

Background

Many women with polycystic ovary syndrome (PCOS) have a delayed diagnosis after seeing multiple health care providers for their symptoms impacting on their physical and emotional well-being¹. In adolescent girls, PCOS diagnosis is even more controversial and challenging than in adult women yet there have been no studies in adolescents evaluating diagnostic experience, their knowledge and concerns. We aimed to evaluate diagnostic experience and concerns regarding PCOS in an adolescent population.

Methods

Cross sectional study including adolescent girls aged 12-19 years who were diagnosed with PCOS by a Doctor (according to International Consortium criteria² if recruited from the clinic).

Ethics approval: Women's and Children's Human Research Ethics Committee (HREC/17/WCHN/15).

Recruitment: 1) Outpatient clinics: Endocrine, gynaecology and adolescent gynaecology/endocrine at Women's and Children's Hospital (WCH, Adelaide, Australia).

2) Online via Polycystic Ovary Syndrome Association of Australia (POSAA), Health Consumer Alliance of South Australia and Health Consumer WCH consumer group.

Data collection: Validated questionnaire¹ that was adapted to be used in adolescents. The questionnaire evaluated the level of satisfaction and experiences with process leading to PCOS diagnosis, information women receive related to managing this condition, and the name of the condition itself.

Results

Fifty six adolescent girls completed the questionnaire (25 via clinics and 31 via online). Four adolescents had a mother diagnosed with PCOS. Demographic characteristics, PCOS diagnosis, experience and information received are summarised in Tables and the Figures below.

Table 1. Demographic characteristics and PCOS diagnosis

Demographic characteristics (mean ± SD)			
Age (years)	17.3 ± 1.5		
Menarche (years)	12.3 ± 1.6		
Body Mass Index (kg/m ²) *	29.0 ± 7.0		
Racial background			
Caucasians	40		
Asians	11		
Aboriginal	5		
Time taken for diagnosis of PCOS from 1st doctor's visit		Time since diagnosis	
< 6 months	28	< 1 year ago	23
6 months- year	13	1-2 years ago	21
1-2 years	6	3-4 years ago	8
> 2 years	9	> 5 years ago	4
Number of health professionals seen prior to diagnosis			
≤2	41		
>2	15		

* BMI data was only available for participants recruited from the clinics. There were 13 with BMI ≥85% and 8 with BMI <85%.

Figure 1. Adolescents rating on PCOS diagnosis (left) and general information received at diagnosis (right)

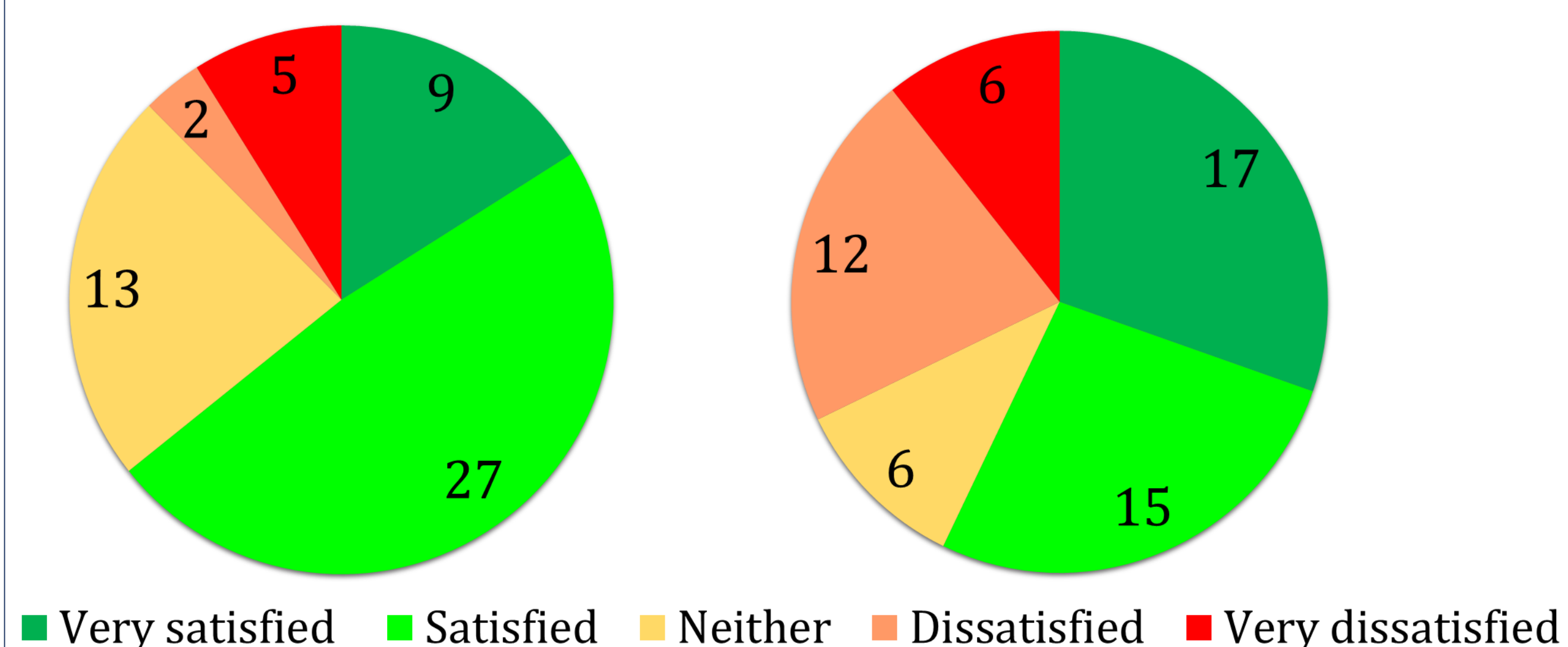


Table 2. Adolescents rating on different aspects of information given at diagnosis

Rating	Lifestyle management	Medical therapy	Long term health complications **	Emotional support & counselling **
Very satisfied	13	11	10	6
Satisfied	14	24	15	8
Neither	8	5	7	6
Dissatisfied	6	2	7	7
Very dissatisfied	5	5	2	6
Not mentioned	10	9	15	23

** Adolescents surveyed online were more likely to report that information regarding long-term health complications and emotional support was not mentioned at diagnosis.

Table 3. Features of PCOS and research areas most important for adolescents, and factors adolescents believe to be associated with PCOS

Four most important features of PCOS for adolescents	Responses	Features associated with PCOS (adolescents can select all responses that applied)	Responses
Irregular menstrual cycles	25	Irregular menstrual cycle	48
Difficulty losing weight	23	Excess hair growth	47
Excess hair	23	Hormone imbalance	45
Weight gain	20	Difficulty losing weight	42
Acne	15	Weight gain	41
Body image dissatisfaction	14	Acne or pimples	39
Anxiety	13	Body image dissatisfaction	37
Hormone imbalance	13	Excess male hormones	37
Depression	9	Ovarian cysts	36
Reduced quality of life	7	Anxiety	33
Scalp hair loss	7	Fertility problems	33
Research areas (adolescents can select up to 5 responses)			Responses
Understanding the changes that occur in PCOS at adolescence			28
Treating excess facial and body hair			23
Achieving weight loss			22
Treating infertility and reduced fertility			21
Treating causes of PCOS (insulin works and preventing diabetes)			17
Achieving regular menstrual cycles/periods			16
Treating PCOS male hormones			16
Sources of support (adolescents can select all responses that applied)			Responses
Provide broadly available educational materials			46
Support and present at patient forums and workshops			30
Maintain a consumer website			21
Send a regular update email on PCOS			19

The majority of the adolescents (n=43) agreed that education is more important than a name change and 33 felt that the name of the syndrome is mostly important for adolescents and women with PCOS.

Conclusions

This is the first study evaluating diagnosis experiences in adolescent girls with PCOS and showed that in contrast to adult women the majority of adolescent girls are overall satisfied with diagnosis experience. Delayed PCOS diagnosis also occurs during adolescence.

References: 1. Gibson-Helm M et al. J Clin Endocrinol Metab. 2017 2. Ibáñez L et al. Horm Res Paediatr. 2017. **Funding:** NHMRC CRE support grant & MS McLeod department research grant.