Women with polycystic ovarian syndrome had excess hair, irregular or absent menstruation, and infertility and felt **freakish, abnormal, and not proper women**


**QUESTIONS:** What are the experiences of women with polycystic ovarian syndrome (PCOS)? How do they negotiate their identities as women?

**Design**
Exploratory qualitative design.

**Setting**
United Kingdom.

**Participants**
30 women (mean age 29 y, 80% white) with PCOS recruited through a mailing to members of a national PCOS self help organisation.

**Methods**
Indepth, semistructured, tape recorded interviews were conducted in the women’s homes and lasted 45–90 minutes. The interview schedule was broad based and wide ranging, and was designed to allow women to tell their own stories. The interview schedule had open ended questions with prompts and follow up questions.

Data were transcribed using simple orthographic notation, and analysis relied on organising sections of the data into recurrent themes.

**Main findings**
PCOS was very important in the everyday lives of most participants. Many women talked about the frustration and anger they felt about delays in diagnosis, the lack of information provided by health professionals, and what they experienced as a general unwillingness of health professionals to take their symptoms seriously.

Thematic analysis revealed pervasive reports of feeling **freakish, abnormal, and not proper women**. These feelings were related to 3 symptoms commonly experienced by these women and found to be the most distressing: “excess” facial and body hair growth; irregular, absent, or disrupted menstrual periods; and infertility. Smooth hairless bodies and faces, regular menstruation, and the capacity to bear children were associated with femininity. Thus, these women questioned their ability to be defined as “normal women”: two thirds said they felt “different” or “abnormal”, and 9 women specifically used the term “freaks” to describe their experience of themselves. Women talked repeatedly about wanting to feel like “normal women.”

The social spectre of the “bearded lady” loomed in the experience of many of the women. Women experienced their bodies and especially facial hair as a betrayal of their identities as women, and all of them took steps to remove it. Because of their daily private hair removal, many women found themselves restricted in their movements, unable to take unexpected overnight trips or holidays. Women talked about the separateness that occurred as a result of disrupted or absent menstruation. Regular menses were desirable, as a sign of womanhood and fertility. These women experienced an added burden of secrecy because they felt that revealing their irregular, disrupted, or absent menstruation could lead to scrutiny of their identities as women. The fertility implications of PCOS added to the women’s feelings of freakishness and of not being real women. Despite the pain caused by infertility, several women said that it was relatively easy to disclose this condition compared with the other symptoms of PCOS.

**Conclusions**
Women with polycystic ovarian syndrome felt they were **freakish, abnormal, and not proper women**. These feelings were associated with excess hair growth; irregular, absent, or disrupted menstruation; and infertility symptoms that distanced them from the dominant feminine ideal.
Women with polycystic ovarian syndrome had excess hair, irregular or absent menstruation, and infertility and felt *freakish, abnormal*, and *not proper women*.

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