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Awareness of polycystic ovarian syndrome in adolescents: A cross-sectional study

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Abstract
Polycystic Ovarian Syndrome (PCOS) is a prevalent endocrine disorder affecting a significant percentage of women of reproductive age. This study aimed to assess the level of PCOS awareness and knowledge among urban adolescent females. A cross-sectional online survey was conducted, involving 218 participants aged 12 to 19 years. Categorical variables were presented in the form of numbers and percentages and quantitative data as the means ± SD and as median with 25th and 75th percentiles (interquartile range). The association of the variables was analyzed using the Chi-Square test and Fisher's exact test. The results revealed a low level of PCOS awareness, with only 23.85% of participants demonstrating sufficient awareness. The main sources of knowledge were friends (31.19%) and social media (26.15%), while healthcare professionals played a minimal role (10.09%).
Furthermore, mean values exhibited limited awareness of PCOS features (Mean ±SD 4.38±2.4) and complications (Mean ± SD 1.56±1.26). Notably, awareness of long-term complications such as cardiovascular disease (25.69%) and diabetes (13.30%) was particularly low. Age, education level, and stream of education showed no significant correlation with awareness. ($p>0.05$).
In conclusion, this study highlights the critical need for improved PCOS education among adolescent females in urban settings. Implementing educational programs in school curricula, increasing healthcare professionals' involvement in patient education, and creating awareness workshops are vital steps to reaching a wider audience promoting healthier lifestyle choices enhancing PCOS awareness, and mitigating its long-term consequences.

Keywords: Polycystic ovarian syndrome, awareness, adolescents, complications, endocrine, reproductive age

Introduction
Polycystic ovarian syndrome (PCOS) is a very common endocrine system disorder affecting about 5-10% of women of reproductive age [1, 2]. It is a heterogeneous disorder that leads to the overproduction of androgens mainly from the ovaries. The etiology of PCOS remains unknown, although it is hypothesized that certain genetic factors contribute to its pathophysiology, where those with a genetic predisposition are more likely to express features of PCOS when exposed to certain environmental conditions [3].

A wide range of clinical presentations is attributed to PCOS which include but are not limited to, symptoms associated with hyperandrogenemia such as hirsutism, acne, abnormal unintended weight gain, male pattern alopecia along with anovulation features of irregular heavy menstruation, oligomenorrhea, amenorrhea, and subfertility. Metabolic features include insulin resistance with hyperinsulinemia, impaired glucose intolerance test, and dyslipidemia. Anovulation combined with hyperinsulinemia leads to the proliferation of endometrial cells increasing the risk of endometrial carcinomas. Females with PCOS have an increased risk of type 2 diabetes, metabolic syndrome, and cardiovascular diseases (CVDs) with a four to seven times higher risk of heart attack than females of the same age group without PCOS. Psychological manifestations include loss of femininity, body dissatisfaction, anxiety, depression, and eating disorders [4-6]. Polycystic ovary syndrome remains an underdiagnosed condition despite the fact that it represents the most common endocrine syndrome in women of reproductive age. Its characteristics like irregular menstruation, hirsutism, acne, and obesity, can profoundly impact the physical, emotional, and psychological well-being of affected adolescents. However, the subtlety and variability of these symptoms often lead to misinterpretation as normal teenage changes.

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This diagnostic delay can result in missed opportunities for early intervention, eventually escalating into complications. Early awareness about PCOS can empower adolescents to distinguish normal hormonal fluctuations from underlying health concerns, enabling them to seek timely medical intervention which is critical in mitigating potential complications [7].

Studies have found a gap in the knowledge of students about PCOS and its symptoms and signs, and that lifestyle preferences may predispose them to PCOS. In light of these gaps in understanding, the present study aims to assess the level of PCOS awareness among adolescent females in an urban setting. This study aims to investigate the current level of awareness of adolescent females identify gaps, and understand factors influencing awareness levels. The information collected from this study will be used to facilitate conversations around PCOS and help adolescents make informed decisions about lifestyle choices, dietary habits, and overall well-being, potentially mitigating the progression of PCOS-related complications.

Materials and Methods
This cross-sectional, observational study was carried out in an urban setting in India over a period of 3 months after obtaining institutional scientific and ethical committee. An online structured questionnaire was developed by using Google Forms, with a description form appended to it. The link of the questionnaire was sent through WhatsApp to the school students of English medium schools and the participants were encouraged to roll out the survey to as many as possible. Thus, the link was forwarded to people apart from the first point of contact and so on. On receiving and clicking the link the participants got auto-directed to the information about the study. A set of several questions appeared sequentially, which the participants were supposed to answer. The identity of the participants was not divulged to the investigators. Female participants with access to the internet and of ages 12 to 19 years who were able to understand English and willing to participate were included.

Informed consent was obtained from all the study participants. A self-constructed questionnaire was used to assess participants' knowledge about PCOS, based on data retrieved from Medscape and in reference to other questionnaires used in similar studies with modifications tailored to the background of the study population. The objective of the study was explained and the time required to fill the questionnaire was informed to the respondents. They were informed that they could refuse to participate and could withdraw from study any time without any loss/penalty. No pressure/coercion was exerted on the participants for participation in the study. Confidentiality of information was assured to all the participants

The questionnaire was drafted with 3 sections. The first set included three questions related to sociodemographic details (age, level, and stream of education). The second set included six questions of personal details (age of menarche, dysmenorrhea, number of pads used in a day, days of menstrual flow, length of the menstrual cycle, and family history of PCOS) followed by a third set of questions on awareness begins with whether they have ever heard about PCOS. If yes, then what was the source of information? This was followed by multiple-choice questions (With more than one correct answer) on signs/symptoms, causes/risk factors, diagnosis, long-term complications, psychological complications, treatment, and preventive measures of PCOS.

Statistical analysis
The presentation of the Categorical variables was done in the form of number and percentage (%). On the other hand, the quantitative data were presented as the means ± SD and as median with 25th and 75th percentiles (interquartile range). The association of the variables which were qualitative in nature were analysed using Chi-Square test. If any cell had an expected value of less than 5 then Fisher's exact test was used. The data entry was done in the Microsoft EXCEL spreadsheet and the final analysis was done with the use of Statistical Package for Social Sciences (SPSS) software, IBM manufacturer, Chicago, USA, 25.0.

For statistical significance, p value of less than 0.05 was considered statistically significant.

The study of Balkis Zaitoun, *et al*. [8] observed that 21.7% of participants had sufficient awareness of the syndrome. Taking this value as reference, the minimum required sample size with 5.5% margin of error and 5% level of significance is 216 participants. To reduce margin of error, total sample size taken is 218.

For awareness assessment, a score was calculated for each participant based on their choice of answers, with those scoring higher than 60% being considered to be aware. In bivariate data analysis, awareness status was correlated with the variables of interest. Given the fact that all variables are categorical, the non-parametric chi-square test was used to obtain the p-value of each correlation. A p-value of 0.05 or less entails a significant correlation between the awareness status and the variable being tested.

Results
This study was conducted on 218 urban adolescent females over a period of 2 months. The data was collected online via Google Forms. The findings of the study are presented as follows:
The Socio-demographic data including age of the participants, the level and stream of education is presented in Table 1.

Table 1: Socio-demographic characteristics distribution.

Socio-demographic characteristics	Frequency	Percentage
Age(years)		
12 to 14	36	16.51%
15 to 17	163	74.77%
18 to 19	19	8.72%
Level of education		
Middle school	16	7.34%
High school	189	86.70%
Undergraduate studies	13	5.96%
Stream of education		
Science	93	42.66%
Non-science	64	29.36%
Other	61	27.98%

Drawing from the data, 163(74.77%) participants belonged to the age group 15 to 17 years, 36(16.51%) to age group 12 to 14 years while 19(8.72%) belonged to the age group of 18-19 years. Of the 218 participants, 189(86.70%) were in high school, 16(7.34%) in middle school and 13(5.96%) participants were undergraduate students.

93(42.66%) out of 218 participants belonged to the science stream of education, 64(29.36%) to the non-science stream and 61(27.98%) participants were from other streams.

Table 2: Personal details distribution.

Personal details	Frequency	Percentage
Age of achieving puberty		
8 to 10	12	5.50%
11 to 12	87	39.91%
13 to 14	105	48.17%
15 to 16	7	3.21%
Not achieved	7	3.21%
Average number of pads used per day		
<2	20	9.17%
2 to 4	145	66.51%
5 to 7	46	21.10%
No cycles	7	3.21%
Duration of menstrual flow		
2 to 4	68	31.19%
5 to 7	120	55.05%
>8	23	10.55%
No cycles	7	3.21%
Length of menstrual cycle		
<21	5	2.29%
21 to 35	128	58.72%
>35	34	15.60%
No cycles	7	3.21%
No fixed period	44	20.18%
Family history of PCOS		
No	117	53.67%
Yes	31	14.22%
Don't know	70	32.11%
Dysmenorrhea (Painful menstruation)		
No	92	42.20%
Yes	119	54.59%
No cycles	7	3.21%

The distribution of the personal details of the participants is given in Table 2. Out of a total of 218 participants, 105(48.17%) participants achieved puberty at the ages of 13 to 14 years, 87 (39.91%) at 11 to 12 years, 12 (5.50%) participants at 8 to 10 years, and 7 (3.21%) participants at 15 to 16 years of age. 7 (3.21%) participants had not achieved puberty yet.

Of the total, 145 (66.51%) participants used an average of 2 to 4 sanitary pads per day, 46 (21.10%) participants used 5 to 7, and 20 (9.17%) participants used less than 2 pads per day. Since 7 (3.21%) participants did not have cycles, no pads were used.

120 (55.05%) participants reported menstrual flow over 5 to 7 days, while 68 (31.19%) participants reported a flow of 2 to 4 days, and 23 (10.55%) participants reported >8 days of menstrual flow. 7 (3.21%) participants did not have cycles.

The length of the menstrual cycle averaged 21-35 days in 128(58.72%), more than 35 days in 34 (15.60%), and less than 21 days in 5 (2.29%) participants. 44 (20.18%) participants did not have any fixed period and 7 (3.21%) participants did not have cycles.

A family history of PCOS was reported by 31(14.22%) participants and 117(53.67%) reported against it. 70(32.11%) participants were not aware of the family history of PCOS.

Dysmenorrhea (Painful menstruation) was present in 119(54.59%) participants.

As in Figure 1, the majority of participants had heard about PCOS (86.24%) as against 13.76% who had not heard about PCOS.
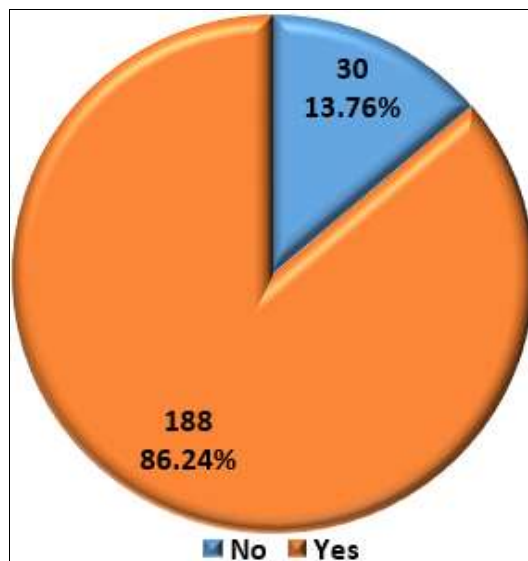

Fig 1: Knowledge about PCOS distribution

Friends were the biggest source of knowledge (31.19%) of participants, followed by social media 57(26.15%) participants. 44(20.18%) participants gained knowledge from family members, 27(12.39%) participants from other sources while only 22(10.09%) participants were informed by a doctor. (Figure 2).
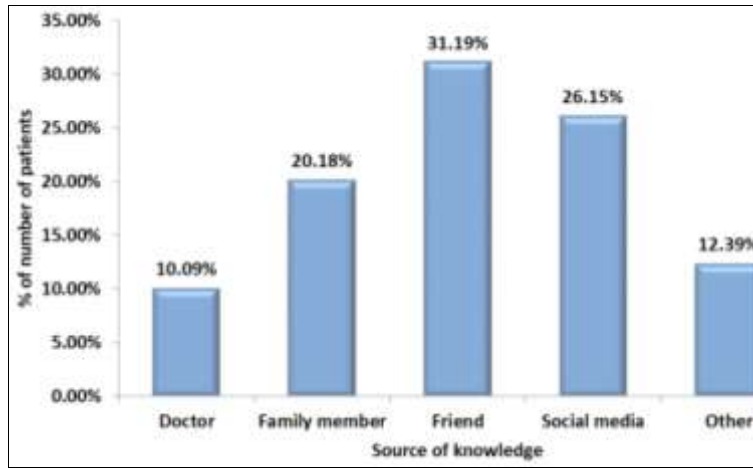
Fig 2: Source of knowledge distribution

The level of awareness of PCOS symptoms was also assessed. The participants were encouraged to answer as many options as they knew. Tables 3 and 4, and Figures 3,4 and 5 demonstrate the frequency at which participants chose each item under every sub-section.

Table 3: How frequently was each feature chosen?

Features of PCOS	Frequency	Percentage
Irregular or absent menses	187	85.78%
Facial acne	60	27.52%
Weight gain	122	55.96%
Abnormal hair growth	132	60.55%
Stress	98	44.95%
Pelvic pain	70	32.11%
Anxiety	71	32.57%
Reduced fertility	159	72.94%
Out-of-control eating	32	14.68%
Frontal hair loss	23	10.55%
I don't know	22	10.09%

As demonstrated in Table 3, the most frequently chosen feature of PCOS was irregular or absent menses followed by reduced fertility and abnormal hair growth. (Table 3).
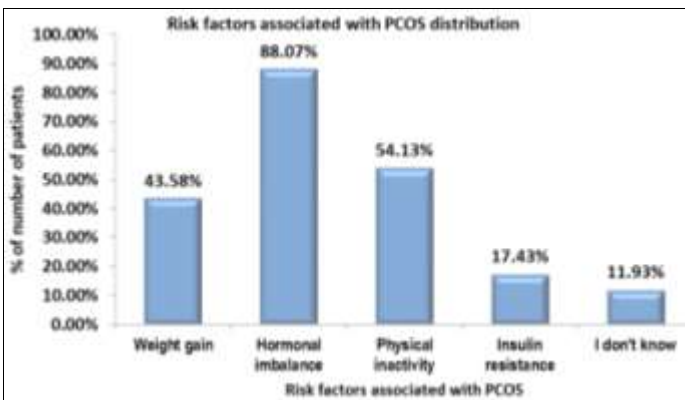

Fig 3: How frequently was each risk factor associated with PCOS

Figure 3 illustrates participants' responses to risk factors of PCOS. As shown, hormonal imbalance was believed to be a cause by most, followed by physical inactivity and weight gain. (Figure 3)

Of the multiple-choice question with more than one correct answer, 136(62.39%) participants out of a total of 218 identified increased androgen levels as a complication of PCOS, 120(55.05%) participants chose endometrial cancer, 56(25.69%) identified cardiovascular disease and 29(13.30%) participants

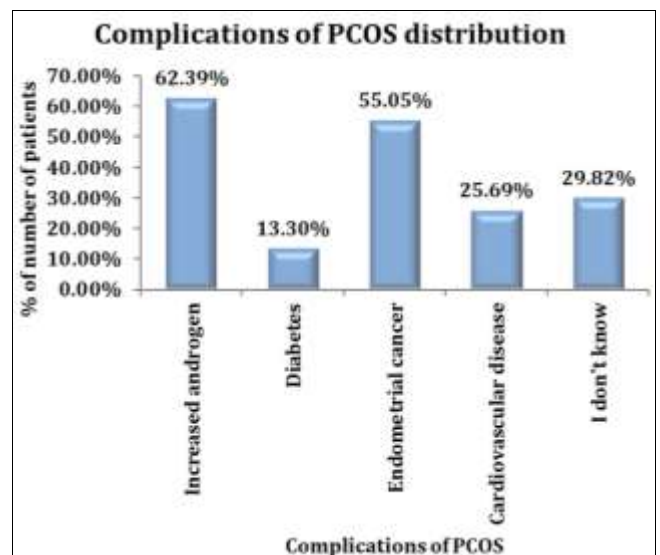selected diabetes. 65(29.82%) participants didn't know. (Figure 4)

Fig 4: How frequently was each complication of PCOS chosen?
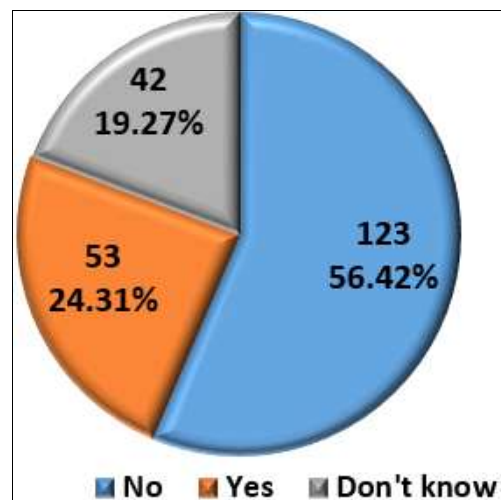

Fig 5: Awareness of psychological complications of PCOS

Out of 218 patients, only 53(24.31%) were aware of the psychological complications of PCOS (Figure 5).

Table 4: How frequently was each preventive measure for PCOS chosen?

Preventive measures for PCOS	Frequency	Percentage
Fiber-rich diet	163	74.77%
Meditation	128	58.72%
Weight loss	109	50.00%
I don't know	36	16.51%

Most participants agreed that a fiber-rich diet helps prevent PCOS while 128 participants selected meditation and 109 participants chose weight loss. (Table 4)
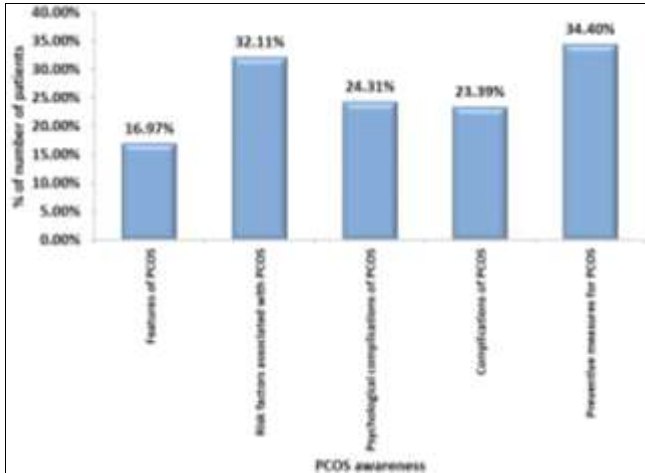

Fig 6: PCOS awareness distribution

Figure 6 reveals that participants were least aware of the features of PCOS (16.97%) closely followed by complications of PCOS (23.39%) and psychological complications (24.31%).

Table 5: Awareness scores distribution

Score	Mean ± SD	Median (25th-75th percentile)	Range
Features of PCOS score	4.38 ± 2.4	4(3-6)	0-10
Risk factors associated with PCOS score	2.03 ± 1.1	2(1-3)	0-4
Complications of PCOS score	1.56 ± 1.26	2(0-2)	0-4
Preventive measures for PCOS score	1.83 ± 1.06	2(1-3)	0-3
Total awareness score	10.91 ± 5.05	11(8-14)	0-23

Mean value of awareness of features of PCOS score, risk factors associated with PCOS score, complications of PCOS score, preventive measures for PCOS score and total awareness score of study subjects was 4.38 ± 2.4, 2.03 ± 1.1, 1.56 ± 1.26, 1.83 ± 1.06 and 10.91 ± 5.05 with median (25th-75th percentile) of 4(3-6), 2(1-3), 2(0-2), 2(1-3) and 11(8-14) respectively. (Table 5, Figure 7)
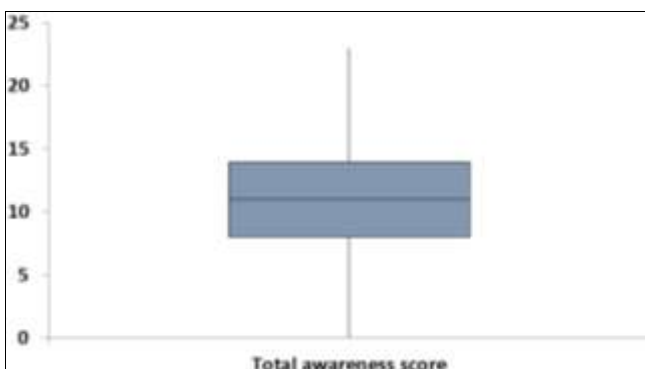

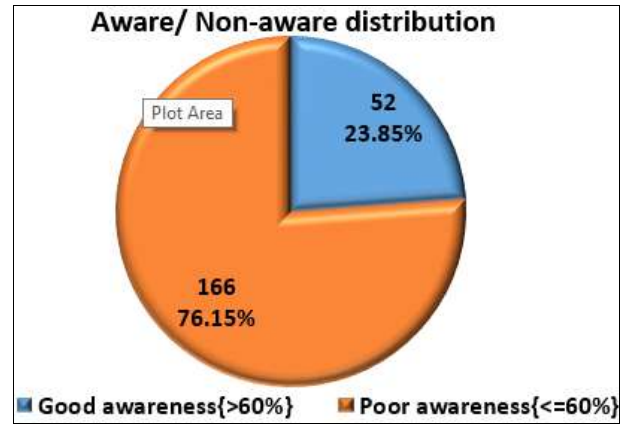**Fig 7:** Descriptive statistics of total awareness score

Fig 8: Good/poor awareness distribution

All in all, 76.15% of participants fell under the non-aware group compared to only 23.85% of participants who demonstrated good awareness (>60%) (Figure 8)

Table 6: Association of socio-demographic characteristics with awareness/non-awareness.

Socio-demographic characteristic	Awareness (>60%) (n=52)	Non-Awareness (<=60%) (n=166)	Total	P value
Age(years)				
12 to 14	8 (22.22%)	28 (77.78%)	36 (100%)	0.4*
15 to 17	37 (22.70%)	126 (77.30%)	163 (100%)	
18 to 19	7 (36.84%)	12 (63.16%)	19 (100%)	
Level of education				
Middle school	4 (25%)	12 (75%)	16 (100%)	0.149*
High school	42 (22.22%)	147 (77.78%)	189 (100%)	
Undergraduate studies	6 (46.15%)	7 (53.85%)	13 (100%)	
Stream of education				
Science	26 (27.96%)	67 (72.04%)	93 (100%)	0.452†
Non-science	14 (21.88%)	50 (78.13%)	64 (100%)	
Other	12 (19.67%)	49 (80.33%)	61 (100%)	

* Fisher's exact test, † Chi-square test

The distribution of awareness was comparable with socio-demographic characteristics (p value>0.05).

Table 7: Association of personal details with awareness/non- awareness

Personal details	Good awareness (>60%) (n=52)	Non-awareness (<=60%) (n=166)	Total	P value
Age of achieving puberty				
8 to 10	1 (8.33%)	11 (91.67%)	12 (100%)	
11 to 12	20 (22.99%)	67 (77.01%)	87 (100%)	
13 to 14	26 (24.76%)	79 (75.24%)	105 (100%)	0.498*
15 to 16	3 (42.86%)	4 (57.14%)	7 (100%)	
Not achieved	2 (28.57%)	5 (71.43%)	7 (100%)	
Average number of pads used per day				
<2	2 (10%)	18 (90%)	20 (100%)	
2 to 4	32 (22.07%)	113 (77.93%)	145 (100%)	0.125*
5 to 7	16 (34.78%)	30 (65.22%)	46 (100%)	
No cycles	2 (28.57%)	5 (71.43%)	7 (100%)	
Duration of menstrual flow				
2 to 4	15(22.06%)	53 (77.94%)	68 (100%)	
5 to 7	30 (25%)	90 (75%)	120 (100%)	0.950†
>8	5 (21.74%)	18 (78.26%)	23 (100%)	
No cycles	2 (28.57%)	5 (71.43%)	7 (100%)	
Length of menstrual cycle				
<21	0 (0%)	5 (100%)	5 (100%)	
21 to 35	34 (26.56%)	94 (73.44%)	128 (100%)	
>35	9 (26.47%)	25 (73.53%)	34 (100%)	0.472*
No cycles	2 (28.57%)	5 (71.43%)	7 (100%)	
No fixed period	7 (15.91%)	37 (84.09%)	44 (100%)	
Family history of PCOS				
No	30 (25.64%)	87 (74.36%)	117 (100%)	
Yes	9 (29.03%)	22 (70.97%)	31 (100%)	0.419†
Don't know	13 (18.57%)	57 (81.43%)	70 (100%)	
Dysmenorrhea (Painful menstruation)				
No	18(19.57%)	74(80.43%)	92 (100%)	
Yes	32 (26.89%)	87 (73.11%)	119 (100%)	0.445†
No cycles	2 (28.57%)	5 (71.43%)	7 (100%)	

* Fisher's exact test, † Chi-square test

No significant correlation was found between PCOS awareness and the personal details of the participants (*p*>0.05)

Table 8: Association of knowledge about PCOS with good/poor awareness.

Knowledge about PCOS	Good awareness [>60%] (n=52)	Non- awareness [<=60%] (n=166)	Total	P value
No	2 (6.67%)	28 (93.33%)	30 (100%)	
Yes	50 (26.60%)	138 (73.40%)	188 (100%)	0.019*
Total	52 (23.85%)	166 (76.15%)	218 (100%)	

* Fisher's exact test

Participants who had heard about PCOS had a statistically significant good awareness of PCOS (26.60%) as compared to participants who had not heard about it. (6.67%). (p value=0.019) (Table 8)

Discussion
PCOS is a complex disorder involving the hypothalamus-pituitary-ovarian axis. It is one of the major endocrine diseases of concern among women and disturbs females' physiological functioning, physical appearance, mental health, and self-perception which in turn affects her family life and social life. A female may need to visit a dermatologist, endocrinologist, gynecologist, dietician, psychiatrist, and physical therapist depending on the presentation of her symptoms [9-11].

Currently, PCOS has no definite cure, but the associated comorbidities can be addressed to improve the quality of life and minimize the long-term complications associated with it. The metabolic disturbances worsen with time, and the prognosis becomes poor gradually over time. The time lag between the appearance of symptoms and diagnosis of PCOS needs to be lessened to reduce the deleterious effects that include infertility, impaired glucose tolerance, insulin resistance, obesity, cardiovascular complications, and endometrial cancer, among others [12-13].

A timely diagnosis of PCOS in symptomatic adolescent girls is important for the initiation of appropriate treatment and management initiatives. However, this can be achieved by spreading awareness through educational interventions and other measures such as educating the susceptible population regarding the symptoms, etiology, age of onset, and PCOS-related healthcare services [12, 14, 15].

This study aimed to evaluate the awareness of PCOS among the urban female adolescent population. Unfortunately, there was an evident lack of awareness among the study sample.

PCOS awareness was found to be 23.85%, which is relatively low despite the fact that a majority of participants belonged to urban high schools (86.7%) and 5.96% were pursuing undergraduate studies. This finding is in line with similar studies [16-18].

Age, year of study, and branch of education were the selected demographic variables of the present study. The finding of the study showed that none of these had a significant association with awareness regarding PCOS among the participants, with age (p-value 0.4), level of education (p-value 0.149), and stream of education (p-value 0.492). Zaitoun B. *et al* found PCOS awareness was only 21.74%. A majority of their participants, (74.1%) had achieved higher education, in addition to nearly

half of them working or studying in the medical field [8]. They observed an association between being in the medical field and awareness about PCOS symptoms and complications. Jabeen A. *et al* observed a significantly low awareness in adolescents when compared to the young girls in the age group of 20-25 years. This probably might be due to less exposure to society with parents of the participants belonging to rural backgrounds restricting their social behavior [12]. No significant correlation was found between the awareness and personal details of the participants (p>0.05). In a study by Zaitoun B. *et al*, females who knew someone diagnosed with PCOS were 5 times more likely to be more aware compared to those who didn't (95% CI = 2.5–10.8; p < 0.001). Age, education level, and nationality showed no correlation with the level of awareness [8]. Similar to our study, Goh JE *et al* found no significant association between the knowledge of PCOS and health-related practices toward PCOS [19] *et al*. observed a significant correlation between awareness of PCOS in participants who has heard of it earlier [16]. A strong association was found between having heard about PCOS before, and knowing it leads to irregular menses (p < 0.001)

In this study, the majority of participants reported friends and social media as their source of knowledge, while doctors were least frequently reported. On the other hand, similar studies reported differently about the most common source of information, reflecting an inconsistency in providing real education to the general public [20-24]. Moreover, Chiu *et al*. found that the online sources of PCOS available for the general population are of low quality and lack sanction and evidence [25], which might explain the inaccurate perceptions of knowledge exhibited by our study group. This calls for the need not just to educate the females about this syndrome but also to inform physicians about thorough patient education and the provision of accurate information.

PCOS awareness distribution revealed that participants were least aware of the features of PCOS (16.97%) closely followed by complications of PCOS (23.39%) and psychological complications (24.31%). Among PCOS complications, increased androgen is their biggest concern, quite understandably so, in the adolescent age group, as it can cause stress and psychological issues, which can further exacerbate the quality of life.

The alarming concern is very low participants are aware of about long-term complications of PCOS especially the risk for cardiovascular diseases and diabetes, a finding that was similarly reported by Zaitoun B. *et al*. [8]

The present study focused and emphasized acknowledging and exploring the awareness, and knowledge of PCOS and its complications among urban adolescent females. Based on the data collected and analyzed, it is evident that PCOS continues to be a formidable health challenge among the study population. Increasing awareness about PCOS is crucial to improve its management and reduce associated health complications.

Conclusion
In conclusion, there is an evident lack of PCOS awareness among all participants regardless of their demographic profile. Mainly sought half-baked information from friends and social media.

Fortunately, the serious complications of PCOS are easily preventable with an early diagnosis, which is only possible if potential patients are well aware of the syndrome. Thus, prevention of this common chronic condition and its consequences relies chiefly on increasing awareness at an early age of life. The present study emphasizes the need for health

education and awareness programmes to be incorporated into the educational system to combat the low knowledge among adolescents, especially by utilizing different sources, and targeted approaches to provide clear, appropriate, and tangible information and preventive measures. PCOS awareness workshops and support groups should be established and health professionals should be encouraged to educate patients and their family members about its long-term consequences. Young females should also be encouraged to have discussions with healthcare professionals about their reproductive health. This will eventually help to prevent much co-morbidity that may occur in their future life.

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