

Polycystic ovary syndrome in Central Australia

Diagnosis and screening of cardiometabolic risk and emotional wellbeing

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Background and objectives

Polycystic ovary syndrome (PCOS) is a common condition that affects fertility, body image and emotional wellbeing in women, as well as significantly increasing a woman's likelihood of developing type 2 diabetes mellitus (T2DM) and other cardiovascular disease risk factors. The objective of this study was to assess how management of PCOS in an Aboriginal primary care setting aligns with national standards for diagnosis and screening of cardiometabolic risk and emotional wellbeing.

Method

We conducted a retrospective clinical audit of 63 women who had PCOS listed as a diagnosis in their clinical record.

Results

Most women (95%) were correctly diagnosed, the most common trigger being menstrual irregularity (83%). Screening for cardiometabolic complications and emotional wellbeing as recommended by the national guideline was applied inconsistently, including 38% of eligible women not being screened for T2DM in the previous 12 months, and no woman being formally screened for emotional wellbeing. Discussion of lifestyle management was nearly universal; most women (75%) were referred to a dietician, although a third did not attend their appointment.

Discussion

Some components of recommended PCOS care were provided at high levels, including correct application of diagnostic criteria. However, PCOS management and screening for complications are being applied inconsistently in a population with high levels of cardiometabolic and emotional wellbeing risk.

POLYCYSTIC OVARY SYNDROME (PCOS) is a common condition that affects fertility, body image and emotional wellbeing in women, as well as significantly increasing a woman's likelihood of developing type 2 diabetes mellitus (T2DM) and other cardiovascular disease (CVD) risk factors.^{1,2} It is more common in Aboriginal and Torres Strait Islander women, with a prevalence of 15.3% in a sample of urban Aboriginal and Torres Strait Islander women,³ increasing to a prevalence of 30.5% in those with a body mass index (BMI) >30 kg/m². PCOS is also undiagnosed in up to 70% of cases,⁴ representing a lost opportunity for the prevention of associated complications, such as T2DM. Management includes regular screening for cardiometabolic risk factors and emotional wellbeing (Box 1), lifestyle change and specific treatments for problems such as hirsutism and infertility.¹ Lifestyle modification is the cornerstone of management, with weight loss and maintenance key to improving symptoms and reducing long-term complications.¹ Given Aboriginal and Torres Strait Islander women experience high rates of insulin resistance, T2DM, CVD and psychological distress compared to non-Indigenous women,⁵ it is imperative that PCOS is recognised and managed appropriately in primary care.

A national evidence-based guideline for PCOS management was published in 2011.¹ There has been limited work evaluating the application of the guideline. An evaluation of a PCOS clinic on Thursday Island in the Torres Strait over 12 months reported that the clinic was largely successful in providing evidence-based care, with up to 78% of patients receiving recommended cardiometabolic screening, 100% emotional screening and 89% lifestyle management.⁶ However, there has been no evaluation of the application of the national guideline with Aboriginal and Torres Strait Islander women outside this dedicated PCOS clinic.

The primary aim of this study was to assess management of PCOS in an Aboriginal primary care setting and alignment with national standards for diagnosis and screening of cardiometabolic risk and emotional wellbeing.

Methods

A retrospective clinical audit was performed at an Aboriginal primary healthcare centre in Central Australia. The study was approved by the Central Australian Human Research Ethics

Committee (HREC-15-343). All Aboriginal women aged between 15 and 45 years who had attended the health service in the last two years and had PCOS listed as a clinical diagnosis on the electronic patient information management system were included. To facilitate access to data about how the diagnosis was made, only women with PCOS diagnosed by the health centre were included.

An electronic clinical audit tool was developed to collate data within each patient's file. Information was collected about demographics, application of the Rotterdam criteria⁷ for diagnosis, frequency with which screening was performed for cardiometabolic risk and emotional wellbeing in accordance with the national guideline,¹ and the results of any screening. Information regarding initial management, such as lifestyle advice and dietician referral, was also collected. Statistical analysis was undertaken using Stata software version 12.1. Descriptive statistics are presented as count and proportion for categorical data, and mean and standard deviation or median and interquartile range for continuous data.

Results

The audit sample contained 63 women who had PCOS listed as a diagnosis in the clinical record. The majority of women

were diagnosed under age 26 years (Table 1), and the most common trigger for diagnosis was menstrual irregularity.

The majority of women were correctly diagnosed using the Rotterdam criteria.^{7,8} Comorbidities associated with PCOS were common at diagnosis, with 60% of women having at least one comorbidity (Table 1).

Just under half of women had their BMI recorded at diagnosis (Table 2); however, most had a BMI recorded in the last 12 months. Of the women with a BMI recorded at diagnosis, nearly all were in the overweight or obese range, and of those who had a BMI recorded again in the last 12 months there was a mean gain of 2.9 BMI points. Less than half of women had their waist circumference measured.

Six women had pre-existing T2DM at the time of diagnosis, leaving 57 women requiring ongoing screening for diabetes. While most of these women had at least one oral glucose tolerance test (OGTT) since diagnosis, less than half of these were in the last 12 months (Table 2). Some women had an alternative diabetes screening test, leaving 44% of eligible women without any diabetes screening in the preceding 12 months. The overall prevalence of T2DM was 24%, and impaired glucose tolerance (IGT) was 27%.

Documentation of smoking status was nearly universal and the smoking

prevalence was 38% (Table 2). Just over three-quarters of women had a blood pressure (BP) check in the last 12 months, but only one-third of those with BMI ≥ 25 kg/m² had a BP check at their last visit. Three-quarters of women had a lipid profile in the last two years, but only half had a lipid profile in the last 12 months and 14% had not had a lipid profile since diagnosis.

No woman had a formal emotional wellbeing assessment at diagnosis using a recognised scale (Table 2). A minority had a documented discussion of emotional wellbeing at the time PCOS was diagnosed.

Three-quarters of women were referred to a dietician but nearly a third did not attend for review (Table 3). Documented discussion of lifestyle management was nearly universal, but discussion of potential long-term complications was much less common and few women were referred to information sources about PCOS.

Discussion

Summary of key findings

This study found Aboriginal women are being correctly diagnosed with PCOS in a primary care setting and, encouragingly, diagnosis is generally occurring at a young age. However, screening and management for cardiometabolic complications and emotional wellbeing is being performed inconsistently. Metabolic complications were frequent, with more than half of women having T2DM or IGT. Suboptimal screening rates, in addition to a high proportion of women with cardiometabolic risk factors, highlights the importance of screening for, and managing, metabolic complications, and indicates the need for strategies to support lifestyle management with a particular focus on optimising BMI.

Interpretation and comparison to existing literature

Diagnosis

The majority of women were diagnosed in accordance with the Rotterdam criteria as recommended by the national guideline. In keeping with international findings,⁹ the most common trigger for diagnosis was menstrual irregularity, supporting the

Box 1. Screening recommendations: Summary from the evidence-based national guideline¹

Screening task	Frequency of task
Weight, BMI and waist circumference	Every visit
Smoking status	Routinely
Lipid profile	
• Normal lipid profile	Two-yearly
• Abnormal lipid profile and/or excess weight	Yearly
Blood pressure measurement	
• BMI <25 kg/m ²	Annually
• BMI ≥ 25 kg/m ²	Every visit
Oral glucose tolerance test	Two-yearly
• Additional risk factors for developing T2DM	Yearly
Emotional wellbeing	Routinely

BMI, body mass index; T2DM, type 2 diabetes mellitus

Table 1. Diagnostic and clinical features of women at time of diagnosis of PCOS (n = 63 unless stated otherwise)

Features at diagnosis	Number of women (%)
Year of diagnosis	
2011–15	29 (46)
2006–10	21 (33)
≤2005	13 (21)
Age at diagnosis (years)	
Mean ± SD	24.1 ± 5.3
<26	40 (63)
26–35	22 (25)
≥36	1 (2)
PCOS diagnostic criteria	
Oligoovulation or anovulation (n = 61)	56 (92)
Clinical hyperandrogenism (n = 37)	32 (87)
Biochemical hyperandrogenism (n = 56)	50 (89)
Polycystic ovary on ultrasound (n = 45)	33 (73)
>2/3 Rotterdam diagnostic criteria satisfied	60 (95)
NIH diagnostic criteria satisfied (n = 59)	50 (85)
Pre-existing comorbidities at PCOS diagnosis	
Infertility	21 (33)
Anxiety/depression	9 (14)
Dyslipidaemia	8 (13)
T2DM	6 (9.5)
Impaired glucose tolerance	6 (9.5)
Chronic kidney disease	3 (4.8)
Gestational diabetes mellitus	1 (1.6)
Impaired fasting glucose	0 (0)
Cardiovascular disease	0 (0)
None	25 (40)
Trigger for PCOS diagnosis	
Menstrual irregularity	52 (83)
Infertility	24 (38)
Hirsutism/acne	15 (24)
Polycystic ovaries	4 (6.4)
Not recorded	0 (0)
Other	4 (6.4)

NIH, National Institutes of Health; PCOS, polycystic ovary syndrome; SD, standard deviation; T2DM, type 2 diabetes mellitus

routine assessment of menstrual history by clinicians and investigation for PCOS accordingly.

Metabolic risk factor screening

Some components of metabolic screening were provided at high levels, including measurement of BMI within the last 12 months. Calculation of BMI is recommended to assist in ascertaining metabolic risk, developing BMI management plans and documenting progress. Weight loss helps restore menstrual regularity, is the recommended first-line management for anovulatory infertility and is important in prevention of diabetes. While BMI measurement at diagnosis was incomplete, the available data indicate that women had generally gained weight since diagnosis and most women were currently overweight or obese.

Regular screening for diabetes is of particular importance. Aboriginal and Torres Strait Islander women have high rates of T2DM and IGT, and this is higher in women with PCOS and appears to be integrally related to insulin resistance, obesity and central fat distribution.^{2,3} The high proportion of women with T2DM (24%) or IGT (27%) in the 62% of women that had screening highlights the imperative of a sustainable method of screening and the importance of prevention. While most women had an OGTT since diagnosis, over one-third of eligible women had no screening in the last 12 months. A study in the US of women with PCOS under specialist care demonstrated similar findings, with most women being screened at diagnosis but approximately half receiving no further screening, suggesting barriers exist to implementation of regular, ongoing screening for diabetes.¹⁰ Screening rates in this study were generally lower than those reported in the Torres Strait,⁶ suggesting that, with appropriate support, increased delivery of recommended care is achievable. One way of improving screening rates for T2DM in this high-risk population is to use glycated haemoglobin (HbA1c) testing rather than OGTT. This test can be performed at the time of consultation and is now endorsed

by the Australian Diabetes Society as an alternative to traditional glucose screening in patients at high risk of undiagnosed diabetes.¹¹

Cardiovascular risk factor screening

In addition to metabolic screening, some areas of cardiovascular screening could be strengthened, including an annual lipid profile as well as BP measurement at every visit for women with BMI ≥ 25 kg/m². The smoking rate was high and similar to previously reported rates in Aboriginal and Torres Strait Islander peoples (42%),¹² highlighting an area where Aboriginal and Torres Strait Islander women with PCOS may need extra support. Smoking is an important modifiable health behaviour to address, as it confers additional cardiovascular risk to a condition already associated with considerable cardiometabolic risk. Cardiovascular screening rates were lower than those found in the Torres Strait, suggesting improved care can be achieved when appropriate systems exist.⁶

Management of cardiometabolic risk

The cardiometabolic findings in this study, particularly for weight and glucose profiles, highlight the importance of screening according to the guideline, discussing lifestyle management and long-term complications with women, ascertaining effective and culturally appropriate ways to support women to optimise their weight, and facilitating access to appropriate support and resources. Documentation of information provision suggested that available information sources are not well used, and the reasons for this should be explored. Similarly, investigation of barriers to suboptimal uptake of dietician referrals, despite high levels of referrals and implementing systems to support referral uptake, is warranted. Patients with PCOS were seen by a dietician at much higher rates in a dedicated clinic for women with PCOS in the Torres Strait than in this study.⁶ This is most likely due to a dietician being onsite at the time of consultation, as opposed to this health centre where the dietician is present only once a week.

Emotional wellbeing screening and follow-up

No woman had a formal emotional wellbeing assessment at diagnosis, despite PCOS being associated with an increased risk of anxiety and depression.¹³ This is of particular concern given the high rates of psychological distress among Aboriginal women.⁵ This was the screening component with the lowest implementation and a stark contrast to the 100% rate seen in the Torres Strait clinic, again demonstrating that a more structured setting can facilitate application of screening guidelines.⁶ Importantly, if screening is increased, appropriate referral pathways and services need to be available to women identified as at risk.

Future research

Increasing the consistent application of the national PCOS guideline will rely on understanding barriers to implementation in a range of primary care settings. Some factors affecting implementation will be commonly experienced across multiple settings, and some will be specific to rural or remote locations or to care for particular populations. Potential barriers across settings include gaps in clinician knowledge and confidence in providing PCOS healthcare; an absence of a formal, health service-wide approach to the management of PCOS; time pressure; and competing health needs and patient priorities. Barriers in specific settings may include cultural or language barriers, health literacy, availability of local services for referral, acceptability of screening or management suggestions, and socioeconomic barriers to lifestyle change.¹⁴⁻¹⁶ Focus groups with Aboriginal and Torres Strait Islander women with PCOS, with other patient groups and with primary healthcare providers to explore how the condition could be managed more effectively is an area for future research.

Suggestions for improving current management include co-development of individually appropriate chronic disease management plans that take into account the woman's specific circumstances and priorities; automatically generated electronic recalls for regular screening

tasks; and advocating for improved availability of support for women to effect lifestyle change, such as exercise programs, affordable healthy food, smoking cessation support and access to dietitians, exercise physiologists and psychologists.

Limitations

The small sample size was a limitation of this study. Evidence^{3,4} suggests there are likely many more women with PCOS attending the health centre than currently identified, although this study was not designed to determine prevalence. It may be that the women diagnosed with PCOS have more overt symptoms and thus higher levels of cardiometabolic risk factors and comorbidities than would be seen in a wider sample of Aboriginal and Torres Strait Islander women with PCOS. Audit data reflect documented provision of care; they rely on provision of care having been recorded correctly and may underestimate actual provision of care.

Conclusion

This small study suggests that, encouragingly, PCOS diagnosis in an Aboriginal primary care setting is being performed correctly and at a young age, suggesting good awareness of the condition and diagnostic criteria. However, subsequent screening and management does not consistently align with the national guideline. This represents a missed opportunity for optimisation of current wellbeing and future health of Aboriginal and Torres Strait Islander women with PCOS. Appropriate and acceptable systems to facilitate evidence-based and woman-centred, effective, long-term management of PCOS is an important area for healthcare improvement.

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Table 2. Screening for risk factors for PCOS-related complications (n = 63)

Risk factor screened	Number of women (%)
Metabolic risk factors	
BMI recorded at diagnosis	29 (46)
Weight recorded at diagnosis	9 (14)
BMI at diagnosis	38 (60)
Mean \pm SD (n = 38)	37.6 \pm 8.5
<25 kg/m ²	2 (5.3)
25-30 kg/m ²	3 (7.9)
>30 kg/m ²	33 (87)
BMI recorded in last 12 months (n = 58*)	47 (81)
Weight recorded in last 12 months (kg) (n = 58*)	2 (3.5)
BMI in last 12 months	49 (84)
Median and interquartile range (n = 49)	37.1 (33.1-42.2)
BMI <25 kg/m ²	2 (4.1)
BMI 25-30 kg/m ²	5 (10.2)
BMI >30 kg/m ²	42 (86)
Change in BMI (diagnosis to last 12 months)	27 (43)
Mean \pm SD (kg/m ²) (n = 27)	2.9 \pm 4.9
Waist circumference recorded	26 (41)
Mean \pm SD (cm) (n = 26)	114.4 \pm 17.1
OGTT since PCOS diagnosis (n = 57*†)	45 (79)
Requested but not performed	5 (8.8)
Not requested	7 (12)
Most recent OGTT results (n = 45)	
Normal	24 (53)
Impaired fasting glucose	0 (0)
Impaired glucose tolerance	12 (27)
T2DM	9 (20)
Alternative to OGTT in last 12 months (n = 27*‡)	10 (37)
Requested but not performed	4 (15)
None requested	13 (48)
Cardiovascular risk factors	
Smoker (n = 61)	23 (38)
BP in last 12 months (n = 58*)	46 (79)
BP at last visit if BMI \geq 25 (n = 57)	18 (32)

Table 2. Screening for risk factors for PCOS-related complications (n = 63) (cont)

Risk factor screened	Number of women (%)
Most recent BP result >140/90 mmHg	0 (0)
Lipid profile in past two years	48 (76)
Requested but not performed	4 (6.4)
Not requested	11 (18)
Lipid profile in last 12 months if at risk [§] (n = 56)	29 (52)
Requested but not performed	7 (12)
Not requested	20 (36)
Lipid profile since diagnosis	54 (86)
Requested but not performed	2 (3.2)
Not requested	7 (11)
Most recent lipid profile abnormal (n = 56)	44 (79)
Emotional wellbeing screening	
Discussion at diagnosis	7 (11)
Any concerns identified (n = 7)	2 (29)
Referral for concerns (n = 2)	2 (100)
Formal screening for emotional wellbeing	0 (0)

BMI, body mass index; BP, blood pressure; OGTT, oral glucose tolerance test; PCOS, polycystic ovary syndrome; T2DM, type 2 diabetes mellitus; SD, standard deviation

*Five women did not attend in the last 12 months
 †Seven women had been diagnosed with T2DM after diagnosis but prior to 12 months
 ‡Alternative tests included random blood glucose levels (n = 1), fasting blood glucose levels (n = 3) and glycated haemoglobin (HbA1c) tests (n = 6)
 §If BMI ≥25 or previous abnormal lipid profile
 ||Total cholesterol (TC):high-density lipoprotein (HDL) ratio >4.4, TC ≥5.5 or HDL ≤1.1 on a non-fasting sample, or any abnormal parameter on a fasting sample¹⁷

Table 3. Management, follow-up and information provided (n = 63)

Component of management	Number of women (%)
Dietician referrals	
– Referred to and seen by dietician	33 (52)
– Referred to but not seen	15 (24)
– Not referred	15 (24)
Discussion of lifestyle management	56 (89)
Discussion of potential long-term complications	33 (52)
Referred to information sources about PCOS	16 (25)
– Yarning about PCOS booklet	10 (16)
– Jean Hailes website	7 (11)
– PCOS Association of Australia	0 (0)
– Other	2 (3.2)

PCOS, polycystic ovary syndrome

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