Debate & Analysis

Polycystic ovarian syndrome: an under-recognised problem?

Polycystic ovarian syndrome (PCOS) is a multisystem condition that can blight the course of a woman's life. The condition is common and for many is associated with considerable distress. We argue the importance of diagnosis in what is currently an under-recognised condition.

Diagnosis of PCOS requires two of the three Rotterdam criteria to be present.¹ Introducing the criteria led to an increase in PCOS prevalence from 6% to 10% in screened women of childbearing age.² However, this is unlikely to be a true reflection of the prevalence among women who choose to consult their GP. A recent retrospective cohort study of over 2 million women in the UK reported that the prevalence of women of reproductive age with PCOS was just 1.34%, rising to 2.27% if probable cases were included.³ The authors suggested that there is significant under-diagnosis occurring, with only about 50% of women with at least two of the three criteria having a recorded diagnosis of PCOS. This might imply that GPs are attempting to avoid overmedicalisation, or it might reflect a lack of awareness. It may also indicate that it is only those women with a more severe phenotype who consult their GP.

PUTTING WOMEN IN CONTROL

We argue, not for mass screening for PCOS, but for greater awareness of the symptoms and for diagnosis of those that do present to their GP. A diagnosis of PCOS is relatively inexpensive (hormone profile and a pelvic ultrasound scan), and the current treatment of choice for women who are overweight is weight loss. Neither the investigations nor treatment have significant risks or side effects. The diagnosis can generally be undertaken in general practice, often without referral to secondary care. A diagnosis of PCOS can provide women with an understanding of their body's metabolism and open up an important dialogue about the importance of weight loss and lifestyle. In many cases, this will encourage the long-term negative health outcomes associated with PCOS to be limited or avoided, for example, ovulation may start spontaneously following weight loss, negating the need for fertility treatment (reported as costing £1233–£1805 per woman with PCOS).⁴ Early identification would allow women to access fertility treatment (if required) at a younger age and hence offer a higher chance of success. Weight loss prior to conception will also impact positively on the chances of a

low-risk pregnancy and delivery.

PCOS puts women at higher risk of diabetes. In making this diagnosis, women may be encouraged to potentially limit this risk with lifestyle changes and the diagnosis flags of increased surveillance. Women with PCOS are at higher risk of endometrial hyperplasia, and a diagnosis allows awareness of the importance of hormone-mediated withdrawal bleeds/intrauterine system to limit this pre-cancerous condition. Rates of depression in those with PCOS are raised, even when adjusted for BMI, family history of depression, and infertility.⁵ A diagnosis should be used as an opportunity to consider both physical and mental health.

There is uncertainty regarding the extent to which women will be affected by PCOS. A milder phenotype may have no long-term complications. However, conveying uncertainty is the norm for GPs and, if the diagnosis is communicated sensitively with an acknowledgment of uncertainty, women's concerns can be addressed. Longitudinal data suggest women with PCOS have equally high levels of distress 12 months before and 12 months following the diagnosis, implying that the distress was secondary to the symptoms of PCOS rather than as a consequence of the diagnosis *per se*.⁶

A diagnosis of PCOS can be used as a catalyst for lifestyle interventions and surveillance of potential longer-term conditions, but the most important reason for offering a diagnosis is because women want to make sense of their health. Delays in making the diagnosis of PCOS is recognised as adversely affecting satisfaction with health services⁷ and also contributing to a woman's distress.⁵ Women with PCOS consistently echo the same message: they want to understand what is happening to their bodies. The trustees from the PCOS support charity Verity relate their experience and reaction to published articles on overdiagnosis: '*... as those who have the condition and have gone through the diagnosis process we as trustees all feel that early diagnosis and intervention would have made a significant impact on our own PCOS journeys*'.⁸

We therefore believe the question should not be about overmedicalisation, but rather how the diagnosis is conveyed. The diagnosis should be made sensitively, promote autonomy, and so empower women to understand why their body and metabolism behave like they do, and how they can limit

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or reverse the effects of PCOS. They should be signposted to appropriate websites (www.verity-pcos.org.uk) for support. To not diagnose PCOS or to withhold information here would be paternalistic, unethical, unsafe, and unacceptable to women.

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Provenance

Commissioned; not externally peer reviewed.

Competing interests

The authors have declared no competing interests.

DOI: <https://doi.org/10.3399/bjgp18X696101>

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