Introduction

Polycystic ovarian syndrome (PCOS) is one of the most prevalent endocrine disorders among women of the reproductive age group.[1] Globally, prevalence estimates of PCOS range from 2.2% to 26%,[2] affecting 6%–18% of adolescent girls.[3] Very few studies have been conducted in India with methodological rigor on the prevalence of PCOS. Prevalence rates between 4.21% and 35.3% are reported from various states of India.[2,4‑7] The disparity in reporting PCOS prevalence across the country is probably due to the varied diagnostic criteria. PCOS does not find any place in government health programs, though it is a significant endocrine disorder affecting women of the reproductive age group. With a meagre budget allocation of funds,[8] the affected women have far less possibility of seeking early diagnosis and treatment services. Of late, a few reports of mistrust among women with PCOS seeking care from a primary care physician has been reported.[9] We may buck this trend if the primary care physician understands the barriers to good compliance to the treatment regimen and its associated factors.

Background: Polycystic ovarian syndrome (PCOS) is a hormonal disorder that affects women of the reproductive age group. Its treatment regimen comprises medication and lifestyle modifications. However, non-adherence to the treatment regimen is the most commonly faced problem among women due to various barriers, resulting in complications like insulin resistance, hyperlipidemia, obesity, and infertility. Primary care physicians see patients with this disorder either at the initiation of treatment or on follow-up care after specialist consultation. So, understanding the barriers to treatment compliance, from a woman’s perspective and finding the solution to the same is crucial to successful therapy. Objectives: The present study aims to assess adherence to the treatment regimen and its barriers among women with PCOS and its associated factors. Methods: A cross-sectional study among 224 women who met the inclusion criteria responded through a Google form. Self-reports were obtained by a demographic proforma, medication adherence rating scale, and barriers assessment questionnaire. Results: Only a third of the women (32.1%) were fully adherent, 36.3% were partially adherent, and 31.6% were non-adherent. The most common barriers among women were lack of knowledge regarding the disease and its management, side effects of the treatment, long duration of the therapy, no relief of symptoms, bland diet, and lack of physical exercise. Treatment adherence was associated with socioeconomic status (P = 0.001) among women with PCOS. Conclusion: Adherence to the treatment regimen in PCOS was poor. Successful adherence depends on how patients understand the severe implications of non-adherence to the prescribed treatment and adjust to lifestyle modifications related barriers. It is also vital for health care providers and patients to identify these barriers, address them and refine treatment strategies.

Keywords: Exercise, hyperandrogenism, medication compliance, menstruation, ovary

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PCOS affects women throughout their reproductive life, and non-adherence to treatment results in complications like hyperlipidemia, cardiovascular diseases, gestational diabetes, preeclampsia, large for gestational age babies, and even increased susceptibility to COVID-19 infection. Hence, much attention is needed to develop an effective treatment plan and adherence strategies, including medications and lifestyle modification. Treatment regimens will not be fruitful if a woman with PCOS does not regularly follow prescribed drugs or participate in physical activity and dietary changes. The first-line treatment is lifestyle modification, regardless of presenting symptoms, as per the 2018 updated PCOS evidence-based guidelines. Previous reviews indicate that adherence to lifestyle modifications, including diet and physical activity, is challenging for patients and is crucial in achieving expected treatment outcomes.

Methods

A cross-sectional research design was adopted for the study. Women between 13 and 45 years of age who were diagnosed with PCOS by the obstetricians using Rotterdam’s criteria, advised for treatment and willing to participate in the study were included. Women who were not able to read English and fill up Google forms were excluded. Women meeting the inclusion criteria were enrolled in the study by snowball sampling. The estimated sample size was 217, keeping a 90% confidence level and 5% error margin. Approximately, about 350 women were identified, of which 224 responded. Data collection was done through an online survey. Collected data were analysed by SPSS-16 software.

Tools

The tools used for data collection were demographic proforma, with nine items on baseline characteristics and seven items on treatment profile, the Medications Adherence Rating Scale and a barrier assessment questionnaire consisting of 19 items.

Ethical consideration

Ethical permission was obtained from the ethical committee, AIIMS BBSR, to conduct the study with reference number IEC/AIIMS BBSR/Nursing/2020-21/07 dated 30.03.2021 Written informed consent was obtained from the participants.

Results

Data collection was carried out from March 31 2021, to April 30 2021. The normality of data was checked by the Kolmogorov-Smirnov test and was found to be distributed normally. The majority of the women were aged 21-29 years (67%), and the mean age ± SD was 24 ± 5.41 years. A majority, 71.9%, were unmarried, with 38.4% having a professional degree, 62.5% being homemakers, 46.9% being upper-middle class, and 45.5% urban residents. More than half of the women (63.8%) had normal body mass index (BMI), and 26% were overweight [Table 1]. More than half of women (55.3%) consumed oral contraceptives. Brisk walking (40.2%) and yoga (34.3%) were the physical activities performed by the highest percentage of the sample.

| Variables                      | f  | %  |
|--------------------------------|----|----|
| Age (years)                    |    |    |
| 13-21                          | 51 | 22.8|
| 21-29                          | 150| 67.0|
| 29-37                          | 13 | 5.7 |
| 37-45                          | 10 | 4.5 |
| Religion                       |    |    |
| Christian                      | 68 | 30.4|
| Hindu                          | 145| 64.7|
| Muslim                         | 11 | 4.9 |
| Marital status                 |    |    |
| Married                        | 63 | 28.1|
| Unmarried                      | 161| 71.9|
| Education                      |    |    |
| Professional Degree            | 86 | 38.4|
| Graduate/Post graduate         | 68 | 30.4|
| Intermediate/post high school diploma | 20 | 8.9 |
| High school certificate        | 38 | 17.0|
| Middle school certificate      | 7  | 3.1 |
| Primary school certificate     | 5  | 2.2 |
| Occupation                     |    |    |
| Clerks                         | 8  | 3.6 |
| Craft and related trade workers| 2  | 0.9 |
| Elementary occupation          | 11 | 4.9 |
| Legislators, senior officials and managers | 2 | 0.9 |
| Professionals                  | 51 | 22.8|
| skilled agriculture and fishery workers | 1 | 0.4 |
| Skilled works and shop and market sells workers | 7 | 3.1 |
| Technicians and associate Professionals | 2 | 0.9 |
| Unemployed                     | 140| 62.5|
| Socio economic status          |    |    |
| Lower Middle Class             | 42 | 18.8|
| Upper Class                    | 28 | 12.5|
| Upper Lower Class              | 58 | 25.8|
| Upper Middle Class             | 96 | 42.9|
| Area of Residence              |    |    |
| Rural                          | 76 | 33.9|
| Urban                          | 148| 66.1|
| BMI                            |    |    |
| Underweight                    | 15 | 6.7 |
| Normal                         | 143| 63.8|
| Overweight                     | 59 | 26.3|
| Obese                          | 7  | 3.2 |

In a developing country like India, poor access to health care, resources and medicines, and limited paying ability may contribute to poor adherence, contributing to the national morbidity burden. Poor adherence reflects the falling health of individuals. To design culturally appropriate care for women with PCOS, documenting the barriers can identify gaps in actual practices and enable planning specific recommendations for future implementations. Therefore, this study aims to assess adherence to treatment regimen and their barriers in women with PCOS, which is the first of its kind conducted in India.
As per the self-reports, a low glycaemic index diet was followed by 72.7% of the women [Table 2]. Complete adherence to the treatment was reported by only 32.1% of the women; others were either non-adherent (31.6%) or partially adherent (36.3%) [Figure 1]. The most common barriers [Table 3] among women with PCOS were personal factors such as insufficient knowledge on PCOS and its management. About half of the women discontinued the diet plan as it was not of the preferred taste and craved for the restricted diet. Long duration of therapy, no relief of symptoms, and side effects were the treatment-related barriers. Long-distance from a health care facility, difficulty in getting medications, lack of privacy during the consultation, lack of communication with gynaecologists and difficulty in getting appointments were reported as health system-related barriers. There was a statistically significant association of socioeconomic status with adherence to treatment protocol ($P = 0.001$).

### Discussion

In our study, the majority of the women with PCOS were between 21 and 29 years. We have no previous literature to compare the data, as most of the studies restricted the age to adolescents or young adults.[2,4,5] We found a strikingly high reporting of PCOS among urban women than rural women, which is supported by another study conducted in India.[3] High cases in urban women may be due to exposure to junk food, unhealthy street food, pollution, overuse of gadgets, and a sedentary lifestyle. Moreover, rural women in India are physically active due to the scarcity of the transport system and machinery compared to urban folks. In our study, nearly half of the women belonged to the upper-middle class, probably fostering a sedentary lifestyle.

Interestingly, three-fourths of women had a normal BMI, similar to other Indian studies.[2] Among the drugs prescribed to the study participants, oral contraceptive pills were the most commonly followed, supported by another study.[5] Brisk walking was the most common exercise performed by the women, followed by yoga. One-third of the women consumed junk food, while many of them had a healthy diet.

The present study findings revealed that barely one-third of the women in India were adherent to the treatment regimen, which is not a good health indicator. A study conducted in Kashmir contradicts the present study findings in which 40.65% of women

### Table 2: Prescribed treatment strategies for women with PCOS ($n=224$)

| Treatment Profile                                                                 | $f$ | $\%$ |
|-----------------------------------------------------------------------------------|-----|------|
| **Drugs**                                                                         |     |      |
| Oral contraceptive pills                                                          | 124 | 55.3 |
| Metformin                                                                          | 52  | 23.2 |
| Anti-androgens                                                                     | 38  | 16.9 |
| Hormonal therapy (synthetic progesterone)                                         | 95  | 42.4 |
| Others                                                                            | 27  | 12.1 |
| **Exercise**                                                                      |     |      |
| Brisk walking                                                                      | 90  | 40.2 |
| Jogging                                                                           | 67  | 29.9 |
| Yoga                                                                              | 77  | 34.3 |
| Aerobics                                                                          | 45  | 20.1 |
| Swimming                                                                          | 5   | 2.2  |
| Sedentary                                                                          | 57  | 25.4 |
| Others (dance, cycling)                                                           | 38  | 16.9 |
| **Diet**                                                                          |     |      |
| Fish, chicken (lean protein)                                                       | 143 | 63.8 |
| Fried food items                                                                   | 94  | 41.9 |
| Fruits, vegetables, sprouts high fiber and low-fat diet                            | 107 | 47.7 |
| Junk foods and packed foods                                                        | 68  | 30.3 |
| Turmeric, tomatoes (anti-inflammatory food and spices)                             | 40  | 17.8 |
| Whole wheat, whole grain, wheat flour, brown rice (low glycemic index diet)        | 163 | 72.7 |
| Others (polished rice, all-purpose flour)                                          | 21  | 9.3  |

### Table 3: Distribution of the barriers to treatment adherence ($n=224$)

| Barriers                                                                 | $f$  | $\%$ |
|--------------------------------------------------------------------------|------|------|
| **Personal Factors**                                                     |      |      |
| Knowledge of PCOS and its management                                     | 156  | 69.6 |
| Fear of infertility                                                      | 68   | 30.4 |
| Visiting a gynaecologist was a burden                                    | 36   | 16.1 |
| Cultural or social taboos                                                | 56   | 25.0 |
| Craving for restricted food                                              | 117  | 52.2 |
| Lack of motivation from family or peer                                   | 68   | 30.4 |
| Lack of time for exercise                                                | 129  | 57.6 |
| Physical exercise tiring                                                 | 137  | 61.2 |
| **Treatment-Related Factors**                                            |      |      |
| Cost of the drug                                                         | 119  | 53.1 |
| Long duration of therapy                                                 | 140  | 62.5 |
| No relief of symptoms                                                    | 172  | 76.8 |
| Bland diet                                                               | 129  | 57.6 |
| Side effects                                                             | 139  | 62.1 |
| **Health Care System Related Factors**                                   |      |      |
| Long-distance from hospital                                              | 80   | 35.7 |
| Lack of informational support from the doctor                            | 17   | 7.6  |
| Lack of privacy during consultation                                       | 41   | 18.3 |
| Lack of proper communication by doctor                                   | 34   | 15.2 |
| Difficulty in getting appointments                                       | 54   | 24.1 |
| Poor access to medications                                               | 40   | 17.9 |
were highly adherent, 33.34% reported medium adherence, and 21.01% reported poor medication adherence.[25] However, in this study, lifestyle modifications were not explored. The present study findings are consistent with a study carried out in China among infertile women, in which only 25.6% of the women showed good adherence.[24] The similarity could be due to women selected from the same age group and similar research designs.

In our study, most women were unsatisfied with the prescribed treatment due to non-relief of symptoms, which was the leading cause for non-adherence. Other barriers related to treatment were the long duration of therapy, side effects during the treatment period, and non-availability of drugs within the affordable price range. A study conducted in Iran reported that the common barriers were side effects such as lethargy, anorexia, hot flushing and mastalgia, long duration of the treatment course, and frequent follow-up visits.[26] Similar results were reported in a study conducted in China, where the patient’s BMI, the convenience of medical treatment, and concerns about adverse drug reactions significantly affected adherence to the treatment.[24] The similarity could be due to the intake of similar groups of drugs like oral contraceptive pills hormonal pills and the implementation of an integrated treatment approach, including lifestyle modification.

In the current study, inadequate knowledge of women regarding PCOS, its treatment, and its adverse reaction was the second most common barrier. The recent study findings were supported by a study conducted in Australia that reported a lack of knowledge among women regarding the importance of lifestyle management and practicality of guidelines in clinical practice as significant barriers to adherence to PCOS treatment.[26] However, in a study conducted in Texas, more than two-thirds of women knew about PCOS, the source of their knowledge being health care workers.[27] In another study, Iranian women had a false perception of PCOS as a common problem in the reproductive age group. They believed it was a self-limiting condition that may resolve after 6 months without treatment.[23]

In our study, women did not adhere to the newly prescribed dietary plan as it was not of their preferred taste. A previous study carried out in Singapore supported the present study’s findings. It reported that women were using eating low-cost street foods, which led to non-adherence to the dietary regimen.[28] The similarity in results could be due to the similar socio-economic status of women, busy life schedules, and easy availability of low-cost street foods.

We also observed that women could not adhere to the recommended physical activity or exercise due to lack of time in the modern busy life schedule and exhaustion. An Australian study reported that women felt less motivated for weight management and lacked time to perform physical exercise.[24] Evidence suggests that insulin resistance and its complications are worsened by increasing weight, while lifestyle interventions and weight reduction can reduce insulin resistance.[23] Lifestyle modifications are the most challenging, yielding slow results; low commitment and poor patient motivation are additional barriers.[18,34] A study conducted in Australia recommends personalised, long-term care over 6 to 12 months by healthcare workers, which is flexible, suiting the woman’s time, and cost-effective to overcome these barriers.[19] However, more research needs to be carried out in the Indian context to design a suitable and culturally acceptable strategy that addresses these barriers, thus enabling primary care physicians to deliver quality care to these women.

The present study found that personal factors, treatment and health care system-related barriers were the common barriers causing non-adherence. Women reported that the family and peers did not support them in buying medications and getting appointments to visit the gynaecologist. Similar findings were reported in a study conducted in Iran where friends and peer members of women recommended them not to visit gynaecologists as diagnostic procedures were painful, and the treatment was expensive.[29]

The present study findings revealed a statistically significant association of socioeconomic status with adherence to treatment (P = 0.001). Women with higher socioeconomic status are more likely to be well educated, have better resources to afford quality healthcare, acquire more information about PCOS, and understand the consequences of non-adherence. Education provides motivation and helps develop a positive attitude in women to overcome cultural barriers, social taboos and negligence.

We used snowball sampling in our study, where primarily selected women nominated other women with PCOS, who are otherwise challenging to locate and cost-effective at the same time. The present study is, however, not devoid of limitations. Through snowball sampling, there is a possibility of selection bias and attrition. The attrition rate was 36%. Presuming an extensive dropout, we recruited a larger sample. Women incapable of filling up a google form were excluded from the study, limiting the population’s representativeness.

Moreover, self-reports possess reporting bias. Additionally, most of our participants were educated. Thus, results may not necessarily reflect the barriers among the general population.

Creating mass awareness among girls and women on PCOS and its management in the country is the need of the day. Health care providers such as primary care physicians, nurses, and dieticians need to work towards patient motivation for lifestyle management. Counselling and reassuring women for smaller incremental improvements as a success may help them overcome the barriers. Future research should be directed towards designing various strategies to overcome the barriers to adherence to PCOS. Utilising grassroot level health workers like Accredited social health activist, public health nurses and paramedics will enable referral services, monitoring, and counselling women with PCOS, thus preventing complications and long-term sequelae.
Conclusion

The present study reflects the problem of non-adherence to treatment in most women with PCOS. Many of these barriers can be overcome by creating awareness among this population, training nurses and allied health care workers, creating support groups, and following up through Tele counselling services.

Key Message/highlight of the present study

Less than one-third of Indian women with PCOS adhered to treatment, while others were partially adherent or non-adherent. A majority of women expressed a lack of knowledge on PCOS and its management as the primary barrier followed by the long duration of treatment. While in western countries, time constraints and financial implications were reported as significant barriers. Improving patient awareness through Information Education Communication materials, direct one-to-one educational sessions and tele-counselling services by primary care health physicians can dispel their misconceptions.

Novelty

To our best knowledge, this study is the first of its kind to explore treatment compliance and its barriers among Indian women with PCOS from a woman’s perspective. The majority of the studies conducted in the developed countries on barriers are from General Practitioners’ perspectives. There is a paucity of data on treatment compliance barriers globally.

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Declaration of patient consent

The authors certify that they have obtained all appropriate patient consent forms. In the form the patient(s) has/have given his/her/their consent for his/her/their images and other clinical information to be reported in the journal. The patients understand that their names and initials will not be published and due efforts will be made to conceal their identity, but anonymity cannot be guaranteed.

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Conflicts of interest

There are no conflicts of interest.

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