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ORIGINAL ARTICLE

Polycystic ovarian syndrome: Prevalence and impact on the wellbeing of Australian women aged 16–29 years

L. Chitra Varanasi[1], Asvini Subasinghe[2,3], Yasmin L. Jayasinghe[4,5], Emma T. Callegari[1], Suzanne M. Garland[2,3,4], Alexandra Gorelik[6] and John D. Wark[1,7]

[1]Department of Medicine, Royal Melbourne Hospital, University of Melbourne, Parkville, Australia

[2]Department of Microbiology and Infectious Diseases, Royal Women's Hospital, Parkville, Australia

[3]Infection and Immunity Theme, Murdoch Childrens Research Institute, Parkville, Australia

[4]Department of Obstetrics and Gynaecology, Royal Women's Hospital, University of Melbourne, Parkville, Australia

[5]Department of Gynaecology, Royal Children's Hospital, Parkville, Australia

[6]Melbourne EpiCentre, Royal Melbourne Hospital, University of Melbourne, Parkville, Australia

[7]Bone and Mineral Medicine, Royal Melbourne Hospital, Parkville, Australia

Correspondence: Lakshmi C. Varanasi, Department of Medicine, Royal Melbourne Hospital, University of Melbourne, Parkville, Victoria 3050, Australia. Email: lcvaranasi@gmail.com

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Background: Polycystic ovarian syndrome (PCOS) is the most common condition among reproductive-aged women. However, its exact prevalence is unknown.

Aims: To determine the prevalence of PCOS in Australian women aged 16–29 years using the National Institutes of Health (NIH) criteria compared to self-reported PCOS, to compare co-morbidities between the groups and to determine the most distressing aspect of a diagnosis of PCOS for these young women.

Materials and Methods: Participants were recruited from the Young Female Health Initiative (YFHI) and Safe-D studies. Participants completed questionnaires, physical examinations and blood tests from 2012 to 2016. In March 2016, two supplementary questionnaires were distributed: the first, comprising questions on reproductive health and impact of diagnosis, was sent to participants who self-reported having PCOS in the original studies. The second, comprising general reproductive health questions, was sent to the remainder.

Results: The prevalence of PCOS, according to the NIH criteria, was 12% (31/254), while the prevalence of self-reported PCOS was 8% (23/300). Only 35% (8/23) of those with self-reported PCOS actually fulfilled the NIH criteria for PCOS. Comorbidities were relatively similar among groups. Finally, approximately 65% (15/23) were unhappy or worried about their initial PCOS diagnosis, with 72% (13/18) stating fertility concerns were the most distressing aspect of their diagnosis.

Conclusions: The lack of consistent and accurate diagnosis of PCOS in young women potentially leads to over-diagnosis. This creates unnecessary fears of health complications, particularly infertility. Therefore, we recommend the development of standardised criteria with set parameters that allow for better diagnosis of PCOS.

KEYWORDS

anovulation, hyperandrogenism, infertility, polycystic ovarian syndrome, prevalence

INTRODUCTION

Polycystic ovarian syndrome (PCOS) is the most common endocrine abnormality in reproductive-aged women.[1] A great deal of research has been devoted to unravelling the complexities of PCOS and its diagnosis, treatment and complications.[2] However, there is still a gap in the literature relating to the prevalence of PCOS globally and in Australia. This uncertainty exists because different criteria are used to determine this prevalence estimate.[3–5] Furthermore, the physical and psychological impact of a diagnosis of PCOS in young women is yet to be elucidated.

Three sets of criteria have been created for the diagnosis of PCOS.[3–5] These are the National Institutes of Health (NIH) criteria (1992),[3] Rotterdam criteria (2003)[4] and Androgen Excess Society (AES) criteria (2006)[5] (Table 1). These criteria comprise oligo/anovulation, clinical or biochemical hyperandrogenism and polycystic ovaries on transvaginal ultrasound, in various combinations. None of these sets of criteria have been implemented as the gold standard due to controversy over which criteria should be included.[6] Furthermore, these criteria are less applicable to adolescents as individual components of the criteria overlap with normal physiological changes of puberty and therefore cannot be considered as pathological changes of PCOS.[2]

There also are increased healthcare costs due to treatment and associated complications of PCOS.[1] These complications include reproductive health issues, obesity, insulin resistance, hypertension, cardiovascular disease and mood disorders.[7,8] These wide range of potential complications can result in women feeling burdened by PCOS, contributing to a reduced quality of life.[9]

In this paper, we describe a sub-study of the Young Female Health Initiative (YFHI) and Safe-D studies. YFHI and Safe-D are comprehensive health and lifestyle studies of young Australian women (aged 16–29 years) recruited via Facebook advertising.[10] The first aim of this sub-study was to determine the prevalence of PCOS in this population using the NIH criteria. The second aim was to examine differences in comorbidities between those who self-reported PCOS and those who did not self-report PCOS, and between those who fulfilled the NIH criteria for PCOS and those who did not fulfil the criteria. It is important to note that self-reported PCOS does not indicate a confirmed diagnosis of PCOS. It refers to responses provided by participants to our questionnaire. Finally, we also investigated which aspects of this condition were particularly distressing to those with self-reported PCOS.

MATERIALS AND METHODS

Ethics

The YFHI and Safe-D studies were approved by the Human Research Ethics Committees (HREC) at the Royal Women's Hospital and Melbourne Health. The PCOS sub-study was approved by the Royal Women's Hospital HREC on 11 March, 2016.

Study design and recruitment

Details of recruitment have been reported for the YFHI and Safe-D studies.[10,11] Briefly, participants were female, aged 16–29 years and living in Victoria, Australia. Targeted Facebook advertisements appeared to individuals who met the eligibility criteria. When clicked, individuals were redirected to the study-specific website to register an expression of interest. Research staff would then contact potential participants and assess eligibility before obtaining informed consent.

After gaining informed consent, the original YFHI and Safe-D questionnaires were completed online via SurveyMonkey and LimeSurvey, respectively, from 2012 to 2016. For this sub-study, two supplementary questionnaires were distributed via SurveyMonkey, from March to June 2016, to participants already enrolled in either study. One questionnaire was sent to women

TABLE 1 The three diagnostic criteria for Polycystic Ovarian Syndrome

Criteria	Definition
National Institutes of Health (NIH) 1992[3]	Requires both of: • Oligo or anovulation† • Clinical or biochemical signs of hyperandrogenism
Rotterdam 2003[4]	Requires any two of three of: • Oligo or anovulation† • Clinical or biochemical signs of hyperandrogenism • Polycystic ovarian morphology on transvaginal ultrasound‡
Androgen Excess Society (AES) 2006[5]	Requires hirsutism and/or hyperandrogenism with either: • Oligo or anovulation† • Polycystic ovarian morphology on transvaginal ultrasound‡

All criteria[3–5] state that other related anovulatory disorders and disorders of androgen excess require exclusion.
†Oligo or anovulation is defined as cycles <21 days or >35 days.
‡Polycystic ovarian morphology is defined as ≥12 follicles 2–9 mm in diameter or ovarian volume >10 mL.

who reported a diagnosis of PCOS in the original YFHI or Safe-D questionnaires. This questionnaire included reproductive health questions and explored the impact of a diagnosis of PCOS, based on components of the PCOS Health-Related Quality of Life Questionnaire (PCOS-Q).[12] Another questionnaire, with only the reproductive health questions, was sent to those who did not report having PCOS. These questionnaires were pilot-tested on a convenience sample of young women before submitting for ethics approval.

Clinical measurements

After completing the original survey, participants were invited to a site visit to measure weight and height using beam balance (Colonial Weighing Australia Pty Ltd, Melbourne, Australia) and stadiometer (Holtain Ltd, Crosswell, UK), respectively. Body mass index (BMI) categories were defined as normal (≤24.9 kg/m^2) and overweight/obese (≥25 kg/m^2). Waist and hip circumferences were measured at the narrowest and widest parts of the body, respectively, using a standard measuring tape to the nearest half-centimetre. Categories for waist-hip (WH) ratio were defined as normal (≤0.85) and overweight/obese (>0.85). Sitting blood pressure was measured using a sphygmomanometer (Vital Signs Monitor from A&D Mercury Pty Ltd TM-2551 Vital Preset Class, Melbourne, Australia). Hypertension was systolic blood pressure ≥140 mmHg or diastolic blood pressure ≥90 mmHg.

Laboratory measurements

Fasting blood samples were also collected at the site visit and analysed in batches. Blood tests that relied on fasting measurements were only included if the participant fasted overnight. The ARCHITECT immunoassay (Abbott Diagnostics, Chicago, Illinois USA), a chemiluminescent microparticle immunoassay, was used for quantitative measurements of DHEAS (dehydroepiandrosterone), SHBG (sex hormone binding globulin) and total testosterone. This assay released total testosterone from the binding proteins and the total amount was measured. It is important to note that from September 2015, blood samples were no longer tested for testosterone or DHEAS so these results were available for 84% (252/300) of the cohort.

Definitions

PCOS

To meet the NIH definition[3] of PCOS, participants needed to exhibit both oligo/anovulation (based on length and regularity of cycles) and biochemical (testosterone) or clinical (acne, hirsutism and androgenic alopecia) hyperandrogenism.

Oligo/anovulation

Oligo/anovulation was defined as average cycle length <21 days or >35 days, or <8 cycles per year,[3] without taking hormonal contraception.

Biochemical and clinical hyperandrogenism

Clinical hyperandrogenism was hirsutism (Ferriman-Gallwey (F-G) Score[13] ≥8, according to a given diagram[14]), presence of acne or androgenic alopecia. No clinical examinations were undertaken to confirm answers. Biochemical hyperandrogenism, based on blood test results, was defined as the 95th percentile of serum total testosterone concentration for the non-self-reported PCOS population of women (2.2 nmol/L).

Pregnancies

A history of pregnancy, regardless of outcome.

Exclusion criteria

Participants were excluded if thyroid stimulating hormone (TSH) was outside the reference range (0.35–4.94 mIU/L), had elevated prolactin (>1120 mIU/L), or had reported other causes of oligo/anovulation.[3–5]

Depression

Self-reported depression was determined by the answer 'yes' to a question in the original YFHI or Safe-D survey, or as determined by Kessler Score.[15] The Kessler Psychological Distress Scale (K10) comprises ten questions about anxiety and depressive symptoms experienced in the most recent four weeks.[15] A K10 score higher than 20 indicates the presence of a mental health disorder.[16]

Statistical analysis

STATA version 11.1 (StataCorp, College Station, TX, USA) was used for data analysis. The answers to the supplementary questionnaires were manually checked and reviewed for errors, such as apparent misunderstanding of the question.

For continuous variables, normality of data was ascertained using the Shapiro–Wilk normality test. Data not normally distributed were presented as median (Quartile 1 (25th percentile) to Quartile 3 (75th percentile)) for continuous data and *n* (%) for categorical data. Mann–Whitney *U*-tests were used to determine significant differences between continuous variables. For categorical variables, Fisher's exact and χ^2 tests were used. A *P*-value of ≤0.05 defined statistical significance.

Multiple logistic regression assessed the relationship between presence of PCOS and other variables.

Thematic analysis, conducted on open questions from the supplementary questionnaire, ascertained the main concerns regarding the impact of PCOS on participants' wellbeing.

RESULTS

Study population

Baseline data were collected for 655 participants (Fig. 1). Of these, 490 (75%) consented to future studies and hence were eligible for this sub-study of whom, 308/490 (63%) agreed to participate. After 8/308 (3%) were excluded due to abnormal blood tests, 300/308 (97%) remained. With regards to diagnostic criteria, 48/300 (16%) reported menstrual irregularity in the preceding 12 months. Hirsutism was present in 75/300 (25%), acne was reported in 184/300 (61%) and 36/300 (12%) reported androgenic alopecia.

Prevalence of PCOS according to the NIH criteria and according to self-report

To determine the prevalence of PCOS by NIH criteria, we excluded participants who responded 'unsure' or 'not applicable'

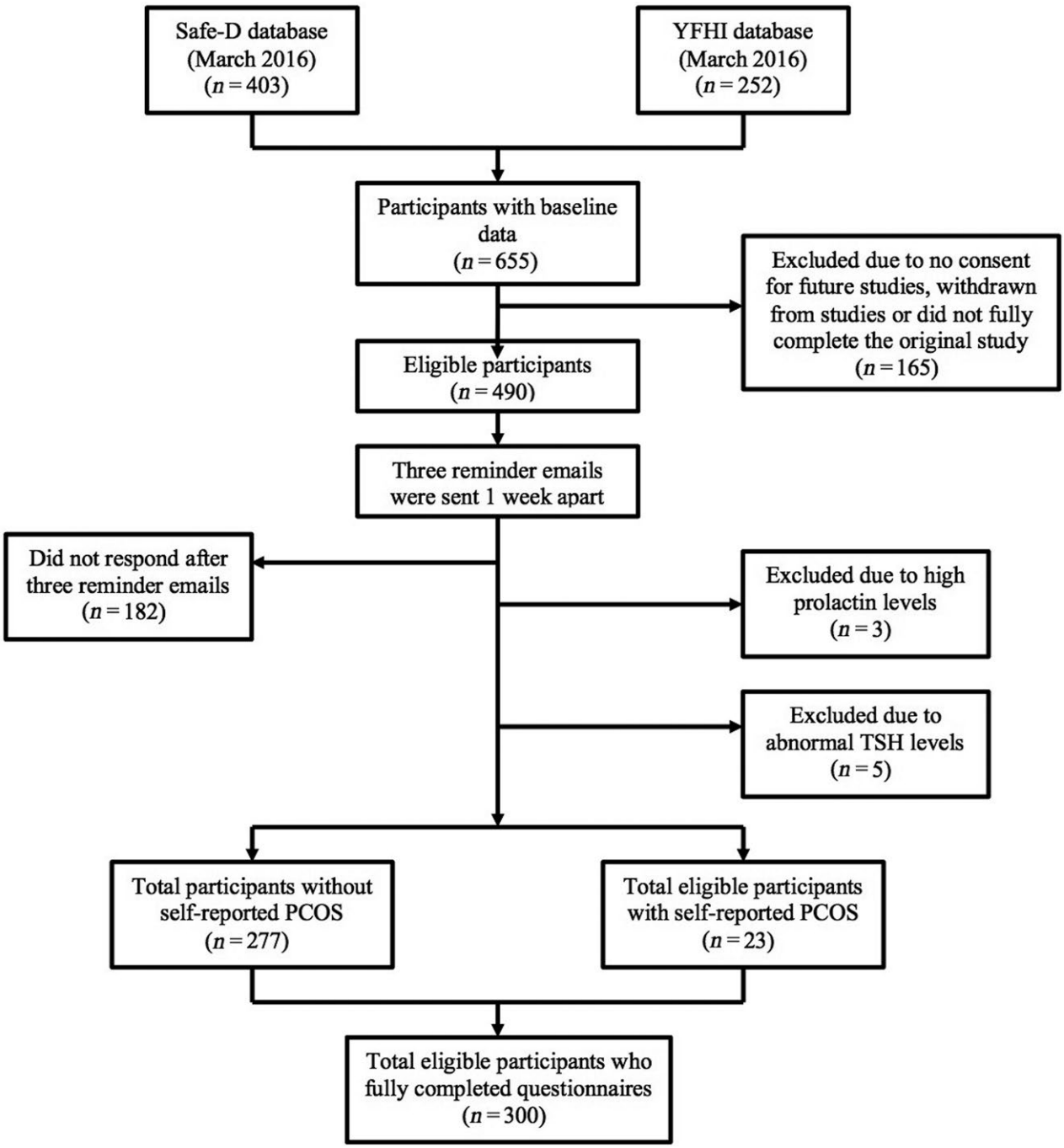

FIGURE 1 Flowchart outlining responses from study cohort.

TABLE 2 Characteristics of participants with PCOS based on the NIH criteria compared with those who did not fulfil the NIH criteria

Variable	Did not fulfil NIH criteria for PCOS (*n* = 223) *n* (%)	Fulfilled NIH criteria for PCOS (*n* = 31) *n* (%)	*P* value†
Study			
YFHI	59 (26)	7 (23)	0.83
Safe-D	164 (74)	24 (77)	
Age at recruitment (years), median (IQR)	22 (21–24)	22 (20–24)	0.85
Age at recruitment (years)			
16–20	54 (24)	9 (29)	0.66
21–25	169 (76)	22 (71)	
BMI‡, median (IQR)	22.9 (21.1–25.5)	23.2 (20.5–27.4)	0.79
BMI‡			
<25	156 (71)	20 (65)	0.53
≥25	65 (29)	11 (35)	
Seifa‡,§, median (IQR)	63 (28–86)	74 (49–90)	0.76
Seifa quartile‡,§			0.21
Lowest	34 (17)	8 (28)	
Highest	161 (83)	21 (72)	
Current smoker‡			
Yes	19 (10)	1 (4)	0.48
No	166 (90)	27 (96)	
WH ratio‡, median (IQR)	0.78 (0.75–0.83)	0.78 (0.75–0.82)	0.96
F-G score, median (IQR)	4 (2–7)	6 (2–9)	0.09
Androgenic alopecia			
Yes	27 (12)	7 (23)	0.15
No	196 (88)	24 (77)	
Presence of acne			
Yes	128 (57)	26 (84)	**0.005***
No	95 (43)	5 (16)	
Severity of acne			
Mild	52 (43)	13 (52)	0.38
Moderate/severe	74 (59)	12 (48)	
Current hormonal contraceptive use			
Yes	137 (61)	14 (45)	0.12
No	86 (39)	17 (55)	
Testosterone (nmol/L)‡, median (IQR)	1.1 (0.9–1.6)	1.3 (0.9–1.8)	0.30
DHEAS (umol/L)‡, median (IQR)	7.1 (5.2–9.6)	7.6 (6.0–10.4)	0.53
SHBG (nmol/L)‡, median (IQR)	81 (49–131)	59 (49–106)	0.25
Fasting insulin (mIU/L)‡,¶,††, median (IQR)	8.4 (6.2–10.4)	7.5 (4.9–12.4)	0.56
Fasting G:I ratio (mg/100 000 U)‡,¶,††, median (IQR)	10.0 (7.9–13.3)	10.0 (6.4–15.3)	0.99
Fasting cholesterol (mmol/L)‡,¶,††, median (IQR)	4.6 (4.0–5.3)	4.7 (4.2–5.2)	0.90
Fasting triglycerides (mmol/L)‡,¶,†† median (IQR)	0.8 (0.6–1.2)	0.8 (0.6–1.1)	0.49
Fasting LDL (mmol/L)‡,¶,†† median (IQR)	2.7 (2.2–3.2)	2.8 (2.0–3.1)	0.75
Fasting HDL (mmol/L)‡,¶,†† median (IQR)	1.5 (1.3–1.7)	1.6 (1.2–2.0)	0.23
Reported depression			
Yes	61 (27)	11 (35)	0.39
No	155 (70)	19 (61)	
Unsure	7 (3)	1 (3)	

(Continues)

TABLE 2 (Continued)

Variable	Did not fulfil NIH criteria for PCOS (*n* = 223) *n* (%)	Fulfilled NIH criteria for PCOS (*n* = 31) *n* (%)	*P* value†
Kessler score (K10)‡‡			
<20	181 (81)	27 (87)	0.62
>20	42 (19)	4 (13)	
Measured hypertension‡			
Yes	9 (4)	2 (7)	0.63
No	214 (96)	28 (93)	
Reported hyperlipidaemia			
Yes	3 (1)	2 (6)	0.12
No	217 (98)	29 (94)	
Unsure	3 (1)	0 (0)	
Reported heart disease or defect			
Yes	5 (2)	1 (3)	0.54
No	218 (98)	29 (94)	
Unsure	0 (0)	1 (3)	
History of pregnancy‡			0.70
Yes	17 (10)	1 (5)	
No	147 (90)	19 (95)	
Number of miscarriages‡			
0	6 (50)	0 (0)	No *P*-value
>1	6 (50)	0 (0)	
Number of terminations or abortions‡			
0	8 (67)	0 (0)	No *P*-value
>1	4 (33)	0 (0)	

†*P*-values were determined using Fisher's exact or χ^2; *P*-value <0.05 was determined statistically significant.
‡Missing data.
§Based on postal area code. Deciles are rankings within Victoria, Australia. The lowest 10% of areas are assigned a decile number of 1 and the highest 10% of areas are given a decile number of 10. Decile 1 is the most disadvantaged relative to the other deciles.
¶Excluded participants who did not fast at time of blood test.
††Excluded two participants as it is unknown if participant had fasted.
‡‡Only used participants age >18 years as a greater number of younger participants (16–17 years) were recruited in Safe-D study than YFHI study.
BMI, body mass index; DHEAS, dehydroepiandrosterone; F-G score, Ferriman-Gallwey Score; G:I, glucose to insulin; HDL, high density lipoprotein; LDL, low density lipoprotein; PCOS, polycystic ovarian syndrome; Seifa, Socio-Economic Indexes for Areas; SHBG, sex hormone binding globulin; WH, waist-hip; YFHI, Young Female Health Initiative. Interquartile range (IQR) is quartile 1 (25th percentile) to quartile 3 (75th percentile).
**p*-value<= 0.05

to menstrual cycle questions (40/300, 13%) and those who appeared to have misunderstood the question (6/300, 2%) (eg had answered five days for average number of days from day one of one period to day one of the next period). Finally, there were 254 (85%) participants eligible for evaluation. Of these, 31 participants fulfilled the NIH criteria for PCOS, a prevalence of 12%.

Eight percent (23/300) self-reported PCOS and 277/300 (92%) did not. Only 8/23 (35%) of those with self-reported PCOS fulfilled the NIH criteria for PCOS.

Differences between participants who fulfilled NIH criteria and those who did not fulfil criteria

When comparing comorbidities, only the presence of acne was significantly greater in those who fulfilled the NIH criteria (*n* = 254, 84% vs 57%, *P* = 0.005) compared to those who did not. There were no other statistically significant differences in demographic or metabolic risk factors between the groups (Table 2).

Differences between participants who self-reported PCOS and those who did not self-report PCOS

There were no significant differences in demographics between those who self-reported PCOS and those who did not (Table 3). Serum testosterone levels were significantly greater in the self-reported PCOS group (1.5 nmol/L (1.3–1.8)), compared with the non-self-reported PCOS group (1.1 nmol/L (0.8–1.5), *P* = 0.005). Those with self-reported PCOS appear more likely to be overweight/obese (*n* = 297, 48% vs 28%, *P* = 0.05),

TABLE 3 Characteristics of participants with non-self-reported PCOS and self-reported PCOS

Variable	Non-self-reported PCOS (*n* = 277) *n* (%)	Self-reported PCOS (*n* = 23) *n* (%)	*P*-value†
Study			
YFHI	71 (26)	5 (22)	0.81
Safe-D	206 (74)	18 (78)	
Age at recruitment (years), median (IQR)	23 (21–24)	22 (21–23)	0.24
Age at recruitment (years)			
16–20	66 (24)	5 (22)	1.00
21–25	211 (76)	18 (78)	
BMI‡, median (IQR)	22.8 (20.9–25.3)	24.2 (20.6–31.8)	0.08
BMI‡			
<25	196 (72)	12 (52)	**0.05***
≥25	78 (28)	11 (48)	
Seifa‡,§, median (IQR)	69 (37–86)	59 (27–78)	0.16
Seifa quartile‡,§			
Lowest	46 (19)	4 (19)	1.00
Highest	198 (81)	17 (81)	
Current smoker‡			
Yes	25 (11)	0 (0)	0.23
No	209 (89)	19 (100)	
WH ratio‡, median (IQR)	0.79 (0.75–0.83)	0.82 (0.77–0.88)	**0.04***
F-G score, median (IQR)	4 (2–7)	5 (3–10)	0.22
Androgenic alopecia			
Yes	31 (11)	5 (22)	0.17
No	246 (89)	18 (78)	
Presence of acne			
Yes	169 (61)	15 (65)	0.83
No	108 (39)	8 (35)	
Severity of acne			
Mild	73 (44)	5 (33)	0.59
Moderate/severe	93 (56)	10 (67)	
Unsure	1 (<1)	0 (0)	
Current hormonal contraceptive use			
Yes	179 (65)	15 (65)	1.00
No	98 (35)	8 (35)	
Testosterone (nmol/L)‡, median (IQR)	1.1 (0.8–1.5)	1.5 (1.3–1.8)	**0.005***
DHEAS (umol/L)‡, median (IQR)	7.1 (5.2–9.4)	6.4 (5.0–8.9)	0.56
SHBG (nmol/L)‡, median (IQR)	80.7 (50–131)	89.5 (37–214)	1.00
Fasting insulin (mIU/L)‡,¶,††, median (IQR)	8.2 (6.0–10.3)	10.1 (6.9–13.2)	**0.03***
Fasting G:I ratio (mg/100 000 U)‡,¶,††, median (IQR)	10.0 (8.0–13.6)	8.2 (5.8–12.5)	0.06
Fasting cholesterol (mmol/L)‡,††, median (IQR)	4.6 (4.1–5.3)	4.7 (4.1–5.3)	0.73
Fasting triglycerides (mmol/L)‡,††, median (IQR)	0.8 (0.6–1.2)	1.0 (0.7–1.5)	0.11
Fasting LDL (mmol/L)‡,††, median (IQR)	2.7 (2.2–3.2)	2.9 (2.0–3.2)	0.82
Fasting HDL (mmol/L)‡,††, median (IQR)	1.5 (1.3–1.7)	1.4 (1.2–1.8)	0.51
Reported depression			
Yes	72 (26)	12 (52)	**0.006***
No	196 (71)	10 (44)	
Unsure	9 (3)	1 (4)	

(Continues)

TABLE 3 (Continued)

Variable	Non-self-reported PCOS (*n* = 277) *n* (%)	Self-reported PCOS (*n* = 23) *n* (%)	*P*-value†
Kessler score‡‡			
<20	227 (82)	21 (91)	0.39
>20	50 (18)	2 (9)	
Measured hypertension‡			
Yes	10 (4)	2 (9)	0.22
No	267 (96)	20 (91)	
Reported hyperlipidaemia			
Yes	5 (2)	2 (9)	0.09
No	269 (97)	21 (91)	
Unsure	3 (1)	0 (0)	
Reported heart disease or defect			
Yes	7 (2)	0 (0)	1.00
No	269 (97)	23 (100)	
Unsure	1 (1)	0 (0)	
History of pregnancy‡			
Yes	14 (7)	5 (26)	**0.01***
No	189 (93)	14 (74)	
Number of miscarriages‡			
0	7 (78)	0 (0)	**0.02***
>1	2 (22)	4 (100)	
Number of terminations or abortions‡			
0	0 (44)	4 (100)	0.11
>1	5 (56)	0 (0)	

†*P*-values were determined using Fisher's exact, χ^2 or Mann–Whitney *U*-test; *P*-value < 0.05 was determined statistically significant.
‡Missing data, values may not add up to 100%.
§Based on postal area code. Deciles are rankings within Victoria, Australia. The lowest 10% areas are assigned a decile number of 1 and the highest 10% of areas are given a decile number of 10. Decile 1 is the most disadvantaged relative to the other deciles.
¶Excluded participants who did not fast at time of blood test.
††Excluded three participants as it is unknown whether participant had fasted.
‡‡Only used participants age >18 years as a greater number of younger participants (16-17 years) were recruited in Safe-D study than YFHI study.
BMI, body mass index; DHEAS, dehydroepiandrosterone; F-G score, Ferriman-Gallwey Score; G:I, glucose to insulin; HDL, high density lipoprotein; LDL, low density lipoprotein; PCOS, polycystic ovarian syndrome; Seifa, Socio-Economic Indexes for Areas; SHBG, sex hormone binding globulin; WH, waist-hip; YFHI, Young Female Health Initiative. Interquartile range (IQR) is quartile 1 (25th percentile) to quartile 3 (75th percentile).
**p*-value<= 0.05

have a higher WH ratio (0.82 (0.77–0.88) vs 0.79 (0.75–0.83), *P* = 0.04) and higher fasting insulin (10.1 (6.9–13.2) vs 8.2 (6.0–10.3), P = 0.03). They also were more likely to self-report a history of depression (*n* = 300, 52% vs 26% *P* = 0.006), history of pregnancy (*n* = 222, 26% vs 7%, *P* = 0.01) and a history of miscarriage (*n* = 13, 100% vs 22%, *P* = 0.02). Using multivariable logistic regression analyses, we found that self-reported PCOS was positively associated with reported depression and a history of pregnancy (Table 4).

Differences between participants who self-reported PCOS and those who did not self-report PCOS if they met the NIH criteria (n = 31)

Among the 31 participants who fulfilled the NIH criteria for PCOS, 8/31 (26%) self-reported PCOS and 23/31 (74%) did not. When comparing these two groups, there were significant differences in current contraceptive use (88% vs 30%, *P* = 0.01), fasting G:I (glucose : insulin) ratio (4.9 (0.9–6.0) vs 10.0 (7.8–15.4), *P* = 0.02) and measured hypertension (38% vs 5%, *P* = 0.05; Table 5).

Qualitative analysis on the impact of self-reported PCOS on wellbeing

Among those who self-reported PCOS, 65% (15/23) were unhappy or worried about their diagnosis. 'Other' reactions included 'depressed', 'upset' or 'understanding'. Seventy-two percent (13/18) reported potential infertility was the most distressing aspect of PCOS. Twenty-eight percent (5/18) did not answer this question. Finally, 50% (11/23) were afraid they could not have children. 'Other' responses included 'angry

TABLE 4 Factors associated with self-reported PCOS on multivariate analysis

	Univariable		Multivariable†	
	OR (95% CI)	*P*-value	OR (95% CI)	*P*-value
Study				
YFHI	1.0	0.68		
Safe-D	1.2		–	
Age (years)				
16–20	1.0	0.82	1.0	0.97
21–25	1.1 (0.4–3.2)		0.9 (0.3–3.7)	
BMI				
<25	1.0	0.06		
≥25	2.3 (1.0–5.4)		–	
Fasting insulin				
≤15	1.0	0.70		
>15	1.2 (0.4–4.6)		–	
Reported depression				
No	1.0	0.008	1.0	0.09
Yes	3.3 (1.4–7.9)		2.2 (0.9–6.0)	
History of pregnancy				
No	1.0	0.008	1.0	0.03
Yes	4.8 (1.5–15.3)		3.9 (1.2–13.3)	

†Multivariable analyses were adjusted for all other variables in the column. Variables with a *P*-value <0.05 were adjusted for in the multivariable models. The multivariable analysis included 214 observations and the pseudo-r^2 was 0.065.
BMI, body mass index; PCOS, polycystic ovarian syndrome; YFHI, young female health initiative.

that I can't fall pregnant without medication', 'concerned it will be difficult' and 'I've had miscarriages before so I wonder if PCOS has anything to do with it. It is emotionally exhausting to think about'.

We asked participants to make some general comments about their experience with PCOS. Some examples included 'was a very long time trying to conceive which was depressing but eventually happened', 'I thought my fertility was sub average – but I have conceived very easily twice', 'I have learnt the hard way that not all women are as infertile as they might be told' and 'Although doctors have said that it's very unlikely that I'll become pregnant without intervention, I'm currently 34 weeks pregnant with no fertility assistance. I think doctors should be careful of the information they provide to clients as this diagnosis caused me a lot of depression and anxiety'.

DISCUSSION

Using the NIH criteria, the prevalence of PCOS in our cohort of young females aged 16–29 was 12%. There were more comorbidities in those with self-reported PCOS than those without self-reported PCOS, and the most concerning aspect for participants with a diagnosis of PCOS was the possibility of infertility.

Our prevalence estimate was greater than determined by Musmar *et al.*[17] (7.3%), who recruited a similar age group, but was within the range when compared to other Australian studies (16.9%,[18] 8.7%,[6] 3.1%[19] and 15.3%[20]).

The difference in prevalence estimates can be partly attributed to the way the diagnostic criteria are applied.[21] Some researchers have published narrower cut-offs for oligo/anovulation, with only ≥35 days[20] or only ≤8 cycles per year.[17] We determined clinical hyperandrogenism on self-reported acne, which was common, thus potentially increasing the diagnosis of PCOS in our cohort; hirsutism, which was subjectively assessed and could have been over- or underestimated; and self-reported androgenic alopecia, which was not assessed in many previous studies.[17–20] For testosterone, the 95th percentile of the non-PCOS group was often the cut-off. However, this value differed greatly between papers (range 2.4 nmol/L[17]–4.5 nmol/L[19]). In our study, the 95th percentile was lower than this range (2.2 nmol/L), potentially increasing the number of participants who fulfilled the criteria. Therefore, we recommend the development of standardised criteria with set parameters that allow comparison between populations. Furthermore, diagnosing adolescents with PCOS is challenging because symptoms overlap with normal pubertal development.[21] Consequently, there is a greater probability of incorrect diagnosis.

There were no differences in comorbidities in women of this age, whether they met the NIH criteria or not (Table 2). While there appeared to be some differences on those diagnosed by self-report versus those not diagnosed, the psychological comorbidity appeared to be significant in those who self-reported a diagnosis (Table 3). Thus, correct diagnosis of PCOS and the way it is conveyed to young women is critical to their mental and physical wellbeing.

We discovered that the three most common reactions to a diagnosis of PCOS were 'unhappy or worried', 'scared' and 'confused'. Those confused about the diagnosis reported that doctors did not explain PCOS properly. Similarly, Trent *et al.*[22] determined that more than 50% of adolescent girls described PCOS negatively, despite only a fraction understanding their illness. In our study, 72% (13/18) claimed fear of infertility was the most distressing aspect of PCOS, a similar result to other papers.[22] Menstrual dysfunction[23,24] and hirsutism[23,24] were also implicated, but possible infertility was the most common feature that reduced health-related quality of life[9].

In our study, over 50% in the self-reported PCOS group were afraid they could not have children. Despite pregnancy rates being higher in this group (Table 3), most still believed their fertility was reduced. Misinformation regarding fertility in this age group leads to unnecessary distress and anxiety.[7,25] Young women must be informed that PCOS is a manageable condition and that reproductive health can be optimised with appropriate medications and lifestyle factors. Providing comprehensive information and having open

TABLE 5 Characteristics of participants who fulfilled the NIH criteria and have self-reported PCOS compared with those who fulfilled the NIH criteria but did not self-report PCOS

Variable	Met NIH criteria but did not self-report PCOS (*n* = 23) *n* (%)	Met NIH criteria and self-reported PCOS (*n* = 8) *n* (%)	*P*-value†
Study			
YFHI	4 (17)	3 (38)	0.36
Safe-D	19 (83)	5 (63)	
Age at recruitment (years), median (IQR)	23 (20–25)	21 (19–23)	0.36
Age at recruitment (years)			
16–20	6 (26)	3 (38)	0.66
21–25	17 (74)	5 (62)	
BMI‡, median (IQR)	22.1 (20.5–26.6)	25.2 (21.8–33.8)	0.26
BMI‡			
<25	16 (70)	4 (50)	0.41
≥25	7 (30)	4 (50)	
Seifa‡,§, median (IQR)	72 (31–94)	31 (8–58)	0.06
Seifa quartile‡,§			
Lowest	5 (24)	3 (38)	0.65
Highest	16 (76)	5 (62)	
Current smoker‡			
Yes	19 (95)	0 (0)	0.71
No	1 (5)	8 (100)	
WH ratio‡, median (IQR)	0.78 (0.75–0.81)	0.80 (0.76–0.82)	0.53
F-G score, median (IQR)	6 (2–9)	6 (4–11)	0.59
Androgenic alopecia			
Yes	4 (17)	3 (38)	0.36
No	19 (83)	5 (62)	
Presence of acne			
Yes	18 (78)	8 (100)	0.23
No	5 (22)	0 (0)	
Severity of acne			
Mild	10 (59)	3 (38)	0.41
Moderate/severe	7 (41)	4 (50)	
Unsure	0 (0)	1 (12)	
Current hormonal contraceptive use			
Yes	7 (30)	7 (88)	**0.01***
No	16 (70)	1 (12)	
Testosterone (nmol/L)‡, median (IQR)	1.1 (0.9–1.5)	1.7 (1.4–1.9)	0.11
DHEAS (nmol/L)‡, median (IQR)	7.7 (5.2–10.4)	7.1 (6.3–9.8)	0.89
SHBG (umol/L)‡, median (IQR)	59 (48–95)	78 (35.5–166)	0.96
Fasting insulin (mIU/L)‡,¶,††, median (IQR)	7.2 (4.9–9.1)	13.8 (7.3–26.0)	0.06
Fasting G:I ratio (mg/100 000 U)‡,¶,††, median (IQR)	10.0 (7.8–15.4)	4.1 (0.9–6.0)	**0.02***
Fasting cholesterol (mmol/L)‡,††, median (IQR)	4.7 (4.2–5.1)	4.7 (4.1–5.2)	0.11
Fasting triglycerides (mmol/L)‡,††, median (IQR)	0.8 (0.5–1.0)	0.9 (0.8–1.4)	0.20
Fasting LDL (mmol/L)‡,††, median (IQR)	2.6 (2.1–3.2)	2.9 (1.9–3.2)	0.95
Fasting HDL (mmol/L)‡,††, median (IQR)	1.7 (1.2–2.0)	1.4 (1.2–1.9)	0.59

(Continues)

TABLE 5 (Continued)

Variable	Met NIH criteria but did not self-report PCOS (*n* = 23) *n* (%)	Met NIH criteria and self-reported PCOS (*n* = 8) *n* (%)	*P*-value†
Reported depression			
Yes	17 (74)	2 (25)	0.07
No	6 (26)	5 (63)	
Unsure	0 (0)	1 (12)	
Kessler score‡‡			
<20	19 (83)	8 (100)	0.55
>20	4 (17)	0 (0)	
Measured hypertension‡			
Yes	1 (5)	3 (38)	**0.05***
No	21 (95)	5 (62)	
Reported hyperlipidaemia			
Yes	1 (4)	1 (12)	0.46
No	22 (96)	7 (88)	
Unsure	0 (0)	0 (0)	
Reported heart disease or defect			
Yes	1 (4)	0 (0)	1.00
No	21(92)	8 (100)	
Unsure	1 (4)	0 (0)	
History of pregnancy‡			
Yes	1 (7)	0 (0)	1.00
No	14 (93)	5 (100)	
Number of miscarriages‡			
0	4 (100)	1 (100)	–
>1	0 (0)	0 (0)	
Number of terminations or abortions‡			
0	4 (100)	1 (100)	–
>1	0 (0)	0 (0)	

†*P*-values were determined using Fisher's exact, χ^2 or Mann–Whitney *U*-test; *P*-value <0.05 was determined statistically significant.
‡Missing data, values may not add up to 100%.
§Based on postal area code. Deciles are rankings within Victoria, Australia. The lowest 10% areas are assigned a decile number of 1 and the highest 10% of areas are given a decile number of 10. Decile 1 is the most disadvantaged relative to the other deciles.
¶Excluded participants who did not fast at time of blood test.
††Excluded three participants as it is unknown whether participant had fasted.
‡‡Only used participants age >18 years as a greater number of younger participants (16–17 years) were recruited in Safe-D study than YFHI study.
BMI, body mass index; DHEAS, dehydroepiandrosterone; F-G score, Ferriman-Gallwey Score; G:I, glucose to insulin; HDL, high density lipoprotein; LDL, low density lipoprotein; PCOS, polycystic ovarian syndrome; Seifa, Socio-Economic Indexes for Areas; SHBG, sex hormone binding globulin; WH, waist-hip; YFHI, Young Female Health Initiative. Interquartile range (IQR) is quartile 1 (25th percentile) to quartile 3 (75th percentile).
**p*-value<= 0.05

discussions about fertility concerns are important parts of managing PCOS.[25] These concerns should not be neglected because of age as these concerns appear to rise as early as adolescence.[25]

To the best of our knowledge, this is the only Australian study of PCOS in which young adult women, a population underrepresented in the literature, were recruited. This was an important group to consider as major health and lifestyle decisions are made at this age. Additionally, our sample was representative of 16–29-year-olds in Australia when compared with demographics from the Australian census data.[10]

There were some methodological limitations to this study. First, we applied one of three established sets of criteria (NIH) to diagnose PCOS as the other two criteria (Rotterdam and AES) require transvaginal ultrasound, to which we did not have access for this study. Second, site visits for five participants were completed up to four years before the supplementary questionnaire was answered. Therefore, these anthropometric data may not be reflective of a participant's current body composition. Additionally, self-reported PCOS was not confirmed with medical records. Serum androgen levels were available in most (84%) but not all

participants, limiting the utility of applying the NIH diagnostic criteria. Finally, we had a relatively small sample size compared to other prevalence studies. With a larger sample size, we may have more power to detect significant associations.

In conclusion, the prevalence of PCOS in this sample using NIH criteria was 12%. There is a great deal of variability in diagnostic criteria between studies, which makes it difficult to calculate and compare prevalence values. This is important for clinicians to recognise as they may be potentially over-diagnosing PCOS in young women, contributing to unnecessary and unwarranted fears of complications, particularly infertility.

REFERENCES

1. Azziz R, Woods KS, Reyna R, *et al.* The prevalence and features of the polycystic ovary syndrome in an unselected population. *J Clin Endocrinol Metab* 2004; **89**: 2745–2749.
2. Fauser BC, Tarlatzis BC, Rebar RW, *et al.* Consensus on women's health aspects of polycystic ovary syndrome (Pcos): the amsterdam Eshre/Asrm-sponsored 3rd pcos consensus workshop group. *Fertil Steril* 2012; **97**(1): 28–38. e1-25.
3. Zawadzki J, Dunaif A. Diagnostic criteria for polycystic ovary syndrome: towards a rational approach. In: Dunaif a, Givens Jr, Haseltine Fp, Merriam Gr, eds. *Polycystic Ovary Syndrome*. Boston: Blackwell Scientific Publications, 1992; 377–384.
4. The Rotterdam ESHRE/ASRM-Sponsored PCOS Consensus Workshop Group Rotterdam, TN. Revised 2003 consensus on diagnostic criteria and long-term health risks related to polycystic ovary syndrome. *Fertil Steril* 2004; **81**(1): 19–25.
5. Azziz R, Carmina E, Dewailly D, *et al.* Positions statement: criteria for defining polycystic ovary syndrome as a predominantly hyperandrogenic syndrome: an androgen excess society guideline. *J Clin Endocrinol Metab* 2006; **91**: 4237–4245.
6. March WA, Moore VM, Willson KJ, *et al.* The prevalence of polycystic ovary syndrome in a community sample assessed under contrasting diagnostic criteria. *Hum Reprod* 2010; **25**: 544–551.
7. Morris S, Grover S, Sabin MA. What does a diagnostic label of 'polycystic ovary syndrome' really mean in adolescence? a review of current practice recommendations. *Clin Obes* 2016; **6**(1):1–18.
8. Palomba S, Santagni S, Falbo A, La Sala GB. Complications and challenges associated with polycystic ovary syndrome: current perspectives. *Int J Womens Health* 2015; **7**: 745–763.
9. Jones GL, Hall JM, Balen AH, Ledger WL. Health-related quality of life measurement in women with polycystic ovary syndrome: a systematic review. *Hum Reprod Update* 2008; **14**(1): 15–25.
10. Fenner Y, Garland SM, Moore EE, *et al.* Web-based recruiting for health research using a social networking site: an exploratory study. *J Med Internet Res* 2012; **14**(1): e20. 1-14.
11. Callegari ET, Reavley N, Garland SM, *et al.* Vitamin D status, bone mineral density and mental health in young australian women: the safe-D study. *J Public Health Res* 2015; **4**: 594.
12. Cronin L, Guyatt G, Griffith L, *et al.* Development of a health-related quality-of-life questionnaire (Pcosq) for Women with polycystic ovary syndrome (Pcos). *J Clin Endocrinol Metab* 1998; **83**: 1976–1987.
13. Ferriman D, Gallwey JD. Clinical assessment of body hair growth in women. *J Clin Endocrinol Metab* 1961; **21**: 1440–1447.
14. Bode D, Seehusen DA, Baird D. Hirsutism in women. *Am Fam Physician* 2012; **85**: 373–380.
15. Kessler RC, Andrews G, Colpe LJ, *et al.* Short screening scales to monitor population prevalences and trends in non-specific psychological distress. *Psychol Med* 2002; **32**: 956–959.
16. Andrews G, Slade T. Interpreting scores on the kessler psychological distress scale (K10). *Aust N Z J Public Health* 2001; **25**: 494–497.
17. Musmar S, Afaneh A, Afaneh A, Mo'alla H. Epidemiology of polycystic ovary syndrome: a cross sectional study of university students at an-Najah National University-Palestine. *Reprod Biol Endocrinol* 2013; **11**(47): 1–6.
18. Hart R, Doherty DA, Norman RJ, *et al.* Serum antimullerian hormone (Amh) levels are elevated in adolescent girls with polycystic ovaries and the polycystic ovarian syndrome (Pcos). *Fertil Steril* 2010; **94**: 1118–1121.
19. Hickey M, Doherty DA, Atkinson H, *et al.* Clinical, ultrasound and biochemical features of polycystic ovary syndrome in adolescents: implications for diagnosis. *Hum Reprod* 2011; **26**: 1469–1477.
20. Boyle JA, Cunningham J, O'Dea K, *et al.* Prevalence of polycystic ovary syndrome in a sample of indigenous women in darwin, Australia. *Med J Aust* 2012; **196**(1): 62–66.
21. Lizneva D, Suturina L, Walker W, *et al.* Criteria, prevalence, and phenotypes of polycystic ovary syndrome. *Fertil Steril* 2016; **106**(1): 6–15.
22. Trent ME, Rich M, Austin SB, Gordon CM. Fertility concerns and sexual behavior in adolescent girls with polycystic ovary syndrome: implications for quality of life. *J Pediatr Adolesc Gynecol* 2003; **16**(1): 33–37.
23. Eggers S, Kirchengast S. The polycystic ovary syndrome–a medical condition but also an important psychosocial problem. *Coll Antropol* 2001; **25**: 673–685.
24. Kitzinger C, Willmott J. 'The thief of womanhood': women's experience of polycystic ovarian syndrome. *Soc Sci Med* 2002; **54**: 349–361.
25. Kaczmarek C, Haller DM, Yaron M. Health related quality of life in adolescents and young adults with polycystic ovary syndrome: a systematic review. *J Pediatr Adolesc Gynecol* 2016; **29**(6): 551–557.