

The challenges with managing polycystic ovary syndrome: A qualitative study of women's and clinicians' experiences

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Abstract

Objective: To explore clinicians' and women's views and experiences with managing polycystic ovary syndrome (PCOS).

Methods: Semi-structured interviews with 36 clinicians and 26 women with PCOS. Clinicians were recruited through advertising via relevant professional organisations, snowballing and contacting clinics across Australia. Women with PCOS were recruited through social media advertising. Transcribed audio-recordings were analysed thematically using Framework analysis.

Results: Findings across women with PCOS and clinician interviews were organised into three themes. Both women and clinicians experienced 1) challenges with managing PCOS, often stemming from the disparate and wide spectrum of presentations, issues with current treatment options (including limited evidence) and the long-term nature of management. Both spoke about 2) online information about PCOS and alternative treatments, including lack of relevant information and widespread misinformation. 3) Follow-up and continuity of care, where we found notable differences between women's and clinicians' expectations.

Conclusions: This is the first study to explore both clinicians' and women's experiences with managing PCOS, illustrating several challenges in managing this heterogeneous condition.

Practice implications: Clarifying and addressing patient expectations, providing personalised counselling and information according to PCOS phenotype and a multidisciplinary approach may reduce uncertainty and improve patient-centred care.

1. Introduction

Polycystic ovary syndrome (PCOS) is a common but complex endocrine disorder affecting reproductive-aged women, with prevalence estimates ranging from 4-22.5% depending on the diagnostic criteria and population [1]. PCOS includes a wide range of heterogeneous symptoms on a spectrum of severity, and is associated with adverse reproductive, metabolic and psychological outcomes. As the aetiology of PCOS is still unclear (likely a mix of environmental factors, genetic causes and in utero exposure), treatment is focused on alleviating symptoms, which can differ substantially across women and PCOS phenotypes. Women with PCOS are more likely to be overweight, and although dependent on the population studied, insulin resistance is common [2] and appears to increase the severity of clinical features of PCOS. Studies have also found weight loss improves PCOS symptoms [3], so healthy lifestyle change is first-line treatment to improve symptoms, reduce weight and associated long-term risks (e.g. type 2 diabetes) [4]. Other symptom-specific treatments include the oral contraceptive pill for menstrual irregularities and acne, anti-androgen medications for hirsutism, and ovulation induction for anovulatory infertility. Metformin is also discussed in recent international guidelines due to the prevalence of insulin resistance [5] and appears to improve some clinical features of PCOS in overweight women [6], although beneficial effects may be similar to lifestyle intervention [7].

Clinicians have raised a number of challenges regarding PCOS diagnosis [8]. These include the lack of standardisation regarding diagnostic cut-offs, the potential for misdiagnosis due to overlap with other conditions, limitations in evidence regarding long-term implications (including by PCOS phenotype [9]) and the risk of under- and overdiagnosis [8]. Multiple diagnostic criteria are also in use despite past Australian and more recent International

PCOS Guidelines endorsing the Rotterdam diagnostic criteria [5, 10]. These uncertainties and complexities have contributed to inconsistent approaches to diagnosis, with considerable variation in care and diagnostic criteria used [11-13]. Little is known about how these challenges may impact clinicians' experiences managing women with PCOS.

Women with PCOS have also reported significant dissatisfaction with the diagnostic process, information provided and treatment prescribed [14-16], with several studies finding persistently increased psychological distress after diagnosis [17-20]. A qualitative study of 10 overweight women with PCOS found that most had difficulties losing weight and perceived PCOS as affecting their ability to lose weight and keep it off [21]. Regarding pharmaceutical treatments, a survey of women with PCOS recruited through specialist clinics found that most were dissatisfied with oral contraceptives or fertility drugs as treatment, with the majority indicating they would prefer alternative treatments [15]. Another survey of women recruited through PCOS support groups found 70% reported using complementary medicine in the previous 12 months [22].

Overall, evidence of women's and clinicians' views and experiences with managing the challenges surrounding PCOS, including barriers to management, are scarce [23]. This study aimed to explore the experience of managing PCOS for both clinicians and a community sample of women with PCOS across the spectrum of symptom severity.

2. Methods

2.1. Design

This qualitative study utilised semi-structured face-to-face and telephone interviews with 36 clinicians and 26 women with PCOS to explore views and experiences regarding the management of PCOS. Ethics approval was obtained from the University of Sydney Human Research Ethics Committee (project numbers 2017/878 and 2017/243). All participants provided written informed consent.

2.2. Participants

Clinicians included general practitioners (GPs), endocrinologists and gynaecologists currently practicing in Australia. Participants with PCOS included women self-reporting a PCOS diagnosis by a medical doctor, currently aged 18-45 years and living in Australia.¹

2.3. Recruitment

Clinician participants were recruited through advertising via relevant professional organisations (e.g. Royal Australian College of General Practitioners, Endocrine Society of Australia), active and passive snowballing, and contacting a random sample of endocrine and gynaecology teams across Australia using publicly available contact details.

Participants with PCOS were recruited through social media (Facebook) advertisements targeting general users (not those in PCOS support groups) in order to recruit a diverse sample in terms of symptom severity. The study advertisement directed interested respondents to information about the study and a form to add their contact details and demographics, including their symptoms and severity of PCOS. This information was used to purposively recruit participants across the spectrum of symptom severity, as previous studies have tended to recruit women from outpatient clinics or PCOS online support

¹ We recognise that non-binary people and people of various gender identities can be affected by PCOS. All participants with PCOS identified as women in the current study, so for the purposes of this paper, the term 'women' will be used throughout.

groups only, where women typically have more severe symptoms [24]. Recruitment stopped when preliminary analysis indicated saturation of key themes.

2.4. Data collection

The semi-structured interview guides were developed by the multidisciplinary research team, reviewed by the team's PCOS consumers, and piloted with a clinician from each specialty (for the clinician interview guide) and three women with PCOS (participants with PCOS interview guide). The multidisciplinary research team had expertise in qualitative methodology (TC, JH, DM, JJ, KM), health psychology (KM, JJ, JH, DM), clinical epidemiology (JD), general practice (JD), and obstetrics and gynaecology (AD, BM). A PCOS consumer panel contributed to developing the study methods to ensure interview topics were relevant and meaningful. The panel consisted of three women who identify across the spectrum of PCOS symptom severity.

The clinician interview guide covered thoughts and experiences with diagnosing PCOS and challenges with diagnosis and management (see Supplementary Data A). The interview guide for women with PCOS covered participants' experiences with diagnosis and management, perceived benefits and harms of receiving the diagnosis, and impact of the diagnosis on their life (see Supplementary Data B). Demographic questions were also asked at the beginning or end of each interview. We reported findings on the diagnostic process and the impact on women separately [8, 25] to enable a sufficiently detailed description of the findings. Clinician interviews were conducted by TC between September 2017 and July 2018, each lasting 20-60 minutes. Interviews with women with PCOS were conducted by TC

between April and July 2018, lasting 25-80 minutes. All interviews were audio-recorded and transcribed verbatim.

2.5. Data analysis

Framework Analysis using a phenomenological approach was used to understand participants' subjective perspectives and experiences [26]. Analysis involved a step-by-step approach with multiple researchers for both women and clinician data. The interviewer (TC) regularly met with colleagues throughout data collection to discuss salient topics as they arose. Five researchers (TC, DM, JJ, JD, JH) read a subset of transcripts to develop a list of emerging topics and salient themes, which were discussed in-depth and formed the basis of the coding framework. Framework Analysis utilises a matrix based approach, where each column depicts a theme and each row contains a participant, enabling the relationship between participants and themes to be explored [27, 28]. The interviews were then coded into their respective frameworks by TC, with iterations to the framework made as required through continuous discussion with DM and JJ. A random subset of the data (10%) was double-coded by DM to ensure consistency. Prominent themes surrounding PCOS management across both clinician and women were then synthesised and discussed to develop the interpretation of the results. Demographic information was summarised descriptively. See Supplementary Data C for the Consolidated Criteria for Reporting Qualitative Studies checklist.

3. Results

3.1. Demographic characteristics

Clinicians

The clinician participants consisted of GPs, gynaecologists (including three who were also reproductive endocrinologists) and endocrinologists, varying in years of experience in their profession. Most worked in an urban location and in a mix of both public and private practice (Table 1).

Table 1. Clinician characteristics (N=36) by specialty

Characteristic	General practitioner n=15	Gynaecologist n=10	Endocrinologist n=11
Years of experience in their profession			
<5	6	1	1
5-10	5	0	2
11+	4	9	8
Location			
Urban	9	10	11
Rural	6	0	0
Sex			
Female	11	7	8
Male	4	3	3
Sector			
Public	2	0	4
Private	11	3	0
Both	2	7	7
Diagnostic criteria used (self-report)			
National Institutes of Health (NIH; 1991)	0	0	5
Rotterdam (2003)	13	6	5
Androgen Excess and PCOS Society (AE-PCOS; 2006)	0	1	0
Clinical expertise	2	3	1

Participants with PCOS (women self-reporting PCOS diagnosis)

Mean age was 29.3 years, more than half had a bachelor degree or higher and the majority had been diagnosed with PCOS between 16-25 years of age. Participants varied widely in number of symptoms at diagnosis and self-reported severity of PCOS (Table 2).

Table 2. Women with PCOS characteristics (N=26)

Characteristic	N (out of 26)
Age at interview (years)	
18-25	9
26-30	6
31-35	6
36-40	2
41-45	3
Age at diagnosis (years)	
12-15	3
16-20	8
21-25	12
26-30	3
Education (highest completed qualification)	
School Certificate (Year 10)	1
Higher School Certificate (Year 12)	3
Diploma/ Trade certificate	6
Bachelor's degree or above	16
Symptoms and signs reported when diagnosed*	
Irregular menstrual cycles	24
Polycystic ovaries on ultrasound	23
Acne (pimples)	17
Hirsutism (excess hair)	15
Weight gain	12
Alopecia (male pattern hair loss)	2
Difficulty falling pregnant	5
Self-reported severity of PCOS*	
Unnoticeable	3
Mild	12
Moderate	8
Severe	3
Possible phenotype of PCOS**	
Oligo/anovulation, signs of hyperandrogenism + polycystic ovaries	13
Oligo/anovulation + signs of hyperandrogenism	3
Signs of hyperandrogenism + polycystic ovaries	1
Oligo/anovulation + polycystic ovaries	8

*Data from recruitment questionnaire responses[25]

**Phenotype is based on self-reported symptoms, so should be interpreted as a rough guide (n=25 as one participant reported polycystic ovaries only despite recalling her doctor diagnosing her with PCOS)

3.2. Thematic findings

Three major themes were identified across women with PCOS and clinician interviews: 1) challenges with managing PCOS, 2) online information about PCOS and alternative treatments, and 3) follow-up and continuity of care. Selected quotes are included below to illustrate themes, see Supplementary Table 1 for additional quotes.

3.2.1. Challenges with managing PCOS

3.2.1.1. No one-size-fits-all treatment and limitations with current medication options

Clinicians

Clinicians unanimously discussed the limited scientific understanding of the aetiology of PCOS, meaning that management focused on the woman's individual symptoms and treatment goals.

"In the absence of having a better diagnostic criteria, we target the things we know might improve symptoms, and that includes lifestyle measures." (Endocrinologist [Endo], practicing 7 years)

However, the multifaceted nature of PCOS and wide variability with regards to both symptom presentation and treatment effectiveness presented key challenges in management.

"I think there is a lot of heterogeneity in terms of their symptoms and how they respond to treatments and that sort of thing. And there isn't really a one-size-fits-all from a treatment perspective. So I think sometimes the biggest thing is just finding what's going to work for them." (GP, practicing 3 years)

Whilst anovulatory infertility was often considered fairly straightforward to treat, clinicians discussed several limitations in the options available for managing other symptoms such as irregular menstrual cycles, acne, hirsutism, alopecia and excess weight. Concerns included the small number of options, limited effectiveness of treatments and lack of supporting evidence for available treatments (Supplementary Table 1: QC1). For example, many clinicians discussed how the oral contraceptive pill ('the pill') and metformin (an oral anti-diabetic drug) are unsuitable for many women, medications for hirsutism are often ineffective, and that alopecia can be hard to treat and very distressing for women. Clinicians had varied views about metformin in particular, with some disagreeing with its use in PCOS, quoting limited evidence of benefit, whilst others described prescribing it regularly.

"The evidence is poor. You know, reduces your weight by half a kilogram and that's negated by the one year or 18-month mark. And really it's no better than a low carb diet and regular walking, which is something you can maintain throughout your life and you don't have to take a medicine, that doesn't cost you anything. So the main thing is I don't think metformin has much of a place." (Gynaecologist [Gyn], practicing 21 years)

Women with PCOS

Similarly, many women expressed dissatisfaction with finding adequate treatment. For example, they discussed how the pill had emotional or physical side-effects or did not improve hirsutism, or they reported intolerable gastrointestinal side-effects from metformin, resulting in cessation of treatment. A few women expressed confusion or concern about being prescribed a 'drug for diabetes' or about hearing that the pill exacerbated the risk of diabetes (QP1).

"I don't want to be called diabetic, you know?" (31 years, age diagnosed: 24)

In addition, some described feeling dissatisfied with the limited options offered by their doctor, expressing dislike at having to take medication which they felt just masked their symptoms and did not fix what many perceived was an underlying imbalance causing their PCOS.

"There was nothing really other than just the recommendation to start a contraceptive pill straightaway, that's it." (32 years, age diagnosed: 30)

Conversely, a few described positive experiences with the pill or metformin, expressing their satisfaction with management.

"I mean for me that [the pill] kind of just solved the issue that I'd been dealing with [irregular cycles] so I could just kind of forget that I had it really" (27 years, age diagnosed: 16)

3.2.1.2. Challenges with the long-term aspect of management – no quick fix

Clinicians

In addition to issues with particular medications, another important challenge frequently raised by clinicians was the long-term nature of management and loss to follow-up.

"I think getting patients to accept that this is actually a long-term illness that is going to require ongoing input from their part like, you know, we've got tablets that help with things but it's not a quick fix. It's not something that we can magically cure overnight." (GP, practicing 3 years)

Whilst the majority described recommending weight management, clinicians frequently discussed the challenges with helping women with PCOS achieve weight loss (QC2).

“Well the single most difficult thing is to get them to lose weight. That’s the hardest thing.” (Gyn, practicing 29 years)

Clinicians described barriers such as affordability and access to services (e.g. weight loss programs, dieticians, personal trainers), myths and misinformation (e.g. PCOS prevents weight loss), and the difficulty maintaining weight loss over time.

“It’s like any other chronic condition, it’s very challenging to keep people on track.”
(GP, practicing 20 years)

Women with PCOS

Although a few women described experiencing positives through focusing on weight management (QP2), many expressed frustration at being told to lose weight when they felt they had already tried everything over several years.

“Her focus was very much on if you lose weight your symptoms will improve, which is a really frustrating thing to hear as a PCOS sufferer who is having difficulty losing weight.” (34 years, age diagnosed: 22)

Similarly, lean women also described frustration at their doctors’ advice to *“keep doing what you’re doing”* and lack of alternative options to improve their condition due to their already healthy weight. For some, this resulted in feeling that clinicians did not take their condition seriously because they were not overweight.

“Usually when I tell new doctors that I have the condition they all look at me and say, you don’t look like you have PCOS, and that’s about as far as the conversation goes.”

None of them have ever offered to do anything about it” (27 years, age diagnosed: 16)

In addition to challenges with weight management, many women described how managing their symptoms was extremely time consuming (e.g. frequent hair removal), expensive (QP3) and that many improvements were short-term only. This led to frustration and despair over the lack of effective, long-term options and solutions (QP4, QP5).

“Nothing has improved in the meantime. It’s actually now at the stage where I don’t even see the gynaecologist anymore. I don’t find any benefit out of seeing them.” (32 years, age diagnosed: 30)

3.2.2. Online information about PCOS and alternative treatments

3.2.2.1. Difficulty finding relevant, high quality information

Women with PCOS

Women’s frustration with the lack of management options offered and unanswered questions about their condition resulted in searching extensively online for more information (QP6) about alternative ways to reduce their symptoms and long-term risks. However, many described feeling further confused by what they found.

“The stuff online is in two sides as well, whether you need to take stuff and whether you don’t need to. There’s not really a huge amount on how else you can manage it. Or why you have to manage it.” (22 years, age diagnosed: 21)

Some described how online support groups were a positive source of information, support and encouragement, highlighting that they were not alone in their experience.

“I was in the PCOS Australia Group and I just found connecting to other women really helpful.” (26 years, age diagnosed: 21)

Others, however, described avoiding online support groups or found them unhelpful because of the disparities in symptoms and severity.

“I’m on a support page on Facebook, which has its ups and downs really, because you don’t really get a lot of information...So something that might affect one person might not affect you and so you really have to try and not base yourself on other people.” (29 years, age diagnosed: 29)

Clinicians

Many clinicians expressed concerns about women with PCOS reading poor quality information online, particularly given the wide spectrum of severity which is not adequately captured, even on reputable sites.

“Just the potential stigmatization, people reading information online that actually doesn’t really apply to them. Because it’s such a wastebasket.” (Gyn, practicing 25 years)

Many described how the internet perpetuated myths and misinformation, which could have significant adverse consequences such as unwarranted anxiety, perceived lack of control over weight (QC3), not using contraception and unintended pregnancies.

“What they then find is that they’re going to be infertile for the rest of their lives when they go online, and that’s an issue.” (Gyn, practicing 17 years)

3.2.2.2. Complementary and alternative management

Women with PCOS

Some women described trying complementary and alternative options promoted online, such as seeing Chinese herbalists, naturopaths, trying natural supplements, herbs and essential oils. These attempts were often described as a result of their dislike of medication (QP7), dissatisfaction with the effectiveness of conventional treatment options or “*out of desperation trying to get pregnant*” (43 years, age diagnosed: 15).

“I tend not to feel great putting medication in my body on a regular basis. Where I can, if there’s another way to manage it then I prefer to take another path.” (35 years, age diagnosed: 25)

A few women also described cutting out particular food groups, such as wheat or dairy. Many, however, reported not trying anything not recommended by their doctor and were more sceptical about the benefits of therapies or diets promoted online.

“I haven’t tried any crazy thing that some online person has suggested.” (31 years, age diagnosed: 20)

Clinicians

Clinicians expressed awareness that many women were seeking natural remedies, and held varied attitudes towards their use. Many described concern over online product advertisements making unsubstantiated claims and some cautioned against the harms of untested products, having seen “*a lot of people who have adverse effects from various complementary medicines.*” (Endo, practicing 15 years)

“I mean there’s so much rubbish on the internet. Like any condition, it makes people vulnerable to a whole lot of proposed treatments that are not evidence based or validated.” (Endo, practicing 30 years)

Some, however, described being comfortable with women trying alternative treatments provided they were not harmful, with a few gynaecologists collaborating with naturopaths (QC4).

“I think most of them are not particularly effective but then most pharmacological ways are not particularly effective. I’m happy for them to try anything, as long as I don’t think it will do them harm.” (Endo, practicing 15 years)

3.2.3. Follow-up and continuity of care

Clinicians

Clinicians described several strategies to handle these challenges and support better management, including taking a holistic view, counselling women in a reassuring and encouraging manner (QC5), and tailoring management to address the woman’s concerns (QC6).

“I very much try and come back and individualise it for women, what this means for them rather than just endure one-size-fits-all.” (Endo, practicing 18 years)

Some specialists also discussed the importance of a multidisciplinary approach (collaborating with *“dieticians, exercise physiologists, sometimes a psychologist,”* Endo, practicing 18 years) and linking women in with their GP for continuity of care.

“We should be creating explanations and plans for people to go back to their general practitioners and have regular care and follow-up and hopefully never see me again.”

(Endo, practicing 25 years)

Views about which women with PCOS to regularly screen for long-term consequences (e.g. glucose intolerance, type II diabetes) and specific tests used, varied widely across and within specialties. For example, a few clinicians described screening all women every few years, regardless of weight and other risk factors, whilst many others raised concerns about over-screening, overdiagnosis and medicalisation, particularly in light of the limited evidence.

“The evidence that PCOS causes heart disease and diabetes in later life is overplayed, and the international experts say we don’t have the evidence for this. Why are we telling this to our patients?” (Endo, practicing 30 years)

These clinicians discussed the risk of overburdening women with unnecessary tests or frequent follow-up, expressing disagreement with the Australian 2011 guidelines[10] and concerns over wasted resources (QC7).

“So people go through a whole heap of testing when they probably didn’t need to. You know, serial testing and follow-up with lots of people and put on medications they probably didn’t need because they were just, some of them were treating the diagnosis rather than what they were actually presenting with.” (Endo, practicing 7 years)

Women with PCOS

Women less frequently reported such management approaches (e.g. reassurance, risk dependent follow-up), with the majority reporting no follow-up for their PCOS specifically (QP8). Those who did have regular tests and follow-up described their care as symptom driven (QP9) or because they were trying to conceive.

"I don't think I've really seen anyone specifically for it since I was 19." (28 years, age diagnosed: 19)

Whilst a few women expressed appreciation for receiving reassurance from their doctors (QP10), others experienced ongoing symptoms, concerns about the associated risks of PCOS or described feeling surprised that there was not more follow-up after diagnosis (QP11).

"They told me it was a genetic condition, there was nothing I could do about it and because I'm not overweight, there's really no need to see a dietician or a diabetes educator. I thought that once you get a diagnosis there'd actually be something done. Some sort of a management plan, you know, how do we go forward from here, whether that be diet, exercise, regular check-ups or whatever, but none of that has happened." (32 years, age diagnosed: 30)

4. Discussion and conclusion

4.1. Discussion

This study highlights several challenges in managing PCOS, the majority stemming from the disparate and wide spectrum of presentations and lack of understanding and evidence around the condition. Clinicians described difficulty with finding suitable treatments for the heterogeneous presentations, limitations in current options (both in terms of lack of effectiveness or limited suitability) and engaging women with the long-term nature of

management. Women similarly expressed frustration with the limited options and there being no long-term solution or cure. Both clinicians and women also described difficulty in finding personally relevant information, with clinicians raising concerns about myths and widespread poor-quality information online.

This data illustrates how the current treatments for PCOS fall short of women's expectations, supporting previous qualitative and quantitative findings [14, 15, 22]. Some clinicians in the current study spoke about trying to adopt a person-centred approach by focusing on what women find bothersome and tailoring management and follow-up accordingly. Some endocrinologists also strongly disagreed with the regular metabolic screening recommended in the 2011 Australian guidelines [10], which they considered non-evidence-based and wasteful for women with PCOS and the health system. This has also been raised by others [29] and could explain why quantitative studies have previously found poor uptake of regular metabolic screening [12, 13]. Indeed, the 2018 international guidelines now recommend less intensive screening than prior guidelines to reduce costs and inconvenience [4]. Many women, however, felt they received inadequate care, were dissatisfied with the lack of solutions, and experienced either ongoing issues with symptoms or long-lasting worry about the associated adverse risks.

Women who struggled with their weight described feeling that any treatments and follow-up were focused on their weight only. On the other hand, women who had no issues with their weight described feeling left out of care, concerned about 'not needing to do anything' despite being diagnosed with a disease, and fearful their condition would worsen. This incongruity in perspectives illustrates disparities in expectations surrounding the diagnosis

– women often expected a solution or cure after being diagnosed with a medical condition and were disappointed that treatment targeted symptoms only. Some clinicians, however, considered PCOS a chronic condition, sometimes described as a variation of normal, where symptoms can be managed and risk minimised, but the underlying predisposition would always be there. It is important to note, however, that we did not interview women-clinician dyads, which may account for some of the incongruous findings. In addition, although healthy lifestyle change is first-line management for improving PCOS symptoms and reducing the associated long-term risks, some women’s frustration over consultations focusing mainly on their weight draws parallels with research on weight bias in health care systems. Studies have found many people with overweight report doctors assuming their symptoms are due to being overweight or focus only on their weight, leaving them feeling dismissed, denied other potential treatments or worried other causes are missed [30]. It is important for clinicians to first address the individual’s presenting concern, as well as link weight management discussions back to PCOS so that women do not feel their diagnosis is pushed to the wayside. Guidelines for weight discussions also note the importance of recognising that many people with overweight or obesity have already tried to lose weight repeatedly, and the importance of using person-centred language free from judgement, making no assumptions about diet and physical activity and setting together with the individual specific, meaningful and realistic goals [31].

One relevant theoretical model that helps to explain our findings in regard to adaption to illness and health outcomes is Leventhal’s Common-Sense Model of Self-Regulation (CSM) [32]. Using the CSM, a recent study assessing psychological distress and illness perceptions in women with PCOS found experiencing more symptoms, perceiving high consequences of

PCOS, perceiving less personal control and having lower perceived understanding of PCOS were significantly associated with higher psychological distress [33]. Together with the current study, these findings reflect women's anxiety over the long-term consequences and difficulty obtaining adequate and reliable information. In addition to addressing illness perceptions and expectations, women need improved counselling, information and transparent conversations about the nature of their PCOS and differences in risk profiles by body mass index and phenotype [9]. If regular follow-up is not required, clinicians need to be explicit about why this is, in order to prevent women feeling neglected or worried that their condition will worsen.

The harms of a diagnosis identified in previous research [25] and the lack of long-term benefit perceived by several women in this study also highlight the importance of ensuring a diagnosis will bring more benefit than harm to avoid overdiagnosis [9]. Furthermore, these results demonstrate the problems of including heterogeneous presentations with differing levels of risk under one diagnostic label. A recent clustering analysis of 893 women with PCOS identified distinct reproductive and metabolic "subtypes" of women with PCOS, indicating that there may be distinct forms of PCOS associated with different underlying biological mechanisms [34]. The analysis concluded that "women with PCOS may be poorly served by being grouped under a single diagnosis because PCOS subtypes may differ in responses to therapy and in long-term outcomes" [34]. Subdividing PCOS into different diagnostic categories may increase capacity to tailor management appropriately [35].

A strength of this study is the purposive sampling of women with PCOS to ensure a diverse sample across the spectrum of severity from the community. This addresses a key limitation

of previous literature, which features overrepresentation by women with more severe symptoms and phenotypes recruited from outpatient clinics or PCOS support groups only [24]. Our interview guides were developed by a multidisciplinary team, with consumer input, and rigorous qualitative analyses were undertaken to identify key themes. A limitation is the self-reported diagnosis of PCOS for women participants, although reported symptoms were consistent with the Rotterdam criteria. There is also possible selection bias of clinician participants, as clinicians more knowledgeable or interested in PCOS may have been more likely to participate. However, the variation in views suggests strong selection bias is unlikely.

4.2. Conclusion

These findings provide valuable insights into the challenges in managing PCOS from the perspectives of both clinicians and women with PCOS. Key challenges included limitations in current treatment options, lack of evidence around the condition and lack of tailored information about PCOS, as well as discrepancies between women's and clinicians' expectations regarding diagnosis and management.

4.3. Practice implications

Better communication including tailored long-term risk counselling based on phenotype is urgently needed, as well as clarifying and addressing women's expectations of PCOS to improve patient-centred care. Different diagnostic categories with different labels to separate the disparate subtypes may be one way to improve tailored management, provide personally relevant information, minimise unwarranted anxiety and dissatisfaction with care.

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Informed consent and patient details: We confirm all patient/personal identifiers have been removed or disguised so the patient/person(s) described are not identifiable and cannot be identified through the details of the story.

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Data statement: The de-identified datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

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