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.

**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”;

**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.