, Boscaro M 1993 Quality of life of hirsute women. Postgrad Med J 69:186-189
- 28. Paulson JD, Haarmann BS, Salerno RL, Asmar P 1988 An investigation of the relationship between emotional maladjustment and infertility. Fertil Steril 49.258-262
- 29. Trent ME, Rich M, Austin SB, Gordon CM 2003 Fertility concerns and sexual behavior in adolescent girls with polycystic ovary syndrome. Implications for quality of life. J Pediatr Adolesc Gynecol 16:33-37
- 30. Bruce-Jones W, Zolese G, White P 1993 Polycystic ovary syndrome and psychiatric morbidity. J Psychosom Obstet Gynaecol 14:111-116
- 31. Matsunaga H, Sarai M 1993 Elevated serum LH and androgens in affective disorder related to the menstrual cycle: with reference to polycystic ovary syndrome. Jpn J Psychiatry Neurol 47:825-842