

# Nurse-led peer support group: experiences of women with polycystic ovary syndrome

Percy, C.A. , Gibbs, T., Potter, L. and Boardman, S.

Author post-print (accepted) deposited in CURVE March 2016

## Original citation & hyperlink:

Percy, C.A. , Gibbs, T., Potter, L. and Boardman, S. (2009) Nurse-led peer support group: experiences of women with polycystic ovary syndrome. *Journal of advanced nursing*, volume 65 (10): 2046-2055.

<http://dx.doi.org/10.1111/j.1365-2648.2009.05061.x>

**Publisher statement:** This is the peer reviewed version of the following article: Percy, C.A. , Gibbs, T., Potter, L. and Boardman, S. (2009) Nurse-led peer support group: experiences of women with polycystic ovary syndrome. *Journal of advanced nursing*, volume 65 (10): 2046-2055, which has been published in final form at <http://dx.doi.org/10.1111/j.1365-2648.2009.05061.x> . This article may be used for non-commercial purposes in accordance With Wiley Terms and Conditions for self-archiving (<http://olabout.wiley.com/WileyCDA/Section/id-820227.html#terms>).

**Copyright © and Moral Rights are retained by the author(s) and/ or other copyright owners. A copy can be downloaded for personal non-commercial research or study, without prior permission or charge. This item cannot be reproduced or quoted extensively from without first obtaining permission in writing from the copyright holder(s). The content must not be changed in any way or sold commercially in any format or medium without the formal permission of the copyright holders.**

**This document is the author's post-print version, incorporating any revisions agreed during the peer-review process. Some differences between the published version and this version may remain and you are advised to consult the published version if you wish to cite from it.**

**CURVE is the Institutional Repository for Coventry University**  
<http://curve.coventry.ac.uk/open>

**Title: Nurse-led peer support group: experiences of women with polycystic ovary syndrome**

First (and corresponding) author  
Carol A Percy PhD, CPsychol.  
Senior Lecturer, Psychology,  
Coventry University, CV1 5FB, United Kingdom  
Email [c.percy@coventry.ac.uk](mailto:c.percy@coventry.ac.uk)

Second author  
Tineke Gibbs  
Polycystic Ovary Syndrome Nurse Specialist,  
South Warwickshire Hospital NHS Trust. Warwick  
CV34 5BW, United Kingdom

Third author  
Lynne Potter BSc  
Research Assistant,  
Coventry University, CV1 5FB, United Kingdom

Fourth author  
Shirine Boardman MRCP  
Consultant Physician and Endocrinologist,  
South Warwickshire Hospitals NHS Trust. Warwick. United Kingdom

**ACKNOWLEDGEMENT**

We would like to thank the women who participated in the study, and the editor and anonymous reviewers who gave constructive feedback on the first draft of this paper.

## **ABSTRACT**

### **Aim**

This paper is a report of a study to explore the experiences of women with polycystic ovary syndrome attending a nurse-led support group.

### **Background**

Polycystic ovary syndrome is a common chronic endocrine disorder associated with high levels of psychological distress. It has been argued that healthcare providers should regularly review the psychological health of women with polycystic ovary syndrome, and that nurses can help women to adjust to the condition by providing education and support. Little is known about the means of providing social support for women with the syndrome, or of any benefits for patients.

### **Method**

Qualitative interviews were conducted with 13 female patients in 2006. The patients attended a support group at a public hospital in the United Kingdom. The data were analysed using deductive and inductive thematic analysis.

### **Findings**

The group provided both socio-emotional and informational social support. Participants reported that attending the group helped to reduce isolation, and provided an opportunity for social comparison and accessible and personally relevant information. Participants described the group as having had a major personal impact for them. They reported feeling empowered and direct positive effects on their self-management behaviours.

## Experiences of women with PCOS attending nurse-led peer support group

### Conclusion

Social support appears to be a key factor mediating the psychosocial impact in women with polycystic ovary syndrome. Healthcare providers should consider running such support groups or referring patients to them. Providing social support may alleviate distress and improve self-management.

### Keywords

polycystic ovary syndrome, psychosocial aspects, self-management, social support, nurse-led, peer-support

## **SUMMARY STATEMENT**

### **What is already known about this topic**

- Polycystic ovary syndrome is a common chronic endocrine condition in women of reproductive age and is associated with high levels of psychosocial distress.
- Social support may enhance health outcomes, such as self-management and health-related quality of life, in a range of long-term conditions.
- Nurses may offer social support interventions for patients with polycystic ovary syndrome, but little is known about the content of such interventions or patients' experiences of using them.

### **What this paper adds**

- A nurse-led peer support group for women with polycystic ovary syndrome offers opportunities for social comparison, which help to reduce distressing feelings of social isolation and stigma.
- More research is needed to identify social support needs in polycystic ovary syndrome, and the effects of interventions on health outcomes such as psychosocial distress and self-management.

### **Implications for practice**

### Experiences of women with PCOS attending nurse-led peer support group

- Nurses working with women with polycystic ovary syndrome should consider providing peer support groups designed to meet patients' socio-emotional and informational support needs.
  
- Education for nurses working with women with polycystic ovary syndrome might usefully include skills development in facilitating support groups.
  
- With appropriate development of their research skills, nurses might design and evaluate their own psychosocial interventions.

## **INTRODUCTION**

Polycystic ovary syndrome (PCOS) is a common endocrine disorder in women of reproductive age (Azziz et al. 2004, Asuncion et al. 2000). Estimates of its prevalence worldwide range from 6-10% (Dasgupta and Mohan 2008, Carmina and Azziz 2006). The condition is characterized by hyperandrogenism, anovulation and insulin resistance. Consequently, women with PCOS may experience absent, irregular, heavy or painful periods, subfertility, miscarriage, obesity, acne, alopecia and/or hirsutism (Chang et al. 2004, Hart and Norman 2006). They also appear to have an increased risk of developing type 2 diabetes, endometrial cancer, stroke and cardiovascular disease (Cattrall and Healy 2004, Wild et al. 2000, Talbott et al. 2007).

## **BACKGROUND**

Understanding psychosocial aspects of PCOS is important for two reasons: first, so that interventions might be offered to ameliorate the any psychosocial distress patients may experience, and, second, so that interventions might be offered to engage patients in appropriate self-management of their condition.

### **Psychosocial distress in PCOS**

There is a growing body of evidence indicating that PCOS affects women psychosocially as well as physically (Snyder 2006). PCOS is associated with psychosocial distress, including depression, anxiety, body dissatisfaction, eating disorders, diminished sexual satisfaction and lower health related quality of life (HRQoL) (Barnard et al. 2007, Himelein and Thatcher

## Experiences of women with PCOS attending nurse-led peer support group

2006). One study has shown that not only do women with PCOS have poorer HRQoL than the general population, but that its psychosocial impact is worse than that of asthma, epilepsy, diabetes, back pain, arthritis and coronary heart disease (Coffey et al. 2006).

It has been argued that healthcare providers should regularly review the psychological health of women with PCOS (Barnard et al. 2007), and that nurses can help women to adjust to the condition by providing education and support (Snyder 2006). However, there are no published studies to date that describe or evaluate such interventions.

### **Self-management in PCOS**

In addition to coping with symptoms and undergoing medical and/or surgical investigations and interventions, patients are often advised to make changes to their lifestyles. Modification of diet and exercise are important in managing PCOS and in mediating associated long-term health risks (Lord and Norman 2006, Hoeger 2006, Norman et al. 2002). Little is known about what interventions may enhance self-management in PCOS, or how they might work.

### **Adopting a biopsychosocial perspective on PCOS**

Research assessing the impact of PCOS on health-related quality of life has gone some way to understanding how subjective wellbeing may be affected. However, most of this research focuses primarily on the way PCOS symptoms affect quality of life. This offers a limited understanding of the psychosocial impact of the condition.



## Experiences of women with PCOS attending nurse-led peer support group

The biopsychosocial model (Engel 1977, Shaver 1985) assumes that there are multiple, multidirectional relationships between biological processes such as endocrine disturbances and anatomical changes, psychological processes such as the subjective experience of symptoms, social processes such as performance of gender roles, and interactions with healthcare services. From this perspective, women's subjective experience of PCOS is more than just the product of symptoms, and one potential mediating factor is women's perceptions of social support.

### **Social support and health outcomes**

There is no published evidence on social support in PCOS, but studies on its role in other women's health issues indicate positive effects. For example, social support can mediate pregnancy outcomes (Orr 2004), and it has also been found to be a mediator of coping and psychological distress in involuntary childlessness (Lechner et al. 2007, Lechner et al. 2006). Social support is positively associated with long-term disease self-management, especially diabetes and dietary change (Gallant 2003, Ford et al. 1998a, Ford et al. 1998b), and enhances perceived control and self-efficacy in weight management (Wolfe 2004).

There are many potential *sources* of social support, including friends and family, one-to-one support from peers or healthcare professionals and group support, with or without professional input. Participation in such groups has been found to be associated with improved knowledge and psychosocial functioning in type 2 diabetes (van Dam et al. 2005). Group-based social support has also been associated with improved psychosocial status in cancer (Taylor et al. 2007b). It has been argued that for some conditions, such as cancer, peer

## Experiences of women with PCOS attending nurse-led peer support group

support groups offer a unique form of social support that does not rely on healthcare professionals for leadership (Ussher et al. 2006a).

It seems likely that different types of support group, whether professional or peer-led, structured or unstructured, and directive or patient-centred, may provide different types of social support (Gottlieb 2000). There are a range of ways in which researchers have classified social support. These typically include *socio-emotional* support, such as companionship, emotional expression, empathy, sympathy; *instrumental/tangible* support, such as practical help and resources; and *informational* support, such as provision of factual information and/or accounts of personal experiences against which the individual can compare themselves (Ostberg and Lennartsson 2007). This last process, referred to as social comparison, has been identified as a key factor in the success of cancer support groups (Taylor et al. 2007a), and is one that merits further investigation.

It appears that it may be the subjective *perception* of support that contributes most to positive health outcomes (Haber et al. 2007). It is therefore worth studying the subjective *experience* of support group membership and the *process* of social support, through the eyes of group participants themselves. There are, to date, no published studies of patients' perceptions of social support in PCOS.

## THE STUDY

### Aim

## Experiences of women with PCOS attending nurse-led peer support group

The aim of the study was to explore the experiences of women with PCOS, attending a nurse-led support group.

The specific research questions were:

1. What do women hope for and expect from a PCOS support group?
2. What is women's experience of attending a PCOS support group?
3. What are women's suggestions for improving a PCOS support group?
4. What functions might a PCOS support group have for women who use it?

### **Design**

The study was exploratory and qualitative, employing semi-structured interviews and thematic analysis. The interviews took place in 2006.

### **Participants**

The data in this paper relate to women's descriptions of a nurse-led PCOS support group. This group was led by a nurse specialising in PCOS, with support from an endocrinologist. Women's experiences of attending the support group were elicited as part of a broader exploratory evaluation of the services for PCOS provided by a public (National Health Service) general hospital in United Kingdom. The services consisted of a PCOS clinic and support group. The larger study was qualitative and investigated the perceived healthcare needs and experiences of women who used PCOS services at the hospital.

## Experiences of women with PCOS attending nurse-led peer support group

The support group was originally set up to provide support for women attending the PCOS clinic, and to reflect the psychosocial needs of the clinic population. An audit of HRQoL in the this population suggests that patients using this service are a diverse group, typically troubled by the following aspects of PCOS (in descending order of adverse impact): weight, body hair, emotions, menstrual problems and infertility (Percy et al. 2007).

The support group met monthly, and was open to women and girls with PCOS and accompanying friends/relatives. Each meeting was organised around an identified theme, such as menstruation, fertility, weight issues or skin problems. A typical meeting consisted of a talk by an invited expert speaker, for example a dermatologist, endocrinologist, gynaecologist, or dietician, followed by a question and answer session, plus unstructured group discussion. The group was open to women who were not patients of the clinic, for example those receiving treatment at other hospitals in the region. The numbers attending meetings varied, and women could choose to attend according to the advertised speaker or topics or their other commitments.

As part of the larger evaluation of services, women attending the PCOS clinic in a two-month period were invited to participate (N=30). The invitation made it clear that interviews would be conducted by a researcher from the university, who was not a member of staff at the hospital. Ten patients opted in to the broader evaluation study, and all ten were interviewed. Nine of these women had used the PCOS support group and were included in the sample for the current study. All women attending the support group in a further two-month period were invited to participate (N=23). Four of these women, who were not patients of the PCOS clinic, contacted the researcher to opt in to the study, and all four were interviewed and their data included in the study. The sample size was comparable to that of other qualitative studies

## Experiences of women with PCOS attending nurse-led peer support group

in which researchers have conducted a preliminary investigation of a phenomenon that has not previously been investigated.

Because the PCOS service as a whole is comparatively small, and because we wanted participants to feel confident that they could speak openly about their experiences, whether positive or negative, limitations were imposed on the individual data collected. To maintain confidentiality, no record was kept of which individual patients had been invited to participate, and clinic staff were not aware of which patients opted in to the study. A commitment was also made that quotations from individual participants would be referred to only by numbers, and that these would not be linked individually to demographic information, such as age or ethnicity, that might render individuals identifiable. We are able therefore only to provide a broad description of these characteristics for the sample as whole. Participants' ages ranged from early 20s to mid-40s. All but one of the participants were of white European ethnic origin. The remaining participant was of South Asian ethnic origin. The length of time participants had been attending the support group for ranged from two months to two years although, as indicated earlier, attendance was episodic.

### **Data collection**

The data were collected by the first author, an academic health psychologist, who was not involved in the patients' care. Semi-structured, face-to-face interviews with individual participants were conducted in a quiet location of their choice. Most elected to be interviewed in their own homes, while others chose a quiet room within the hospital. With participants' informed consent, the interviews were audio-recorded and transcribed verbatim by the third author.

## Experiences of women with PCOS attending nurse-led peer support group

The interview guide consisted of questions on the following topics:

1. Prior and current experience of PCOS, for example: When did you first experience problems? What did you do? Is there any aspect of PCOS that you are most concerned about now?
2. Expectations and aspirations for PCOS services, for example: What were you expecting the clinic to be like? What were you hoping to get from the clinic? What were you expecting the support group to be like? What were you hoping to get from the support group?
3. Experience of PCOS services, for example: What has the clinic been like? What has the support group been like?
4. Suggestions for improving services, for example: If you had any advice to the service providers on how to improve the PCOS clinic or support group, what would that be?

### **Ethical considerations**

The study was approved by the appropriate research ethics committee. Participants were recruited by invitation as described above and gave written informed consent. They were told that their personal data would be confidential to the two members of the research team, who were neither employed by the hospital nor involved in their healthcare. It was made clear that only anonymised quotations from interviews would be available to members of the team who were involved in their healthcare, and in any reports written of the study. Participants

Experiences of women with PCOS attending nurse-led peer support group

were given standard debriefing packs produced by a national PCOS charity: Verity; these contained a leaflet about PCOS and sources of support,.

### **Data analysis**

The first author undertook the preliminary data analysis by reading and re-reading the transcripts. She then conducted a systematic thematic analysis, using a combination of deductive and inductive techniques. Thematic analysis lends itself to this type of design, as it is a flexible method to identify themes in qualitative data, which may allow for both an inductive or data-driven element to the analysis, as well as a deductive element in which data are used to test theory or address specific research questions (Braun and Clarke 2006).

In the first, deductive, stage of analysis, the first author selected all sections of transcript that referred to the support group or experience of attending it. All such sections were coded inductively, following the principles of interpretive phenomenological analysis (Smith and Osborn 2003). This involved attending in detail to the characteristics of experience being described by participants, for example finding out about other people in the same position, being worried about skin flare-ups, hoping that there might be others in the group with the same problem. Coding consisted of creating a short phrase that captured each description. These descriptive codes were compared across interviews to identify common themes, such as 'reducing the sense of isolation and difference', and 'being able to help others'. The next stage of analysis moved back to a deductive approach, in that it related themes that had been developed inductively to the original research questions for the study.

## **Rigour**

The following steps were taken to ensure the rigour of the analysis. The first author engaged in a process of constant comparison between the themes derived from the data and the raw data themselves. As an external check on rigour, the third author compared the analysis with the raw data as she had transcribed it. To provide evidence that the data extracts presented represent the range of participants' responses, each of the quotations discussed below is accompanied by the reference number of the individual interview from which it was drawn.

## **FINDINGS**

Table 1 is a thematic map of the analysis, giving an overview of the main themes. The key themes that identified were hopes and expectations about the group prior to attendance, functions served by the group and the personal impact of attending. Criticisms made were accompanied by suggestions for improving the way the group operated.

### **Expectations and hopes**

Participants described a mixture of hopes, expectations, fears and curiosity before attending the support group. They described what they had hoped to gain from it, which included both information about PCOS and the chance to meet others who might have similar problems:

Participant 1[P1] ... finding out a bit more about sort of different types of treatment available, meeting and seeing other people and hearing what they had gone through.



## Experiences of women with PCOS attending nurse-led peer support group

P2: At the time I had a lot of worry about my skin, I thought it was flaring up ... I was hoping that a few of the group ... had similar skin stuff going on.

Some participants had an image in their minds of what the group would be like, while others did not know what to expect:

P3: .In my mind I kept having this thing, this circle thing where everybody sat in a circle [laughs] and you have to say “my name is...”

Several participants described feeling very nervous before attending their first meeting:

P4: The meeting was something about seven or quarter past seven. And because of the job I do, I was there for like ten past six... So I sat there, I smoked about 20 fags [cigarettes] with nerves.

The stereotypical image of a group sitting in a circle was rather off-putting to some participants, but most were relieved to find that the group did not force personal disclosures:

P5: It was my first time, I thought “I don’t want to kind of, get up there and (talk)”... that was my biggest fear... but ‘cos there wasn’t many other women there, I suppose I could choose to speak to other women there, really.

### **Positive functions of the support group**

## Experiences of women with PCOS attending nurse-led peer support group

### *Socio-emotional function*

Of the positive comments made about the support group, many referred to its socio-emotional value. One of the fundamental benefits of the group was in reducing participants' sense of isolation and difference. This was mentioned frequently in interviews:

P7: It's really interesting to find out so many people there are. I remember texting my mum and saying, "Yep I'm in the right room; there's a lot of hairy big women here!" (laughs) that's me, that's my group!

P8: You find out there's other people in your situation as well. You're not alone. I didn't realise how many women had the same problem.

P1: Just to sit in a room with 30 odd other people ... to hear people say, "I've had to have laser surgery because of the hair I've got"... it just makes you feel more sort of normal, and "Thank God for that. I'm not a complete freak", which is how it feels sometimes.

Some participants used the group for social comparison, while some compared themselves with others who they felt were worse off:

P9: I think it's also nice to know that there are many people who have the same or worse, probably worse problems, people who are struggling to have babies for example, or people who are struggling to lose weight. And I don't have this problem so I thought, "I'm even lucky compared to them"

## Experiences of women with PCOS attending nurse-led peer support group

Participants also made upward social comparisons and used other women who had success stories as positive or inspirational role models:

P10: The one that I thought was particularly good was the woman who came along and said, "I had this patient who had been incredibly fat and unable to do anything about" and then of course revealed that it was her. That was marvellous.

They described the atmosphere of the group as very positive and supportive:

P10: People aren't reluctant to talk about their symptoms or what they have, and I would imagine that most people in their general life don't go around saying, "I've got a terrible facial hair problem", whereas in that room they feel that they're able to talk about that.

One woman said that she wished there had been a support group available when she was younger and first had problems which turned out to be PCOS:

P11: It felt as though you'd got nobody to talk to. It wasn't something that was recognised in my time. And with it being quite a personal thing, with regards to talk about periods, and this that and the other - it's not something you would speak about.

In addition to benefits for themselves, some participants also valued the opportunity the group presented to help other women with PCOS:

## Experiences of women with PCOS attending nurse-led peer support group

P8: Once they started having the support group, I couldn't believe how many people ... I've actually helped my customers, and I've actually helped my friend who's got polycystic ovaries ... I'm helping other people, which is good.

### *Informational function*

In addition to the socio-emotional functions already discussed, participants also cited information as one of the key functions of the group. This was true for both recently diagnosed patients and those who had been undergoing treatment for a long time:

P12: It was really lovely, actually, when I came to the support group for the first time, and it all started to, the fog just cleared a bit ... I feel like, the vast majority of my medical knowledge about PCOS and the demystifying of it all has come from the support group.

Participants valued the range of topics offered by speakers and being able to attend meetings that offered personally relevant information:

P9: I like the fact that there are different specialists every time. Like, one time they talk about periods and one time they talk about hair. Then they talk about hair loss and being overweight, dieting. I like that it's mixed, gives you a variety of information. ...

## Experiences of women with PCOS attending nurse-led peer support group

Some women emphasised the accessibility of both the information and the specialist speakers:

P10 It's all about information, and information that's presented in an accessible fashion.

They valued the opportunity to ask questions of speakers and the staff running the group.

P3: You know that if you wanted to ask something, you could.

The group was described as a useful way to find out about treatment options:

P1: I'd never heard of things like metformin [insulin sensitising medication] ... when I went to the very first one, but there were certainly different treatments that they talked about that I hadn't heard of, so that was quite useful ... I've definitely learned things from them.

In some cases, meetings offered new information, especially about diet and lifestyle, while for others they helped to consolidate existing knowledge:

P12: They had actually a session on GI [glycaemic index] food ... by that time I'd actually read quite a lot and did know quite a lot about that ... That was from the preceding meetings they'd had somebody talking about, talking about insulin levels, and rise and fall, and how you can affect that, and not allowing your levels to drop low, and the sorts of things to eat, and it's been a bit of a revelation really.

### **Personal impact of PCOS support group**

Several participants described the support group as having had a major personal impact for them. This included making them feel empowered, and having a direct impact on their health behaviours:

P12: I do feel very much like it's, um, empowered me with information. And that may not end up changing anything with my fertility, but longer term it will hopefully help with my longer-term health. And it's already changed dramatically the way I eat, for example. The way I eat has changed 95% in the last 18 months. There is no doubt, no doubt for me that it has radically changed the way I view PCOS, the support group has.

Another participant who had attended the group had been stimulated to take action to self manage more effectively as a result:

P10: And I'm slightly more of a "do help yourself" kind of a person, but I think since, I've done more since coming to the group than I did before, because like I was saying, that would be all in isolation, so that would be all kind of on your own doing it, whereas you come here and then you can go away and look for something else.

### **Criticisms and suggestions for change**

## Experiences of women with PCOS attending nurse-led peer support group

Very few criticisms were made of the support group, and these related almost exclusively to practical issues such as car parking costs on the hospital site and access to the building where meetings were held.

The only comments relating to the group itself and the experience of attending were concerned with the format of meetings and opportunities for interaction. Four participants commented that they had expected to have more opportunity for unstructured discussion with their peers, and would have liked the meeting to be less focused on information delivered by expert speakers:

P13: It wasn't a sort of support group as people supporting each other goes ... I would have liked to have heard what other people were going through.

P6: I did think it went on a bit ... there can be limit to how much you can listen to somebody talking about PCOS. Perhaps it would have been nice to have a shorter time listening to that and maybe more time to get to know other people in the same bo

For these participants, the information they could glean from other women's experiences was at least as valuable to them as factual information delivered by healthcare experts.

## **DISCUSSION**

### **Study limitations**

## Experiences of women with PCOS attending nurse-led peer support group

One limitation of this study is the nature of the sample, which consisted of volunteers recruited from one public general hospital in one region of the United Kingdom. It is also possible that the experiences reported by volunteer participants might have been more positive than those who chose not to be interviewed. In addition, the perspectives of these women may not accord with those attending support groups in different service settings and different national contexts.

This particular format of support group offered both peer support and support from a nurse specialist and endocrinologist. It is apparent from participants' comments that these different sources of support were valued. What is not clear, however, is how useful participants would find a wholly peer-led group, without any input from healthcare professionals. More research is needed on a range of different formats to identify any differences in the value of these from the patient's perspective.

Because the design of this study was cross-sectional and qualitative, its assessment of how the support group affected women's lives is based on their subjective descriptions, given in retrospect. In order to assess the effect of the support group more rigorously, longitudinal studies would be required in which data were collected prior to and after attending. Further rigor might be added by using quantitative measures of psychosocial outcomes, such as anxiety, depression, and HRQoL. Ultimately, different formats of support group might be compared with each other, and with normal care, in a controlled trial.

### **Relationship of findings to previous research**



## Experiences of women with PCOS attending nurse-led peer support group

Women in this study reported a degree of psychosocial distress, which included feelings of isolation, freakishness, and a lack of helpful information about their condition. Several reported disordered eating, as for example the participant who described binge eating to comfort herself when she felt low or angry. This accords with the findings of previous studies on the adverse psychosocial impact of the condition (Snyder 2006, Barnard et al. 2007, Himelein and Thatcher 2006).

Participants described the atmosphere of the support group as very positive and supportive. Women valued being able to attend meetings that offered accessible and personally-relevant information. In some cases, meetings offered new information, especially about diet and lifestyle, while for others, meetings helped to consolidate existing knowledge. This is consistent with the previous findings, which indicate that groups may provide informational and socio-emotional support (Gottlieb 2000, Ostberg and Lennartsson 2007). Participants also suggested that the group helped to address their feelings of social isolation and freakishness or difference. This was achieved through the process of social comparison, which has been observed in studies of cancer support groups (Taylor et al. 2007a).

The women in our study reported positive health benefits from attending the group. This appears to accord with findings from other studies of the relationship between social support and health outcomes (Orr 2004, Lechner et al. 2007, Lechner et al. 2006, Gallant 2003, Ford et al. 1998a, Ford et al. 1998b, Wolfe 2004). However, as this was a qualitative study we did not test for measurable effects on health status. Further studies are needed to address this issue more fully.

## Experiences of women with PCOS attending nurse-led peer support group

Our study provides some evidence to support the suggestion that nurses can help women to adjust to PCOS by providing education and support (Snyder 2006); however, as indicated in the limitations discussed above, the format of the particular support group investigated makes it difficult to draw definitive conclusions about the importance of nurses' specific role.

For some women in this study, the opportunity for interaction with others who shared their diagnosis appears to have been at least as valuable as the support they received from healthcare professionals who attended meetings. This accords with some previous work indicating that patients specifically value the peer interaction element of groups (Ussher et al. 2006b). However, the mixed format of our support group makes it difficult to assess whether a wholly peer-led group might be of more or less benefit than a one with some input from healthcare professionals.

Some of our participants reported direct positive effects of group attendance on their self-management behaviours. Although our findings are necessarily tentative, they do suggest that further research into social support might inform the development of interventions to promote self-management in PCOS, such as the lifestyle modifications recommended by many experts in the field (Lord and Norman 2006, Hoeger 2006, Norman et al. 2002).

In this study we addressed a gap in the literature by investigating both the nature of social support in PCOS and its possible impact on health. Although our study had some limitations, we have carried out an in-depth exploration of participants' subjective experiences. In doing so, we have attended to calls for more qualitative research on psychosocial aspects of PCOS (Moreira and Azevedo 2006), and on the subjective experiences of social support in general (Haber et al. 2007).

## CONCLUSION

Our findings suggest that healthcare professionals working with PCOS patients should consider providing peer support groups as a means to alleviate patients' distress and to promote self-management activities such as lifestyle modification. Ideally, groups should be designed to meet patients' support needs and expectations, and should be evaluated regularly.

Nurses are potentially well-placed to provide psychosocial support for women with PCOS, at an individual or group level. Education for nurses working with PCOS patients might usefully include skills development in facilitating support groups. In the current study, the data on patients' experiences were collected by a health psychology researcher, who was not part of the clinic team. With appropriate development of their research skills, nurses might design and evaluate their own psychosocial interventions.

More research is needed to identify social support needs in PCOS, and the extent to which these may be met by various forms of intervention. Qualitative research is required to ensure that work in this field is grounded in patients' subjective experiences. This may be supplemented by quantitative measures of social support, which will enable collection of data from larger samples. Such measures might then be used to examine the relationship between social support and clinically-relevant outcomes such as depression, health-related quality of life and self-management.

## REFERENCES

**Comment [c1]:** Give all journal titles in full

Experiences of women with PCOS attending nurse-led peer support group

- Asuncion, M., Calvo, R. M., San Millan, J. L., Sancho, J., Avila, S. and Escobar-Morreale, H. F. (2000) A Prospective Study of the Prevalence of the Polycystic Ovary Syndrome in Unselected Caucasian Women from Spain. *Journal of Clinical Endocrinology & Metabolism*, **85**(7), 2434-2438.
- Azziz, R., Woods, K. S., Reyna, R., Key, T. J., Knochenhauer, E. S. and Yildiz, B. O. (2004) The prevalence and features of the polycystic ovary syndrome in an unselected population. *Journal of Clinical Endocrinology and Metabolism*, **89**(6), 2745-2749.
- Barnard, L., Ferriday, D., Guenther, N., Strauss, B., Balen, A. H. and Dye, L. (2007) Quality of life and psychological well being in polycystic ovary syndrome. *Human Reproduction*, **22**(8), 2279-2286.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, **3**(2), 77-101.
- Carmina, E. and Azziz, R. (2006) Diagnosis, phenotype, and prevalence of polycystic ovary syndrome. *Fertility and Sterility*, **86**, S7-S8.
- Cattrall, F. R. and Healy, D. L. (2004) Long-term metabolic, cardiovascular and neoplastic risks with polycystic ovary syndrome. *Best Practice & Research in Clinical Obstetrics & Gynaecology*, **18**(5), 803-812.
- Chang, J., Azziz, R., Legro, R., Dewailly, D., Franks, S., Tarlatzis, R., Fauser, B., Balen, A., Bouchard, P., Dahlgren, E., Devoto, L., Diamanti, E., Dunaif, A., Filicori, M., Homburg, R., Ibanez, L., Laven, J., Magoffin, D., Nestler, J., Norman, R., Pasquali, R., Pugeat, M., Strauss, J., Tan, S., Taylor, A., Wild, R., Wild, S., Ehrmann, D. and Lobo, R. (2004) Revised 2003 consensus on diagnostic criteria and long-term health risks related to polycystic ovary syndrome. *Fertility and Sterility*, **81**(1), 19-25.
- Coffey, S., Bano, G. and Mason, H. D. (2006) Health-related quality of life in women with polycystic ovary syndrome: A comparison with the general population using the

Experiences of women with PCOS attending nurse-led peer support group

Polycystic Ovary Syndrome Questionnaire (PCOSQ) and the Short Form-36 (SF-36).

*Gynecological Endocrinology*, **22**(2), 80-86.

Dasgupta, S. and Mohan, R. B. (2008) Present status of understanding on the genetic etiology of polycystic ovary syndrome. *Journal of Postgraduate Medicine*, **54**(2), 115-125.

Engel, G. L. (1977). The need for a new medical model: a challenge for biomedicine.

*American Journal of Psychiatry*, **137**, 535-544.

Ford, M. E., Tilley, B. C. and McDonald, P. E. (1998a) Social support among African-

American adults with diabetes, part 1: Theoretical framework. *Journal of the National Medical Association*, **90**(6), 361-365.

Ford, M. E., Tilley, B. C. and McDonald, P. E. (1998b) Social support among African-

American adults with diabetes, part 2: A review. *Journal of the National Medical Association*, **90**(7), 425-432.

Gallant, M. P. (2003) The influence of social support on chronic illness self-management: A review and directions for research. *Health Education & Behavior*, **30**(2), 170-195.

Gottlieb, B. H. (2000) Selecting and planning social support interventions. In *Social Support Measurement and Intervention: A Guide for Health and Social Scientists*(Eds, Cohen, S., Underwood, L. G. and Gottlieb, B. H.) Oxford University Press, New York, pp. 195-220.

Haber, M. G., Cohen, J. L., Lucas, T. and Baltes, B. B. (2007) The relationship between self-reported received and perceived social support: A meta-analytic review. *American Journal of Community Psychology*, **39**(1-2), 133-144.

Hart, R. and Norman, R. (2006) Polycystic ovarian syndrome - prognosis and outcomes. *Best Practice & Research Clinical Obstetrics & Gynaecology*, **20**(5), 751-778.

Himelein, M. J. and Thatcher, S. S. (2006) Polycystic ovary syndrome and mental health: A review. *Obstetrical & Gynecological Survey*, **61**(11), 723-732.

Experiences of women with PCOS attending nurse-led peer support group

- Hoeger, K. M. (2006) Role of lifestyle modification in the management of polycystic ovary syndrome. *Best Practice & Research Clinical Endocrinology & Metabolism*, **20**(2), 293-310.
- Lechner, L., Bolman, C. and van Dalen, A. (2006) Definite infertility: Coping, social support and distress. *Psychology & Health*, **21**, 87-88.
- Lechner, L., Bolman, C. and van Dalen, A. (2007) Definite involuntary childlessness: associations between coping, social support and psychological distress. *Human Reproduction*, **22**(1), 288-294.
- Lord, J. M. and Norman, R. (2006) Obesity, polycystic ovary syndrome, infertility treatment - Lifestyle modification is paramount. *British Medical Journal*, **332**(7541), 609-609.
- Moreira, S. N. T. and Azevedo, G. D. (2006) Incorporating qualitative approaches is the path to adequate understanding of the psychosocial impact of polycystic ovary syndrome. *Human Reproduction*, **21**, 2723-2724.
- Norman, R. J., Davies, M. J., Lord, J. and Moran, L. J. (2002) The role of lifestyle modification in polycystic ovary syndrome. *Trends in Endocrinology & Metabolism*, **13**(6), 251-257.
- Orr, S. T. (2004) Social support and pregnancy outcome: A review of the literature. *Clinical Obstetrics and Gynecology*, **47**(4), 842-855.
- Ostberg, V. and Lennartsson, C. (2007) Getting by with a little help: The importance of various types of social support for health problems. *Scandinavian Journal of Public Health*, **35**(2), 197-204.
- Percy, C. A., Gibbs, T., Boardman, S. and Todkill, D. (2007) Quality of life in women attending a patient-centred, nurse-led endocrine clinic for management of polycystic ovary syndrome. *Endocrine Abstracts*, **13 P189**.

Experiences of women with PCOS attending nurse-led peer support group

- Shaver, J. F. (1985). A biopsychosocial view of human health. An effective approach to nursing care must encompass all factors that act, either singly or in combination, on human health. *Nursing Outlook*, 33(4), 186-191.
- Smith, J. A., & Osborn, M. (2003). Interpretative phenomenological analysis. In J. Smith (Ed.), *Qualitative psychology: A practical guide to research methods* (pp. 51-80). London: Sage.
- Snyder, B. S. (2006) The lived experience of women diagnosed with polycystic ovary syndrome. *Jognn-Journal of Obstetric Gynecologic and Neonatal Nursing*, 35, 385-392.
- Talbott, E. O., Zborowski, J. V., Rager, J. R., Kip, K. E., Xu, X. H. and Orchard, T. J. (2007) Polycystic ovarian syndrome (PCOS): A significant contributor to the overall burden of type 2 diabetes in women. *Journal of Womens Health*, 16(2), 191-197.
- Taylor, C. L. C., Kulik, J., Badr, H., Smith, M., Basen-Engquist, K., Penedo, F. and Gritz, E. R. (2007a) A social comparison theory analysis of group composition and efficacy of cancer support group programs. *Social Science & Medicine*, 65(2), 262-273.
- Taylor, C. L. C., Kulik, J., Badr, H., Smith, M., Basen-Engquist, K., Penedo, F., Gritz, E. R. and Aq (2007b) A social comparison theory analysis of group composition and efficacy of cancer support group programs. *Social Science & Medicine*, 65(2), 262-273.
- Ussher, J., Kirsten, L., Butow, P. and Sandoval, M. (2006a) What do cancer support groups provide which other supportive relationships do not? The experience of peer support groups for people with cancer. *Social Science & Medicine*, 62(10), 2565-2576.
- Ussher, J., Kirsten, L., Butow, P., Sandoval, M. and Al (2006b) What do cancer support groups provide which other supportive relationships do not? The experience of peer

- Experiences of women with PCOS attending nurse-led peer support group support groups for people with cancer. *Social Science & Medicine*, **62**(10), 2565-2576.
- van Dam, H. A., van der Horst, F. G., Knoops, L., Ryckman, R. M., Crebolder, H. F. J. M. and van den Borne, B. H. W. (2005) Social support in diabetes: a systematic review of controlled intervention studies. *Patient Education and Counseling*, **59**(1), 1-12.
- Wild, S., Pierpoint, T., McKeigue, P. and Jacobs, H. (2000) Cardiovascular disease in women with polycystic ovary syndrome at long-term follow-up: a retrospective cohort study. *Clinical Endocrinology*, **52**(5), 595-600.
- Wolfe, W. A. (2004) A review: Maximizing social support - A neglected strategy for improving weight management with African-American women. *Ethnicity & Disease*, **14**(2), 212-218.



**Table 1: Thematic map of the analysis**

<b>Themes</b>	<b>Examples</b>
Expectations and hopes	Getting information about polycystic ovary syndrome A chance to meet others with similar problems Feeling nervous
Socioemotional function	Reducing a sense of isolation and difference Engaging in social comparison A positive and supportive atmosphere Wishing a group had been available years ago A chance to help other women
Informational function	Finding new information A choice of personally relevant information Accessible information The chance to ask questions Finding out about treatment options Consolidating existing knowledge
Personal impact of the support group	Feeling empowered Making changes in health behaviours Taking action to self manage more effectively
Criticisms and suggestions for change	Practical problems: car parking and access to building A preference for less information from experts, and more chance for unstructured discussion