



The psychosocial experience of women with PCOS

A case control study

Polycystic ovary syndrome (PCOS) is a common endocrine disorder affecting 5–10% of women.¹ It is characterised by androgenisation and anovulation, with sufferers being at increased risk of metabolic problems such as noninsulin dependent diabetes mellitus and dyslipidaemia. An increased risk of cardiovascular disease is speculated.¹ Clinically, sufferers may experience acne, obesity, hirsutism and/or male pattern baldness.

There is some variation in the definition of PCOS. The National Institute of Health/National Institute of Child Health and Human Development have defined PCOS as:

- hyperandrogenism and/or hyperandrogenaemia
- ovulatory dysfunction, and
- exclusion of related disorders such as hyperprolactinaemia, thyroid disorders, and nonclassic adrenal hyperplasia.²

The above definition is often used for research purposes.

The European Society of Human Reproduction and Embryology and American Society for Reproductive Medicine proposes a diagnosis of PCOS in the presence of any two of the following:

- polycystic ovaries on ultrasound examination
- clinical or biochemical hyperandrogenism
- menstrual dysfunction with anovulation.³

Accordingly, there is variation in clinical diagnosis with gynaecologists being more likely to seek polycystic ovaries (which may be present in normal women) on ultrasound.⁴

Common symptoms of PCOS such as obesity, hirsutism and infertility would seem to influence psychosocial parameters; the psychosocial experience of PCOS patients has drawn some attention in the literature. Patients with PCOS have been found to experience higher levels of depression and overall psychological morbidity.⁵ In addition, there is evidence that they experience lower health related quality of life (HRQoL), in particular in the areas of the health, self and sex.⁶ In one study of HRQoL in the areas of: work, finances, leisure activities, marriage and relationship,

and friends and relatives, PCOS patients did not differ from controls.⁷ Another study found that PCOS patients reported less involvement in family activities.⁸

This study aimed to compare the level of social support and the levels of psychological distress experienced by PCOS patients with those experienced by a control group.

Methods

Data was collected as part of the 2006 Northern Sydney Central Coast Community Health Survey (NSCCH).⁹ Respondents were selected using a two stage sampling process. Interviews were conducted until a large number of respondents was achieved: 1000 for the Central Coast and 1500 for northern Sydney (including Hornsby-Kuring-Gai, North Shore, Ryde and northern beaches).

Cases were defined as having answered in the affirmative to the question: 'Have you ever been told by a doctor or at a hospital that you have polycystic ovary syndrome?' Thirty-four women aged 18–45 years were identified; 559 controls were selected from those who answered 'no' to the above question. Controls were additionally defined as:

- being female
- being 18–45 years of age inclusive
- having reported normal menstrual cycles
- not having reported difficulty conceiving
- not having reported hirsutism
- not having reported scalp hair thinning.

Instruments and measures

Kessler Psychological Distress Scale – 10

The Kessler Psychological Distress Scale (K-10) is a measure of general psychological distress. It consists of 10 questions pertaining to recent symptoms of anxiety and depression (past 4 weeks). Potential scores range from 10–50 with a higher score reflecting a higher level of psychological distress. It is sensitive as a screening instrument for detecting depressive and anxiety states as defined by the DSM-IV.¹⁰ It is less sensitive (but still associates significantly) for other psychological disorders.¹¹ It was included in the

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2000 Australian Health and Wellbeing Survey (AHWS)¹² and the ongoing NSW Population Health Survey. Four categories were used to score the K-10 in the AHWS (*Table 1*).

Social support items

Participants were asked a series of questions relating to their social support and social capital (*Table 2*). Questions were drawn from the Duke Social Support Index (DSSI)¹³ and the NSW Population Health Survey. Neither scale was completely included in the NSCCH community survey.

Data analysis

Participants who answered 'don't know' or 'refused' were excluded from the analysis of the relevant question. Data was analysed using SAS version 9.1 on a Windows XP based PC.

Results

Women with PCOS had a median score one unit higher than the control group (14 vs. 13) using the Wilcoxon 2 sample test, $p=0.03$. This indicates a statistically significant difference in psychological distress. Cases did not differ significantly from controls in their levels of social support (all $p>0.05$) using the Wilcoxon Exact method.

Discussion

This study supports the literature in suggesting that PCOS sufferers have higher levels of psychological distress than controls. The median K-10 score for cases was low, therefore the study may not reflect a clinically significant result. The features which led to participants in the survey being excluded as controls, namely hirsutism, infertility and male pattern baldness are possible confounders; these factors might all be independent causes of psychological distress. The potential contribution of these symptoms to the psychological distress experienced by women with PCOS makes controlling for them difficult. It is possible that

Table 1. Scoring of the K-10 in the 2000 Health and Wellbeing survey

10–15	Low
16–21	Moderate
22–29	High
30–50	Very high

Table 2. Social support questions

How many persons who live within 1 hour travelling time from your home do you feel you can depend on or feel very close to; other than members of your own family?

Potential answers:

- No one
- 1 person
- 2 people
- 3 or more people
- Don't know

Other than at work how many times during the past week did you spend time with someone who does not live with you?

Potential answers:

- Time range: 0–7 times
- Don't know

Other than at work, how many times did you talk to someone – friends, relative or others – on the telephone in the past week (either they called you, or you called them)?

Potential answers:

- Time range: 0–7 times
- Don't know

Other than at work, about how often did you go to meetings of social clubs, religious meetings, or other groups that you belong to in the past week?

Potential answers:

- 1–7 times
- Don't know

In the past 3 months, how often have you helped out any local group or organisation such as a school, scouts and brownies, a sporting club, or hospital as a volunteer, or other organisation?

Potential answers:

- About once a week
- Once every 2–3 weeks
- Once a month or less
- No, not at all
- Don't know

In the past 6 months, how often have you attended a local community event such as a church or school fete, school concert, or a street fair?

Potential answers:

- Three times or more
- Twice
- Once
- Never
- Don't know

Are you an active member of a local organisation, church or club, such a sport, craft, or social club?

- Yes, very active
- Yes, somewhat active
- Yes, a little active
- No, not an active member
- Don't know

the difference in psychological distress may be due only to the presence or absence of one of these symptoms. The association between PCOS caseness and a higher score on the K-10 should be heeded, however, as a potential indicator of the psychological impact of the disease and all its manifestations.

Another limitation was the number of doctor diagnosed PCOS cases in our sample (n=34, 5.7%). This falls within the reported PCOS prevalence of 5–10%,¹ however it is in the lower end of the range. Although the study attempted to address this by excluding participants as controls if they had any hirsutism, amenorrhoea, infertility or male pattern baldness, there may have been some misallocation of cases as controls. Such misallocation may bias results.

Lack of uniformity in diagnostic criteria for PCOS, and reliance of doctor diagnosis for case definition is another weakness. Nonetheless, doctors are more likely to diagnose patients with more severe manifestations of the disease. Reliance in the study on doctor diagnosis may have lent itself to the inclusion of only more severe cases of PCOS.

Taking into account the limitations of the study in assessing levels of social support, our results nonetheless lend support to existing evidence that PCOS does not affect relationships, family, friends and leisure. Although the sample size is small, it is similar to those studies achieving significant results.

Limitations include the absence within the survey of a complete measure for social support necessitating responses to questions be analysed individually. As a result we are left without a complete picture of women's social experience and need to consider the answers to the questions in isolation. Another weakness of the study is the use of questions from the DSSI. The DSSI – although validated for use with older people – is, to our knowledge, unvalidated with younger people. The presence of a previous or known psychological disorder was not excluded in controls, perhaps confounding the results.

Doctor diagnosed PCOS sufferers exhibited higher levels of psychological distress than controls, however they remained in the low range. No difference was found between PCOS patients and controls across a range of indicators of social support. This supports the suggestion

that women with PCOS do not fare worse than controls in terms of relationships, family, friends and leisure.

Implications for general practice

- Women with PCOS may experience higher levels of psychological distress than those without.
- This psychological distress is more likely to be in the lower range.
- Women with PCOS do not fare worse in terms of relationships, family, friends and leisure.

Conflict of interest: none declared.

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