Psychological implications of infertility in women with polycystic ovary syndrome


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BACKGROUND: In polycystic ovary syndrome (PCOS), one of the main features is chronic anovulation associated with lower pregnancy rates. Little is known regarding the psychological aspects associated with infertility in these patients. Therefore, we examined the influence of an unfulfilled wish to conceive on various aspects of psychological functioning in PCOS women. METHODS: Standardized questionnaires assessing quality-of-life (36-item short-form health survey, SF-36), depressiveness (Beck Depression Inventory), emotional distress (Symptom Check List 90, SCL-90-R), sexual satisfaction and self-worth (visual analogue scales), and a questionnaire on the desire for a child (FKW) were administered at the outpatient endocrine clinic to consecutive PCOS patients. RESULTS: Questionnaires from 115 PCOS patients were analysed. The majority (76.1%) worried about remaining childless in the future, and 51.3% reported a current wish to conceive. 23.9% of patients had scores indicating mild to moderate depression, and 25.2% had scores indicating clinically relevant depression. Furthermore, all quality-of-life scores were significantly lower compared with normative data (P < 0.001). Unexpectedly, comparisons of patients with a current unfulfilled desire to conceive to those with no present wish for a child revealed no discernable impact on depressive symptoms, quality-of-life or emotional distress. Reduced sexual satisfaction and self-worth were largely determined by partnership status and not infertility. However for PCOS patients who wished to conceive, the wish for a child was a significantly greater priority when compared with normative data from infertile patients. CONCLUSIONS: PCOS represents a major risk factor for psychosocial and emotional problems, but at least in this sample of PCOS patients, infertility does not appear to constitute a primary determinant of psychological problems.

Keywords: PCOS; infertility; depression; quality-of-life; sexual satisfaction

Introduction

Polycystic ovary syndrome (PCOS) affects >6% of women of reproductive age (Knochenhauer et al., 1998; Asuncion et al., 2000; Azziz et al., 2004). It is characterized by both gynaecological and endocrine symptoms, including chronic anovulation, hyperandrogenism, insulin resistance and the metabolic syndrome (Azziz, 2004; Chang, 2004; Rotterdam ESHRE/ASRM-Sponsored PCOS Consensus Workshop Group, 2004; Azziz et al., 2006). PCOS is also one of the leading causes of infertility and involuntary childlessness (Franks, 2003; Homburg, 2003), which can represent major stress factors in female life (Greil, 1997; Guerra et al., 1998; Oddens et al., 1999). Indeed, PCOS women reportedly suffer from marked reductions in quality-of-life, emotional distress and a markedly increased incidence of depression (Himelein and Thatcher, 2006b).

Despite a growing body of evidence demonstrating the negative impact of the diagnosis on psychosocial and emotional functioning, the determinants of psychological problems in PCOS women remain elusive. The importance of changes in physical appearance, particularly obesity and hirsutism, has been relatively well-established (Elsenbruch et al., 2003; Coffey and Mason, 2003; Hahn et al., 2005a; McCook et al., 2005; Trent et al., 2005; Barnard et al., 2007; Ching et al., 2007), whereas other possible factors, including effects of hyperandrogenism (Weiner et al., 2004) or insulin resistance (Rasgon et al., 2003) have been less well-studied. Infertility and involuntary childlessness have also been proposed as major contributors
to emotional problems and reduced quality-of-life in PCOS (Eggers and Kirchengast, 2001; Trent et al., 2003; Schmid et al., 2004), which would be consistent with the notion that PCOS women suffer from a lack of feminine identity (Kitzinger and Willmott, 2002), and evidence of reduced sexual self-worth (Elsenbruch et al., 2003; Hahn et al., 2005a).

In infertile women or couples with infertility from various causes (not PCOS specifically), several studies have implicated psychological problems in a proportion of patients (Downey et al., 1989; Downey and McKinney, 1992; Wischmann et al., 2001; Fassino et al., 2002; Cwikel et al., 2004; Ragni et al., 2005; Chachamovich et al., 2007; Cousineau and Domar, 2007). To date, few studies have specifically addressed the psychosocial implications of infertility or fear of infertility in PCOS, and the findings are inconsistent. Whereas a role of infertility has been documented in adolescent girls with PCOS (Trent et al., 2003) and Moslem immigrants (to Austria) (Schmid et al., 2004) with PCOS, results from two of our studies on German PCOS women (Elsenbruch et al., 2003; Hahn et al., 2005a) and recently published data by Himelein and Thatcher (2006a) on an American PCOS sample provided no convincing support for a pivotal role of infertility. On the other hand, in our recent report we found in regression models that a current wish to conceive did in fact contribute to reduced psychological quality-of-life in PCOS (Elsenbruch et al., 2006).

Given the high prevalence of PCOS, and the fact that infertility is one of the main implications of the diagnosis, the psychological consequences of infertility-associated worries and fears in PCOS as well as of the actual experience of the failure to conceive clearly deserves further study. Therefore, we compared psychosocial functioning in PCOS women with and without a present unfulfilled wish to conceive in order to test the hypothesis that PCOS women with a present unfulfilled wish to conceive would experience more psychological problems, particularly increased rates of depression, lower quality-of-life, and decreased sexual satisfaction and self-worth, when compared with PCOS patients without the present desire to conceive. Furthermore, we addressed the expectations and apprehensions in connection with pregnancy, birth and parenthood in PCOS women with an unfulfilled wish to conceive using a specific, validated questionnaire on the desire for a child (FKW, Hölzle, 2001) and compared this to normative data from a sample of women presenting to infertility clinics with defined infertility.

Materials and Methods

Diagnostic work-up and clinical characterization of patients

The diagnosis of PCOS was established based on the criteria derived from the 1990 NIH conference, when either oligomenorrhea (cycles lasting longer than 35 days) or amenorrhea (less than two menstrual cycles in the past 6 months) and either clinical signs of hyperandrogenism (hirsutism or obvious acne or alopecia) and/or an elevated testosterone (normal range: testosterone < 2.0 nmol/l) and/or an elevated total testosterone in combination with an elevated free androgen index (FAI) (testosterone normal range < 2.0 nmol/l, FAI normal range < 4.97) were found, and other pituitary, adrenal or ovarian diseases could be excluded. All patients also met the diagnostic criteria for PCOS according to the Rotterdam criteria (Rotterdam ESHRE/ASRM-Sponsored PCOS Consensus Workshop Group, 2004).

During diagnostic work-up, participants were carefully characterized with regard to medical history and clinical and sociodemographic parameters using questionnaires, interview, and physical examination, as previously described in detail (Hahn et al., 2005b). Briefly, for PCOS-specific clinical parameters, hirsutism was evaluated using the modified Ferriman–Gallwey score (Hatch et al., 1981). Anthropometric measurements were accomplished, including body mass index (BMI, calculated as weight/(height)$^2$ (kg/m$^2$)), LH, FSH, testosterone, blood glucose (ADVIA Centaur, Siemens, Germany), insulin and sex hormone-binding globulin (SHBG) (IMMULITE 2000, Siemens, Germany) were also determined. Intra-assay variation was < 5% and inter-assay variation was < 8% for all measured parameters. The FAI was calculated as testosterone (nmol/l)/SHBG (nmol/l) × 100. The homeostasis model assessment of insulin resistance (HOMA-IR) was used to calculate insulin resistance using the following formula: HOMA-IR = fasting plasma immunoreactive insulin (μU/l) × fasting plasma glucose (nmol/l)/22.5 (Matthews et al., 1985). Except for amenorrhoic women, all laboratory parameters were determined in the early follicular phase of the menstrual cycle. The study protocol was approved by the Ethics Committee of the University of Essen. All subjects gave written informed consent before entering the study.

Psychological measures

Method of administration

Questionnaires were completed by consecutive, currently untreated PCOS patients presenting between June 2005 and December 2006 to our outpatient endocrine clinic (Division of Endocrinology, Department of Medicine, University Hospital of Essen Medical School) or an endocrinologist of our research team who is now in private practice (S.H.). Of note, the present sample did not consist of patients we reported on previously (Elsenbruch et al., 2003; 2006; Hahn et al., 2005a, c), and no patient was currently undergoing any type of infertility treatment. All patients presenting with a suspected or previously established diagnosis of PCOS were approached by the treating physician, with the exception of individuals not fluent in German. Patients completed the questionnaires at the clinic in the morning of their routine diagnostic work-up (usually during the waiting periods during oral glucose tolerance test), and then returned the completed set of questionnaires prior to departing from the clinic in a sealed envelope addressed to the Department of Medical Psychology. Hence, patients could be sure that their treating physician did not have access to the questionnaire data. Given this method of administration, there was a near 100% response rate. Questionnaires from patients in whom the diagnosis could not be confirmed or where diagnostic work-up revealed the presence of other exclusionary conditions were excluded post hoc.

Questionnaires

Psychological measures included four validated questionnaires; while several aspects of sexual self-worth and satisfaction were measured with visual analogue scales (VAS), described in detail below.

(i) Depressive symptoms were assessed with the German version of the Beck Depression Inventory (BDI), with sum scores ≥ 11 indicating mild to moderate depressive symptoms and scores ≥ 18 severe depressive symptoms (Hautzinger et al., 1995). Normative data are available from various healthy and patients samples.

(ii) Health-related quality-of-life was assessed with the German version of the 36-item short-form health survey (SF-36),
which quantifies various aspects of health-related quality-of-life on eight subscales, i.e. physical function, physical role function, bodily pain, general health perception, vitality, emotional role function, social function and mental health. Scores on these primary scales are combined into two global health measures, i.e. the SF-36 Physical Sum score and the SF-36 Psychological Sum score. Normative data are available from various healthy and patients samples (Bullinger and Kirchberger, 1998). Higher scores indicate better quality-of-life. Of note, there is an English version of a disease-specific questionnaire (i.e. the PCOSQ) which addresses various aspects of quality-of-life in PCOS, and also includes an infertility domain (Cronin et al., 1998; Guyatt et al., 2004). We used a generic instrument (i.e. the SF-36) rather than the PCOSQ since no validated German version of the PCOSQ exists. Although generic instruments lack specificity, their advantage is the availability of normative data allowing for comparisons with non-PCOS populations.

(iii) The German version (Franke, 1995; Schmitz et al., 2000) of the Symptom Check List 90 (SCL-90-R) (DeRogatis, 1983) was used to assess emotional distress. This widely used screening tool, which can be used to screen to identify putative cases of psychiatric/psychological illness, contains 90 items with a five-point scale (0 = not at all, 4 = extremely), and assesses symptomatology in nine areas (somatization, obsessive-compulsive, interpersonal sensitivity, depression, anxiety, aggression, phobia, paranoid ideation, psychosoma)

The average score of all 90 items yields the global severity index (GSI), which represents the overall level of distress. GSI scores ≥ 63 identify cases with possible mental disorder (SCL cases) (DeRogatis, 1983; Schmitz et al., 2000). In addition, two additional global scores are calculated, the positive symptom distress index (PSDI) which indicates the intensity of distress, and the positive symptom total (PST), which is the total number of distress-inducing symptoms. Higher scores on the scales of the SCL-90-R indicate higher distress; it should be noted individual scales cannot be interpreted in diagnostic categories. Normative data are available from various healthy and patients samples (Franke, 1995).

(iv) The questionnaire on the desire for a child (FKW questionnaire) by Hölzle and Wirtz (2001) was used to characterize the expectations and apprehensions in connection with pregnancy, birth and parenthood in women with PCOS. This questionnaire was chosen since to the best of our knowledge, no alternative, internationally established infertility-specific, validated instrument with normative data exists for the German language. The questionnaire has previously been validated (Hölzle and Wirtz, 2001), and is specially designed to characterize various relevant psychological and motivational aspects associated with the desire to conceive a child in men and women in the reproductive phase and with a current desire to conceive. It has been shown to be sensitive to differences in the psychological processes associated with infertility in couples with infertility compared with couples with undisturbed fertility. There are normative data from a large, multi-centre study in Germany, which included data from n = 1025 infertile women (mean age of normative sample: 31.78 years, average duration of desire to conceive: 4.43 years; average duration of prior infertility treatment: 3.37 years) presenting at reproductive clinics. The questionnaire contains 20 items, all rated on a Likert-type scale from 1 (not at all) to 5 (very strong). Analysis yields scores on two primary scales, namely ‘enhancement of self-esteem and emotional stabilization’ (Scale 1), and ‘ambivalence’ (Scale 2), as well as a total score which is based on the two primary scales. Example items for Scale 1 are ‘I would be proud if I could at last answer yes to the question ‘Do you have children?’’ and ‘Only if I had a child would I feel that I had a real home’; for Scale 2 ‘I fear that a child might strain my relationship with my partner’ and ‘There are other things in life I find just as fulfilling as having a child’. In the analyses, for the calculation of the total score, scores on Scale 2 are reverse-coded, such that higher total scores indicate that the current wish for a child is very intensive and of great priority, and that much of the self-esteem and emotional stability depends on the ability to conceive a child. At the same time, higher total scores support that there exist little doubts or ambivalent motivations regarding conception (Scale 2). The FKW has previously been found sensitive to differences in self-esteem derived from having a child, between couples with idiopathic infertility and non-idiopathic sterile couples (Wischmann et al., 2001).

(v) No applicable validated questionnaire exists to address PCOS-relevant aspects of sexual self-worth and sexual satisfaction. Therefore, 100-mm VAS were used to address various aspects of sexual satisfaction, ranging from ‘not at all’ at the 0-mm mark to ‘very much’ at the 100-mm mark, as previously described (Elsenbruch et al., 2003; Hahn et al., 2005a). Included were items regarding the impact of hirsutism on sexuality and on the ability to make social contacts, the importance of a satisfying sex life, satisfaction with sex life during the past month, sexual thoughts and fantasies during the past month, frequency of pain during sexual intercourse and the feeling of being sexually attractive. Women were instructed to place a mark at the point that best corresponded with their feelings. The partnership situation of the subjects and the frequency of sexual intercourse during the past month were also recorded. Given that normative data for these scales do not exist, we show data from n = 50 healthy females previously recruited by our group, and presented in an earlier publication (Elsenbruch et al., 2003) as reference values (see Table II). However, since statistical comparisons between these healthy controls and another sample of PCOS women is already published, we did not conduct statistical comparisons between these healthy controls and the present sample of PCOS patients, but rather only compared PCOS women with and without the current wish to conceive.

Statistical analyses
All validated questionnaires were scored and analysed according to the published guidelines. Initially, group means on all four validated scales (FKW, SCL-90-R, SF-36, BDI) were compared with the respective female German reference populations (German norm) using independent samples t-tests. In addition, for the BDI, the percentage of patients in the clinically relevant cut-off area was calculated, as was the percentage of probable psychiatric cases based on SCL-90-R GSI scores > 63. To address the impact of infertility/infertile wish to conceive on depressive symptomatology, quality-of-life, emotional distress, and various aspects of sexual self-worth and satisfaction in PCOS, patients with and without the present wish to conceive were compared using independent samples t-tests for comparisons of means of the different questionnaire scales and VAS scores, or using chi-square tests for analyses of frequency distributions (e.g. sociodemographic and clinical parameters). Within PCOS women with an unfulfilled wish to conceive, a possible effect of duration was addressed by comparing women with a desire to conceive ≥ 12 versus < 12 months.
To avoid inflation of the risk of Type I error by multiple comparisons, alpha levels were adjusted using the conservative Bonferroni method, which applies an adjusted alpha level that is calculated based on the number of scales in each questionnaire (Dunn, 1961). Data are presented as mean ± SD in text and tables, and mean ± SEM in graphs.

Results

Sociodemographic and clinical characteristics

The total sample consisted of \( n = 115 \) PCOS patients, all currently medically untreated (i.e. in most cases prior to the initiation of treatment with metformin).

Sociodemographic and clinical data for the entire PCOS as well as for PCOS with and without an unfulfilled wish to conceive are presented in Table I. Out of all patients, 76.1% expressed anxiety about remaining without a child in the future. About 51.3% reported a current wish to conceive. In those with a current desire to conceive, the wish to become pregnant had been present for an average of \( 27.8 \pm 27.1 \) months (median: 24 months, range: 1–120 months, 95th confidence interval 20.2–35.4). In 72.5%, the unfulfilled wish to conceive had been present for one year or longer. Approximately half of the population (41.0%) with a desire to conceive had previously undergone infertility treatment, but no patient was currently undergoing any type of infertility treatment.

Depressive symptomatology (BDI)

Within the total PCOS sample, 50.4% of patients had BDI scores indicating no depression (BDI scores <11), whereas 23.9% presented with scores in the range of mild to moderate depression (BDI scores 11–17), and a remarkable 25.2% of PCOS scored within the range of clinically relevant depression (BDI scores ≥18). The mean BDI depression score was 12.7 ± 10.8, and this was significantly greater than scores reported for the representative German normative population without any psychiatric diagnosis (mean 6.45 ± 5.2, \( P < 0.001 \)) (Hautzinger et al., 1995). PCOS patients’ mean BDI score was comparable to the published normative population of psychosomatic patients consisting primarily of patients with various pain syndromes (mean 11.4 ± 7.6), but was significantly lower than the published data of patients diagnosed with depression at psychiatric clinics prior to initiation of treatment (mean 23.7 ± 9.8, \( P < 0.01 \)) (Hautzinger et al., 1995).

Addressing possible differences between PCOS women with and without a current unfulfilled wish to conceive with regard to depressive symptomatology, the results documented no significant differences in mean BDI scores (11.7 ± 9.2 with unfulfilled wish to conceive versus 14.25 ± 11.1). Similarly, the percentage of patients with an unfulfilled wish to conceive in the various BDI categories did not differ significantly, i.e. no depressive symptoms (50.9 versus 48.9% in patients with no desire for a child), mild to moderate depressive symptoms (28.3 versus 22.4%), clinically relevant depression (20.8 versus 28.6%) (chi-square test). Furthermore, a longer duration of infertility had no visible effect given that no differences between PCOS with an unfulfilled wish to conceive for more versus <12 months were observed (data not shown).

Health-related quality-of-life (SF-36)

With regard to health-related quality-of-life, measured with the SF-36, the total sample of PCOS had significantly lower scores on all SF-36 scales, indicating markedly reduced quality-of-life compared with the published German normative data for females of this age group (Bullinger and Kirchberger, 1998) (all \( P < 0.001 \), Fig. 1). However, no differences were observed on any scale between PCOS with and without a current wish to conceive (Fig. 1) or in those with an unfulfilled wish to conceive for >12 months (data not shown).

Figure 1: Health-related quality-of-life, measured with the German version of the SF-36, in PCOS patients with infertility and PCOS patients without infertility, compared with the German female reference population, i.e. the published German normative data (Bullinger and Kirchberger, 1998). The entire sample of PCOS patients had significantly lower scores, indicating reduced quality-of-life, on all scales (PHYS, physical function; ROLE, physical role function, PAIN, bodily pain; HEAL, general health perception; VITA, vitality; SOCI, social function; EMOT, emotional role function; MENT, mental health) compared with the German norm (*all \( P < 0.001 \) following alpha adjustment), irrespective of the presence of infertility. No group differences were observed between PCOS patients with, and PCOS patients without, infertility. All data are shown as mean ± SEM.
significant.) The total sample of PCOS patients had significantly higher scores, indicating greater psychological distress, on both global indices \((**P<0.001\text{ versus German norm})\), but no differences were found between PCOS patients with and without infertility. All data are shown as mean ± SEM. GSI, global severity index; PSDI, positive symptom distress index.

**Emotional distress (SCL-90-R)**

Consistent with reduced quality-of-life and increased depression in the total PCOS sample, the whole PCOS patient population also demonstrated significantly more pronounced emotional distress, assessed with the scales of the SCL-90-R, compared with the published female German norm (Franke, 1995). PCOS patients demonstrated significantly increased scores on the primary scales somatization, obsessive-compulsive, interpersonal sensitivity and depression (all \(P<0.001\) following alpha adjustment, data not shown) compared with the norm, indicating greater distress. Accordingly, PCOS patients’ GSI (Fig. 2), PSDI (Fig. 2) and PST (data not shown) were all significantly elevated compared with the normative data, indicating increased psychological disturbances (all \(P<0.001\) following alpha adjustment). However, no significant differences in PCOS patients with and without an unfulfilled wish to conceive were found for any of the SCL-90-R scales, and no effect for the duration of infertility was observed. In the total PCOS sample, 26.8% of PCOS had GSI scores \(\geq 63\) indicating a probable psychiatric disorder, without differences between the group with unfulfilled desire to conceive \((20.7%\text{ of patients with a GSI score} \geq 63)\) and the group of patients without the current desire to conceive \((33.3%)\).

**Psychological and motivational aspects associated with the desire to conceive (FKW)**

Analysis of the FKW questionnaires was carried out by initially comparing scale scores of women with an unfulfilled wish to conceive and those without the present wish to conceive. Expectedly, women with the desire to conceive had significantly greater scores on Scale 1 ‘enhancement of self-esteem and emotional stabilization’ \((51.5±7.1\text{ versus } 42.6±11.2, \ P<0.001)\), lower scores on Scale 2 ‘ambivalence’ \((14.2±4.6\text{ versus } 17.8±5.5, \ P<0.001)\) and a greater total score \((79.4±9.9\text{ versus } 66.6±14.3, \ P<0.001)\). Exclusion of women without a partner did not affect these results.

Subsequently, PCOS women with an unfulfilled wish to conceive were compared with the normative population of infertile women. Interestingly, PCOS women had significantly higher scores than the norm on Scale 1 (‘enhancement of self-esteem and emotional stabilization’: \(50.8±6.9\text{ versus } 47.5±8.8, \ P<0.001\)) as well as a significantly greater total score \((78.7±9.7\text{ versus } 75.5±10.43, \ P<0.05)\), indicating greater priority of the wish for a child. No differences between PCOS and the norm were observed for Scale 2 ‘ambivalence’ \((14.3±4.5\text{ versus } 13.9±3.99)\).

PCOS women with an unfulfilled wish to conceive for \(\geq 12\) months demonstrated significantly lower scores on Scale 1 than PCOS women who reported a desire to conceive of \(<1\) year \((30.0±3.5\text{ versus } 32.0±1.6, \ P<0.01)\), higher

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### Table II. Frequency of sexual intercourse, sexual self-worth and sexual satisfaction in women with PCOS and controls.

<table>
<thead>
<tr>
<th></th>
<th>PCOS with infertility ((n=57))</th>
<th>PCOS without infertility ((n=55))</th>
<th>(P)-value*</th>
<th>Controls+ ((n=50))</th>
</tr>
</thead>
<tbody>
<tr>
<td>Frequency of sexual intercourse [past 4 weeks, % ((n)]]</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0 times</td>
<td>10.5 (6)</td>
<td>52.7 (29)</td>
<td>&lt;0.001</td>
<td>22 (11)</td>
</tr>
<tr>
<td>1–5 times</td>
<td>45.6 (26)</td>
<td>30.9 (17)</td>
<td>26 (13)</td>
<td></td>
</tr>
<tr>
<td>5–10 times</td>
<td>35.1 (20)</td>
<td>10.9 (6)</td>
<td>22 (11)</td>
<td></td>
</tr>
<tr>
<td>&gt;10 times</td>
<td>8.8 (5)</td>
<td>5.4 (3)</td>
<td>10 (5)</td>
<td></td>
</tr>
<tr>
<td>During the past four weeks [mean (SD)]</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How satisfied were you with your sex life?</td>
<td>47.7 (29.7)</td>
<td>37.9 (35.7)</td>
<td>NS</td>
<td>73.8 (27.4)</td>
</tr>
<tr>
<td>How many sexual thoughts and fantasies did you have?</td>
<td>51.2 (29.0)</td>
<td>51.3 (28.1)</td>
<td>NS</td>
<td>58.0 (28.7)</td>
</tr>
<tr>
<td>How important is a satisfying sex life for you?</td>
<td>79.5 (20.2)</td>
<td>75.8 (20.6)</td>
<td>NS</td>
<td>76.3 (24.1)</td>
</tr>
<tr>
<td>In general [mean (SD)]</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you find yourself sexually attractive?</td>
<td>31.9 (27.7)</td>
<td>33.3 (28.8)</td>
<td>NS</td>
<td>58.5 (29.3)</td>
</tr>
<tr>
<td>How much does excessive body hair impact your sexuality?</td>
<td>32.7 (32.6)</td>
<td>47.3 (42.1)</td>
<td>(P&lt;0.05)</td>
<td>12.2 (33.3)</td>
</tr>
<tr>
<td>How often do you experience pain during intercourse?</td>
<td>17.1 (23.4)</td>
<td>28.6 (31.2)</td>
<td>(P&lt;0.05)</td>
<td>15.8 (23.8)</td>
</tr>
<tr>
<td>Does your appearance make it difficult to make social contacts?</td>
<td>23.2 (25.5)</td>
<td>39.5 (32.4)</td>
<td>(P&lt;0.01)</td>
<td>12.7 (24.5)</td>
</tr>
</tbody>
</table>

*\(P\)-values are the result of chi-square test (frequency of intercourse) or independent samples t-tests (VAS scales); †Given that normative data for these scales are not available, shown here are data from \(n=50\) healthy females previously recruited by our group, presented in an earlier publication (Elsenbruch et al., 2003) as reference values. Since statistical comparisons between these healthy controls and PCOS women were previously published, they were not used for statistical analyses herein; ‡assessed with 100 mm VAS (minimum: ‘not at all’ =0-mm, maximum: ‘very much/very often’ = 100 mm); shown as mean ± SD. NS, not significant.
and accordingly a significantly lower total score (77.2 ± 10.4 versus 83.7 ± 4.7, P < 0.01).

Sexual self-worth and satisfaction (VAS scales)
As one important area of quality-of-life not addressed in the validated questionnaires presented above, sexual satisfaction was assessed in patients with and without the present wish to conceive using VAS (Table II). Compared with PCOS patients without the desire for a child, PCOS patients with the present wish to conceive reported a significantly higher frequency of sexual intercourse in the past month. No differences between PCOS groups were observed regarding the amount of sexual thoughts and fantasies, the importance of a satisfying sex life, the actual satisfaction with the sex life or with the perceived sexual attractiveness. However, PCOS women without the current desire for a child indicated to have experienced more pain during sexual intercourse, to experience a more negative effect of excessive body hair on sexuality and to perceive more difficulties forming social contacts due to changes in outer appearance (Table II). For the interpretation of these data it is relevant to note that significantly more PCOS women with the current wish to conceive were in a relationship (98.3% married or with a steady partner), compared with women without the present wish for a child (54.4%, see Table I). Therefore, we conducted supplementary analyses including only patients with a partner, and no differences between groups according to the presence versus absence of infertility remained (data not shown).

Finally, given the absence of published normative data for the VAS scales used and the fact that we did not recruit a non-PCOS control group for this study, we show data from a previously published (Elsenbruch et al., 2003) healthy female control group as reference values (Table II). Although we abstained from using the data for statistical comparisons given the prior publication, inspection of the values supports our previously published findings from an earlier PCOS cohort (Elsenbruch et al., 2003). As a group, PCOS women (irrespective of infertility) again indicated lower satisfaction with their sex life, lower perception of their own sexual attractiveness and more perceived difficulties making social contacts due to outer appearance.

Discussion
Given the frequency of infertility in PCOS patients, we addressed the psychological consequences of infertility and infertility-associated worries and fears in a sample of German PCOS patients. Approximately half (51.3%) of our sample of consecutive PCOS women seeking treatment at our specialized endocrine clinic reported a current wish to conceive. Of those, the majority (72.5%) had been unsuccessfully trying to conceive for 1 year or longer, and 41% had previously undergone some form of infertility treatment. Even if not currently trying to conceive, a large percentage of the entire sample (76.1%) expressed worries about remaining childless in the future. These results underscore the awareness for and relevance of this issue in women with PCOS. Clearly, the vast majority of women with PCOS are aware of possible infertility, and the majority report anxiety about this, irrespective of current attempts to conceive. This finding is relevant, particularly in connection with our observation that a current desire to conceive is greatly determined by sociodemographic factors including partnership status, which appear to have a strong and possibly inseparable influence on psychological well-being. Given evidence that infertility from various causes can cause psychosocial distress (Cwikel et al., 2004; Chachamovich et al., 2007; Cousineau and Domar, 2007), we aimed to address the hypothesis that PCOS women with a current unfulfilled wish to conceive would experience more psychological problems than PCOS patients without the present desire to conceive. Against our expectation, there were no differences in depressive symptoms, quality-of-life, or emotional distress between PCOS patients with, and PCOS patients without, the current desire to conceive. Instead, the entire PCOS cohort (irrespective of infertility) presented with pronounced limitations in psychosocial and emotional functioning when compared with the published normative data from German women of similar age. This apparent lack of specific psychological effects of infertility is consistent with data we reported earlier (Elsenbruch et al., 2003; Hahn et al., 2005a), as well as with findings from another group which applied similar questionnaires in a large sample of German patients with infertility from various causes (Wischmann et al., 2001). Furthermore, it was recently reported that fertile PCOS women had significantly higher depression scores and greater body dissatisfaction compared with the women with infertility from causes other than PCOS, which would also support the contribution of PCOS factors other than infertility (Himelein and Thatcher, 2006a). Together, these findings suggest that current infertility does not appear to represent a single, prominent factor which would explain reduced quality-of-life and increased emotional distress in PCOS. It rather appears that relative to other features of the diagnosis, particularly obesity and hirsutism, which are known to strongly reduce emotional well-being and quality-of-life, infertility does not (further) impact psychosocial functioning to a significant extent.

However, our data must be interpreted with caution, and any conclusion that infertility is irrelevant for psychological well-being in PCOS would be premature. Indeed, several studies do report correlations between psychological well-being and infertility (Trent et al., 2003; Elsenbruch et al., 2006; Barnard et al., 2007), including a study showing that concerns about infertility were associated with reductions in quality-of-life in adolescent girls with PCOS (Trent et al., 2003). In explaining these disparities, it is important to consider that one limitation of our approach consists of the inclusion of PCOS women reporting an anxiety about remain childless (but no current desire to conceive) in the comparison group. This may have led to misclassification and hence failure to detect an effect of infertility and/or infertility-related concerns on psychological variables. Furthermore, our dataset did not lend itself to a meaningful analysis of potential psychological consequences of previous failure to undergo infertility treatment in a subgroup of patients as a separate factor. We
did conduct adjunct analyses, including a comparison of the small number of PCOS women who did not express anxiety about remaining childless and the remainder of the sample, as well as regression analyses to predict depression and quality-of-life scores using infertility-related items. However, these analyses did not reveal any effects which would change the interpretation of the results from the primary analyses (data not shown).

Whereas PCOS with and without infertility did not differ in psychological well-being or quality-of-life, we did observe several group differences in several specific aspects of sexual satisfaction and self-worth. PCOS women without a wish to conceive reported fewer sexual contacts, more pain during intercourse, a greater negative impact of excessive body hair on sexuality, as well as greater difficulties forming social contacts due to changes in outer appearance. However, these findings are likely explained by the fact that the percentage of women in a steady relationship was expectedly much lower in the group of women with no present desire for child (i.e. 54.4%) compared with the group of patients actively trying to conceive (98.3%).

Indeed, group differences disappeared when follow-up analyses were carried out after excluding women without a steady partner. However, as a group, PCOS women indicated lower satisfaction with their sex life, lower perception of their own sexual attractiveness and more perceived difficulties making social contacts due to outer appearance when compared with the healthy women, irrespective of the presence or absence of infertility (Elsenbruch et al., 2003). Hence, whereas reduced sexual self-worth is clearly an important facet of PCOS, infertility-related differences within the PCOS population in sexual activity and the experience of sexuality appear to be largely determined by partnership status, which is also one of the determinants for the presence or absence of the current desire for a child.

The second aim of this study was to address the expectations and apprehensions in connection with pregnancy, birth and parenthood in PCOS women with an unfulfilled wish to conceive using a specific, validated questionnaire on the desire for a child (FKW) (Holzle and Wirtz, 2001) in comparison with the published normative data from a sample of women with defined infertility presenting to infertility clinics following several years of prior infertility treatment. PCOS women had a significantly greater total FKW score as well as a significantly greater score on the scale ‘enhancement of self-esteem and emotional stabilization’ compared with the female normative data. These results indicate that in the PCOS patients, the current wish for a child is of greater priority, and that their self-esteem and emotional stability depend to a greater extent on the ability to conceive a child. These findings are consistent with the notion that PCOS patients feel stigmatized and are sometimes regarded as lacking femininity (Kitzinger and Willmott, 2002), and with evidence that girls with PCOS had greater concerns about infertility than healthy peers (Trent et al., 2003). Unexpectedly, the psychological consequences of the unfulfilled desire to conceive appeared to be more pronounced in women with a desire to conceive of <1 year compared with those with a longer history of unsuccessful conception. The most likely explanation for this finding is that there exist coping mechanisms which ‘buffer’ the experience of infertility given time. However, in light of the lack of studies on coping mechanisms in PCOS, this interpretation remains speculative, and should be addressed in future studies.

Taken together, these data support that (i) infertility or fear of infertility has specific psychological implications in PCOS. In PCOS, the current unfulfilled desire for a child is of greater priority compared with infertile patient controls at reproductive clinics. Furthermore, in PCOS women, self-esteem and emotional stability depend to a greater extent on the ability to conceive a child than in this patient comparison group. (ii) As a group, PCOS women are at increased risk for depression, markedly reduced quality-of-life and low sexual self-worth. The relevance of infertility in causing these psychological problems ultimately remains unclear. Although the present findings do not support a major role of infertility alone beyond the role of the clinical, sociodemographic and cultural factors associated with PCOS, methodological limitations call for future studies. (iii) Given elevated depression scores in approximately half of the PCOS women in this German sample, and similarly alarming depression rates in samples from other countries (Barnard et al., 2007; Hollinrake et al., 2007), it is of utmost importance that clinicians recognize that the diagnosis of PCOS constitutes a major risk factor for psychosocial and emotional problems. However, clinicians and researchers should expect large inter-individual differences between patients regarding which factor(s) contribute to poor psychosocial adjustment. Not only do patients present with different clinical symptom constellations, but also with highly variable psychosocial situations and cultural backgrounds, which interact in determining a given individual’s coping resources and psychological adjustment.

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**References**


