

Volume 4 Issue 08

# A Qualitative Study of Barriers and Facilitators to Polycystic Ovary Syndrome Treatment

# **Adherence: Iranian Context**

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Received date: 09 September 2023; Accepted date: 30 September 2023; Published date: 07 October 2023

Citation: Ameli N, Brown M (2023) A Qualitative Study of Barriers and Facilitators to Polycystic Ovary Syndrome Treatment Adherence:

Iranian Context. J Comm Med and Pub Health Rep 4(08): https://doi.org/10.38207/JCMPHR/2023/OCT040801118

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## Abstract

**Introduction:** Due to the adverse impacts of polycystic ovary syndrome (PCOS) on patients' health and well-being, it has received significant attention in developing optimal approaches for treatment. This study aimed to explore barriers and facilitators of PCOS treatment adherence amongst PCOS-diagnosed women in Mashhad, Iran.

**Methods:** Employing a qualitative approach, this study conducted semi-structured interviews with ten women (20 to 40 years old) diagnosed with PCOS for over a year.

**Results:** The findings revealed that barriers to PCOS treatment adherence include inadequate knowledge about PCOS symptoms among patients and their families, insufficient information from doctors, long waiting times at appointments and short consultation sessions, lack of empathy from doctors, personal time constraints, social norms, side effects of the drugs, and lack of enjoyment of the treatment. Facilitators of PCOS treatment adherence included knowledge of PCOS consequences and remedies, family and peer support, social pressures, improved health outcomes, and personal improvement goals.

**Conclusion**: This study finds some key barriers and facilitators to treatment adherence in the context of Iran, which imply the need to increase PCOS awareness among girls, women, family members, and the general community, improve healthcare professionals' care (information provision, empathy, and prioritizing women's health), and enhance intrinsic motivation among PCOS-diagnosed women. These findings are among the first concerning facilitating and impeding factors associated with PCOS treatment adherence. The results relating to social pressure as a facilitator are novel in the broader context of the relevant literature.

**Keywords:** PCOS, Polycystic ovary syndrome, Barriers, Facilitators, Treatment, Adherence, Theoretical domains framework, lifestyle, lifestyle changes

## **1. Introduction**

Polycystic ovary syndrome (PCOS) is recognized as a significant public health concern worldwide [1] and is one of the most common hormonal disorders occurring in women [2,3]. PCOS is characterized by hyperandrogenism, ovulatory dysfunction, and polycystic ovarian morphology - with excessive androgen production by the ovaries [4]. Subject to diagnostic criteria and study sample size, worldwide PCOS prevalence ranges from 6% to 20% of reproductive-aged women [5] Due to the adverse impacts of PCOS on patients' health and wellbeing, PCOS has received much attention in developing optimal pharmaceutical and lifestyle management treatment approaches using careful diagnosis [11]. The treatment models to improve symptoms of PCOS include medications (i.e., progesterone, oral contraceptives, anti-androgens, and metformin) and lifestyle management such as healthy diets, more physical exercise, and quitting smoking [12-14]. The effectiveness of these treatments in improving various symptoms of PCOS is well-documented across the literature. For instance, drug treatments such as insulin-sensitizing medications positively affect insulin resistance, irregular menstrual, anovulation, hirsutism, and obesity [15]. In addition, lifestyle management is found to improve insulin resistance and lead to weight loss, enhancing PCOS features, psychological, cardio-metabolic, including endocrine, and reproductive features [16,17]. However, the effectiveness of these treatments is highly reliant on persistent adherence from the patients [11,18], where the term adherence recognizes the patient's right to

and affects one in ten women of childbearing age [6]. In the shortterm, PCOS leads to absent, infrequent, or irregular periods, hirsutism, androgenic alopecia, difficulty in weight management, acne, raised cholesterol, over or underactive thyroid, and infertility [7], which in turn could lead to mood swings, low self-esteem, and depression [7–9]. In the long-term, PCOS-diagnosed women suffer from being overweight and face a higher risk of developing diabetes, gestational diabetes, hypertension, heart disease, low HDLcholesterol and high LDL-cholesterol, and sleep apnea [10].



choose whether they follow the treatment plan suggested by the doctors [19]. Therefore, given the impact of PCOS on women's lives and the substantial role of adherence in the effectiveness of PCOS treatments, it is essential to investigate factors that facilitate or prevent patients' PCOS treatment adherence. Key barriers and facilitators to PCOS treatment adherence observed across the literature are individual-level (e.g., time and financial pressure, psychological comorbidities, and lack of motivation for maintaining a healthy lifestyle) [20,21], treatment-related (e.g., high cost and long duration of treatment, and no relief of symptoms), system-level (e.g., lack of professional support and empathy, and unavailability of allied health professionals) [19,20], and environmental barriers (e.g., lack of social support and exercise environment) [21].

In the context of Iran, a country with 3% to 19% PCOS prevalence [22,23] and where barriers to treatment adherence may be exacerbated by its developing status and foreign sanctions that impact its medical field [24], documenting barriers and facilitators to PCOS treatment adherence can help identify practical gaps and recommendations in designing culturally appropriate healthcare for PCOS-diagnosed women. However, to our knowledge, only Bazarganipour et al. [19] investigated facilitating and inhibiting factors related to treatment adherence in the Iranian context. The study sample included 20 PCOS-diagnosed Iranian women (21 - 34 years old) and found impeding factors to have financial issues, patient-related (perception and knowledge), disease-related (side effects of medication and long treatment time), and healthcare provider-related factors (lack of informational support and absence of holistic care). In contrast, social factors (family, friends, and peers) were found to be both facilitating and inhibiting.

Thus, to enrich this strand of literature and expand the evidence in the Iranian context, the present study explores facilitators and barriers to PCOS treatment adherence in a sample of ten PCOS-diagnosed women (18 to 45 years old) from Mashhad, Iran.

#### 2. Materials and Methods

This study used semi-structured interviews to explore barriers and facilitators to PCOS treatment adherence; purposive sampling was utilized. This study was approved by the Research Ethics Committee, School of Health and Social Care, Swansea University (Reference Number: 180722; Date: 04/08/2022). Informed consent was obtained from all the participants and two gynecologists from the target clinics. The participants included ten women (18 to 45 years old) diagnosed with PCOS for more than one year and who reside in the city of Mashhad in Iran. The age range is appropriate to reduce the potential confounding effects of menopause [25] and other associated hormonal and metabolic changes [26]. In addition, since symptoms of PCOS are familiar with some other disorders, such as adrenal hyperplasia, the syndromes of severe insulin resistance, androgen- secreting neoplasms, hyperprolactinemia, and thyroid abnormalities [27], the participants with a history of such disorders were excluded.Data were collected using one-to-one semi-structured interviews. Theinterviews were conducted between 19th August and 2nd September 2022. Thematic analysis was used to analyze the data. This involved identifying, analyzing, and reporting themes and patterns in the data [28,29]. To systematically structure the report, articles relating to barriers and facilitators of PCOS treatment adherence were compared against the validated version of the Theoretical Domains Framework (TDFv2) as developed by Michie et al. [30]. See Appendix A for tabulated TDFv2 mapping of the observations of the present study. The use of this framework in developing interventions consists of a theory-based and systematic approach that aligns with the recommendations of the Medical Research Council on intervention programs [31]. The use of this approach in investigating barriers and facilitators of PCOS treatment adherence is also prevalent across the literature; see Pirotta et al. [20].

## 3. Results

#### **3.1 Sample Characteristics**

Ten PCOS-diagnosed female residents of Mashhad, Iran, participated in online interviews, each lasting 25 to 45 minutes (mean duration 40 mins). The mean age of the sample was 29.7 years (SD = 6.12), with a minimum age of 20 and a maximum of 40. See (**Table 1**) for a summary of the participants' characteristics.

Two themes were developed: barriers and facilitators. They are outlined in the following section and supported by participant extracts. Several sub-themes were developed for each.

Characteristics	N (%)
Age group (years)	
18-29	5 (50%)
30 - 45	5 (50%)
Marital Status	
Single	6 (60%)
Married	4 (40%)
Education	
Diploma	1 (10%)

Citation: Ameli N, Brown M (2023) A Qualitative Study of Barriers and Facilitators to Polycystic Ovary Syndrome Treatment Adherence: Iranian Context. J Comm Med and Pub Health Rep 4(08):



University Student	3 (30%)
Bachelor's degree	5 (50%)
Master's Degree	1 (10%)
1 <sup>st</sup> PCOS Diagnoses (Years)	
1-3	6 (60%)
4-8	3 (30%)
> 8	1 (10%)

## **3.2 Barriers to PCOS Treatment Adherence**

This theme captured factors that act as an impediment to patients' adherence to PCOS treatment. Factors identified were matched to five TDFv2 sub-themes, including Inadequate knowledge about PCOS symptoms, environmental context and resources, social norms, side effects of PCOS medication, and lack of enjoyment.

## 3.2.1 Sub-theme 1: Inadequate Knowledge about

## **PCOSSymptoms**

Participants identified inadequate knowledge about early PCOS symptoms as the main barrier to delayed diagnosis.

'I had symptoms but did not know anything about this disease. At that time, I gained much weight and had unexpected hair fall. Most of that I thought was because of the high amount of stress from work, so I just tried to take more rest and did not check up the symptoms soon.'–

## Participant 1, Page 3

Participant 1 had symptoms and from an early age, but she normalized them by relating them to work matters, therefore underestimating the severity of their symptoms, and did not opt for diagnosis. Like Participant 1, participant 7 also normalized PCOS symptoms to stress, while Participant 4 thought these symptoms were common for her age.

Several participants recalled a lack of support from family, inhibiting their pursuance of treatment.

'I have been suffering from this disease for a year. I did not know anything about this disease. ... At first, when I shared my problems with my mom, she did not consider it seriously. She just played it as having bad periods. This also discouraged me from looking more into it, so I also did not follow up much after that.' – **Participant 4, Page 3** 

'Before diagnosis, I shared my concerns with my spouse, but he did not take my symptoms seriously and always brushed them off as normal mainly because he did not know much about this syndrome.' – **Participant 9, Page 3**  Participants reported that their primary source of information had been their specialist doctor. However, participants expressed concerns about the insufficiency of data from the doctors. One participant highlighted a need for more specificity in the doctor's advice about the role of diet and exercise.

'My specialist doctor gave no exceptional advice regarding diet and exercise. I am still under treatment and still have irregular periods'

## – Participant 7, Page 3

Concerning inconveniences in access to the healthcare provider, while all the participants had access to a doctor at the time of the interview, they reported long waiting times and short consultation sessions as a barrier to treatment.

'Waiting time in doctor's offices is very long and tiring. Unfortunately, the sessions with the doctor were too short, and the doctor did not detail my condition because of many waiting patients. So, I didn't go to the doctor for two months.' – **Participant 9, Page 3** Similarly, a lack of health professional support was reported, including a lengthy time diagnosis and a lack of empathy from the doctors.

'I went to a specialist doctor due to infertility, and at first, they did not diagnose PCOS ... the previous doctor's diagnosis was that it was genetic. At first, the doctor wouldn't care to diagnose my condition further, and I didn't feel any support from her at all.' – **Participant 9**, **Page 3** 

A lack of health professional support was also reported. This consisted of perceived inattention, quick dismissal, and lack of empathy from the doctor when first seeking the symptom diagnosis. Or failure to consider PCOS.

'First, when I had these symptoms, I shared them with a general practitioner. But at the time, I didn't get any serious attention and was told that there was "nothing wrong." So, I also thought the same.' – **Participant 1, Page 3** 

## **3.2.2 Sub-theme 2: Environmental Context and**

## Resources

This sub-theme related to the role of environmental factors as either a facilitator or barrier to participants' PCOS treatment adherence. Need for more information, inconveniences in access to the health care provider, lack of health professional support, and time resource constraints were reported by participants. Finally, although some participants identified the roles of exercise and a healthy diet in managing PCOS conditions, they expressed an inability to adhere to these treatments due to time constraints. For example, several participants reported difficulty making time for physical activity due to family responsibilities and employment. 'Taking care of my one-year-old child is full-time work for me, and I cannot make time to do exercise.' – **Participant 7, Page 3** 

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## Journal of Community Medicine and Public Health Reports OISSN: 2692-9899

## 3.2.3 Sub-theme 3: Social Norms

Although highlighted by only one participant, the adverse impact of consuming traditionally recommended herbs delayed her diagnosis and worsened her symptoms.

'In the beginning, unfortunately, to deal with my irregular periods, at the suggestion of my mother and grandmother, I used herbal medicines such as "Aslab" and "Gol gav zaban" instead of going to the doctor, but with these herbal medicines, the situation worsened.' -

## Participant 5, Page 3

## 3.2.4 Sub-theme 4: Side Effects of PCOS Medication

Negative experience related to treatment side effects was a significant barrier to treatment adherence. Participants reported avoiding medications because of side effects such as allergies, weight gain, morning sickness, and daily fatigue. Another discussed concerns about treatment and fertility, and another noted that the perceived ineffectiveness of therapy led to a complete halt in taking the medications.

'In the first phase of treatment, I took medicine to at least have a regular period. My thyroid was also affected, and I was not feeling well. I stopped the medicines and preferred to continue controlling this disease with exercise and diet.' – Participant 4, Page 3

'The drugs he prescribed for fertility affected period pains but did not affect fertility. ... I was disappointed with the drugs that were prescribed for infertility and stopped them.'- Participant 9, Page 3

#### **3.2.5 Sub-theme 5: Lack of Enjoyment**

Participants discussed their discomfort and lack of enjoyment for various treatments as barriers to PCOS treatment adherence.

'Also, I don't find any interest in physical activities, and I don't feel comfortable doing exercise in the crowded gym center.'- Participant

#### 7, Page 3

'But it is difficult to stop myself from snacking, especially when hanging out with friends or watching movies. So, I usually can't stick to a diet plan.' - Participant 5, Page 3

#### **3.3 Facilitators of PCOS Treatment Adherence**

This second theme reflected factors that encouraged patients' adherence to PCOS treatment. Matched to four TDFv2 sub-themes, this theme includes knowledge about PCOS consequences and medicine, social factors, beliefs about the health benefits of treatment adherence, and personal goals.

controlled, it causes miscarriage, premature birth, infertility, diabetes during pregnancy, and in more advanced cases, it causes uterine cancer. I cannot imagine what kind of effect cancer will have on my life, so I always try to follow the treatment as I can.'-Participant 2, Page 2

'As per my doctor, PCOS can lead to some problems during pregnancy and can also have some serious problems like cancer. So I think we have to treat it carefully.' - Participant 5, Page 3

Participants also shared their understanding of the effectiveness of various treatment methods, including medicinal and lifestyle changes. Participants acknowledged the effectiveness of combining treatments to improve symptoms of PCOS.

'In my opinion, the combination of drug therapy, diet therapy, and exercise multiplies the effect of treatment. I have been trying to balance between these methods to realize the most benefit of the treatment.' – **Participant 1, Page 3** 

'In my opinion ... the treatment for this disease is long-term .... However, I still think these treatments are temporary, and the disease will return. So, I have to maintain my pace over time.'- Participant

## 3, Page 3

Exhibiting a good understanding of the duration of the PCOS treatment, one participant identified that PCOS treatments do not lead to a complete recovery, which motivated her persistent treatment. As such, knowledge about PCOS treatment methods facilitated patients' compliance with treatment.

#### **3.3.2 Sub-theme 2: Social Factors**

This sub-theme emphasizes the role of social factors such as social support and social pressures in promoting PCOS treatment adherence among the participants. Most participants received support and encouragement from their families.

For example, participants emphasized that family members encouraged them to pursue and maintain treatment by supporting dietary changes. Eight participants reported family support to access the doctor for an initial consultation, and that family helped them to maintain physical activity, healthy diet, and medical treatments.

'My spouse and family have been very supportive to the extent that they have adapted their diet to encourage me to continue the treatment.' – **Participant 4, Page 3** 

Two participants explored the role of social and cultural pressure to marry, conceive a child, and give birth as a driving factor to treatment

## 3.3.1 Sub-theme 1: Knowledge about PCOS

## **Consequences and Treatment**

Most participants (70%) identified the disease's various short- and including depression, infertility, long-term consequences, miscarriage, premature birth, diabetes during pregnancy, and, in advanced cases, uterine cancer. Understanding and awareness of such was a significant concern for most, motivating their action toward treatment adherence.

'After diagnosing this disease, I got more information about polycystic ovary through the Internet.... If this disease is not

adherence.

'Honestly, at that time, I felt like I was not a normal woman because my family and I think people believe women are important to give birth and continue the family. These factors push me to follow the treatment.' – Participant 3, Page 4 3.3.3 Sub-theme 3: Beliefs about Health Benefits of

## **Treatment Adherence**

This sub-theme reflects the importance of the positive role of perceived health benefits and perceived improvements in health outcomes as a facilitator of treatment adherence. These improvements



included improved menstrual cycles, pain reduction, and reduced heavy bleeding during menstruation, and a reduction in depressive symptoms and obesity was reported by participants.

'I got the fastest response from drug treatment. After taking the drug, I got my period immediately, and the menstrual period became somewhat more regular. The rest of the symptoms, such as depression and obesity, improved over a longer period with the help of diet and exercise. ..., taking some Infertility pills gave me an acceptable response during one or two courses. .... I was always encouraged to continue treating this disease every time I took it ....'– **Participant 1, Page 3** 

#### 3.3.4 Sub-theme 4: Personal Goals

Personal goals were presented as intrinsic motivations for participants' treatment adherence.

For one participant, motivated by her social interactions, improving her appearance by losing weight encouraged her to partake in healthy lifestyle changes. For another, the desire to improve symptoms of PCOS (i.e., excess hair) to satisfy her spouse was highlighted as the motive for her commitment to drug therapy.

'... My job requires me to be involved in social contacts. Because of my obesity, I feel embarrassed in front of my customers. So, weight loss to have a fit body is my priority. Despite the challenges of strict diet and physical exercises, a good-looked appearance motivates me and keeps me on track.' – **Participant 1, Page 3** 

'Personally, the symptoms of PCOS relating to excess hair are very concerning for me, and it has decreased my confidence, especially when I am with my husband... So, I want to try to reduce this symptom as much as possible.' – **Participant 4, Page 3** 

As such, achieving a better physical appearance was highlighted as the personal goal that motivated treatment adherence.

## **4.** Discussion

This study explored factors that inhibit and facilitate PCOS treatment adherence of PCOS-diagnosed women in Mashhad, Iran. The semistructured interview revealed that barriers to PCOS treatment adherence included inadequate knowledge about PCOS symptoms among patients and their families, insufficient information from doctors, long waiting times at appointments and short consultation sessions, lack of empathy from doctors, personal time constraints, social norms, side effects of the drugs, and lack of enjoyment of the effects of the medications resulting in drug avoidance [18,19], personal time constraints to take up lifestyle changes such as exercise [20,35], lack of enjoyment in taking drugs and disinterest in physical exercise [20,35], long waiting time for short consultation sessions [19], lack of empathy and dismissal from their doctor [19,33], lack of informational support [19,20], and inefficacy in engaging in healthy lifestyle changes such as avoiding unhealthy foods [20].

These findings can be mapped to the health belief model (HBM) [36], widely used to explain and predict the changes in individuals' health behaviors [36]. Perceived susceptibility relates to the participants' perceived risk of getting diagnosed with PCOS, which is expected to lead to high treatment compliance. *Perceived benefits* are captured by the participants' reports of taking medications associated with maintaining regular periods and exercise and diet-based being linked with improvements in depressive symptoms and obesity. About half of the participants also stated that these improvements in their health encouraged them to stay committed to the treatments. Perceived barriers to PCOS treatment adherence included inadequate knowledge about PCOS symptoms among patients and their families, participants' concern about side effects of PCOS medicines, time constraints, lack of enjoyment, inconveniences in access to the healthcare provider, and lack of health professional support, and social norms. Concerning *cues to action*, while social support and social pressure encouraged treatment adherence, insufficient information resulted in the opposite. Finally, a lack of self-efficacy resulted from a participant's inability to engage and commit to a healthy diet. Appendix B discusses these findings in more detail. The study incorporates some limitations. First, a small sample was selected, which impedes generalisability. However, this is expected of qualitative research to provide a deeper understanding of topics, in this case, knowledge, experience, and barriers and facilitators of PCOS among Iranian women. Second, participants were educated, with some even having medical backgrounds; thus, the results do not capture a socioeconomically diverse group of women.

## **5.** Conclusion

By conducting semi-structured interviews with ten PCOS-diagnosed women (mean age of 29.7 years), this study examined the barriers and facilitators of PCOS treatment adherence amongst PCOS-diagnosed women in Mashhad, Iran. Barriers to PCOS treatment adherence

treatment. Facilitators of PCOS treatment adherence included knowledge of PCOS consequences and remedies, family and peer support, social pressures, improved health outcomes, and personal improvement goals. These findings align with the existing literature, including relating to the facilitating roles of patients' positive experience of medication and lifestyle management [20,32] and support from families, partners, or friends to consult a doctor and take up lifestyle changes [19,20], and inhibiting roles of inadequate knowledge about early PCOS symptoms among participants and their parents, leading to delayed diagnosis [33,34], the experience of side

included inadequate knowledge about PCOS symptoms among patients and their families, insufficient information from doctors, long waiting times at appointments and short consultation sessions, lack of empathy from doctors, personal time constraints, social norms, side effects of the drugs, and lack of enjoyment of the treatment. On the other hand, factors such as knowledge of PCOS consequences and treatments, family and peer support, social pressures, improved health outcomes, and personal improvement goals facilitated PCOS treatment adherence. These findings are among the first in the context of Iran, thus laying the foundation for future empirical examinations



of factors in the context of Iran. More notably, the findings relating to social influences (i.e., social pressure and social norms) are novel in the current study.

The study findings lead to some key recommendations. First, timely diagnosis can be encouraged through increased awareness about the syndrome [37,38], reduced stigma surrounding the disease [39], and enhanced social support [38]. These can be achieved through education and public health interventions [34,37]. Second, healthcare professionals should be encouraged and trained to provide patients with more informational support relating to PCOS [37] and trained not to dismiss and ignore patients and their symptoms [37]. Finally, a healthy lifestyle can be encouraged by reinforcing intrinsic motivation among PCOS-diagnosed women by encouraging them to partake in physical activities they enjoy [40].

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## Conflict of Interest: None

## **Author's Contribution**

#### Nima Ameli

As the primary researcher, Dr. Nima Ameli designed this research project, including various survey forms and data collection and analysis procedures; conducted interviews; cleaned and analyzed the data; and interpreted and reported the results based on extensive research.

#### Menna Brown

Dr. Meena Brown supervised the whole research process; revised the survey forms and data collection and analysis procedures to ensure compliance with the committee standards; reviewed, revised, and edited the research drafts, finalizing the research outcomes and attaining research objectives.

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Citation: Ameli N, Brown M (2023) A Qualitative Study of Barriers and Facilitators to Polycystic Ovary Syndrome Treatment Adherence: Iranian Context. J Comm Med and Pub Health Rep 4(08):



# Appendix A. Thematic Grid

Table 1	Themes	and sub-	themes t	elating t	o harriers	and f	<b>Eacilitators</b> (	to PCOS	S treatment	adherence	manned to	o TDFv2
I abit I	Themes	and sub-	function i	clating t	0 Daniers	anu i	acintators		<i>i</i> ucatinent	auncience	mapped u	J I D I V Z

Knowledge       Knowledge about PCOS consequences       'After I learned that this disease increases the probability of infertility and depression.' – Participant 1, Page 2         'If this disease is not controlled, it causes miscarriage, premature birth, infertility       If this disease is not controlled, it causes miscarriage, premature birth, infertility	causes
depression.' – Participant 1, Page 2 'If this disease is not controlled, it causes miscarriage, premature birth, infe	
'If this disease is not controlled, it causes miscarriage, premature birth, infe	
	ertility,
diabetes during pregnancy, and in more advanced cases, it causes uterine ca	ncer. I
cannot imagine what kind of effect cancer will have on my life so I always	try to
follow the treatment as I can.' – Participant 2, Page 2	
'But the fear of infertility in the future always worried me and my fam	ily' –
Participant 3, Page 3	
'As per my doctor, PCOS can lead to some problems during pregnancy and co	an also
have some serious problems like cancer. So I think we have to treat it carefu	ully.' –
Participant 5, Page 3	
'I know that PCOS can cause cancer, especially if we don't do treatment early	v on'–
Participant 6, Page 3	
", and that women with PCOS are more vulnerable to type 2 diabet	es and
endometrial cancer' – Participant 10, Page 2	
Knowledge about PCOS symptoms 'I had symptoms, but I did not know anything about this disease. At that time, I	gained
a whole lot of weight and had unexpected hair fall. Most of that I though	t were
because of the high amount of stress from work so I just tried to take more re	est and
did not check up the symptoms soon.' – Participant 1, Page 3	
'When I encountered this disease, I was very young and did not know much abo	out this
syndrome. I was 18 years old when my symptoms started. I had very pain	ul and
prolonged periods of 10-12 days and heavy bleeding. At first, I thought it was	s just a
part of being a teenager and did not take it seriously. But now, I realise th	at they
were obviously not normal, and I needed to seek diagnosis earlier.' – Partici,	pant 3,
Page 4	
'I used to think that these acnes were due to stress, so I didn't consider any n	eed for
doing check-up for a long time, ' – Participant 7, Page 3	
'I have been suffering from this disease for a year. I did not know anything ab	out this
disease. At first, when I shared my problems with my mom, she did not con	sider it
seriously. She just played it as having bad periods. This also discouraged m	e from
looking more into it, so I also did not follow up much after that.' – Particip	oant 4.
Page 3	,
"Refore diagnosis I shared my concerns with my snouse but he did not t	the my
symptoms seriously and always brushed them off as normal mainly because	ho did
not know much about this syndrome ' – Participant 9 Page 3	

'I had a lot of information about this disease because of my job, which is a nurse, and my friends who were diagnosed with the disease before me, ..., It also started the treatment process on time' – Participant 6, Page 4 'Before the disease, I knew a little about this disease because my cousin was also suffering from this disease. This helped me seek diagnosis early from when I noticed some symptoms in myself.' – Participant 8, Page 3 '..., in our family, PCOS was hereditary, and my sister, aunt and cousin's daughter were affected. Because of this family history and my background, I have known about

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		this disease from before, Which is why we were fast to check for this disease for
		myself and I was able to diagnose my disease early on ' – Participant 10, Page 3
	Knowledge about PCOS treatments	'In my opinion, the combination of drug therapy, diet therapy and exercise multiply
		the effect of treatment. I have been trying to balance between these methods to realise
		the most benefit of the treatment. ' – Participant 1, Page 3
		'Based on my information from my doctor and searching on internet, I know that
		exercise and good diet are very helpful in losing weight and controlling the
		symptoms, so I walk every day and control my weight and it has had a significant
		impact on my recovery process. ' – Participant 4, Page 3
		'Before the disease, I knew a little about this disease because my cousin was also
		suffering from this disease From her experience I also learned that it is important
		to follow the proper treatment which include the medicine, healthy diet, and exercise.
		This was very useful in starting my treatment early.' – Participant 8, Page 3
		'As a doctor, it was easy for me realise the benefits of early treatment, especially, I
		focused on exercise and diet which can help in improving the symptoms and lower
		the long-term risks associated with PCOS such as diabetes and cardiovascular
		disease. Moreover, I was encouraged to use metformin due to its positively affects
		menstrual irregularities and insulin resistance. – Participant 10, Page 3
		In my opinion the treatment for this disease is long-term However I still think
		that these treatments are temporary and the disease will come back again So I have
		to maintain my pace over time. ' – Participant 3. Page 3
	Informational resources	<i>'I got more information about the disease through the internet and from a specialist</i>
		doctor' – Participant 1, Page 3
		'I have the most information from the specialist [doctor], but after the diagnosis of
		this disease. I got more information about polycystic ovary through the Internet.' –
		Participant 2, Page 3
		" based on my past personal experience and the information I have from my
		specialist doctor, the treatment for this disease is long-term' – Participant 3, Page
		4
		'I wish that my previous doctor gave me more clear information about PCOS effects
		sooner so that could take it more seriously when I first had the symptoms.' $-$
		Participant 4, Page 3
		'I have this information [relating to PCOS treatment] from my doctor and other
Environmental		specialists whom I have consulted before. I also have information from Instagram.'
context and		– Participant 5, Page 3
resources		
		T only recently found what insulin resistance is. I didn't know about this from my
		aoctor visus bejore. – Participant 2, Page 5
		Where [Instagrum pages], I also jound many alerary recommendations such as Mediterranean diet Paleo diet and IGI [low alycaemic index] diet but I didn't know
		which one was correct to follow for me' – Participant 4 Page 3
		<i>'My specialist doctor did not give any special advice regarding diet and exercise. I</i>
		am still under treatment and still have irregular periods' – Participant 7, Page 3
	Access to healthcare providers and	'The long and time-consuming waiting in the doctor's office is very difficult,' –
	health professional support	Participant 4, Page 3
		'Waiting time in doctor's offices is very long and tiring. Unfortunately, the sessions
		with the doctor were too short and the doctor did not go into details of my condition

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Journal of Community Medicine and Public Health Reports	•	ISSN: 2692-9899

		because of many waiting patients. So, I didn't go to the doctor for two months.' – Participant 9, Page 3 'First when I had these symptoms, I shared with a general practitioner. But at the time, I didn't get any serious attention and was told that these were "nothing wrong". So, I also thought the same.' – Participant 1, Page 3 'When I first encountered this disease, the first problem and obstacle was the lack of a doctor's diagnosis, and it took a long time for them to diagnose PCOS.' – Participant 3, Page 4
	Time resource constraints	<ul> <li>'I find myself very busy with work, so I have time to only visit a specialist doctor every six months and any problem I don't have the time to visit the doctor and pay for the medicine' – Participant 6, Page 4</li> <li>'Taking care of my one-year-old child is a full-time work for me and I cannot make time to do exercise.' – Participant 7, Page 3</li> <li>'The doctor recommended me a diet of vegetables and fruits and exercise. I follow the diet to some extent, but I don't exercise much because I am busy with work, but when I exercise, my period pains are reduced.' – Participant 8, Page 3</li> </ul>
Social influences	Social support	' I had the support of my family all the time, and this caused the worry to decrease to a great extent.' – Participant 1, Page 3 'The support of my family made me more eager to continue the treatment.' –
		'The support of my family made me more eager to continue the treatment.' – Participant 2, Page 3 ' my family always encouraged me to pursue the treatment process.' – Participant 3, Page 4 'My spouse and family have been very supportive to the extent that they have adapted their diet to encourage me to continue the treatment.' – Participant 4, Page 3 'My family, especially my mother, supported me a lot My mother took a specialist doctor and I received hormone ampoules,' – Participant 5, Page 3 'My family is fully aware of the disease, but I mostly talk about this with my friends, some of whom were also affected, and drive my incentives to pursue the treatment of this disease.' – Participant 6, Page 4 'My family and spouse have always supported me,' – Participant 7, Page 3 'My family and my spouse encourage me to continue treatment.' – Participant 8, Page 3 ' my family was very worried and persistent about the treatment and their emphasis was on lifestyle change and exercise.' – Participant 10, Page 3
		at all, but my parents were very worried and persistent because my mother had surgery on her uterus due to fibroids. I did not have a special diet, but my food intake is very small. I walk 30 to 90 minutes a day. ' – Participant 9, Page 3
	Social pressure and norms	'In the beginning, unfortunately, to deal with my irregular periods, at the suggestion of my mother and grandmother, I used herbal medicines such as "Aslab" and "Gol gav zaban" instead of going to the doctor, but with these herbal medicines, the situation worsened.' – Participant 5, Page 3
		'Honestly, at that time, I felt like I was not a normal woman because my family and I think that people believe that women are important to give birth and continue the family. These factors push me to follow the treatment.' – Participant 3, Page 4

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treatmentThe rest of the symptoms, such as depression and obesity, improved over a long period with the help of diet and exercise, by taking some Infertility pills, I got a acceptable response during one or two courses I was always encouraged continue treating this disease every time I took it' – Participant 1, Page 3 'the improvement of severe symptoms such as pain and heavy bleeding durid menstruation, made me more eager to continue the treatment.' – Participant 2, Pag 3 ' I know that exercise and good diet are very helpful, so I walk every day and control my weight and it has had a significant impact on my recovery process.' Participant 4, Page 3 I don't know if there is a definitive treatment or not, but as long as I have a regul period, I think I should continue the treatment with the acceleration of not period, I think I should continue the treatment.
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I don't know if there is a definitive treatment or not, but as long as I have a regul period, I think I should continue the treatment with the acceleration of n
period, I think I should continue the treatment with the acceleration of n
recovery process and the regularity of my periods, I was encouraged to continue t
treatment.' – Participant 5, Page 3
'Even now, when I take this medicine [low dose contraceptives] regularly, I have
regular periods, but if I stop, it becomes irregular again.' – Participant 8, Page 3
Side effects of PCOS medications 'In the first phase of treatment, I took medicine to at least have a regular period. N
thyroid was also affected, and I was not feeling well at all. I stopped the medicin
and preferred to continue controlling this disease with exercise and diet.' –
Participant 4, Page 3
Some of the side effects that I have had with the medicines I have used so far we
morning sickness and daily fatigue, but my specialist changed the medicine and no
I have no problems.' – Participant 5, Page 3
'At first, the doctor prescribed a drug called letrozole, but due to allergies such
itching and hives, my doctor stopped it and prescribed LD tablets [low do
contraceptives] I sometimes use multivitamin and zinc pills, but it increases n
appetite and cause weight gain, so I don't take them regularly.' – Participant 8, Pa
The drugs he prescribed for fertility had an effect on period pains but did not affe
jertuity I was alsappointed with the arugs that were prescribed for infertuity an
Intentione and Demond cools
mitentions and Personal goals My job requires me to involve in social contacts. Because of my obesity, I je
goals embarrassea in front of my customers. So, weight loss to have fit body is my fit
appearance motivates me and keeps me on track ' – Participant 1 Page 3
'Personally the symptoms of PCOS relating to excess hair is very concerning for m
and it has decreased my confidence especially when Lam with my husband. So
want to try to reduce this symptom as much as possible '- Participant 4 Page 3
Enjoyment 'Also. I don't find any interest in physical activities, and I don't feel comfortable
do exercise in the crowded gym centre. ' – Participant 7. Page 3
'From a mental point of view, taking pills flow dose contraceptive pills I daily is n
pleasant for me at all. So, I tried to stop taking pills, which caused my disease
return. ' – Participant 8, Page 3
'But it is difficult to try to stop myself from snacking, especially when hanging o
with friends or watching movies. So, I usually can't stick to a diet plan. '- Participa
5, Page 3

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## **Appendix B. Detailed Discussion**

In this section, to analyze how various factors under TDFv2 facilitate or inhibit PCOS treatment adherence, the findings are discussed under the health belief model (HBM) in detail [1]. The HBM is used to explain and predict the changes in individuals' health behaviors.

### **Perceived Susceptibility**

The present study's findings reveal two types of risk perception of PCOS among the participants. First is affective risk perception, related to worry and anxiety associated with PCOS [2]. Meta-analysis showed that affective risk perception is related to preventative behaviors [3]; therefore, Participant 10 is expected to commit highly to PCOS treatment. Second, perceiving PCOS as controllable, Participant 1 exhibited dispositional optimism is related to adopting preventive behaviors due to high self-confidence in overcoming the threat 4. Therefore, Participant 1 is also expected to engage in PCOS treatment.

To sum up, the perception of the high risk of getting PCOS among the study's participants is predicted to lead to high PCOS treatment compliance. **Perceived Severity** 

The present study captures perceived severity through participants' knowledge of PCOS consequences and their experiences of the physical and psychological effects of PCOS.

Most participants (70%) knew about the consequences of PCOS, including depression, infertility, miscarriage, premature birth, diabetes during pregnancy, and, in advanced cases, uterine cancer. As such, the present study has a higher awareness of PCOS consequences than the relevant literature. For example, Patel and Rai [5] stated that 36% knew about the relationship between PCOS, cancer, and infertility. Similarly, Alessa et al. [6] found that 39% of their sample knew PCOS was associated with decreased fertility. This difference in findings may be attributed to the fact that the participants in the current study are mostly highly educated, with some also having medical qualifications.

The positive link between perceived severity and the likelihood of adopting preventative health behavior is documented in the literature. For example, Luo et al. [7] found that those who underestimated the seriousness of COVID-19 did not take appropriate preventive measures. As such, the overall high level of perceived severity by the study's participants is expected to prompt action toward adhering to PCOS treatments.

#### **Perceived Benefits**

Perceived benefits of adopting PCOS treatments were reflected in the participants' knowledge and experience of the effectiveness of PCOS treatments.

Half of the participants highlighted the benefits of PCOS treatment approaches, including medication and lifestyle management, in improving their symptoms. In particular, taking the medications regularly was reported to help maintain regular periods. On the other hand, exercise and diet-based treatment were associated with improvements in depressive symptoms and obesity. The effectiveness of these treatment approaches is also well-documented across the literature. Relating to drug treatment, insulin-sensitizing medications are found to positively affect insulin resistance, irregular menstrual, anovulation, hirsutism, and obesity **[8]**, with metformin having been primarily supported in empirical studies 9–11. In addition, lifestyle management is found to manage insulin resistance and lead to weight loss, which improves PCOS features, including the psychological, cardio-metabolic, endocrine, and reproductive features **[12–14]**.

The impact of individuals' perception of the benefits of adopting desirable health behavior can outweigh the effects of personal susceptibility and severity **[15]**, meaning that individuals with high perceived susceptibility and severity may only take action if they perceive potential benefits from that action **[15]**. Therefore, with the health benefits of PCOS treatments experienced by the participants, they may be inclined to adhere to the treatments. About half of the participants also stated that these improvements in their health encouraged them to stay committed to the treatments. The findings that improved health outcome facilitates PCOS treatment adherence are consistent with Pirotta et al. **[16]** and Rajkumar et al. **[17]**.

#### **Perceived Barriers**

Perceived barriers to PCOS treatment adherence are found in the form of inadequate knowledge about PCOS symptoms among patients and their families, participants' concern about side effects of PCOS medicines, time constraints, lack of enjoyment, inconveniences in access to the healthcare provider, and lack of health professional supports, and social norms. Perceived barriers are the most significant predictors of preventive health

behavior across all literature **[18]**. This implies that even if an individual perceives the threat of a health condition and perceives the benefits of a particular action in reducing these threats, perceived barriers may prevent her from taking action.

Inadequate knowledge about early PCOS symptoms was reported as a barrier to diagnosis, especially when the participants normalized these symptoms to their age or work stress. The lack of knowledge about PCOS symptoms among parents, which led to their ignorance about their children's symptoms, was also opined by the participants. This finding aligns with Ismayilova and Yaya [19] and Wasata et al. [20]. Patients' unawareness of PCOS symptoms may lead to underestimation of these symptoms, which can delay diagnosis, and for parents, this would discourage seeking medical attention for their daughters [19].

Relating to the side effects of the medications, some participants reported the undesirable influence of these drugs, including allergies, weight gain, morning sickness, and daily fatigue. The concerns relating to side effects of PCOS medications align with previous studies [17,21–23], which report that PCOS patients' negative evaluation of the drugs and lower perceived need to take them could lead to medical avoidance.

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Although some participants identified the roles of exercise and a healthy diet in managing PCOS conditions, they expressed an inability to adhere to these treatments due to time constraints imposed by their responsibilities towards their family and work. As discussed above, these time constraints also extended to the participants' ability to visit doctors, which can be a very time-consuming process. The time constraints and impediments to PCOS treatment adherence are well-documented across the relevant literature **[16,24,25]**.

Discomfort and lack of enjoyment in different treatment methods, including displeasure from the medication and lack of interest in physical exercise, were reported as some barriers to treatment adherence. The finding relating to a lack of enjoyment in undertaking physical activity aligns with Pirotta et al. [16] and Arentz et al. [25].

While all the participants had access to doctors during the interview, they reported the barrier of access to healthcare providers due to long waiting times for short consultation sessions. The waiting time to consult a doctor in Iran is also highlighted by Bazarganipour et al. [21], where participants reported the long waiting time for the doctor to be an inhibiting factor in their doctor visits. These findings emphasize the need for more specialist doctors in Iran, a country with one of the region's lowest numbers of doctors per capita, about 5.3 physicians per 10,000 citizens, and short consulting sessions of five minutes instead of the expected minimum of 15 minutes [26].

Some patients also pointed out their experience with inattention, lack of empathy, and dismissal from their doctor. This finding is consistent with Ismayilova and Yaya [19] and Tomlinson et al. [23]. Doctor's unwillingness to listen and understand a patient's conditions and concerns can be perceived as a lack of empathy and support by the patient, thus negatively influencing patient-doctor interactions and patient trust levels [19], which, in turn, can impede patient's treatment adherence. In Iran, Bazarganipour et al. [21] also found inattention from healthcare providers. However, their findings revealed a lack of privacy during treatment sessions.

One of the participants highlighted the adverse impact of social norms, such as traditional treatment, in the worsening of her symptoms and delayed diagnosis. The prevalence of the use of conventional medicines is also reported by only one other study, Rajkumar et al. [17]. However, unlike the present research, Rajkumar et al. [17] do not establish if these traditional drugs promoted, inhibited, or were irrelevant to the PCOS treatment adherence among its participants. Therefore, in the scope of the present study's literature review, this finding is novel.

## **Cue to Action**

While social support and social pressure were identified as cues to action, insufficient information resulted in a lack of signals to move. The HBM posits that a trigger or cue is needed to prompt action in healthy behavior [27].

All participants received support and encouragement from their families, partners, or friends in consulting a specialist doctor, maintaining dietary changes, and engaging in physical exercise. The findings from the present study highlight the importance of family support in improving the physical difficulties and well-being of the patients [17,28] and mostly align with that of Pirotta et al. [16]. On the other hand. At the same time, Lim et al. [24] found that partners played an inhibiting role in PCOS patients' treatment adherence. Bazarganipour et al. [21] observed that family members and peers facilitated and inhibited treatment adherence among PCOS patients.

One participant also identified social pressure as a cultural component that pressures women toward their gender roles, such as getting married, conceiving a child, and giving birth. For Participant 3, this pressure motivated her to seek treatment. Although the challenges in PCOS women's perception of themselves as "ordinary women" are documented in Iran (see Amiri et al., 2014), exploring social pressure as a facilitator of treatment adherence is exciting and novel to examine the present study's findings.

Some participants reported needing to improve the information their doctors or specialists relayed, particularly before diagnosis. For instance, a patient must understand the role of various treatment methods, such as diet and exercise. Lack of informational support is also found across the relevant literature **[16,19,21,23]**. Inadequate doctor information can impact patients' success in managing their PCOS 19. If a patient has incomplete information on her condition, she may lack awareness of the significance of her disease, leading to underestimating her situation and the need for management efforts **[19]**.

## **Self-Efficacy**

Self-efficacy plays a vital role in initiating and maintaining behavioral change [15]. To successfully execute a behavioral change, people must

have confidence in overcoming perceived barriers to action [15].

This study observed a need for more self-efficacy about the inability to engage in a healthy diet. Remarkably, despite consultations with her doctor, Participant 5 could not stick to a healthy diet because she could not avoid junk food. Pirotta et al. **[16]** also found that easy access to processed food and snacks impeded the ability to commit to dietary improvements.

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Citation: Ameli N, Brown M (2023) A Qualitative Study of Barriers and Facilitators to Polycystic Ovary Syndrome Treatment Adherence: Iranian Context. J Comm Med and Pub Health Rep 4(08):