

Women's experiences of diagnosis and management of polycystic ovary syndrome:

a mixed-methods study in general practice

Abstract

Background

Polycystic ovary syndrome (PCOS) is a common lifelong metabolic condition with serious associated comorbidities. Evidence points to a delay in diagnosis and inconsistency in the information provided to women with PCOS.

Aim

To capture women's experiences of how PCOS is diagnosed and managed in UK general practice.

Design and setting

This was a mixed-methods study with an online questionnaire survey and semi-structured telephone interviews with a subset of responders.

Method

An online survey to elicit women's experiences of general practice PCOS care was promoted by charities and BBC Radio Leicester. The survey was accessible online between January 2018 and November 2018. A subset of responders undertook a semi-structured telephone interview to provide more in-depth data.

Results

A total of 323 women completed the survey (average age 35.4 years) and semi-structured interviews were conducted with 11 women. There were five key themes identified through the survey responses. Participants described a variable lag time from presentation to PCOS diagnosis, with a median of 6–12 months. Many had experienced mental health problems associated with their PCOS symptoms, but had not discussed these with the GP. Many were unable to recall any discussion about associated comorbidities with the GP. Some differences were identified between the experiences of women from white British backgrounds and those from other ethnic backgrounds.

Conclusion

From the experiences of the women in this study, it appears that PCOS in general practice is not viewed as a long-term condition with an increased risk of comorbidities including mental health problems. Further research should explore GPs' awareness of comorbidities and the differences in PCOS care experienced by women from different ethnic backgrounds.

Keywords

diagnosis; general practice; patient experience; polycystic ovary syndrome.

INTRODUCTION

Polycystic ovary syndrome (PCOS) is a multisystem condition that is typically characterised by hyperandrogenism, ovulatory dysfunction, and polycystic ovarian morphologic features on ultrasound. Women with PCOS may seek advice or treatment in primary care for various conditions that are associated with the syndrome, including infertility, miscarriage, obesity, type 2 diabetes, sleep apnoea, hirsutism, and acne.^{1–3} PCOS can adversely affect mental health,^{4,5} and carries an increased risk of endometrial hyperplasia and non-alcoholic fatty liver disease.^{6,7} According to the NHS website: *'It's difficult to know exactly how many women have PCOS, but it's thought to be very common, affecting about 1 in every 5 women in the UK.'*⁸

Evidence suggests that lifestyle changes for women with PCOS (in particular, diet, exercise, and behaviour) can reduce obesity, clinical hyperandrogenism, and many of the symptoms and risks associated with PCOS.⁶

However, evidence is lacking as to whether lifestyle/weight modification is routinely discussed in UK general practice in relation to having PCOS. Likewise, it is not known whether the potential long-term consequences of PCOS are discussed routinely with women who are living with the condition, and if PCOS is viewed as a multisystemic long-term health condition that requires long-term follow-up.

A retrospective cohort study published in 2016 using UK primary care databases found that almost 50% of women with PCOS are underdiagnosed.⁹ Another study published in 2017 described that women report a considerable delay between when they first present with PCOS-related problems and a definitive diagnosis being made, and that they are often dissatisfied with the information and advice that healthcare professionals provide about the condition.¹⁰ However, the study concentrated on patient satisfaction about PCOS diagnosis and management, and was based on an international cohort that included patients from both primary and secondary care.

Even though most women with PCOS in the UK are managed in general practice, there is limited information about detection, diagnosis, management, and women's experiences. Hence, the current study aimed to explore women's experiences of how their PCOS was diagnosed and managed in general practice in the UK. The objectives were to establish who made their diagnosis, how long the 'lag time' was to diagnosis, what information was provided by GPs regarding their diagnosis and its associated comorbidities, how the condition was managed by the GP, the effects PCOS has had on the patient's fertility and mental health, and whether they discussed these effects with their GP.

METHOD

Data about women's experience of PCOS care in general practice were collected using

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How this fits in

Polycystic ovary syndrome (PCOS) is a lifelong condition with serious associated comorbidities. Recent evidence points to delays in diagnosis and a lack of trust by women with PCOS towards their primary care providers. This study explores women's experiences of how PCOS is diagnosed and managed in UK general practice. Women's experiences suggest that PCOS is not viewed as a multisystem hormonal imbalance with serious associated long-term comorbidities and a strong association with mental health problems. Instead, for some women, too much emphasis is placed on the reproductive problems attributed to PCOS. Further research should focus on increasing GPs' awareness of PCOS-associated comorbidities and the chronic, multisystem nature of the condition. Further research is also needed to explore how ethnicity impacts on the experiences of women with PCOS.

a mixed-methods approach with an online survey and one-to-one semi-structured interviews. This enabled triangulation of the data to add depth to the findings.

Online survey

A detailed 36-item survey was developed by two of the authors, drawing on a literature review looking at patient satisfaction in PCOS and diagnosis delay. The survey was revised following comments from members of the charities Verity and Fertility Friends. It was piloted for comprehensibility with staff at Warwick Medical School (more information available from the authors on request).

The survey was accessible online between January 2018 and November 2018, and was promoted through the social media site Mumsnet and the Facebook pages of the charities Verity, Ladies' Circle, and Fertility Friends Network. It was also promoted through the diabetes support organisation (<https://www.diabetes.org.uk>). To encourage participation by women of varied ethnic backgrounds, it was promoted on BBC Radio Leicester alongside an interview with a British Indian woman living with PCOS.

The survey included binary questions, multiple-choice questions, open-ended free-text questions, and Likert scales. It captured participants' age, ethnicity, the region in which they resided (grouped as North England, South England, Midlands, and devolved nations), age when first

presented with a PCOS-related symptom to general practice (grouped as ≤ 15 years, 16–25 years, and 26–35 years), lag time between first symptom(s) and diagnosis (grouped as ≤ 2 years, 3–5 years, and >5 years), and years since diagnosis was made (grouped as ≤ 2 years, 3–10 years, and >10 years). The survey covered the diagnosis of PCOS and its management in general practice, problems with fertility, mental health, and comorbidities, and whether these were discussed with their GP.

Semi-structured interviews

Semi-structured interviews were carried out with women recruited either as a result of volunteering on completion of the survey, or having seen the research promoted on the social media pages of PCOS charities or through local radio. All women who requested to be recruited were interviewed. An interview guide for the semi-structured interview was designed to add depth to the survey findings (more information available from the authors on request). Interviews were conducted over the telephone by one of the authors who has a background in qualitative methodology, and were transcribed verbatim.

Data analysis

Descriptive statistics were used to summarise the answers to the survey. A total of 25 bivariate analyses were conducted with χ^2 tests between demographic characteristics (ethnicity, area of UK, age of first symptom, lag time since diagnosis, years since diagnosis) and survey answers (yes or no). $P < 0.05$ was considered statistically significant. Logistic regression models were conducted when bivariate analyses indicated that more than one demographic characteristic was significantly associated with a survey question. All statistical analyses were conducted using Stata (version 15).

Data from the free-text answers in surveys and the semi-structured interviews were analysed using framework analysis.^{11,12} To gain familiarisation of the interviews, transcripts were read and re-read by two authors. Key concepts and recurrent themes were noted.

A thematic framework was then built from the identification of themes and subthemes, and applied to the data. The framework was refined as transcripts were added, and was agreed between two authors.

The analysis was an iterative process and it was believed that data saturation was reached. All text was indexed numerically

Table 1. Characteristics of women participating in the online survey

Demographic characteristics	Sample size, n ^a	%
Age, years		
Mean 35.4 (range 19–51, SD = ±6.9)	267	
Ethnicity	269	
White British	165	61.3
British Asian	84	31.2
Other	20	7.4
Region of residence	240	
North England	29	12.1
Midlands	76	31.7
South England	110	45.8
Devolved nations	25	10.4
Diagnosis made by	290	
GP	113	39.0
Specialist	88	30.3
Participant	51	17.6
Friend/family member	38	13.1
BMI		
Median 30.8, IQR 25.9 to 35.8	254	
Underweight (<18.5)	2	0.8
Normal weight (18.5–25)	48	18.9
Overweight (25–30)	68	26.8
Obese (>30)	136	53.5

^aParticipants did not complete all questions hence why the number of responders has been given for each question. BMI = body mass index. IQR = interquartile range. SD = standard deviation.

Box 1. Key themes

1. Symptoms, signs, and associated conditions of polycystic ovary syndrome (PCOS)

- 1a Fertility
- 1b Weight
- 1c Associated conditions (including mental health)

2. Information and diagnosis

- 2a Receiving the diagnosis
- 2b Information

3. The GP and PCOS

- 3a Significance placed by GP on having PCOS
- 3b Common condition
- 3c Sex of the GP
- 3d GP as gatekeeper

4. Treatment for PCOS

- 4a Pharmacology
- 4b Self/lifestyle as treatment
- 4c Peer support as treatment
- 4d Treat symptom not root cause

5. Women's emotional relationship with PCOS

- 5a Having hope
- 5b Blame
- 5c Women's ongoing relationship with PCOS
- 5d PCOS: it's all in a name
- 5e Taboo subject

using the framework, with numbers placed in the margin beside the text, and were charted using Excel. To support the triangulation of findings, the quantitative and qualitative analysis were synthesised under the thematic framework, including statistically significant findings.

RESULTS

Participant characteristics

A total of 334 women completed the survey; 11 participants were subsequently excluded because they lived outside of the UK and hence their care experiences were not directly relevant to this study, leaving a final sample of 323 women. Participant characteristics are presented in Table 1.

Participants did not complete all questions hence why the number of responders has been given for each question. The mean age of responders was 35.4 years (range 19–51 years, standard deviation [SD] = ±6.9 years), most were white British ($n = 165$, 61.3%), and almost half resided in the South of England ($n = 110$, 45.8%).

Almost a third ($n = 89$, 30.7%) stated that they had either made the diagnosis themselves or that it had been a friend or family member who had suggested the diagnosis. The median body mass index

(BMI) (self-reported) was 30.8 (interquartile range 25.9 to 35.8).

Telephone interviews were conducted with 11 women (median age 36.0 years, SD = ±7 years), of whom six identified as white British and five as British Asian.

Each interview lasted between 15 minutes and 45 minutes; the mean length was 21 minutes.

Bivariate analyses

The ethnicity of women with PCOS was associated with discussing fertility and mental health problems with their GP.

The age at which a woman first approached a GP with a PCOS symptom was associated with discussion about mental health problems with the GP. These are described in greater detail later in the article (more information is also available from the authors on request).

Key themes

There were five key themes identified through the survey (free-text comments) and the interviews, and these are listed along with their subthemes in Box 1.

Quotations that are indicative of the themes are presented in the discussion below.

Theme 1: Symptoms, signs, and associated conditions of PCOS

Fertility. Many women described their experience of the signs and symptoms of PCOS. The key feature for most was fertility and their hope and uncertainty around having children. Survey responses showed that 69.6% ($n = 199/286$) of women said they had discussed their fertility with a GP, and 71.0% ($n = 198/279$) reported having problems with their fertility.

Women described the difficulties and delay they had experienced in conceiving, and how this had elicited positive, proactive help from their GP or a negative response with feelings of dismissal:

'My GP was actually lovely and said that for most women with PCOS it is a "when" not "if" you will have a baby. She said that even though we had only been trying for 8 months, because I had had no period at all she would push for an early referral to the fertility clinic.' (Survey response)

'We were trying for a baby and it had been 6 months and so far there'd been nothing and she said "oh, all you need to is just keep trying. You know, lots of sex." ... So then, I felt kind of brushed off at that point.' (Participant [P]1)

Some felt that the emphasis when discussing PCOS with their GP, family, or friends was often too focused on fertility. There may have been other features of the condition that women wanted to discuss with the GP:

'As someone who isn't particularly inclined to have children, I thought it [the consultation] was a bit too focused on fertility rather than some of the symptoms [of PCOS] ... almost like they were secondary to the fertility thing.' (P2)

Women who had not discussed fertility with their GP were asked why they had not discussed this. They explained that they themselves deemed it to be irrelevant, that the topic was not raised either by themselves or the GP, or that it had been addressed by a specialist in hospital; however, many women described being unsure why it had not been discussed.

Bivariate analysis showed that women who identified as being white British were significantly more likely to discuss their fertility (75.8%, $n = 125/165$) than women who identified as being British Asian (60.7%, $n = 51/84$) or other ethnicity (55.0%, $n = 11/20$) ($P = 0.038$).

Weight. PCOS is often associated with increased body mass. Of those who completed the survey, 80.3% ($n = 204/254$) of women reported a BMI that was consistent with being overweight or obese. Only 33.8% ($n = 23/68$) of women with a BMI classified as overweight and 49.3% ($n = 67/136$) of women with a BMI classified as obese recalled that weight loss was explored by their GP as a treatment option for PCOS.

Improving PCOS symptoms were described by many women as a motivator for losing weight; however, PCOS lends itself to difficulties in losing weight and being in a perpetual weight loss, weight gain cycle. Many women wanted help with weight loss, including direction by their GP to resources that might help:

'I am always trying to control my weight.' (Survey response)

Associated conditions (including mental health). Women were asked if their GP discussed health conditions that may be associated with PCOS. Only 19.0% ($n = 53/279$) of women could recall any such discussion. Women spoke about the associated long-term health conditions in PCOS, such as diabetes and, to a lesser extent, cardiovascular risk, mental health

problems, and endometriosis; however, no participant recalled a higher rate of endometrial hyperplasia, sleep apnoea, or non-alcoholic fatty liver disease being discussed. They also described (both within the interviews and survey) how the effects and signs of PCOS, particularly hirsutism and acne, affected their daily life, their mental health, and, in particular, their feelings around femininity:

'But you don't look like, you know, you actually look like a woman, but you look at your face you look like a bloke ... it the facial hair, the being fat that doesn't help ... you don't feel like a complete woman.' (P9)

While 74.9% ($n = 209/279$) of women completing the surveys reported that having PCOS had adversely affected their mental health, only 34.9% ($n = 97/278$) recalled discussing this with their GP. Bivariate analysis showed that both ethnicity and age of first symptoms were significantly associated with discussing their mental health with their GP. White British women with PCOS were more likely to discuss their mental health with their GP compared with British Asian women (odds ratio [OR] = 1.66; 95% confidence interval [CI] = 1.04 to 2.63).

Women who were older when they first presented with symptoms of PCOS (aged ≥ 25 years) were less likely to discuss their mental health with their GP compared with younger women (aged < 25 years) who presented with first symptoms of PCOS (OR = 0.64; 95% CI = 0.41 to 0.98). It was not apparent from the qualitative data why ethnicity or age at presentation of first symptoms would determine whether a woman discussed her mental health with her GP.

Theme 2: Information and diagnosis

Participants' recollection of the lag time between first presenting to the GP with symptoms and receiving a diagnosis of PCOS from a healthcare professional ranged between < 1 week and > 10 years (median 6–12 months).

Some women felt that they should have presented to the GP with the symptoms earlier, or been more assertive in asking for a diagnosis as they had established that PCOS was likely:

'If I could go back in time and be that positive person I am now, if I'd just put my foot down and said, "I'm really worried about this can you test me?":' (P3)

Many women felt that they were not provided with enough information about PCOS following diagnosis, particularly around the management of the condition and longer-term risks. Some suggested this was due to the general lack of evidence around PCOS and the need for more research, while others suggested that it was due to their GP's lack of knowledge around PCOS:

'[patients should be] given advice on long-term risks and management of PCOS rather than only short-term dealing with fertility.' (Survey response)

Many viewed knowledge as an enabler to help them take control of their condition. The general need for follow-up consultations with their GP was discussed and that a one-off appointment was felt to be inadequate. Suggestions for increasing awareness around the condition included public health campaigns and education in schools:

'I was at school noticing these sorts of things ... but there is no mention of things that could be going wrong or any education around it.' (P2)

Theme 3: The GP and PCOS

Most women (83.1%, $n = 231/278$ of those completing the survey) felt that their GP could have done more to help regarding their PCOS.

They described positive experiences where they had felt the diagnosis had been taken seriously and they had been listened to, and conversely when their condition and experiences were felt to have been trivialised:

'They said "It's very common to have irregular periods and as for the facial hair, it's very common, maybe I have Spanish ancestors", which I think was the worst thing I was told by a GP.' (P3)

'Listen to me carefully, try to understand the inner turmoil I was going through.' (Survey response)

The relatively high prevalence of PCOS was perceived by women as something that may have led to their diagnosis being underplayed by GPs.

The GP was described as a gatekeeper who could be obstructive, particularly in gaining access to specialist PCOS or fertility services:

'I know the ladies in the group [a Verity group] have helped each other write official

letters to GPs saying "look, I've got this, this, and this; it's pretty clear to me what it is, is it possible to have this referral?" ... There seems to be a bit of a barrier, for whatever reason, to refer.' (P8)

Theme 4: Treatment for PCOS

Women spoke about the medications they had been prescribed to help them live with PCOS. In particular, they felt that antidepressants were overprescribed:

'All they did was give you antidepressants ... it doesn't actually solve anything 'cause once you're off the course, you're back to square one, nothing has resolved.' (P9)

Women described reaching a conclusion that they themselves were part of the treatment (in terms of lifestyle adjustments) and that peer support was also important to their wellbeing. There was also a dialogue around the need to find a 'root cause' for their PCOS as opposed to taking medication:

'I don't want to be pumped full of medication, I want someone to tell me why I have got this ... go to the source and treat the problem.' (P6)

Theme 5: Women's emotional relationship with PCOS

Women spoke about having hope for the future in contrast to the uncertainty associated with PCOS and its potential effects on fertility. They described blaming themselves or their genetic make-up for the condition:

'My first thought was I'm faulty.' (P1)

Women described an ongoing relationship with the condition as a chronic lifelong entity, often comparing living with the condition as a 'battle' or 'struggle':

'It's a daily battle. Some things are positive, some things are negative, but I think I've learnt to live with that. You know, it's part of me. I won't let it define me, though.' (P10)

Many felt that the term 'polycystic ovary syndrome' did not capture the broader aspects of PCOS, placing too much emphasis on ovaries and fertility:

'People think ovaries, they assume fertility, they don't always think hormone imbalance.' (P2)

Some women also described the fact that PCOS was associated with stigma and

not widely discussed. This emerged from the interviews, and seemed to be more of an issue for women from a British Asian background:

'I'm Asian and a lot of women ... I've never ever heard any female talk about a period problem before.' (P1)

DISCUSSION

Summary

This study has described women's experiences of how PCOS is diagnosed, treated, and managed in general practice in the UK. Triangulation, using two data collection methods, led to the emergence of five key themes. In line with the study objectives, the diagnosis of PCOS was mostly made by a GP or hospital specialist, but often it was made by the woman herself or by a friend or family member who first suspected it. From the participants' perspectives, potentially serious associated comorbidities had been inconsistently considered, screened, and followed up in general practice, with only 19.0% of women recalling any comorbidities being discussed at all. Instead, some women described feeling that their condition is trivialised by healthcare providers, including GPs. Women often did not recall weight loss being explored as a management option for PCOS, even for women with self-reported BMIs that are in the overweight or obese category, and felt that advice and signposting towards weight loss strategies was often lacking. Most participants believed that more information about PCOS and follow-up for the condition are needed.

Although fertility was important for many women with PCOS, the study found that some women believed too much emphasis was placed on PCOS being a 'reproductive health' condition. Participants described mental health problems associated with PCOS, but often these had not been disclosed to GPs or been enquired about, so they had not received help from their GP. A woman's ethnicity affected whether she spoke about her fertility or associated mental health problems with the GP.

Strengths and limitations

To capture the experiences of women with PCOS in general practice across the UK the project was advertised through social media and a local Leicester radio station (BBC Radio Leicester), and women were allowed to complete the survey anonymously. This enabled national participation and so allowed experiences from a diverse range of healthcare providers to be included;

however, recruiting through charities and the radio may have biased participation to those who have had a particularly positive or negative experience. Recruitment through general practice may instead have allowed for more diverse recruitment, as well as reaching those who do not use social media, but who may have been biased towards practices with an interest in PCOS.

Research investigating recruiting participants to healthcare studies via social media found that significantly more participants were university educated, had greater psychological distress, and live in a disadvantaged neighbourhood compared with a population-based sample.¹¹

The women who completed the survey were mostly white British or British Indian, with other ethnicities relatively under-represented. The survey was completed by a relatively small sample and was not powered to look for difference in response by ethnicity. The sample size for semi-structured interviews was small but data saturation was reached and common themes were also found within the free-text questions embedded in the survey. Despite being a small sample size, the group was geographically diverse and the ethnicity of participants mirrored those who completed the survey.

This work focused on women's experiences rather than GPs' experiences of managing women with PCOS. Many women believed they had self-diagnosed the condition. It may be that GPs do not volunteer as much information if they perceive the patient to be an 'expert'. Exploring this would require separate research where GPs are asked how they feel they manage the condition and the facilitators and barriers they experience when giving information to patients.

Comparison with existing literature

Research previously published in this area has not distinguished between women's experiences of PCOS diagnosis and management in primary and/or secondary care.¹⁰ This is the first time that the experiences of women with PCOS have been explored specific to UK general practice, and drawing on qualitative interview data added further depth to the findings.

As with previous studies,¹⁰ women were dissatisfied with the amount of information provided regarding the condition and how it can be managed. This may in part account for why women with PCOS have reported greater overall distrust in their primary care providers' opinions and more disagreements

with their healthcare providers than women without PCOS.¹²

As in the current study, previous research has shown that women do not feel that they received adequate information about serious comorbidities associated with PCOS,¹⁰ and that PCOS is not viewed by their GP as a lifelong multisystem comorbid condition with serious long-term outcomes.¹⁰

In addition to confirming findings described previously about patient experience in PCOS, the current study discovered that many women feel that too much emphasis is placed on fertility. Therefore, a more holistic approach may be needed to address different concerns at different life stages.

Aligned with previous literature,^{4,5} this study found that women often experience mental health problems associated with their PCOS; however, in addition, the present study discovered that a large proportion of those who consider PCOS to have affected their mental health do not discuss this with their GP, and that women from British Indian and other Black, Asian, and minority ethnic backgrounds were less likely than white British women to discuss

their mental health problems associated with PCOS with their GP.

The present study also found that women did not recall weight loss advice as having been discussed by their GP as a management option for their PCOS, even for those whose self-reported BMIs were overweight or obese.

In contrast with previous published literature, the median lag time to diagnosis of PCOS was just 6–12 months, although the range was wide.¹⁰

Implications for research

Future work should focus on improving awareness of GPs and the public about the effects of PCOS on immediate and longer-term conditions associated with PCOS, and on interventions to reduce the risks of type 2 diabetes and endometrial hyperplasia. Further work should focus on how PCOS-associated mental health problems can be supported with attention to weight, body image, and fertility.

Research should also address how women from Black, Asian, and minority ethnic backgrounds access and experience care for PCOS.

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Ethical approval

The study was approved by University of Warwick Biomedical and Scientific Research Ethics Committee (ref: REGO-2017-2065).

Provenance

Freely submitted; externally peer reviewed.

Competing interests

The authors have declared no competing interests.

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