

Fertility concerns and related information needs and preferences of women with PCOS

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STUDY QUESTION: What are the fertility and childbearing concerns and related information needs and preferences of women with polycystic ovary syndrome (PCOS)?

SUMMARY ANSWER: Women with PCOS have concerns about fertility and childbearing mainly because they believe that it will be difficult for them to conceive, and identify a need for evidence-based information and preconception care so that they can make informed decisions about having children and achieve their reproductive goals.

WHAT IS KNOWN ALREADY: Women with chronic conditions seek reproductive health information from a range of sources, including their healthcare provider, the internet, other women with the condition, patient associations and support groups, and scientific publications. Little is known about the fertility concerns and information needs of women with PCOS or their preferences for how and when to receive information about the effect of their condition and its treatment on fertility and childbearing.

STUDY DESIGN, SIZE, DURATION: A qualitative study of 13 women of reproductive age with self-reported PCOS living in Australia participated in an online discussion group conducted from May to June 2018. Women were recruited via targeted advertisements on social media.

PARTICIPANTS/MATERIALS, SETTING, METHODS: In a closed-group moderated discussion, participants responded to questions about fertility concerns and the related information needs and preferences of women with PCOS. Non-identifiable demographic information was sought via a separate online anonymous survey. The discussion transcript was analysed thematically.

MAIN RESULTS AND THE ROLE OF CHANCE: Women identified a number of concerns about childbearing including whether they could become pregnant, how to prepare for pregnancy and what they should do before trying to conceive given their PCOS. Women reported seeking information about fertility and PCOS from a range of sources, and views about the most useful types and sources of fertility information for women with PCOS varied.

LIMITATIONS, REASONS FOR CAUTION: Due to the small sample size and recruitment of participants via advertisements on Facebook, women who participated in the study may not be representative of women with PCOS in the general population. Women currently contemplating childbearing or who have recently had children or fertility difficulties may also have been more likely to participate in the study. Women in this study self-reported PCOS, and this may not necessarily reflect a confirmed diagnosis of PCOS. No formal diagnostic criteria were used to confirm their PCOS status.

WIDER IMPLICATIONS OF THE FINDINGS: Women with PCOS would benefit from evidence-based information in a range of formats to help them make informed decisions about childbearing and achieving their reproductive goals. Preconception care, including counseling and information about appropriate interventions and self-management strategies to optimise health and improve chances of conception, may be of particular assistance to women with PCOS.

STUDY FUNDING/COMPETING INTEREST(S): The Victorian Assisted Reproductive Treatment Authority (VARTA) commissioned researchers at Monash University to generate evidence to guide the development of resources to assist women with PCOS make informed fertility and childbearing decisions and achieve their reproductive goals. The authors have no conflict of interests to declare.

TRIAL REGISTRATION NUMBER: Not applicable.

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WHAT DOES THIS MEAN FOR PATIENTS?

This study asked women with polycystic ovary syndrome (PCOS) about concerns they may have about fertility and childbearing given their condition, and the sort of information they would like about fertility and PCOS and when they would like to receive it.

Women with PCOS took part in an online discussion group. Women said they had a number of concerns about childbearing including whether they could become pregnant and what they should do before they tried to become pregnant given their PCOS. Women also said that they tried to get information about fertility and PCOS from many different sources, including their healthcare provider, the internet, other women with the condition and PCOS support groups but they found it difficult to find information that was up-to-date, relevant and reliable.

Women wanted information about fertility and PCOS to help them make decisions about having children and also wanted to be provided with information in a number of different ways including fact sheets, trustworthy websites and podcasts with health professionals.

The researchers suggest that women with PCOS may benefit from preconception care, including counselling and information about what they can do to improve their chances of becoming pregnant, in order to help them achieve their childbearing goals.

Introduction

Polycystic ovary syndrome (PCOS) is the most common endocrine disorder in women of reproductive age and affects ~6–21% of women (Azziz et al., 2004; March et al., 2010; Varanasi et al., 2018). Information about PCOS usually includes that the condition is associated with fertility difficulties (Family Planning NSW, 2012; Healthdirect, 2016; Better Health Channel, 2017; Melbourne IVF, 2018; Jean Hailes for Women's Health on behalf of the PCOS Australian Alliance, 2015). As a result, many women with PCOS believe that they will be unable to become pregnant (Trent et al., 2003; Jones et al., 2011).

Women with a chronic condition such as PCOS often seek reproductive health information from a range of sources, including their healthcare provider, the internet, other women with the condition, patient associations and support groups, and scientific publications (Holton et al., 2012). However, they frequently report that they are unable to access reproductive health information relevant to their needs (Avery and Braunack-Mayer, 2007; Ching et al., 2007; Meneses et al., 2010; Holton et al., 2012).

A recent Australian study concluded that women with PCOS need nuanced information about their fertility potential because, although they may experience fertility difficulties due to their condition, many conceive spontaneously (Holton et al., 2018). To avoid unplanned pregnancies women with PCOS need to be aware of this and the need to use reliable contraception if they do not want to conceive.

The findings of other studies also highlight the need for high-quality condition-specific reproductive health information for women with PCOS. Many participants in a study which investigated quality of life in Australian women with PCOS rated the information they had received about PCOS and fertility as poor (33%) or fair (31%) (Ching et al., 2007). A study of a community-based sample of reproductive-aged women in Australia who had a medical diagnosis of PCOS found that more than half of the respondents (57%) reported dissatisfaction with

the information about PCOS and fertility provided at diagnosis (Gibson-Helm et al., 2014). Similarly, another Australian study reported that many of the women surveyed were highly dissatisfied with the information they had received and reported difficulties discussing many aspects of PCOS with their healthcare providers (Khan et al., in press 2018). A review of 15 PCOS information websites found that none provided complete information about the condition (Mallappa Saroja and Hanji Chandrashekar, 2010). Women with PCOS who participated in a study conducted in the UK also expressed frustration over the lack of information provided by healthcare providers about their condition (Kitzinger and Willmott, 2002). A qualitative study of reproductive-aged women with PCOS (diagnosis confirmed by Rotterdam criteria) living in the UK found that most women reported a lack of information from their healthcare providers and insufficient advice and assistance about fertility (Tomlinson et al., 2017). These findings suggest that many women with PCOS have unmet information needs.

Nevertheless, little is known about the specific fertility concerns and information needs of women with PCOS or their preferences for how and when to receive information about the effect of their condition and its treatment on fertility and childbearing.

The aim of this study was to identify the fertility and childbearing concerns and related information needs and preferences of women with PCOS.

Materials and Methods

Study design

A qualitative method was used to yield an in-depth understanding of the fertility and childbearing concerns and related information needs and preferences of women in Australia with PCOS. Using Facebook as the online platform, a discussion group was held with women of reproductive age who have PCOS. We have previously used this method successfully to

identify barriers to effective fertility management among women and men in Australia (Holton *et al.*, 2016), and the childbearing concerns of women with cystic fibrosis (Holton *et al.*, under review). Social networking sites, such as Facebook, are extremely popular; it is estimated that there are more than 15 million active Facebook users in Australia (more than 60% of the Australian population) (Social Media News Australia, 2018). The use of Facebook as the platform for the discussion group enables participation at times that suit participants. Facebook is also easy to access via personal computers, smartphones and tablets, removing the need for a physical venue for data collection and is a space in which people are comfortable and open to discussing their ideas and opinions.

Sample and recruitment

Women with a self-reported diagnosis of PCOS aged 20–40 years living in Australia who are Facebook users and can write and speak English were invited to participate in the study via targeted advertisements on Facebook.

Procedure

A 'closed' (private) group was created on Facebook. Potential participants requested permission from the convener (SH) to join the group.

In May 2018, an advertisement (Fig. 1) briefly describing the research and discussion group was placed on the Facebook pages of all users meeting the eligibility criteria. Age was identified from the user's profile (a

mandatory field on all personal Facebook accounts), and location was established from the Internet Protocol Address (IPA; Facebook, 2017).

Those who clicked on the advertisement were taken to the project page where details about the research and what participation involved was provided. Women who wanted to participate requested to join the group by clicking on a link on the Facebook project page.

In order to develop a summary of group members' characteristics, participants were also asked to provide demographic information in a brief online anonymous survey located outside the group discussion.

A discussion guide was used to initiate and prompt discussion. It canvassed participants' fertility concerns, preferred sources of reproductive health information, and their perspectives about which types of resources would be most helpful, acceptable and feasible to assist women with PCOS make informed reproductive decisions.

Participant responses were read daily by the moderator (SH) and regularly discussed by the research team. The moderator asked additional or clarifying questions as appropriate and did not censor personal anecdotes. Members of the group also commented on each other's posts. The moderator posted a new question every few days.

Data management and analysis

The transcript of the group discussion was copied from Facebook and pasted into a Word document. Participants were identified in the analysis by number only. Transcripts were analysed using thematic analysis techniques commonly used in qualitative research (Braun and Clarke, 2006). The analysis was conducted by the first author and interpretations discussed within the research team until consensus was reached. Quotes have been used in the text to illustrate the findings.

Ethical approval

The main ethical considerations were privacy and voluntary participation. Facebook allows users to determine how much of their personal information is publicly displayed. Profile security settings can be public (that is, allowing access to the complete profile by any Facebook user) or private (that is, limiting access of some or all profile information). Participation in the group was voluntary, and participants could withdraw at any time. A request to join the group was taken as informed consent to participate.

The project was approved by the Monash University Human Ethics Research Committee (14 May 2018, Project Number: 13735).

Results

Participants

The Facebook advertisement (Fig. 1) reached 2333 women and resulted in 122 post-engagements, such as commenting on or sharing the advertisement, or clicking on the link to the Facebook page. Thirteen women who had seen the Facebook advertisement requested to join the group. All requests were accepted. The group ran for 3 weeks, from 21 May 2018 to 8 June 2018.

Demographic data were provided by all participants. As the survey which collected the demographic data was anonymous, it was not possible to distinguish the demographic information of participants who contributed posts on particular topics from those who did not, or associate demographic information with individual posts.

The mean age of participants was 30.8 years (22–43 years), and the mean age at PCOS diagnosis was 23.5 years (15–31 years). Most participants were born in Australia and had completed a post-secondary school qualification such as a certificate, diploma or university degree.

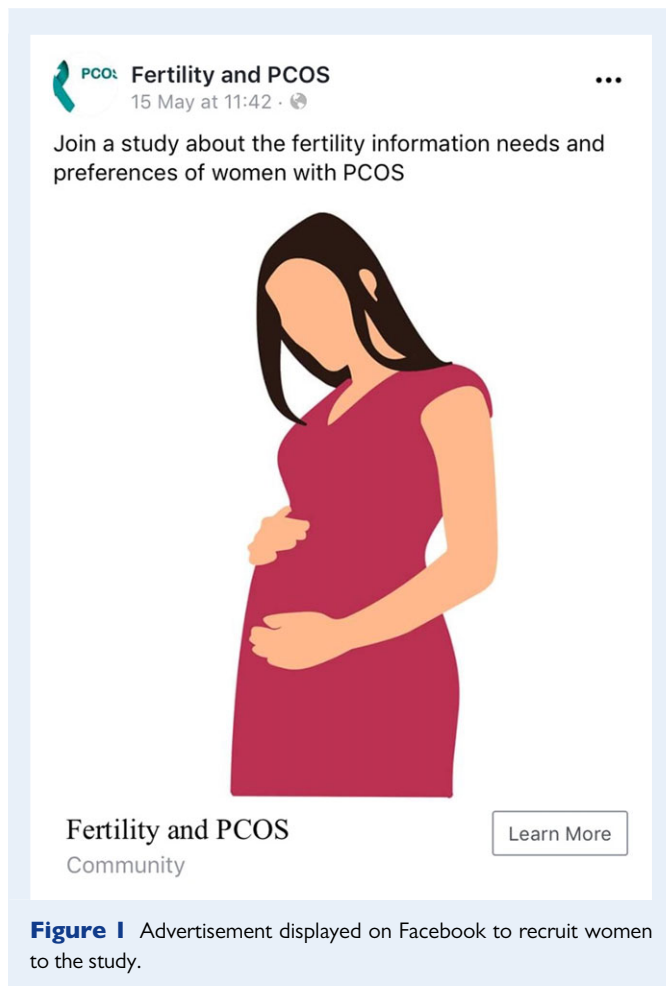


Figure 1 Advertisement displayed on Facebook to recruit women to the study.

More than two-thirds were married or living in a heterosexual relationship while two (18.2%) were not currently in a relationship. More than half of the participants lived in a metropolitan location, and most lived in an area of socioeconomic advantage (Table I).

More than two-thirds of the participants ($n = 9$, 69.2%) had tried to get pregnant, the remaining four had not. Of those who had tried to conceive, four had been successful but five remained childless. No participant stated that they did not want children, and most said that their ideal number of children was between 1 and 4 (mean = 2.3). However, there was a discrepancy between participants' ideal number of children and their expected number of children. In general, the number of children participants thought they would actually have was lower than the number they desired. None of the participants reported an unplanned pregnancy, and of those who had attempted to conceive (9/13), almost two-thirds stated that they had tried to conceive for longer than 12 months (Table I).

Key themes

Guided by questions posted by the moderator, the discussion focused on two areas: the fertility and childbearing concerns of women with PCOS; and women's needs and preferences for fertility information. Analysis revealed several themes related to each of these aspects of fertility.

Table I Demographic characteristics and reproductive experiences of women with polycystic ovary syndrome who participated in the online survey.

Characteristic	Participants (N = 13)
Mean age (range)	30.8 years (22–43 years)
Mean age at PCOS diagnosis (range)	23.5 years (15–31 years)
Born in Australia	11 (84.6%)
Has a post-secondary school qualification	11 (84.6%)
Partnered	9 (69.2%)
Live in a metropolitan location	7 (53.8%)
Socioeconomic status	
Mean SEIFA ^a score	1012.4 (929.0–1117.1)
Live in an area of socioeconomic advantage	7 (53.8%)
Tried to get pregnant	9 (69.2%)
Number of children	
0 children	9 (69.2%)
1 child	2 (15.4%)
2 children	2 (15.4%)
Mean ideal number of children (range)	2.3 (1–4)
Mean expected number of children (range)	1.5 (0–3)
Unplanned pregnancy	0 (0.0%)
Tried for more than 12 months to conceive	6 (66.6%)

PCOS: polycystic ovary syndrome.

^aA Socioeconomic Index for Advantage and Disadvantage (SEIFA) score (Australian Bureau of Statistics, 2013) was assigned to each respondent's residential postcode. SEIFA is a standardised measure of advantage and disadvantage.

Fertility and childbearing concerns

Participants identified a number of concerns that women with PCOS have about fertility and childbearing. These were mainly related to whether they could become pregnant, and how to prepare for pregnancy or what they should do before trying to conceive given their PCOS.

Theme 1.1: concerns about achieving a pregnancy. Participants worried that it would be 'difficult' for them to conceive given their condition.

I am aware that it might take me way longer than average [to conceive] or require medical intervention. (Participant #1)

[Even though] we now have a very healthy 3 month old baby girl, I do still worry about becoming pregnant. (Participant #5)

My GP has said that being 24 [years old] I shouldn't be worried about starting a family, I am worried though. ... I am worried [because I have PCOS] I'll never have children. ... [I've been told by health care providers] that natural conception could be difficult. (Participant #6)

Theme 1.2: preparing for pregnancy. Participants also reported that they often found it difficult to find adequate information about what to do before trying to conceive.

I have not enough information at all. I've struggled to find a GP who will answer any of my questions. For instance, I've no idea if I even ovulate. I've no idea what PCOS treatment would look like for someone trying to conceive as all my docs have just pushed me to go on the pill, despite my explanation that we'll be looking to try to conceive within the next 1-2 years. I've been told literally nothing [about what to do before trying to get pregnant], other than to go to the doc if we've been trying for a year with no luck. (Participant #1)

I was diagnosed [with PCOS] officially after I had my first child. I wasn't given any information about fertility should I want more children though. It was only when I went back to my gynaecologist for some further testing that he mentioned there might be issues with conceiving again. He helped me to medically manage trying to conceive again when the time came. (Participant #3)

Other women had actively sought information about conceiving from their healthcare provider but were still concerned that there was more they should be doing to improve their chances of conception.

I just recently saw a new female GP in the hope to have some answers. I asked if she could assist me in creating a PCOS management plan so that I am on top of the potential issues I may have when it's time to try and conceive. I am going to be 28 soon and even though I know there is still plenty of time to have children, I fear that if I don't start preparing my body/ managing my condition now, that perhaps it will influence the successfulness of trying to conceive easily. ... She said the best thing I could do right now would be to just continue leading a healthy and balanced lifestyle to keep my weight regular and my hormones as balanced as possible. I guess what I would like to know, is this really the only thing I can be doing in the present moment to help with my fertility options in the future? (Participant #4)

Needs and preferences for fertility information

Participants identified their current sources of fertility information as well as their preferred types, sources and timing of fertility information.

Theme 2.1: current sources of information. Participants reported seeking information about fertility and PCOS from a range of sources including their healthcare provider, other women with PCOS and the internet.

My GP has been very supportive and has given me a lot of information. (Participant #5)

I have found information but it was on the Internet. ... [and from] other women with PCOS (family and friends) [and] I just joined a PCOS support group on Facebook. (Participant #6)

Theme 2.2: preferred types and sources of information. Participants had differing views about the best types and sources of fertility information for women with PCOS. Some preferred fact sheets whilst others wanted a 'trusted' website or podcasts with a health professional. Nevertheless, all agreed that 'detailed', 'reliable' information resources based on medical evidence would be the most useful.

I don't want videos, fact sheets, or podcasts. I feel like these formats often totally lack detail and are very generalised. (Participant # 1)

I find government/doctor type fact sheets lacking in information/specificity but find academic papers too information dense/specific. I want something in between which is just a good overview of the known science, treatment options, symptoms, etc all in one place. (Participant # 1)

I'd prefer well written fact sheets. (Participant # 2)

I'd prefer fact sheets or podcasts with a doctor. YouTube videos wouldn't be what I'd find 'reliable' information, as I'd be wondering about how different that woman's situation is to mine. A trusted website with information I can access when I feel I'm ready that ends with who wrote that article and what their qualifications are. (Participant # 3)

Theme 2.3: preferred timing of information. Women's preferences for the timing of fertility information varied. Some women preferred to receive information just before needing it, such as when considering pregnancy, whilst others would have liked information at the time they were diagnosed with PCOS.

I personally think that as soon as you are diagnosed, your GP or specialist should explain clearly the best process for you to manage your condition for your specific individual needs regardless of whether you are in the position of trying to conceive or not. I think it would give peace of mind knowing all of the information as soon as possible so that you are aware of everything you can be doing prior to trying to fall pregnant. (Participant # 4)

I think with diagnosis should come the relevant information not only about ongoing management but also how [PCOS] may affect fertility. ... a discussion with your healthcare provider is good but needs to be supplemented with printed materials as there is so much information to take in at diagnosis. (Participant # 3)

I think it would be best to get the information way before thinking about falling pregnant if possible to then create a healthy lifestyle to have the best chance and to be mentally prepared it may not be easy. (Participant # 5)

Participants also commented that it would be useful to 'revisit' fertility information with their healthcare provider each time they considered pregnancy even if they had already conceived successfully in the past.

Discussion

This study found that women with PCOS are concerned about fertility and childbearing mainly because they believe that it will be difficult for them to conceive. They want to be better informed about the impact of their condition on their reproductive capacity but find it challenging to access reliable, relevant and timely information. They identify a particular need for information about what actions they should take, given their condition, before attempting to become pregnant in order to

increase their chances of conceiving. Women with PCOS want evidence-based information provided in a variety of formats including fact sheets, trusted websites and podcasts with health professionals.

PCOS is associated with difficulties conceiving (Melo *et al.*, 2015; McDonnell and Hart, 2017) and, consistent with another recent Australian study (Varanasi *et al.*, 2018), one of the main concerns of women in this study was whether or not they could become pregnant. Similar to the findings of other studies (Snyder, 2006; Avery and Braunack-Mayer, 2007; Crete and Adamshick, 2011; Satveit, 2017), women with PCOS in this study found it difficult to access information about their condition and its reproductive implications. In particular, women reported wanting information about self-management strategies to increase their chances of conception.

Optimising health in the preconception period is crucial to increasing the chances of conception (Dorney and Black, 2018), particularly for women with PCOS. Conception for women with PCOS often requires a multifaceted approach that includes lifestyle interventions, pharmacological treatments or ART (Artini *et al.*, 2018). According to the international evidence-based guideline for the assessment and management of PCOS, factors such as weight, smoking, alcohol, diet, exercise, sleep and mental, emotional and sexual health need to be optimised in women with PCOS in order to improve reproductive and obstetric outcomes (Teede *et al.*, 2018).

Strengths and limitations of current study

The use of Facebook as the platform for the online discussion group was an efficient and cost-effective way to engage women from diverse locations in Australia. Another benefit of using an online discussion group was that, unlike with traditional face-to-face focus groups, the participants and researchers had time to read comments and reflect before responding (Lijadi and van Schalkwyk, 2015). Nevertheless, it has been suggested that non-verbal communication, such as facial expressions and body language, is not captured in online discussion groups and that this may affect the quality and depth of data obtained (Stewart and Williams, 2005; Graffigna and Bosio, 2006). Yet, consistent with the findings of Lijadi and van Schalkwyk (Lijadi and van Schalkwyk, 2015), we found that the discussion in our online discussion group was dynamic and participants commented both positively and negatively on each other's posts. We also summarised and paraphrased participants' posts to ensure accuracy and that nuances were not lost or comments misinterpreted, monitored the interaction between participants and attempted to maintain the flow of the online conversation.

Similar to Lijadi and van Schalkwyk (2015), we also found that participants used other forms of 'non-verbal' communication in their posts such as emoticon applications including the 'Facebook like - thumbs up', 'sad face', 'smiley face' and 'love heart' emoticons. These added richness to the participants' comments and data, similar to non-verbal cues in a traditional face-to-face discussion group.

Due to the relatively small sample size and recruitment of participants via advertisements on Facebook, women who participated in the study may not be representative of women with PCOS in the general population. Women currently contemplating childbearing or who have recently had children or fertility difficulties may also have been more likely to participate in the study. Women in this study self-reported PCOS, and this may not necessarily reflect a confirmed

diagnosis of PCOS. No formal diagnostic criteria (for example, National Institutes of Health, Rotterdam) were used to confirm their PCOS status.

Implications for policy/practice

The findings of this study suggest that women with PCOS would benefit from evidence-based information in a range of formats to help them make informed decisions about childbearing and achieve their reproductive goals. Preconception care, including counselling and information about appropriate interventions and self-management strategies to optimise health and improve chances of conception, may be of particular assistance to women with PCOS.

Conclusion

This study found that women with PCOS have concerns about fertility and childbearing and want to be better informed but often find it difficult to access reliable, relevant and timely information. Women identified a need for evidence-based information so that they can make informed decisions about having children and achieve their reproductive goals. The women with PCOS in this study appeared to prefer information delivered in ways that take advantage of new technology, including the internet and podcasts, as well as printed materials (fact sheets).

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Authors' roles

All authors contributed to the study design. S.H. and K.H. contributed to data analysis, interpretation of results, manuscript write-up and management of the study. L.J. contributed to manuscript write-up and revisions of the manuscript. All authors read and approved the final manuscript.

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