Original Article

Patients' perception about polycystic ovarian syndrome (PCOS) in Sub-Himalayan region of India-A facility-based cross-sectional study

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Abstract

Background: In modern times, metabolic disorders are most common and one of them is polycystic ovarian syndrome (PCOS) in women, which causes high morbidity and complications. PCOS has largely been a neglected and less researched area; however, it is gaining importance in recent times as PCOS is increasing as well as it can be prevented to a considerable extent. **Methods:** A cross-sectional study was conducted to assess knowledge among females in government hospitals in Northern India. Data were collected using a pretested structured questionnaire on 300 women (completed 270), selected by proportionate sampling technique, and admitted in government hospitals. Data were analyzed by SPSS version 23. **Results:** The results showed that the mean age of respondents was 33.02 ± 9.039 years, the mean age at menarche was 12.33 ± 2.13 years, and the mean of gravida status was 1.82 ± 0.78 years. Only half of the respondents had good knowledge about PCOS. **Conclusion:** This study suggests that efforts are needed to reinforce women's knowledge through setting-based awareness campaigns and health education in this context to enable them to identify and seek timely treatment and improve their quality of life.

Keywords: Endometrial cancer, gravida, morbidity, ovarian cancer, PCOS

Introduction

Polycystic ovarian syndrome (PCOS) has been defined by the National Institutes of Health and Rotterdam criteria as "a hormonal disorder characterized by the presence of at least one polycystic ovary (presence of multiple cysts) accompanied by ovulatory dysfunction and excessive secretion of androgens." The determinants of polycystic ovarian syndrome have been linked to both hereditary and environmental factors. Insulin resistance, which is of high prevalence in the Indian population, has been consistently reported as a strong determining factor for the occurrence of PCOS in Indian adults and adolescents.[1]

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The third and newest definition was proposed in 2006 by the Androgen Excess Society (AES) has considered the following criteria for the diagnosis of PCOS[2]: Hirsutism or hyperandrogenism, oligo-ovulation, and an-ovulation or polycystic ovaries, increased level of androgens or related disorders.

However, the studies related to PCOS are confined to developed countries and urban regions. PCOS has largely been a neglected and less researched area; however, it is gaining importance in recent times as PCOS is increasing as well as it can be prevented to a considerable extent. Knowledge about PCOS is important to avert this problem among girls and improve their quality of life. Very few studies are available in the northern part of India; for this reason, we have conducted this study.

PCOS occurs in both normal-weight and overweight women and obesity is a frequent co-morbidity that often precedes the development of PCOS.[3,4] A meta-analysis concluded that women with PCOS have three times more risk than other women to develop endometrial cancer.[5]

The recent childhood obesity epidemic including an increasing proportion of children becoming extremely obese (13–15) gives rise to numerous concerns about short- and long-term health consequences of obesity in youth and young adults.[5-9] The aim of the study was to assess the knowledge regarding polycystic ovarian syndrome (PCOS) among female patients in government hospitals in Shimla, Himachal Pradesh. Our study objectives were to assess the knowledge regarding PCOS among female patients and examine any association between the knowledge and demographic variables.

Material and Methods

Study setting: The study area was Shimla, the main city of District Shimla (one of the 12 districts of Himachal Pradesh). The study population for this research was the females admitted to the in-patient department (IPD) in Shimla, Himachal Pradesh. Female patients in the IPD of government hospitals in Shimla, Himachal Pradesh, were recruited.:

Study design: A cross-sectional descriptive design was adopted in the study.

Study duration: The study was conducted from January to July 2018.

Sample size and sampling: As the population to be surveyed was <50,000; the formula for the finite population was used as below:

$$n = NZ^2P(1 - P)$$

$$d^2(N - 1) + Z^2P(I - P)$$

where, n = sample size N = population = 1,025

d = degree of accuracy = 5% = 0.05; P = expected prevalence = 0.5

Z = standard normal variate statistic at 95% level of confidence = 1.96; $n = (1025 \times 3.84 \times 0.5 \times 0.5)/(0.0025 \times 1024)+(3.84 \times 0.5 \times 0.5)$

$n = 279.6 = 280$

Assuming the non-response rate of 5%, the sample size = 280 + 280 × 5/100 = 294 Therefore, the final sample size was 294. For convenience, the sample has been kept as 300. However, we were able to collect the data of 270 patients only. The present study adopted the proportionate sampling technique. The total number of female IPD patients was 1,025. Proportionate sampling for the selection of female patients of government hospitals of Shimla, Himachal Pradesh (total females = 300/1,025). We included females admitted to the IPD of Government Hospitals, Shimla, who were interested to participate in the study and who were available at the time of data collection at the hospital units. We excluded the patients who refused to participate in the study, who were absent in the study area during the study period, who were mentally unstable, and who were diagnosed with cancer, thyroid disorder, diabetes, Cushing's syndrome, or any metabolic disorders. A pre-test of tool was carried on a sample of 20 female IPD patients who were not included in the main study. The overall observations obtained from the pilot study were analyzed and necessary modifications were incorporated in the tool to make it suitable for the study.

Data collection: Data were collected using a pretested and validated structured questionnaire which was composed of two sections. Section A consisted of 14 items regarding sociodemographic variables. Section B consisted of 11 items regarding knowledge assessment. The data were collected by approaching individual female patients admitted to the IPD of government hospitals. The tool was administered after a brief introduction of the purpose of the study and subsequently, their difficulties were addressed as per their need. As there were 40 items of knowledge in the tool and the correct response for each item carried 1 score, the range of knowledge scores was 0–40. The criteria taken for categorizing into four categories of knowledge were as follows: <10 score was considered as poor, 11–20 as average, 21–30 as good, and 31-40 as excellent. The data were collected using the following steps: Formal permission was obtained from the appropriate authority. Participants were selected using the proportionate sampling technique. Ethical consideration was followed throughout the period of study. Data were collected regarding sociodemographic profile, and knowledge regarding PCOS by a structured questionnaire, and 20 min were spent on each subject.

Data analysis: The data were analyzed using both descriptive and inferential statistics in SPSS. Frequencies and percentages distribution were used to analyze the demographic profile of

the subjects. Mean and standard deviation was used to analyze the knowledge about PCOS and screening of PCOS signs and symptoms among females. The Chi-square test was used to find the association of the knowledge score of females regarding PCOS with the selected sociodemographical variables and the association of endometrial and ovarian cancer with PCOS. Analysis of variance (ANOVA) test was used to compare the knowledge of females. **Ethical clearance:** The study was approved by the Research Ethics Committee of the Eternal University, Baru Sahib.

Results

This study was conducted on PCOS regarding knowledge among 270 admitted female patients of government hospitals, Shimla, Himachal Pradesh from January to July 2018. Data were collected using a pretested structured questionnaire, processed through SPSS version v. 23, and analyzed using appropriate tests.

Demographic details are given in Table 1.

Out of 270 respondents (excluding cancer patients), most women (76.3%) had heard of PCOS and 58.1% were aware that PCOS is an inherited disease. Also, 56.7% of respondents did not know that the shape of ovaries changes in PCOS. The majority of respondents (62.6%) knew that patients suffering from PCOS have small multiple cysts in their ovaries. In all, 53.7% of respondents knew that PCOS affects ovulation. Most of the respondents (63.3%) were also aware that obesity causes PCOS. The majority (88.9%) were not aware that pre-diabetic conditions can cause PCOS as well as that there is an increased level of testosterone in PCOS. The majority of our respondents (83.3%) knew irregular menstruation as a sign of PCOS. Also, 53% of respondents did not know that facial acne is a sign of PCOS and 64.1% of respondents had no knowledge about *hirsutism*. Reduced fertility was known to 77% of respondents as one of the signs of PCOS and 75.6% of women were aware that weight gain occurs in PCOS; however, a similar number of respondents did not know that frontal hair loss can be a sign of PCOS. Also, 76.7% of respondents said that pelvic pain is a symptom of PCOS, and 53% of respondents also knew that frequent abortions can be a sign of PCOS. Only 13% of female respondents were aware that in PCOS there can be early puberty and only 11.5% were aware of *Acanthosis nigricans* (discoloration or dark patches on skin). Also, diabetes and hypertension were known to only 12.6% and 23.7% of respondents, respectively. In all, 80% of respondents were aware of psychological disturbances such as mood swings and irritation as symptoms of PCOS. In total, 72.2% of respondents did not know that diabetes can be a complication of PCOS. Only 36.7% were aware of hypertension, 80.7% were aware of breast, ovary, and uterine cancer and 47.8% of respondents knew of excessive increase in hormones in PCOS. Also, 85.6% of respondents knew that obesity is a complication of PCOS and 89.6% of respondents were aware of infertility; 71.1% of respondents were aware of anxiety, and depression, and 77.4% of psychological disturbances such as mood swings and irritation. It was observed that 81.1%

Table 1: Demographic profile of the respondents

Demographic variables	Frequency (*n*=270)	Percentage (%)
Age in years		
21-30	147	49.0
31-40	98	36.29
41-50	4	1.3
51-60	14	4.7
61-70	6	2.0
71 and above	1	0.3
Educational status		
Non-formal education	39	13.0
Primary	7	2.3
Middle	23	7.7
Secondary	29	9.7
Senior secondary	98	36.29
Graduate	67	22.3
Postgraduate	7	2.3
Religion		
Hindu	162	60.0
Sikh	99	33.0
Muslim	6	2.0
Christian	3	1.0
Marital status		
Unmarried	58	19.3
Married	212	78.51
Type of family		
Nuclear	157	58.14
Joint	113	37.7
Area of living		
Urban	196	65.3
Rural	104	34.7
Socioeconomic status		
>40,430	29	9.7
40,429-20210	92	34.07
20,209-15,160	85	31.48
15,159-10,110	26	8.7
10,109-6060	17	5.7
6059-2021	14	4.7
<2020	7	2.3
Gravida status		
0-2	180	66.66
3-5	90	30.0
Dietary pattern of patient		
Vegetarian	64	23.7
Eggetarian	170	56.7
Mixed veg + non-veg	36	12.0
Do you eat junk food		
Yes	243	91.0
No	27	9.0
Amount of water intake		
500-1000 mL	229	84.84
1000-2000 mL	27	9.0
>2000 mL	14	4.7
Physical activity in (h)		
0-2	7	2.3
3-5	166	61.48
6-8	97	32.3

of respondents knew that doing exercise and losing weight is a preventive measure for PCOS. Also, 58.5% were aware of using contraceptive pills or hormone therapy, 86.7% were aware of eating healthy diets such as vegetables and fruits, 79.3% were aware of eating a protein-rich diet, and 64.1% were aware of eating non-fat food to prevent PCOS. It was observed that 84.8% of respondents were aware of any treatment of PCOS. Next, 64.4% knew about contraceptive pills or hormone therapy, 83.7% were aware of weight loss and diet adjustment, 80% knew about surgery, only 6.3% knew about anti-diabetic medicines and 64.8% of respondents knew that there are other medicines such as well as treatment options for PCOS. The mean overall knowledge score was 22.7, the mean general knowledge score about PCOS was 3.80, the mean knowledge score about signs and symptoms was 6.14, the mean knowledge score about complications of PCOS was 5.25, the mean knowledge score about prevention of PCOS was 3.70, and mean knowledge score about the treatment of PCOS was 3.84. Our study revealed that 7.4% of respondents had poor knowledge of PCOS and 25.6% of respondents had average knowledge of PCOS. Only 50.7% of respondents had good knowledge about PCOS and only 16.3% of respondents fall in the category of excellent knowledge.

Table 2 shows the association between socio-demographic characteristics and probable cases of PCOS. Statistically significant association of probable cases of PCOS was observed with age at menarche ($P = 0.001$), religion ($P = 0.023$), marital status ($P = 0.010$), and gravida of patient ($P = 0.004$), and highly significant association between PCOS probable cases and educational status ($P = 0.000$), socioeconomic status ($P = 0.000$), and dietary pattern ($P = 0.000$).

Discussion

The present study concluded that only half of the respondents had good knowledge about PCOS. Hormonal imbalances are becoming increasingly common due to changes in diet and other environmental factors. PCOS, one of the most common metabolic disorders, has been reported to be associated with an increased risk of infertility, endometrial cancer, and late menopause, apart from metabolic abnormalities, including insulin resistance, type 2 diabetes mellitus, dyslipidemia, and cardiovascular diseases. This descriptive cross-sectional study aimed to gauge the knowledge and look for the association with demographic variables among

Table 2: Association of probable cases of PCOS (non-cancerous) with socio-demographic variables

Socio-demographic variables	Chi square value	Df	*P*
Age at menarche	19.546	7	0.001**
Educational status	70.434	6	0.000***
Religion	9.623	3	0.023*
Marital status	8.306	1	0.010*
Socioeconomic status	22.233	6	0.000***
Gravida of patient	13.090	4	0.004**
Dietary pattern	24.268	2	0.000***

300 female patients admitted to the IPD of government hospitals in Shimla, Himachal Pradesh, using a structured questionnaire. In the present study, about half (49%) of the respondents were in the 21 to 30 years age group. The mean age of respondents was 33.02 ± 9.039 years, which differed from the mean age of 40.3 ± 9.3 years in a cross-sectional population-based study on the prevalence and causes of primary infertility conducted on Iranian women in Tehran, Iran.[10] In the present study, 42.7% were educated upto senior secondary, 22.3% were graduates, and 13% of respondents had no formal education, whereas the majority of respondents (72.9%) were graduates according to a population-based cross-sectional study conducted in Saudi Arabia about PCOS awareness on Saudi Arabian women.[11] In the current study, the majority of respondents (64%) were Hindu and 33% were Sikh. The present study depicted that 80.7% were married, in contrast to 49.6% who were married according to a population-based cross-sectional study conducted in Saudi Arabia about PCOS awareness in Saudi Arabian women.[11] In the present study, 62.3% hailed from the nuclear family and 65.3% from urban areas. According to a population-based cross-sectional study conducted in Saudi Arabia about PCOS awareness in Saudi Arabian women, 96.4% of respondents were from urban areas.[11] In the present study, 76.3% had heard of PCOS. All, that is, 100% of the respondents had heard of PCOS in a study on the prevalence and knowledge of PCOS among female science students at different public universities in Quetta, Pakistan.[12] More than half of females (58.1%) were aware that PCOS is an inherited disease, and only 10.4% were aware of it in a population-based cross-sectional study conducted in Saudi Arabia on Saudi Arabian women.[11] In the current study, 43.3% of respondents knew that the shape of ovaries changes in PCOS, whereas among Saudi Arabian women, only 23.9% were aware of this.[11] In the present study, 62.6% knew that patients suffering from PCOS have small multiple cysts in their ovaries but another study among female science students of different public universities in Quetta, Pakistan, stated that 86.9% knew about multiple cysts in PCOS.[12] Also, 53.7% of the respondents knew that PCOS affects ovulation. Among Saudi Arabian women, 45.8% knew that PCOS affects ovulation.[11] In the current study, 63.3% were aware that obesity causes PCOS and in a study in Quetta, Pakistan, 87.1% were aware among female science students.[11] In all, 88.9% were not aware that a pre-diabetic condition can cause PCOS and that there is an increased level of testosterone in PCOS, whereas in contrary responses, 75.6% and 87.8% were aware in Quetta, Pakistan.[12] The present study showed that the majority of respondents (83.3%) knew irregular menstruation as a sign of PCOS. Also, 53% of respondents did not know that facial acne is a sign of PCOS and 64.1% of respondents had no knowledge about hirsutism. Reduced fertility was known to 77% of respondents as one of the signs of PCOS. Also, 75.6% of females were aware that weight gain occurs in PCOS, but a similar number of respondents did not know that frontal hair loss occurs in PCOS. Also, 76.7% of respondents said yes that pelvic pain is a symptom of PCOS, and 53% of respondents also knew about frequent abortions. In total, 87% of respondents were not aware of early puberty. Also, 87.4%

and 76.3% were not aware of diabetes and hypertension as signs and symptoms of PCOS, respectively. Also, 80% of respondents said yes to psychological disturbances in PCOS. The findings from other studies conducted on Saudi Arabian women found awareness of irregular menstruation (51.9%), facial acne (27.7%), hirsutism (31.7%), reduced fertility (39%), weight gain (32.8%), frontal hair loss (18.9%), pelvic pain (34.7%), abortion (23.2%), early puberty (6.5%), diabetes (12.9%), hypertension (7.7%), and psychological disturbances (31.3%), and a study conducted in Quetta, Pakistan among female science students were as irregular menstruation (97.1%), an unusual amount of hair growth (92.2%), acne during menstruation (89.6%), and hair loss from scalp (75.6%), which are largely comparable.[11,12] The present study revealed that 72.2% and 63.3% did not know that diabetes and hypertension, respectively, are complications of PCOS. Also, 80.7% of respondents were aware of breast, ovary, and uterine cancer complications. A total of 52.2% of respondents did not know about the excessive increase in hormones as a complication in PCOS. Also, 71.1% and 77.4% of respondents knew about anxiety, depression, and psychological disturbances, respectively. Among Saudi Arabian women, the findings of awareness about complications were 14.5% (diabetes), 5.1% (hypertension), 30.2% (heart diseases,), 28.3% (breast and uterus cancer), 30% (excessive increase in hormones), and 34.1% (anxiety and psychological disturbances).[11] Another study from Quetta, Pakistan, stated that 80.9%, 75.6%, and 86.7% knew about diabetes, heart diseases, and anxiety as complications of PCOS, respectively.[12]

This current study depicted that 81.1% of the respondents knew that doing exercise and losing weight is a preventive measure for PCOS. In a study on Saudi Arabian women, an overall 56.7% of women were aware.[11] In the current study, more than half of respondents (58.5%) were aware that using contraceptive pills or hormone therapy is also a preventive measure for PCOS. Eating a healthy diet such as vegetables and fruits, eating a protein-rich diet, and eating non-fat food was known to 86.7%, 79.3%, and 64.1% of respondents, respectively, as a preventive measure of PCOS. Contrary results were seen for doing exercise and losing weight (39.9%, 45.3%), using contraceptive pills (29.7%), eating vegetables and fruits (34.2%), and eating protein-rich food (16.2%) among Saudi Arabian women.[11] In the present study, respondents were also found to be aware of the treatment options. Out of all, 84.8% of respondents were aware of any treatment of PCOS. Most of the respondents (64.4%) knew that contraceptive pills or hormone therapy are treatment options for PCOS. The majority (83.7%) were aware of weight loss, and diet adjustment, and 80% of respondents knew that PCOS can be treated by surgery. A large number (93.7%) of respondents did not know that anti-diabetic medicine is the treatment option for PCOS. Also, 64.8% of respondents knew that there are other medicines as well for the treatment of PCOS, whereas in Quetta, Pakistan, hormone therapy, anti-diabetic medicine, and surgery were known to 82.3%, 76.1% and 77.2% of the respondents, respectively.[12] The mean overall knowledge score of respondents was on higher side compared to a Delhi based study.[13] All inclusively, 7.4% of respondents had poor knowledge about PCOS and 25.6% of respondents had average knowledge about PCOS, only half of the respondents, that is, 50.7% of respondents had good knowledge about PCOS and only 16.3% of respondents fall in the category of excellent knowledge. So, respondents were found to be quite aware of PCOS. However, a sharp contrast was observed in other studies; 90.2% of respondents had adequate knowledge about PCOS in a study on prevalence and knowledge of PCOS among female science students at different public universities of Quetta, Pakistan,[12] whereas in a cross-sectional study of PCOS among young women in Bhopal, Central India, an overall 78.4% of girls were not aware of PCOS.[14]

Limitations-This study was primarily limited by its small sample size; the time duration was not sufficient for the inclusion of a large sample and the study was hospital-based; it would have been better if we performed it in the community.

Conclusion and Global Health Implications

The present study concluded that only half of the respondents had good knowledge about PCOS. There is a need to educate women and school teachers about PCOS, its signs and symptoms, causes, prevention, complications, and treatment options, and also about adequate diet, the vital importance of regular light exercise, and lifestyle modification for them to be able to cope with the challenges associated with PCOS.

In addition, health-related programs on comprehensive reproductive education to include PCOS should be promoted by government and non-government agencies at community, school, and college levels. The finding of this study indicates the need for appropriate intervention through lifestyle changes.

Key messages

- The present study concluded that only half of the respondents had good knowledge about PCOS.
- There is a need to educate women by school teachers about PCOS, its signs and symptoms, causes, prevention, complications, and treatment options.
- They should be informed about adequate diet, the vital importance of regular light exercise, and lifestyle modification for them to be able to cope with the challenges associated with PCOS.

Ethics approval

Taken from Institute's Ethics Committee.

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Conflicts of interest

There are no conflicts of interest.

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