The role of an on-line peer-to-peer health community in addressing psychosocial concerns and social support in polycystic ovary syndrome

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Acknowledgement

Introduction

This paper reports the findings of a study of on-line peer-to-peer communication about a common health condition, which augments the information about patient concerns collected in questionnaire studies conducted in clinic settings. The study also investigated the extent to which on-line peer-to-peer communication addressed users' psychosocial support needs.

Polycystic ovary syndrome (PCOS) is a common endocrine disorder in women of reproductive age, with estimates of prevalence from 8- 26% (Balen and Michelmore, 2002). While debate continues regarding the diagnostic criteria, symptoms reported in PCOS typically include menstrual disturbances, subfertility, obesity, acne and hirsutism (Hart and Norman, 2006).

PCOS has been shown to have a significant adverse psychosocial impact, including impairments to health related quality of life, distress regarding gender identity, and

difficulties adjusting to diagnosis (Kitzinger and Willmott, 2002, Snyder, 2006, Himelein and Thatcher, 2006).

The psychosocial impact of PCOS has been studied using both qualitative and quantitative approaches. A small number of qualitative studies have explored the experience of PCOS in depth, revealing the adverse impact the condition has on gender identity and femininity, and the difficulties women encounter coping with and adjusting to their diagnosis (Kitzinger and Willmott, 2002, Snyder, 2006)

One condition specific measure of Health Related Quality of Life (HRQoL) has been developed for use in PCOS, the Polycystic Ovary Syndrome Questionnaire (PCOSQ) (Cronin et al., 1998, Jones et al., 2004). This questionnaire assesses the impact of PCOS symptoms on quality of life in five domains: emotions, body hair, weight, infertility, and menstrual problems.

Studies using the PCOSQ have found that women with PCOS have impaired quality of life across all five domains (Percy et al., 2007, Coffey et al., 2006, McCook et al., 2005, Guyatt et al., 2004). The domains in which the greatest impairment has been found vary from study to study, and there has been some debate about which aspects of PCOS have the greatest impact on distress and/or quality of life (Moreira and Azevedo, 2006, Elsenbruch et al., 2006).

PCOS is a variable condition, and women included in the studies above were recruited from different clinical settings. It is perhaps not surprising then that concerns reported by women attending a fertility clinic differed from those recruited via a clinical trial for hirsutism. Therefore attempts to assess the psychosocial impact of PCOS are limited if data are collected only within specialist clinics. In addition, the authors responsible for psychometric validation of the PCOSQ have acknowledged that some symptoms (e.g. acne) are not addressed at all in the questionnaire (Jones et al., 2004). Critics have also pointed out that the PCOSQ conflates symptom experience and quality of life in some domains (Speight and McCann, 2006, Malik-Aslam et al., 2008). It might be argued then that studies using closed response questionnaires, focusing largely on symptoms, and collected in clinic populations, capture only a very limited picture of the experience and concerns of women with PCOS. Researchers hoping to gain a richer sense of how women are affected by their condition, and what their health-related concerns are, might consider collecting data from alternative sources, using other methodologies.

A further problem with research to date on psychosocial aspects of PCOS, is that most research effort has focused on measuring adverse health impacts. A few studies have addressed factors that may mediate the psychosocial impact of PCOS. However, there are even fewer studies that have examined how women cope with their condition, e.g. by seeking information, or engaging in active self-management.

The biopsychosocial model advocated by health psychologists, and a growing number of health professionals, suggests that people with health conditions are not passive

'sufferers' assailed by symptoms, but active participants in appraising, coping with, and actively self-regulating their own health. There is considerable scope for further research that addresses the processes by which women with PCOS understand their condition, cope and self-manage, for example by seeking health information and social support.

We know that women with PCOS may have unmet information needs, and that women who perceive themselves as having received inadequate information may experience poorer health-related quality of life (Ching et al., 2007).

A study with Australian women found that they preferred to use the internet to find information about PCOS, rather than relying on information from healthcare providers, on the basis that internet sources often had more detailed information, as well as being more convenient, accessible and private (Avery and Braunack-Mayer, 2007). What is not yet apparent from research to date, is whether women's perceived information needs are fully met by the sources they access on-line.

There is a growing body of research suggesting that the internet is an important source of not just information, but also support for women with a range of health conditions, for example, breast cancer (Hoybye et al., 2005, Winzelberg et al., 2003), systemic lupus erythematosus (Mendelson, 2003), and health concerns , such as infertility (Malik and Coulson, 2008) and hysterectomy (Bunde et al., 2007).

The role of social support in adjustment to chronic illness is well established (Cohen and Wills, 1985), but little is known about its role specifically in PCOS. While health professionals, friends and family are potential sources of social support, the development of the internet has offered new possibilities for individuals with the same condition to communicate and offer social support on-line.

(Caplan and Turner, 2007) argue that on-line social interaction is, in theory, uniquely placed to facilitate effective comforting communication, for three main reasons. In developing an "appraisal theory of comforting communication" (p.986), the authors suggest that the internet provides a comfortable and safe environment in which it is acceptable to discuss upsetting issues, that participants in on-line support communities are actively encouraged to focus on their thoughts and feelings about a distressing experience, and are offered the opportunity to create personal narratives in which they may adaptively reappraise their experiences.

In a systematic review of the effects of health related virtual communities and electronic support groups, (Eysenbach et al., 2004) argue that more research is needed to assess how effective on-line health groups are in providing social support. A number of studies have begun to address this, by examining the social support content of messages posted in on-line health forums. For example, (Coulson, 2005) studied the different types of social support within messages on a forum for Irritable Bowel Syndrome (IBS). Messages were analysed for the following different types of support:

- Informational, e.g. guidance on symptoms, treatments, etc.

- Emotional, e.g. expressions of empathy

- Esteem, e.g. positive evaluative comments

- Network, e.g. encouragement to interact with others and share experiences.

- Tangible, e.g. practical actions such as emailing individuals directly outside of the forum

Coulson identified the types of social support most often provided within the IBS forum, but raised questions about the extent to which users' social support needs were actually met by the responses they received on-line.

The current study set out to examine the type of social support sought in messages posted on a PCOS-related internet support group, and the type of support offered in return.

The research questions for the current study were

1: To what extent do the psychosocial concerns expressed by women with PCOS using the internet as a source of health information, mirror those identified in clinic-based, symptoms-focused Health Related Quality of Life studies?

2: To what extent do women with PCOS participating in a peer-to-peer on-line health community use it as a source of social support?

3. What types of social support (if any) are sought in messages posted on a peer-to-peer on-line PCOS discussion forum?

4. What types of social support (if any) are provided in replies to messages posted on a peer-to-peer on-line PCOS discussion forum?

5. To what extent are on-line health messages requesting social support met with replies offering social support?

Methodology

There are numerous on-line health communities worldwide that provide information and discussion related to PCOS. The forum chosen for the current study was selected on the basis that it was run by an established Registered Charity, in the United Kingdom. That charity is a well known provider of patient information on PCOS, has links with healthcare providers in the UK, and provides health professionals with training, and patient education materials. Users of the site are chiefly UK based, but also include users from English speaking countries worldwide. The on-line community in question: "Verity Discussion Board: Sharing the Truth about PCOS", is likely to feature towards the top in a list of hits generated by anyone conducting a search for "PCOS support", from with the UK. The discussion board includes Welcome, News and General Discussion areas, as well as boards devoted to specifically to Living with PCOS.

Sampling

Messages were sampled from those posted on-line between 1st October 2006 and 31st

January 2007: www.verity-pcos.org.uk

The forums sampled were as follows: One general introductory forum: 'Verity Cafe

(General discussion area. Just been diagnosed? Need to share your story and get some

peer support?)'. Nine forums under the heading 'Living with PCOS': 'Hair & Skin';

'Irregular cycles'; 'Trying to Conceive'; 'Pregnancy & Motherhood'; 'Weight & Healthy

Eating'; 'Medications & Complementary Therapies'; 'Insulin Resistance and Diabetes';

'Emotional aspects of PCOS'; 'Other problems'.

The researchers aimed to sample the first 30 messages in each forum, while retaining

threads of related messages intact. This decision was based on two criteria:

representativeness and researcher workload. Rather than focusing on one particular

forum, with one specific focus, e.g. pregnancy, the researchers wanted to capture

exchanges across a range of forums. Because the intention was to use a detailed coding

framework, in particular to track responses to specific individual posts, the data coding

process was time consuming and labour intensive. To manage this within the timeframe

of an undergraduate project, the researchers decided to set a target of 30 messages to be

sampled per forum. In the event that the 30th message was not the last in a particular

thread, the researchers included all messages in that thread. This was done to reduce the

likelihood that requests for support appeared in our analysis to go unanswered, simply

due to a sampling decision to cut a thread of messages at an arbitrary point. Using these criteria, 277 messages, from 136 unique sender names were downloaded for analysis.

Coding framework

For the research question regarding the psychosocial concerns expressed by users of the forum, the messages were coded using a content analysis that began with a framework of *a priori* categories that was extended inductively.   Specifically, *a priori* categories were created to account for concerns assessed or expressed in previous research on PCOS. These included the symptom domains included within the PCOSQ: emotions, body hair, weight, infertility, and menstrual problems. Further categories were added to the coding framework as and when required. For example, if a message expressed concern about a symptom or problem not included in the PCOSQ, such as acne, this was added as a category within the coding framework. Once all the messages had been read, and the coding framework was complete, the framework was applied to every message in the sample. Each message was coded for each category that applied to it. A message could be coded into more than one category, if it expressed more than one category of concern. For example, a message that expressed concern about both acne and menstrual problems would be coded into both these categories.

For the research questions regarding social support, each message was coded if it requested or provided social support, and for the type of support requested/provided. Each message was coded for each category that applied to it. A message could be coded

into more than one category. For example, a message that requested both informational and emotional support would be coded into both these categories.

To illustrate this, we present the following worked example, based on a message that started a thread:

"just been diagnosed with PCOS, worried sick about not being able to have kids. i've got such bad guilt running through me, a couple of years ago i was with a bad partner & fell pregnant, was pushed into an abortion & regretted it ever since. now i have PCOS - feel like its punishment for what i did, are the two related? is it my fault? god if i cant have kids after i did that, i dont know what i'll do!!! & my doctor is so unhelpful, i have no idea what the next step is, or what treatments are out there? does anyone know if they're related????"

This message was coded as expressing concern about *fertility* "worried sick about not being able to have kids ", *adverse interactions with health professionals* "my doctor is so unhelpful", and *information needs* "i have no idea what the next step is, or what treatments are out there". It was further coded as *seeking informational support* "are the two related?", "what treatments are out there?"; *emotional support* "worried sick", "I don't know what I'll do!!!"; and *esteem support* "is it my fault?".

The next message in the thread was a reply to the first:

"No, its not likely to be related. PCOS is a hormonal problem and has nothing to do with any previous abortions etc, dont worry yourself that its your fault. Another point to make is that having PCOS doesn't mean you wont have children, yes, its a cause of infertility but usually this means that if you cant conceive on your own there are options to help, either by pills or minor ops - all before you reach ivf stages and beyond so dont panic yourself that you wont have a family, the fact that you have fallen pregnant before is a good indicator that you need not worry too much. Just take a look at the pregnancy and motherhood board to realise that it can and does happen for ladies who have PCOS. Next steps, well that depends on where you are in your life and what your symptoms/problems are your doctor should discuss that with you but examples would be going on the pill or taking medication to help with any weight/hair issues etc."

This message was coded as providing *informational support* "No, its not likely to be related. PCOS is a hormonal problem and has nothing to do with any previous abortions etc", "having PCOS doesn't mean you wont have children", and both *emotional and esteem support* "don't worry yourself that it's your fault".

To begin analysis, the two researchers jointly coded a sample of 30 messages to ensure they were using the coding framework in the same way. Where there was potential for ambiguity, the two researchers discussed the case and agreed on appropriate coding. For example, in the reply presented above, the suggestion "Just take a look at the pregnancy and motherhood board to realise that it can and does happen for ladies who have PCOS",

could potentially be considered an instance of network support. However our definition of network support included specifically encouragement to *interact* with others and share *experiences*. As it was not clear whether the message was encouraging interaction, or simply directing the user to information, we decided not to code this as an instance of network support. Following the initial coding check, the second author then coded the remainder of the messages sampled. Any cases where there was ambiguity were discussed with the first author and agreement was reached. As a final check on the reliability of coding, the first author sampled a further 30 messages and coded them independently. Comparison of the coding done by the two researchers was compared. The research protocol was for any cases of disagreement to be discussed and agreed, but in the event no such cases emerged.

The coded data were then analysed for each of the following:

- Total number of messages seeking social support.
- Total number of messages providing social support.
- Numbers of messages seeking and providing social support in each of the categories: informational, emotional, esteem, network, and tangible.

Where a message requesting social support was posted, it was noted whether one or more subsequent messages within the same thread provided social support, and whether this was the same type of support as that requested.

Findings

Psychosocial concerns within messages

All the messages sampled referred to psychosocial concerns directly or indirectly related to PCOS. The topics most frequently referred to in the messages were emotional/affective issues (22.3% of all messages), menstruation (14.4%), weight (13.4%), pregnancy (12.9%), fertility (12.3%), long term health (10.5%) and hirsutism (9.7%). However, these were closely followed by concerns not reflected in previous research with clinic samples and/or the PCOSQ questionnaire. These included additional symptoms such as mental (2.5%) and physical fatigue (6.8%); appetite difficulties (3.9%) such as cravings and binge eating; non-menstrual pain (3.9%) such as headache; skin problems (3.9%), including acne and hair loss (1.8%).

Adverse treatment effects such as unwanted drug side effects were referred to in 8.6% of messages. Adverse interactions with health professionals, for example being treated unsympathetically by their doctor were referred to in 8.3% of messages. 4.3% of messages referred to information needs and 3.6% to self-management concerns such as difficulty adhering to exercise, dietary or medical regimes.

Social support content of messages

All messages posted to begin a message thread requested some form of social support.

The type of social support most frequently requested was informational (23.1%), followed by emotional (10.5%), esteem, (8.3%) network (1.8%) and tangible (0.4%). The type of social support most frequently provided was esteem (51.2%), followed by emotional (35.7%), informational (28.5%), network (9.4%), and tangible (2.9%). 82% of messages seeking social support received replies providing support, and of these 74% received the type of social support requested. Messages requesting informational support were the least likely to receive 'matching responses'. When participants were unable to provide informational support in response to these requests, they typically provided emotional or esteem support instead.

Discussion

Analysis of the messages posted on the discussion forum provided an insight into both the psychosocial concerns of its users, and the social support function of the site.

1. To what extent do the psychosocial concerns expressed by women with PCOS using the internet as a source of health information, mirror those identified in clinic-based, symptoms-focused Health Related Quality of Life studies?

The analysis suggests that women using this on-line discussion forum have concerns about their condition that extend beyond the domains assessed in the quality of life questionnaire they might be given in clinic. These include worries about their longer

term health (e.g. risk of stroke or cancer) and concerns typical of chronic illness in general, such as pain and fatigue.

Furthermore, while users of this on-line forum expressed some concerns similar to those found in previous studies with clinic populations, affective/emotional concerns feature more prominently in messages on the discussion forum than might be expected from studies conducted with the PCOSQ.

One source of concern apparent in the discussion forum, but not assessed in the PCOSQ studies, is difficulties resulting from healthcare intervention. For example, some users described frustration and distress at being treated unsympathetically by their healthcare providers. Others were troubled not just by PCOS symptoms but by the effects of treatments.

These findings suggest that, while the PCOSQ may be a rough measure of the psychosocial impact of PCOS, it does not provide a comprehensive or fully systematic assessment.

2. To what extent do women with PCOS participating in a peer-to-peer on-line health community use it as a source of social support?

All messages posted to begin a message thread requested some form of social support. The data suggest that this on-line forum is an important potential source of social support for women with PCOS.

3. What types of social support (if any) are sought in messages posted on a peer-to-peer on-line PCOS discussion forum?

The type of social support most frequently requested was informational, followed by emotional, esteem, network and tangible. This suggests, at first glance, that what users were seeking most was information about PCOS, and about treatment options. This is concordant with the findings of previous work, such as (Ching et al., 2007, Avery and Braunack-Mayer, 2007), which indicates that women with PCOS have unmet support needs, and are likely to seek to address these using internet sources. That emotional support should be the second most common type of support sought is not surprising, given that emotional and affective issues were the commonest concern expressed on the forum, and are commonly found in clinic samples of PCOS patients. A more complicated picture emerges, however, when the findings regarding the provision of support are examined.

4. What types of social support (if any) are provided in replies to messages posted on a peer-to-peer on-line PCOS discussion forum?

The type of social support most frequently provided in replies posted on the forum was esteem, followed by emotional, informational, network, and tangible. This suggests that many replies to requests for social support offered positive validations of the person who posted the original message, or expressions of empathy. This is generally supportive of the claims made by (Caplan and Turner, 2007), that internet communities offer an opportunity for users to experience the empathic concern of others. However, on closer examination of the relationship between messages and replies, the picture is not so positive.

5. To what extent are on-line health messages requesting social support met with replies offering social support?

Most messages seeking social support received replies providing support, and of these most received the type of social support requested. However, messages requesting informational support were the least likely to receive 'matching responses'. When participants were unwilling or unable to provide informational support in response to these requests, they typically provided emotional or esteem support instead. This suggests, at first glance, that some users of the forum are likely to have information needs that are still unmet, even after posting a message and receiving replies from other users.

Unmet information needs or emotional support requests framed as informational queries?

One simple explanation of the apparent mismatch between the number of requests for informational support, and the number of replies providing esteem and emotional support, is that users of this particular health discussion forum lacked the information or expertise to answer informational queries from individual women. It may be the case that, as PCOS is a diverse condition, and limited information is provided by health professionals, users have precious little information to meet their own needs, much less to provide with confidence to other women using the forum. It might be the case that, rather than leave a message unanswered, forum users prefer to provide support in a form that they do feel qualified to offer.

Another possibility is that messages that appear, on first glance, to be requests for information, e.g. about symptoms or treatment options, are actually requests designed to elicit other forms of social support. For example, a message which describes difficulty in accessing treatment and frustration at not being taken seriously by one's General Practitioner, may request information on General Practitioners who specialize in the treatment of PCOS. It is impossible to infer the intentions of the individual who posted such a message, on the basis of message content alone. The message might indeed be primarily seeking information about named General Practitioners within a given geographical area, but it might also be intended to elicit sympathy for the user's frustration, empathy and validation, from other users who may describe similarly frustrating experiences, and to make a rhetorical case for better healthcare availability in general. These considerations highlight some limitations of the methodology adopted in the current study.

Strengths & limitations of current study

From a methodological perspective, the approach adopted in the current study offered some further insight into the process of seeking and providing social support on-line. The study both extended the scope of research assessing the psychosocial concerns of women with PCOS, and provided a more detailed analysis of social support than previous studies.

There are a number of limitations to the current study. The number of messages selected for analysis represents only a small snapshot of those exchanged within this particular health discussion forum, on which messages continue to be posted daily. The forum selected for study is UK based, with messages posted in English, from sources which appear to be mainly UK in origin, with occasional contributions from users in other English-speaking countries of origin. This represents a rather limited sample of the experience of PCOS and on-line social support globally.

The framework used to code messages for their psychosocial concerns was developed inductively, drawing on what we already know about concerns in PCOS, augmented with new categories of concerns grounded in the data themselves. The coding process was validated by two researchers coding the messages independently – but the coding was done on the basis of the manifest content of the messages themselves.

In order to draw more confident conclusions, both about psychosocial concerns in PCOS, and the process of social support on-line, further studies are required. These should employ larger samples of user data, derived from a number of different on-line sources, from other PCOS support sites, particularly those from non English-speaking countries. Such studies are necessary to address the possibility that there may be national and cultural variations in women's concerns about PCOS, and in the provision of information and support.

It would also be advantageous to evaluate forum users' experiences qualitatively. Future research might, for example, elicit from forum users their views as to what their needs were when they chose to use the on-line forum, what they were seeking from on-line peer-to-peer interaction, and whether their needs for information or support were met. This would necessitate researchers' recruiting individuals who posted messages and replies to take part in. for example, questionnaire of interview studies, rather than observing on-line interaction without taking part in it themselves.

Researchers might also consider conducting a discursive analysis of the exchange of messages within threads. It has been argued that individuals describing their experiences of health and illness are involved, to some extent in identity work – managing their personal accountability for being ill, and not recovering (Horton-Salway, 2001). So an alternative approach to analysing the message threads on the forum, would be to conduct a detailed examination of the identity work that might achieved within them.

Finally, on-line health forums may not only used by people who actively post messages on them. Most messages posted on the site in our study had received many more *views* than responses. Analysis of messages by the patterns of viewing as well as responding may shed further light into the behaviour of people who appear not to actively participate in discussion.

Conclusion

This paper has suggested that it is worth studying on-line peer-to-peer health communities for at least two reasons: 1. As a means of gaining further insight into the concerns patients have about their health conditions, and 2. To evaluate their effectiveness as a means of addressing users' psychosocial support needs.

The findings have implications for both researchers interested in PCOS, and those with a broader interest in on-line health communities. In order to develop a truly biopsychosocial model of the impact of PCOS, we need to consider the impact not just of symptoms, but also of experiences in using healthcare. On-line discussion forums appear to be an important source of social support for women with PCOS. However, a closer examination of the interchange of messages suggests that forums may fail to meet all women's information needs about the condition. Web-based communities offer healthcare researchers a novel window onto the experience of health and illness. Communication on-line may tell us much about healthcare users' concerns, particularly those that relate to the context of healthcare provision, rather than the experience of symptoms *per se*.

It would appear that the on-line community described in this particular study was a place where the experience of PCOS could be, at least to some extent, *personally* defined by individual users. This may contrast with other environments where discussion of PCOS is permissible, for example during healthcare consultations. Participants in this on-line community were able to define their experiences, not within a received framework of clinical signs and symptoms (though there were numerous instances where medical and technical terms were used), but in a more holistic way.

The on-line community was also a place where users could offer help to others, rather than always being the 'needy' patient seeking support from health professionals or others. In addition to direct exchanges of social support, the site also offered an opportunity to engage in social comparison. Finding out that they were not alone in experiencing certain symptoms may have reduced feelings of stigma or isolation for users. Furthermore, when they compared experiences of healthcare provision, users were able to identify perceived shortcomings in their own care. In this community it was socially acceptable to express anger or dissatisfaction with healthcare provision. In this respect it seems to provide an outlet for feelings that are not considered legitimate to express when one is a patient in clinical context. Further research might investigate the extent to which participation in on-line communities has an impact on healthcare usage, expectations and satisfaction in the non-virtual world.

References

AVERY, J. C. & BRAUNACK-MAYER, A. (2007) The Information Needs of Women Diagnosed with Polycystic Ovarian Syndrome – Implications for Treatment and Health Outcomes. *BMC Women's Health,* 7.

BALEN, A. & MICHELMORE, K. (2002) What is polycystic ovary syndrome?: Are national views important? *Hum. Reprod.,* 17**,** 2219-2227.

BUNDE, M., SULS, J., MARTIN, R. & BARNETT, K. (2007) Online hysterectomy support: Characteristics of website experiences. *Cyberpsychology & Behavior,* 10**,** 80-85.

CAPLAN, S. E. & TURNER, J. S. (2007) Bringing theory to research on computer-mediated comforting communication. *Computers in Human Behavior,* 23**,** 985-998.

CHING, H. L., BURKE, V. & STUCKEY, B. G. A. (2007) Quality of life and psychological morbidity in women with polycystic ovary syndrome: body mass index, age and the provision of patient information are significant modifiers. *Clinical Endocrinology,* 66**,** 373-379.

COFFEY, S., BANO, G. & MASON, H. D. (2006) Health-related quality of life in women with polycystic ovary syndrome: A comparison with the general population using the Polycystic Ovary Syndrome Questionnaire (PCOSQ) and the Short Form-36 (SF-36). *Gynecological Endocrinology,* 22**,** 80-86.

COHEN, S. & WILLS, T. A. (1985) Stress, Social Support, And The Buffering Hypothesis. *Psychological Bulletin,* 98**,** 310-357.

COULSON, N. S. (2005) Receiving Social Support Online: An Analysis of a Computer-Mediated Support Group for Individuals Living with Irritable Bowel Syndrome. *CyberPsychology & Behavior,* 8**,** 580-584.

CRONIN, L., GUYATT, L., GRIFFITH, E., WONG, R., AZZIZ, W., FUTTERWEIT, W., COOK, D. & DUNAIF, A. (1998) Development of a Health-Related Quality-of-Life Questionnaire (PCOSQ) for Women with Polycystic Ovary Syndrome (PCOS). *Journal of Clinical Endocrinology and Metabolism,* 83**,** 1976-1987.

ELSENBRUCH, S., BENSON, S., HAHN, S. & JANSSEN, O. E. (2006) Reply: Incorporating qualitative approaches is the path to adequate understanding of the psychosocial impact of polycystic ovary syndrome. *Human Reproduction,* 21**,** 2724-2725.

EYSENBACH, G., POWELL, J., ENGLESAKIS, M., RIZO, C. & STERN, A. (2004) Health related virtual communities and electronic support groups: Systematic review of the effects of online peer to peer interactions. *BMJ: British Medical Journal,* 328**,** 1166-1166.

GUYATT, G., WEAVER, B., CRONIN, L., DOOLEY, J. A. & AZZIZ, R. (2004) Health-related quality of life in women with polycystic ovary syndrome, a self-administered questionnaire, was validated. *Journal of Clinical Epidemiology,* 57**,** 1279-1287.

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

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

HORTON-SALWAY (2001) Narrative identities and the management of personal accountability in talk about ME: A discursive psychology approach to illness narrative. *Journal of Health Psychology,* 6**,** 247-259.

HOYBYE, M. T., JOHANSEN, C. & TJORNHOJ-THOMSEN, T. (2005) Online interaction. effects of storytelling in an Internet breast cancer support group. *Psycho-Oncology,* 14**,** 211-220.

JONES, G. L., BENES, K., CLARK, T. L., DENHAM, R., HOLDER, M. G., HAYNES, T. J., MULGREW, N. C., SHEPHERD, K. E., WILKINSON, V. H., SINGH, M., BALEN, A., LASHEN, H. & LEDGER, W. L. (2004) The polycystic ovary syndrome health-related quality of life questionnaire (PCOSQ): a validation. *Human Reproduction,* 19**,** 371-377.

KITZINGER, C. & WILLMOTT, J. (2002) 'The thief of womanhood': women's experience of polycystic ovarian syndrome. *Social Science & Medicine,* 54**,** 349-361.

MALIK-ASLAM, A., REANEY, M. D. & SPEIGHT, J. (2008) The suitability of Polycystic Ovary Syndrome-Specific Questionnaires for measuring impact of PCOS on quality of life in clinical trials *International Society for Pharmacoeconomics and Outcomes Research, 11th Annual European Congress.* Athens, Greece.

MALIK, S. H. & COULSON, N. S. (2008) Computer-mediated infertility support groups: an exploratory study of online experiences. *Patient Education & Counseling,* 73**,** 105-113.

MCCOOK, J. G., REAME, N. E. & THATCHER, S. S. (2005) Health-related quality of life issues in women with polycystic ovary syndrome. *Jognn-Journal of Obstetric Gynecologic and Neonatal Nursing,* 34**,** 12-20.

MENDELSON, C. (2003) Gentle hugs - Internet listservs as sources of support for women with lupus. *Advances in Nursing Science,* 26**,** 299-306.

MOREIRA, S. N. T. & 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.

PERCY, C. A., GIBBS, T., BOARDMAN, S. & 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.

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.

SPEIGHT, J. & MCCANN, M. (2006) Assessment of quality of life in polycystic ovary syndrome (PCOS): a systematic review. Paper presented to *The British Psychological Society, Division of Health Psychology Annual Conference.* University of Essex, United Kingdom.

WINZELBERG, A. J., CLASSEN, C., ALPERS, G. W., ROBERTS, H., KOOPMAN, C., ADAMS, R. E., ERNST, H., DEV, P., TAYLOR, C. B. & CU (2003) Evaluation of an Internet support group for women with primary breast cancer. *Cancer,* 97**,** 1164-1173.